

JMIR Mental Health

Journal Impact Factor (JIF) (2023): 4.8

Volume 6 (2019), Issue 4 ISSN 2368-7959 Editor in Chief: John Torous, MD, MBI

Contents

Original Papers

Codeine Addiction and Internet Forum Use and Support: Qualitative Netnographic Study (e12354) Eleanor Lee, Richard Cooper,	4
Service Use History of Individuals Enrolling in a Web-Based Suicidal Ideation Treatment Trial: Analysis of Baseline Data (e11521) Quincy Wong, Aliza Werner-Seidler, Michelle Torok, Bregje van Spijker, Alison Calear, Helen Christensen,	13
Utilization of Patient-Generated Data Collected Through Mobile Devices: Insights From a Survey on Attitudes Toward Mobile Self-Monitoring and Self-Management Apps for Depression (e11671) Ralf Hartmann, Christian Sander, Noah Lorenz, Daniel Böttger, Ulrich Hegerl,	24
Evaluating the Feasibility of an Innovative Self-Confidence Webinar Intervention for Depression in the Workplace: A Proof-of-Concept Study (e11401) Wan Wan Mohd Yunus, Peter Musiat, June Brown,	32
Use of a Mobile Phone App to Treat Depression Comorbid With Hypertension or Diabetes: A Pilot Study in Brazil and Peru (e11698) Paulo Menezes, Julieta Quayle, Heloísa Garcia Claro, Simone da Silva, Lena Brandt, Francisco Diez-Canseco, J Miranda, LeShawndra Price, David Mohr, Ricardo Araya,	47
Supporting Self-Management in Bipolar Disorder: Mixed-Methods Knowledge Translation Study (e13493) Erin Michalak, Emma Morton, Steven Barnes, Rachelle Hole, CREST.BD, Greg Murray,	59
Digital Presence of a Research Center as a Research Dissemination Platform: Reach and Resources (e11686) Sarah Lord, Katherine Seavey, Sonia Oren, Alan Budney, Lisa Marsch,	76
User Involvement in Developing the MYPLAN Mobile Phone Safety Plan App for People in Suicidal Crisis: Case Study (e11965) Niels Buus, Anette Juel, Hila Haskelberg, Hanne Frandsen, Jette Larsen, Jo River, Kate Andreasson, Merete Nordentoft, Tracey Davenport, Annette Erlangsen,	102
A Clinical Care Monitoring and Data Collection Tool (H3 Tracker) to Assess Uptake and Engagement in Mental Health Care Services in a Community-Based Pediatric Integrated Care Model: Longitudinal Cohort Study (e12358) Michael McCreary, Armen Arevian, Madeline Brady, Ana Mosqueda Chichits, Lily Zhang, Lingqi Tang, Bonnie Zima,	114

Young People's Satisfaction With the Online Mental Health Service eheadspace: Development and Implementation of a Service Satisfaction Measure (e12169)	126
Debra Rickwood, Alison Wallace, Vanessa Kennedy, Shaunagh O'Sullivan, Nic Telford, Steven Leicester.....	
Applicability of Motivational Interviewing for Chronic Disease Management in Primary Care Following a Web-Based E-Learning Course: Cross-Sectional Study (e12540)	139
Karoline Lukaschek, Nico Schneider, Mercedes Schelle, Ulrik Kirk, Tina Eriksson, Ilkka Kunnamo, Andrée Rochfort, Claire Collins, Jochen Gensichen.....	
Profiling Commenters on Mental Health–Related Online Forums: A Methodological Example Focusing on Eating Disorder–Related Commenters (e12555)	148
Duncan McCaig, Mark Elliott, Cynthia Siew, Lukasz Walasek, Caroline Meyer.....	
Seasonality Patterns of Internet Searches on Mental Health: Exploratory Infodemiology Study (e12974)	165
Noam Soren, Duncan Cameron, David Streiner, Karen Rowa, Randi McCabe.....	
Guided Digital Cognitive Behavioral Program for Anxiety in Primary Care: Propensity-Matched Controlled Trial (e11981)	175
Megan Oser, Meredith Wallace, Francis Solano, Eva Szigethy.....	
Instant Stress: Detection of Perceived Mental Stress Through Smartphone Photoplethysmography and Thermal Imaging (e10140)	190
Youngjun Cho, Simon Julier, Nadia Bianchi-Berthouze.....	
The Relationship Between Nomophobia and Maladaptive Coping Styles in a Sample of Italian Young Adults: Insights and Implications From a Cross-Sectional Study (e13154)	213
Nicola Bragazzi, Tania Re, Riccardo Zerbetto.....	
Framing Mental Health Within Digital Games: An Exploratory Case Study of Hellblade (e12432)	236
Joseph Fordham, Christopher Ball.....	
Transdiagnostic Mobile Health: Smartphone Intervention Reduces Depressive Symptoms in People With Mood and Psychotic Disorders (e13202)	263
Dror Ben-Zeev, Benjamin Buck, Phuonguyen Chu, Lisa Razzano, Nicole Pashka, Kevin Hallgren.....	
Identifying Treatment Modalities for a Multidisciplinary and Blended Care Intervention for Patients With Moderate Medically Unexplained Physical Symptoms: Qualitative Study Among Professionals (e12203)	271
Paula van Westrienen, Martijn Pisters, Marloes Gerrits, Cindy Veenhof, Niek de Wit.....	
Exploring Associations Between the Self-Reported Values, Well-Being, and Health Behaviors of Finnish Citizens: Cross-Sectional Analysis of More Than 100,000 Web-Survey Responses (e12170)	280
Anita Honka, Elina Helander, Misha Pavel, Holly Jimison, Pekka Mustonen, Ilkka Korhonen, Miikka Ermes.....	

Review

Web-Based Multidomain Lifestyle Programs for Brain Health: Comprehensive Overview and Meta-Analysis (e12104)	85
Linda Wesselman, Astrid Hooghiemstra, Linda Schoonmade, Marjolein de Wit, Wiesje van der Flier, Sietske Sikkes.....	

Editorial / Patient Perspective

Mental Health Apps in Psychiatric Treatment: A Patient Perspective on Real World Technology Usage
([e12292](#))

Emil Chiauzzi, Amy Newell..... 224

Viewpoint

The Potential of Game-Based Digital Biomarkers for Modeling Mental Health ([e13485](#))

Regan Mandryk, Max Birk..... 250

Original Paper

Codeine Addiction and Internet Forum Use and Support: Qualitative Netnographic Study

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Abstract

Background: The use of codeine as an analgesic is well-recognized, but there are increasing concerns that for some individuals continued use may lead to misuse, dependence, and fatalities. Research suggests that those affected may represent a hard-to-reach group who do not engage with formal treatment services.

Objective: This study sought to explore the experiences of people with self-reported addiction to codeine and, specifically, how a social media forum is used to communicate with others about this issue.

Methods: Using a qualitative netnographic methodology, the social media forum Mumsnet was used, with permission, and searches were undertaken in 2016 of any posts that related to codeine and addiction. A total of 95 relevant posts were identified; a purposive sample of 25 posts was selected to undertake subsequent six-stage thematic analysis and development of emerging themes. These 25 posts were posted between 2003 and 2016 and comprised 757 individual posts.

Results: Individuals created posts to actively request help in relation to usually their own, but occasionally their partner's or relative's, problems relating to codeine use and self-reported "addiction." Varying levels of detail were provided in narratives of problematic codeine use. There were both positive and negative descriptions of side effects emerging, problems experiencing withdrawal, and failed attempts to discontinue codeine use. Mainly positive and supportive responses to posts were identified from those with either self-reported health profession experience or lay respondents, who often drew on their own experiences of similar problems. Treatment advice emerged in two main ways, either as signposting to formal health services or to informal approaches and often anecdotal advice about how to *taper* or use *cold turkey* techniques. Some posts were more critical of the original poster, and arguments and challenges to advice were not uncommon. Shame and stigma were often associated with users' posts and, while there was a desire to receive support and treatment advice in this forum, users often wanted to keep their codeine use hidden in other aspects of their lives. Distinctly different views emerged as to whether responsibility lay with prescribers or patients. Some users expressed anger toward doctors and their prescribing practices.

Conclusions: This study provides a unique insight into how a public internet forum is used by individuals to confirm and seek support about problematic codeine use and of the ways others respond. The pseudonymous use of internet forums for such information and variation in treatment options suggested by often lay respondents suggest that increased formal support and awareness about codeine addiction are needed. There may be opportunities for providing further support directly on such online forums. Improvements in prescribing codeine and in the over-the-counter supply of codeine are required to prevent problematic use from occurring.

(*JMIR Ment Health* 2019;6(4):e12354) doi:[10.2196/12354](https://doi.org/10.2196/12354)

KEYWORDS

codeine; addiction; abuse; opioid; internet; prescription; over-the-counter

Introduction

Opioid medicines are an important group of medicines that are widely used for the treatment of pain [1]. Their use is also increasing; in the United Kingdom, there has been a five-fold increase in their use between 1991 and 2009 [2]. This trend has increased concerns about possible opioid harms, such as dependency and addiction. In England, there has also been an increase in the number of deaths caused by codeine, rising from 131 in 2016 to 156 in 2017 [3]. Globally, estimates of opioid addiction have varied or are lacking in many countries, but data in the United States suggests that between 8% and 12% of patients may be addicted [4]. Patients affected may not present, or be referred, to specialist addiction clinics [5,6], and the number of individuals treated may be an underestimate and reflect a “hidden” population [6]. Of those who presented to formal drug services in England in 2016-2017, 1618 patients were treated where a prescribed opioid, and no illicit substance use, was identified; a further 554 sought treatment involving nonprescription or over-the-counter opioids (information was acquired via a freedom-of-information request sent to Public Health England in July 2018 regarding over-the-counter and prescription medicine data from the National Drug Treatment Monitoring System). Research is inconclusive about the profile of those affected, although some studies have identified females as being more likely to misuse over-the-counter medicines [7]. It should also be noted that a number of terms are used to describe problematic use of medicines, reflecting different clinical and social manifestations and interpretations related to this issue [7]. Current clinical terminology relates to substance use disorder of differing severity and subtypes [8]; however, in this paper it will be argued that *addiction* is justified methodologically as a lay term, but *misuse* is justified as a more neutral term when presenting findings.

Codeine is one of the most frequently supplied opioids; it is supplied via prescription but also over-the-counter from pharmacies in some countries [9]. Codeine is a relatively weak analgesic and is commonly coformulated with other analgesics, such as paracetamol and ibuprofen. In addition to the potential for dependence and addiction to codeine, these compound formulations are associated with incidents of hepatotoxicity and gastric bleeding [10,11]. This has led to examples of upregulation of codeine; in Australia, the drug was recently removed from pharmacy sale to prescription-only use [9].

Support and treatment for those affected by problematic use of codeine is available from several sources [6], ranging from formal drug and alcohol treatment service, group support such as Narcotics Anonymous, private clinics, involvement of general practitioners, online groups, and self-treatment. Those affected have been recognized as a hard-to-reach group [6,12], who may not want others to know about their misuse and so may not present to formal treatment services.

The role of the internet in relation to medicine misuse represents an emerging area of concern. Research has explored how individuals communicate and discuss narratives of codeine misuse and experimentation. This has been identified through written posts about codeine *trips* [13] and *glamorizing* codeine

misuse through images and specific media, such as Instagram [14] or Twitter for illegal prescription opioid sales [15]. Such insights do not capture how the internet is used to seek support for misuse of medicines such as codeine. Using the internet in this way represents one aspect of the wider topic of how different online resources are used by the public to obtain information and support about their health and illness. A total of 49% of individuals surveyed in 2015 in Great Britain reported searching for health-related information in the previous 3 months, compared to only 18% in 2007. Searching for disease-specific information has also been identified [16], particularly to enable diagnosis [17,18]. A recent survey found the internet to be the most common source used for seeking help for codeine use (12%) compared to only 3% of respondents using their doctor in the United Kingdom and Ireland [19]. Historically, specific online groups such as Codeinefree.me and Over-Count [20] have provided support for prescription and over-the-counter medicines and may be important for confirming self-reported “addiction” and for gaining more information [6]. Such online sites are private and represent only a minority of online opportunities to obtain help and support, including many general social media sites. Social media sites encourage discussions and have been argued to be particularly helpful in the “absorption of knowledge” [18]. An associated concern, however, relates to the quality of information on such sites, although it has been noted that *counterbalancing comments* can correct incorrect information [18]. Regarding wider substance misuse, the use of online resources such as social media has been recognized as being important in relation to digital recovery [21,22]. Nearly half of a sample of US individuals receiving substance misuse treatment felt that social media content triggered cravings but around half also reported beneficial recovery information on social media [22].

The primary aim of this study was to explore how a social media discussion forum was used to discuss self-reported codeine addiction. Further aims were to understand the types of information and support provided by others and any self-reported harms related to codeine.

Methods

A qualitative netnographic methodology was used to explore this topic, involving the selection and analysis of online posts and interactions and, in particular, differences between core and peripheral contributors [23]. Mumsnet [24] was chosen as the host forum site as it represents a popular site that has been used in previous research and presents posts and associated threads publicly [18], avoiding any ethical concerns about *lurking* on private forums. Mumsnet was approached and permission was gained from the website to use their data.

Ethical approval was obtained from The University of Sheffield. Consent was not obtained from those contributing to posts based on current guidance as to the use of online social media posts. However, to maintain anonymity, users’ names will not be presented, and all quotes will be paraphrased having been checked in Mumsnet and Google that they cannot be used to identify the thread. Evidence on a specific link between parenting and misuse of medicines is scant, but groups such as

pregnant and parenting women have been considered particularly concerning in relation to opioid misuse [25] and effects on children [26].

Data collection involved accessing the Mumsnet site and using its standard search function. A variety of search terms were trialed based on previous reviews of the literature [7]; the phrase “codeine addiction” was eventually selected, as using other search terms resulted in too many nonsalient threads or too few threads. Using “codeine addiction” resulted in a total of 141 threads being identified during searches in July 2016; however, on subsequent checks, only 100 of these were available to search further, which was thought to have resulted from original posts having been removed. Of these 100 resulting threads, 5 (5.0%) were excluded as they were surveys, advertisements, or links back to other threads. Of the 95 remaining, a purposive sample of 25 threads (26%) were selected based on variables described in Table 1, such as year of posting, whether the original person posting did so about themselves or on behalf of another, involvement of prescription or over-the-counter medicines, and previous Mumsnet research [27]. Excluded threads included predominant reference to noncodeine medication (eg, tramadol addiction); questions about side effects of codeine; and concerns, but not actual experience, of being prescribed codeine.

Posts from each of the 25 threads were extracted and converted to electronic offline text documents. These data were then analyzed initially by one of the researchers (EL), using Braun and Clarke’s six phases of thematic analysis [28]. These phases are linear, although each can be revisited throughout the process. The six phases are as follows: (1) data familiarization, (2) generating initial codes, (3) searching for themes, (4) reviewing

themes, (5) defining themes, and (6) writing up. We began this process with immersion in the data in order to become familiar with the dataset, using printed versions of each thread. On first reading, initial thoughts and notes were annotated. Coding by hand provided reassurance of comprehensive coding, even though it would be more difficult to search for and find codes within the data compared to using computer software [28]. When coding the threads, notes were written on paper for ease. A challenge with coding in this study of forum posts was to retain the context, especially when the text is split into fragments [29]. Initial coding was open, also referred to as semantic by Braun and Clarke, which involved attempts to provide literal and descriptive codes related to sections of threads. Following this, latent coding was undertaken, which involved searching for underlying ideas and conceptualizations. After the initial codes were decided, they were grouped into overarching themes to categorize all the data. Next, coding was repeated to ensure that the analysis was complete. The data were reread to confirm that the themes were accurately depicted and reviewed. This ensured that the dataset was well-understood and that there was no missing information. Analysis was initially undertaken by one researcher (EL); another researcher (RJC) then selected a sample of threads and undertook independent coding and theme generation using the same process with printed copies of threads and hand-annotation. Subsequent comparison and discussion of emerging codes and themes were undertaken. A high level of agreement was found based on the sample analyzed and, consistent with the constructionist epistemological basis [30] of qualitative research, evaluation of interrater reliability was not undertaken. Respecting the anonymity of the Mumsnet users, respondent validation was not undertaken.

Table 1. Summary of key themes and related subthemes.

Theme	Subtheme
Original post and requests for help	<ul style="list-style-type: none"> Original reason for codeine use Requests for help Anonymity and identity Acquisition of codeine
Side effect highs and lows	<ul style="list-style-type: none"> Positive effects of codeine Negative effects of codeine Withdrawal side effects
Support and treatment advice variation	<ul style="list-style-type: none"> General support Lay and professional advice Specific treatment advice Anecdotal: weaning and cold turkey Formal services
Stigma and shame	<ul style="list-style-type: none"> Comparison to illicit drug users Hiding misuse from others
Responsibility and blame	<ul style="list-style-type: none"> Individual and health professional responsibilities
Absent endings	<ul style="list-style-type: none"> Progress for the original poster How other users have progressed

Results

Overview

Analysis of the 25 threads revealed that they originated from various requests for help and guidance based on the narrative summaries provided. These included recurrent themes of side effects, both negative and positive, and strategies used to resolve problematic use and a variety of often negative emotions, such as stigma, shame, and embarrassment from those creating threads. Responses to original posts often offered support based on the lay responder's similar experiences and associated empathy; responses also offered anecdotal suggestions to either seek formal health care treatment or use informal means of stopping codeine use (see [Table 1](#)).

Threads varied considerably in terms of characteristics, with the number of posts varying between 3 and 202; some posts were active for only a few days, but in some cases additional contributions were identified weeks or years later. Thread titles also varied and were often quite dramatic in tone, succinctly summarized the problem, and often posed a question. The majority of sampled posts related to individuals seeking help for themselves, but some involved a partner or relative (see [Table 1](#)). Threads also varied in terms of tone, style, interactions between posters, and the content and opinions of the posters. Contributors frequently used specific Mumsnet abbreviations such as OP (ie, original poster), DP (ie, dear partner), or XP (ie, ex-partner) to refer to others; they also used common phrases such as TBH (ie, to be honest) and AIBU (ie, am I being unreasonable), suggesting familiarity with website conventions. A recurrent theme was deleted posts across the threads; it was not possible to analyze such content or understand why posts had been deleted. One instance was identified where a Mumsnet moderator had become involved, but it was not clear why this had happened. The emerging themes are described in more detail in the following sections; participant names are not presented, and illustrations of quotes are paraphrased. Although this study sought insights into those who expressed self-reported "addiction," the less pejorative term *misuse* will be used in the findings.

Original Post and Requests for Help

Threads usually involved a combination of descriptions of a problem involving codeine in the original post and subsequent requests for help and support. Original posts contained narratives that varied in the level of detail but often used emotive language and captured aspects such as why codeine had been used; how it was obtained; side effects experienced; and, for some but not all, what had been done to manage problematic codeine use. The latter reflected an important temporal aspect of the original posts, indicating the current situation of the person using codeine; this appeared to vary, with some reporting a problem that had recently been identified and others describing problems over a much longer time period. The excerpt below illustrates how the original post summarized the latter:

I'm struggling to say this, but I've got a painkiller addiction involving codeine. I really would like to get help but I'm unsure of how to do this. It's been going on for over three years now and is getting worse. I

have to take two as soon as I wake and use two main brands, and this keeps on happening all day. I have attempted to stop two times before last year, but sickness and bad headaches stopped me. I am aware I am causing myself harm and know I should stop, but how? Ideas of how to stop would be really appreciated. [Thread 12, Original Poster]

This was typical of almost all posts in ending with a request for help. It also illustrates how users appeared to have an awareness of a problem, specifically addiction, and how those responding to posts offered similar and often candid reflections of themselves, as in the quote below:

My name is...and I know I'm an addict. It's not an addiction to alcohol or street drugs and I've never smoked, but I am starting to realize I've got an addiction to painkillers. [Thread 6, Original Poster]

Concerns about anonymity were common; users referred intentionally to *name changing* and altering their usual forum username to another to avoid being recognized. Some original posters used terms such as *ashamed*, *worried*, or *embarrassed* to describe themselves in pseudonyms. Original posters referred to using such online forums for help and support as they did not feel they had support and encouragement in other aspects of their lives:

My husband is very angry about this...I am so ashamed of this, I can't talk to anyone about it. [Thread 1, Original Poster]

The majority of forum users stated that they had originally started taking codeine due to a problem that had required a health professional interaction. They described codeine use being initiated from a doctor's prescription or from receiving advice from a pharmacist to take codeine combined with ibuprofen or paracetamol. The former presentations reflected conditions such as musculoskeletal problems and obstetric complications; the latter included more self-limiting conditions:

I'd been using pharmacy painkillers that have codeine in them for a long time. I used them occasionally to begin with but then regularly. If I had things like period pain or maybe a hangover, I knew the Nurofen Plus or Solpadeine would make things better. [Thread 8, Original Poster]

For some, codeine appeared to have been used alongside several other analgesics, but only occasional references were made by original posters and respondents about other addictions, such as dependency to alcohol or tobacco, and even less frequently about illegal substances. The doses consumed were only mentioned in some posts and respondents did not often seek such information. A recurrent theme in posts related to how codeine was acquired; for some, this was merely descriptive and involved reference to different durations of prescribing. Other accounts involved alternative routes to obtaining codeine, such as the use of multiple pharmacies or ordering online to avoid suspicion or detection:

My partner has been getting lots and lots of codeine in over-the-counter Nurofen Plus over the years by

going to different pharmacies. [Thread 7, Original Poster]

I've also bought it online via online pharmacies. It's the branded stuff I buy online and from trusted NHS [National Health Service]-approved online pharmacies, so it's not fake. [Thread 23, Original Poster]

Side Effects of Codeine: Highs and Lows

A second key emerging theme related to the duality of side effects related to codeine use. Positive effects were reported not only in terms of codeine's ability to relieve pain and allow individuals to function, but also in relation to perceived positive side effects, such as improving mood, inducing euphoria, and reducing anxiety. These were also associated with a perceived increased ability to cope. Posts invariably included more negative aspects related to negative side effects. These varied in type and intensity but included constipation, headache, sickness, lethargy, stomach pains, and a lack of concentration. The following original post illustrates this in relation to contrasting codeine side effects and the impact on the poster, particularly at work:

I really liked the haziness, and the pills helped with my stress and pain...but at work it meant I made little mistakes and couldn't focus. It wasn't that bad, but people thought I was lazy. [Thread 8, Original Poster]

Requests for help often arose because of difficulties managing negative side effects of codeine. These were particularly acute in relation to withdrawal symptoms when individuals had recognized the need to reduce or stop their use of codeine. These were described by users who had attempted to stop codeine previously as well as by the original poster, as they often updated their thread with their progress. Side effects reported in relation to codeine withdrawal included headaches, gastrointestinal problems, flu-like symptoms, and general malaise:

I've now started to feel lethargic in the mornings and been sick quite a lot. In the last couple of weeks, I've tried to stop taking them, but by the end of the day I get stomach cramps and I sweat. I feel sick and have a massive headache. [Thread 4, Original Poster]

Support and Treatment Advice Variation

In every thread, at least one user offered advice and support to the original poster but, as noted, the total number of respondents and posts varied considerably. Analysis did not reveal any obvious pattern as to whether aspects of the original post led to more or fewer responses. On most occasions, multiple users wrote positive comments even if they had no knowledge on the topic, as typified by a respondent:

Nothing that new to add, just wanted to give support. [Thread 2, Respondent]

Support responses could be distinguished from specific treatment advice, provided more general encouragement, and relied on psychological or emotional responses to try and reassure the original poster:

Don't feel ashamed. You can deal with this with help. It's good that you want to do something about it though. [Thread 9, Respondent]

In contrast, other users gave more opinionated responses and warnings, which appeared to be intended to shock the original poster and to encourage action:

It is codeine you are addicted to and the excessive paracetamol and also ibuprofen that will have potentially disastrous effects. [Thread 8, Respondent]

The other category of response related to more specific treatment advice. Two distinct categories of treatment advice were apparent, involving either self-treatment or engaging with treatment services. Of the former, two main types emerged relating to either *tapering*, involving reducing the dose of codeine gradually over a period of time, and using the *cold turkey* method, which involved an abrupt cessation of codeine. Some users gave experiences of both options and how to carry out such methods, such as involving supportive people and indicating how to gradually reduce the dose over time. Such advice was often experiential and appeared to be based on a respondent's own attempts or from those they knew:

I would try to stop by going cold turkey, but with the withdrawal it was too much. I had sweats, chills, and fatigue... [Thread 23, Respondent]

You can wean yourself off them. I was taking a similar amount to what you were taking or more, and I managed to stop after a couple of weeks. You might find things are better without them, it does make you feel quite gloomy. [Thread 11, Respondent]

Other users suggested alternative medicines to assist with stopping codeine; examples included using essential oils, acupuncture, exercise, and yoga. Again, these appeared to be suggested based on experiential success by those offering the advice. However, some advice appeared to be more controversial and triggered more opinionated exchanges and responses from others:

Smoking cannabis helps a lot with any addictions, and me and lots of others think it's a godsend. [Thread 3, Respondent 1]

Be careful with rubbish advice. There are others asking for help who are vulnerable. [Thread 3, Respondent 3]

Some respondents self-identified as having a health professional background and offered varying levels of detail and advice. At times, this professional knowledge and insight was used to influence or guide a thread in terms of correcting previous advice given, as typified in this exchange:

No doctor who is worth their salt will prescribe methadone for codeine detoxification and especially not if they mention feeling suicidal. [Thread 7, Respondent 1]

Many users, including professionals, replied to this message:

Doctors actually do prescribe methadone for codeine dependency. [Thread 7, Respondent 3]

I'm a doctor in drug work, and I'd treat this person with methadone or Subutex. Overdose risks are managed by having a supervised consumption regime... [Thread 7, Respondent 4]

More commonly, though, original posters were advised to seek additional professional help beyond the forum. In some cases, this related to advice about where to seek help from other online forums where benefits were suggested, often allowing anonymity to be retained. In other responses, advice was given about other services such as Narcotics Anonymous and specialist drug services:

I would suggest getting help with Narcotics [Anonymous]. I think they will treat your difficulties more seriously than your GP [general practitioner]. [Thread 9, Respondent]

Stigma and Shame

Two related and negative aspects of codeine misuse emerged in relation to concerns about it being stigmatizing as well as resulting in shame. Stigma often arose when comparisons were made between codeine and illicit drugs users. There was a perception that codeine misuse shared similarities to the use of illicit drugs such as heroin, despite being legal, and carried some of the stigmatizing negative societal views of illicit drug addiction:

There's a huge problem with heroin where I live, and the thought of queuing next to heroin users in my pharmacy fills me with horror. I suppose I'm not so different to them and it's just that my little addiction is a legal one. [Thread 8, Original Poster]

References to being ashamed were very common in posts and, as noted previously, this arose in relation to changed usernames that contained such wording. In addition, a common manifestation of shame related to a desire to keep addiction secret from family members, doctors, and friends. Users expressed concern about the consequences of their addictions being on medical records, especially when they had responsibilities such as children and jobs. Others did not want to seek help from their doctor due to perceived negative consequences:

If I go to my GP and admit it, what will happen? Will they take my baby away? [Thread 4, Original Poster]

I'm scared of going to my GP because I work with his wife and it will go down on my medical record. [Thread 6, Original Poster]

Codeine addiction appeared to place a strain on relationships with partners and family members. On multiple occasions, users became upset and expressed worry about the impact of addiction on their children, as well as the risk that their children may be taken away from them.

Responsibility and Blame

A further negative cluster of themes concerned views about who was perceived to be responsible for codeine addiction and where blame lay. Views differed and some arguments arose between individuals about this issue. Some commented that the

person taking the codeine should be responsible for their own actions:

If I'd known about the addiction risk, I would have kept away from them [the drugs]. I don't think the surgery was to blame, by the way. Not at all...I think it was my naivety blaming the surgery, by the way, not at all, it was me being naive. [Thread 24, Original Poster]

I feel sorry for you...[quotes question from original poster about whether anyone has enough time to read leaflets]. Anyone with any sense? You're arguing that no one warned you, but the warnings were there each time you took medicine from the packet. [Thread 9, Respondent]

You were prescribed drugs and foolishly did not take personal responsibility, just as any addict does not. [Thread 9, Respondent]

In contrast, others identified blame as arising with doctors for not giving proper advice and information about medicines with the potential for abuse and addiction:

I wish that I'd not taken them at the start...it does make me question whether medical professionals should monitor this more...before it gets out of hand. [Thread 11, Original Poster]

Absent Endings

The final theme concerned the relative absence of updates within threads about how the original poster's situation had developed over time, even in those with many posts and over long time periods. Few users posted progress updates, but these were often only in the short term. A characteristic of all posts was the distinct absence of resolution or closure about the situation described in the original post. The following quote illustrates a post when an update was provided:

I didn't take any today, but I still feel terrible. I find it hard to sit because my legs really hurt and I'm very nauseous and have pain everywhere. [Thread 6, Original Poster]

Where such progress was reported, other users offered their continued support, and sometimes other users posted at a later date asking about the original poster's situation. Some respondents did describe their own experiences; in these, there was often more of a sense of finitude in contrast to the original post. These tended to be historic and were often also positive experiences that respondents offered as encouragement, linking to the earlier themes around support.

Discussion

Principal Findings

This study has provided a unique insight into how an internet forum is used by individuals to seek and receive help and support in relation to self-reported addiction to codeine and of the harms that can occur. This sample of Mumsnet users appeared to be candid, in terms of both the degree to which original posters offered often highly personal but anonymized accounts of problematic codeine use, as well as from those

responding and offering their own experience and opinions and even challenging others. Self-reported addiction to codeine appeared to involve considerable anxiety for individuals, and side effects were a particular concern.

Limitations

Study limitations relate to the use of only one medicine, codeine, and one internet forum; it is possible that other medicines and forums may have different user profiles and narratives [18]. The term *addiction* used in relation to codeine was self-reported; doses consumed were often not stated so may not reflect a clinically recognized addiction. User profiles were anonymous, so details relating to gender, age, and socioeconomic status could not be ascertained. As noted by Rier [31], the veracity of accounts provided could not be checked, nor did this study specifically seek to analyze the quality of information provided [18]. Further research is suggested involving other medicines and other sites.

Comparison With Previous Work

Several themes in this study are suggestive of previously identified characteristics of prescription and over-the-counter medicine addiction, including the initial legitimate reason for starting codeine, which has also been identified among over-the-counter medicine misuse [6]. Posts also described the change in use and exploitation of what were perceived as positive effects, such as a “fuzzy effect” and euphoria; these data share similarities with some of the trip narratives described in more recreational drug use online posts [13]. Similarly, experiences of negative side effects also reflected those previously reported [7,32]. Strategies to address the problem also reflected what previous research has identified. Both individual and informal approaches, such as gradually reducing use or stopping use immediately, appeared most commonly as what had been tried or what had been suggested by others. Of note was that many suggestions were made about seeking formal addiction treatment support but with concerns from original posters about confidentiality [6].

Although this study did not seek to assess the quality of advice provided, there appeared to be variation in the quantity and type of treatment advice provided. However, there was also evidence of what have been termed *counterbalancing comments*, which have been argued to offset poor-quality advice; these have been identified in other online sites for health conditions [18]. However, given the relative absence of updates and conclusions to the original poster’s narratives, it is not possible to comment on the degree to which the original poster acted on the advice given. This finding, along with original posters initially seeking to use such public online sites as well as explicit concerns about not wanting to be identified via formal services, suggests that more still needs to be done to best support individuals affected

by codeine, particularly in terms of treatment options. Concerns about existing treatment and support have emerged in previous research in relation to codeine and other medicines [6,33]. While this study does not offer specific recommendations for treatment change, it suggests that these online sites may represent important opportunities to provide support and their use should not be underestimated.

This research has additional implications for practice and further research. A key implication relates to the need to raise awareness among patients and the public regarding the harms related to codeine. A second implication and related recommendation is that online resources could be used more; there may be potential for online forums to be monitored and for more active support to be offered based on the content posted. Research involving nonsuicidal self-injury and analysis of posts about this topic on sites such as Instagram revealed that searches could detect problematic posts and that current warnings provided could be further enhanced [34]. There are opportunities for online forums to consider adding such warnings based on keywords relating to codeine addiction and other implicated medicines. Further research would be needed to consider the benefits and acceptability of such schemes. With regard to digital recovery, this research also has implications for how individuals affected by medicine misuse may gain benefits from social media sites by obtaining treatment or recovery information, as previous research has suggested [22]. This would also require further research and evaluation, particularly to address this study’s findings of *absent endings*.

Conclusions

Codeine is an important analgesic available both by prescription and over-the-counter in the United Kingdom and around the world. This study offers further evidence that the use of codeine can become problematic; caution is needed in relation to prescribing and supplying codeine as well as in being vigilant in changes in use among patients. This study provides a unique additional insight into how a popular public internet forum can be used by individuals to explore problematic codeine use. In particular, the interactive nature of the forum offers a range of opportunities for others to provide advice and support. However, while this was often very positive, some negative comments emerged and treatment advice also varied. Self-reported codeine addiction was associated with considerable negativity in terms of the harms and side effects reported, the impact it had on individuals, and the associated blame and stigma. Increasing understanding of this issue is still needed for both health professionals and the public, but there may be unique opportunities in the online forums themselves to offer additional support and information. Uncertainty about treatment options suggests that more guidance and support is needed for those affected to help them overcome their problems.

Conflicts of Interest

None declared.

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Abbreviations

GP: general practitioner

NHS: National Health Service

Edited by C Eichenberg; submitted 28.09.18; peer-reviewed by S Acquilano, B Curtis, R Ashford, R Vadde; comments to author 07.11.18; revised version received 31.01.19; accepted 13.03.19; published 25.04.19.

Please cite as:

Lee E, Cooper RJ

Codeine Addiction and Internet Forum Use and Support: Qualitative Netnographic Study

JMIR Ment Health 2019;6(4):e12354

URL: <http://mental.jmir.org/2019/4/e12354/>

doi: [10.2196/12354](https://doi.org/10.2196/12354)

PMID: [31021328](#)

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Original Paper

Service Use History of Individuals Enrolling in a Web-Based Suicidal Ideation Treatment Trial: Analysis of Baseline Data

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Abstract

Background: A significant recent innovation is the development of internet-based psychological treatments for suicidal thinking. However, we know very little about individuals experiencing suicidal ideation who seek help through Web-based services and, in particular, their previous health service use patterns.

Objective: We aimed to examine service use history and its correlates among adults experiencing suicidal ideation who enrolled in a Web-based suicidal ideation treatment trial.

Methods: We used baseline data of 418 individuals seeking Web-based treatment for their suicidal ideation recruited into a randomized controlled trial of a 6-week Web-based self-help program. Participants at preintervention reported demographic information, clinical characteristics, and health service use over the previous 6 months.

Results: Participants had a high rate of service use in the 6 months before enrolling in the treatment trial (404/418, 96.7% of participants had contact with services). The two most common contact points were general practitioners (385/418, 92.1% of participants) and mental health professionals (295/418, 70.6% of participants). Notably, those with a previous single suicide attempt had lower odds of contact with any service than those with no attempt (odds ratio [OR] 0.21, 95% CI 0.05-0.86; *P*=.03). Those living in rural or remote areas had lower odds of contacting general practitioners (OR 0.35, 95% CI 0.13-0.91; *P*=.03) or mental health professionals (OR 0.44, 95% CI 0.23-0.83; *P*=.01) than those living in metropolitan areas.

Conclusions: Individuals enrolling in an electronic health intervention trial have often received treatment from general practitioners or mental health professionals. These services can therefore play an important role in preventing the escalation of suicidal thinking. Enrollment in our Web-based treatment trial suggested, though, that face-to-face health services may not be enough. Our study also highlighted the need to improve the provision of coordinated and assertive care after a suicide attempt, as well as health service availability and utilization for those living in rural and remote areas.

Trial Registration: Australian New Zealand Clinical Trials Registry ACTRN12613000410752; <https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=364016> (Archived by WebCite at <http://www.webcitation.org/6vK5FvQXy>); Universal Trial Number U1111-1141-6595

(*JMIR Ment Health* 2019;6(4):e11521) doi:[10.2196/11521](https://doi.org/10.2196/11521)

KEYWORDS

internet; treatment; service use; health service; suicidal ideation; suicide, attempted; suicide; facilities and services utilization; telehealth

Introduction

Background

Suicide and its precursors (suicidal thinking, plans, and attempts) are associated with individual and societal burden, making them an important public health concern [1]. Recognition that many people with suicidal thoughts do not seek help [2], coupled with rapid advances in technology and their uptake, has led to the development of internet-based cognitive behavioral treatments for suicidal thinking [3-5]. Such interventions are an important innovation in the prevention of suicidal behaviors, as they (1) target suicidal thinking (the earliest precursor to suicide), and this has the potential for important downstream effects on reducing the possibility of suicidal thoughts converting to suicidal behavior; and (2) can help to overcome several barriers to treatment, including wanting to handle the problem alone, the desire for anonymity, stigma, treatment availability, and financial and time costs [2,6]. Despite the increasing availability of e-delivery platforms targeting suicidal thoughts and behavior [7], we know very little about the historical patterns of health service use among individuals who engage with Web-based treatment programs. Understanding the previous health service use patterns of individuals who seek online help for suicidal thoughts is critically important because it can help to identify who is most likely to use such electronic health (eHealth) programs, to determine service provision gaps, and to provide new insight into the characteristics of service users to inform the design and delivery of targeted interventions.

Existing research has focused on suicidal behavior and health care use by conducting population health surveys rather than assessing users of suicide prevention services. Previous research has shown that between 31% and 57% of individuals reporting past-year suicidal ideation and 52% to 68% of individuals reporting past-year (planned) suicide attempts across high-income countries had contact with (inpatient and outpatient) mental health services in the same period [2,8]. Accessing mental health services for those with any past-year suicidal behavior (ideation, plans, and attempts) was associated with higher education, higher income, and never-married status [2]. Moreover, past-year suicidal ideation has been associated with service use after controlling for sociodemographic and clinical factors [9], whereas other research has found that being married increased and being male decreased the likelihood of service use following a suicide attempt [10]. Collectively, however, the factors associated with any form of mental health service use are not well understood. More specifically, to our knowledge, the health service use histories and correlates of adults who are seeking Web-based treatment for different suicidal behaviors have not been investigated.

Objective

We used baseline data from a recent randomized controlled trial (RCT) conducted by our group (The Healthy Thinking Trial) that recruited adults seeking Web-based treatment for their suicidal ideation [5], to identify the patterns and correlates of participant health service use in the 6 months prior to enrolling in the study. The specific aims were to (1) examine health service use in the 6 months prior to enrollment in the study

among those who experienced suicidal ideation only and those who experienced suicidal ideation and suicide attempts; and (2) describe the demographic and clinical characteristics associated with health service use.

Methods

Participants

We recruited participants for an RCT (registered with the Australian New Zealand Clinical Trials Registry: ACTRN12613000410752) testing the efficacy of a 6-week Web-based self-help program aimed at reducing suicidal thoughts compared with a 6-week attention-matched control program [5,11]. Between November 2013 and December 2015, we recruited community-dwelling adults via online media, which included relevant websites, popular social networking sites, and advertising on popular search engines. Interested individuals were given a link to a webpage that allowed them to provide consent and complete an online screener that verified their eligibility for the trial. The following eligibility criteria were applied: aged between 18 and 65 years; having a valid email address; having a reliable internet connection; being located in Australia; being fluent in English; having no history of a diagnosed psychotic disorder; currently experiencing suicidal thoughts; and having made no suicide attempts in the past month. These criteria were assessed by single self-report questions to which participants answered “yes” or “no” (eg, participants responded yes or no to the question “Are you currently experiencing suicidal thoughts?”). Eligible individuals were informed that the trial was not intended to replace treatment as usual. They were encouraged to continue any treatments they were already receiving or seek other treatments if they were not receiving any at the time.

Measures

This study focused on the participant baseline data of the RCT.

Demographics Questionnaire

We collected the following standard demographic information: age, sex, relationship status (married or de facto; separated, divorced, or widowed; never married), education (postsecondary qualification, secondary school qualification only, no qualification), employment status (employed, unemployed, not in the labor force), and region of residence (metropolitan; regional; rural or remote). Note that rural and remote categories for region of residence were initially separate categories but were ultimately combined because of the low number of participants endorsing the remote category (n=4). We modeled the demographic categories and subcategories on previous research [8,12]. We also asked participants to indicate the number of previous suicide attempts in their lifetime.

Center for Epidemiologic Studies Depression Scale

The 20-item Center for Epidemiologic Studies Depression Scale (CES-D) [13] assesses the symptoms of depression over the past week. The CES-D has good psychometric properties (eg, in this study, Cronbach alpha=.87; see also Radloff [13]).

Generalized Anxiety Disorder Scale

The 7-item Generalized Anxiety Disorder (GAD-7) scale [14] assesses the symptoms of anxiety over the past 2 weeks. The GAD-7 scale has good psychometric properties (eg, in this study, Cronbach alpha=.85; see also Spitzer et al [14]).

Columbia-Suicide Severity Rating Scale

We used a self-report version of the Columbia-Suicide Severity Rating Scale (C-SSRS) [15] to indicate the severity of suicidal ideation over the past week. The C-SSRS has 5 items (answered yes/no) that assess the presence of 5 increasingly severe levels of suicidal thought (from 1 = wish to be dead to 5 = active suicidal ideation with specific plan and intent to act). A score of zero is assigned when no ideation is present. In this study, participants who reported more than one level of severity of suicidal ideation were coded with the most severe level.

Client Service Receipt Inventory

The original Client Service Receipt Inventory (CSRI) [16] assesses participant accommodation, employment, income, and use of health and social care services in the previous 12 months. For this study, we adapted the CSRI for the Australian context and modified it to focus on assessing whether there was any contact with the following services over the previous 6 months: general practitioner (GP), mental health professionals (including psychiatrists and psychologists), hospital services for mental health (including inpatient and outpatient services), acute services (including psychiatric crisis support team, and police or ambulance for mental health crisis), mental health helplines (eg, Lifeline), and other health services (including social worker, counsellor, and self-help group). We modeled these service use categories on previous research (eg, [2,17]).

Procedure

We obtained ethical approval from the Human Research Ethics Committees of the University of New South Wales, Sydney (HC13117) and the Australian National University, Canberra, Australia (2012/471).

Eligible individuals were provided with an information statement, which specified the trial's safety procedures that allowed individuals to remain anonymous in the trial if they so chose [5,11]. Subsequently, they provided consent, a valid email address, a name or nickname to register, and a phone number (nonmandatory). Participants then completed the baseline measures, which included the demographics questionnaire, CES-D, GAD-7 scale, C-SSRS, CSRI, and other measures (for details of other measures, see [5,11]), and were subsequently randomly assigned to a condition. **Multimedia Appendix 1** shows the flow of participants through the trial. **Multimedia Appendix 2** shows a screenshot of the Web-based self-help program aimed at reducing suicidal thoughts.

Analyses

We used descriptive statistics to describe the full sample's demographics and clinical characteristics and to determine the number of participants in the full sample who had contact with different health services. We also obtained these statistics for 3 subsamples (ie, those with suicidal ideation only, those with suicidal ideation and a single past suicide attempt, and those with suicidal ideation and multiple past suicide attempts). We used multivariate logistic regression models to examine variations in health service use associated with demographic variables (age, sex, relationship status, education, employment status, and region of residence) and clinical variables (depression and anxiety symptoms, suicidal ideation severity, and lifetime suicide attempt status). We conducted all analyses with IBM SPSS version 25 (IBM Corporation).

Results

Sample Characteristics and Health Service Use

Table 1 shows the descriptive statistics for the demographics, clinical characteristics, and past 6-month service use of the full sample and the subsamples of participants with ideation only, 1 previous suicide attempt, and multiple previous suicide attempts. A large majority of those with ideation only (186/191, 97.4%), single suicide attempts (83/89, 93%), and multiple suicide attempts (135/138, 97.8%) in our sample reported some form of contact with health services in the 6 months before enrolling in the Web-based suicidal ideation treatment trial. The two most common contact points were GPs (179/191, 93.7% of participants with ideation only had contact; 78/89, 88% of participants with a single attempt had contact; and 128/138, 92.8% of participants with multiple attempts had contact) and mental health professionals (128/191, 67.0% of participants with ideation only had contact; 60/89, 67% of participants with a single attempt had contact; and 107/138, 77.5% of participants with multiple attempts had contact). Notably, 14 of the 418 participants (3.3%) in the full sample did not have any contact with health services in the previous 6 months.

Multivariate Logistic Regression Predicting Service Use

Table 2 shows the predictors of 6-month health service use specifically regarding contact with any service, general practitioners, and mental health professionals in the full sample. **Table 3** shows the predictors of 6-month health service use specifically regarding contact with hospital services for mental health, acute services, mental health helplines, and other services in the full sample. Female participants had higher odds of contact with any service than did male participants ($P=.03$). Of note was that those who had experienced a single suicide attempt reported lower odds of contact with any service than did those with ideation only (ie, no previous suicide attempt; $P=.03$).

Table 1. Demographics, clinical characteristics, and 6-month service use of the sample^a.

Characteristics	Full sample (N=418)	Ideation only (n=191)	Single attempt (n=89)	Multiple attempts (n=138)
Age (years), mean (SD)	40.64 (11.94)	41.77 (12.67)	39.93 (11.39)	39.52 (11.16)
Sex, n (%)				
Male	93 (22.2)	53 (27.7)	15 (17)	25 (18.1)
Female	323 (77.3)	138 (72.3)	74 (83)	111 (80.4)
Relationship status, n (%)				
Married or de facto	160 (38.3)	82 (42.9)	31 (35)	47 (34.1)
Separated, divorced, or widowed	72 (17.2)	30 (15.7)	16 (18)	26 (18.8)
Never married	186 (44.5)	79 (41.4)	42 (47)	65 (47.1)
Education, n (%)				
Postsecondary school qualifications	349 (83.5)	161 (84.3)	76 (85)	112 (81.2)
Secondary school qualification only	44 (10.5)	19 (9.9)	8 (9)	17 (12.3)
No qualification	25 (6.0)	11 (5.8)	5 (6)	9 (6.5)
Employment status, n (%)				
Employed	248 (59.3)	129 (67.5)	60 (67)	59 (42.8)
Unemployed	66 (15.8)	27 (14.1)	13 (15)	26 (18.8)
Not in labor force	104 (24.9)	35 (18.3)	16 (18)	53 (38.4)
Region, n (%)				
Metropolitan	253 (60.5)	125 (65.4)	49 (55)	79 (57.2)
Regional	107 (25.6)	43 (22.5)	29 (33)	35 (25.4)
Rural or remote	56 (13.4)	22 (11.5)	11 (12)	23 (16.7)
Clinical characteristics, mean (SD)				
CES-D ^b	40.26 (9.62)	39.06 (8.88)	39.99 (9.69)	42.09 (10.33)
GAD-7 ^c scale	13.27 (5.07)	12.90 (5.12)	12.78 (5.40)	14.10 (4.70)
C-SSRS ^d ideation severity	3.18 (1.18)	2.95 (1.17)	3.31 (1.06)	3.51 (1.11)
Service use, n (%)				
Any service	404 (96.7)	186 (97.4)	83 (93)	135 (97.8)
General practitioner	385 (92.1)	179 (93.7)	78 (88)	128 (92.8)
Mental health professionals ^e	295 (70.6)	128 (67.0)	60 (67)	107 (77.5)
Hospital services for mental health ^f	93 (22.2)	26 (13.6)	18 (20)	49 (35.5)
Acute services ^g	84 (20.1)	19 (9.9)	16 (18)	49 (35.5)
Mental health helplines	126 (30.1)	46 (24.1)	26 (29)	54 (39.1)
Other services ^h	120 (28.7)	45 (23.6)	25 (28)	50 (36.2)

^aIn the full sample, 2 participants did not indicate their sex as male or female, and 2 participants did not provide information on region. There were no other missing data.

^bCES-D: Center for Epidemiologic Studies Depression Scale.

^cGAD-7: 7-item Generalized Anxiety Disorder.

^dC-SSRS: Columbia-Suicide Severity Rating Scale.

^eIncludes psychologists and psychiatrists.

^fIncludes inpatient and outpatient services.

^gIncludes psychiatric crisis support team and police or ambulance for mental health crisis.

^hIncludes social worker, counsellor, and self-help group.

Table 2. Predicting 6-month service use in the full sample: contact with any service, general practitioners, and mental health professionals.

Characteristics	Any service, OR ^a (95% CI)	General practitioner, OR (95% CI)	Mental health professionals ^b , OR (95% CI)
Age	1.02 (0.96-1.07)	1.03 (0.99-1.06)	1.00 (0.98-1.02)
Sex			
Male	1 [reference]	1 [reference]	1 [reference]
Female	4.33 (1.19-15.72) ^c	2.10 (0.89-4.94)	1.52 (0.89-2.61)
Relationship status			
Married or de facto	1 [reference]	1 [reference]	1 [reference]
Separated, divorced, or widowed	3.69 (0.42-32.66)	1.39 (0.41-4.73)	0.90 (0.48-1.69)
Never married	2.43 (0.61-9.59)	1.00 (0.41-2.42)	1.30 (0.77-2.19)
Education			
Postsecondary school qualifications	1 [reference]	1 [reference]	1 [reference]
Secondary school qualification only	1.34 (0.14-12.55)	1.99 (0.42-9.51)	1.37 (0.62-3.06)
No qualification	0.14 (0.02-1.14)	0.70 (0.14-3.51)	0.44 (0.17-1.10)
Employment status			
Employed	1 [reference]	1 [reference]	1 [reference]
Unemployed	1.68 (0.26-10.89)	0.74 (0.26-2.13)	1.58 (0.82-3.07)
Not in labor force	1.48 (0.26-8.50)	0.82 (0.29-2.29)	2.08 (1.12-3.85) ^d
Region			
Metropolitan	1 [reference]	1 [reference]	1 [reference]
Regional	N/A ^e	1.32 (0.48-3.65)	1.35 (0.78-2.35)
Rural or remote	0.35 (0.09-1.28)	0.35 (0.13-0.91) ^c	0.44 (0.23-0.83) ^f
Clinical characteristics			
CES-D ^g	0.99 (0.92-1.07)	1.05 (1.00-1.10)	0.99 (0.96-1.02)
GAD-7 ^h scale	1.11 (0.97-1.27)	1.08 (0.99-1.18)	1.05 (1.00-1.11)
C-SSRS ⁱ ideation severity	1.00 (0.61-1.66)	0.77 (0.54-1.10)	1.06 (0.86-1.31)
Lifetime suicide attempt			
Ideation only	1 [reference]	1 [reference]	1 [reference]
Single attempt	0.21 (0.05-0.86) ^c	0.47 (0.18-1.19)	0.95 (0.54-1.69)
Multiple attempts	0.66 (0.13-3.40)	0.88 (0.33-2.32)	1.37 (0.79-2.38)

^aOR: odds ratio.^bIncludes psychologists and psychiatrists.^c $P=.03$.^d $P=.02$.^eN/A: not applicable. All participants in the regional category (n=107) had used some form of health service. As there were no noncases, an OR was not computed.^f $P=.01$.^gCES-D: Center for Epidemiologic Studies Depression Scale.^hGAD-7: 7-item Generalized Anxiety Disorder.ⁱC-SSRS: Columbia-Suicide Severity Rating Scale.

Table 3. Predicting 6-month service use in the full sample: contact with hospital services for mental health, acute services, mental health helplines, and other services.

Characteristics	Hospital services for mental health ^a , OR ^b (95% CI)	Acute services ^c , OR (95% CI)	Mental health helplines, OR (95% CI)	Other services ^d , OR (95% CI)
Age	0.98 (0.96-1.01)	1.00 (0.97-1.02)	0.97 (0.95-0.99) ^e	1.00 (0.97-1.02)
Sex				
Male	1 [reference]	1 [reference]	1 [reference]	1 [reference]
Female	2.14 (1.02-4.47) ^f	1.34 (0.67-2.68)	1.39 (0.76-2.55)	1.71 (0.94-3.09)
Relationship status				
Married or de facto	1 [reference]	1 [reference]	1 [reference]	1 [reference]
Separated, divorced, or widowed	0.46 (0.20-1.07)	0.68 (0.31-1.49)	0.65 (0.31-1.37)	1.24 (0.66-2.34)
Never married	0.85 (0.48-1.50)	0.81 (0.44-1.46)	1.43 (0.86-2.40)	0.85 (0.51-1.43)
Education				
Postsecondary school qualifications	1 [reference]	1 [reference]	1 [reference]	1 [reference]
Secondary school qualification only	1.67 (0.75-3.74)	2.19 (0.99-4.82)	0.54 (0.24-1.19)	1.54 (0.76-3.13)
No qualification	2.41 (0.90-6.49)	1.08 (0.36-3.22)	0.97 (0.37-2.56)	1.79 (0.74-4.34)
Employment status				
Employed	1 [reference]	1 [reference]	1 [reference]	1 [reference]
Unemployed	1.02 (0.49-2.11)	0.74 (0.34-1.61)	1.12 (0.60-2.09)	1.22 (0.66-2.26)
Not in labor force	1.85 (0.99-3.43)	1.34 (0.71-2.51)	0.97 (0.53-1.75)	0.91 (0.51-1.62)
Region				
Metropolitan	1 [reference]	1 [reference]	1 [reference]	1 [reference]
Regional	1.29 (0.72-2.31)	1.20 (0.66-2.18)	1.29 (0.76-2.21)	1.08 (0.64-1.81)
Rural or remote	0.78 (0.34-1.76)	1.07 (0.49-2.35)	1.97 (0.99-3.91)	0.97 (0.50-1.89)
Clinical characteristics				
CES-D ^g	1.03 (0.99-1.07)	1.01 (0.97-1.04)	1.04 (1.00-1.07) ^f	1.02 (0.99-1.05)
GAD-7 ^h scale	0.97 (0.91-1.03)	1.02 (0.96-1.09)	1.02 (0.97-1.08)	0.98 (0.93-1.03)
C-SSRS ⁱ ideation severity	1.34 (1.03-1.73) ^j	1.26 (0.98-1.63)	1.23 (0.98-1.53)	0.95 (0.77-1.17)
Lifetime suicide attempt				
Ideation only	1 [reference]	1 [reference]	1 [reference]	1 [reference]
Single attempt	1.29 (0.64-2.59)	1.80 (0.86-3.79)	1.03 (0.56-1.90)	1.18 (0.66-2.13)
Multiple attempts	2.59 (1.43-4.72) ^k	4.18 (2.22-7.85) ^l	1.54 (0.90-2.65)	1.71 (1.01-2.90) ^m

^aIncludes inpatient and outpatient services.^bOR: odds ratio.^cIncludes psychiatric crisis support team and police or ambulance for mental health crisis.^dIncludes social worker, counsellor, and self-help group.^e $P=.004$.^f $P=.04$.^gCES-D: Center for Epidemiologic Studies Depression Scale.^hGAD-7: 7-item Generalized Anxiety Disorder.ⁱC-SSRS: Columbia-Suicide Severity Rating Scale.^j $P=.03$.^k $P=.002$.^l $P<.001$.^m $P=.046$.

There were also different patterns of predictors across service categories (see [Tables 2](#) and [3](#)). Compared with living in the city, living in rural or remote areas was associated with lower odds of contact with a GP ($P=.03$) and lower odds of contact with mental health professionals ($P=.01$). Compared with those who were employed, those not in the labor force had higher odds of contact with mental health professionals ($P=.02$). Female participants ($P=.04$), those with more severe suicidal ideation ($P=.03$), and those who had experienced multiple suicide attempts ($P=.002$) had higher odds of contact with hospital services for their mental ill health. Not surprisingly, those who had experienced multiple suicide attempts also had higher odds of contact with acute services ($P<.001$) and other services (social worker, counsellor, and self-help group; $P=.046$). Older individuals had lower odds of contact with mental health helplines ($P=.004$), whereas those with more severe depressive symptoms had higher odds of contact with mental health helplines ($P=.04$).

Discussion

Principal Findings

This study aimed to examine health service use and its correlates among adults participating in a Web-based suicidal ideation treatment trial. The overwhelming majority of the sample had some form of contact with health services in the 6 months before enrolling in the Web-based suicidal ideation treatment trial, with the two most common contact points being GPs and mental health professionals. It is not possible to tell from our data whether suicidal thoughts or behaviors were addressed during contact with any of these health services because we did not assess this. That is, we cannot assume that suicidal thinking or suicide attempts were discussed during participant contact with the various health services, although they could have been. Nonetheless, the rates of service use of our sample, which was recruited for a treatment trial, were generally higher than those found in previous international [\[2\]](#) and Australian [\[8\]](#) general population studies. The relatively high rates of service use reported in our study may be due to several factors, one being the high proportion of women who participated, given that women are more likely than men to use health services (eg, [\[18\]](#)). Other factors that may have resulted in a higher than usual representation of service users may be the high rates of metropolitan residency, employment, and tertiary qualifications noted among the participants, which are all likely to increase geographical and financial access to services [\[19-22\]](#). However, for a comparison in the Australian context, Johnston and colleagues' [\[8\]](#) sample actually had similar rates of metropolitan residency and employment to that of our sample, but lower rates of women and postsecondary qualifications (see also [\[23\]](#)). The higher rates of women and postsecondary qualifications may thus have accounted for the greater rate of service use in our sample. Moreover, the relatively high rates of service use in our sample may also indicate a greater propensity to seek help, given that higher education has been linked to higher levels of knowledge of mental health and treatment availability [\[24\]](#).

The high rate of service use of our participants, together with their enrollment in the Web-based intervention, has two main

implications. First, it suggests that some individuals experiencing suicidal ideation may want more help beyond in-person treatments. This may be because contact with various face-to-face services is not sufficient to meet their needs (eg, shame or discomfort disclosing suicidal thoughts or behaviors face-to-face), or they may be willing to try any intervention that may provide additional help. Future research should investigate these possibilities. Second, it suggests that the treatment trial, from which we derived this study's sample, did not attract individuals experiencing suicidal ideation who do not normally seek help. This is despite one of the aims of the treatment trial to reach such individuals, for example, by permitting anonymous participation (see [\[5,11\]](#)). Another important direction for future research will be to further improve Web-based treatments to reach this group of individuals.

With respect to the correlates of health service use, the majority of results were as expected, but two findings stood out. First, we found that a previous single suicide attempt (compared with ideation only [no previous suicide attempt] status) was associated with lower odds of contact with any service. The data we collected did not allow us to determine for those participants with a previous single suicide attempt when their attempt actually occurred in their lifetime, and thus the temporal relationship with service use assessed in our study (eg, the attempt may have occurred many years prior to participating in the study, and this could explain the relatively lower odds of contact with services). However, given that a suicide attempt predicts future suicide attempts and death by suicide [\[25\]](#), and given that these participants with a previous single suicide attempt enrolled in our Web-based treatment trial (indicating the presence of suicidal ideation), it is of concern that these participants had a relatively lower rate of contact with any service. One reason that might account for this finding is that, in relation to a first suicide attempt, a lack of coordinated and assertive care after the attempt may lead to a general disengagement from health services [\[26\]](#). Alternatively, distressing treatment experiences after the attempt may discourage health service use in general [\[26,27\]](#). The second notable result from our analysis, also of concern, was that among adults participating in our Web-based treatment trial, those living in rural or remote areas had lower odds of previous 6-month contact with a GP and mental health professionals than did those living in metropolitan areas. This result is consistent with previous research demonstrating similar findings (eg, [\[9,21\]](#)) and, in Australia, may reflect relatively lower rates of help-seeking by individuals living in rural or remote locations, as well as the shortage of GPs and mental health professionals limiting service access in these areas [\[28,29\]](#). This result continues to highlight a critical need for strategies to improve health service provision and use in rural and remote areas. In this regard, eHealth interventions may hold significant promise for delivering more accessible, evidence-based interventions to at-risk persons.

Several critical considerations emerge from this study. Given that the two most common services used by individuals with suicidal ideation before enrolling in a Web-based treatment trial were GPs and mental health professionals, it is important that such services are aware that they may be crucial intervention

points to prevent the escalation of suicidal thinking. In the case of GPs, as noted above, it was not possible to ascertain why individuals in our sample consulted their GP, but it may not have been for a mental health problem or for suicidal thoughts or behaviors. Indeed, previous research has shown that only 15% of individuals who died by suicide revealed suicidal thoughts or intentions in consultations with their GPs prior to suicide [30]. This suggests that there is scope for GPs to play an important role in preventing the escalation of suicidal thinking through the routine screening of patients for suicidal thoughts and behaviors, and upskilling in terms of their capacity to treat or refer suicidal patients to appropriate services [31-33]. Notably, in a mental health service model integrating e-mental health interventions with face-to-face services, GPs would be integral in referring suitable patients to evidence-based Web-based therapies that target suicidal thinking and reduce suicide risk [5]. Our study also highlighted the need for the provision of coordinated and assertive care after a suicide attempt, especially after the first suicide attempt, to encourage engagement with health services and prevent the maintenance or escalation of suicidal thinking. Finally, as noted above, there is a need for continued emphasis on improving health service availability and use for those living in rural and remote areas who experience suicidal ideation.

Limitations

Several limitations of our study should be considered. First, participants in our study were recruited to a trial and not users of a service. Future research should replicate our study in a sample of suicide prevention service users. Second, our sample enrolled in a Web-based suicidal ideation program after meeting inclusion criteria (and not meeting exclusion criteria) from an initial pool of 12,474 individuals who visited the registration

website (see [5]). Although the exclusion of individuals was a necessity of the trial, results may have been different had these individuals been included. Third, the group of participants who did not use any services was very small, and future research should improve the recruitment of such individuals to further investigate the reasons behind their lack of service use and their decision to enroll in a treatment trial examining a Web-based intervention for suicidal ideation. Fourth, we assessed the number of past suicide attempts with a single self-report item, and future studies should improve the accuracy of identifying suicide attempts with a more in-depth assessment [34]. Fifth, our study examined cross-sectional baseline data, and we do not know the temporal relationships between the variables in our study. Sixth, as previously noted, although we assessed health service use history, we did not specifically assess whether suicidal thoughts or behaviors were addressed during contact with services. Future research should collect this information.

Conclusions

Our study highlighted, for the first time, health service use history and its correlates among adults participating in a Web-based suicidal ideation treatment trial. Our study highlighted that these individuals had a high rate of contact with health services, particularly GPs and mental health professionals. These services can therefore play an important role in preventing the escalation of suicidal thinking. Enrollment in the Web-based treatment trial, despite this high contact with services, suggests, though, that face-to-face health services may not be enough for individuals with suicidal ideation and that they may want more help. Finally, our study highlighted the need to improve the provision of coordinated and assertive care after a suicide attempt, as well as health service availability and use for those living in rural and remote areas.

Acknowledgments

This study was supported by a grant from the Australian National Health and Medical Research Council (NHMRC; GNT1046317) and forms part of the program of research conducted by the NHMRC Centre of Research Excellence in Suicide Prevention (CRESP; GNT1042580). The funder did not have any role or ultimate authority in the study design; collection, management, analysis, and interpretation of data; writing of the report; and the decision to submit the report for publication. ALC and HC are supported by NHMRC Fellowships 1122544 and 1056964, respectively. We thank Professor Ad Kerkhof and Associate Professor Phil Batterham for helpful comments on an earlier draft of this paper. We also acknowledge the contributions of Ms Julia Reynolds and Mr Matthew Johnstone to the Web-based self-help program for suicidal ideation.

Conflicts of Interest

BvS is an author of the original Dutch Web-based suicidal ideation program referred to in this paper. BvS is also an author of, and receives royalties from, an adapted paper version of the program (van Spijken B, Kerkhof A. *Piekeren Over Zelfdoding*. Amsterdam: Boom; 2012). BvS and HC are authors of the English translation of the Web-based program used in the Healthy Thinking Trial referred to in this paper. The remaining authors declare no conflicts of interest.

Multimedia Appendix 1

Participant flow diagram for the randomized controlled trial that recruited adults seeking Web-based treatment for their suicidal ideation (reproduced from van Spijker et al [5]).

[[PDF File \(Adobe PDF File\), 83KB - mental_v6i4e11521_app1.pdf](#)]

Multimedia Appendix 2

Example screenshot of the Web-based self-help program aimed at reducing suicidal thoughts.

[[PDF File \(Adobe PDF File, 224KB - mental_v6i4e11521_app2.pdf](#)]

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Abbreviations

CES-D: Center for Epidemiologic Studies Depression Scale

CSRI: Client Service Receipt Inventory

C-SSRS: Columbia-Suicide Severity Rating Scale

eHealth: electronic health

GAD-7: 7-item Generalized Anxiety Disorder

GP: general practitioner

RCT: randomized controlled trial

Edited by G Eysenbach; submitted 09.07.18; peer-reviewed by R Bipeta, S Berrouiguet, K Bentley; comments to author 07.10.18; revised version received 18.01.19; accepted 27.01.19; published 02.04.19.

Please cite as:

Wong QJJ, Werner-Seidler A, Torok M, van Spijker B, Calear AL, Christensen H
Service Use History of Individuals Enrolling in a Web-Based Suicidal Ideation Treatment Trial: Analysis of Baseline Data
JMIR Ment Health 2019;6(4):e11521

URL: <https://mental.jmir.org/2019/4/e11521/>

doi: [10.2196/11521](https://doi.org/10.2196/11521)

PMID: [30938686](https://pubmed.ncbi.nlm.nih.gov/30938686/)

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Original Paper

Utilization of Patient-Generated Data Collected Through Mobile Devices: Insights From a Survey on Attitudes Toward Mobile Self-Monitoring and Self-Management Apps for Depression

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Abstract

Background: Depression is a severe psychiatric disease with high prevalence and an elevated risk for recurrence and chronicity. A substantial proportion of individuals with a diagnosis of unipolar depressive disorder do not receive treatment as advised by national guidelines. Consequently, self-monitoring and self-management become increasingly important. New mobile technologies create unique opportunities to obtain and utilize patient-generated data. As common adherence rates to mobile technologies are scarce, a profound knowledge of user behavior and attitudes and preferences is important throughout any developmental process of mobile technologies and apps.

Objective: The aim of this survey was to provide descriptive data upon usage and anticipated usage of self-monitoring and self-management of depression and preferences of potential users in terms of documented parameters and data-sharing options.

Methods: A Web-based survey comprising 55 questions was conducted to obtain data on the usage of mobile devices, app usage, and participant's attitudes and preferences toward mobile health apps for the self-monitoring and self-management of depression.

Results: A total of 825 participants provided information. Moreover, two-thirds of the sample self-reported to be affected by depressive symptoms, but only 12.1% (81/668) of those affected by depression have ever used any mobile self-monitoring or self-management app. Analysis showed that people want personally relevant information and feedback but also focus on handling sensitive data.

Conclusions: New mobile technologies and smartphone apps, especially in combination with mobile sensor systems, offer unique opportunities to overcome challenges in the treatment of depression by utilizing the potential of patient-generated data. Focus on patient-relevant information, security and safe handling of sensitive personal data, as well as options to share data with self-selected third parties should be considered mandatory throughout any development process.

(*JMIR Ment Health* 2019;6(4):e11671) doi:[10.2196/11671](https://doi.org/10.2196/11671)

KEYWORDS

mHealth; depression; adherence; mobile applications, self-management

Introduction

Depression is a severe disease with large effects on well-being and quality of life [1]. Major depressive disorder (MDD) is highly prevalent [2-5] and is a prime cause for years lived with disability [6] and a major source of the global burden of disease

[1,7]. Furthermore, MDD is associated with a high risk of recurrence and chronicity [8]. Although diagnostics and evidence-based treatments (eg, pharmacotherapy, psychotherapy) for depressive disorders [9-12] are available, a substantial proportion of individuals with a diagnosis of unipolar depressive disorder do not receive treatment as advised by national guidelines [13]. Consequently, self-monitoring and

self-management become ever more important. The opportunities that have arisen from the digital and mobile revolution of recent years [14] bear the potential to meet these challenges. Mobile devices such as smartphones or wearable biosensors can assess and record multimodal data such as physiological data, self-ratings, user behavior, or environmental data. Such patient-generated data become increasingly available and have promising potential to be utilized for self-monitoring, self-management, and medical care. However, this field of research is young and it displays much dynamic [15]. Throughout any process of development or implementation of mobile systems or apps for self-monitoring and self-management, a profound knowledge of readiness for use and user behavior is necessary [16] as common adherence to mobile health (mHealth) systems or apps is often weak [17]. So far, only a few studies have explored preferences and usage of mHealth apps in general [18,19] or for specific fields of interest [20] but not for depression. The aim of this survey was to provide descriptive data to answer the following questions: to what extent are mobile apps for the self-monitoring and self-management of depression (for the purpose of readability, the following abbreviation is used henceforth: MSSD) currently used, what is the anticipated future use, and what do potential users prefer in terms of documented parameters and data-sharing options.

Methods

Survey

We conducted a Web-based comprising 55 questions survey using Unipark, an Web-based survey tool to program and evaluate surveys for academic research provided by Questback GmbH. The survey was available from January 2017 to March 2017. It was accessible via any internet browser on stationary and mobile devices. It was hosted on the servers of Unipark. The internal procedures of Unipark for tests of consistency were used. The link to the survey was prominently posted on the website of the German Depression Foundation (GDF), the “Depressionsforum,” a discussion forum about depression-related topics, which is run by the GDF. GDF is a nonprofit organization in Germany to promote information, knowledge and acceptance of depression, and treatment options within Germany. It was also attached to newsletters of the GDF during the period the survey was available.

Sample

A total of 1174 participants commenced the survey. Of them, 159 participants were excluded because they did not complete the survey, and in addition, 17 participants were excluded because of missing age data. The remaining sample consisted of 998 participants with a mean age of 38.29 (SD 12.358, range 18-84) years. Gender was not distributed evenly, with 67.2% (671/998) of the sample being female. Of them, 668 participants indicated by self-rating to have been diagnosed with unipolar

depressive disorder at least once in their life. This subsample of affected individuals was included in subsequent analyses.

Procedure

The survey was adaptive in a way that depending on individual responses, participants were provided specific sections of the questionnaire. The main filter question was a self-rating question enquiring about whether or not individuals suffer from depressive symptoms at the moment or if they did ever before (for German questionnaire, see [Multimedia Appendix 1](#)). To address our research questions, we provided different blocks of questions. The first block of question assessed the mere usage and duration of usage of MSSDs by self-rating. Individuals who responded with no to the first block were provided separate questions to assess their self-rated anticipated future usage of MSSDs. The second block of questions assessed the mere usage and duration of usage of wearables (eg, fitness tracker or any product of similar functionality to monitor physiological parameters such as skin conductance, heart rate, temperature, or position) by self-rating. Individuals who responded with no were provided separate questions to assess their self-rated anticipated future usage of wearables. The penultimate block of questions assessed what parameters participants would prefer to be documented by MSSDs regardless of the method of data collection (eg, self-rating, sensor-based automatic recording). We provided categories of distinct parameters from which individuals could pick their respective favorites by multiple choice. The last block of questions assessed with whom participants might want to share data for specific purposes. We provided distinct groups of social agents from which individuals could pick their respective favorites by multiple choice.

Statistical Analyses

SPSS (SPSS 24, IBM, Chicago, IL, USA) was used to perform statistical analyses. Descriptive analyses and Chi-square tests were performed to address our research questions.

Results

Demographics of the Sample of Affected Individuals

Demographics of the analyzed sample of affected individuals can be found in [Table 1](#). Within the affected sample, the proportion of women was at 76.9% (514/668). There were significant gender differences for the self-estimated duration of smartphone usage per day ($\chi^2_3=13.1$; $P=.005$). More women estimated their smartphone usage duration per day to be more than 2 hours compared with men. We found no age differences and collapsed age for subsequent analyses. We found no significant group differences for demographics between nondepressive individuals and depressive individuals. We found no significant group differences for demographics between users of MSSDs or wearables and individuals who did not use MSSDs or wearables.

Table 1. Characteristics and descriptive data of the subsample of affected individuals (N=668).

Characteristics	Statistics
Gender, n (%)	
Female	514 (76.9)
Male	154 (23.1)
Age (years), mean (SD)	39.31 (12.857)
Occupation, n (%)	
Employed	334 (50.0)
Self-employed	26 (3.9)
In education: completing education	87 (13.0)
Taking care of household	27 (4.0)
Retired	88 (13.2)
Unemployed	70 (10.5)
Other	36 (5.4)
Relationship, n (%)	
Single	262 (39.2)
Married	347 (52.0)
Other	59 (8.8)

Table 2. Self-reported duration of usage of mobile apps for the self-monitoring and self-management of depression in the subsample of affected individuals (n=111; 1=less than 1 month, 2=more than 1 month).

“For how long do you use the app?”	Relative amount of entries, n (%) ^a
Installed but discarded	24 (21.6)
Installed for a short (1) period, used irregularly	29 (26.1)
Installed for a short (1) period, used regularly	16 (14.4)
Installed for a long (2) period, used irregularly	8 (7.2)
Installed for a long (2) period, used regularly	28 (25.2)
Provided categories not applicable	6 (5.4)

^aPercentages do not sum up to 100% due to rounding errors.

Usage and Anticipated Future Usage of Mobile Apps for the Self-Monitoring and Self-Management of Depression

Within the affected sample, a proportion of 81 individuals (12.1%, 81/668) reported to have installed and used an MSSD at least once in their life. Moreover, 24 individuals installed an MSSD but did not use it (3.6%, 24/668). The majority of the subsample of affected individuals (78.0%, 521/668) stated to have never used any respective app. For the duration of usage, see [Table 2](#). From those who did not use any app at the moment, a total of 391 (75.1%, 391/521) individuals could imagine using any such app in the future ([Table 3](#)).

Usage and Anticipated Future Usage of Wearables

From the affected sample, a proportion of 94 individuals (14.1%, 94/668) indicated to use wearables, 553 (82.8%, 553/668) reported no prior usage, and 21 individuals refused to answer. For period of usage of wearables throughout a day, see [Table](#)

[4](#); for the duration of usage of wearables, see [Table 5](#). From the subsample of nonusers of wearables, 71.2% (394/553) could imagine doing so in the future at least sometimes. However, when people were asked at what time during the day they would usually wear such wearables, responses are heterogeneous (see [Table 6](#)).

Only a small proportion of individuals from the whole sample indicated to have used a wearable and an MSSD simultaneously (3.6%, 24/668). The majority of individuals who indicated to have used a wearable before had never used an MSSD before (74%, 70/94).

Preferences for Documentable Parameters

Categories of documentable parameters and results are presented in [Table 7](#). Low preferences were found for 2 categories: 502 (75.1%, 502/668) individuals reported to not prefer any tracking of location and movement by Global Positioning System (GPS) and 439 (65.7%, 439/668) individuals reported to not prefer any tracking of social interaction or communication.

Table 3. Self-reported anticipated future use by nonusers of mobile apps for the self-monitoring and self-management of depression (MSSDs) in the subsample of affected individuals (n=521).

“Can you imagine using a MSSD in the future?”	Relative amount of entries, n (%)
I can imagine using such an app	391 (75.1)
I do not know	120 (23.0)
No, I would not use such an app	10 (1.9)

Table 4. Self-reported period of usage of wearables throughout 1 day for those that own wearables in the subsample of affected individuals (n=94).

“When do you use a fitness tracker?”	Relative amount of entries, n (%) ^a
Only for sports	11 (11.7)
Only at daytimes	29 (30.9)
Only at night	1 (1.1)
All the time	53 (56.4)

^aPercentages do not sum up to 100% due to rounding errors.

Table 5. Self-reported duration of usage of wearables for those that own wearables in the subsample of affected individuals (n=94).

“For how long did you use a fitness tracker?”	Relative amount of entries, n (%)
A few days	12 (12.8)
A few weeks	21 (22.3)
A few months	61 (64.9)

Table 6. Self-reported anticipated future use by nonusers of wearables in the subsample of affected individuals (n=553).

“When would you use a fitness tracker?”	Relative amount of entries, n (%) ^a
Only for sports	71 (12.8)
Only at daytime	153 (27.7)
Only at night	7 (1.3)
All the time	163 (29.5)
Never	159 (28.8)

^aPercentages do not sum up to 100% due to rounding errors.

Table 7. Self-reported preferred category options of documentable parameters in the subsample of affected individuals (N=668).

“Which options of documentable parameters would you use?”	Agreement, n (%)	Disagreement, n (%)
Mood	568 (85.0)	100 (15.0)
Stress	507 (75.9)	161 (24.1)
Sleep	479 (71.7)	189 (28.3)
Goals	451 (67.5)	217 (32.5)
Sports	427 (63.9)	241 (36.1)
Medication	331 (49.6)	337 (50.4)
Social interaction	229 (34.3)	439 (65.7)
Location (GPS ^a)	166 (24.9)	502 (75.1)

^aGPS: Global Positioning System.

Table 8. Self-reported preferences for data-sharing options in the subsample of affected individuals (N=668).

“With whom would you share personal data?”	Agreement, n (%)	Disagreement, n (%)
Science	417 (62.4)	251 (37.6)
Psychotherapist	417 (62.4)	251 (37.6)
Psychiatrist	345 (51.6)	323 (48.4)
General practitioner	294 (44.0)	374 (56.0)
Family	126 (18.9)	542 (81.1)
Other users of the app	124 (18.6)	544 (81.4)
Friends	85 (12.7)	583 (87.3)
Health insurance companies	30 (4.5)	638 (95.5)

Preference for Data-Sharing Options

The frequencies of the different categories of data sharing options are presented in **Table 8**. Low preferences were found for sharing data with health insurance companies (4.5%, 30/668) and sharing data with friends (12.7%, 85/668). We found significant gender differences for category “General Practitioner” ($\chi^2_1=9.0$; $P=.003$) and for category “psychiatrist” ($\chi^2_1=12.8$; $P<.001$).

Discussion

Principal Findings

For a successful utilization of the multitude of patient-generated data through mobile devices, patients often need to generate monotonous and repetitive data over a long period. To ameliorate their motivation and engagement to do so, it is inevitable to respond to their readiness, user behavior, and preferences.

Usage and Anticipated Future Usage of Mobile Apps for the Self-Monitoring and Self-Management of Depression

Usage of MSSDs was scarce within our sample. Although 30% of individuals used an MSSD for at least 1 month or longer on a regular basis, the majority of the sample used it for shorter periods and irregularly. Despite perceived and anticipated benefits of smartphone apps for the self-monitoring and self-management of depression and/or wearable fitness trackers to support and shape attempts of self-monitoring and self-management, the mere usage of such instruments is still poor. Even if such digital helpers have been used once, duration of usage is mostly limited, and only a small proportion uses them constantly and regularly. This might have different reasons. First of all, the market of mHealth apps is diverse, and finding suitable options can be confusing. Yet, information about evidence-based effects is scarce. Interested users might find it difficult to decide upon which program might fit their own specific needs. An inappropriate choice might disengage further motivation to search for and use MSSDs. Recently proposed guidelines for the evaluation and informed decision-making might help overcome those limitations [21]. Second, mHealth apps often require a constant stream of data and information input to work properly and provide support. Repetitive and

monotonous data input for a long period might result in motivational losses as individuals’ prior drive declines after they started a program. Developers might thrive for an appetizing user interface and data acquisition mechanisms to maintain individuals’ drive until it is integrated into their daily routine.

Usage and Anticipated Future Usage of Wearables

Within our sample, usage of wearables was scarce. Only a small proportion of those who use wearables applied them to their daily routine throughout 24 hours a day. This might be because of different reasons. Wearables have advantages as well as disadvantages with respect to different aspects such as reliability or energy management [22]. Potential users also have individual preferences in terms of design, color, haptics, and weight. Most individuals did not use wearables and MSSDs together. Wearables might be perceived as gadgets for personal activity or sports but not as part of systems to support self-monitoring and self-management of depression. However, individual responses to anticipated future use are heterogeneous.

Preferences for Documentable Parameters

This survey assessed information about individual preferences and expectations people would want from digital assistants for self-monitoring and self-management of depression. The possibilities to document daily mood, personal goals, sports, sleep, and stress level receive broad agreement. The documentation of medication was only important to half the sample. This is maybe more a question of practicality than a question of desire. Less than a third of our sample agreed to the documentation of social interaction. Individuals do not favorably evaluate gathering data about their communication behavior with others, which includes communication channels, number of communication partners, time and amount of communication, as well as content and quality of social interaction. One possible explanation might be that individuals do not expect meaningful outcomes from such data. Moreover, these findings might partly reflect the individual strive to booster their self-esteem and their denial of contrasting or interfering information to that [23,24]. They might not want to be confronted with difficulties and failures of their social interactions and communication behavior. They also might want to avoid actualizing unpleasant interactions and experiences. Detailed information about one’s own communication behavior and alterations and suggested modification based on such information interfere with one’s

own perception of the self as a competent agent. This might be of particular interest for the research of self-enhancement and self-improvement states and traits [25]. More interestingly, we found that individuals have specific issues when it comes to tracking of location data via GPS, accelerometers, and gyroscopes. Within our sample, the majority of the people do not want to be tracked in detail where they are or where they were. However, this finding has to be considered carefully. It does not mean that individuals do not want tracking in general. However, individuals want to keep control of such sensitive data and just do not want to share it with everybody or more precisely with third-party agents from whom negative consequences could arise from, such as German public health insurance, for instance. People are worried about being tracked at places that indicate risk behavior or self-damaging behavior, which could result in financial consequences (eg, higher insurance rates or loss of treatment reimbursement). Furthermore, people do not want to share tracking data with commercial agents because they do not want to be spammed with advertising, unwanted offers, or customized products. People are interested in tracking and analyzing tracked location data for their own and privileged purpose to find correlations with their idiosyncratic disease. We interpret the findings as an individual desire for privacy and control of personal data. Hence, sensitive data should be stored securely in devices the individual has control of, and they can voluntarily decide with whom to share this information.

Preference for Data-Sharing Options

There is agreement on sharing data with professionals such as physicians, psychotherapists, and scientists. As gathering data requires detailed, precise, and reliable analysis and interpretation, there is a strong need for expertise and well-trained personnel to provide such service. In the field of psychiatric disorders and psychological conditions, this expertise is usually delivered by mental health professionals, respectively, psychiatrists and/or psychotherapists. There seems to be no difference if the professional is a psychiatrist, a psychotherapist, or a general practitioner. Individuals know that professionals need information to decide upon medication and psychotherapeutic treatments and therefore accept the disclosure of sensitive data. Moreover, men quoted medical professionals (general practitioner, psychiatrist) more often than women as a

sharing option. However, against the odds, people also do not want their family and close friends to know about where they are. This might be partly reasoned by the fact that social interactions even with close friends are characterized by at least a minimum of specific undisclosed aspects of their life [26,27]. Individuals might be afraid to reveal disclosures, such as places, habits, or activities, to avoid effects on self-esteem or maintain control [28,29].

Conclusions and Limitations

Nonetheless, our survey embodies some important limitations. First, we do not have a representative sample because of the biased distribution via the networks of the GDF solely through internet-based pathways. Furthermore, the limitations that come with Web-based surveys might corrupt our results. To be specific, this means that we took much effort to prevent double entries, fake entries, or robot entries. However, there is no chance of keeping results totally clear of such influences. Another aspect that confounds our results is that we used precategorized questions to address our questions. This simplifies answers and reduces variance. We used an adaptive structure for the survey to comfort the user. This might limit comparisons between groups. Gender distribution within the sample was skewed, and more women answered the questionnaire. From the literature, we expected to find women to be overrepresented in the affected individuals' sample [2,4]. The gender balance within the respective subsample of affected individuals was at an expected ratio of 1:3. Finally, we did not assess information about future usage and continuation of usage and what reasons lead to discontinuation.

This survey provides information about usage and preferences toward eHealth app for the self-monitoring and self-management of depression. New mobile technologies and smartphone apps, especially in combination with mobile sensor systems, offer unique opportunities to overcome challenges in the treatment of depression by utilizing the potential of patient-generated data. Throughout any development process of such mobile smartphone apps or systems, a focus on patient-relevant data, security and safe handling of sensitive personal data, as well as degrees of freedom to share data with self-selected third parties should be considered mandatory. This can melt down barriers, make digital helpers much more attractive, and consequently sustain and ameliorate adherence.

Acknowledgments

This publication is supported by a grant of the Federal Ministry of Education and Research of Germany (project number 13GW0162B). All responsibilities for the content of this publication are assumed by the authors.

Conflicts of Interest

Within the last 3 years, UH was an advisory board member for Lundbeck, Takeda Pharmaceuticals, Servier and Otsuka Pharma. UH was a consultant for Bayer Pharma and a speaker for Bristol-Myers Squibb, Medice Arzneimittel, Novartis, and Roche Pharma. The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Multimedia Appendix 1

Patientenbefragung, Web-based German Questionnaire.

[PDF File (Adobe PDF File), 231KB - [mental_v6i4e11671_app1.pdf](#)]

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Abbreviations

GDF: German Depression Foundation

GPS: Global Positioning System

MDD: major depressive disorder

mHealth: mobile health

MSSD: mobile apps for the self-monitoring and self-management of depression

Edited by G Eysenbach; submitted 25.07.18; peer-reviewed by M Rawsthorne, D Estrin, K Mathiasen, Y Leykin; comments to author 08.10.18; revised version received 30.11.18; accepted 31.12.18; published 03.04.19.

Please cite as:

Hartmann R, Sander C, Lorenz N, Böttger D, Hegerl U

Utilization of Patient-Generated Data Collected Through Mobile Devices: Insights From a Survey on Attitudes Toward Mobile Self-Monitoring and Self-Management Apps for Depression

JMIR Ment Health 2019;6(4):e11671

URL: <https://mental.jmir.org/2019/4/e11671/>

doi: [10.2196/11671](https://doi.org/10.2196/11671)

PMID: [30942693](https://pubmed.ncbi.nlm.nih.gov/30942693/)

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Original Paper

Evaluating the Feasibility of an Innovative Self-Confidence Webinar Intervention for Depression in the Workplace: A Proof-of-Concept Study

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Abstract

Background: Depression in the workplace is a very common problem that exacerbates employees' functioning and consequently influences the productivity of organizations. Despite the commonness of the problem and the currently available interventions, a high proportion of employees do not seek help. A new intervention, a webinar (Web-based seminar), was developed, which integrated the use of technology and the traditional guided therapist support to provide accessible help for the problem of depression in the workplace.

Objective: The aim of this study was to explore the feasibility, preliminary outcome, and acceptability of the webinar intervention conducted in organizations.

Methods: In total, 2 organizations were invited to participate, and 33 employees participated in this proof-of-concept study. The webinar intervention consisted of 6 1-hour sessions conducted via the Adobe Connect platform, developed by Adobe Inc. The intervention was developed based on a systematic review, focus group studies, and face-to-face self-confidence workshops that utilized cognitive behavior therapy (CBT). The final webinar intervention used CBT and the coping flexibility approach. The structure of the intervention included PowerPoint presentations, animation videos, utilization of chat panels, and whiteboard features. The intervention was conducted live and guided by a consultant psychologist assisted by a moderator. Study outcomes were self-assessed using self-reported Web surveys. The acceptability of the intervention was assessed using self-reported user experience Web surveys and open-ended questions.

Results: The findings showed: (1) evidence of feasibility of the intervention: the webinar intervention was successfully conducted in 3 groups, with 6 1-hour sessions for each group, with 82% (23/28) participants completing all 6 sessions; (2) positive improvements in depression: the linear mixed effects modeling analysis recorded a significant overall effect of time primarily for depression ($F_{2, 48.813}=31.524; P<.001$) with a Hedge g effect size of 0.522 at 1-month follow-up. Individually, 8 subjects showed significant reliable and clinically significant changes, with 3 subjects showing clinically significant change only; and (3) encouraging evidence regarding the acceptability of the webinar intervention among the employees: the user experience score was above average for 4 out of 6 domains measured (perspicuity mean 1.198 [95% CI 0.832-1.564], efficiency mean 1.000 [95% CI 0.571-1.429], dependability mean 1.208 [95% CI 0.899-1.517], and stimulation mean 1.323 [95% CI 0.987-1.659]). The open-ended questions also yielded 52% (47/91) of the responses that reported facilitators, whereas only 12% (11/91) of the responses reported barriers.

Conclusions: The self-confidence webinar intervention appears to be a potentially feasible, effective, and acceptable intervention for depression in the workplace that merits further investigation.

(*JMIR Ment Health* 2019;6(4):e11401) doi:10.2196/11401

KEYWORDS

online; videoconferencing; cognitive behavioral therapy; depression; workplace

Introduction

Background

Depression has been shown to cost employers in Europe £77 billion each year [1]. However, despite the high prevalence of depression, employees are reluctant to seek help. One possible reason for this is that employees view seeking help as a sign of weakness rather than a medical condition that can be treated [2]. Obstacles to seeking help can also be seen in the general public. The general public often conceptualizes depressive symptoms as *problems of living* rather than symptoms of a mental illness [3]. Recent studies have found that interventions that used nondiagnostic labels such as *self-confidence* rather than depression are important in engaging groups who may prefer not to medicalize mental health [4,5]. This also provides an alternative and accessible route to psychological help, which is more congruent with the health beliefs of the public [5]. This self-confidence program has also been shown to maintain effects after 2 years [6].

Self-confidence workshops using a self-referral system, which were designed to be accessible to adults with depression in the community, found the workshops to be clinically effective and reached a large number of people who were reluctant to engage [5]. However, participants were largely not employed [5,7]. This suggested that a different approach would be needed for the workplace. It has been suggested that the workplace is an ideal setting to provide information about depression to employees [2].

A systematic review by Wan Mohd Yunus et al [8] reported that most evidence-based workplace interventions for depression were delivered face-to-face either individually or in groups. However, more recently, technological advances have been used in the mental health services and showed promising results, using methods such as interventions on the internet, software packages, and mobile apps. The integration of therapist support with technology-mediated interventions could also have a strong influence on new intervention processes and outcomes. It is likely that these technological advances could improve access and have other advantages such as reduced stigma, facilitating some people to share about sensitive issues, shortening waiting lists and cost-effectiveness [9]. Despite these available interventions, mental health services are still underutilized by employees [10,11].

Given the technological advances, the importance of depression in the workplace and the problems in reaching people with depression who are employed, a more interactive form of computerized cognitive behavior therapy (CBT) using a webinar (a seminar delivered over the Web) was developed. Using the self-confidence label to make the intervention more accessible

to people with depression, the webinar aimed to combine aspects of traditional face-to-face interventions and also take advantage of the technology that is currently available to develop an innovative webinar package for reducing depression in the workplace.

The intervention development process was in line with the Medical Research Council guideline for developing and evaluating complex interventions [12]. It involves a systematic review [8] and results from focus groups [13], as well as previous research by Brown et al [5,6,14,15] and Cheng et al [16,17]. The new intervention incorporates a self-confidence webinar delivered during working hours in the workplace and is, to our knowledge, the first webinar intervention developed to target depression in the workplace. This webinar also used the more *user-friendly* and nondiagnostic label of self-confidence to reach out to more people, especially to those who were previously reluctant to seek help [4,5,15]. This research reports on the preliminary findings of this new webinar intervention regarding its feasibility, preliminary outcomes, and acceptability, which was tested pragmatically with interested organizations.

Aim

The aim of this study was to assess feasibility, preliminary outcomes, and acceptability of running the self-confidence webinar in the workplace. This is in line with Eldridge et al's recommendation that feasibility studies should include *studies assessing whether a future study, project or, development can be done* [18].

Objectives

The first objective of this study was to assess whether the self-confidence webinar was feasible and whether the intervention could be implemented as planned. It was decided that the intervention would be feasible if these objectives were met:

1. At least 20 employees were recruited;
2. A total of 6 sessions were able to be conducted;
3. Dropout rates were below 32%;
4. Completion rates were at least 80% (participants attending all 6 sessions);
5. There were no major technical issues that significantly affected the running of each session.

The second objective was to investigate the preliminary outcomes of a self-confidence webinar to reduce depression and to investigate whether there was an improvement in other measures including anxiety, self-esteem, coping flexibility, absenteeism, and presenteeism. The third objective was to investigate the acceptability of the intervention and whether participants were satisfied with the intervention.

Methods

Design

This proof-of-concept study employs a single-group pre-post design. Assessments were taken at baseline, postintervention, and 1 month postintervention. The study was granted ethical approval by the King's College London Research Ethics Committee (LRS-14/15-0857).

Procedure of Recruiting Organizations and Participants

The recruitment processes involved several stages: (1) Identifying interested organizations; (2) initial communication with interested organizations; (3) meeting with line managers and well-being teams to obtain permission from the organization; (4) if the organization was interested, on-site testing of technical aspects of readiness for the webinar was conducted; (5) organizations were provided with information about the study, which was then disseminated to the organizations' employees. Employees thus received flyers and an information sheet about the webinar and research from the gatekeeper (the lead person from each organization). The information sheet included detailed information about the study, whereas the flyer included an invitation to the introductory meeting; and (6) If any employees were interested, they were asked to contact the first author and were invited to the introductory meeting held in an office in the organization. Alternatively, if they were unable to attend the introductory meeting, interested employees were provided with further information about the study. To maintain confidentiality, employees' managers were not informed about which employees had participated.

Before the webinar, consent from line managers or team leaders was obtained as the sessions were to be conducted during

Textbox 1. Main elements of each session.

Session 1: Introduction to self-confidence in the workplace

- Introduction to the whole program; self-confidence and challenges at work; the self-confidence model; how low self-confidence develops

Session 2: Thinking differently

- Negative automatic thoughts; understanding unhelpful thinking beliefs; identifying and challenging negative thoughts; distraction, thought stopping, and coping self-statements

Session 3: Changing our self-image

- Development of poor self-image; changing our self-image; what can influence my self-image; anxiety and performance

Session 4: What you can do (Part 1)

- Behavior and self-confidence; problem-solving skills; managing time effectively; brief relaxation

Session 5: What you can do (Part 2)

- Assertiveness; our support system; making change happen; setting our goals

Session 6: Being more flexible

- Coping flexibility concept; the process of coping flexibly; how to use coping strategies flexibly; case study

working hours, as this was a strong view from the focus group that was conducted before the webinar was offered [13].

Intervention

The Template for Intervention Description and Replication checklist and guide was employed to describe the intervention [19]. The self-confidence workshop program was offered as Web-based seminars using a Web-based webinar provider (Adobe Connect) with the participating employees. The webinar intervention for improving self-confidence lasted 6 weeks, with 1 session per week. Every session involved an hour-long live webinar, which included time for questions as well as homework. Each session involved a PowerPoint presentation with videos and comic strips, an *Interactive Zones* component where participants interacted with each other, a virtual whiteboard, use of the chat feature, and a webcam feature for the therapist. To attend the sessions, participants could use a computer, laptop, or mobile device including smartphones (iPhones or Android phones) and tablets (iPads and tablets). Thus, attendance at these sessions was possible wherever the internet was available. The content of the sessions was based on a cognitive-behavioral approach by Brown et al [5,6,14,15] and coping flexibility by Cheng et al [17] and is outlined in **Textbox 1. Multimedia Appendix 1** includes screenshots of the webinar sessions.

Measures

Depression

The Beck Depression Inventory II (BDI-II) is a widely recognized 21-item self-report inventory for the assessment of depressive symptoms. Each item consists of 4 statements scored on a scale ranging from 0 to 3 with higher scores indicating higher depressive symptoms. The scores can be calculated and categorized into 4 levels of severity: minimal (0 to 13); mild (14 to 19); moderate (20 to 28); and severe (29 to 63) [20].

Anxiety

The Beck Anxiety Inventory is a 21-item self-report inventory to assess overall anxiety. Respondents are asked to rate the severity of each symptom using a 4-point scale with higher scores reflecting higher anxiety. The sum of all items corresponds to 4 levels of severity: minimal anxiety (0 to 9); mild anxiety (10 to 16); moderate anxiety (17 to 29); and severe anxiety (30 to 63) [21].

Self-Esteem

The Rosenberg Self-Esteem Scale is a 10-item self-report inventory to measure individual self-esteem. Each item comprises a 4-point scale which contains 5 positively and 5 negatively worded items. The scores of all items are totaled with a higher score suggesting a higher level of self-esteem [22].

Coping Flexibility

Coping flexibility was measured using the 10-item Coping Flexibility Scale. This self-report inventory measures an individual's ability to evaluate coping strategies and adopt alternative coping strategies depending on the situation. Respondents are required to respond to the items on a 4-point scale, and the sum of all items represents the overall score of coping flexibility with a higher score indicating a higher level of coping flexibility [23].

Presenteeism and Absenteeism

The short form World Health Organization Health and Work Performance Questionnaire is a self-report inventory that measures absenteeism and presenteeism. For absenteeism, respondents respond to 8 items that relate to the number of hours lost per month, with a higher score indicating a higher amount of absenteeism. Absolute absenteeism is measured in raw hours where a negative lower bound suggests that employees work more than expected and a higher score indicates a higher amount of absenteeism. Relative absenteeism is expressed as the percentage of expected hours whereby a negative number suggests that individuals work more than expected, and a score of 1.0 suggests that the individual is always absent [24]. There are 3 items for presenteeism that correspond to reduced work performance with a higher score indicating a lower amount of lost performance. An absolute presenteeism score with a lower bound of 0 suggests a total lack of performance during the time on the job, whereas an upper bound of 100 indicates no lack of performance during the time on the job. For relative presenteeism, a minimum score of 0.25 indicates the worst relative performance compared with other employees, whereas a maximum score of 2.0 indicates the best performance compared with other employees [24].

User Experience Questionnaire for Acceptability Measure

The User Experience Questionnaire (UEQ) is a self-report inventory to assess the ability of a product to engage the user. It consists of 26 items grouped by 6 domains: Attractiveness, Efficiency, Perspicuity, Dependability, Stimulation, and Novelty. Each item is randomly ordered along a 7-point scale representing 2 graded contrasting attributes [25]. Values between

-0.8 and 0.8 represent a neutral evaluation of the corresponding scale. On the contrary, values >0.8 represent a positive evaluation, whereas values <-0.8 represent a negative evaluation. Although the range of the scale is between -3 (horribly bad) and +3 (extremely good), it is extremely unlikely to observe values above +2 or below -2 [26].

Open-Ended Satisfaction Questions

Additionally, 4 open-ended questions were also included in the postintervention Web-based questionnaire. The questions were as follows:

1. "If the webinar was to run again, can you please recommend things we should start doing that we are not currently doing?"
2. "What are the things we should stop doing that we did during this webinar that did not work for you?"
3. "What are the things that worked well that we should continue doing?"
4. "Please type in the space below if you have any other comments/feedback or suggestions about the webinar program."

Data Analysis for Outcome Measures

Descriptive statistics were used to report the scores at baseline (T_0), postintervention (T_1), and 1-month postintervention (T_2). The data were then analyzed using a mixed model analysis or a nonparametric Friedman test to analyze the difference in scores at T_0 , T_1 , and T_2 . For linear mixed effects modeling, the required assumptions were initially met for self-esteem and coping flexibility. Attempts to transform the data were performed on other variables but were only successful for depression and anxiety by using square root transformation. For absolute absenteeism, relative absenteeism, absolute presenteeism, and relative presenteeism variables, the nonparametric Friedman test was performed.

Effect sizes and reliable and clinically significant changes were computed using data from completers at 1-month follow-up as well as those who only provided postintervention data but did not respond to the follow-up. Postintervention data were used instead if the follow-up data were not available.

The standardized effect size was calculated using both Cohen d_{av} and Hedge g correction. Lakens [27] recommended the use of Cohen d_{av} for within-subject research design but because this is positively biased as it is based on a sample estimate, Hedges g_{av} correction was also applied. The effect size (Hedge g_{av}) of the change in scores was calculated manually using a scientific calculator based on the following formula:

$$\text{Hedges } g_{av} = M_{\text{diff}} / [(SD_1 + SD_2)/2] \times [1 - 3/[4(n_1 + n_2) - 9]]$$

The reliable and clinically significant changes for depression were calculated using the following formulas [28-30]:

$$\text{Reliable Change Index (RCI)} = \sqrt{2 [SD_{\text{pre}} \times \sqrt{1 - \alpha}]}^2 \times 1.96$$

$$\text{Clinically significant change} = [(mean_{\text{clin}} \times SD_{\text{norm}}) + (mean_{\text{norm}} \times SD_{\text{clin}})] / (SD_{\text{norm}} + SD_{\text{clin}})$$

The number of participants and their depression level classification at each time point are also described.

Results

Participating Organizations

In total, 2 participating organizations were recruited. One organization was an administrative body funded directly by the government. The other organization was a local authority of one of the 32 London borough councils in the United Kingdom.

Participants

In total, 33 employees volunteered to participate. Table 1 displays the demographic characteristics of the study participants.

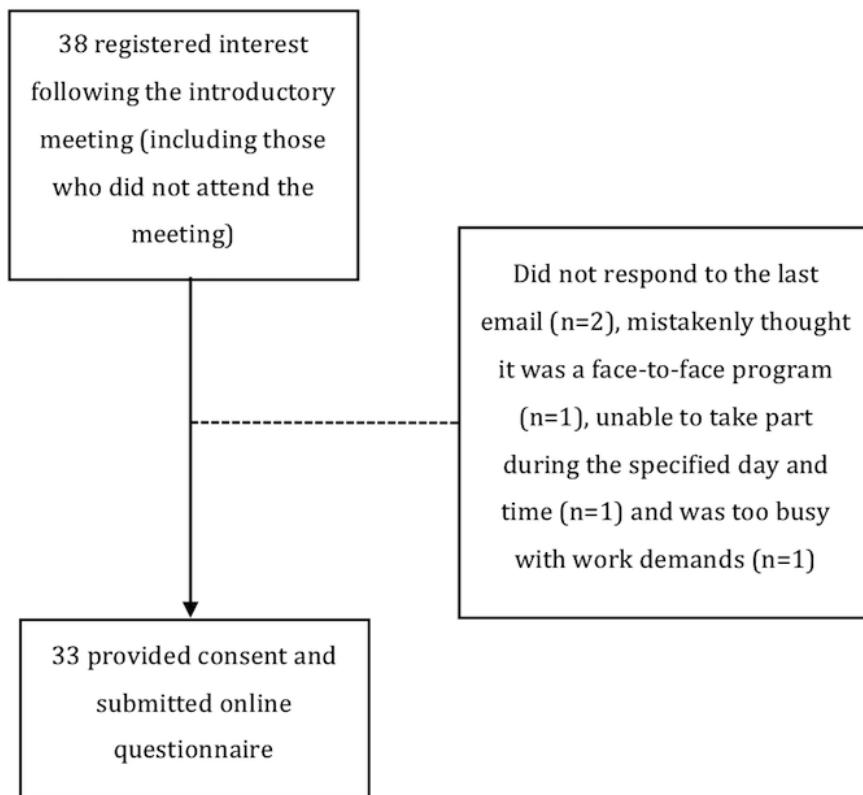
Objective 1: Feasibility of the Self-Confidence Webinar

All feasibility criteria were met, indicating that the self-confidence webinar was feasible for a larger study in the future. This study showed that:

1. 33 employees were recruited;
2. The webinar was successfully conducted for 3 groups, with 6 sessions for each group;
3. The dropout rate was 24% (8/33);
4. All 6 sessions were completed by 82% (23/28) participants;

Table 1. Demographic characteristics (n=33).

Demographics	Statistics
Age (years), mean (range)	39.6 (21-62)
Gender, mean (SD)	
Female	30 (90.9)
Male	3 (9.1)
Marital status, mean (SD)	
Single	12 (36.4)
Married or civil partnership	10 (30.3)
Living together	9 (27.3)
Divorced	2 (6.1)
Highest level of education, mean (SD)	
University degree	17 (51.5)
Postgraduate degree	6 (18.1)
A level or National Vocational Qualification	5 (15.2)
Diploma or Business and Technology Education Council	5 (15.2)
Ethnicity, mean (SD)	
White—English or Welsh or Scottish or Northern Irish or British or Irish or any other white background	18 (54.5)
Black or African or Caribbean or black British—Caribbean or African	6 (18.2)
Asian or Asian British—Indian or Bangladeshi or any other Asian group	6 (18.2)
Mixed or multiple ethnic groups—white and black Caribbean or white and black African	3 (9.1)
Work experience (years), median (range)	18 (2-45)

Figure 1. Summary of the recruitment process.

In total, 2 organizations participated and each held one introductory session. Owing to the timing preferences of the employees, 3 webinar groups were held for 33 participants. The webinar presenter and first author, who acted as the moderator, conducted all 6 sessions of the webinar, giving a total of 18 sessions conducted for the 3 groups.

Of the 33 participants who initially registered, 28 took part in the first session and 25 took part in the sixth session, meaning 8 participants dropped out (24%). However, if only those who attended session 1 are included, the dropout rate was only 11% (3/28). Notably, 82% (23/28) participants completed all 6 sessions and 86% (24/28) participants completed at least 4 sessions. The reasons for not being able to attend the live session included attending other meetings and being on leave. The follow-ups at postintervention and at 1-month postintervention

were conducted over the Web and blind-carbon copies, with reminder emails, were also sent intermittently. A total of 73% (24/33) postintervention questionnaires were obtained at postintervention and 70% (23/33) questionnaires obtained at 1-month follow-up.

Objective 2: Preliminary Outcomes of the Self-Confidence Webinar

Descriptive Data

Table 2 shows the means and SDs of the outcome measure scores. Depression, anxiety, absolute absenteeism, and relative absenteeism decreased at T₁ and T₂, whereas self-esteem, coping flexibility, absolute presenteeism, and relative presenteeism increased at T₁ and T₂.

Table 2. Means and SDs of outcome measure scores. T₀: baseline; T₁: postintervention; T₂: 1-month postintervention.

Measures	T ₀ (n=33), mean (SD)	T ₁ (n=24 ^a), mean (SD)	T ₂ (n=23 ^a), mean (SD)
Depression	13.91 (9.77)	8.63 (8.71)	9.09 (8.47)
Anxiety	11.42 (9.17)	10.42 (10.98)	9.09 (9.96)
Self-esteem	18.15 (4.87)	19.63 (5.75)	20.09 (5.67)
Coping flexibility	14.27 (6.17)	18.42 (4.93)	18.96 (5.14)
Absolute absenteeism	8.52 (27.51)	1.54 (17.30)	5.20 (25.58)
Relative absenteeism	0.06 (0.20)	0.02 (0.15)	0.03 (0.18)
Absolute presenteeism	57.58 (14.15)	69.58 (15.46)	71.30 (13.92)
Relative presenteeism	0.78 (0.18)	1.01 (0.23)	1.19 (0.65)

^aOnly available data are included.

Linear Mixed Effects Modeling

To get a preliminary estimate of the improvement in the outcome measures in a group of participants for the webinar intervention, linear mixed effect modeling was conducted. Time of assessment (T_0 , T_1 , and T_2) was included as a main effect in the fixed factors of the model to account for the 3 different time points of the assessment. A random intercept by participants was included in the model to account for the different scores at baseline. An autoregressive -AR(1) covariance matrix was used to account for constant variance at each time point assuming that the

correlation gets less as time points get further apart (T_0 , T_1 , and T_2). Maximum Likelihood estimation was therefore chosen to fit the models.

The overall effect of time was significant for all measures: depression ($F_{2,48.813}=31.524$; $P<.001$), anxiety ($F_{2,49.428}=3.945$; $P=.03$), self-esteem ($F_{2,49.519}=31.524$; $P=.02$), and coping flexibility ($F_{2,48.623}=14.184$; $P<.001$). Table 3 shows the summary of the result of the mixed models analyses for depression, anxiety, self-esteem, and coping flexibility.

