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Original Paper

# A Personalized, Interactive, Cognitive Behavioral Therapy–Based Digital Therapeutic (MODIA) for Adjunctive Treatment of Opioid Use Disorder: Development Study

Björn Meyer<sup>1</sup>, PhD; Geri-Lynn Utter<sup>2</sup>, PsyD; Catherine Hillman<sup>3</sup>, PsyD

<sup>1</sup>GAIA AG, Hamburg, Germany

<sup>2</sup>Orexo US, Inc, Morristown, NJ, United States

<sup>3</sup>Central Behavioral Health, Norristown, PA, United States

**Corresponding Author:**

Björn Meyer, PhD

GAIA AG

Hans-Henny-Jahnn-Weg 53

Hamburg, 22085

Germany

Phone: 49 40351052 ext 31

Email: [bjoern.meyer@gaia-group.com](mailto:bjoern.meyer@gaia-group.com)

## Abstract

**Background:** Opioid use disorder (OUD) is characterized by the inability to control opioid use despite attempts to stop use and negative consequences to oneself and others. The burden of opioid misuse and OUD is a national crisis in the United States with substantial public health, social, and economic implications. Although medication-assisted treatment (MAT) has demonstrated efficacy in the management of OUD, access to effective counseling and psychosocial support is a limiting factor and a significant problem for many patients and physicians. Digital therapeutics are an innovative class of interventions that help prevent, manage, or treat diseases by delivering therapy using software programs. These applications can circumvent barriers to uptake, improve treatment adherence, and enable broad delivery of evidence-based management strategies to meet service gaps. However, few digital therapeutics specifically targeting OUD are available, and additional options are needed.

**Objective:** To this end, we describe the development of the novel digital therapeutic MODIA.

**Methods:** MODIA was developed by an international, multidisciplinary team that aims to provide effective, accessible, and sustainable management for patients with OUD. Although MODIA is aligned with principles of cognitive behavioral therapy, it was not designed to present any 1 specific treatment and uses a broad range of evidence-based behavior change techniques drawn from cognitive behavioral therapy, mindfulness, acceptance and commitment therapy, and motivational interviewing.

**Results:** MODIA uses proprietary software that dynamically tailors content to the users' responses. The MODIA program comprises 24 modules or "chats" that patients are instructed to work through independently. Patient responses dictate subsequent content, creating a "simulated dialogue" experience between the patient and program. MODIA also includes brief motivational text messages that are sent regularly to prompt patients to use the program and help them transfer therapeutic techniques into their daily routines. Thus, MODIA offers individuals with OUD a custom-tailored, interactive digital psychotherapy intervention that maximizes the personal relevance and emotional impact of the interaction.

**Conclusions:** As part of a clinician-supervised MAT program, MODIA will allow more patients to begin psychotherapy concurrently with opioid maintenance treatment. We expect access to MODIA will improve the OUD management experience and provide sustainable positive outcomes for patients.

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**KEYWORDS**

MODIA; opioid use disorder; digital therapeutic; cognitive behavioral therapy; medication-assisted treatment; Broca

## Introduction

Opioid use disorder (OUD) is characterized by loss of control of opioid use; recurrent opioid use despite efforts to cut down and despite having persistent physical, psychological, social, or interpersonal problems associated with opioid use; impaired social functioning; craving; tolerance; and withdrawal [1]. Despite attempts in recent years to combat the situation in the United States, the burden of opioid misuse and OUD is a national crisis with substantial public health, social, and economic implications [2]. A 2019 report from the Substance Abuse and Mental Health Services Administration found that in the past year, 9.5 million American adults misused opioids [3]. The same report found that 1.5 million American adults had OUD in the past year [3]. The opioid crisis has led to significant loss of life, with 63%-82% of drug overdose deaths involving 1 or more opioids [4-6]. Drug overdose deaths involving prescription opioids have risen steadily over the past 2 decades, reaching 17,029 in 2017 [7]. Meanwhile, deaths from nonprescription synthetic opioids such as fentanyl have increased exponentially in recent years, from fewer than 5000 in 2013 to 28,466 in 2017 [7]. The opioid crisis also comes with debilitating financial costs. In 2015, the overall economic burden of the opioid crisis was estimated to be US \$504 billion [4].

Medication-assisted treatment (MAT) is the current standard treatment for opioid addiction and involves the use of medications, in combination with counseling and behavioral therapies, to provide a “whole-patient” approach to the treatment of OUD [8]. MAT has been demonstrated to reduce illicit opioid use and opioid craving, improve treatment retention, and help sustain recovery [9-11]. One modality of therapy used in the MAT population is cognitive behavioral therapy (CBT), an evidenced-based type of psychotherapy built on the idea that cognitions (eg, thoughts, beliefs, and schemas) and behaviors play a central role in the etiology and maintenance of psychopathology [12]. CBT is considered an evidenced-based approach for the treatment of many psychiatric conditions [12] and has demonstrated added benefit when combined with OUD pharmacotherapies [13-17]. In addition, CBT alone has demonstrated preliminary efficacy in relation to other forms of drug counseling and psychosocial support in patients with OUD [18,19]. Multiple OUD medications—namely methadone, extended-release naltrexone, buprenorphine monotherapy, and buprenorphine/naloxone combination product—are available as part of an MAT program. These drugs are indicated for use as part of a comprehensive treatment plan that includes counseling conducted by a mental health professional and psychosocial support [20-25].

Despite these indications and the demonstrated efficacy of MAT, access to effective counseling, psychotherapy, and psychosocial support is a limiting factor in the treatment of OUD and a significant problem for many patients and physicians. There are an insufficient number of addiction psychiatrists and counselors in the United States, and many clinicians lack the proper training to provide adequate, evidence-based counseling or psychotherapy such as CBT for patients with OUD [26,27]. In a survey of physicians actively prescribing buprenorphine, 93% thought most patients would benefit from counseling, but

only 36% reported an adequate number of counselors in their area [28]. Medical providers also lack the financial incentives and training to deliver and coordinate psychological interventions. Current reimbursement models are disproportionately focused on the pharmacotherapy aspect of OUD treatment, with the behavioral component significantly underfunded [29]. Moreover, many reimbursement models do not support care coordination and psychosocial services, and development of models to support MAT delivery are needed [30].

The shortage of counselors likely translates to deficits in psychological intervention because in a survey of 400 patients who were taking buprenorphine, 41% reported not receiving counseling in their first 30 days of treatment [31]. The limited access and use of psychological interventions are likely to continue in the future. Under one scenario analyzed by the National Center for Health Workforce Analysis, multiple provider types, including psychiatrists and substance abuse and behavioral disorder counselors, are predicting a shortage of more than 10,000 full-time equivalent positions by 2025 [32].

In addition to the limited availability of effective counseling services, attitudinal barriers such as stigma can also prevent individuals from seeking or receiving counseling or psychotherapy [33-35]. Patients often worry about how their doctor will react to a disclosure of substance use and potential consequences of having this information in their medical records [34]. These concerns appear somewhat warranted because negative attitudes toward patients with OUD among providers limit access to treatment, harm reduction services, and may lead to the receipt of suboptimal care [33]. Logistical issues, such as busy lifestyles and difficulty traveling, can also complicate access to counseling and prescriptions [36]. Furthermore, barriers to MAT are exacerbated for vulnerable populations, including older people, racial minorities, people who live in rural communities, and those who are homeless, unemployed, or require payment assistance for treatment [33,36-38].

The opioid crisis has placed an enormous burden on the US health care system and has prompted significant support for new and innovative treatment alternatives. One such alternative is digital therapeutics (also discussed under labels such as internet-based interventions, web-based self-help, web-based psychological intervention, and computerized or electronic CBT, among others), an innovative new category of medical mobile apps that help prevent, manage, or treat diseases by delivering therapy through the use of software programs [39]. Digital therapeutics can circumvent barriers to uptake, improve treatment adherence, and enable broad delivery of evidence-based management strategies to meet service gaps [40,41]. Digital therapeutics have been shown to be effective across a broad range of psychiatric conditions, including depression, anxiety, and addictive disorders [42-45]. However, few digital therapeutics have thus far specifically targeted OUD.

A notable digital therapeutics platform for OUD that has been described in the literature is reSET-O, a prescription CBT digital therapeutic intended to be used as an adjunct to outpatient buprenorphine treatment that encompasses contingency management (CM). In an unblinded, controlled clinical trial,

addition of reSET-O significantly increased retention in a 12-week treatment program. Although patients were generally compliant with the program, addition of reSET-O did not decrease illicit drug use in comparison with buprenorphine plus CM alone [44]. reSET-O was cleared by the US Food and Drug Administration (FDA) in 2018 [46] for use by patients who are currently under the supervision of a clinician as an adjunct to outpatient treatment that includes transmucosal buprenorphine and CM, validating the potential of digital therapeutics for OUD [47].

Because there is only 1 FDA-cleared digital therapeutic for OUD currently on the market, additional options are needed, especially those that maximize the personal relevance and emotional impact of the interaction to potentially increase learning effects and enhance overall treatment effectiveness. Multiple studies suggest that individually tailored digital interventions tend to be more effective than their nontailored counterparts, possibly because tailoring increases perceived personal relevance, which then leads to more elaborated cognitive processing and greater therapeutic impact [48-50]. MODIA is a novel digital therapeutic that aims to engage patients with OUD in a series of “simulated dialogues” in which a broad range of CBT skills and exercises are conveyed and practiced. The program is designed to tailor the content and style of these CBT skills, as described below, to maximize the relevance to individual patients’ needs and preferences. Here, we describe the development of MODIA with the aim of providing effective, accessible, and sustainable management for patients with OUD.

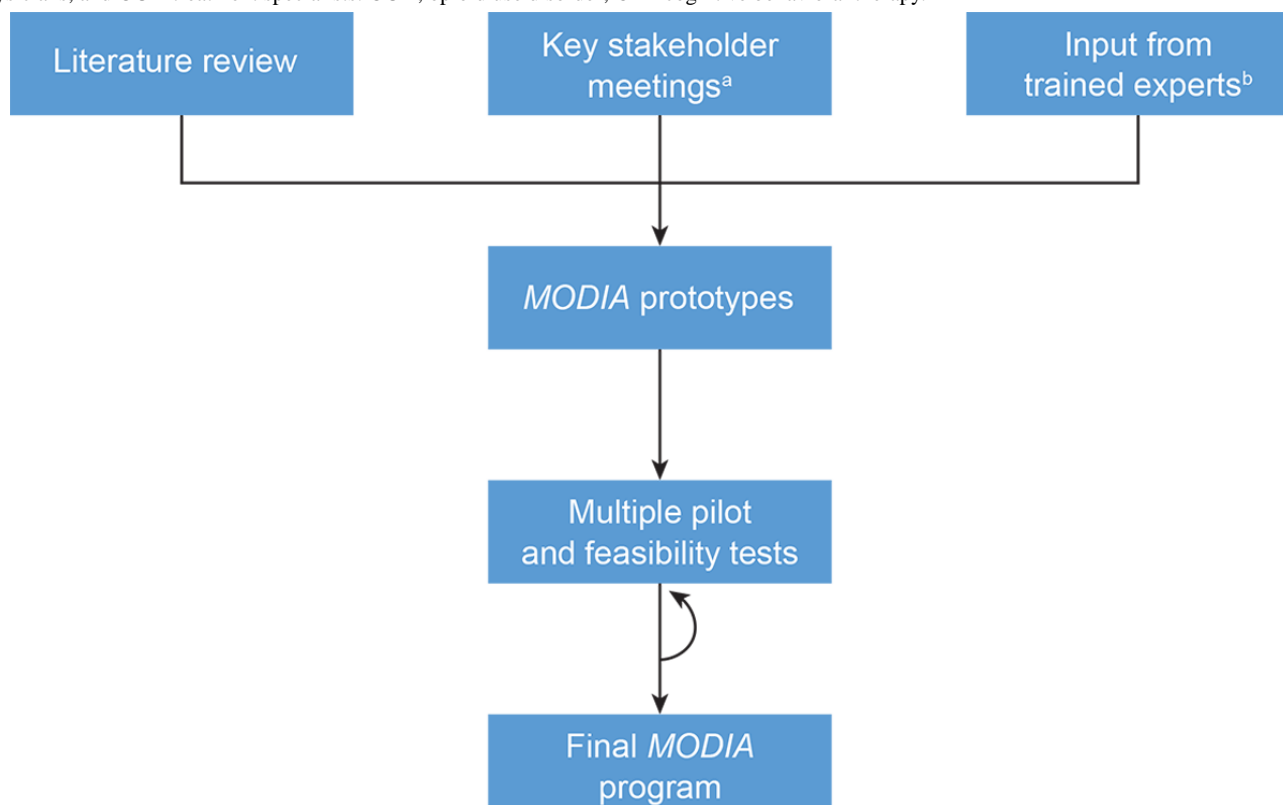
## Methods

MODIA is a digital therapeutic for the treatment of OUD, which is rooted in evidence-based treatment techniques that are consistent with a CBT framework. It is intended to be used as part of a clinician-supervised MAT program. MODIA tailors content to the individual user, providing a personalized and interactive psychotherapy intervention that engages end users in CBT exercises and aims to empower them with skills to cope

with cravings, withdrawal symptoms, potential trigger situations, and emotional symptoms accompanying OUD (eg, anxiety and depression). MODIA also allows users to develop a customized relapse prevention plan that encompasses risk behaviors, triggers, cravings, and coping strategies on the basis of patient inputs collected throughout the module exercises.

MODIA was developed by a multidisciplinary, international development team associated with GAIA AG in Hamburg, Germany. The development process followed a framework developed by GAIA over the course of more than a decade and is generally consistent with models such as the patient-focused, person-centered approach described by Yardley et al [51-54]. The MODIA development team included several licensed clinical psychologists and CBT therapists, software engineers, creative writers, graphic artists, and professional speakers. Prior to the development of the program, relevant treatment manuals, intervention descriptions, guidelines, patient reports, and trial results were reviewed by the development team (Figure 1). Several members of the development team (including BM and GU) also met in person on several occasions with experienced physicians, OUD treatment specialists, and patients at various stages of recovery. Some of these meetings took place in areas that are most severely affected by the current opioid crisis, including the Kensington neighborhood in Philadelphia, Pennsylvania. In the spirit of participant observation [55], members of the development team also attended a Narcotics Anonymous meeting in this neighborhood and had informal conversations with a variety of patients and MAT providers. Throughout the development process, several small pilot and feasibility evaluations were conducted with prototypes of the program, and results were used to refine and improve the program. Because these evaluations were part of the commercial product development process rather than academic studies, their specific results are not reported here; however, brief summaries are available upon request from the authors. On the basis of the findings of the development team, a broad range of behavior change techniques were incorporated into MODIA and are described in Table 1 [56].

**Figure 1.** MODIA Development Process (September 2019 to January 2021). a: Key stakeholders included experienced physicians, OUD treatment specialists, and patients at various stages of recovery. b: Trained experts included clinical psychologists, CBT therapists, software engineers, experienced physicians, and OUD treatment specialists. OUD, opioid use disorder; CBT cognitive behavioral therapy.



**Table 1.** Behavior change techniques included in MODIA.

| Technique                              | Representative examples   |
|--|---|
| Action planning and mental contrasting | <ul style="list-style-type: none"> <li>• Envisioning how to act in high-risk situations</li> <li>• Envisioning how to overcome obstacles</li> </ul>   |
| Avoidance                              | <ul style="list-style-type: none"> <li>• Reducing exposure to cues</li> <li>• Reflecting on people, places, and things associated with prior opioid use</li> <li>• Restructuring the social environment to support recovery</li> </ul>    |
| Behavioral substitution                | <ul style="list-style-type: none"> <li>• Encouraging engagement in alternative behaviors in high-risk situations</li> </ul>   |
| Credible source                        | <ul style="list-style-type: none"> <li>• Explaining how specific claims and techniques have been validated in well-designed studies</li> </ul>  |
| Decisional balance exercises           | <ul style="list-style-type: none"> <li>• Reflection of advantages and disadvantages of using opioids</li> </ul>   |
| Direct therapeutic advice              | <ul style="list-style-type: none"> <li>• How to use simple therapeutic techniques</li> </ul>  |
| Functional analysis                    | <ul style="list-style-type: none"> <li>• Identifying individual antecedents and consequences of opioid use</li> <li>• How to change sequences of triggers</li> </ul>  |
| Goal setting and progress review       | <ul style="list-style-type: none"> <li>• Expression of commitment to abstinence</li> <li>• Normalization and validation of relapse</li> </ul>   |
| Homework                               | <ul style="list-style-type: none"> <li>• To practice a variety of cognitive behavioral therapy techniques covered in each chat</li> </ul>   |
| Humor                                  | <ul style="list-style-type: none"> <li>• “Bruce the parrot” verbalizing unhelpful thoughts to convey “cognitive defusion”</li> </ul>  |
| Mental imagery                         | <ul style="list-style-type: none"> <li>• Envisioning a “healthy future self”</li> <li>• Guided meditation</li> </ul>  |
| Metaphors and images                   | <ul style="list-style-type: none"> <li>• Cravings as “ocean waves”</li> <li>• Unhelpful thoughts as “leaves floating on a stream”</li> </ul>  |
| Problem solving                        | <ul style="list-style-type: none"> <li>• Teaching effective skills and general problem-solving strategies</li> </ul>  |
| Psychoeducation                        | <ul style="list-style-type: none"> <li>• Cognitive behavioral therapy techniques</li> <li>• Basic neurobiological processes underlying opioid dependence</li> <li>• Role of exercise, nutrition, and sleep hygiene in recovery</li> </ul> |
| Reward                                 | <ul style="list-style-type: none"> <li>• Praise for continued program engagement</li> <li>• “Stars and crowns” (images) to reward progress</li> </ul>   |
| Simulated role-plays                   | <ul style="list-style-type: none"> <li>• Resisting social pressures to use drugs</li> <li>• Assertive communication</li> </ul>  |
| Self-monitoring and feedback           | <ul style="list-style-type: none"> <li>• Interactive self-report questionnaires</li> </ul>  |
| Self-talk                              | <ul style="list-style-type: none"> <li>• Teaching patients to practice internal monologue to support recovery</li> </ul>  |
| Storytelling                           | <ul style="list-style-type: none"> <li>• Presentation of fictional cases</li> </ul>   |
| Therapeutic writing                    | <ul style="list-style-type: none"> <li>• Writing about personally relevant issues</li> </ul>  |
| Validation                             | <ul style="list-style-type: none"> <li>• Patients are not judged for their behavior</li> <li>• Patients’ efforts are recognized and valued</li> </ul>   |

## Results

MODIA uses proprietary software technology (Broca) that dynamically tailors content to the users’ responses. This software is the basis for several other digital therapeutic programs

developed by this group and has been shown to be effective in multiple clinical trials [42,52-54,57-59]. Broca-based programs utilize an interactive approach in which the patient selects at least 1 option from predetermined menus within the program. Patients’ responses dictate what content is subsequently

presented, creating a “simulated dialogue” experience between the patient and program. On the basis of patients’ responses, various aspects of the intervention are customized to match individual needs and preferences; for example, content is conveyed in either a more empathic/warmer style or a more directive/irreverent style; patients can choose to skip certain sections or case examples; and they are offered brief exercises relevant to their situation (eg, a brief exercise on coping with shame is offered only to patients who indicate that they have felt a sense of shame and would like to learn how to cope with it). MODIA uses simple, colloquial language to enhance user engagement. The purpose of presenting therapeutic content in an informal, dialogical fashion is to simulate key characteristics of human therapeutic interactions, such as responsiveness to patient requirements, personal relevance, empathy, and the therapeutic alliance. Consistent with this approach, evidence has shown that the quality of the therapeutic alliance with a Broca-based digital therapeutic predicts therapeutic improvement [60] and that individually tailored digital interventions tend to outperform their nontailored counterparts [49].

Before using MODIA, patients receive a 12-digit personal registration code. After entering this code and accepting the program’s terms and conditions, patients are asked to enter their email and set a password, which they can use to access the program for 180 days on any suitable device, including smartphones and desktop, laptop, or tablet computers. The MODIA program comprises 24 modules or “chats.” The term “chat” is used to be consistent with the idea that the program engages in a simulated therapeutic dialogue with the patient, which is a central metaphor guiding the patient’s experience. Patients are instructed to work independently by completing 1 to 2 chats per week. Each chat can be completed in approximately 15 to 30 minutes, depending on factors such as

reading speed, selection of optional audio recordings, and individual response options or paths through the program. In addition to these chats, MODIA also includes brief motivational text messages that are sent regularly to prompt patients to use the program and help them transfer therapeutic techniques into their daily routines. Screenshots that convey the look and feel of MODIA are shown in [Figures 2-6](#).