Table 3. Pairwise comparison from linear mixed effects modeling analysis. T_0 : baseline; T_1 : postintervention; T_2 : 1-month postintervention.

Time point	Depression ^a		Anxiety ^a		Self-esteem		Coping flexibility	
	Mean (95% CI)	<i>P</i> value	Mean (95% CI)	<i>P</i> value	Mean (95% CI)	<i>P</i> value	Mean (95% CI)	<i>P</i> value
T_0	3.492 (3.030-3.954)	— ^b	3.064 (2.529-3.599)	—	18.152 (16.375-19.928)	—	14.273 (12.371-16.175)	—
T_1	2.400 (1.920-2.880)	—	2.717 (2.159-3.276)	—	19.510 (17.651-21.369)	—	18.550 (16.487-20.613)	—
T_2	2.514 (2.001-2.993)	—	2.415 (1.836-2.994)	—	20.324 (18.394-22.254)	—	19.380 (17.217-21.542)	—
T_0 versus T_1	1.092 (0.751 to 1.433) ^{c,d}	<.001	0.346 (-0.078 to 0.770) ^{c,d}	.14	-1.359 (-2.813 to 0.095) ^{c,d}	.07	-4.277 (-6.434 to -2.120) ^{c,d}	<.001
T_0 versus T_2	0.995 (0.530 to 1.460) ^{c,d}	<.001	0.649 (0.075 to 1.223) ^{c,d}	.02	-2.173 (-4.133 to -0.212) ^{c,d}	.02	-5.107 (-7.861 to -2.353) ^{c,d}	<.001

^aDue to non-normality of the residuals, square root transformation was performed.

^b—: not applicable.

^cSignificance level $P<.05$.

^d M_{diff} (95% CI).

Friedman Tests

Both absolute and relative absenteeism were maintained throughout the 3 time points at T_0 , T_1 , and T_2 (median=0), and the differences were not statistically significant (absolute absenteeism, $\chi^2_2=2.358$; $P=.31$; Relative absenteeism, $\chi^2_2=1.701$; $P=.43$).

For presenteeism outcomes, pairwise comparisons were performed with a Bonferroni correction for multiple comparisons. Absolute presenteeism was statistically significantly different at the different time points during the study period; $\chi^2_2=22.116$; $P<.001$. A posthoc analysis revealed statistically significant differences in absolute presenteeism from T_0 (median=60.00) to T_1 (median=70.00; $P=.006$) and T_0 to T_2 (median=80.00; $P<.001$). Relative presenteeism was statistically significantly different at the different time points during the study period; $\chi^2_2=26.325$; $P<.001$. A posthoc analysis revealed statistically significant differences in absolute presenteeism from T_0 (median=0.750) to T_1 (median=1.000; $P=.002$) and T_0 to T_2 (median=1.125; $P<.001$).

Effect Sizes

The results are summarized in Table 4. Overall, improvements were recorded for all measures at T_1 and T_2 when compared with T_0 with the highest effect size recorded for presenteeism measures, followed by coping flexibility and depression. The positive Hedges g_{av} indicated a reduction in scores, whereas the negative Hedges g_{av} indicated an increase in scores.

Reliable Change

The reliable and clinically significant change analysis only includes participants who completed the assessment at all 3 time points or those who completed the assessment at T_0 and T_1 or T_2 . The SD of the BDI-II at baseline (SD_{pre}) was 10.18, whereas the calculated Cronbach alpha was .92. The calculated RCI was 7.98. Thus, the changes in BDI-II scores can be categorized into 3 groups: a reliable increase in depression symptoms (an increase of 8 points more on the BDI-II), no reliable change (less than 8 points increase or decrease on the BDI-II), and reliable improvement in depression symptoms (a reduction of 8 points or more on the BDI-II). On the basis of the data in Table 5, a total of 35% (9/26) participants showed reliable change and a reduction in depression symptoms. In contrast, 65% (17/26) participants showed a change smaller than this.

Table 4. Hedges g_{av} effect sizes of outcome measure scores. T_0 : baseline; T_1 : postintervention; T_2 : 1-month postintervention.

Measures	Hedges g_{av}	
	T_0 versus T_1	T_0 versus T_2
Depression	0.563	0.522
Anxiety	0.098	0.240
Self-esteem	-0.275	-0.363
Coping flexibility	-0.738	-0.817
Absolute absenteeism	0.307	0.123
Relative absenteeism	0.219	0.156
Absolute presenteeism	-0.799	-0.963
Relative presenteeism	-1.107	-0.962

Table 5. Cross tabulation summary of reliable change against clinically significant change.

Clinically significant change (score criterion of >12)	Total at baseline	Reliable change postintervention (change of score of >8)	
		Yes	No
Started lower than the criterion for clinically significant change (baseline score <12)	10	0	10
Started higher than the criterion but failed to achieve clinically significant change (baseline score >12 but postintervention score still >12)	5	1	4
Clinically significant change (baseline score >12; postintervention score <12)	11	8	3
Total	26	9	17

Clinically Significant Change

To calculate this change, normative data from a community sample of 7500 respondents in another European study using BDI-II were used, which showed a mean score of 10.6 and an SD of 10.9 [31]. Hence, using the formula in the Methods section, the clinically significant change criterion score was calculated to be 12.34. In summary, 38% (10/26) participants started with baseline BDI-II scores below the criterion and therefore did not show clinically significant change and none showed reliable improvement. In total, 19% (5/26) participants started with baseline scores above the criterion but failed to improve to a lower score below the criterion, with 4% (1/26) participant showing reliable improvement. In total, 12% (3/26) participants did not record reliable change despite recording clinically significant change. This suggests that it is not sufficient to imply that the change is not influenced by simple measurement unreliability [28]. Finally, 42% (11/26) participants showed clinically significant change, of whom 31% (8/26) also showed reliable improvement. **Table 5** summarizes the data for reliable and clinically significant change.

Depression Level at Different Time Points

The distribution of scores for depression at each time point is presented in **Figure 2**. The figure only includes available data

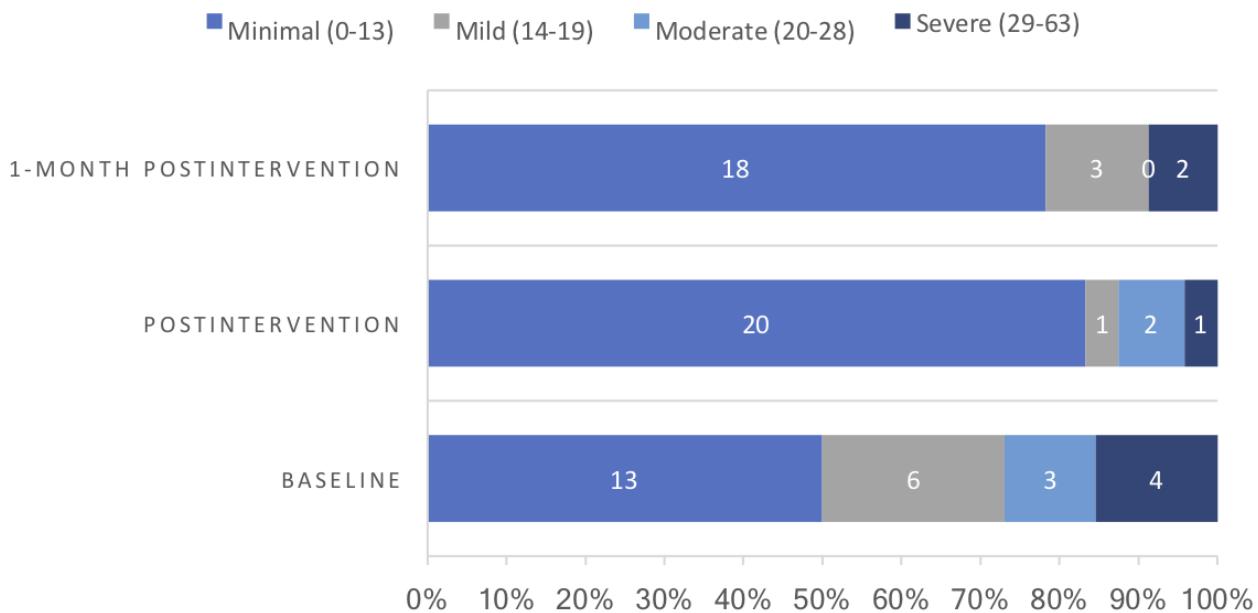
at the 3 time points. At baseline, nearly a quarter of the participants had a moderate-to-severe level of depression symptoms. Generally, improvement was observed in terms of the depression severity when compared with baseline. The percentage of employees in moderate and severe depression severity decreased when compared with baseline.

Objective 3: Acceptability of the Self-Confidence Webinar

User Experience

On the basis of the result of the UEQ, participants reported satisfaction in all domains: Attractiveness, Perspicuity, Efficiency, Dependability, Stimulation, and Novelty.

Although figures are not available for comparing the webinar intervention with any other type of psychological intervention, the UEQ is able to compare the measured user experience with the results from 163 different types of products such as business software, Web pages, Web shops, and social networks with a total of 4818 participants [26]. **Table 6** displays the user experience results and the interpretation of the results of the webinar intervention compared with the user experience of other products.

Figure 2. Distribution of scores for depression.**Table 6.** Interpretation of the webinar intervention in comparison with other interactive products.

Scale	Mean (95% CI)	Relative comparison to other products	Interpretation
Attractiveness	1.618 (1.242-1.994)	Good	10% of results better; 75% of results worse
Perspicuity	1.198 (0.832-1.564)	Above average	25% of results better; 50% of results worse
Efficiency	1.00 (0.571-1.429)	Above average	25% of results better; 50% of results worse
Dependability	1.208 (0.899-1.517)	Above average	25% of results better; 50% of results worse
Stimulation	1.323 (0.987-1.659)	Above average	10% of results better; 75% of results worse
Novelty	1.083 (0.718-1.449)	Good	10% of results better; 75% of results worse

Open-Ended Questions

Facilitators, barriers, suggestions, and general comments were analyzed separately using qualitative content analysis on each question using Microsoft Excel. As this was likely to be the first study exploring the application of a webinar intervention within the workplace setting, an inductive approach was chosen [32]. The responses were divided into 4 main categories: facilitators 52% (47 out of 91), barriers 12% (11 out of 91), suggestions 14% (13 out of 91), and general comments 22% (20 out of 91). Example quotes from the feedback corresponding to each category are presented in the [Multimedia Appendix 2](#).

Discussion

Principal Findings

The findings of this study indicate that the innovative self-confidence webinar intervention is feasible, and positive improvements were observed particularly on depression, presenteeism, and other outcome measures. Moreover, employees also reported that the webinar intervention was very acceptable.

Feasibility

The webinar recorded low dropout rates and high completion rates among employees who registered. Although the sample size was small, the self-confidence webinars also had low dropout rates with high completion rates among those who attended the first session. Of the 33 registered participants, 25 (76%) completed the final session, giving a dropout rate of 24%. Of the 85% (28/33) participants who attended the first session, 82% (23/28) completed all 6 sessions, giving a dropout rate of 18%. These figures are favorable than the completion rates (66%) in a much larger multicenter randomized controlled trial (RCT) of face-to-face psychoeducational CBT workshops [5] and multiservice practice research using the Stress Control (SC) program that recorded a completion rate of 70% [33]. The SC program study highlights the importance of participants' subsequent attendance as one of the predictors for a positive outcome.

There is much evidence of the high dropout rate for computerized CBT. A systematic review on barriers and uptake of computerized CBT reported that those receiving computerized CBT were twice as likely to drop out as those receiving face-to-face CBT [34]. Another meta-analysis on computer-based psychological treatment for depression however found a variation and reported a dropout rate of 28% for interventions with therapist support, 38.4% for administrative

support, and 74% for no support [35]. The dropout rate of 24% found in this study is therefore comparable with that of supported psychological therapies.

The fact that the presenter and moderator played significant roles in the webinar throughout all sessions indicates that it was a highly guided intervention. Hence, the dropout rates and completion rates among the webinar participants were comparable with other guided internet interventions. A meta-analysis review of the dropout rates for guided internet interventions compared with face-to-face interventions showed no significant difference [36]. Moreover, the percentage of completed sessions by the subjects was also found to be comparable between guided internet-based interventions and face-to-face interventions for depression. A study reported that the mean completion rate for face-to-face CBT was 83.9%, whereas the mean completion rate for guided internet CBT was 80.8% [37]. The review highlights the importance of the guided component within a technology-mediated intervention.

It is also important to note that the self-confidence webinar was accessed by employees in different age ranges (range=21-62; mean 39.6), as age has been found to be a highly significant factor in accessibility and utilization of the internet and new technology [38]. It has been argued that the use of the internet falls off sharply with age, owing to factors such as attitudinal beliefs, age-related changes, cognitive barriers, and privacy concerns [39]. It was not found to be the case with the webinar.

However, there are several challenges that need to be highlighted. First, the difficulties in the recruitment process of organizations need to be mentioned. One organization had undergone restructuring during the study period, which involved the movement of employees, which in turn affected the communication between the first author and the organization. Olsen et al [40] highlighted these challenges and suggested that changes in the organizations should be considered when planning intervention studies; this, in turn, can cause delays and communication problems with the research.

Another aspect was the competing time commitments of employees. Owing to the live nature of the webinar, employees are required to access the webinar intervention during a predetermined date and time. Although recorded versions of the webinar were available, it was felt that the learning experience and contribution of participants would be more restricted than attending live sessions. When this problem did occur, employees were provided with the full recording of that particular webinar session. With this, they were able to follow the session asynchronously and obtain some input about the session.

Technical barriers to accessing the webinar program may be important. For instance, in one of the organizations, there was an initial difficulty in accessing the webinar program because of the tight internet security settings used by the organization. This was used to restrict the use of internet connection to only Web pages and links that were directly related to work. Although this issue was successfully overcome, it is important for future research to take note of this problem and make sure that on-site testing is conducted before the intervention is implemented. Furthermore, it is important to make sure that the computer,

laptop, or mobile devices fulfill the minimum technical specification required to run the webinar program.

Outcomes

The follow-up results after 1 month suggested positive changes for all outcome measures. For depression, the analysis indicated that symptoms of depression significantly improved at postintervention and 1 month postintervention compared with baseline with moderate effect sizes of 0.563 and 0.522, respectively. This result was lower than the 0.844 effect size obtained in the RCT study of group face-to-face self-confidence workshops to reduce depression for the public [5]. Nevertheless, the outcome of this webinar study suggested that adaptations to the intervention content, through a webinar platform, produce encouraging results for the intervention in the workplace, especially considering that this is a universal intervention. This small pre-post study provides preliminary support for the position that a guided webinar form of delivery of an intervention can provide positive effects for individuals.

Notably, although the intervention was presented as *self-confidence* and targeted self-esteem, it was interesting that the difference in effect sizes for self-esteem was less significant than that of depression with recorded effect sizes of 0.563 postintervention and 0.522 at follow-up for depression and -0.275 postintervention and -0.363 at follow-up for self-esteem. More importantly, this may suggest that the use of a nondiagnostic label of *self-confidence*, compared with the more medicalized label of *depression*, was successful in attracting people with some degree of depression. Consistent with other studies, the use of a diagnostic label, such as *depression* or *insomnia*, may affect the uptake and engagement of intervention with people who would prefer not to medicalize mental health [4,5,15].

An important finding from this study was that the largest effect size found at 1 month postintervention was for the outcome measurement of presenteeism (absolute presenteeism=-0.963 and relative presenteeism=-0.962). This is a significant finding as the intervention contributes a positive impact to work-related outcomes such as presenteeism.

Although the positive outcomes may be contributed to by intervention content, it is also important to highlight the *group* nature of the webinar. During each session, participants interacted with other participants, as well as the webinar presenter; this was especially the case during the *interactive zones*. Previous studies have provided the benefits of group intervention, such as providing natural social networks, being cost-effective and more accessible, providing opportunities to learn and support others, having less stigma, and obtaining more neutral views from other participants rather than the therapist, as well as being useful for those who are uncomfortable or struggle with individual intervention [41-44].

Owing to the universal nature of the intervention, it was expected that participants would consist of those with mixed levels of self-reported depression. It follows that there were participants with few or no depressive symptoms reported at baseline as well as participants with varying depressive severity levels, supporting the findings from a systematic review that

universal interventions also attract those with higher levels of depression [8]. The mean score for depression among the participants was 13.91 on the BDI-II, indicating mild depression. More importantly, in line with previous self-confidence workshops that used a self-referral system and where 75% met diagnostic levels of problems [7], the webinar intervention also attracted those with higher levels of depression and not just those who are *worried well*.

Acceptability of the Self-Confidence Webinar

The majority of webinar participants gave positive and encouraging feedback about the acceptability of the self-confidence webinar. In terms of user experience, participants indicated that they really liked the webinar and found it to be attractive. In line with Daft and Lengel's Media Richness Theory [45], the webinar can be considered as a *rich* medium as it utilizes a number of different channels and cues to enhance the effectiveness of the communication. The participants also reported it to be exciting and motivating, suggesting most stayed throughout the program. Additionally, they also found it easy to use, felt in control, and able to use the webinar effortlessly, as well as considered it innovative and creative.

Furthermore, positive facilitator factors were identified; the *interactive zones* and content recorded the highest number of positive feedback comments. The webinar consists of 2 main components: visual (eg, share visual files, webcam, and virtual whiteboard) and audio (eg, telephone or voice over internet protocol) components that provide different ways to facilitate interaction [46]. It is reassuring that participants found the content and intervention to be useful for them, indicating that the material had been well-adapted for this purpose. Most of the positive feedback was related to the implementation of the *interactive zones*, which was the main adaptation made to allow engagement between participants and the webinar's presenter. This is encouraging, as this finding suggests that the application of a Web-based interaction platform through the webinar was well-received by the intervention participants. Previous evidence has also reported that webinars with its interactive features may facilitate participant interaction while being capable of providing a communication environment that is nearly the same as a face-to-face environment [47]. Notably, an important element of the webinar is the presence of a therapist and moderator. Moreover, with consent from the participants, each session was also recorded, and the participants could access the session anywhere and anytime. These benefits are in line with the findings from a Delphi study that highlighted the importance of effective moderation within an online discussion forum and 24-hour mobile access for the design of a Web-based intervention [48].

An important feature of the webinar that emerged during the study was that it can be accessible without restricting geographical context. In this study, a participant reported attending a session from abroad during a 3-week holiday. Another participant also reported attending a session at home while on leave rather than at work. Even with limited evidence, this study showed that some of the barriers to accessing

treatment, which may be present in normal face-to-face intervention, were overcome in the webinar intervention.

Limitations and Future Directions

There were several limitations of this study. First, the timeframe and nature of the recruitment process made it possible to only have an intervention group with no control group. The absence of a control group means it is not possible to determine whether the improvement in outcome scores is because of the intervention or other factors not covered in the study, such as time or a placebo effect. Second, the small sample size limits the ability to generalize from these results about other employees in other organizations. Hence, the results and conclusions derived from this study need to be interpreted with caution. Third, the unbalanced number of male and female participants may limit the extent to which the results can be generalized to males. Although this is a common pattern among mental health intervention studies, it needs to be noted. Fourth, all outcome measures were based on self-reports, which limits the quality of the data; this was the case for the absenteeism measure. Access to data on absenteeism via the participating organizations was not planned nor deemed feasible within the research timescale. Finally, the study only utilizes a short follow-up (1 month postintervention). This short follow-up time limits the study findings to the short-term only.

Given the promising results, there needs to be further evaluation of the effectiveness of the intervention. This can be done gradually by starting with a simpler research design (eg, nonrandomized control trial) to a more complex research design (eg, RCT), depending on the feasibility, timeframe, and available expertise. Additionally, it would be more informative to assess the effects of the webinar intervention with longer follow-up (eg, 3 months). Given that this is a universal intervention, the intervention can be compared with other forms of universal interventions in the workplace as well as with a wait-list control group. As this was a complex intervention, further investigations are also needed in terms of understanding the active ingredients and change processes through a mediation and mediator analysis, as well as assessing the cost-effectiveness. These figures can then be compared with those for other face-to-face or internet interventions.

As this intervention is designed for employees within the workplace, it is also important to consider the study design possibilities bearing in mind the hierarchical nature of the organization, in which employees can be nested in teams and departments within the organization's organizational structure. In relation to this, future trials may consider cluster randomization as opposed to individual randomization considering that each employee is usually attached to the work structure of their respective teams or departments or organizations. Additionally, future trials need to also include procedures and time for recruiting at the organization and individual levels, which involved identifying and recruiting interested organizations, obtaining organizational permission and agreement, on-site technical readiness assessment, and introductory meetings as well as recruiting employees.

Conclusions

This proof-of-concept study provides preliminary evidence that self-confidence webinars can be a potentially feasible, effective, and acceptable intervention for depression in the workplace. The webinar intervention appears to be feasible as indicated by the successful recruitment of employees, the webinar sessions successfully running, relatively low dropout, and high completion rates as well as no major technical issues. The outcome analysis reported a lower level of depression, anxiety, absenteeism, and presenteeism as well as improved self-esteem and coping flexibility among employees postintervention and

1 month after completion of the intervention. It has also been shown to be acceptable.

In addition to its potential effectiveness in an RCT, the self-confidence webinar intervention is likely to be acceptable among employees in the workplace. Apart from its accessibility advantage, the webinar offers an interactive environment that may not be possible in other technology-mediated or face-to-face interventions. The webinar was able to maintain some elements of face-to-face intervention while utilizing economical delivery and technological features that were available. This may serve as an alternative and fruitful way of reaching depressed people in the workplace.

Acknowledgments

WMAWMY was a PhD candidate funded by a scholarship from the Malaysian Ministry of Education under Universiti Teknologi Malaysia without which this research could not be possible. The funder had no involvement in the conduct of the research.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Screenshots during the webinar sessions.

[[PDF File \(Adobe PDF File, 5MB - mental_v6i4e11401_app1.pdf](#)]

Multimedia Appendix 2

Example quotes from the feedback corresponding to each category.

[[PDF File \(Adobe PDF File, 54KB - mental_v6i4e11401_app2.pdf](#)]

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Abbreviations

BDI-II: Beck Depression Inventory II

CBT: cognitive behavior therapy

RCI: Reliable Change Index

RCT: randomized controlled trial

SC: stress control

UEQ: User Experience Questionnaire

Edited by G Eysenbach; submitted 10.07.18; peer-reviewed by M Deady, S Pezaro; comments to author 07.10.18; revised version received 13.12.18; accepted 10.02.19; published 26.04.19.

Please cite as:

Wan Mohd Yunus WMA, Musiat P, Brown JSL

Evaluating the Feasibility of an Innovative Self-Confidence Webinar Intervention for Depression in the Workplace: A Proof-of-Concept Study

JMIR Ment Health 2019;6(4):e11401

URL: <http://mental.jmir.org/2019/4/e11401/>

doi: [10.2196/11401](https://doi.org/10.2196/11401)

PMID: [31025943](https://pubmed.ncbi.nlm.nih.gov/31025943/)

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Original Paper

Use of a Mobile Phone App to Treat Depression Comorbid With Hypertension or Diabetes: A Pilot Study in Brazil and Peru

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Abstract

Background: Depression is underdiagnosed and undertreated in primary health care. When associated with chronic physical disorders, it worsens outcomes. There is a clear gap in the treatment of depression in low- and middle-income countries (LMICs), where specialists and funds are scarce. Interventions supported by mobile health (mHealth) technologies may help to reduce this gap. Mobile phones are widely used in LMICs, offering potentially feasible and affordable alternatives for the management of depression among individuals with chronic disorders.

Objective: This study aimed to explore the potential effectiveness of an mHealth intervention to help people with depressive symptoms and comorbid hypertension or diabetes and explore the feasibility of conducting large randomized controlled trials (RCTs).

Methods: Emotional Control (CONEMO) is a low-intensity psychoeducational 6-week intervention delivered via mobile phones and assisted by a nurse for reducing depressive symptoms among individuals with diabetes or hypertension. CONEMO was tested in 3 pilot studies, 1 in São Paulo, Brazil, and 2 in Lima, Peru. Depressive symptoms were assessed using the Patient Health Questionnaire-9 (PHQ-9) at enrollment and at 6-week follow-up.

Results: The 3 pilot studies included a total of 66 people. Most participants were females aged between 41 and 60 years. There was a reduction in depressive symptoms as measured by PHQ-9 in all pilot studies. In total, 58% (38/66) of the participants reached treatment success rate (PHQ-9 <10), with 62% (13/21) from São Paulo, 62% (13/21) from the first Lima pilot, and 50% (12/24) from the second Lima pilot study. The intervention, the app, and the support offered by the nurse and nurse assistants were well received by participants in both settings.

Conclusions: The intervention was feasible in both settings. Clinical data suggested that CONEMO may help in decreasing participants' depressive symptoms. The findings also indicated that it was possible to conduct RCTs in these settings.

(*JMIR Ment Health* 2019;6(4):e11698) doi:[10.2196/11698](https://doi.org/10.2196/11698)

KEYWORDS

depression; mHealth; pilot study; feasibility study; PHQ-9

Introduction

Background

Depression is a leading cause for the burden of disease worldwide, with 4.4% of the world's population suffering from depression [1,2]. Depression is associated with poverty, low education, and social exclusion, all of them more common in low- and middle-income countries (LMICs) [3-5]. Depression is also associated with chronic physical diseases and disabilities [3,6]. The comorbidity of depression with other chronic diseases worsens the outcomes in physical and mental conditions, decreases quality of life, and increases the economic burden [3,7-10].

In LMICs, people with depression are commonly underdiagnosed and undertreated [5]. One in every 27 people with depression receive treatment and only 15% of these receive adequate care [11]. There are marked staff shortages in LMICs, especially of the more specialized resources such as psychiatrists, psychologists, and psychiatric nurses [5,12]. Much of this gap has to be covered through the strategy of task shifting or transferring responsibilities for the care of the mentally ill to a lower cadre of health workers [13]. However, task shifting also requires resources to identify, train, and supervise nonspecialized health care workers or lay counsellors, which are frequently not available, making it difficult to scale it up in many environments. Digital mental health technologies, which can provide treatment to patients via apps and connect patients to a care coordinator, can simplify care coordination tasks, reducing the amount of training, thereby providing a more scalable process [14]. There is a growing body of evidence that mobile interventions for common mental health problems, such as depression and anxiety, delivered through an app can be effective in reducing symptoms. Whether they are more effective when accompanied by support from a coach or care coordinator than stand-alone solutions is still controversial [15].

The Latin America Treatment and Innovation Network in Mental Health seeks to develop and test a blended intervention for depression and comorbid chronic health problems such as hypertension and/or diabetes. We developed *Emotional Control* (CONEMO), a low-intensity psychoeducational 6-week intervention delivered via mobile phones assisted by a nurse for reducing depressive symptoms among individuals with diabetes or hypertension.

The intervention aims to reduce depressive symptoms among patients with comorbid diabetes or hypertension recruited from different health service units in São Paulo (Brazil) and Lima (Peru). Therefore, the focus of this project is on providing patients tools through mobile phones, with low-intensity support that can be provided in minimal time by nurses or nurse assistants (NAs), who are available in the clinics but have no specialized training in mental health. These professionals receive specialized supervision provided by the study staff to perform their tasks. This intervention is unique in LMICs in terms of

using a technological platform and integrating the care of chronic mental and physical conditions [16].

Objectives

This pilot study aimed to:

1. Explore the potential effectiveness and feasibility of using the CONEMO intervention to help people with or hypertension or diabetes and comorbid depressive symptoms;
2. Test recruitment strategies to estimate how many participants should be screened to reach our target sample for fully powered randomized controlled trials (RCTs);
3. Assess acceptability and satisfaction of patients with the CONEMO intervention.

Methods

Study Design, Settings, and Participants

We conducted 3 pilot studies between 2015 and 2016, of which 1 was in São Paulo, Brazil, and 2 in Lima, Peru. São Paulo is the largest city of Brazil with 11.2 million inhabitants [17]. Brazil offers universal health coverage to its population with primary care playing a key role. The Family Health Care Strategy (FHCS) aims to provide primary care close to where inhabitants live through family health teams composed of 1 family or general physician, 1 nurse, 2 NAs, and 5 to 6 community health agents [18]. Currently, there are more than 43,000 Family Health Teams covering 65% of the total population in the country and 40% of the population in the city of São Paulo [19]. A large survey estimated that approximately 10% of the population in São Paulo fulfilled criteria for major depression in the past 12 months, with 80% presenting moderate-to-severe depression [20]. A recent census indicated that Brazil currently has 5 psychiatrists per 100,000 inhabitants, but the majority work only in the private sector.

Lima, the capital of Peru, has approximately 9 million inhabitants, one-third of the total Peruvian population [21]. The prevalence of depression has been estimated as 17.5% [22]. In Peru, health care is offered both in public and private sectors, from the primary to tertiary care level, and although the current mental health reform is aiming at shifting mental health care toward a community approach, the majority of mental health care is still restricted to tertiary care-level facilities [23]. The Peruvian health care system is administered by different entities: the Ministry of Health (MINSA; covering 60% of the population), EsSalud, which is a social and health insurance for employees (30% coverage), and armed forces, police, and private sector (covering the remaining 10%) [24]. In Peru, there are 0.6 psychiatrists per 100,000 inhabitants, well below the average for LMICs.

In São Paulo we conducted the pilot study with 4 teams from 2 FHCS clinics. In Lima, the first pilot study took place in the endocrinology and cardiology outpatient consultation area of a tertiary-level hospital from the MINSA, whereas in the second

pilot, patients were recruited in 2 primary care health centers, mostly in the elderly adult consultation programs, where people with noncommunicable diseases are monitored, at EsSalud.

Participants were eligible according to the following inclusion criteria:

1. Aged 21 years or above;
2. Had hypertension or diabetes;
3. Had depressive symptoms, evaluated by the PHQ-9 (score ≥ 10); and
4. Self-reported reading ability in Portuguese (São Paulo) or Spanish (Lima).

The exclusion criteria were as follows:

1. Psychosis symptoms detected by a 5-item screening questionnaire;
2. Pregnancy (self-reported);
3. High suicidal risk detected by a positive answer in item 9 of the PHQ-9 followed by a protocol to assess suicidal risk (Suicide Risk Assessment Protocol); and
4. Cognitive impairment detected by a 4-item questionnaire.

Table 1. Description of instruments used in the pilot studies, time of application, and purpose (São Paulo, Brazil, and Lima, Peru).

Instrument	Time	Purpose
First informed consent (S1 ^a)	Prescreening	Introduction of the study and obtaining consent for screening
PHQ ^b -2/PHQ-9/S-RAP ^c (S2 ^d)	Screening	Assessment of depressive symptoms and suicidal ideation
Second informed consent (B1 ^e)	Before baseline	Consent to the study
PHQ-9	Screening/risk assessment (1 and 3 weeks)/follow-up	Full screening for depressive symptoms
S-RAP	Screening/risk assessment (1 and 3 weeks)/follow-up	Assess Suicidal Risk
PSQ ^f	Screening	Assess the presence of psychosis
CSI-D ^g	Screening	Evaluate cognitive impairment
Demographic and socioeconomic characteristics	Baseline	Information about participants' socioeconomic and family background
Clinical data	Baseline	Medical history
WHODAS ^h II	Baseline/follow-ups	Assess functional disability
EQ-5D ⁱ	Baseline/follow-ups	Assess quality of life

^aS1: prescreening

^bPHQ: Patient Health Questionnaire.

^cS-RAP: Suicide Risk Assessment Protocol.

^dS2: screening.

^eB1: baseline.

^fPSQ: Psychosis Screening Questionnaire.

^gCSI-D: Community Screening for Dementia.

^hWHODAS: World Health Organization Disability Assessment Schedule.

ⁱEQ-5D: EuroQoL (Quality of Life)-5 dimensions.

We also used data from participants captured automatically by the CONEMO system to monitor patients' progress, including completion of sessions, intervals between accessing sessions, or sessions missed. We collected information from participants

We used convenience samples in the 3 pilot studies. We envisaged that with 20 participants in each pilot, we would be able to achieve the aims proposed.

Measurements

We collected information about socioeconomic and demographic characteristics, depressive symptoms, suicidal ideation, presence of psychosis symptoms, cognitive impairment, quality of life, adherence to medical treatment, and disabilities (Table 1).

To explore the potential effectiveness of the CONEMO intervention, we used the Patient Health Questionnaire-9 (PHQ-9) as the main measure of outcome [25]. We applied the PHQ-9 at baseline and at the end of the 6-week intervention to assess severity of depressive symptoms.

To rule out the presence of psychotic symptoms, we used the Psychosis Screening Questionnaire [26]; to assess cognitive impairment, we used the Community Screening for Dementia [27]; and to estimate quality of life, the EuroQoL (Quality of Life)-5 dimensions (EQ-5D) was used [28]. Disabilities were assessed with the World Health Organization Disability Assessment Schedule II [29].

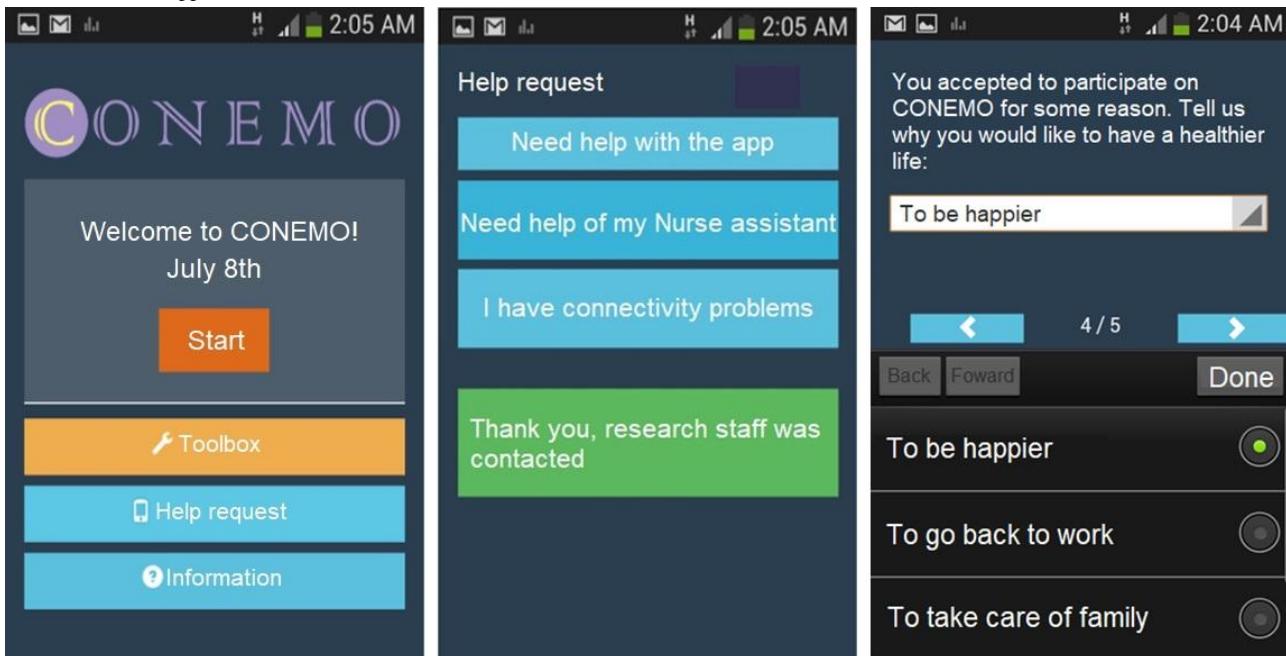
about the acceptability and satisfaction with the CONEMO app and the dashboard through a questionnaire using a Likert scale of 5 points, where 1 is *disagree* and 5 is *agree*, at the end of the pilot study.

Emotional Control (CONEMO) Intervention

We tested an intervention that could be delivered in existing general medical care settings by available local personnel. The choice of a psychological intervention as the main component relates to the public health need for these approaches in most LMICs. CONEMO is a mobile phone-delivered intervention, supported by an NA or a nurse, using a task-shifting model, as recommended by the World Health Organization [13,30]. CONEMO consists of 18 behavioral activation sessions, delivered over 6 weeks (3 sessions per week). As part of the behavioral activation program, CONEMO aims at increasing daily life activities, especially pleasant ones, healthy ones, and tasks, as well as providing further information and health self-care messages, and increasing motivation (Figure 1). Participants received a device from the project, with the CONEMO app installed, for use during the 6-week program, which had to be returned to the respective nurse after that period.

The tasks of the nurse or NA were as follows: (1) an initial contact by phone to schedule a training session for the participant; (2) a face-to-face training session to introduce the CONEMO app; (3) a monitoring call after week 1 to answer possible queries from participants and to reinforce motivation to participate; (4) a monitoring call after week 4 with the same objectives as above; (5) a phone call to schedule the closing meeting; and (6) a final face-to-face appointment with the participant to finish the intervention and collect the mobile phone. Nurses or NAs received weekly face-to-face supervision from research clinical psychologists.

Figure 1. CONEMO app screenshots. CONEMO: Emotional Control.



Results

Assessment of Recruitment Strategy

We carried out 1 pilot study in São Paulo and 2 pilot studies in Lima. In São Paulo, 4 nurses from the 2 participating FHCS clinics were responsible to support the CONEMO intervention

Data Analysis

To test recruitment strategies, we analyzed the data gathered during the process of recruiting and enrolling participants (Aim 2). The comparison of participants' PHQ-9 scores at baseline and at follow-up allowed a preliminary assessment of potential effectiveness (Aim 1), and the number of sessions completed and ratings on the satisfaction with the CONEMO intervention gave us an insight into the acceptance of the CONEMO intervention (Aim 3).

The main outcome measure was patients' PHQ-9 scores at the end of the 6-week intervention. We considered that patients had recovered when the PHQ-9 score at follow-up was <10. The secondary outcomes, such as disability levels and quality of life, were also examined at the end of the pilots. Descriptive statistics were also used to assess participants' perceptions at the end of the study. We conducted all data analysis using STATA 11 by StataCorp [31].

Ethical Considerations

The pilot studies were approved by local Institutional Review Boards and the US National Institute of Mental Health Data and Safety Monitoring Board. Participants consented to participate in the study and interviews took place after collecting the participants' signatures on informed consent forms. All investigators and research assistants involved in the data collection and analysis completed ethics and human research good clinical practices training before starting their activities in the project.

for participants recruited into the study. In the first pilot in Lima, we employed a nurse to support the delivery of the intervention, whereas in the second pilot study in Lima, we worked with 6 nurses employed by 2 public health care facilities. We included 66 patients in the 3 pilot studies after approaching 793 people (Figure 2). Of the 216 subjects approached in São Paulo, 9.7% (21/216) were included in the pilot study. In the 2 pilot studies

in Lima, we approached 577 subjects and included 7.7% (45/577), 21 in the first and 24 in the second pilot studies. To recruit participants, we spent 30 days in the field in São Paulo, 21 days in Lima's first pilot study, and 24 days in Lima's second

pilot study. Most participants were women aged between 41 and 60 years (Table 2). In São Paulo, participants had a lower educational level than those in Lima.

Figure 2. Flow chart of recruitment and intervention in Lima, Peru, and São Paulo, Brazil. IC: informed consent.

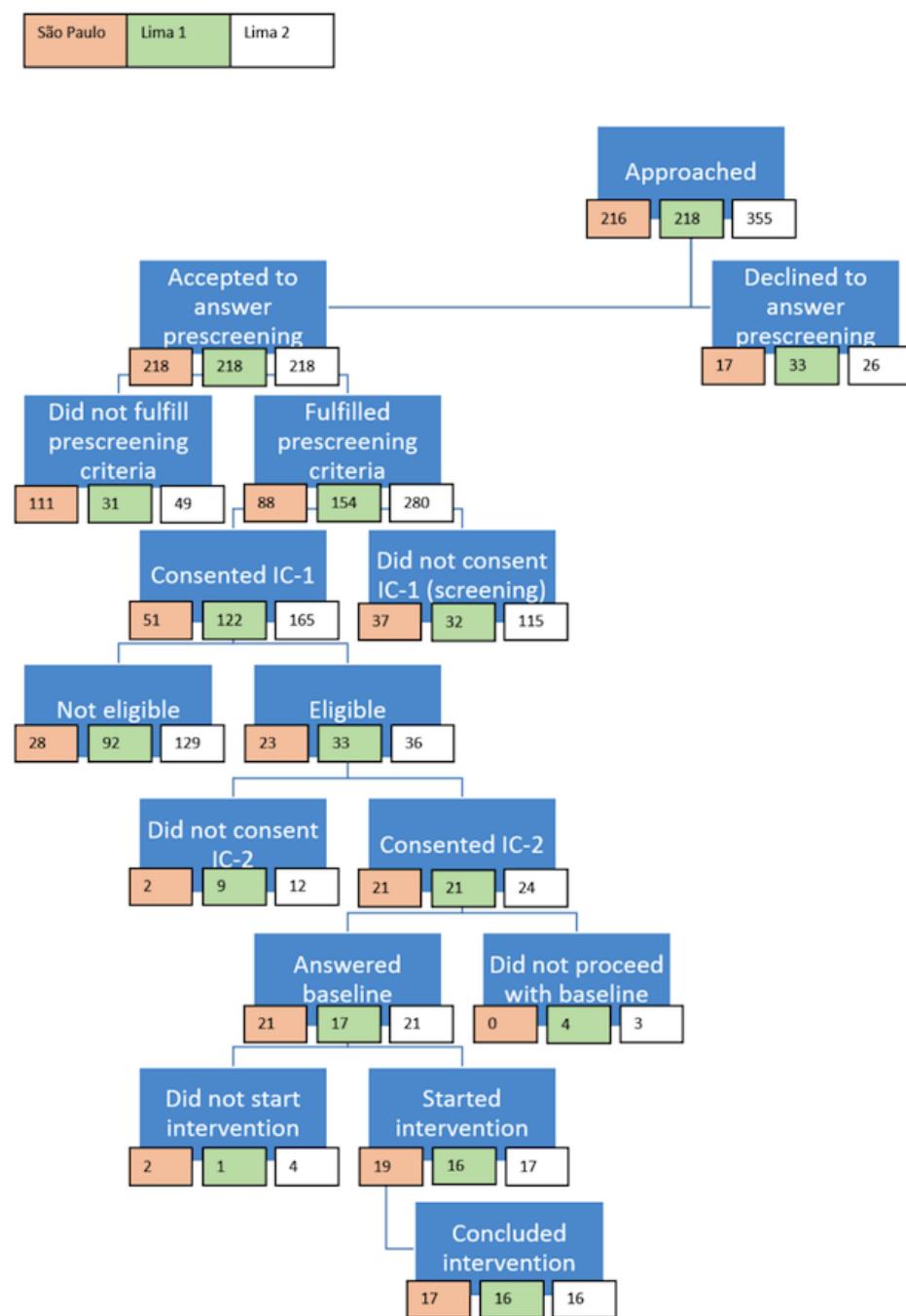


Table 2. Socioeconomic and demographic characteristics of participants included in the pilot studies in São Paulo, Brazil, and Lima, Peru.

Characteristics	São Paulo (N=21), n (%)	Lima—pilot 1 (N=21), n (%)	Lima—pilot 2 (N=24), n (%)	Total (N=66), n (%)
Age (years)				
21-40	3 (14)	0 (0)	1 (4)	4 (6)
41-60	11 (52)	13 (62)	11 (46)	35 (53)
≥61	7 (33)	8 (38)	12 (50)	27 (41)
Gender				
Male	5 (24)	8 (38)	6 (25)	19 (29)
Female	16 (76)	13 (62)	18 (75)	47 (71)
Chronic disease				
HBP ^a	14 (67)	1 (5)	9 (38)	24 (36)
DM ^b	1 (5)	12 (57)	6 (25)	19 (29)
HBP and DM	6 (28.6)	8 (38)	9 (38)	23 (35)
Educational level				
Primary school	12 (57)	3 (14)	4 (17)	19 (29)
High school	6 (29)	8 (38)	5 (21)	19 (29)
Technical course	3 (14)	4 (19)	7 (29)	14 (21)
University or postgraduate	0 (0)	2 (10)	5 (21)	7 (11)
Unknown	0 (0)	4 (19)	3 (13)	7 (11)
Income (Brazilian minimum wage)				
0-4	14 (67)	— ^c	—	14 (21)
>4	7 (33)	—	—	7 (11)
Income Peru (Soles)				
0-1500	—	9 (42.9)	7 (29)	16 (24)
>1500	—	7 (33.3)	12 (50)	19 (29)
Do not know/did not answer	—	5 (23.8)	5 (21)	10 (15)

^aHBP: high blood pressure (hypertension).^bDM: diabetes mellitus.^c—: not applicable.

Potential Effectiveness and Feasibility of Emotional Control (CONEMO) Intervention

At the 6-week follow up, there was 5% (1/21) loss to follow-up in São Paulo and 28.6% (6/21) in the first and 33% (8/24) in the second Lima pilot studies. Among participants who completed follow-up assessments, 11 out of 20 (55%) had moderately severe or severe symptoms of depression at baseline in São Paulo (Figure 3). In Lima, considering both pilots, none had severe symptoms at baseline and 8 out of 31 (26%) had moderately severe symptoms. At follow-up assessment, 65% (13/20) of participants had recovered from depression (PHQ-9 <10) in São Paulo, 87% (13/15) in the first Lima pilot study, and 75% (12/16) in the second Lima pilot study (Figure 3). Only

2 out of 16 (13%) participants in Lima's second pilot study worsened their level of depressive symptoms. Furthermore, 6 out of 20 participants (30%) presented mild suicide risk at baseline in São Paulo, whereas in Lima none of the participants presented suicide risk. In the follow-up assessments of the 3 pilot studies, no participant presented suicide risk.

In São Paulo and Lima, all participants presented some level of functional disability at baseline, with more than 50% presenting moderate or severe functional disability. In all pilot studies, there was a trend toward a reduction in levels of functional disability at the follow-up assessments (Table 3). Regarding quality of life, we observed small inconsistent variations on EQ-5D scores from baseline to 6-week follow-up (Table 3).

Figure 3. Severity of depressive symptoms at baseline and 6-week follow-up, according to Patient Health Questionnaire-9 (PHQ-9) scores, for the 3 pilot studies (São Paulo, Brazil, and Lima, Peru).

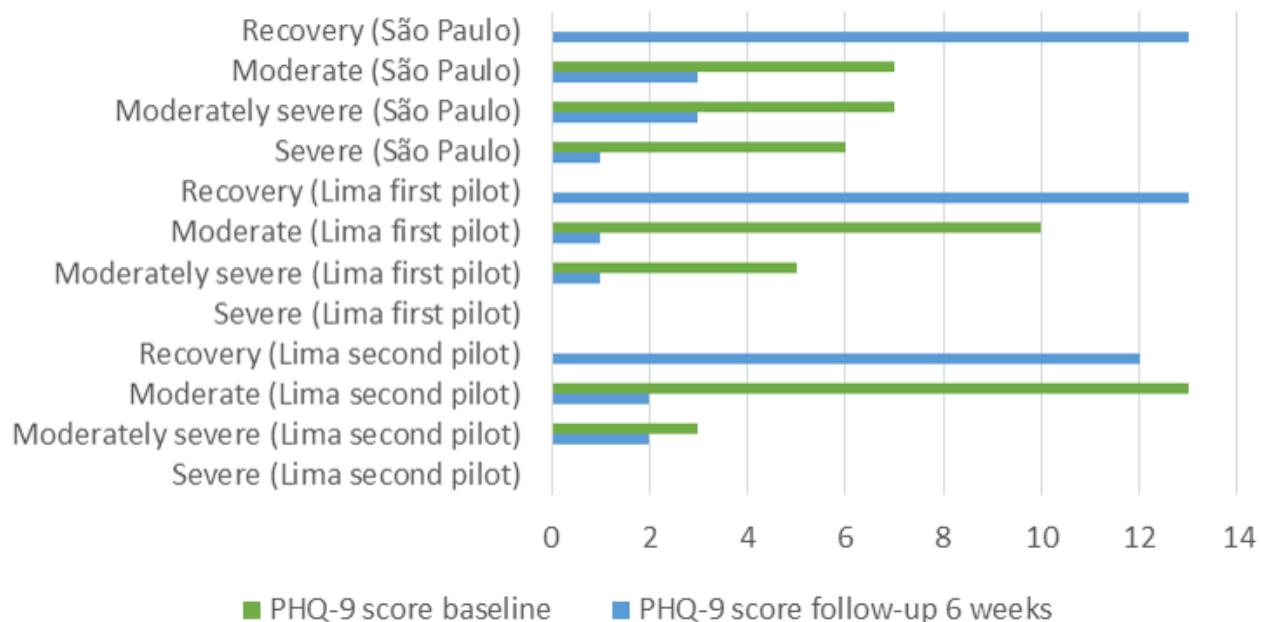


Table 3. Functional disability and quality of life during baseline and at 6-week follow-up in São Paulo, Brazil, and Lima, Peru.

Scales and categories	São Paulo (N=20), n (%)		Lima—pilot 1 (N=15), n (%)		Lima—pilot 2 (N=16), n (%)	
	Baseline	6-week follow-up	Baseline	6-week follow-up	Baseline	6-week follow-up
World Health Organization Disability Assessment Schedule						
No disability	0 (0)	2 (10)	0 (0)	1 (7)	0 (0)	0 (0)
Mild disability	9 (45)	10 (50)	5 (33)	9 (60)	7 (44)	9 (56)
Moderate disability	8 (40)	5 (25)	7 (47)	5 (33)	7 (44)	7 (44)
Severe disability	3 (15)	3 (15)	2 (13)	0 (0)	2 (13)	0 (0)
EuroQoL (Quality of Life)-5 dimensions						
Problems to walk	10 (50)	11 (55)	10 (67)	7 (47)	7 (44)	5 (31)
Problems washing or dressing	9 (45)	5 (25)	3 (20)	2 (13)	1 (6)	0 (0)
Problems with performing usual activities	9 (45)	9 (45)	8 (53)	4 (27)	5 (31)	5 (31)
Moderate or extreme pain/discomfort	14 (70)	16 (80)	14 (93)	11 (73)	13 (81)	11 (69)
Moderate or extreme anxiety/depression	17 (85)	15 (75)	7 (47)	7 (47)	12 (75)	8 (50)

Access of participants to the CONEMO sessions decreased progressively over time in the São Paulo and in the second Lima pilot study (Figure 4), whereas in the first Lima pilot study, access started to decrease only after 4 weeks of the intervention. Percentages of completion of sessions were 70% in São Paulo and 88% and 58% in the first and second pilot studies in Lima, respectively. In São Paulo, 87% of the participants accessed all first 6 sessions, whereas 95% and 76% did so in the first and second pilot studies in Lima, respectively. Furthermore, 69% of participants in São Paulo and 91% and 50% in Lima's first and second pilot studies, respectively, accessed sessions 7 to 12. Adherence decreased for sessions 13 to 18, with 55% in São

Paulo and 80% and 48% in the first and second pilot studies in Lima, respectively.

The CONEMO app (participant interface) worked adequately during the trial, despite some connectivity issues when receiving information on participants' performance. These issues did not affect the intervention or data collection.

We collected data on acceptability and satisfaction with CONEMO from 20 participants in São Paulo, 15 in Lima's first pilot, and 16 in Lima's second pilot. The evaluation of the intervention by participants was generally positive: all mean ratings were above 3.5 points (maximum of 5 points), both in

São Paulo and Lima. Patients considered that the objectives were attained and that the intervention helped their physical and mental health and helped them to get organized. In their opinion the duration of the intervention, the amount of contacts with the nurse or NA, and the training received were adequate (Table 4).

Participants considered the CONEMO app easy to use, were able to access videos and other resources included in the app,

Figure 4. Percentage of participants who accessed the CONEMO app sessions in the pilot studies in São Paulo, Brazil, and Lima, Peru. CONEMO: Emotional Control.

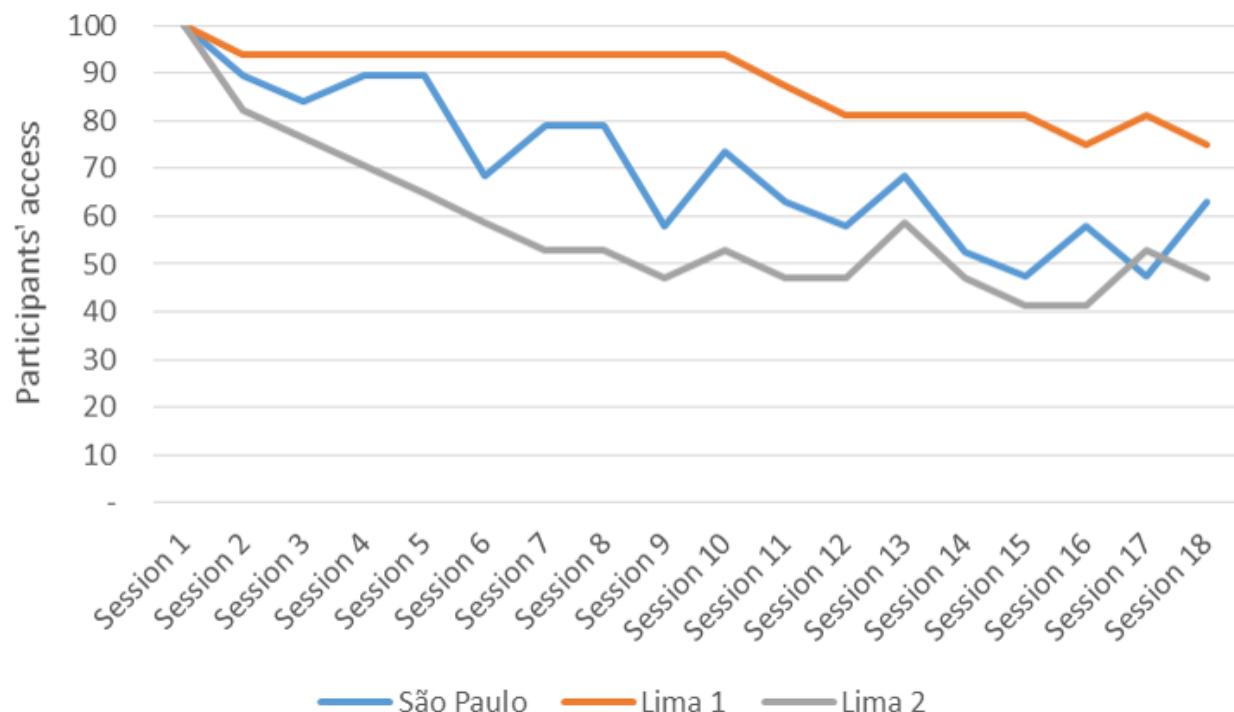


Table 4. Evaluation of participants regarding CONEMO (Emotional Control) intervention in the pilot study in São Paulo, Brazil, and Lima, Peru.

Intervention aspects evaluated	São Paulo (average grade)	Lima pilot study 1 (average grade)	Lima pilot study 2 (average grade)
Helped with physical health	4.1	4.0	3.8
Helped with mental health	4.4	4.4	4.3
Helped having the will to do things	3.9	4.3	4.3
Helped to get organized	3.6	4.3	4.3
Count on nurse assistant or nurse	4.5	4.1	4.1
Nurse assistant or nurse helped	4.4	4.3	3.8
Number of contacts	4.1	3.6	3.2
Training quality	4.1	3.7	3.1
Intervention duration	4.1	2.8	2.9
Achievement of objectives	4.1	4.2	4.2
Satisfaction with results	4.3	4.4	4.3
Would indicate to a friend	3.6	4.6	4.5

Table 5. Evaluation of participants regarding technological aspects of the CONEMO (Emotional Control) app used during the pilot studies in São Paulo, Brazil, and Lima, Peru.

Technological aspect	São Paulo (average grade)	Lima pilot study 1 (average grade)	Lima pilot study 2 (average grade)
Easy to use	4.4	4.3	3.8
Usefulness	4.6	4.7	4.4
Adequacy of frequency of sessions	4.3	3.3	3.9
Content interesting	4.4	4.6	4.5
Video quality	4.4	4.6	4.4
Sound quality	3.9	4.6	4.3
Choices presented	4.1	4.6	4.5
Training session	4.3	4.0	4.3
Reminders	3.6	3.0	4.3

Discussion

Principal Findings

The main aim of this pilot study was to explore the feasibility and potential effectiveness of the CONEMO intervention for depressed people with comorbid hypertension or diabetes. We also wanted to assess the feasibility of undertaking fully powered RCTs to test the effectiveness of this intervention. We found that patients were able to use the CONEMO app, that they tended to show improvement in the severity of depressive symptoms by the end of the intervention, and that they were satisfied with the intervention. Our results are encouraging and suggest that the intervention is feasible and potentially effective with this population.

To carry out RCTs, we needed to ensure that we would be able to recruit participants in the numbers needed. On average, out of every 13 participants screened, we were able to include 1 eligible participant in the study. In São Paulo and Lima, recruitment took place in primary health care units and, additionally, in the outpatient consultation areas of a public hospital in the first pilot study in Lima, with patients presenting different conditions apart from hypertension and diabetes. In both sites, many participants were unable to read or write. As a result, it was necessary to prescreen twice as many patients than we first anticipated to reach the numbers we had planned for each pilot study. This information allowed us to prepare a more realistic recruitment strategy and plan.

The instruments and measures were well understood by participants, and research assistants also provided positive feedback on their use. The outcome measures seemed sensitive to change and allowed a useful characterization of the study sample. The research assistants did not refer problems from the participants in understanding the instructions or questions included in the study. As only 1 participant showed cognitive impairment or psychotic symptoms in the screening, the assessment of these conditions may not be needed in the full trials. This will decrease the time taken for screening interviews, also reducing costs for running the trials.

Overall, there was a noticeable trend in all pilot studies for a reduction on depressive symptoms over time, as measured by

the PHQ-9. Our approach was categorical, using PHQ-9 cutoff points to decide on caseness and severity. The proposed measure of clinical success, having a PHQ-9 score ≤ 9 at follow-up (recovery), was considered a stringent but good measure. Nevertheless, all our estimates need to be taken with caution as this pilot study was not powered to detect any statistically significant changes.

Other secondary measures of success of the intervention also yielded some results in the expected direction. Disability levels seemed to improve by the end of the intervention. This trend was not as clear for the quality of life measure (EQ-5D).

This study also found that participants were satisfied with the intervention and nurse or NA support. Other studies have also shown benefits in the use of collaborative care and task-shifted approaches in the treatment of depression [32-34]. Participants found the CONEMO app useful, easy to use, and with interesting content. There was a decrease in adherence to the sessions over time, which is consistent with a large majority of digital mental health interventions. This suggests a need to review the content and organization of the sessions before the start of the RCTs. Changes should include shortening sessions, making language simpler, and adding more video material. Reviewing our strategy for persuasive design could also improve longer term adherence, such as including more tailoring and personalization, improving the quality of automated notifications (eg, positive reinforcement for engagement), and leveraging contact with the nurse coordinator. We are hopeful that these changes will improve session adherence in the RCTs.

Strengths and Limitations

To the best of our knowledge, this is the first study that pilot tested a mobile intervention for symptoms of depression among individuals with chronic conditions in 2 settings of middle-income countries of Latin America. Our samples were small, so the pilot studies were not powered to test the efficacy of the intervention; however, our results were in the predicted direction, and the proportions of treatment success in each sample are useful to calculate full trial sample sizes. We found that many potentially eligible participants could not participate because of difficulties to read or write. This could potentially affect the generalizability of the results. However, with the increasing literacy trend in younger generations in Latin

America, these difficulties will decrease, and more people will be able to benefit from similar apps in the future.

Conclusions

The technological system, CONEMO, seems feasible to use in these settings with different languages to help patients with

diabetes or hypertension and comorbid depressive symptoms. The results from the 3 pilot studies are promising and support the implementation of fully powered trials. The CONEMO intervention will be one of the first evidence-based mobile interventions tested in large samples in 2 different settings in LMICs.

Acknowledgments

This study was supported by the National Institute of Mental Health (1U19MH098780).

Conflicts of Interest

None declared.

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Abbreviations

- CONEMO:** Emotional Control
- EQ-5D:** EuroQoL (Quality of Life)-5 dimensions
- FHCS:** Family Health Care Strategy
- LMIC:** low- and middle-income country
- mHealth:** mobile health
- MINSA:** Ministry of Health
- NA:** nurse assistant
- PHQ-9:** Patient Health Questionnaire-9
- RCT:** randomized controlled trial

Edited by G Eysenbach; submitted 26.07.18; peer-reviewed by O Uthman, H Mergen; comments to author 08.10.18; revised version received 21.12.18; accepted 23.01.19; published 26.04.19.

Please cite as:

Menezes P, Quayle J, Garcia Claro H, da Silva S, Brandt LR, Diez-Canseco F, Miranda JJ, Price LN, Mohr DC, Araya R. Use of a Mobile Phone App to Treat Depression Comorbid With Hypertension or Diabetes: A Pilot Study in Brazil and Peru. *JMIR Ment Health* 2019;6(4):e11698

URL: <http://mental.jmir.org/2019/4/e11698/>

doi:10.2196/11698

PMID:31025949

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Original Paper

Supporting Self-Management in Bipolar Disorder: Mixed-Methods Knowledge Translation Study

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Abstract

Background: Self-management is increasingly recognized as an important method through which individuals with bipolar disorder (BD) may cope with symptoms and improve quality of life. Digital health technologies have strong potential as a method to support the application of evidence-informed self-management strategies in BD. Little is known, however, about how to most effectively maximize user engagement with digital platforms.

Objective: The aims of this study were (1) to create an innovative Web-based Bipolar Wellness Centre, (2) to conduct a mixed-methods (ie, quantitative and qualitative) evaluation to assess the impact of different sorts of engagement (ie, knowledge translation [KT]), and (3) to support engagement with the self-management information in the Bipolar Wellness Centre.

Methods: The project was implemented in 2 phases. In phase 1, community-based participatory research and user-centered design methods were used to develop a website (Bipolar Wellness Centre) housing evidence-informed tools and strategies for self-management of BD. In phase 2, a mixed-methods evaluation was conducted to explore the potential impact of 4 KT strategies (Web-based webinars, Web-based videos, Web-based one-to-one *Living Library* peer support, and in-person workshops). Quantitative assessments occurred at 2 time points—preintervention and 3 weeks postintervention. Purposive sampling was used to recruit a subsample of participants for the qualitative interviews, ensuring each KT modality was represented, and interviews occurred approximately 3 weeks postintervention.

Results: A total of 94 participants were included in the quantitative analysis. Responses to evaluative questions about engagement were broadly positive. When averaged across the 4 KT strategies, significant improvements were observed on the Bipolar Recovery Questionnaire ($F_{1,77}=5.887$; $P=.02$) and Quality of Life in Bipolar Disorder ($F_{1,77}=8.212$; $P=.005$). Nonsignificant improvements in positive affect and negative affect were also observed. The sole difference that emerged between KT strategies related to the Chronic Disease Self-Efficacy measure, which decreased after participation in the webinar and video arms but increased after the Living Library and workshop arms. A subsample of 43 participants was included in the qualitative analyses, with the majority of participants describing positive experiences with the 4 KT strategies; peer contact was emphasized as a benefit across all strategies. Infrequent negative experiences were reported in relation to the webinar and video strategies, and included technical difficulties, the academic tone of webinars, and feeling unable to relate to the actor in the videos.

Conclusions: This study adds incremental evidence to a growing literature that suggests digital health technologies can provide effective support for self-management for people with BD. The finding that KT strategies could differentially impact chronic disease self-efficacy (hypothesized as being a product of differences in degree of peer contact) warrants further exploration. Implications of the findings for the development of evidence-informed apps for BD are discussed in this paper.

KEYWORDS

bipolar disorder; eHealth; self-management; knowledge translation; community-based participatory research; mHealth

Introduction

Background

The tremendous impact of mental disorders—for the people who live with them, their families, and society—is well established. Mental health conditions account for 14% of the global burden of diseases worldwide and 37% of all healthy life years lost from chronic diseases [1]. Millions of people worldwide are suffering and losing quality of life (QoL) due to mental disorders, and many will lose their lives. Bipolar disorder (BD)—a mood disorder characterized by pronounced variability in mood, activity, and energy levels [2]—contributes significantly to this global burden of disease. Robust epidemiological studies indicate a 1% to 2% lifetime prevalence for BD [3], and it is estimated that 6% to 10% of people with this condition will die by suicide [4]. However, these “misery statistics” [5] do not tell the whole story; people with BD can and do experience good health and QoL [6-8].

Effective support for self-management—“the plans and/or routines that a person with BD uses to promote health and QoL” [9]—is viewed as 1 important route to optimizing outcomes in BD. Our Collaborative Research Team to study psychosocial issues in Bipolar Disorder (CREST.BD) has spent the past decade incrementally advancing the literature on self-management and BD. Outputs have included qualitative explorations of self-management application in BD [7,8,10], a Delphi Consensus Consultation project [9], and a review of electronic health/mobile health (mHealth) apps for self-management of the condition [11]. These findings complement a solid international literature speaking to the importance of self-management in terms of impacting health and QoL in people with BD and recommendations for supported self-management in international BD clinical treatment guidelines (eg, [12]). However, as recently noted, “means to support these self-management interventions...are critically needed” [13].

Digital health technologies offer clear potential as 1 route to support the application of evidence-informed self-management strategies in BD, and there is no doubt that people with the condition are seeking health information on the Web. An international survey of 1222 people with a diagnosis of BD from 17 countries reported that 81% of respondents described themselves as internet users; 78% of this sample sought Web-based information related to their diagnosis [14,15]. The most commonly cited reasons for internet searching were to seek more information on the symptoms of BD, prescription drug information, the general course of illness, coping strategies, and medication side effects. Notably, 67% of respondents said that seeking Web-based information helped them to cope with their BD “sometimes or frequently.” Respondents were more likely to report a positive impact of Web-based information on their ability to cope if they were “always able to find what they were looking for” [14]. Our own research into information

seeking on the Web in youth with BD has indicated that what youth “are looking for” is credible, safe, and stigma-free Web-based information about their condition [16]. However, there are prevailing concerns about the quality and accuracy of health information on the Web [17,18].

Taken together, the key messages from emerging research in the BD digital technology arena are 2-fold. First, it is clear that people with BD are looking for Web-based information and support to optimally manage their condition. Accordingly, BD research and clinical communities need to rise to the challenge of providing high-quality, evidence-informed Web-based information and resources to meet this need. Second, we need to advance our understanding of how to best maximize user engagement with the Web-based tools we produce. This mixed-methods study was designed to address these needs by assessing the impact of a range of digital and face-to-face engagement (ie, knowledge translation [KT]) strategies on user engagement and health-related outcomes in Canadians with BD developed for a Bipolar Wellness Centre website.

This Study

The aim of this project was to advance understanding of KT strategies in BD. To this end, we investigate 4 distinct strategies for encouraging engagement with a Web-based BD resource. The strategies were all face-valid methods for engaging people with lived experience with health information but differed in terms of resource intensiveness and accessibility. The 4 strategies were Web-based webinars, Web-based videos, Web-based one-to-one *Living Library* peer support, and in-person workshops. The Web resource to which these KT strategies related (the Bipolar Wellness Centre) was a newly developed website structured around our group’s approach to the domains of QoL in BD. Funding from the Canadian government in the form of a 2-year Canadian Institutes of Health Research (CIHR) “Knowledge to Action” grant supported the development of the central website and the accompanying mixed-methods investigation of how different KT strategies impacted engagement with the content held within it. The research project is positioned as the initial phase of a longer-term developmental program of research to advance understanding of the potential utility of digital health technologies for supporting self-management in people with BD.

Methods

Overview

The project was conducted under the auspices of CREST.BD [19], a Canadian-based network dedicated to collaborative research and KT in BD. CREST.BD specializes in community-based participatory research (CBPR), where researchers and knowledge users (in this case, people with BD and BD health care providers) work hand-in-hand [20]. Informed by a decade of research and integrated KT, CREST.BD has

developed a specific model of CBPR for BD [21] and dedicated Web and social media platforms [22].

The project was implemented across 2 study phases over a 2-year period. In the first phase, we applied the principles of integrated KT, CBPR, and user-centered design to develop a website (the Bipolar Wellness Centre, described below) to house evidence and tools on self-management strategies for BD. In the second phase, we conducted a mixed-methods (quantitative and qualitative) evaluation of the impact of 4 bespoke (Web-based or in-person) KT strategies designed to foster engagement with the content housed within the Bipolar Wellness Centre. The primary aims of the quantitative study component were to assess whether the 4 KT strategies (1) represented effective engagement strategies and (2) impacted health-related outcomes in study participants with BD. The aim of the qualitative study component were to explore whether the 4 KT strategies represented effective engagement strategies. Participants in the study self-selected 1 of the 4 KT strategies in which to participate.

Development of the Bipolar Wellness Centre

During the first phase of the study, we developed, within an integrated KT and CBPR framework, our signature website, CREST.BD “Bipolar Wellness Centre” [23]. The primary goal of the Bipolar Wellness Centre is to support self-management in people with BD and empower them to manage and improve their health and QoL. Structurally, the website’s design emulates our theoretical understanding of QoL in BD, developed on the basis of our longstanding program of research exploring the QoL construct in BD (eg, [6,24]). Self-management categories were presented according to the 14 domains of QoL measured by our Quality of Life in Bipolar Disorder (QoL.BD) scale [25] and its Web-based counterpart, the QoL Tool [26], which assesses the cardinal life areas impacted by BD (eg, mood, sleep, physical health, and cognition), more concrete life areas (eg, finances, home, work, education, and leisure), and some which are more psychosocially orientated (relationships, self-esteem, spirituality, identity, and independence).

In keeping with the principles of CBPR, we fused the expertise of academic researchers, people with BD, and health care providers to cocreate the content in the Bipolar Wellness Centre. First, we conducted 3 consultation events in partnership with the Mood Disorders Association of Ontario (MDAO) in the Canadian cities of Toronto, Bowmanville, and Guelph, to develop the “look and feel” of the website. These consultations with people with BD resulted in the selection of an overarching nautical metaphor (effective self-management of BD has been likened to “to a ship that’s always righting itself” [7]). Identification of the research evidence and tools for the Bipolar Wellness Centre was a thoroughgoing process. To determine the content for each of the 14 self-management areas, we first appointed a CREST.BD lead and then conducted academic and grey literature reviews. Draft section content was created, revised by a plain language writer, and then reviewed by the

CREST.BD Community Advisory Group. Our early design consultations also prioritized accessibility of website content for people with BD who were struggling with symptoms or cognition problems. The research evidence was, therefore, presented in succinct text form and audio version and augmented by brief “key messages” and ways to “take action.” Also provided are key scientific references and carefully curated (and annually updated) area-specific resources and tools (eg, evidence-informed tools to support the application of self-management strategies for sleep).

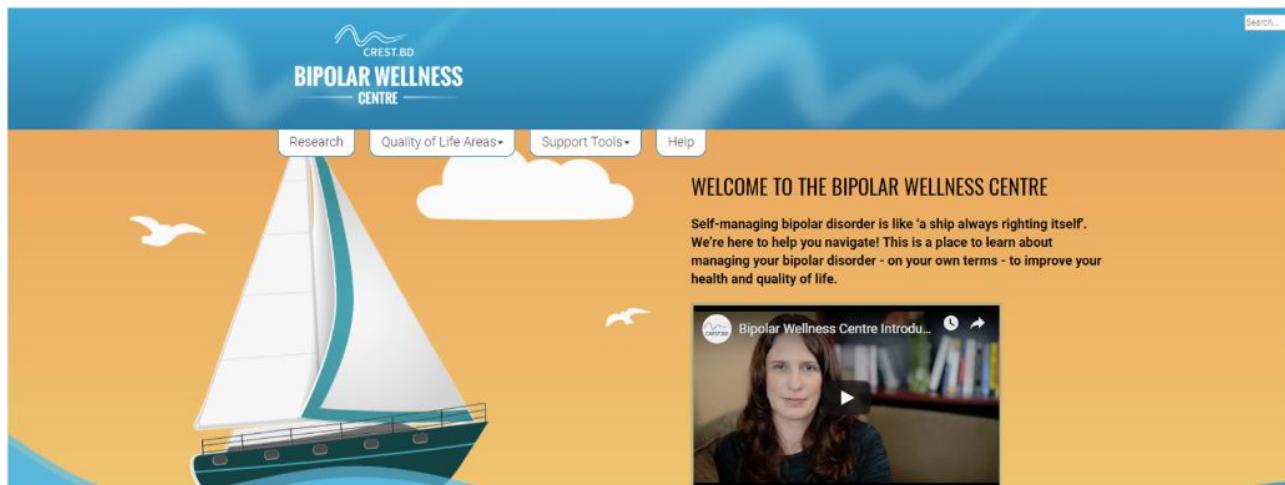
The official launch of the Bipolar Wellness Centre (see Figure 1) occurred on World Bipolar Day (March 30, 2015). The project to evaluate the impact of the 4 KT strategies (ie, webinars, videos, Living Library, and workshops, described in full below) was conducted throughout 2015. After the evaluation of the KT strategies was complete, the webinars and the videos (but not the Living Library nor workshop strategies) were made publicly available through the website (funding parameters did not permit implementation or longer-term sustainability of the Living Library or workshop strategies).

Development of and Evaluation Methods for the Bipolar Wellness Centre Knowledge Translation Strategies

During the second phase of the study, we developed (again within an integrated KT and CBPR framework) and evaluated 4 bespoke Bipolar Wellness Centre KT strategies (see Figure 2).

Web-Based Webinars

A total of 14 webinars [27] (see Figure 3) were produced, 1 corresponding to each self-management area; each webinar was delivered by a CREST.BD member with internationally recognized expertise in the focal self-management area. Overall, 12 of the webinar presenters were academics (one of whom, coauthor SJB, also has BD) and 2 presenters provided lived experience of BD. Webinars were 15 to 20 min in length (not including questions and answers [Q&A]) and each followed a structured delivery format, covering (1) education about the specific self-management area (eg, the importance of sleep as a self-management strategy and its relation to QoL, as summarized in the text section relating to sleep and BD on the Bipolar Wellness Centre); (2) some key messages from the current research evidence in that area (eg, as provided in the text and literature on the Bipolar Wellness Centre); and (3) how to take action (eg, recommendations for tools to support self-management strategies for sleep, as housed on the Bipolar Wellness Centre). The webinars (split screen of video of presenter and PowerPoint slides) were prerecorded to ensure audio quality and delivery fidelity. The actual webinars were, however, delivered “live” (ie, the prerecorded webinar with a live Q&A with the presenter) to research participants. Following evaluation, a recording of the webinar and Q&A was made publicly available through the website.

Figure 1. Bipolar Wellness Centre.

RESOURCES BY QUALITY OF LIFE AREAS

Access CREST.BD's Bipolar Wellness Centre resources here, organized by quality of life domain. Includes a feature that enables website users to rate and comment on the quality and usefulness of specific resources.

Life Areas:

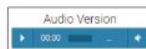


Why relationships are important to your quality of life

Humans are social beings by nature. While we can survive on our own, we truly thrive when we're surrounded by supportive others. Here we'll give you some reasons why, share information about relationships and give a few suggestions on how you could improve yours.

'Social support' describes helpful support from others: emotional support (e.g., love, compassion, etc.), informational support (e.g., giving advice) and tangible support (e.g., help with day to day needs)¹. While we, as social creatures, instinctively sense that social support is helpful, many research studies show just how important it is for wellness.

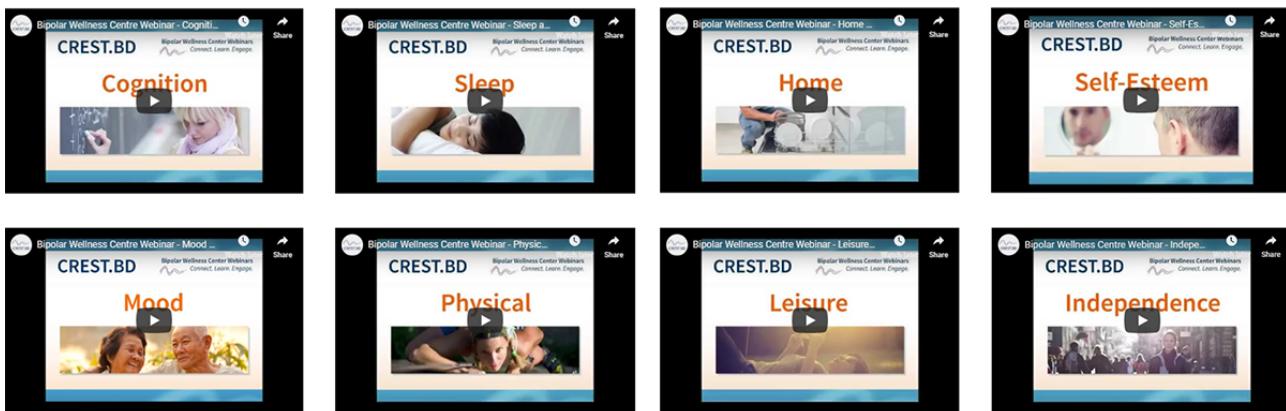
Social support is linked to physical health (i.e., immune functioning, stress hormones and cardiovascular function)², as well as psychological benefits. People with mental health challenges who live in close contact with others report feeling less isolated and lonely and more comfortable in having someone to discuss distressing symptoms or life events³. Even contact through more distant and casual relationships, such as



Key Messages

- Social support comes in all shapes and sizes
- Social support can include emotional, informational and tangible forms of support
- People with bipolar disorder often experience low social

Figure 2. Overview of knowledge translation strategies. CREST.BD: Collaborative Research Team to study psychosocial issues in Bipolar Disorder; KT: knowledge translation.

Figure 3. Webinars.

Web-Based Videos

Overall, 6 videos [28] (see [Figure 4](#)) were developed in collaboration (with the production company *As You Like It*) in the areas of mood, sleep, relationships, physical health, finances, and home life. Videos were 2 to 4 min in length and all featured CREST.BD member Victoria Maxwell, an actor and mental health educator who lives well with BD. Video content (development of which was informed by the self-management area content on the Bipolar Wellness Centre) was similarly structured across the 6 videos, with the actor or narrator introducing the key self-management area, followed by pragmatic examples of self-management behaviors in everyday life (eg, how to apply the principles of good sleep hygiene).

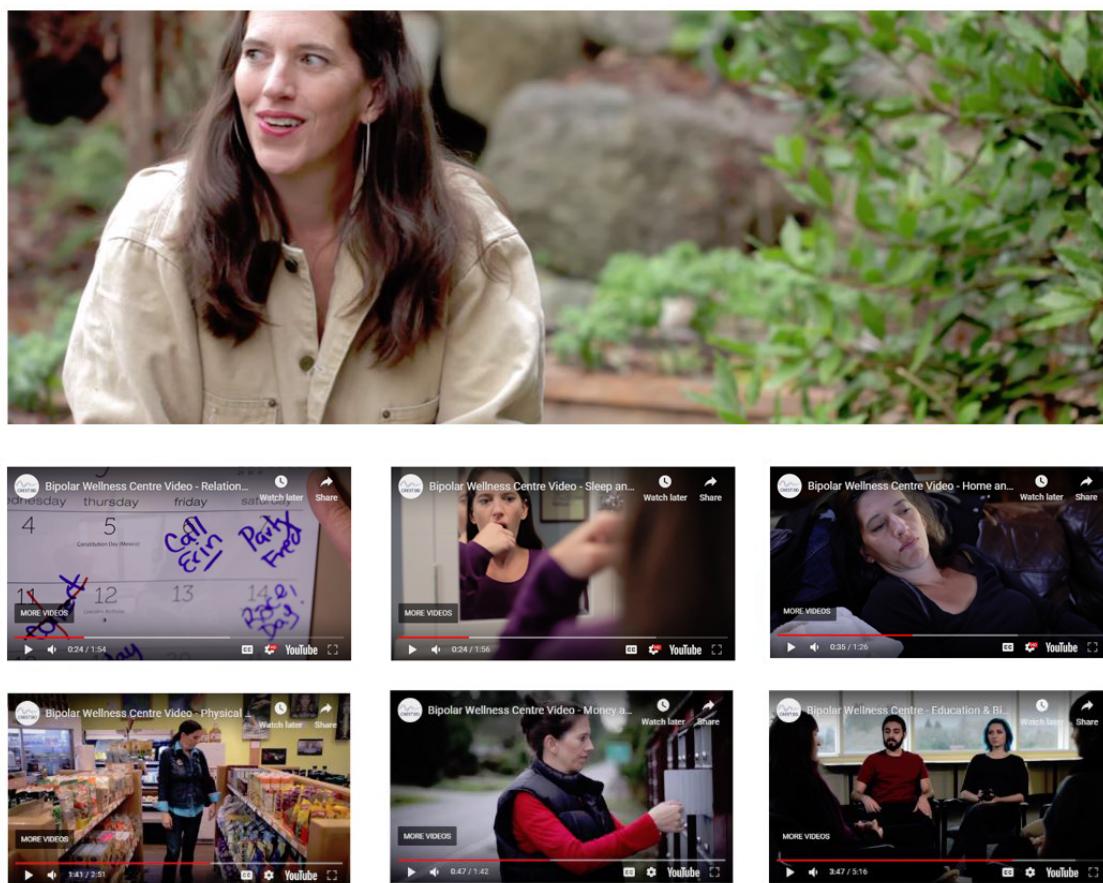
Web-Based Living Library

The Living Library KT strategy ([Figure 5](#)) consisted of a single 45-min session between the research participant and a Living Library “expert” (ie, 1 of 5 experienced peer-researchers living well with BD who had undergone thorough training in Bipolar

Wellness Centre content and navigation) via a secure Web-based telehealth system (Medeo). Sessions were relatively unstructured, but the Living Library experts were instructed to explore the research participant’s priorities for self-management focus and to navigate the participant through the germane content areas and tools in the Bipolar Wellness Centre (with the exception of the videos and webinars, which were not, at that time, made available via the website).

In-Person Workshops

A structured 2.5-hour in-person group workshop ([Figure 6](#)) was developed focused on 2 self-management domains (mood and sleep, cardinal BD self-management areas). Workshops were codelivered by 3 CREST.BD team members (coauthors EEM and GM and Victoria Maxwell) and provided structured delivery of didactic, role-play, and small group work. They were delivered 3 times in the Canadian cities of Ottawa, Kingston, and Toronto (sample size at each workshop was 6, 10, and 16, respectively) in partnership with MDAO.

Figure 4. Videos.

Recruitment

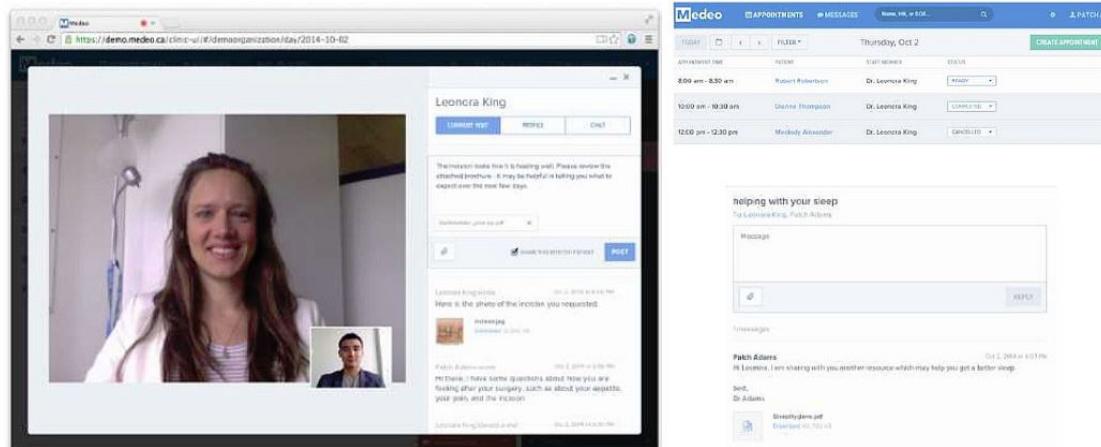
To be eligible, participants were required to be (1) aged 19 years or above, (2) able to communicate in English, (3) able to provide informed consent, (4) a resident of Canada, and (5) have a self-reported diagnosis of BD (Type I, II, or not otherwise specified). Participants were recruited via diverse methods including CREST.BD face-to-face (eg, outreach at community events and conferences), Web-based (eg, news releases on the CREST.BD website and blog), and social media communications (eg, CREST.BD Facebook and Twitter accounts), and notices were sent to those individuals with BD who had been recruited for previous studies for whom we had ethical permission to contact. Participants were free to self-select which of the 4 KT strategies they wanted to engage with. Participants were remunerated with a Can \$10 gift certificate to recognize their time in the webinar or video (quantitative) arms, Can \$20 for participation in the workshop or Living Library (quantitative) arms, and an additional Can \$20 for participation in the qualitative arm.

Quantitative Methods, Statistical Analysis, and Assessment Scales

Ethics approval for the study was granted by the University of British Columbia's Behavior Research Ethics Board. All participants received written information on the study and gave written informed consent. Participants consenting to the

quantitative arm of the study were given the option of consenting to be re-contacted for a qualitative interview.

Quantitative assessments of the experience and impact of the KT strategies were conducted in 2 ways. First, we investigated the subjective experience of participating in the KT strategy immediately upon completion of contact ("immediate posttest"). Participants rated each of the 4 statements related to a particular KT strategy (ie, "learned something new," "applicable to me," "met my expectations," and "would recommend to others with BD") on a Likert scale from Strongly Agree (1) to Strongly Disagree (5). Second, we investigated the short-term impact of the KT strategy by comparing 3-week follow-up ratings (Time 2) with baseline scores (preintervention, in the week before engagement with the KT strategy [Time 1]). Only a 3-week assessment time frame was feasible for this exploratory project. Quantitative assessment of the impact of the KT strategies on health outcomes utilized 4 scales, assessing QoL (via the 56-item QoL.BD, a condition-specific QoL scale, which is sensitive to change in clinical state over 7-10 days [25]); recovery (via the 36-item Bipolar Recovery Questionnaire (BRQ) [29]); mood (via the Positive and Negative Affect Schedule (PANAS), a self-report questionnaire that consists of two 10-item scales to measure both positive affect (PA) and negative affect (NA) [30]); and Chronic Disease Self-Efficacy (SECD, via the 5-item "Manage Disease in General" subscale of Stanford's Chronic Disease Self-Efficacy Scales [31,32]). Quantitative data were analyzed using the Statistical Package for the Social Science (software) version 24.

Figure 5. Living Library.**Figure 6.** Workshops.

By necessity, the data collection approach differed slightly by the KT arm. In the webinar arm, research participants self-selected a single webinar to participate in based on their own interests; webinars were scheduled at a rate of approximately 3 per week from April to May 2015. A week before the webinar, research participants were sent a unique link to the Time 1 assessments. After participating in the webinar and Q&A, they were sent a link to the immediate posttest questions, and 3 weeks after that, another link to the Time 2 assessments. In the video arm, the videos were embedded directly into the Qualtrics system; participants conducted the Time 1 assessments, viewed the video, immediately conducted the immediate posttest questions, and were sent a link to the Time 3 assessments 3 weeks later. In the Living Library arm, participants were sent a link to the Time 1 a week before their scheduled Living Library session, sent a link to the immediate posttest questions on completion of the session, and then a link to the Time 2 assessments 3 weeks later. Finally, for the workshops, delivered in May to June 2015, the Time 1 and 2 assessments were administered via Qualtrics, but the immediate posttest questions were completed by paper and pencil at the end of the workshop.

Qualitative Methods and Data Analysis

Purposeful criterion sampling [33] was used to ensure the breadth of KT modalities was represented. Consenting participants were contacted via email approximately 2 weeks after participating in the KT strategy to schedule a telephone interview; interviews occurred approximately 3 to 4 weeks following participation in the KT strategy. A total of 43 interviews were conducted by coauthor EM. Interviews ranged from 20 to 70 min in length (mean 39.4, SD 11.2). A semistructured interview schedule was developed with 3 main sets of open-ended questions. The first set of questions asked participants about their engagement with the information shared in the KT session. The second set of questions explored any attempts to implement self-management strategies. Finally, participants were asked about their QoL, including any changes to their QoL following exposure. Probes and reflective listening were used to elicit depth in participant responses. The interviews were digitally recorded and transcribed verbatim by EM (24/43, 56%) or research assistants (checked by EM for accuracy; 19/43, 44%).

Thematic analysis [34] of participants' perceptions and responses to the content and delivery of the self-management information in the KT strategy occurred. Themes describing participants' experiences of engaging with a KT strategy are discussed in detail elsewhere [10]. For the purposes of this paper, a secondary analysis was conducted that focused on information that would add to or clarify understanding of the quantitative study results. Step 3 of Braun and Clarke's [34] analytic process informed the analysis producing *descriptive, literal categories* of the data. Examples of positive and negative experiences relating to the KT modalities were identified. Data were assigned brief descriptive codes in the qualitative data management software NVivo [35]. Codes were examined, and overarching categories were identified. The content of categories

was reviewed for coherency, and transcripts were revisited as the themes were developed to ensure all relevant data were adequately described. The essence of the most important categories in relation to understanding quantitative data was then described in a report with illustrative transcript extracts. To reduce the risk of bias and to address analytic validity, authors EEM and RH reviewed both the descriptive accounts of themes and transcripts for coherency and validity of interpretation, with disagreements resolved via consensus.

Results

Participants

A total of 94 participants were included in the quantitative analyses, with a modal age range of 45 to 54 years and the majority (n=53, 56%) identifying as female. The most frequently reported diagnosis was BD Type I (46/94, 49%), followed by BD-II (31/94, 33%). In the 43 participants in the qualitative analyses, modal age range was 45 to 54 years; n=30 (70%) participants were female, with n=24 (56%) reporting BD Type I and 16 (37%) reporting BD Type II.

Quantitative Results

We first analyzed the immediate postintervention data to explore participants' perceptions of the different types of KT strategies. Data were analyzed using a one-sample *t* test comparing the difference between the mean response and the neutral rating of 3. As shown in Table 1, participants were very positive about all KT strategies with modal response of Agree or Strongly Agree in each case and responses significantly better than neutral for 15 of the 16 cells.

To understand the impact of participation in the 4 KT strategies over time, we first conducted a multivariate repeated-measures (pretest to follow-up on each of BRQ, QoL.BD, PA, NA, and SECD) analysis of variance with KT strategy (ie, webinar, video, Living Library, and workshop) as the between-subjects variable. The analysis revealed a main effect of Time: when averaged across the 4 strategies, participation led to improvements across the 5 outcomes (upper 5 rows of Table 2). Posthoc analyses found nonsignificant improvements in PA and NA and significant improvement as measured on the BRQ ($P=.02$) and QoL.BD ($P=.005$). Chronic Disease Self-Efficacy as measured by SECD was the outlier, with a small (nonsignificant) decrease when averaged across the 4 strategies.

Second, we looked at the 5 outcome variables separately, via a Time \times Strategy interaction (bottom 5 rows of Table 2). For BRQ, QoL.BD, PA, and NA, there was no difference between the KT strategies in terms of their ability to improve outcomes (ie, there was no significant Time \times Strategy effect for these 4 variables). Interestingly, the data showed that for SECD, there was a significant Time \times Strategy effect ($P=.01$; the sole outcome that showed a negative average impact across strategies). Figure 7 shows that SECD declined in the 2 conditions that were more technology-dependent (webinar and video), but actually improved in the 2 conditions that had more peer or interpersonal contact (Living Library and workshop).

Table 1. Ratings of satisfaction with 4 knowledge translation strategies (1=Strongly Agree and 5=Strongly Disagree). Data in the table are mean (mode) responses. Superscripted letters refer to the significance of one-sample *t* test comparing mean with neutral response (ie, rating of 3).

Strategy	Something new, mean (SD)	Applicable, mean (SD)	Expectations, mean (SD)	Recommend to others with bipolar disorder, mean (SD)
Webinar (n=22)	2.41 (2) ^a	1.77 (1) ^b	2.55 (1)	1.77 (1) ^b
Video (n=26)	2.35 (2) ^a	1.85 (2) ^b	2.50 (2) ^c	1.65 (2) ^b
Workshop (n=32)	1.78 (2) ^b	1.34(2) ^b	1.81 (2) ^b	1.56 (2) ^b
Living Library (n=14)	1.93 (2) ^b	1.86 (1) ^b	2.21 (1) ^c	1.43 (1) ^b
Combined (n=94)	2.11 (2) ^b	1.66 (1) ^b	2.23 (2) ^b	1.62 (1) ^b

^a*P*<.005.^b*P*<.001 (survives Bonferroni adjustment for 16 comparisons).^a*P*<.05.**Table 2.** Results of multivariate analysis of variance, testing change in 5 outcome measures between pretest and follow-up (upper 5 rows are main effect of time and lower 5 rows are the interaction between time and knowledge translation strategy).

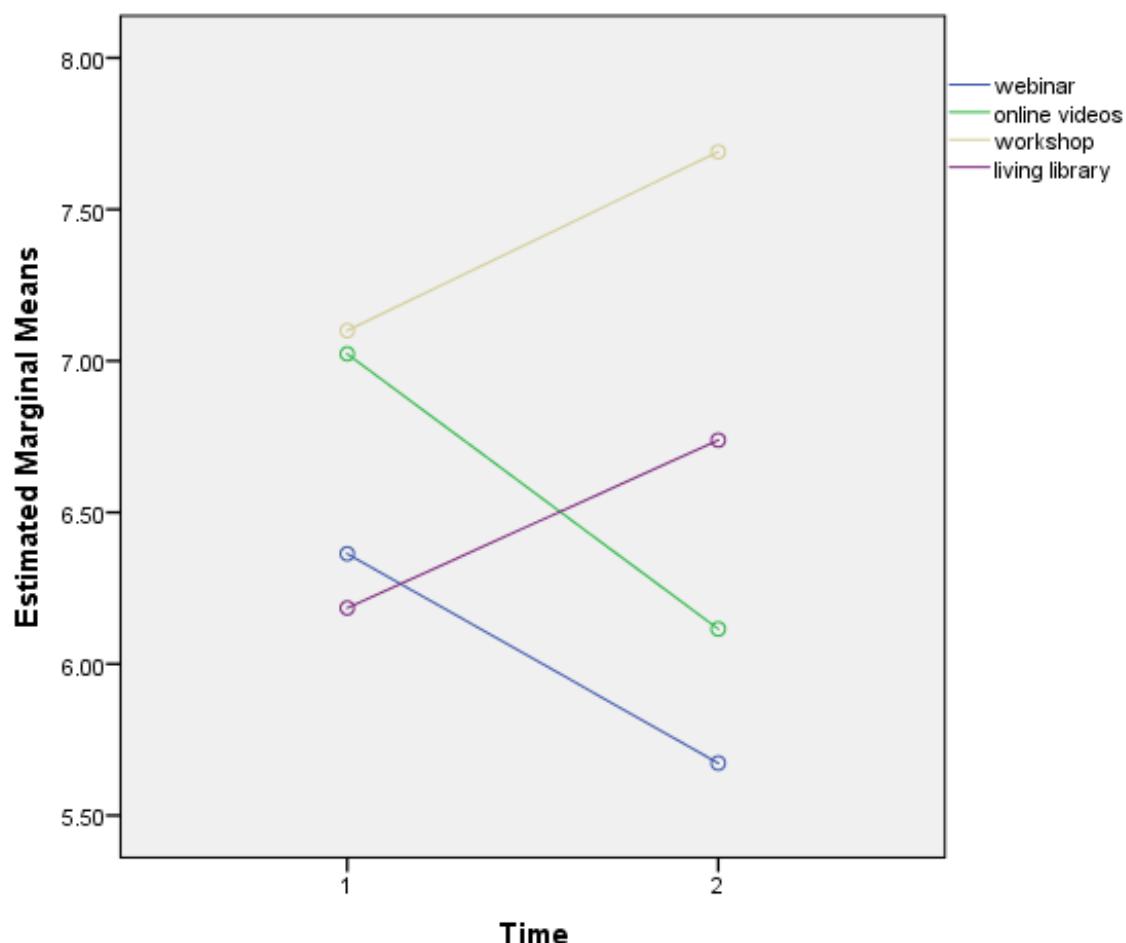
Analysis and measure	Mean square	F (df)	P value
Time			
Bipolar Recovery Questionnaire	205.053	5.887 (1,77)	.02
Quality of Life in Bipolar Disorder (scale)	1.252	8.212 (1,77)	.005
Positive Affect ^a	0.457	1.889 (1,77)	.17
Negative Affect ^a	1.236	3.059 (1,77)	.08
Chronic Disease Self-Efficacy	0.490	0.283 (1,77)	.60
Time X Strategy			
Bipolar Recovery Questionnaire	23.241	0.667 (3,77)	.58
Quality of Life in Bipolar Disorder (scale)	0.302	1.982 (3,77)	.12
Positive Affect ^a	0.091	.376 (3,77)	.77
Negative Affect ^a	0.404	0.999 (3,77)	.40
Chronic Disease Self-Efficacy	6.339	3.652 (3,77)	.02

^aA measure from the PANAS scale.

Qualitative Results

Participant descriptions of both positive and negative experiences specifically associated with the webinar, video, Living Library, and workshop arms are summarized in **Tables 3-6**, respectively. Positive aspects of the various KT strategies emphasized by participants included the interactive nature of the webinars and the depth of information provided, and the brevity and visual accessibility of the videos. Across the KT modalities, peer contact was consistently emphasized as a helpful or appreciated aspect, but descriptions of how peer

contact was experienced varied by modality. Participants in the workshop arm emphasized appreciating the opportunity to learn from others managing the same condition and reducing self-stigma through normalization of shared experiences. The Living Library was described as a helpful place to share experiences with an expert who could understand and relate to them, and some participants described being inspired by having access to somebody who lived well with BD. Participants in the video arm often felt able to relate to the actor or narrator, which helped them better understand their own experiences as well as identify the personal relevance of strategies.

Figure 7. Pretest to follow-up change in chronic disease self-efficacy by strategy (difference in slopes $P=.01$).**Table 3.** Qualitative findings: positive and negative experiences of webinars.

Category description	Quote
Positive experiences	
Interactive (n=7)	“I also really liked that they had a question and answer period at the end.” [F, BD-II, 25-34]
Depth of information (n=5)	“I find them very informative, and I personally like webinars.” [F, BD-I, 55-64]
Peer presence as normalizing or providing community (n=3)	“I saw the people on the right, the people who had signed in, and the comments. So it just said, ‘Well, you’re in good company, and you can do this, and you’re doing things right,’ kind of.” [F, BD-I, 55-64]
Negative experiences	
Overly academic or clinical (n=4)	“What kind of triggered me at the beginning was a lot of what I call MBA type language...I find that really, really frustrating, because the emphasis on quality indicators and efficacy and all this kind of stuff, really is never about the person.” [M, BD-NOS, 45-54]
Technical difficulties (n=1)	“Well for one thing I entered the webinar rather late because I was having some system problems, so I had to contact the webinar organisers and get everything sorted out. So I might not have learned as much as I could have.” [F, BD-I, 55-64]

Table 4. Qualitative findings: positive and negative experiences of videos.

Category description	Quote
Positive experiences	
Succinct (n=3)	“It’s not overwhelming, it’s not like reading a thousand page book, the videos are short and sweet and I think that’s good.” [M, BD-I, 55-64]
Visualizing self-management (n=3)	“Watching somebody do things...that’s how I learn, and I found the video is really helpful in that...It gave me a sort of visual concept of what it’s about.” [F, BD-I, 55-64]
Relatability of the narrator (n=5)	“Just seeing how that video was, like first of all, how her life was with her depression or how she was feeling, her mood, how things were cluttering her world, I recognize that that’s what happens to me, but to know it, to actually see it was helpful.” [F, BD-II, 45-54]
Negative experiences	
Difficulty identifying with a person living well with bipolar disorder (n=4)	“I didn’t connect with the video as much as I would have liked to, because I felt like a bit of a personal failure because it wasn’t that easy for me, it was so much harder.” [F, BD-II, 45-54]
Amount of information (n=2)	“I found that the videos were very short and not very, from a user’s point of view, not that informative.” [M, BD-I, 35-44]

Table 5. Qualitative findings: positive and negative experiences of Living Library.

Category description	Quote
Positive experiences	
Living Library expert understands my experiences (n=2)	“One of strongest points of our talk was finding out that [the Living Library expert] was also bipolar. And that’s what I’ve been searching for, is to talk to others that live it, and not just read about it in a book, because even then, when I read some of the books, it doesn’t quite fit what I’ve experienced and maybe I’m looking for others like me” [F, BD-I, 45-54]
Being inspired by the Living Library expert (n=4)	“Knowing that people go through the same stuff and probably manage the condition better. So just knowing that helped.” [M, BD-I, 25-34]
Negative experience	
Lack of information provided by the Living Library expert (n=1)	“I learned absolutely nothing...She didn’t understand the program herself, she couldn’t help me get into some of the stuff.” [F, BD-I, 55-64]

Table 6. Qualitative findings: positive and negative experiences of workshops.

Category description	Quote
Positive experiences	
Learning what works for others with bipolar disorder (n=5)	“I found that was also helpful, sharing with other people, you know suggestions about things that have helped them and so on.” [M, BD-II, 35-44]
Normalizing difficulties (n=4)	“I felt when I was there that I didn’t stand out. It was just kinda like everybody was there and everybody has their own little struggles.” [F, BD-I, 35-44]
Negative experience	
Scheduling (n=1)	“I would have preferred if the workshops had been a bit earlier, especially because we ended up going later. I found that hard, you know, we’re talking about sleep - we’re talking about going to bed at the regular, you know, for setting up the pattern. And I ended up going to bed late that night. So that was, that was a bit frustrating, to be talking about setting up a regular sleep time and then, set back, from doing that, rolling my sleep schedule off.” [F, BD-I, 35-44]

Reports of negative experiences of KT modalities were infrequent, particularly in participant descriptions of the workshop and Living Library arms (2 participants across both these arms described unique negative experiences). As such, description of negative experiences in this section focuses on the webinar and video arms, where a small number of participants described feeling disengaged or discouraged by the interventions. Overall, 4 participants in the webinar arm described the academic style of information delivery in the webinar as off-putting and 1 reported technical difficulties.

Some participants found it difficult to relate to the depiction of a woman living well with BD in the videos, resulting in a sense of discouragement or frustration. Although the length of the videos was described by some participants as a positive, others found that their brevity limited the amount of useful information conveyed. Finally, of note, a preference for in-person services was described by some participants across both the webinar and video arms.

Discussion

Overview

The potential for digital technologies to produce a transformative impact in the mental health arena is profound. Research is burgeoning in this space, driven in part by recognition of the remarkable rate at which society is adopting technology into their everyday lives, the pressures on health care systems for services to be delivered flexibly in a patient-centered manner, and acknowledgment of the empowerment that digital technologies can bring to patients by enabling them to make choices about when and how they access care [36]. Technology-supported self-management holds significant potential to improve the health and QoL of people facing mental health challenges and represents 1 avenue to reduce the substantial health care costs associated with chronic illnesses [37]. However, the production of evidence-based self-management support technologies is time and resource intensive and requires sustained maintenance; the identification of effective approaches to optimize user engagement with them is therefore paramount. This mixed-methods study explored the impact of 4 KT strategies on user engagement and health-related outcomes in people with BD.

Principal Findings

Quantitatively, at a broad level, participants evaluated all 4 KT strategies positively. When the KT strategies were examined collectively, we observed a nonsignificant trend toward increased PA and decreased NA following exposure to the KT strategies and significant improvements in perceived recovery and QoL. A modest nonsignificant decrease in perceived self-efficacy to manage chronic illness was observed after exposure. Exploration of the impact of the KT strategies individually indicated that all 4 KT strategies positively impacted perceived recovery, QoL, and both PA and NA. Chronic disease self-efficacy was observed to significantly decline in the more technology-dependent conditions (webinar and video) but improve in the 2 conditions with more peer and interpersonal contact (workshop and Living Library).

This study adds one piece of incremental evidence to a growing literature, suggesting that Web-based technologies can represent an effective conduit for, or complement to, care for people with BD. In a recent systematic review of Web and mHealth apps for self-management in BD, for example, we identified 15 studies, several of which demonstrated positive impacts of digital interventions on QoL [11]. The most commonly supported self-management strategy categories delivered by Web-based interventions identified in the review were “ongoing monitoring,” “maintaining hope,” “education,” and “planning for and taking action”; the least commonly supported categories were “relaxation” and “maintaining a healthy lifestyle.”

Qualitatively, user experiences of the 4 KT strategies tested were also largely positive. Most dominant was an appreciation of the opportunity for peer contact. Negative descriptions of experiences tended to focus on the webinar and video strategies, citing issues such as disliking the academic tone of the webinars, or an inability to identify with the woman living well with BD depicted in the videos. Broadly speaking, our qualitative findings

suggested that there was no “one size fits all” approach for determining the right type of KT strategy for BD self-management information. Other qualitative analyses of this qualitative dataset have been published, with a focus on participants’ experiences of self-management more broadly as well as perception of their QoL [10,38]. Although this analysis focused on perceptions of the KT strategies embedded in the overall self-management intervention, an evaluation of experiences of engaging with the self-management intervention more broadly as well as attempts to enact self-management strategies was conducted [10]. Feelings of empowerment and responsibility to self-manage BD were discussed, whereas a minority of participants felt that self-management strategies lacked power to control BD symptoms. The relationship of self-management to the health care system was also discussed, with opportunities to develop a sense of partnership between clinicians and patients via attention to self-management identified. A more in-depth discussion of the links of such experiences to self-efficacy, recovery, and therapeutic alliance is presented therein. In addition, a qualitative analysis focusing on individuals’ subjective experiences of their QoL was conducted [38]. The relativity of subjective QoL judgments to self, others, and possible futures was explored, and the possible implications of the flexibility of reference point usage for future therapeutic interventions were discussed.

Our observation that chronic disease self-efficacy may be differentially impacted by the mode of KT strategy (ie, ones containing more vs less peer interaction) is intriguing. On the one hand, existing literature clearly points to the potential benefits of Web-based peer support in terms of increasing feelings of social connectedness, group belonging, and serving as an avenue to share self-care strategies [39]. Web-based peer support for people with mental health problems can occur in diverse ways, including via general support forums (eg, [40]); advanced interactive forums dedicated to sharing illness experiences such as PatientsLikeMe [41]; discussion forums that are embedded within formal Web-based treatment interventions (as being evaluated, eg, in the BD Mood Swings 2.0 [42,43] and ORBIT [44] trials); or through social media platforms such as Twitter, Facebook, and Reddit [39,45] and blogging [46] or video-based platforms [47,48]. Regardless of the conduit, it appears that engagement rates with apps that foster social connections may be higher [49].

Web-based engagement should not be viewed, however, as entirely without risk; Naslund et al [39] note that interactions on the Web can result in exposure to unreliable information, hostile or derogatory comments, or feelings of uncertainty or anxiety about one’s mental health condition. Our finding, albeit from a modest dataset, that chronic disease self-efficacy may be negatively impacted by KT strategies with less peer support may be 1 example of how digital interventions might also have unintended negative consequences. In a recent study, Williams et al [47] qualitatively explored users’ experiences of lived experience videos on an interactive recovery-oriented website (the Self-Management and Recovery Technology or “SMART” program) designed for people with psychosis. Although the delivery and focus of the videos in the SMART program differed from those of this study (SMART program videos were focused

on recovery principles rather than on self-management strategies and were designed to be viewed either with a mental health worker or independently), results from that study are germane to this project. In particular, participants' experiences of the videos were clearly situated for many in the context of their personal recovery journey, as the authors' state:

Responses to the videos appeared to be influenced by the participants' existing ways of coping with life and managing their recovery, as well as by how they used technology. Participants who did not relate to the peers as role models perceived that their ways of coping were too different, or they were at a point in their recovery journey where they did not want to identify with peers.

In summary, our quantitative (ie, decreased chronic disease self-efficacy scores in the video and webinar arms) and qualitative (ie, some participants reporting difficulties identifying with the actor living well with BD in the videos) findings suggest 2 things. First, participants' experiences of KT strategies appear to be influenced by their understandings of their position in their own recovery journey. Second, there appears to be benefit of KT strategies that incorporate peer support. Future research is needed to more fully explore the precise relationship between peer support and engagement with, or enactment of, concrete self-management strategies.

Limitations

A number of limitations to this study should be noted. First, participants self-reported their diagnosis of BD; although confirmation of diagnosis by structured psychiatric interview would have been preferable, there is some evidence that people who self-identify as living with BD typically do meet diagnostic criteria [50]. Second, this study was positioned as an exploratory phase in a longer-term program of research to advance understanding of the utility of digital health technologies for supporting self-management in people with BD. Participants were volunteers who were paid a modest honorarium for their participation and were free to self-select which KT modality they wanted to engage with, likely biasing toward an engagement method they were intrinsically attracted to, which in turn may have impacted the range of positive and negative experiences reported, limiting the generalizability of the results to routine health service delivery settings. Third, the assessment time frame for the examination of quantitative outcomes was short, that is, 3 weeks. Many digital health intervention studies apply assessment periods of 4 to 8 weeks (eg, [51]). Furthermore, changes in the outcomes of interest in this study, such as QoL, are anticipated to emerge relatively slowly in BD compared with changes in symptoms (eg, [52]), and changes in self-management behaviors are fully expected to take time to incorporate into everyday life. Longer assessment time frames in future work are called for to fully capture expected trajectories of change in QoL outcomes and self-management behaviors. Unlike QoL, a sense of personal recovery as measured on BRQ might be expected to shift quite quickly as people adopt new attitudes toward their role in managing BD. Responses to BRQ items such as "I have the resources to manage my health" and

"The activities I do make a difference to others" could shift solely via insights gained from interactions in the intervention. Fourth, as there was no control group of participants who did not partake in any strategy, nonspecific causes (such as attention, time, demand characteristics, or the honorarium paid for participation) cannot be ruled out as an explanation for the observed quantitative outcomes.

Implications and Future Directions

Despite the aforementioned limitations, this study provides a useful mixed-methods evaluation of the potential impact of a range of KT strategies on health-related outcomes in people with BD. The study was conducted between 2014 and 2016; our CREST.BD program of research has been focused since then on meeting emerging opportunities and needs of the digital mental health landscape. Moving forward, we are seeking funding for work to incorporate the evidence and tools held in the Bipolar Wellness Centre [23], our Web-based QoL Tool [26], and the findings from this study to inform the development of a new mHealth app—"Bipolar Bridges." In doing so, we are carefully addressing some of the key challenges currently being faced by the digital-technology space, which relate prominently to issues of information credibility, safety, and privacy.

More than 10,000 mental health apps are available for immediate download today; worryingly, most mental health apps in commercial marketplaces are not evidence-based nor conform to clinical guidelines [53]. A 2015 systematic review found the majority of apps for BD (82/571 available apps were reviewed) were not aligned with clinical guidelines or established self-management principles and did not cite sources of evidence [54]. Some may even offer dangerous recommendations (eg, 1 app recommends that people experiencing BD mania drink alcohol at bedtime to assist with sleep [54]). Furthermore, many available apps do not respect the privacy of personal health information [53-55]. Thus, there are significant barriers for people facing mental health challenges in identifying safe, evidence-informed apps [56,57]. Data from adults with BD [58] report "wish list features" for new apps inclusive of "social interaction capability" and "between-app integration" and receptiveness to digitally supported self-management [59]. Data from youth with BD report prioritization of ease-of-use, scientific quality, customization, and data privacy [16]. At a broad level, the BD field needs to advance in terms of creating technology-supported spaces, which are inclusive of diverse people, regardless of their gender, sexual orientation, socioeconomic status, digital literacy, geography, and ethnicity. Finally, the results of this study indicate that more work is needed to inform how to best advance social connectivity via apps. Looking ahead, our Bipolar Bridges project aims to address some of these key challenges via the creation of a new app designed to enable diverse users with BD to optimize their QoL via supported self-management, resting on an innovative and secure blockchain-based platform. The results of this study will be applied to hone a comprehensive mixed-methods (quantitative, qualitative, and machine learning) investigation of the feasibility, engagement, adoption, impact, and mechanisms of change associated with the use of the app.

Acknowledgments

This study was supported by a CIHR Knowledge to Action grant, grant #201210KAL-259464. The authors gratefully acknowledge the research participants who were involved in this project, the expertise of the CREST.BD Community Advisory Group and CREST.BD network members, and the support of MDAO.

The members of CREST.BD are as follows: Erin Michalak, Greg Murray, Steven Barnes, Barbara Pesut, Catriona Hippman, Cindy Holmes, Colin Depp, David Kreindler, David Miklowitz, Emma Gliddon, Emma Morton, Eric Youngstrom, Fiona Lobban, Georgina Hosang, Guillermo Perez Algorta, Ivan Torres, Jehannine Austin, Jennifer Nicholas, Joanna Cheek, Joanna Jarecki, Kathryn Fletcher, Lakshmi Yatham, Lesley Berk, Lisa O'Donnell, Luke Clark, Martin Provencher, Melinda J Suto, Michael Berk, Nasreen Khatri, Rachelle Hole, Raymond W Lam, Rob Tarzwell, Roumen Milev, Sagar Parikh, Samson Tse, Sara Lapsley, Sheri Johnson, Steve Hinshaw, Steven Jones, Thomas D Meyer, Victoria Maxwell, Carolyn Ziegler, Catherine Simmons, Don Kattler, Natasha Kolida, Raymond Tremblay, Ryan Tine, Sandra Dawson, Hailey Tremain, Nusha Balram, Sharon Hou, Susan Lauder, Veronika Zarnoch, and Yan Yang.

Conflicts of Interest

None declared.

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Abbreviations

BD: bipolar disorder
BRQ: Bipolar Recovery Questionnaire
CBPR: community-based participatory research
CIHR: Canadian Institutes of Health Research
CREST.BD: Collaborative Research Team to study psychosocial issues in Bipolar Disorder
KT: knowledge translation
MDAO: Mood Disorders Association of Ontario
mHealth: mobile health
NA: negative affect
PA: positive affect
PANAS: Positive and Negative Affect Schedule
Q&A: questions and answers
QoL.BD: Quality of Life in Bipolar Disorder
QoL: quality of life

Edited by J Torous; submitted 25.01.19; peer-reviewed by F Lobban, MS Aslam; comments to author 14.02.19; revised version received 19.02.19; accepted 22.02.19; published 15.04.19.

Please cite as:

Michalak EE, Morton E, Barnes SJ, Hole R, CREST.BD, Murray G
Supporting Self-Management in Bipolar Disorder: Mixed-Methods Knowledge Translation Study
JMIR Ment Health 2019;6(4):e13493
URL: <http://mental.jmir.org/2019/4/e13493/>
doi:10.2196/13493
PMID:30985287

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Original Paper

Digital Presence of a Research Center as a Research Dissemination Platform: Reach and Resources

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Abstract

Background: Web-based platforms can be powerful tools for research dissemination. By leveraging the advantages of mass media and interpersonal channels of communication, Web-based dissemination platforms may improve awareness about, and subsequent adoption of, evidence-based practices (EBPs). Digital dissemination strategies can augment traditional dissemination models, improving stakeholder access to digestible and actionable information and promoting translation of EBPs.

Objective: This study aimed to describe the reach and content of the Web presence of a National Institute on Drug Abuse Center of Excellence and how it is used to disseminate research related to digital behavioral health approaches.

Methods: The Center for Technology and Behavioral Health (CTBH) has a website and regularly updated Facebook and Twitter accounts. The website features include summaries of digital behavioral health approaches and related empirical literature, a blog feed focused on the state of the science and technology concerning digital health care approaches, and a newsletter about Center activities. We extracted website usage metrics from Google Analytics and follower counts from social media accounts for the period from March 1, 2013, to July 17, 2018.

Results: Since the implementation of analytic tracking, 70,331 users have initiated 96,995 sessions on the CTBH website. The website includes summaries of 86 digital therapeutic programs, encompassing 447 empirical articles. There are 1160 posts in the CTBH blog feed, including 180 summaries of scholarly articles. The Twitter and Facebook accounts have 577 and 1500 followers, respectively. The newsletter has reached a growing subscriber network and has a high open rate relative to industry standards.

Conclusions: The CTBH Web presence serves as a model for how to leverage accessible and easily updatable digital platforms as research dissemination channels. Digital dissemination tools can augment traditional dissemination strategies to promote awareness about evidence-based digital therapeutic approaches for behavioral health and health care more broadly.

(JMIR Ment Health 2019;6(4):e11686) doi:[10.2196/11686](https://doi.org/10.2196/11686)

KEYWORDS

telemedicine; internet; social media; behavioral sciences; implementation science; information dissemination

Introduction

Background

The limited translation of research to practice is a long-standing issue in health care [1-3], and adoption of innovations to support evidence-based treatment for substance use and mental health conditions is no exception. Barriers to translation include limited

stakeholder awareness of evidence-based practices (EBP) and their demonstrated impact for target patient populations as well as clinician expectations that adoption of new practices may increase burden [4-6]. Strategies to make communication of research findings more relevant, digestible, and actionable to clinician and policy stakeholders may improve dissemination and adoption of empirically supported practices [7].

The Promise of Digital Treatment Approaches to Substance Use and Mental Health Care

Technology offers great promise for addressing many of the barriers to adoption of EBP [5,8]. Digital behavioral health approaches, such as Web-based programs, mobile apps, and text messaging, can transcend the time and geographic boundaries of traditional clinical practice settings and offer evidence-based care to broad patient audiences when and where they need it. Different mixed media (eg, text, audio, and video) can be used in digital therapeutic approaches to appeal to a broad range of learning styles [9] and promote engagement [10,11]. There is strong and growing evidence for digital therapeutic approaches targeting substance use and mental health conditions [12-17]. These digital behavioral health approaches have demonstrated efficacy for identifying symptoms [18,19], evoking positive behavior change [20-28], and facilitating recovery support [29]. Despite a promising impact, digital therapeutic approaches for behavioral health have yet to see widespread implementation in practice.

Technology as a Platform for Research Dissemination

Technology—and, in particular, the internet—can also serve as a powerful platform for science dissemination to patient, provider, researcher, and policy stakeholders. Digital platforms can bridge approaches to dissemination and diffusion of research, allowing information to reach broad audiences with little effort required from the researcher beyond posting the information. According to the diffusion of innovations theory [30], key dissemination channels include interpersonal and mass media channels of communication. Mass media channels of communication are the most efficient, but interpersonal communication channels are the most persuasive [30]. Web platforms may be able to leverage the strengths of both channels of communication. There is preliminary evidence that Web platforms share features of mass media (eg, reaching many people at once) and interpersonal channels of communication (eg, the ability to cultivate homophilous communities) [31]. Web-based platforms may fall into an entirely new channel of communication: *new media*, which shares the efficiency of mass media and personalization of interpersonal communication [32].

Studies have highlighted the internet, including social media, as a useful tool for researchers to disseminate information about EBPs to the public [33-36]. Websites related to research, such as blogs, can have higher traffic than Web-based journal articles about comparable topics [37]. Through digital media, research findings can be disseminated to broad audiences using language that is relevant and accessible, user-friendly, and integrated with social media to promote communication [34-36]. Such Web-based dissemination efforts can complement and extend dissemination of research via scientific publications; presentations to scientific, policy, and community audiences; and mass media coverage. To our knowledge, only 1 other study has described how an academic institutional website was used as a tool for research dissemination—in this case, focused on implementation of shared decision making in primary care [38].

Current initiatives by the National Institute on Drug Abuse (NIDA), the Substance Abuse and Mental Health Services Administration, and the Center for Substance Abuse Treatment

focus on closing the science-to-practice gap through greater attention to the promotion of successful dissemination and implementation strategies for EBPs [39-41]. In this paper, we describe how website and social media features of a NIDA-designated P30 *Center of Excellence* (the Center for Technology and Behavioral Health [CTBH]) are used to disseminate research about digital therapeutic approaches for substance use and mental health conditions. Established in 2011, CTBH is a national and international leader in research focused on development, evaluation, dissemination, and implementation of digital behavioral health treatment approaches. CTBH maintains a website [42] as well as social media accounts to foster dissemination of research focused on digital behavioral health approaches and to promote awareness of CTBH activities and resources. The publicly available CTBH website and Facebook and Twitter accounts (collectively, CTBH Web presence) have the potential to reach broad audiences, including patients, clinicians, researchers, and policy makers.

Leveraging digital platforms for research knowledge translation has received little attention in translational research. Digital platforms can extend the reach of scientific knowledge to stakeholders who may not read academic journals [43]. Digital dissemination channels can allow for ready access to continuously updated information. Abundant and current content on a website promotes audience engagement [44]. Furthermore, posting about research on social media (eg, Twitter) facilitates uptake of research [37,45,46]. These digital channels are a key part of the mission of CTBH to be a national and international resource underscoring science-based digital behavioral health. The purpose of this paper was to present a model for leveraging digital platforms as research dissemination tools by describing CTBH's Web presence and presenting data about its content and reach.

Methods

Center for Technology and Behavioral Health Web Presence

CTBH maintains a center-specific website and Twitter and Facebook accounts to keep users informed about the state of the science regarding digital behavioral health approaches and CTBH activities. CTBH launched its website in May 2012. Screenshots of the website features are available in [Multimedia Appendix 1](#). What follows is a brief description of the website content.

The Center

The *Center* is the gateway to pages listing CTBH leadership, members and affiliates, publications and presentations, active projects, hosted seminars, and announcements (eg, recruitment for research studies) and news stories about CTBH activities. Users can view and subscribe to the CTBH newsletter from this page.

Program Review

The *Program Review* is a filterable compendium of annotated summaries of empirical literature for specific digital approaches for the treatment of substance use disorders, co-occurring disorders, mental health conditions, and HIV. Programs are

identified for review through scoping literature searches of academic databases for digital interventions targeting the aforementioned conditions. Literature for each program review is extracted from the searches, lists of works by the investigators, and bibliographies of relevant articles.

Program reviews include descriptions of each intervention and information about the target populations with which each intervention has been evaluated (eg, age, race, and gender), delivery method (eg, Web-based or mobile app), guiding theoretical models (eg, community reinforcement approach, cognitive behavior therapy, or self-regulation theory), intervention target (eg, substance use or depression), outcomes (eg, reduced substance use, abstinence, symptom severity, or treatment adherence), and languages and countries in which the intervention has been delivered and evaluated. Each program review includes summaries of the studies evaluating the digital therapeutic tool, including methodology, results, and implications, and citations for nonevaluation articles related to the program (eg, study protocols). The key characteristics identified in program reviews are associated with fostering successful implementation [47] and align with recent recommendations for standardization of reporting on digital therapeutic tools [48,49]. Users can filter programs by target age group, target substance or condition, type of program, and commercial availability. Program review summaries are updated monthly.

Eye on Innovation

Eye on Innovation is a blog-style newsfeed that includes links to, and excerpts from, news stories relating to recent developments in digital health and an annotated bibliography of recently published empirical literature related to emerging technology and health (*Cutting Edge Literature*). Content features are tagged to allow for easy filtering by users. The newsfeed is updated weekly.

Social Media and Newsletter

CTBH launched its Twitter account in September 2013 and Facebook account in August 2014. These accounts feature posts about news related to technology in behavioral health, innovative research, and updates about CTBH activities. The Twitter and Facebook accounts are updated at least daily. CTBH distributes

a quarterly newsletter by email to a subscriber distribution list. Subscribers can join this list from the CTBH website or by signing up at CTBH-hosted events.

Sources of Data

We used Google Analytics to collect data on CTBH website usage. Information about social media audience is publicly displayed on the Facebook and Twitter accounts. We used information available from distribution service (MailChimp) reports to describe the audience and engagement with the newsletter over time.

Data Extraction

CTBH began using Google Analytics to track user activity on the website in March 2013. For this report, we extracted data from March 1, 2013, to July 17, 2018, on the number of users, number of sessions initiated, number of page views, percentage of sessions initiated by new users, average number of pages viewed per session, average time spent on the site per session, most viewed pages, and countries where users were located. Information about numbers of Twitter and Facebook followers and posts was extracted from the CTBH Facebook and Twitter accounts. We used newsletter reports to extract data about the number of people who received and opened the first (April 2012) and most recent (December 2017) electronic newsletters and about the number of newsletter subscribers over time.

Results

Website Metrics

Between March 1, 2013, and July 17, 2018, 70,331 users initiated 96,995 sessions on the CTBH website. About 72.50% (70,317/96,995) of the sessions were initiated by new users. On average, users viewed about 2.4 pages per session and spent 1 min and 57 seconds on the site per session. Annual website usage metrics are available in Table 1. The most popular pages were the homepage (29,113 views), The Center (11,644 views), and the Program Review landing pages (10,826 views; Table 2). Users most often viewed the website from the United States (80.2%). Approximately 20% of the users were based in other countries (Table 3).

Table 1. Usage statistics for the Center for Technology and Behavioral Health website by year (March 1, 2013, to February 28, 2018).

Year ^a	Visits	Users	Page views	New user-initiated sessions, n (%)	Average pages per session	Average time per session
2013-2014	9365	6364	34,230	6297 (67.24)	3.7	2:57
2014-2015	17,383	12,379	48,035	12,198 (70.17)	2.8	2:12
2015-2016	17,534	13,156	46,697	12,959 (73.91)	2.7	1:57
2016-2017	17,062	12,130	52,779	11,983 (70.23)	3.1	2:35
2017-2018	25,288	19,173	39,881	19,008 (75.17)	1.6	1:18
Total (2013-2018)	86,632	63,505	221,622	62,445 (72.08)	2.6	2:03

^aYears begin on March 1st and end on the final day of February of the following year.

Table 2. Most popular pages on the Center for Technology and Behavioral Health website based on page views (March 1, 2013, to July 17, 2018).

Page	Views (n)
Home	29,113
The Center	11,644
Program Review	10,826
Center Director	9654
Center Members	9465
Active Projects	6317
Eye on Innovation	5906
Center Leadership	5647
Programs for Substance Use Disorders	4354
Center Highlights	4257

Table 3. Most common locations from which users access the Center for Technology and Behavioral Health website: number and percentage of sessions (March 1, 2013, to July 17, 2018).

Country	Sessions, n (%)
United States	77,823 (80.23)
Canada	2514 (2.59)
United Kingdom	2026 (2.09)
India	1589 (1.64)
Australia	947 (0.98)

Program Review

As of July 17, 2018, research related to 86 digital behavioral health therapeutic approaches were included in the Program Review. Within the 86 program reviews, there are 308 summaries of empirical studies evaluating the different digital behavioral health approaches and citations for 139 related articles (eg, secondary analyses). The most frequently viewed program review was Therapeutic Education System [21], a Web-based intervention for substance use based on the community reinforcement approach (4337 page views).

Eye on Innovation and Cutting Edge Literature

As of July 17, 2018, the Eye on Innovation feed contained 1160 posts, including 180 Cutting Edge Literature pieces. Tags for individual posts are extracted from a total of 171 tags. The most commonly used tags are mHealth (ie, an abbreviation for mobile health; 326 posts), mobile apps (262 posts), mental health (140 posts), substance use (129 posts), and policy and regulation (107 posts). The most frequently viewed post describes the Mobile App Rating Scale [50] (202 page views).

Social Media and Newsletter

CTBH has made 4849 tweets on the CTBH Twitter account since its creation. The Twitter account has 577 followers. As of July 17, 2018, there were 701 posts on the CTBH Facebook account. The Facebook page has been liked 1478 times and has 1500 followers.

The first newsletter in April 2012 was sent to 337 subscribers and was opened by 21% of the recipients. The most recent

December 2017 newsletter was sent to 1132 subscribers and was opened by 34% of the recipients. The number of newsletter subscribers has increased each year since it has been recorded.

Discussion

The Center for Technology and Behavioral Health Web Presence as a Dissemination Strategy

The usage statistics associated with the CTBH Web presence indicate that the digital dissemination strategy was effective in reaching large audiences with research information related to digital therapeutics for behavioral health. Although users were primarily from the United States, about a quarter of users were based internationally. Although we were not able to determine user characteristics in this study, anecdotal evidence from email inquiries from the CTBH website from an array of stakeholders, including researchers, policy makers, clinicians, and patient consumers, suggests that we were able to reach diverse user audiences. To our knowledge, the only other study describing the reach of a Web-based research dissemination platform saw an average of 7906 visits by 5382 users each year [38]. The CTBH Web presence sees thousands of users and visits each year and has seen a growth in audience since its inception, suggesting a high and expanding reach of this digital dissemination strategy.

In addition, the CTBH website shows evidence of *stickiness*, commonly defined as a user's willingness to use and continue using a website [51,52]. An important metric of website stickiness is session duration. According to the Nielsen Group, users typically spend less than 1 min on a Web page, on average

[53]. The average session duration on the CTBH website was 1 min and 57 seconds, indicating higher than average levels of stickiness. The CTBH newsletter has also seen a growing number of subscribers since its launch and has been consistently opened by a high percentage of subscribers. The open rate of the most recent newsletter (34%) is impressive compared with the first newsletter in April 2012 (21%) and with the industry average open rate (Education and Training: 22%) [54]. The CTBH Twitter and Facebook accounts provide hundreds of followers with daily updates about digital behavioral health research.

The CTBH Web presence can serve as a model for research dissemination. Anecdotally, we have heard from researchers that they wish they could use their website more effectively for research dissemination. We present several features of the CTBH Web presence as a demonstration of the variety of ways websites and social media can be effectively leveraged to disseminate research. We also present the quantity of content on the CTBH website to illustrate the abundance of updated content continuously available to users.

Though the content on a website is not necessarily indicative of successful dissemination, user engagement is related to websites having enough content to attract repeat visitors and having current information [44]. Similarly, posts on social media are not necessarily indicative of successful research dissemination, but early evidence suggests that social media promotion or discussion of research may promote engagement with research. Notably, articles that were frequently linked in tweets were found to be 11 times more likely to be highly cited in academic publications than articles that were less frequently mentioned in tweets [45]. Similarly, Valdez Soto et al [46] identified a potential link between social media promotion and enrollment in Web-based training, and Hoang et al [37] found that above-average activity on Web-based articles coincided with social media promotion, though increases in engagement in either study could not be concretely linked to social media promotion.

The use of multiple digital dissemination channels (eg, website, social media, and electronic newsletter) provides users with greater flexibility in how they access information about the science of digital behavioral health therapeutic approaches. End users may choose to check the website for updates, receive quarterly newsletters, or follow CTBH social media accounts for daily updates. The growing audiences on the website and followers on social media accounts demonstrate the success of the model for promoting reach and awareness about research related to digital therapeutic approaches. We hope that by describing the features of the CTBH Web presence, we can help other researchers to optimize their own Web presence for research dissemination to attract and engage user audiences.

Limitations and Future Directions

One limitation of this study is that we did not conduct statistical analyses comparing website use with users' actual use of evidence-based digital behavioral health approaches in practice or research. Evaluating the impact of this research dissemination model on user behavior is an important direction for future research. Another limitation is that we could not examine the

early growth of website usage because Google Analytics was not implemented for the site until the year after its launch. In addition, usage data from Google Analytics did not allow us to get a detailed picture of those who viewed the website, including professions of users and whether users were affiliated with CTBH or from outside of the CTBH network. Future features of the Web presence will include metrics to assess user characteristics.

The data extracted from the CTBH social media accounts only offer a current picture of user interaction with the accounts; we were unable to extract historical usage data for the accounts. Finally, it is also relevant to mention that spam accounts on social media, although relatively infrequent, can distort user interaction statistics [55]. It may be difficult to identify spam accounts from a list of followers. Although some spam account behavior is markedly different from the behavior of legitimate accounts, other spam accounts display patterns of interaction similar to the behavior of legitimate accounts [56].

Future directions for the CTBH website as a research dissemination platform include expansion of existing features and addition of features to encourage interaction among users of the CTBH Web presence components. A *Resources* page of the website was introduced in 2017, which includes a developing compendium of measures for assessing implementation of digital therapeutic interventions across the stages of treatment development research continuum [57] and roadmaps for implementation of digital behavioral health therapeutic approaches in different care settings. Future resources will include Web-based consent protocols and best practice methods for research study participant recruitment on social media. CTBH plans to engage its audience through social media to promote conversation among user stakeholders about interests and experiences with digital behavioral health approaches, with the goal of fostering collaborations for future implementation studies.

CTBH aims to continue to disseminate timely information about the state of digital approaches to behavioral health and will further explore the potential of social media to personalize the digital dissemination experience. There is limited research on the role of new media as facilitators in the translation of research to practice. We have demonstrated that our digital dissemination strategy has achieved a good reach to end user stakeholders compared with other published work [38]. We plan to investigate the persuasiveness of this approach for promoting the use and adoption of digital therapeutics in future work.

Conclusions

In this paper, we demonstrated the potential of digital strategies to successfully disseminate information about research related to digital behavioral health therapeutic approaches. Although Web presence can promote awareness about existing research, successful translation depends on the application of knowledge and implementation skills to promote the use of these digital approaches by patients-clients, providers, and researchers [58]. In future research, we will examine how stakeholders utilize information from the CTBH digital dissemination platforms. We will also explore strategies for using these platforms to promote collaboration among stakeholder groups to promote

research agendas focused on the successful implementation of digital behavioral health approaches in diverse settings.

Acknowledgments

This research is supported by the CTBH, a P30 Center of Excellence funded by NIDA (P30: #5P30DA029926-05; PI: LM). The authors would like to thank Fort Point Design for their work in developing and maintaining the CTBH website and associated features.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Screenshots of the Center for Technology and Behavioral Health Web presence features. Images were extracted on July 23, 2018.

[[PDF File \(Adobe PDF File, 6MB - mental_v6i4e11686_app1.pdf](#)]

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Abbreviations

CTBH: The Center for Technology and Behavioral Health

EBP: evidence-based practice

NIDA: The National Institute on Drug Abuse

Edited by G Eysenbach; submitted 24.07.18; peer-reviewed by C Ronquillo, B Cotner; comments to author 21.09.18; revised version received 18.01.19; accepted 23.01.19; published 05.04.19.

Please cite as:

Lord SE, Seavey KM, Oren SD, Budney AJ, Marsch LA

Digital Presence of a Research Center as a Research Dissemination Platform: Reach and Resources

JMIR Ment Health 2019;6(4):e11686

URL: <https://mental.jmir.org/2019/4/e11686/>

doi: [10.2196/11686](https://doi.org/10.2196/11686)

PMID: [30950800](https://pubmed.ncbi.nlm.nih.gov/30950800/)

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Review

Web-Based Multidomain Lifestyle Programs for Brain Health: Comprehensive Overview and Meta-Analysis

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Abstract

Background: The number of people living with dementia is increasing worldwide, mainly because of aging of the population. To date, there is no pharmaceutical intervention to delay or treat cognitive decline or dementia. As an estimated one-third of dementia cases might be attributable to modifiable lifestyle factors (such as cognitive and physical activity), multidomain lifestyle interventions are a promising way to maintain or improve brain health. Offering programs online would enable large-scale implementation. An overview of multidomain Web-based lifestyle programs for brain health would facilitate comparison and improvement of such programs to develop effective and sustainable interventions.

Objective: This study aimed to (1) provide a comprehensive overview of Web-based multidomain lifestyle programs aimed at optimizing brain health in healthy adult populations and (2) describe the programs and targeted lifestyle factors, availability, and evaluation of adherence and user experience. In addition, a meta-analysis was performed to evaluate the effectiveness of these programs.

Methods: Electronic databases (PubMed, EMBASE, and PsycINFO) were searched for Web-based lifestyle programs that were included when the program (1) aimed to optimize brain health, (2) focused on multiple lifestyle factors, (3) was completely Web-based (website, Web application or mobile app), (4) consisted of multiple sessions, and (5) focused on a healthy adult population. Program characteristics (target population, duration, frequency, tailoring, platform, and availability) and results of program evaluations (effectiveness, user evaluations, and adherence) were extracted and compared. Studies using a controlled design were included in a random-effects meta-analysis on the effectiveness on brain health outcomes. Study quality was assessed using the physiotherapy evidence database (PEDro) scale.

Results: The electronic searches yielded 44 documents describing 14 Web-based lifestyle programs; physical and cognitive activities were targeted in all programs. Four programs (4/14, 29%) were publicly available and free of charge, whereas others were restricted to research settings (5/14, 36%), available after payment (1/14, 7%), or not available at all (2/14, 14%). User evaluations were reported for 8 (57%) of the 14 programs. Reported dropout of the intervention groups ranged from 2% to 52%. Overall, 3 studies evaluated the effectiveness of a program using a controlled design and were included in the meta-analysis (moderate-to-high quality). Pooled results showed a significant small-to-medium effect of the Web-based multidomain lifestyle

interventions on outcome measures for brain health (global cognition score, subjective cognitive score, and lifestyle risk score; standard mean difference=0.45; 95% CI 0.12-0.78), with a high degree heterogeneity across studies ($I^2=75\%$; $P=.02$).

Conclusions: In total, 14 Web-based multidomain lifestyle programs aimed at optimizing brain health were found. The programs showed heterogeneity in both characteristics and effectiveness evaluation. Despite this heterogeneity, this meta-analysis suggests that Web-based lifestyle programs can positively influence brain health outcomes and have the potential to contribute to the prevention of dementia.

(*JMIR Ment Health* 2019;6(4):e12104) doi:[10.2196/12104](https://doi.org/10.2196/12104)

KEYWORDS

meta-analysis; telemedicine; internet; lifestyle; healthy aging; cognition; dementia; health promotion; primary prevention

Introduction

Background

Dementia is characterized by a gradual decline of cognitive functioning and impairment in daily functioning [1]. Several neurodegenerative diseases can cause dementia, of which Alzheimer disease (AD) is the most common [2,3]. In 2015, 46 million people were living with dementia worldwide, and this number is estimated to increase to 131.5 million by 2050 [4] because of aging of the society [5]. Dementia causes a large burden on society and health care, with a worldwide estimated cost of \$818 billion in 2015 [4,5].

To date, there is no pharmaceutical intervention to delay or treat cognitive decline or dementia. It is estimated that 30% of dementia cases are attributable to modifiable risk factors, including lifestyle factors such as physical activity, social activity, mood, and smoking [6-8]. Therefore, lifestyle interventions aimed at improving brain health and cognitive functioning before the onset of dementia (ie, in healthy persons) might delay or even prevent the occurrence of cognitive decline or dementia [6-9].

Studies on lifestyle interventions and cognition are mainly observational, with relatively limited evidence from large randomized trials [9]. However, evidence indicates that simultaneously targeting multiple lifestyle factors increases efficacy compared with programs focusing on a single lifestyle factor [10-12]. Furthermore, 2 nonsystematic reviews [10,13] and a systematic review with a meta-analysis [14] studied the effect of multidomain face-to-face interventions on cognitive outcomes. These latter studies reported that multidomain lifestyle interventions exerted overall positive effects on cognitive outcomes in healthy older people and in individuals with subjective cognitive decline. The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) trial, a 2-year face-to-face multidomain intervention study (ie, diet, exercise, cognitive training, and vascular risk monitoring), demonstrated maintained global cognitive functioning in a group of participants at risk for cognitive decline, compared with a control group receiving general health advice [15].

Despite their potential, practical barriers of these face-to-face programs include the requirement of training appropriate staff and resources such as location and personnel to provide the intervention. An attractive alternative is to offer lifestyle programs online, making use of the rapidly developing landscape

of electronic health (eHealth) [16]. This strategy is appealing for several reasons. First, in most countries, the majority of people have access to the internet [17], allowing them to reach larger audiences than face-to-face interventions. Second, Web-based programs have the potential to be cost-effective in the long run, with relatively low additional costs per person [18]. Third, Web-based programs might be more easily accessible at any convenient time, fitting them more easily into daily schedules and thereby increasing adherence. Finally, Web-based programs generate and collect data that can be used to automatically tailor content, for example, based on changes in lifestyle, as assessed by questionnaires. Criteria could then be set beforehand and tracked by the system. Web-based programs are easier to tailor than face-to-face programs, which need human involvement to adapt or to choose a protocol. Tailored programs improve the personal relevance of the program itself and, thus, may increase both adherence and effectiveness [19,20].

A comprehensive overview and meta-analysis of Web-based lifestyle programs for brain health is currently lacking but is required to explore the potential of these programs to benefit brain health. An overview of the programs and their evaluation might contribute to the development and implementation of more successful programs and, thereby, enable more effective and sustainable Web-based interventions.

Objectives

Therefore, this study provides an overview of Web-based multidomain lifestyle programs that aim to optimize brain health and focuses on program characteristics, current availability, evaluation of adherence, and user evaluations. In addition, a meta-analysis is performed on the effectiveness of Web-based programs on outcome measures for brain health.

Methods

Search Strategy

A systematic literature search based on the PRISMA statement was performed in collaboration with a medical librarian (LS). The databases of PubMed, EMBASE, and PsycINFO (via Ebsco) were examined from inception to June 5, 2018 (see [Multimedia Appendix 1](#) for the full search strategy). Search terms included indexed terms from the thesaurus in PsycINFO, MeSH in PubMed, and EMtree in EMBASE as well as free-text terms. The references of the identified articles were searched for additional relevant publications. As the primary goal was

to provide an overview of existing Web-based multidomain lifestyle programs, programs were included irrespective of the stage of their development or evaluation. Original research articles were included as well as conference abstracts, reviews, and doctoral theses mentioning (the development of) a program.

In addition, included were documents that described a program that (1) aimed to optimize brain health or cognitive functioning, as appeared from the aim of the study, program descriptions, or choice of outcome measures; (2) focused on multiple lifestyle factors; (3) was completely Web-based (website, Web application or app) and self-administered with no need for a visit to or from a health care professional; (4) consisted of multiple sessions (ie, not a single exercise); and (5) focused on a healthy adult population. Documents not available in the English language were excluded.

Furthermore, 2 independent researchers (LW and MW) screened the documents and used Covidence [21] to record the process. First, all documents were assessed for relevance based on the title and abstract. Selected documents were retrieved in full text and checked for eligibility criteria. Differences in judgment were resolved through a consensus procedure including an independent third reviewer (AH). Project websites mentioned in articles were searched for additional publications. In addition, the literature databases and Google were searched to identify additional publications on the included programs, using the name of the program and the authors. To assess availability of the identified programs, Google, Google Play Store, and Apple store were searched. If necessary, the authors were contacted for additional information, for example, regarding the availability of the program.

Data Extraction

The electronic searches yielded 11,972 documents: 3571 in PubMed, 5106 in EMBASE, and 3295 in PsycINFO. After removing duplicates, 7537 titles remained and were screened based on title and abstract; of these, 7461 were excluded. The majority of the excluded documents did not describe an intervention or a Web-based program that could be self-administered without the need for a health care professional. Of the remaining 76 studies, the full-text documents were scrutinized, applying the inclusion and exclusion criteria. The final selection for this review comprised 44 documents describing 14 Web-based lifestyle programs (see [Multimedia Appendix 2](#) for the systematic search flowchart; see [Table 1](#) for retrieved documents and the programs they describe).

A total of 24 (24/44, 55%) journal articles, 19 (19/44, 43%) conference abstracts, and 1 (1/44, 2%) doctoral thesis were retrieved. Half of the journal articles (12/24; 50%; denoted by footnote a in [Table 1](#)) were original research articles investigating 10 (71%) of the 14 programs. For 4 of the programs (4/14, 29%), no original research article was found. Data were extracted based on program characteristics, target population, duration (length of intervention), frequency of the program (eg, number of sessions and number of modules), tailoring of content, lifestyle factors, platform of the program (website or app), current availability, and evaluation of the program.

Evaluation of Web-Based Multidomain Lifestyle Programs

Effectiveness

Results of studies that used a controlled design were pooled to perform a meta-analysis on the effectiveness of Web-based multidomain lifestyle programs on outcome measures relevant for brain health or cognitive functioning. This resulted in a meta-analysis including 3 studies entitled *Body Brain Life* [23], *Keep your brain fit* [53], and *Long Lasting Memories* [58]. For these studies, 2 raters (LW and AH) assessed the study quality and risk of bias using the physiotherapy evidence database (PEDro) scale [65-67]. The PEDro scale evaluates the internal validity by assessing the eligibility criteria, allocation, blinding and reporting of outcome measures, between-group comparisons, and variability. For this review, we deemed the PEDro item *blinding of therapists* not to be applicable, as interventions were provided as self-administered on the internet and not by therapists.

User Evaluations

During the development and evaluation of Web-based interventions, the involvement of users for evaluation of *user experience* and *usability* is important; however, discussion continues as to what these terms exactly entail [68]. We based our definitions on the International Organization of Standardization (ISO) guidelines (ISO 9241-2010, ISO/IEC 25010) and selected parts of the guidelines to summarize the extracted information. First, *user experience* includes all the users' emotions, beliefs, preferences, perceptions, physical and psychological responses, behaviors, and accomplishments that occur before, during, and after use of the Web-based program. Second, we defined *usefulness* as the users' perception on whether the program served their needs and purpose and was helpful in any way. Finally, *usability* was defined as whether the program was convenient and easy to use, taking into account the technical aspects of the platform. For each study, we assessed whether our definitions of user experience, usefulness, or usability were described. Subsequently, we indicated whether methods used for this evaluation were clearly described, by defining whether it would be possible to replicate the design. *Qualitative debriefing* or *survey with open question* were deemed not specific enough, whereas specific questionnaire items that were used to collect information on user experience were deemed sufficient.

Adherence

Assessing adherence to the usage of an eHealth technology can be challenging, as also noted in a recent review [69]. However, because the majority of the programs in this review did not describe the intended use of the program, it was not possible to assess usage adherence (ie, not in terms of number of log-ins or time spent). Therefore, adherence was assessed as the percentage of participants completing the intervention and postintervention measurement or in relation to the number of participants that started the intervention.

Table 1. Characteristics of the 14 included Web-based lifestyle programs.

Number	Program (acronym and full name)	Target population	Program characteristics	Website or app	Availability
1	Body Brain Life: [22] + [23] ^a	Nonsymptomatic adults at risk for Alzheimer disease	Duration: 12 weeks; number of sessions: 12; frequency: 1/week; and tailored: yes, Lifestyle-Q ^b	Website	Available: yes; public: no
2	Brain Aging Monitor [24,25] + [26] ^a	Dutch workforce and general population	Duration: 52 weeks; number of sessions:— ^c ; frequency:—; tailored: yes, Lifestyle-Q and goals set	Website	Available: no
3	Brainy app [27,28] + [29] ^a	General population	Duration: 4 weeks; number of sessions:—; frequency:—; tailored: yes, Lifestyle-Q	iOS app and Android app	Available: yes; public: yes; Free of charge: yes Link
4	Brain-Heart Health Plus program [27,28] + [29] ^a	General population	Duration: 4 weeks; number of sessions:—; frequency:—; tailored: yes, Lifestyle-Q	Website	Available: yes; but redesigned format; public: yes; free of charge: yes Link
5	DoReMi: Decrease of cOgnitive decline, malnutRition and sedEntariness by elderly empowerment in lifestyle Management and social Inclusion [30,31]	General population, elderly	Duration: 13 weeks; number of sessions: 36; frequency: 3/week; tailored: yes, acquired data	Android app	Available: No
6	Gray Matters [32-34] + [35] ^a	General population	Duration: 26 weeks; number of sessions:—; frequency:—; tailored: yes; and Lifestyle-Q	iOS app and Android app	Available: yes; public: no
7	HATICE: Healthy Aging Through Internet Counselling in the Elderly [12,36-47] + [48,49] ^a	Elderly with cardiovascular risk factors, cardiovascular disease or diabetes mellitus	Duration: 78 weeks; number of sessions:—; frequency: 1/week; tailored: yes, goals and topic interest	Website	Available: yes; public: no
8	InMINDD: INnovative, Midlife INtervention for Dementia Deterrence [50,51]	Individuals with 1 modifiable risk factor based on Lifestyle for Brain Health (LIBRA) score [52]	Duration: 26 weeks; number of sessions:—; frequency:—; tailored: yes, demographic, health behavior, and clinical information	Website	Available: yes; public: no
9	Keep your brain fit [53] ^a	General population	Duration: 4 weeks; number of sessions:—; frequency:—; tailored: yes, Lifestyle and cognition monitor'	Website	Available: yes; public: yes; free of charge: yes Link
10	LEAP: Lifestyle Enrichment for Alzheimer Prevention [54] ^a	Individuals with upcoming retirement	Duration: 8 weeks; number of sessions:—; frequency:—; tailored: yes, Lifestyle-Q and Goals	Website	Available: yes; public: yes; free of charge: yes Link
11	Long Lasting Memories [13,55-57] + [58,59] ^a	Older adults with or without neurocognitive disorders	Duration: 10 weeks; number of sessions: 24; frequency: 4/week; tailored: yes, patient group	Website + Android or iOS app for cognitive component	Available: yes; public: no; free of charge: no; physical component: €100/6 months, cognitive component: €100/6 months Link
12	Maintain your brain [60,61]	Adults with 2 risk factors for dementia	Duration: 208 weeks (4 years); number of sessions: (4x10-week modules in the first year); frequency:—; tailored: yes, current lifestyle	—	Available: Yes; public: no
13	Smart Aging [62]	General population, seniors	Duration: 16 weeks; number of sessions:—; frequency: 7/week; and tailored:—	—	—

Number	Program (acronym and full name)	Target population	Program characteristics	Website or app	Availability
14	Vital Aging Program (e-learning version) [63,64] ^a	Population based (students from university programs for older adults)	Duration: 13 weeks; number of sessions: —; frequency: 1/week; and tailored: —	Website	—

^aOriginal research articles.

^bLifestyle-Q: Lifestyle Questionnaire.

^cInformation that was not specified.

Statistical Analysis and Meta-Analysis

IBM SPSS Statistics (version 22) [70] was used to calculate descriptive statistics to summarize program characteristics. For the studies that assessed effectiveness, postintervention means, SDs, and group size were pooled. We used the results that were reported for the primary outcome measure that assessed brain health or cognitive functioning (ie, objective and subjective measures). Results were inverted if necessary, making higher scores represent better scores. Review Manager (version 5.3, The Cochrane Collaboration, Copenhagen, Denmark) was used to perform a random-effects meta-analysis. The overall effect of lifestyle interventions on brain health outcomes was estimated, and the results were presented as a forest plot. The Cochrane X^2 was used to test for heterogeneity across the included articles, with a $P < .05$ indicative of heterogeneity. The I^2 ($100 \times (X^2 - df/X^2)$) [71] was used to measure the degree of heterogeneity (25%, low; 50%, moderate; and 75%, high [72]).

Preferred Reporting Items for Systematic Reviews and Meta-Analysis Statement

As the scientific output in this field is somewhat limited, not all the items of the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement were deemed applicable. Information that contributed to the aim of this review is reported and includes the characteristics, availability, and evaluation.

Results

Characteristics of the Web-Based Multidomain Lifestyle Programs

Table 1 provides an overview of the 14 included Web-based lifestyle programs (with full names and their characteristics). Overall, 8 programs (8/14, 57%) were developed for a general adult population (*Brain Aging Monitor* [24], *Brainy app* [29], *Brain-Heart Health Plus Program* [29], *Decrease of cOgnitive decline, malnutRition and sedEntariness by elderly empowerment in lifestyle Management and social Inclusion (DoReMi)* [30], *Gray Matters* [35], *Keep your brain fit* [53], *Smart Aging* [62], and *Vital Aging program* [63]). In addition, 6 programs (6/14, 43%) described a more specific target population: *Body Brain Life* [22] and *Maintain your Brain* [60] focused on nonsymptomatic adults at risk of AD, *Healthy Aging*

Through Internet Counselling in the Elderly (HATICE) [36] targets elderly with cardiovascular risk factors and cardiovascular disease, and *INnovative, Midlife INtervention for Dementia Deterrence (InMINDD)* [50] targets individuals with 1 modifiable risk factor. The *Lifestyle Enrichment for Alzheimer Prevention (LEAP)* [54] program was developed for individuals with upcoming or recent retirement and *Long Lasting Memories* [58] for individuals with or without a cognitive impairment.

The programs were offered on a website (8/14, 57% [22,24,29,36,50,53,54,63]), a mobile app (3/14; 21% [29,30,35]), or both (1/14, 7% [55]), whereas the platform was not specified for the remaining 2 [60,62]. Only 4 (4/14, 29%) programs were available publicly and free of charge [29,53,54]. Overall, 5 programs (5/14, 36%) were available within a research setting [22,35,36,50,60] and 1 (1/14, 7%) after payment [58]. In addition, 2 programs (2/14, 14%) were not available online at all [25,30], and for 2 programs (2/14, 14%), it was not clear whether they were still available [62,63]. Mean intervention duration was 33.9 (SD 54.1; range 4-204) weeks. Furthermore, 3 programs [22,30,55] specified the total number of sessions (mean 24, [SD 12]; range 12-36 sessions), and 6 programs [22,30,36,55,62,63] indicated a frequency per week (mean 2.8 [SD 2.4]; range 1-7 sessions/week). For the remaining programs, the number of sessions and the frequency per week were flexible.

Most programs tailored the content of the program to previously acquired information. Content was mainly tailored based on current lifestyle (eg, assessed with a questionnaire on lifestyle and risk factors; 9/14, 64% [22,24,29,35,36,50,53,60]). Furthermore, 3 programs (3/14, 21%; [25,36,54]) additionally tailored content based on goals that were set within the program, and 2 programs (2/14, 14%; [62,63]) did not specify information on tailoring. The number of lifestyle factors targeted in the programs ranged from 2 [58] to 9 [60] (Table 2). In short, all interventions targeted a physical and a cognitive component. Furthermore, most programs included a nutritional component (13/14 programs, 93%; all except *Long Lasting Memories* [58]) as well as a social component (10/14 programs, 71%; [22,29,30,35,50,53,54,62,63]). Half of the programs included smoking cessation (7/14, 50%; [24,29,36,50,60,62]), and other factors included alcohol intake, vascular risk factors, stress management, sleep, and mood.

Table 2. Lifestyle factors targeted in the included programs. Per row, the factors per program are presented. Per column, the programs including this specific lifestyle factors are presented.

Program	Physical	Cognitive	Nutrition	Social	Smoke	Vascular ^a	Alcohol	Stress	Sleep	Mood	Other ^b
Body Brain Life	x ^c	x	x	x	—	—	—	—	—	—	x
Brain Aging Monitor	x	x	x	—	x	—	x	x	x	—	—
Brainy app	x	x	x	x	x	x	x	—	—	—	—
Brain Heart Health Plus Program	x	x	x	x	x	x	x	—	—	—	—
Decrease of cOgnitive decline, malnutRition and sedEntariness by elderly empowerment in lifestyle Management and social Inclusion	x	x	x	x	—	—	—	—	—	—	—
Gray Matters	x	x	x	x	—	—	—	x	x	—	—
Healthy Aging Through Internet Counseling in the Elderly	x	x	x	—	x	x	—	—	—	—	—
INnovative, Midlife INtervention for Dementia Deterrence	x	x	x	x	x	x	x	—	—	x	—
Keep your brain fit	x	x	x	x	—	—	—	x	x	x	—
Lifestyle Enrichment for Alzheimer Prevention	x	x	x	x	—	—	—	—	—	—	x
Long Lasting Memories	x	x	—	—	—	—	—	—	—	—	—
Maintain your brain	x	x	x	—	x	x	x	x	x	x	—
Smart Aging	x	x	x	x	x	x	—	—	—	—	—
Vital Aging Program	x	x	x	x	—	—	—	—	—	x	x
Total number of programs targeting the lifestyle factor	14	14	13	10	7	6	5	4	4	4	3

^aVascular: this category summarized vascular and physical variables often used in vascular risk management, for example, blood pressure and weight.

^bOther factors included were for Body Brain Life: dementia literacy, dementia risk factors, and health self-management; for Lifestyle Enrichment for Alzheimer Prevention: time management, and for Vital Aging Program: body caring.

^cPer column it is indicated whether a program does (x) or does not (—) include the specific lifestyle factors.

Evaluation of Web-Based Multidomain Lifestyle Programs

Effectiveness, Study Quality, and Meta-Analysis

Effectiveness was measured on a range of brain health outcomes, such as an AD risk questionnaire (eg, lifestyle factors associated with the development of AD such as food intake or level of physical activity), cognitive test performance, and the subjective experience of cognitive problems. [Table 3](#) presents an overview of the outcome measures.

For 4 programs (4/14, 29%), effectiveness was evaluated, of which 3 (3/14, 21%) used a controlled design. The latter 3 were

included in the meta-analysis: *Body Brain Life* [23], *Keep your brain fit* [53], and *Long Lasting Memories* [58] (not included [26,59]). On the PEDro scale, the quality of the studies ranged from moderate (5/10 [58]) to high (8/10 [23]; [Table 4](#)). All 3 studies specified recruitment of participants and eligibility criteria. At baseline, the experimental groups were comparable with the control groups. In addition, all used an intention-to-treat analysis and reported between-group comparisons as well as point estimates with measures of variability. Points were lost on the PEDro items for randomization, blinding of subjects and assessors, and the cutoff of 85% of participants completing follow-up measurement.

Table 3. Outcome measures. The outcome measures per study are shown, as described in the retrieved documents. If authors delineated primary and secondary outcome measures, this is indicated in the column *Priority*. For primary outcome measures, the specific outcome measure is described.

Program	Priority	Outcome measure per domain	Specific outcome measure
Body Brain Life	Primary	Lifestyle-risk factors-Q ^a	ANU Alzheimer's Disease Risk Index (ANU-ADRI) [73]
Body Brain Life	Secondary	Cognition: objective; body measurements; other: dementia recognition, and dementia knowledge	— ^b
Brain Aging Monitor	Primary	Cognition: objective; Lifestyle-risk factors-Q; and Goal setting	BAM-COG games [74] Lifestyle score (including physical activity, nutrition, and sleep) [24]
Brain Aging Monitor	Secondary	Body measurements and other: change in self-efficacy and change in self-control	—
Brainy app + Brain-Heart Health Plus program (not prioritized)	—	Lifestyle-risk factors-Q and other: Dementia risk reduction knowledge and attitudes to changing behavior	Not specified; 10 factors (risk/protective for dementia); eg, motivation to reduce dementia risk
Decrease of cOgnitive decline, malnutRition and sedEntariness by elderly empowerment in lifestyle Management and social Inclusion (not prioritized)	—	Cognition: objective; Lifestyle: measurement and Body measurements	Montreal Cognitive Assessment (MoCA) [75], Token test [76]; Mini Nutritional Assessment (MNA) (version not specified) [77]; BMI ^c , waist-to-hip ratio, waist and arm circumference, and blood pressure related to the 6-min walk test
Gray matters	Primary	Body measurements and Lifestyle-risk factors-Q	BMI, blood pressure, blood biomarkers including physical and cognitive activity, nutrition (Diet History Questionnaire + DASH score), sleep, social engagement, and stress
Gray matters	Secondary	Lifestyle-risk factors-measurement; cognition: objective; other: mood and psychological stress; metacognition, intrinsic motivation; readiness to change, sleep quality; and social engagement, couple satisfaction	—
Healthy Aging Through Internet Counselling in the Elderly	Primary	Body measurements	Composite score (systolic blood pressure, low-density lipoprotein, and BMI)
Healthy Aging Through Internet Counselling in the Elderly	Secondary	Body measurements; lifestyle-risk factors-Q; cognition: objective; clinical measurement; goal setting; other: mood, cost-effectiveness	—
INnovative, Midlife INtervention for Dementia Deterrence	Primary	Lifestyle-risk factors-Q	Lifestyle for Brain Health (LIBRA) score [52]
INnovative, Midlife INtervention for Dementia Deterrence	Secondary	Lifestyle-risk factors-Q	—
Keep your brain fit	Primary	Cognition: subjective	Subj cognitive functioning (MIA) [78], cognitive failure (CFQ; [79,80]), Self-evaluative questions [81]
Keep your brain fit	Secondary	Cognition: objective; other: Depression, anxiety, stress, Self-rated health, Feelings of loneliness, Difficulties in recovering from work, General health, and QoL ^d	—
Lifestyle Enrichment for Alzheimer Prevention	Primary	Lifestyle-risk factors: measurements	Dietary intake [82] and physical activity (accelerometry); weight, BMI, waist circumference, body fat mass, fat-free mass, today body water, body weight, and waist circumference; and cognition, physical capability, physiological, and psychosocial well-being
Lifestyle Enrichment for Alzheimer Prevention	Secondary	Body measurements; Battery of Healthy aging phenotype (HAP) measurements; and other	—
Long Lasting Memories (not prioritized)	—	Body measurements; cognition: objective; Lifestyle-risk factors-Q; and other: mood, Quality of Life, IADL	Physical fitness (composite score Senior fitness test); eg, Mini Mental State Examination, MoCA, Trail Making Test, California Verbal Learning Test; and Social Life Questionnaire

Program	Priority	Outcome measure per domain	Specific outcome measure
Maintain your brain	Primary	Cognition and clinical measurement	Unspecified and Dementia incidence
Maintain your brain	Secondary	Lifestyle-risk factors-Q; goal setting; clinical measurements; and medication	—
Smart Aging	—	Other: QoL	—
Vital Aging Program (e-learning)	—	Other: reported changes and intended future changes	—

^aQ: Questionnaire.

^bInformation either not available (priority) or not specified (secondary outcome measures).

^cBMI: body mass index.

^dQoL: quality of life.

Table 4. Quality assessment of pooled studies. This table presents the quality and bias assessment of the studies that were pooled in the meta-analysis, based on the physiotherapy evidence database scale (PEDro). Blinding of therapist was deemed not applicable for all 3 studies, as the interventions were offered by automated systems. Concealed allocation was deemed not applicable for Long Lasting Memories, as participants were not randomized. Blinding of assessors was deemed for Keep your brain fit, as the assessment was conducted within the Web-based system.

Items	Body Brain Life [23]	Keep your brain fit [53]	Long Lasting Memories [58]
Eligibility criteria and source specified	+	+	+
Random allocation	+	+	— ^b
Concealed allocation	+	—	N/A ^c
Baseline comparability	+	+	+
Blinding of subjects	—	—	—
Blinding of therapists	N/A	N/A	N/A
Blinding of assessors	+	N/A	—
More than 85% follow-up	—	—	—
Intention-to-treat analysis	+	+	+
Reporting of between-groups statistical comparisons	+	+	+
Reporting of point measures and measures of variability	+	+	+
Total PEDro score 0-10	8	6	5

^aCriteria fulfilled.

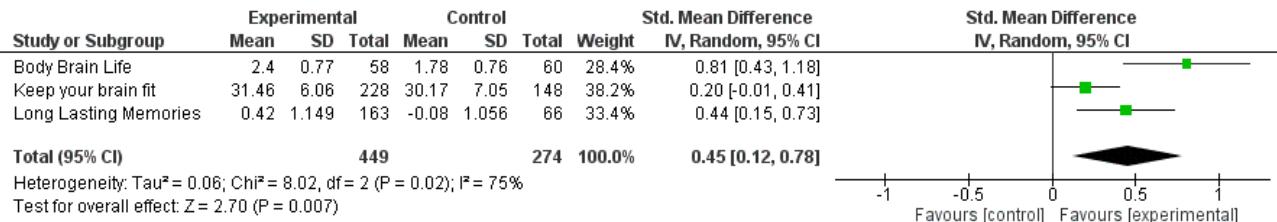
^bCriteria not fulfilled or it was unclear whether criteria were fulfilled.

^cCriteria not applicable.

Directly after the intervention, participants of *Body Brain Life* [23] showed no significant reduction in risk for AD compared with the control group. However, at 26-week follow-up, the intervention group showed a significant reduction in risk compared with the control group (intervention group mean score pretest=−1.07 [SD 0.72], posttest=−3.63 [SD 0.77]; control group pretest=−1.38 [SD 0.70], posttest=−1.93 [SD 0.73]; beta: −.37, SE 0.16, $P=.05$). This result was mainly because of an increase in protective lifestyle behaviors and not because of a decrease in risk factors, such as smoking or high cholesterol. For *Keep your brain fit* [53], there was a significant effect of group on perceived change in memory functioning (intervention group mean score pretest=29.99 [SD 6.22], posttest=31.46 [SD 6.06]; control group pretest=28.97 [SD 7.50], posttest=30.17 [SD 7.05]; $P=.007$), showing a small effect (Cohen $d=.20$). Moreover, a significant effect of group was found on a cognitive

failure questionnaire (intervention group mean score pretest=66.15 [SD 11.36]; posttest=65.85 [SD 10.30]; control group pretest=63.76 [SD 11.98], posttest=65.11 [SD 12.25]; $P=.03$); however, this could be explained by baseline group differences. There was no significant effect of group on perceived memory capacity. Compared with an active control group, the participants of *Long Lasting Memories* [58] showed a significant improvement in global cognition ($t_{219}=3.2$; $P=.002$), with a medium effect (Cohen $d=.31$). The cognitive status of the participants of *Long Lasting Memories* ranged from healthy to dementia, and exploratory analysis in the effectiveness study [58] indicated that the effect did not differ for the different diagnostic groups; therefore, this latter study is included in the meta-analysis, despite the inclusion of cognitively impaired participants.

Figure 1. Forest plot meta-analysis. This figure presents the results of the random-effect meta-analysis that included data from 3 effectiveness studies using a controlled design. Outcome measures were measures for brain health (Body Brain Life: ANU Alzheimer's Disease Risk Index and lifestyle risk score; Keep your brain fit: Meta Memory in Adulthood scale and subjective cognitive functioning, and Long Lasting Memories: Mini Mental State Examination and global cognition score). Duration of the interventions: Body Brain Life, 12 weeks; Keep your brain fit, 4 weeks; Long Lasting Memories, variable, with an average of 6 weeks.



Results of these 3 studies were pooled in a meta-analysis, combining a lifestyle risk score (ANU Alzheimer's Disease Risk Index Questionnaire [73] for *Body Brain Life* [23]), a subjective cognitive measure (Meta memory in Adulthood Questionnaire [78] for *Keep your brain fit* [53]), and a global cognitive measure (Mini Mental State Examination [83] for *Long Lasting Memories* [58]). Pooled results (see Figure 1) showed a significant overall small-to-medium effect of the Web-based multidomain lifestyle interventions on outcome measures for brain health or cognitive functioning in the intervention group compared with the control group (standardized mean difference [SMD]=0.45; 95% CI 0.12-0.78). The degree of heterogeneity across studies was high ($I^2=75\%$; $P=.02$).

User Evaluations

For 8 programs (8/14, 57%), 10 studies [29,32,35,36, 48,49,53,54,62,63] reported user evaluations: all 10 reported results on usability and 7 (7/14, 50%) also reported results on usefulness and usability (for evaluations see Table 5). The methods to evaluate user experiences, usefulness, and usability were qualitative debriefing, a survey, Likert scales ranging from 0 to 10 for specific topics (eg, satisfaction and simplicity), and the percentage of participants that reported the program to be usable and user-friendly. User evaluations offered input regarding content and technical features to improve the Web-based multidomain lifestyle programs. Overall, the programs were evaluated as usable. In general, the reported barriers were mainly technical, such as password setting and navigation method. In addition, 2 studies evaluating the user-based concepts of 3 programs described their methods clearly and in a reproducible way [29,54]. In 1 study, the *Brain Heart Health Plus Program* and the *Brainy app* were compared directly [35]. Most participants evaluated both programs as overall positive and reported that the information was interesting, easy to understand, easy to navigate, and insightful. Users of the *Brain Heart Health Plus Program* website were more positive than users of the app, which the authors attributed to the difference in platform and the lack of instructions on how to use the app.

In their evaluation of *LEAP* [54], participants rated the modules on physical activity, social activity, and eating well as the highest; design, navigation, and technical issues were problematic for a few users.

The other 5 programs described results of user evaluations using a variety of methods: a few representative findings are presented here. Participants of *Gray Matters* [32,35] used the app regularly, with on average 3 app launches per week, and ranked 6 behavioral domains in order of importance: physical activity, cognitive stimulation, healthy food choices, stress management, sleep quality, and social engagement. Participants of *HATICE* [36,49] provided input on the password difficulty and deemed an instruction video necessary. Interactive features and healthy lifestyle content were valued, and participants liked to print the content. Using interviews, user-friendliness, usefulness, and perceived benefit were identified as important factors for initial use. Expectation of, and experience with lifestyle changes, and incorporation into daily routine were deemed important for sustained platform use [48]. Participants of *Keep your brain fit* [53] evaluated the program with a mean score of 7.3 (SD 1.09) out of 10 (n=228). Most recommendations for improving the intervention were technical (eg, more time to complete the intervention or more reminders) or content related (better explanation of the concepts). For the *Vital Aging Program*, most participants reported that the course was interesting, expectations were sufficiently met, and the content was helpful to improve their daily living (95.8%, 94%, and 96%, respectively) [63].

Adherence and Dropout

Overall, 6 studies included data on adherence to the intervention period [23,26,29,53,54,58]. In total, 1455 (1455/3598, 40.44%) participants dropped out of the active programs before completing the intervention period and postintervention measurement (mean 243 [SD 473.9]; range 1-1205 participants). The high dropout rate was mainly because of the study on the *Brain Aging Monitor* [26] (1205/2305, 52.27%). Excluding this study, a total of 250 (250/1293, 19.33%) participants dropped out (mean 50 [SD 53.4]; range 1-128 participants). The dropout rates of the intervention group of the other studies were 2% (1/58; *Body Brain Life* [23]), 10.8% (45/415; *Brainy app* and *Brain Heart Health Plus program* combined [29]), 36.0% (128/356; *Keep your brain fit* [53]), 4% (2/50; *LEAP* [54]), and 31.2% (74/237; *Long Lasting Memories* [58]). Reported reasons for dropping out were time constraints, dissatisfaction with the content, family issues, and physical illness. Dropouts were younger, had a higher education level, were more likely to work full time, and had a job that required mental and physical activity [29,53]. The other programs found no differences between the completers and noncompleters.

Table 5. User evaluations. This table shows whether the concepts of user experience, usefulness, and usability were evaluated and whether the evaluation methods were clearly described. For definitions, see Methods section User Evaluations.

Program	User experience	Usefulness	Usability
Body Brain Life	– ^a	–	–
Brain Aging Monitor	–	–	–
Brainy app [29]	+ ^b	+	+
Brain Heart Health Plus Program [29]	+	+	+
Decrease of cOgnitive decline, malnutRition and sedEntariness by elderly empowerment in lifestyle Management and social Inclusion	–	–	–
Gray Matters [32,35]	–	~ ^c	~
Healthy Aging Through Internet Counselling in the Elderly [36,48,49]	+	+	~
INnovative, Midlife INTervention for Dementia Deterrence	–	–	–
Keep your brain fit [53]	~	–	~
Lifestyle Enrichment for Alzheimer Prevention [54]	+	+	+
Long Lasting Memories	–	–	–
Maintain your brain	–	–	–
Smart Aging [62]	~	~	~
Vital Aging Program [63]	~	~	~

^aUser-based concepts were not evaluated or it was unclear whether the concepts were evaluated.

^bResults were described and methods were specified.

^cResults were described but methods were unspecified.

Discussion

Principal Findings

In this systematic review of Web-based multidomain lifestyle programs, 14 programs that aimed to optimize brain health were found. Comparison of these programs showed strong heterogeneity between program characteristics, targeted lifestyle factors, and program duration. In addition, detailed information on user evaluation methods and results was often lacking. Pooling of 3 studies that evaluated the effect of a Web-based program [23,53,58] showed a small-to-medium beneficial effect of Web-based multidomain lifestyle interventions on brain health outcomes.

Our main finding that Web-based multidomain lifestyle interventions have a beneficial effect on brain health is in line with previous results from face-to-face lifestyle programs, both reporting modest effect sizes [84,85]. This indicates that Web-based programs have the potential to yield health benefits comparable with those of face-to-face interventions, although no head-to-head comparisons have been made.

For 3 programs, effectiveness was evaluated using a controlled design [23,53,58]. In this meta-analysis, heterogeneity between the studies was high, with notable differences in outcome measures. We pooled data from a global cognitive score, a subjective cognitive score, and a risk-score questionnaire. The study on *Long Lasting Memories* [58] included a group of individuals with heterogeneous cognitive status, ranging from healthy to dementia. Exploratory subgroup analyses showed that the effect of the total intervention group might be

conservative and an underestimation for healthy individuals. Although our meta-analysis included individuals over the whole cognitive spectrum, it is noteworthy that the overall intervention effect might be larger in a group of solely healthy individuals.

All described programs stimulated both physical and cognitive activities, that is, 2 lifestyle factors that have been extensively investigated in both healthy and cognitively impaired individuals [86-88]. The content of the Web-based lifestyle programs could be extended by including other lifestyle factors such as smoking, mood, and social activity. Although their influence on brain health may be less well understood, literature suggests that they could be part of a lifestyle that is beneficial for brain health and cognitive functioning [6].

With regard to the targeted lifestyle factors in the meta-analysis, 2 to 7 lifestyle factors (including physical and cognitive activity) were included in their programs. The program with the largest effect size (Body Brain Life [23]; SMD=0.81, 95% CI 0.43-1.18) targeted 4 lifestyle factors, whereas the program with the smallest effect size (Keep your brain fit [53]; SMD=0.20 95% CI -0.01 to 0.41) targeted 7 lifestyle factors. However, the duration of Body Brain Life was longer than Keep your brain fit (12 weeks and 4 weeks, respectively). Long Lasting Memories ([58]; SMD=0.44 95% CI 0.15-0.73) targeted 2 lifestyle factors, and, with a 10-week duration, it was in between the 2 latter programs. Due to the heterogeneity, no conclusions can be drawn about the specific successful factors of these programs, other than that at least a physical and cognitive activity were included in all programs and, therefore, seem beneficial for brain health. Better and head-to-head evaluations

are necessary to compare the number of lifestyle factors, intervention duration, and potential synergistic effects.

Overall, the results of this study are promising, as small-to-medium effect sizes may translate to large public health gains when implemented on a large scale [19,20]. In particular, in the context of a global health care burden, given that a 1-year delay of onset of AD may translate to the prevention of 9 million cases worldwide in 2050, large-scale prevention with a small effect may be very cost effective [89].

Most of the included programs were not currently available for the general public. The majority were only available in a research setting, and 2 programs were not available online at all [25,30]. A sustainable implementation proves a key challenge in the eHealth field [90]. We need to create a bridge between the innovation in health care and the users in the general population. Proper education of health care professionals could increase the perceived usefulness and recommendation of eHealth innovations and, thereby, increase overall implementation success. Fitting the intervention to the needs of the user and making the intervention accessible could improve adherence rates and contribute to this sustainability. Therefore, it is recommended to involve users during every step of the developmental process [90,91]. Feedback from users helps to elucidate what a user experiences, which elements are appreciated, and/or to impose a boundary to participate. As concepts in the field of user evaluations are still evolving and used interchangeably [68], clear descriptions of methods and results could contribute to the comparability of the findings. In this review, half of the studies included user evaluations. However, the descriptions of user evaluations were often unclear, with an incomplete or lacking description of methods or lack of specification regarding which questions were asked to evaluate usability, usefulness, and user experience. In the studies that included user evaluations, facilitators for the use of the program were mentioned [29,32,35,48,62,63], such as a program being easy to understand, easy to navigate, and containing interesting content. Barriers that were most often mentioned were of a technical nature [36,49,53,54]. This highlights that the technical development of a program is just as important as the development of content. We recommend to develop the innovation step by step, together with both the technical team and the future users [90], to minimize technical barriers and create content that users deem interesting and useful. Technical features, such as a clear navigation or the possibility to receive reminders, are one of the aspects that influence adherence to a Web-based program.

Sustained adherence to Web-based programs is also an important issue in the eHealth field [92,93]. The adherence rates of the described studies were moderate to good and might be related to the tailoring of content [19,20]. Although most programs reported to be tailored, it was often unclear on what specific information tailoring was based and how the content was personalized based on this information. When comparing adherence rates between Web-based and face-to-face programs, we found comparable or higher adherence in face-to-face programs than in Web-based programs. For example, the face-to-face multidomain FINGER trial in elderly with cardiovascular risk factors for dementia [15] had high adherence

rates (7% dropout at 12 months), whereas, for example, a face-to-face multidomain study in the frail elderly reported a 24% dropout mainly because of health problems [94]. Behavior change techniques and the role of communication with peers or a health coach might also influence the adherence rate. These aspects were not included in this review on self-administered programs and, because of the limited description of these aspects in the included documents, overall comparison of this matter with face-to-face programs was not possible.

Despite our extensive search, the small number of original research papers retrieved reflects the limited description of the included Web-based lifestyle programs for brain health and their evaluation. Descriptions might be improved by using a more rigorous design and report. To facilitate a standardized reporting, the CONSORT-EHEALTH (Consolidated Standards of Reporting Trials of Electronic and Mobile HEalth Applications and onLine TeleHealth) Group developed a checklist [95] that could be used during the development of eHealth interventions. This list includes recommendations on the design and, moreover, on the elements that should be included in the reporting of studies. Using this list may improve reporting and provide a basis for evaluation of the validity and applicability of eHealth trials, which might help the field to move forward.

Strengths and Limitations

A limitation of this study is that the meta-analysis was performed on a small subset of studies. This limitation highlights the premature stage of Web-based lifestyle programs for brain health. Specific limitations of the meta-analysis include the heterogeneous study outcomes, differences in duration of the intervention, differences in the targeted lifestyle factors, and the heterogeneity in the sample of 1 study. However, based on the increasing use of eHealth and the need for dementia prevention strategies, more articles describing a Web-based multidomain lifestyle intervention and its evaluation are expected in the near future.

This overview of Web-based lifestyle programs for brain health was based on an elaborative search in 3 scientific databases, including journal papers as well as gray literature (eg, abstracts). The gray search was useful, as not all programs were described in the full research papers. We used a broad scope of search terms for the inclusion of studies, by widely applying inclusion criteria, for example, not specifying target populations. This broad scope contributes to the generalizability of the findings of this study. Screening of abstracts and full texts was performed by 2 independent raters and, if necessary, consensus meeting with a third rater took place, contributing to the reliability of our findings. Although the studies were highly heterogeneous, systematic elements were combined, resulting in a structured overview of programs and their evaluation. The subset included in the meta-analysis was small and heterogeneous, limiting generalization of the results. Nevertheless, the findings justify further exploration of the possibilities to implement Web-based lifestyle program to optimize brain health.

Conclusions

In conclusion, we have provided a systematic overview and meta-analysis of studies on Web-based multidomain lifestyle programs to optimize brain health. Our findings suggest that these programs have a beneficial effect on brain health outcome measures. It would benefit the field if the program characteristics, methods, and results of evaluation of the

programs were described in a more consistent way. This would facilitate comparison between programs and contribute to the development and implementation of effective and sustainable programs. Having shown their potential to optimize brain health in large groups of individuals, the implementation of Web-based lifestyle programs may well contribute to the prevention of dementia.

Acknowledgments

This project was supported by a research grant from the EU Joint Programme—Neurodegenerative Disease Research (JPND_PS_FP-689-019; ZonMw grant no. 733051043)—and a research grant from Stichting Equilibrio. Alzheimer Center Amsterdam is supported by Alzheimer Nederland and Stichting VUmc fonds. Research of the Alzheimer Center Amsterdam is part of the neurodegeneration research program of Neuroscience Amsterdam.

Authors' Contributions

LW, AH, and SS drafted the manuscript. LW and LS performed the literature search. LW and MW performed screening, study selection, and data extraction. AH, WF and SS supervised the process of screening and data extraction. WF and SS helped with interpretation of the results and manuscript evaluation. All authors have read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Search strategy.

[[PDF File \(Adobe PDF File, 43KB - mental_v6i4e12104_app1.pdf](#)]

Multimedia Appendix 2

Systematic search flow chart.

[[PDF File \(Adobe PDF File, 57KB - mental_v6i4e12104_app2.pdf](#)]

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Abbreviations

AD: Alzheimer disease

eHealth: electronic health

FINGER: Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability

HATICE: Healthy Aging Through Internet Counselling in the Elderly

ISO: International Organization of Standardization LEAP: Lifestyle Enrichment for Alzheimer Prevention

PEDro scale: physiotherapy evidence database scale

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analysis

SMD: standardized mean difference

Edited by P Bamidis; submitted 07.09.18; peer-reviewed by E Madero, P Simon, F Nuñez-Benjumea, C Tziraki; comments to author 05.12.18; revised version received 28.01.19; accepted 14.02.19; published 09.04.19.

Please cite as:

Wesselman LMP, Hooghiemstra AM, Schoonmade LJ, de Wit MCJ, van der Flier WM, Sikkes SAM
Web-Based Multidomain Lifestyle Programs for Brain Health: Comprehensive Overview and Meta-Analysis

JMIR Ment Health 2019;6(4):e12104

URL: <http://mental.jmir.org/2019/4/e12104/>

doi: [10.2196/12104](https://doi.org/10.2196/12104)

PMID: [30964438](#)

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Original Paper

User Involvement in Developing the MYPLAN Mobile Phone Safety Plan App for People in Suicidal Crisis: Case Study

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Abstract

Background: The effect of safety planning for people in suicidal crisis is not yet determined, but using safety plans to mitigate acute psychological crisis is regarded as *best practice*. Between 2016 and 2017, Australian and Danish stakeholders were involved in revising and updating the Danish MYPLAN mobile phone safety plan and translating the app into a culturally appropriate version for Australia.

Objective: The objective of this study was to examine the negotiation of stakeholders' suggestions and contributions to the design, function, and content of the MYPLAN app and to characterize significant developments in the emerging user-involving processes.

Methods: We utilized a case study design where 4 focus groups and 5 user-involving workshops in Denmark and Australia were subjected to thematic analysis.

Results: The analyses identified 3 consecutive phases in the extensive development of the app: from phase 1, *Suggesting core functions*, through phase 2, *Refining functions*, to phase 3, *Negotiating the finish*. The user-involving processes continued to prevent closure and challenged researchers and software developers to repeatedly reconsider the app's basic user interface and functionality. It was a limitation that the analysis did not include potentially determinative *backstage* dimensions of the decision-making process.

Conclusions: The extended user involvement prolonged the development process, but it also allowed for an extensive exploration of different user perspectives and needs.

KEYWORDS

mobile apps; patient participation; primary prevention; self-injurious behavior; suicide, attempted

Introduction

Mobile apps have the potential to provide evidence-based health care interventions to people who would not otherwise receive services. The major barriers to access include limited resources, geographical location, and poor help-seeking capabilities [1]. Mobile health (mHealth), the use of mobile and wireless technologies to promote health, can assist people in assessing, monitoring, and tracking their mental and physical health; acquiring health information and psychoeducative resources; accessing real-time, recorded, or virtual psychotherapy; and connecting with social networks [2]. However, the potential benefits are counterbalanced by the current limitations to mHealth. Unlike most other health care interventions, the provision of health apps is not highly regulated [3]. There is a plethora of mental health apps, but very little research has explored their efficacy [1,4,5], and there is a growing concern about the effects, usefulness, or potential harmfulness of health apps [6,7].

From the mid-1990s, safety plans have been used in mental health outpatient services as an approach to work with suicidal persons. Without robust evidence, safety planning is considered *best practice* and used as part of different psychological therapies, such as Attempted Suicide Short Intervention Program [8], Cognitive Therapy for Suicide Prevention [9], and Emergency Department Safety Assessment and Follow-Up Evaluation [10]. This has led to some studies regarding the feasibility and acceptability of safety plans [9,11] as well as implementation fidelity and variability [12]. Bryan et al [13] published the first effectiveness study and evaluated the crisis response planning for prevention of suicide attempts. This randomized clinical trial included active duty army soldiers (N=97) presenting an emergency behavioral health appointment. In the trial, the participants received (1) a contract of safety (control group), (2) a standard crisis response plan, or (3) an enhanced crisis response plan. The results from baseline to 6-month follow-up suggest a 76% reduction in suicide attempts and no difference between the enhanced and standard crisis response plan. It was also associated with decline in suicide ideation, fewer inpatient hospitalization days, and larger reduction in negative emotional states [13].

Presently, there is only very limited research on the effectiveness of suicide prevention apps [14,15]. However, 2 published reviews of the design and function of suicide prevention apps provide some insights: Aguirre et al [16] identified 27 apps that could be linked to suicide prevention and assessed them according to (1) research or evaluation of the app, (2) privacy, (3) usability and accessibility, and (4) appropriateness of functionality. In particular, they noted that 12 of the apps did not include a direct link to a crisis hotline. Larsen et al [6] reviewed 49 apps that included at least 1 suicide prevention feature and were available in the Australian Google Play store

or the Australian iTunes store. Each app's features were mapped against 18 suicide prevention strategies and ranked according to these strategies' level of evidence (from 1 to 4), as identified in the research literature. Only 10 of the 24 suicide-specific apps contained a crisis support or helpline, which was rated as the highest level of evidence, that is, *strong evidence*. Furthermore, the 2 most used app features were peer support (16 apps) and safety planning (13 apps), which were evaluated as having *some evidence* or being *best practice*, respectively. However, it is difficult to make a balanced interpretation of Larsen et al's findings as they counted the 10 apps available for both Android and iPhone as 20 apps. Both Aguirre et al and Larsen et al concluded that suicide prevention apps need to be supported by stronger research evidence.

In contrast, Nicholas et al [17] made a case for abandoning the traditional evidence base for mobile phone apps, including randomized controlled trials (RCTs). The authors reasoned that the fast-paced mobile market requires alternative and more rapid research evaluation methods, such as iterative participatory research and single case designs. Furthermore, they argued for developing new, alternative ways of accrediting high-quality apps. In accordance with Nicholas et al's suggestions, we have presented a case study of the iterative user-involving processes that led to the gradual development of the revised version of the mobile safety plan app, MYPLAN [18,19].

MYPLAN was originally a Danish app modeled after Stanley and Brown's [11] paper-based safety planning tool. The app's target group includes anyone with a smartphone in, or at risk of, a crisis. This tool combines at least 3 preventive strategies: (1) cognitive, problem-solving, and personalized safety planning (identifying a personal warning sign of an imminent crisis and self-management strategies); (2) encouragement to contact peers and professionals (social support and professional crisis support); and (3) encouragement to limit access to lethal means [11]. The original Danish version of MYPLAN from 2013 also augmented the *encouragement to contact professional support* by including a map with directions to the nearest emergency room. The original version of MYPLAN is currently available in English, Danish, and Norwegian for Android and iPhone [18]. MYPLAN is developed by the Danish MinPlan company.

Democratizing knowledge and ensuring the relevance of research and design to end users are key elements of user involvement [20]. Between 2015 and 2017, the original version of MYPLAN was revised by involving Danish and Australian users with the purpose of developing a cross-cultural adaptation [21] and translation into Australian English. In addition, the revised app's data storage changed from being app-based to cloud-based, which, for instance, allowed users to share strategies through a Web-based strategy bank (see Table 1 for a brief description of MYPLAN's key functions in the original and revised app).

Table 1. MYPLAN's key functions in the original versus revised app.

Original MYPLAN	Revised MYPLAN
— ^a	Progressive onboarding: Introductions to the key functions
—	Speed dialing buttons: Customizable speed dialing buttons placed on front page pre-programmed with contact details to emergency services and 24/7 crisis support
—	<i>Contacts</i> : Customizable list of personally important contacts
<i>My symptoms</i> : Customizable list of personal signs of crisis	<i>Warning signs</i> : Customizable list of personal signs of crisis
<i>Strategies and solutions</i> : Customizable list of personal strategies for coping with crisis	<i>Strategies</i> : Customizable list of personal strategies for coping with crisis
—	<i>Hope box</i> : Electronic 'shoe box' where personal pictures, videos, and music can be stored and viewed when needed
—	<i>Mood ratings</i> : Suicidal Ideation Attributes Scale [22], a psychometric measure of suicidal ideation, and emoji ratings of mood tracked in a calendar
—	<i>Rant box</i> : A place where unpleasant thoughts, represented as texts and pictures, can be destroyed by prolonged pressure on the screen
—	<i>Quick messages</i> : A space for writing and saving personal text message templates for making quick contact in the future
—	<i>Share my location</i> : Sends a text message with the phone's location using Google Maps
<i>Nearest emergency</i> : Directions to the nearest emergency room using Google Maps	<i>Nearest emergency room</i> : Directions to nearest emergency room using Google Maps
<i>Network</i> : Personally customizable list of important contacts	—
Telephone contact details to 24/7 crisis support	—

^aNot applicable.

The aim of this study was to examine the negotiation of stakeholders' suggestions and contributions to the design, function, and content of the MYPLAN app and to characterize significant developments in the emerging user-involving processes.

Methods

We conducted an instrumental case study [23], which is a useful method for gaining insight into a particular event, such as the user-involving processes that led to the gradual development of the MYPLAN app's revised design and function.

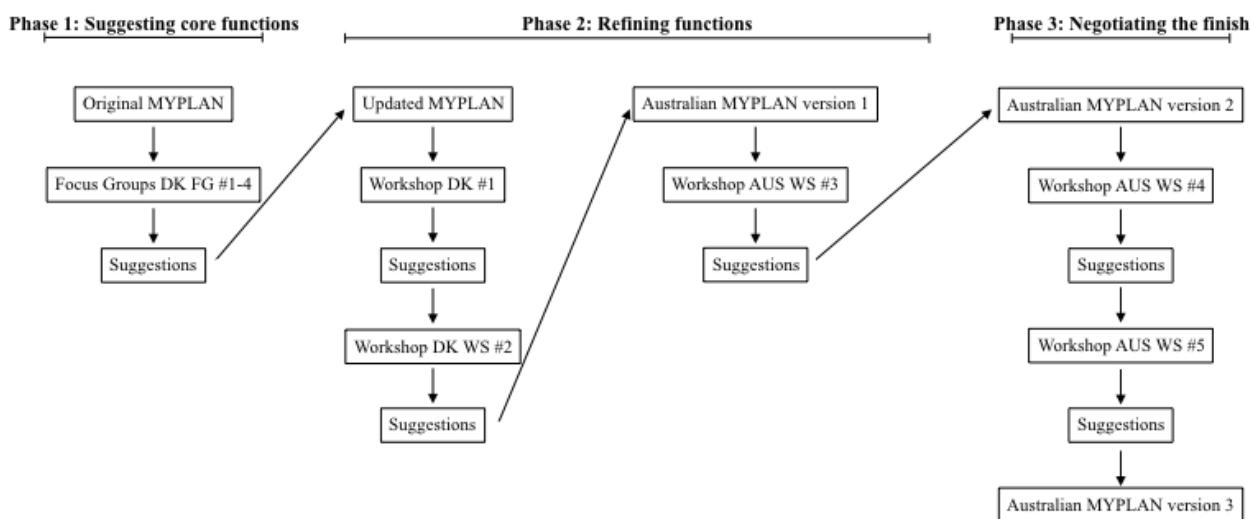
Study Context and Participants

Participants were involved in focus groups in Denmark and participatory workshops in Denmark and Australia. The user-involving development process was an opportunistic, emerging design process that began in 4 Danish focus groups. In these focus groups, users suggested that a more interactional setting (workshop discussions between moderators and users) could be beneficial in the ongoing development of the app. Furthermore, the opportunity to develop an Australian English version of the app arose when the first author moved to Australia and 3 workshops were planned across 2 university departments. As outlined below, participants included users, relatives, and clinicians, with the vast majority of participants being users of the app.

The focus groups and workshops are detailed in [Figure 1](#) and [Table 2](#).

Recruitment and Inclusion

In late 2015, 4 Danish (DK) focus groups (FG; DK FG #1-4) were held with key stakeholder participants (adult and young service users, relatives, and clinicians) [19]. All participants were recruited after responding positively to a written invitation distributed by the clinical administrative staff at 2 Danish Suicide Prevention Clinics where the users had received psychosocial treatment for suicidal behavior. The relatives were next of kin of these service users. The focus groups were thematically organized to allow focus on (1) discussing personal experiences of using MYPLAN and (2) participants' suggestions for improving design and function. In particular, participants were asked to consider whether a safety plan on a smartphone should include auto-generated communication (eg, notifications and prewritten messages), digital memory (eg, a hope box), Global Positioning System (GPS; eg, monitoring), and self-assessment (eg, monitoring and testing). Notable suggestions included incorporating an alarm speed-dialing button, a safety plan for relatives, GPS monitoring, notifications, prewritten messages, a hope box (that could possibly also be shared by a group of users), capacity to share coping strategies, and psychometric tests [19].

Figure 1. Organization of the app development process.**Table 2.** Focus groups and workshops.

Focus groups (FG) and workshops (WS)	Participants	Date	Length (min)	Knowledge of the app
Focus group #1 Denmark: <i>DK FG #1</i>	Young users (n=5); mean age: 16.0 years; and moderators (n=2; NB and JSL)	December 2015	126	Used original version of MYPLAN
Focus group #2 Denmark: <i>DK FG #2</i>	Adult users (n=8); mean age: 22.5 years; and moderators (n=2; NB and JSL)	November 2015	132	Used original version of MYPLAN
Focus group #3 Denmark: <i>DK FG #3</i>	Relatives (n=3); mean age: 49.0 years; and moderators (n=2; NB and JSL)	December 2015	129	Received original version of MYPLAN leading up to the session
Focus group #4 Denmark: <i>DK FG #4</i>	Clinicians (n=10); mean age: 46.0 years; and moderators (n=2; NB and JSL)	November 2015	120	Used original version of MYPLAN
Workshop #1 Denmark: <i>DK WS #1</i>	Users (n=3) ^a ; software programmer (n=1); and moderators (n=2; NB and JSL)	January 2016	155	Used original version of MYPLAN and reviewed wireframes of revised MYPLAN during the session
Workshop #2 Denmark: <i>DK WS #2</i>	Users (n=2) ^a and moderators (n=2; NB and JSL)	August 2016	156	Used original version of MYPLAN and reviewed wireframes of revised MYPLAN during the session
Workshop #3 Australia: <i>AUS WS #3</i>	Users (n=80) ^a and moderators (n=3; including TD)	August/September 2016	Up to 180	Reviewed wireframes of revised MYPLAN during the session
Workshop #4 Australia: <i>AUS WS #4</i>	Users (n=3) ^a and moderators (n=2; NB and JR)	December 2016	141	Received latest version of revised MYPLAN leading up to the session
Workshop #5 Australia: <i>AUS WS #5</i>	Users (n=3) ^a and moderators (n=3; NB, JR, and HH)	January 2017	188	Received latest version of revised MYPLAN leading up to the session

^aWe did not collect data on these participants' ages.

In 2016, 2 Danish participatory workshops (WS; *DK WS #1-2*) were held where end users were invited to evaluate the updated design and function and to suggest further changes to the app. The workshop participants were recruited from participants in the *adult users* focus group, which had been the most active in

suggesting changes to the app. The software programmer took part in the first of these workshops.

In 2016, 10 Australian (AUS) participatory workshops (AUS WS #3) were held with 80 participants, including young service users, supportive others, and clinical or service staff from a

youth mental health service, headspace. Recruitment for AUS WS #3 was based on inviting potential participants directly through displayed posters and postcards as well as some social media sent out by the participating headspace centers. Over a 3-hour period, the participants examined the wireframes of several apps, including MYPLAN, through an accelerated process of discovery, evaluation, and prototyping (Tracey Davenport, personal communication January 2019).

Finally, in late 2016 and early 2017, there were 2 Australian participatory workshops (AUS WS #4-5) where young service users were invited to evaluate the app for the Australian context. The workshops focused primarily on functions and the culturally appropriate wording of the Australian version, in particular, of the progressive onboarding, which gradually provides users with information when they use the app for the first time. These service users were recruited after responding to a written invitation distributed through Australian mental health services and organizations, such as headspace and ReachOut. All participants were given access to an English prototype of MYPLAN before the workshops.

During the user-involving process, the software developers continually summarized suggestions, developed prototypes, and listed all participant suggestions, which were then evaluated and prioritized with regard to importance and cost.

Data

As the user-involving processes had an opportunistic emergent design, the available data were heterogeneous. Data from the 4 focus groups (DK FG #1-4) and 4 of the workshops (DK WS #1-2 and AUS WS #4-5) were collected through (1) audio recording of the focus groups and (2) qualitative field notes summarizing suggestions and discussions in workshops. In AUS WS #3, data were collected through (1) written comments made by participants, (2) hand-drawn mock-ups, and (3) qualitative field notes written during the workshops. These latter data were independently knowledge-translated by a representative user team (young people, supportive others, and clinician and service staff) (Tracey Davenport, personal communication January 2019). In addition, written notes produced during the workshops as well as the software developers' list of suggestions were collected and analyzed.

Analysis

Data were subjected to thematic analyses [24,25], which included the following: (1) reading or listening to the full dataset to familiarize researchers with content, (2) mapping trajectories of suggestions from inception to rejection or from inception to implementation, (3) parallel coding of full dataset and written summaries by 2 researchers, (4) gradual development of descriptions of thematic content and discrete phases, and (5) corroboration of the description of phases by re-examining data.

Ethics

We notified the relevant Danish regional research ethics committee and the Danish Data Protection Agency about the Danish focus groups and workshops (DK FG #1-4 and DK WS #1-2); neither institution reported any reservations toward the study. The University of Sydney Human Research Ethics

Committee approved the research of Australian participatory workshops (AUS WS #3: reference #2016/529 and AUS WS #4-5: reference #2016/749). All participants gave their informed consent to participate based on written and oral information about the study. Interview responses were handled in full confidentiality, and all details that could potentially be used to identify individual participants have been altered in the data extracts presented in the Results section below.

Results

Overview

The analysis identified 3 temporal phases during the user-involving processes, which were characterized by distinct types of negotiations. The first phase, *Suggesting core functions*, was characterized by a focus on discussing the potential inclusion of basic app features. The second phase, *Refining functions*, was characterized by testing and negotiating the design of newly implemented app features. The third phase, *Negotiating the finish*, was characterized by tests and discussions about the final layout and wording. The 3 data extracts presented in the sections below were selected because they were characteristic of the different phases.

Discussions in all 3 phases were characterized by very low levels of displayed disagreement. For instance, when different opinions were voiced, participants would most often resolve disagreement by suggesting that a given app feature should ultimately be optional and adaptable by individual users. Tables 3 and 4 illustrate the different phases with 2 examples, speed dialing buttons and mood rating.

The development and implementation of the speed dial buttons was gradual and characterized by minor edits of the software developer's responses that were only slightly different from what users had originally suggested.

The development and implementation of the mood rating was gradual but characterized by reluctance from the users regarding its usefulness, in particular, the Suicidal Ideation Attributes Scale (SIDAS) questionnaire. The texts introducing and describing SIDAS scores were completely rewritten by users before final implementation.

Phase 1: Suggesting Core Functions

The first phase primarily took place during the Danish focus groups, where the functions of the original MYPLAN app were discussed along with ideas for new functions, which were introduced by the researchers. Participants raised some principal issues about the app's design and functions:

First, some participants voiced different understandings of what users might enter into the app's core problem-solving function: *Warning signs*. They noted that the concept was unclear and could be interpreted as either *signs of a potential crisis* that could be used in an early intervention to avoid a crisis or as *signs of a current acute crisis* that could be used to mitigate an ongoing crisis. While in phase 1, these discussions did not lead to explicit suggestions for changes to the app; the discussions reappeared in phase 3 with regard to whether the app should be used as a safety plan or suicide prevention tool (see below).

Table 3. Examples of the phases in the user-involvement processes: speed dial buttons.

Phase 1: Suggesting core functions, DK focus groups #1-4	Between phase 1 and phase 2	Phase 2: Refining functions, DK workshops #1 and #2 and AUS workshop #3	Between phase 2 and phase 3	Phase 3: Negotiating the finish, AUS workshops #4 and #5	After phase 3
Users suggested speed-dialing buttons. The colors of the buttons should reflect the <i>degree of emergency</i> (yellow or red). They should be simple to use: an emergency call should be made with no more than 2 clicks	Development of wire-frames with different types of menus and different opportunities for placing an alarm button	The location of the 2 buttons was discussed and they were placed at the bottom of the front page. The yellow button should be named <i>Help</i> and was assigned a telephone icon. The red button should be named <i>Alarm</i> and was assigned an exclamation mark icon. The way to assign contacts to the buttons was discussed and the number of possible contacts to assign to the yellow button should be 10	Implementation of 2 buttons on the front page. A yellow <i>Help</i> button with a telephone icon and a red <i>Emergency</i> button with a white exclamation mark. Alarm call in 2 clicks from front page (but a 4-digit access code was also added). A maximum of 10 yellow contacts was implemented	The need for better onboarding information, explaining the way to add contacts to buttons, was noted. The icon on the yellow button should be a telephone and a head in a circle. The icon on the red button should be a white cross in a red circle	Onboarding information about how to assign contacts to the 2 buttons was discussed. Implementation of 2 buttons on the front page. A yellow <i>Help</i> button with a telephone icon and a red <i>Emergency</i> button with a telephone icon

Table 4. Examples of the phases in the user-involvement processes: mood ratings.

Phase 1: Suggesting core functions, DK focus groups #1-4	Between phase 1 and phase 2	Phase 2: Refining functions, DK workshops #1 and #2 and AUS workshop #3	Between phase 2 and phase 3	Phase 3: Negotiating the finish, AUS workshops #4 and #5	After phase 3
Users discussed the usefulness of tests and here the idea to use emojis for the mood rating arose. In general, users argued against using tests in the app. Suggestion of making mood rating customizable	Introduction to different types of emoji-based mood trackers	The selected emojis were reviewed and edited (they looked angry rather than sad). The wording of the mood tracking function was discussed and changed. Suggestion of clear introductory text. The function of mood rating, including its reminders, should be customizable	Implementation of emoji-based mood tracker and SIDAS ^a , suicidal ideation measure. The presence of mood ratings in the menu became customizable by individual users	Objection to the wording of SIDAS's response categories. Introductory text to SIDAS is reformulated. The feedback from SIDAS should be gentler and less demoralizing	Implementation of revised onboarding information about SIDAS and its response categories

^aSIDAS: Suicidal Ideation Attributes Scale [22].

Second, users were aware not to overcomplicate the app by suggesting too many functions, which occasionally happened when participants started outbidding each other with numerous interactive Facebook-inspired features. For participants, the focus on *need to have* functions rather than *nice to have* functions was related to concerns about developing an app that could be used in an emergency where simplicity would be paramount.

In the following data extract from focus group DK FG #4 (see **Textbox 1**), which included relatives of MYPLAN users, the

participants discussed the potential use of GPS. The prompt for the discussion was a vignette about a young girl who switched on her GPS when she felt suicidal, which would automatically alert parents and clinicians, who would then be able to follow her phone's location. After expressing concerns that MYPLAN users might be bluffing and that there would be a need for sincerity from the users, the relatives started reflecting on the personal costs such alerts would have on themselves as well as issues of intrusions that GPS surveillance might inflict on their sons or daughters.

Textbox 1. Data extract 1.

Moderator: *I hear you describing something like the existing ‘Find My iPhone’ feature that parents use to check if the kids are at school or other places. What are your thoughts?*

Emma: *No. That would not be OK for me. Ian [her son] would definitely be too old for that, so I would find that it was intruding on his private space.*

Jenny: *That would send Rachel [her daughter] round the bends; you would be stalking her, right? I think it is good, you could use it in crisis situations or that they can use it in crisis situations.*

Emma: *It must not turn into surveillance, because they will just switch it off.*

Rachel: *It has to be optional.*

Moderator: *So it would be ok if you had an agreement with your daughter for a while?*

Rachel: *Yes, if I could cope with it, my daughter would have to control it herself.*

Emma responds to the moderator’s question by refusing the idea of monitoring her adult son, as it would be too intrusive. Jenny follows up by agreeing that it would not be good for her daughter, but she adds that it might be good in a crisis. She revises her own initial statement when she describes GPS monitoring as something “you” could use in a crisis situation, to something “they” (their sons and daughters) could use, which could indicate that she preferred to describe it as the offspring’s tool and not the parents’. Emma continues by voicing a similar concern and emphasizes that it must not have a character of surveillance as that would be unacceptable and the children would simply not use it. Rachel emphasizes that it has to be optional for the children to be followed by GPS and concludes by stressing that it would require an agreement and that her daughter would have to control it. However, she also states that she, herself, would need to be able to cope with being able to monitor her daughter, which could indicate that it would be emotionally taxing to have access. The option of GPS seems to trigger these participants’ ambivalence about, on one hand, having control and certainty and, on the other hand, the anxiety of a hands-off approach to their vulnerable children.

In phase 1, the researchers ultimately controlled the discussions as they introduced the focus group agenda highlighting the core app features. However, participants were invited and most often able to voice concerns that had a direct impact on the development of the first draft designs of the core functions.

Phase 2: Refining Functions

The second phase primarily took place during workshops DK WS #1-2 and AUS WS #3 after the software developers and programmers had created a first revision of the app. The majority of app changes were only available as printed wireframes, and discussions were focused on developing additional ideas.

As in phase 1, there was a continual flow of suggestions that were extensively negotiated in the groups as well as suggestions that were never discussed in any significant depth because of their apparent complexity (eg, when you speed dial the emergency services, the phone should automatically send your

GPS coordinates or the phone should be able to prompt you or your network if you come near certain risky locations according to data you have entered yourself, for instance a bar or a tall building). Only 1 new core function was developed for the app in this phase. This was the Rant Box, which was introduced following the AUS WS #3. The Rant Box was a place where self-selected text and images could be destroyed by applying prolonged pressure to the touch screen.

In workshops DK WS #1 and 2, relatively structured discussions organized by the moderators took place. The moderators closed the workshop by restating the key points raised and decisions made. In DK WS #1 and 2, moderators both implicitly and explicitly drew on insights from the focus groups. Points were mostly discussed by stating ideas one after the other without much explicit disagreement. There were several instances in DK WS #1 where the participating software programmer funneled the discussions in a particular direction based on arguments linked to the concrete programming of features and economy. Finally, there was an incident where the software designers chose to keep a feature, the structured (SIDAS [22]) suicidality rating scale, despite repeated pushback from user participants who perceived it as redundant and unnecessary (see Table 4). The software developers’ motives for keeping SIDAS despite the users’ pushback were not clear in the available data as the decision, or the lack of a decision, was made in *backstage* negotiations away from focus groups and workshops.

The following data extract 2 (see [Textbox 2](#)) illustrates the typical collaborative nature of negotiating and refining a function during a workshop. The participants were discussing different ways of designing a speed-dialing function and had previously settled on a solution with 2 buttons at the bottom of the home screen, a yellow for subacute situations and a red for acute crisis. Now, the key issue was to discuss how much flexibility a user had in terms of assigning particular functions to each of the buttons. Interactions were fast, and in the data extract, “...” indicates that the next speaker started talking by interrupting the previous speaker slightly.

Textbox 2. Data extract 2.

James: *My idea would be that it [the red button] would do only one thing. When you press the red one then you call a particular person or 112 [emergency call].*

Linda: *I think that too. Alternatively, you could, if you wanted both 112 and Lifeline, then you could add two...*

Moderator 1: *Or you made 112 the red [button] and Lifeline the yellow [button].*

Linda: *Yes, yes, then you'd...*

James: *Yes, of course...*

Moderator 1: *I believe that the red one should be—only need one click. You shouldn't have to make any decisions...*

James: *That's also what I think. The yellow is meant for when you feel terrible and you need to talk to someone. When I have been so far out that I simply needed to talk to someone. That would be how I saw the yellow phone [button] whereas the red phone is when I'm almost out of reach. I need to get hold of someone before things go really wrong. Therefore, as you say, the red one is for one person whereas with the yellow you might choose between several. There needn't be a maximum, but between five and six persons. Having 20 persons to choose from should not confuse you.*

James starts out by explaining his ideas about the differences between the buttons' functions, and Linda follows up by explicitly agreeing but, at the same time, adding that the red button could be linked to several numbers. The moderator disagrees by emphasizing that he believes that the red button should be simple to use. James expresses his agreement with that and expands on his idea for the 2 buttons by explicitly drawing on his personal experiences of being in a crisis. He concludes by rewording the issue regarding simplicity that had previously been forwarded by moderator 1.

The workshops were highly interactive, with moderators being actively engaged. The researchers had a high degree of control through their ongoing engagement and a systematic and structured summarizing, which ultimately funneled a consensus about each discussion point. However, the very explicit and consensus-seeking approach gave participants a direct influence on decisions. The individuals who had participated in both a focus group and the workshops seemed to display more ownership of the process and had a better understanding of what was being developed, which strengthened and qualified their contributions in discussions.

Phase 3: Negotiating the Finish

The third phase primarily took place during workshops AUS WS #4 and 5 when MYPLAN's core functions had been designed, tested, and refined. Fixing glitches continued to take place as it had been done in phase 2, with all issues listed and fed back to the software developers to prioritize and resolve.

Unlike the Danish participants, Australian user participants were not introduced to the app by health care professionals who they had met in the clinic. Therefore, the Australian workshop participants relied heavily on the built-in electronic introductions (e-introductions), which they did not find intuitive or helpful. The Australian participants identified a need for better e-introductions and suggested progressive onboarding to MYPLAN's functions. The participants from workshops AUS WS #4 and 5 were engaged in writing and editing the introductory texts for the app, both during the workshops and via email after the workshops. These texts were sent to the software developers, who implemented them in both the Australian and Danish versions. Later, the text introductions were supplemented by video clips.

The Australian participants felt that the text introductions, which were relatively noninteractive, made the app's particular clinical language use unacceptable. The following data extract 3 is taken from AUS WS #4 where a participant, Sarah, highlighted her discomfort concerning the image and text she read after responding to the 5 items of the SIDAS:

It says the word suicide a lot and it says a lot of words that probably when you are in distress you don't need to be confronted with. And more importantly, it is talking about and not to you again, which is really kind of demoralizing. I feel like it could be a lot shorter and more pleasant very easily. [Sarah]

Sarah continued to elaborate on her position that the language use came from a medical and paternalistic position, which, to her, objectified the user and was not helpful for a person in a crisis. This led to a series of discussions about the general coherency: was it a problem that MYPLAN was, on one hand, a personalized self-help tool and, on the other hand, employed medical surveillance and medical psychoeducation? The Australian workshop participants strongly supported the development of a completely nonmedicalized and nonpathologized self-help safety plan, asserting that this would be acceptable for people who felt distressed but who would not identify as being in a crisis (a crisis management plan), let alone being suicidal (a suicide prevention plan).

The pushback from the Australian workshops was a genuine surprise for the researchers who were forced to reconsider their own core assumptions about the app's purpose and its users. Nevertheless, they appreciated the feedback and welcomed the user participants as authors of the app's onboarding texts and features.

Discussion

Principal Findings

The case study identified 3 temporal phases during the user-involving processes, which were characterized by distinct types of negotiations: (1) *suggesting core functions*, (2) *refining functions*, and (3) *negotiating the finish*. The phases most probably reflected that the MYPLAN app was developed gradually over an extended period of time. Researchers controlled most of the concrete user-involving processes, but as stakeholders were presented with increasingly finalized

revisions of the app, they were able to grasp new designs and engage more collaboratively with researchers and software developers.

Models of user involvement often classify levels of involvement according to the distribution of power and control between user participants and researchers [26]. For example, Hanley et al [27] differentiate among the following: (1) *Consultation*, where service users' perspectives are explored by researchers and potentially brought in to decision-making processes; (2) *Collaboration*, where researchers are actively committed to engaging in ongoing partnerships with service users; and (3) *User control*, where "the locus of power, initiative, and subsequent decision making is with service users rather than with the professional researchers" [27]. Although the user-involving processes analyzed in this study clearly included elements of *consultation*, it remained debatable to what extent the software developers and researchers were committed to *collaborate* and genuinely share control. For example, the software developers were adamant in maintaining the SIDAS despite user dissent. In addition, although study participants were consulted over extended periods of time and occasionally designed direct suggestions to the app, which resembled elements of *user-controlled* involvement, the researchers ultimately controlled the data-collection sessions and the information that was recorded, prioritized, and fed back to the software developers and programmers.

Although users are regularly involved in the evaluation, design, and development of mental health apps (see for instance [28,29]), the actual levels of involvement remain challenging to ascertain. We were, at times, surprised by the users' nonconsensus-seeking language and their multifaceted, nuanced, and layered suggestions that were not as distinct as we had anticipated, and it was hard to pinpoint when a *suggestion* had been made. This, in effect, made it impossible to track the historical trajectories of distinct suggestions, and it was not possible to identify a specific level of user involvement. The identification of distinct levels of user involvement would most probably rely on preplanned and highly structured negotiation processes that could inadvertently silence the users' voice. Finally, difficulties in ascertaining user involvement are complicated by the fact that there is no agreed terminology for describing *user involvement* practices. Terms such as co-design, coproduction, and co-development often imply that users are only being *consulted*, that is, not involved as a resource in their own right, and continue to have very little actual power and control in health research and development. We were not able to identify any study on actual user involvement in the research and development of mental health apps. Hence, more research in this area is needed to determine the actual levels of involvement and the benefits of involvement.

It was also difficult to gauge if and how the user-involving processes enhanced the MYPLAN app. Hawton et al's [30] Cochrane review suggested possible mechanisms as to how the preventive strategies implemented in the app might mitigate suicidal crisis. These include enhancing problem-solving and coping skills (achieved by linking warning signs and strategies) and an increased sense of social connectedness (achieved by listing social contacts and quick messages). Although Stanley

and Brown's [11] paper version of the safety-planning tool drew on at least 3 different preventive strategies, the original as well as the revised MYPLAN apps added further features, in particular, by making use of smartphone technology (telecommunication, digital memory—for instance, the personal hope box or the shared inspiration bank—automatic communication, psychometric testing, and GPS). Moreover, control was handed over to users in the workshops' discussions, which led to surprising (for researchers) suggestions, for example, the use of nonpathologizing and clinical crisis language. In line with the general aims of user-involving strategies, these processes were perceived to be relevant by users but added complexity to the designing process, and it remains unclear whether the actual and proposed changes could have unintended negative consequences on the design of the app.

In addition, when compared with a paper version of a safety plan, the numerous preventive strategies added to the app could hypothetically decrease transparency and user-friendliness and obstruct *simple* safety planning. O'Toole et al [14] identified the potential negative effects of the use of a multifunction suicide prevention strategy and suggested that this could be related to users having to learn to use new technology (LifeApp'tite) and being prompted to self-rate on a daily basis. Interestingly, many of the functions that O'Toole et al listed as potentially having an adverse effect were functions that users in this study objected to and which led to the design of MYPLAN as a demedicalized crisis management app with comprehensive onboarding resources. It is possible that the involvement of end users can assist app developers, clinicians, and researchers in developing mHealth technology that remains simple and relevant to users.

As noted by Grundy et al [3], adverse events and possible harm are rarely mentioned in disclaimers of mental health care apps. However, no reports of harm were voiced during any of the sessions and participants' reports of potential ambivalence or adversity were managed *in situ* and in the ongoing design of the app. Grundy et al [3] also noted that mental health care apps have a tendency to claim easy and rapid improvement of mental health in their presentations in the app store. However, contrary to these visible and positive claims, the formal app disclaimers tended to distance themselves from presenting the app as a medical service [3]. Arguably, this happens to clearly and conveniently differentiate a given app from a *medical device*, which would be subjected to extensive—and expensive—medicolegal regulation. Regulation would, of course, be necessary if an app intends to be used for diagnosis, prevention, monitoring, treatment, or alleviation of medical diseases. However, phase 3 of this study's user-involving process included a strong push toward demedicalizing the management of everyday feelings of distress, rather than preventing suicide, which could make the app relevant to a much wider audience. This, *in effect*, moved the app away from potentially being classified as a medical device. To some extent, the revised design of the app begs the question of whether there might be a need for a parallel version of the app that was a medical device and had a strong explicit focus on suicide prevention.