The chats are grouped into 4 clusters. [Table 2](#) shows the chat topics, goals, and content outlines for clusters 1 and 2 as examples of the content found within a cluster; content outlines for all 4 clusters are presented in [Multimedia Appendix 1](#). In brief, the first cluster is “Basic Techniques and Principles,” in which patients are oriented to the program, learn about the neurobiology of opioid dependence, and acquire basic CBT skills. In the “Learning Psychological Flexibility Skills” cluster, patients are taught 6 core skills to increase “psychological flexibility” or the capacity to tolerate distress [61,62]. In the third cluster, “Applying Therapeutic Skills to Important Life Domains,” patients learn to apply the techniques they have learned to various relevant life domains such as interpersonal relationships, coping with depression or anxiety/worries, anger management, and insomnia. Finally, the “Facilitating Personal Growth and Development: Solidifying Your Healthy Self-Identity” cluster emphasizes the strengths, talents, and personal resources of the patient. Patients are taught to practice compassion, engage in exercises that build self-esteem and confidence, discover personal strengths, and cope successfully with slips and relapses. Building life skills such as these can help patients manage stressful situations and environmental cues that may trigger cravings and relapse. Furthermore, skills that patients develop through CBT are likely to remain even after treatment has ceased [63]. Patient-friendly language (ie, lay terms rather than medical jargon) is used in the program to describe the clusters and chats.




Figure 2. MODIA screenshot 1.

modia Menu ▾ Sam ▾

The mindfulness meditation I want to show you isn't simply about sitting still and repeating a mantra. Although, if that works for you, great.

Our **brain-boosting meditation of the day** includes another visit with **your healthy future self**.



Remember, your future self is **your north star**, the image guiding you along your path. The stronger we cement that image in our brain, the more cemented those **healthy neural networks** become.

Oh yeah! I love my healthy future self. >

I totally forgot about my healthy future self. >


Figure 3. MODIA screenshot 2.

modia

Menu ▾ Sam ▾

Great, because we're about to spend some time with them.

I've got **an audio all set up** for you here. As usual, if you can find a quiet place for a few minutes, great.



If you're only able to read the text, that's fine as well, but try to take a moment afterwards **to really let it sink in.**

Good to go?


Yep. >

I'm gonna skip this for now. >

Figure 4. MODIA screenshot 3.

modia Menu ▾ Sam ▾

I mean, acceptance can sound like giving up, can't it? But that's a sort of diagonal view of what we're talking about. So, let's try to get a square perspective.



Let's face it, all of us have something going on that's just too hard, and we wish we could change it, or make it go away. Do you know what I mean, Sam? Does anything leap to mind for you?

Like the fact that I have issues with opioids? ➤

There are tons of stuff in my life I'm struggling to accept. ➤

Nope, I'm good with everything. ➤

**Figure 5.** MODIA screenshot 4.


modia Menu ▾ Sam ▾

You too!

Here's a little reminder: You can always find all summaries, worksheets, and audios from the previous chats in the menu under [My Skills](#).

Hey Sam, guess what?

This is chat number twenty. TWENTY! Can you believe how far we've come?



That's twenty meditations, twenty skills, and twenty quizzes you've got in the bag. And may I just say, that: You. Are. Awesome.

Thanks. I'm pretty proud of myself. >

Eh. If I wasn't a screwup to begin with, I wouldn't have needed these in the first place. >

I could use a little break before we jump into the chat. >

Figure 6. MODIA screenshot 5.


modia

### Chat 20 Summary | Self-esteem and self-confidence

This chat begins with an examination about how we feel about ourselves. We take a look under the hood at our **self-confidence** and **self-esteem**. These two facets of your personality can be a game changer when it comes to avoiding relapse. Conversely, if you're feeling bad about yourself and lack confidence, it can make some people more likely to use. So, today's chat is all about building those things up.

**First, we define our subjects:**

- Low self-esteem is bad thoughts, feelings, and beliefs about yourself.
- Low self-confidence is negativity about your being capable.



The human mind is a great storyteller. It tells us stories of who we are and aren't, who we wish we could be, or a dreaded future. Sometimes this stuff is factual, but most of the time, we don't really know if these stories are true, and it doesn't really matter. What matters is, are these stories helping us or not?

**We work on a few techniques** to take the power away from these negative thoughts and reframe them. First, we play, 'I'm having the thought that...' in which we place that phrase before any negative or unwanted thought. So 'I suck' becomes 'I'm having the thought that I suck.' Or 'I need to eat a whole tub of ice cream right now' becomes 'I'm having the thought that I need to eat a whole tub of ice cream right now.' The difference is subtle, but proven to work.

**The next technique:** musical thoughts, where we take a negative thought and sing in, on repeat, to the tune of 'Happy Birthday.' Repeat if necessary, but it leeches away the power of the thought before long.

We follow that by introducing the idea of cognitive restructuring, a step-by-step process of how to question our thoughts and assumptions, particularly when they're bringing a lot of negativity into our lives. Here's what you do:

1. **Self-monitoring** – what are the thoughts?
2. **Question your assumptions** – Ask yourself if these are thoughts or facts? What evidence do you have to their accuracy or inaccuracy? Is it a black and white situation or are there shades of gray?
3. **Gather evidence** – Figure out where these thoughts came from, what triggered them? Also, gather concrete, factual evidence for or against these thoughts.
4. **Cost-benefit analysis** – What do you gain by having these thoughts? What do you lose?
5. **Generating alternatives** – how can you replace the negativity with positivity?

In our audio meditation we had a visit with our healthy future self, hearing about how their self-esteem and self-confidence has grown simply through the actions of their everyday life.

**Homework**    Either say one minute of positive things about yourself, play the 'I'm having a thought' game, or sing some negative thoughts out in a Happy Birthday tune.

MODIA | CHAT 21 SUMMARY | POSITIVE SIDES OF THE PERSONALITY

**Table 2.** Content outline of MODIA clusters 1 and 2.

| Topic (chat title) <sup>a</sup>                                  | Main goal of the chat   | Content outline <sup>b</sup>   |
|--|---|--|
| <b>Cluster 1: “Basic techniques and principles”</b>              |   |  |
| 1. Introduction to MODIA (“Meet and greet”)                      | Orient and engage patients; provide basic education and motivation to continue using MODIA.   | <ul style="list-style-type: none"> <li>• Introduction to the program’s function and purpose</li> <li>• Facilitating hope and positive expectancies</li> <li>• Interactive exploration of patient’s background</li> <li>• Risk and safety information</li> <li>• Recommendations for optimal program use</li> </ul>   |
| 2. Enhancing motivation (“Taking the measurements”)              | Build motivation by encouraging patients to reflect on the advantages of abstaining and the disadvantages of continuing to use opioids.             | <ul style="list-style-type: none"> <li>• Interactive exploration of current motivation to stop using opioids</li> <li>• Exploration of motivational stages of change</li> <li>• Enhancing motivation by building awareness of personal reasons for and ability to change</li> </ul>  |
| 3. Functional analysis (“The bird’s eye view”)                   | Empower patients to gain greater clarity on trigger situations and teach simple techniques to improve their ability to resist urges to use opioids. | <ul style="list-style-type: none"> <li>• Build awareness of personal high-risk situations and triggers</li> <li>• Introduction to functional analysis</li> <li>• Simple techniques to cope with triggers</li> <li>• Audio mental imagery/mindfulness meditation exercise to build skills to resist triggers and cravings</li> </ul>  |
| 4. Behavioral coping with triggers (“Look over there!”)          | Empower patients by teaching them how to identify and avoid high-risk situations and use simple behavioral techniques to cope with such situations. | <ul style="list-style-type: none"> <li>• Interactive functional analysis and structured assessment of: <ul style="list-style-type: none"> <li>• Personal trigger situations</li> <li>• Automatically elicited thoughts and feelings</li> <li>• Typical behaviors in high-risk situations</li> <li>• Short-term consequences</li> <li>• Negative long-term consequences</li> </ul> </li> <li>• Interactive exploration of potential approaches to altering contingencies; using behaviors for distraction coping</li> </ul> |
| 5. Cognitive coping with triggers (“The stranger in the mirror”) | Empower patients by teaching them simple methods targeting cognitions that increase risk for opioid use.  | <ul style="list-style-type: none"> <li>• Use of mental strategies rather than physical distraction activities to cope with triggers or urges to use</li> <li>• Audio exercise: revisiting the “healthy future self”</li> <li>• Fictional case example to illustrate successful and unsuccessful coping</li> <li>• Interactive exploration of cognitive coping techniques</li> <li>• Recognizing common cognitive distortions</li> </ul>  |
| 6. Review of first cluster (“Let’s get physical”)                | Review previously learned CBT <sup>c</sup> techniques and educate patients on role of healthy lifestyle in recovery.                                | <ul style="list-style-type: none"> <li>• Review of key techniques from previous five “chats”</li> <li>• Integrating the CBT techniques to encourage having a healthy lifestyle</li> <li>• Interactive exploration of the role of nutrition in opioid dependence</li> <li>• Interactive exploration of sleep habits and review of principle of sleep hygiene</li> <li>• Audio exercise: mental imagery to review key techniques from Cluster 1</li> </ul>   |
| <b>Cluster 2: “Learning psychological flexibility skills”</b>    |   |  |
| 7. Defusion and emotional distancing (“The defusion solution”)   | Teach patients to learn “defusion” techniques to distance themselves from unhelpful thoughts and feelings.  | <ul style="list-style-type: none"> <li>• Introduction to the core topic of Cluster 2: “psychological flexibility”</li> <li>• Overview and interactive exploration of the 6 components of PF<sup>d</sup> (eg, defusion, acceptance, presence, self-discovery, values, and committed action)</li> </ul>  |

| Topic (chat title) <sup>a</sup>                                   | Main goal of the chat  | Content outline <sup>b</sup>   |
|---|--|--|
| 8. Acceptance and distress tolerance (“The acceptance conundrum”) | Teach patients acceptance skills to improve distress tolerance while remaining committed to recovery-related goals.  | <ul style="list-style-type: none"> <li>• Introduction to acceptance as a key psychological flexibility technique</li> <li>• Interactive exploration of aversive thoughts and feelings</li> <li>• Experiential exercise to illustrate difficulties with thought suppression</li> <li>• Therapeutic metaphors to convey the principle of acceptance</li> <li>• Introduction of the acceptance and commitment therapy concept and the skill of “willingness”</li> <li>• Mental imagery story-based exercise to experience and practice willingness</li> </ul> |
| 9. Mindfulness and presence (“Enter the Buddha”)                  | Teach patients mindfulness techniques to reduce stress and improve coping with cravings, urges to use, and other aversive mental and emotional experiences.        | <ul style="list-style-type: none"> <li>• Brief step-by-step guided experiential mindfulness exercise</li> <li>• Mindfulness meditation exercises</li> <li>• Guided mindfulness exercise</li> <li>• Fictional case examples to convey the personal relevance of mindfulness meditation</li> </ul>   |
| 10. Self-discovery (“Who am I?”)                                  | Teach patients self-discovery skills to help them cope with high-risk situations and improve their general ability to remain committed towards healthy life goals. | <ul style="list-style-type: none"> <li>• Introduction to the 3 facets of self-discovery: the “conceptual self,” contacting the “stream of consciousness,” and “the observing self”</li> <li>• Invitation to engage in expressive writing exercise</li> <li>• Fictional case example to illustrate expressive writing; exercises to discover and observe the stream of consciousness</li> <li>• Experiential exercise on the “observing self”</li> </ul>  |
| 11. Values clarification (“The best values”)                      | Teach patients to clarify valued life directions to orient them toward a healthy life “beyond opioid dependence” and thereby support their recovery goals.         | <ul style="list-style-type: none"> <li>• Mental imagery exercise (“revisiting your healthy future self”)</li> <li>• Interactive introduction to personal values clarification as a key component of psychological flexibility</li> <li>• Fictional case example to illustrate the relevance of personal values</li> <li>• Interactive review of importance and time investment with regard to common core values</li> <li>• Interactive exploration of relevance of personal values in the context of opioid dependence</li> </ul>                         |
| 12. Commitment to healthy actions (“Do it!”)                      | Teach patients “behavioral commitment” techniques to support their efforts to achieve healthy recovery goals.  | <ul style="list-style-type: none"> <li>• Introduction to the “committed action” psychological flexibility facet</li> <li>• Review of potential obstacles that might prevent patient from pursuing core values</li> <li>• Fictional story to illustrate the concept of “SMART” (specific, measurable, adaptive, realistic, and time-framed) goals</li> <li>• Exploration of simple strategies to increase commitment to value-consistent actions</li> <li>• Mindfulness-based audio recording on committed action</li> </ul>                                |

<sup>a</sup>Please see [Multimedia Appendix 1](#) for a full outline of all 4 MODIA content clusters.

<sup>b</sup>Most “chats” also include a brief review of the patients’ emotional state, a review quiz, and homework assignment.

<sup>c</sup>CBT: cognitive behavioral therapy.

<sup>d</sup>PF: psychological flexibility.

Although MODIA is aligned with CBT principles, it was not designed to present any 1 specific CBT treatment in digital format; rather, it uses a broad range of evidence-based behavior change techniques drawn from CBT, mindfulness, acceptance and commitment therapy (ACT), and motivational interviewing (MI) (Table 2). Mindfulness and ACT encourage patients to observe and accept negative thoughts and emotions without judgment, and MI encourages patients to articulate their reasons to change [64-66]. Techniques learned from these therapeutic modalities focus on increasing patient psychological flexibility or distress tolerance to support patients’ efforts to achieve recovery from OUD, consistent with recent evidence

demonstrating the effectiveness of such techniques for substance use disorders [62].

## Discussion

### Principal Findings

Innovative, effective, and evidence-based management strategies are needed to address the opioid crisis, the substantial burden of OUD, and the limitations in access to effective counseling and care for individuals with OUD. To this end, a multidisciplinary team developed MODIA on the basis of a review of the relevant literature and in-person meetings with key stakeholders to offer individuals with OUD a tailored,

interactive digital psychotherapy intervention. The purpose of this custom-tailored individualization and personalization is to maximize the personal relevance and emotional impact of the interaction because these aspects may increase learning effects and enhance overall treatment effectiveness [49,67]. The content of MODIA is CBT-consistent but also unique and innovative, utilizing psychological flexibility-based techniques that may be particularly effective in the treatment of substance use disorders [62]. Moreover, MODIA integrates principles and techniques from MI, which encourage the patient to build awareness of personal reasons to change, to effectively direct them toward change [66], and to acquire skills for enhanced psychological flexibility, which can be regarded as a cornerstone of mental health [61]. Notably, MODIA does not use a financially based contingency management element because this may hinder product adoption at both a health care professional (HCP) level and an insurer level. In addition, contingency management may create perverse patient incentives if rewards are designed to reinforce program use rather than recovery.

MODIA is also unique in that it adapts content on the basis of user input, enabling the delivery of an individualized therapeutic experience. MODIA is intended to alleviate barriers to psychological interventions and enable ready access to effective counseling for those who may not have the opportunity to retain counseling services. The self-directed nature of MODIA allows patients to complete the program on their own time and at their own pace without additional oversight by a therapist or counselor. This aspect of MODIA is aided by self-rated questionnaires that are embedded throughout the program and allow for self-monitoring of symptoms and progress. Although MODIA is intended to be used under guidance from a MAT prescriber, MODIA respects patient privacy and is not designed to report symptoms to the patients' HCPs.

## Limitations

Although MODIA was developed with the intention of lowering barriers to psychological interventions, it is not without limitations. Like other digital therapeutics, MODIA requires an internet connection and a suitable device. Hence, those with limited access to the necessary technology may not be able to use the program. In addition, while multiple randomized controlled trials have demonstrated the clinical value of Broca-based programs using the simulated dialogue approach, some patients may require more intensive or other forms of psychological support.

MODIA is being brought to market under the FDA COVID guidance for industry. MODIA is intended to provide digital CBT for patients with OUD, 18 years of age or older, as a part of a clinician-supervised MAT program for OUD. MODIA is a prescription-only device to be ordered by a clinician. MODIA has not been clinically tested and may therefore have unknown benefits and risks.

## Conclusions

A multidisciplinary team of experts developed MODIA—a fully automated, custom-tailored digital therapy for the management of OUD. As part of a clinician-supervised MAT program, MODIA will allow more patients to begin psychotherapy at the same time they start opioid maintenance treatment. We expect that access to MODIA will improve the MAT experience and provide sustainable positive outcomes for patients with OUD. A randomized controlled trial will be conducted in the future to evaluate the efficacy of MODIA. Additional future studies may evaluate the long-term effects of MODIA; impact on treatment engagement, adherence, and early termination; as well as intervention effects on secondary outcomes such as mental health-related quality of life.

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## Conflicts of Interest

BM is an employee of GAIA AG. GU is an employee of Orexo US, Inc. CH has no competing interests to disclose.

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## Multimedia Appendix 1

Content outline of the 24 MODIA "chats."

[[PDF File \(Adobe PDF File\), 694 KB - mental\\_v8i10e31173\\_app1.pdf](#)]

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## Abbreviations

- ACT:** acceptance and commitment therapy
- CBT:** cognitive behavioral therapy
- CM:** contingency management
- FDA:** Food and Drug Administration
- HCP:** health care professional
- MAT:** medication-assisted treatment
- MI:** motivational interviewing

**OD:** opioid use disorder

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Original Paper

# Validity and Reliability of the Self-administered Psycho-TherApy-SystemS (SELPASS) Item Pool for the Daily Mood Tracking of Depressive Symptoms: Cross-sectional Web-Based Survey

Gwendolyn Mayer<sup>1\*</sup>, Dr sc hum; Svenja Hummel<sup>1\*</sup>; Nadine Gronewold<sup>1</sup>, MSc; Neele Oetjen<sup>1</sup>, MSc; Thomas Hilbel<sup>2</sup>, Prof Dr; Jobst-Hendrik Schultz<sup>1</sup>, PD, MD

<sup>1</sup>Department of General Internal Medicine and Psychosomatics, University Hospital Heidelberg, Heidelberg, Germany

<sup>2</sup>Electrical Engineering and Applied Sciences, Westphalian University of Applied Sciences, Gelsenkirchen, Germany

\*these authors contributed equally

**Corresponding Author:**

Gwendolyn Mayer, Dr sc hum  
Department of General Internal Medicine and Psychosomatics  
University Hospital Heidelberg  
Im Neuenheimer Feld 130 3  
Heidelberg, 69120  
Germany  
Phone: 49 6221 56 35685  
Email: [gwendolyn.mayer@med.uni-heidelberg.de](mailto:gwendolyn.mayer@med.uni-heidelberg.de)

## Abstract

**Background:** e-Mental health apps targeting depression have gained increased attention in mental health care. Daily self-assessment is an essential part of e-mental health apps. The Self-administered Psycho-TherApy-SystemS (SELPASS) app is a self-management app to manage depressive and comorbid anxiety symptoms of patients with a depression diagnosis. A self-developed item pool with 40 depression items and 12 anxiety items is included to provide symptom-specific suggestions for interventions. However, the psychometric properties of the item pool have not yet been evaluated.

**Objective:** The aim of this study is to investigate the validity and reliability of the SELFPASS item pool.

**Methods:** A weblink with the SELFPASS item pool and validated mood assessment scales was distributed to healthy subjects and patients who had received a diagnosis of a depressive disorder within the last year. Two scores were derived from the SELFPASS item pool: SELFPASS depression (SP-D) and SELFPASS anxiety (SP-A). Reliability was examined using Cronbach  $\alpha$ . Construct validity was assessed through Pearson correlations with the Patient Health Questionnaire-9 (PHQ-9), the General Anxiety Disorder Scale-7 (GAD-7), and the WHO-5-Wellbeing-Scale (WHO-5). Logistic regression analysis was performed as an indicator for concurrent criterion validity of SP-D and SP-A. Factor analysis was performed to provide information about the underlying factor structure of the item pool. Item-scale correlations were calculated in order to determine item quality.

**Results:** A total of 284 participants were included, with 192 (67.6%) healthy subjects and 92 (32.4%) patients. Cronbach  $\alpha$  was set to .94 for SP-D and  $\alpha=.88$  for SP-A. We found significant positive correlations between SP-D and PHQ-9 scores ( $r=0.87$ ;  $P<.001$ ) and between SP-A and GAD-7 scores ( $r=0.80$ ;  $P<.001$ ), and negative correlations between SP-D and WHO-5 scores ( $r=-0.80$ ;  $P<.001$ ) and between SP-A and WHO-5 scores ( $r=-0.69$ ;  $P<.001$ ). Increasing scores of SP-D and SP-A led to increased odds of belonging to the patient group (SP-D: odds ratio 1.03, 95% CI 1.01-1.05;  $P<.001$ ; SP-A: 1.05, 1.05-1.01;  $P=.01$ ). The item pool yielded 2 factors: one that consisted of mood-related items and another with somatic-related items.

**Conclusions:** The SELFPASS item pool showed good psychometric properties in terms of reliability, construct, and criterion validity. The item pool is an appropriate source for daily mood tracking in future e-mental health apps among patients with depression. Our study provides general recommendations for future developments as well as recommendations within the item pool.

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**KEYWORDS**

self-management; mood tracking; validity; reliability; item pool; questionnaire; depression; anxiety; mood assessment

## Introduction

### Mood Tracking and Symptom Monitoring in e-Mental Health Apps

e-Mental health apps targeting depression and anxiety play an increasing role in mental health care ranging from smartphone-based monitoring apps to extensive treatment applications [1-3]. Their evidence is regularly reviewed and shows that especially guided interventions are as successful as treatment-as-usual controls [4,5]. However, some barriers are still prevalent to fully exploit the potential of e-mental health apps in clinical practice. This might be owing to the fact that apps from clinical studies are not necessarily available in app stores, and choosing the right app poses difficulties among potential users [6]. Moreover, web-based interventions are subject to high attrition rates, as users may drop out soon after downloading apps [7,8]. The reasons for this low user engagement were identified beside others in the poor usability, the lack of user-centric design, and in their low ability to identify a crisis [9].

Regular mood tracking and symptom monitoring is a necessary step to identify sudden fluctuations that may hint at a suicidal crisis. The purpose of mood tracking in e-mental health apps for depression lies in the enhanced opportunities for self-reflection on mood and on their patterns and potential triggers of symptom aggravation [10]. Mood tracking is already implemented in a major share of e-mental health apps for depression. A recent review of Qu et al [11] on the functionality of 29 top-rated depression apps found that 19 (66%) included tools for mood tracking based on regular self-reports. Another review that focused on both, mobile apps and browser-based programs for depression, found mood-tracking functionalities in 86% [1]. Repeated measurement of a person's mood or behavior in real time is referred to as ecological momentary assessment [12], and recent studies have shown the predictive power of mobile technology for depressive symptoms by capturing step counts and sedentary behavior [13], or vital parameters including sleep quality and heart rate [14]. However, currently available apps and programs hardly exploit the full technological potential of connecting wearable functionalities of the mobile phone or sensor data to regular mood queries [15].

Regarding anxiety apps, there is only scarce data on the availability and technical realization of mood tracking thus far. The last comprehensive study [2] that contributed to this question was published in 2017 and found 52 apps, 29% of which provided "emotional ratings." It remains unclear if these ratings target mood tracking or rather initial screenings.

### Digital Mood-Related Self-assessment Tools

Digital versions of self-report scales regarding psychiatric symptoms show a comparable reliability to paper-pencil versions [16,17]. However, a detailed review of the diagnostic provenance of questions used in e-mental health apps has been missing thus far. The most frequently used questionnaire in

depression management apps and chatbots is either the depression module of the Patient Health Questionnaire (PHQ-9) or self-developed questions [11,18].

The PHQ-9 is a brief depression screening instrument that has been validated across a variety of medical conditions [19,20]. The patients' task is to self-assess the severity of 9 depressive symptom criteria over a span of the past 2 weeks; cut-off scores then allow for the assessment of depression severity. However, there are several disadvantages of the use of the PHQ-9 in a self-management app for depression. First, mood tracking in common e-mental health apps should be performed at least on a daily basis to provide timely information on the progression or worsening of symptoms and to make suggestions for symptom-specific interventions [1]. In such high-frequency self-assessment, it is important to ensure variety within the daily survey process to avoid the test routine. It has been shown that participants' compliance to give valid responses to frequent mood assessment declines with high repetition rates [21]. The PHQ-9 is a self-assessment instrument that is not conceptualized for daily use, as the adherence to answering the same 9 questions every day may be low. Moreover, the questions refer to the past 2 weeks, and patients with depression may experience negative memory bias [22]. Finally, the PHQ-9 items screen depression criteria on the basis of DSM-IV [19], which differs slightly from the International Classification of Diseases (ICD) criteria. In general, DSM-IV diagnostic criteria require the presence of fewer symptoms than ICD-10 criteria, which reveals a slightly higher prevalence of depression in countries that rely on DSM rather than ICD [23]. Therefore, depression criteria that target an ICD-based diagnostic health system, similar to European countries, should not only rely on PHQ-9 items, even though it is an accepted tool in the clinical routine.

### Comorbidity of Depression and Anxiety

Recently since the introduction of the mixed anxiety-depressive disorder (F41.2) category in the ICD-10 in 1992, the complexity of differential diagnostics of anxiety and depression became evident [24]. Data on the prevalence of mental disorders in the United States reveal that 50%-60% of individuals with major depressive disorder (MDD) have also received a diagnosis of an anxiety disorder [25], and comparable data have been reported in Germany [26]. Theories on the relationship between the 2 diseases existed early on. Clark et al [27] described with their "tripartite model of anxiety and depression" that the general negative feelings are common to both syndromes, while the lack of positive feelings distinguishes depression from anxiety. According to them, only scales with symptom-specific content can sufficiently distinguish between the 2 syndromes [27,28]. In clinical practice, screening instruments are used specifically for 1 of the 2 diseases; for example, the PHQ-9 for depression [19] and the Generalized Anxiety Disorder Scale-7 (GAD-7) [29] are both modules of the PHQ [30]. However, some instruments cover both in the same test; for example, the Hospital Anxiety and Depression Scale (HADS) [31]. Developing an item pool for the usage of web-based daily mood assessments, while considering symptoms of comorbid anxiety

in patients with depression, is necessary to provide symptom-specific intervention suggestions.

### Somatic Aspects in the Presentation of Depression

Somatic symptoms play an essential role in depressive symptomatology over the lifespan. Recent results have pointed out that depressive symptoms tend to shift with increasing age from a mood-related profile of symptoms to rather vegetative somatic symptoms including psychomotor agitation, gastrointestinal problems, or sleep disturbances [32]. Few vegetative symptoms are considered part of the diagnostic routine; for example, fatigue, loss of appetite, and sleep [33]. Understanding the individual burden profile has been found to be crucial for targeted treatment, as patients with higher values in self-criticism respond better to psychotherapy than those with a somatic symptom profile [34]. As a result, in developing an item pool for daily mood tracking in e-mental health apps, somatic symptoms should be considered to a certain extent. With regard to comorbid anxiety symptoms, somatic aspects of a panic disorder, which are associated with the characteristics of specific illnesses, have as well been detected early on [35].

### Scale Development Process

Scale development is a defined procedure that has been described comprehensively [36-38]. In short, 5 major steps are usually followed, beginning with (1) the generation of an item pool that is based on an extensive literature review and definition of the core concepts and the targeted population for the future scale. Item writing should involve simple and straightforward language while avoiding complex, ambiguous items. If a Likert-scale format is chosen, considerations about allowing midrange ratings are highly dependent on targets and core assumptions regarding the response behavior. Hence, no general conclusion regarding which response format is best is feasible [39]. (2) Qualitative analysis of the so far generated items and their content is the second step to (3) prepare a pilot with a small sample size. After that, (4) a larger evaluation study with a selected sample should be carried out by applying psychometric properties for reliability and different types of validity. Only then, norm values with a representative sample would be established [36]. The following investigation includes steps 1 to 4, while step 3 was included in a feasibility study that is currently being prepared for publication.

### Objectives

The aim of this study is the development of an item pool of mood-related questions for daily self-assessment in an e-mental health app to cover the main aspects of depressive symptoms in accordance with the diagnostic criteria of ICD-10 and comorbid symptoms of anxiety. We investigated the psychometric properties' reliability, construct validity, criterion validity, and item-scale correlation of the item pool, which may be used for future self-management apps with suggestions for symptom-specific interventions. Thus, we aim to develop recommendations for the integration of mood-tracking items in future e-mental health apps.

## Methods

### The Self-administered Psycho-Therapy-SystemS App

The mobile app Self-administered Psycho-Therapy-SystemS (SELPASS) was developed in a German study that received federal funding. This app was designed to improve the self-management of patients with depression on the basis of an individualized daily mood score. The target group comprises patients diagnosed with depression, who often wait a long time for a face-to-face psychotherapy [40]. The app allows for daily monitoring of depressive symptoms on the one hand and daily interventions to support patients on the other hand. SELFPASS does not claim to replace a face-to-face psychotherapy but rather to help patients during the waiting period, in order to bridge the treatment gap [41].

An item pool of 52 depression- and anxiety-related questions was developed to cover the main aspects of depressive symptoms and to provide suggestions for a pool of individualized interventions. Out of all items, 40 questions refer to depressive and 12 to anxiety symptoms. All questions are presented in [Multimedia Appendix 1](#) in the original German version and translated to English ([Multimedia Appendix 2](#)). The item pool was developed jointly by mental health experts, who were part of an interdisciplinary team of psychologists and physicians in the clinic of psychosomatics. Items were translated by the authors and critically checked by active colleagues from the United States and other English-speaking countries. The main development approach was a rational construction strategy; that is, the process was guided mainly by theoretical considerations on the nature of depressive symptomatology [42]. The content of the depression items followed the major and minor symptoms of major depression in accordance with ICD-10 criteria, of which major symptoms are depressed mood, loss of interest, and loss of energy. Minor symptoms referred to the commonly listed ones including lack of concentration, feelings of worthlessness, guilt, pessimistic future expectations, suicidal ideation, sleep disturbances, and loss of appetite [33]. We used the following standardized diagnostic instruments as an additional source of information regarding the nature of symptom queries; however, all questions were rephrased: depression screening using 2 questions [43], PHQ-9 [19], HADS [31], and the short version of the Beck Depression Inventory (BDI-V) [44]. As these instruments are part of routine diagnostics [45] and are also validated in their German version [46,47], they provided an evidence-based foundation for the development of the SELFPASS items. We considered the following as anxiety symptoms: nervousness, excessive worry, accompanied by the inability to stop them, restlessness and not being able to relax, tendency to panic, and the fear of something awful happening. Anxiety questions were inclined toward clinical instruments (GAD-7), and further psychometric scales [48] including the State-Trait Anxiety Inventory (STAI) [49] and the anxiety subscale of the HADS, all of which have shown good validity in their German version [49,50]. Moreover, we included 2 of our own anxiety-related questions targeting the feeling of tightness in the chest and difficulty breathing, which are common symptoms of a panic attack [35].

All questions were rephrased. Each symptom was assessed through 4 different items in accordance with recommendations in the literature regarding test construction [51]: 2 of them were formulated in a negative direction and 2 in a positive direction to ensure diversion and to control for response bias (for example, “I have trouble concentrating on something” and “I can stick to one thing and concentrate fully on it”). The items were scored on a 6-point Likert scale ranging from 0=don’t agree to 5=agree. After starting the SELFPASS app, the user is asked to complete a daily self-assessment of at least 6 items from the SELFPASS item pool. Two of the questions relate to major depressive symptoms, 2 of them to minor symptoms, and the remaining 2 to anxiety symptoms. The number of daily questions may increase on the basis of the answers of the previous day, as the algorithm is designed to track individual symptoms. If a value of 3 is exceeded (positively formulated questions were automatically recoded by the algorithm), the symptom will be assessed again with an alternative formulation on the next day. Thus, the app is able to generate an individualized symptom profile based on the patient’s most prevalent current symptoms of the respective last 3 days and suggests 3 potentially appropriate interventions. For example, a result of highly prevalent anxiety symptoms will recommend relaxation interventions, while symptoms of ruminating and self-doubt will lead to an intervention suggestion for behavioral activation and cognitive restructuring.

### Study Design

We used a cross-sectional, web-based survey design to investigate the validity and reliability of the SELFPASS item pool. The study population consisted of 2 groups. The first group included healthy subjects, who reported not having any affective disorder within in the last 3 years. The second group included patients, who have received a diagnosis of any depressive disorder within the last year. We excluded patients with bipolar disorder, a psychosis, or suicidal ideation. Ethical approval for this study was granted by the Ethics Commission of the Medical Faculty of Heidelberg University (S-031/2020).

### Recruitment

The survey was made available on the internet via the [soscisurvey.de](https://www.soscisurvey.de) [52] platform with 1 link each for patients and healthy subjects. The 2 versions included the same questionnaires except for demographic details. Thus, potentially psychiatric disorders in healthy subjects, who might take part in the study coincidentally, could be excluded. Exclusion criteria were a diagnosis with a bipolar affective disorder, a psychosis, or another psychiatric disorder within the last 3 years, and suicidality. Potentially suicidal participants were forwarded to an extra page with contact information for support. The group of healthy adults was recruited through social media channels and personal contact networks.

Patients were recruited within the Heidelberg University Hospital. They were contacted personally, via email or by post, and received a weblink to the study. Thus, the presence of a physicians’ diagnosis could be ensured, which is a prerequisite to assess criterion validity. Exclusion criteria were applied in advance.

### Validation Procedures

We provided 4 major parts of mood-related questions in random order: the German versions of the PHQ-9, GAD-7, WHO-5-Wellbeing-Scale (WHO-5) [53], as well as the SELFPASS item pool.

The PHQ-9 is a 9-item tool to assess depressive symptoms. The responses are rated on a 4-point Likert scale ranging from 0=not at all to 3=nearly every day. GAD-7 assesses 7 anxiety items on a scale from 0=not at all to 3=nearly every day. Both the PHQ-9 and GAD-7 consider a cut-off score of 10, with higher values indicating MDD [54] or moderate anxiety symptoms [55].

WHO-5 consists of 5 items, rated on a scale from 0=no time to 5=all of the time, for subjective well-being of the participant, with a high score indicating higher well-being. It was initially introduced by the World Health Organization (WHO) in 1998 as a first step in a 10-item screening process of depression and is usually followed by a diagnostic interview [56].

In this study, all psychometric instruments are used for construct validation, which refers to the alignment of the concepts measured by the instrument with their theoretical construct [57]. While the outcomes of the PHQ-9 and GAD-7 relative to SELFPASS scores serve as an indicator for convergent validity, the relationship between WHO-5 scores and SELFPASS scores demonstrate divergent validity. In turn, criterion validity targets the relationship between the results by the tested measures to an external criterion [57]. In our study, we considered the presence or absence of a valid physicians’ depression diagnosis as an external criterion to show the validity of the SELFPASS scores.

### Data Analysis

Statistical analysis was carried out in multiple steps using SPSS (version 24; IBM Corp) [58].

We excluded those data sets with a relative speed index of  $>1.75$  as well as above 10% missing data per participant following pragmatic considerations and recommendations of the literature [59,60]. The option “no specification” for the SELFPASS items was treated as missing values for all statistical analyses.

After descriptive analysis of all participants (including means, SDs, and frequencies) we calculated subscales among the 40 SELFPASS depression (SP-D) and the 12 SELFPASS anxiety (SP-A) items.

We used Cronbach  $\alpha$  to determine internal consistency of the subscales. Cronbach  $\alpha > .80$  was considered a threshold for acceptance [61,62].

Convergent validity was assessed using Pearson correlation coefficients of SP-D with PHQ-9 and SP-A with GAD-7. Pearson correlation coefficients were also computed for WHO-5 and SP-D and for the sum of SP-A and SP to assess discriminant validity. Following Cohen’s [63] definition,  $r > 0.30$  can be interpreted as a moderate and  $r > 0.50$  a strong correlation.

Logistic regression analysis was performed to analyze the power of SP-D and SP-A to distinguish between patients and healthy subjects. The results will serve as criterion validation. We



considered the  $R^2$  value in accordance with Nagelkerke [64] as good if it fell within a range of  $R^2=0.20$  and  $0.40$ .

We carried out an explorative factor analysis to investigate the underlying factor structure of the items. At first, we applied the analysis to the whole sample, and a more detailed investigation studied the factor structure within the data of only the patients. The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was interpreted as acceptable if its value exceeded  $0.50$  [65]. The Bartlett test [66] of sphericity revealed a significant ( $P<.001$ ) result, which indicated that the items were appropriate for factor analysis [67]. We chose a principal axis factor analysis approach followed by oblimin rotation, as recommended for factors that might show intercorrelations [67].

Finally, we correlated the items' values with the respective scale value to obtain the individual item-scale correlation for the analysis of the discriminatory power of each item. We applied the rule of thumb to remove items with a correlation below  $r=0.30$  [68,69]. The share of missing values of single items and their inter-item correlations was as well interpreted as an indicator for low item quality. We considered items with more

than 20 inter-item correlations below  $r=0.20$  as critical in accordance with recommendations from the literature [70]. However, the final decision about deletion of the respective items was made jointly together after the analysis of missing values and discriminatory power. All results on the level of single items are reported in [Multimedia Appendix 3](#).

A level of  $P<.05$  was considered significant in all statistical tests.

## Results

### Participants

In total, 329 participants responded to the web-based questionnaire from end-March to mid-August 2020. After excluding respondents with a relative speed index of  $>1.75$  ( $n=31$ ) and more than 10% of missing items ( $n=4$ ), as well as healthy subjects with a psychiatric diagnosis ( $n=10$ ), the final sample comprised 284 participants. The sample consisted of 192 (67.6%) healthy subjects and 92 (32.4%) patients. The demographic characteristics of the participants are shown in [Table 1](#).

**Table 1.** Demographic characteristics of the study sample (N=284).

| Characteristics                  | Participants             |                 |              |
|----------------------------------|--------------------------|-----------------|--------------|
|                                  | Healthy subjects (n=192) | Patients (n=92) | Total        |
| Age (years), mean (SD)           | 29.02 (9.70)             | 40.46 (14.91)   | 32.73 (12.8) |
| <b>Gender, n (%)</b>             |                          |                 |              |
| Male                             | 43 (22.4)                | 38 (41.3)       | 81 (28.5)    |
| Female                           | 148 (77.1)               | 53 (57.6)       | 201 (70.8)   |
| Other                            | 1 (0.5)                  | 1 (1.1)         | 2 (0.7)      |
| <b>Family status, n (%)</b>      |                          |                 |              |
| Single                           | 162 (84.4)               | 46 (50.0)       | 208 (73.2)   |
| Married                          | 19 (9.9)                 | 31 (33.7)       | 50 (17.6)    |
| Divorced                         | 7 (3.6)                  | 7 (7.6)         | 14 (4.9)     |
| Widowed                          | 0 (0)                    | 2 (2.2)         | 2 (0.7)      |
| Separated                        | 0 (0)                    | 5 (5.4)         | 5 (1.8)      |
| Other                            | 4 (2.1)                  | 1 (1.1)         | 5 (1.8)      |
| <b>Level of education, n (%)</b> |                          |                 |              |
| No degree                        | 0 (0)                    | 3 (3.3)         | 3 (1.1)      |
| High school                      | 64 (33.3)                | 37 (40.2)       | 101 (35.6)   |
| College                          | 123 (64.1)               | 47 (51.1)       | 170 (59.9)   |
| Dissertation/PhD                 | 5 (2.6)                  | 2 (2.2)         | 7 (2.5)      |
| Other                            | 0 (0)                    | 3 (3.3)         | 3 (1.1)      |
| <b>Profession, n (%)</b>         |                          |                 |              |
| Self-employed                    | 3 (1.6)                  | 1 (1.1)         | 4 (1.4)      |
| Worker                           | 5 (2.6)                  | 9 (9.8)         | 14 (4.9)     |
| Civil servant                    | 3 (1.6)                  | 3 (3.3)         | 6 (2.1)      |
| Employee                         | 51 (26.6)                | 37 (40.2)       | 88 (31.0)    |
| Not working                      | 3 (1.6)                  | 11 (12.0)       | 14 (4.9)     |
| Student/pupil                    | 123 (64.1)               | 17 (18.5)       | 140 (49.3)   |
| Retired                          | 3 (1.6)                  | 5 (5.4)         | 8 (2.8)      |
| Other                            | 1 (0.5)                  | 9 (9.8)         | 10 (3.5)     |

### Psychometric Scores and SELFPASS Subscales

The mean scores of all psychometric scales and the SELFPASS subscales are presented in [Table 2](#). On average, the healthy

subjects had lower scores on all scales than the patients, except for the WHO-5.

**Table 2.** Scores of healthy subjects and patients on the psychometric scales.

| Scale  | Healthy subjects (n=192), mean (SD) | Patients (n=92), mean (SD) |
|--|-------------------------------------|----------------------------|
| SELPASS <sup>a</sup> for depression              | 53.33 (24.62)                       | 87.40 (29.27)              |
| SELPASS for anxiety                              | 18.63 (9.65)                        | 31.37 (11.62)              |
| Overall Self-administered Psycho-TherApy-SystemS | 71.96 (32.37)                       | 118.77 (38.63)             |
| Patient Health Questionnaire-9                   | 5.39 (3.95)                         | 10.40 (5.23)               |
| General Anxiety Disorder Scale-7                 | 5.03 (3.88)                         | 8.76 (4.53)                |
| WHO-5-Wellbeing-Scale                            | 14.46 (4.86)                        | 8.57 (5.47)                |

<sup>a</sup> SELFPASS: Self-administered Psycho-TherApy-SystemS.