Strengths and Limitations

We collected observational data from a range of meetings over a long period of time, which allowed a basic mapping of the introduction and negotiation of ideas over time. However, we did not have observational data of the separate negotiations with the app designers. Such negotiations included discussions among software developers about which of the listed suggestions should be prioritized in light of their complexity and costs and decisions taken by the app programmers. From a methodological perspective, we believe that users' involvement might be perceived as less impactful if these *backstage* negotiations were part of the analysis. Arguably, users should be formally involved in as many of these crucial design processes as possible to achieve more genuine collaboration.

Most participants were offered to join several sessions, which allowed them to voice their opinion as the app was developed gradually over time and to strengthen their sense of personal ownership. However, despite elaborate recruitment strategies, most workshops included only a very limited number of participants. Although we held several workshops and most participants had strong voices and opinions, it would have been advantageous to recruit larger and more diverse groups of participants.

Conclusions

The analyses identified 3 consecutive phases in the extensive development process of a safety plan provided as an app.

Acknowledgments

DK focus group #1-4 and DK workshop #1 and #2 were supported by TrygFonden under Grant 133722. AUS WS #3 was funded through phase 1 of Project Synergy, which originally received Aus \$5.5 million in Australian Federal Government investment in 2014 to 2016.

Conflicts of Interest

None declared.

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Abbreviations

e-introduction: electronic introduction

GPS: Global Positioning System

mHealth: mobile health

RCT: randomized controlled trial

SIDAS: Suicidal Ideation Attributes Scale

Edited by J Prescott; submitted 17.08.18; peer-reviewed by Y Perry, T Donker, W van Ballegooijen, E Heim; comments to author 08.11.18; revised version received 15.01.19; accepted 25.01.19; published 16.04.19.

Please cite as:

Buus N, Juel A, Haskelberg H, Frandsen H, Larsen JLS, River J, Andreasson K, Nordentoft M, Davenport T, Erlangsen A. User Involvement in Developing the MYPLAN Mobile Phone Safety Plan App for People in Suicidal Crisis: Case Study. JMIR Ment Health 2019;6(4):e11965

URL: <http://mental.jmir.org/2019/4/e11965/>

doi: [10.2196/11965](https://doi.org/10.2196/11965)

PMID: [30990456](https://pubmed.ncbi.nlm.nih.gov/30990456/)

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Original Paper

A Clinical Care Monitoring and Data Collection Tool (H3 Tracker) to Assess Uptake and Engagement in Mental Health Care Services in a Community-Based Pediatric Integrated Care Model: Longitudinal Cohort Study

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Abstract

Background: National recommendations for pediatric integrated care models include improved capacity for care coordination and communication across primary care and specialty mental health providers using technology, yet few practical, short-term solutions are available for low-resource, community-based pediatric integrated care clinics.

Objective: The goal of the paper is to describe the development and features of a Web-based tool designed for program evaluation and clinician monitoring of embedded pediatric mental health care using a community-partnered approach. In addition, a longitudinal study design was used to assess the implementation of the tool in program evaluation, including clinical monitoring and data collection.

Methods: Biweekly meetings of the partnered evaluation team (clinic, academic, and funding partners) were convened over the course of 12 months to specify tool features using a participatory framework, followed by usability testing and further refinement during implementation.

Results: A data collection tool was developed to collect clinic population characteristics as well as collect and display patient mental health outcomes and clinical care services from 277 eligible caregiver/child participants. Despite outreach, there was little uptake of the tool by either the behavioral health team or primary care provider.

Conclusions: Development of the H3 Tracker (Healthy Minds, Healthy Children, Healthy Chicago Tracker) in two community-based pediatric clinics with embedded mental health teams serving predominantly minority children is feasible and promising for on-site program evaluation data collection. Future research is needed to understand ways to improve clinic integration and examine whether promotion of primary care/mental health communication drives sustained use.

Trial Registration: ClinicalTrials.gov NCT02699814; <https://clinicaltrials.gov/ct2/show/NCT02699814> (Archived by WebCite at <http://www.webcitation.org/772pV5rWW>)

(*JMIR Ment Health* 2019;6(4):e12358) doi:[10.2196/12358](https://doi.org/10.2196/12358)

KEYWORDS

integrated health care systems; data collection methods; community-based participatory research; community mental health services

Introduction

Pediatric primary care providers are well positioned to detect developmental delays and mental health problems early, but access to community-based mental health programs and information exchange across providers is often poor [1]. Because of this, integrating pediatric and behavioral health care has been an important part of recent efforts to enhance health care delivery and impact [2-7]. Integration facilitates increased access to behavioral health care, improved infrastructure, and enhanced financial efficiency through reorganized financial and reimbursement structures [3]. It is also associated with increased use of primary care, with patients more likely to visit their primary care doctor and make more frequent visits to primary care [8]. In integrated care, primary and mental health specialists are able to develop a relationship, helping to bring together different caregivers to develop a coordinated health care plan for patients [5]. Further, a key feature of collaborative care is tracking clinical outcomes, which has been shown to greatly increase patient response to treatment [9,10].

National recommendations for pediatric integrated care models include improved capacity for care coordination and communication across primary care and specialty mental health providers using technology [11-13]. Improved communications technology can allow therapists or other providers to be alerted when a course of treatment is ineffective or harmful, predicting treatment failure, risk of hospitalization, or other negative outcomes [9]. For patients, being able to track clinical outcomes can be encouraging, decreasing patient skepticism about the course of treatment by providing evidence of successes, thus improving patient commitment to treatment [9]. Through developing technology, three of the largest barriers to adoption of clinical tracking systems—cost to health care systems, user relevancy, and time required to learn about the tool [9]—can be mitigated because of the decreased costs associated with creating systems with this capacity, increased relevance for patients and providers through tool customization and flexibility of modification, and decreased time required to use the tool due to customization and increased user relevancy.

While the importance of coordination and communication in the health care system has been widely documented [2,4-7], these efforts are often costly, requiring system organization, privacy control, and mental and physical health system financial integration that only larger, wealthier health care organizations have [1,12,14,15]. Electronic health records (EHRs) are integral to enhancing patient care, and an effective EHR system provides more efficient contact between patients and their care team, resulting in substantial cost savings through more effective care [16-19]. When EHRs are siloed within one care system and mental and physical health services are performed through different systems, coordination of these services requires information exchange that can be infeasible for many organizations [15,19-23]. Further, the ever-changing landscape of health care can require adjustments to the EHR, and these

modifications require either a large outlay of capital or internal staff with programming capabilities, less likely to be present within smaller health care organizations [23-26]. The advantages that come from EHRs, however, cannot be realized without a customized, user-centered EHR system [19,20,25,27,28].

To introduce a practical short-term solution for community-based pediatric integrated care models, this paper describes the development and implementation of the H3 Tracker, a Web-based clinical care documentation and data collection tool for use in two federally qualified health care centers with embedded mental health teams serving low-income, predominantly racial and ethnic minority children and their families. Objectives are as follows:

- To describe the development of the Web-based tool using a community-partnered participatory approach and its features;
- To assess the implementation of the tool for clinical monitoring of embedded mental health care as well as data collection for program evaluation using a longitudinal cohort study design.

Methods

Project Overview

Healthy Minds, Healthy Children, Healthy Chicago (H3) is a project funded by the Illinois Children's Healthcare Foundation to improve access to and engagement in child mental health services at two federally qualified health care centers through implementation of community-based pediatric integrated care models [29]. The proposed mechanism was to integrate primary and mental health care services, improving access and engagement of these services for the prevention and early detection of children's mental health problems [30]. Two clinic sites were selected to develop integration strategies tailored to the needs of their patient populations, staff, clinic organization, and available resources. Both clinics were located in the Chicago metropolitan area, serving low-income children and their families.

The program evaluation aims were to assess the implementation of the care models, with metrics conceptualized as uptake and engagement in mental health services, and examine the relationship between use of on-site mental health care and child- and parent-level clinical outcomes at 3, 6, and 12 months using standardized measures. To meet these aims, the H3 Tracker was developed to align with clinic workflow analyses and program evaluation design. The H3 Tracker collected data on the overall clinic population demographics; baseline and 3-, 6-, and 12-month follow-up surveys for participants; and embedded mental health or case management services provided to the children and primary caregivers enrolled in the evaluation. The study time period was 24 months, from April 2016 to March 2018. The original 1-year baseline data collection time period was extended to 18 months to improve subject enrollment. Thus,

the sample of children eligible for 12-month follow-up interviews was restricted to those who completed baseline surveys within the first 12 months. Eligibility for the study was determined by a positive score on the Pediatric Symptom Checklist (PSC) corresponding to need for further mental health assessment with the option of a clinical override by clinic staff [31]. Study and informed consent procedures as well as the design and content of the H3 Tracker were approved by the institutional review boards of the University of California at Los Angeles (UCLA) and University of Illinois at Chicago. This study is also registered with ClinicalTrials.gov [NCT02699814].

Development of the H3 Tracker

The need to develop the H3 Tracker to support program evaluation was identified during the development of the partnered evaluation process. Clinic sites and the academic team in Los Angeles explored strategies on how to transfer clinic data to the academic partner. Direct transfer from the EHR system to a secure server at UCLA was proposed; however, the resources and workforce needed to coordinate these systems and appropriately organize the data were outside of the scope of the project. Abstraction of specific data elements from existing administrative data (ie, sociodemographics) was also explored, but the team decided to have the site data coordinator (SDC) enter information directly into the H3 Tracker because overall it was less time-consuming. Further, additional elements that the evaluation required were not collected in the EHR, so creating a tool to fulfill these requirements was necessary.

Biweekly meetings were convened over the course of 12 months led by the academic partners with participation from community clinic staff and the project funder [30]. The tool was developed using a participatory framework in consultation with the principal investigator, working from a detailed evaluation design plan and clinic workflow diagrams to structure the features of the tool. Input on the development of the H3 Tracker was solicited from the data collection team, clinic physicians, mental health clinicians, and other care team members, with the majority of feedback coming from the mental health and data collection team because of their familiarity with project demands and availability. The feedback was used to refine H3 Tracker features, change wording or the ordering of questions, and add other features when possible. An iterative approach was taken, and when feature requests were unable to be incorporated due to infrastructure limitations or project needs, more feedback was solicited, with other ideas discussed and related design changes incorporated.

After sufficient discussion about project goals and H3 Tracker design, a prototype was constructed. The H3 Tracker was developed using the Chorus participatory technology platform, customized to fit the needs of a diverse clinic population as well as varying needs of the different end user types. Chorus is a Web application that allows the user to create personalized Web-based and mobile apps through a simplified visual interface without the need for computer programming skills [32,33]. The Chorus application was developed using AngularJS, Ruby, and MySQL and is a hosted service provided through UCLA. Data

in Chorus are encrypted, password-protected, and stored on a secure server located at UCLA.

The prototype was presented at an in-person meeting with site data collectors and other clinic staff from both project sites, with usability tests used to inform additional modifications to the tool. During the training, participants entered mock data into the tool, and afterwards the functionality and design of each page was discussed. Particular attention was paid to aligning H3 Tracker features to the common elements of the clinics' work flows. Together, this feedback also guided the development and refinement of the training manual.

Additionally, some areas for refinement were discovered during implementation of the tool at the clinic sites, and when possible, these were actualized during the course of the project. One was the ability to document contact attempts of participants, when the SDC would call participants to try to collect follow-up surveys. The SDCs would keep a record of their participant contact attempts on a separate document, not within the H3 Tracker, but felt that being able to document this within the H3 Tracker itself would help increase the awareness and accuracy of the documentation of previous contact attempts. Being able to respond to user demands and modify the tool accordingly helped increase the acceptability of the tool since it was more tailored to the wants and needs of users. The ability to change or add features after deployment in the clinic allowed issues to be addressed that were difficult to anticipate beforehand, which allowed for more appropriate use of the tool in the clinic workflow over what it would have been with only preimplementation user-centered design.

To assess the adoption of the tool, data on the number of user interactions were analyzed. In addition, feasibility was represented by the time spent on each page of the tool, the number of participants enrolled in the project, and the number of times a user was able to record services administered by clinic staff for each participant.

Results

Tool Customization: User Types and Clinics

Through discussions with academic and clinic partners, it was determined that 3 user types would be developed: (1) clinic SDC, (2) mental health clinician, and (3) pediatric primary care provider. The SDCs would input the majority of project data and record services administered to study participants. The mental health clinicians would have access to the same surveys to allow option to administer more sensitive measures (eg, trauma exposure). The primary care providers would be able to view a timeline of embedded mental health care processes for each patient as well as view the results of all of the surveys.

In addition to user types, the tool was customized for different clinic needs. Because one of the clinics served predominantly Spanish-speaking patients, a Spanish language version was created using a two-step back and forth translation approach. The tool contained validated measure translations when available, but when no validated translation existed, measures were translated by the study team.

Tool Features and Workflow

The enrollment and data collection process is summarized in **Figure 1** (see [Multimedia Appendices 1](#) and [2](#) for the data flow and data structure diagrams). The main features of the H3 Tracker are the Daily Census of Clinic Patients, Program Evaluation Eligibility Check, Surveys, and Clinical Care Monitoring.

Daily Census of Clinic Patients

The Daily Census of Clinic Patients (hereafter referred to as the Daily Census) was developed to collect general demographic information about the clinic population. In addition to demographic information, details about the child's visit and eligibility for the study were documented. Data from the Daily Census were collected to describe the pool of eligible subjects and assess potential sources of selection bias for the evaluation.

Figure 1. Process flow diagram. H3: Healthy Minds, Healthy Children, Healthy Chicago.

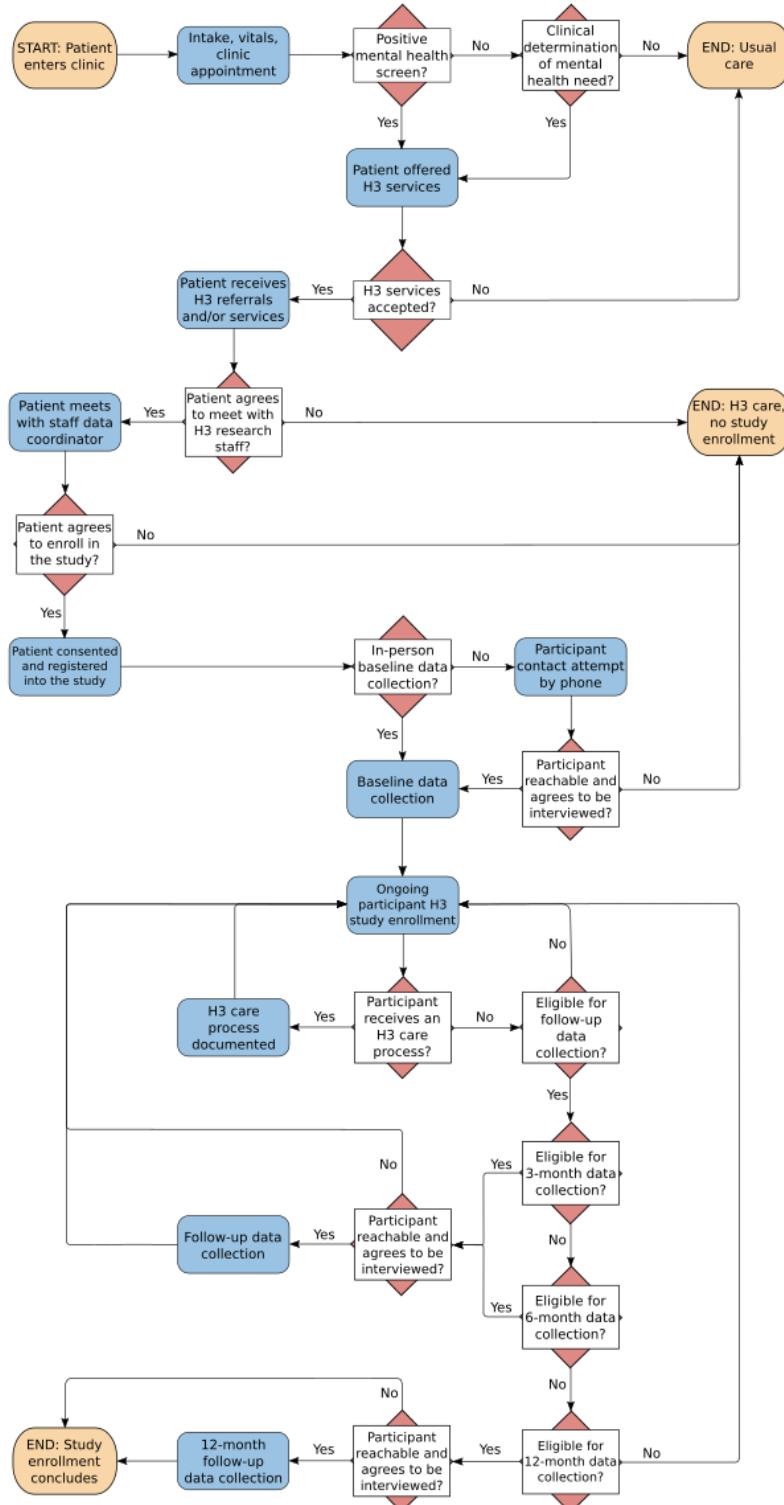


Figure 2. Daily Census page.

The Daily Census page (Figure 2) was modified for flexibility to the workflow of the SDCs. The assumption when the page was first developed was that the SDCs would enter patients as they came into the clinic. As project implementation progressed, it became clear that the workflow of the SDC would not often permit this; rather, the previous day's information would be entered when the SDC did not have recruitment or other project obligations. To accommodate this change, functionality was built to allow the SDCs to edit the Daily Census date so information could be entered for patients who came in on a previous date. All of the information entered for the selected date was visible at the bottom of the screen, so that information could be tracked and, if entered incorrectly, flagged and reported. The feature to self-edit the data was not developed to limit accidental data erasures.

Program Evaluation Eligibility Check

The SDCs accessed the Program Evaluation Eligibility Check (Eligibility) section after a potential participant was identified. The Eligibility section was used to confirm that the patient met all eligibility criteria. Inclusion criteria were being a child aged 0 to 16.99 years and having English or Spanish language fluency and a total score on the PSC above the cut-point corresponding to need for further child mental health assessment or clinical

judgement of an unmet need for child mental health care (ie, clinical override). Exclusion criteria were receipt of any on-site mental health care or case management in the past 3 months (to ensure entry of children more likely to be receiving a new episode of H3 care) and having a sibling enrolled in the study (to safeguard against clustering within families). Anyone excluded from the study could still receive H3 care at the clinic but would not be enrolled in the evaluation. If the information indicated that the patient was not eligible for the program evaluation, the entry would be flagged and a warning page would appear. Otherwise, the patient would meet with the SDC after their clinic appointment, and if there was agreement to participate, the patient would be registered in the study and baseline data would be collected. If the patient was not able to stay, the SDC would follow up with the parent by phone.

Surveys

After registration in the study, a reference to the parent/child dyad would appear in the Surveys section. This section contained a list of patients needing baseline or follow-up data collection, organized under the headings baseline, 3-month follow-up, 6-month follow-up, and 12-month follow-up. The lists of patients were labeled with the parent and child's name and enrollment date, which allowed the SDC to prioritize patient

outreach. Their name would appear here upon enrollment or two weeks prior to the date of the 3-, 6-, and 12-month follow-up phone interviews to allow the SDC time to contact the parent and/or youth and schedule the interview.

Upon selection of a patient in the survey list, a page appeared that allowed the SDC to log a participant contact event. If the participant was not available, the SDC would record up to 6 contact attempts until the participant was considered a soft refusal for participation, at which time the participant was removed from the list of surveys to be completed. The participant could also decline participation, and the SDC would indicate this on the page, which would remove the participant from the list.

After the SDC indicated a successful contact attempt, a list of measures would appear indicating which items needed to be collected. Data from all parent- and youth-reported measures were collected directly by the SDC with two exceptions: site 2 chose to collect data from the PSC and Traumatic Events Screening Inventory (TESI) by the on-site mental health clinicians as part of the clinic's existing mental health screening or assessment. At both sites, these data were entered into the H3 Tracker by the SDC.

The list of measures varied by child age as well as by respondent, so the interface was programmed to only display measures relevant for the child's age, with an indication of who should respond to the measure, the parent or the child (Table 1). The clinical outcome measures in the tool were tailored to the child's development, addressing a unique need in pediatric integrated care models [34,35]. There were three age groups for the study, each of which received a different collection of surveys. One group was children aged 0 to 2 years. This page showed all measures except those focused on emotional and behavioral functioning of the child and trauma exposure. A second group included children aged 3 to 11 years. This page showed the emotional-, behavioral-, and trauma-focused measures for children in addition to resilience measures and measures of parental depression and parenting stress. The third group was a parent/child dyad where the child was older than 11 years. This group was given the youth version of same standardized measures for the 3- to 11-year-olds as well as a high-risk behavior measure adapted by the principal investigator to integrate clinic partners' experience in caring for youth in their communities. After completion, the SDC would indicate that the participant had completed the baseline set of measures and surveys, which would remove the participant from the patient list of surveys to be collected.

Table 1. Data summary by child age group and study time point.

Measure (informant)	Child age			Time point	
	<3 yrs	≥3 yrs, <12 yrs	≥12 yrs, <17 yrs	Baseline	Follow-up
Background information (parent)	x ^a	x	x	x	— ^b
PSI-SF ^c (parent)	x	x	x	x	x
CD-RISC-25 ^d (parent)	x	x	x	x	x
PHQ-9 ^e (parent)	x	x	x	x	x
CIS ^f (parent)	—	x	—	x	x
PSC ^g (parent)	—	x	—	x	x
TESI ^h (parent)	—	x	—	x	—
Behavioral questions (parent)	x	x	—	x	x
Behavioral questions (youth)	—	—	x	x	x
Teen High Risk Behavior Survey (youth)	—	—	x	x	x
CIS (youth)	—	—	x	x	x
PSC (youth)	—	—	x	x	x
TESI (youth)	—	—	x	x	—
PHQ-9 (youth)	—	—	x	x	x
Social and behavioral health services received by patient at visit (SDC ⁱ)	x	x	x	x	—

^ax: indicates measure was offered to participant subgroup.

^b—: indicates measure was not offered to participant subgroup.

^cPSI-SF: Parenting Stress Index Short Form.

^dCD-RISC-25: Connor-Davidson Resilience Scale 25.

^ePHQ-9: Patient Health Questionnaire.

^fCIS: Columbia Impairment Scale.

^gPSC: Pediatric Symptom Checklist.

^hTESI: Traumatic Events Screening Inventory.

ⁱSDC: site data coordinator.

Clinical Care Monitoring

In addition to the measures, the SDC was asked to log any mental health services or case management contacts provided during the 12-month time period of study enrollment (see [Multimedia Appendix 3](#)). Case management contacts included advocacy for special education as well as referral to and follow-up support for social services [31]. The H3 Clinical Care Monitoring (H3 Care) section allowed services to be recorded throughout a participant's enrollment in the project, with a date assigned to each service and a timeline of services received for each patient. The services entered here were customizable, so that if a service was overlooked at the start of the project, it could be added as a new category to the list of services. This section was developed with two objectives in mind: record the use of mental health and social services by participants and

provide the clinical care team a simple way to view the services received by participants in the study.

Implementation

Adoption

Frequency of use of the tool was investigated to better understand how successfully it was adopted within the clinic. This helped to understand use by different user groups and determine the usefulness of various pages or features for the various users. The H3 Tracker comprised 48 pages for participants to document or track participant information with an additional 18 pages developed for provider use. Interactions with the tool were often quick, ranging from one interaction in a minute to as many as 13 interactions per minute (one interaction every 4.6 seconds).

Table 2. Most frequently accessed pages in the H3 Tracker.

Interaction (section)	Accessed, n (%)
Daily census (Daily Census)	21,771 (30.03)
Participant contact log (Surveys)	10,389 (14.33)
Participant list (Surveys)	9025 (12.45)
Survey list (Surveys)	7806 (10.77)
Home page (N/A ^a)	6417 (8.85)
Document clinical care service (H3 Care)	3868 (5.34)
Select patient for clinical care service documentation (H3 Care)	2398 (3.31)

^aN/A: not applicable.

The most used feature of the H3 Tracker was the Daily Census, responsible for 30.03% (21,771/73,949) of the total interactions with the tool. Next was the participant contact documentation page in the Survey section, with 14.33% (10,389/73,949) of the total interactions on the site. Following this was the participant list page (also in the Survey section), with 12.45% (9025/73,949) of total interactions, and the survey list page, with 10.77% (7806/73,949) of total interactions. Additional pages and their uses can be observed in [Table 2](#).

Use of the tool differed by user type, with 96.28% (71,201/73,949) of the interactions completed by the SDC, 3.71% (2744/73,949) by the integrated health assistant or family resource developer, typically filling in when the SDC was out of the office, and less than 1% (4/73,949, 0.01%) by the behavioral health counselor or social worker. For one site, there was no adoption by the behavioral health counselors, despite significant outreach, and uptake was very limited for this role at the other site. There was no adoption at either site by the primary care providers despite outreach.

Feasibility

The H3 Tracker was used to recruit participants, collect clinic and participant data, and collect participant service use information. A total of 20,166 visits were documented by the H3 Tracker, with 10,986 well-child visits and 9178 sick visits. There were 724 positive screens or clinical overrides, which includes 49 sick visit clinical overrides. Those who accepted H3 services numbered 507, with 340 of these recruited into the study. In total, 277 participants were enrolled in the project using the H3 Tracker and completed a baseline measure, with 1861 clinical care services documented by project staff.

Of the clients who completed a baseline survey, more than one-quarter (79/277, 28.5%) started baseline measures on the same day as their initial clinic appointment, with 24.5% (68/277) completing the baseline measures on that day, presumably using the H3 Tracker in person after their appointment. At 3-month follow-up, 66.8% (185/277) completed a phone interview, consistent with other similar studies [36-38]. In addition, the 6- and 12-month follow-up response rates were 59.2% (164/277) and 53.3% (56/105) respectively.

Sample Characteristics

The majority of children in the study were from racial and ethnic minority backgrounds (site 1: Latino 192/202, 95.1%; site 2:

African American 71/75, 95%), consistent with general clinic population characteristics. Children in the study were predominantly English speaking, with 75.8% (210/277) reporting their primary language as English. Caregivers were mostly female (263/277, 94.9%) while the gender of children was more evenly distributed, with slightly more male than female (male: 152/277, 54.9%; female: 125/277, 45.1%). Caregivers were most often the parent of the child, with 95.6% (263/275) of cases reported to be the mother or father, 3.6% (10/275) grandparent, and less than 1% (1/275, 0.4%) other legal guardian (nonrelative). Most of the children were younger than 12 years (214/277, 77.3%) and 32.9% (91/277) were younger than 6 years, with a mean age of 8.1 (SD 4.2) years.

Discussion

Principal Findings

Findings from this study suggest that it is feasible to develop a Web-based clinical monitoring and data collection tool using a community-partnered participatory approach for two pediatric integrated care models serving low-income, predominantly racial and ethnic minority children and their families [33]. Through an iterative, partnered approach, capacity was built within the H3 Tracker to serve these dual purposes. Using the Chorus platform enabled the app to be developed visually by study staff, eliminating the need for involvement of computer programmers in the development process. The H3 Tracker had the built-in capacity to allow the primary care/mental health team to chronologically track the delivery of on-site mental health services and case management activities as well as clinical outcomes using standardized child, youth, and parent-reported measures, consistent with national recommendations for a pediatric medical home [39]. Further, uptake and use of the main features for data collection at baseline and 3 follow-up time points during pilot testing of the care models was highly promising.

Additional modifications could increase adoption, use, and capacity of the H3 Tracker. Having the data integrated into the existing EHR systems could facilitate easier access to the information, increasing the perceived utility of the EHR [21,40,41] as well as its adoption and use [42]. While input from clinicians was obtained during the development process, a more engaged approach to obtaining clinician feedback on the tool may be appropriate. Further, including a liaison in

integrated care systems has been identified as a key factor to the development and operationalization of integrated care [43], leading to more effective care integration [44]. Therefore, another step would be to examine whether a technology liaison may improve clinician engagement with the tool to help integrate quality-of-care monitoring into clinical practice. Other modifications of the H3 Tracker could include expanding the main features to accommodate capturing the workflow of usual care processes in addition to mental health and social services and building capacity to communicate health information directly to patients. Future research is needed to develop approaches that facilitate clinician use, reduce end-user burden, and better align with existing workflow, EHR documentation, and billing requirements.

Limitations

Findings from this study should be interpreted in light of several limitations. The purpose of the larger study was to evaluate the care model, so we did not collect the number of screened participants. Further, although capacity was built for three end users, adoption of the H3 Tracker varied by purpose and user groups. Uptake and use as a data collection tool far exceeded use of the tool's capacity to monitor mental health care delivered and clinical outcomes. Low uptake by clinical staff hindered the fidelity of the study, as large parts of the tool went mostly unused. The tool was designed for a research project and not as a permanent feature of clinic workflow, and time demands may have made it difficult for the clinical staff to learn a new tool, given that it would only be a temporary part of clinic processes. In addition, the tool tracked information on a small fraction of

the total clinic population, as most of the information collected by the H3 Tracker was only for those enrolled in the study. A number of studies have outlined the difficulties faced by busy clinic staff in incorporating new technology into their workflow, with usefulness as a key indicator for adoption of the technology [15,24,42].

Conclusions

Overall, a tool like the one described here could help assist health care organizations in need of collaborative care coordination but lacking the institutional capacity of larger health care systems. The tool provides a secure, low-cost solution that staff with little to no computer programming experience can develop, tailored to the specific needs of each user and individual clinic, hospital, or other health care facility. The simplicity of the development process could allow multiple care team members to help develop features of the system, which can lead to improved customization to the needs of individual clinics and/or the type of user accessing the system. This leads to a system that is more representative of users' needs, leading to improved usability.

The goal of building a comprehensive system where physical and mental health care is seamlessly integrated is still a very difficult task for many health care providers. Systems such as the one discussed here could be an important bridge to promoting communication across pediatric primary care providers and an embedded mental health team while the hurdles associated with full-scale integration, cost issues, system specifications, type of system to use, and data security and storage are resolved.

Acknowledgments

This study was funded by the Illinois Children's Healthcare Foundation, California State Behavioral Health Center of Excellence (SB-852), and the National Institute of Mental Health (MH093676-02S1). The authors would also like to acknowledge the clinic partners for their help in developing the tool, including Hannah Chi MPH, Jewel Davies LCPC, Kristen Kenan MPH, MD, Michelle Churcley-Mims MSW, LCPC, Vikki Rompala MSW, LCSW, Lamorris Perry MD, Pastor Dr Willie L Johnson, and Sylvia Gonzalez MPH.

Conflicts of Interest

AA is founder of Insight Health Systems, Arevian Technologies, and Open Science Initiative. AA developed the Chorus platform which is licensed to Insight Health Systems from the University of California, Los Angeles.

Multimedia Appendix 1

Data flow diagram.

[[PDF File \(Adobe PDF File\), 84KB - mental_v6i4e12358_app1.pdf](#)]

Multimedia Appendix 2

Data structure diagram.

[[PDF File \(Adobe PDF File\), 175KB - mental_v6i4e12358_app2.pdf](#)]

Multimedia Appendix 3

Clinical care monitoring services recorded by the H3 Tracker.

[[PDF File \(Adobe PDF File\), 74KB - mental_v6i4e12358_app3.pdf](#)]

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Abbreviations

EHR: electronic health record

H3: Healthy Minds, Healthy Children, Healthy Chicago

PSC: Pediatric Symptom Checklist

SDC: site data coordinator

TESI: Traumatic Events Screening Inventory

Edited by J Torous; submitted 28.09.18; peer-reviewed by A Bauer, K Tingay, K Sobowale; comments to author 14.11.18; revised version received 03.01.19; accepted 01.03.19; published 23.04.19.

Please cite as:

McCreary M, Arevian AC, Brady M, Mosqueda Chichits AE, Zhang L, Tang L, Zima B

A Clinical Care Monitoring and Data Collection Tool (H3 Tracker) to Assess Uptake and Engagement in Mental Health Care Services in a Community-Based Pediatric Integrated Care Model: Longitudinal Cohort Study

JMIR Ment Health 2019;6(4):e12358

URL: <http://mental.jmir.org/2019/4/e12358/>

doi:10.2196/12358

PMID:31012861

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Original Paper

Young People's Satisfaction With the Online Mental Health Service eheadspace: Development and Implementation of a Service Satisfaction Measure

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Abstract

Background: Online youth mental health services are an expanding approach to meeting service need and can be used as the first step in a stepped-care approach. However, limited evidence exists regarding satisfaction with online services, and there is no standardized service satisfaction measure.

Objective: This study implemented an online youth mental health service satisfaction questionnaire within eheadspace, an online youth mental health service. The aims were to test the questionnaire's psychometric properties and identify current levels of satisfaction among service users, as well as to identify client and service contact characteristics that affect satisfaction.

Methods: Data were collected from 2280 eheadspace clients via an online questionnaire advertised and accessed through the eheadspace service platform between September 2016 and February 2018. Client and service contact characteristics, potential outcomes, and session and service feedback data were collected.

Results: The service satisfaction questionnaire demonstrated high internal consistency for the overall satisfaction scale ($\alpha=.95$) and its three subscales: session satisfaction, potential outcomes, and service satisfaction. A three-factor model was the best fit to the data, although including a higher order unidimensional construct of overall satisfaction was also a reasonable fit. Overall, young people were very satisfied with eheadspace (mean 3.60, SD 0.83). Service characteristics, but not client characteristics, were significantly associated with satisfaction. Young people were more satisfied with eheadspace when they had greater engagement as evident through receiving esupport rather than briefer service provision, having a longer session and greater interaction with the clinician, and not previously attending a face-to-face headspace center.

Conclusions: The online youth mental health service satisfaction questionnaire developed for and implemented in eheadspace showed good psychometric properties. The measure is brief, has good internal consistency, and has a clear factor structure. The measure could be adapted for use in other online youth mental health services. The young people using eheadspace and completing the feedback survey were highly satisfied. Greater engagement with the online service was shown to be associated with greater satisfaction. No specific client demographic groups were shown to be more or less satisfied.

(*JMIR Ment Health* 2019;6(4):e12169) doi:[10.2196/12169](https://doi.org/10.2196/12169)

KEYWORDS

mental health; adolescent; telemedicine; counseling; internet; satisfaction; feedback; telehealth; young people

Introduction

Mental health problems peak in young people between the ages of 12 and 25 years [1], and more than one in four young people experience a mental illness each year [2]. Three-quarters of all mental health problems have their first onset before the age of 25 [3]. The delay between first symptoms and access to effective treatment can extend to 15 years [4]. Poor mental health in childhood and adolescence increases vulnerability to mental health problems in adulthood, revealing the importance of prevention and early intervention for this age group [5-7]. It has been estimated that up to half of lifetime mental illnesses may be prevented through early intervention and prevention methods [8]. Yet, only 13% of young men and 31% of young women seek professional help [9]. Although treatment rates have improved in Australia following the introduction of subsidized services, help-seeking remains substantially lower for mental health problems compared to physical health conditions [10].

Online mental health services have emerged as an innovative way to promote self-referral, increase help-seeking behaviors, and meet the high level of unmet service demand, through accessible youth-friendly technology [11,12]. The internet is the main source of information for young people [13], and the Australian Bureau of Statistics reports that 98% of youth aged 15 to 17 years, and 97% of young adults aged 18 to 24 years, accessed the internet during 2014 to 2015 [14]. The internet has escalated as a source of information for mental health issues in recent years [15-17]. A cross-sectional study of 2000 Australian young people aged 12 to 25 years in 2008 found that 30.8% seek online mental health information and that 21% of those aged 12 to 17 years and 34% of those aged 18 to 25 years reported searching online for mental health help [18]. Factors associated with internet use for mental health information included being female and using the internet after 11 pm. Research also shows that young people feel comfortable accessing online information about mental health issues, which may improve help-seeking behaviors for those who may not otherwise seek help using traditional approaches [19].

A growing range of online options are available, from self-help psychoeducation to interactive sessions with a mental health clinician [11]. These can be incorporated within integrated systems of mental health care, including emerging stepped-care approaches, which are staged systems comprising a hierarchy of interventions from least to most intensive that are matched to an individual's needs [20]. Although such approaches need to be flexibly implemented so that they are appropriate to severity, need, and stage of presentation, online resources and services can comprise part of the spectrum of interventions [21]. Importantly, e-therapy can be included in ways that complement and extend traditional therapeutic approaches. E-therapy has been shown to be particularly effective for mild to moderate presentations and for the common mental health problems of anxiety and depression, but applications in more complex and serious presentations are also emerging [22]. Online services have many advantages, including increasing mental health literacy [23], potentially improving help-seeking behaviors for face-to-face therapy [4], and providing support that is easily

and widely accessible, while reducing the costs to service providers as part of an integrated system of care [24].

Nevertheless, the growth of mental health services available online provides a challenge for young people, because there is a wide range of choice that is difficult to navigate [11]. Importantly, most young people self-refer to online services [25], so it is important that they are directed to high-quality and evidence-based services [26]. Service satisfaction feedback to measure young people's experiences, the quality of services, and outcomes achieved is essential for service development, and to ensure that young people can access online services that meet their needs.

Service satisfaction is a broad term that can encompass a range of factors relating to care. Self-report feedback tools provide service providers with important information regarding clients' progress [27]. Regular feedback is recommended for all mental health practice, as clinicians are not always able to recognize treatment failure as it is happening [28,29]. However, there is a lack of formal feedback measures for child therapy, giving young clients "little voice in the services they receive" [30]. Simmons et al [31] emphasized the importance of satisfaction scales covering the relevant areas for youth mental health because much research to date in youth satisfaction has focused on parental or caregiver satisfaction [32].

The few examples of youth-targeted service satisfaction measures include the Multidimensional Adolescent Satisfaction Scale [33] and the headspace Youth (mental health) Service Satisfaction Scale [31,34]. The Youth Service Satisfaction Scale is one of the few service satisfaction measures specifically developed for use in early intervention youth mental health services for young people aged 12 to 25 years. It has demonstrated good psychometric properties and revealed a high level of satisfaction with headspace center-based (face-to-face) services. To our knowledge no youth satisfaction questionnaires targeted toward online services exist; therefore, this study aimed to redress this gap.

This study involved the development and implementation of a service satisfaction questionnaire in an online youth mental health service—eheadspace—an online mental health support and counseling service for young Australians aged 12 to 25 years implemented as part of headspace, the National Youth Mental Health Foundation funded by the Australian Government's Department of Health. The eheadspace service provides free and confidential access to mental health clinicians via Web chat, email, and phone from 9 am to 1 am AEST 7 days per week. This extends the reach of headspace centers, which provide face-to-face services through 110 centers across Australia. Like headspace centers, young people can access eheadspace for any reason, although the service is promoted as providing support and counseling. The eheadspace service began in 2011, in recognition of the high demand for youth mental health care that could not be met by face-to-face services alone. There has been a high level of uptake of the eheadspace service, and young people have been shown to access the service when they are feeling highly distressed [25]. However, many young people only access once, and there has been little examination to date of young people's experience of and their satisfaction

with this service approach. Understanding user satisfaction is essential to avoid premature disengagement and to ensure that young people receive a service that they value and that meets their needs.

The aims of this study were to:

1. Adapt the headspace center Youth Service Satisfaction Scale for use in eheadspace and examine its psychometric properties;
2. Establish current levels of satisfaction among young people accessing eheadspace; and
3. Determine whether satisfaction varies according to client characteristics or characteristics associated with the service contact.

Methods

Participants

Participants consisted of 2280 young people aged 12 to 25 years (mean 17.8, SD 3.2), who registered with eheadspace Web chat between September 20, 2016 and February 20, 2018, wanted help for themselves (rather than a friend), and completed at least one service satisfaction survey. Young people were included if they received a direct eheadspace service, which could be either (1) a brief service provision engaging the young person, identifying the presenting problems, and using brief therapeutic strategies to address these problems; or (2) an esupport-targeted strategy delivered following initial contact and engagement of the young person guided by a care plan and following a full assessment.

All young people registering for eheadspace Web chat during the survey period were invited to voluntarily participate. The survey response rate was 8.7%, from a total of 26,234 eligible young people who accessed the service during this period. The eheadspace users can complete a feedback survey each time they access the service; however, if users had completed more than one survey, only the first complete survey was analyzed in this paper.

Procedure

Service satisfaction surveys were collected from eheadspace clients via an online questionnaire advertised and accessed through the eheadspace service platform. The platform provides other service options (eg, a link to the Digital Work and Study Service and support for family and friends), but only young people who used the eheadspace online service were offered the service satisfaction questionnaire. To access eheadspace online, a user clicks on a link to “online chat” and then provides required registration or log-in information. When a young person logged in and selected the online chat option, a blue box appeared on the side, asking: “Do you have a spare minute or two to complete our survey about your chat today? Thanks in advance if you do.” Young people were invited to click a link to access the questionnaire once they had finished their online chat, which subsequently directed them to the participant information page. Participation was voluntary.

Survey data were combined with demographic information, clinical characteristics, and service information that was

extracted from the eheadspace administrative Minimum Data Set. All young people electronically enter data when they first log in to access the service, and each time they access the service and it has been 14 or more days since they last did so. All clinicians enter data at the end of each service session.

Ethics approval was obtained from Melbourne Health.

Measures

Client Characteristics

Demographic characteristics included gender (male, female, trans, intersex, and another gender [please specify]), age group (12-17 or 18-25 years), sexuality (heterosexual, lesbian, gay, bisexual, questioning, and other sexuality [LGBTIQ]), Aboriginal and/or Torres Strait Islander person (yes or no), and area of residence (metropolitan or regional). Note that gender was analyzed only as male or female due to the small sample size for the nonbinary categories.

Reason for attending was measured using clinician-rated responses to a list of options asking the main issue for which the young person presented. This was categorized into mental health or other issues. Other issues included situational issues, vocational assistance, alcohol or other drugs, physical health, sexual health and “other.”

Clinical stage was estimated for those presenting with mental health issues to provide a general indication of diagnostic complexity. Clinicians were asked to estimate an approximation of the clinical stage using responses from options based on the clinical staging heuristic [35]. Stage 0 indicated none or few depressive or anxiety symptoms and little or no impairment in functioning; stage 1a indicated mild to moderate *Diagnostic and Statistical Manual of Mental Disorders-IV* (DSM-IV) disorder of depression, generalized anxiety disorder (GAD), or impairment in functioning; stage 1b indicated stage 1a plus additional features falling short of stage 2; stage 2 indicated moderate to severe symptoms meeting threshold diagnosis; stage 3 indicated periods of remission (<6 months of symptom improvement) but no recovery; and stage 4 indicated ongoing severe symptoms with no asymptomatic periods. If the young person accessed eheadspace for a non-mental health-related issue, “not applicable” was selected; if the clinician was unable to adequately assess clinical stage, “not enough information available” was selected.

Service Contact Characteristics

Service characteristics included the type of direct service (brief service provision or esupport), wait time before an eheadspace session (the time between the user completing their registration and log-in for the online chat and the time the clinician responds, ranging from 0 to 106 minutes), session start time (9 am to 1 am), session duration (<15 minutes to ≥90 minutes), number of words conveyed by the young person (0 to 2599 words), number of words conveyed by the clinician (0 to 3583 words), and the number of times the young person had previously received a direct service (0 to 2 or more sessions). Young people were also asked if they had visited a headspace center prior to using eheadspace (yes or no) and referral information (self-referred or referred by other).

Service Satisfaction

To develop a measure of eheadspace service satisfaction, relevant items were adapted from the headspace center Youth Service Satisfaction Scale [34] and supplemented by items from a review of existing satisfaction surveys and consultation with eheadspace staff and clients. This resulted in 13 items comprising statements that were each responded to on a 5-point Likert scale from strongly disagree to strongly agree, with higher scores indicating higher levels of satisfaction. The items focused on three different satisfaction domains:

1. Session satisfaction: session focused on young person's main concern, young person felt listened to and understood, session helped the young person to understand their situation more clearly, young person was provided with skills or resources to help them manage their situation going forward, session made young person feel more hopeful and optimistic.
2. Potential outcomes: young person feels better day-to-day, can manage the things they do better, copes better, has improved relationships.
3. Service satisfaction: young person feels comfortable sharing information with eheadspace clinicians, eheadspace is easy to use, young person would recommend eheadspace to a friend, eheadspace met the young person's expectations.

Analysis

Data were analyzed using IBM SPSS version 24 and AMOS version 25. An exploratory principal components factor analysis of the 13 original eheadspace feedback survey items was first conducted. Confirmatory factor analysis (CFA) with maximum-likelihood estimation was then used to further test the factor structure. Cronbach reliability analysis was conducted to confirm internal consistency.

Descriptive statistics were computed for all variables. Independent *t* tests and one-way analyses of variance were then used to determine group differences in satisfaction scores based on client characteristics (gender, age group, sexuality, Aboriginal and/or Torres Strait Islander status, areas of residence, reason for attending, clinical stage), and service contact characteristics (type of service, wait time before session, session start time, duration, prior access to a headspace center, number of previous direct service sessions, word count per client and clinician, referral information). Significance was set at $P<.01$ due to the high power from the large sample size.

Results

Client and Service Contact Characteristics

Of the 2280 participants, 77.76% (n=1773) were female, and 55.04% (n=1255) were aged between 12 and 17 years, whereas 44.96% (n=1025) were between 18 and 25 years. There were 64.96% (1481/2280) who identified as heterosexual, 70.44% (1606/2280) who lived in a metropolitan area, and 3.77% (86/2280) who identified as an Aboriginal and/or Torres Strait Islander person.

For presenting issue, 58.82% (1341/2280) contacted eheadspace for mental health problems and 26.32% (600/2280) contacted

for another issue (14.87%, 339/2280 missing). Of those with a clinical stage rating (ie, excluding "not applicable" and "not enough information available"), more than half (54.38%, 522/960) were rated stage 1a indicating mild to moderate DSM-IV disorder of depression, GAD, or impairment in functioning.

The majority of clients (85.13%, 1941/2280) had an esupport session, whereas 14.87% (339/2280) had a brief service provision session on the day of completing the survey. Half (50.39%, 1149/2280) the sessions lasted 31 to 60 minutes, but sessions ranged from less than 15 minutes to 90 or more minutes. More than half (57.96%, 1125/1941) of esupport sessions lasted 31 to 60 minutes, whereas only 7.08% (24/339) of brief service provisions lasted this long. Only 5.04% (115/2280) did not have to wait to access eheadspace when they visited, 41.49% (946/2280) had to wait less than 5 minutes, and 53.46% (1219/2280) had to wait more than 5 minutes (maximum wait time was 106 minutes). Most (83.29%, 1899/2280) sessions occurred before 11 pm, but 16.71% occurred between 11 pm to 1 am. On average, young people inputted a mean 397.01 (SD 290.05) words, compared to a mean 686.18 (SD 343.25) words from clinicians. The majority of young people (71.84%, 1638/2280) input fewer than 500 words per session, compared with only 30.04% of clinicians (685/2280). Most young people (67.72%, 1544/2280) self-referred to eheadspace, with 30.35% (692/2280) referred by others. Only 21.80% (497/2280) of participants had visited a headspace center prior to accessing eheadspace. Before the session on the day of survey completion, 64.04% (1460/2280) had not previously received esupport, 16.49% (376/2280) had previously received one, 7.54% (172/2280) had previously received two, and 11.84% (270/2280) had previously received three or more esupport sessions.

Factor Analysis of Satisfaction Scale

The 13 original items of the eheadspace feedback survey were subjected to principal components analysis (PCA) to identify the factorial structure. Inspection of the correlation matrix revealed all coefficients above 0.30. The Kaiser-Meyer-Olkin value observed was 0.95, which exceeded the recommended value of 0.60 [36], and the Bartlett test of sphericity [37] was statistically significant, supporting the factorability of the correlation matrix.

The PCA revealed the presence of one component with an eigenvalue of 8.3, explaining 63.8% of the variance. Standardized factor loadings for 12 of 13 items were strong and positive (range 0.64-0.87), except for "eheadspace is easy to use," which was 0.50. The eigenvalues and factor loadings supported a unidimensional solution, and an inspection of the scree plot revealed a clear break after the first factor [38].

A CFA was run to further test the factor structure (see Table 1 and Figure 1). The following fit indexes were employed to assess model fit: chi-square closest to zero, root mean square error of approximation less than 0.06 (with the lower bound of its 90% confidence interval less than 0.05 to indicate close fit), the comparative fit index greater than 0.90, and adjusted goodness of fit index greater than 0.90 [39]. Based on the recommendation of Holmes-Smith et al [40], the model with

the smallest Akaike information criterion (AIC) / consistent AIC (CAIC) was considered the best-fitting model.

Examination of the modification indexes revealed that the item “the session made me feel more hopeful/optimistic” may relate to both the session and expectations subscales. Only by deleting this item altogether did the model fit improve.

Models were rerun with the remaining 12 items. Results revealed that the original one-factor solution was not a good fit for the data. Consequently, the originally hypothesized three-factor solution was considered, along with other possibilities. Examination of the AIC and CAIC indexes showed that a three-factor model was the best fit to the data, but that a

three-factor model with a higher order unidimensional construct of overall satisfaction was also a reasonable fit.

Note that the potential outcomes items included a “not applicable” option, as eheadspace clinicians felt that each of these outcomes may not be applicable for some clients. Consequently, to include participant responses to these items for the CFA (which cannot accept missing data), where only some items were not applicable, responses were substituted as neither agree nor disagree. Those who responded not applicable to all potential outcome items were excluded from analyses. Models were run with and without the substituted not applicable responses included, and all were a similar fit as shown in Table 1. Including those who chose not applicable to some questions, but still completed the full survey, reduces bias.

Table 1. Results of the confirmatory factor analysis.

Model	χ^2 (df)	P value	RMSEA ^a	AGFI ^b	CFI ^c	AIC ^d	CAIC ^e
One factor	3418.7 (56)	<.001	0.180	0.591	0.821	3462.7	3606.3
Two factor	2008.7 (54)	<.001	0.140	0.723	0.896	2056.7	2213.3
Three factor without total	533.6 (51)	<.001	0.071	0.926	0.974	533.6	763.8
Three factor without N/A ^f responses	880.9 (51)	<.001	0.094	0.884	0.949	934.9	1111.1
Final three-factor solution	787.8 (53)	<.001	0.086	0.897	0.961	837.8	1001.0

^aRMSEA: root mean square error of approximation.

^bAGFI: adjusted goodness of fit index.

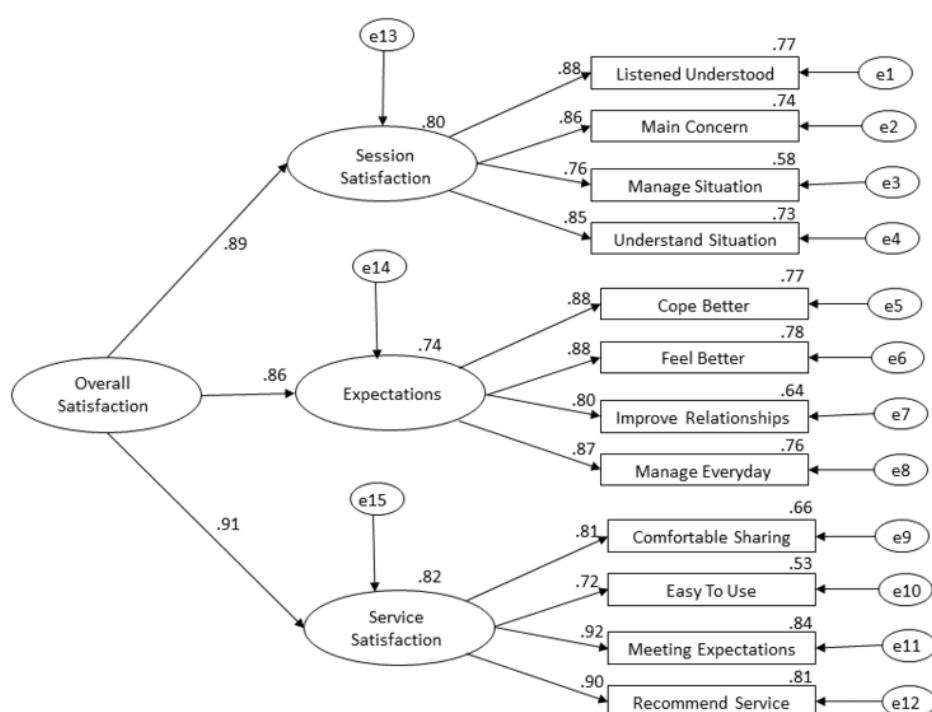
^cCFI: comparative fit index.

^dAIC: Akaike information criterion.

^eCAIC: consistent Akaike information criterion.

^fN/A: not applicable.

Figure 1. Modified three-factor model with total satisfaction as a second-order factor. Standardized coefficients (range .53-.92). e: error.



Reliability of Satisfaction Scale

Cronbach alpha statistics showed high internal consistency for the total scale and all subscales (see [Table 2](#)). If any individual items were removed the internal reliability of the scales would be reduced. Item-total correlations were calculated, and all subscales showed strong interitem correlations: session satisfaction items ($r=.67\text{--}.82$), potential outcomes items ($r=.70\text{--}.80$), and service satisfaction items ($r=.66\text{--}.82$). Furthermore, session, outcomes, and service items were moderately to strongly correlated ($r=.34\text{--}.82$). This further supports a second-order factor of total satisfaction.

[Table 2](#) shows that overall young people were satisfied with eheadspace; all subscale means were above the scale midpoint and negatively skewed. Young people were most satisfied with the eheadspace service followed by their session, and they were least satisfied with their potential outcomes.

Client characteristics were not shown to influence total satisfaction scores (see [Table 3](#)). There were no significant differences in total satisfaction between males and females, adolescents and young adults, those who were heterosexual and those who were LGBTIQ, those who were an Aboriginal and/or

Torres Strait Islander person and those who were not, and between young people who lived in metropolitan or regional locations. Those who attended because of a mental health issue were significantly less satisfied than those who attended for other reasons, although the effect was small. There was no effect of clinical stage.

Many service contact characteristics were significantly associated with satisfaction. [Table 4](#) shows that young people who received esupport were more satisfied than those who received a brief service provision. Those who accessed prior to 11 pm were more satisfied than those who accessed late at night. Young people with contact of more than 30 minutes were more satisfied than those with shorter sessions. Clients who conveyed more than 500 words were more satisfied than those who conveyed 300 or less. Similarly, greater satisfaction was evident when clinicians conveyed more than 500 words. Young people who had not previously accessed a headspace center were more satisfied with eheadspace than those who had previously been to a headspace center. Wait time before session, previous eheadspace access, and referral source did not influence total satisfaction.

Table 2. Descriptive statistics for satisfaction scales (N=2280).

Satisfaction domain	Mean (SD)	Skewness	SE	Cronbach alpha
Session satisfaction	3.77 (1.07)	-1.085	0.051	.93
Potential outcomes	3.16 (0.86)	-0.604	0.051	.92
Service satisfaction	3.88 (0.91)	-0.320	0.051	.91
Total satisfaction	3.60 (0.83)	-0.918	0.051	.95

Table 3. Total satisfaction scores by client characteristics (N=2280).

Client characteristic	Satisfaction, mean (SD)	F (df1,df2)	P value	Partial η^2
Gender		1.34 (2165,593)	.18	.028
Male	3.66 (0.81)			
Female	3.60 (0.83)			
Age		2.40 (2081,2278)	.02	.057
12-17 years	3.64 (0.79)			
18-25 years	3.56 (0.88)			
Sexuality		1.29 (2042,1054)	.20	.027
Heterosexual	3.62 (0.84)			
LGBTIQ ^a	3.57 (0.81)			
Aboriginal and/or Torres Strait Islander person		1.61 (2278,91)	.11	.032
Yes	3.74 (0.85)			
No	3.60 (0.83)			
Area of residence		-0.02 (2251,1262)	.98	.000
Metro	3.61 (0.84)			
Regional	3.61 (0.79)			
Reason for attending		-2.89 (1939,1208)	.004	-.062
Mental health issue	3.67 (0.76)			
Other	3.77 (0.72)			
Clinical stage estimate^b		1.80 (3,956)	.15	.006
Stage 0	3.72 (0.76)			
Stage 1a	3.70 (0.70)			
Stage 1b	3.61 (0.77)			
Stage 2	3.51 (0.79)			

^aLGBTIQ: Lesbian, Gay, Bisexual, Transgender, Intersex and Questioning.

^bNote that no participants were rated in stages 3 or 4.

Table 4. Total satisfaction scores by service contact characteristics (N=2280).

Service characteristic	Satisfaction, mean (SD)	F (df1,df2)	P value	Partial η^2
Type of service		11.40 (403,2278)	<.001	.282
esupport	3.70 (0.75)			
Brief service	3.04 (1.03)			
Session start time		17.87 (3,2276)	<.001	.023
9 am-5 pm	3.66 (0.78)			
5 pm-8 pm	3.66 (0.81)			
8 pm-11 pm	3.66 (0.81)			
11 pm-1 am	3.32 (0.94)			
Wait time before session		0.62 (3,2276)	.61	.001
None	3.60 (0.87)			
<5 minutes	3.63 (0.83)			
<10 minutes	3.59 (0.80)			
≥10 minutes	3.58 (0.83)			
Session duration		9.37 (3,1937)	<.001	.014
<15 minutes	3.52 (0.88)			
15-30 minutes	3.57 (0.82)			
31-60 minutes	3.73 (0.72)			
>60 minutes	3.84 (0.68)			
Word count per client		54.23 (3,2276)	<.001	.067
1-300	3.46 (0.88)			
301-500	3.69 (0.73)			
>500	3.81 (0.71)			
Word count per clinician		73.09 (3,2276)	<.001	.088
1-300	2.96 (1.06)			
301-500	3.50 (0.87)			
>500	3.73 (0.83)			
Number of previous direct support sessions		0.13 (3,2274)	.94	.000
0	3.60 (0.85)			
1	3.61 (0.80)			
2	3.59 (0.85)			
≥3	3.63 (0.75)			
Referral information		0.11 (1414,2234)	.92	.000
Self-referred	3.60 (0.84)			
Referred by other	3.60 (0.79)			
Prior access to a headspace center		-2.91 (790,1986)	.004	-.068
Yes	3.50 (0.88)			
No	3.63 (0.81)			

Discussion

This study examined the implementation of a service satisfaction measure adapted from the headspace center-based satisfaction measure in the online youth mental health service, eheadspace.

The aim was to determine the psychometric properties of the adapted measure in the online service environment and establish the level of service satisfaction among young people using the service, while examining whether this varied by client characteristics.

Psychometric Properties of the Satisfaction Scale

The satisfaction measure showed good psychometric properties. There was high internal consistency for the overall satisfaction scale and its three subscales. A three-factor model of the eheadspace satisfaction feedback survey was shown to be the best fit to the data and the hypothesized subscales of session satisfaction, potential outcomes, and service satisfaction were evident. A three-factor model with a higher order unidimensional construct of overall satisfaction was also a reasonable fit. A higher order unidimensional overall satisfaction construct is supported by the literature. For example, Simmons et al [31] found support for a global construct of satisfaction in the development of a satisfaction scale for young people attending headspace centers.

Consistent with other service satisfaction research and literature, the measures of service satisfaction were negatively skewed, with most respondents indicating high satisfaction. The measure can help identify the characteristics of clients who are dissatisfied with the service, but it may be less useful in distinguishing among those with positive experiences [41,42]. Consequently, it may be difficult to demonstrate “improved satisfaction” when scores are already so high.

Current Satisfaction of Young People Accessing eheadspace

Young people were generally very satisfied with eheadspace, and this did not vary across any demographic characteristics. No demographic differences were evident in this study unlike the findings of Rickwood et al [34] from face-to-face headspace center services, which found that men, younger clients, and those influenced by others to attend were less satisfied. This suggests that the eheadspace service is experienced in a similarly positive way across the demographics measured. However, the demographics of eheadspace clients are quite different from those of the headspace centers, as they are much more likely to be female and present with a high level of psychological distress [25]. This was reflected in that almost 78% of our participants were female, similar to the 80% who are female who access the service. Although the young men who accessed the service were equally satisfied, they were much less likely to access in the first place. The few client characteristics that were measured also did not substantially affect satisfaction. Those who attended because of a mental health issue were less satisfied than those who attended for other reasons, although the effect was small. It did not vary according to the estimate of clinical stage, which suggests that clients were equally highly satisfied regardless of the complexity of their issue. However, it should be noted that the measure of reason for attending was broad, comprising only mental health versus other issues, and the estimate of clinical stage was not obtained via a comprehensive clinical interview. It may be that satisfaction varies according to different types of mental health problems, as the online environment may be better suited to some than others and may be most useful as an adjunct to face-to-face therapy for some more serious and complex conditions.

Service contact characteristics were associated with satisfaction. Overall, young people who had a more comprehensive engagement with eheadspace were more satisfied. They were

more satisfied when they received the more substantial esupport service rather than brief service provision, had a longer session, used more words, did not access the service very late at night, and had not previously experienced services from a face-to-face headspace center. This is consistent with research showing that eheadspace clients who had greater engagement showed more progress and depth of counseling and greater alleviation of psychological distress [43].

Similar to the findings regarding satisfaction from face-to-face headspace center services, satisfaction was lowest for perceived outcomes [34]. Many young people only access eheadspace once, so expectations of longer-term outcomes are unlikely to be well-formed. It is possible that many people might not know how to answer, especially if it is one of their first visits or their only visit, and if they only received information and not therapy as part of their session. Further, earlier research revealed that eheadspace clients have high service expectations [44], which are unlikely to be met with the minimal engagement that is typical.

Limitations

The results of this study should be interpreted in light of its limitations. Notably, providing service satisfaction was optional, and the response rate was less than 10%. Although this was expected, it indicates likely response bias. It may be that only the more satisfied clients chose to complete the questionnaire. Finding ways to encourage more clients to complete the measure, and ensuring that those who are dissatisfied and who have less service engagement respond, are challenges for service satisfaction measures. Other indicators of service satisfaction should also be monitored, such as the number of site visits and drop-off rates.

Some of the measures were limited by the brief online nature of the data collection. In particular, the measure of clinical staging was an estimate. This measure was included to gain some understanding of the potential impact of client complexity, but it is acknowledged that a brief, online minimum data collection procedure cannot provide a robust measure of clinical stage such as can be ascertained through clinical interview within mental health services that adopt a transdiagnostic clinical staging approach (see [21]).

Implications for Practice

The satisfaction results are regularly monitored and analyzed by the eheadspace service and evaluation staff and are used to guide service improvement. By identifying patterns in client satisfaction, the areas where the service needs to be tailored to better meet different client needs can be identified. Patterns over time can also be used to evaluate the impact of changes in practice.

Note that currently the satisfaction results are only analyzed in aggregate and not linked to individual clients. There is the potential to also examine session satisfaction monitored over time for individual clients through routine outcome monitoring. This is a repeated measurement process carried out therapeutically to improve treatment outcomes, which has been shown to improve treatment engagement and outcomes [45]. An even briefer measure may be required, however, to

implement repeatedly, and clients would need to be informed that their individual feedback would be available to their service providers.

The satisfaction measure used in eheadspace solely assessed youth satisfaction as a form of feedback. Much youth mental health research has previously focused on parental and caregiver satisfaction [33]. Parents and caregivers often have different views about service satisfaction [41]. Their views are also important in assessing online youth mental health services, although this may be less relevant for online services where self-referral is predominant and young people can easily access without parental support. Nevertheless, parents and caregivers often play a primary role in whether younger people attend, engage with, and complete treatment, demonstrating the importance of their satisfaction [46]. Patel et al [1] suggested that both young person and parental feedback is essential in assessing satisfaction with mental health services and this should be explored in the online service domain.

Finally, the measure was adapted from the headspace center Youth Service Satisfaction Scale [34]. This scale has been successfully implemented in the face-to-face services, and it was of interest to have a comparative measure for the online service. Given the briefer and more transitory nature of the online service interactions, further adaptations may be required to make the measure most suitable to the online modality.

Conclusions

This paper has described a service satisfaction measure for an online mental health service for young people. The eheadspace satisfaction measure is brief, and it demonstrated sound psychometric properties with good internal consistency and a clear factor structure. The measure showed high levels of satisfaction overall that were responsive to greater levels of engagement with the service. The measure could be adapted for use with other online youth mental health services, which are emerging as a critical setting for mental health service provision as part of stepped-care approaches in mental health [18].

Acknowledgments

The headspace National Youth Mental Health Foundation is funded by the Australian Government Department of Health. The authors would like to thank the young people who contributed data for this paper.

Conflicts of Interest

All authors are employed by or directly involved with headspace National Youth Mental Health Foundation.

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Abbreviations

AGFI: adjusted goodness of fit index

AIC: Akaike information criterion

CAIC: consistent Akaike information criterion

CFA: confirmatory factor analysis

CFI: comparative fit index

DSM-IV: Diagnostic and Statistical Manual of Mental Disorders Version 4

GAD: generalized anxiety disorder

LGBTIQ: Lesbian, Gay, Bisexual, Transgender, Intersex and Questioning

PCA: principal components analysis

RMSEA: root mean square error of approximation

Edited by J Torous; submitted 24.09.18; peer-reviewed by C Edridge, O Santesteban-Echarri; comments to author 22.11.18; revised version received 17.12.18; accepted 19.12.18; published 17.04.19.

Please cite as:

Rickwood D, Wallace A, Kennedy V, O'Sullivan S, Telford N, Leicester S

Young People's Satisfaction With the Online Mental Health Service eheadspace: Development and Implementation of a Service Satisfaction Measure

JMIR Ment Health 2019;6(4):e12169

URL: <http://mental.jmir.org/2019/4/e12169/>

doi: [10.2196/12169](https://doi.org/10.2196/12169)

PMID: [30994470](https://pubmed.ncbi.nlm.nih.gov/30994470/)

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Original Paper

Applicability of Motivational Interviewing for Chronic Disease Management in Primary Care Following a Web-Based E-Learning Course: Cross-Sectional Study

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Abstract

Background: Motivational interviewing (MI) is an established communication method for enhancing intrinsic motivation for changing health behavior. E-learning can reduce the cost and time involved in providing continuing education and can be easily integrated into individual working arrangements and the daily routines of medical professionals. Thus, a Web-based course was devised to familiarize health professionals with different levels of education and expertise with MI techniques for patients with chronic conditions.

Objective: The aim of this study was to report participants' opinion on the practicality of MI (as learned in the course) in daily practice, stratified by the level of education.

Methods: Participants (N=607) of the MI Web-based training course evaluated the course over 18 months, using a self-administered questionnaire. The evaluation was analyzed descriptively and stratified for the level of education (medical students, physicians in specialist training [PSTs], and general practitioners [GPs]).

Results: Participants rated the applicability of the skills and knowledge gained by the course as positive (medical students: 94% [79/84] *good*; PSTs: 88.6% [109/123] *excellent*; and GPs: 51.3% [182/355] *excellent*). When asked whether they envisage the use of MI in the future, 79% (67/84) of the students stated *to a certain extent*, 88.6% (109/123) of the PSTs stated *to a great extent*, and 38.6% (137/355) of GPs stated *to a great extent*. Participants acknowledged an improvement of communication skills such as inviting (medical students: 85% [72/84]; PSTs: 90.2% [111/123]; GPs: 37.2% [132/355]) and encouraging (medical students: 81% [68/84]; PSTs: 45.5% [56/123]; GPs: 36.3% [129/355]) patients to talk about behavior change and conveying respect for patient's choices (medical students: 72% [61/84]; PSTs: 50.0% [61/123]; GPs: 23.4% [83/355]).

Conclusions: Participants confirmed the practicality of MI. However, the extent to which the practicality of MI was acknowledged as well as its expected benefits depended on the individual's level of education/expertise.

KEYWORDS

motivational interviewing; e-learning; web-based learning; primary care; health behavior change; disease management

Introduction

Background

Motivational interviewing (MI) is an evidence-based client-centered method of intervention focused on enhancing intrinsic motivation and behavior change by exploring and resolving ambivalence [1,2]. The term *motivational interviewing* was first coined by US psychologist Professor William Miller in 1983 and evolved from his experiences supporting problem drinkers [3]. It has since been applied to a wide range of behavior change, including weight loss, exercise, managing long-term conditions, pain management, anxiety and depression, and other issues where behavior change and self-confidence are desired.

A large body of literature studying the effectiveness of MI has led to several systematic reviews and meta-analyses published in support of MI effectiveness for a range of client outcomes and settings, including primary care [2,4-10]. Training professionals in MI not only improves their skills but also seems to have follow-on impacts for patients [11]. Although MI can improve the doctor-patient relationship and efficiency of the consultation [12], general practitioners (GPs) often lack time, basic training, or continuous education opportunities to update their knowledge and skills regarding clients' motivation for change [6,13].

E-learning, defined as instruction delivered on a digital device [14], can reduce the cost and time involved in providing continuing education, as it is decentralized and asynchronous [15,16]. It offers flexibility with regard to learning times and locations and thus can be easily integrated in individual working arrangements and the daily routines of medical professionals [17]. Knowledge acquisition and clinical skill development by e-learning have been shown to be equal or superior to those observed with face-to-face instruction [18,19].

Objectives

Given the already extensive literature on the effectiveness of MI for a range of client populations and of e-learning for medical professions, we focused on the individuals participating in the Web-based MI training course. Following the Dreyfus and Dreyfus model, each developmental stage of skill acquisition, moving from novice to expert, is characterized by differences in knowledge, skills, attitudes, and performance [20]. Thus, this study primarily aimed to investigate how physicians with different clinical experience levels (medical students, physicians in further education in general medicine, and specialists in general medicine), who had participated in an online training course on MI, evaluated the applicability of MI in their clinical practice. This study also aimed to assess if the Web-based MI training course would have an effect on their intention to use MI and their self-reported communication skills during MI.

Methods

Study Design

We conducted descriptive research using a cross-sectional study design to investigate the acceptability of a Web-based training course on MI for physicians with different clinical experience levels. The ethics committee of the Friedrich Schiller University (Jena, Germany), Medical Faculty, approved the study on June 18, 2014 (approval number 4120-0614).

Participants

Participation in both the course and the subsequent survey was open to GPs (physicians with a completed medical specialist training, *Facharzt*), physicians in specialist training (PSTs; postgraduate clinical specialization training), medical students (undergraduate medical training), medical employees (eg, paramedics), and (examined) nurses. Professions were self-reported.

The project was advertised in German and English language medical journals specialized in general practice, at medical congresses (eg, Deutschen Gesellschaft für Allgemeinmedizin und Familienmedizin, World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians Europe, European Academy of Teachers in General Practice), and through the specialist distribution lists of general medicine departments or general medical professional associations.

Motivational Interviewing E-Learning Course

Course Developers

The European Society for Quality and Safety in Family Practice (EQuIP) [21] developed a Web-based training course on MI consultation for family physicians regarding obesity and alcohol abuse, chronic conditions frequently encountered in primary care.

Development Process

The course followed the model developed by the Finnish Medical Society Duodecim. The international author team culturally adapted the course to the German and English language setting.

Revision and Updating

The course and its contents could not be changed during the observation period.

Quality Assurance

The course was evaluated using an online questionnaire (see below). No further quality assurance was performed.

Digital Preservation

The course and evaluation were only available for the study period.

Table 1. Questions and answers of the evaluation of the Web-based course on motivational interviewing.

Item	Question	Answers
1	My profession	Medical student/general practitioner/physician in specialist training/nurse/other
2	I took the course	In my workplace between other jobs/at home in my own time/at a school or university in association with my studies
3	Applicability of the skills and knowledge I obtained from the course in my clinical practice	Excellent/good/fair/poor
4	I feel that the course helped to improve my skills and competence	Fully agree/partly agree/do not agree
5	The course motivated me to learn and reflect upon the topic	Yes/somewhat/only a little/not at all
6	The following teaching methods are particularly useful in supporting my learning	Text parts/photos, drawn images/videos/speech, sound tracks/interactive animations/the examination
7	After taking the course I know better how to invite the patient to talk about behavior change.	Not at all/minimal/to some extent/a certain extent/a great extent
8	After taking the course I know better how to encourage the patient to talk about behavior change.	Not at all/minimal/to some extent/a certain extent/a great extent
9	After taking the course I know better how to actively convey respect for the patient's choice about behavior change.	Not at all/minimal/to some extent/a certain extent/a great extent
10	After taking the course I and the patient exchange ideas about how the patient could change current behavior.	Not at all/minimal/to some extent/a certain extent/a great extent
11	In MI ^a it is important to listen empathically to the problems, but not engaging in them, to really concentrate and act on change talk. After taking the course I know better how to get a good balance in my consultations between empathic listening to problems and active engagement in change talk.	Not at all/minimal/to some extent/a certain extent/a great extent
12	In MI it is important to know that the tool is not useful for every consultation. After taking the course I know better how to select the right patients at the right time to use MI.	Not at all/minimal/to some extent/a certain extent/a great extent
13	After taking the course I think it is feasible for me to perform MI (with some patients) in my daily general practice.	Not at all/minimal/to some extent/a certain extent/a great extent
14	After taking the course I plan to use MI in my daily practice.	Not at all/minimal/to some extent/a certain extent/a great extent
15	The most beneficial aspect of the course for me was	Free text
16	My suggestions to improve the course	Free text
17	I would like to have e-learning courses of the following topics in the future	Free text

^aMI: motivational interviewing.

Access

The course was available in an English and a German version. The English language course is available online [22]. The voluntary evaluation in the English or German language [23] started directly after completing the course. Both the Web-based course and the evaluation were available for 18 months.

Mode of Delivery, Content, and Use Parameters

Using different teaching methods, the online course provided the core characteristics of MI [24]. In total, the course comprised 49 slides. The course included information and summary boards and 3 case studies on using MI with patients suffering from chronic conditions typical for a primary care setting. The cases were presented using 2 videos showing consultation scenarios regarding overweight (one showing patient and nurse interaction), and the other showing patient and physician interaction), 1 dialogue between the patient and physician on excessive alcohol

consumption, and an animation on starting long-term medication in a patient suffering from type 2 diabetes and hypertension. All cases were accompanied by practical exercises.

It took about 45 min to work through the Web-based course. Users could take the course in their own time. Users could navigate within the course as desired.

Online Evaluation Questionnaire

Inspired by the Behaviour Change Counselling Index (BECCI) [25], a self-administered questionnaire containing 17 items was developed (see Table 1). Different-level Likert scales and open-ended questions were given as answer options.

With regard to the focus of this publication, that is, how various health professionals evaluated the practicality of applying the methods they learned in the MI course, a pivotal question was about the *applicability of the skills and knowledge obtained from the course in clinical practice* (item 3). Other

study-relevant items were regarding the improvement of communication skills when talking to patients about behavior change (items 7, 8, and 9). The 3 lowest answer options (not at all, minimal, to some extent) were summarized to one category, *disagree*, indicating that the participant did not concur with the particular statement.

Item 13 on the feasibility of performing MI in daily general practice and item 14 about actual plans to use MI in daily practice were summarized by mean values into one statement reflecting how participants envisage MI use in the future (answer options were coded 0=not at all, 1=minimal, 2=to some extent, 3=a certain extent, and 4=a great extent). The mean values were recoded to the standard possible responses (0=0; 0.5 to 1.5=1; 1.6 to 2.5=2; 2.6 to 3.5=3; 3.6 to 4=4). The statistically descriptive evaluation was carried out using IBM SPSS Statistics, Version 23.

Human Involvement, Cointerventions, and Prompts

No support or assistance was given to participants while they were taking the course or answering the questionnaire. There were no cointerventions or prompts.

Results

Participants

In total, 607 participants from 24 European countries evaluated the Web-based MI course. Of these, 74.0% (449/607) completed the English version and 26.0% (158/607) completed the German version. The majority of participants were GPs (355/607, 58.5%), followed by PSTs (123/607, 20.3%), medical students (84/607, 13.8%), and nurses (6/607, 1.0%). A small group did not fall within these professions (referred to as *others*; 22/607, 3.6%), and 17 out of 607 (2.8%) participants refused to specify their profession. Owing to the small number of nurses and the lack of homogeneity of the group labelled *others*, we excluded these 2 groups from the analysis. Thus, the final study sample consisted of 562 participants.

Evaluation of Motivational Interviewing Practicality by Profession

Table 2 presents the absolute and relative frequencies of answers to the study-relevant items (3, 7, 8, 9, and the combined items 13 and 14) by profession.

Applicability of Motivational Interviewing

Medical students were more likely to rate the applicability of the skills and knowledge (item 3) as *good* (94%, 78/84), whereas the majority of PSTs (88.6%, 109/123) rated item 3 as *excellent*. The assessment of GPs varied to a greater extent, with 51.3% (182/355) selecting *excellent*, 29.9% (106/355) selecting *good*, and 17.2% (61/355) selecting *fair*.

Intention to Use Motivational Interviewing

When asked whether they had the intention to use MI in the future (combined items 13 and 14), 79% (67/84) of the students answered to *a certain extent*, compared with 88% (109/123) of the PSTs stating to *a great extent*. The response pattern of GPs is less definitive (**Table 2**).

Improvement of Communication Skills

Regarding the improvement of communication skills, medical students agreed to *a certain extent* that after taking the course, they know better how to invite patients to talk about behavior change (85%, 72/84) or to encourage patients to talk about behavior change (81%, 68/84) and 72% (61/84) agreed to *a great extent* that they actively convey respect for the patient's choices about behavior change.

The majority of PSTs (90.2%, 111/123) agreed to *a great extent* that they now know better how to invite patients to talk about behavior change. They also agreed to *a great extent* or *a certain extent* that they could now encourage the patient to talk about behavior change (45.5%, 56/123 and 50.4%, 62/123 respectively) or that they could convey respect for the patient (49.9%, 61/123 and 44.7%, 55/123, respectively).

GPs' responses were more evenly distributed: 37.2% (132/355) agreed to *a great extent* and 40.6% (144/355) agreed to *a certain extent* to now knowing better how to invite patients to talk about behavior change; 36.3% (129/355) agreed to *a great extent*, 27.3% (97/355) agreed to *a certain extent*, and 33.9% (120/355) *disagreed* to encourage patients to talk about behavior change; and 40.3% (143/355) agreed to *a certain extent* to actively convey respect for the patients' choices.

Table 2. Absolute and relative frequency of answers in the 3 professions: medical students, physicians in specialist training, and general practitioners.

Rating options	Medical students (N=84), n (%)	Physicians in specialist training (N=123), n (%)	General practitioners (N=355), n (%)	Total (N=562), n (%)
Applicability of the skills and knowledge I obtained from the course in my clinical practice (Question 3)				
Excellent	2 (2)	109 (88.6)	182 (51.3)	293 (52.1)
Good	79 (94)	10 (8.1)	106 (29.9)	195 (34.7)
Fair	2 (2)	3 (2.4)	61 (17.2)	66 (11.7)
Poor	0 (0)	1 (0.8)	0 (0.0)	1 (0.2)
N/A ^a	1 (1)	0 (0.0)	6 (1.7)	7 (1.2)
Motivational interviewing in daily practice is feasible and intention to use (Questions 13 and 14)				
Agreed to a great extent	2 (2)	109 (88.6)	137 (38.6)	248 (44.1)
Agreed to a certain extent	67 (79)	8 (6.5)	133 (37.5)	208 (37.0)
Disagreed	11 (13)	4 (3.3)	74 (20.9)	89 (15.8)
N/A	4 (4)	2 (1.6)	11 (3.1)	17 (3.2)
After taking the course I know better how to invite the patient to talk about behavior change (Question 7)				
Agreed to a great extent	5 (6)	111 (90.2)	132 (37.2)	248 (44.1)
Agreed to a certain extent	72 (85)	7 (5.7)	144 (40.6)	223 (39.7)
Disagreed	3 (3)	3 (2.4)	70 (19.7)	76 (13.5)
N/A	4 (4)	2 (1.6)	9 (2.5)	15 (2.7)
After taking the course I know better how to encourage the patient to talk about behavior change (Question 8)				
Agreed to a great extent	5 (6)	56 (45.5)	129 (36.3)	190 (33.8)
Agreed to a certain extent	68 (81)	62 (50.4)	97 (27.3)	227 (40.4)
Disagreed	7 (8)	3 (2.4)	120 (33.9)	130 (23.1)
N/A	4 (4)	2 (1.6)	9 (2.5)	15 (2.7)
After taking the course I know better how to actively convey respect for the patient's choice about behavior change (Question 9)				
Agreed to a great extent	61 (72)	61 (49.6)	83 (23.4)	205 (36.5)
Agreed to a certain extent	17 (20)	55 (44.7)	143 (40.3)	215 (38.3)
Disagreed	2 (2)	5 (4.1)	121 (34.1)	127 (22.6)
N/A	4 (4)	2 (1.6)	8 (2.3)	14 (2.5)

^aN/A: not applicable.

Discussion

General Findings

In general, participants from 3 different levels of clinical experience positively evaluated the applicability of skills and knowledge gained by a Web-based course, and the practicality of MI in their daily routine. Our results suggested that health care professionals were able to use a Web-based training course for MI to develop skills related to health behavior change.

Course Satisfaction and Motivational Interviewing Applicability

Nevertheless, GPs, the largest and most experienced group in our sample, were less enthusiastic about MI skills learned in the course than medical students or PSTs. Equally, GPs were more reluctant to envision MI implementation in their daily practice in the future. We have explained our results as follows: First, GPs are at the highest level of training and professional

expertise in our group of participants. They may intuitively use skills similar to MI and thus the methods explored in the course might not have been entirely new to them. This may also explain why GPs did not rate the improvement of their communication skills as highly as students or PSTs. Second, it is also possible that GPs were not as pleased as their less-experienced colleagues with the Web-based format of the course. In a meta-analysis, Cook et al showed that physicians were less in favor of internet-based learning compared with alternate instructional media than medical students regarding knowledge outcome and behaviors in practice and effects on patients [18]. Third, the course instructional strategies might not have met with participants' expectations and skills. The Dreyfus and Dreyfus model provides a framework for skill acquisition that describes developmental stages beginning with novice and progressing through advanced beginner and competent and proficient to expert [20,26]. Each of these levels is characterized by qualitative differences in knowledge, skills, attitudes, and

performance [27]. The Dreyfus and Dreyfus model has been successfully adopted by medical educators to assess students and residents as they learn to practice clinical medicine [28]. Owing to differences in their knowledge level, expert and novice learners demand different instructional approaches. In fact, research indicates that instructional methods that are effective for novices either have no effect or, in some cases, depress the learning of learners with more expertise [29]. For the novice, basic science knowledge is important in providing the substrate for the analytic process of clinical reasoning. Thus, exposure of students to clinical cases and examples is important [28] and was provided by the case studies in our course. Experts, on the contrary, need challenge, ongoing experience, and exposure to interesting and complex cases to avoid complacency [28]. Thus, for GPs, our course might not have provided enough challenge. The skills and attitudes of the professionals offering MI may influence its success; they may impact on the professionals' willingness to offer MI as well as their proficiency or effectiveness using the techniques involved [30]. The next step is to optimize the tailoring, structure, and content of a Web-based MI training course to meet participants' specific requirements with regard to their knowledge and experience [15]. Adaptive e-learning environments (AEEs) can provide tailored instruction to health professionals and students by adapting the training to each user [31,32]. However, the effectiveness of AEEs for the education of health professionals and students of health professions remains unclear and should be investigated [32]. Future research should also explore to what extent participants of the Web-based MI course actually implemented MI in their daily routine. Factors influencing the implementation of MI might be therapeutic commitment—the motivation, task-specific self-esteem and work satisfaction toward chronic patients, and role security—the skills, knowledge, and owning a role of working with them, although this theory is debated [13,33]. Future research should focus on the causal relation between practitioners' attitudes, their actual behavior, and care improvement strategies to enhance implementation science.

Evaluating the effects of e-learning on real clinical behavior and client outcomes still remains a challenge [34]. Zwane et al suggest that the mere fact of being surveyed might actually change behavior in medical settings [35]. However, a standard, feasible, and preferred method for establishing MI adherence in practice has not yet been developed [9]. With regard to patient benefit, Rochfort et al showed that when health professionals

undergo training in empowering patients for self-management of chronic conditions, it is possible to achieve improvement in patients' self-efficacy, autonomy and motivation to change, functional capacity, pain-free days, and quality of life [36].

Strength and Limitations

The strength of this study was its focus on the participants of a Web-based MI course from 3 different levels of professional expertise. Thus, we were able to paint a unique and user-oriented picture of MI practicality. As limitations, we neither had information on the eligible study population nor on nonresponders. Therefore, a selection effect cannot be excluded, which may result in overestimated positive results. In a heterogeneous group such as ours, including medical professionals with very limited time resources, we opted for as few questions as possible; thus, we did not collect data on the sex or age of the participants. The BECCI survey was developed and validated as a clinical assessment. The modified version as a self-assessment could not be validated for this study because of limited resources. The questionnaire was self-reported only; we did not validate the participants' self-reported professional level. At the time of responding to the items, respondents may not have answered truthfully, a phenomenon known as social desirability bias [37]. Gaining valid answers to questions is an age-old problem in offline and online survey research. However, we did not ask overly sensitive questions, so we assume that the answers were truthful in general. Measuring outcomes from training in enabling behavior change in patients should go beyond the simple measurement of acquisition of new skills by clinicians. It needs to show improvement in patient outcomes. In addition, the primary care setting is an environment within the health care sector which has a complex and unique set of barriers and benefits to supporting behavior change over time [38], and so we call for behavior change research to be conducted in family practice.

Conclusions

The knowledge and skills obtained by the Web-based MI course were assessed by the participants as being beneficial and appropriate for use in primary care practice. However, participants evaluated various aspects of the course differently, depending on their level of expertise. Before we recommend this course for wider use, the actual change in the behavior of the participating clinicians and the benefit to their patients should be investigated, and data other than self-reports should be incorporated.

Acknowledgments

In February 2012, the WONCA Europe Network EQuIP won the WONCA Europe 20th Anniversary Research Fund for this 3-year international project [39]. This study was funded by the WONCA Europe 20th Anniversary Research Fund and supplemented by the authors' institutions and EQuIP (a network organization of WONCA Europe). This study was in part supported by the *Multiplikatorenprogramm* of the center of leadership and people management of the Ludwig-Maximilians-Universität München (LMU).

Authors' Contributions

KL wrote the main manuscript text and prepared the manuscript and tables. NS performed the statistical analysis, prepared tables and was involved in data collection and the critical revision of the manuscript. MS was involved in course content and data

collection. UBK was involved in data collection, course development and content, and the critical revision of the manuscript. TE and IK were involved in course development and content. AR provided clinical background on MI and was involved in the critical revision of the manuscript. CC was involved in data collection, course content, and critical revision of the manuscript. JG was involved in the initial conception and design of the study, course development and content, and the critical revision of the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

AEEs: adaptive e-learning environments

BECCI: Behaviour Change Counselling Index

EQuIP: European Society for Quality and Safety in Family Practice

GPs: general practitioners

MI: motivational interviewing

PSTs: physicians in specialist training

WONCA: World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians

Edited by J Torous; submitted 18.10.18; peer-reviewed by G Fontaine, J Welch, C McGregor; comments to author 05.12.18; revised version received 30.01.19; accepted 18.02.19; published 29.04.19.

Please cite as:

Lukaschek K, Schneider N, Schelle M, Kirk UB, Eriksson T, Kunnamo I, Rochfort A, Collins C, Gensichen J. Applicability of Motivational Interviewing for Chronic Disease Management in Primary Care Following a Web-Based E-Learning Course: Cross-Sectional Study. *JMIR Ment Health* 2019;6(4):e12540

URL: <http://mental.jmir.org/2019/4/e12540/>

doi:10.2196/12540

PMID:31033446

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Original Paper

Profiling Commenters on Mental Health–Related Online Forums: A Methodological Example Focusing on Eating Disorder–Related Commenters

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Abstract

Background: Understanding the characteristics of commenters on mental health–related online forums is vital for the development of effective psychological interventions in these communities. The way in which commenters interact can enhance our understanding of their characteristics.

Objective: Using eating disorder–related (EDR) forums as an example, this study detailed a methodology that aimed to determine subtypes of mental health–related forums and profile their commenters based on the other forums to which they contributed.

Methods: The researchers identified all public EDR forums (with ≥ 500 contributing commenters between March 2017 and February 2018) on a large Web-based discussion platform (*Reddit*). A mixed-methods approach comprising network analysis with community detection, text mining, and manual review identified subtypes of EDR forums. For each subtype, another network analysis with community detection was conducted using the EDR forum commenter overlap between 50 forums on which the commenters also commented. The topics of forums in each detected community were then manually reviewed to identify the shared interests of each subtype of EDR forum commenters.

Results: Six subtypes of EDR forums were identified, to which 14,024 commenters had contributed. The results focus on 2 subtypes—proeating disorder and thinspiration—and communities of commenters within both subtypes. Within the proeating disorder subtype, 3 communities of commenters were detected that related to the body and eating, mental health, and women, appearance, and mixed topics. With regard to the thinspiration group, 78.17% (849/1086) of commenters had also commented on pornographic forums and 16.66% (181/1086) had contributed to proeating disorder forums.

Conclusions: The article exemplifies a methodology that provides insight into subtypes of mental health–related forums and the characteristics of their commenters. The findings have implications for future research and Web-based psychological interventions. With the publicly available data and code provided, researchers can easily reproduce the analyses or utilize the methodology to investigate other mental health–related forums.

(*JMIR Ment Health* 2019;6(4):e12555) doi:[10.2196/12555](https://doi.org/10.2196/12555)

KEYWORDS

mental health; eating disorders; social media; social networks

Introduction

Background

Compared with clinician-delivered psychological interventions, Web-based interventions targeting mental health conditions offer several benefits, such as cost-effectiveness [1], and potentially reach a larger number of the target population [2]. However, for these interventions to be effective, it is important that users adhere to them. A recent review indicated that several characteristics (eg, gender and impersonality of intervention content) are important predictors of adherence to Web-based psychological interventions [3]. Therefore, if adherence to Web-based psychological interventions is to be improved, a clearer understanding of the characteristics of target populations (eg, online mental health-related communities) is vital. This study has used the example of eating disorder-related (EDR) forums to outline a reproducible methodology that can enhance our understanding of the characteristics of online mental health-related communities.

Eating Disorder–Related Forums

EDR forums are easily accessible online, and their content can be defined broadly as either *proeating disorder* or *prorecovery* [4]. Proeating disorder content encourages the enactment of eating-disordered behaviors (eg, fasting and excessive exercise) without indicating a desire for recovery and typically portrays eating disorders as a lifestyle choice rather than a mental health condition [4]. The term *thinspiration* is often used to refer to proeating disorder material (eg, photos) that encourages eating disordered behaviors [5]. In contrast, prorecovery (or *antieating disorder*) content encourages recovery from eating disorders or confronting eating-disordered behaviors [4]. In addition to the proeating disorder or prorecovery distinction, EDR forums can also be characterized as relating to eating disorders in general or specific diagnostic categories (eg, anorexia nervosa, bulimia nervosa, or binge eating disorder).

A deeper understanding of proeating disorder forums is particularly important [6]. Emphasizing this importance, semistructured interviews with current eating disorder patients found that they perceived proeating disorder websites as having reinforced and maintained their eating disorders [7]. Furthermore, a recent meta-analysis [8] showed that greater engagement with proeating disorder forums is associated with increased body dissatisfaction, dieting, and negative affect but not bulimic symptoms. Despite this issue's importance, few studies have attempted to elucidate the characteristics of people who engage with EDR forums.

Survey-Based Research

Most existing studies attempting to characterize users of EDR forums have used survey-based methods and samples recruited directly from EDR forums or student samples. For example, Peebles et al [9] recruited participants from proeating disorder websites and found that they were predominantly young women within the healthy body mass index range. Over 70% of the respondents also indicated that they had purged, binged, or used laxatives to control their weight. Exemplifying the use of student samples, Harper et al [10] asked undergraduate women to

complete self-report questions about viewing EDR websites. Compared with controls who had not viewed EDR websites, participants who had viewed proeating disorder websites reported higher appearance dissatisfaction, dietary restriction and bulimic symptoms, and more frequent viewing of cosmetic surgery websites.

Although the research detailed above provides insight into commenters' characteristics using standardized self-report scales, the studies' samples are unlikely representative of everyone who engages with EDR forums. For example, survey respondents on forums might differ from those who do not respond [9] and relatively small student populations might not be representative of the actual forum users [10].

Textual Analyses of Online Content

Textual analyses of online content offer an alternative methodology to surveys and complement findings obtained through self-report measures. Such analyses can be approached in different ways, including manual qualitative methods (eg, thematic analysis and content analysis) and computerized methods (eg, word counts and topic modelling). However, these approaches all address a similar aim in identifying themes discussed on EDR forums.

Through using manual qualitative methods, researchers have found that most EDR forum commenters are women [4] and that eating and shape concerns are the most commonly expressed symptoms in a proeating disorder forum [11]. Despite variability between studies, applications of computerized word count methods have indicated that prorecovery and proeating disorder commenters differ in terms of factors such as affect and self-directed attention [12,13] and mentions of fitness tracking technology [14]. A combination of both manual and computerized textual analyses has also indicated that recovery is less frequently mentioned by commenters in the least recovery-focused eating disorder stages of change (ie, precontemplation and relapse) [15]. Recently, Moessner et al [16] employed sophisticated computerized topic modelling to characterize a proeating disorder community in terms of the themes that its commenters discuss, including feedback and social support and weight gain or loss.

Interaction Between Forum Users

A complementary approach to textual analyses is to explore the way in which users on a forum interact. In the same study detailed above, Moessner et al [16] investigated how commenters within a proeating disorder forum interacted and were able to identify particularly influential commenters. In contrast, 2 studies have explored the interaction between communities of commenters on *Twitter* [13,17]. Tiggemann et al [17] theoretically selected and compared *thinspiration* and *fitspiration* (ie, content encouraging health and fitness) posts on *Twitter*. During a 2-week period, the researchers identified users that included *thinspiration* or *fitspiration* tags in their posts and found minimal overlap (ie, interaction) between commenters in the 2 communities. Using a more data-driven approach, Wang et al [13] detected 2 communities of commenters who posted comments with EDR tags. The 2 communities were found to

reflect proeating disorder and prorecovery stances, with network analyses indicating minimal overlap between the communities.

Although Moessner et al [16] explored the user interaction *within* a forum, Tiggemann et al [17] and Wang et al [13] investigated the user interaction *between* 2 communities. However, these approaches could be extended to explore the overlap between, theoretically, an infinite number of communities. Although researchers have previously used network analyses to investigate traffic between over 500 EDR websites [18], this has not been done with online discussion forums nor at the level of the individual user.

Reddit

In February 2018, *Reddit* was the sixth most visited website in the world, with 234 million unique visitors [19]. *Reddit* is a large Web-based discussion platform comprising thousands of forums (ie, *subreddits*) and is perfectly suited to investigate the overlap between online communities on a large scale. Each subreddit relates to a specific topic (eg, politics or films) and can be conceptualized as a community of people with a shared interest. A member of a subreddit can start a conversation (ie, *thread*) or join a conversation by responding to an existing comment. *Reddit* can be viewed as a microcosm of the internet, as users are likely to engage only with a relatively small number of subreddits that interest them. *Reddit* therefore provides a unique opportunity to explore how online forums are related in terms of whether the same people comment on them. Furthermore, by identifying a group of commenters and identifying the other forums to which they contribute, the communities to include in analyses can be determined in a largely data-driven way, in contrast to the theoretical approach used in previous studies [17,18]. Finally, as eating disorders are the explicit focus of several subreddits and have been the focus of previous studies [11,12,16], *Reddit* presents a particularly beneficial opportunity to investigate the characteristics of EDR forums in greater detail.

Objectives

Although it is common for studies to consider EDR online discussion forums in isolation [11,14,16], recent studies have investigated how similar forums overlap in terms of commenters [17]. This study built on the latter approach and used publicly available data from *Reddit* [20] to achieve 2 separate objectives, as detailed below.

Objective 1: Determining Subtypes of Eating Disorder–Related Subreddits

The first objective of this study was to identify subtypes of EDR forums on *Reddit*. To achieve this, large EDR subreddits were identified, and the way in which they overlapped with regard to commenters was calculated. A mixed-methods approach was then applied, comprising network analysis with community detection, text mining, and manual review of the EDR subreddits' focuses. This enabled the grouping of EDR subreddits into subtypes and, as a result, facilitated the elucidation of thematic heterogeneity in EDR subreddits (eg, proeating disorder and prorecovery). The output regarding Objective 1 also determined the grouping of subreddits for the analyses relating to Objective 2.

Objective 2: Profiling Eating Disorder–Related Commenters Based on Contributions to Ancillary Subreddits

The second objective of this study was to profile each subtype of EDR forums (see Objective 1) in terms of their main interests, as represented by the topics of subreddits to which the commenters also contributed. To achieve Objective 2, all the other (public) subreddits to which EDR commenters had contributed (*ancillary subreddits*) were identified. A mixed-methods approach was then conducted consisting of network analysis with community detection and manual review of the ancillary subreddits' topics. The overall topics of the subreddits comprising each detected community then enabled the profiling of groups of EDR commenters in terms of the other topics in which they were interested.

Methods

Corpus Selection and Data Analysis

All public *Reddit* comments, excluding the initial post to which commenters respond, are regularly archived and freely available [20]. Although the archive includes all comments from December 2005, this study's corpus comprises all comments posted between March 2017 and February 2018 (inclusive). This represents the 1-year period preceding the most recent month's data that were available when beginning the study. As publicly available data were used, this study was outside the remit of the University of Warwick's Biomedical and Scientific Research Ethics Committee, from whom an exemption from ethical review was obtained. All data were extracted, preprocessed, and analyzed with the Python (Python Software Foundation) programming language [21], except where otherwise stated. The code used in this study is available as [Multimedia Appendix 1](#) and can be used to replicate the analyses.

Objective 1: Determining Subtypes of Eating Disorder–Related Subreddits

A list of search terms was created to identify EDR subreddits, which is provided in [Multimedia Appendix 2](#). This list was generated through a consultation of EDR sections of 2 clinical references, DSM-V and ICD-10 [22,23], and previous research concerning EDR online communities [14,24]. Search terms were developed that related to (1) eating disorders in general (eg, eating disorder); (2) specific eating disorder diagnostic categories (eg, anorexia nervosa, bulimia nervosa, or binge eating disorder); or (3) online content associated with eating disorders (eg, thinspiration). Subreddits were included that contained at least 1 search term in their name or brief description but excluded if they (1) were unrelated to eating disorders (eg, *Anorexiclizardpeople*) or (2) were private. For each subreddit identified through this search and inclusion strategy, each comment and commenter's name were then extracted from the *Reddit* data [20]. To focus the analyses on the largest EDR subreddits, any subreddits with fewer than 500 commenters contributing within the 1-year period were excluded. The *Reddit* commenters *AutoModerator* and *[deleted]* were not included in this count and were excluded from all subsequent analyses.

A mixed-methods approach was then used to identify subtypes of the EDR subreddits. This approach comprised 3 techniques that are described below and were conducted in the order presented: (1) network analyses with community detection; (2) text mining; and (3) manual review of EDR subreddits' focuses.

Network Analyses With Community Detection

To conduct the network analyses with community detection, a list of commenters was compiled separately for each of the included EDR subreddits. For each pairwise comparison of the subreddits (eg, *subreddit A* compared with *subreddit B*), the proportion of each subreddit's commenters who had posted on the other subreddit was calculated, with the result ranging from 0 (no commenters overlap) to 1 (all commenters overlap). For example, a proportion of 0.4 (40/100) of *subreddit A*'s commenters might post on *subreddit B*, whereas 0.8 (40/50) of *subreddit B*'s commenters post on *subreddit A*. The mean of these 2 proportions (ie, 0.6) was calculated to account for the differences in the number of commenters on each subreddit. A matrix was then created using all these pairwise comparisons, where each cell within the matrix represented the mean commenter overlap between each pairing of the EDR subreddits.

Using this matrix, a weighted and undirected (ie, associative) network analysis was conducted using the *qgraph* package [25] for *R* statistical software [26]. Many techniques exist for the purpose of detecting communities (ie, subreddits with similar commenters) within networks. The *walktrap* algorithm [27] was used for this purpose, as it is recommended for networks with fewer than 1000 nodes (ie, subreddits) [28] and was observed to detect communities more reliably than other suitable algorithms [28].

As with individual subreddits, the detected communities might also overlap in terms of commenters (ie, a commenter might contribute to subreddits from more than one community). As such, for each detected community, commenter lists were compiled and used to calculate the mean commenter overlap between communities in the same way as detailed above for the pairwise comparisons of subreddits. In the event of more than 2 communities being detected, the *VennDiagramR* package [29] was used to visualize these commenter overlaps using unscaled Venn diagrams.

Text Mining

An existing text-mining approach was used to establish the degree to which each EDR subreddit was recovery-focused [14]. For each EDR subreddit, the percentage of its comment threads that contained at least 1 recovery term (ie, *recovery*, *recover*, *recovers*, *recovered*, and *recovering*) was calculated. A higher percentage of threads containing at least 1 reference to recovery was interpreted as representing a greater recovery focus, in line with findings that recovery is less frequently mentioned by people in the precontemplation or relapse eating disorder stages of change [15]. For example, between May 2015 and January 2018 (inclusive), 10% of the subreddit *proED*'s threads contained a reference to recovery, compared with 50% of the subreddit *EatingDisorders*' threads [14]. As this represented a 40% difference between the two, *EatingDisorders* was interpreted as having a greater recovery focus than *proED*.

Manual Review of Eating Disorder–Related Subreddits' Focuses

A manual review of each EDR subreddit's name and brief description was undertaken to define whether each EDR subreddit is related to (1) eating disorders in general; (2) specific eating disorder diagnostic categories (eg, anorexia nervosa, bulimia nervosa, or binge eating disorder); or (3) online content associated with eating disorders (eg, thinspiration). This step reflects the previously detailed distinctions used in the generation of the initial search terms. The definitions were then considered together with the results from the previous 2 steps (ie, network analysis with community detection and text mining) to guide the categorization of the EDR subreddits. For example, 2 EDR subreddits specific to anorexia nervosa would have been categorized differently if they were present in 2 distinct communities representing different levels of recovery focus. All of the researchers reached an agreement on the categorization of EDR subreddits at this stage.

Objective 2: Profiling Eating Disorder–Related Commenters Based on Contributions to Ancillary Subreddits

For each of the subtypes of EDR subreddits identified through the previously described methods (Objective 1), a list was compiled of all the commenters who had contributed within the 1-year period to at least 1 subreddit within the subtype (excluding *AutoModerator* and [*deleted*] commenters). To focus this report on the largest subtypes of EDR subreddits, only subtypes with 1000 or more commenters were included in the analyses. The following analyses were repeated separately for each included subtype of EDR subreddits.

Using the respective list of commenters for the EDR subtype, all of the other subreddits to which the commenters had contributed (ie, ancillary subreddits) in the 1-year period were identified. Any ancillary subreddits to which fewer than 1% of the EDR subtype's commenters had contributed were excluded at this stage. This exclusion was made as ancillary subreddits with so few EDR commenters would not have been included in the final steps of the analysis (detailed below) and therefore represented unnecessary data to extract.

The ancillary subreddits were then ranked separately in the descending order of (1) the number of the EDR subtype's commenters who had contributed to each ancillary subreddit and (2) the proportion of each ancillary subreddit's total commenters (ie, not only the EDR subtype's commenters) that had also commented on at least 1 subreddit within the EDR subtype. For each ancillary subreddit, the mean of these 2 ranks was then calculated. Owing to the large number (ie, tens of thousands) of ancillary subreddits associated with each EDR subtype and to improve the interpretability of the results, the mean rank was used to identify the most representative ancillary subreddits for inclusion in the following analyses. Specifically, the 50 ancillary subreddits with the highest mean rank were included, resulting in the inclusion of ancillary subreddits that were both large in size (ie, comprised many commenters) and included a large proportion of the EDR subtype's commenters. This avoided the inclusion of ancillary subreddits that were very large in terms of the number of commenters but of which the

EDR subtype's commenters comprised a very small proportion (eg, general subreddits, such as *AskReddit*). At the same time, this step also avoided the inclusion of very small subreddits that had very high proportions of the EDR subtype's commenters (eg, subreddits comprising a few commenters who had all contributed to at least 1 subreddit within the EDR subtype). As this threshold (ie, the top 50 subreddits) was used solely to facilitate a clear interpretation of the results, extensions of this study could set different thresholds to explore the communities at varying levels of detail.

A mixed-methods approach was then used to profile the EDR subtype's commenters in terms of their main interests, as represented by the thematic focuses of the ancillary subreddits. This approach comprised 2 techniques that are described below and were conducted in the order presented: (1) network analyses with community detection and (2) a manual review of the ancillary subreddits' topics.

Network Analyses With Community Detection

The network and community detection analyses were conducted in the same way as detailed for Objective 1. The only difference was that the commenter overlaps (relating to both the ancillary subreddits and detected communities) were calculated using only the EDR subtype's commenters (ie, excluding commenters on each ancillary subreddit who had not contributed to at least 1 of the EDR subtype's subreddits).

Manual Review of Ancillary Subreddits' Topics

A manual review of each ancillary subreddit's name and brief description was undertaken to describe each subreddit's general

topic. For example, the general topic of the subreddit *loseit* was described as *weight loss*. All ancillary subreddits comprising the detected communities were then reviewed, and a label was produced to represent the general content of each community. For example, a community containing ancillary subreddits that related to eating behaviors and weight loss was labelled *Eating/Body*. To ensure transparency at every stage of this process, the name and labels of all included ancillary subreddits are presented in tables in the Results section, along with a summary of how each label for the detected communities was generated.

Results

Objective 1: Determining Subtypes of Eating Disorder–Related Subreddits

The search and inclusion strategy led to the identification of 50 EDR subreddits, a list of which is provided in [Multimedia Appendix 2](#). Following the exclusion of any subreddits with fewer than 500 commenters, 9 EDR subreddits were identified: *BingeEatingDisorder*, *bulimia*, *EatingDisorders*, *eating_disorders*, *fuckeatingdisorders*, *MyProAna*, *proED*, *ProEDmemes*, and *thinspo*. In total, 14,024 commenters posted on these 9 EDR subreddits. Of these commenters, 0.69% (97/14,024) included the term *bot* within their account name, with these commenters contributing a mean of 9 comments (SD 16; median 3, minimum 1, maximum 94) to the EDR subreddits. The network analysis with community detection corresponding to the 9 EDR subreddits is presented in [Figure 1](#).

Figure 1. Eating disorder–related subreddits network. Letters correspond to eating disorder–related subreddits (A=*proED*, B=*BingeEatingDisorder*, C=*ProEDmemes*, D=*thinspo*, E=*MyProAna*, F=*fuckeatingdisorders*, G=*EatingDisorders*, H=*eating_disorders*, and I=*bulimia*). Light-gray circles represent community 1 (low recovery focus), and dark-gray circles represent community 2 (high recovery focus). Thickness of the lines represents the mean degree of commenter overlap between each pair of subreddits (thicker line=larger overlap).