## Reliability

The internal consistency of the 40-item SP-D subscale and the 12-item SP-A subscale was assessed from a Cronbach  $\alpha$  of .94 for SP-D (n=240) and .88 for SP-A (n=275).

## Construct Validity

Table 3 shows the results of construct validity analysis. Regarding convergent validity, the SELFPASS depression and

anxiety subscale show positive correlations with the scores of PHQ-9 and GAD-7, respectively, as valid depression and anxiety measures. The data reveal significant negative correlations among all 3 SELFPASS scores with WHO-5 scores, showing discriminant validity.

**Table 3.** Pearson correlation analysis to determine the correlation between the scores of SELFPASS<sup>a</sup> subscales with those of the Patient Health Questionnaire-9, General Anxiety Disorder Scale-7, and WHO-5-Wellbeing-Scale.

|                                  | Pearson correlation coefficient |                     |                    |
|----------------------------------|---------------------------------|---------------------|--------------------|
|                                  | SELPASS for depression          | SELPASS for anxiety | Overall SELFPASS   |
| <b>Convergent validity</b>       |                                 |                     |                    |
| Patient Health Questionnaire-9   | 0.87 <sup>b</sup>               | 0.74 <sup>b</sup>   |                    |
| General Anxiety Disorder Scale-7 | 0.70 <sup>b</sup>               | 0.80 <sup>b</sup>   |                    |
| <b>Discriminant validity</b>     |                                 |                     |                    |
| WHO-5-Wellbeing-Scale            | -0.80 <sup>b</sup>              | -0.69 <sup>b</sup>  | -0.80 <sup>b</sup> |

<sup>a</sup> SELFPASS: Self-administered Psycho-TherApy-SystemS.

<sup>b</sup>  $P < .01$ .

## Criterion Validity

The results of the logistic regression analysis for patients and healthy subjects are presented in Table 4. The overall model

was significant ( $\chi^2_2=91.39$ ;  $P < .001$ ;  $N=284$ ) as well as the coefficients SP-D and SP-A. Increasing scores for depression and anxiety increase the odds of being part of the patient group. Details are presented in Table 4.

**Table 4.** Results of logistic regression analysis indicating the probability of being part of the patient group on the basis of the scores of the SELFPASS depression and anxiety subscales<sup>a</sup>.

| Predictor              | $\beta$ (SE) | P value | Odds ratio (95% CI) |
|------------------------|--------------|---------|---------------------|
| Constant               | -4.15 (0.49) | <.001   | 0.02                |
| SELPASS for depression | 0.03 (0.01)  | <.001   | 1.03 (1.01-1.05)    |
| SELPASS for anxiety    | 0.05 (0.02)  | .01     | 1.05 (1.01-1.10)    |

<sup>a</sup> SELFPASS: Self-administered Psycho-TherApy-SystemS; Omnibus test:  $\chi^2_2=91.39$ ;  $P < .001$ ; Hosmer-Lemeshow test:  $\chi^2_8=7.16$ ;  $P = .52$ ; Nagelkerke  $R^2=0.38$ .

## Exploratory Factor Analysis and Item Analysis

A principal axis analysis with the whole sample revealed a 2-factor solution after scree plot analysis. The 2 factors accounted for 36.70% of the variance, and oblique rotation was performed. The intercorrelation of the 2 factors was  $r=0.40$ . The KMO measure of sampling adequacy was 0.94. Four items showed inter-item correlations with coefficients less than  $r=0.20$  in more than 20 cases (SP 20, 23, 25, and 39). Item 25 was not answered in 23 of 240 (8.1%) cases. Item-scale correlations were calculated and helped evaluate the following items as critical: SP 20, 23, 24, 25, 33, and 41. After excluding them,

another exploratory factor analysis explained 40.95% of the variance. Details on the level of single items as well as the item-scale correlations are presented in Multimedia Appendix 3.

The patient subgroup showed a KMO measure of 0.70. A principal axis analysis with the patient sample accounted for 32.77% of the variance. After excluding the critical items, 35.90% of the variance was accounted for. The intercorrelation of the 2 factors was  $r=0.21$ .

The items as well as the loadings of the items in the whole sample and the patient subsample are presented in Table 5.

**Table 5.** Items, associated symptoms, and results of the principal axis factor analysis of the whole sample after oblique rotation (N=284), and of the patients' sample (n=92).

| Item                                      | Item formulation   | Symptom           | Factor 1<br>(all) | Factor 1<br>(patients) | Factor 2<br>(all) | Factor 2<br>(patients) |
|---|--|-------------------|-------------------|------------------------|-------------------|------------------------|
| <b>SELPASS<sup>a</sup> for depression</b> |  |                   |                   |                        |                   |                        |
| SP1                                       | I feel depressed, sad or hopeless.                                     | CS <sup>b</sup> 1 | 0.73              | 0.73                   |                   |                        |
| SP2                                       | I easily burst into tears.   | CS1               | 0.40              | 0.42                   |                   |                        |
| SP3                                       | I am cheerful and in good spirits.                                     | CS1               | 0.87              | 0.82                   |                   |                        |
| SP4                                       | I feel easy and carefree.  | CS1               | 0.88              | 0.77                   |                   |                        |
| SP5                                       | I have much less desire and enjoyment for things I usually like to do. | CS2               | 0.76              | 0.72                   |                   |                        |
| SP6                                       | I have no interest in people around me.                                | CS2               | 0.33              | 0.37                   |                   |                        |
| SP7                                       | I can laugh at funny moments.  | CS2               | 0.54              | 0.54                   |                   |                        |
| SP8                                       | I can enjoy pleasant things and be happy about them.                   | CS2               | 0.63              | 0.53                   |                   |                        |
| SP9                                       | I feel exhausted and sluggish.   | CS3               | 0.82              | 0.68                   |                   |                        |
| SP10                                      | I can't force myself to do anything.                                   | CS3               | 0.61              | 0.47                   |                   |                        |
| SP11                                      | Decision making is easy for me.  | CS3               | 0.48              | 0.34                   |                   |                        |
| SP12                                      | I am full of drive and energy.   | CS3               | 0.86              | 0.83                   |                   |                        |
| SP13                                      | I have problems in concentrating on something.                         | AS <sup>c</sup> 1 | 0.74              | 0.72                   |                   |                        |
| SP14                                      | My thoughts keep on slipping away.                                     | AS1               | 0.63              | 0.64                   |                   |                        |
| SP15                                      | I can dwell on one thing with my full concentration.                   | AS1               | 0.69              | 0.59                   |                   |                        |
| SP16                                      | I am not easily distracted.  | AS1               | 0.54              | 0.49                   |                   |                        |
| SP17                                      | I am just not good enough.   | AS2               | 0.54              | 0.40                   |                   |                        |
| SP18                                      | Others can do things much better than I can.                           | AS2               | 0.35              | 0.35                   |                   |                        |
| SP19                                      | I am satisfied with myself.  | AS2               | 0.76              | 0.60                   |                   |                        |
| SP20 <sup>d</sup>                         | I take care of my appearance.  | AS2               | 0.20              |                        |                   | 0.32                   |
| SP21                                      | I should have done things much differently in the past.                | AS3               | 0.43              | 0.40                   |                   |                        |
| SP22                                      | I have made mistakes. It's not surprising I feel bad.                  | AS3               | 0.47              | 0.51                   |                   |                        |
| SP23 <sup>d</sup>                         | I am not perfect. But who is?  | AS3               | 0.29              | 0.24                   |                   |                        |
| SP24 <sup>d</sup>                         | I don't deserve to feel bad.   | AS3               | -0.03             | -0.23                  |                   |                        |
| SP25 <sup>d</sup>                         | It can only get worse.   | AS4               | 0.19              | 0.14                   | 0.19              |                        |
| SP26                                      | The future has nothing to offer for me.                                | AS4               | 0.53              | 0.62                   |                   |                        |
| SP27                                      | I am looking forward to the future.                                    | AS4               | 0.67              | 0.67                   |                   |                        |
| SP28                                      | Time heals all wounds. Everything will be alright.                     | AS4               | 0.61              | 0.46                   |                   |                        |
| SP29                                      | Sometimes I think it would be better to be dead.                       | AS5               |                   |                        | 0.59              | 0.45                   |
| SP30                                      | I think a lot about death.   | AS5               |                   | 0.33                   | 0.41              |                        |
| SP31                                      | I think about putting hands on myself.                                 | AS5               |                   |                        | 0.56              | 0.31                   |
| SP32                                      | I have already thought about how to kill myself.                       | AS5               |                   |                        | 0.63              | 0.46                   |
| SP33 <sup>d</sup>                         | I sleep too much.  | AS6               | 0.16              |                        |                   | 0.35                   |
| SP34                                      | I have trouble falling asleep and/or wake up constantly.               | AS6               | 0.55              | 0.40                   |                   |                        |
| SP35                                      | My sleep was restful and sufficient.                                   | AS6               | 0.76              |                        |                   | 0.45                   |
| SP36                                      | I slept well.  | AS6               | 0.74              | 0.44                   |                   |                        |
| SP37                                      | I feel a constant hunger or appetite for food.                         | AS7               |                   | -0.06                  | 0.08              |                        |

| Item                       | Item formulation                                      | Symptom         | Factor 1<br>(all) | Factor 1<br>(patients) | Factor 2<br>(all) | Factor 2<br>(patients) |
|----------------------------|---|-----------------|-------------------|------------------------|-------------------|------------------------|
| SP38                       | I don't feel like eating anything.                    | AS7             | 0.33              | 0.30                   |                   |                        |
| SP39                       | I have a good appetite.                               | AS7             | 0.28              |                        |                   | 0.27                   |
| SP40                       | I eat enough and I follow a balanced diet.            | AS7             | 0.42              |                        |                   | 0.43                   |
| <b>SELPASS for anxiety</b> |   |                 |                   |                        |                   |                        |
| SP41 <sup>d</sup>          | I hope that I don't get sick.                         | CA <sup>e</sup> |                   | 0.18                   | 0.07              | -0.36                  |
| SP42                       | Sometimes I have an oppressive feeling in my stomach. | CA              | 0.56              | 0.55                   |                   |                        |
| SP43                       | I am worried that something terrible will happen.     | CA              | 0.37              | 0.59                   |                   |                        |
| SP44                       | Sometimes I start panicking suddenly.                 | CA              | 0.52              | 0.58                   |                   |                        |
| SP45                       | When I'm worried, I still can keep my control.        | CA              | 0.56              | 0.46                   |                   |                        |
| SP46                       | Disturbing thoughts run through my mind.              | CA              | 0.52              | 0.66                   |                   |                        |
| SP47                       | I'm calm.   | CA              | 0.79              | 0.78                   |                   |                        |
| SP48                       | When I think of my current affairs, I get anxious.    | CA              | 0.59              | 0.61                   |                   |                        |
| SP49                       | I feel safe and secure                                | CA              | 0.77              | 0.69                   |                   |                        |
| SP50                       | I'm worried about something going wrong soon.         | CA              |                   | 0.48                   | 0.43              |                        |
| SP51                       | Sometimes I feel tightness in my chest.               | CA              | 0.66              | 0.63                   |                   |                        |
| SP52                       | Sometimes I can't breathe properly.                   | CA              | 0.53              | 0.59                   |                   |                        |
| Eigen value                |   |                 | 16.95             | 14.27                  | 5.65              | 4.10                   |

<sup>a</sup>SELPASS: Self-administered Psycho-TherApy-SystemS.

<sup>b</sup>CS: core symptom.

<sup>c</sup>AS: additional symptom.

<sup>d</sup>items that should be excluded or reformulated.

<sup>e</sup>CA: comorbid anxiety.

## Discussion

### Principal Findings

This study aimed to investigate the psychometric properties of an item pool of mood-related questions for daily self-assessment, which cover symptoms of depression and comorbid anxiety to make suggestions for symptom-specific interventions. The item pool was developed for the use within the e-mental health app SELFPASS and for future developments. Through a web-based cross-sectional survey design, the instrument emerged as reliable and valid. The psychometric properties are shown in a representative study population of healthy subjects and patients with a diagnosis of depression within the past year. Considering that average PHQ-9 scores of 10.4 indicate a moderate severity of depression [54] and GAD-7 scores of 8.76 indicate mild symptoms of anxiety [55], the patients seemed to be considerably affected and were hence eligible to test the SELFPASS item pool appropriately.

Both subscales assessing symptoms of depression (SP-D) and anxiety (SP-A) showed high correlations with standardized psychometric instruments (PHQ-9 and GAD-7). This demonstrates a high inherent construct validity. The WHO-5 as an indicator of subjective well-being was negatively correlated with SP-D and SP-A, which in turn reveals good discriminatory construct validity. The negative association of the WHO-5 with depression and anxiety scales has already been

shown in other validation studies [71,72]. Moreover, the results of the SELFPASS subscales in the whole sample were able to predict the affiliation to the patient group, which was interpreted as concurrent criterion validity. As expected, increasing scores for depression and anxiety measured through SELFPASS increase the odds of being part of the patient group.

An exploratory factor analysis indicated an underlying 2-factor structure of the item pool that covered a mood-related factor on the one hand and a somatic factor on the other hand in the whole sample. The factor structure of the patient sample even increased this structure, including more items in the second factor, which were related to paying attention to appearance, suicidal thoughts, sleep, appetite, and the fear of becoming sick. There was 1 item that did not fully seem to fit to this interpretation ("I'm worried about something going wrong soon"). A potential explanation might lie in the timing of investigation, as many patients were concerned with becoming infected with SARS-CoV-2 at that time [73].

A closer investigation of screening instruments for depression shows that validation studies of the PHQ-9 among different populations; for example, in palliative care, these instruments show a comparable 2-fold factor structure of 1 factor focusing on cognitive and affective aspects and another one relating to somatic symptoms [74]. Although for palliative patients with a high somatic burden, this might be an obvious result; however, similar results were obtained in a psychiatric sample [75].

Therefore, somatic aspects of depression might reveal an underlying structure of depression and anxiety, which is reminiscent of the “Tripartite model of depression and anxiety,” which states that beside the already described “generally negative affect” as a third factor “somatic symptoms” [27,75]. Moreover, suicidal ideation has been identified as particularly crucial among patients with depression with somatic syndrome [74,75].

Enhancing the quality of e-mental health apps, especially with regard to a successful crisis management in case of symptom exacerbation, has already been identified as a necessary step to reduce dropout rates and increase adherence to digital interventions [9]. The integration of appropriate mood-tracking items, as provided by the presented item pool in future e-mental health apps, is a necessary measure in integrating digital assistance in routine clinical practice.

## Recommendations for the Use of the SELFPASS Item Pool

The SELFPASS item pool is suitable for daily mood assessment in any kind of web-based intervention or e-mental health app. It is designed for highly frequent repetitive use providing approximately 6 items every day out of the total item pool based on the results of the previous days. Following this purpose, we recommend reformulating items 20, 23, 24, 25, 33, and 41 for appropriate use and future validation studies. For any other use, the items may be dropped as well. Although item 31, 32, 37, and 39 also showed a lack of quality after item analysis, we recommend retaining these items as they assess important depressive symptoms.

Based on our experience with the development and validation of the SELFPASS item pool, some general recommendations may be provided to ensure optimization of the items (Table 6). Simultaneously, we summarized recommending conclusions within the SELFPASS item pool.

**Table 6.** Recommendations for the future use of the SELFPASS<sup>a</sup> item pool.

| Topic                | General recommendation  | Recommendation for use within the SELFPASS item pool  |
|----------------------|---|---|
| Item presentation    | Provide a diversion in item presentation to increase adherence.   | Ask for 2 main symptoms, 2 additional symptoms and two anxiety symptoms per day. If 1 symptom exceeds a critical score, pursue this symptom with an alternative item. |
| Symptom coverage     | Cover somatic, cognitive, and emotional aspects of symptomatology.  | Provide a random choice of daily items following the rules described above to cover a broad range of symptoms.  |
| Crisis management    | Include crisis management in case of positive answers to suicidal ideation.   | Same as the general recommendation.   |
| Discriminatory power | Evaluate each question with regard to whether it might be able to sufficiently differentiate between healthy subjects and patients. Hence, symptoms including increased appetite and sleep were excluded by the Beck Depression Inventory [76], but we do not follow this approach. | Reformulate items 20, 23, 24, 25, 33, and 41. A closer focus on the manifestation of these symptoms in patients with depressive and anxiety symptoms is recommended.  |
| External validation  | Provide validation of single assessments, such as BMI, as matching self-assessments of body weight or sleep parameters delivered by a sensor as control for self-assessed sleep quality.  | Same as the general recommendation.   |
| Variation            | Provide positive and negative directions of items.  | Same as the general recommendation.   |
| Targeted use         | Be aware of the target population of the questionnaire.   | The item pool addresses patients with a pre-existing diagnosis of depression for daily monitoring of their symptoms.  |

<sup>a</sup>SELPASS: Self-administered Psycho-TherApy-SystemS.

## Directions of Future Research

With the introduction of the ICD-11, some diagnostic criteria for depressive episodes will change, which should be considered for further use of the SELFPASS item pool. It is expected that the previous 3 main symptoms of depression will be reduced to 2. Fatigue and lack of drive are then considered additional symptoms [76]. Feelings of worthlessness and guilt will be summarized to one, as well as sleep and appetite. Then, psychomotor agitation or retardation, formerly included in the somatic symptoms, will be considered as own symptoms [77]. This could be relevant for apps that provide symptom-specific intervention suggestions as SELFPASS does.

Moreover, much evidence has been provided that ecological momentary assessments delivered through mobile data have

the potential to become behavioral markers for mental health symptoms; for example, movement profiles collected from GPS data and circadian sleep rhythms recorded through phone usage [78]. Unfortunately, mental health apps beyond scientific studies hardly make use of data processing technologies that allow for personalized intervention content based on the activities of the users [15]. Future studies may focus on validation approaches of different data sources in one instrument; for example, daily questions for self-assessment, sensor data, and further behavioral markers delivered through mobile devices. Validation with the help of sensor data, finally, is a powerful approach to verify the validity of the item pool during use over a longer period, to ascertain its test-retest validity. As of this writing, the item pool might serve as an ecological momentary assessment tool based on questions only, which might be asked several times per day.

Beside the somatic symptoms outlined above and considered in our item pool, it should be noted that depression is often accompanied by several somatic conditions including obesity, cardiovascular diseases, diabetes, pain, or even multimorbidity [79]. However, existing monitoring apps thus far do not target the simultaneous management of mental and somatic conditions, except for medication adherence [80]. Future approaches should build upon existing results and integrate single solutions to transdiagnostic apps that thus far exist within the field of mental health [81] but rather do not pertain to mental and physical conditions. Our item pool might serve as a valuable source and can be complemented by physical conditions.

### Limitations

There are some limitations to this study, which should be considered. First, the data were collected during the 2020 COVID-19 pandemic, which might have had an impact on the mental health of the participants [82,83]. In addition, the patient and healthy subject group differ in terms of group size, age, and gender. Regarding criterion validity, only a diagnosis of depression was defined as an inclusion criterion for the patient group. Owing to the described comorbidity of both disorders, anxiety was nevertheless also considered an external criterion to determine criterion validity. Another study should focus on comparing patient populations with validated diagnoses of both depression and anxiety separately. Thus, another confirmatory factor analysis should be performed to clarify the factor structure of the item pool. We provide a validation of a whole item pool

of 52 questions, although the number of the daily questions is much lower based on the symptom profile of the respective user. A validation of this process of choice would require a substantially high number of patients with different symptomatology, which was not possible to carry out in our study design. Moreover, we did not carry out cognitive interviewing with a small sample size of patients, which is sometimes carried out during test construction [84]. However, as the symptoms of depression are already well studied, we decided to rely on the experience of the existing diagnostic instruments. As a final limitation, delusional and psychotic symptoms that are relevant in case of a psychotic depression were not considered in the SELFPASS item pool. Psychotic depression is a subtype of depression in ICD-10, and no changes regarding ICD-11 are expected [85]. Thus, if future e-mental health apps focus as well on more severe forms of depressive disorders, further items should be added and validated.

### Conclusions

The SELFPASS item pool is a valid and reliable source for daily self-assessment in e-mental health apps. It follows diagnostic standards of depression and comorbid anxiety symptoms. The item pool is a valuable source of questions for daily mood tracking in future e-mental health apps. Further developments have to focus on optimizing the wording of single items as well as the adaptations that are expected from ICD-11 in the near future.

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### Conflicts of Interest

None declared.

#### Multimedia Appendix 1

Self-administered Psycho-Therapy-SystemS (SELPASS) question catalogue (German original).

[DOCX File, 15 KB - [mental\\_v8i10e29615\\_app1.docx](#) ]

#### Multimedia Appendix 2

Self-administered Psycho-Therapy-SystemS (SELPASS) question catalogue (English translation).

[DOCX File, 27 KB - [mental\\_v8i10e29615\\_app2.docx](#) ]

#### Multimedia Appendix 3

Results of the item analysis of SELFPASS depression (SP-D) and SELFPASS anxiety (SP-A): Means, SD, Item-scale-correlation, missing values (N, %) and number significant inter-item correlations per item (N). SELFPASS: Self-administered Psycho-Therapy-SystemS.

[DOCX File, 33 KB - [mental\\_v8i10e29615\\_app3.docx](#) ]

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## Abbreviations

- BDI-V:** Beck Depression Inventory
- GAD-7:** General Anxiety Disorder Scale-7
- HADS:** Hospital Anxiety and Depression Scale
- ICD:** International Classification of Diseases
- KMO:** Kaiser-Meyer-Olkin
- PHQ-9:** Patient Health Questionnaire-9
- SELPASS:** Self-administered Psycho-TherApy-SystemS
- SP-A:** SELFPASS anxiety
- SP-D:** SELFPASS depression
- STAI:** State-Trait Anxiety Inventory
- WHO:** World Health Organization
- WHO-5:** WHO-5-Wellbeing-Scale

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Original Paper

# Outcomes of a Blended Care Coaching Program for Clients Presenting With Moderate Levels of Anxiety and Depression: Pragmatic Retrospective Study

Monica S Wu<sup>1</sup>, PhD; Shih-Yin Chen<sup>1</sup>, MSc; Robert E Wickham<sup>2,3</sup>, PhD; Shane O'Neil-Hart<sup>1</sup>, LCSW; Connie Chen<sup>1</sup>, MD; Anita Lungu<sup>1</sup>, PhD

<sup>1</sup>Lyra Health, Burlingame, CA, United States

<sup>2</sup>Department of Psychological Sciences, Northern Arizona University, Flagstaff, AZ, United States

<sup>3</sup>Department of Psychology, Palo Alto University, Palo Alto, CA, United States

**Corresponding Author:**

Monica S Wu, PhD

Lyra Health

287 Lorton Ave

Burlingame, CA, 94010

United States

Phone: 1 877 505 7147

Email: [mwu@lyrahealth.com](mailto:mwu@lyrahealth.com)

## Abstract

**Background:** Depression and anxiety are leading causes of disability worldwide, but access to quality mental health care is limited by myriad factors. Cognitive-behavioral coaching is rooted in evidence-based principles and has the potential to address some of these unmet care needs. Harnessing technology to facilitate broader dissemination within a blended care model shows additional promise for overcoming barriers to care.

**Objective:** The aim of this study is to evaluate the outcomes of a blended care coaching (BCC) program for clients presenting with moderate levels of anxiety and depression in real-world settings.

**Methods:** This study examined retrospective data from US-based individuals (N=1496) who presented with moderate levels of depression and anxiety symptoms and who received blended care coaching services. Using a short-term framework, clients met with coaches via a secure video conference platform and also received digital video lessons and exercises. To evaluate the effectiveness of the BCC program, mixed effects modeling was used to examine growth trajectories of anxiety and depression scores over the course of care.

**Results:** Out of the total sample of 1496 clients, 75.9% (n=1136) demonstrated reliable improvement, and 88.6% (n=1326) recovered based on either the Generalized Anxiety Disorder-7 scale (anxiety) or Patient Health Questionnaire-9 (depression). On average, clients exhibited a significant decline in anxiety and depression symptoms during the initial weeks of coaching, with a continued decline over subsequent weeks at a lower rate. Engaging in a coaching session was associated with lower anxiety (b=-1.04) and depression (b=-0.79) symptoms in the same week, as well as lower anxiety (b=-0.74) and depression (b=-0.91) symptoms the following week ( $P<.001$ ).

**Conclusions:** The BCC program demonstrated strong outcomes in decreasing symptomology for clients presenting with moderate levels of anxiety and depression. When clients received coaching sessions, significant decreases in symptoms were observed, reflecting the importance of session attendance. Additionally, the steepest declines in symptoms tended to occur during the initial weeks of coaching, emphasizing the importance of client buy-in and early engagement. Collectively, these findings have implications for addressing unmet mental health care needs in a more accessible, cost-effective manner.

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**KEYWORDS**

blended care; coaching; cognitive; behavior; depression; anxiety; digital health; retrospective; mental health; CBT; cognitive behavioral therapy; outcome; video conference

## Introduction

Depression and anxiety are leading causes of disability worldwide and incur significant societal costs [1,2]. The burden is especially apparent in the workplace, as evidenced by decreased productivity, poorer performance, absenteeism, and medical costs [3,4]. There is a robust empirical base supporting the efficacy of cognitive-behavioral therapy (CBT) for anxiety and depression [5], but access to evidence-based care is encumbered by various barriers. In addition, the stigma associated with receiving psychotherapy, cost of seeing out-of-pocket providers, long waitlists, and limited access to quality providers all contribute to delays in seeking and receiving treatment [3,6].

To bridge this gap, coaching has emerged as a contender to address some of these unmet mental health care needs. Historically, coaching has been proposed to facilitate improvements in well-being and performance in personal or professional capacities, using a results-oriented process [7]. As such, coaching has typically targeted individuals who do not meet criteria for clinically significant mental health problems but may present with elevated stressors or difficulties. Coaching is suited to target these broader life and performance challenges, using approaches such as establishing goals, problem-solving, and enhancing self-efficacy. Indeed, compared to psychotherapy, coaching tends to approach care using a life-enhancing model (encouraging interventions that improve the client's overall well-being vs treating a "disorder"), and it takes a less directive stance to empower clients to devise their own solutions. Additionally, because coaching does not require advanced educational degrees or formal licensing, more coaches may be available to assist individuals, circumventing limitations in availability for licensed therapists and psychologists.

Within this context, it is important to note that less regulation in the training and qualifications of coaches does lend to more variability to the quality of care and theoretical frameworks used in coaching [8,9]. Specifically, coaches have identified myriad psychological approaches in their work, including cognitive-behavioral, psychodynamic, solutions-focused, narrative, positive psychology, and mindfulness [10,11]. Because of the significant natural variability in approaches, it is important to consider how coaching can be augmented with rigorous provider selection, cognitive behavioral training, and quality assurance, and delivered within an evidence-based framework similar to those observed in psychotherapy. To address this need, cognitive-behavioral coaching (CBC) could be a promising way to operationalize and strengthen the theoretical principles used by coaches.

Cognitive-behavioral coaching has the potential to be a cost-effective method for adapting CBT principles for use within a coaching context. However, empirical support for CBC effectiveness has been variable, and the studies that do exist widely differ in their methodology [8,12]. In addition, prior studies have primarily focused on subclinical populations experiencing heightened stress or undesired health outcomes [9,13]. The relative dearth of studies examining the utility of CBC among individuals with more moderate levels of

symptomology underscores the need to examine the effectiveness of CBC in a sample that generalizes to real-world settings. Additionally, a great deal of opportunity remains to augment the accessibility and delivery of these services within a short-term framework.

To decrease barriers to access, technological advancements have been increasingly effective in facilitating the dissemination of evidence-based care, especially CBT [14]. More specifically, blended care models have garnered growing empirical support, as the pairing of traditional face-to-face interventions with relevant digital activities has implications for greater dissemination, decreased costs, and robust treatment outcomes [15,16]. Although blended care has largely been examined in therapeutic contexts, there is a notable gap in the field for blended care coaching (BCC). In BCC, face-to-face sessions with coaches (in person or via teletherapy) work symbiotically with digital activities to introduce and reinforce key coaching concepts and skills. In general, the digital part of BCC exhibits a range of flexibility; some coaching programs are more regimented, with preset content and digital activities that are assigned to clients to be completed chronologically, while others are more flexible and personalize the assigned content based on what is discussed in the coaching sessions. Preliminary BCC studies have been tested for health outcomes [17,18]; however, these studies notably use psychologists, physicians, and other professionals with advanced degrees as the coaches. Consequently, further studies are needed to examine the effectiveness of BCC programs for psychological symptoms with greater real-world generalizability.

To date, there have been no studies examining CBC outcomes for addressing moderate levels of anxiety and depression using a blended care model. To fill this gap, the present study will examine the effectiveness of a BCC program in a real-world setting, using retrospective data of US-based clients receiving coaching services through Lyra Health. Establishing the effectiveness of BCC would have implications for addressing unmet mental health care needs in a more accessible, cost-effective manner.

## Methods

### Study Design and Procedures

This retrospective study used existing data from Lyra Health, Inc, and Lyra Clinical Associates for delivering BCC services. Lyra Health offers a behavioral health benefit to companies through which employees and dependents have access to CBC within a blended care model. Clients interested in receiving behavioral health benefits completed an initial battery of assessments to establish a baseline level of severity and determine appropriateness for services. Those who were interested in and qualified for coaching services received an average of 4 coaching sessions over 5 weeks. Assessments of depressive and anxiety symptom severity were collected at each session thereafter to track progress. All coaching sessions, assessments, and digital activities were performed through Lyra's web-based, Health Insurance Portability and Accountability Act (HIPAA)-compliant platform. This pragmatic, retrospective analysis of deidentified data gathered

from coaching offered by Lyra Clinical Associates was determined to not be human subjects research by the Western Institutional Review Board.

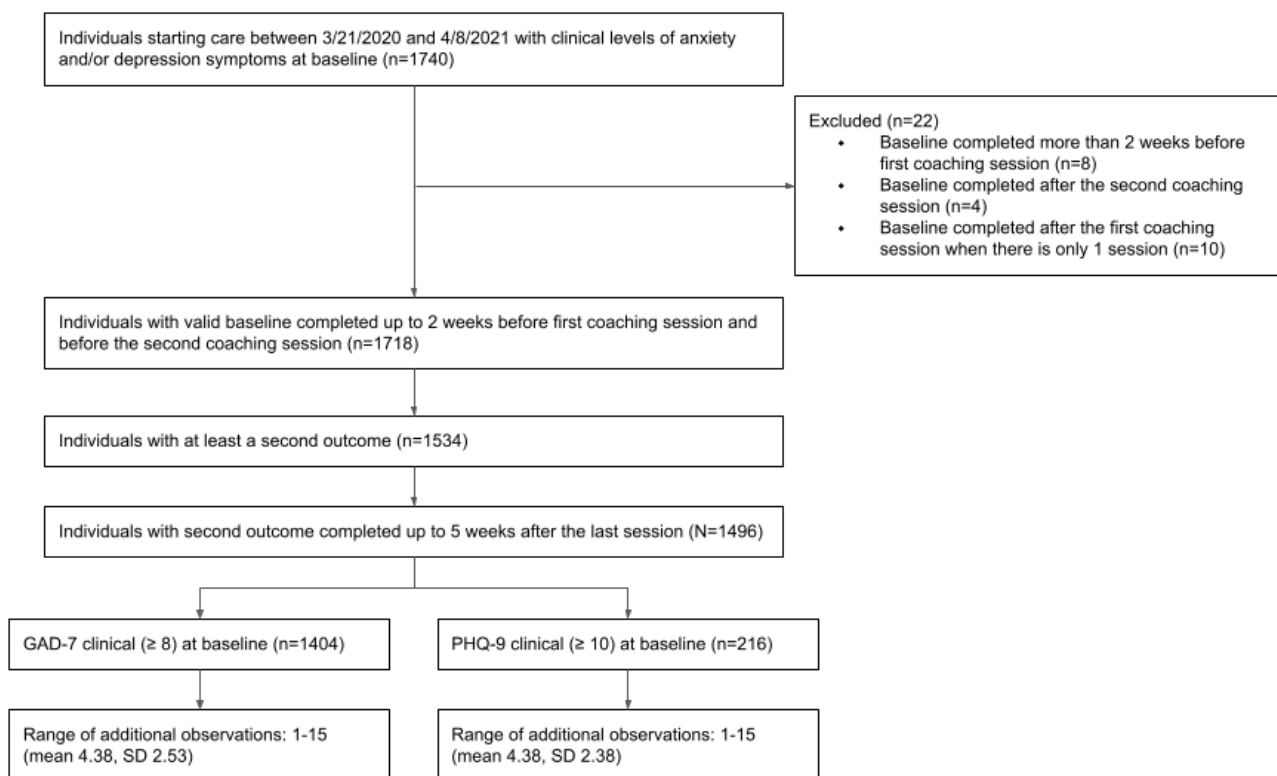
### Participants and Data Inclusion

Participants included clients who participated in the BCC program between March 21, 2020, and April 8, 2021. They must have scored above the clinical cutoff for either the Patient Health Questionnaire-9 (PHQ-9, score  $\geq 10$ ) or the Generalized Anxiety Disorder-7 scale (GAD-7, score  $\geq 8$ ) on a valid baseline assessment (N=1740). Participants were excluded if their baseline assessment or second assessment were considered invalid (n=22). Clients were excluded from coaching if their initial scores met these criteria: (1) GAD-7  $\geq 15$ , (2) PHQ-9  $\geq 12$ , or (3) GAD-7=12-14 and PHQ-9  $\geq 10$ . Other exclusionary criteria included any past psychiatric hospitalization, suicidal/homicidal ideation in the past year, significant traumatic event in the past 6 months, extensive substance use, current violence in a relationship, mandated reporting concerns, or active treatment with a therapist. Other than high baseline scores,

clients were most commonly excluded for currently seeing a therapist (13.3%), panic symptoms leading to change of behavior (12.4%), disordered eating concerns (11.5%), or suicidal ideation or self-harm (17.4%). Approximately 43% of clients searching for care were shown coaching, highlighting that the majority of searchers are not shown coaching due to reporting more severe symptomology or meeting exclusionary criteria.

Coaches had ongoing access to clinical consultation with licensed mental health clinicians for determining when a care transition to therapy was indicated. We also excluded assessments if they were collected more than 12.9 weeks after the first coaching session (representing the mean plus one standard deviation of the coaching duration for the sample). Based on these data inclusion and exclusion criteria, a total of 1496 participants were included in the final sample for analysis (Figure 1). Of the total final sample, there was a 17.5% attrition rate (262/1496 clients), which is defined as the percentage of clients who dropped out of coaching. Demographic information for the final sample is included in Table 1.

**Figure 1.** Participant flowchart. GAD-7: Generalized Anxiety Disorder-7 scale; PHQ-9: Patient Health Questionnaire-9.



**Table 1.** Demographic information and engagement with coaching services. The samples included for the analyses on depression symptoms and on anxiety symptoms partially overlap, as participants with clinical levels of both depression (PHQ-9 score  $\geq 10$ ) and anxiety (GAD-7 score  $\geq 8$ ) were included in both analyses.

| Characteristic                         | Value                 |                                    |                                   |
|--|-----------------------|------------------------------------|-----------------------------------|
|  | Entire group (N=1496) | GAD-7 <sup>a</sup> sample (n=1404) | PHQ-9 <sup>b</sup> sample (n=216) |
| Age, mean (SD)                         | 33.64 (8.62)          | 33.49 (8.43)                       | 34.28 (9.60)                      |
| Female gender, n (%)                   | 921 (61.56)           | 860 (61.25)                        | 140 (64.81)                       |
| <b>Race/ethnicity</b>                  |                       |                                    |                                   |
| Member of minority group, n (%)        | 676 (45.19)           | 631 (44.94)                        | 100 (46.30)                       |
| Unknown, n (%)                         | 68 (4.55)             | 64 (4.56)                          | 7 (3.24)                          |
| Baseline PHQ-9 score, mean (SD)        | 6.04 (3.00)           | 5.75 (2.86)                        | 10.74 (1.25)                      |
| Baseline GAD-7 score, mean (SD)        | 9.58 (2.05)           | 9.85 (1.77)                        | 7.82 (2.54)                       |
| Coaching sessions completed, mean (SD) | 4.48 (2.31)           | 4.48 (2.32)                        | 4.50 (2.22)                       |
| Duration of care (weeks), mean (SD)    | 5.73 (4.85)           | 5.73 (4.84)                        | 5.68 (4.58)                       |

<sup>a</sup>GAD-7: Generalized Anxiety Disorder-7 scale.

<sup>b</sup>PHQ-9: Patient Health Questionnaire-9.

## Coaching Program

The recruited coaches completed an International Coaching Federation–accredited coach training program, demonstrated a minimum of 100 hours of coaching experience, and passed an observational coaching demonstration. Coaches maintained key elements from the coaching approach, including a stance that clients are the experts of their own life, do not need to be fixed, and have the resources to find the solutions to their own problems [19]. Once selected, the coaches underwent intensive, experiential training as part of their onboarding with Lyra, covering evidence-based principles drawn from acceptance and commitment therapy (ACT), dialectical behavior therapy (DBT), and CBT, in addition to an orientation to the blended care content. This training included lectures and demonstrations of core principles (eg, acceptance, values), self-practice/self-reflection of these principles and skills, ongoing consultation and quality assurance, and case presentations. Coaches used a 6-session model (45 minutes each) with the option for clients to request additional sessions; these were generally approved, with the exception of clients needing more intensive care.

## Digital Activities and Coaching Platform

Coaches used Lyra's secure, web-based platform to see clients via video conference, access assessment data, and assign and review digital activities. Consistent with the blended care model, coaches had access to a variety of digital activities that could be personalized and assigned to clients for use between sessions. Digital activities entailed digital video lessons and exercises, and they were derived from evidence-based interventions (eg, CBT, DBT, ACT). Video lessons introduced core CBT concepts and skills through a storytelling approach, which have been found to be engaging and relatable for users [20]. Digital exercises were akin to digitized versions of traditional CBT worksheets or logs, encouraging practice of skills in between sessions. Examples of concepts and skills covered in these digital activities include mindful awareness, challenging

avoidance, cognitive reappraisal, and distress tolerance. Clients could receive feedback on their completed digital exercises through the web-based platform and engage in asynchronous messaging with their coach as needed.

## Self-report Measures

### Demographics

Demographic information about the client is collected through a self-report questionnaire via the web-based platform, including items assessing sex, race/ethnicity, and birthdate.

### The PHQ-9

The PHQ-9 is a 9-item self-report questionnaire that assesses depressive symptom severity over the past week [21]. A clinical cutoff score of  $\geq 10$  on the PHQ-9 has been validated as a threshold for individuals likely to meet diagnostic criteria for major depression.

### The GAD-7

The GAD-7 is a 7-item self-report measure that evaluates anxiety symptom severity over the past week [22]. A score of  $\geq 8$  on the GAD-7 was used as the most specific and sensitive clinical cutoff for identifying individuals with a diagnosis of generalized anxiety disorder [23].

For both the PHQ-9 and GAD-7, responses are provided on a Likert scale from 0 to 3; a total score can be calculated by summing the items, with higher scores indicating more severe symptomology. Both measures have been used extensively in various clinical trials in different settings, demonstrating strong psychometric properties as evidenced by high reliability, validity, and treatment sensitivity [24].

## Data Analyses

### Reliable Improvement and Recovery

Reliable improvement (evaluates whether a change in score is greater than the measurement error of the questionnaire) and recovery (scores changing from clinical to subclinical range)

were calculated for the entire group as well as for the anxiety and depression subsamples. Individuals achieve reliable improvement when their GAD-7 score decreases by  $\geq 4$  points or their PHQ-9 score decreases by  $\geq 6$  points [25].

### Growth Curve Modeling

Mixed effects modeling was used to examine the growth trajectories of the anxiety and depression scores over the course of the coaching sessions. The growth curve modeling approach allows incorporation of predictor variables at the response (PHQ-9, GAD-7) level and accounts for participant-level variability, obtaining average trajectories of the responses while acknowledging and accommodating differences/variability among participants. The results for each outcome are presented in a stepwise fashion, beginning with a null model containing

only fixed and random effects corresponding to the growth function, followed by a series of conditional models incorporating response level predictors. All models featured a random effect on the intercept at the provider level as well as random effects for the intercept and linear effect of time (week) at the participant level.

## Results

### Reliable Improvement and Recovery

At baseline, 1404 (93.85%) of the 1496 clients scored in the clinical range on the GAD-7, and 216 clients (14.44%) scored in the clinical range on the PHQ-9. Table 2 reports the rates of reliable improvement and recovery based on the entire sample, as well as anxiety and depression subsamples.