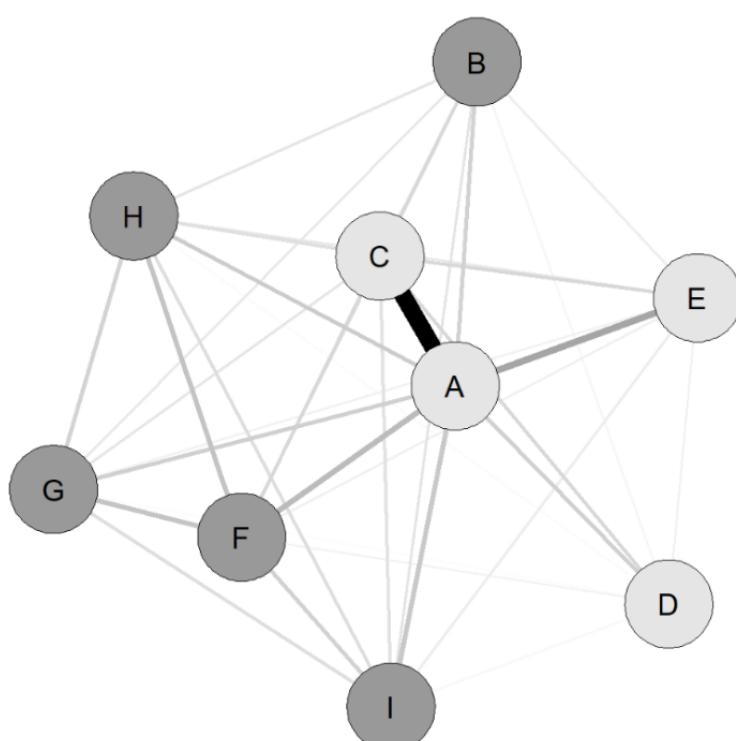


Figure 1 shows that the community detection algorithm identified 2 communities in the EDR subreddits network. The text-mining analyses found that community 1 (light-gray circles) comprised the 4 EDR subreddits with the lowest percentage of threads mentioning recovery: *MyProAna* (9.9%; 47/471), *proED* (11.72%; 2390/20,396), *ProEDmemes* (2.38%; 39/1639), and *thinspo* (0.23%; 3/1323). In contrast, community 2 (dark-gray circles) comprised the 5 EDR subreddits with the highest percentage of threads mentioning recovery: *BingeEatingDisorder* (19.30%; 411/2129), *bulimia* (40.0%; 167/417), *eating_disorders* (32.1%; 179/557), *EatingDisorders* (46.3%; 192/414), and *fuckeatingdisorders* (45.5%; 191/419). These findings supported a conceptualization of community 1 comprising *low recovery-focus* EDR subreddits and community 2 comprising *high recovery-focus* EDR subreddits.

Of the 14,024 commenters, 65.97% (9252/14,024) *only* posted on subreddits within the low recovery-focus community, whereas 28.69% (4023/14,024) *only* commented on subreddits within the high recovery-focus community. However, 5.34% commenters (749/14,024) posted on subreddits within *both* communities, indicating relatively little commenter overlap between the communities.

In addition to the degree of recovery focus, the EDR subreddits also differed in terms of whether they concerned eating disorders in general (eg, *EatingDisorders*), a specific eating disorder diagnostic category (eg, *BingeEatingDisorder*), or online content associated with eating disorders (eg, *thinspo*). Each subreddit's focus was therefore used to categorize the subreddits within each detected community. Consequently, the low recovery-focus community comprised 3 subtypes of EDR subreddits: *pro-eating disorder*, consisting of *proED* and *ProEDmemes* (8166 commenters); *thinspiration*, consisting of *thinspo* (1580 commenters); and *pro-anorexia nervosa*, consisting of *MyProAna* (731 commenters). As with the low recovery-focus

Figure 2. Proeating disorder network. Letters correspond to ancillary subreddits. Black circles represent community 1 (*Eating/Body*), dark-gray circles represent community 2 (*Mental health*), and light-gray circles represent community 3 (*Women/Appearance/Mixed*). The size of circles represents the ancillary subreddit mean rank (larger circle=higher rank), and thickness of the lines represents the mean degree of commenter overlap between each pair of subreddits (thicker line=larger overlap). No lines representing <0.25 mean commenter overlap are displayed.

community, the high recovery-focus community comprised 3 subtypes: *pro-recovery eating disorder*, consisting of *EatingDisorders*, *eating_disorders*, and *fuckeatingdisorders* (1986 commenters); *pro-recovery binge eating disorder*, consisting of *BingeEatingDisorder* (2520 commenters); and *pro-recovery bulimia nervosa*, consisting of *bulimia* (524 commenters).

Objective 2: Profiling Eating Disorder–Related Commenters Based on Contributions to Ancillary Subreddits

To focus this report on the largest subtypes of EDR subreddits, subtypes with fewer than 1000 commenters were excluded at this stage (ie, *MyProAna* and *bulimia*). Consequently, the analyses regarding Objective 2 were conducted for 4 subtypes of EDR subreddits: 2 that are conceptualized as low recovery focus (ie, proeating disorder subreddits and thinspiration) and 2 that are conceptualized as high recovery focus (ie, prorecovery eating disorder subreddits and prorecovery binge eating disorder). To examine the networks in sufficient detail and owing to the particular importance of the proeating disorder communities [6], only the analyses for the low recovery-focus subtypes are presented below. The analyses for the high recovery-focus subtypes are provided in [Multimedia Appendix 2](#) (supplementary analyses).

Low Recovery Focus: Proeating Disorder

In total, 974 ancillary subreddits had been contributed to by at least 1% (82) of the 8166 commenters associated with the *pro-eating disorder* subtype (ie, *proED* and *ProEDmemes*). 50 ancillary subreddits were identified, on which 61.95% (5059/8166) of the proeating disorder subtype's commenters also posted. The network analysis with community detection is presented in [Figure 2](#), with a summary of the 50 ancillary subreddits presented in [Table 1](#).

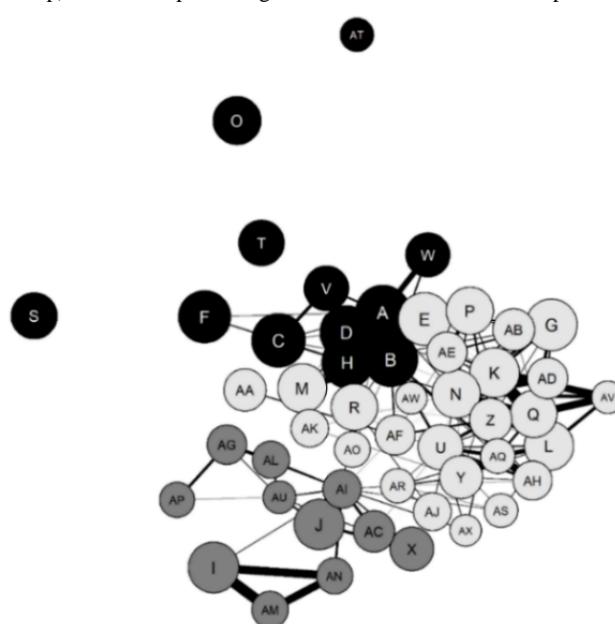


Table 1. Names and descriptions of ancillary subreddits on which proeating disorder commenters posted.

Community	Rank	Label	Subreddit name	Description
1 ^a	1	A	1200isplenty	1200kcal daily energy intake
1	2	B	fatlogic	Weight-loss
1	3	C	fasting	Fasting
1	4	D	progresspics	Photos of “body transformations”
1	6	F	BingeEatingDisorder	Binge eating disorder (19.08% threads mention recovery)
1	8	H	loseit	Weight-loss
1	15	O	EDFood	Food in the context of eating disorders
1	19	S	MyProAna	Anorexia nervosa (10.26% threads mention recovery)
1	20	T	thinspo	Thinspiration (0.24% threads mention recovery)
1	22	V	intermittentfasting	Fasting
1	23	W	1200isjerky	1200kcal daily energy intake
1	46	AT	proEDadults	Eating Disorders
2 ^b	9	I	selfharm	Self-harm
2	10	J	BPD	Borderline personality disorder
2	24	X	bipolar	Bipolar disorder
2	29	AC	morbiddarkquestions	Ask “dark questions”
2	33	AG	depression	Depression
2	35	AI	SanctionedSuicide	Suicide
2	38	AL	Anxiety	Anxiety
2	39	AM	selfharmpics	Self-harm
2	40	AN	MadeOfStyrofoam	Self-harm
2	42	AP	SuicideWatch	Suicide
2	47	AU	mentalhealth	Mental health
3 ^c	5	E	xxfitness	Female fitness
3	7	G	femalefashionadvice	Advice on female fashion
3	11	K	MakeupAddiction	Make-up addiction
3	12	L	muacirclejerk	Make-up addiction
3	13	M	fatpeoplestories	Stories about “fat people”
3	14	N	SkincareAddiction	“Everything skincare”
3	16	P	TheGirlSurvivalGuide	“A survival guide of ‘life pro-tips’ for the everyday girl”
3	17	Q	muacjdiscussion	Make-up addiction
3	18	R	vegan	Veganism
3	21	U	badwomensanatomy	Women’s anatomy
3	25	Y	awfuleyebrows	Photos of eyebrows that are judged to be “embarrassing, ugly, and downright weird”
3	26	Z	TrollXChromosomes	Women
3	27	AA	raisedbynarcissists	“Support group for people raised by (or being raised by) a narcissistic parent”
3	28	AB	FancyFollicles	Hair
3	30	AD	AsianBeauty	Beauty brands, cosmetics and skincare from Asia
3	31	AE	AskWomen	Ask women about any subject
3	32	AF	childfree	People who do not have or want children

Community	Rank	Label	Subreddit name	Description
3	34	AH	antiMLM	Multi-level marketing schemes
3	36	AJ	piercing	Piercing
3	37	AK	amiugly	Commenter posts photo and asks for feedback on appearance
3	41	AO	vegetarian	Vegetarianism
3	43	AQ	Youniqueamua	Make-up addiction
3	44	AR	Shoplifting	Shoplifting
3	45	AS	thesims	Computer game (life simulation game)
3	48	AV	BeautyGuruChatter	Discuss beauty "influencers" and "YouTubers"
3	49	AW	bulletjournal	Method of organisation
3	50	AX	actuallesbians	Cis- or trans-lesbians

^aCommunity 1=Eating/Body.

^bCommunity 2=Mental health.

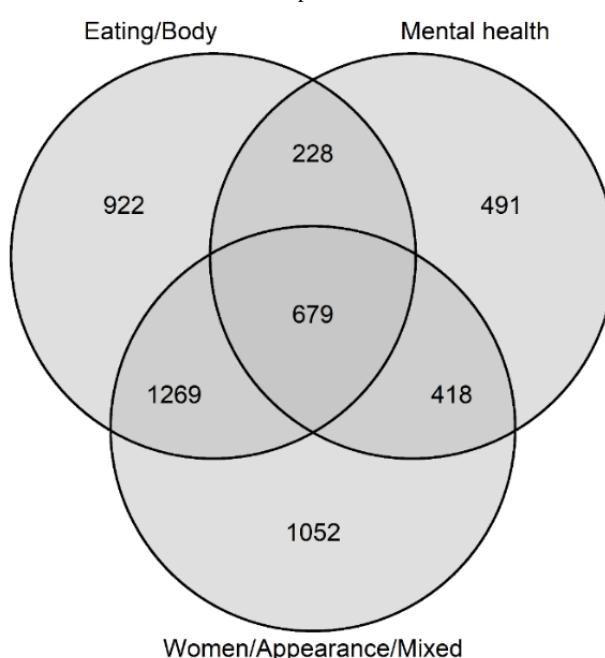
^cCommunity 3=Women/Appearance/Mixed.

As shown in [Figure 2](#) and [Table 1](#), the algorithm detected 3 communities within the proeating disorder network. Community 1 (black circles) was labelled *Eating/Body* as the ancillary subreddits were related to restrictive eating (eg, *1200isplenty*, *fasting*, and *intermittentfasting*), weight loss or body transformations (eg, *loseit*, *fatlogic*, and *progresspics*), or eating disorders (ie, *BingeEatingDisorder*, *MyProAna*, and *proEDadults*). Community 2 (dark gray circles) was labelled *Mental health* as the subreddits mainly related to mental health conditions (eg, *depression*, *Anxiety*, and *bipolar*) or related issues (eg, *selfharm*, *SanctionedSuicide*, and *SuicideWatch*). Community 3 (light-gray circles) was labelled

Women/Appearance/Mixed as the subreddits related to women (eg, *xxfitness*, *TheGirlSurvivalGuide*, and *AskWomen*), appearance (eg, *MakeupAddiction*, *BeautyGuruChatter*, and *amiugly*), or mixed topics (eg, *vegan*, *childfree*, and *raisedbynarcissists*).

Of the 5059 proeating disorder commenters, 67.56% (3418) also posted on ancillary subreddits within the Women/Appearance/Mixed community, compared with 61.24% (3098) and 35.90% (1816) in the Eating/Body and Mental health communities, respectively. [Figure 3](#) presents the commenter overlaps between the 3 proeating disorder communities.

Figure 3. Commenter overlap between proeating disorder communities. Values represent the number of commenters in the proeating disorder network (n=5059) who posted in the 3 communities (represented by the 3 circles). Values in overlapping areas indicate the number of commenters who posted in 2 or more communities. The areas of circles are unscaled and do not represent the size of communities.



Low Recovery Focus: Thinspiration

In total, 3932 ancillary subreddits had been contributed to by at least 1.01% (16) of the 1580 commenters associated with the *thinspiration* subtype (ie, *thinspo*). A total of 50 ancillary subreddits were identified on which 68.73% (1086/1580) *thinspiration* subtype's commenters also posted. The network analysis with community detection is presented in [Figure 4](#), with a summary of the 50 ancillary subreddits presented in [Table 2](#).

As shown in Figure 4 and Table 2, the algorithm detected 5 communities within the thinspiration network. Community 1

Figure 4. Thinspiration network. Letters correspond to ancillary subreddits. Black circles represent community 1 (*Pornography: 1*), dark-gray circles represent community 2 (*Pornography: young/small*), mid-gray circles represent community 3 (*Pornography: 2*), the light-gray circle represents community 4 (*ProEDmemes*), and the white circle represents community 5 (*proED*). The size of circles represents the ancillary subreddit mean rank (larger circle=higher rank), and thickness of the lines represents the mean degree of commenter overlap between each pair of subreddits (thicker line=larger overlap). No lines representing <0.25 mean commenter overlap are displayed.

(black circles) was labelled *Pornography*: 1 as the ancillary subreddits were all pornographic in nature. Community 2 (dark-gray circles) was labelled *Pornography*: *young/small* as it mainly comprised pornographic subreddits that explicitly referred to women being young (eg, *LegalTeens* and *18_19*) or small (eg, *xsmallgirls*, *TinyTits*, and *dirty small*). Community 3 (mid-gray circles) was labelled *Pornography*: 2 as all the subreddits were pornographic. Community 4 (light-gray circle) was labelled *ProEDmemes* as it comprised only 1 subreddit, *ProEDmemes*. Similarly, community 5 (white circle) was labelled *proED*, as it consisted of *proED* only.

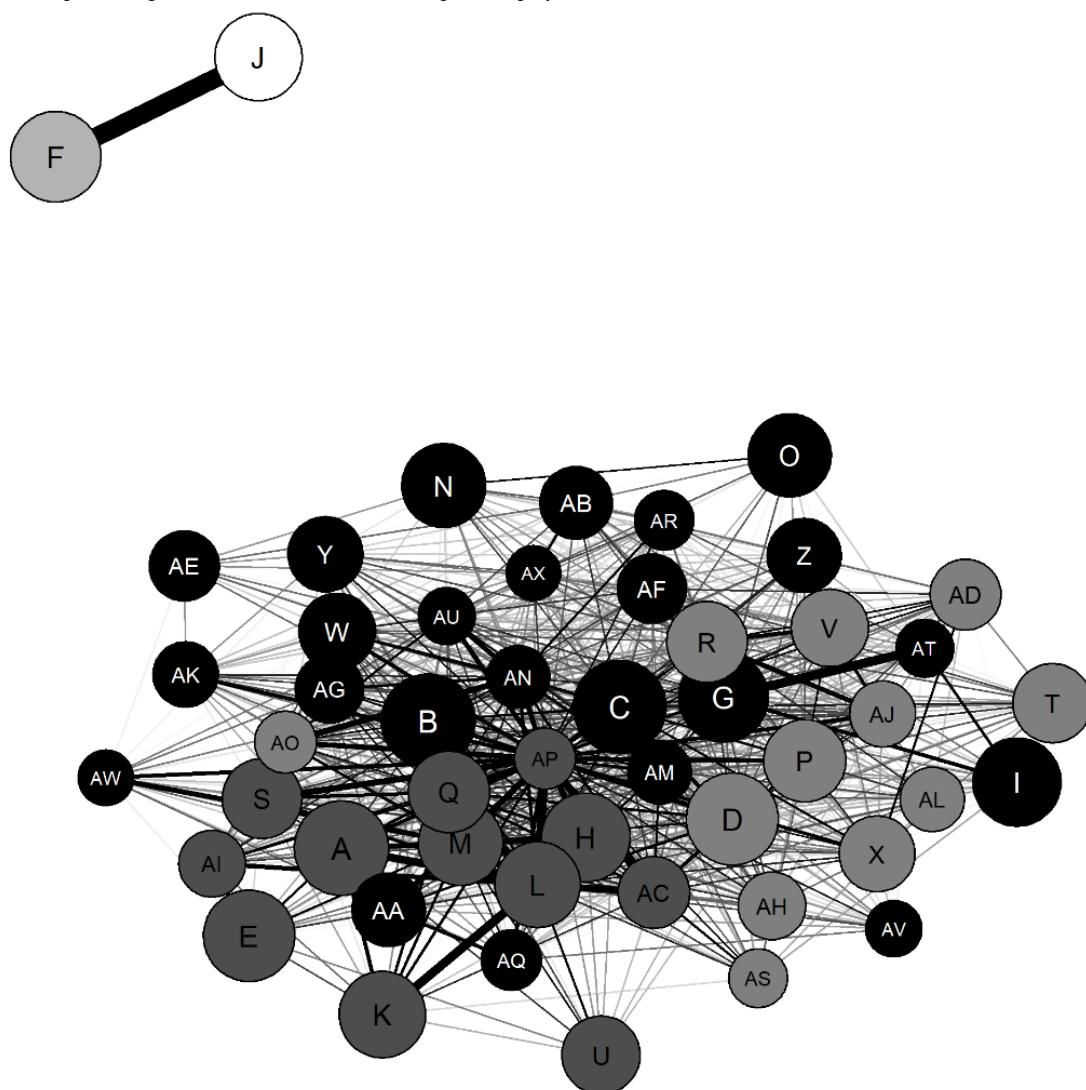


Table 2. Names and descriptions of ancillary subreddits on which thinspiration commenters posted.

Community	Rank	Label	Subreddit name	Description
1 ^a	2	B	CuteLittleButts	Pornography ^b
1	3	C	SexyTummies	Pornography
1	7	G	fitgirls	Pornography
1	9	I	SkinnyWithAbs	Pornography
1	14	N	(omitted from report) ^c	Pornography
1	15	O	(omitted from report) ^c	Pornography
1	23	W	Ifyouhadtopickone	Pornography
1	25	Y	WtSSTaDaMiT	Pornography
1	26	Z	theratio	Pornography
1	27	AA	HugeDickTinyChick	Pornography
1	28	AB	goddesses	Pornography
1	31	AE	NSFWfashion	Pornography
1	32	AF	lingerie	Pornography
1	33	AG	FestivalSluts	Pornography
1	37	AK	uncommonposes	Pornography
1	39	AM	ginger	Pornography
1	40	AN	HappyEmbarrassedGirls	Pornography
1	43	AQ	distension	Pornography
1	44	AR	Ohlympics	Pornography
1	46	AT	hardbodies	Pornography
1	47	AU	girlskissing	Pornography
1	48	AV	GirlswithNeonHair	Pornography
1	49	AW	whenitgoesin	Pornography
1	50	AX	PrettyGirls	Pornography
2 ^d	1	A	xsmallgirls	Pornography
2	5	E	skinnytail	Pornography
2	8	H	funsized	Pornography
2	11	K	aa_cups	Pornography
2	12	L	TinyTits	Pornography
2	13	M	dirtysmall	Pornography
2	17	Q	LegalTeens	Pornography
2	19	S	18_19	Pornography
2	21	U	petite	Pornography
2	29	AC	palegirls	Pornography
2	35	AI	tanlines	Pornography
2	42	AP	adorableporn	Pornography
3 ^e	4	D	datgap	Pornography
3	16	P	bodyperfection	Pornography
3	18	R	tightdresses	Pornography
3	20	T	legs	Pornography
3	22	V	randomsexiness	Pornography

Community	Rank	Label	Subreddit name	Description
3	24	X	BonerMaterial	Pornography
3	30	AD	bikinis	Pornography
3	34	AH	nsfwoutfits	Pornography
3	36	AJ	girlsinyogapants	Pornography
3	38	AL	pokies	Pornography
3	41	AO	StraightGirlsPlaying	Pornography
3	45	AS	SexyFrex	Pornography
4 ^f	6	F	ProEDmemes	Eating disorders (2.42% threads mention recovery)
5 ^g	10	J	proED	Eating disorders (11.75% threads mention recovery)

^aCommunity 1=*Pornography*: 1.

^bThe term *Pornography* is used generally to describe any subreddit featuring material for the ostensibly exclusive purpose of sexual arousal.

^cThe name of the subreddit relates to a specific person and is omitted from the report.

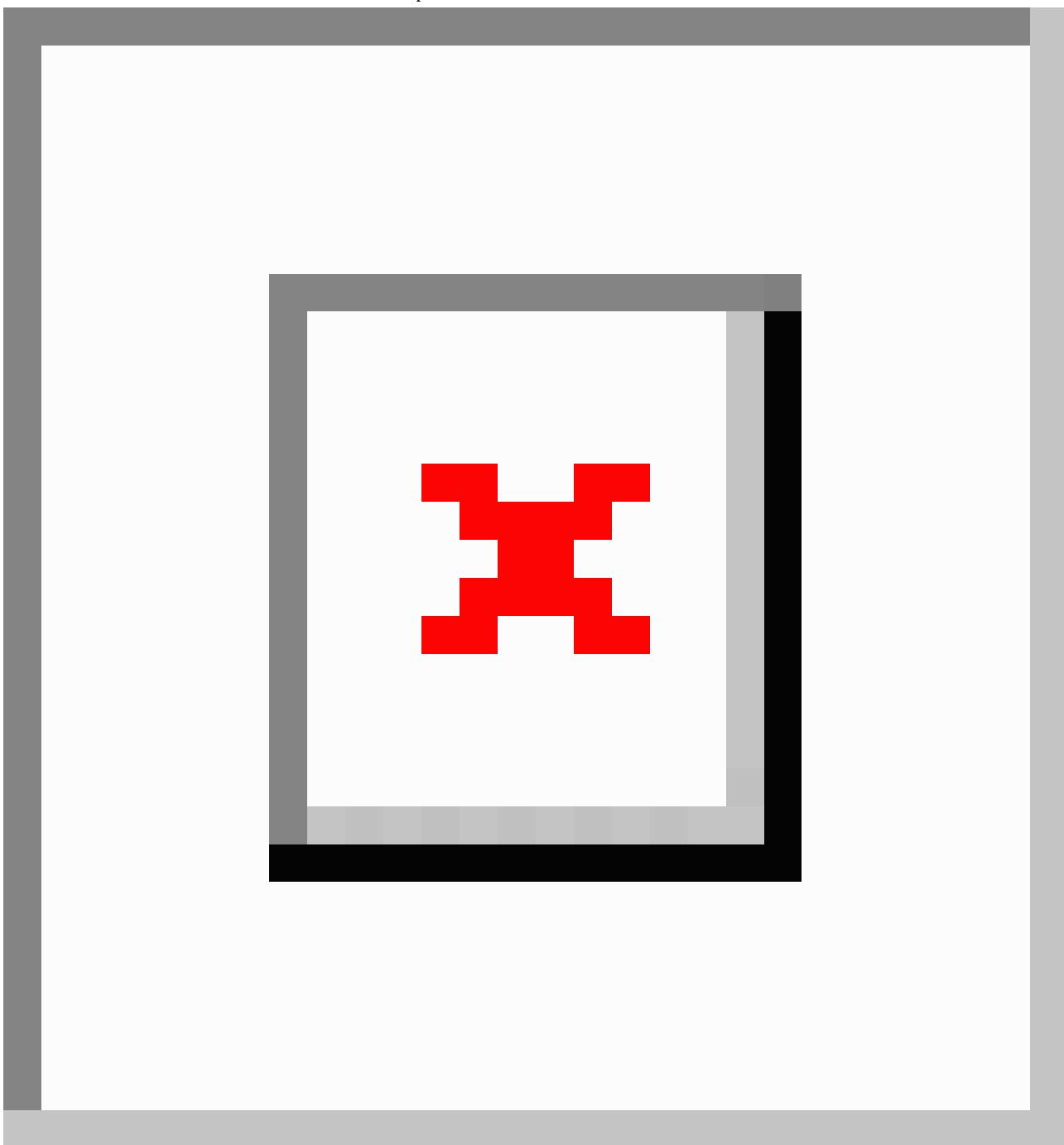
^dCommunity 2=*Pornography: young/small*.

^eCommunity 3=*Pornography*: 2.

^fCommunity 4=*ProEDmemes*.

^gCommunity 5=*proED*.

Figure 5. Commenter overlap between thinspiration communities. Values represent the number of commenters in the thinspiration network (N=1086) who posted in the 5 communities (represented by the 5 ovals). Values in overlapping areas indicate the number of commenters who posted in 2 or more communities. The areas of ovals are unscaled and do not represent the size of communities.



Of the 1086 thinspiration commenters, 67.59% (734) also posted on ancillary subreddits within the Pornography: 1 community, compared with 59.85% (650), 46.13% (501), 20.99% (228), and 10.87% (118) in the Pornography: young/small, Pornography: 2, *proED*, and *ProEDmemes* communities, respectively. Figure 5 presents the commenter overlaps between the 5 thinspiration communities.

As shown in Figure 5, a clear distinction was observed between the pornography communities (ie, Pornography: 1, Pornography: 2, and Pornography: young/small) and proeating disorder communities (ie, *ProEDmemes* and *proED*). As such, the overlap between these 2 groups of communities was calculated.

Of the 1086 commenters in the thinspiration commenter network, 78.18% (849/1086) only posted on ancillary subreddits within the pornography communities, whereas 16.67% (181/1086) only commented on subreddits within the proeating disorder communities. However, 5.16% (56/1086) of the commenters posted on subreddits within both groups of communities, indicating a small commenter overlap between these groups.

Discussion

Summary

Using the example of EDR subreddits, this study demonstrated a methodology that addressed 2 objectives: (1) determine subtypes of forums related to a similar mental health issue and (2) elucidate the characteristics (ie, shared interests) of the subtypes' commenters by identifying other forums to which they contribute (ie, ancillary subreddits) and investigating the commenter overlap between these subreddits. These 2 objectives were achieved using mixed-methods approaches, comprising techniques that included a network analysis with community detection, text mining, and a manual review of the forums' topics. Following the identification of 6 subtypes of EDR subreddits, the report focused on 2 specific subtypes—proeating disorder and thinspiration. The proeating disorder commenters also contributed to subreddits relating to the body and eating, mental health, and women, appearance, and mixed topics. Regarding the thinspiration subtype, 78% (849/1086) of the commenters also contributed to pornographic subreddits, whereas 17% (181/1086) also commented on proeating disorder subreddits.

Principal Findings

Objective 1: Determining Subtypes of Eating Disorder–Related Subreddits

Concerning the first objective, through the use of network analyses with community detection and a previously detailed text-mining technique [14], 2 communities of EDR subreddits were identified that differed in terms of their degree of recovery focus (ie, low recovery focus and high recovery focus). The detection of these 2 communities and the relatively small (5%) commenter overlap between them is in line with similar findings relating to the proeating disorder and prorecovery communities on *Twitter* [13]. Furthermore, previous analyses of online data from an EDR online forum indicated that commenters in the least recovery-focused eating disorder stages of change (ie, precontemplation and relapse) used recovery words less frequently than commenters in more recovery-focused stages of change [15]. The findings in this study offer support for this, as recovery was indeed mentioned less frequently in ostensibly proeating disorder subreddits (ie, *MyProAna*, *proED*, *ProEDmemes*, and *thinspo*) than more recovery-focused subreddits (ie, *BingeEatingDisorder*, *bulimia*, *eating_disorders*, *EatingDisorders*, and *fuckeatingdisorders*). Although the text-mining approach used textual data to assess the frequency of words' occurrence in comment threads, the network analyses with community detection utilized behavioral data (ie, data about the subreddits to which commenters contributed). As the results of the text-mining approach (ie, degree of recovery focus) clearly align with the detected communities (ie, the communities appear to differ on the basis of recovery focus), a strength of this mixed-methods approach is that the 2 distinct techniques appear to provide a degree of convergent validity to each other.

Objective 2: Profiling Eating Disorder–Related Commenters Based on Contributions to Ancillary Subreddits

With regard to the second objective, the topics in which commenters on proeating disorder subreddits were interested are in line with other research [10,11,16]. Specifically, commenters on proeating disorder subreddits were also found, unsurprisingly, to be interested in the body, eating, mental health, and appearance. As several identified subreddits were specific to women (eg, *femalefashionadvice* and *TheGirlSurvivalGuide*), the results also supported previous findings that suggest women are more likely to engage with pro-EDR online content [4,9,30].

In contrast to the proeating disorder results, the findings concerning thinspiration commenters were of great surprise. Namely, a clear majority of thinspiration commenters (78%) had also contributed to pornographic subreddits. Furthermore, a specific group of commenters contributed to pornographic subreddits that had names suggesting that women were young (including terms such as *legal* or *18*) or small (including terms such as *tiny*, *petite*, and *small*). This finding is in line with previous research, which concluded that thinspiration images were typically sexually suggestive [30-32]. In fact, one study [32] actually identified pornographic images in their search for thinspiration (and fitspiration) content, although these were excluded from the subsequent analyses. As indicated in this study, the distinction between thinspiration and pornographic material is not clear. As such, it is important that researchers do not exclude specific material (eg, pornographic images) from future analyses as this might lead to a sanitized understanding of thinspiration content. This study therefore highlights an issue of potentially great concern. Specifically, as thinspiration content typically comprises photos of extremely thin women [30], the people submitting this content might not be fully aware of how their content is subsequently used. Speculatively, this lack of a complete understanding might lead to people unintentionally entering into vulnerable situations and would therefore clearly warrant further research.

Although the findings of this study might suggest that people engage with thinspiration for pornographic reasons, it is also possible that engagement with pornography and eating disorder symptomatology are related. For example, pornographic content might be viewed for the purpose of body comparison. However, only 2 studies appear to have explicitly investigated the relationship between pornography use and eating disorder symptomatology, both of which recruited male samples exclusively [33,34]. Given the apparent lack of research investigating this relationship in a female sample and owing to proeating disorder commenters typically being women [9], this topic also represents an important avenue for future research.

Overall, a strength of the findings in this study is that they complement previous studies. Although there are limitations (detailed below) to the current mixed-methods approach, its techniques can compensate for the methodological limitations of the previous studies. For example, survey-based studies concerning users of online forums are unlikely to have representative samples. As the current approach used data

concerning all the commenters on public forums, it is not subject to this limitation. As a result, by consolidating the findings generated from these distinct methodological approaches, there can be greater confidence that results do not simply represent an artefact of one particular technique [35].

Limitations

The findings in this study must be considered in relation to the limitations of the data and methodology. First, it is important to note that the *Reddit* data are unsolicited. Although this represents a strength of the data (eg, the data are not liable to demand characteristics), this also results in a significant amount of noise in the data. Steps were taken to reduce this noise, such as only including 50 ancillary subreddits with a large number and proportion of EDR commenters in the network analyses. This approach identified the most representative subreddits by excluding very small subreddits (many of which had a high proportion but small number of EDR commenters) and very large subreddits (many of which had a large number but low proportion of EDR commenters). However, the effects of other sources of noise in the data are more difficult to mitigate. For example, the same person might have more than one *Reddit* username, which might lead to an underestimation of commenter overlap. Additionally, *bots* (ie, automated software) exist that comment widely on subreddits and which might contribute to an overestimation of commenter overlap. Although strategies exist to identify bots [16,36], these might also exclude actual users. For this reason, bots (except *AutoModerator*, a generic *Reddit* bot) were not excluded, to adopt a conservative approach to our analyses. To minimize the effects of these sources of noise, the conclusions are based on communities of subreddits, rather than individual subreddits. Although not necessarily a limitation of this study, caution should be exercised in generalizing these findings to people who have read, but not commented on, the online content. Exploring communities based on the content that users read would be important but ethically problematic, as this would likely require access to data that are not publicly available. Despite not being able to generalize to the readers of forums, Aardoom et al [37] found that most survey respondents (87.2%) recruited from a prorecovery EDR forum posted content, whereas the remainder only read content. Furthermore, algorithms exist that recommend subreddits in which users might be interested [38]. Therefore, by focusing on commenters, users can be ensured to be actively engaged with the content, rather than being passively exposed to it. Similarly, private subreddits were not included in this study for primarily ethical reasons. However, a private recovery-focused EDR subreddit is advertised on a number of the public EDR subreddits. As such, the results regarding the high recovery-focus subreddits (detailed in [Multimedia Appendix 2](#)) might have differed if the private subreddit's commenters were included. However, the private recovery-focused subreddit is less likely to influence the low recovery-focus analyses presented above.

Implications

With regard to the approach used for the first objective, the findings in this study have implications for how mental health-related online communities should be conceptualized

and investigated in future research. Specifically, when comparing multiple communities, the degree of user overlap between these should be acknowledged. For example, a previous study compared the frequency of fitness tracker mentions between 3 EDR subreddits (ie, *proED*, *fuckeatingdisorders*, and *EatingDisorders*) [14]. By considering how these forums overlap, a clearer and more detailed interpretation of the characteristics of these forums' commenters could be achieved.

Concerning the second objective's methodological approach, the findings have implications for future research and the design of Web-based psychological interventions for mental health issues. With regard to future research, the approach presented here is entirely reproducible and can be used to explore similar questions in other groups of commenters of particular theoretical interest (eg, relating to other mental health conditions). The methodology could also be easily extended to explore longitudinal—and, therefore, causal—patterns of commenting. The approach is also useful for hypothesis generation and identifying new avenues of research. As detailed above, this study generated a surprising finding, in that over 3 quarters of *thinspiration* commenters also commented on pornography. As this relationship had not been identified before, it is a clear indicator of how this approach can be used to identify areas that require greater research attention. Concerning implications for psychological interventions, the current approach can identify other topics that are of interest to people commenting on mental health-related online discussion forums. For example, proeating disorder commenters were observed to be also interested in topics such as body, eating, mental health, and appearance. Consequently, these topics confirm the importance of existing EDR intervention focuses (eg, eating and body shape and weight concerns) [39]. These findings could also be used to more accurately tailor interventions to the target population's characteristics (eg, topics of interest), potentially increasing adherence to the programs [3]. Another implication for psychological interventions is that this approach can identify other forums in which there is a high activity of mental health-related forums' commenters. In the case of proeating disorder commenters, they were also observed to be active in subreddits including *1200isplenty*, *loseit*, and *progresspics*. As some mental health-related communities (eg, proeating disorder) might be unlikely to promote psychological interventions, the current approach could be utilized to identify the communities in which these users also tend to post. As a result, these communities could be approached to provide an alternative way in which to reach these people and to target prevention-focused interventions.

Conclusions

In summary, this study has presented a reproducible and primarily data-driven methodology that can be used to (1) identify subtypes of mental health-related forums and (2) identify the interests of the commenters who post on the forums comprising these subtypes. This offers a powerful technique for hypothesis-generation and informing strategies for psychological intervention. Employing different methodologies to explore the same research question is vital to ensure that findings are not solely a result of a particular methodological design [35]. This approach therefore offers one way in which

to triangulate methodologically the findings obtained through, contributes to a more robust evidence base. for example, previous survey-based research and consequently

Acknowledgments

The authors would like to extend their gratitude to Miss Helen A Fay and Dr Lara Ayala-Nunes for their feedback on aspects of an early draft of this manuscript. DM is the recipient of a doctoral studentship from WMG, University of Warwick, and Coventry and Warwickshire NHS Partnership Trust. CSQS is supported by an Overseas Postdoctoral Fellowship from the National University of Singapore. The authors also extend their gratitude to the peer-reviewers of this paper, whose feedback was both considered and constructive in nature.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Runnable code.

[[ZIP File \(Zip Archive\), 20KB - mental_v6i4e12555_app1.zip](#)]

Multimedia Appendix 2

Supplementary material.

[[PDF File \(Adobe PDF File\), 823KB - mental_v6i4e12555_app2.pdf](#)]

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Abbreviations

EDR: eating disorder-related

Edited by J Torous; submitted 19.10.18; peer-reviewed by CA Almenara, S Cristol; comments to author 01.12.18; revised version received 16.01.19; accepted 30.01.19; published 22.04.19.

Please cite as:

McCaig D, Elliott MT, Siew CSQ, Walasek L, Meyer C

Profiling Commenters on Mental Health–Related Online Forums: A Methodological Example Focusing on Eating Disorder–Related Commenters

JMIR Ment Health 2019;6(4):e12555

URL: <http://mental.jmir.org/2019/4/e12555/>

doi: [10.2196/12555](https://doi.org/10.2196/12555)

PMID: [31008715](https://pubmed.ncbi.nlm.nih.gov/31008715/)

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Original Paper

Seasonality Patterns of Internet Searches on Mental Health: Exploratory Infodemiology Study

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Abstract

Background: The study of seasonal patterns of public interest in psychiatric disorders has important theoretical and practical implications for service planning and delivery. The recent explosion of internet searches suggests that mining search databases yields unique information on public interest in mental health disorders, which is a significantly more affordable approach than population health studies.

Objective: This study aimed to investigate seasonal patterns of internet mental health queries in Ontario, Canada.

Methods: Weekly data on health queries in Ontario from Google Trends were downloaded for a 5-year period (2012-2017) for the terms “schizophrenia,” “autism,” “bipolar,” “depression,” “anxiety,” “OCD” (obsessive-compulsive disorder), and “suicide.” Control terms were overall search results for the terms “health” and “how.” Time-series analyses using a continuous wavelet transform were performed to isolate seasonal components in the search volume for each term.

Results: All mental health queries showed significant seasonal patterns with peak periodicity occurring over the winter months and troughs occurring during summer, except for “suicide.” The comparison term “health” also exhibited seasonal periodicity, while the term “how” did not, indicating that general information seeking may not follow a seasonal trend in the way that mental health information seeking does.

Conclusions: Seasonal patterns of internet search volume in a wide range of mental health terms were observed, with the exception of “suicide.” Our study demonstrates that monitoring internet search trends is an affordable, instantaneous, and naturalistic method to sample public interest in large populations and inform health policy planners.

(JMIR Ment Health 2019;6(4):e12974) doi:[10.2196/12974](https://doi.org/10.2196/12974)

KEYWORDS

anxiety; depression; OCD; schizophrenia; autism; suicide; seasonality; Google; internet; infodemiology; infoveillance; mental health

Introduction

There is emerging evidence on the existence of seasonal patterns of public interest in psychiatric disorders and conditions [1]. The increasing number of studies on the topic is associated with several factors such as the identification of seasonal patterns of population behavior in humans [2,3] and animals [4] and the

realization that understanding temporal variation of public interest in health-related issues has important theoretical as well as practical implications on service planning and delivery [5-7]. The terms “infodemiology” or “infoveillance” were coined to describe novel methods to analyze search and publication behavior (for example, tweets) on the Internet to study trends and human behaviour to inform public health practice and policy

[6]. For example, the availability of up to date information on internet searches may lead to radical rethinking of the need to reduce the optimal interval between service planning and delivery [6] and affect the frequency by which public health policies are updated. There is ample evidence that psychiatric disorders and symptoms often have seasonal patterns [8]: Seasonal affective disorder [9], in which depressive symptoms worsen during a typical time each year, is perhaps the best example of seasonal changes in psychiatric symptoms. In addition, studies have reported seasonality patterns for anxiety disorders [10], obsessive-compulsive disorder (OCD) [10], and psychotic disorders [11]. Most recently, evidence showed that seasonality patterns are similar across different climate zones [1].

Until recently, the sampling of populations for information on mental health was mostly conducted using epidemiological surveys, which have been widely used to study evidence on the level of disorders in the general population [12,13]. However, the majority of epidemiological surveys involve a compromise between the need to acquire frequent measurements and lengthy follow-up periods, whereas the study of seasonality effects requires high-resolution and accurate time-series measurements. Furthermore, population surveys are costly and limited by respondents' reticence associated with privacy and stigma. For example, respondents are reluctant to report data that are associated with social stigma [14] or may expose their income [15]. Finally, there is evidence of progressive, constant reduction in response rates to epidemiologic public health studies [16].

Limitations of existing epidemiological surveys are associated with a dearth of knowledge surrounding the possible existence of seasonal changes in public interest of psychiatric disorders and conditions. This knowledge gap is of importance, given the growing recognition of public interest in mental health and psychiatric issues [17], the need for effective population informatics, and limited temporal resolution of existing clinical databases or traditional epidemiological surveys [18].

Over the last two decades, progress has been made in our ability to assess public interest in mental health issues by tracking internet searches. The internet became the most relied upon health search resource as early as 2006 [19], and there is evidence that internet search volumes are associated with real-time markers of illness [6,20]. Internet searches for health information appear to be more common in individuals who experience difficulty accessing health care services [21]. There is evidence that individuals with a history of mental health issues are more likely to use the internet for mental health searches than those without any mental health issues [22]. Thus, tracking internet search queries may represent an advance in our ability to monitor continuous population trends related to mental health issues [1]. However, although recent studies recognize the potential of internet search studies to address existing gaps in the epidemiological literature [23,24], the field is still in its early stages.

Internet searches are most frequently performed using the Google search engine. In 2017, Google search accounted for 67.5% of overall searches in Canada, over three times the number of Yahoo searches (21.5%) [25]. A recent study of

Google mental health queries in the United States and Australia suggested the presence of seasonal patterns of mental health searches [1]. Specifically, the authors reported that winter peaks and summer troughs accounted for 14% and 11% of the differences in search volumes for the United States and Australia, respectively. The authors reported that seasonal patterns were evident, with some variation, for specific mental health categories (ie, anxiety, attention-deficit-hyperactivity disorder, anxiety, bipolar disorder, depression, anorexia or bulimia, OCD, schizophrenia, and suicide). However, the study targeted two large, geographically and demographically diverse countries that cover opposite climate zones. There is at least preliminary evidence [26] that factors associated with climate (eg, temperature and evaporation) may be associated with seasonal variations in mental health problems, and there is a need to study the seasonality of mental health symptoms in smaller areas in a more homogenous climate.

To date, however, no studies of internet queries have examined aspects of seasonality of interest in psychiatric conditions in smaller geographical areas that are relatively homogenous with regard to climate. This exploratory study investigated seasonal patterns of Google queries on mental health diagnoses and symptoms in Ontario, Canada's most populous province and home to over 13 million individuals. Given the lack of existing research in this field and the inability to record specific population demographic information, the sample was limited to Ontario in order to reduce the possible influence of different climate zones.

Methods

Data Collection

Data were downloaded from Google Trends [27], the public database of Google queries. Google Trends presents data as a relative search volume in a normalized format. The period with the highest proportion of searches related to the key term within a category receives a value of 100, and a value of 50 is 50% of that maximum proportion, that is, the point over the course of the selected period (5 years in this study) at which the search volume is greatest for a search term is provided a value of 100, and the remaining values are assigned as a proportion of the points of the maximum search volume. Google Trends allows extraction of data for only a single search term at a time and does not provide absolute values of search data.

English search terms were captured from Google Trends data in Ontario for the 5-year period from August 2012 to August 2017. For the purpose of this study, primary search terms were similar to those chosen by Ayers and colleagues [1]—“anxiety,” “autism,” “bipolar,” “depression,” “OCD,” “schizophrenia,” and “suicide”—these terms were then run within and downloaded from Google Trends’ mental health category.

We measured seasonality of search interest in general aspects of health by downloading search results for the term “health” in the general health category. To measure the seasonality of even broader search interests that extend well beyond health-related issues, we downloaded search results for the content-agnostic term “how” that can be used as an adverb, a

conjunction, or a noun. Due to the paucity of research in this area, these search terms were not based on previous study but were rather decided upon based on consensus opinion between the authors.

Using Google Trends' related-term option, we extracted the top 10 related searches for each of our items in their respective categories. We then excluded searches that were ostensibly unrelated to the question of this study (eg, the term "Suicide Squad" denoting a blockbuster movie rather than a mental health query). Terms that included overlap between search terms (eg, "anxiety and depression") were excluded from both search lists. Thereafter, the original search term (eg, "bipolar") and the remaining related searches were used to calculate the mean value for the weekly data point of the 5-year time series.

Data Analysis

Seasonal Components

Our primary aim was to assess whether a significant seasonal signature was detected for each of the search terms across a 5-year period. Using the R package WaveletComp [28], separate continuous wavelet transform analyses were performed to explore periodicity in the 5-year time series for each search term. A wavelet transform is a function which, in this study, was used to divide a continuous time series signal into smaller components (wavelets) and then examine the intensity and timing of the seasonal periodicity of the original time series. The process is similar to a Fourier transform but can effectively increase the signal-to-noise ratio, providing a more accurate representation of the trend underlying the time series [29]. In this study, the wavelet transform was used for smooth high-resolution time series data (ie, weekly data points over a 5-year period) to reduce noise, allowing for more clear observation of trends in the data over time. This method can be applied to any high-resolution data over time to decompress the signal (or data) in order to observe trends over time. Some other applications of the wavelet transform include image processing (eg, neuroimaging), pattern recognition, or noise reduction of any waveform data (eg, electroencephalogram signal).

Each series was decomposed in the time-frequency domain using a continuous wavelet transform. The resulting wavelet power spectrum was used to identify whether a significant 52-week periodic component was detected ($P<.05$). If no significant seasonal pattern was detected for a particular search term, no further analysis was performed for that term. The coefficients for each wave function were then extracted and plotted.

Seasonal Pattern Differences

Phase angle differences were calculated to assess timing differences between the wave functions of our search terms. Phase angle (measured from peak to peak) is the angular position along a sinusoidal function from -180° to $+180^\circ$, where these extreme values represent two waves that are completely out of phase, while 0° would represent waves that are completely in phase. In the case of this study, with a 52-week periodicity, a phase shift of $\pm 180^\circ$ would indicate that the peaks of two waves being compared (ie, peak search volume for two search terms) are occurring exactly 6 months apart, with a positive angle indicating that the second wave shifted later in the year and a negative value indicating that the second wave shifted earlier in the year, relative to the first wave. Phase angle difference was also calculated within each search term, across each of the 5 years in order to assess a shift in the peak search volume from year to year. In order to translate the phase angle difference value into approximate weeks of the year, the value in degrees was divided by 360° and multiplied by 52.

Finally, we measured differences in the magnitude of seasonal changes between our search terms. First, percent change in search volume from summer to winter was calculated for each of the 5 years of the study. Means and SD of percent change from summer to winter in search volume were calculated for each term. We then performed a one-way analysis of variance, followed by posthoc tests, to assess differences between search terms in their percent change in search volume between August 2012 and August 2017. A one-way analysis of variance was chosen over multiple *t* tests to reduce the risk of type I error.

Results

Seasonal Components

A significant 52-week seasonal component was found for all search terms, with the exception of "suicide" and our general control search term "how." The waves for the terms showing a significant seasonal component are shown in [Figure 1](#), and the raw data for search terms that showed no significant seasonality patters are featured in [Figure 2](#). Significant seasonal components for all items had peak search volumes over the winter months and troughs during the summer months. Amplitude changes of search volume, as represented in the difference from the mean search volume for each year, showed an upward trend across the 5-year period for each of the searches. In other words, the seasonal variability in interest observed for each term tended to increase from year to year (with the exception of a slight decrease in 2017), and higher peaks were seen in winters and lower troughs were seen in summers over time.

Figure 1. Change in relative search volume over time between search terms from August 2012 to August 2017. OCD: obsessive-compulsive disorder.

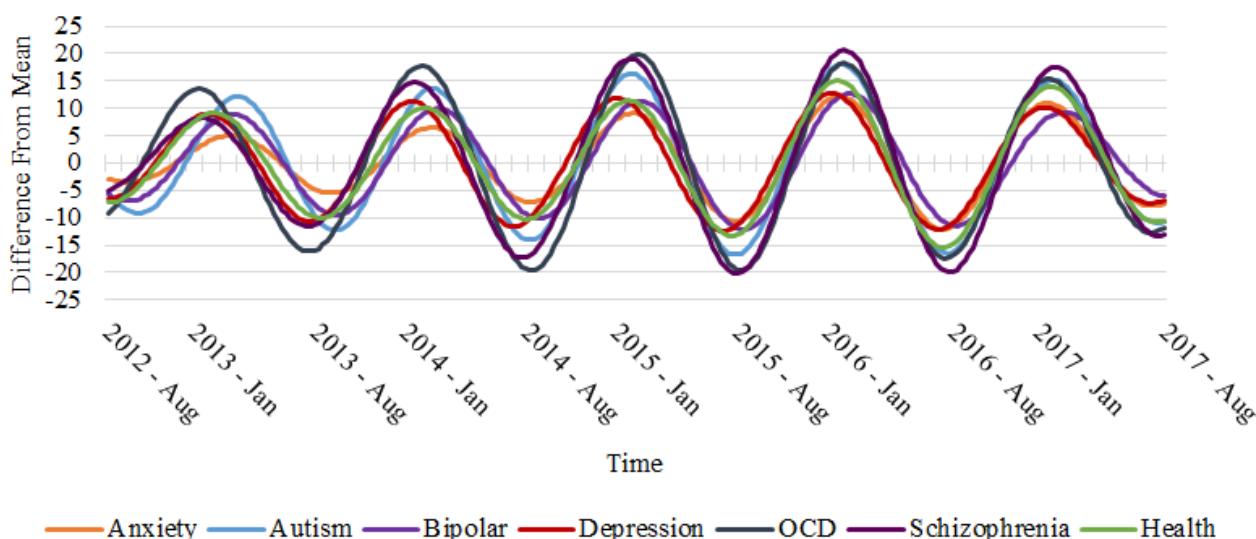
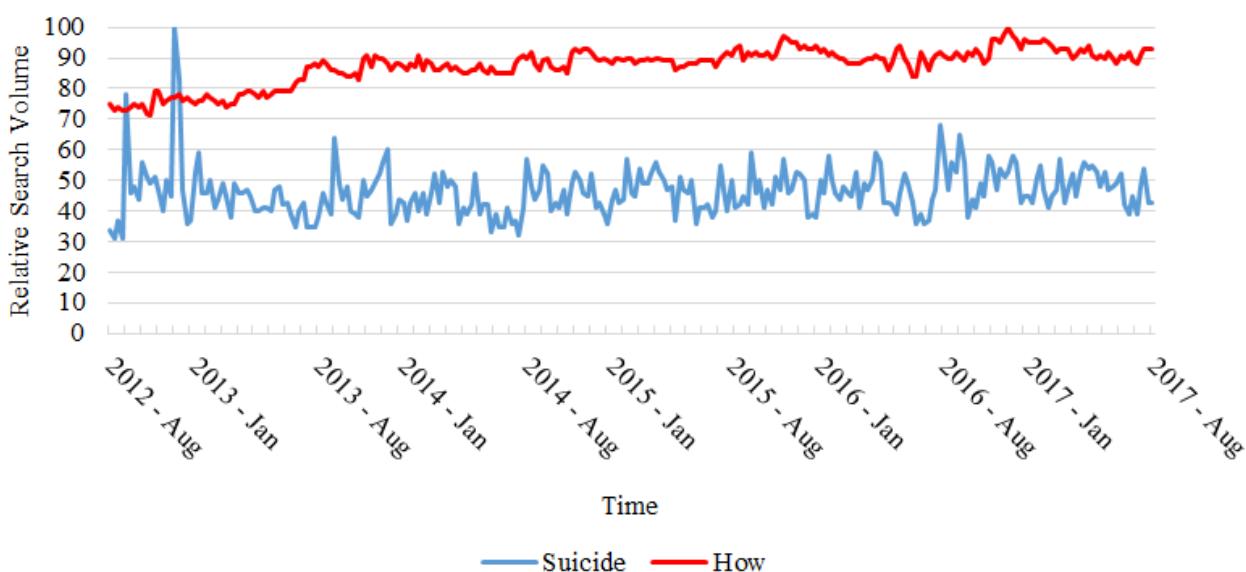


Figure 2. Nonseasonal search terms (raw data).



Magnitude of Seasonal Difference

Investigation of individual disorders showed that mean percent difference from winter to summer months was greatest for OCD (45.2%, SD 4.9%; 95% CI 40.8%-49.6%) and schizophrenia (43.3%, SD 10.5%; 95% CI 34.1%-52.5%). This indicates that the average 5-year peak search volumes for these terms were 45% and 43% higher in the winter than the lowest point in the summer, respectively. Autism also showed a similarly marked change in search volume, with a 37.5% difference from winter to summer (SD 6.6%; 95% CI 31.6%-43.4%). The differences for the remaining search terms were as follows: 21.2% for anxiety (SD 7.6%; 95% CI 14.6%-27.8%), 26.6% for bipolar disorder (SD 3.9%; 95% CI 23.5%-29.7%), and 28.7% for

depression (SD 2.5%; 95% CI 26.5%-30.9%). Our term for searches related to “health,” in general, showed a mean seasonal change of 31.6% (SD 6.4%; 95% CI 26.0%-37.2%).

The one-way analysis of variance comparing the mean percent change in search volume between all search terms was significant ($F_{6,28}=9.04$; $P<.001$; $\eta^2_p=.693$), indicating that the change in mean search volume from August 2012 to August 2017 was different between search terms. Results of the Tukey Honest Significant Difference posthoc comparisons are presented in Table 1. The greatest differences observed were for anxiety-schizophrenia ($P<.001$) and anxiety-OCD ($P<.001$), while the smallest differences were for bipolar-depression ($P>.99$) and OCD-schizophrenia ($P>.99$).

Table 1. Comparison of percent change in peak search volume and mean phase angle difference between terms across 5 years (August 2012 to August 2017). Phase angle values represent the difference in the timing of peak search volume between search terms across the 5-year search period. A positive phase angle difference represents a comparison in which the peak search volume for the second term is occurring later in the year relative to the first term, while a negative value indicates that peak volume for the second term occurs earlier in the year relative to the first. The value in parentheses is the value of the phase angle difference represented in weeks of the year.

Comparison	Mean difference (%) ^a	P value	Phase angle (degrees), weeks
Anxiety-autism	-16.2	.009	10.1 (1.5)
Anxiety-bipolar	-5.4	.85	14.6 (2.1)
Anxiety-depression	-7.5	.56	-22.3 (-3.2)
Anxiety-OCD ^b	-22.1	<.001	-7.5 (-1.1)
Anxiety-schizophrenia	-23.9	<.001	-10.8 (-1.6)
Anxiety-health	-10.4	.21	-21.0 (-3.0)
Autism-bipolar	10.8	.16	-4.5 (-0.7)
Autism-depression	8.7	.39	-36.9 (-5.3)
Autism-OCD	-5.9	.80	-22.1 (-3.2)
Autism-schizophrenia	-7.7	.53	-25.4 (-3.7)
Autism-health	5.8	.79	-16.7 (-2.4)
Bipolar-depression	-2.1	>.99	-32.4 (-4.7)
Bipolar-OCD	-16.7	.007	-17.6 (-2.5)
Bipolar-schizophrenia	-18.6	.002	-20.9 (-3.0)
Bipolar-health	-4.9	.89	-12.2 (-1.8)
Depression-OCD	-14.6	.02	14.8 (2.1)
Depression-schizophrenia	-16.4	.008	11.5 (1.7)
Depression-health	-2.8	.99	20.2 (2.9)
OCD-schizophrenia	-1.8	>.99	-3.3 (-0.5)
OCD-health	11.7	.11	11.5 (1.7)
Schizophrenia-health	13.6	.04	-5.4 (-0.8)

^aMean percent change in search volume between each pair of search terms are the results of the Tukey Honestly Significant Difference posthoc comparisons following one-way analysis of variance.

^bOCD: obsessive-compulsive disorder.

Timing Differences Between Search Terms

To assess differences in the timing for peak search volume between search terms across the 5-year period, the mean phase angle difference was estimated between all pairs of search terms (Table 1). Analysis of phase angle difference showed that the greatest difference in timing between any two search terms was between autism and depression, with a mean phase angle difference of -36.9° , corresponding to approximately 5.3 weeks, indicating that peak search volume occurred, on an average, 5.3 weeks earlier in the year for depression than for autism. The minimum phase angle difference was observed between “OCD” and “schizophrenia,” with a mean difference of -3.3° (or 0.48 weeks), indicating that these two searches were almost completely in phase, that is, peak search volume for these two terms occurred at almost exactly the same time for these two terms.

Five-Year Shift in Peak Search Volume

Phase angle difference was also calculated within each search term between consecutive years. As seen in Figure 3, there is a general negative shift in the search volume over the course of the 5-year period, indicating that peak search volume occurred slightly earlier in the winter months each year. The greatest year 1 to year 5 phase-angle shift was observed for autism, with a peak search volume occurring 7.5 weeks earlier in the winter of 2017 compared to that of 2013 (phase angle difference of -52.2°). The greatest difference between peaks in any range was from year 1 to year 3 for depression, with the peak in 2015 occurring 8.5 weeks earlier (phase angle difference of -58.7°) than that in 2013. Schizophrenia and OCD were the only searches to show a positive shift, with peak volume occurring later in the season from year to year. Complete results for each of these comparisons are presented in Table 2.

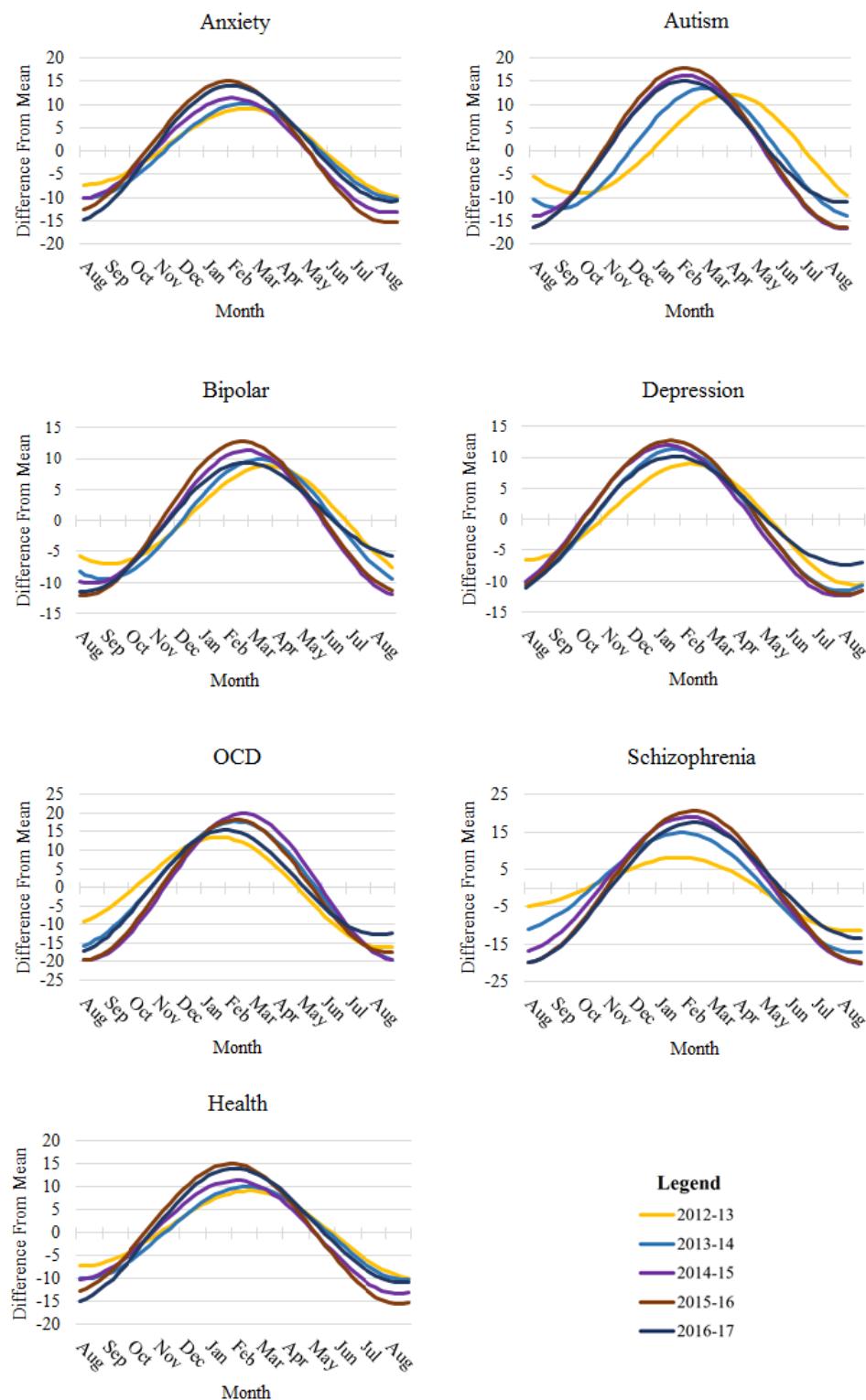
Figure 3. Peak search volume of search terms in different years. OCD: obsessive-compulsive disorder.

Table 2. Phase angle difference between years within each search term. The value in each cell is the phase angle difference for that year relative to the peak search volume for year 1 (column two). The value in parentheses is the phase angle difference converted to the corresponding number of weeks. A negative value indicates a shift earlier in the year, relative to the first, and a positive value indicates a shift later in the year, relative to the first.

Condition	Peak search, year 1	Year 2, phase angle (weeks)	Year 3, phase angle (weeks)	Year 4, phase angle (weeks)	Year 5, phase angle (weeks)
Anxiety	March, week 3	-31.3° (-4.5)	-44.7° (-6.5)	-48.4° (-7.0)	-42.3° (-6.1)
Autism	April, week 1	-29.8° (-4.3)	-52.7° (-7.6)	-53.9° (-7.8)	-52.2° (-7.5)
Bipolar	March, week 4	-17.2° (-2.5)	-33.3° (-4.8)	-36.2° (-5.2)	-29.5° (-4.3)
Depression	February, week 2	-50.7° (-7.3)	-58.7° (-8.5)	-54.7° (-7.9)	-49.0° (-7.0)
Obsessive-compulsive disorder	January, week 3	29.0° (4.2)	19.5° (2.8)	27.5 (4.0)	38.3° (5.5)
Schizophrenia	January, week 4	41.8° (6.0)	34.0° (4.9)	28.9° (4.2)	27.0° (3.9)
Health	February, week 3	-31.3° (4.5)	-44.7° (6.5)	-48.4° (7.0)	-42.3° (6.1)

Discussion

The present study was the first to investigate seasonal patterns of Google searches on psychiatric conditions in Ontario, Canada. We found evidence of seasonal patterns for the following search terms and their related queries: “anxiety,” “autism,” “bipolar,” “depression,” “OCD,” “schizophrenia” and “health.” Specifically, we found that winter-to-summer search query differences were maintained for all items with the exception of “suicide” and our general search term (“how”).

In general, our results are in line with previous clinical [11], population [10], or internet [1] studies that report seasonality patterns of mental health issues. Although we did not find seasonal effects for the general, content-agnostic term “how,” our findings demonstrate a similar, increased search interest in health, in general, and mental health terms, in particular, in Ontario during winter months as compared to summer months.

Interestingly, the magnitude of the majority of winter-to-summer search interest peaks in this study were higher than those previously reported for Australia and the United States [1], two large, geographically heterogeneous catchment areas. The difference may be partially accounted for by this study’s focus on Ontario, a single Canadian province that is more geographically homogenous.

The finding of winter peaks and summer troughs in search volumes of general health and mental health terms in Ontario may have several possible explanations. First, it is possible that this finding reflects a general increase in overall internet search activity. Theoretically, a winter decrease in outdoor activity may leave more time for internet searches, in general. There is evidence that Canadians spend less time outdoors in winter than their US counterparts [30]. This hypothesis is not supported, however, by the lack of a seasonality pattern for our general, content-agnostic, search term. Alternatively, it is possible that increases in general health and mental health search volumes in winter reflect decreased happiness in the population as well as increased severity or frequency of health-related issues. A recent study of nearly half-a-billion Twitter and Facebook social media posts [31] reported that cold weather, in particular, was associated with an increase and a decrease in negative and positive expressions of sentiment, respectively. Similarly, there is evidence that cold weather is associated with increased

respiratory illness [32] and mortality [33]. Although this is a plausible explanation, it is important to note that the finding of similar temporal patterns for different search terms does not necessarily imply shared or even related underlying risk factors.

Our findings suggest a potential overlap between public interest in OCD and schizophrenia, as interest peaks for the two search terms were almost completely in phase, suggesting very similar peak times during the year. In addition, the mean 5-year seasonal search interest differences were the largest for OCD and schizophrenia terms (45% and 43%, respectively), which were even higher than those for seasonal affective disorder, the prototypical seasonal disorder. Differences in percent change in peak search volumes between OCD and schizophrenia terms were not significant, and the two terms differed significantly from bipolar disorder, depression, and anxiety. These search term similarities are intriguing, given evidence of marked endophenotype differences between OCD and schizophrenia [34]. A possible explanation is that OCD and schizophrenia involve unusual and concerning cognitions and behaviors that are often hard to distinguish from one another [35] and may thus generate overlapping, higher internet search volumes.

We did not observe seasonal patterns of search interest for the term “suicide” and its related searches. Of our mental health-related search terms, “suicide” was the only one that does not pertain to a specific diagnostic category. Indeed, suicidal ideation and suicide rates are associated with multiple risk factors, some of which are not directly related to mental health disorders [36-38] and may have different or absent seasonal patterns. In addition, our findings are in agreement with a recent cross-sectional study in Italy [39] that did not show a statistically significant pattern for suicide and related search terms, resulting in white noise. However, existing studies on the occurrence of suicide have clearly and repeatedly reported a seasonal pattern. For example, a recent systematic review of the temporal distribution of suicide mortality [40] stated that 81.5% of studies of the monthly distribution of suicide monthly peaks corresponded, by study hemisphere, to spring and early summer. Similar results were observed for studies that examined suicide by season [40]. The difference between these findings and our own highlights the complex relationship between suicide-related search volumes and rates of completed suicide or suicide attempts. Solano and colleagues [39] examined the correlation between Google Search and Google News search volumes for

the words “suicide,” “to commit suicide,” and “how to commit suicide” and the national suicide rates in Italy between 2008 and 2012. Although the authors reported a significant correlation between searches for “suicide” and suicide rates, the search term lagged suicide attempts by 3 months, raising questions about the nature of the reported association. Furthermore, there was no association between suicide rates and Google searches for “how to commit suicide” or “to commit suicide.” Taken together, our study further highlights the complex association between internet searches on suicide and suicidal behavior, in particular, and internet searches and psychiatric disorders and conditions, in general.

Strengths of the study include its focus on a well-defined geographical area that lacks extreme within-region climate variations; reliance on a 5-year period with weekly data points; and the choice of the continuous wavelet transform, which allowed the isolation and identification of a significant seasonal component for each time series. On the other hand, an important limitation of the study is that the study of internet queries presents unique validation challenges, as seeking information on mental health conditions may not necessarily correspond to

actual mental illness in the individual performing the search. In addition, our ability to interpret the results is limited by the lack of demographic information on the sampled population. A third limitation of the present study is that, although there is evidence that the internet has become the most publicly available information search method, Google Trends data do not include absolute numbers. This limitation should be viewed in the context of the ability to quickly track very recent population behavior, which is a clear advantage. Thus, the use of internet query analysis for mental health planning and delivery should be viewed as complementary rather than a replacement for conventional population studies.

In conclusion, our study was the first to focus on mental health searches in Ontario. Seasonal components were detected for all mental health terms, with the exception of “suicide.” Overall, our study demonstrates the feasibility of performing longitudinal tracking of interest in mental health terms in Ontario, a complementary approach to traditional population health studies. Future studies should explore the association between internet search volumes and other online or offline markers of mental health.

Authors' Contributions

NS extracted the data and drafted the Introduction and Discussion sections. DC completed the analysis and drafted the Methods and Results sections. DS provided advice on all statistical analyses and contributed to all drafts of the manuscript. KR and RM provided advice on the methodology and contributed to all drafts of the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

OCD: obsessive-compulsive disorder

Edited by J Torous; submitted 28.11.18; peer-reviewed by P Chow, V Santos; comments to author 28.01.19; revised version received 11.02.19; accepted 13.03.19; published 24.04.19.

Please cite as:

Soreni N, Cameron DH, Streiner DL, Rowa K, McCabe RE
Seasonality Patterns of Internet Searches on Mental Health: Exploratory Infodemiology Study
JMIR Ment Health 2019;6(4):e12974
URL: <https://mental.jmir.org/2019/4/e12974/>
doi:[10.2196/12974](https://doi.org/10.2196/12974)
PMID:[31017582](https://pubmed.ncbi.nlm.nih.gov/31017582/)

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Original Paper

Guided Digital Cognitive Behavioral Program for Anxiety in Primary Care: Propensity-Matched Controlled Trial

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Abstract

Background: Cognitive behavioral therapy (CBT) is the gold standard treatment for adult anxiety disorders but is often not readily available in a scalable manner in many clinical settings.

Objective: This study examines the feasibility, acceptability, and effectiveness of a coach-facilitated digital cognitive behavioral program for anxious adults in primary care.

Methods: In an open trial, patients who screened positive for anxiety (General Anxiety Disorder-7 [GAD7] score ≥ 5) were offered the digital cognitive behavioral program (active group, n=593). Primary outcomes included anxiety, quality of life (QoL), and ambulatory medical use over 6 months. Intent-to-treat (ITT) and modified intent-to-treat (mITT) analyses were completed. Subsequently, we compared the outcomes of participants with those of a matched control group receiving primary care as usual (CAU; n=316).

Results: More than half of the patients downloaded the cognitive behavioral mobile app program and about 60% of these were considered engaged, which was defined as completion of ≥ 3 techniques. The active group demonstrated medium size effects on reducing anxiety symptoms (effect size $d=0.44$; $P<.001$) and improving mental health QoL ($d=0.49$; $P<.001$) and showed significantly improved physical health QoL ($d=0.39$; $P=.002$) and a decreased likelihood of high utilization of outpatient medical care (odds ratio=0.49; $P<.001$). The active group did not significantly outperform the CAU group in anxiety reduction or QoL improvement ($d=0.20$; $P=.07$). However, intent-to-treat analysis showed that the active group had a significantly lower likelihood of high utilization of outpatient medical care than the enhanced CAU group ($P<.0001$; odds ratio=0.09).

Conclusions: A coach-facilitated digital cognitive behavioral program prescribed in primary care is feasible and acceptable. Primary care patients prescribed a digital cognitive behavioral program for anxiety experienced significant improvements in anxiety symptoms, QoL, and reduced medical utilization. This effect was observed even among patients with chronic medical conditions and behavioral health comorbidities. Although the primary outcomes in the active group did not improve significantly more than the CAU group, health care utilization declined, and some secondary outcomes improved in participants who engaged in the program compared to the CAU group.

Trial Registration: ClinicalTrials.gov NCT03186872; <https://clinicaltrials.gov/ct2/show/NCT03186872>

(*JMIR Ment Health* 2019;6(4):e11981) doi:[10.2196/11981](https://doi.org/10.2196/11981)

KEYWORDS

anxiety; cognitive behavioral; digital; mobile; primary care; technology

Introduction

Untreated anxiety disorders are common and their management is expensive, particularly in medical settings where they can often drive excessive health care utilization [1,2]. When anxiety is identified, treatment is generally administered in primary care; very few patients are referred to specialized mental health care [2] and even fewer receive adequate pharmacotherapy using medications with known efficacy for anxiety disorders or empirically supported cognitive behavioral therapy (CBT) [3,4]. Most cases of clinically significant anxiety in primary care are treated using psychotropic medications, even though CBT is recommended as the first-line treatment [2,4].

Despite the valuable CBT dissemination and implementation work and substantiated models of integrating CB approaches into primary care, scalability remains a problem [5,6]. Digital CB programs are emerging as a solution to this problem [7]. Digital CBT is effective in treating anxiety [8,9] even in non-US primary care settings [10,11]; however, its viability and effectiveness for addressing anxiety in a US primary care setting are not known.

This study is an open trial aimed at determining the feasibility, acceptability, and effectiveness of a digital coach-facilitated CB program for patients receiving routine primary care. In addition, we aimed to compare the primary care sites providing a digital CB program and sites practicing usual primary care. The pragmatic study design allows evaluation of a digital behavioral intervention in routine medical care with minimal disruption of the clinical ecosystem. Although symptom reduction is a key outcome, there is a critical need to address behavioral health factors that contribute to inappropriate medical utilization. Building a scalable approach to effectively manage anxiety symptoms and reducing the negative health and financial impact of unmanaged behavioral health conditions are essential in the era of population health care. We hypothesize that integration of a digital CB program for anxiety within primary care will allow for better access to evidence-based behavioral health care and be effective at reducing anxiety, improving quality of life (QoL), and decreasing high and potentially inappropriate medical utilization. We subsequently compare these outcomes with those of primary care as usual.

Methods

Design

All study procedures complied with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, revised in 2008. This prospective pragmatic open trial (Trial

Registration: ClinicalTrials.gov NCT03186872) evaluated a digital CB program over a 6-month time period within two primary care sites. The treatment group was then compared to a matched control group from two comparable primary care clinics. Details about the primary care clinics are provided in previous publications [12,13].

Intervention Condition (Lantern)

The digital CB program Lantern [14] is based on empirically supported CBT protocols for generalized anxiety disorder (GAD) [15,16] with six core skill components (education/awareness, relaxation, thoughts, behavior change/exposure, mindfulness, and habit formation/skill maintenance; [Table 1](#)).

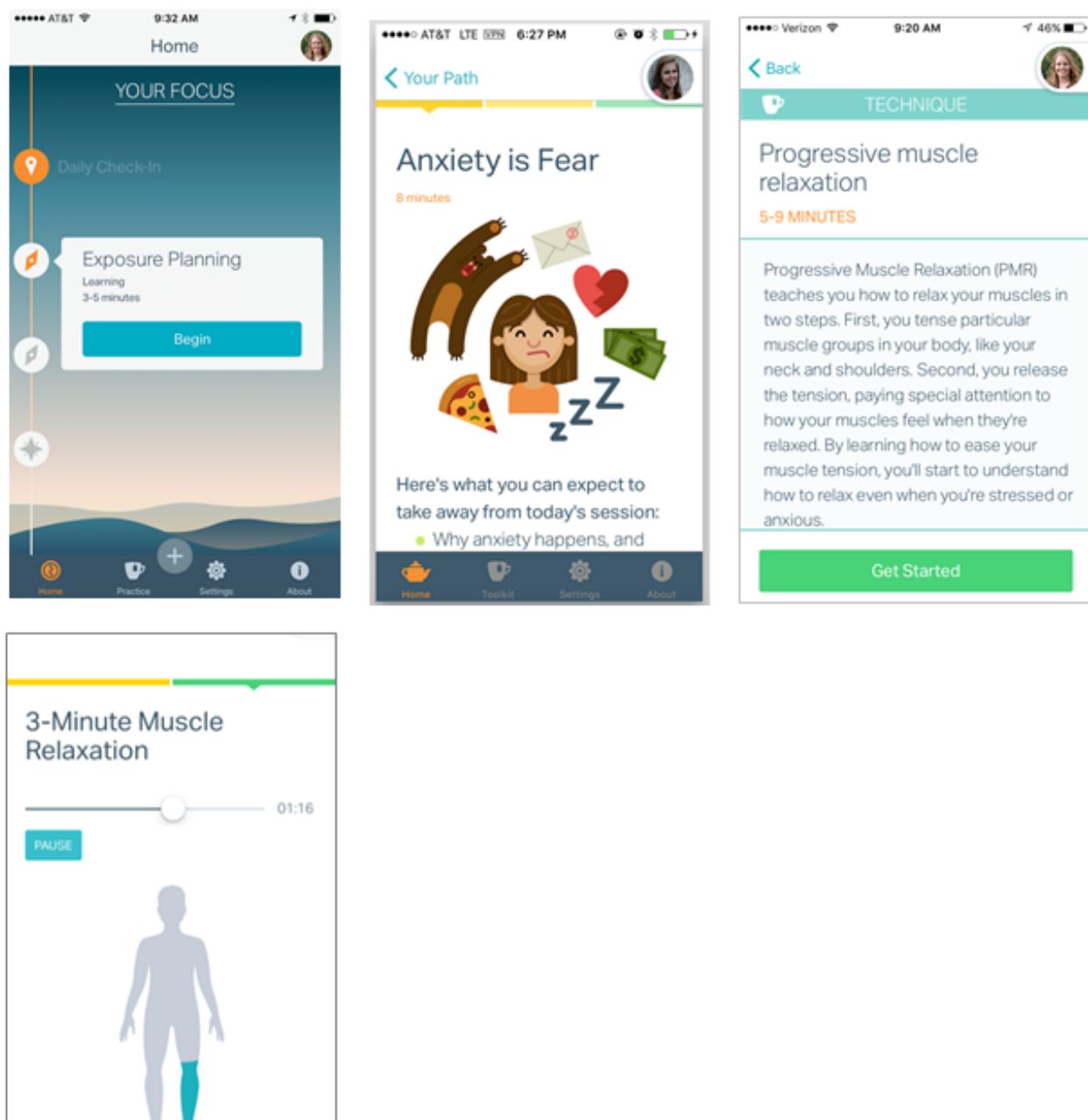
Lantern was developed in partnership with academic settings, treatment developers, and experts in digital mental health. A scientific advisory board reviewed the entirety of the program to ensure clinical validity. Ideally, users learn all six core skill components to equip themselves with the empirically supported skills to most effectively manage anxiety. The six core skill components of the anxiety program are delivered throughout a series of 40 brief 10- to 15-minute interactive units that introduce a total of 26 techniques, providing behavioral (eg, diaphragmatic breathing) and cognitive (eg, thought-challenging exercises) tools for practice, which users can complete quickly and apply immediately. Patients accessed Lantern via mobile phones ([Figure 1](#)).

The Lantern program includes integrated asynchronous texting with a human coach for personalized motivational behavioral coaching. The Lantern coaches provide human support to increase engagement by using motivational techniques, answering questions, monitoring progress throughout the intervention, facilitating goal setting, and reinforcing the content and skills presented to help shape the skill practice into the users' daily lives. They provide skill coaching through brief text messages through the app. The coaches rely on an internal coaching portal that provides a dashboard for each user. The dashboard shows all user inputs in the program (direct messages to coaches and all content they have completed in the program). Coaches respond to each user a maximum of once per day.

Coaches had backgrounds in health/wellness coaching or education or mental health treatment. All coaches had at least a bachelor's degree, and the majority of coaches had an advanced degree in their respective fields (master's level). A doctoral level licensed psychologist supervised the coaches. Coaches were trained in CBT theory and applied techniques, CBT-specific skill-coaching framework, and risk-management protocols. All user messages were reviewed daily for potential risk.

Table 1. Core Lantern components.

Core component	Description
Education	Education about anxiety and relationships between thoughts, emotions, and behaviors and what perpetuates anxiety
Relaxation	Relaxation exercises such as diaphragmatic breathing, guided imagery, and progressive muscle relaxation
Cognitive Restructuring	Guidance and techniques to challenge anxiety-maintaining thoughts in the service of developing more adaptive thoughts
Exposure	Further education about the relationship between anxiety and avoidance and how systematic exposure can interrupt the anxiety cycle and facilitate new learning
Mindfulness	Mindfulness explanation and exercises for observing thoughts and emotions without judgement
Habit Formation and Skills Generalization	How to generalize Lantern skills to one's life and sustain healthy habits

Figure 1. Example of Lantern screenshots.

Comparison Condition

The comparison sites with similar site demographic characteristics to the active practices were offered primary care as usual (CAU), wherein the primary care physician (PCP) managed anxiety as per the standard protocol after positive screening. To enhance CAU at the comparison sites, staff were trained to offer patients a National Institute of Mental Health educational brochure about GAD and its treatment [17] and were provided referral information for mental health clinics with intake availability within 3 months.

Participants and Recruitment

Patients were enrolled over a 1-year period (2016-2017). Eligibility criteria included age of 20-65 years; ability to speak English; a GAD-7 score ≥ 5 , which is a screening measure part of routine primary care; and access to a mobile phone. At the clinic visit check-in, when a patient scored ≥ 5 points on the GAD-7, a best-practice alert was generated in the electronic medical record (EMR) to prompt the PCP that the patient is eligible for the digital CB intervention. The PCP decided whether it was appropriate to offer this behavioral health intervention to the patient. If it was appropriate, the PCP referred the patient to the program during the visit. After the patient consented to the study, the PCP ordered the digital CB program via the EMR. Participants could download the mobile app and sign up for the program during the office visit or after the medical appointment. Each participant had access to the digital CB program for 2 years after enrollment.

The comparison group (matched controls) included patients between 20 and 65 years of age who spoke English and had a GAD-7 score ≥ 5 at screening and a second GAD-7 score 6-months after screening. Figure 2 presents the study recruitment and flow. This study was approved by the University of Pittsburgh Institutional Review Board. The process of patient recruitment and Lantern integration within primary care is detailed in previous publications [12,13].

Measures

Demographics

Data including date of birth, gender, ethnicity, race, and insurance type were abstracted from the EMR.

Anxiety Symptom Severity

The GAD-7 scale is a validated self-report questionnaire used to identify probable cases of evaluating the severity of seven diagnostic GAD symptoms occurring in the past 2 weeks [18]. The total scores range from 0 to 21 points. The cutoff of ≥ 8 points was used to indicate “clinically elevated anxiety.” This cutoff offers the highest sensitivity and specificity balance for GAD and other anxiety disorders and is recommended when

evaluating anxiety in primary care with comorbid medical conditions [19,20].

Quality of Life

The Short Form Health Survey (SF-12) is a 12-item validated self-report measure assessing health-related QoL (HRQoL) [21]. Results are derived from two component summary scales—Physical Component Summary (PCS-12) and Mental Component Summary (MCS-12)—and scored using the Research and Development (RAND) norm-based methods. Both PCS-12 and MCS-12 summary scores range from 0 to 100 points, with a mean of 50 (SD 10) points, in the general US population. Scores > 50 points represented above-average health status.

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Level 1 Cross-Cutting Symptom Measure

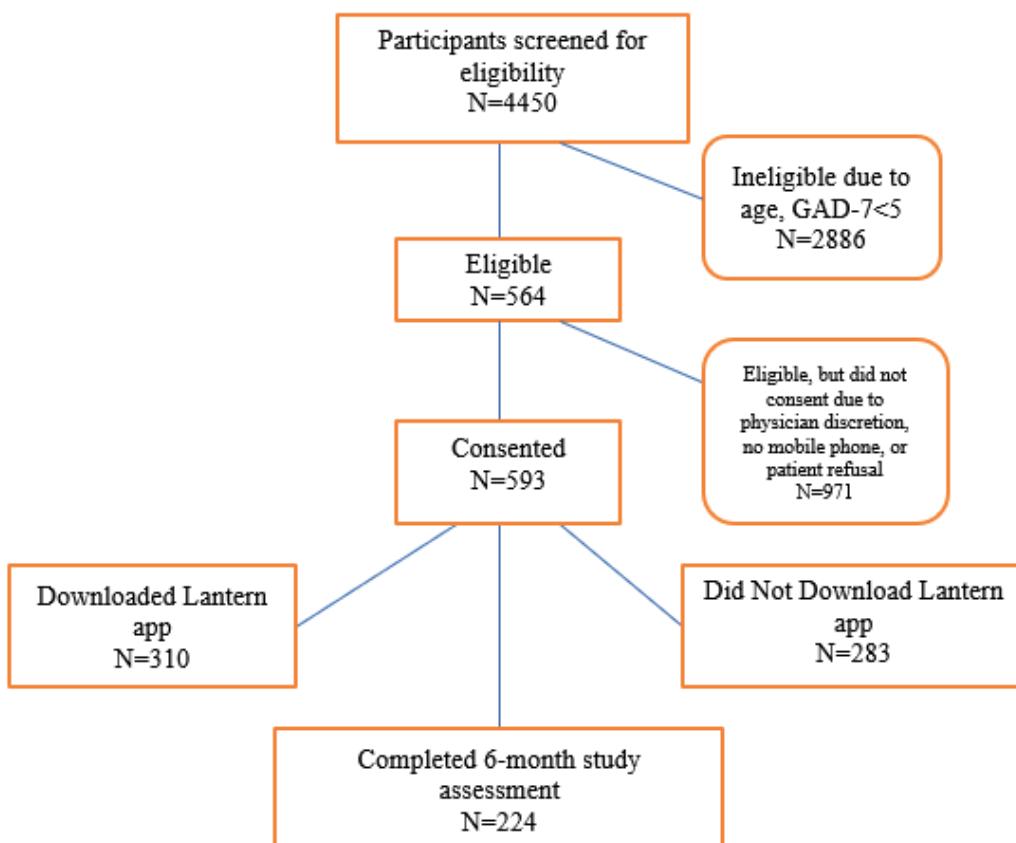
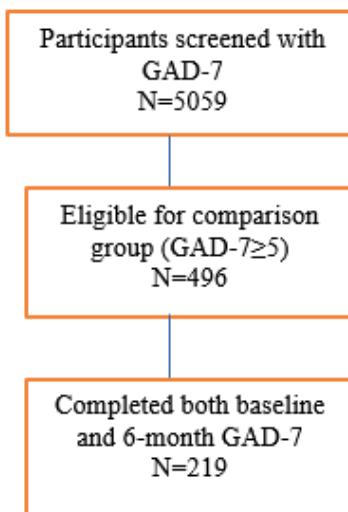
This 23-item self-report measure assesses 13 mental health domains across a range of psychiatric diagnoses [22,23]. We abbreviated the measure to 19 questions assessing depression, anger, mania, anxiety, somatic symptoms, sleep problems, repetitive thoughts and behaviors, dissociation, personality functioning, and substance use. Each item rates how much the person was bothered by a specific symptom during the past 2 weeks (0=none to 4=severe or nearly every day). This measure was only administered to active site patients with baseline GAD-7 scores ≥ 10 who could be reached by phone within 2 weeks of their screening date.

Medical Diagnoses and Utilization

Information on 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) code diagnoses during the lifetime, psychotropic medication history in the past 6 months, and medical utilization was obtained from the EMR. A medical complexity score was derived based on the total number of ICD-10 diagnoses in the EMR. Medical utilization includes primary care and specialty medical care ambulatory visits. Information on medical utilization was requested 6 months prior to and 6 months after study enrollment. High utilization was defined as ≥ 4 outpatient medical visits in the 6 months prior to the study, which was at the 75th percentile.

Lantern Helpfulness and Satisfaction Scale

This 14-item self-report scale was administered to patients in the active condition. Respondents rated the helpfulness of and satisfaction with Lantern, length of the program, and the coach and reported the likelihood of recommending Lantern to family/friends.

Figure 2. Participant flow sheet.**Active Group****Comparison Group****Lantern Utilization**

Usage was assessed within the Lantern mobile app for each participant. Usage metrics included the number of units completed, the number of techniques practiced, and the number of days the participant logged into the Lantern mobile app over 6 months. Engagement was defined as completion of ≥ 3 techniques.

Statistical Analyses

Data analytic methods were specified *a priori* in the published protocol [13]. Feasibility and acceptability were assessed at the provider and patient levels. Feasibility was assessed using the following early adoption criterion: Among the first 50 patients, at least 50% of eligible participants meeting the inclusion criteria should accept participation in the study. Acceptability was evaluated by patient engagement in the Lantern program and patient satisfaction with the program. As outlined in the

published study protocol, to set a rigorous standard for a real-world clinical setting, we set the acceptability threshold as follows: At least 50% of participants that initiate Lantern should complete at least 3 techniques. Descriptive statistics characterize participants' satisfaction with Lantern.

Handling of Missing Data

Approximately 60% of the active group was missing the 6-month data (n=369) because of the manner in which the active group was enrolled and the naturalistic nature of this pragmatic trial. Consequently, we did not perform imputation as per published recommendations [24]. We compared the baseline differences between active group participants who completed the 6-month assessment and those who did not. Compared to active group participants who did not complete the 6-month GAD-7, those who completed the 6-month GAD-7 used more techniques ($P<.001$), were less likely to be high medical utilizers in the prior 6 months ($P=.05$), and were less likely to be female ($P=.05$).

Analytic Plan

To test our first aim of a pre-post within-group trial, we characterized baseline characteristics (Table 2) and change scores for continuous outcomes of the full active group sample (N=593). We computed the Cohen d value with 95% CIs to summarize within-group effect sizes. For *a priori* hypothesis testing of repeatedly measured outcomes, we used linear mixed-effects models GAD-7, SF12 Mental Health Component (SF12-MHC), and SF12 Physical Health Component (SF12-PHC) or generalized linear mixed-effects models with a logit link (utilization status). To appropriately model the covariance structure, we included a random subject effect nested within the random clinic effect.

An intent-to-treat (ITT) analysis was performed for the active group participants with baseline and 6-month GAD-7 scores; in addition, a modified ITT (mITT) analysis was performed for participants who completed 3 or more techniques. The mITT analysis facilitates interpretation of the ITT findings by providing better estimates of effects among the patients initiating the intervention [25,26]. Clinically meaningful change and intervention response were calculated for participants with clinically elevated anxiety (GAD-7 cutoff score ≥ 8). This cutoff score for clinically elevated anxiety offers the highest sensitivity and specificity balance for GAD and other anxiety disorders and is recommended when evaluating anxiety in primary care with comorbid medical conditions [19,20]. Finally, to evaluate the association between Lantern usage, anxiety, and QoL changes, linear mixed model regressions were performed.

Propensity Matching

Using the full (unmatched) sample, we performed descriptive statistics, *t*-tests, and chi-square tests to compare the baseline characteristics between active group participants who completed the 6-month assessment and the comparison group. Table 2 describes the difference between the unmatched active and control groups at baseline. Next, propensity score matching was used to develop a matched sample of active and comparison participants with complete baseline data on relevant matching covariates and 6-month follow-up GAD-7 data. When selecting variables for matching, we used an iterative process aimed at striking a balance between attaining a matched sample and retaining power to test effects [27]. In each step of this process, we included variables hypothesized *a priori* to be related to either treatment or outcome (age, gender, race, complexity score, opioid use in past 6 months, and baseline measures of each outcome) and additional variables that differed by group and were endorsed by at least 10% in one group in the resulting matched sample. If the inclusion of one or more (non-*a priori*) variables resulted in $>10\%$ loss of sample size, it was not included in order to retain adequate power. For each iteration, the matching procedure effectiveness was assessed by examining standardized mean differences between groups for each matching variable, ensuring all standardized mean differences were less than a "small" effect (Cohen $d<0.2$), and testing for differences in variables that were not used for matching. Final matched variables were age, gender, race, complexity score, medical utilization, baseline GAD-7 scores, baseline SF12-PHC score, baseline SF12-MHC scores, and opioid and antidepressant prescriptions in the past 6 months. Insurance type and presence of diabetes did not match across groups and were not included in order to retain the sample size; however, in the sensitivity analyses, we adjusted the models for these two variables. The final matched sample included 158 active and 158 comparison participants.

Using the final matched sample (N=316), we performed comparison analyses. We computed the Cohen d value with 95% CIs to summarize within- and between-group effect sizes. Using this matched sample, we performed ITT and mITT analyses. For hypothesis testing of repeatedly measured outcomes, we used linear mixed-effects models (GAD-7, SF12-MHC, and SF12-PHC) or generalized linear mixed-effects models with a logit link (utilization status). These models included time (baseline and 6 months), treatment (active and comparison), and the time \times treatment interaction. To appropriately model the covariance structure, we included a random subject effect nested within the random clinic effect. Clinically meaningful change and intervention response were calculated for participants with clinically elevated anxiety (GAD-7 cutoff score ≥ 8).

Table 2. Matched group comparisons at baseline.

Characteristics	Original unmatched samples			Matched samples		
	Comparison group (n=219)	Active group (n=593)	P value	Comparison group (n=158)	Active group (n=158)	P value
Gender - female, n (%)	143 (65.3)	426 (71.8)	.09	100 (63.3)	100 (63.3)	1.00
Age in years, mean (SD)	47.76 (11.94)	41.49 (13.06)	<.001	45.86 (12.64)	44.03 (13.38)	.21
Race - white, n (%)	212 (96.8)	537 (90.6)	.01	151 (95.6)	149 (94.3)	.80
GAD-7 ^a , mean (SD)	10.40 (4.9)	11.24 (4.90)	.03	10.46 (5.10)	10.91 (4.97)	.43
SF-12^b, mean (SD)^c						
Mental health	35.51 (10.18)	35.55 (9.90)	.97	36.04 (10.27)	35.23 (9.44)	.46
Physical health	37.04 (12.36)	42.61 (11.59)	<.001	40.21 (11.93)	40.88 (12.27)	.63
Medical complexity score	3.19 (2.44)	2.26 (2.07)	<.001	2.75 (2.28)	2.73 (2.28)	.94
High utilizer prior to study ^d , n (%)	82 (37.44)	166 (27.99)	.01	43 (27.22)	43 (27.22)	1.00
Any inpatient encounter in the past 6 months	30 (13.70)	60 (10.12)	.19	14 (8.86)	20 (12.66)	.36
Any emergency room visit in the past 6 months	53 (24.20)	116 (19.56)	.18	34 (21.52)	31 (19.62)	.78
Insurance type, n (%)						
Medicare	44 (20.09)	48 (8.36)	<.001	23 (14.56)	15 (9.49)	.23
Medicaid ^e	64 (29.22)	104 (18.12)	.001	45 (28.48)	29 (18.35)	.05
Commercial ^e	111 (50.68)	422 (73.52)	<.001	90 (56.96)	114 (72.15)	.01
Medications in past 6 months, n (%)						
Other antidepressants	102 (46.6)	309 (52.11)	.19	80 (50.6)	85 (53.8)	.65
Tricyclic antidepressants	15 (6.9)	31 (5.23)	.47	8 (5.1)	10 (6.3)	.81
Benzodiazapines	57 (26.0)	122 (20.6)	.12	42 (26.6)	42 (26.6)	1.00
Sleep medications	20 (9.1)	49 (8.3)	.80	10 (6.3)	15 (9.5)	.40
Stimulants	5 (2.3)	6 (1.0)	.29	4 (2.5)	1 (0.6)	.37
Mood stabilizers	46 (21.0)	56 (9.4)	<.001	26 (16.5)	22 (14.0)	.64
Buspirone	7 (3.2)	11 (1.9)	.38	4 (2.5)	4 (2.5)	1.00
Atypical antipsychotics	11 (5.0)	26 (4.4)	.84	4 (2.5)	7 (4.4)	.54
Opioids	82 (37.4)	100 (16.9)	<.001	31 (19.6)	33 (20.9)	.89
ICD-10^f codes, n (%)						
Depression	91 (41.6)	230 (38.8)	.526	55 (34.8)	70 (44.3)	.11
Anxiety	92 (42.0)	248 (41.8)	1	61 (38.6)	73 (46.2)	.21
Substance abuse	7 (3.2)	22 (3.7)	.89	4 (2.5)	6 (3.8)	.75
ADHD ^g	4 (1.8)	6 (1.0)	.56	4 (2.5)	2 (1.3)	.68
Medical conditions^h, n (%)						
Hypertension	83 (37.9)	118 (19.9)	<.001	54 (34.2)	44 (27.9)	.27
Chronic GI ⁱ condition	66 (30.1)	131 (22.1)	.02	43 (27.2)	45 (28.5)	.90
Hyperlipidemia	60 (27.4)	93 (15.7)	<.001	39 (24.7)	38 (24.1)	1.00
Obesity	48 (21.9)	91 (15.4)	.04	28 (17.7)	28 (17.7)	1.00
Asthma	45 (20.6)	71 (12.0)	.003	27 (17.1)	21 (13.3)	.43
Diabetes ^b	44 (20.1)	41 (6.9)	<.001	28 (17.7)	14 (8.9)	.03
Chronic pain	35 (16.0)	83 (14.00)	.55	19 (12.0)	23 (14.6)	.62

Characteristics	Original unmatched samples			Matched samples		
	Comparison group (n=219)	Active group (n=593)	P value	Comparison group (n=158)	Active group (n=158)	P value
Arthritis	37 (16.9)	54 (9.1)	.003	22 (13.9)	15 (9.5)	.29

^aGAD-7: Generalized Anxiety Disorder-7.

^bSF-12: Short Form Health Survey.

^cFor the original unmatched samples, n=216 in the comparison group and n=559 in the active group.

^dDefined as four or more outpatient medical encounters in 6 months prior to study enrollment.

^eP<.05; cells show mean (SD) for continuous variables or n (%) for categorical variables.

^fICD-10: International Statistical Classification of Diseases and Related Health Problems, 10th revision.

^gADHD: attention-deficit hyperactivity disorder.

^hReporting only those medical conditions with at least 10% prevalence.

ⁱGI: gastrointestinal.

Results

Participant Characteristics

Baseline characteristics are presented in Table 2. On average, our sample was above the GAD-7 clinical threshold and reported below-average HRQoL (SF-12 < 50 points). About 40% of the sample was diagnosed with depression. The three most commonly prescribed medications in the past 6 months were antidepressants (60.1%), benzodiazepines (26.6%), and opiates (19.6%). Hypertension, chronic gastrointestinal conditions, and hyperlipidemia were the three most prevalent medical conditions. From the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Cross-Cutting Symptom Measure (n=88), the following proportions of patients endorsed domain scores, indicating the need for further assessment into current psychiatric symptoms: anxiety, 84%; depression, 67%; sleep problems, 62%; anger, 58%; personality functioning, 39%; repetitive thoughts and behaviors, 23%; somatic symptoms, 19%; dissociation, 16%; mania, 8%; and substance use, 8%.

Primary Outcomes

One of two feasibility/acceptability *a priori* criteria were met. The first benchmark was not attained. Among the first 50 patients, less than 50% of the patients who met the inclusion criteria participated in the study. Among the initial cohort of 50 eligible patients, 22% were prescribed Lantern; they had consented to participate in the study and the PCP decided that Lantern would be appropriate for them. This low conversion occurred largely because electronic behavioral health screening was newly launched in primary care, resulting in some technical issues. Among the next set of 50 eligible patients, 36% were prescribed Lantern and among the third set of 50 eligible patients, 44% were prescribed Lantern. There was an incremental increase in study enrollment among the first 150 patients over a 4-week period. The second feasibility/acceptability benchmark was met. More than 50% of participants who initiated Lantern completed ≥ 3 techniques. There were no adverse events.

Lantern Usage

A total of 310 participants (of 593, 52.3%) downloaded the Lantern mobile app and completed an average of 6.2 units (SD 9.4, median=2.0, range=0-40 units). Completion of the first 6

units indicated that the participants were exposed to psychoeducation, tracking anxiety cues, motivational interviewing, readiness to change, self-assessment of barriers to change and personal strengths, grounding exercises, applied muscle relaxation, diaphragmatic breathing, mindful walking, and psychoeducation about worry. On average, participants completed 10.4 techniques (SD 17.4, median=4.0, range=0-137) and used Lantern for 16.6 days (SD 21.3, median=9.0, range=0-116) over 6 months. Of the 310 patients who downloaded the app, 27% (n=84) never started the program (ie, completed 0 techniques). Almost 60% (n=183) of participants who downloaded Lantern were considered to be “engaged” in the program (defined as completing ≥ 3 techniques). Engaged Lantern participants completed an average of 10.3 (SD 10.43) units, which covers automatic thoughts and cognitive reframing. Engaged Lantern participants used Lantern on an average of 26.0 (SD 23.17) days over 6 months.

Satisfaction and Helpfulness of Lantern

Participants who downloaded Lantern were administered a questionnaire assessing the helpfulness of and satisfaction with Lantern. The satisfaction and helpfulness survey was completed by 122 participants (Multimedia Appendix 1). On a scale of 1-7, with 7 being the highest score, 52% rated the general helpfulness of Lantern as ≥ 5 and 49% reported their satisfaction with Lantern as ≥ 5 . The majority (65%) reported that the length of the units and overall program was “just right,” 27% felt that they were too long, and 8% reported that the program length was too short. The majority (63.7%) reported that the skillfulness and degree of interest/concern of their Lantern coach was “high.” The majority of study participants (68%) were likely to recommend Lantern to family/friends.

Anxiety Symptom Severity, Quality of Life, and Outpatient Medical Utilization

The ITT sample included active group participants who completed the 6-month GAD-7 assessment. In the ITT sample (N=224), anxiety symptoms ($\beta=-2.61$; standard error [SE]=0.34; $P<.001$; $d=-0.44$) significantly decreased over time. Mental health QoL ($\beta=5.71$; SE=0.71; $P<.001$; $d=0.49$) and physical health QoL ($\beta=2.37$; SE=0.61; $P<.001$; $d=0.25$) significantly improved over time. From the baseline to 6 months, the odds of being a high outpatient medical utilizer decreased

significantly ($OR=0.49$; $\beta=-0.72$; $SE=0.17$; $P<.001$) and was 2.04 times (1/0.49) higher than the odds of not being a high utilizer over 6 months.

Using the same mixed-effects model, an mITT analysis was performed using engaged Lantern participants. The engaged Lantern subgroup demonstrated significantly reduced anxiety symptoms with a medium effect size ($\beta=-3.74$; $SE=0.49$; $P<.001$; $d=-0.66$). In addition, mental health QoL ($\beta=7.00$; $SE=1.16$; $P<.001$; $d=0.59$) and physical health QoL ($\beta=3.04$; $SE=0.97$; $P=.002$; $d=0.39$) significantly improved over time. From the baseline to 6 months, the odds of being a high utilizer decreased significantly for engaged Lantern participants (odds ratio=0.15, $\beta=-1.88$, $SE=0.61$; $P=.002$). The use of Lantern was associated with a 6.67 times increase (1/0.15) in the odds of not being a high utilizer from baseline to 6 months.

Clinically Meaningful Change and Response Rates

We examined clinically meaningful improvement and deterioration among active group participants who met the clinical threshold for anxiety (GAD-7 score ≥ 8 ; $n=150$). Such an improvement or deterioration was defined as at least a 4-point reduction or increase, respectively, on the GAD-7 score. Among the ITT sample, clinically meaningful improvement was observed in 54% (81/150) of participants. Clinically meaningful deterioration occurred in 8.7% (13/150) of participants. Intervention response (attaining at least 50% reduction in anxiety) was observed in 30% ($n=45$) of participants. Among the engaged Lantern patients (mITT), 60.8% (45/74) experienced clinically meaningful improvement and 5.4% (4/74) experienced deterioration.

Relations Between Lantern Usage and Outcomes

Typically, the usage of digital behavioral health interventions is not linearly related to clinical outcomes [28,29]. Examinations of visual plots of usage in relation to anxiety and QoL confirmed that the relationships are nonlinear in this sample, primarily among participants with higher anxiety at baseline. The following post hoc analyses were considered exploratory. Based on quantiles and sample size, we created three categories—0, 1-9, and ≥ 10 —for the number of techniques completed. We explored whether 1-9 or ≥ 10 techniques were associated with better outcomes (relative to 0 techniques). In the full unmatched sample, the use of 1-9 techniques was significantly associated with improved anxiety ($\beta=2.30$; $SE=0.92$; $P=.01$) and improved physical health QoL ($\beta=3.74$; $SE=1.46$; $P=.01$) as compared to the use of 0 techniques. However, the use of ≥ 10 techniques was not associated with improved anxiety ($\beta=1.24$; $SE=0.94$; $P=.19$) or physical health QoL ($\beta=0.96$; $SE=1.75$; $P=.58$) as compared to the use of 0 techniques. Although not statistically significant, the same pattern emerged, whereby the use of 1-9 techniques was more strongly related to improvements in mental health QoL ($\beta=3.11$; $SE=1.84$; $P=.09$). Both the visual plots and exploratory analyses suggested that completion of 5-10 techniques was most strongly related to better outcomes. This initial interpretation of the data leads the way for a more

nuanced analysis of optimal Lantern usage in the future. All comparative analyses that follow rely on the matched sample.

Matched Comparisons of Anxiety Symptom Severity, Quality of Life, and Outpatient Medical Utilization

Among the matched active group ITT sample, reduction in anxiety symptoms did not significantly differ from that in the matched comparison group (CAU; Table 3). The matched active group resulted in significantly improved mental health QoL with a medium effect size ($d=0.50$) as well as physical health QoL with a small effect ($d=0.31$). There were meaningful but small effect sizes between the active and control group mental health and physical health composite scores ($d=0.20$ and $d=0.21$, respectively; $P=.07$) between groups. There was a significant time \times condition effect on high utilizer status. From the baseline to 6 months, the odds of being a high utilizer decreased significantly more for the active group as compared to the comparison group ($OR=0.09$, $P<.001$). To facilitate this interpretation, we further examined only the participants who were high utilizers at baseline. Among the 43 high utilizers at baseline in the comparison group, 81% ($n=35$) remained high utilizers at 6 months. However, among the 43 high utilizers at baseline in the active group, only 35% ($n=15$) remained high utilizers at 6 months.

Using the same mixed-effects model, an mITT analysis was performed using engaged Lantern participants ($n=69$; Table 4). The engaged Lantern subgroup demonstrated significantly reduced anxiety symptoms with a medium effect size. Relative to the CAU group (matched comparison group; $n=158$), there was a larger difference in anxiety reduction, favoring the active group but not reaching significance ($d=0.22$; $P=.14$). The effect size increased in the active group, indicating more improvement in mental health QoL ($d=0.28$; $P=.06$). There was a significant time \times condition effect on physical health QoL, and engaged Lantern participants demonstrated significantly more improvement than the comparison group ($d=0.40$; $P=.01$). There was a significant time \times condition effect on high utilizer status. From the baseline to 6 months, the odds of being a high utilizer decreased significantly more for the engaged Lantern participants than the comparison group (odds ratio=0.09, $P<.001$). Among the 23 high utilizers at baseline who engaged in Lantern, only 8 (35%) were still high utilizers at 6 months.

Clinically Meaningful Change and Response Rates Between Matched Groups

Among the patients with baseline GAD-7 scores ≥ 8 , clinically meaningful improvement was observed in 53.5% of the active group (54/101) and 45.8% of the comparison group (44/96). Clinically meaningful deterioration occurred in 11.9% of the active group and 16.7% of the comparison group. Among engaged Lantern patients (mITT), 56.3% (27/48) experienced clinically meaningful improvement. Substantially lower rates of deterioration occurred among engaged Lantern participants (6.3%, 3/48) as compared to 16.7% (16/96) of comparison participants. Intervention response was observed in 27.7% of the active group and 26% of the matched comparison group.

Table 3. Anxiety, Quality of Life, and Medical Utilization. Significant findings after adjusting for diabetes and insurance type. Effect sizes of 0.2, 0.5, and 0.8 indicate small, moderate, and large clinically meaningful effects, respectively.