**Table 2.** Reliable improvement and recovery rates. Clients achieved reliable improvement when the decrease in their GAD-7 score was  $\geq 4$  and/or the decrease in their PHQ-9 score was  $\geq 6$ . Recovery only considers clients who started in the clinical range on the measure of interest.

| Participant subgroup               | Reliable improvement <sup>a</sup> , n (%) | Recovery <sup>b</sup> , n (%) | Reliable improvement and recovery <sup>c</sup> , n (%) | Reliable improvement or recovery <sup>d</sup> , n (%) |
|------------------------------------|---|-------------------------------|--|---|
| Entire group (N=1496)              | 1136 (75.94)                              | 1326 (88.64)                  | 1108 (74.06)   | 1339 (89.51)  |
| GAD-7 <sup>e</sup> sample (n=1404) | 1046 (74.50)                              | 1229 (87.54)                  | 1034 (73.65)   | 1241 (88.39)  |
| PHQ-9 <sup>f</sup> sample (n=216)  | 148 (68.52)                               | 202 (93.52)                   | 148 (68.52)  | 202 (93.52)   |

<sup>a</sup>Calculated as reliable improvement in GAD-7 or PHQ-9 score.

<sup>b</sup>Calculated as recovery on the GAD-7 or PHQ-9.

<sup>c</sup>Calculated as reliable improvement and recovery on the GAD-7 or reliable improvement and recovery on the PHQ-9.

<sup>d</sup>Calculated as reliable improvement or recovery on the GAD-7 or reliable improvement or recovery on the PHQ-9.

<sup>e</sup>GAD-7: Generalized Anxiety Disorder-7 scale.

<sup>f</sup>PHQ-9: Patient Health Questionnaire-9.

### Growth Curve Modeling

A series of individual growth curve models were specified in the SAS PROC MIXED procedure (SAS Institute) and estimated using restricted maximum likelihood.

#### GAD-7 Results

Results from the unconditional analysis (Model 1) suggests that on average, participants exhibited a significant initial decline in GAD-7 during the first week of coaching ( $b=-1.27$ , 95% CI  $-1.32$  to  $-1.22$ ;  $P<.001$ ), defined as 1 to 7 days after the initial session. Moreover, the presence of a significant quadratic coefficient ( $b=0.08$ , 95% CI  $0.08$  to  $0.09$ ;  $P<.001$ ) indicates that the rate of decline in GAD-7 scores diminished over the course of coaching. More specifically, GAD-7 scores declined quickly over the first few weeks of coaching, although the average trajectory flattened gradually during the middle stages of coaching and more rapidly during the later stages.

In Model 2, significant coefficients emerged for coaching sessions ( $b=-0.90$ , 95% CI  $-1.03$  to  $-0.78$ ), which suggests that

engaging in a coaching session was associated with a 0.90 decrease in the GAD-7 score during that same week (1 to 7 days after the session).

Model 3, the final model selected as representing the best fit for the data, incorporated the lagged engagement predictor, and a significant coefficient emerged for lagged coaching sessions ( $b=-0.74$ , 95% CI  $-0.87$  to  $-0.61$ ). This effect suggests that engaging in a coaching session was associated with 0.74 lower GAD-7 scores the following week (8 to 14 days after the coaching session). In this final model, all other coefficients from Model 1 (first week of coaching and quadratic coefficient) and Model 2 (coaching sessions in the past week) remained significant. Taken together, the clients exhibited a significant initial decline in anxiety symptoms during the first week of coaching as well as over the course of coaching, and engaging in a coaching session was associated with lower anxiety symptoms for the week immediately after that session and the following week. Results for each model are displayed in Tables 3 and 4.



**Table 3.** Growth curve modeling results on the Generalized Anxiety Disorder-7 scale (n=1404).

|                       | Model 1                |                    | Model 2                |                    | Model 3                |                    |
|-----------------------|------------------------|--------------------|------------------------|--------------------|------------------------|--------------------|
|                       | Estimate (95% CI)      | t (observed)       | Estimate (95% CI)      | t (observed)       | Estimate (95% CI)      | t (observed)       |
| Intercept             | 8.40 (8.29 to 8.51)    | N/A <sup>a</sup>   | 8.68 (8.56 to 8.79)    | N/A                | 8.87 (8.75 to 8.99)    | N/A                |
| Week                  | -1.27 (-1.32 to -1.22) | 54.05 <sup>b</sup> | -1.19 (-1.24 to -1.15) | 50.21 <sup>b</sup> | -1.03 (-1.08 to -0.97) | 36.75 <sup>b</sup> |
| Week <sup>2</sup>     | 0.08 (0.08 to 0.09)    | 33.24 <sup>b</sup> | 0.07 (0.07 to 0.08)    | 29.53 <sup>b</sup> | 0.06 (0.05 to 0.06)    | 19.98 <sup>b</sup> |
| Sessions, last 7 days | N/A                    | N/A                | -0.90 (-1.03 to -0.78) | 14.38 <sup>b</sup> | -1.04 (-1.17 to -0.92) | 16.45 <sup>b</sup> |
| Sessions, 8-14 days   | N/A                    | N/A                | N/A                    | N/A                | -0.74 (-0.87 to -0.61) | 11.00 <sup>b</sup> |

<sup>a</sup>N/A: not applicable.

<sup>b</sup> $P < .001$ .

**Table 4.** Model selection criteria results on the Generalized Anxiety Disorder-7 scale (n=1404).

| Criterion                      | Model 1 | Model 2 | Model 3 |
|--------------------------------|---------|---------|---------|
| Deviance (-2 log-likelihood)   | 32572.6 | 32373.7 | 32257.6 |
| Akaike information criterion   | 32582.6 | 32383.7 | 32267.6 |
| Bayesian information criterion | 32600.3 | 32401.3 | 32285.2 |

### PHQ-9 Results

Preliminary analyses on PHQ-9 scores revealed a relatively small degree of heterogeneity in patient level trajectories, sometimes resulting in a nonpositive definite covariance matrix of random effects at the patient level. However, sensitivity analyses revealed that this issue was resolved by constraining the intercept-slope covariance to 0. Several alternative specifications for patient-level random effects were also examined, though all configurations yielded the same conclusions for fixed-effect parameters. Results from the unconditional analysis (Model 1) revealed a steep initial decline in depression scores during the first week of coaching ( $b = -1.62$ , 95% CI -1.74 to -1.49;  $P < .001$ ), and the significant quadratic coefficient ( $b = 0.11$ , 95% CI 0.10 to 0.12;  $P < .001$ ) indicates that the rate of decline in PHQ-9 scores diminished as coaching progressed. As seen in the anxiety analysis, depression scores declined rapidly over the first few weeks of coaching, but the average trajectory became flatter during the later stages.

In Model 2, significant coefficients emerged for coaching sessions ( $b = -0.62$ , 95% CI -0.94 to -0.30) indicating that

engaging in a coaching session was associated with .62 lower PHQ-9 scores during that same week (1 to 7 days after the session).

Model 3, the final model selected as representing the best fit for the data, incorporated the lagged engagement predictor, and a significant coefficient emerged for lagged coaching sessions ( $b = -0.91$ , 95% CI -1.25 to -0.56). This effect suggests that each coaching session delivered was associated with 0.91 lower PHQ-9 scores in the following week (8-14 days after that coaching session). In this final model, all other coefficients from Model 1 (first week of coaching and quadratic coefficient) and Model 2 (coaching sessions in the past week,  $b = -0.79$ , 95% CI -1.11 to -0.46) remained significant. Taken together, clients exhibited a significant initial decline in depressive symptoms during the first week of coaching, as well as over the course of coaching, and engaging in a coaching session was associated with lower depressive symptoms for the week immediately after that session and the following week. Results for each model are displayed in Tables 5 and 6.

**Table 5.** Growth curve modeling results on the Patient Health Questionnaire-9 (n=216).

|                       | Model 1                |                    | Model 2                |                    | Model 3                |                    |
|-----------------------|------------------------|--------------------|------------------------|--------------------|------------------------|--------------------|
|                       | Estimate (95% CI)      | t (observed)       | Estimate (95% CI)      | t (observed)       | Estimate (95% CI)      | t (observed)       |
| Intercept             | 9.01 (8.68 to 9.34)    | N/A <sup>a</sup>   | 9.20 (8.87 to 9.54)    | N/A                | 9.43 (9.09 to 9.77)    | N/A                |
| Week                  | -1.62 (-1.74 to -1.49) | 26.04 <sup>b</sup> | -1.55 (-1.68 to -1.42) | 24.07 <sup>b</sup> | -1.34 (-1.49 to -1.19) | 17.72 <sup>b</sup> |
| Week <sup>2</sup>     | 0.11 (0.10 to 0.12)    | 16.90 <sup>b</sup> | 0.10 (0.09 to 0.12)    | 15.12 <sup>b</sup> | 0.08 (0.07 to 0.10)    | 10.44 <sup>b</sup> |
| Sessions, last 7 days | N/A                    | N/A                | -0.62 (-0.94 to -0.30) | 3.76 <sup>b</sup>  | -0.79 (-1.11 to -0.46) | 4.76 <sup>b</sup>  |
| Sessions, 8-14 days   | N/A                    | N/A                | N/A                    | N/A                | -0.91 (-1.25 to -0.56) | 5.15 <sup>b</sup>  |

<sup>a</sup>N/A: not applicable.

<sup>b</sup> $P < .001$ .

**Table 6.** Model selection criteria results on the Patient Health Questionnaire-9 (n=216).

| Criterion                      | Model 1 | Model 2 | Model 3 |
|--------------------------------|---------|---------|---------|
| Deviance (-2 log-likelihood)   | 5117.4  | 5105.3  | 5081.0  |
| Akaike information criterion   | 5125.4  | 5113.3  | 5089.0  |
| Bayesian information criterion | 5136.7  | 5124.6  | 5100.3  |

## Discussion

Clients presenting with moderate levels of anxiety and depression exhibited a significant decrease in symptomology over the course of coaching, with close to 90% of clients with moderate anxiety and/or depression achieving reliable improvement or recovery. These findings suggest that cognitive-behavioral coaching is a promising method for managing these symptoms within a blended care context, assuming appropriate client selection. Additionally, it is noted that almost half of the sample belongs to an ethnic minority group. Achieving these strong outcomes within a diverse sample highlights the impact of providing culturally responsive care, as well as the potential for BCC to address some mental health disparities. Collectively, our findings are particularly exciting, as a substantial unmet need for mental health treatment remains in the United States given the shortage of licensed mental health providers.

When clients presented for coaching sessions, significant decreases in anxiety and depressive symptoms were observed for that same week as well as for the following week, reflecting the importance of session attendance. These findings highlight the crucial role of the coach in introducing and reinforcing the clinical concepts and skills in each session, which is an integral part of the blended care model. Coaches are also able to personalize the digital activities and place them in the context of the clients' presenting issues, enhancing the precision of care. Additionally, the sessions are valuable opportunities to troubleshoot emergent issues and mitigate issues with homework compliance. Given that between-session homework compliance is a significant driver of symptom change [26], the increased accountability afforded by the coaching sessions is imperative for optimal outcomes. Taken together, coaching sessions allow for personalization of care and enhance engagement with clinical concepts and skills, contributing to durable decreases in anxiety and depression symptoms.

Additionally, the steepest declines in symptoms tended to occur during the initial weeks of coaching, emphasizing the importance of client buy-in and early engagement. The beginning stages of coaching are crucial for establishing the foundational rationale for the work to come. Solid psychoeducation about the purpose of a BCC model and how it can alleviate anxiety and depression is imperative for establishing positive expectations. Indeed, more positive expectations have been linked to better outcomes [27], highlighting the importance of collaborative care and dedicating time to clarify goals and expectations at the outset [28]. Establishing this initial momentum will also highlight the

results of clients' efforts firsthand, which is expected to maintain their buy-in and motivation to continue their work in BCC.

These findings should be considered within the context of certain limitations and future directions. First, over half of individuals seeking care were never offered the BCC program due to more severe clinical presentations such as suicidality, which limits the generalizability of the findings. Although it is a limitation to generalizability, the careful consideration that was given in determining who would be appropriate for this modality of care (eg, clients with moderate or lower levels of anxiety and depression) is arguably a strength of this program, as it is not suggested that coaching should be a substitute to therapy across a range of clinical severity. Second, the clients included in our analysis most commonly presented with anxiety and depression; future studies should evaluate the effectiveness of a BCC program for other psychiatric issues. Third, coaches in this program received extensive training in cognitive behavioral concepts, whereas traditional coaching focuses more narrowly on motivational interviewing and goal setting. Fourth, as coaching session outcomes were determined via client self-reports, it could be informative to incorporate multimethod (eg, clinical interview), multi-informant (eg, reports from significant others/family members) assessments in future evaluations for a more comprehensive understanding of symptomology and functioning. Finally, although there were robust reductions of anxiety and depression, findings were derived from a naturalistic study that examined retrospective data, which limits our ability to account for regression to the mean effects. As such, it would be helpful to conduct randomized controlled trials to impart further confidence in the effectiveness of BCC programs in reducing these symptoms beyond a control condition. Future dismantling studies should also be conducted to determine which components of the BCC model contributed to the biggest change in symptom severity. Engagement with digital CBT content (independent of coaching) has been shown to yield positive symptom improvement. By teasing apart the unique contributions of the digital components and the face-to-face coaching sessions, the active ingredients for change can be identified and fortified.

Ultimately, these data provide strong support for the use of an evidence-based CBC program within a blended care model for clients presenting with moderate levels of anxiety and depression. Under appropriate clinical supervision to ensure proper client selection and oversight, coaching appears to be a promising modality to expand access to timely mental health treatment.

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## Authors' Contributions

All authors were responsible for writing components of the original manuscript draft, as well as review and editing. MSW, AL, and CC were responsible for conceptualization. S-YC was responsible for data curation and formal analysis. S-YC, REW, and MSW were responsible for data validation. SON-H was responsible for clinical management and supervision of the blended care coaching program.

## Conflicts of Interest

MSW, S-YC, and AL are employed by Lyra Health, receive income from Lyra Health, and have been granted equity in Lyra Health. SON-H and CC are employed by Lyra Health and Lyra Clinical Associates, receive income from Lyra Health and Lyra Clinical Associates, and have been granted equity in Lyra Health. REW is a paid consultant for Lyra Health.

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## Abbreviations

- ACT:** acceptance and commitment therapy  
**BCC:** blended care coaching  
**CBC:** cognitive-behavioral coaching  
**CBT:** cognitive behavioral therapy  
**DBT:** dialectical behavior therapy  
**GAD-7:** Generalized Anxiety Disorder-7 scale  
**HIPAA:** Health Insurance Portability and Accountability Act  
**PHQ-9:** Patient Health Questionnaire-9

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Original Paper

# Internet Search Activity of Young People With Mood Disorders Who Are Hospitalized for Suicidal Thoughts and Behaviors: Qualitative Study of Google Search Activity

Khatiya C Moon<sup>1,2</sup>, MD; Anna R Van Meter<sup>1,2,3</sup>, PhD; Michael A Kirschenbaum<sup>1,2</sup>, MD; Asra Ali<sup>1,3</sup>, MA; John M Kane<sup>1,2,3</sup>, MD; Michael L Birnbaum<sup>1,2,3</sup>, MD

<sup>1</sup>Department of Psychiatry, Zucker Hillside Hospital, Glen Oaks, NY, United States

<sup>2</sup>Department of Psychiatry, The Donald and Barbara Zucker School of Medicine at Hofstra/Northwell, Hempstead, NY, United States

<sup>3</sup>Feinstein Institute of Medical Research, Manhasset, NY, United States

**Corresponding Author:**

Khatiya C Moon, MD

Department of Psychiatry

Zucker Hillside Hospital

75-59 263rd Street

Kaufmann Building, Suite k204

Glen Oaks, NY, 11004

United States

Phone: 1 7184704367

Email: [kmoon2@northwell.edu](mailto:kmoon2@northwell.edu)

## Abstract

**Background:** Little is known about the internet search activity of people with suicidal thoughts and behaviors (STBs). This data source has the potential to inform both clinical and public health efforts, such as suicide risk assessment and prevention.

**Objective:** We aimed to evaluate the internet search activity of suicidal young people to find evidence of suicidal ideation and behavioral health-related content.

**Methods:** Individuals aged between 15 and 30 years (N=43) with mood disorders who were hospitalized for STBs provided access to their internet search history. Searches that were conducted in the 3-month period prior to hospitalization were extracted and manually evaluated for search themes related to suicide and behavioral health.

**Results:** A majority (27/43, 63%) of participants conducted suicide-related searches. Participants searched for information that exactly matched their planned or chosen method of attempting suicide in 21% (9/43) of cases. Suicide-related search queries also included unusual suicide methods and references to suicide in popular culture. A majority of participants (33/43, 77%) had queries related to help-seeking themes, including how to find inpatient and outpatient behavioral health care. Queries related to mood and anxiety symptoms were found among 44% (19/43) of participants and included references to panic disorder, the inability to focus, feelings of loneliness, and despair. Queries related to substance use were found among 44% (19/43) of participants. Queries related to traumatic experiences were present among 33% (14/43) of participants. Few participants conducted searches for crisis hotlines (n=3).

**Conclusions:** Individuals search the internet for information related to suicide prior to hospitalization for STBs. The improved understanding of the search activity of suicidal people could inform outreach, assessment, and intervention strategies for people at risk. Access to search data may also benefit the ongoing care of suicidal patients.

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**KEYWORDS**

suicide; mood disorders; depression; internet; search engine; Google search; digital health; mobile health; adolescent; young adult

## Introduction

The high prevalence of suicidal behaviors is a public health crisis. Suicide is a leading cause of death among young people in the United States and accounts for nearly 1 million deaths annually worldwide [1]. Suicidality is a major target of both preventative public health efforts and clinical behavioral medicine. Nonetheless, after decades of research, little progress has been made in the prediction and reduction of suicide incidence [2]. Innovative approaches are needed to identify individuals at high risk for suicide and to engage them in care.

Technology has the great potential to aid these efforts by improving the current methods for assessing suicidal thoughts and behaviors (STBs) both in and outside of clinical settings. STBs are traditionally evaluated with intermittent semistructured patient interviews or with patient self-report measures. Unfortunately, both purposeful concealment and the underreporting of STBs are common [3,4]. Additionally, traditional clinical assessment does not occur often enough to reveal the day-to-day fluctuations of STBs that patients experience [5-7]. Prior studies have demonstrated that data gathered from various digital platforms, including smartphone apps, wearable devices, social media, and internet search engines, can enhance the traditional evaluation of STBs and other psychiatric symptoms [5,6,8-10]. The use of these information sources is acceptable to patients [9,11,12], and data gathered from digital platforms can be collected passively in real time and in the same settings in which patients are likely to experience symptoms. Thus, digital data have greater potential to provide a more complete assessment of STBs compared to data collected via traditional methods. There is also emerging evidence that aggregates of digital data can be used to create digital phenotypes—clusters of symptoms and behaviors that correlate with outcomes—of patients with STBs [13]. The improved characterization of these phenotypes could enhance suicide risk prediction models for both individuals and populations.

Little is known about the internet search activity of people with STBs, but this digital data source has the potential to improve both clinical and public health efforts, such as suicide risk assessment and prevention. Google is the most highly trafficked website in the world [14]. In a survey, a majority (59%) of young people reported learning about suicide from web-based sources [15]. Young people who report that they engage in STBs also report that they have been exposed to web-based, suicide-related content [16,17]. Incorporating search data into the assessment of STBs confers a number of advantages over traditional clinical assessment methods. For example, search data do not rely on self-reports, making these data less susceptible to purposeful concealment, accidental omission, or recall bias. Additionally, search data leave a longitudinal record that can provide a more accurate characterization of the temporal evolution of STBs. Finally, search data can facilitate the delivery of search engine-driven, just-in-time interventions that aim to prevent suicide attempts—a feat that is incredibly challenging to accomplish with the current interval clinical assessment model [10].

Most previous literature on examining suicide-related internet search activity has relied on either population-level data from search trends or self-reports of search activity from samples of participants in the community whose suicide risk levels and psychiatric histories are unknown. These methods have some important limitations, including the fact that population-level data do not necessarily correlate with individual-level behavior patterns, thus limiting their clinical utility [18]. Additionally, studies that rely on self-reports are limited by recall bias as well as a lack of objective corroboration of symptoms and behaviors.

To determine if search data are capable of providing information on the clinically meaningful contexts surrounding suicidality, we performed a qualitative analysis of search data collected from adolescents and young adults who were diagnosed with mood disorders and hospitalized for STBs. To our knowledge, this is the first study in which search archives were extracted directly from participants with confirmed clinical diagnoses and established STBs. We hypothesized that participants' search activity would include references to behavioral health and suicide-related information in the months before a psychiatric hospitalization for STBs.