Measures	Mean change (SD)	Effect size (Cohen <i>d</i>)		Mixed-effects model		
		Within group (95% CI)	Between group (95% CI)	Beta	SE ^a	<i>P</i> value
Generalized Anxiety Disorder-7 (n=316)						
Active	−1.97 (6.06)	−0.32 (−0.55 to −0.10)	0.001 (−0.22 to 0.22)	−0.01	0.66	0.99
Control	−1.96 (5.75)	−0.34 (−0.56 to −0.12)				
Short Form Health Survey Mental Composite Score (n=290)						
Active	5.57 (11.08)	0.50 (0.26 to 0.74)	0.198 (−0.03 to 0.43)	2.27	1.27	0.07
Control	3.4 (10.77)	0.32 (0.09 to 0.54)				
Short Form Health Survey Physical Composite Score (n=292)						
Active	2.81 (9.07)	0.31 (0.07 to 0.55)	0.205 (−0.03 to 0.44)	1.92	1.06	0.07
Control	0.95 (9.12)	0.10 (−0.12 to 0.33)				
High utilizer at 6 months (yes/no)	— ^b	—	Odds ratio=0.09	−2.40	0.49	<.001

^aSE: standard error.^bNot applicable.**Table 4.** Anxiety, Quality of Life, and Medical Utilization among engaged Lantern participants. Significant findings after adjusting for diabetes and insurance type.

Measures	Mean change (SD)	Effect size (Cohen <i>d</i>)		Mixed-effects model		
		Within group (95% CI)	Between group (95% CI)	Beta	SE ^a	<i>P</i> value
Generalized Anxiety Disorder-7 (n=227)						
Active	−3.16 (5.38)	−0.59 (−0.93 to −0.24)	0.22 (−0.07 to 0.50)	−1.20	0.81	.14
Control	−1.96 (5.75)	−0.34 (−0.56 to −0.12)				
Short Form Health Survey Mental Composite Score (n=205)						
Active	6.47 (11.22)	0.58 (0.18 to 0.98)	0.28 (−0.04 to 0.60)	3.23	1.71	.06
Control	3.4 (10.77)	0.32 (0.09 to 0.54)				
Short Form Health Survey Physical Composite Score (n=207)						
Active	4.72 (9.4)	0.50 (0.10 to 0.90)	0.40 (0.08 to 0.72)	3.79	1.46	.01
Control	0.95 (9.12)	0.10 (−0.12 to 0.33)				
High utilizer at 6 months (yes/no)	— ^b	—	Odds ratio=0.04	−3.20	0.69	<.0001

^aSE: standard error.^bNot applicable.

Discussion

Principal Findings

This pragmatic open trial demonstrated partial feasibility and adequate acceptability among patients who were prescribed Lantern by their PCPs. Although conversion rates from eligibility to consent improved after resolving clinic electronic screening issues, it is plausible that more patients would have enrolled if Lantern was offered systematically to all patients meeting the eligibility criteria. PCPs used their discretion to prescribe Lantern, which impeded our ability to differentiate provider adoption and willingness to prescribe Lantern from patient willingness to participate.

About 73% of patients who downloaded the app started Lantern and nearly 60% engaged in the Lantern program. The average of ≥ 10 usage days among those who downloaded the Lantern app is comparable to the 10 distinct mobile app use benchmarks followed in digital CBT intervention literature; very few coach-guided CB mobile apps reach this level [30-33]. This above-average engagement in a medical setting is likely related to delivery of Lantern in brief interactive segments, which is aligned with how patients interact with mobile apps via their mobile phones, and coach integration to promote engagement, skills acquisition, and generalization. However, usage patterns suggest that more use is not universally better, which likely represents differences in anxiety severity, types of underlying anxiety disorders, and psychiatric/medical comorbidities. Our exploratory analyses suggest that for some patients, a moderate

level of program completion was linked to best clinical outcomes. Thus, it is possible that patients adequately self-dosed the amount of skill training they needed [34-36].

Although there was a significant reduction in anxiety and QoL improvement in the active group receiving Lantern, this reduction did not significantly outperform the matched comparison group in the ITT analysis. One reason for this lack of difference is that patients in the comparison group received CAU, wherein behavioral health resources were provided to PCPs in addition to psychotropic medications prescribed by PCPs. The reduction in anxiety symptoms, the magnitude of effect sizes ($|d| = 0.34-0.35$), and proportion of participants attaining clinically meaningful improvement (46%) in primary CAU is about twice that generally observed from care as usual, as reported in the literature [4,37]. This may be because the usual primary care practices were provided with feasible up-to-date behavioral health referral resources, thus potentially enhancing the likelihood that these comparison patients also received behavioral health treatment. Furthermore, the comorbidity of depression and anxiety in this sample may have contributed to the lack of group differences in anxiety and QoL. In addition, the lack of significant differences between the groups is consistent with the results of the 2017 meta-analysis of mobile phone apps targeting anxiety, which showed that stand-alone mobile phone apps did not outperform control conditions in 3 efficacy studies [9]. However, effect sizes of the engaged Lantern participants are comparable to those from a recent investigation of internet-delivered CBT for anxiety in primary care [10]. Furthermore, Lantern may have a greater impact on mitigating clinical worsening of anxiety. Clinical deterioration occurred less often when participants were engaged in Lantern (6.3%) as compared to when they received primary CAU (16.7%).

Interestingly, Lantern had a greater impact on HRQoL than anxiety. Although anxiety has a significant impact on HRQoL, they are sufficiently distinct [38,39]. The mental health component of the SF-12 (HRQoL measure) is a broader outcome capturing many specific behavioral health conditions (depression, anxiety, and loss of behavioral/emotional control) [40,41]. Moreover, the presence of posttraumatic stress disorder (PTSD) or comorbid major depressive disorder has uniquely predicted worse HRQoL among patients with anxiety disorders [37,42]. In a meta-analysis, findings from internet-delivered CBT for anxiety revealed that the largest effects in QoL improvement were found in PTSD, followed by obsessive compulsive disorder, panic disorder, and social anxiety disorder. The smallest effect sizes were observed in GAD [43].

HRQoL improved with patients who used the Lantern anxiety program, which could have occurred via reduction of PTSD symptoms, comorbid depressive symptoms, or other symptoms of anxiety conditions rather than GAD symptoms measured by the GAD-7. In this sample, 44% of patients had a diagnosis of depression in their medical record, and among the subgroup with scores above the anxiety clinical threshold, 67% reported current depression symptoms, 62% reported current sleep difficulties, and 58% reported current anger. Although a specific measure of depressive symptom severity was not used, an improvement in depressive symptoms may have occurred, as

prior Lantern evaluations have found significant reductions in depressive symptoms [44,45]. Given the high comorbidity of depression and anxiety, it would be prudent to develop a transdiagnostic program for anxiety and depression conditions in future iterations of Lantern. Furthermore, it is interesting that the sample had high rates of hypertension, chronic gastrointestinal conditions, obesity, and chronic pain—all conditions associated with reduced QoL, anxiety, and depression. Thus, effective management of anxiety or depression could secondarily improve some underlying medical conditions.

The most robust finding is that with Lantern, the likelihood of high outpatient medical utilization was significantly lower than that in a matched comparison group. Both groups showed an average of about three outpatient medical visits within 6 months prior to the study. This is consistent with the average outpatient utilization among patients with anxiety disorders who are untreated or undertreated [1]. A total of 62%-65% of Lantern participants were no longer high medical utilizers in the follow-up period, whereas the comparison group had more than twice the number of patients who remained high utilizers at 6 months. Although Lantern can improve self-reported QoL and anxiety, its most significant impact is in reducing anxiety-related behavior (outpatient medical visits). A subsequent evaluation will focus on high medical utilizers.

Limitations

This was an open pre-post pragmatic trial. Careful propensity matching allowed for the most rigorous comparison in the absence of randomization. However, it was important to show what results were possible in a pragmatic trial with little research infrastructure to be able to generalize our findings for real-world settings. Information provided to PCPs was minimal. PCPs may benefit from better guidelines for selecting appropriate candidates for Lantern. Due to the absence of a research infrastructure to guide study recruitment and retention, there was a high percentage of missing outcome data in the active group, which limits interpretation of the findings but still offers value as a feasibility trial. We are not aware of how frequently PCPs referred to psychotherapy or prescribed psychotropic medications at the comparison sites. When comparing the minimally engaged subsample (mITT group) to the matched controls, it is important to remember that the comparison group was matched to the full ITT sample and not the mITT sample. Thus, it may be that more likely that patients who showed improvements continued to use the app as a source of survival bias. However, the purpose of the mITT evaluation was to facilitate interpretation of the effect size in relation to the ITT group. There is also a possibility of a “digital placebo” effect, whereby the benefits may be due to placebo engagement in the mobile app intervention rather than the active components of the CB program itself [46]. This is particularly likely in the subgroup of engaged users and can be tested in future investigations using a different study design. The results should also be interpreted in light of the predominately white sample and rely on the ICD-10 codes for identifying comorbidities.

Conclusions

Lantern demonstrated moderate effectiveness for addressing anxiety symptoms over 6 months, but not more than primary

CAU. Lantern led to a robust decrease in the number of high outpatient medical utilizers among primary care patients with other morbidities such as depression, obesity, hypertension, chronic pain, chronic gastrointestinal conditions, and use of psychotropic medications. The surprising effectiveness seen in primary CAU may have suppressed group differences typically observed with standard CAU. However, with the minimal research infrastructure of this pragmatic study and limited resources to optimize PCP uptake and effectiveness of prescribing Lantern, these outcomes are meaningful from a

population health and medical cost-offset perspective. This may be the first study to show that a coached CB program delivered via a mobile app provided in primary care reduces outpatient medical utilization compared to a matched control group. Whether this decreased utilization was diverted to other types of medical utilization (eg, emergency department visits) remains unknown. Future analyses of 12-month follow-up data will provide information about the extent to which Lantern has an impact on improving appropriate healthcare utilization.

Acknowledgments

This research was funded by UPMC Enterprises. This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors. The authors would like to thank all the participants who took part in this research study. We would like to acknowledge the valuable contributions of Meredith Strassburger, Kathryn McAuliff, Katie Scott, Michelle Sloane, Dina Perry, and the primary care physicians and practices that participated in this study.

Conflicts of Interest

EMS received grants from NIH and consultant fees from AbbVie and APPI. MO was a shareholder in Thrive Network, Inc (DBA, Lantern) at the time this study was conducted. UPMC Enterprises has a financial interest in Thrive Network, Inc, which develops and commercializes Lantern's products and services. EMS is a scientific advisor and consultant to UPMC Enterprises. MLW and FS have no competing financial interests. MLW is an independent statistician.

Multimedia Appendix 1

Lantern satisfaction and helpfulness questionnaire (n=77) results.

[[PNG File, 61KB - mental_v6i4e11981_app1.PNG](#)]

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Abbreviations

CAU: care as usual
CBT: cognitive behavioral therapy
EMR: electronic medical record
GAD: Generalized Anxiety Disorder Questionnaire
HRQoL: health-related quality of life
ICD-10: International Statistical Classification of Diseases and Related Health Problems, 10th revision
ITT: intent to treat
MCS: mental composite score
MHC: Mental health composite
mITT: modified intent-to-treat
PCP: primary care physician
PCS: physical composite score
PHC: physical health composite
PTSD: posttraumatic stress disorder
RAND: Research and Development
SE: standard error
SF-12: Short Form Health Survey
QoL: quality of life

Edited by J Torous; submitted 20.08.18; peer-reviewed by E Hermes, J Firth; comments to author 31.08.18; revised version received 13.11.18; accepted 30.11.18; published 04.04.19.

Please cite as:

Oser M, Wallace ML, Solano F, Szigethy EM

Guided Digital Cognitive Behavioral Program for Anxiety in Primary Care: Propensity-Matched Controlled Trial

JMIR Ment Health 2019;6(4):e11981

URL: <https://mental.jmir.org/2019/4/e11981/>

doi: [10.2196/11981](https://doi.org/10.2196/11981)

PMID: [30946022](https://pubmed.ncbi.nlm.nih.gov/30946022/)

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Original Paper

Instant Stress: Detection of Perceived Mental Stress Through Smartphone Photoplethysmography and Thermal Imaging

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Abstract

Background: A smartphone is a promising tool for daily cardiovascular measurement and mental stress monitoring. A smartphone camera-based photoplethysmography (PPG) and a low-cost thermal camera can be used to create cheap, convenient, and mobile monitoring systems. However, to ensure reliable monitoring results, a person must remain still for several minutes while a measurement is being taken. This is cumbersome and makes its use in real-life situations impractical.

Objective: We proposed a system that combines PPG and thermography with the aim of improving cardiovascular signal quality and detecting stress responses quickly.

Methods: Using a smartphone camera with a low-cost thermal camera added on, we built a novel system that continuously and reliably measures 2 different types of cardiovascular events: (1) blood volume pulse and (2) vasoconstriction/dilation-induced temperature changes of the nose tip. 17 participants, involved in stress-inducing mental workload tasks, measured their physiological responses to stressors over a short time period (20 seconds) immediately after each task. Participants reported their perceived stress levels on a 10-cm visual analog scale. For the instant stress inference task, we built novel low-level feature sets representing cardiovascular variability. We then used the automatic feature learning capability of artificial neural networks to improve the mapping between the extracted features and the self-reported ratings. We compared our proposed method with existing hand-engineered features-based machine learning methods.

Results: First, we found that the measured PPG signals presented high quality cardiac cyclic information (mean pSQI: 0.755; SD 0.068). We also found that the measured thermal changes of the nose tip presented high-quality breathing cyclic information and filtering helped extract vasoconstriction/dilation-induced patterns with fewer respiratory effects (mean pSQI: from 0.714 to 0.157). Second, we found low correlations between the self-reported stress scores and the existing metrics of the cardiovascular signals (ie, heart rate variability and thermal directionality) from short measurements, suggesting they were not very dependent upon one another. Third, we tested the performance of the instant perceived stress inference method. The proposed method achieved significantly higher accuracies than existing precast features-based methods. In addition, the 17-fold leave-one-subject-out cross-validation results showed that combining both modalities produced higher accuracy than using PPG or thermal imaging only (PPG+Thermal: 78.33%; PPG: 68.53%; Thermal: 58.82%). The multimodal results are comparable to the state-of-the-art stress recognition methods that require long-term measurements. Finally, we explored effects of different data labeling strategies on the sensitivity of our inference methods. Our results showed the need for separation of and normalization between individual data.

Conclusions: The results demonstrate the feasibility of using smartphone-based imaging for instant stress detection. Given that this approach does not need long-term measurements requiring attention and reduced mobility, we believe it is more suitable for mobile mental health care solutions in the wild.

(*JMIR Ment Health* 2019;6(4):e10140) doi:[10.2196/10140](https://doi.org/10.2196/10140)

KEYWORDS

stress detection; mobile applications; photoplethysmography; thermography; psychophysiology; heart rate variability; physiological computing; affective computing; machine learning

Introduction

Human physiological events are controlled by the actions of the sympathetic nervous system (SNS) and the parasympathetic nervous system (PSNS). Of the many different types, cardiovascular and respiratory events have been shown to be important for monitoring a person's mental health and stress [1-5]. Recent studies have demonstrated that it is possible to use smartphone cameras (ie, Red Green Blue vision) to measure blood volume pulse (BVP) [6-10] and mobile thermal cameras attached to a smartphone (or integrated into it, for example, Cat S60) to measure respiratory cycles [11]. These encouraging results suggest that smartphones could become a powerful apparatus for monitoring and supporting mental stress management on a daily basis through biofeedback [12]. Indeed, the combination of RGB and thermal cameras in one device has the potential to provide a very large set of physiological measurements for stress monitoring in our daily life. Smartphone apps with such capabilities are increasingly desired as possible tools for facilitating stress self-management [13-15] as people are often unaware of their level of stress and of being stress-sensitive to particular situations, for example, chronic pain can cause a fear of movement [16]. There is also a strong interest within the industry in complementing typically used questionnaires in order to enable improved assessment of well-being with personnel as well as revisiting work plans and work environments [17]. Given their size and mobility, such sensors could be embedded into employees' aids for ease of use. Although these low-cost sensors are still not perfect, the literature shows that their reliability is increasing, and we are contributing to this body of work. At the same time, we hope that our work contributes to the literature in general using these signals as stress measures [18-20]. In this paper, we aim to focus on 2 important cardiovascular events that can be captured by low-cost, low-resolution sensors: cardiac cyclic events with smartphone photoplethysmography (PPG) and vasoconstriction/dilation-induced nose tip temperature dynamics with a low-cost thermal camera. In particular, we investigate how to instantly capture stress-induced variability of such physiological patterns.

Heart rate variability (HRV) is the time series of variation in heartbeats. It has been used to measure a person's mental stress [4,18,20-25]. HRV's popularity arises from the fact that it has been shown to abstract information about the sympathovagal balance between the SNS and PSNS. When confronted with a stressor, the autonomic nervous system can produce a sequence of fight-or-flight responses [1]. These manifest themselves as alternations of accelerated and decelerated cardiovascular patterns [1,26]. To characterize the HRV, various authors [4,21,22,27] have proposed a variety of hand-crafted HRV metrics that are computed over time intervals between heartbeats. Although most of the HRV metrics were originally built based on the RR intervals from electrocardiogram (ECG) measurements [28], the metrics have been applied to the PP

intervals from PPG measuring BVP [18,20,25,29]. In the case of PPG, the term pulse rate variability (PRV) or PPG HRV is often used to clarify the different type (even if related) of event measured [26,29-31] with respect to ECG. Among the most commonly used are statistical metrics (such as the standard deviation of RR or PP intervals) and frequency-band metrics (eg, the normalized power in a frequency band of interest). In particular, various studies have found that the Low Frequency (LF; 0.04 Hz-0.15 Hz) and High Frequency (HF; 0.15 Hz-0.4 Hz) bands of the time intervals in heart rates appear to reflect the SNS and PSNS activities [21]. Based on this observation, many studies have proposed to use the LF/HF ratio as a stress indicator [4,22,24,32]. However, the use of such metrics has remained controversial in that they tend to oversimplify physiological phenomenon [33-35]. In particular, a single physiological metric itself does not strongly contribute to automatically detecting a person's stress levels (ie, machine learning tasks) [33,36]. Hence, multiple HRV metrics-derived features have been used together with those from other physiological activities such as perspiration and respiratory activities for automatically inferring mental stress, for example, during driving tasks [37] and desk activities [25]. To ensure reliable measurements with such features, a relatively long-term window of data (several minutes to a few hours) must also be used [25,36]. Although this is acceptable in specialist settings or with medical devices, it is highly inconvenient in the real world with unstructured settings using low-cost devices (in particular, the PPG). For example, if smartphone-based finger PPG was to be used, a user would have to continuously make sure their finger is held stably in front of the camera. Another issue is that changes in ambient light levels, as a user moves around, can corrupt long-term measurements.

Another documented cardiovascular event that happens as a reaction to mental stressors is vasoconstriction of blood vessels in a person's nasal peripheral tissues [38,39]. This causes blood flow to drop, resulting in a decrease in temperature, which can be detected by monitoring the temperature of the nose tip. This study [40] found that a contact-based multi-channel thermistor was able to detect a significant decrease in temperature of the nasal area as relative to the forehead in mentally stressful conditions. The same result has been repeatedly reported from the use of thermal imaging in mental stress induction studies [38,41], indicating that the thermal directionality (ie, temperature drop) can be a potential barometer of mental stress. However, studies show similar limitations as they require keeping the head still (often authors use a chinrest). In addition, they also require measuring baseline temperatures to compute the thermal direction, which may limit its use in real-life applications [42,43]. In this work, we address the former issue by using a state-of-the-art tracking method [11]. Furthermore, we rely only on the instant measurement with the area of interest (nose tip) to address the latter.

The reason for proposing the use of 2 sensors in this study rather than just 1 is that despite the potential of thermal imaging in

measuring BVP [44], its accuracy is low and its ability in measuring PP intervals has not been yet validated. Instead, camera-based PPG has been shown to be more reliable [9,45] and can be used simultaneously with thermal imaging, possibly compensating each unimodal performance in inference tasks. In addition, the use of finger PPG and thermal camera raises much less privacy concerns than RGB-based facial analysis, that is, remote PPG [8]. Furthermore, the use of multiple measurements increases reliability of stress monitoring. Finally, even if not investigated in this paper, low-cost thermal imaging could provide further measurements of stress-related phenomena—respiration rate [11,36] has already shown to be possible with a mobile thermal camera and possibly sweat [46]—to provide a wide battery of cues for reliable assessment.

Rather than focusing on all possible physiological signals that could be later added, this paper investigates the possibility to build a fast stress recognition system that only requires a very short time window of PPG and thermal measurements. This is to ensure the possible use in real-life ubiquitous situations. In particular, we contribute to the literature on 4 fronts. First, we propose new preprocessing techniques to enhance the quality of the signals that are extracted from both the smartphone-based PPG and thermal camera and to reliably produce PP intervals and thermal variability data as low-level features. This is particularly important when working with ultrashort measurements [47]. Second, we explore correlations between currently used metrics from thermal and PPG signals over a short period of time and self-reported stress scores. Third, instead of using the existing metrics as high-level features, we propose to use the low-level features and let artificial neural networks (NNs) learn informative high-level ones themselves. We evaluate the approach on a multimodal dataset purposely collected for this study. Finally, we further investigate sensitivities of different labeling strategies from self-reported stress scores within the perceived stress recognition performance.

Methods

Overview

This section presents a method that enables quick inference of a person's perceived stress level using smartphone-integrated PPG and thermography. We call these measurements *instant measurements* to differentiate them from the *short measurements* (typically between 2 min and 5 min), which have been previously defined in the literature [47].

First, we describe software we implemented. This includes a recording setup and a set of techniques to produce reliable PPG-derived HRV profiles and sequential nose tip thermal variations (called hereafter the *thermal variability sequence*) from the thermal imaging sensor. We then introduce our study protocol to induce different levels of mental stress and collect

short sequences (20 seconds) of cardiac pulse-related and thermal events together with self-reports of perceived mental stress scores. Third, we extract low-level (1-dimensional PP intervals and thermal variability sequences) and high-level hand-engineered features, comparing the performance of our system over the 2 sets of features and sensor modalities. We conclude by comparing our approach to data labeling with standard approaches to discuss the effect of intersubjective variability in reporting stress scores.

Toward Smartphone as a Reliable Multiple Cardiovascular Measure

The main cardiovascular sensing channels of this work are the rear RGB camera of a mobile phone (LG Nexus 5) and a low-cost thermal camera (FLIR One 2G) attached to the phone. Figure 1 shows the smartphone with the attached thermal camera, the required finger placement and light emission for PPG, and the physiological measurement interface.

Although the smartphone imaging-based PPG measurement can be performed in either a contact [6,7] or a contactless manner [8], in our work, we only focus on a contact-based imaging PPG. The reason is based upon previously repeated investigations within clinical studies [6,10] reporting its high accuracy. In addition, given that a normal RGB camera is only sensitive to a narrow electromagnetic spectral range of visible light in the so-called visible spectrum [48], adequate lighting is required before it can be used as a PPG sensor. Hence, a light emission from the rear flash light-emitting diode (LED) is used and a user is required to hold the smartphone body and place his/her finger over both the back camera and flash light (Figure 1). Unfortunately, the use of the back flash limits the duration of the measurements in some devices since its heat can potentially burn a person's skin. As shown in Figure 2, a large amount of heat is produced by the LED emission from the chosen smartphone (LG Nexus 5) in just 25-30 seconds of operation. A similar amount of heat was observed from another mobile phone (Samsung Galaxy 6 in Figure 1). Since temperatures above 50°C are potentially damaging to human skin tissues, for example, skin erythema could occur from 25 seconds heating at 51.07°C [49], we limit the cardiovascular measurement to a 20-second time period. This is also the required minimum duration for obtaining valid HRV metrics values, particularly LF/HF [47].

To capture a time series of apparent thermal sequences, we developed bespoke recording software using the FLIR One library (FLIR Systems). The interface is shown in Figure 1. Considering the thermal properties of human skin, the emissivity of the thermal imaging sensor was fixed at 0.98 [50]. As the thermal imaging system does not guarantee a consistent frame rate [48], the recording interface stores the time stamp with each image frame.

Figure 1. Smartphone RGB and thermal camera–based physiological measurement: (a) a smartphone with an add-on thermal camera, (b) flash light-emitting diode emission and finger placement for photoplethysmography measurement, and (c) designed software interface to collect blood volume pulse and 1D thermal signature from the nose. LED: light emitting diode.

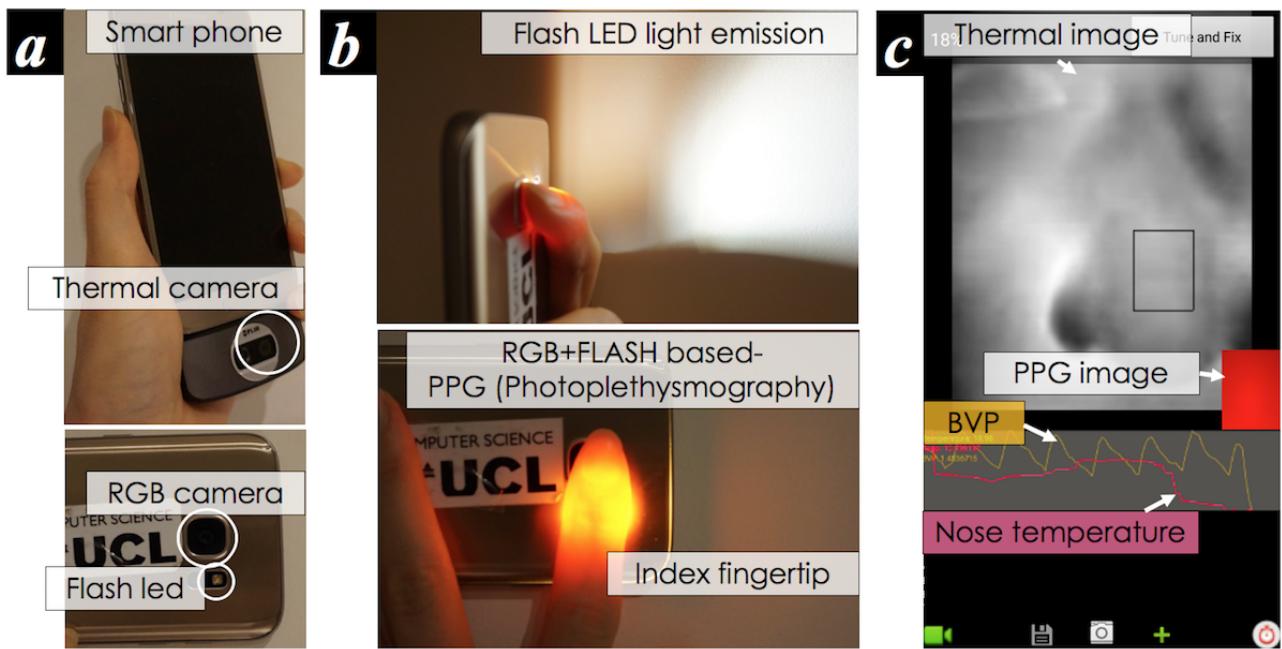
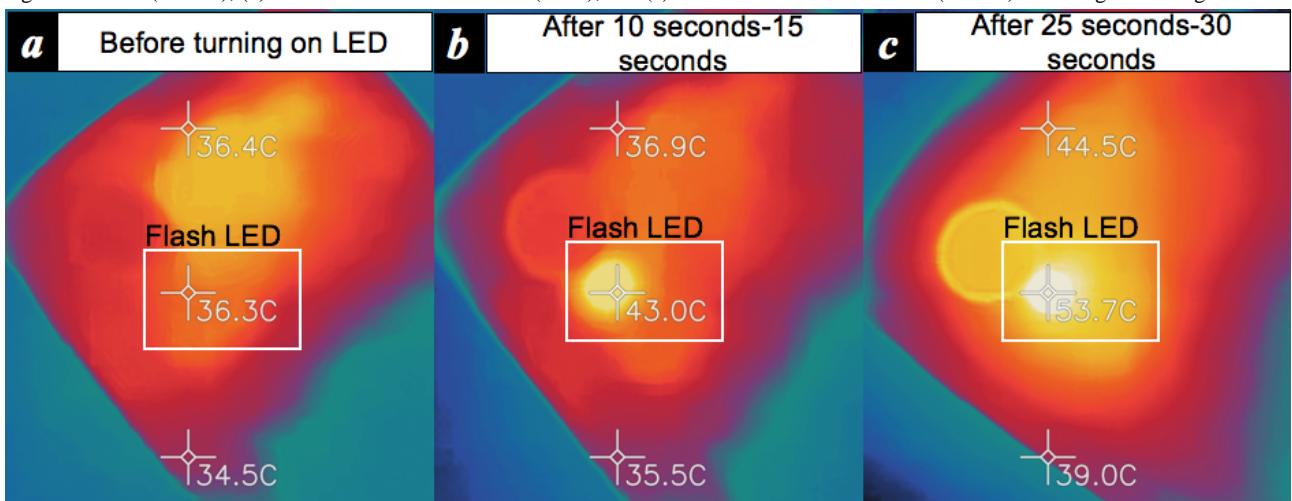


Figure 2. Heat produced by the rear flash light-emitting diode of a smartphone (LG Nexus 5), measured by a thermal camera (FLIR One): (a) before turning on the LED (36.3°C), (b) after 10 seconds–15 seconds (43°C), and (c) after 25 seconds–30 seconds (53.7°C). LED: light emitting diode.



Blood Volume Pulse and PP Interval Estimation Through Photoplethysmography

Figure 3 summarizes the approach we use to extract BVP and PP intervals through the smartphone imaging PPG. Following previous studies [6,7,10], our method estimates the BVP signals by capturing subtle color variations associated with light absorptivity patterns of hemoglobin in the capillaries of a person's skin. However, rather than using average values of the pixels of the red (or green) channel to estimate the BVP value, which is the most widely used method [6,7,9], we propose to use the negative temporal variations in spatial Shannon entropy [51] of sequential R-channel images ($-H_t(X)$) as raw BVP signals. This is because of averaging, which tends to ignore fairly small but important variations in color distribution [11]. The estimated BVP value at a given time t can be expressed in the following manner (equation 1):

where $x_{i,j}$ is the brightness of pixel (i,j) and $p(x_{i,j})$ is the probability distribution, which is generally estimated using a grayscale histogram in image analysis [52] (here, for the R channel).

As our interest is in measuring raw PP intervals from PPG signals, we used a simple signal processing technique to create similar amplitudes of each peak of BVP, which helps detect peaks for measuring the time interval (ie, PP interval) between the peaks. This was done by the subtraction of the k -sample moving average signals from the raw entropy signal (Figure 3) which can be expressed in the following manner (equation 2):

Figure 3. Overall procedure of blood volume pulse and PP interval estimation from a person's finger through the smartphone-imaging photoplethysmography. See text for details. BVP: blood volume pulse.

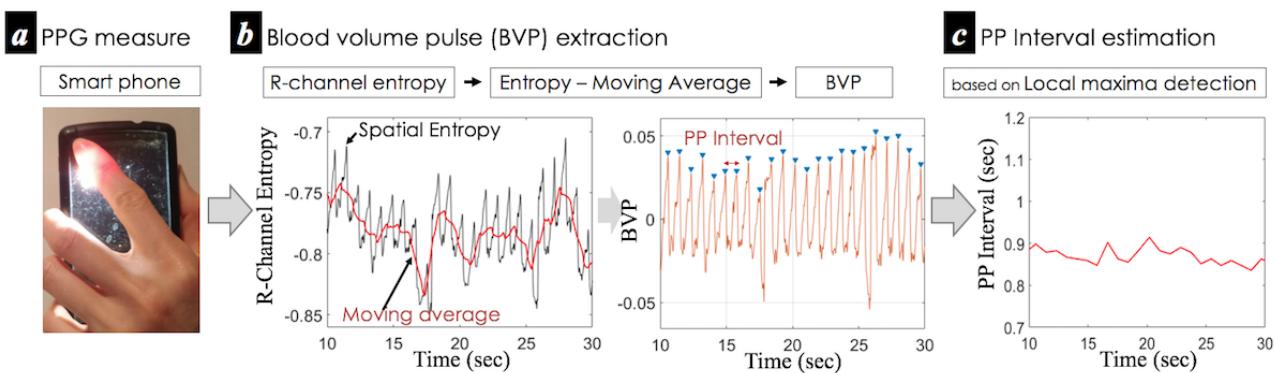
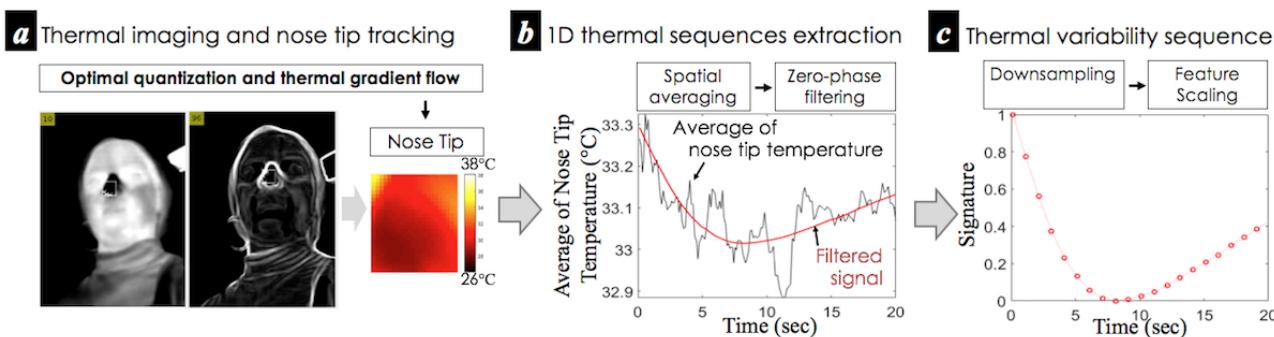


Figure 4. Overall procedure of the extraction of 1-dimensional thermal variability signature from a person's nose tip through smartphone thermal imaging.



Since a high sampling rate produces a higher sensitivity of the PP intervals [53], we upscaled the raw sequences to 256 Hz with spline interpolation and used a 1 second moving average to smooth heartbeat induced variations within the duration where at least one heartbeat of a normal person is expected to appear [54]. Finally, we used the simple local maxima detection [55] with a 0.5 second sliding window to recover PP intervals (Figure 3).

Continuous Extraction of Nose Tip Thermal Variability Sequence

To extract the 1D sequential nose tip thermal changes, our approach uses the 3 computational steps shown in Figure 4. These are (1) nose tip region-of-interest (ROI) tracking, (2) breathing artifact reduction, and (3) postprocessing for extracting low-level features representing thermal variability.

For ROI tracking, we can take advantage of recent advances in thermal ROI-tracking techniques, which help minimize the effects of motion artifacts and thermal environmental changes. In particular, we used the Optimal Quantization and Thermal Gradient Flow methods (Figure 4) introduced in a study by Cho Y et al [11]. Through the use of these techniques, we can continuously extract a spatial average temperature sequence over the ROI. As breathing causes thermal changes in the area close to the nose tip (see Figure 4), we need to remove such effects from the ROI for reliable measurements. This is necessary despite the fact that breathing dynamics are significant indicators of mental stress [3,36]. For this, we propose to use a low-pass filter with a cutoff frequency lower than the normal range of breathing rates of healthy people, for example, 0.1

Hz-0.85 Hz [11]. As a thermal directional change is a relatively slow physiological event [56], we set this to 0.08 Hz, which is lower than the low boundary. For the implementation, we used a zero-phase filtering (seventh-order, Butterworth) to avoid a phase-shifted result. Finally, we computed the thermal variability sequences of the nose tip (Figure 4) by downsampling with a linear interpolation and feature scaling the signal. Here, downsampling (1 Hz) is used to address the unsteady frame rate of the thermal camera and compute successive temperature differences sampled at regular temporal points. Feature scaling (Figure 4) was applied to minimize the effect of different levels of nasal temperatures across participants and sessions and to explore the thermal temporal variability within short-term data. As this new method helps extract nose tip thermal variability sequences continuously, it can produce richer feature sets in comparison with earlier methods [38,40,41]. In turn, this could possibly provide useful information, even from an instant measurement, contributing to the automatic inference of a person's stress.

Data Collection Protocol

A data collection study was carried out to gather physiological data from participants during different tasks that induced different levels of mental load. The data collection protocol is described below.

Participants

A total of 17 healthy adults (mean age 29.82 years, SD 12.02; 9 female) of varying ethnicities and different skin tones (pale white to black) were recruited from the University College London (UCL) and nonresearch community through the UCL

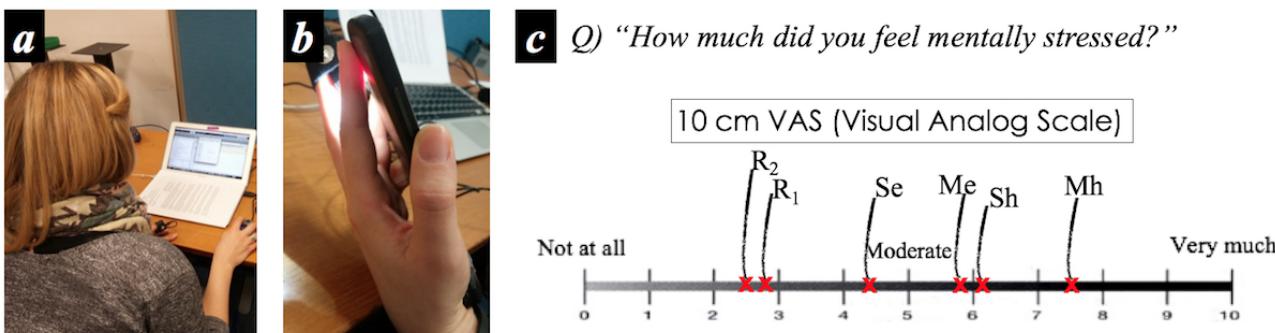
psychology subject pool system. Participants completed prescreening through the system that was designed to exclude participants with any history of psychiatric disorders or medicine intakes, which may influence their physiological signatures. Each participant was given the information sheet, asked to provide a signed consent to take part in the study, and to fill in the demographics form before the start of data acquisition. The study was conducted in a quiet lab room with no distractions. Participants were informed that they could stop the study at any time if they felt uncomfortable. Only 1 experimenter was present in the room during the data collection but kept his distance from the participant (further than 1.5 m). We compensated each participant with an £8 Amazon voucher after completion of the study. The experimental protocol was approved by the Ethics Committee of the University College London Interaction Centre (ID Number: STAFF/1011/005).

Task Structure and Instant Measurements of Lasting Stress-Induced Physiological Events

We designed a stress induction study protocol to collect physiological data and subjective self-reports in association with mental stress levels [1,57]. From the literature on mental stress induction studies in psychology, neuroscience, and affective computing [2,25,58,59], we chose 2 cognitive-load induction tasks—the Stroop Color-Word test [60] and the Mathematical Serial Subtraction test [61]. These tests were selected as they have been shown in various studies to induce mental stress by increasing cognitive load. They have also been used in other thermal imaging studies [39,41]. Each task was divided into 2 subtasks with varying difficulty levels to elicit different stress levels (easy and hard: Se=Stroop easy, Sh=Stroop hard, Me=Math easy, Mh=Math hard) and each subtask was counterbalanced in a Latin squared design as done in a study by Cho Y et al [36]. Between subtasks, we added a break period encouraging participants to fully recover (without any measurements, constraints) so as to avoid potential effects from previous sessions.

Although it has been shown that the Stroop and Math tasks lead to cognitive overload [2,59], they are limited in the amount of

Figure 5. Experimental setup and self-report question: (a) during each stress-induction task session, (b) 20-second physiology measurement after sessions, and (c) 10 cm VAS-based questionnaire (R1, R2: Rest from Session 1 and 2, Se: Stroop easy, Sh: Stroop hard, Me: Math easy, Mh: Math hard). The red marks (x) represent an example of self-reported score of 1 participant over the different tasks. The task labels have been added by the researchers for the purpose of this figure.



Textbox 1. Study protocol.

1. Introduction
 - Waiting in the corridor, introduction and entering the study room (5 min-10 min)
 - Information/consent/demographics forms filled in (5 min-10 min)
2. Session 1
 - Rest 1: sitting, resting (5 min)
 - 20-second measurement and self-reporting of perceived stress (1 min-2 min)
 - Task 1: Stroop Test 1 (5 min)
 - 20-second measurement and self-reporting of perceived stress (1 min-2 min)
 - Break (5 min)
 - Task 2: Stroop Test 2 (5 min)
 - 20-second measurement and self-reporting of perceived stress (1 min-2 min)
 - Break (3 min)
3. Session 2
 - Rest 2: sitting, resting (5 min)
 - 20-second measurement and self-reporting of perceived stress (1 min-2 min)
 - Task 3: Math Test 1 (5 min)
 - 20-second measurement and self-reporting of perceived stress (1 min-2 min)
 - Break (5 min)
 - Task 4: Math Test 2 (5 min)
 - 20-second measurement and self-reporting of perceived stress (1 min-2 min)
 - Break (5 min)
4. Closing
 - Wrap-up and participant's feedback (5 min-20 min)

Automatic Inference of Perceived Mental Stress From Instant Measurement**Low-Level and High-Level Features From Cardiovascular Events**

The 20-second cardiovascular measurement with the developed interface (Figures 1 and 5) simultaneously produces the following *signals*: (1) 1-dimensional PP intervals and (2) 1-dimensional thermal variability sequence

We take the PP intervals (Figure 3) and thermal variability sequence (Figure 4) as *low-level* features representing each modality throughout this paper.

In order to evaluate the effectiveness of our approach against standard approaches, we also extracted high-level engineered features for both BVP and nose tip temperature variations as the evaluation benchmark for our approach. We followed earlier studies on stress inference using HRV metrics as the features [25,37,68,69] (in our case, PPG-derived HRV; for readability, hereafter simply called PRV), although we excluded features directly from HR given its minor role repeatedly found in stress inference studies [25]. After the preprocessing method described above, we extracted the following PRV features:

1. PRV F1 (LF Power)
2. PRV F2 (HF Power)
3. PRV F3 (LF/HF ratio)
4. PRV F4 (SDPP: Standard Deviation of PP intervals)
5. PRV F5 (RMSSD: Root Mean Square of the Successive Differences of PP intervals)
6. PRV F6 (pPP50: Proportion of the number of the successive differences of PP intervals greater than 50 ms *of the total number of the intervals*)
As for *high-level* features representing the nose tip thermal signature, we used the most primarily used feature in the literature [38,40-42]:
7. Nose temperature F1 (TD: Temperature Difference between data from the start and the end).
In addition, we extracted basic statistical features from the processed thermal variability sequence, similar to SDPP from the PP intervals:
8. Nose temperature F2 (SDSTV: Standard Deviation of the Successive differences of the Thermal Variability sequence)
9. Nose temperature F3 (SDTV: Standard Deviation of the Thermal Variability sequence).

The sliding window was not used to extract these features given the short period of time over which they were measured.

Labeling Strategy and Machine Learning Classifiers

Given the focus on automated inference of a person's perceived stress level, the labeling of self-reported stress scores is an important step. However, interpersonal variability has been repeatedly found from self-reports of perceived mental stress [24,36,70]. This is a key issue that must be addressed if we are to create automatic stress recognition systems that can generalize across people. Following our earlier work [36], we use the normalized K-means clustering technique to label the measured events, as the K-means has been shown to be effective in handling self-reported data [71]. In detail, all perceived stress scores collected from each participant are normalized through feature scaling that identifies the minimum and maximum scores for a participant and rescales all the scores so that the range is the same across all participants. Then, the K-means algorithm ($k=3$) is used to group the participants' VAS scores into 3 levels of perceived stress scores corresponding to "None or low stress," "Moderate," and "Very high" on the VAS we used (see Figure 5). In this paper, we focus on discriminating between 2 levels of stress, *No-Stress* and *Stress*, given the limited amount of data for a more refined discrimination. Hence, a third step is required. We split the labels into 2 groups: the *No-Stress* group referring to the K-mean "None or low stress scores" cluster and the *Stress* group containing both the K-mean "Moderate" and "Very high" score clusters. A total of 2 obtained labelled groups are hence used to label the related physiological signatures from each 20-second window (L1).

Furthermore, we explored the possible effect of different data labeling strategies: (1) L2, combining the first and second K-means clusters (from $k=3$) into No-Stress by contrast with L1, (2) L3, K-means with $k=2$, and (3) L4, the original stress scores divided by directly dividing the VAS scale into 3 equal sections and then combining the "Moderate" and "Very high" stress classes into 1, that is, "Not at all" and "Moderate+Very high" (threshold at point 3.334 on the VAS scale in Figure 5). The aim of L2 and L3 was to understand the sensitivity of our approach in separating the moderate level of stress with the other 2 classes. L4 was used as a way to compare with more standard techniques used in the field [72].

A total of 2 machine learning algorithms were tested. First, we used a single hidden-layer NN, which is suitable to work with low-level features (ie, PP intervals and thermal variability vectors), capturing their temporal dynamics. The use of artificial NNs can empower automatic learning of informative physiological features with backpropagation to repeatedly tune internal parameters to let the features emerge from the data (this is also called representation learning). Second, with the high-level engineered features, we used the k-Nearest Neighbor classifier (denoted as kNN, $k=1$) as a benchmark stress inference model given that this is typically used in this area [69]. By choosing this second algorithm, we aim to assess the limitations of the use of handcrafted features, which may simplify a person's dynamic physiological events, and in turn possibly miss out some fast, informative moments. In particular, in the case of instant measurements (short period of time), this cannot be compensated by the use of a sliding window producing sequential feature values, for example, 120 seconds sliding

window used in a study by McDuff DJ et al [25] to continuously produce PRV features during a 180-second task session.

For the implementation of NNs, we tested 2 sizes of hidden layer nodes: (1) small ($n=80$, NN1) and (2) large ($n=260$, NN2)—each node size was empirically chosen. The mean and standard deviation of the training dataset were used to normalize both the training and testing dataset. The sigmoid was used as an activation function. In the training process, a fixed learning rate of 0.5 was used for 100 epochs.

Results

In this section we evaluate our proposed approach. First, we report the statistical analysis of the collected data. Second, we discuss the recognition performance of our system over the different modalities and types of features. Finally, we compare the results for the different labeling approaches.

Reliability of Measured Physiological Patterns

First of all, we tested the reliability of the physiological measurements. From the 17 participants, we collected 102 sets of the estimated BVP signals, PP intervals, and thermal variability sequences from 20-second instant measurements taken after each Stroop and Math task and after each resting session. However, 2 sets of data were not recorded because of phone battery issues at the end of 1 experiment, and 1 set was not recorded as 1 participant clicked the turn-off button on the phone by mistake. A total of 6 further sets had to be discarded because some participant's nose was not visible on thermal images (nose outside of the range of view because of sudden severe coughing during the 20 seconds, or because of head turned toward the experimenter, or the nose was covered by a person's hand). Although these disturbances were often transient, they meant that data could not be collected within the 20 seconds immediately following the end of the stressor. An analysis of the thermal data from Rest 1 also showed some extreme patterns in the nose tip temperature (eg, sudden increase in temperature). This may be explained by the fact that the experiment was conducted during the winter and temperatures outside of the experimental room were often significantly lower. This included both outdoors and indoors, in the corridor where the participants waited for the experiment. Despite the temperature changes, the Rest 1 data were kept in the dataset. A total of 93 sets were used for the study.

As the measurement capability of smartphone PPG has previously been thoroughly investigated in earlier studies [6,9,10], we only tested the reliability of the cardiac pulse signals measured with our approach and compared it with the mean brightness intensity-based method, which has been dominantly used [6,7,9]. For this, we used the relative power Signal Quality Index (pSQI), which is to assess the strength of physiological signals in a frequency range of interest as a measure of quality [11,53,73,74]. The pSQI for the BVP signals can be expressed in the following manner (equation 3):



where $0 \leq P \leq 1$, \boxed{P} is the power spectral density of BVP signals (in our case, \boxed{P} in equation 2), and \boxed{P} are the lower and upper boundary of expected HRs, respectively. Here, we set the expected HR range to 0.8 Hz (48 bpm) to 2.0 Hz (120 bpm) given that HRs of healthy adults mostly fall into this range [54]. To minimize effects of the baseline wander and high-frequency noise on this signal quality test [6,74], we used band-pass filtered BVP signals (0.7 Hz-4.0 Hz) as in a study by Chan P-H et al [6]. Figure 6 shows the better quality of the estimated BVP signals \hat{B} from the proposed method—Equation (2)—than that from the mean intensity method (*Proposed*: mean 0.755, SD 0.068; *Traditional*: mean 0.692, SD 0.075).

Figure 7 shows examples of thermal images taken from the participants during the data collection study. From our observations, we found that respiration influences the nasal tip temperature measurement in some cases. For instance, in Figure 7, thermal images of a person's nose tip surface, which were sequentially captured, show that inhaled air changed the nose tip temperature. Hence, we tested how much participants' respiratory cycled events affected the nose tip temperature measurements by using the pSQI in Equation (3) with the expected respiratory rate of interest (from 0.1 Hz-0.85 Hz) as used by Cho Y et al [11]. Figure 7 demonstrates how the measured nose tip temperatures involved respiratory cyclic patterns (respiratory pSQI: mean 0.714, SD 0.163), indicating that such affected temperature patterns may lead to wrong stress-level classification. On the other hand, the processing technique we propose to use (Figure 4) instead led to reducing respiratory artifacts on the measurement (respiratory pSQI: mean 0.157, SD 0.091).

Self-Reported Stress Ratings and Hand-Engineered Metrics

An important step was the analysis and possible normalization of the self-reported stress scores. The boxplot in Figure 8 (top) shows the distribution of the self-reported scores over the resting periods and the different sessions and tasks. It is clear that the

stress elicitation procedures did overall produce the wanted levels of stress with the hard sessions scoring higher than the easy sessions and the latter scoring higher than the resting periods (Rest from Session 1: mean 1.49, SD 1.94; Rest from Session 2: mean 1.30, SD 1.26; Stroop Easy: mean 2.17, SD 1.46; Math Easy: mean 2.66, SD 1.80; Stroop Hard: mean 3.92, SD 2.11; Math Hard: mean 5.17, SD 2.55) despite 2 outliers. However, the wide boxplots also show intersubject variability in self-reporting. In addition, the ranges (maximum-minimum) in scores for each participant differ quite highly (Maximum range: 8.75, Minimum range: 1.5; mean 4.7, SD 2.1), further suggesting the need for normalization of the scores.

Therefore, we normalized the data for each participant with respect to their range of scores over all the sessions. Figure 8 (middle) shows the original data and Figure 8 (bottom) shows the normalized data. The normalization helps to identify 2 main modes in the score distributions, suggesting the presence of 2 main clusters of stress levels. Given the subjectivity of stress ratings and the limited amount of data sets to carry a multilevel model, in this paper, we focused on binary classification of perceived mental stress: no/low stress versus medium/high (or very high) stress. The K-means separation between the 2 clusters is represented by each different color in Figure 8 (bottom).

We tested the correlations among the original self-reported scores, normalized self-reported scores, and the high-level hand-crafted PRV and thermal metrics as summarized in Table 1 (using Pearson correlation coefficients). The normalized self-scores maintained a high correlation with the original scores ($r=.752, P<.001$). Although some metrics of each physiological sensing channel were significantly correlated among themselves (eg, PRV F2-F4: $r=.838, P<.001$; Thermal F1-F3: $r=.803, P<.001$), the correlation values were lower across sensing channels. In addition, only SDSTV shows approaching significance but low correlation with the self-report scores ($r=.196, P=.059$), indicating that each individual engineered metric alone could not lead to high discrimination among perceived levels of stress.

Figure 6. Signal extraction quality comparison of our spatial entropy-based method (equation 2) with the mean intensity approach by using power Signal Quality Index (pSQI): (a) box plot, (b) histogram. BVP: blood volume pulse; pSQI: power Signal Quality Index.

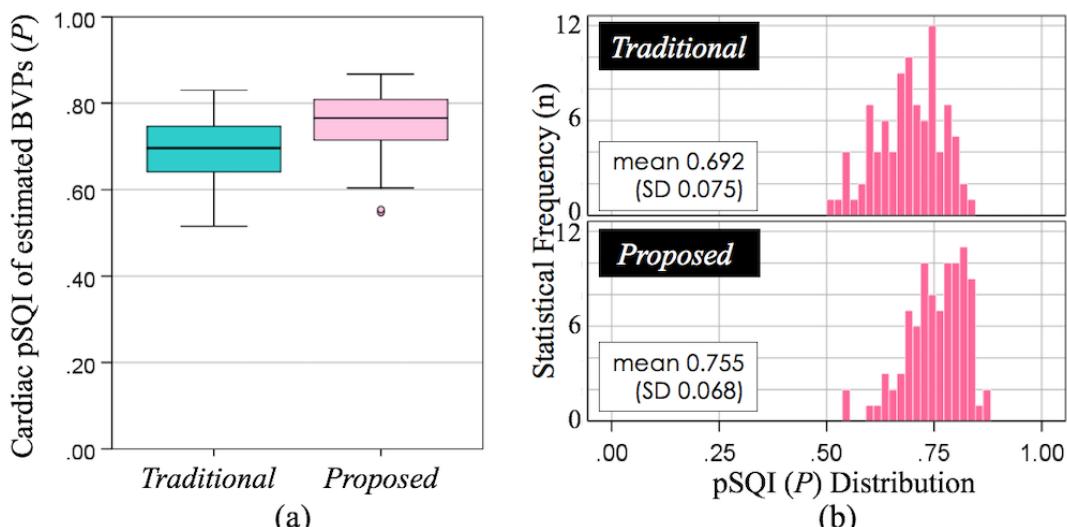
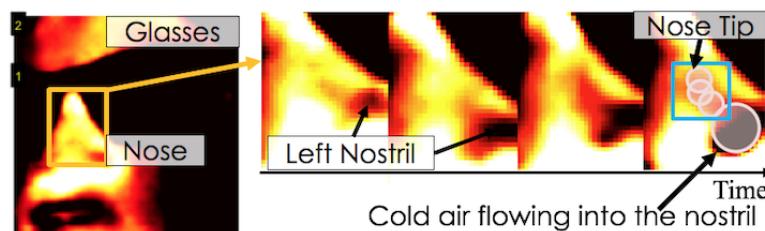


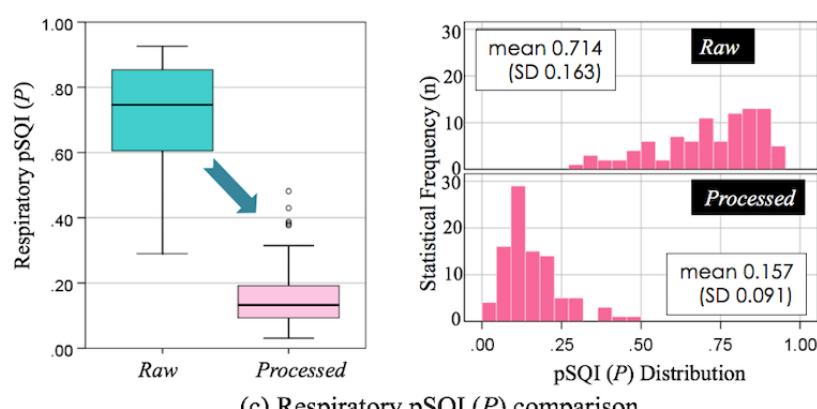
Figure 7. A person's respiratory activity influences the nasal tip temperature: (a) examples of thermal images from participants (view angles were not constrained), (b) the nasal temperature changes during inhalation (yellow: warmer, red: moderate, black: colder), and (c) respiratory signal quality test using pSQI. pSQI: power Signal Quality Index.



(a) Examples of thermal images collected from the 20s measurement



(b) Nose tip temperature affected by breathing cycles (inhalation phase)



(c) Respiratory pSQI (P) comparison

Figure 8. (a) Intersubject variability shown from the original self-reported stress scores of the 17 participants (box plot, 95% CI) across each section (Rest1, Stroop Easy, Stroop Hard, Rest2, Math Easy, Math Hard). (b) Overall self-reported stress score distributions (from 17 participants over the sessions including the resting periods), (c) normalized stress scores (normalization of scores from each participant) clustered into No-stress and Stress groups along with outputs of K-means.

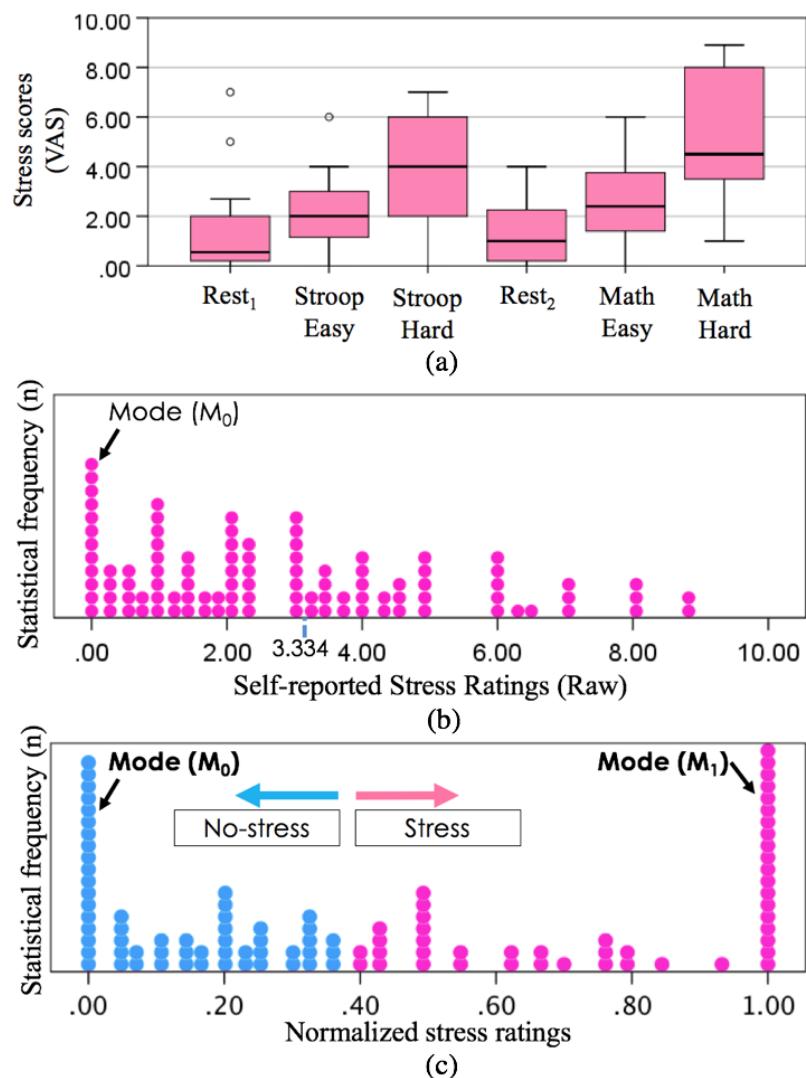


Table 1. Pearson correlation coefficients across self-reports, PRV (PPG derived HRV) and thermal metrics (high-level features). HF: high frequency; HRV: heart rate variability; LF: low frequency; PPG: photoplethysmography; pPP50: proportion of the number of the successive differences of PP intervals greater than 50 ms of the total number of the intervals; PRV: pulse rate variability; RMSSD: root mean square of the successive differences of PP intervals; SDSTV: standard deviation of the successive differences of the thermal variability; SDTV: standard deviation of the thermal variability sequence; TD: temperature difference.

Scores	Self-reports PRV (PPG derived HRV)						Nose Temperature					
	S1 ^a	S2 ^b	LF (F1)	HF (F2)	LF/HF (F3)	SDPP (F4)	RMSSD (F5)	pPP50 (F6)	TD (F1)	SDSTV (F2)	SDTV (F3)	
Self-report												
S1	Corr ^c	1	.752	.007	.011	-.044	.03	.146	.058	-.154	.196	.02
S1	<i>P</i>		<.001	.94	.91	.66	.77	.15	.57	.14	.059	.85
S2	Corr		1	-.079	-.044	-.082	-.002	.083	.097	-.153	.197	.032
S2	<i>P</i>			.44	.66	.42	.99	.41	.34	.14	.06	.76
PRV (PPG derived HRV)												
F1	Corr		1	.394	.573	.638	.098	.134	.016	.12	.047	
F1	<i>P</i>			<.001	<.001	<.001	.34	.19	.88	.25	.66	
F2	Corr			1	-.293	.838	.13	.39	.083	.2	.054	
F2	<i>P</i>				.003	<.001	.20	<.001	.43	.054	.61	
F3	Corr				1	.007	-.027	-.178	.056	.057	.123	
F3	<i>P</i>					.95	.79	.08	.60	.59	.24	
F4	Corr					1	.139	.571	.1	.198	.084	
F4	<i>P</i>						.17	<.001	.34	.06	.43	
F5	Corr						1	-.067	-.059	.174	-.067	
F5	<i>P</i>							.51	.57	.095	.52	
F6	Corr							1	.134	.212	.127	
F6	<i>P</i>								.2	.042	.23	
Temperature												
F1	Corr							1	.213	.803		
F1	<i>P</i>								.039	<.001		
F2	Corr								1	.487		
F2	<i>P</i>									<.001		
F3	Corr									1		
F3	<i>P</i>											

^aS1: normalized self-reported scores.

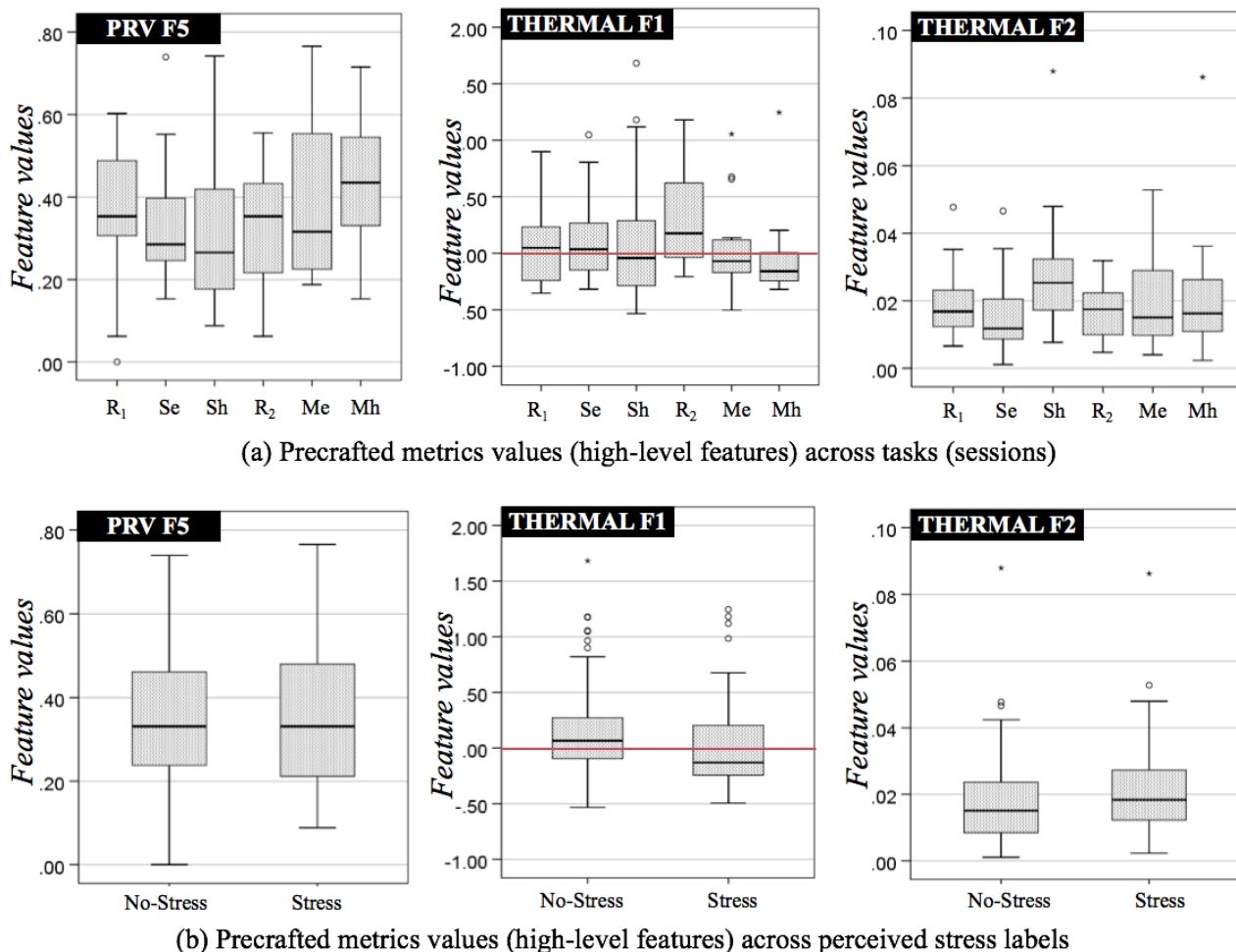
^bS2: original self-reported scores.

^cCorr: correlation coefficients.

Figure 9 shows values of each precrafted metric across the sessions (rest and 3 stressful events, ie, Stroop: easy/hard and Math: easy/hard) and across the labels produced by the labeling technique. As shown in Figure 9, there was no common pattern found between 2 easy or hard tasks, although they were designed to induce similar levels of mental stress (eg, easy: low stress level, hard: high stress level). For example, Thermal F1 appeared to strongly decrease during the Math hard task but not during the Stroop hard task, Thermal F2 increased with the Stroop hard

task but less during the Math hard task. PRV F5 was generally high after both Math easy and hard task sessions than the Stroop hard session. This can further indicate that each metric alone from the instant measurement is less likely to contribute to the inference of each session. On the other hand, when we applied our labeling technique, Thermal F1 values grouped into Stress were generally lower than No-Stress data as shown in Figure 9, consistent with findings from the literature [38,40,41].

Figure 9. Box plots of 95% confidence intervals in values of each precrafted metric across (a) each session (R1: Rest 1, Se: Stroop easy, Sh: Stroop hard, R2: Rest 2, Me: Math easy, Mh: Math hard) and (b) label produced by our labeling technique. The 3 features (having best correlations with self-reports) are PRV F5: RMSSD, root mean square of the successive differences of PP intervals, Thermal F1:TD, temperature difference between from the start and the end (a red line is drawn to show negative or positive thermal direction), F2: SDTV, standard deviation of the successive differences of thermal variability sequence.



Instant Stress Inference Results

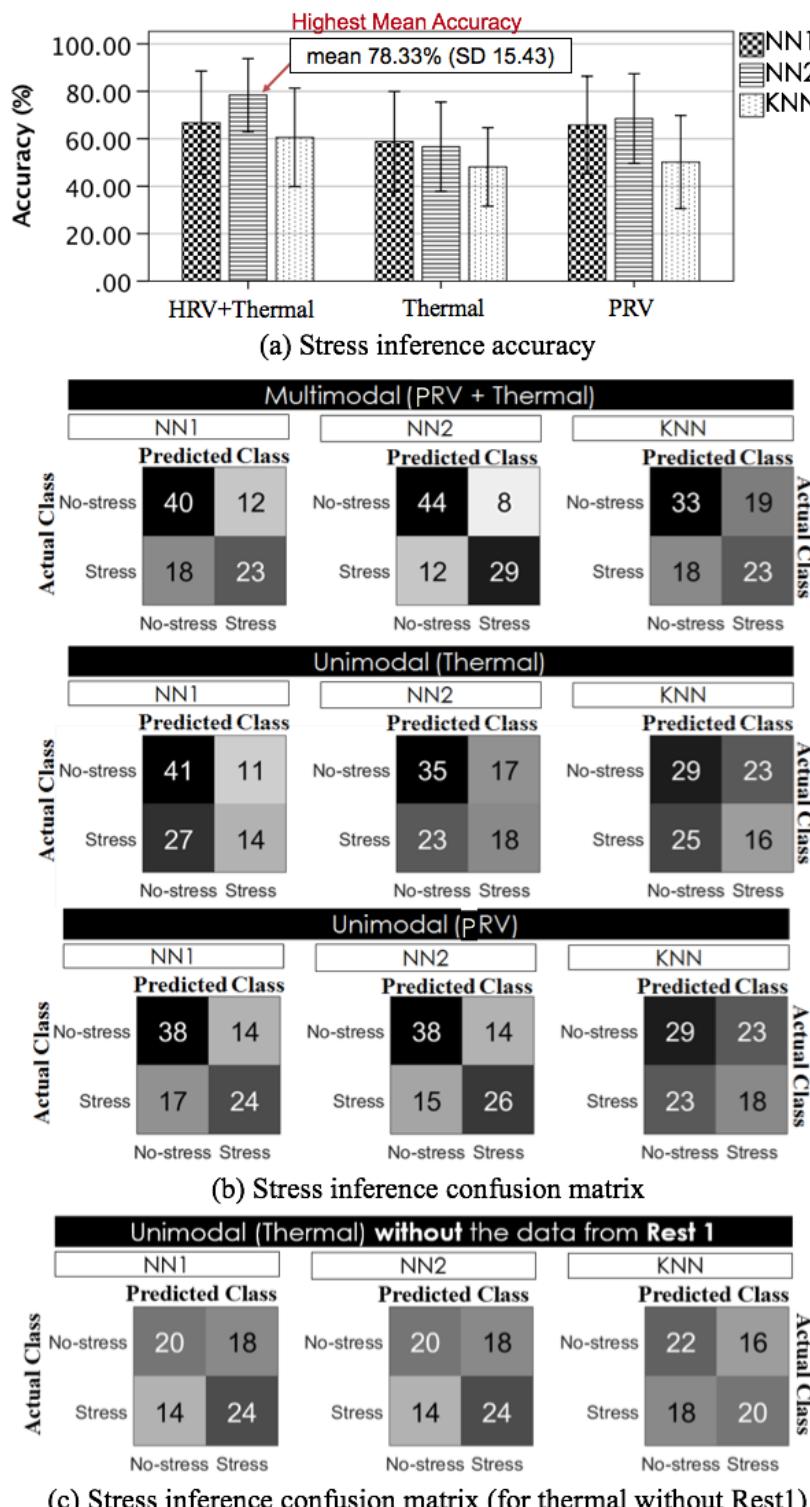
To evaluate the performance of instant stress recognition, we used a 17-fold leave-one-subject (participant)-out (LOSO) cross-validation. LOSO was chosen to test the ability to generalize to unseen participants (*one size fits all*) [36,70].

Figure 10 summarizes the accuracy results of the 3 classifiers (NN1, NN2, and kNN) using LOSO ($N=17$) for 3 different cases: (1) multimodal approach by simply combining features from both sensing channels (PRV, Thermal), (2) unimodal approach using thermal features, and (3) unimodal approach using PRV features. Both NN1 and NN2 used our proposed low-level features only (ie, PP intervals and thermal variability sequences). Overall, the NN2-based multimodal approach produced the highest mean accuracy of 78.33% (SD 15.43), mean F1 score of 77.92%, in discriminating between no-stress and perceived stress (see confusion matrix in Figure 10 for details). The NN1 (whose hidden layer is smaller than that for NN2) produced a lower accuracy (mean 66.76%, SD 21.75). From all cases of modality, the kNN with the high-level features (ie, using the hand-engineered 6 PRV and 3 thermal metrics) performed worst. A similar pattern can be seen for the PRV

unimodal channel (NN1: mean 65.78%, SD 20.55; NN2: mean 68.53%, SD 18.89; kNN: mean 50.20%, SD 19.63). For the thermal channel, the NN1 appears to perform marginally better (mean 58.82%, SD 21.11) than the NN2 (mean 56.67%, SD 18.79), but both NNs again perform better than the kNN (mean 48.14%, SD 16.52).

However, it should be noted that, for all the models, the confusion matrices for the thermal case (Figure 10, Thermal) show a clear bias toward the no-stress class. Given this bias and the fact that thermal data from the Rest 1 sessions appeared to be affected by the large variation in temperature between the waiting space and the experiment room (in addition, some participants had just arrived from the outside while others had already been indoor for sometimes), we reran the models, discarding the data from the Rest 1 sessions. Although the overall performance over this modality did not largely change (NN1: mean 58.14%, SD 23.33; NN2: mean 58.14%, SD 21.59; kNN: mean 55.88%, SD 22.38) and NN1 and NN2 still perform better than the kNN with hand-engineered features, all the confusion matrices (Figure 10 bottom) show more balanced results and a better prediction of the stress class overall.

Figure 10. Summary of (a) mean inference accuracy results across 17 folds, (b) accumulated (from 17 LOSO folds) confusion matrices for the 3 classifiers NN1, NN2, and kNN along with each set of modalities (Multimodal: PRV+Thermal, Unimodal: Thermal, PRV), (c) confusion matrices for the temperature-based unimodal approach built without the Rest 1 data. Each number in the confusion matrices refers to the number of instances. kNN: k-Nearest Neighbor; NN: neural network.



A repeated measures analysis of variance was carried out on results from the 17 folds (including the Rest 1 data) to compare the 2 NN modeling approaches (that use our proposed low-level features) with the kNN (that uses hand-engineered metrics) to determine whether there was a statistical mean difference in performance. The results show significant differences between the methods for the multi and the PRV

modalities—PRV+Thermal: $F_{2,32}=3.763$, $P=.034$, $\eta_p^2=.190$; PRV: $F_{2,32}=6.001$, $P=.006$, $\eta_p^2=.273$. No differences were found for the thermal case—Thermal: $F_{2,32}=2.304$, $P=.116$, $\eta_p^2=.126$. Posthoc paired t test with Bonferroni correction (see Figure 11) showed that NN2 performed significantly better than kNN for the unimodal PRV case (PRV: $P=.023$). For the multimodal

case, NN2 approached significantly better performance than kNN (PRV+Thermal: $P=.064$) and NN1 (PRV+Thermal: $P=.052$). NN1 did not significantly perform better than kNN; however, it presented a positive trend in the unimodal PRV case (PRV: $P=.091$). Even if no significance differences were found over the unimodal thermal case, the graphs in Figure 11 show how the 2 NN models performed slightly better than the kNN for all cases including the thermal one. It could be expected that in the case of deployment, a larger sample of data for each class could indeed lead to statistical significance.

Lastly, we investigated the effect of the normalization and K-means clustering of self-reported scores in inferring the perceived stress levels. For this part of the study, we removed the Rest 1 data. There were 2 reasons for this. First, we wanted to avoid the noise from the set of data affecting the comparison among the labeling methods. Second, this was also to obtain a more balanced number of instances in each class for testing different labeling methods, less biasing the learning process. The comparison of models over the different labeling techniques did not aim to obtain better performance but to understand how normalization and different clustering approaches could affect the modeling by acting on class separation and interperson variability in subjective self-reports. We were also interested

in understanding how sensitive the system was in separating stress scores by using the same dataset and merging the intermediate levels with 1 of the 2 classes (L1 and L2).

We tested the 3 models (NN1, NN2, and kNN) for the multimodal approach with the different labeling strategies (L2-L4, introduced in the previous section). Figure 12 summarizes the accuracy results for 4 different strategies—L1: the main method, L2: K-means with $k=3$, but combining no-stress and moderate level stress scores as 1 group, L3: K-means with $k=2$, dissecting the moderate level scores into no-stress and stress, and L4: original scores divided by a point between no-stress and moderate levels (ie, 3.334 of 10, see Figure 5c). The results showed that the L1 performed best in separating the bimodal distribution of normalized self-reported scores and helped address the interpersonal variability issue. Indeed, all 3 models obtained the best accuracy with L1 and the worst performance for L3 and L4 with L4 being marginally better than L3. Finally, it should be noted that in the case of L3 and L4, the best performance was obtained with NN2 rather than NN1. This may indicate that mapping feature values to perceived stress scores may benefit from a larger hidden layer to capture the complexity of the relation.

Figure 11. Differences in performance over each fold (ie, LOSO—for each tested participant data) between the three models over the three modalities. They show how NN2 and to a certain extent NN1 generalize to unseen participants better than kNN. LOSO: leave-one-subject-out; kNN: k-Nearest Neighbor; NN: neural network.

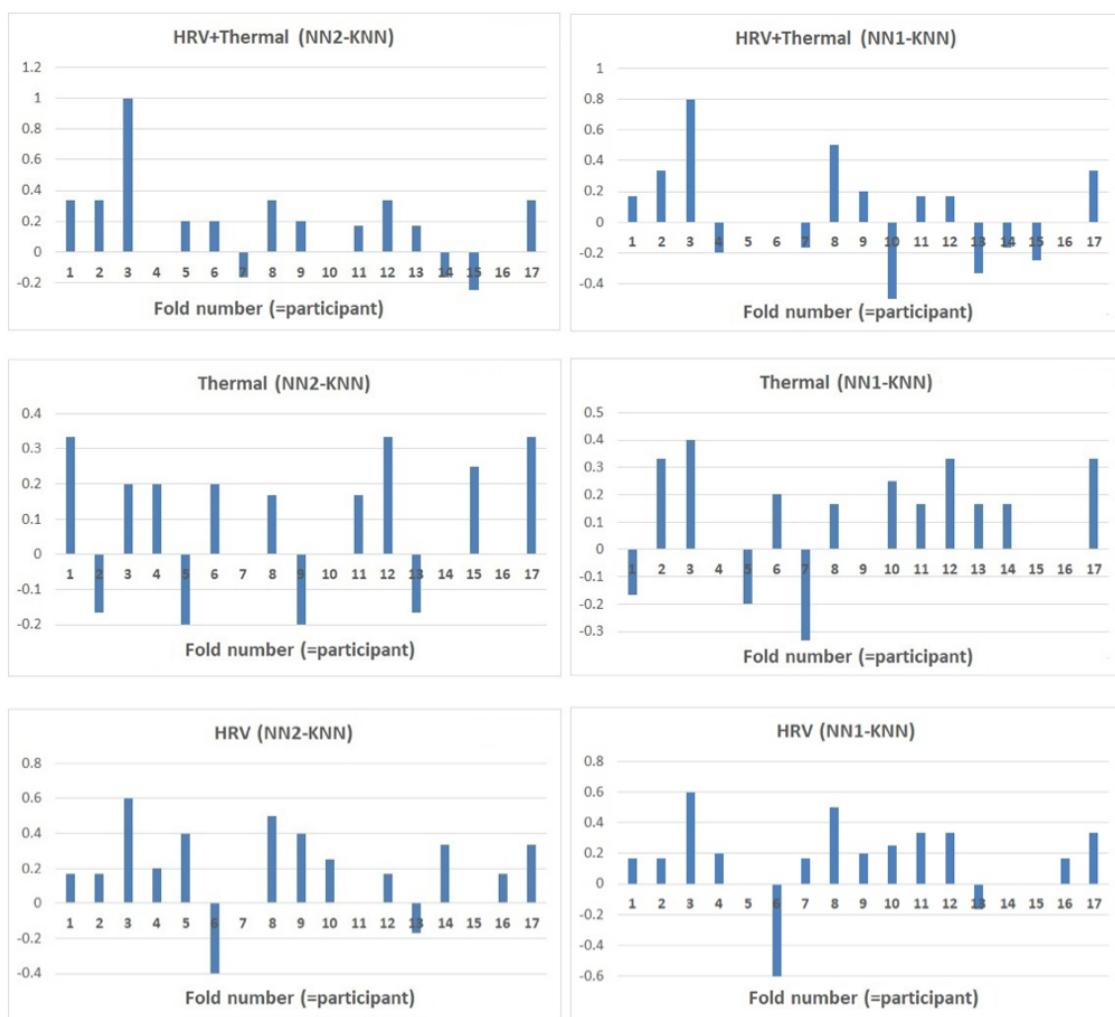
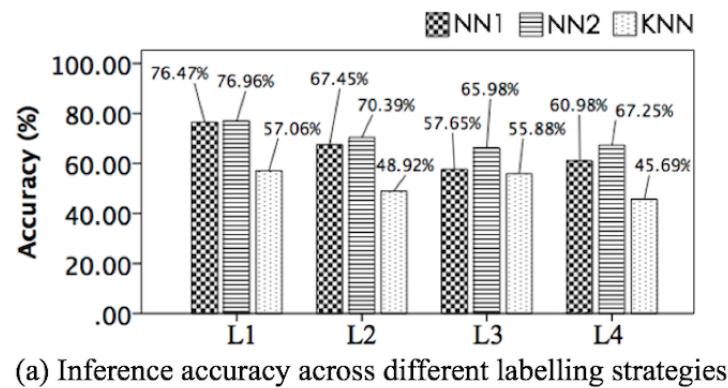
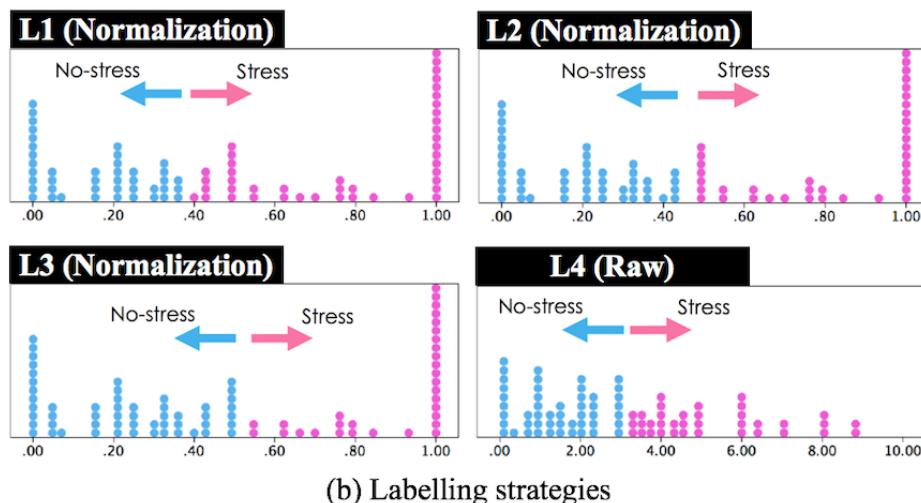


Figure 12. Summary of (a) inference accuracy along with (b) different labelling approaches (L1: K-means with $k=3$ and combining moderate and high stress scores, L2: K-means with $k=3$ and combining no-stress and moderate level stress scores, L3: K-means with $k=2$, L4: original scores divided by the border between no-stress and moderate levels). NN: neural network; kNN: k-Nearest Neighbor.



(a) Inference accuracy across different labelling strategies



Discussion

This paper contributed to the body of work that aims to make mobile measurements of mental stress more feasible and robust. We focused on 2 stress-related cardiovascular signals: BVP and vasoconstriction/dilation-related nose tip temperature. They have been widely investigated in both the mental health and computing literature [22,39,41,47,75], but their applicability together with low-cost sensing offered by mobile devices has not been explored. Our work makes 4 key contributions: (1) a set of methods to improve the quality of the sensed signal, (2) a demonstration of the limited capability of typically used engineered features in the context of very short-term (*instant*) measurements, (3) a new set of low-level features to capture the dynamical variability of the 2 signals, and (4) the feasibility of using 20-second measurements to discriminate between no-stress and stress responses. Finally, we report on the lesson learned from the analysis of different labeling methods and their effect on the modeling process. Below are detailed discussions of these contributions.

Toward Smartphones as Reliable Cardiovascular Measures

Our first contribution is to develop a new set of preprocessing techniques to enhance the quality of the signal extracted from either the PPG channel, which detects blood pulse variability,

or the thermal camera, which detects vasoconstriction/dilation induced nasal temperature variability. This is particularly important in mobile, ubiquitous settings where physiological sensing setups are still of lower quality and have to be less controlled in comparison with the ones generally used in medical environments.

With the data collected from our stress-inducing tasks, we wanted to test the possibility of building algorithms that can reliably and continuously capture (1) a person's BVP pattern from the smartphone camera and (2) nose tip temperature sequence from the add-on thermal camera. Reliable BVP recording is critical, particularly for short-term measurements [26,47]. The conducted signal quality test with the pSQI showed that our method produced higher quality BVP signals than the ones obtained with traditional camera-based PPG approaches [6,7,9] (see Figure 6). In addition, we found that a person's respiratory cycles interfered with capturing thermal variations accurately from a person's nasal area (Figure 7). Hence, we built a new technique to minimize such effects and gather a more reliable nose tip thermal signature. This was achieved through the use of an advanced thermal ROI tracking [11] and signal processing techniques to filter out breathing cyclic events (Figure 4) on measured temperatures from the nose area.

However, it should be noted that despite the use of the quantization approach that helps handle environmental

temperature changes [11], thermal data during Rest 1 was affected by the difference in temperature between the waiting area and experiment area. This effect was further enhanced when the participants just arrived from outdoors with body temperature being strongly influenced by the cold weather outdoors (winter season). This is important because if the system has to be used, it is crucial for the person to use it in the same environment where stressful events occur. It should also be tested in future studies if a decrease in nose tip temperature may be saturated by very cold environments and therefore be less informative in such situations for automatically detecting mental stress.

Traditional Cardiovascular Metrics Do Not Capture Stress-Related Variability From an Instant Measurement

We found that the capability of the HRV metrics, used as high-level features in the literature [18,20,25], in instantly quantifying stress was very limited (see Table 1). This is important as despite their general use (eg, literature in psychology or affective computing), there have still been arguments of such metrics with regard to the possibility of oversimplifying physiological responses [33-35]. It should be noted that although we used PPG-derived metrics rather than the more investigated ECG-derived metrics, strong correlations have been found between the 2 signal metrics in the case of healthy participants and limited physical movement [29,45]. Stressors in general affect cardiac pulse-related events even if the 2 types of events (heart rate and BVP) may be differently affected within nonhealthy or elderly population and extreme situations (hot temperature) [75-77]. It should also be noted that although mathematically, a shorter measurement period could lead to a lower resolution of data in the frequency domain resulting in a lower accuracy in computing metrics such as LF/HF [21], recent studies have validated the use of them with very short measurements, from 10 seconds to 30 seconds [47].

Similarly, the metrics applied to short-term nasal thermal data (eg, TD: Temperature Difference) did also weakly contribute to stress quantification. This may explain inconsistent findings in the literature where such metrics have been used to capture thermal responses to stressful events [41,78]. All in all, the results suggested the need to develop a novel way that describes dynamical information of BVP and vasoconstriction/dilation-related nasal temperature to help improve the understanding and capturing of their complex phenomenon.

Overcoming Limitations to Mobile Automatic Stress Inference

On the basis of the low correlation between perceived mental stress levels and typically engineered metrics for these 2 signals, we proposed to use thermal variability and PP interval sequences as a novel set of low-level features to capture stress responses of cardiovascular activities. With this, we investigated how to benefit from automatic feature learning capabilities of machine learning classifiers (ie, NNs) in instantly inferring mental stress. The results showed clear improvements in performance. Indeed, our proposed method with the 2 cardiovascular signals achieved 78.33% correct recognition accuracy with the NN2, whereas only 60.59% from the kNN with the hand-engineered

features. Similarly, using the HRV-related features only, there was an improvement by 18.33% with respect to the traditional approach (50.20%). The improvement on the thermal channel was smaller but still evident from the results.

In addition, 2 further contributions can be highlighted from our approach to the modeling of automatic stress inference: *instant measurements* and *no need for baseline*. First, previous work required relatively long-term measurements of between 2 minutes and 5 minutes [25,41,54]. Indeed, our results demonstrated the possibility to use just a 20-second measurement to automatically discriminate between stress and nonstress moments. This approach achieved state-of-the-art performance when compared with approaches using much longer measurements, up to around 70%-80% correct recognition from LOSO cross-validation [70]. This is very important given that stillness is critical during PPG measurements and for thermal imaging to a certain extent. In fact, even if automatic ROI-tracking methods may help with thermal measurements, people tend to easily move away from the camera or cover their nose with their hands (5 participants did so at least once even for 20 seconds).

Second, our approach (more reliable signal and richer features) led to state-of-the-art results without the use of a baseline. This is critical to everyday life settings as in everyday life, such baselines may be difficult to establish. Resting periods just before a stressful event cannot be planned, and continuously gathering such measures can be costly, whereas at the same time, nonstressful resting periods would also need to be automatically detected. In addition, our data from resting periods show that such a gold standard resting situation does not exist and environment temperature may change drastically, affecting skin temperature. This could have been because of a lab effect but general everyday life may also have specific effects on the data. Even when using differential features (eg, temperature differences between 2 areas of the face-forehead and nose tip), a baseline period was used [42]. The lack of a baseline is overcome here by proposing richer features capturing informative physiological variations over time.

How Do We Define the Ground Truth: What is the Best Approach?

Setting the ground truth is a difficult process when dealing with subjective reports. How to use self-reports to label the data is a critical issue in the field because of their subjectivity. Interpersonal variability has been repeatedly reported as a critical barrier for building stress inference or quantification systems that can generalize across people [24,70]. The intersubjectivity of self-reports and the need to reduce the number of classes along with types of applications or the size of the dataset require some decisions on how to refine the labels to be taken. In doing so, there is the danger to add noise to the dataset and hence to the modeling process. We explored how different labeling techniques may affect the modeling process.

We proposed to address this problem. The first step was to use a standard normalization technique to take into account personal score ranges over all tasks that aimed to induce a wide range of stress levels (from none to medium to quite high). This transformation led to a bimodal distribution highlighting at least

2 opposite levels of stress (low and high), whereas it still maintained its strong correlation with the original scores ($r=.752$, $P<.001$). The bimodal distribution is interesting as, given the low number of participants, it suggests the moderate level of stress is not well separated from the other 2 classes. A binary classification was hence a sensible approach to take in this paper; however, with larger datasets, a more refined analysis and modeling should be carried out. Second, we used a machine learning clustering technique, K-means, to improve separation of the scores into 2 classes of stress. The results obtained from the comparison of our approach (L1) with its variation (L2) and the more typically used approaches (L3 and L4) led to an interesting lesson on how to create a more reliable ground truth rather than increase noise in labeling.

Then, how should the data be clustered? According to the number of stress levels to be recognized or according to the number of stress levels the data collection experiment was set to induce? The latter approach appeared to be more successful. All labeling methods using K=3 (L1, L2, and to a certain extent L4) performed better than L3 using K=2. This suggests that directly clustering according to the number of classes to be recognized (2 in our case) may spread instances with similar stress-level responses (in this case, medium responses) across classes introducing noise rather than overcoming the problems of intersubjectivity. However, it should be noted that the normalization step was important. Indeed, the models built on either L1 and L2 using the normalized scores performed better than L4 where the original scores were used instead.

Another important issue to be addressed is how should the data be grouped when the number of classes to be detected is smaller than the number of levels induced? This decision could be needed either because there were no sufficient instances for a more refined inference or because the application at hand did not require such level of granularity (at the risk of introducing noise because of intersubjective variability). The results showed that L1, collapsing the moderate level into the high-level class, led to better performance than L2, where medium and no/low stress scores were instead combined. This may suggest that unless the stress level is very low, stress responses share more similarities than with no-stress responses. A more in-depth analysis of this aspect could be part of a future work and it may require an in-depth analysis of individual responses and validations over other datasets.

Although the results provide some interesting insights on how to cluster data from experiments, a question remains on how to deal with data from real-life situations. It is expected that in real-life situations, larger datasets may enable finer levels of discrimination personalized to a specific person. In such situations, as the dataset grows, parameters for labeling may need to be adapted to optimize the personalization. However, such rules we used could be helpful to bootstrap models on the basis of experimental datasets or well-structured initial real-life data collections. The bootstrapped models could then be personalized to specific users and recognition levels as data would be continuously collected by the person.

Limitations and Future Directions

Despite the findings and contributions described above, there is still space for improvement. First, our proposed approach did not perform properly on multiple levels of stress (labeling the data using perceived self-scores). As discussed, this was most probably because of the limited size of the dataset, especially for the medium level of stress (out of 3 levels). Deploying built software in real life could be a way to build a larger dataset. With a function to collect self-reported person's perceived stress scores (eg, digitalized VAS sliding bar in an app), this data collection in the wild could produce a sufficient size of cardiovascular signal sets to support more reliable performance in inferring multiple levels. In addition, it would be interesting to investigate how the transformation of the self-reported scores could be used to support multiclass classification.

Second, this work focused on sedentary situations (but without constraining one's mobility) and did not include physical activity (eg, walking). It is well-known that physical activity induces cardiovascular changes, in turn affecting stress inference performance [58]. Hence, it would be interesting to test the instant stress inference ability of our system in situations where there is a considerable amount of physical activity, for example, industrial factory work floor.

Finally, investigating the reliability of mobile sensing technologies themselves was outside the scope of this paper—see reviews on this topic [79]. We aimed to contribute a better stress inference method that can be used independently regardless of what sensing technology is used. This may be even more crucial when the sensing technology may not be as accurate and fine-grain as more expensive and medically approved technology.

Conclusions

With the long-term aim of building a stress monitoring system for mobile, everyday use, this paper focuses on the use of smartphone-based imaging capabilities: PPG and thermal imaging. To overcome the difficulties in using smartphone imaging for long period measurements, we propose a novel method that quickly infers a person's perceived level of stress from instant physiological measurements. This is achieved by (1) developing a more reliable PPG-sensing technique to extract a person's BVP and its variability, (2) building a thermal imaging-based vasoconstriction monitoring system, (3) investigating the performance of widely used high-level features from PPG and nasal temperature in instant stress inference tasks, (4) proposing novel low-level features to represent HRV and thermal variability, (5) building an automatic feature learning-based multimodal perceived stress recognizer, and (6) investigating effects of clustering self-report scores to take into account the subjectivity of self-reports and ensure clear separation among the levels of stress to be modeled.

Through the data collection study with 17 participants and a series of stress-inducing tasks with different levels, we demonstrated how this system was able to achieve state-of-the-art performance using 20 seconds of data, rather than 2 to 5 minutes typically required by existing methods. This work makes smartphone imaging-based physiological

computing capabilities more feasible for real-life applications, support apps and research. opening new possibilities for the development of mental-stress

Acknowledgments

The authors thank all the participants who participated in the experiment.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Single hidden-layer Neural Network (NN) and k-Nearest Neighbor (kNN).

[[PDF File \(Adobe PDF File\), 190KB - mental_v6i4e10140_app1.pdf](#)]

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Abbreviations

BVP: blood volume pulse

ECG: electrocardiogram

HF: High Frequency

HRV: heart rate variability

kNN: k-Nearest Neighbor

LED: light-emitting diode

LF: Low Frequency

LOSO: leave-one-subject-out

NN: neural network

PPG: photoplethysmography

pPP50: Proportion of the number of the successive differences of PP intervals greater than 50 ms of the total number of the intervals

PRV: pulse rate variability

PSNS: parasympathetic nervous system

pSQI: power Signal Quality Index

RMSD: root mean square of the successive differences of PP intervals

ROI: region of interest

SDPP: standard deviation of PP intervals

SDSTV: standard deviation of the successive differences of the thermal variability

SDTV: standard deviation of the thermal variability sequence

SNS: sympathetic nervous system

TD: temperature difference

UCL: University College London

Edited by J Torous; submitted 15.02.18; peer-reviewed by A Sano, F Andrasik, M Lang; comments to author 13.03.18; revised version received 21.08.18; accepted 05.12.18; published 09.04.19.

Please cite as:

Cho Y, Julier SJ, Bianchi-Berthouze N

Instant Stress: Detection of Perceived Mental Stress Through Smartphone Photoplethysmography and Thermal Imaging

JMIR Ment Health 2019;6(4):e10140

URL: <https://mental.jmir.org/2019/4/e10140/>

doi:10.2196/10140

PMID:30964440

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Original Paper

The Relationship Between Nomophobia and Maladaptive Coping Styles in a Sample of Italian Young Adults: Insights and Implications From a Cross-Sectional Study

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Abstract

Background: Information technologies have become an integral part of the modern society; however, it is speculated that their overuse would result in addiction. Nomophobia refers to the irrational fear of being out of contact with virtual communication platforms. Generally, upon exposure to stress, humans adjust by employing cognitive mechanisms and behavioral efforts known as coping strategies.

Objective: The goal of the research was to explore coping styles implemented in subjects with nomophobia.

Methods: This was a cross-sectional study involving young adult participants (undergraduate students and younger subjects) who were recruited via an online survey using a snowball approach. The Italian version of the Nomophobia Questionnaire was administered to subjects. The measurement of coping styles was done using the 28-item Brief COPE questionnaire. Continuous data were computed as means and standard deviations, whereas categorical data were expressed as percentages, where appropriate. Correlation analysis was performed between the Nomophobia Questionnaire and Brief COPE scores. Multivariate regression analyses were conducted in order to shed light on the determinants of each coping style and its association with nomophobia.

Results: A total of 403 subjects took part in the study. Subjects with higher nomophobia scores responded when confronted with stress with behavioral disengagement ($r=.16, P<.001$), denial ($r=.19, P<.001$), self-blame ($r=.12, P=.02$), self-distraction ($r=.22, P<.001$), venting ($r=.28, P<.001$), use of emotional ($r=.25, P<.001$), and instrumental support ($r=.16, P=.001$).

Conclusion: Nomophobia subjects adopt maladaptive coping strategies when confronted with stress. The acknowledgment of how nomophobia subjects react provides insight and introduces a focus for preventative and interventional measures in this population.

(*JMIR Ment Health* 2019;6(4):e13154) doi:[10.2196/13154](https://doi.org/10.2196/13154)

KEYWORDS

nomophobia; coping styles; behavioral addiction; mobile phone addiction

Introduction

In the digital era, the advent of new information and communication technologies (ICTs) has provided an avenue

for rapid communication, efficient data retrieval, and access to the internet, the widest world global communication network [1]. The pervasive and ubiquitous use of ICTs has raised the possibility of whether their overuse/misuse can eventually result in addiction [2]. Portable phones have become an indispensable

tool of our daily life [3], and preoccupation with up-to-the-minute mobile apps can indeed foster an environment where people tend to spend more time with technology than with their peers [4]. Nomophobia, a portmanteau of the words “no mobile phone” and “phobia,” represents a new emerging psychological construct describing the discomfort of being without mobile contact and the irrational fear and anxiety arising from the feeling of disconnection from virtual communication platforms [5,6].

Inspecting the construct from a broader aspect, various elements have been suggested to play an integral part of nomophobia. Of note, ringxiety (combination of the words “ring” and “anxiety”) is the state of disquietude and malaise, characterized by the need to constantly check the mobile phone to see whether messages or calls have been received. Additional features include (1) incurring debts as a result of over-expenditure on mobile technology, (2) the need to sleep with phone in close proximity, which may lead to impaired, fragmented sleep, and (3) the unease of turning the phone off [7].

Prevalence of nomophobia is highly variable, ranging from approximately 20% to 70%, depending on the study design, country, population, sampling technique, and cultural habits [7]. However, a body of circumstantial evidence seems to suggest that it is quite widespread and common.

In response to daily life stressors, humans can adopt coping strategies in order to deal with them. Coping refers to any adjustment mechanism or skill, whether behavioral or cognitive, that mitigates or counteracts a perceived psychological stress or event [8,9]. The current paradigm classifies coping styles into two broad categories: problem-focused and emotional-focused. The former target causes of stress aiming at achieving stress reduction or removal, whereas the latter try to diminish the negative emotional response associated with stressors [10].

In view of the ever-increasing attachment to ICTs, the emerging fear of being disconnected and the resultant deleterious impact on daily functioning and psychological well-being, this study investigated coping skills implemented in subjects with nomophobia.

Methods

Study Design and Participant Selection

For this cross-sectional study, participants (mainly undergraduate students and younger subjects) were recruited via an online survey using a snowball approach. For the purpose, Google Forms, an open-source tool for developing online questionnaires, was used.

All procedures were carried out according to the ethical standards of the 1964 Helsinki declaration and its subsequent amendments. The study protocol NOMO-001234-016 was reviewed and approved by the United Nations Educational, Scientific, and Cultural Organization Chair, “Health Anthropology Biosphere and Healing Systems,” University of Genoa, Genoa, Italy. Participants signed a written informed consent and were advised of the aims of the survey and its

anonymous nature, in that data could not be associated with the single individual who had provided them and were analyzed on an aggregated basis.

Instruments

The Italian version of the Nomophobia Questionnaire (NMP-Q), translated from the instrument originally developed by Yildirim and Correia [11], was administered. Exploratory factor analysis had previously demonstrated good psychometric properties of the instrument (Cronbach alpha coefficient of .95, .94, .89, and .88 for the overall questionnaire and its three factors, respectively). Furthermore, validity of the questionnaire was confirmed by conducting regression analysis with number of hours spent on mobile phone as regressor. However, in the Italian version a three-factor structure was found (factor 1: not being able to access information, factor 2: giving up convenience/losing connectedness, and factor 3: not being able to communicate), which is different from the other translated versions (in Spanish, Persian, or Chinese) [12-15].

Coping styles, the strategies exploited by individuals to cope with problems and stress, were investigated by administering the 28-item Brief COPE questionnaire, originally developed by Carver [16], based on Carver and Scheier’s self-regulation theory. This instrument was translated into the Italian language by Conti [17] and demonstrated good reliability and internal consistency. The questionnaire comprises 14 subscales: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame. The score for each item of the instrument ranges on a Likert scale from 1 (not at all) to 4 (a lot) and, given that the score of a subscale can be obtained by summing two items, its score ranges from 2 to 8. Moreover, besides computing the score of each subscale, overall coping strategy was defined as problem-oriented if the sum of the problem-solving items of the questionnaire (items 2, 7, 10, 14, 23, and 25) was greater than the sum of the emotional items (5, 12, 15, 17, 22, and 27). When the opposite was true, the coping style was defined as emotion-oriented. Coping styles were also grouped into adaptive or maladaptive strategies and analyzed accordingly.

Statistical Analysis

Continuous data were computed as means and standard deviations, whereas categorical data were expressed as percentages, where appropriate.

Correlation analysis was performed between the NMP-Q and Brief COPE scores. The magnitude of the Pearson coefficient was interpreted using the following rule of thumb developed by Hinkle and coauthors [18]: the strength of the correlation was deemed negligible if the r coefficient ranged from 0 to .30, low from .30 to .50, moderate from .50 to .70, high from .70 to .90, and very high from .90 to 1.00. Correlation was also computed between the Brief COPE scores and the number of hours spent on mobile phones using the Spearman rank coefficient.

Furthermore, multivariate regression analyses were conducted in order to shed light on the determinants of each coping style.

All statistical analyses were performed using the commercial software SPSS Statistics version 21.0.0 (IBM Corp). Figures with P values less than .05 were considered statistically significant.

Results

A total of 403 subjects aged 27.91 (SD 8.63) years (males 160/403, 39.7%, and females 243/403, 60.3%) took part in the study. In detail, 11.2% (45/403) of subjects spent less than 1 hour on their mobile phone per day, 23.3% (94/403) spent 1 to 2 hours, 17.1% (69/403) spent 2 to 3 hours, 14.4% (58/403) spent 3 to 4 hours, 11.9% (48/403) spent 4 to 5 hours, 7.2% (29/403) spent 5 to 7 hours, 8.9% (36/403) spent 7 to 9 hours, and 6.0% (24/403) spent more than 10 hours. Stratifying the population according to the severity of the psychological construct, 51.1% (206/403) of individuals suffered from mild nomophobia, whereas 41.4% (167/403) and 7.4% (30/403) individuals reported moderate and severe nomophobia, respectively. For further details related to the characteristics of the sample, the reader is referred to our previous publication [7]. Brief COPE scores are reported in [Table 1](#), while [Table 2](#) lists the correlations between these scores and the scores obtained with the NMP-Q instrument.

Behavioral disengagement correlated with the overall score ($P=.001$) and with D2 ($P<.001$), whereas denial correlated with

overall score ($P<.001$), D1 ($P=.02$), D2 ($P<.001$), and D3 ($P=.03$). Religion correlated with D2 ($P=.04$), self-blame was associated with overall score ($P=.02$), D1 ($P=.006$), and D3 ($P=.02$). Self-distraction correlated with overall score ($P<.001$), D1 ($P<.001$), D2 ($P=.002$), and D3 ($P<.001$). Use of emotional support was associated with overall score ($P<.001$), D1 ($P<.001$), D2 ($P<.001$), and D3 ($P<.001$). Use of instrumental support correlated with overall score ($P=.001$), D1 ($P=.003$), D2 ($P=.02$), and D3 ($P=.002$), while venting was associated with overall score ($P<.001$), D1 ($P<.001$), D2 ($P<.001$), and D3 ($P<.001$). Planning negatively correlated with D2 ($P=.04$). Denial ($P=.004$), self-blame ($P=.004$), self-distraction ($P<.001$), use of emotional support ($P=.003$), use of instrumental support ($P=.003$), and venting ($P=.006$) correlated with the number of hours spent on mobile phones ([Table 3](#)).

At the multivariate regression analysis, several predictors were found for adaptive coping strategies scores ([Table 4](#)). In particular, active coping was associated with D2 ($P=.004$), whereas planning with D1 ($P=.01$) and D2 ($P=.002$). Positive reframing correlated with D3 ($P=.04$), while religion correlated with D1 ($P<.001$) and D2 ($P=.002$).

Concerning maladaptive coping strategies ([Table 5](#)), behavioral disengagement and denial correlated with D2 ($P<.001$ for both). Substance use was found to be associated with D1 ($P=.01$) and D2 ($P=.002$), while venting with D1 ($P=.04$).

Table 1. Scores of the Brief COPE questionnaire.

Subscale	Score, mean (SD)
Acceptance	5.9 (1.3)
Active coping	6.5 (1.5)
Behavioral disengagement	3.2 (1.4)
Denial	3.1 (1.4)
Humor	4.4 (1.6)
Planning	6.5 (1.4)
Positive reframing	5.6 (1.6)
Religion	4.0 (2.2)
Self-blame	5.8 (1.4)
Self-distraction	5.2 (1.6)
Substance use	2.5 (1.2)
Use of emotional support	5.2 (1.8)
Use of instrumental support	5.7 (1.6)
Venting	5.0 (1.6)

Table 2. Correlation between Brief COPE and Nomophobia Questionnaire scores.

Subscale	Overall score		D1 ^a (not being able to access information)		D2 ^b (giving up convenience/losing connectedness)		D3 ^c (not being able to communicate)	
	<i>r</i> ^d	<i>P</i> value	<i>r</i>	<i>P</i> value	<i>r</i>	<i>P</i> value	<i>r</i>	<i>P</i> value
Acceptance	-.07	.14	-.03	.54	-.09	.09	-.07	.15
Active coping	.02	.76	.06	.25	-.08	.12	.07	.18
Behavioral disengagement	.16	.001	.09	.06	.25	<.001	.08	.11
Denial	.19	<.001	.12	.02	.26	<.001	.12	.03
Humor	.07	.19	.06	.25	.09	.08	.03	.56
Planning	-.02	.69	.05	.33	-.11	.04	.01	.81
Positive reframing	-.003	.96	-.02	.70	-.04	.47	.05	.35
Religion	.01	.71	-.09	.07	.10	.04	.02	.63
Self-blame	.12	.02	.14	.006	.06	.22	.11	.02
Self-distraction	.22	<.001	.22	<.001	.16	.002	.20	<.001
Substance use	-.001	.98	-.06	.20	.09	.09	-.03	.49
Use of emotional support	.25	<.001	.23	<.001	.20	.001	.22	<.001
Use of instrumental support	.16	.001	.15	.003	.11	.02	.16	.002
Venting	.28	<.001	.27	<.001	.22	<.001	.24	<.001

^aD1: first dimension (not being able to access information).^bD2: second dimension (giving up convenience/losing connectedness).^cD3: third dimension (not being able to communicate).^d*r*: Pearson coefficient.**Table 3.** Correlation between Brief COPE scores and number of hours spent on mobile phones.