## Methods

### Recruitment

Participants aged between 15 and 30 years who had previously been diagnosed with a primary mood disorder were screened for eligibility by Northwell Health's Zucker Hillside Hospital inpatient and outpatient psychiatric departments. We focused on individuals with mood disorders because STBs are a more common reason for hospitalization in this population. Only individuals who had been hospitalized due to STBs were included in this study. Recruitment occurred between March 2016 and December 2018. This study was approved by the Institutional Review Board of Northwell Health. Written informed consent was obtained from adult participants and legal guardians of participants aged under 18 years. Assent was obtained from participating minors. All participants were receiving treatment as usual.

### Data Collection

Participants were asked to extract their search activity by logging on to their Google account and requesting their data archive. Participation involved 1 to 2 visits after consent, during which all historical search data were requested, downloaded, and collected. These data archives included user-generated search terms that were time-stamped. Historical clinical data, including dates of psychiatric hospitalizations, presenting symptoms, and diagnoses, were obtained from medical records.

For this study, we focused just on search data from the 3-month period prior to each psychiatric hospitalization for STBs. We selected 3 months because we thought that this amount of time represented a period that was long enough to adequately capture suicide-related searches (SRSs) that were conducted as symptoms escalated to the point of necessitating hospitalization. If a participant experienced multiple hospitalizations, each hospitalization was evaluated as a distinct entity with its own corresponding search history. Thus, there were more search

histories than there were participants. If a participant had multiple hospitalizations in a 3-month period, overlapping search queries were only analyzed once.

### Data Analysis

Five reviewers (authors AA, MLB, MAK, ARVM, and KCM) simultaneously manually reviewed each search query and extracted those that included terms related to suicide and behavioral health. Relevant searches were highlighted. The findings were then discussed as a team to reach a consensus and identify relevant search categories. Extracted search terms were then coded into 5 thematic categories. These included STBs, help seeking, symptoms of mental health disorders, trauma and negative life events, and drugs of abuse. A similar method of categorization was previously used successfully by our group in a study of the search queries of patients with psychosis [8]. These thematic categories coincided with factors that are recognized as modulators of suicide risk [19] and were chosen because they were thought to be sufficiently broad enough to capture a wide array of behavioral health-related symptoms and behaviors that are searched for by individuals.

The reviewers excluded ambiguous searches unless additional clinical context was available. For example, searches involving the name of prescription medications that could also be used as drugs of abuse (ie, Adderall [dextroamphetamine-amphetamine] and Xanax [alprazolam]) were counted in the analysis only if they included additional content that could guide categorization

(eg, “how to overdose on klonopin” or “side effects of adderall”) but not if they were limited to the name of the medication alone. We also excluded searches that were not germane to suicide or behavioral health.

The reviewers familiarized themselves with the available clinical documentation prior to the assessment of search histories. The available clinical documentation included patient demographics, the primary diagnosis, the reason for hospitalization, and the attempted or planned method of suicide. Knowledge of the clinical documentation was used to contextualize search content and assess if flagged search queries were in fact related to the participants’ clinically documented symptoms and behaviors. Reviewers met as a team to resolve discrepancies in the appropriate categorization of individual search queries.

## Results

### Participants’ Characteristics and Search Themes

A total of 43 participants provided access to their Google search data. These 43 participants had 63 hospitalizations for STBs (number of hospitalizations per person: mean 1.5). Search histories from the 3-month period prior to each hospitalization were extracted and analyzed. A total of 37,738 search queries were reviewed. Participant demographics are summarized in [Table 1](#). The prevalence of different search themes among participants is presented in [Table 2](#).

**Table 1.** Participant demographics.

| Characteristic                     | Value      |
|------------------------------------|------------|
| Age (years), mean (SD)             | 20.6 (3.1) |
| <b>Gender, n (%)</b>               |            |
| Male                               | 18 (42)    |
| Female                             | 25 (58)    |
| <b>Race, n (%)</b>                 |            |
| Black or African American          | 8 (19)     |
| Asian American or Pacific Islander | 6 (14)     |
| White                              | 21 (48)    |
| Mixed or other                     | 8 (19)     |
| <b>Ethnicity, n (%)</b>            |            |
| Hispanic or Latino                 | 10 (23)    |
| Not Hispanic or Latino             | 32 (74)    |
| Unknown                            | 1 (2)      |
| <b>Primary diagnosis, n (%)</b>    |            |
| Major depressive disorder          | 37 (86)    |
| Bipolar disorder                   | 5 (12)     |
| Unspecified mood disorder or other | 1 (2)      |

**Table 2.** Prevalence of search themes.

| Search theme                    | Number of participants (%) | Number of search histories <sup>a</sup> (%) |
|---------------------------------|----------------------------|---|
| Suicide                         | 27 (63)                    | 36 (57)                                     |
| Help seeking                    | 33 (77)                    | 43 (68)                                     |
| Substance use                   | 19 (44)                    | 25 (40)                                     |
| Mood and anxiety symptoms       | 19 (44)                    | 24 (38)                                     |
| Trauma and negative life events | 14 (33)                    | 17 (27)                                     |

<sup>a</sup>Each search history contains searches that were conducted during the 3-month period prior to a unique hospitalization.

### SRS Queries

Queries related to suicide were found in 36 search histories representing 27 out of the 43 (63%) unique participants. Participants' SRSs varied in terms of their temporal proximity to hospitalization. Further, 4 participants conducted all of their SRSs in the week preceding hospitalization, 6 participants conducted all of their SRSs within 3 weeks before hospitalization, and 14 participants conducted all of their SRSs  $\geq 4$  weeks before hospitalization.

Exemplars of search queries are presented in Table 3. SRSs included queries related to the television show *13 Reasons Why*—a popular show about a teenage girl who dies by suicide that was airing during the recruitment period—as well as other suicide-related topics in news media. Some participants searched for highly specific and unusual suicide methods. For example, one participant conducted numerous searches related to giving themselves cancer and was investigating the possibility of purchasing live cancer cells on web-based platforms. This participant also searched for a specific species of poisonous frog and investigated the cyanide content of apple seeds. Another participant performed numerous searches related to methods, such as how to overdose on various medications, “how

to take apart a shaving razor,” and “how to get the blade out of a pencil sharpener.” Another participant searched “easy ways to get pneumonia,” and another searched “how long can a human go without food.” Other participants conducted SRSs that were less specific but nonetheless indicated thoughts about death. For example, one simply searched “I want to die,” another queried “would you say suicide is a cry for help,” and a third asked “why wont I just kill myself already?” Search queries about suicide-related tattoos, famous suicide-related quotes, and literature about suicide were made by 6 participants. Searches for suicide chat rooms were conducted by 2 participants.

Of the 43 participants, 9 (21%) searched for information that was directly related to their planned or chosen method of suicide. These 9 participants were represented by 10 search histories. In all of these cases, the planned or used method of suicide was drug overdose, as noted in the clinical record. For example, one such participant who was hospitalized after attempting suicide by overdosing on NyQuil (doxylamine and acetaminophen) conducted 8 searches in the week before hospitalization regarding overdosing on NyQuil, including “how many Nyquil [sic] pills does it take to kill me?”



**Table 3.** Notable search queries.

| Themes and participants                | Queries  |
|--|--|
| <b>Suicide</b>                         |  |
| Participant A                          | <ul style="list-style-type: none"> <li>“pro suicide chat rooms”</li> </ul>   |
| Participant B                          | <ul style="list-style-type: none"> <li>“giving your self cancer”</li> <li>“live cancer cells for sale”</li> <li>“poison dart frog for sale”</li> <li>“apple seeds cyanide”</li> </ul>  |
| Participant C                          | <ul style="list-style-type: none"> <li>“how to take apart a shaving razor”</li> <li>“how to get the blade out of a pencil sharpener”</li> <li>“how painful is slitting your wrists”</li> <li>“if you bang your head against the wall can you die”</li> <li>“least painful way to commit suicide”</li> </ul>  |
| Participant D                          | <ul style="list-style-type: none"> <li>“best pills to overdose on”</li> </ul>  |
| Participant E                          | <ul style="list-style-type: none"> <li>“would you say suicide is a cry for help”</li> </ul>  |
| <b>Help-seeking behavior</b>           |  |
| Participant A                          | <ul style="list-style-type: none"> <li>“mobile crisis hotline”</li> <li>“psychiatrist works with aetna”</li> <li>“top psychiatrist near me”</li> </ul>   |
| Participant B                          | <ul style="list-style-type: none"> <li>“how does a therapist help with anxiety”</li> </ul>   |
| Participant C                          | <ul style="list-style-type: none"> <li>“how does a psychologist decide if you need medication”</li> <li>“what does a psychologist do”</li> </ul>   |
| Participant D                          | <ul style="list-style-type: none"> <li>“can I turn myself into a mental hospital”</li> </ul>   |
| <b>Drugs and other substances</b>      |  |
| Participant A                          | <ul style="list-style-type: none"> <li>“funniest things to do after eating an edible”</li> <li>“does heating up weed make it smell”</li> </ul>   |
| Participant B                          | <ul style="list-style-type: none"> <li>“cbd for newbies”</li> </ul>  |
| <b>Mood and anxiety symptoms</b>       |  |
| Participant A                          | <ul style="list-style-type: none"> <li>“do you have to cut yourself to be depressed”</li> <li>“what make me doubt myself all the time”</li> <li>“what does dreading everything mean”</li> <li>“why are there days where I be confused and don’t know what to do and I have a feeling in my chest”</li> <li>“what if I don’t know what I want to do for my future because I don’t see a future for myself”</li> <li>“waking up with a panic feeling in my chest”</li> </ul> |
| Participant B                          | <ul style="list-style-type: none"> <li>“everything seems too overwhelming and pointless”</li> </ul>  |
| Participant C                          | <ul style="list-style-type: none"> <li>“screaming in sleep”</li> <li>“different person after depression”</li> </ul>  |
| Participant D                          | <ul style="list-style-type: none"> <li>“how to be happy”</li> <li>“I am so lonely”</li> </ul>  |
| Participant E                          | <ul style="list-style-type: none"> <li>“I am so done”</li> </ul>   |
| <b>Trauma and negative life events</b> |  |
| Participant A                          | <ul style="list-style-type: none"> <li>“how do you get over a heartbreak?”</li> </ul>  |
| Participant B                          | <ul style="list-style-type: none"> <li>“how to deal with losing a best friend”</li> </ul>  |

## Help-Seeking Searches

Queries related to behavioral health care were found in 43 search histories representing 33 of the 43 participants (77%). Searches regarding suicide hotlines or crisis lines were only conducted by 3 participants. Most commonly (n=13), search histories contained queries regarding outpatient resources, including searches for specific behavioral health clinics and general information about outpatient behavioral health care. The names of specific behavioral health providers were queried 11 times. Information about the etiology of, differences among, and clinical course of different psychiatric disorders were queried in 12 search histories. Queries regarding inpatient psychiatric care were found in 10 search histories, including questions about the conditions and rules of a psychiatric unit. For example, one participant searched whether they would be able to use their phone while hospitalized. Search histories also contained queries about substance abuse resources (n=4), crisis resources (n=4), public assistance programs (n=2), and social support (n=3). In 5 search histories, participants searched for alternative interventions, such as pet therapy, meditation apps, and complementary medicine. In 19 search histories, 15 of the 43 participants (35%) searched for information about psychiatric medications, including side effects, desired effects, dosages, and general psychoeducation.

## Drugs and Other Substances

Queries related to drugs of abuse were found in 25 search histories representing 19 of the 43 (44%) participants. Alcohol was the most commonly queried substance; it was represented in 13 search histories. Cannabis-related searches were present in 10 search histories. Two participants searched for unusual ways to attain intoxication; one asked “can ibuprofen get you high,” and the other queried “how to properly get high off computer duster.” One participant conducted a search about purchasing a drug testing kit. Other participants conducted searches for salvia, ketamine, tobacco and nicotine, amphetamines, and crack cocaine.

## Mood and Anxiety Symptoms

Queries related to mood and anxiety symptoms were found in 24 search histories representing 19 of the 43 individuals (44%). Such searches included those for music, movies, tattoos, internet memes, and quotes related to depression. For example, one participant searched “depression movies,” another searched “mental illness quotes” and “tattoos about depression,” and another searched “15 saddest country songs.” Other participants searched for information related to despair. For example, one participant queried “I am so lonely,” another queried “can no longer focus on anything or learn,” and a third queried “everything seems too overwhelming and pointless.”

## Trauma and Negative Life Events

Queries related to traumatic or otherwise negative life events were found in 17 search histories representing 14 of the 43 participants (33%). In this category, 4 participants conducted searches related to sex crimes, including searches about how to report rape, how to escape domestic violence, and general information regarding sexual assault and harassment and searches related to support groups for sexual assault survivors.

Further, 3 participants conducted searches related to unwanted pregnancies, including those about seeking abortion and emergency contraception. Additionally, 7 participants conducted searches related to difficulties in interpersonal relationships, including the dissolution of friendships and romantic relationships. Finally, 1 participant searched for information on dealing with bullies, and 2 participants conducted searches related to notorious gun violence events, including the Newtown, Connecticut, school shooting.

## Discussion

### Principal Findings

In this study we explored the internet search queries of young people with mood disorders that were made in the months leading up to a hospitalization for STBs. This study yielded a number of important findings. Our study confirms that patients with STBs conduct SRSs and other clinically meaningful searches prior to hospitalization.

A majority (27/43, 63%) of the participants in our sample conducted SRSs. This finding is consistent with those of previous research showing that people with self-reported STBs search for suicide-related content on web-based platforms [20,21]. However, to our knowledge, ours is the first study to extract search data from individuals with clinically confirmed STBs. Additionally, in a sizable minority of cases (9/43, 21%), suicide methods that were searched exactly matched participants' planned or selected method of attempting suicide in real life. Although more research is needed to understand how the presence or content of SRSs relates to suicidal behavior, our data suggest that SRSs may indicate a heightened suicide risk because, at least for some individuals, the internet likely aids suicide planning.

Search queries that were not explicitly related to suicide nonetheless revealed highly sensitive and clinically meaningful experiences that can otherwise go unreported in a traditional clinical interview. For example, searches about experiences with sexual abuse, the dissolution of relationships, bullying, loneliness, panic, and substance use could put clinical symptoms into context if they are known to a clinician. In addition, many searches related to the self-expression of mood symptoms were found in our sample, such as searches regarding movies, books, memes, and tattoos about depression. This finding suggests that suicidal young people are interested in consuming and sharing content related to their experiences with behavioral health, though the influence that this type of content has on symptoms and behaviors is unclear.

We also found that a majority (33/43, 77%) of our participants searched for help seeking-related information, including information about behavioral health services and psychoeducational resources. Unfortunately, there is a substantial body of prosuicide content on the internet and evidence that exposure to prosuicide content can increase the incidence of suicidal ideation and worsen mood symptoms in young people [22,23]. Our data reinforce the need for point-of-search interventions that counteract prosuicide information. The fact that young people are searching for

help-seeking and suicide-related information on web-based platforms represents a potential opportunity to intervene. For example, if help-seeking searches were known to a clinician, they could serve as a jumping-off point for talking about treatment options. In addition, although search engines currently return information for suicide prevention hotlines when people search for the term *suicide*, we have shown that many suicide-related, mood-related, and help-seeking searches do not include this term. Only 3 individuals in our sample specifically searched for suicide hotlines, suggesting that this may not be an appealing intervention for many individuals. Optimizing algorithms to identify likely suicide-related, symptom-related, and help-seeking terms may result in the development of more impactful point-of-search interventions and improve pathways to care.

Previous research supports the idea that the incidence of suicidal ideation does not increase in a linear fashion in the days immediately preceding a suicide attempt and has a high level of moment-to-moment variability over a given period of time [6,7,24]. Such research also suggests that individuals with STBs can be grouped into different phenotypes—those whose suicidal ideation varies considerably in frequency and intensity and those whose suicidal ideation is more stable over time. These different groups may require different types of assessment and intervention. In our sample, 4 participants completed all of their SRSs in the week before hospitalization, possibly suggesting that their STBs were escalating prior to hospitalization. In contrast, 14 individuals stopped conducting SRSs 3 weeks before their hospitalization, possibly suggesting that the STBs that resulted in hospitalization may have been more impulsive. Although additional research is required to understand the motivation behind and impact of each search, our findings support the notion that different patterns in the temporal evolution of SRSs exist and suggest that internet search data, along with other digital and clinical data, can be used to identify STB phenotypes and tailor interventions accordingly in the future [13].

### Limitations

Our study has several important limitations. First, the study was conducted at a single site with a small, albeit diverse, population of young people aged 15 to 30 years. The generalizability of our results is therefore limited. In addition, we are unable to comment on the prevalence or content of SRSs among older adults or younger children. This study was limited to participants with mood disorders; comorbidities and other primary diagnoses were not considered.

Second, our study lacked a formal comparison group, so we cannot state conclusively that the results are unique to individuals with STBs. However, notably, a similar previous study of individuals with psychosis did not yield significant numbers of SRSs, suggesting that these types of searches do not occur at similar rates across patient populations [8].

Third, search queries alone do not provide enough context for confidently stating the motivations and intentions behind each search. For example, searches about suicide chat rooms or memes could represent suicidal intent, help-seeking behavior, curiosity, or other intentions. It is also possible that people with

access to participants' devices conducted searches while on participants' accounts, further limiting our understanding of participants' intentions. We sought to mitigate uncertainty by cross-referencing search queries with clinical data when such data were available in the medical records, which provided context for categorization, and conferring with one another to resolve ambiguity in the meanings of or intentions behind queries. However, even these actions introduce bias into the assessment and thematic categorization of search queries. Future studies should consider accessing browser histories, which could provide additional information that is related to motivation and is based on what websites participants visited after making their queries.

Fourth, it is possible that some clinically relevant search queries were not captured in our data set. Participants who were motivated to conceal their searches may have done so. For example, search queries that were conducted while participants used Google's incognito mode were unavailable to us, as were searches that participants deleted prior to the download of this study's data. In addition, searches that were conducted through alternative search engines were not assessed in this study.

Finally, we only analyzed searches that were conducted 3 months before a hospitalization. It is possible that individuals conduct SRSs well before this time or that only searches that are conducted in close temporal proximity to hospitalization have predictive value. Future research should consider not only the temporal association between an individual's searches and STBs but also whether the time of day, search frequency, or other non-content-related information about searches relates to suicide risk.

### Future Directions

The understanding that people at high risk for suicide are indeed searching for suicide-related content represents an opportunity to use these data for treatment planning and risk assessment. For example, in the future, internet search data could potentially be used as clinical collateral, particularly during initial psychiatric assessments where patients may be hesitant to share their experiences with STBs. Additionally, the search data of established patients could augment infrequent psychiatric assessments by allowing for the closer monitoring of STBs in between clinical appointments. Access to this information can help both clinicians and patients understand STBs in the context of surrounding life events and mood symptoms with more granularity than is currently typical.

Although it is currently not possible to systematically use search data in clinical evaluation and management, patients can download and share their own web-based activity with their treatment providers. However, for this to occur, statistical tools that can process search data and return relevant information in a format that is clinically usable and scalable need to be developed. Additionally, our work suggests that search histories can be used to establish novel risk factors for suicide. Ultimately, the further clarification of such risk factors may be better suited to more robust statistical approaches (such as machine learning approaches) for analyzing larger numbers of participants. Furthermore, questions about legal considerations, effectiveness, integration into clinical workflows, and

reimbursement also need to be addressed before these methods can reasonably be implemented.

Finally, the clinical use of internet search data must be undertaken with the utmost concern for patient privacy. Search data often contain highly sensitive information that people may

be uncomfortable sharing. If search data are to be integrated into clinical workflows or search engine-led interventions, it is important that users consent to the review of search data and that they be continuously informed about how these data might be used in a transparent and collaborative manner.

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## Conflicts of Interest

MLB owns stock in Northshore Therapeutics. JMK is a consultant to or receives honoraria from Alkermes, Allergan Inc, Dainippon Sumitomo Pharma, H. Lundbeck A/S, Intra-Cellular Therapies, Janssen Pharmaceuticals, Johnson & Johnson, LB Pharmaceuticals Inc, Merck, Minerva, Neurocrine Biosciences, Otsuka Pharmaceutical, Reviva Pharmaceuticals, Roche, Saladex Biomedical Inc, Sunovion, Takeda, and Teva Pharmaceuticals. JMK receives grant support from Otsuka Pharmaceutical, H. Lundbeck A/S, Sunovion, and Janssen Pharmaceuticals. He is a shareholder in Vanguard Research Group and LB Pharmaceuticals Inc.