Subscale	Spearman correlation with number of hours	
	rho	<i>P</i> value
Acceptance	-.02	.74
Active coping	-.08	.09
Behavioral disengagement	.05	.30
Denial	.14	.004
Humor	-.04	.47
Planning	-.08	.10
Positive reframing	-.04	.44
Religion	-.03	.50
Self-blame	.14	.004
Self-distraction	.20	<.001
Substance use	-.03	.58
Use of emotional support	.15	.003
Use of instrumental support	.15	.003
Venting	.14	.006

Table 4. Multivariate regression of adaptive coping strategies scores and their association with nomophobia.

Parameter	Nonstandardized coefficients		Standardized coefficient (beta ^b)	T value	P value
	B ^a	SD			
Acceptance					
(Constant)	6.28	.46	— ^c	13.78	<.001
Number of hours spent on a mobile phone	.002	.04	.003	0.05	.96
Age	-.01	.01	-.05	-0.87	.38
Gender	-.14	.14	-.05	-0.99	.32
Schooling level	.06	.08	.04	0.72	.47
D1 ^d (not being able to access information)	.01	.01	.07	0.92	.36
D2 ^e (giving up convenience/losing connectedness)	-.01	.01	-.10	-1.35	.18
D3 ^f (not being able to communicate)	-.01	.01	-.05	-0.74	.46
Active coping					
(Constant)	5.40	.50	—	10.82	<.001
Number of hours spent on a mobile phone	-.02	.04	-.03	-0.57	.57
Age	.01	.01	.04	0.78	.44
Gender	-.09	.15	-.03	-0.55	.58
Schooling level	.22	.09	.13	2.48	.014
D1 (not being able to access information)	.02	.01	.12	1.61	.11
D2 (giving up convenience/losing connectedness)	-.03	.01	-.21	-2.91	.004
D3 (not being able to communicate)	.02	.01	.13	1.81	.07
Humor					
(Constant)	4.70	.54	—	8.77	<.001
Number of hours spent on a mobile phone	-.05	.05	-.06	-1.00	.32
Age	-.01	.01	-.05	-0.86	.39
Gender	-.37	.17	-.12	-2.25	.025
Schooling level	.10	.10	.06	1.05	.30
D1 (not being able to access information)	.01	.02	.04	0.45	.65
D2 (giving up convenience/losing connectedness)	.02	.01	.12	1.62	.11
D3 (not being able to communicate)	-.01	.01	-.03	-0.44	.66
Planning					
(Constant)	6.14	.48	—	12.68	<.001
Number of hours spent on a mobile phone	-.05	.04	-.07	-1.20	.23
Age	-.002	.01	-.01	-0.24	.81
Gender	-.28	.15	-.10	-1.86	.064
Schooling level	.21	.09	.12	2.40	.02
D1 (not being able to access information)	.03	.01	.19	2.53	.012
D2 (giving up convenience/losing connectedness)	-.03	.01	-.22	-3.10	.002
D3 (not being able to communicate)	.01	.01	.05	0.74	.46
Positive reframing					
(Constant)	6.06	.54	—	11.18	<.001
Number of hours spent on a mobile phone	-.01	.05	-.02	-0.28	.78
Age	-.004	.01	-.02	-0.39	.69

Parameter	Nonstandardized coefficients		Standardized coefficient (beta ^b)	T value	P value
	B ^a	SD			
Gender	-.15	.17	-.05	-0.91	.37
Schooling level	-.02	.10	-.01	-0.22	.82
D1 (not being able to access information)	-.01	.02	-.05	-0.67	.50
D2 (giving up convenience/losing connectedness)	-.01	.01	-.09	-1.19	.24
D3 (not being able to communicate)	.03	.01	.15	2.03	.04
Religion					
(Constant)	8.10	.72	—	11.32	<.001
Number of hours spent on a mobile phone	-.05	.06	-.05	-0.88	.38
Age	-.02	.01	-.09	-1.73	.09
Gender	-.74	.22	-.17	-3.36	.001
Schooling level	-.56	.13	-.21	-4.33	<.001
D1 (not being able to access information)	-.07	.02	-.26	-3.62	<.001
D2 (giving up convenience/losing connectedness)	.05	.02	.21	3.15	.002
D3 (not being able to communicate)	.03	.02	.11	1.59	.11
Use of emotional support					
(Constant)	2.37	.57	—	4.16	<.001
Number of hours spent on a mobile phone	.01	.05	.01	0.11	.92
Age	-.02	.01	-.08	-1.61	.11
Gender	.78	.18	.22	4.44	<.001
Schooling level	.32	.10	.15	3.10	.002
D1 (not being able to access information)	.02	.02	.07	1.00	.32
D2 (giving up convenience/losing connectedness)	.02	.01	.09	1.25	.21
D3 (not being able to communicate)	.01	.01	.07	0.99	.33
Use of instrumental support					
(Constant)	4.51	.54	—	8.31	<.001
Number of hours spent on a mobile phone	.04	.05	.05	0.76	.45
Age	-.02	.01	-.09	-1.70	.09
Gender	.35	.17	.11	2.09	.04
Schooling level	.12	.10	.06	1.20	.23
D1 (not being able to access information)	.01	.015	.04	0.47	.64
D2 (giving up convenience/losing connectedness)	-.001	.01	-.01	-0.08	.94
D3 (not being able to communicate)	.02	.01	.10	1.38	.17

^aB: nonstandardized regression coefficient.

^bBeta: standardized regression coefficient.

^cNot applicable.

^dD1: first dimension (not being able to access information).

^eD2: second dimension (giving up convenience/losing connectedness).

^fD3: third dimension (not being able to communicate).

Table 5. Multivariate regression of maladaptive coping strategies scores and their association with nomophobia.

Parameter	Nonstandardized coefficients		Standardized coefficient (beta ^b)	T value	P value
	B ^a	SD			
Behavioral disengagement					
(Constant)	4.37	.46	— ^c	9.47	<.001
Number of hours spent on a mobile phone	-.04	.04	-.05	-0.92	.36
Age	-.02	.01	-.10	-1.95	.05
Gender	-.24	.14	-.08	-1.68	.09
Schooling level	-.19	.08	-.11	-2.26	.03
D1 ^d (not being able to access information)	-.01	.01	-.05	-0.67	.50
D2 ^e (giving up convenience/losing connectedness)	.05	.01	.33	4.69	<.001
D3 ^f (not being able to communicate)	-.01	.01	-.07	-0.94	.35
Denial					
(Constant)	3.37	.46	—	7.35	<.001
Number of hours spent on a mobile phone	.03	.04	.04	0.74	.46
Age	.000	.01	-.001	-0.02	.98
Gender	.12	.14	.04	0.83	.41
Schooling level	-.29	.08	-.17	-3.47	.001
D1 (not being able to access information)	-.01	.01	-.05	-0.72	.47
D2 (giving up convenience/losing connectedness)	.05	.01	.30	4.40	<.001
D3 (not being able to communicate)	-.01	.01	-.07	-0.94	.35
Self-blame					
(Constant)	4.92	.48	—	10.21	<.001
Number of hours spent on a mobile phone	.04	.04	.06	0.94	.35
Age	-.01	.01	-.07	-1.18	.24
Gender	.13	.15	.05	0.89	.37
Schooling level	.13	.09	.08	1.45	.15
D1 (not being able to access information)	.02	.01	.10	1.29	.20
D2 (giving up convenience/losing connectedness)	-.01	.01	-.07	-1.01	.31
D3 (not being able to communicate)	.01	.01	.06	0.89	.38
Self-distraction					
(Constant)	3.93	.52	—	7.54	<.001
Number of hours spent on a mobile phone	.07	.04	.09	1.60	.11
Age	-.01	.01	-.06	-1.07	.29
Gender	.38	.16	.12	2.38	.02
Schooling level	-.02	.09	-.01	-0.18	.86
D1 (not being able to access information)	.02	.01	.11	1.49	.14
D2 (giving up convenience/losing connectedness)	-.01	.01	-.03	-0.45	.65
D3 (not being able to communicate)	.02	.01	.09	1.28	.20
Substance abuse					
(Constant)	2.39	.39	—	6.08	<.001
Number of hours spent on a mobile phone	.05	.03	.09	1.51	.13
Age	.01	.01	.06	1.17	.24

Parameter	Nonstandardized coefficients		Standardized coefficient (beta ^b)	T value	P value
	B ^a	SD			
Gender	-.27	.12	-.11	-2.21	.03
Schooling level	.07	.07	.05	1.01	.32
D1 (not being able to access information)	-.03	.01	-.20	-2.56	.01
D2 (giving up convenience/losing connectedness)	.03	.01	.23	3.18	.002
D3 (not being able to communicate)	-.004	.01	-.04	-0.50	.62
Venting					
(Constant)	2.15	.52	—	4.13	<.001
Number of hours spent on a mobile phone	.02	.04	.02	0.40	.69
Age	.01	.01	.07	1.23	.22
Gender	.66	.16	.20	4.09	<.001
Schooling level	.09	.09	.05	0.93	.36
D1 (not being able to access information)	.03	.01	.15	2.04	.04
D2 (giving up convenience/losing connectedness)	.01	.01	.07	1.06	.29
D3 (not being able to communicate)	.01	.01	.06	0.80	.43

^aB: nonstandardized regression coefficient.

^bBeta: standardized regression coefficient.

^cNot applicable.

^dD1: first dimension (not being able to access information).

^eD2: second dimension (giving up convenience/losing connectedness).

^fD3: third dimension (not being able to communicate).

Discussion

Principal Findings

In this study, we found that when confronted with stress, subjects with higher nomophobia scores were significantly more likely to respond with behavioral disengagement, denial, self-blame, self-distraction, venting, and use of emotional and instrumental support. Similarly, increased number of hours spent on mobile phones correlated with significantly higher use of denial, self-blame, self-distraction, venting, and use of emotional and instrumental support. Taken together, we found that nomophobic subjects tended to adopt dysfunctional coping strategies, which has been revealed to be independently associated with anxiety [19,20].

Our findings are consistent with the results published by Dziurzyńska et al [21], demonstrating an increased likelihood of individuals at risk of mobile phone addiction to cope with stress using substitute gratification, resignation, passivity, dejection, blaming others, pitying themselves, and hopelessness. Furthermore, nomophobic subjects were shown to ruminate over their suffering, withdraw from social interactions, and react with aggressiveness.

Roberts and collaborators [22] disclosed that heavy use of cellular communication during stress is regarded as a form of self-distraction or substitute gratification, or a kind of addiction. Moreover, subjects with neuroticism reported using their mobile phone and internet to feel a sense of belonging and escape loneliness as a means to cope with stress [23].

Li et al [24] inquired into problematic internet use and its relationship to stressful life events and coping styles. Subjects' reported high preoccupation with the internet correlated positively with self-blame, fantasy, and withdrawal scores. Additionally, higher internet addiction scores correlated with social-communication and daily hassle scores. Further, stressful life events and generalized problematic internet use were shown to be mediated by avoidant coping style. Similarly, chronic stress, low emotional stability, female gender, and young age were significantly associated with excessive and dysfunctional mobile use [25]. Among other possibilities on mobile phones are game playing and music listening, which have been consistently shown to provide means to respond to stress by diverting attention from problems by seeking substitute gratification [4]. Similarly, subjects with pathological use of internet games and addiction to computer games employed nonadaptive coping [26,27]. Wan et al [28] indicated that addiction to online game playing provided means of emotional coping with stress allowing subjects to escape loneliness and isolation and relieve anger and frustration.

Arpaci et al [29] explored the effect of mindfulness on the relationship between attachment styles and nomophobia. Their analysis demonstrated a positive direct effect of avoidant and anxious attachment styles on nomophobia. Emotional and dependent people display higher stress when they have no access to their phones. Thus their anxious attachment is projected upon an object, in that case a mobile phone. Komorowska-Pudlo [30] found that anxious attachment correlated with denial, venting, self-blame, and suppression of activities. Further, subjects with

avoidant attachment style used less active coping mechanisms, preferring suppression of activities.

Socioeconomic factors such as education have been shown to have substantial influence on coping mechanisms. Roohafza et al [31] demonstrated a positive correlation between higher education levels and adaptive coping strategies, and an inverse relationship to maladaptive coping styles was found. Similarly, low education and low income were linked to maladaptive coping strategies attainment.

In the study conducted by Matud et al [32], women scored significantly higher in emotional and avoidance coping styles as compared to men. Counterintuitively, in our study, male gender in nomophobic subjects was a predictor for avoidant coping style, self-distraction, venting, and use of emotional support. Dissimilarly, turning to religion, sense of humor, and planning were adopted by female nomophobic subjects.

Limitations

This study has some limitations that warrant discussion. The major shortcoming is given by the study design: being cross-sectional and not longitudinal, our investigation cannot capture dynamic relationships between the variables under scrutiny. Second, like other subjective self-reported studies, it is not immune from the response bias. Furthermore, the Brief COPE measure assumes general tendency toward a specific strategy rather than opting for a dynamic approach in dealing with encountered problems. Our study has some strengths including its novelty and the use of a relatively large number of subjects, who were, however, selected using a nonprobability purposive sampling technique.

Conflicts of Interest

None declared.

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Abbreviations

ICT: information and communication technology

NMP-Q: Nomophobia Questionnaire

Edited by G Eysenbach; submitted 15.12.18; peer-reviewed by D Prestia, G Del Puente, L Gutierrez-Puertas; comments to author 17.01.19; revised version received 06.02.19; accepted 09.02.19; published 24.04.19.

Please cite as:

Bragazzi NL, Re TS, Zerbetto R

The Relationship Between Nomophobia and Maladaptive Coping Styles in a Sample of Italian Young Adults: Insights and Implications From a Cross-Sectional Study

JMIR Ment Health 2019;6(4):e13154

URL: <http://mental.jmir.org/2019/4/e13154/>

doi:10.2196/13154

PMID:30763254

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Editorial / Patient Perspective

Mental Health Apps in Psychiatric Treatment: A Patient Perspective on Real World Technology Usage

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Abstract

For many people who use mobile apps, the primary motivations are entertainment, news, gaming, social connections, or productivity. For those experiencing health problems, particularly those with chronic conditions such as psychiatric disorders, the stakes are much higher. The digital tools that they select may be the difference between improvement and decompensation or even life and death. Although there has been a wide expansion of mental health apps with promise as well as hype, the current means of researching, evaluating, and deploying effective tools have been problematic. As a means of gaining a perspective that moves beyond usability testing, surveys, and app ratings, the primary objective of this patient perspective is to question the *killer app* and condition-specific mentality of current mental health app development. We do this by reviewing the current mobile mental health app literature, identifying ways in which psychiatric patients use apps in their lives, and then exploring how these issues are experienced by a software engineer who has struggled with her bipolar disorder for many years. Her *lived experience* combined with a technology perspective offers potential avenues for using technology productively in psychiatric treatment. We believe that this responds to *JMIR Publications*' call for patient perspective papers and provides encouragement for patients to share their views on mental health and technology.

(*JMIR Ment Health* 2019;6(4):e12292) doi:[10.2196/12292](https://doi.org/10.2196/12292)

KEYWORDS

bipolar disorder; mobile phone; mHealth; mental disorders; mental health; mobile applications

Introduction

Background

Mental illness is a common condition in the United States, as 44.7 million adults have been diagnosed with these disorders in the past year [1]. These statistics include 10.4 million Americans with serious mental illnesses such as major depression, anxiety disorders, and schizophrenia, but only 6.7 million have received treatment in the past year. To address patient difficulties accessing traditional mental health services, digital health tools offer the potential to scale treatment [2]. There are now over 300,000 mobile health apps available worldwide, with mental health accounting for the largest proportion of the rapidly growing disease-specific app market segment [3]. Owing to the broad use of mobile phones by people

with mental health problems [4], it is not surprising that many patients have expressed an interest in exploring the use of these apps as part of their treatment efforts. Accordingly, these trends have driven an upsurge in clinical app research in anxiety, major depression, post-traumatic stress disorder, bipolar disorder, schizophrenia, and other mental health disorders [5-10].

Challenges in Applying the Killer App Mentality to Mental Health Treatment

Finding the Features That Patients and Clinicians Want

In many cases, developers are seeking to design and market *killer apps* defined as follows:

A new software application used to attract consumers and motivate new hardware device purchases. Often innovative and cutting edge, killer apps are known

for creating a large following. Over time, killer apps become an essential factor related to hardware or device purchases. [11]

The *killer app* concept suggests that a single app can meet the needs of the target audience. However, this may be a questionable assumption with patients who have mental disorders.

From the perspectives of patients and clinicians, market share and profits are less of a concern than usability and successful treatment outcomes. What would a perfect *killer app* look like and what do patients want? Patients may not use the term *killer app* but, in general, they report an interest in using their mobile phones to track their mental health [12]. Symptom-monitoring is generally considered helpful and supportive by people with mental health problems [13]. Unfortunately, mental health app developers often *overengineer* their solutions rather than capitalize on the basic popular functions such as texting communication and medication adherence [14,15]. Patients seem less focused on elaborate features and more on optimizing their immediate goals (eg, daily functioning) and may require multiple apps to achieve these goals [16]. Lifestyle factors such as managing fitness, nutrition, lifestyle and stress, and diet and nutrition are critical in mental health [13] and are the most common reasons why people with chronic diseases download health apps [17].

Despite these proposed standards and patient needs, mental health apps often lack key features and suffer from inconsistent patient engagement. Critical features such as tailored feedback or recommendations for response to emergency or high-risk situations or features that support lasting behavior change are generally lacking [18]. In terms of engagement, 23% of users abandon mobile apps after 1 use [19], and retention is highly variable even within controlled studies among mental health users [2]. Adherence is an issue, as downloaded mood apps are used as intended for no more than 2 weeks [20]. These challenges may be magnified with older psychiatric patients who have serious and persistent disorders [21]. On the basis of a lack of highly controlled, longer-term outcomes in available research, there is no strong case for recommending any particular mental health mobile app [22].

In addition, despite general agreement on desirable app features and characteristics, the determination of quality seems to be in the eye of the beholder when evaluating individual apps. Available evidence indicates that ratings of effectiveness, ease of use, and performance have poor inter-rater reliability among professional stakeholders (clinicians, researchers, and technology experts) [23]. Among patients, mental health apps are more widely available in app stores, so users are generally left to evaluate their app choices based on user ratings. This is a questionable strategy, as the level of comprehensiveness of information and adherence to best-practice guidelines do not correlate with average user mental health app ratings [9]. Moreover, 1 study of almost 1000 depression apps found that only 35% were clinically relevant and only about 3% of these reported clinical effectiveness [8], suggesting that users should be careful about interpreting 5-star ratings. Taken together, these

findings suggest serious challenges in defining and creating *killer* apps from a clinical quality perspective.

Determining What Works

Despite suggestions that mental health apps for certain conditions (eg, depression or anxiety) may be worthy of consideration in clinical guidelines [3], there are a variety of clinical and research challenges that make it difficult for clinicians and patients to identify tools that can supplement treatment efforts. First, a variety of studies and meta-analyses have demonstrated promising early outcomes, but findings are limited by a lack of appropriate control groups, short follow-ups, poor definition of content, lack of clinically valid mental health information, and poor usability [5-8,18,24]. Mobile health app development is driven more by commercial than scientific motivations [25]. Researchers tend to focus more on safety and efficacy, whereas commercial entities focus more on user engagement [26]. In 1 systematic review of 3000 mental health apps available on the Android, Apple, and Microsoft platforms, only 8 were evidence-based [24].

Deciding How to Integrate Apps Into Clinical Sessions

Mobile health apps for health care are generally not distributed through health care providers or settings [27], likely owing to a variety of barriers. Furthermore, 1 survey found that 77% of clinicians refer patients to informational websites but only 19% suggest the use of mobile apps to their patients to enhance clinical communication [28]. For clinical app usage to take hold, clinicians need to be more willing to collect patient data, require training in interpreting data outputs [29], and may have hesitance about billable time, therapeutic boundaries, privacy, and liability [30]. Attitudinal issues may be prominent, as clinicians may adopt paternalistic attitudes and have doubts about the validity of clinical information in digital tools [31]. There has also been concern about *digital transference* and the potential risks of digital technology to the provider-patient relationship [32]. Among patients, technology-based therapies may not be viewed as a replacement for live support [33]. There are indications that mobile mental health apps work better when paired with live support [34-36], but it is not clear if these apps provide added value to traditional face-to-face psychotherapy or treatment-as-usual [22]. For clinicians to accept mobile app solutions, apps need to be optimized to address technology competency, available resources, reimbursement, regulatory issues, and organizational infrastructure [37]. Without such optimizations, clinicians may not be well positioned to recommend mental health apps.

Taking Safety and Privacy Precautions

Finally, there are significant deficiencies in many apps with regard to potential harms that might result from inadequate safety or privacy protections, clinically questionable content, and potential stigma [38,39]. Many people are suffering enormously, lack even basic access to psychiatric care, may feel disrespected by the doctors they do get to see, and are not receiving adequate symptom relief. Under those circumstances, it is not surprising that people actively seek to diagnose and treat themselves. However, based on the questionable content in many apps, these individuals may not attain symptom relief

or potentially experience harmful effects. Among those who are experiencing mood disruptions within the normal range, mental health apps may promote medicalization of symptoms [40]. In addition, users are seldom aware of the extent of data collected, the potential for these data to be sold to third parties, and the ways in which the data are used to drive risk calculations and personal profiling [38]. Torous et al [41] sum up the current state of affairs by stating that the “growing consensus is that most commercially available apps are not evidence-based and some are even dangerous.”

Can Single Disease-Specific Apps Do it All?

In consideration of patient usage of mental health apps (and apps in general), previous research has highlighted the importance of usability and engagement [18]. Formal usability testing and iterative design with individual users are the preferred ways to optimize software performance [42]. However, we would like to expand this discussion to patterns of app usage as part of the lived experience of mental health patients. Given the profound effect that psychiatric disorders have on the quality of life [43], patients need to find solutions for problems on many fronts, so reliance on a single mental health app may not be realistic.

Qualitative studies suggest that people with chronic conditions do not rely solely (or even primarily) on disease-specific apps for management of their health [4,16,17,44]. Despite a high level of expressed interest, only 10% of psychiatric patients use mental health apps [45]. Some patients who are managing diabetes, depression, weight, and sleep issues may rely on a fitness app without using a disease-specific app [44]. Patients may use a mixture of apps focused on their menstrual cycles, blood pressure, calorie and weight management, pain management, fitness, or sleep [44]. Mental health patients may utilize multiple, widely available, and popular health apps to cope with their symptoms and can be highly creative, for example, coloring, brainteaser, and day planner apps [16], perhaps to manage cognitive symptoms. People with schizophrenia responding to a National Association of Mental Illness survey reported that their most common use of technology as a coping tool was to listen to music or audio files to block or manage auditory hallucinations [46]. Indeed, the distinctions between mental health and other apps may be more important to researchers and clinicians than patients [4].

On the basis of the above challenges, Hatch et al [36] have concluded that *the killer app approach is not the right mindset*. As a result, the primary purpose of this paper is to consider how individuals with mental health disorders can capitalize on more flexible and individualized app strategies to address self-management of their conditions. In our view, such considerations should be patient-centered, that is, what patients want and need, how can apps be best integrated into mental health treatment, and pragmatic, patient-centered technology capabilities that can be mobilized to address patient needs in more immediate ways. The issues above highlight a convergence between what is found in the literature and lived experience in managing psychiatric symptoms. We question the practicality

of relying on single, condition-specific mobile mental health apps instead of focusing more flexibly on the diverse needs of mental health patients. This may involve the use of multiple apps and/or the use of condition-specific apps.

In response to *JMIR Publications*’ encouragement for patients to submit their perspectives on mental health and technology, we offer Amy’s experiences with the challenges described above, as well as her real-world recommendations. The latter are based both on her history of psychiatric treatment and her background in software development. Our goal is not to suggest that one individual can speak for all but to offer potential hypotheses and creative solutions that may drive the conversation toward a more flexible technology-based approach in mental health clinical care.

Amy’s Perspective on the Role of Apps in Mental Health Treatment

I am a 43-year-old woman who has suffered from bipolar disorder since the age of 9. I have treatment-resistant rapid-cycling type 2 bipolar disorder and spend about 80% of my days mildly to severely depressed. I frequently struggle with challenging symptoms like panic attacks, delusional hypochondria, suicidal ideation, irritability, despair, anhedonia, and exhaustion. I have self-harmed, and I have self-medicated. I understand that my disease is chronic, it is debilitating, and there is no cure for it. I have tried multiple modes of treatment over decades, including over a dozen medications (lithium, Depakote, multiple antipsychotics and antidepressants, multiple benzodiazepines), electroconvulsive therapy, and ketamine infusion, as well as multiple modes of therapy (dialectical behavior therapy, cognitive behavior therapy, acceptance and commitment therapy, mindfulness, etc) and alternative treatments (exercise, fish oil, meditation, reiki, etc).

Despite my struggles, I have managed to build and maintain a life that I value. I am a highly engaged patient, and I know many other people who are trying to do the same. I have spent decades working in the software industry, including 8 years as a software engineer at PatientsLikeMe, a community website for patients. This combination of experiences has led me to adopt a problem-solving attitude toward living with serious mental illness. In my view, the question is not what will fix or cure me, but what tips, tricks, apps, processes, books, resources, clinicians, and caregivers can help me live as well as possible with my disease.

On the basis of my own experience as a patient with bipolar disorder and as a software engineer, I would like to move the conversation away from what needs to be developed that will somehow solve the crisis of modern mental health care. How can clinicians who would like to use digital technology now to help their patients with mental illness live better today do so? What kinds of apps have I and other people with mental illness found helpful, and how can clinicians integrate those apps into their care? What are some general recommendations for evaluating apps and making use of them?

Table 1. Suggestions for app selection.

Challenge, key considerations	Strategy	Potential tools
Finding the features that patients want		
Mindfulness	General wellness behavior; Use push notifications	Headspace [48]
Help with daily life	Calendar, <i>to do</i> , banking, budgeting, laundry, and food delivery apps	Productive [49]; Bullet Journaling; Ridesharing apps such as Uber and Lyft
Informed choices about medications	Get information about the use and effects of medications, balance difficult choices about side effects, integrate medications into a daily routine	Stahl's psychopharmacology [50]; Iodine [51]
Distress tolerance	Music to motivate physical activity, Facebook photo groups, and games for distraction	Apple Watch [52] electrocardiogram function
Physical activity	Exercise as an evidence-based tool for symptom management	Yoga apps; Apps that book exercise classes; Activity trackers: Fitbit, Apple Watch [52]
Determining what works		
Experiment with different apps	Offer trial periods and then are 1-time purchases or are sold on a freemium model	Web-based technology reviews, for example, New York Times and Wirecutter [53]
Deciding how to integrate apps into clinical sessions		
Secure communications with clinicians	Crisis help and status updates	Signal [54]
Tracking	Mood tracking; Important for clinician to explain evidence base for tracking recommendations; Clinicians should show a commitment to tracking by reviewing data regularly in sessions	Daylio [55]
Taking safety and privacy precautions		
Crisis help	Keep key support phone numbers readily accessible as favorites	Crisis hotlines, numbers for providers, and local Samaritans
Privacy and security	Understand personal tolerance for data sharing; Privacy and security are real concerns and cannot be guaranteed	Use secure messaging tools with providers

From the standpoint of a patient, I think it is important that clinicians avoid *prescribing* apps. It is much better to start from what problems patients are trying to solve, not from clinical ideas of what apps they should use and why. I have found it more helpful when I am engaged in treatment choices as problem-solving rather than being directed in what to do. The truth is people do not do things just because their doctors tell them to. They need to see the benefit of what they do.

Clinicians may think a patient needs to track their medication adherence with a particular tracking app, but both parties should agree that this is a priority. If not, patients are unlikely to do so. The problem of engagement and retention for mental health apps is no different than that for other kinds of apps; it is enormously difficult to create habits in other people. Apps with high retention (*adherence*) either have push notifications and *dopamine hits* going for them (social apps) or they are providing features and services that users find valuable [47].

The following sections review my personal experiences in the use of technology tools in my treatment. Table 1 summarizes the preferences and strategies that work for me or others whom I know but which may or may not work for others.

Finding the Features That Patients Want

I would like to see clinicians expand their understanding of what kind of apps might improve outcomes for the mentally ill. In general, I prefer apps that have only a few features to those

that try to do too many things at once. In my experience, more features reduce usability, which reduces the likelihood of using the app. Using multiple apps for different purposes is not a problem for me if each app works well. In my experience, there are several broad areas where such apps can help the mentally ill live well.

Mindfulness

There is solid evidence that practicing mindfulness is helpful for a wide variety of symptoms, and practicing mindfulness is increasingly viewed as a general wellness behavior that improves psychological health [56]. As a result, there are multiple good apps out there to support mindfulness practice, including subscription-based, single-time purchase and free apps. I have practiced mindfulness as a component of my own wellness plan for 15 years, and I find that using an app is helpful.

What do I look for? I prefer apps that are marketed to the general consumer, so I do not feel stigmatized as a patient for using it—apps for people rather than patients. Push notifications remind me to meditate at a set time every day and offer me the opportunity to practice mindfulness in other moments throughout the day. My app also tracks the total minutes I have meditated since I started using it, which is motivating. Variety is important. For example, I use my meditation app to help me sleep, deal with anxiety, be mindful while doing chores or walking to work, or calm down in an intense moment. I also find it useful to get data about my use of the app. For example, Headspace (the app

that I use) emailed me to let me know that I had meditated over 200 days in the last year. This made me feel good about my efforts to take better care of myself even if it is not a perfect daily habit. Many of the features I mention here are available in other mindfulness apps that are widely available, high-quality, and pleasant to use. All of these qualities may increase retention (ie, what clinicians might call *adherence*). In my view, mindfulness apps are the closest thing we have to *killer apps* for mental health because of the evidence for the effectiveness of mindfulness in reducing the suffering associated with mental illness [57].

Help With Daily Life

It is important for clinicians to explore with their patients what kinds of problems they are facing living their day-to-day lives and whether there are apps that can assist them. Many of the mentally ill suffer from problems with organization and executive functioning; difficulties completing daily tasks like getting around, managing their money, and engaging in basic habits of self-care [16]. As a result, clinicians and patients should cast a wide net for what might be helpful. For example, apps that make public transit easier to use may also help people get out and about more. Calendar, *to do*, banking, budgeting, laundry, and food delivery apps may all help patients solve daily living problems and allow them to live richer lives. I have an app called Productive (Table 1) that allows me to create recurring *to-dos*. Swiping away each *to-do* when I brush my teeth or take a shower gives me a feeling of pleasure and a sense of accomplishment. I often panic on public transit, am too tired to walk places, and too medicated or manic to feel that I can safely drive. Ridesharing apps like Uber and Lyft help me get where I want to go so that I can live my life without having to overcome as much anxiety or inertia. When I have trouble focusing, making use of an app that blocks my use of other apps helps me get more done. Again, there are multiple apps out there, of varying degrees of quality, and patients should be encouraged to explore and find what works for them. Most of them will not stick. That is fine. Some will.

Help Making Informed Choices About Medication and Then Taking the Medication as Prescribed

I understand that medication adherence is a huge issue for clinicians. In my experience, every day brings very challenging considerations and decisions about taking medications. Apps can help patients both gather medication information and manage their medication regimens. There are significant difficulties around getting information about the use and effects of medications, around balancing difficult choices about side effects, and around merely integrating medications into a daily routine. In my own experience, clinicians are frequently short on time to fully discuss medications they are prescribing, so I use apps like Stahl's psychopharmacology (Table 1) which they themselves are using, to get the medical practitioners' view of a particular med. Crowdsourced sites like PatientsLikeMe [58] and Iodine (Table 1) then supplement the medical view with real-world reports from patients, which is important, because clinical trials often fail to take into account patients' viewpoints when designing research outcomes [59]. As far as medication management is concerned, setting alarms on my phone has helped me remember, for example, that I need to take my Latuda

around 7 pm with dinner or it will not be fully absorbed. Some patients may want to work in a more focused way with their doctors about ensuring that they are taking their meds. For many patients, making day-to-day choices about medications reflect their own real-world priorities rather than those of their doctors [60]. This is especially true when managing serious side effects that interfere with daily functioning.

Distress Tolerance

Apps that might be helpful for distress tolerance really vary so much by individual. As discussed elsewhere in this paper, many patients find a music app to be critical in tolerating distressing symptoms. I find music helpful in changing my mood and motivating me to be more physical. Some people may find certain games to allow them to distract themselves long enough to get over a challenging emotional state. I belong to a Facebook group composed exclusively of people posting pictures of very fat cats. Cute animal pictures are a common method that many internet users use to self-soothe and should not be overlooked in the distress tolerance arsenal. Some may question the value of these methods when there are more evidence-based apps delivering dialectical behavior therapy and cognitive behavior therapy [61]. I cannot speak for which of these are more clinically useful than others, but when it comes to distress tolerance, I am focused less on the evidence base and more on what works for me. What works might even just be a list on a notes app of activities to try to ease distress in the moment. Furthermore, 1 trick I have found helpful for dealing with my recurrent panic attacks that I am dying is to use a pulse oximeter to remind myself that although I might feel that I am dying, if there is oxygen in my blood, my death is not imminent. I know of several other people who have gotten relief from this hack. The Apple Watch's new electrocardiogram function (Table 1) (monitors heart rate variability, which has been linked to stress and depression [62]. Perhaps, this function can be used for reality-checking powerful feelings to tolerate them better.

Help With Getting Physical Activity

It is well established that exercise is beneficial to brain health [63]. I use a yoga app and an app that allows me to book exercise classes to help me get more exercise. Exercise trackers such as Fitbit and the Apple Watch allow users to passively track their exercise and encourage them to get more. In the context of encouraging patients to get more exercise, encourage them to experiment with apps that make it easier and more motivating to do so.

Determining What Works

How should a person suffering with mental illness go about finding good apps and evaluating their effectiveness? There is no foolproof method for doing this. App stores are full of apps. When I am searching for a new category of app to help me with a problem in my life, I look for apps that are well designed, seem easy to use, and offer appropriate push notifications. They should have plenty of reviews (I am less concerned about whether the reviews are good or bad, just that they exist) and appear to be actively supported. I prefer apps that offer trial periods and then are 1-time purchases or sold on a freemium model because I prefer to understand how a business is making its money, and apps that have income are often better-supported

and a more pleasant experience to use than those that are free. Review sites on the internet (eg, Wirecutter, [Table 1](#)) offer roundups of classes of apps that can be helpful (especially for productivity apps). In my experience, the only way to truly find out if an app is effective is to download it and give it a try for a few weeks. I tried three mood-tracking apps before I settled on the one that I would use on a kind of regular basis. This is no different from trying out different medications to find one that has the right balance of symptom relief and side effects to encourage me to take it regularly.

Deciding How to Integrate Apps Into Clinical Sessions

Although I have just outlined several areas in which I think currently existing apps have the potential to help patients lead better lives and manage their mental illness more successfully, I want to clarify that I see apps as secondary to the core of good mental health care: personal attention from someone who cares. I do not believe that digital interventions will solve the crisis of mental health care we currently face, because in the end an app is just an app. As a result, any approach to integrating apps into mental health care must put the personal encounter front and center. A visit to a doctor or therapist should never come to resemble what so many of our medical visits now seem to be, where the doctor is increasingly focused on a computer or on data rather than on the suffering human seated in front of them. When I go to my doctor or therapist, I want their focus to be on providing empathy for my suffering and on helping me solve my problems and alleviate my symptoms as best as I can while recognizing that I suffer from an incurable chronic, debilitating disease. I do not want to be told what to do for my own good or because my doctor says so, and I do not want to spend the whole time looking at data or fiddling with devices.

Clinicians can thoughtfully inquire about how their patients are currently making use of technology to alleviate their pain and in the process of helping their patients solve problems, gently offer apps that might help solve those problems. Clinicians working with a patient on mindfulness skills might recommend that they download and try out some mindfulness apps. If recommending a new medication, a dosage change, or a lifestyle alteration that they are unsure of, clinicians can suggest tracking so that both parties use the data to make decisions *together*. If a patient is currently tracking anything, spending a couple minutes checking in about the data at the beginning or end of a session is not too time-consuming or disruptive to the main intent of the office visit, which should be about the personal interaction. If data can be emailed or provided in advance, so much the better.

Secure Communication With Clinicians

Being able to easily message with my therapist keeps her up-to-date on my status and provides timely assistance during crises. Most messaging methods are not particularly secure, as evidenced by reports of Facebook selling the contents of direct messages to other tech companies [\[64\]](#). Owing to my experience in software, I have low expectations of privacy on internet-enabled devices. However, Signal [\[54\]](#) is a secure messaging app with end-to-end encryption that can be valuable for more confidential clinician-patient communications.

Tracking

Many clinicians see tracking as necessary and valuable to their patients' care. Routinely tracking health can have a significant effect on health management [\[65\]](#), for example, moods, sleep, and other factors like medication adherence, but it is challenging in implementation. Daily tracking, although it may seem easy, is a difficult habit to start and maintain over time, and generally, people will only do it if they see some obvious benefit to it. The desire to track multiple aspects of daily life varies a lot from person to person. Recommending tracking without (1) discussing the evidence base that certain kinds of tracking may improve outcomes or (2) understanding how tracking addresses patient goals is unlikely to result in ongoing use of any tracking app. As a patient of mental health clinicians for 20 years, I do not remember a single time a clinician either took the time to go over an evidence base with me or worked with me together to find some value I could gain from tracking. And yet, I do use a simple daily mood tracker on my phone. When I made the decision to go off Latuda because I was concerned about its expense and some associated weight gain, my daily mood tracking showed that I had a very rough couple of months after that. As a result of that tracking, I decided to re-start the drug, confident that it was providing value. When my psychiatrist requested that I stop drinking for a month in exchange for agreeing that I could try stopping lithium, I saw via daily mood tracking that total abstention resulted in a more stable mood than I had experienced in the previous years during the same month, which is typically very difficult for me. I was not excited to discover the link between drinking and mood but was willing to accept it. This realization led to a significant change in my relationship with alcohol. I drink much less generally and try to abstain completely during high-risk times. I recently used my simple mood tracker to see that I had not logged a good day in 2 months. I asked my psychiatrist to re-start an antidepressant with me to improve things. Other people may have other goals for tracking (ensuring medication adherence, determining how dosing affects symptoms, tracking use of as-needed meds) or a greater tolerance for tracking more than one thing at once. Selecting mood-tracking apps that suit individual needs and motivations is critical.

Taking Safety and Privacy Precautions

Crisis Help

I am aware that the app research literature indicates that many mental health apps lack features that can be activated in a crisis [\[18\]](#). However, my personal view is that I do not expect an individual app, tailored for mental health use or not, to assist me during a mental health crisis. My mobile phone itself is a simple way to get help if I need it. If a patient frequently has suicidal ideation, it is not difficult to ensure that they have the number of a crisis hotlines and other resources saved and easily accessible in their favorites. I keep my local Samaritans as a favorite in my phone, along with the numbers for my therapist and my psychopharmacologist. Many crisis hotlines accept text messages now as well as phone calls, which can lower the barrier to reaching out. I suggest that providers make sure their patients understand when and how they should reach out directly

to their mental health provider versus making use of a crisis hotline.

Privacy and Security

As a software engineer, I am quite concerned about the privacy protections (or lack thereof) on internet-enabled devices. A recent newspaper headline stated, “Who’s making sure your mental health app is safe? No one, experts say” [66]. I know how the security and privacy internet *sausage is made*, it is full of holes, and breaches have been well documented [67]. The most realistic default assumption is that any information users provide to their devices in any app whatsoever may be subject to privacy breaches at the app level, at the operating system level, and while traveling over cellular and Wi-Fi networks. Mental health patients need to be aware that if they want to assure secrecy, they should not put personal information on their devices. I have personally made my peace with the lack of privacy in the modern world and am prepared to deal with the consequences of inadvertent breaches of my private data. Each mental health patient needs to balance the risks and benefits of their technology use.

That said, some apps can be expected to offer more privacy than others. Free services like Facebook and Google earn money off the data people provide them, including usage patterns. Email and text messaging are not secure methods of communication. If security and privacy in communications are concerns, use apps designed for more secure communications, like Signal. Some companies place a greater emphasis on privacy and security than others. Unfortunately, it can be impossible for even tech-savvy people to determine an app’s level of security. The best you can say of an app that has security and privacy front and center is that security-minded professionals have probably done some due diligence around it, that terms of service are easy to understand, and that the company’s business model is not making money from selling user data.

Privacy and security are real concerns and cannot be guaranteed. In my experience, it is helpful to accept that patients may not always feel comfortable making use of their devices. If a patient suffers from paranoia or feelings of persecution, there may be times they are more concerned about privacy and security. Feelings of paranoia are exacerbated by the real risks. For myself, I try to distinguish between my awareness that anything I say or do around internet-enabled devices might be accessed by others (which is not paranoia) and a belief that there are people out there who are persecuting me personally via my devices. (Some people may have real reasons to fear that others in their lives are tracking them via their devices, such as those in abusive relationships.) When patients cannot or do not want to use devices because of symptoms they are experiencing, it may be helpful to temporarily revert to nondigital interventions, such as tracking mood and medications on a traditional paper monthly mood chart.

Appropriate Use of Devices

A final consideration around the safety of using devices is that our digital devices are not an unalloyed good for anyone, including those of us struggling with mental illness. For people who experience mania, for example, they make it very easy to do a great deal of damage very quickly. If I am experiencing

symptoms of mania, I can (and have) very quickly, on my phone, at any time of the day or night, spend a great deal of money with a few clicks and send multitudes of inappropriate messages. There are times when the best advice to patients may be to temporarily lock up their phones. As with a patient experiencing security worries, a patient who is causing damage to their life via their phone can revert temporarily to a predigital lifestyle. For those who have real trouble in this area, an old-style flip phone can be used during those times so that their need to be able to be in contact is balanced with limiting the damage that can be done by the combination of poor impulse control and *the world at your fingertips*.

Second, there are dark sides to our digital lives. Social apps can be used for bullying or to cause people to feel inadequate. They may contribute to consumerist and competitive values. Phones can be used addictively, sapping our focus and ability to think deeply. For those who lack concentration, excessive phone usage will make matters worse. Screen time controls and limits on use of certain apps (via built-in methods or apps like Freedom, which control usage) can be helpful to manage this problem. Sometimes low-tech methods work well. Recently I started Bullet Journaling (see Table 1). This is an entirely paper-based method of managing my thoughts and to-dos), reducing the time I spend on my devices, increasing my ability to focus, and helping me stay in the present. I still make heavy use of my devices, but more mindfully. Just as with medications, patients and doctors need to consider the costs and benefits of technology, which may change as individual symptoms wax and wane.

Discussion

Key Clinical Considerations and Strategies

As stated earlier, the goal of this perspective is not to generalize the experiences of 1 woman experiencing bipolar disorder to all, but to show the need for more flexible app solutions within the context of mental health treatment. On the basis of the literature and Amy’s experience, it appears that apps can be useful if they are tailored to help manage the broad psychosocial needs and symptoms that are characteristic of psychiatric problems. Amy has highlighted the value of flexible skills such as mindfulness, the use of nonmental health apps for mental health goals, anchoring app usage as an adjunct to the therapeutic relationship, the need for individuals to balance privacy considerations on personal benefits and risks, the importance of clinician explanations of evidence-based outcomes for technology use, the difficulties of overengineered apps and the value of simplicity, and the need for creative solutions such as music and games for distress tolerance. Of course, the number of apps used, the symptoms targeted, and how they will be integrated into treatment will vary greatly from person to person. Such an approach requires technology-informed clinicians and suggests that the use of apps and other digital tools should become part of clinician training.

Basing mental health app development on existing tools and platforms would recognize ways to more broadly support patients in mental health recovery and to also invite in those

who have less access to potential costly and elaborate mental health apps. In addition, tools that enhance mental health goals may be better integrated into apps that are used on a regular basis. As stated by Schueller et al [4]:

...the distinction between mental health apps and health apps might be more salient to mental health researchers and practitioners than to consumers. Going a step further, it could be that the wave of the future is neither health nor mental health apps, but more mental health app features integrated into commonly used apps like our calendars, conversational agents, or messaging platforms or apps focused on health more broadly.

This would follow the concept of *nudge*, which requires less conscious thought builds on well-established, automatic responses [68]. Rather than introduce something that requires a large commitment, why not work with what people are already using (or may be interested in) and consider a nudge?

Some key questions arise. First, what would such an arrangement look like in clinical encounters? Despite the questions surrounding the long-term value of current mental health apps, reality dictates that they are a worthy topic of discussion in therapeutic interactions. Many patients are likely using mobile phones and smartwatches with apps for mental health and other health goals, so forward-thinking clinicians can find creative ways of integrating them in treatment. For example, are there ways to use apps that capitalize on healthy habits related to nutrition, mindfulness, sleep, exercise, and social support with social networks, all of which can help improve psychiatric outcomes? Clinicians may also want to review how patients can use technology to support the activities of daily living so that they can function well with their disease. Asking patients about digital tools that they use and trying to understand how they may further personal goals can be part of a therapeutic plan. Clinicians may want to discuss their availability to patients via secure messaging. Discussions about more targeted apps, for example, apps for symptom tracking, can emphasize potential advantages for a patient's own decision-making and self-management. Finally, clinicians can play an important role in assisting their patients to adopt a responsible and balanced use of technology to avoid the possibility of social disengagement. Waiting for a mental health app that meets all the clinical criteria will only delay potential opportunities for patients to make empowered decisions by using already available technology. We need to maximize current tools until that day (hopefully) arrives.

There has also been increasing interest in delivering interventions that address symptoms that cross diagnostic boundaries between anxiety, depression, and other psychiatric disorders [18,69,70]. Interventions such as Intellicare [71] capitalize on this notion. A recent consumer evaluation of apps targeting bipolar disorder found that users requested features such as multiple category-tracking (sleep, medication, diet, mood triggers, exercise, anxiety, and substance use), ability to track fluctuations throughout the day, access to a Web-based community, and data-sharing abilities with clinicians [9]. Rather than funneling patients into single disorder apps, there may be

opportunities for mental health providers to suggest combinations of apps that best meet individual patient needs [72]. Such a *toolbox* approach may better address the problems that patients face, reduce stigma, and ultimately encourage app adoption. This approach can also be implemented today by any clinician, using features and apps that are already available.

Second, if mental health apps are to be considered as part of an intervention, how can the issues of quality and training be addressed? The issue of quality cannot be separated from the need for clinician education, as the National Institute of Mental Health has stressed the need for the development of new technology-training models for clinician and task shifting through technology apps delivered by trained paraprofessionals [73]. A part of this training should be devoted to the best ways to educate patients about the value of digital health tools and how clinicians can utilize these tools in treatment. There are app standards developed by academic groups (PsyberGuide [74]), private companies (AppScript [75]), professional organizations (American Psychiatric Association App Evaluation Model [76]), and governmental organizations (United Kingdom-based National Health Service Apps Library [77]). These groups have attempted to establish more rigorous evaluation standards based on the ease of use, clinical value, rigorous evidence-base outcomes, and a regard for patient safety and privacy. Torous et al [72] have developed an acronym called ASPECTS (Actionable, Secure, Professional, Evidence-based, Customizable, TranSparent) to describe ideal characteristics of health apps and to help patients. These resources and criteria can be used to help patients and clinicians identify the latest health technology, for example, tracking patient functioning between office visits.

Finally, how can the approach described in this paper be leveraged to address the needs of those who are not ready or able to access treatment or who lack an understanding of how to use apps to enhance their mental health? Those who might benefit the most from using health apps, that is, poor health or inadequate physical activity, are least likely to download and utilize digital health tools [17]. Such a finding makes it more imperative to reach outside of a mental health framework to identify ways in which mental health interventions (emotional management, countering negative cognitions, coping with symptoms such as fatigue and pain, and improving sleep) can be integrated into daily scheduling, goal setting, and social media apps. Mobile phone penetration is high across all strata, as almost every developing country has reached a rate of 90% ownership [78]. In addition, mobile phone users and app users are virtually synonymous—only 1 in 10 mobile phone users does not use apps [79]. By eliminating the barrier of labeling an app for *mental health* (or even *health*), there may be opportunities to invite new audiences to interventions that can improve their mental health in the context of lifestyle management.

Conclusions

We believe that the application of mental health apps and other technologies in psychiatric treatment has not sufficiently accounted for the nuanced expectations, experiences, and challenges that patients face when to make practical use

of technology. Amy's experience shows how 1 woman has developed a personalized and creative strategy with mental health apps to cope with bipolar disorder. We believe that the key to effective deployment of apps in psychiatric treatment rests on the flexible use of apps rather than sole reliance on condition-specific (*mental health*) apps. Rather, the use of

technology should address the broad range of lifestyle challenges presented by bipolar and other mental disorders. On the basis of the existing literature and examples such as Amy's lived experience, there are potential avenues for further hypothesis testing and program development with such tailored strategies.

Acknowledgments

The authors would like to thank Paul Wicks, PhD, for his helpful comments in reviewing the paper.

Conflicts of Interest

None declared.

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Edited by J Torous; submitted 21.09.18; peer-reviewed by V Genaro Motti, J Apolinário-Hagen, P Slevin; comments to author 01.11.18; revised version received 29.01.19; accepted 12.03.19; published 22.04.19.

Please cite as:

Chiuzzi E, Newell A

Mental Health Apps in Psychiatric Treatment: A Patient Perspective on Real World Technology Usage

JMIR Ment Health 2019;6(4):e12292

URL: <http://mental.jmir.org/2019/4/e12292/>

doi: [10.2196/12292](https://doi.org/10.2196/12292)

PMID: [31008711](https://pubmed.ncbi.nlm.nih.gov/31008711/)

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Original Paper

Framing Mental Health Within Digital Games: An Exploratory Case Study of Hellblade

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Abstract

Background: Researchers and therapists have increasingly turned to digital games for new forms of treatments and interventions for people suffering from a variety of mental health issues. Yet, the depiction of mental illness within digital games typically promotes stigmatized versions of those with mental health concerns. Recently, more games have attempted to implement more realistic and respectful depictions of mental health conditions.

Objective: This paper presents an exploratory analysis of a contemporary game that has the potential to change the way researchers, practitioners, and game designers approach topics of mental health within the context of gaming.

Methods: A case study of Hellblade: Senua's Sacrifice was conducted using frame analysis to show how key design choices for this game present the potential for new ways of approaching games and mental health.

Results: A case study of Hellblade's development shows how research-informed collaborative design with mental health practitioners, scientists, and individuals with mental health problems can lead to a realistic depiction of mental illness in games. Furthermore, the use of frame analysis demonstrates how to harness narrative, mechanics, and technology to create embodied experiences of mental health, which has the potential to promote empathetic understanding.

Conclusions: This paper highlights an exemplary case of collaborative commercial game design for entertainment purposes in relation to mental health. Understanding the success of Hellblade's depiction of psychosis can improve serious games research and design. Further research must continue to provide deeper analysis of not only games that depict mental illness, but also the design process behind them.

(*JMIR Ment Health* 2019;6(4):e12432) doi:[10.2196/12432](https://doi.org/10.2196/12432)

KEYWORDS

video games; electronic gaming; psychosis; stigma

Introduction

Background

The growth of digital games in terms of both popularity and technology has pushed games into various roles beyond simply entertainment. Digital games and game design practices have been applied to fitness [1], job training [2], education [3], and even therapeutic practices [4]. Not only are games being applied to various roles, but designers are also approaching more serious

topics such as humanitarian crises [5], the realities of war [6], and mental health [7]. The integration of *serious* topics within digital games brings with it debates regarding the acceptability of “playing” with such serious subject matter [8]. These issues, particularly notions of trivialization or stigmatization, are common among larger commercial games created primarily for profit. Researchers and smaller independent game designers frequently create *serious games* that are typically smaller games

or game-like experiences whose primary purpose is not simply entertainment.

Hellblade: Senua's Sacrifice, hereby also referred to as Hellblade, is a digital game developed and independently published by Ninja Theory, which is a British game development studio based out of Cambridge, England [9]. In Hellblade, players take on the role of Senua, a female Pict warrior on a quest that quite literally tests her sanity. Hellblade's presentation of Senua's psychosis provides interesting insights into how games can depict challenging, controversial topics [10,11]. Hellblade is significant because it is one of only a very few commercial video games to ever tackle the serious topic of mental illness [12] and perhaps the most successful, returning a profit in sales after only 3 months [13]. As a result, Hellblade is a game that could contribute to numerous conversations across various fields, such as psychology and game studies.

This paper analyzes Hellblade in two ways. First, Hellblade is used as a case study in which a formal analysis was conducted. This formal analysis was used to identify the components, actions, and goals present in Hellblade [14]. Secondly, this study turns to the use of frame analysis in order to better understand the design and development decisions used by Ninja Theory to depict symptoms of psychosis and how future games can emulate Hellblade's success. Specifically, we examine how various frames and design choices were used to create a compelling experience related to mental illness while alleviating concerns of trivializing such a serious topic. The results of this study should help us better understand Hellblade's depiction of mental illness but also the collaborative design process behind its creation.

Games and Mental Health

With regard to games and mental health, researchers and therapists have increasingly turned to digital games for new forms of treatments and interventions for those dealing with mental health issues. Research shows that games appear to be well-suited for promoting mental health awareness and possibly as interventions [15,16]. Games can increase the impact of mental health interventions due, in part, to their broad appeal, accessibility, and ability to keep participants engaged [17]. In fact, a number of commercial games have been adopted and tested as unique forms of therapy [18,19]. Thorens et al [20] argue that the naturalistic use (ie, outside of traditional interventions) of digital games may be particularly helpful given game design practices that motivate players to continue to play, such as online, social play, and reward schemes. This is noteworthy given the number of people who play digital games and, by extension, the potential to reach those who face mental health issues but do not seek out or receive treatment [17]. As Goodman et al [21] point out, the nature of online gaming communities provides interesting possibilities in terms of possible health interventions and support.

Unfortunately, the combination of games and mental health comes with several potential issues. Most notably, there is a lack of cooperation between game designers and mental health specialists, as well as the exclusion of individuals dealing with these disorders, which leads to a lack of games that are both beneficial and engaging [22]. This is evident in publications

from both mental health and game design researchers attempting to prescribe a formula for working across these disciplines successfully [22-24]. Mental health researchers and practitioners attempting to make use of serious game-based interventions often deal with the lack of an engaging, well-constructed gameplay experience [17]. Similarly, serious games and apps crafted without oversight by mental health professionals risk both ethical issues and possible conflict with therapeutic goals [25]. Meanwhile, commercial games depicting various forms of mental illness tend to be crafted with problematic, stigmatized versions of individuals dealing with mental health issues in such a way that shows little-to-no understanding of the actual disorders they claim to depict [16].

The inclusion of mental health disorders within digital games has often been viewed as troublesome. This is most notable in relation to horror-themed games, which often rely on heavily stigmatized versions of the "mentally ill" as prone to violence and mental health hospitals as dark, haunted asylums [11,26]. Sender [27] argues that mental illness has increasingly been presented by the media because of society's growing desensitization and fascination toward these disorders. Many media forms, particularly games, turn to a base notion of "insanity" to explain seemingly inexplicable acts of violence perpetrated by the game's villains [28]. Games such as *Outlast* (Red Barrels), *Manhunt* (Rockstar Games), and *The Evil Within* (Bethesda Softworks) include harmful, stereotypical depictions of these characters, including murderous patients or abusive caretakers [16,29]. These troublesome portrayals of individuals experiencing forms of mental illness promote fear and stigma toward people dealing with these issues while perhaps also promoting forms of self-stigmatization, which may inhibit people dealing with mental health concerns from attempting to seek help and support [26].

This is not to say that all games that choose to depict aspects of mental illnesses are as problematic. However, video games that tackle serious topics in an accurate and empathetic way are not only rare, but are often much smaller, independently developed games that struggle to find a wide audience amidst larger commercial releases. Games such as *Depression Quest* (Zoe Quinn) and *Pry* (Tender Claws) have received praise for allowing players to navigate narratives related to mental health issues [7,29-31]. *Depression Quest* is a text-driven game that asks the player to take on the role of a person dealing with depression. In a similar vein to a choose-your-own-adventure book, players make decisions based on various prompts similar to events experienced in daily life. Over time, players find that certain choices are visible but not accessible to them, alluding to struggles with anxiety, fatigue, and pessimism that are common symptoms for those dealing with depression. *Pry* acts similarly to an interactive or visual novel. *Pry* asks the player to explore the mind of a soldier dealing with posttraumatic stress disorder. Players are given access to various pictures and text and are given the ability to interact with these various prompts to learn more about their character's memories, all while attempting to balance the line between the real world and the soldier's subconscious. Smaller, independent games such as *Depression Quest* and *Pry* are largely text-driven and usually developed by individuals or, at best, fairly small teams of

designers. These serious-topic focused *indie* games are typically meant to share a message rather than simply be “played” in a traditional entertainment sense; they also receive little commercial consideration. While such games are commendable for tackling important topics in a more careful and accurate way, they often suffer from mixed reviews and relatively low sales.

Larger commercial games that call upon various forms of psychological disorders are typically met with a great deal of skepticism. As mentioned earlier, the notion of “playing” these types of games typically brings accusations of trivializing or exploiting topics that are perceived to require a more reverent approach. Chapman and Linderoth [8] refer to this notion of certain themes being deemed inappropriate for inclusion within the context of games as the “limits of play.” In their work on Nazism in games, Chapman and Linderoth [8] argue that “the tension between the inevitable un-seriousness of games and sensitive themes is only likely to survive if an overarching frame is established.” In that vein, it is essential that researchers and designers attempt to examine not only the portrayal of mental illness and mental health in video games, but also the design practices that encourage an increased empathetic understanding of people with mental health problems [32]. Therefore, we need a better understanding of the process by which we can develop games that not only address issues related to mental health, but also have the potential to reach a wider audience. In this exploratory study, we attempt to address both of these needs by conducting a formal analysis of one particular game, Hellblade: Senua’s Sacrifice [9].

Hellblade: A Collaborative Design Template

This paper presents an exploratory case study of a single game, Hellblade, from its development to reception, as a lens through which to understand how games can depict mental illness in a respectful and nonstigmatizing fashion. Unlike most serious games or the previously mentioned Depression Quest and Pry, Hellblade was created by an established AAA game design studio, Ninja Theory, as a fully developed commercial title that was released across multiple gaming platforms. In general, AAA games are considered to be of a high quality, created by relatively large studios and with relatively large budgets [33]. Despite their game’s commercial aspirations, the designers at Ninja Theory devoted themselves to creating a respectful depiction of psychosis, going so far as to develop the game independent of publisher support and funding. Hellblade was created and published solely by Ninja Theory to ensure the game they envisioned was not subject to outside pressures, a process they referred to as “the independent AAA proposition” [34]. This proposition resulted in one of the most noteworthy and best-selling digital games to focus on serious subject matter such as mental health [13].

This paper argues that Ninja Theory’s willingness to collaborate with mental health professionals, researchers, and individuals actively dealing with mental health disorders resulted in design choices that allow Hellblade to present a respectful and engaging depiction of psychosis. Specifically, using frame analysis [35], we illustrate how elements of Hellblade’s design allowed Ninja Theory to successfully craft a game built upon notions of

psychosis. This analysis is reinforced through development diaries and press interviews given throughout the game’s creation. Through a formal analysis of Hellblade and further frame analysis of Ninja Theory’s developmental process and design choices, this paper provides insights into how the cooperation of designers, researchers, practitioners, and individuals with mental health problems can allow games to depict challenging, controversial topics successfully.

Methods

Case Study

This paper presents a case study of Hellblade: Senua’s Sacrifice (PC). In order to accomplish this, a formal analysis of the game was performed by both researchers (JF and CB) through sessions of both active gameplay and the observation of recorded gameplay by the authors [14]. Formal analysis with relation to game studies, also referred to as aesthetic analysis [36] or simply game analysis [37], is an examination based primarily upon the “playing of a game and attempting to understand how the game system works” [14]. This analysis relies on the base categories of “objects, interface, and interactions” put forth by Consalvo and Dutton [37]. The study of a single game and its components could easily fill an entire book, yet, as Aarseth [36] argues, this form of inquiry requires the researcher to focus and pursue the aspects that make a game noteworthy.

In terms of methodology, this form of analysis must rely primarily upon the act of playing a particular game. Lankoski and Bjork [14] point out that “game dynamics are more easily understood in actual gameplay” with an eye to “the elements that constitute the parts of the work and the role of each element in the composition as a whole.” In that sense, gameplay logs [37] were kept by researchers throughout multiple play and viewing sessions. These logs noted objects within the game space (eg, lorestones), the presence or lack of an interface (eg, no on-screen health bar, but darkening of the screen to denote danger), and interactions possible within the game (eg, activating and listening to lorestones or discovering glyphs) (see Figure 1). These initial logs provided a base understanding of Hellblade’s gameplay, structure, and the world it presents.

While Aarseth [36] argues that “informed game scholarship must involve play,” he also notes that this should be reinforced through secondary sources such as interviewing players or developers. The initial gameplay logs were further informed by a 25-minute documentary created by Ninja Theory and included with every copy of Hellblade [38]. This documentary focused primarily on the role of psychosis within Hellblade’s design and on how these decisions were informed by the researchers and individuals dealing with these symptoms whom Ninja Theory included throughout the development process. For further data on Hellblade’s development, 30 developer diaries, three question-and-answer sessions held by the lead developers, and a masterclass session given by creative director Tameem Antoniades for the British Academy of Film and Television Arts (BAFTA) were accessed via the official website for Hellblade as well as through Ninja Theory’s YouTube portal [9,39].

Figure 1. Example of Norse lorestones in the game Hellblade (screenshot).

Ninja Theory's developer diaries span the length of Hellblade's development. The first, published in August 2014, details the creation of the game's announcement trailer, which had been released 2 weeks prior [40]; the final diary (#30), detailing Hellblade's launch and early reception, was posted 3 months after the game's release in 2017 [41]. Each diary focuses on a singular aspect of the game's design: from art and narrative inspirations and character design to the inclusion of mental health researchers and practitioners throughout the development and playtesting process. These diaries were made publicly available on both Ninja Theory's YouTube channel and the official website for Hellblade. These diaries were led by the game's creative director Tameem Antoniades and lead producer Dominic Matthews, although other designers, character actors, and mental health professionals were also included, depending on each video's topic.

These developer insights helped provide further context for the initial gameplay logs as well as new insight into Hellblade's design. A final playthrough and observation of Hellblade was performed that was particularly focused on identifying and further understanding how game design elements contributed to the game's depiction of Senua's psychosis. Through this process, four main themes were chosen to discuss how Ninja Theory framed their depiction of psychosis within Hellblade: narrative and storytelling, in-game mechanics, platform and technological affordances, and an open dedication to collaboration and care.

Frame Analysis

Frame analysis has become an increasingly common analytical tool for game scholars [42,43]. Goffman's notion of a *frame* relates to the meaning we attribute to a situation. These frames are largely based upon social or cultural understandings and how we use them to interpret meaning. For instance, the act of

playing a game is typically viewed as not serious as well as separate from real life. Thus, when playing violent video games, most players have no qualms performing criminal activities they would likely never perform in the real world. This notion of a game frame [44], or what Chapman and Linderoth [8] refer to as the *ludic frame*, typically involves the redefinition of an object or activity based on its inclusion within a game. This ludic frame suggests a more playful and less serious approach to a given topic through a process Goffman refers to as *keying* [35].

Keying is the shift in the meaning of an activity that occurs within a given frame. For example, the ways in which a player engages with a game will change dependent upon the situation and meaning attributed to the play session. Professional athletes may approach the act of playing a game under the premise of training rather than simply leisure enjoyment. This additional frame of *professional sport* adds new meaning to the act of playing, a process known as *upkeying* [26,45]. In contrast, the act of *downkeying* involves the removal of additional frames toward a traditional understanding of a given situation.

With relation to games and depictions of mental illness, it is important to consider the steps developers are taking in order to signal certain meanings to players. Chapman and Linderoth [8] discuss this negotiation between what is and is not deemed appropriate for digital games in their study of the depiction of Nazism in games. In particular, they note that "ludic frames seem to have an intrinsically trivializing property," [8] yet concerns over the depiction of controversial topics in games can sometimes be alleviated by developers positioning their work within frames of artistic expression, education, or a documentary-like devotion to accuracy. These various forms of framing content allow for an upkeying of the game activity to a more serious understanding of a game's content.

Commercial games depicting aspects of mental health conditions are often criticized for their stigmatized portrayal of these disorders. While numerous indie games approach topics of mental health in creative and respectful ways, these larger commercial products are promoted and distributed by large-scale publishers and typically reach much larger audiences [16]. Depictions of fear and violence attributed to mental health disorders within these larger games promote the same stigmas and stereotypes commonly seen in television and film [11]. In order to create a game that may help alleviate these stigmas and present an engaging representation of psychosis, Ninja Theory relied on design choices that help to frame Hellblade as a respectful interpretation of these conditions, upkeying the play experience to a more serious, meaningful tone. By identifying the ways in which Hellblade presents its depiction of psychosis to the player, this paper helps illustrate methods with which game designers can better approach more serious topics and why these more positive depictions of stigmatized populations are important areas for games to explore.

Results

A Narrative of Psychosis

Hellblade approaches the topic of mental health in ways that reflect both its commercial and serious aspirations. Commercial games, typically focused on violence or horror, tend to depict those with mental health issues as antagonists. There is usually little exploration or explanation as to their situation, relying on stereotyped notions of mental health as a generic explanation for dangerous, violent characters within a larger, fantasy narrative [11]. Serious and independent games that deal with mental health issues typically devote the entire game to their depiction of these disorders. For example, the previously mentioned Depression Quest immediately places the player in the role of someone dealing with depression and task them with making decisions about this character's everyday life. Hellblade attempts to combine these approaches: placing players in the role of Senua and attempting to present a faithful representation of psychosis, while presenting players with a larger narrative and world to explore.

In Hellblade, players are given control of Senua, a female Pict warrior struggling with psychosis after her village is destroyed and the love of her life is killed (see [Figure 2](#)). The game centers on Senua's perceived journey through the Norse mythological land of Helheim in order to save her love from the Norse goddess of death, Hela (see [Figure 3](#)). Throughout the game, Senua fights her way through a number of seemingly demonic Norse warriors and mythological creatures while also dealing with various symptoms of her illness, such as auditory and visual hallucinations (see [Figure 4](#)). Through the game's use of storytelling and narrative, Hellblade presents a novel and engaging depiction of psychosis that is crafted within the game's mechanics.

Hellblade is a game rooted in a time and historical setting that frames Senua's mental health disorder as a curse. Through visions and stories, players learn that much of the tension in Senua's life arises from the stigma attached to societal reactions to her "curse" rather than the disorder itself [46]. This stigma includes an abusive relationship with her father and imposed isolation from her community. These past traumas are frequently touched upon with relation to how Senua deals with her disorder, her memory of her mother who also suffered from similar symptoms, and her own role in society. Senua's father acts as one of the many voices within Senua's mind as she progresses in the game, consistently demeaning her choices and abilities. These themes of isolation and stigma speak to the ever-present nature of these societal misunderstandings for those who deal with mental illnesses today.

Hellblade's story, though largely informed by Senua's psychosis, includes a larger narrative built upon Senua's journey through Norse mythology. These depictions of Norsemen and their lands are shaped by Senua's own understandings of Norse mythology told to her by a mysterious man known as Druth who shared these stories with her while she had been exiled from her village. As such, players see horrific representations of Norse warriors attempting to stop Senua during her journey. These monstrous enemies provide more intimidating enemies for players to deal with while also flipping the common depiction of those with mental illness as dangerous or homicidal back onto those around Senua. This dual narrative of traversing Norse mythology while also discovering Senua's own past and internal strife is important because it provides Hellblade with an engaging setting. Unlike other serious games that explicitly focus on a disorder, psychosis is instead purely a part of the gameplay, experienced through the game's mechanics. Rather than a game about psychosis, Hellblade is an attempt to create a game that allows the player to experience symptoms similar to psychosis.

This interplay between creating a game and respectfully presenting psychosis was essential to Hellblade's success. As mentioned before, depictions of more serious topics in games are typically met with accusations of trivialization or further propagating stigmatized stereotypes [47]. That being said, it is also important to ensure that games pertaining to serious topics such as mental health are approachable. For instance, the inclusion of Norse mythology and demonic Viking enemies helps promote an upkeying of Hellblade to the ludic frame, a play experience. Various scenes or interactions within the game, such as Senua's pleading for her auditory hallucinations to stop, can lead to a downkeying of the play experience as players begin to frame the experience as serious or simply no longer ludic. The ability to shift between these frames is important in not only keeping the player actively engaged with the larger narrative of Senua's quest to Helheim, but also allows the developers to bring more serious, empathetic moments.

Figure 2. The player-character, Senua, in the game Hellblade (screenshot).**Figure 3.** Hellblade's representation of the Norse mythological land of Helheim (screenshot).

One of the more interesting aspects of the overall story Hellblade provides is the fact that Senua's reality is never fully questioned [46]. In a game rife with questions of sanity and what is or is not real, Senua's journey is never placed in relation to "true reality." Much like those who deal with these hallucinations, Hellblade leaves this question of reality solely for the player to decide. Throughout interviews and diaries, Antoniades argues that reality itself is nothing more than our own interpretation, thus there is no reason to ever relate Senua's journey to some other point of reference [38]. Players are meant to experience

Senua's reality, as it is wholly real to her. By the end of the game, it is unclear what aspects of Senua's tale are a part of her psychosis versus reality. By taking this approach, Ninja Theory continues to validate Senua's experience and reinforces her perspective, rather than removing the veil and re-establishing the player as the driving narrative force [12].

The Mechanics of Mental Illness

Throughout the game, numerous game mechanics illustrate a variety of possible symptoms of those suffering from psychosis.

Visual and narrative twists are frequently presented through the use of hallucinations and altered realities. Furthermore, various environmental puzzles rely on visual hallucinations and notions of pareidolia, the finding and forming of seemingly insignificant patterns in the everyday (see [Figure 5](#)).

Unlike most combat-oriented games, Hellblade includes no extra visual information for the player on the screen, which is referred to as a heads-up display. There is no health meter, no

compass to help with direction, and no real tutorial to teach the player combat. In fact, combat within the game is largely repetitive, persisting of 1-2 buttons pressed repeatedly to perform combinations. This is likely because the true goal of Hellblade is not to fight your way through the various Norse enemies present in the game, but to truly engage with Senua's story. De-emphasizing combat once again helps to frame the experience of Hellblade toward a more serious presentation of psychosis.

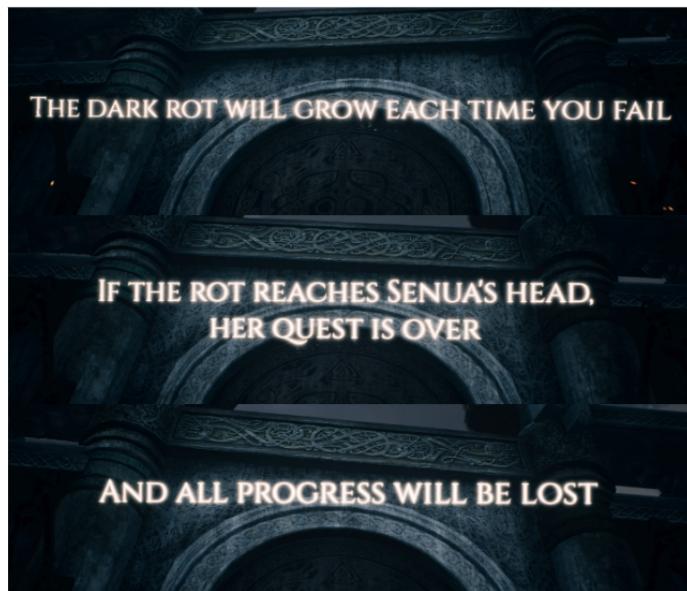
Figure 4. Senua preparing to fight against Norsemen in the game Hellblade (screenshot).



Figure 5. Example of a pareidolia pattern puzzle in the game Hellblade (screenshot).



Figure 6. Sequence of permadeath warnings in the game Hellblade (screenshot).



The inclusion of permadeath, a game mechanism in which players lose all progress within the game after failing to complete it within a given number of tries, is introduced early in the playthrough of Hellblade and was one of the most controversial topics after the game was released (see [Figure 6](#)). While this turned out to be a bluff intended to promote feelings of dread and anxiety for players akin to those suffering with various mental health disorders, the sheer possibility of a permadeath mechanic within the game was viewed by some as a heavy-handed metaphor for a full break from sanity or suicidal machinations [43]. This sort of response suggests that the rumored inclusion of a permadeath mechanic acted as an upkeying or loosening of Hellblade's depiction of psychosis, which some may consider inappropriate.

The Technology of Mental Illness

These initial efforts to address the playful nature of digital games and the ludic frame are important in setting Ninja Theory's desired tone of Hellblade for the player. Yet, the design choices inherent within Hellblade also work to further downkey the ludic nature of the game. Ninja Theory's focus is on providing an immersive experience with a level of technological detail rarely seen in games to draw the player toward identifying with Senua. Senua's struggle is brought to life via the acting of Melina Juergens and the use of both 3D motion capture and facial camera rigs. These were used in an attempt to capture every minor change in facial expression, while also providing harrowing levels of character detail as she experiences the anguishes associated with her journey [47]. This level of graphical fidelity also allowed the designers to experiment with various forms of environmental changes and camera tricks to replicate hallucinations and visual irregularities reported in their interviews with those dealing with mental illness [47].

The most notable aspect of Hellblade is how it presents sound. Throughout the game, the player hears an ongoing chorus of voices within Senua's mind. Using binaural 3D microphones, Ninja Theory was able to produce an experience of directional

auditory hallucinations that Dr Charles Fernyhough, a professor of psychology investigating auditory hallucinations, argues is one of the best representations of these experiences he has ever used [48]. The use of these various voices pushes the player to understand the internal struggles present for Senua, but their use also acts as a mechanic within the game itself, providing players with information and warnings. These voices are present throughout the game, giving advice, questioning the player's decisions, and doubting the player's abilities. These voices address the player directly from the opening scene, which illustrates Senua's awareness of not only these voices, but seemingly of the player as well. The constant interaction between the voices and the player can be off-putting at first, as players adjust to the sheer amount of information being pushed through their headphones. Research has found that exposing individuals to simulations of hallucinations can increase empathy and understanding in relation to sufferers of mental illness [49,50].

The Collaboration Process

Throughout the developer diaries and the included documentary on the making of Hellblade, Ninja Theory stresses the role of mental health professionals, scientists, and individuals with mental health problems as advisors throughout the game's development. In fact, the opening credits of the game begin with credits for both the "mental health advisor" and "historical advisor" positions, rather than the game's lead designers (see [Figure 7](#)). The game's depiction of Senua's psychosis was built to reflect conversations, prototyping, and playtesting with these experts to ensure a level of fidelity that is uncommon across most media depictions of mental illness. One fan responded with the following [51]:

I've never known how to describe what happens in my mind. You have put words and pictures to how I feel. I showed it to those I've been unable to be honest with and connected with the people I love on a level I never have before.

Figure 7. Opening credits of the game, which begin with professional advisors (screenshot).



From the initial decision to include a depiction of mental health within Hellblade, Ninja Theory reached out to researchers, mental health professionals, and those who were currently dealing with various symptoms of mental health disorders to craft a genuine representation within their game. This devotion to collaboration is evident within the game's opening scene, as the very first person credited is Dr Paul Fletcher, a psychiatrist and professor of health neuroscience at the University of Cambridge. Dr Fletcher's expertise was sought-after early in the design process and continued throughout development [38].

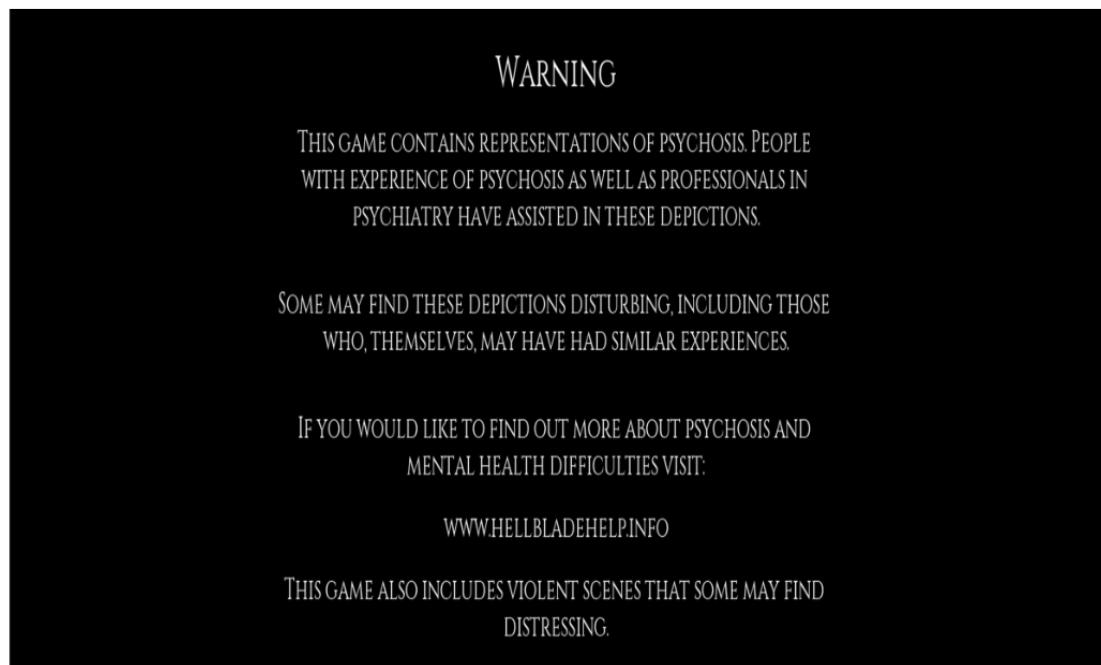
Dr Fletcher's own work with psychosis served as a source for Hellblade's focus on pattern-seeking behaviors and themes of isolation and stigma in Senua's past. This connection with Dr Fletcher along with the support of Wellcome Trust, a charitable organization dedicated to supporting projects devoted to improving global health, allowed Ninja Theory to collaborate further with other mental health professionals and service users via interviews and collaborative prototyping [47]. One key resource was Recovery College East, which is located in England. This is a small group of mental health practitioners and people dealing with mental health problems who willingly shared their own experiences, particularly various forms of visual hallucinations, and helped to playtest certain aspects of the game [41]. For audio hallucinations, a number of other experts, such as Dr Charles Fernyhough, were consulted. These consultations typically involved readings, research talks, playtesting, and prototyping [48]. In this way, Ninja Theory ensured that their game design decisions were being seen and revised based on experts' knowledge in these fields.

A common thread throughout every interview with experts during their work with Hellblade spoke to the problems associated with stigmatization of these symptoms and illnesses [47]. In response to Hellblade, one fan spoke to the game's impact [51]:

I had a psychotic break several years ago, my brother never understood. I overheard him say he was ashamed of me. After this game, he turned to me and said he was sorry. You got a message across that I never could.

The chance to collaborate with game developers on a project related to mental health was met with hopes of helping alleviate these stigmas. This level of research and expertise is particularly uncommon within commercially driven game design, yet helps to illustrate lead designer Tameem Antoniades' devotion to a respectful presentation of Senua's mental illness. This devotion is contextualized even further through the inclusion of a 25-minute video detailing the various research and resources Ninja Theory used to depict psychosis as well as resources for more information for those interested in learning more [38]. Ultimately, the inclusion of these contextual elements outside of the game itself work to change the frame of the gameplay experience toward one that is serious, respectful, and educational.

In an interview with PC Gamer, Ninja Theory's founder Tameem Antoniades noted the stress and sense of obligation he felt in attempting to successfully and respectfully depict symptoms of mental illness in a meaningful way [52]. Similar to Chapman and Linderoth's [8] educational framing, Hellblade is presented as a vehicle for awareness and destigmatizing mental illness. Hellblade and Ninja Theory's websites include various resources for players to learn more about mental illness and potential places to seek help. When loading the game, players are met with an initial warning message that explains the game's focus on psychosis, the use of experts to provide a faithful representation, and resources for anyone who wants to learn more (see Figure 8). By producing this information before a player can even reach the main menu, Ninja Theory is attempting to immediately downkey from the ludic frame of playing a game to emphasize the seriousness of the topic.

Figure 8. Opening warning screen for the game Hellblade (screenshot).

Even before the game's release, Ninja Theory's willingness to share their design experience through these developer diaries emphasized their hopes for Hellblade to respectfully present the realities of mental illness. These developmental diaries began as a chronicle and guide for other small teams of developers to independently create and publish a major commercial game. Given outside interest in Hellblade's depiction of mental illness throughout the game's development, these diaries and interviews also shifted toward a primer for how game developers can approach serious topics through collaboration with experts, prototyping with caretakers and those who have lived experience with these illnesses, and designing game mechanics that make these issues tangible.

Discussion

Principal Findings

In Ninja Theory's final developmental diary, the creators of Hellblade admitted to a growing sense of fear as they approached the game's release. Tameem Antoinades, the lead developer, and Melina Juergens, the actress for Senua, both openly admit dreading the idea that the game may, in some way, offend those dealing with psychosis or other forms of mental illness [41]. While much of the reception for Hellblade was positive, including five awards from the BAFTA Game Awards, it did not escape criticism for its use of mental illness within a game setting. Some commentators posited that Hellblade may have overstepped by gamifying aspects of psychosis, appropriating mental illness for commercial use, and even reinforcing myths about mental illness [43].

In this paper, we have argued that it is essential that we examine the design practices that encourage an increased empathetic understanding of people experiencing mental health disorders. Furthermore, we also argue that we must examine the design decisions that allow for a game to effectively represent mental illness within a larger-scale project, rather than a short game

designed solely for intervention. In order to do so, we conducted a case study that analyzes Hellblade and discusses the design processes of Ninja Theory. Hellblade is important because it is perhaps the best-reviewed and best-selling video game to attempt a well-researched and appropriate representation of mental health through the medium of digital games [13]. The results of this exploratory study shed light on how design practices can build upon collaboration between researchers and developers to present a successful and potentially helpful depiction of mental disorders.

Our analysis indicates that games should continue to approach depictions of mental health through collaborative design and prototyping with experts. In particular, researchers and game designers should begin working together from the earliest stages of development. Game design should be informed by a strong body of research when dealing with more serious topics, as Ninja Theory demonstrated by promptly seeking Dr Paul Fletcher's consultation. Perhaps more importantly, for the sake of serious games, researchers and practitioners must take an active role in game design as early as possible. This allows for innovation in design that can provide new forms of embodied experiences, which may help to promote empathy and awareness of mental health issues [51,52]. One perceived benefit of games with relation to mental health interventions is the ability to present new ways of engaging with users [17], but poor game design choices will usually result in poor outcomes [20]. Researchers must be willing to develop or work with game designers to create games that can not only successfully approach mental health topics, but also capitalize on the advantages inherent in using digital games. Knowledge of how games and their mechanics can be understood from both the ludic frame and possibly rekeyed toward a more referential understanding, as noted in our analysis of Hellblade, can facilitate a successful reception of a commercial video game that addresses mental health.

First, transparency is essential. Ninja Theory was very transparent regarding their intentions to make an accurate and empathetic portrayal of mental illness via their development diaries, documentaries, and the warning screen that welcomed new players. Second, input from key stakeholders is also essential. Ninja Theory's consultation of mental health professionals, scientists, and those with various mental illnesses throughout the development of Hellblade resulted in an accuracy and educational legitimacy rarely seen in mainstream video games.

Finally, technological accuracy that leverages the affordances of video games can help convey mental illness in new and effective ways. Ninja Theory's use of technologies, such as motion capture and binaural sound recordings in an attempt to provide an empathetic experience similar to the lived experience of those suffering with mental illness, is needed to help destigmatize mental health. These downkeying design decisions culminated in a game that was well-received not only by reviewers, but also the gaming public, going on to sell millions of copies while sparking new conversations and understanding around mental health.

While Hellblade is one of a select few commercial games to put so much reliance on collaboration with researchers and professional advisors, serious game design relies on developers and researchers working together to create a beneficial experience [53]. As digital games have grown with technology and culture acceptance, the ability to portray more realistic content has resulted in an increased desire for fidelity in games. Researchers and professional advisors as collaborators have become common for games that are providing increasingly more realistic depictions of the world around them [54]. Although it is unlikely that large-scale game development will have a major shift toward better-informed, less stereotypical depictions of serious topics, Ninja Theory has shown that more conscientious efforts can be made in the AAA game development space and

be successful. As the technological affordances of games continues to grow and games challenge notions of play, experience, and art, developers will need expert advisors to create these experiences. Likewise, willing mental health practitioners and researchers should be open to consult on these larger, commercial projects to ensure a more sincere, potentially empathetic depiction of those suffering from mental ill-health.

Limitations

Though this study provides an important first step toward understanding the design and impact of one of the more interesting cases of digital games addressing mental health, it is not without several limitations. First, this work is largely exploratory. Future studies may wish to more systematically examine the impact of Hellblade via online forums such as Reddit or Discord. Second, while Hellblade provides an incredibly important case study for both game designers and psychological practitioners, it is still a single case study. Future studies may wish to conduct a frame analysis and community-impact assessment via more case studies to better understand how the framing of games helps benefit games' attempts to overcome the stigma associated with depictions of more serious topics.

Conclusions

Hellblade provides numerous avenues for interesting research questions. This paper argues that the framing and design decisions in Hellblade allow it to successfully tackle the potentially troubling topic of mental illness in a video game. For us to adequately explore the capabilities of commercial games that deal with controversial topics, we must examine not only the games themselves, but the design processes behind them. Our hope is that this paper will act as a stepping stone for further research in two ways: first, by illustrating the value of a single game case study, from design to reception, and second, to inform future research possibilities related to games dealing with serious topics such as Hellblade.

Conflicts of Interest

None declared.

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Abbreviations

BAFTA: British Academy of Film and Television Arts

Edited by M Birk; submitted 05.10.18; peer-reviewed by M Lucassen, J Newell; comments to author 08.11.18; revised version received 07.02.19; accepted 02.03.19; published 18.04.19.

Please cite as:

Fordham J, Ball C

Framing Mental Health Within Digital Games: An Exploratory Case Study of Hellblade

JMIR Ment Health 2019;6(4):e12432

URL: <http://mental.jmir.org/2019/4/e12432/>

doi:10.2196/12432

PMID:30998224

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Viewpoint

The Potential of Game-Based Digital Biomarkers for Modeling Mental Health

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Abstract

Background: Assessment for mental health is performed by experts using interview techniques, questionnaires, and test batteries and following standardized manuals; however, there would be myriad benefits if behavioral correlates could predict mental health and be used for population screening or prevalence estimations. A variety of digital sources of data (eg, online search data and social media posts) have been previously proposed as candidates for digital biomarkers in the context of mental health. Playing games on computers, gaming consoles, or mobile devices (ie, digital gaming) has become a leading leisure activity of choice and yields rich data from a variety of sources.

Objective: In this paper, we argue that game-based data from commercial off-the-shelf games have the potential to be used as a digital biomarker to assess and model mental health and health decline. Although there is great potential in games developed specifically for mental health assessment (eg, Sea Hero Quest), we focus on data gathered “in-the-wild” from playing commercial off-the-shelf games designed primarily for entertainment.

Methods: We argue that the activity traces left behind by natural interactions with digital games can be modeled using computational approaches for big data. To support our argument, we present an investigation of existing data sources, a categorization of observable traits from game data, and examples of potentially useful game-based digital biomarkers derived from activity traces.

Results: Our investigation reveals different types of data that are generated from play and the sources from which these data can be accessed. Based on these insights, we describe five categories of digital biomarkers that can be derived from game-based data, including behavior, cognitive performance, motor performance, social behavior, and affect. For each type of biomarker, we describe the data type, the game-based sources from which it can be derived, its importance for mental health modeling, and any existing statistical associations with mental health that have been demonstrated in prior work. We end with a discussion on the limitations and potential of data from commercial off-the-shelf games for use as a digital biomarker of mental health.

Conclusions: When people play commercial digital games, they produce significant volumes of high-resolution data that are not only related to play frequency, but also include performance data reflecting low-level cognitive and motor processing; text-based data that are indicative of the affective state; social data that reveal networks of relationships; content choice data that imply preferred genres; and contextual data that divulge where, when, and with whom the players are playing. These data provide a source for digital biomarkers that may indicate mental health. Produced by engaged human behavior, game data have the potential to be leveraged for population screening or prevalence estimations, leading to at-scale, nonintrusive assessment of mental health.

(*JMIR Ment Health* 2019;6(4):e13485) doi:[10.2196/13485](https://doi.org/10.2196/13485)

KEYWORDS

digital games; digital phenotyping; mental health; computational modeling; big data; video games; biomarkers

Introduction

Playing games on computers, gaming consoles, or mobile devices (ie, playing digital games) has become a leading leisure activity of choice, with consumer spending on digital games exceeding US \$134 billion [1] and outranking spending on music and movie tickets combined [2-4]. There are approximately 200 million gamers in North America, 354 million in Europe, 330 million in the Middle East and Africa, 234 million in Latin America, and 1.2 billion in Asia, which represents between 55% (Latin America) and 67% (North America) of the global online population [1].

When people play commercial digital games, they produce a lot of data—data that are not only related to play frequency, but also include performance data reflecting low-level cognitive and motor processing; text-based data that are indicative of affective state; social data that reveal networks of relationships; content choice data that imply preferred genres; and contextual data that divulge where, when, and with whom the player is playing. The game-based data produced by players are a rich source of information with the potential to be used for the assessment and modelling of health and health decline. In this paper, we argue that *game-based data from commercial off-the-shelf games can be used as a digital biomarker to assess and model mental and cognitive health and health decline*.

Assessment for mental health is performed by experts using interview techniques, adjacent to questionnaires and test batteries, and following standardized manuals [5]. However, there is interest in finding behavioral correlates that are predictive of mental and cognitive health and can be used for population screening or prevalence estimations [6]. When behavioral correlates are already known, researchers can develop *custom games* that are intended to place a player in a situation and monitor their response, response time, or performance. There are several examples of custom assessment games that have been developed to assess aspects of physical [7] and mental [8] health. For example, Sea Hero Quest [9], an internet game to track and assess dementia through navigational skills, can assess a large number of people very quickly, providing huge data sets with information on health decline over time for demographic groups and individuals.

Although there is great potential in custom games for assessment, we believe that the activity traces left behind by *natural interactions with digital games* can be used as a *digital biomarker* of health and health decline. As such, in this paper, we focus on the less-studied topic of data that can be gathered from “in-the-wild” gameplay of *commercial off-the-shelf games* and how natural gameplay data can yield insights into a person’s mental health.

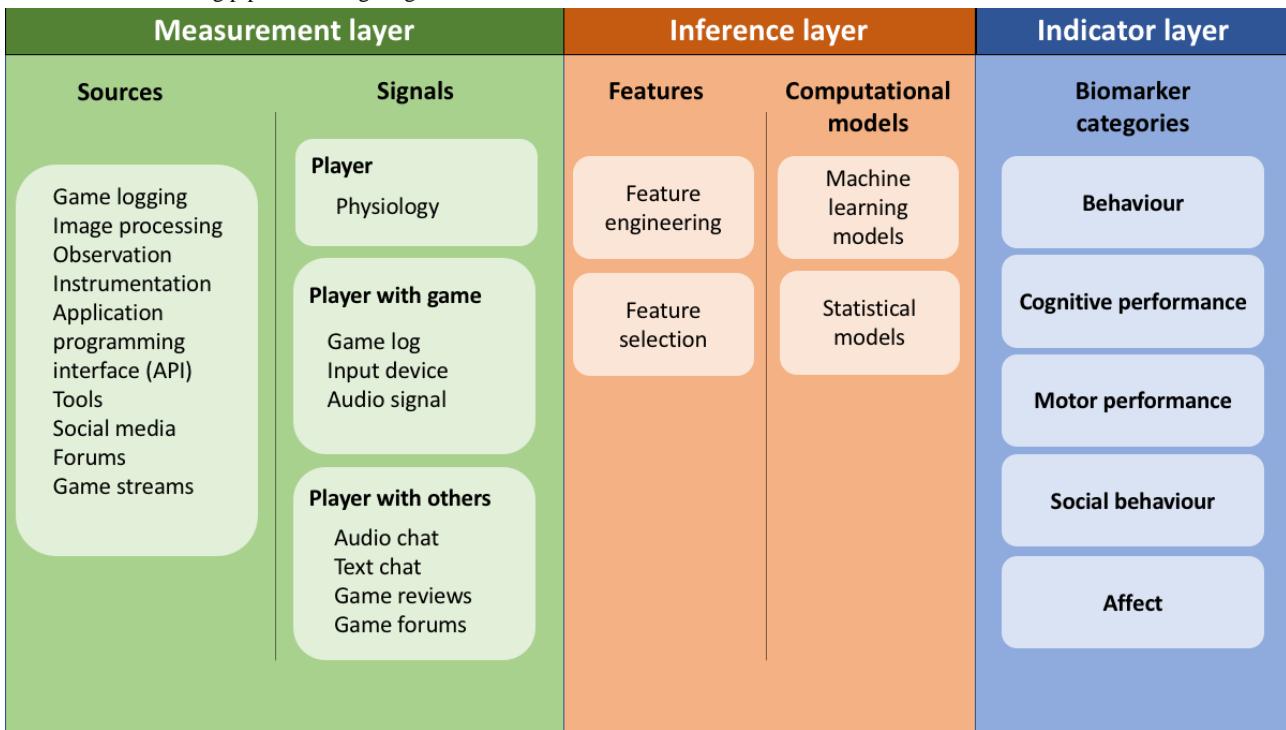
Furthermore, although there are sources of data from games that may inform physical health or health decline (eg, identifying tremor development in patients with Parkinson disease from mouse kinematic data in a targeting-based game), we focus on the potential of game-based biomarkers in the context of *mental and cognitive health*. We consider the scope of mental health as defined by the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition [5], which includes assessment criteria for mental disorders including developmental disorders (eg, autism spectrum disorder), neurodevelopmental disorders (eg, Parkinson disease), anxiety-related disorders, and depressive and personality disorders.

We first present a primer on games, the types of data, and the sources of data that are generated from natural digital gameplay. We then provide a description of five categories of digital biomarkers that can be derived from game-based data, including behavior, cognitive performance, motor performance, social behavior, and affect. We end with a discussion on the ethics, limitations, and potential of data from commercial off-the-shelf games for use as a digital biomarker of mental health.

Primer on Games and Game Data**Overview**

Digital game play yields a variety of data that can be used to create novel digital biomarkers for health. Commercial games, as well as those created for research purposes, embed logging software that tracks interaction with the game. Game analytics—the tracking, analysis, and visualization of game-related data—is an important tool used by game designers, developers, and studios to inform about player experience [10-12]. Used both when games are under development as well as after release, game analytics leverage a variety of data types, the most common of which are player-generated data from interaction with the game [13].

To understand how data gathered from gameplay can be used as a digital biomarker, we describe a standard machine learning pipeline [14]—starting with observations (eg, game log data), progressing to feature extraction based on the observed signals, and ending with predictions (ie, digital biomarkers)—in the context of gameplay. *Figure 1* demonstrates this pipeline in the context of gameplay data and biomarkers for mental health. In the *measurement layer*, raw signals are gathered from various sources. In the *inference layer*, features are extracted and computational models are applied in an iterative process [14]. This computational modeling process results in final predictions, which are shown in the *indicator layer*. In this section, we briefly describe the measurement and inference layer; the next section focuses on the indicator layer and the five categories of game-based digital biomarkers that we propose.

Figure 1. Machine learning pipeline for digital game-based biomarkers.

Measurement Layer

The first stage of generating digital biomarkers from game data is measurement of the data. Game data are available from a variety of sources, including the player, the player's interaction with the game, and the player's interactions with others within and around the game. Although the biggest source is derived from the player interacting with the game, data from the players themselves and from the players' interactions with others can also provide value by building on research advances in digital biomarkers from nongame sources, for example, within the fields of affective computing [15] and natural language processing [16]. However, data from the interaction with the game is a novel source of signal with great potential for inference, but one that requires future research to interpret and understand.

Player Data

Player data are gathered from the players themselves. Signals such as heart rate, electrical activity of the brain, and galvanic skin response have all been explored in game contexts to infer player experience [17,18]. Although physiological data may not be easily accessible at the resolution gathered by medical-grade devices, novel methods of gathering physiological data in situ continue to emerge; sensors are embedded into game controllers for use in biofeedback games [19], to engage spectators [20], or simply as an innovative game input [21]. Further, physiological signals such as heart rate [22], blink rate, and facial expressions [23] can be derived from webcam-based signals along with facial expressions.

Player Interaction Data

Data from a player's interaction with the game is primarily gathered from the game logs and includes high-level data (eg, number of active daily players) and low-level data (eg, each

bullet fired in a shooting game, as was done in Gears of War 3 [Microsoft Studios, Redmond, WA; 2011]. Game developers insert logging software that tracks interaction with the game, and common metrics that derive from player interaction data include usage data (eg, login frequency, play time, and role choices), performance data (eg, win/loss data, death rate, kill rate, and score), and social data (eg, teammate records). Researchers can also use low-level input device data to infer information about the player. For example, the motion kinematics (eg, characteristics of the velocity or acceleration of a movement [24]) of the mouse or thumbstick movements could be used to infer information, or the pressure exerted on a screen in a touch-based game [25] or on the buttons of a game controller [26] could provide information on the experience state of the player. Finally, researchers could leverage the audio signals used in many online games to infer information; for example, environmental noise sensed through the microphone and coughing or respiration patterns of the player [27] could provide a rich source of data.

Data from Players' Interactions with Others

Data from a player's interaction with other players, spectators, or fans yield signals that are social in context, but can be used in the development of individual digital biomarkers. For example, text-based data from in-game chats could be analyzed using a keystroke dynamics approach, which leverages the timing and variability in typing rhythms (analyzing both time spent dwelling on keys and moving between keys, known as flight time) of common two-letter combinations (digraphs) and three-letter combinations (trigraphs) to infer the emotional state [28]. Further, sentiment analysis of social media posts for detecting suicidal ideation [29] could be modified and applied to text data generated in and around games. Text data are available from various sources, including in-game chat logs, game reviews, and texting about games on platforms such as

Discord (Discord Inc, San Francisco, CA; 2015). Audio chat between players also generates a valuable signal; building on previous work that determines the emotional tone of the speech signal [30] might prove useful in the context of mental health modeling.

Gathering Game Data

Game data can be gathered from a single game; the majority of mobile games, as well as console games and computer games, record login and performance data as part of their game analytic engines. Much of these data are accessible to researchers through game application interfaces (APIs), including for the multiplayer online battle arena League of Legends (Riot Games, West Los Angeles, CA; 2009) [31], which boasts of 100 million active players monthly, or for the massively multiplayer role-playing games EVE online (CCP Games, Reykjavik, Iceland; 2003) [32] and Guild Wars 2 (ArenaNet, Bellevue, WA; 2012) [33]. However, in the context of modeling mental health, the aggregate play across game genres and titles may be more relevant.

Although aggregate usage data can be difficult for health researchers to gather (eg, PlayStation account data are not publicly accessible), there are methods by which overall play data can be gathered. Specifically, some game publishers provide an API to their suite of games; for example, battle.net features an API for a collection of games developed by Blizzard Entertainment [34] that includes the massively multiplayer role-playing game World of Warcraft, the role-playing game Diablo III, and the real-time strategy game Starcraft II, which is a popular title in the competitive electronic sports (e-sports) domain. Steam is the largest online portal for game play on computers (as opposed to dedicated gaming consoles), which features thousands of games and 100 million members; Steam has an API [35] that gives access to usage data and much more. Further, some data are available through other game portals such as Google Play [36] or Facebook Game Services [37], or through APIs that interface with games servers, such as the Sponge API [38] for the popular construction game Minecraft (Microsoft Studios, 2014). Further game streaming platforms (eg, twitch.tv) have recently been investigated as a potential source of data for research [39]. APIs generally provide limited access to the vast data available to the game publishers themselves, and collaborating with game companies to access richer datasets would be a valuable approach.

Inference Layer

Computational approaches used to make predictions in data science derive inferences from features that are extracted from signals, which are observed in the previously described measurement layer. The quality of predictions derived from machine learning approaches (including, for example, deep learning [40] and clustering [41]) depends greatly on the quality of the features that are extracted from the signal. Selecting features and creating new ones [42] require expertise in the signals, their meaning, and the mathematical and computational approaches that are used in data science. Selecting and creating meaningful features (known as feature engineering [42]) are challenging and are the point in the pipeline where the expertise of the researcher makes a difference between a black box

machine learning model (which blindly applies prediction algorithms to extracted data) and an informed expert-driven model that is built on theory, hypotheses, and iterative testing [42].

Although feature selection for some types of data is already well established in the literature (eg, sentiment analysis of text excerpts using natural language processing [16]), there are still open questions on how to best characterize signals derived from novel data sources such as video games. Game-based signal data require specific considerations, because players interact with the games on several levels (eg, explicit interaction with the game and implicit interaction around the game on third-party channels). A full description of the inference layer (or the machine learning approaches that are used within it) is beyond the scope of this paper; however, there are many standard resources to guide researchers who wish to leverage game-based signals to derive digital biomarkers of mental and cognitive health in the process of feature creation, feature selection, and machine learning [40,42-44].

Game-Based Digital Biomarkers

Indicator Layer

The data generated by digital games for player experience understanding can be used to extract features, from which researchers can predict characteristics of a player that may inform models of mental health. This prediction is part of the *Inference Layer* in Figure 1. In this section, we describe five categories of digital biomarkers for health that we feel can be extracted from game-based data—behavior, cognitive performance, motor performance, social behavior, and affect. In each section, we describe why this source of data is important for mental health modeling, the game-based sources from which it can be derived, and relevant literature that associates it with mental health.

Behavioral Biomarkers

Behavioral biomarkers refer to metrics that are derived from the act of playing (eg, time spent playing and play frequency), high-level behaviors of players within a game (eg, role choices and play styles), and lower-level behaviors that reflect interaction with the game (eg, gaze fixation and low-level interface interactions).

Dosage as Behavior

In the context of health, frequency is often referred to as *dosage* and reflects both the overall engagement of the player with the game system and more complex patterns of engagement. For example, researchers may wish to know simply how much time is spent daily playing digital games (ie, quantity), but may also be interested in when gaming sessions occur, how long gaming sessions last, how much variability (ie, predictability) there is in the overall patterns of play—referred to as *entropy* in research on the computational analysis of human behavior [30]—or the context in which play is occurring (eg, where, with whom, and on which device).

Usage data, in terms of logins and play frequency, are available through in-game logging. There has been some research on the

relationship between game play dosage and mental health from the perspective of addiction research. For example, research on pathological gaming has used definitions of addictive behavior to describe problematic or obsessive video game playing [45]; however, associations between excessive play and psychosocial health have not been consistently evident, even among gamers classified as “addicted” [46].

Although there may be meaning inferred from the overall dosage of play, there is likely even more richness in the patterns of play. For example, Lemola et al [47] showed that habitual computer game playing at night (between 10 pm and 6 am) is associated with increased depression scores, even after controlling for the total time played, suggesting that the timing of play could be predictive of mental health (eg, sleep-wake disorders). Further, research suggests that the context of play can moderate the associations of gaming behavior and well-being [48]. In-depth analysis of the contextualized patterns of play may indicate mental health; by considering variability in the timing, device, or location of play, there is likely predictive potential in behavioral data beyond dosage estimation.

Content and Preference Choices as Behavior

What we play and how we play tell us about who we are. Do we prefer games with complex, visually stunning, narrative heavy, open-world play (eg, *Skyrim*); games that gain their depth from complex interdependent choices (eg, *SimCity*); or games built around challenging puzzles (eg, *The Witness*)? When we play a specific genre, how do we play: Do we prefer to investigate every aspect of an environment or move through in-game quests quickly? When playing with others, do we play a supportive role (eg, healer) or do we prefer to play characters that drive progress (eg, damage dealer)? Do we play multiplayer games at all or do we prefer single-player games? Do we prefer to play games that are easy to progress through or do we choose ultra-hard modes to challenge our own abilities? There are several ways in which we can differentiate between different types of players [49], and the consideration of individual preferences that are observed through behavior may prove useful for identifying patterns related to mental health.

Research on predominantly male players who display problematic online play behavior (for example, play for long hours, aggressive behavior when forced to stop playing, and financial struggles as a result of play) shows that social anxiety is most prevalent among massively multiplayer role-playing game players and lowest for first-person shooter players [50], suggesting that genre preference could be an indicator of mental health. Further, self-discrepancy (ie, how well who we are aligns with who we want to be) research has shown that people with low mental well-being ascribe more desirable attributes (eg, kindness and creativity) to a self-created character than to themselves [51]. Finally, content or preference choices that deviate from predictable patterns may indicate changes in life circumstances (eg, change in relationships or work status) that could contextualize other observed differences, which may help better predict and assess mental health.

Low-Level Game Interaction as Behavior

Play behavior is the composite of myriad low-level interactions, such as selecting a menu item or checking the health bar [52]. Low-level interactions that create events, such as firing a bullet, can be measured by including the logging code in the game software. Although low-level interactions such as clicking a button to fire a shot carry a signal, there is additional information in the interactions with the system itself (eg, moving the mouse) that precede the final event (ie, shooting). For example, we can learn about the visual cues a person responds to by analyzing eye gaze patterns or investigating mouse movement patterns during inventory search behavior. There is reason to believe that gaze patterns might help indicate mental health; for example, saccadic gaze behavior has been used extensively in the study of schizophrenia and bipolar affective disorder [53-55].

Measuring low-level interactions such as mouse movements or eye gaze requires either special equipment (ie, eye tracker) or needs to be implemented during development (ie, cursor logging software). Assessing low-level interactions during play of off-the-shelf games is challenging, because the game code cannot be modified to measure input (eg, click behavior), and bringing third-party equipment (eg, gaze tracking) to the user is logistically challenging and would influence play behavior. To overcome these challenges, researchers must determine ways to measure the signals unobtrusively. For example, research on older adults has leveraged image processing to investigate measuring cognitive performance through the card game Klondike Solitaire [8]. Although measuring low-level interactions is challenging outside of the laboratory context, there are many open questions about which player characteristics can be inferred. Does frequent non-goal-directed click behavior indicate nervousness? Can looking up the same in-game hint (eg, a password on a note in the inventory) multiple times indicate forgetfulness? Are quick changes in gaze fixation indicative of cognitive performance and information processing? The behavior that we show unconsciously might be hardest to access, but because implicit behaviors are difficult for players to influence, they have huge potential for inferring mental health.

Cognitive Performance Biomarkers

Many games incorporate cognitive challenges such as memorizing sequences that rely on short-term memory (eg, *Shadowrun*), making decisions under certain conditions (eg, first-person shooter games), recognizing patterns (eg, *Bejeweled*), or analyzing complex information (eg, *SimCity*). Game difficulty can generally be adjusted (or adjusted dynamically), so that the cognitive performance required to succeed is well matched to the player’s abilities [56]. When players tackle cognitive challenges in games, they generate performance data such as the number of attempts, time spent to overcome a challenge, reaction times to stimuli, or the highest level they were able to complete without failure. There are a variety of game sources from which one can identify and measure cognitive performance in games. Leaderboards and achievements are aggregated indicators of game performance [57]: Leaderboards provide a high score in comparison with other players or personal bests, whereas achievements represent specific challenges a player has overcome, such as a challenging

attack sequence, collecting a specific set of items, or taking out a certain number of enemies. Other performance indicators are ranks or titles of a player (eg, Platinum or Diamond rank in League of Legends), the rarity of owned items (eg, Stunted Direhorn in World of Warcraft), or a player's player-vs-player statistic; however, these performance indicators may be more related to time investment than to the underlying cognitive ability.

To access cognitive performance biomarkers through games, we can look to specific game mechanics that map well to cognitive abilities. For example, the number of dodged hits in a fighting game is indicative of a player's ability to anticipate and react, a difficult skill prevalent in elite athletes [58] and reduced in people with depression [59]. The turn-based role-playing game Shadowrun: Hong Kong (Harebrained Schemes, Seattle, WA; 2015) features a two-staged hacking challenge that requires players first to repeat an increasingly difficult sequence of numbers—a common task for assessing short-term memory [60]. The puzzle game The Witness (Johnathan Blow, 2016) presents challenges that require spatial rotation and abstract thinking (eg, one puzzle requires players to first identify the path through a three-dimensional maze and to then redraw the pathway on a two-dimensional input device).

Cognitive performance is an indicator of many mental health issues such as depression, anxiety, Alzheimer disease, Parkinson disease, or attention-deficit disorders [5]. People experiencing symptoms of depression, for example, show differences in executive functioning, sustained attention, and memory [61,62], which debilitates a player's ability to play games that rely on these cognitive systems. Digital assessment software such as Cambridge Neuropsychological Test Automated Battery [63] have shown that many of the resulting divergences in cognitive performance related to mental health can be detected through simple tasks that are likely mirrored in digital games. Further, performance in games can be used to naturally assess cognitive abilities such as attentional [64] or visuospatial [39] biases.

Motor Performance Biomarkers

Most games require motor input to interact with them. The input device used in games varies, but is generally comprised of touch input (ie, in mobile games); mouse and keystroke input (ie, in desktop games); and controller input, which consists of buttons to press and thumbsticks or mini joysticks to control (ie, in console games). Gaming consoles additionally sometimes have cameras that capture the user's movements (eg, Microsoft Kinect and Sony PlayStation Camera). The level of motor interaction needed to play a game varies widely: Many games require complex sequences of input (eg, Street Fighter), whereas others take a very simple motor action, but require it to be completed quickly and repeatedly (eg, clicking in Cookie Clicker) or in combination with cognitive choices (eg, keystrokes in Starcraft).

Motor data in games can be gathered through the types of sources listed in the Measurement Layer section; however, researchers interested in millisecond accuracy of motor input can also write third-party logging software that captures interaction with the device [28]. Leveraging research in human-computer interaction, the kinematics of mouse movements (eg, velocity, acceleration, and percentage of time

spent decelerating [24]) or the variability in mouse kinematics could be indicative of mental or cognitive health. Further, keystroke dynamics (ie, the low-level timing of typing actions) have been used to predict the stress of the typist [28,65], which could potentially inform stress-related mental health disorders. Game console cameras could be used to detect players' movements, which has been associated with various emotional states [66] that might be indicative of mental health or health decline. In addition, the pressure exerted on gaming controls has been linked to frustration for both button presses [26] and touch input [25], which provides relevance in terms of players' resilience to stressful stimuli. Leveraging an entire touch gesture can also provide interesting signals; for example, in Fruit Ninja gestures, timing and pressure features were used to discriminate low and high arousal and valence, both of which are relevant in the context of mental health [67].

Motor performance data have particular potential as a digital biomarker for neurodegenerative diseases such as Alzheimer, Parkinson, and Huntington diseases, which are characterized, in part, by psychomotor decline [5]; monitoring patients' motor performance in games over time could reveal valuable information about the rate of disease progression.

Social Biomarkers

Social rather than individual play is quickly becoming the dominant form of digital game play: Gamers spend an average of 6 hours/week playing with others online and 5 hours/week playing with others in person [68]. When people play digital games with others, they generate social behavioral data (for example, with whom are they playing and what role did they take in that interaction) as well as social communication data (for example, what words were exchanged and in which channels).

In terms of social behavior, some multiplayer game APIs (eg, League of Legends) provide information on who people were playing with; more subtle cues of social interaction, such as being part of a guild (eg, in World of Warcraft), the number of social contacts as compared to population averages, choices of predefined texts (eg, "good game") sent (eg, Hearthstone), or the ratio of the type of games played (eg, single-player games vs team-based games) could be indicative of mental health. Communication-based game data can be drawn from primary sources such as in-game chats, forum posts, or voice-over-internet protocol applications (eg, Discord or Team Speak) and secondary channels such as social media (eg, Reddit, Twitter, and Facebook) or video commentary (eg, Twitch and YouTube). Natural language processing approaches allow researchers to identify word categories used and gives insights into the way we use language, for example, the ratio of self-references to social references in written texts [69]. Further, sentiment analysis allows us to gauge the valence of an attitude (ie, positive, neutral, or negative) toward a specific topic. Applied to written text or spoken words from game-based sources, these techniques provide insights into how users present themselves when interacting with others.

Social behavior is an important indicator in many mental health disorders and therefore important for health modelling. People suffering from depression, for example, show higher use of

negatively valenced phrasing [70], a tendency to use more self-referencing words such as “I” or “me” [70,71], and use of fewer emoticons [72]. It also matters with whom they have contact; research on game play suggests that playing socially may be linked to well-being [73-75]. In game play, this might be reflected in the consistency with which we play with other specific players.

Although online communication has been found to negatively affect one’s well-being despite its social nature [76], the issue is more complex and requires nuanced consideration of the usage purpose, context, and individual differences [77,78]. A large proportion of research on digital biomarkers to predict mental well-being has focused on depression and anxiety; however, psychiatric research [6] suggests that the range of mental illnesses reflected in digital traces also applies to mental illnesses such as borderline disorder or bipolar disorder. Bipolar disorders might, for example, be reflected in increased parallel conversations, high levels of text output, and fluctuation of social relationships during up swings, while down swings would be characterized by disengagement and negatively valenced communication patterns.

Affective and Emotional Biomarkers

Quantifying the emotional state of the player has been of interest to affective computing researchers and game designers who wish to understand or improve player experience [79]. Researchers detect affect using physiological signals [80], behavioral signals (eg, posture [81]), speech signals [30], eye gaze and fixation data [82], and sentiment analysis of text data [69].

Within game play, sources of measurement for affective biomarkers include in-game chat (text data), in-game audio for communication during online play, audio during streaming (eg, on twitch.tv), and the input data discussed in relation to motor performance biomarkers. In the game, there are also game-based text data that can be gathered from forums and chat platforms (eg, Discord) as well as game-related posts on social media. Physiological data are not necessarily straightforward to gather in the context of commercial off-the-shelf computer game play; however, recent advances in sensing over a distance, such as heart rate [83] or facial expression [84], gathered via webcam and increased prevalence of physiological input devices in commercial games [21] suggest that third-party logging could be used to link physiological sources with game APIs.

Understanding the emotional experience of players is of particular interest in the context of mental health, as many prevalent mental health issues (eg, depression and generalized anxiety) are closely tied to emotional wellness or can be predicted by aberrant responses to specific stimuli (eg, posttraumatic stress disorder) or in-game self-representations (eg, anorexia nervosa). For example, eye gaze patterns have been used to characterize individuals with various depression and anxiety disorders [85]. Impulse control and conduct disorders are characterized by difficulty in the self-regulation of emotions and behaviors [5], whereas emotional self-regulation difficulties are also characteristic in some developmental disorders (eg, autism spectrum disorder [5]).

Discussion

Overview

Digital biomarkers are increasingly being used to indicate potential mental health issues [86-89]. Computational phenotyping—the digital quantification of disease phenotypes—extracts the observable traits (eg, morphology, development, and behavior) of an entity from data sources that can be complex and heterogeneous. In this paper, we propose using data generated from natural play of off-the-shelf digital games (ie, *digital biomarkers*) as one such complex data source. Five categories of game-based digital biomarkers—behavior, cognitive performance, motor performance, social behavior, and affect—were argued to include observable traits that could be indicative of mental health or health decline.

Multiple Data Sources and Sensor Fusion

Each of the five described digital biomarkers mentioned has the potential to indicate mental health or illness; however, it may be in their combination that the true power of game data as a digital biomarker of mental health can be seen. Further, combining game data with other observable traits derived from smartphone data (eg, geolocation, accelerometer, and Bluetooth devices), sentiment from social media (eg, Google search, Reddit, Twitter, and Facebook), or physiology from integrated trackers (eg, Fitbit) may allow for rich and predictive models of mental health that leverage sensor fusion (ie, the use of multiple sources of data in combination [42]) for accurate modeling. We do not suggest that game-based data can be the sole biomarker for mental health in isolation, but that considering its inclusion in a suite of behavioral indicators may improve modeling in the context of mental and cognitive health.

To interpret data generated by different sources, data collected from a large sample with the intention to create a norm has several advantages. Sea Hero Quest [90], for example, generates insights into humans’ general capability to navigate and then identify behavior that deviates from norms as an indicator for early onset dementia. Establishing norms in game-based biomarkers is a complex undertaking but may have value when looking for deviations from norms as an indicator of mental health decline.

Limitations

There are various factors that may compromise the predictive potential of game-based digital biomarkers. For example, pharmaceutical treatment or remission through therapy can interfere with accurate prediction: In terms of impulsivity, depressed people in remission are often grouped with control subjects rather than depressed participants [91], whereas in terms of visual acuity, depressed participants, regardless of the pharmaceutical treatment, are differentiated from the control group, but not each other [92]. As use of game-based biomarkers is a novel approach, researchers must carefully establish whether and how treatment or remission affects the behavior underlying the biomarker. Further, as with all digital biomarkers derived from in-the-wild data sets, events unrelated to the characteristic being predicted can greatly interfere; for example, a player who is on holiday, has a cold, has an upcoming deadline, or is

experiencing harsh weather can exhibit behaviors that appear to be erratic, but which are driven by circumstance and not mental health.

Another limitation is that game-based biomarkers will only be relevant for assessment of populations who play games. People of all ages play games; however, preferences for various genres and platforms change with age [93]. A greater proportion of people of color in America play games, identify as gamers [94], own a gaming system, and form a faster-growing market than their white non-Hispanic counterparts [95]. In addition, almost half of all gamers self-identify as female; however, social gaming and mobile gaming are more important to female gamers than male gamers [96]. Demographic factors will need to be accounted for in any model of mental health built on game-based biomarkers. Finally, research on game-based biomarkers is in its early infancy: In this paper, we hypothesize that the potential biomarkers are based on existing scientific literature; however, significant research is needed to demonstrate the efficacy of game-based biomarkers and to identify specific game-based biomarkers for specific groups of mental health disorders.

Ethics, Privacy, and Legal Use of Game Data

The use of data derived from digital sources is part of a larger discussion [97-99]; as with all digital data, game-based biomarkers require consideration for topics such as inferring identity, communicating mental health assessment, privacy of in-game conversations, and legality of gathering data unobtrusively.

Rare events in game-based data (eg, a difficult-to-unlock achievement) allows for the identification of individual players. As a result, researchers need to consider information reported on their players. When working with public players such as e-sports athletes or streamers, the in-game identity can be publicly linked to the actual identity of a player, which therefore requires considerations for privacy.

Technologies such as Mindstrong Health Services [100] or Facebook's Suicide detection [101] show how data gathered from digital sources can be used to infer mental health and reach out to individuals who are at risk. Game-based biomarkers could result in similar services. However, communicating detected potential mental health issues might have negative consequences for users; for example, it is unclear what the consequences are of false positives (ie, a player being urged to seek help when there is actually no issue at all). Researchers need to consider the potential consequences of reporting mental health to players and the methods by which they communicate with players about the detected mental health issues.

Forums, in-game chats, and game streams require extra attention when analyzed, because users do not intend to have their information stored and may use phrasing and communication

patterns that misrepresent conversations out of context. Consent to allow researchers to monitor conversations needs to be given explicitly, and player-initiated removal of unwanted data from further storage (eg, the use of a derogative term) requires consideration.

In addition to standard ethical considerations of data-driven inference, game-based data have characteristics that require special attention. First, the expectation that mental health could be inferred from a player's pressure profile of a button press during game play is lower than that from explicitly posted texts about suicidal ideation on social media platforms [101,102]. Players should be clearly notified of the implications of implicit assessment from natural in-game behaviors that are, in the player's view, unrelated to mental health. Further, extensive play for the purposes of assessment should not be a "slippery slope" into pathological play behaviors. Second, players often behave differently in games by enacting fantasies [103], trying out different personalities [104], or behaving in ways congruent with gameplay, which are incongruent with out-of-game expectations, such as acting violently or ultra competitively. Applying value judgements from models of behavior generated out of games may not apply within games and could increase the risks of false positives if not properly considered.

Conclusions

Mental illness has become a major disease burden globally: Depression is currently the leading cause of disability worldwide [105]. Untreated mental illness has serious consequences; the estimated US \$2.5-8.5 trillion globally in lost output attributed to mental, neurological, and substance use disorders is expected to almost double by 2030 [106]. In addition to these financial costs, people experience costs to their well-being that range from a lower quality of life [107] to a loss of life [108]. The emergence of smartphone and wearable devices has begun to show promise for the assessment of mental health, for example, for real-time assessment of suicidal thoughts [109] or acute phases of psychosis among people with schizophrenia [110]; however, there is additional work to be done before researchers can reliably use game-based biomarkers to predict a decline in a person's mental health, such as the onset of a depressive episode, the progression of dementia, or behavioral changes that are related to social anxiety.

In this paper, we argued that owing to the prevalence of digital game play, there are several untapped sources of data, including behavior, cognitive performance, motor performance, social behavior, and affect. Further, we proposed that due to existing statistical associations between these five game-based digital biomarkers and mental health, there is untapped potential in game data for computational modeling that predicts mental health and mental health decline.

Acknowledgments

We thank the Natural Sciences and Engineering Research Council of Canada, the EWR Steacie Memorial Fellowship, and the Saskatchewan-Waterloo Gamers User Research (SWaGUR) training program for the funding, and the Interaction Lab at the University of Saskatchewan and the Eindhoven University of Technology for support.

Conflicts of Interest

None declared.

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Abbreviations

API: application programming interface

e-sport: electronic sport

Edited by J Torous; submitted 24.01.19; peer-reviewed by M Colder Carras, O Danilina, A Korchi, MS Aslam; comments to author 14.02.19; revised version received 11.03.19; accepted 11.03.19; published 23.04.19.

Please cite as:

Mandryk RL, Birk MV

The Potential of Game-Based Digital Biomarkers for Modeling Mental Health

JMIR Ment Health 2019;6(4):e13485

URL: <http://mental.jmir.org/2019/4/e13485/>

doi: [10.2196/13485](https://doi.org/10.2196/13485)

PMID: [31012857](https://pubmed.ncbi.nlm.nih.gov/31012857/)

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Original Paper

Transdiagnostic Mobile Health: Smartphone Intervention Reduces Depressive Symptoms in People With Mood and Psychotic Disorders

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Abstract

Background: Depression is the most prevalent mental health problem. The need for effective treatments for depression far outstrips the availability of trained mental health professionals. Smartphones and other widely available technologies are increasingly being leveraged to deliver treatments for depression. Whether there are patient characteristics that affect the potency of smartphone interventions for depression is not well understood.

Objective: This study aimed to evaluate whether patient characteristics including clinical diagnosis, depression severity, psychosis status, and current use of antidepressant medications impact the effects of an evidence-based smartphone intervention on depressive symptoms.

Methods: Data were collected as part of a 2-arm randomized controlled trial comparing a multimodal smartphone intervention called FOCUS with a clinic-based intervention. Here, we report on 82 participants assigned to 12 weeks of FOCUS treatment. We conducted assessments of depressive symptoms using the Beck Depression Inventory-second edition (BDI-II) at baseline, postintervention (3 months), and follow-up (6 months). We tested for differences in the amount of improvement in BDI-II scores from baseline to posttreatment and 6-month follow-up between each of the following patient subgroups using 2 (group) \times 2 (time) mixed effects models: diagnosis (ie, schizophrenia spectrum disorder vs bipolar disorder vs major depressive disorder), depression severity (ie, minimal-mild vs moderate-severe depression), psychosis status (ie, presence vs absence of psychotic symptoms), and antidepressant use (ie, taking antidepressants vs not taking antidepressants).

Results: The majority of participants were male (60%, 49/82), African American (65%, 53/82), and middle-aged (mean age 49 years), with a high school education or lower (62%, 51/82). There were no differences in patient demographics across the variables that were used to stratify the analyses. There was a significant group \times time interaction for baseline depression severity ($F_{1,76.8}=5.26$, $P=.02$ [posttreatment] and $F_{1,77.4}=6.56$, $P=.01$ [6-month follow-up]). Participants with moderate or severe depression had significant improvements ($t_{42}=3.20$, $P=.003$ [posttreatment] and $t_{42}=4.20$, $P<.001$ [6-month follow-up]), but participants with minimal or mild depression did not ($t_{31}=0.20$, $P=.84$ [posttreatment] and $t_{30}=0.43$, $P=.67$ [6-month follow-up]). There were no significant group \times time interactions for diagnosis, psychosis status, or antidepressant medication use. Participants with minimal or mild

depression had negligible nonsignificant improvements (<1 point on the BDI-II). Reduction in depression in all other groups was larger (range 1.7-6.5 points on the BDI-II).

Conclusions: Our results suggest that FOCUS can be deployed to treat moderate to severe depressive symptoms among people with schizophrenia spectrum disorders, bipolar disorder, and major depressive disorder, in concert with antidepressant medications or without them, in both people with and without active psychotic symptoms. The study results are consistent with research on transdiagnostic models in psychotherapy and extend our knowledge about the potential of transdiagnostic mobile health.

Trial Registration: ClinicalTrials.gov NCT02421965; <http://clinicaltrials.gov/ct2/show/NCT02421965> (Archived by WebCite at <http://www.webcitation.org/76pyDlvAS>)

(*JMIR Ment Health* 2019;6(4):e13202) doi:[10.2196/13202](https://doi.org/10.2196/13202)

KEYWORDS

mHealth; schizophrenia; bipolar disorder; depression; illness management; symptoms; transdiagnostic

Introduction

Background

Depression is a universal experience. Symptoms of depression are the most common mental health concern reported across nationalities, ethnicities, and age groups worldwide [1,2]. Depression is prevalent in all clinical settings, either as the primary issue that brings people to seek mental health care [3,4] or as a significant comorbid concern that emerges in those contending with medical illnesses [5-8], physical disabilities [9,10], relationship problems [11], work and educational difficulties [12], or substance use problems [13]. Depression is a source of enormous financial and societal burden. It is the second leading cause of years lived with disability worldwide [14], with overall medical and job loss costs estimated at US \$210.5 billion annually [15]. It is also implicated in half to two-thirds of all completed suicides [16]. The need for effective treatments for depression far outstrips the availability of resources that can be delivered by trained mental health professionals. This tension has led to the emergence of new models of care that are no longer dependent on the availability of highly trained mental health specialists, including integration of depression treatments into the offerings of primary care settings [17-19], training of paraprofessionals and family members to provide support [20], and using new technology to expand the breadth and reach of depression management resources [21,22].

It is only fitting that in recent years the most common mental health problem is starting to be addressed with the aid of one of the most widely used technologies on the planet: the mobile phone [23,24]. Smartphones—contemporary mobile phones with multimedia players, internet connectivity, and the ability to host apps—are increasingly being leveraged to deliver treatments for depression. A recent meta-analysis of 18 randomized controlled trials (RCTs) of smartphone-based mental health interventions for depressive symptoms found that these treatments had positive effects in comparison with both active interventions and inactive control conditions. Therapeutic effects were found for those with self-reported mild to moderate depression but were not seen among those with diagnoses of major mood disorders [25]. The authors of the meta-analysis outlined that these findings may be linked to the small and underpowered subsample sizes used in the studies involving those with clinical diagnoses and emphasized the need for

further research to deepen our understanding of which populations stand to benefit the most from smartphone interventions for depressive symptoms. Digital treatments are very novel in mental health care, and there is still uncertainty about whether these approaches are appropriate for all patients [26,27]. Research evaluating the effects of mobile health (mHealth) on people with both mild and more severe symptomatology can address this gap in our knowledge.

Objectives

Given that depressive symptoms commonly emerge in many forms of psychopathology [28], in this study, we examined the effects of an evidence-based smartphone intervention called FOCUS on depressive symptoms transdiagnostically among people with mood and psychotic disorders. We evaluated whether several patient clinical characteristics (ie, diagnosis, depression symptom severity, psychosis symptoms, and antidepressant medication use) impact the effects of the smartphone intervention on depressive symptoms in an RCT.

Methods

Study Descriptions

We conducted an assessor-blind, 2-arm, RCT between 2015 and 2017. The project was conducted in partnership with a large Chicago-based mental health agency that provides services to a range of people with psychiatric conditions. The study was approved by the Institutional Review Boards of the University of Washington and Dartmouth College and monitored continuously by an independent safety monitoring board. All study participants completed informed consent. Individuals were randomized (1:1 ratio) into 1 of the 2 treatment arms: an mHealth intervention delivered via smartphone (FOCUS) or a clinic-based group intervention (Wellness Recovery Action Plan). Interventions were deployed for a period of 12 weeks. We conducted assessments at baseline, postintervention (3 months), and follow-up (6 months). Participants were compensated \$30 per assessment. The study was registered in ClinicalTrials.gov, and the main RCT comparison outcomes were reported in an earlier publication [29]. Here, we conducted a secondary analysis focusing specifically on patients who received the FOCUS smartphone intervention, examining whether several patient clinical characteristics preintervention affected the impact of the intervention on their depressive symptoms.

Smartphone Intervention

FOCUS is a multimodal, smartphone-delivered intervention that was originally designed to support the recovery of people with schizophrenia [30] but has since been deployed among multiple diagnostic groups [29,31,32]. The FOCUS intervention comprises a FOCUS app that is used independently by patients, a Web-based clinician dashboard that summarizes participants' responses to self-assessments and their use of various FOCUS resources, and an mHealth support specialist who helps participants make meaningful use of the FOCUS intervention and provides technical troubleshooting assistance via brief weekly phone calls [32]. FOCUS treatment content targets 5 broad domains: mood (ie, depression and anxiety), voices (ie, auditory hallucinations), sleep problems, medication use, and social functioning. Content takes the form of either brief video, audio, or sequences of digital screens with written material coupled with visual displays. The FOCUS app includes preprogrammed daily prompts (questions that take over the home screen), followed by tailored intervention content. Participants who identify as having significant difficulties with depression at baseline may be assigned *mood* focused prompts, but all content is accessible on demand to all users 24/7 without restriction.

Participants

A total of 82 participants who were assigned to the FOCUS smartphone arm in the RCT are included in this report; posttreatment and 6-month follow-up data were available for 75 (91.5%) and 74 (90.2%) participants, respectively. Participants were identified by research staff and clinical teams at 3 agency sites. Study inclusion criteria included the following: chart diagnosis of schizophrenia, schizoaffective disorder, bipolar disorder, or major depressive disorder; aged 18 years or older; and a rating of "3" or lower on 1 of the 3 items comprising the *Domination by Symptoms* factor from the Recovery Assessment Scale [33]. Exclusion criteria included hearing, vision, or motor impairment (ie, that could affect the operation of a smartphone); less than 5th-grade English reading ability (per the Wide Range Achievement Test-4) [34]; and exposure to study interventions in the past 3 years. Participants continued to be eligible for all other clinical services including crisis intervention, assertive community treatment, supported employment, psychiatric evaluation, medication monitoring, psychosocial rehabilitation, and case management. Services were delivered in-person in the community or at 1 of the agency's multiple locations.

Measures

The primary outcome (depression symptoms) was measured with the Beck Depression Inventory-second edition (BDI-II) [35]. The BDI-II is a self-report questionnaire with 21 items rated on a 4-point scale that can be summed for a continuous total depression severity score ranging from 0 to 63; scores can also be categorized to characterize symptom severity (0-13=minimal, 14-19=mild, 20-28=moderate, and 29-63=severe). For subgroup analyses, participants were

categorized based on whether they had minimal to mild depression versus moderate to severe depression at baseline. Psychotic symptoms were assessed with the Psychotic Symptom Rating Scales (PSYRATS) [36], a semistructured interview instrument that assesses the severity of auditory hallucinations (eg, frequency, duration, loudness, and distress) and delusions (eg, preoccupation, conviction, and disruption). The PSYRATS comprises 17 items, each rated on a 4-point scale and summed for a total psychotic symptoms score. Given the distribution of psychotic symptoms at baseline in our sample (63.8% endorsing none), we dichotomized our sample based on whether individuals had any psychotic symptoms (vs none) at baseline. Antidepressant medication use was recorded by study assessors during baseline interviews and follow-up calls where participants were asked to read their medication labels to study staff. We dichotomized our sample based on whether study participants were actively taking any antidepressant medications (vs not) before commencing study interventions. Participants' diagnosis was recorded from the electronic health records. Diagnoses are determined by licensed clinical social workers or licensed clinical professional counselors who interview clients about their mental health challenges and history, examine any prior medical records, and consult with the agency's medical director who is a board-certified psychiatrist.

Data Analytic Plan

We conducted a series of 2 (group) \times 2 (time) mixed effects models to evaluate whether there were differences in the amount of clinical improvement in BDI-II scores between each of the following groups: (1) Diagnosis, schizophrenia spectrum disorder versus bipolar disorder versus major depressive disorder; (2) Depression severity, minimal-mild versus moderate-severe depression; (3) Psychosis symptoms, presence versus absence of psychotic symptoms, and (4) Antidepressant medications, taking antidepressants versus not taking antidepressants. Any significant group \times time interactions would indicate that the amount of clinical improvement was moderated by the baseline group variable; interactions that were significant were followed by paired sample *t* tests to evaluate the significance of the amount of changes in BDI-II scores within each specific group.

Results

Demographics and Study Variables

Descriptive statistics are presented in Table 1. The majority of participants were male and African American; the mean age was 49 years. Most participants had a high school education or lower (62%, 51/82) and had used a smartphone before entering the study (73%, 60/82). The 3 diagnostic categories specified as inclusion criteria (schizophrenia, schizoaffective disorder, bipolar disorder, and major depressive disorder) were well represented within the sample. There were no differences in patient demographics across the baseline measures that were used to stratify our analyses (diagnosis, depression severity, psychosis symptoms, and antidepressant medications).

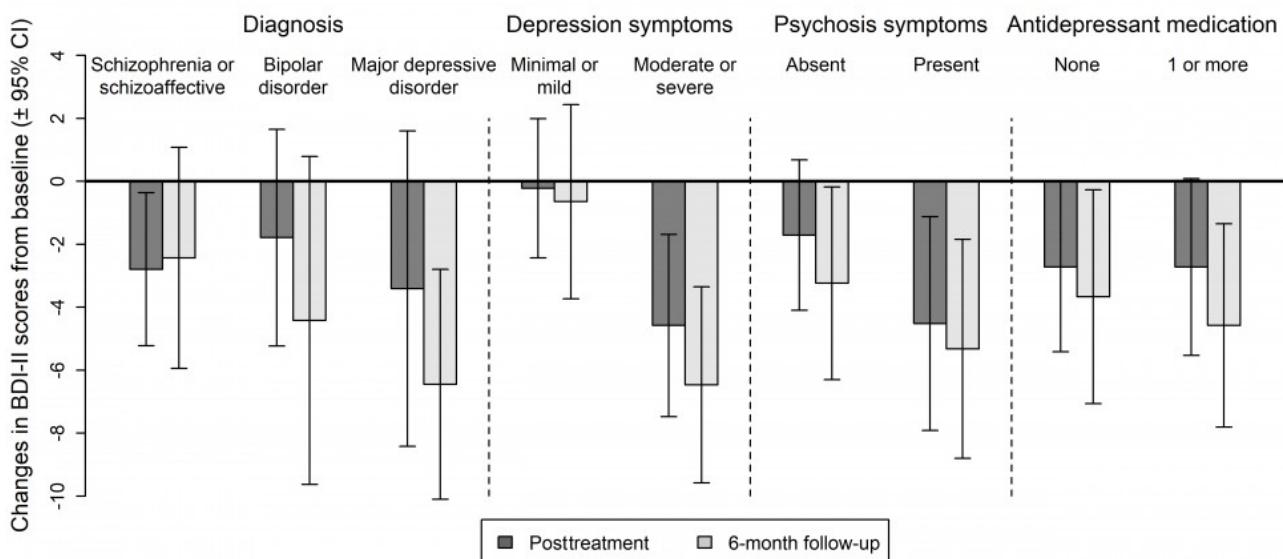
Table 1. Descriptive statistics at baseline (N=82).

Demographic and study variables	Statistics
Age (years), mean (SD)	49 (10.1)
Male, n (%)	49 (60)
Previously used smartphone, n (%)	60 (73)
Race, n (%)	
White	22 (27)
African American	53 (65)
Other or more than 1 race	7 (9)
Education, n (%)	
High school or less	51 (62)
More than high school	31 (38)
Diagnoses, n (%)	
Schizophrenia/schizoaffective disorder	38 (46)
Bipolar disorder	21 (26)
Major depressive disorder	23 (28)
Depression, n (%)	
Minimal or mild	35 (43)
Moderate or severe	47 (57)
Psychosis symptoms, n (%)	
Absent	51 (62)
Present	31 (38)
Antidepressant medications, n (%)	
None	34 (41)
One or more	46 (56)
Unknown	2 (2)

6-Month Follow-Up and Posttreatment Results

As was also reported in the parent trial [29], participants in the FOCUS condition had significant reductions in BDI-II scores at posttreatment (mean change=−2.72; $t_{74}=-2.80$; $P=.006$) and 6 months (mean change=−4.03; $t_{73}=-3.53$; $P<.001$) over baseline, indicating that for the full sample, depression symptoms improved during the FOCUS intervention and that these improvements were maintained at the 6-month follow-up. There were no significant group \times time interactions for diagnostic group ($F_{2,73.8}=0.16$, $P=.86$ [posttreatment] and $F_{2,74.5}=1.07$, $P=.35$ [6-month follow-up]), psychosis symptoms ($F_{1,75.1}=1.89$, $P=.17$ [posttreatment] and $F_{1,75.0}=0.70$, $P=.41$ [6-month follow-up]), or antidepressant medication use ($F_{1,77.3}<0.01$, $P=.95$ [posttreatment] and $F_{1,80.0}=0.20$, $P=.65$) [6-month follow-up]), indicating that there were no significant differences in the amount of improvement participants experienced over time between the subgroups that were defined

by these 3 baseline variables. However, there was a significant group \times time interaction for baseline depression severity ($F_{1,76.8}=5.26$, $P=.02$ [posttreatment] and $F_{1,77.4}=6.56$, $P=.01$ [6-month follow-up]), indicating that the amount of improvement in depression scores was different between participants with minimal or mild depression symptoms compared with participants with moderate or severe depression symptoms. Follow-up tests within these groups indicated that participants with minimal or mild depression did not have significant reductions in depression symptoms from baseline to posttreatment (difference=−0.22; $t_{31}=-0.20$; $P=.84$) or follow-up (difference=−0.65; $t_{30}=-0.43$; $P=.67$); however, participants with moderate or severe depression did have significant reductions in depression symptoms at posttreatment (difference=−4.58; $t_{42}=-3.20$; $P=.003$) that were also maintained at follow-up (difference=−6.57; $t_{42}=-4.20$; $P<.001$). Average levels of change within all subgroups (with 95% CIs) are further characterized (see Figure 1).

Figure 1. Changes in BDI-II edition depression scores by patient characteristics at baseline. BDI-II: Beck Depression Inventory-second edition.

Discussion

Principal Findings

The results of this study deepen our understanding of patient clinical characteristics that may impact the effectiveness of FOCUS on their level of depression, independent of their assigned diagnostic label. We found that (1) FOCUS produced significant and sustained (at 6-month follow-up) reduction in depression among people who had moderate to severe depressive symptoms, effects that were not seen among people with minimal to mild depressive symptoms; (2) FOCUS produced significant and sustained reductions in depression among people with schizophrenia/schizoaffective disorder, bipolar disorder, and major depressive disorder; (3) FOCUS produced significant and sustained reductions in depression among people with psychotic symptoms and among people without any indication of psychosis; and (4) FOCUS produced significant and sustained reduction in depression in both people who were taking antidepressant medications and people who were not.

Our findings suggest that FOCUS might be a useful intervention to address moderate to severe depressive symptoms among individuals with an array of mental illnesses. Depressive symptoms are common among people experiencing psychosis [37], are linked with poorer outcomes [38,39], and often persist or recur even with antidepressant treatment [40]. Our findings go against current skepticism about the viability of computerized interventions for people with psychosis [26] as FOCUS produced significant positive effects in both individuals with and without active psychotic symptoms and in both people with and without a schizophrenia spectrum diagnosis.

In the context of precision medicine in mental health care [41] and the growing interest in customization of treatment for well-defined populations, this study can inform practical clinical decision making. Our results suggest that FOCUS can be deployed to effectively treat depression transdiagnostically among people with moderate to severe depressive symptoms,

in concert with antidepressant medications or without them, in both people with and without co-occurring psychotic symptoms.

Limitations

The study has several limitations. First, because mHealth was adjunctive to existing service provided through the community agency, other services may also have contributed to the positive changes that occurred during the study period. Second, the original study was designed with sufficient power to detect treatment changes in the overall sample, and thus, the subgroup analyses presented here should be interpreted with caution. Finally, dichotomous groups based on baseline variables were broad; a larger sample would allow examination of more fine-grained or continuous relationships between demographic or clinical characteristics and treatment benefit.

Conclusions and Future Directions

FOCUS was designed to maximize accessibility for those who are most impaired [30] while targeting several domains that are relevant transdiagnostically. Multicomponent mHealth systems are needed for users who may have diverse and evolving cognitive, emotional, and behavioral challenges. The study results are consistent with research on transdiagnostic models in clinic-based psychotherapy [42] and computerized interventions [43,44] and extend what we know about transdiagnostic mHealth. The findings also contribute to our growing awareness that mental health difficulties are multidimensional [45]. As we uncover more about heterogeneity within clinical conditions and advance our understanding of dimensionality in psychopathology, we will increasingly move away from categorical conceptualizations of “healthy” versus “ill” and “diagnosis A” versus “diagnosis B” [46]. Our mHealth interventions will likely follow suit, and like FOCUS, will continue to evolve into multidimensional and multicomponential systems [47,48]. As such, mHealth will become a more versatile mental health management approach that can serve a broader spectrum of needs.

Acknowledgments

The authors would like to thank the staff and members of Thresholds in Chicago for participating and contributing to the study.

Conflicts of Interest

DB-Z consults for eQuility and has had an intervention content licensing agreement with Pear Therapeutics. KH has provided consultation to Pear Therapeutics.

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Abbreviations

BDI-II: Beck Depression Inventory-second edition

mHealth: mobile health

PSYRATS: Psychotic Symptom Rating Scales

RCT: randomized controlled trial

Edited by J Torous; submitted 20.12.18; peer-reviewed by J Firth, D Fulford, K Mishina; comments to author 27.01.19; revised version received 29.01.19; accepted 12.02.19; published 12.04.19.

Please cite as:

Ben-Zeev D, Buck B, Chu PV, Razzano L, Pashka N, Hallgren KA

Transdiagnostic Mobile Health: Smartphone Intervention Reduces Depressive Symptoms in People With Mood and Psychotic Disorders

JMIR Ment Health 2019;6(4):e13202

URL: <http://mental.jmir.org/2019/4/e13202/>

doi: [10.2196/13202](https://doi.org/10.2196/13202)

PMID: [30977736](https://pubmed.ncbi.nlm.nih.gov/30977736/)

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Original Paper

Identifying Treatment Modalities for a Multidisciplinary and Blended Care Intervention for Patients With Moderate Medically Unexplained Physical Symptoms: Qualitative Study Among Professionals

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Abstract

Background: Medically unexplained physical symptoms (MUPS) are a substantial health problem in primary care with a high burden for patients, general practitioners, and the health care system. Most studies focus on chronic MUPS patients. Little research is conducted in patients with moderate MUPS, and an effective primary care intervention for prevention of chronic MUPS is lacking.

Objective: The objective of our study was to identify treatment modalities based on expert opinions for the development of a multidisciplinary and blended intervention for patients with moderate MUPS to prevent chronicity.

Methods: Two focus groups with 8 and 6 experts (general practitioners, physical therapists, psychologists, and mental health nurses) were carried out. The focus groups were structured using the nominal group technique.

Results: A total of 70 ideas were generated from two nominal group meetings, and 37 of these got votes, were included in the rank order, and were sorted into 8 separate themes. According to the participants, the most important treatment modalities for a multidisciplinary and blended intervention in patients with moderate MUPS were (1) coaching to a healthier lifestyle, (2) education regarding psychosocial factors, (3) therapeutic neuroscience education, (4) multidisciplinary intake, (5) multidisciplinary cooperation and coordination, (6) relaxation or body awareness exercises, (7) clear communication by professionals to the patient, and (8) graded activity. Five independent researchers checked the ideas and linked them to themes to confirm the content analysis and check the validity of the themes.

Conclusions: From professional expert perspectives, 8 themes should be included in a multidisciplinary and blended intervention to prevent chronicity. These themes provide a first step in developing an intervention for patients with moderate MUPS. Future research should focus on further development steps in which patients with moderate MUPS should be involved to determine if the intervention matches their needs.

(*JMIR Ment Health* 2019;6(4):e12203) doi:[10.2196/12203](https://doi.org/10.2196/12203)

KEYWORDS

medically unexplained physical symptoms; intervention development; primary care; qualitative study; nominal group technique

Introduction

Medically unexplained physical symptoms (MUPS) are physical complaints (eg, pain, fatigue, dizziness) that last for at least a few weeks and cannot be explained by a medical condition after adequate medical examination [1,2]. Approximately 20% of patients with MUPS still experience unexplained physical symptoms after 3 months, and a third of patients presenting with MUPS maintain unexplained symptoms after 5 years [3]. Symptoms can be categorized into moderate MUPS and chronic MUPS [2,4]. Moderate MUPS symptomatology can be of any type and intensity in 2 or 3 domains (eg, musculoskeletal, fatigue, cardiology-respiratory) with psychological and physical distress. Chronic MUPS symptomatology is within more domains with psychological and physical dysfunction (eg, fibromyalgia, chronic fatigue syndrome, irritable bowel syndrome) [2,4]. The estimated prevalence of moderate MUPS is 15%, and chronic MUPS occurs in approximately 2.5% of patients in primary care [4-6]. The burden (eg, physical, social, emotional) of MUPS is high based on the decrease in quality of life and increase in health care use for patients [7-9]. Furthermore, the burden is high for general practitioners and society since general practitioners do not recognize patients with MUPS early, and they experience difficulties in treating and managing patients with MUPS [10-12], leading to increased direct health care costs and indirect costs (eg, work- and insurance-related costs) [9].

Many studies have already been conducted in patients with chronic MUPS to assess the efficacy of psychological, pharmacological, exercise therapy, or combined treatment approaches [13-18]. So far, systematic reviews based on low-quality evidence suggest that cognitive behavioral therapy might be an effective psychological treatment [17,18]. The focus of pharmacological interventions should be on action of the central nervous system (eg, antidepressants) instead of restoration of peripheral physiological dysfunction (eg, nonsteroidal anti-inflammatory drugs) [16]. Furthermore, compelling evidence for neuroscience education is found on pain, disability, catastrophization, and physical performance [13]. In a session on neuroscience education, the patient is educated on the neurobiology and neurophysiology of pain and pain processing by the nervous system [13]. Systematic reviews based on low- to moderate-quality evidence suggest that exercise therapy has a positive effect on physical function [14,15]. Despite the evidence for the more isolated interventions, it is suggested that treatments should be multimodal in patients with MUPS, with components of exercise, education, and integrating aspects of a psychological approach [13,16,17].

For the development of multimodal interventions, expert opinions and patient needs should be taken into account [19]. Different studies have already focused on the management of MUPS. In a qualitative analysis on expert opinions, some relevant elements were identified for successful management of MUPS: creating a safe therapeutic environment and using generic (eg, motivational interviewing) and specific (eg,

cognitive approaches) interventions [20]. Furthermore, earlier research has indicated that explanation of the symptoms is an important management strategy in patients with MUPS [21,22].

Many qualitative and quantitative studies have focused on patients with chronic MUPS [13-18,21,23-26]. Little research has been conducted in patients with moderate MUPS, but preventing chronicity in moderate MUPS to decrease the burden for patients, general practitioners, and society is important [27]. Recently, we developed a screening method (PRESUME: preventive screening of medically unexplained physical symptoms) to identify patients with moderate MUPS using the electronic medical records of the general practitioner. The method consists of 3 steps based on consultation frequency, exclusion of medical and/or psychiatric diagnosis, and identification of chronic MUPS and moderate MUPS. Patients are identified with chronic MUPS when they are diagnosed with a functional somatic syndrome (eg, fibromyalgia, chronic fatigue syndrome, or irritable bowel syndrome), and patients with moderate MUPS have MUPS-related symptoms without a MUPS diagnosis. Despite its limited prognostic accuracy, the PRESUME screening method facilitates identification of patients with moderate MUPS. In the next step we aim to develop an effective multidisciplinary and blended primary care intervention to prevent chronicity in patients with moderate MUPS. The expectation is that the integration of face-to-face sessions with eHealth modules, called blended care, will promote self-management. Furthermore, a blended care intervention may lead to a decrease of costs since the face-to-face sessions are not performed on a weekly basis. Blended care has already been proven effective in other studies [28,29]. The intervention will be performed in primary care; therefore, a physical therapist and mental health nurse should be involved in the intervention since both disciplines treat patients with MUPS in primary care in the Netherlands [2]. For development of the intervention, the Medical Research Council (MRC) framework will be used. The MRC framework include several phases: development, feasibility and piloting, evaluation, and implementation [19]. In this study we focused on identifying existing relevant themes for the intervention as a first part of the development phase of the MRC framework. Professionals involved in the clinical management of MUPS were asked to participate. The aim of this study was to identify expert-based treatment modalities for a multidisciplinary intervention for patients with moderate MUPS in primary care.

Methods**Design**

A qualitative study using focus groups according to the nominal group technique (NGT) was performed [30]. Preconditions were that the intervention will be multidisciplinary and blended, with the focus on self-management.

Participants

Professionals involved in the clinical management of patients with MUPS were approached to participate in the study. Eligible participants were selected through purposive sampling and finally included based on availability. Purposive sampling was applied to obtain variation in disciplines (general practitioner, psychosomatic physical therapists, health care psychologists, and mental health nurses). The number of participants in a nominal group meeting was based on the recommendation of a maximum of 9 or 10 participants per group [31]. Based on the involvement of different disciplines, multiple nominal group meetings were organized [32]. We started with organizing 2 nominal group meetings, so the participants were divided into 2 groups. If there were no agreement between the items mentioned in the first 2 meetings, extra meetings with other participants would be organized until data saturation was achieved. The study was carried out according to Dutch privacy legislation rules. Written informed consent was obtained from all participants before the start of the focus group. In the first focus group, one general practitioner, one physical therapist, 2 psychosomatic physical therapists, 2 health care psychologists, 2

and 2 mental health nurses participated. In the second focus group, 2 general practitioners, one physical therapist, 2 psychosomatic physical therapists, and one psychologist/physical therapist participated. Since the results of the second group discussions did not add major new ideas compared to the ideas identified in the first group, saturation was assumed and no additional group sessions were held.

Participants had a median work experience of 18 years (interquartile range [IQR] 20), where 21% (3/14) had less than 10 years of work experience, 29% (4/14) had 10 to 20 years of working experience, and 50% (7/14) had 20 years or more of work experience. In addition, participants had a median experience of treating patients with MUPS of 9 years (IQR 18), where 50% (7/14) had less than 10 years of experience in treating patients with MUPS, 21% (3/14) had 10 to 20 years of experience in treating patients with MUPS, and 29% (4/14) had 20 years or more experience in treating patients with MUPS. Some participants had other work activities besides their profession such as a researcher, teacher, or public administrator. Demographic characteristics of the participants are shown in Table 1.

Table 1. Demographic characteristics of the participants (n=14).

Characteristics	Values
Profession, n (%)	
General practitioner	3 (21)
Physical therapist	2 (14)
Psychosomatic physical therapist	4 (29)
Psychologist/physical therapist	1 (7)
Health care psychologist	2 (14)
Mental health nurse	2 (14)
Female, n (%)	9 (64)
Age in years, median (IQR ^a)	46.5 (20)
Years of general work experience, median (IQR)	18 (20)
Years of experience treating patients with MUPS ^b , median (IQR)	9 (18)
Other work activities^c, n (%)	
Research assistant	1 (7)
Junior researcher	1 (7)
Postdoctorate researcher	1 (7)
Senior researcher	1 (7)
Clinical health scientist	1 (7)
Clinical epidemiologist	1 (7)
Teacher	5 (36)
General practitioner, special interest musculoskeletal	1 (7)
General practitioner, special interest mental health care	1 (7)
Public administrator	1 (7)

^aIQR: interquartile range.

^bMUPS: medically unexplained physical symptoms.

^cSome participants are classified in multiple categories.

Procedure

NGT is a formal stepwise consensus procedure that uses structured interaction within the group. Ideas were generated focusing on optimization of moderate MUPS management [30]. NGT is a structured group meeting, which is of interest in a heterogenic group of participants [33]. This technique enables participants to gather individual ideas, obtain ideas from other members, and rank ideas with equal input from all participants.

- Introduction of the nominal question: welcome and introduction of NGT and the nominal question.
- Silent generation of ideas: participants are asked to write down their individual list of ideas that come to mind regarding the nominal question without discussing with or consulting others.
- Presenting of ideas: sheets with individual ideas are gathered, and each participant presents their ideas to the group without discussion.
- Group discussion: all ideas are evaluated, clarified, and discussed one by one. Ideas can be specified when necessary. Similar items can be merged but only after agreement of all participants.
- Voting and ranking of ideas: participants are asked to individually rank the 5 most important items without discussion with other group members. Scores are summed (an item receives 5 points for a number 1 position, 4 points for a number 2 position, etc), and a final rank order is presented.

A week before the meeting, participants received information about the meeting, and the research question was introduced by the principal researcher: “Which treatment modalities should be part of the multidisciplinary treatment program for moderate MUPS to prevent chronic MUPS?” At the beginning of the meeting, participants were introduced and the role of the facilitator (assistant; presents all ideas and rankings in PowerPoint) and principal researcher (moderator of the discussion) were explained. In addition, the purpose and procedure of the meeting were explained, the research question was displayed, and the definition of moderate MUPS was specified (patients who have had at least 5 general practice consultations during the past 12 months of which at least 3 were based on the presence of MUPS-related symptoms; furthermore, patients should have psychological and physical distress). Subsequently, the 4 structured steps according to the NGT procedure were explained and followed [30].

The first step is silent generation, where all participants wrote down ideas around the question individually and privately for approximately 20 minutes. The second step was a round-robin format, where all participants shared their ideas one by one with the group. One participant at the time stated a single idea, which was presented on a screen in front of the group by the facilitator. This process was continued until all ideas from participants were listed and displayed on the screen. There was no discussion at this stage. In the third step, all collected ideas were clarified and discussed in the group. Similar ideas were grouped together but only after agreement by all participants. Discussion ended when no new ideas were generated or grouped together and data saturation within the group was thus achieved. In the fourth

step, participants were able to independently rank 5 ideas from all generated ideas. In this ranking process, participants gave 5 votes to the most important idea and the fifth most important idea got one vote. After the 4 steps, the facilitator collected the voting sheets, and the scores for each idea were presented. The group meeting was audiotaped to verify data and use the information for ongoing analysis after the meeting.

Data Analysis

NGT enables participants to be involved in data analysis by composing a rank order. Rank orders of the 2 groups were merged into one final rank order using a structured method for analyzing multiple group data [34]. All ideas were listed in the final rank order to combine ideas into themes by the principal researcher (content analysis). Subsequently, each theme got a definition. To confirm the content analysis as well as increase the reliability, 5 independent researchers who were not involved in the study checked the ideas and decided to which theme they belonged to determine if themes should be more clearly defined or maybe combined or redivided [34]. In the last step, all themes were ranked according to the number of ideas that formed the theme, the number of times the ideas were ranked in the top 5, and the relative score of the ideas within the group rankings. Only the ideas that had received votes were included in the rank order. Multigroup data analysis procedure [34] is as follows:

- Capture data on computer: sets of items with the individual and group scores for each item can be entered on a spreadsheet.
- Identifying the overall top 5 per group: sets of items were ordered according to the importance of the items as scored by each group. Subsequently, the top 5 of the most important items of each group are identified as described by the steps of van Breda et al [34].
- Content analysis of the data: the principal investigator (EvW) will combine the items from all groups into groups of items. This process is repeated a few times, and themes are created. An item can fall into one theme only. Subsequently, a definition to each theme is created. This is a time-consuming process.
- Confirm the content analysis: the content analysis is peer-reviewed by independent researchers who have not been involved in the NGT research process. Subsequently, the principal investigator determines whether themes should be more clearly defined or maybe combined or redivided.
- Calculating combined ranks: the relative importance of each theme to all the groups combined is calculated. The final rank provides a consolidation of all items generated and ranked by the participants.

Results

From the 2 nominal group meetings, 70 ideas were generated (37 in group 1 and 33 in group 2), of which 37 received scores from the participants (19 in group 1 and 18 in group 2). All ideas from both focus groups were ordered according to the scores of the participants. Subsequently, the top 5 ideas were identified. The idea with the highest score in both focus groups was “education about the complaints of the patient.” Both focus groups indicated that it should be at the start of an intervention.

Participants of the first focus group scored as the second most important idea “education about factors which affect the complaints, to make the connection with possible perpetuating factors.” The third most important idea was the “treatment demand.” The participants found it important that the treatment demand should be clear at the end of the intake for a tailored intervention. The fourth most important idea was that professionals should pay attention to patients’ lifestyle, where self-management in general daily life of patients is of interest. The fifth most important idea of the first focus group was that “patients should get more insight in their emotions, behavior, and thoughts in relation with the complaints.” In the second focus group, the participants scored as second most important idea “interdisciplinary collaboration.” The third most important idea was “the patient should have problem-solving skills.” Participants expected that patients with problem-solving skills would recognize challenges as well as develop self-management strategies. Fourth, “cognitive behavioral interventions are of interest to help patients managing their problems.” The participants found it important that patients learn to make the connection between their thoughts, feelings, and behavior and their complaints with cognitive behavioral interventions. Finally, participants in the second focus group mentioned “education and coaching on lifestyle” as the fifth most important idea.

After the identification of ideas and their ranking in both focus groups, the ranked ideas were merged into one final rank order according to the structured method for analyzing multiple group data [34]. This final rank order was analyzed, and all ideas were divided into themes by the principal researcher ([Multimedia Appendix 1](#)). Eight separate themes with definitions were composed by the principal researcher.

1. Coaching to a healthier lifestyle: coaching to a healthier lifestyle and behavioral changes through self-management as well as a balance between burden and capacity with attention to coping strategies
2. Education regarding psychosocial factors: education on possible precipitating and maintaining factors of the complaints with the connection between thoughts, emotions, and behavior
3. Therapeutic neuroscience education: education of central sensitization
4. Multidisciplinary intake: a multidisciplinary intake with both physical aspects (eg, by the physical therapist) and mental aspects (eg, by a mental health nurse). During the intake, both disciplines should focus on the complaints (also checking if the patient has doubts about having a medical diagnosis), cognitions, emotions, behavior, and social environment of the patients, but from a different perspective. Additionally, the treatment demand and goals of the patient should be clear before the actual start of the intervention
5. Multidisciplinary cooperation and coordination: multidisciplinary cooperation between, for example, the general practitioner, physical therapist, and mental health nurse with established consultation meetings where the general practitioner will have the coordinating role during the intervention

6. Relaxation or body awareness exercises: relaxation or body awareness exercises should be part of the intervention (eg, general relaxation techniques [progressive relaxation or autogenic training], mindfulness, and exercises according to psychomotor therapy)
7. Clear communication of professionals to the patient: professionals should express themselves in the same way toward the patient during education sessions and should have insight into their own cognitions about MUPS
8. Graded activity: gradually increasing the amount of physical activity in a time-contingent way based on individual goal setting, using preset quotas and principles of operant conditioning

The composed themes were validated by 5 independent researchers who were not involved in the study. They checked the ideas and decided in which theme they belong. This led to the adjustment of 7 ideas into other themes and a more clear definition of 3 themes. After validating our composed themes, the relative importance of each theme was determined according to a ranking score. “Coaching to a healthier lifestyle” had the highest ranking score and was the first theme. “Graded activity” had the lowest ranking score. This ranking score indicated which parts of the multidisciplinary and blended primary care intervention were most important from a professional expert perspective.

Discussion

Principal Findings

The aim of this study was to determine treatment modalities according to professional experts for the development of a multidisciplinary and blended primary care intervention in patients with moderate MUPS to prevent chronic MUPS. According to the ideas and their ranking, 8 themes were important. Our study is the first qualitative study focusing on patients with moderate MUPS, since earlier research focused on patients with chronic MUPS [20,21]. Additionally, qualitative studies on MUPS and health care professionals included general practitioners only. As far as we know this is the first qualitative study in which all health care professionals involved in management of MUPS in primary care were included.

Although comparison with results of earlier research is difficult since it focused on management of chronic MUPS, some of the themes we created in our study were also proven effective in patients with chronic MUPS [2,13,35,36]. The Dutch Multidisciplinary Guideline for MUPS and Somatoform Disorders advises to start the intake by exploring the somatic, cognitive, emotional, behavioral, and social dimensions of the complaints [2], which is in line with the results of the nominal group meetings. Evidence for neuroscience education is found for patients with chronic musculoskeletal pain disorders [13]. Furthermore, progressive muscle relaxation as a relaxation exercise is effective on intensity and number of symptoms, quality of life, and comorbid symptoms for patients with multiple somatoform symptoms [36], and graded activity had a medium effect for patients with chronic fatigue syndrome on fatigue severity reduction [35]. These similarities could possibly be due to the fact that professional experts might know the

effective interventions for patients with chronic MUPS and found them also applicable for patients with moderate MUPS. It can also be related to the clinical presentation, as both patients with moderate MUPS and patients with chronic MUPS experience physical and psychological problems [4]. Although the themes partly overlap with the key management aspects of chronic MUPS, none of the intervention studies on patients with chronic MUPS integrated all aspects in a multidisciplinary and blended primary care intervention.

Strengths and Limitations

This study has a few strengths. First, a group of experts with representatives in all relevant disciplines was included. Therefore, an answer as broad as possible to our question was gathered. Second is the choice of the nominal group technique. Since the intervention for patients with moderate MUPS will be multidisciplinary, we provided a qualitative study with a heterogeneous group of professional experts. The structure of the NGT enables group discussion and assures equal input from all participants instead of the possibility that only one participant is mostly speaking [37]. A third strength is that we checked our content analysis by letting independent researchers who were not previously involved in the study check the ideas and decide in which theme they belong [34]. This step in the data analysis of the study is to test the content validity of our themes and enhances the interrater reliability. Beside the strengths, some limitations should be noted. Firstly, a limitation of the purposive sampling strategy is the nonrandom selection of participants. However, with this nonrandom selection of participants, a representative group of all relevant disciplines involved in the clinical management of patients with MUPS was gathered. Furthermore, all participants were aware of the last scientific findings in MUPS research. If a random selection of participants were conducted, the possibility existed that not all relevant disciplines would be selected. Second, some participants seemed to have difficulties with the focus on patients with moderate

MUPS as a target group and therefore mentioned ideas that had probably more focus on chronic MUPS. At the beginning of the meeting, the principal researcher pointed out the definition of moderate MUPS and specified to mention ideas that focused on treatment modalities for patients with moderate MUPS. The participants got the definition of moderate MUPS on paper. During the discussion step of the NGT, participants addressed to each other that some ideas might better fit as treatment modalities for patients with chronic MUPS. This led to the removal of some ideas by participants but only after agreement of all participants. In this way, ideas with the focus on treatment modalities for patients with moderate MUPS remained and could get ranked during the last step of the NGT procedure. A third limitation is that generalizability to foreign countries might be complex due to the differences with respect to the health care systems of other countries. Despite these differences, our identified themes for an intervention can be applied in other health care systems or countries since the context for an intervention will not differ.

The results of this study are the basis for the development of a multidisciplinary and blended primary care–focused intervention for patients with moderate MUPS to prevent chronicity. A new primary care intervention would be of great value in clinical practice. In the next step, principles of the Center for eHealth Research road map can be used to focus on the integration of face-to-face sessions using the eHealth modules [38].

Conclusion

From professional expert perspectives, 8 themes should be included in a multidisciplinary and blended intervention to prevent chronicity. These themes provide a first step in developing an intervention for patients with moderate MUPS. Future research should focus on further development steps of the MRC framework in which patients with moderate MUPS should be involved to determine if the intervention matches their needs.

Acknowledgments

The authors would like to thank the professionals who participated in the nominal group meetings for their contributions.

Conflicts of Interest

None declared.

Multimedia Appendix 1

All ideas from both focus groups divided into eight themes.

[[PDF File \(Adobe PDF File, 17KB - mental_v6i4e12203_app1.pdf](#)]

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Abbreviations

IQR: interquartile range

MRC: Medical Research Council

MUPS: medically unexplained physical symptoms

NGT: nominal group technique

PRESUME: preventive screening of medically unexplained physical symptoms

Edited by A Tsanas; submitted 13.09.18; peer-reviewed by M Mizani, E Valavani; comments to author 17.11.18; revised version received 30.01.19; accepted 14.02.19; published 12.04.19.

Please cite as:

van Westrienen PE, Pisters MF, Gerrits M, Veenhof C, de Wit NJ

Identifying Treatment Modalities for a Multidisciplinary and Blended Care Intervention for Patients With Moderate Medically Unexplained Physical Symptoms: Qualitative Study Among Professionals

JMIR Ment Health 2019;6(4):e12203

URL: <http://mental.jmir.org/2019/4/e12203/>

doi: [10.2196/12203](https://doi.org/10.2196/12203)

PMID: [30977737](#)

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Original Paper

Exploring Associations Between the Self-Reported Values, Well-Being, and Health Behaviors of Finnish Citizens: Cross-Sectional Analysis of More Than 100,000 Web-Survey Responses

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Abstract

Background: Understanding the relationship between personal values, well-being, and health-related behavior could facilitate the development of engaging, effective digital interventions for promoting well-being and the healthy lifestyles of citizens. Although the associations between well-being and values have been quite extensively studied, the knowledge about the relationship between health behaviors and values is less comprehensive.

Objective: The aim of this study was to assess retrospectively the associations between self-reported values and commitment to values combined with self-reported well-being and health behaviors from a large cross-sectional dataset.

Methods: We analyzed 101,130 anonymous responses (mean age 44.78 years [SD 13.82]; 78.88%, 79,770/101,130 women) to a Finnish Web survey, which were collected as part of a national health promotion campaign. The data regarding personal values were unstructured, and the self-reported value items were classified into value types based on the Schwartz value theory and by applying principal component analysis. Logistic and multiple linear regression were used to explore the associations of value types and commitment to values with well-being factors (happiness, communal social activity, work, and family-related distress) and health behaviors (exercise, eating, smoking, alcohol consumption, and sleep).

Results: Commitment to personal values was positively related to happiness (part $r^2=0.28$), communal social activity (part $r^2=0.09$), and regular exercise (part $r^2=0.06$; $P<.001$ for all). Health, Power (social status and dominance), and Mental balance (self-acceptance) values had the most extensive associations with health behaviors. Regular exercise, healthy eating, and nonsmoking increased the odds of valuing Health by 71.7%, 26.8%, and 40.0%, respectively ($P<.001$ for all). Smoking, unhealthy eating, irregular exercise, and increased alcohol consumption increased the odds of reporting Power values by 27.80%, 27.78%, 24.66%, and 17.35%, respectively ($P<.001$ for all). Smoking, unhealthy eating, and irregular exercise increased the odds of reporting Mental balance values by 20.79%, 16.67%, and 15.37%, respectively ($P<.001$ for all). In addition, lower happiness levels increased the odds of reporting Mental balance and Power values by 24.12% and 20.69%, respectively ($P<.001$ for all).

Conclusions: The findings suggest that commitment to values is positively associated with happiness and highlight various, also previously unexplored, associations between values and health behaviors.

KEYWORDS

value orientation; happiness; health behavior; healthy lifestyle; cross-sectional survey

Introduction

Background

Suboptimal health behaviors are significant determinants of poor health outcomes. However, the adoption of healthy lifestyles has not been sufficient at the population level, and obesity levels are increasing worldwide. In addition, the burden of mental health problems is growing [1,2]. Personal electronic health (eHealth) and mobile health (mHealth) interventions have great potential in empowering individuals to take care of their health and well-being in a cost-effective way [3,4]. However, the problem of low user engagement commonly prevents these interventions from achieving their full potential [4,5].

Various computer-tailored eHealth interventions have demonstrated that personalizing the content to the characteristics of individual users tend to be efficacious for promoting healthy behaviors [4,6,7], though engaging the unmotivated proportion of the population, not actively interested in their health, is always challenging [8]. The common tailoring variables found in eHealth or mHealth interventions are health behaviors and the readiness to change behavior [9,10], and some have also considered demographics, clinical risk factors, and personal information needs [11]. However, addressing the motivational factors that influence the attitude toward a healthy lifestyle by personalizing interventions to match the needs, motives, and preferences of individuals could result in more engaging and effective health interventions [4,12]. It is well known, for example, from the experiments conducted based on the theories of reasoned action and planned behavior, that the attitude one holds toward a behavior is one of the key determinants for forming the intention to engage in the behavior (or readiness to change the behavior) [13,14].

Values act as guiding principles in life by determining what is important to people [15,16]. According to Schwartz and Bilsky [17], “values (a) are concepts or beliefs, (b) about desirable end states or behaviors, (c) transcend specific situations, (d) guide selection or evaluation of behavior and events, and (e) are ordered by relative importance.” Values are considered as rather stable motivational characteristics of people, which are related to personality traits [18,19], although changes in value priorities may take place because of changes in life and social conditions [15,18]. As values by definition reflect the motives, needs, and preferences of people, and thereby are one of the factors influencing attitudes [14,20], personalizing eHealth and mHealth interventions according to values may increase the appeal of the interventions and result in higher user engagement. This type of approach has been successfully applied in social marketing, where the message is tailored to the needs and preferences of different target groups [12,21].

To effectively utilize values for personalizing eHealth and mHealth interventions, understanding the relationships between

values, well-being, and health behaviors is important. Results of previous studies regarding healthy and unhealthy values in terms of well-being are quite inconsistent (eg, [22-24]), and studies focusing on the relationship between values and health behaviors are sparse. This paper aims to contribute to the knowledge of the associations between values and commitment to values combined with well-being and health behaviors observed in the Finnish population.

Previous Work

Commitment to Values and Well-Being

Previous research indicates that living up to the values one holds important is beneficial for subjective well-being (SWB) [22,25,26]. SWB has been considered as a scientific term for happiness, which comprises 3 primary components—positive affect, negative affect, and life satisfaction [27]. Sharing similar value priorities with one’s social group seems to enhance SWB, as the prevailing environment supports the value-congruent behavior of the person [22,28] and fosters positive interpersonal relationships [29]. Similarly, having values that conflict with social norms may hinder value-congruent behavior [30] and pose a negative influence on SWB [22]. Moreover, people are not always aware of their true, intrinsic value priorities, and differentiating personal values from social expectations may be challenging [26]. Hence, the cognitive process of value clarification and the conscious decision to behave according to or commit to one’s values are sometimes needed for increasing value-congruent behavior and improving well-being [31]. Value clarification and commitment to value-congruent behavior are central concepts in the so-called third wave of cognitive-behavioral therapies [32], which have been effective in treating mental health problems (eg, [33]).

Value Types, Well-Being, and Health Behaviors

Schwartz value theory [34] is an extensively studied value classification system, which originally defined 10 broad value types based on the basic human needs, representing different motive orientations. The values form a circumplex structure with 2 axes—openness to change versus conservation and self-transcendence versus self-enhancement. Schwartz value types and the value structure have been recognized and verified in more than 65 different countries. Therefore, the theory is considered as near-universal and applicable across different cultures [34-36]. However, individual differences in the perceived importance attributed to each value type can be substantial [30]. More recently, a version of 11 Schwartz value types has been applied in research, where the Universalism value is divided into 2 subtypes—Nature and Social concern (eg, [37-39]).

A significant amount of research has been focused on the relationships between distinct value types and SWB, (eg, [19,23,24,40,41]). On the basis of the nature of the motivational goals underlying the values, it has been theoretically postulated

that values expressing intrinsic goals of autonomy, relatedness, and competence [42] as well as growth needs [18], that is, Self-direction, Stimulation, Universalism, Benevolence, and Achievement, should enhance SWB [22,23]. In contrast, values expressing extrinsic goals such as wealth and fame [42], or deficiency and self-protection needs, that is, Power, Security, Conformity, and Tradition, should have a negative impact on SWB [23,24]. These assumptions were based on early findings, which indicated positive associations of intrinsic goals [43,44] and negative associations of extrinsic goals [43] with SWB.

Recently, Sortheix and Schwartz [24] theorized that values expressing person-focused growth needs (ie, Stimulation, Self-direction, and Hedonism) and the need for relatedness (Benevolence) should be positively associated with SWB. The authors found empirical support for these associations in their large, cross-cultural sample of 32 countries. However, earlier findings regarding the associations between value types and SWB have been quite inconsistent [19,22-24,41]. The most consistent evidence can be found for the negative relationship between valuing Power and SWB [24]. In addition, the observed correlations between the value types and SWB have been mostly weak or moderate [19,22-24,41]. The inconsistent findings could be partly explained by the differences found in socioeconomic and cultural contexts, which can either support or constrain individuals in pursuing their values. For instance, the observed relations of Tradition, Universalism, and Achievement with SWB seem to be opposite in countries with high versus low socioeconomic and egalitarian development [24,45].

The research regarding the associations between value types and health behaviors is sparse and scattered across different behaviors. Most of the studies focus on eating habits (the consumption of fruit and vegetables, calorie-dense food, or meat; and eating out habits) and substance usage (alcohol, tobacco, or drugs). Among Australian participants, Universalism has been observed to be associated with healthy eating habits [46-49], and Hedonism may be associated with overeating [30]. The associations between values and substance usage have been studied particularly among adolescents. One study observed that smoking behavior was related to valuing broadmindedness, independence, and freedom as well as disvaluing obedience [50]. Another study found that extrinsic aspirations (eg, wealth, fame, and public image) were associated with substance use [51]. However, Young and West [52] concluded in their longitudinal study that values may not predict youngsters' substance use in the long term.

Some studies report a relationship between values and stress-enhancing, exercise, or certain high-risk health behaviors. Valuing health seems to be more related to behaviors that are preventive of direct (eg, drunk driving and smoking) than indirect (eg, seat belt usage and health information seeking) health risks [53]. Furthermore, a study among youngsters found that the (negative) correlations between valuing exciting life and reporting health-risk preventive behaviors were higher than the (positive) correlations with valuing health, whereas for middle-aged adults valuing health was more related to direct health-risk preventive behaviors than valuing exciting life [54]. In eastern and central Europe, risky sexual behavior has been found to have a moderate but consistent relationship with

Achievement, Power, Hedonism, Stimulation, and Self-direction [55]. Hedonism may be associated with stress-relieving (relaxing) behavior, whereas Achievement appears to be associated with stress-enhancing behavior (taking on many commitments) [30]. Universalism has been observed to be associated with regular physical activity [47].

Except for the cross-cultural study of Sortheix and Schwartz [24], the reviewed studies regarding values, well-being, and health-related behaviors were relatively small, involving some hundreds of participants. Furthermore, the studies involved mostly younger adults (students) or teachers, thereby limiting the generalizability of the results. Overall, the evidence for associations between values and well-being is still quite inconsistent, and comprehensive research focusing on a multitude of health-related behaviors is lacking.

This Study

This study aims to discover the associations between self-reported values (commitment to values and value priorities), perceived well-being, and various self-reported health behaviors from a large, cross-sectional dataset of open Web-survey responses, available from more than 100,000 Finnish citizens. The data were collected as part of the Finnish Happiness-Flourishing Study (FHFS), which was a national effort to promote mental well-being and healthy behaviors in the Finnish population [56]. The survey included questions assessing various dimensions of well-being and several different health behaviors. The measures for well-being factors included happiness, depression, life satisfaction, impact of major negative and positive life events on happiness, family- and work-related distress, and communal social activity. The health behavior-related factors comprised exercise, intake of fruits and vegetables, sleep hours, alcohol consumption, and smoking. The data regarding personal values were unstructured including free-text responses.

We adopted an exploratory approach for the data analysis to study whether (1) commitment to values was related to well-being, (2) certain value types could be considered healthier than others in terms of their associations with well-being or health-related behaviors, and (3) previous findings could be replicated with the extensive data at hand. On the basis of previous research, we hypothesized positive associations between well-being and commitment to values [26] as well as between well-being and the value types reflecting intrinsic goals of relatedness and person-focused growth needs [24,43]. Value types reflecting extrinsic aspirations or deficiency needs were expected to be negatively associated with well-being [24]. Associations between value types and health-related behaviors were also expected, especially between Universalism, healthy eating, and regular exercise (eg, [47]).

Methods

Study Design

The data were collected at the public website of the FHFS campaign over the period of 1 year, between 2009 and 2010 [56]. FHFS was a national effort to promote mental well-being and a healthy lifestyle in the Finnish population. The study

campaign was implemented in collaboration among the National Institute for Health and Welfare, Duodecim Medical Publishing Ltd, a Finnish television (TV) production company (Tarinatalo), and the national public broadcasting company (YLE). The campaign produced a reality TV series about happiness and depression, where celebrities were learning happiness-related skills. The series attracted roughly 250,000 weekly viewers. The FHFS website and the Web survey were part of the campaign (see [Multimedia Appendix 1](#) for the FHFS survey items in Finnish). The FHFS Web survey was advertised during the series episodes and at the website of the broadcasting company. It was freely available to all Finnish-speaking individuals having access to internet. The purpose of the Web survey was to allow participants to measure their happiness levels with the Happiness-Flourishing scale [56] and to encourage them to identify the key sources in life that contributed to their happiness. However, the survey also involved questions about a variety of other well-being factors and health behaviors. On the website of the FHFS survey, it was clearly stated that the collected data would be used for creating public summary reports regarding happiness and the related factors.

The study we conducted was a retrospective and explorative data analysis of the FHFS campaign data, which was driven by our hypotheses regarding the associations between values, well-being, and health behaviors.

Participants

Altogether, 139,462 anonymous responses were received to the Web survey. The respondents, who did not provide their age or gender, or reported ages below 18 or above 110 years, were excluded from the analyses of discovering associations between variables. In addition, the responses that involved 2 or more unrealistic values for numeric variables were considered unreliable and hence excluded from the study sample. If a response involved an implausible value for 1 numeric variable only, this value was treated as a missing input. The numeric values were considered unrealistic if they did not fall into the following variable-specific ranges—alcohol consumption (0-150 units/week), smoking (0-100 cigarettes/day), weight (30-250 kg), height (70-220 cm), body mass index (BMI, 10-50 kg/m²), sleep hours (3-16 hours/day), years of education (from 9 years to the current age of the respondent minus 3, “age-3” years; the compulsory education in Finland takes 9 years), and income

(0-5,000,000 Euros/year). After applying these exclusion criteria, 101,130 responses remained in the study sample, of which, 62,625 responses included a list of personal value items. The basic demographics of the study sample are provided in [Table 1](#).

Materials

Well-Being Factors

Perceived happiness was measured using the Happiness-Flourishing scale [56] (Cronbach alpha=.93), which involves 10 items evaluated with a 7-point Likert scale. The score is the sum of the item-specific answers ranging from 10 (*very unhappy*) to 70 (*very happy*). Depression was measured with the Depression Scale [57] (Cronbach alpha=.92). Life satisfaction was assessed by the 7-point Likert-item “How satisfied are you with your life situation right now” (1= *completely unsatisfied* and 7= *completely satisfied*). The validity of employing single-item measures for life satisfaction has been shown in the study by Cheung and Lucas [58].

The impact of major positive and negative life events on happiness was assessed in 3 parts. First, it was enquired whether one had experienced in the past significant negative (eg, divorce, loss of a loved one, prison sentence, unemployment, or serious illness) or positive (eg, new relationship, marriage, retirement, childbirth, new job, or work promotion) changes in life that still mattered. Second, the perceived significance of the reported event was assessed with the item “Estimate the influence of the life event on your happiness nowadays,” having a response scale from 1 (*no influence*) to 10 (*significant negative or positive influence*). Finally, the timing of the event was enquired with 5 predefined response options (*within the past 6 months, 1 year, 2 years, or 5 years, and earlier*).

Family- and work-related distress as well as communal social activity were addressed with the following questions: “Do you experience problems in your relationship with your partner?” (problems with partner), “Have your children caused you particular problems?” (problems with children), “How often are you troubled with having to push yourself to the limit in order to cope with your present job or work load?” (work stress), and “How often do you participate in communal social activities or events related to e.g. handicrafts, culture or religion?” (communal social activity). The response options for these questions are presented in the Results section.

Table 1. Self-reported demographics of the respondents included in the study sample (N=101,130).

Characteristics	Valid, n (%) ^a	Proportions, %
Gender	101,130 (100)	
Male		21.12
Female		78.88
Age (years)	101,130 (100)	
18-29		17.12
30-44		30.37
45-54		24.60
55-64		21.22
≥65		6.70
Years of education^b	86,698 (85.73)	
<12 (comprehensive school)		13.48
12-14 (upper secondary education)		27.10
15-17 (bachelor's degree or equivalent)		35.04
>17 (master's or doctoral degree)		24.39
Gross household income (Euros/year)	89,821 (88.82)	
0-17,999		24.94
18,000-35,999		24.79
36,000-59,999		21.12
≥60,000		29.15
Body mass index (kg/m²)	99,434 (98.32)	
<18 (underweight)		1.70
18-24.99 (normal weight)		50.63
25-29.99 (overweight)		31.49
≥30 (obese)		16.19

^aProportion of respondents with data available.

^bThe education level (in parenthesis) is estimated based on the Finnish education system.

Health-Related Behavior

Physical activity level was assessed with the question “On the average, how much do you exercise or strain yourself physically during your leisure time?” with 4 response options defined by the Gothenburg Scale [59]. According to World Health Organization’s global physical activity recommendations, people should do moderate-intensity activities for at least 2.5 hours per week or vigorous-intensity activities for at least 1 hour and 15 min per week to gain health benefits [60]. Overall, 3 of the 4 response options (performing at least 4 hours of moderate-intensity activities per week, 3 hours of fitness training per week, and athlete training several times a week) indicated of meeting the public health recommendations for physical activity and thus were interpreted as regular exercise and dichotomized into a binary variable.

Healthy eating habits were assessed with the following 2 questions: “On the average, how often do you eat fresh fruits or berries?” and “On the average, how often do you eat fresh vegetables” with 4 response options (*less than once a week, 1-2*

times per week, 3-5 times per week, once a day, and more often). According to public health recommendations, people should consume at least 5 portions of fruits and vegetables per day [61]. Thus, the response options of the 2 questions were combined into a binary variable, describing the daily consumption of vegetables, fruits, or berries (healthy eating).

Sleep duration was assessed with the open question “On the average, how many hours do you sleep?” Sleeping 7 to 8 hours per night was regarded as a healthy amount of sleep [62] and dichotomized into a binary variable. Alcohol consumption was assessed with the open question “How many units of alcohol do you drink per week?” accompanied with an explanation for an alcohol unit (1 unit is equivalent to 10-14 g of pure alcohol such as 0.33 L of average-strength beer [4%-7%], 12 cL of wine [10%-15%], or 4 cL of spirits [35%-40%]; [63]). Smoking was assessed with the open question “How many cigarettes, cigars, or pipefuls do you smoke per day?,” and a binary variable was created for representing nonsmoking.

Personal Values

The FHFS Web survey was not designed for the purpose of value research; hence, it did not include a validated value survey for assessing personal values. Commonly used tools for value research include the 57-item Schwartz Value Survey (SVS) [34,35] and the Portrait Value Questionnaire (eg, PVQ-21) [64], which define values as “guiding principles in your life” or concepts that are important in one’s life. In the Web survey, the respondents were asked to define the key ingredients of their happiness and were presented with a predefined set of value items via an interactive user interface that allowed to name or choose up to 20 values. A library of more than 200 value items was available in the Web-system, and the respondents could select values from this library as well as freely enter their own items. The predefined value items were presented via a space-like animation, where items from the value library appeared and disappeared in a random order, attempting to resemble twinkling stars in the night sky. The respondents could select values from this value-space by clicking the appearing terms; type words into a search box with predictive text input utilizing the library; or alternatively, enter text from outside the library.

In spite of not employing a traditional value survey, we consider the collected data to represent a good approximation for personal values for the following 2 reasons: (1) one’s “key ingredients of happiness” are most likely personally important concepts in life, just like values are important [15-17]; and (2) exposing the respondents to a predefined library of value items provided a clear clue about the type of data expected from them. Similarly, in the SVS, a list of value items are presented to the respondents [34,35].

Finally, the commitment to live up to one’s personal values (commitment to values) was assessed with the 7-point Likert-item “I have firm values that I strive to nurture” (1= *I totally disagree* and 7= *I totally agree*).

Statistical Analysis

Associations With Commitment to Values

The statistical analyses were performed with the IBM SPSS (version 20) and the free R (version 3.3.1) statistical software. The connections between commitment to values and variables related to well-being factors and health-related behaviors were assessed with multiple linear regression. Visual inspection, pairwise correlations (Pearson and Spearman), descriptive statistics, and principal component analysis (PCA) were used to identify mutually strongly correlated variables among the well-being factors and health behaviors. Depression ($r_{81124}=-.78$, $P<.001$) and life satisfaction ($r_{91876}=.72$, $P<.001$) correlated strongly with happiness. According to the results of PCA, these variables appeared to align along a common dimension—all had high loadings (.93 for happiness, -.90 for depression, and .87 for life satisfaction) on the same, single component, which explained 80.57% of the overall variability in the data. Variables that did not correlate strongly with each other ($|r|<.4$) were included in the regression model as independent variables. Among the 3 highly correlated variables, only happiness was chosen to be included in the regression model to avoid the

problem of multicollinearity. The other variables included were problems with partner, problems with children, work stress, communal social activity, regular exercise, healthy eating, healthy amount of sleep, nonsmoking, alcohol consumption, age, and gender.

One-third of the responses (27,599 out of 82,919), which involved self-assessments regarding commitment to values, had at least 1 of the independent variables missing. Instead of omitting these responses from the regression analysis, multiple imputation (MI) with fully conditional specification (FCS), available in SPSS, was used. MI with FCS is a statistically valid method for creating imputations in large complex datasets that involve both continuous and categorical variables [65]. All the independent variables were included in the imputation model, and 5 sets of imputations were created. For the integer-valued scale variables, the imputed values were rounded. The highest proportion of missing values (20,765/101,130, 20.53%) was imputed for nonsmoking. For most of the other variables, the proportions of missing (imputed) values were less than 5%. The regression analysis was applied on the imputed dataset. The results are presented via the unstandardized beta (B) and its 95% CI. Furthermore, squared semipartial correlations (part r^2) were calculated separately for each independent variable, adjusted for age and gender, and reported as a measure for the effect size.

The association between commitment to values and the impact of major life events on happiness was assessed separately from the model presented above to involve the timing of the events as a controlling factor. Linear regression was used to study whether commitment to values, controlled for age, gender, and the timing of a major life event, was associated with the impact of the life event. Distinct regression models were built for negative and positive life events. These analyses were performed using the original data, as the impact of major life events was not part of the imputation process. Compared with the other variables of interest, only a small proportion of the responses were related to major life events—altogether, 28,709 and 29,671 responses were included in the analyses regarding negative and positive life events, respectively.

Classification of Value Items

The reported value items were classified into value groups based on the Schwartz value theory. Altogether, 779,392 value items described with 23,552 different terms or expressions, including the items with typing errors, were reported in the study sample. Typing errors and infrequent entries were discarded by selecting only those items for classification, which occurred at least 50 times in the data, resulting in 723 different terms.

The classification procedure was conducted in 2 phases. The first phase was performed manually by AH. Obvious synonyms and words, which could be clearly identified to belong under a superordinate category, were renamed with a descriptive common term. For instance, the synonymous words “buddies,” “good friends,” “friendship,” and “friend” were renamed as “friends,” and the words “wife,” “husband,” “spouse,” “boyfriend,” and “girlfriend” were renamed as “partner.” After the renaming procedure, the number of distinctive terms was

reduced to 472. This set of terms was then grouped according to the 11 Schwartz value types [37-39] and the related 57-item SVS [34,35]. The words having the same meaning with a Schwartz value item as defined in the SVS were located under the corresponding Schwartz value type. However, many of the reported terms were not represented in the list of Schwarz value items, and language-specific nuances introduced some uncertainty for the matching. Hence, additional non-Schwartz value groups were created for the terms that described similar concepts but could not be matched with any of the Schwartz value items with a complete certainty. Even rather alike concepts were grouped separately to minimize the information loss at this point, despite increasing the likelihood of resulting in highly correlated value groups. As a result, 27 non-Schwartz groups were created in addition to the 11 Schwartz value types.

The second phase of the classification procedure was computational, aiming at investigating whether (1) some value groups correlated strongly with each other and, therefore, could be merged or (2) some value items should be relocated to a different group. The manually classified value items were transformed into a matrix, where the columns represented value types and the rows represented the number of value items each respondent had reported per value type. PCA based on the promax oblique rotation method was used to identify highly correlated dimensions in the value matrix and to verify the appropriate grouping of value items. Only the respondents who had more than 90% of their value items classified with at least 4 classified value items were included in the PCA to diminish the impact of the possible nonsense responses on the classification. The details of the PCA procedure are explained in [Multimedia Appendix 2](#). As a result, the number of non-Schwartz types (groups) was reduced from 27 to 20. Finally, the value types were recoded into binary variables (0=*no items reported* and 1=*at least one item reported* for the value type).

Associations With Value Types

Logistic regression was used to study the relationships between the 20 most common value types observed in the study sample and the following well-being and health behavior-related factors: happiness, regular exercise, healthy eating, nonsmoking, and alcohol consumption. Only the respondents who had reported at least 4 value items considered in the value classification were included in the analysis (55,539 out of the 62,625 responses available). This restriction was made to decrease the probability of including nonsense responses that were provided without actual contemplation, for instance, for testing the interactive user interface. Separate logistic regressions were performed for each pair of well-being or health behavior factor and value type, having the binary value type as the dependent. The analyses were adjusted for age and gender. For reference, similar analyses were performed to assess the relationships between the selected well-being or health behavior factors and reporting value items in general (ie, at least 4 classified items) with 92,394 eligible respondents. The results are presented using odds ratios (ORs) with the corresponding *P* values.

Results

Statistics of the Responses

A slight majority (52.06%, 43,166/82,919) of the population reported strong commitment to values, and most (63.57%, 64,286/101,130) of the respondents provided a list of their personal value items. A slight majority (51.56%, 48,785/94,617) reported to be happy, though many suffered from work stress and experienced problems with their partners every now and then. Most of the respondents (59.73%, 60,403/101,130) did not share their experiences regarding major negative or positive life events. A clear majority reported healthy behaviors. The descriptive details of the responses are presented in [Table 2](#).

Table 2. The self-reported mental well-being and lifestyle characteristics in the study population (N=101,130).

Variable	Valid, n (%) ^a	Proportions, %
Commitment to values (scale 1-7)	82,919 (82)	
Weak (1-3)		7.21
Moderate (4-5)		40.73
Strong (6-7)		52.06
Number of reported value items	101,130 (100)	
None		36.43
1-3		6.03
4-13		47.62
14-20		9.91
Happiness (score 10-70)	94,617 (93.6)	
Unhappy (10-30)		5.59
Neutral (31-50)		42.46
Happy (51-70)		51.56
Impact of major negative life events (scale 1-10)	39,016 (38.58)	
Weak (1-4)		34.73
Moderate (5-7)		38.93
Strong (8-10)		26.34
Impact of major positive life events (scale 1-10)	40,727 (40.27)	
Weak (1-4)		3.94
Moderate (5-7)		21.24
Strong (8-10)		74.83
Problems with partner	97,809 (96.72)	
Not in a relationship		26.62
Never		22.16
Sometimes		43.87
Almost all the time		7.35
Problems with children	97,903 (96.81)	
No children		33.56
Rarely or never		45.52
Sometimes		14.24
Almost all the time		6.67
Work stress	97,303 (96.22)	
Not working or studying		13.85
Rarely or never		24.35
Sometimes		38.60
Almost all the time		23.20
Communal social activity	98,872 (97.78)	
At least once a week		27.49
At least once a month		25.53
Once or twice a year		22.60
Rarely or never		24.39

Variable	Valid, n (%) ^a	Proportions, %
Regular exercise	99,580 (98.47)	
Yes		76.51
No		23.49
Daily intake of vegetables, fruits, or berries	97,621 (96.53)	
Yes		62.25
No		37.75
Sleep 7 to 8 hours	98,502 (97.40)	
Yes		74.17
No		25.83
Alcohol consumption (units/week)	92,285 (91.25)	
0		28.24
1-5		44.37
6-10		16.23
11-16		5.91
>16		5.26
Nonsmoker	80,365 (79.47)	
Yes		81.47
No		18.53

^aThe proportion of respondents with data available.

Associations With Commitment to Values

A significant regression equation was found ($F_{20,82898}=2123.11$, $P<.001$, adjusted $r^2=0.34$) for demonstrating the associations between commitment to values and various well-being and health behavior-related factors. The regression results are presented in Table 3. Among all the variables, happiness showed the strongest (positive) association with commitment to values (part $r^2=0.28$). Involvement in communal social activities (summed part $r^2=0.09$), regular exercise (part $r^2=0.06$), and daily intake of vegetables, fruits, or berries (part $r^2=0.04$) were also positively but weakly associated with commitment to values. Problems with partner, problems with children,

work-related stress, healthy amount of sleep, smoking, alcohol consumption, age, and gender were not associated with commitment to values.

Commitment to values was inversely associated with the perceived impact of major negative life events ($B=-0.35$, 95% CI -0.37 to -0.33 , part $r^2=0.03$) and positively associated with the perceived impact of major positive life events ($B=0.28$, 95% CI 0.27 to 0.30 , part $r^2=0.04$) on happiness, after controlling for age, gender, and the timing of the events. Both regression models were significant ($F_{8,28701}=20427.54$, $P<.001$, adjusted $r^2=0.85$ and $F_{8,29663}=97850.55$, $P<.001$, adjusted $r^2=0.96$ for negative and positive life events, respectively), though the associations were very weak.

Table 3. Linear regression results regarding the associations between commitment to values and various well-being and health behavior-related factors (n=82,919).

Variable	B (95% CI)	Part r^2 ^a
Intercept	2.51 (2.46 to 2.57)	— ^b
Gender (reference=male)		
Female	0.11 (0.09 to 0.12)	0.006
Age (years)	0.00 (−0.0 to 0.0)	0.009
Happiness score	0.06 (0.06 to 0.06)	0.281
Problems with spouse (reference=not in a relationship)		
Never	−0.04 (−0.06 to −0.01)	0.014
Sometimes	−0.07 (−0.09 to −0.05)	0.001
Always	0.04 (0.01 to 0.07)	0.004
Problems with children (reference=no children)		
Never	0.01 (−0.01 to 0.03)	0.003
Sometimes	0.00 (−0.02 to 0.03)	0.000
Always	0.08 (0.04 to 0.11)	0.001
Work stress (reference=not working or studying)		
Never	−0.06 (−0.08 to −0.03)	0.008
Sometimes	−0.06 (−0.09 to −0.04)	0.002
Always	−0.02 (−0.05 to 0.01)	0.003
Communal social activity (reference=less than yearly)		
Weekly	0.39 (0.37 to 0.41)	0.050
Monthly	0.27 (0.25 to 0.29)	0.029
Yearly	0.15 (0.13 to 0.17)	0.010
Regular exercise (reference=no)		
Yes	0.35 (0.33 to 0.36)	0.055
Daily intake of vegetables, fruits, or berries (reference=no)		
Yes	0.20 (0.18 to 0.22)	0.035
Sleep 7 to 8 hours (reference=no)		
Yes	0.00 (−0.02 to 0.02)	0.009
Alcohol consumption (units/week)	−0.01 (−0.01 to −0.01)	0.010
Smoking (reference=yes)		
No	−0.01 (−0.03 to 0.01)	0.009

^aObtained from separate regression models for each variable, adjusted for age and gender.^bNot applicable.

Associations With Value Types

The classified value items covered 94.30% of the 779,392 value-related words or expressions reported. The classification resulted into 11 Schwartz and 20 non-Schwartz value types. However, in this paper, we report results regarding the value types that were expressed at least by 10% of the eligible respondents, that is, all the 11 Schwartz value types and 9 non-Schwartz value types (see [Multimedia Appendix 3](#) for the definitions and exemplary value items for these value types). The 3 most common value types represented in the study sample were the appreciation of Loved ones (non-Schwartz), Hedonism

(Schwartz), and Health (non-Schwartz). The most common value type, Loved ones, was reported by 73.13% (40,616/55,539) of the respondents. The prevalence of different value types are provided in [Multimedia Appendix 4](#). The median number of value items classified under the value types was 20 items (range: 1-47 items). Most people used 1 to 2 value items to express a value type, but several value items were also used. For instance, Loved ones could be expressed with a single item “family,” or with several items such as “father,” “mother,” “little sister,” “big brother,” and “child.”

The observed associations between value types and happiness; exercise; intake of vegetables, fruits, or berries; alcohol consumption; and smoking are summarized in [Multimedia Appendix 4](#). The value types having the most significant and extensive associations with happiness and health behaviors, after controlling for age and gender, were Power (social status, dominance—Schwartz), Mental balance (self-acceptance—non-Schwartz), and Health. Smoking; irregular intake of vegetables, fruits, or berries (unhealthy eating); irregular exercise; a 10-unit decrease in the happiness score; and the increase of alcohol consumption by 10 units per week increased the odds of reporting Power values by 27.80%, 27.78%, 24.66%, 20.69%, and 17.35%, respectively. A 10-unit decrease in the happiness score, smoking, unhealthy eating, and irregular exercise increased the likelihood of reporting Mental balance-related values by 24.12%, 20.79%, 16.67%, and 15.37%, respectively. Regular exercise, nonsmoking, and the daily intake of fruits, vegetables, or berries (healthy eating) increased the odds of valuing Health by 71.71%, 39.96%, and 26.76%, respectively.

Other meaningful associations between value types and happiness or certain health behaviors were observed for Tradition (commitment to traditions or religion—Schwartz), Universalism-nature (Schwartz), Stimulation (exciting life—Schwartz), Conformity (with social norms—Schwartz), and the appreciation of Loved ones and Culture (non-Schwartz). The decrease of weekly alcohol consumption by 10 units increased the likelihood of valuing Tradition by 29.30%. Regular exercise increased the odds of reporting Universalism-nature values by 26.09%. Smoking increased the odds of reporting values related to Stimulation and Conformity by 22.62% and 20.48%, respectively, whereas nonsmoking increased the likelihood of valuing Loved ones and naming Culture values by 18.34% and 15.12%, respectively. Unhealthy eating increased the likelihood of reporting Conformity values by 19.46%, whereas healthy eating increased the odds of naming Culture and Universalism-nature values by 15.20% and 13.94%, respectively. A 10-unit increase in the happiness score increased the odds of valuing Loved ones by 17.23%.

A 10-year increase in age increased the odds of naming Conformity values by 29.43%, whereas a 10-year decrease in age increased the odds of valuing Work (non-Schwartz) by 19.12%. Women were more likely to value Home (non-Schwartz), Loved ones, Universalism-nature, Quality of relationships (non-Schwartz), and Health than men with increased odds by 91.19%, 69.73%, 59.74%, 41.06%, and 31.85%, respectively. For men, the odds of reporting Intellectualism (non-Schwartz), Perseverance (non-Schwartz), Conformity, and Achievement (Schwartz) values were increased by 62.52%, 53.54%, 37.80%, and 28.75%, respectively.

In general, women were more likely to report value items than men with the increased odds of 77.08%. There were no major differences observed in the age, happiness, and health-related behaviors between the respondents who reported values and those who did not.

Discussion

Principal Findings

We explored whether the self-assessed commitment to one's values and the reported value items were related to self-reported well-being and health behavior-related factors in a large, cross-sectional sample of Finnish citizens. In our analyses, perceived happiness was considered as the main measure of well-being. As hypothesized, commitment to values was positively, and strongly, associated with happiness. The presumed associations between the value types and happiness were partially supported by our findings. Furthermore, several associations between different value types and health behaviors were observed.

Comparison With Previous Work

Commitment to values was explored in relation to various well-being and health behavior-related factors. In addition to observing a strong relation between commitment to values and happiness, we discovered that commitment to values was positively associated with frequent communal social activity, regular exercise, and the daily consumption of fruits, vegetables, or berries, though these associations were much weaker compared with happiness. Furthermore, commitment to values seemed to diminish the impact of major negative life events on perceived happiness and strengthen the impact of positive events but with weak associations. Family- and work-related distress, sleep hours, smoking, and alcohol consumption were not associated with commitment to values.

None of the Schwartz values, considered to express the intrinsic aspirations for relatedness and autonomy, or the person-focused growth needs (Stimulation, Self-direction, Hedonism, and Benevolence) were positively associated with happiness, which is somewhat at odds with previous findings [22-24]. However, the appreciation of Loved ones (non-Schwartz value) was positively, although weakly, associated with happiness. We consider valuing Loved ones to express the intrinsic aspiration relatedness—the need to connect with and care for others [42]. Thus, this finding supports earlier observations regarding the positive relation between the aspirations for relatedness and SWB [43,44]. Interestingly, Benevolence was not associated with happiness, though conceptually it may seem similar to Loved ones. Apparently, the motives behind these 2 value types differ somewhat from each other—Valuing Loved ones may reflect both the desire to enhance the welfare of others and the personal need for company, whereas Benevolence values may express mostly the former motive. Hence, valuing Loved ones might express relatedness more fully than Benevolence. However, in the traditional value surveys, these 2 motives are not differentiated from each other.

The Schwartz value Power (social status, wealth, and dominance), considered to express extrinsic aspirations, was negatively associated with happiness, which is consistent with previous findings [24]. In addition, Mental balance (self-acceptance—non-Schwartz) values were negatively associated with happiness. In the study sample, Mental balance values reflected the active process of learning to survive with external pressures, manage stress, and accept one's

incompleteness, which we consider to express deficiency needs. Hence, the finding regarding Mental balance is aligned with the previous results indicating that expressing deficiency needs is negatively associated with SWB [22,24,43].

Our findings confirm many of the previous results regarding the associations between value types and health behaviors but also suggest new, previously unexplored associations. We found that Power, Mental balance, and Health (non-Schwartz) values had the most significant and extensive associations with several health behaviors. Unhealthy behaviors (smoking; insufficient intake of vegetables, fruits, or berries; and irregular exercise) were more prevalent among the respondents who reported Power or Mental balance values compared with those who did not report them. In addition, Power values were associated with slightly increased alcohol consumption. Extrinsic aspirations such as wealth and public image have been previously observed to be related to substance abuse [51]. Furthermore, regular exercise and nonsmoking were considerably more prevalent among respondents who reported Health values compared with those who did not, and healthy eating habits were also related to valuing Health. Likewise, positive associations between valuing Health and reporting healthy behaviors have been observed before [53,54].

In addition, we observed associations between several other value types and selected health behaviors. Reporting Tradition (commitment to traditions or religion—Schwartz) values was associated with decreased alcohol consumption. Conformity (with social norms—Schwartz) and Stimulation (exciting life—Schwartz) values were associated with smoking. The link between smoking and Stimulation values has also been observed before [54]. The appreciation of Universalism—nature (Schwartz) value was associated with regular exercise and healthy eating, though the association with healthy eating was weak. Previously, it has been observed that Universalism values, in general (nature and social concern), are related to healthy habits [46-48]. Our results suggest that this may be true particularly for the nature dimension of Universalism.

Significant gender differences were observed for value priorities. Women especially valued Home (non-Schwartz), Loved ones, and Universalism—nature values, but Quality of relationships (non-Schwartz) and Health values were also important. Men especially valued Intellectualism (non-Schwartz) and Perseverance (non-Schwartz) values, but Conformity and Achievement (Schwartz) values were also common. These results are consistent with the past research on gender differences in personality types (see eg, [66]). At the population level, it has been observed that women score higher in nurturance, gregariousness, and neuroticism traits and seem to be more sensitive to emotions than men. Men tend to be more assertive and intellectually or idea oriented than women. Though these differences have been shown to be pervasive across cultures, they are modest when compared with the individual variation within each gender [66]. Regarding the observed age differences in this sample, Conformity values were more prevalent among older respondents and Work (non-Schwartz) values among younger respondents.

Each of the 11 Schwartz value types were represented in the study sample, but 9 additional value types, reported at least by 10% of the study population (n>5554), were also identified. This finding is unsurprising, as the Schwartz value theory was developed to represent distinctive motive orientations within and across cultures instead of representing all the possible human values [34,35]. Schwartz et al acknowledge that other values do exist, but their meaning may vary considerably between cultures or individuals [36,67]. For instance, valuing health could express either Security (avoiding illness) or Hedonism (enjoying the pleasure of a healthy body) [36].

Strengths and Limitations

The study is unique in terms of the large sample size and diverse data, including information about various well-being and health behavior-related factors, coupled with personal values. Most of the previous, relevant studies have been restricted regarding the sample size and have involved mostly students or teachers. A welcome exception to these limitations is the recent, large, cross-cultural study of Sortheix and Schwartz [24], which focuses on the associations between value types and SWB. This study covers a broader set of aspects by also including self-reported health behaviors and commitment to values. The age distribution in this sample was representative of the Finnish working-age population at the time of the study. However, the sample is biased toward female respondents and the education level of the respondents was higher than in the general population (Statistics Finland Web database, years 2009-2010 [68]), which is important to keep in mind when considering the generalizability of the results.

We note that the Web survey received responses from people who were attracted by the FHFS campaign, and many of them might have followed some episodes of the happiness-related reality TV series. Thus, especially those people who had a special interest in their well-being, and/or were seeking ways to improve their happiness, might have noticed the survey. Furthermore, those respondents who actively followed the TV series might have already learned some strategies to improve their happiness before answering the Web survey, which could be reflected in their responses, for example, in the value items reported. The social-desirability bias could have also influenced the respondents to evaluate their state of well-being and health behaviors in a more positive light than in reality. However, as this study does not seek to estimate the state of well-being or the value distribution in the population, we consider that the abovementioned matters do not have a significant influence on the results. Although the distributions for happiness, healthy behaviors, and commitment to values were positively skewed, the employed measures captured enough variability to reveal associations between values, happiness, and health behaviors. Furthermore, a variety of value types, covering all the Schwartz value types, was represented in the sample.

We acknowledge that the employed nonvalidated, uncontrolled method for collecting personal values, and assessing commitment to values with a single-item measure could reduce the reliability of the results. However, our study is not the first of a kind to extract knowledge about values from unstructured data and apply the Schwartz value theory in an unconventional

setting. Bardi et al [69] measured the national patterns of Americans' values from newspaper texts by utilizing a value lexicon they derived based on SVS and demonstrated the validity of their approach. Our methods share similarities with their approach, though our study setting was considerably more controlled, as the collected data were closely related to personal values. The single-item measure for commitment to values might have been interpreted slightly differently among the respondents, for example, providing a low score could mean unfamiliarity with the concept of values in general or awareness of one's values without commitment to them. Nonetheless, the measure was associated positively with the happiness scale, and the observed association was strong.

The major differences between the employed and traditional value surveys are related to the value definition (ie, the question format), survey structure, and the importance ratings of the value items. In the FHFS Web survey, values were defined as the "key ingredients of happiness," whereas traditionally they are defined as the "guiding principle in your life" or concepts that are important in one's life [34,35,64]. We suggest that in practice, these definitions are sufficiently similar to each other, as the concepts that produce happiness must also be personally important; therefore, people strive to fulfill them in their choices in life, which is characteristic to values [15-17]. According to the qualitative research of Delle Fave et al [70], the terms used by lay people to describe happiness involve concepts very similar to value items, such as stability, respect to others, just society, harmony, joy, achievement, and autonomy. Moreover, in the Web survey, the respondents were exposed to a predefined library of value items, which provided a clear clue about the type of data that were expected from them. However, responses were not restricted, so people could decide for themselves as to which items were worth reporting. Thus, it is reasonable to assume that the values reported were somehow personally meaningful and hence important.

The value classification scheme was partly subjective, as many of the value items were manually located under Schwartz value types based on the reasoning of one person (AH). However, the exemplary list of value items defined in the 57-item SVS [34,35] was strictly followed; only the items for which obvious, conceptual counterparts could be identified from the SVS were located under Schwarz value types. In addition, PCA was used to verify the hypotheses regarding the appropriate grouping of the remaining ambiguous items.

Despite the abovementioned limitations, the study has the following strengths, which reduce the potential variability and bias in the results. First, we have addressed the main challenges posed by the uncontrolled and unstructured nature of the data in the employed analysis methods. Second, we have a large sample size that is likely to compensate for some of the shortcomings. Conclusions at the population level have been drawn before also from large datasets collected in uncontrolled, scientifically nonvalidated settings, for example, regarding the sleep quality among the users of commercial wearable devices [71]. Third, our interpretations are based on effect sizes rather than on statistical significance in terms of *P* values. Fourth, the resulting value classification is consistent with the results of previous work, as each of the 11 Schwartz values were

represented in the study sample. Furthermore, many of the non-Schwartz values, which emerged from our study, are consistent with the classification of Delle Fave et al [70], which is based on qualitative and unstructured data, similar to ours.

Implications

Understanding the connections between values, well-being, and health-related behaviors could provide valuable insight for the development of engaging eHealth and mHealth interventions that are effective in promoting behavior change and well-being. This large study replicates many of the previous findings related to the associations between value priorities, well-being, and health behaviors and highlights the positive relationship between commitment to values and happiness. In addition, because of the qualitative and unstructured data on values, we found previously unexplored associations—pondering over mental balance issues appeared to be negatively associated with happiness and several health behaviors. Gender differences in reporting values were stark; women emphasized "soft" values (eg, nurture, nature, and health), whereas majority of men reported "hard" values (eg, persistency, achievement, and influence). Valuing Loved ones emerged as a separate value from Benevolence and was associated with happiness, whereas Benevolence was not.

Though this study does not determine causal relations between values and the factors related to well-being and health behaviors, the strong motivational nature of values in guiding attitudes and behaviors, in general, suggests that values could predict behavior, at least via attitudes [17,20,30]. The observed positive association between commitment to values and happiness supports the previously suggested benefits of encouraging value clarification and value-congruent behavior in mental health interventions [31]. Furthermore, knowledge of the associations between values and health behaviors could help identify some of the reasons why one is not motivated to lead a healthy lifestyle, which would enable personalizing interventions to tackle these barriers. People endorsing values that express strong deficiency needs may have more pressing needs to attend before they are able to focus on healthy behaviors. These observed associations between unhealthy behaviors and reporting Mental balance values support this line of thinking. As values reflect the motives, needs, and preferences of people, they could also be utilized for reframing the goals of health behavior change in a more personally appealing way, attempting to create positive personal outcome expectations (ie, behavioral beliefs) associated with healthy behaviors, which in turn would result in a more favorable attitude toward taking action [14]. This type of approach may help engage the unmotivated proportion of the population, not actively interested in health benefits. For example, presenting healthy lifestyle as a means for increasing productivity at work and professional influence might appeal to people valuing Power.

These results along with the motivational nature of values indicate that it is worth to explore how values could be used to personalize and reframe behavior change goals in eHealth and mHealth interventions, and whether this approach would be effective in increasing user engagement at the individual level. The population-level knowledge provided by this study could

be utilized in formulating educated hypotheses on how addressing values in eHealth and mHealth interventions may influence user engagement. However, testing these hypotheses would require rigorous research with well-defined, controlled study settings.

Finally, we consider this study as a successful demonstration of the potential of exploiting data collected in uncontrolled settings. Nowadays, the challenge of refining knowledge from unstructured and incomplete data has become ever so relevant, as data from citizens are becoming increasingly available because of the digitalization of societies. This development also provides interesting opportunities for studying the preferences, attitudes, and behavior of citizens.

Conclusions

This large study suggests that commitment to values is positively associated with happiness and replicates many of the previously observed relationships between value priorities and factors related to well-being and health behaviors. Previously unexplored associations between values, health behaviors, and happiness were also found. Health, Power, and Mental balance values were most relevant in terms of happiness and health behaviors. The results could be utilized in formulating educated hypotheses on how addressing values in eHealth and mHealth interventions may influence user engagement to be tested in controlled study settings.

Acknowledgments

This retrospective analysis was supported by the grant 313401 (Sisu at work) from the Academy of Finland and the grants 1703/31/2010 (SalWe research program), 609/31/2014, 2895/31/2015 (Digital Health Revolution initiative), and 63/31/2012 (Finland Distinguished Professor program) from Tekes (Finnish Funding Agency for Innovation). The authors warmly thank Tuomas Lehto (PhD) for his valuable comments on an early version of the manuscript and feedback regarding the value classification procedure. The authors also thank Heimo Langinvainio (MD, PhD) for feedback regarding the value classification. Dr Langinvainio also designed the library of value items included in the FHFS Web survey.

Authors' Contributions

AH, ME, IK, PM, HJ, and MP contributed to the conception or design of the work; AH and EH performed the data analysis and interpretation; AH drafted the article; and all the coauthors critically revised the paper and have approved the final version for publication.

Conflicts of Interest

None declared.

Multimedia Appendix 1

The Finnish Happiness-Flourishing Study (FHFS) Web Survey.

[[PDF File \(Adobe PDF File\), 66KB - mental_v6i4e12170_app1.pdf](#)]

Multimedia Appendix 2

Details of the principal component analysis (PCA) procedure applied for the classification of value items.

[[PDF File \(Adobe PDF File\), 21KB - mental_v6i4e12170_app2.pdf](#)]

Multimedia Appendix 3

Definitions of the value types expressed by the respondents.

[[PDF File \(Adobe PDF File\), 73KB - mental_v6i4e12170_app3.pdf](#)]

Multimedia Appendix 4

Associations between value types, happiness, and health behavior-related factors.

[[PDF File \(Adobe PDF File\), 81KB - mental_v6i4e12170_app4.pdf](#)]

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Abbreviations

eHealth: electronic health

FCS: fully conditional specification

FHFS: Finnish Happiness-Flourishing Study

mHealth: mobile health

MI: multiple imputation

OR: odds ratio

PCA: principal component analysis

SVS: Schwartz Value Survey

SWB: subjective well-being

TV: television

Edited by P Bamidis; submitted 11.09.18; peer-reviewed by H Yang, F Lautenbach; comments to author 06.11.18; revised version received 31.01.19; accepted 14.02.19; published 22.04.19.

Please cite as:

Honka AM, Helander E, Pavel M, Jimison H, Mustonen P, Korhonen I, Ermes M

Exploring Associations Between the Self-Reported Values, Well-Being, and Health Behaviors of Finnish Citizens: Cross-Sectional Analysis of More Than 100,000 Web-Survey Responses

JMIR Ment Health 2019;6(4):e12170

URL: <http://mental.jmir.org/2019/4/e12170/>

doi: [10.2196/12170](#)

PMID: [31008710](#)

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Publisher:
JMIR Publications
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