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## Abbreviations

**SRS:** suicide-related search

**STB:** suicidal thought and behavior

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Original Paper

# Digital Health Literacy in Bipolar Disorder: International Web-Based Survey

Emma Morton<sup>1</sup>, BSc, PhD; Kendall Ho<sup>2</sup>, MD, FRCPC; Steven J Barnes<sup>3</sup>, MA, PhD; Erin E Michalak<sup>1</sup>, PhD

<sup>1</sup>Department of Psychiatry, University of British Columbia, Vancouver, BC, Canada

<sup>2</sup>Department of Emergency Medicine, University of British Columbia, Vancouver, BC, Canada

<sup>3</sup>Department of Psychology, University of British Columbia, Vancouver, BC, Canada

**Corresponding Author:**

Erin E Michalak, PhD

Department of Psychiatry

University of British Columbia

420-5950 University Blvd

Vancouver, BC, V6T 1Z3

Canada

Phone: 1 604 827 3393

Email: [erin.michalak@ubc.ca](mailto:erin.michalak@ubc.ca)

## Abstract

**Background:** Web-based resources can support people with bipolar disorder (BD) to improve their knowledge and self-management. However, publicly available resources are heterogeneous in terms of their quality and ease of use. Characterizing digital health literacy (the skillset that enable people to navigate and make use of health information in a web-based context) in BD will support the development of educational resources.

**Objective:** The aim of this study was to develop understanding of digital health literacy and its predictors in people with BD.

**Methods:** A web-based survey was used to explore self-reported digital health literacy (as measured by the e-Health Literacy Scale [eHEALS]) in people with BD. Multiple regression analysis was used to evaluate potential predictors, including demographic/clinical characteristics and technology use.

**Results:** A total of 919 respondents (77.9% female; mean age 36.9 years) completed the survey. Older age ( $\beta=0.09$ ;  $P=.01$ ), postgraduate education ( $\beta=0.11$ ;  $P=.01$ ), and current use of self-management apps related to BD ( $\beta=0.13$ ;  $P<.001$ ) were associated with higher eHEALS ratings.

**Conclusions:** Levels of self-reported digital health literacy were comparable or higher than other studies in the general population and specific physical/mental health conditions. However, individuals with BD who are younger, have completed less education, or are less familiar with mental health apps may require extra support to safely and productively navigate web-based health resources. Relevant educational initiatives are discussed. Future studies should evaluate skill development interventions for less digitally literate groups.

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**KEYWORDS**

eHealth; health literacy; bipolar disorder; self-management

## Introduction

Self-management, the process of monitoring and responding to the signs, symptoms, and consequences of an illness [1,2], is central to living well with bipolar disorder (BD). To do this effectively, individuals require information about symptoms, quality of life impacts, treatments, and effective wellness strategies [3]. However, substantive barriers to accessing these resources exist. Individuals with BD experience delays of up

to 8 years between symptom onset and diagnosis [4,5]. Availability of appropriate care is limited: 50%-65% of people with serious mental illnesses (SMI) such as BD report having received treatment in the previous year [6], and it is estimated that only 50% of patients in treatment for BD receive psychosocial services [7]. People with BD experience high rates of stigma [8], which can discourage help-seeking [9]. Finally, physical distancing measures implemented to mitigate the

COVID-19 pandemic have introduced further obstacles to obtaining in-person care [10,11].

Web and mobile-based (ie, smartphone) educational materials and self-management supports (referred to collectively as eHealth) may be accessed by individuals independently of health care services, circumventing barriers to treatment [12,13]. Unsurprisingly, individuals with BD are increasingly turning to eHealth resources: up to 75% of people with BD use the internet as a source of information regarding their illness and treatment options [14–18], and the majority of individuals with SMI report a willingness to receive support for mental health needs delivered via a computer or smartphone [19,20]. However, using such sources is not without risk: they may be difficult to understand, contain inaccurate or irrelevant information, be developed to sell products and services, or compromise a user's privacy [21].

The quality of existing, publicly available eHealth resources for BD is highly heterogeneous. While one review of top search-engine results for “bipolar disorder” and “manic depressive illness” found websites had reasonably accurate content [22], a different analysis found prominent websites were largely commercial in nature and of variable quality [23]. The latter study also noted that the ranking of websites in internet search results did not correlate with their quality appraisals. As internet search results are influenced by a number of factors in addition to credibility (including the presence of keywords, website popularity, and the user's location/search history) the authors noted concerns that patients would be unlikely to identify high-quality offerings via casual browsing (ie, within the first 20 search results). Publicly available apps for BD share similar limitations: a review found the majority of these failed to provide evidence-based educational content, did not use validated screening measures, and did not address recommended core components of self-monitoring [24].

Digital health literacy, a construct related to (but incorporating aspects distinct from) health literacy, describes a set of competencies necessary to seek out, understand, appraise, and productively use eHealth resources [25]. This overarching construct is comprised of six core skills [26] including (1) traditional literacy (basic reading and writing skills), (2) health literacy (the ability to understand and act on health information, specifically), (3) information literacy (knowledge of how information is stored and how to search effectively), (4) scientific literacy (understanding of health research processes, limitations, and potential biases), (5) media literacy (the ability to think critically about media content, particularly source credibility and potential biases) and (6) computer literacy (the ability to access and use new technologies/software). A growing body of research has sought to describe the presence of this skillset (and the consequent need for educational interventions/alternative information delivery), particularly in underserved populations (eg, older adults, ethnic minorities, low-income groups, and rural communities) who may be unable to access face-to-face support with their health needs [27], as well as individuals with chronic health conditions who may turn to web-based resources for information and self-management support [28].

Digital health literacy skills are of clear importance for people living with BD, given the variable quality of web and app-based offerings for this condition. In addition, people with BD may experience specific challenges in identifying and using health information in digital contexts [21]: many experience cognitive difficulties (including problems with memory, attention, planning, problem-solving, and processing speed) that may impact their ability to search effectively or critically appraise the trustworthiness of web-based resources. Further, people with BD often have complex health questions that are not readily addressed by simple search strategies (eg, related to polypharmacy and comorbid conditions). Lack of eHealth literacy skills may have negative consequences for people with SMI, as they risk both using unhelpful/unsafe web-based resources, as well as failing to identify resources or tools with the potential to support their self-management. This potentially limits the reach of evidence-based eHealth interventions. Indeed, there is evidence to show that individuals with lower health literacy are less likely to adopt eHealth resources or perceive them as useful, while simultaneously overestimating the privacy protections offered by health apps [29]. While ideally, the onus for ensuring the quality of digital health resources would be on developers themselves or regulators, in practice the international web-based context and commercial interests of platforms that host information/tools present numerous barriers to institutional oversight. Similarly, while ideally clinicians would play a role in screening and recommending appropriate web-based resources for SMI, many find it difficult to keep abreast of the rapidly evolving web-based context. A recent survey of health care providers showed that the majority report lacking the confidence and knowledge to recommend apps to patients with BD [30]. It has been suggested that although people with SMI increasingly have access to smartphones, many lack the skills to use them effectively, such as navigating app stores and selecting safe and effective options [31]. While some efforts are underway to increase the ability of clinicians to identify relevant and safe digital mental health resources [32], the fact remains that at present, many people with BD are left to independently search for and screen health information on the internet.

Given the above, characterizing the presence of eHealth literacy skills and the factors that predict them is necessary to identify groups at risk of using poor-quality health information and support the development of targeted education materials. To our knowledge, levels of digital health literacy in people with BD have not been formally investigated. The present study aimed to (1) describe levels of digital health literacy and associated behaviors in people with BD and (2) explore predictors of digital health literacy.

## Methods

### Study Design

An overarching international, web-based, cross-sectional survey was conducted with the aim to investigate use of and attitudes towards apps amongst people with BD (survey items are presented in full in [Multimedia Appendix 1](#)). The present analysis focuses on responses to items concerning digital health

literacy and associated behaviors. Use of apps is briefly summarized to contextualize the sample.

Questionnaires were administered via Qualtrics. Data collection occurred between February 19 and July 20, 2020. The study received ethics approval from the University of British Columbia Behavioral Research Ethics Board. Data in the study were treated confidentially and survey responses stored on a secure server in Canada. Participants received written information on the study and indicated their consent before proceeding.

### Participants and Recruitment

Participant recruitment was conducted with a combination of social media (Facebook, Instagram, and Twitter) advertising, Collaborative REsearch Team to study psychosocial issues in Bipolar Disorder (CREST.BD) email newsletters, and emails to health care providers or organizations associated with CREST.BD. Surveys were also advertised at a number of CREST.BD-hosted web-based (webinar) and in-person events for individuals with BD. Participants were offered the opportunity to be entered into a prize draw for 1 of 2 Can \$50 (US \$39.87) Visa gift cards. Inclusion criteria were (1) age  $\geq 19$  years and (2) a self-reported diagnosis of BD.

### Measures

#### Use of Apps

Individuals were asked to provide details about their frequency of use of apps in general, as well as use of apps specifically related to 2 core foci of self-management in BD (mood and sleep). Participants were asked to describe the sources of information they used to select apps; multiple options could be selected.

#### Digital Health Literacy

The e-Health Literacy Scale (eHEALS) was used to evaluate respondents' perceived self-efficacy in identifying, applying, and evaluating the quality of digital health resources [33]. Eight self-report Likert-type items (1="Strongly Disagree" to 5="Strongly Agree") are summed to create an overall score (range 8-40), with higher scores indicating greater knowledge and skills. Two additional Likert-type items (not included in the overall score calculation) are used to characterize respondents' perception of the utility and importance of digital health resources. The unidimensional structure and reliability of the eHEALS has been demonstrated in the general population [33-35], as well as chronic physical and mental health conditions [36-38]. In the present sample, reliability of the scale was high (Cronbach  $\alpha=.90$ ).

To characterize self-reported confidence across specific competencies, Likert-scale ratings were simplified: the top 2

("agree" and "strongly agree") and bottom 2 ("disagree" and "strongly disagree") options were collapsed to indicate "agree" and "disagree," respectively.

### Data Analysis

Descriptive statistics were used to summarize survey responses. Multiple regression analysis was performed to evaluate the effects of demographic variables (age, gender, education level, and BD diagnosis) and app use behaviors (frequency of app use in general and use of BD-related health apps; ie, those designed to measure/support mood and sleep) on self-reported digital health literacy. Categorical variables were dummy-coded in reference to the following variables: gender (male), diagnosis (BD-I), education level (any high school), frequency of app use (less than daily), use of BD-related health apps (no). Prior to conducting regression analyses, appropriateness of eHEALS data for regression was confirmed via inspection of the Normal P-P plot, skew (-0.9), kurtosis (1.0), and Durbin-Watson statistics (2.0), variance inflation factors, and a plot of standardized residuals against predicted values. Statistical significance was set a  $P<.05$ . Data were analyzed using SPSS (version 26, SPSS Inc).

### Ethical Standards

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the 2008 revision of the Helsinki Declaration of 1975. All participants provided written informed consent.

### Availability of Data

Data are not publicly available in accordance with ethics approval given by the ethics board from the participating university. Interested investigators may submit inquiries to the corresponding author.

## Results

### Sample

A total of 919 people with BD responded to the web-based survey (see Table 1 for demographic/clinical characteristics and technology use behaviors). Overall, 81.3% of participants completed the survey between June 21 and July 20. The sample was primarily female ( $n=716$ , 77.9%), of White/European ethnicity ( $n=560$ , 61%), had a mean age of 36.9 (SD 12) years, and most commonly self-reported a diagnosis of BD II ( $n=477$ , 51.9%). The majority of the sample had completed some form of education beyond high school ( $n=551$ , 77.4%).



**Table 1.** Sample characteristics.

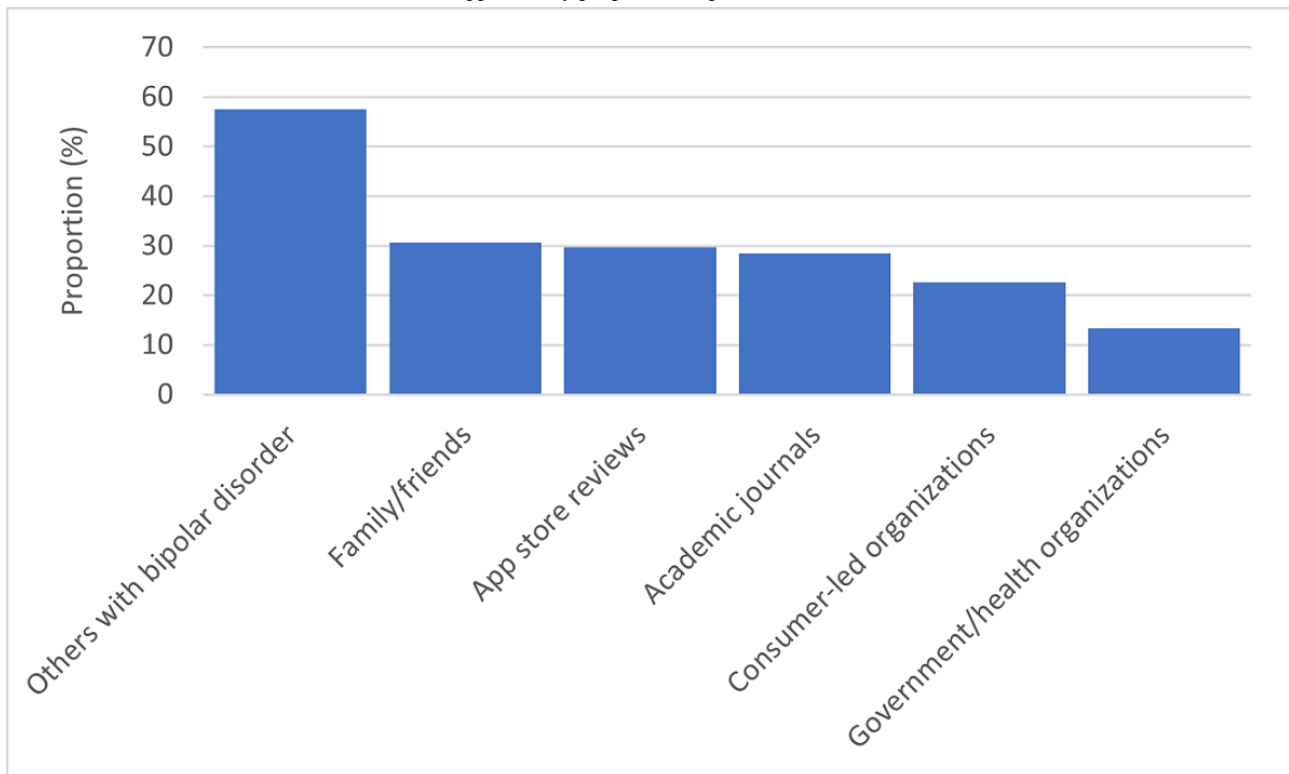
| Demographic variable  | Value      |
|---|------------|
| Females, n (%)  | 716 (77.9) |
| Age (years), mean (SD)                                      | 36.9 (12)  |
| <b>Bipolar disorder diagnosis, n (%)</b>                    |            |
| Bipolar disorder I  | 321 (34.9) |
| Bipolar disorder II   | 477 (51.9) |
| Other bipolar disorders/No formal diagnosis                 | 121 (13.2) |
| <b>Ethnicity, n (%)</b>                                     |            |
| White   | 560 (61.0) |
| Black/African   | 40 (4.4)   |
| Asian   | 152 (16.6) |
| Middle Eastern  | 22 (2.4)   |
| Latin American  | 48 (5.2)   |
| Other or multiple ethnicities                               | 96 (10.5)  |
| <b>Education level, n (%)</b>                               |            |
| Any high school   | 177 (19.3) |
| Postsecondary   | 214 (23.3) |
| Undergraduate   | 324 (35.3) |
| Postgraduate  | 173 (18.8) |
| Other   | 31 (3.4)   |
| <b>How often do you use apps?, n (%)</b>                    |            |
| Less than daily or not at all                               | 76 (8.3)   |
| Up to 2 hours a day   | 268 (29.2) |
| 2-4 hours a day   | 297 (32.3) |
| 5 or more hours a day                                       | 278 (30.3) |
| <b>Use of bipolar disorder – related health apps, n (%)</b> |            |
| Mood  | 228 (24.8) |
| Sleep   | 242 (26.3) |

## Use of Apps

Daily use of apps in general was reported by 91.7% (n=843) of the sample. A smaller proportion of respondents (n=382, 41.6%) endorsed using apps related to 2 core foci of self-management in BD: mood (n=228, 24.8%) or sleep (n=242, 26.3%).

Respondents obtained information on health apps from a variety of sources (Figure 1); recommendations from other people with BD were commonly relied on (n=529; 57.6%), while government/health organizations were least commonly used (n=122; 13.3%).

**Figure 1.** Preferred sources of information on health apps used by people with bipolar disorder.



**Digital Health Literacy**

Participants regarded the internet as useful in making decisions about their health (mean 4.1, SD 0.8) and placed a high degree of importance on being able to access health resources on the internet (mean 4.4, SD 0.7). The mean level of self-reported

digital health literacy as measured by the eHEALS was 31.7 (SD 6.3). Figure 2 illustrates the response frequencies for each eHEALS item; the majority of participants agreed with statements indicating they had the knowledge and skills to effectively search for, evaluate, and use web-based health information.

**Figure 2.** Endorsement of eHEALS (e-Health Literacy Scale) statements.



The regression model was statistically significant ( $F_{11, 831}=4.2$ ;  $P<.001$ ), and explained 5.3% of the variance in eHEALS scores (Table 2). Of demographic variables, older age ( $\beta=0.09$ ;  $P=.01$ ) and postgraduate education ( $\beta=0.11$ ;  $P=.01$ ) were significant predictors of higher eHEALS scores. Other/unclear BD

diagnosis was associated with significantly lower eHEALS scores ( $\beta=-0.11$ ;  $P=.01$ ). Finally, among variables describing current app use, only the use of apps related to BD was associated with significantly higher eHEALS scores ( $\beta=0.13$ ;  $P<.001$ ).

**Table 2.** Regression model predicting digital health literacy in bipolar disorder.

| Variable                                      | B (SE)       | $\beta$ | <i>t</i> test | <i>P</i> value |
|---|--------------|---------|---------------|----------------|
| Age   | 0.05 (.02)   | 0.09    | 2.62          | .01            |
| Gender (female)                               | -0.05 (0.54) | -0.003  | -0.09         | .92            |
| <b>Bipolar disorder diagnosis<sup>a</sup></b> |              |         |               |                |
| Bipolar disorder-II                           | -0.56 (0.46) | -0.04   | -1.21         | .22            |
| Other bipolar disorder/no formal diagnosis    | -2.45 (0.82) | -0.11   | -3.0          | .01            |
| <b>Education level<sup>b</sup></b>            |              |         |               |                |
| Postsecondary                                 | 0.57 (0.66)  | 0.04    | 0.87          | .39            |
| Undergraduate                                 | 0.90 (0.60)  | 0.07    | 1.50          | .14            |
| Postgraduate                                  | 1.79 (0.70)  | 0.11    | 2.56          | .01            |
| <b>Frequency of app use<sup>c</sup></b>       |              |         |               |                |
| Up to 2 hours a day                           | 0.66 (0.84)  | 0.05    | 0.78          | .43            |
| 2-4 hours a day                               | 1.20 (0.84)  | 0.09    | 1.44          | .15            |
| 5 or more hours a day                         | 0.83 (0.85)  | 0.06    | 0.98          | .34            |
| Use of bipolar disorder-related health apps   | 1.71 (0.44)  | 0.13    | 3.91          | <.001          |

<sup>a</sup>Bipolar disorder diagnosis variables have the reference category: bipolar disorder-I.

<sup>b</sup>Education variables have the reference category: any level of high school.

<sup>c</sup>Frequency of app use variables have the reference category: less than daily/no use.

## Discussion

### Principal Findings

Individuals with BD are increasingly turning to web- and mobile-based resources to obtain information about the disorder and support self-management practices; however, concerns exist about their safety and credibility [21,24]. This survey of app use in BD offers encouraging findings regarding the ability of this group to identify, understand, appraise, and apply health information in a web-based context. Levels of digital health literacy in the sample were comparable to or higher than those in studies in the general population [38-41] and chronic physical health [36,38] and mental health conditions [37,38].

Of demographic variables, older age and postgraduate education (ie, master's degree/PhD) were associated with self-reported digital health literacy in BD. The influence of higher education levels is replicated in a number of general population studies [27,39,41-43]. Although it may be expected that older age is associated with lower levels of familiarity and confidence with eHealth resources [27,39], there is evidence to suggest that the influence of younger age on digital health literacy is not observed in some physical illnesses [38,44-46]. Potentially, individuals with chronic health conditions by necessity have greater familiarity with digital health resources. Indeed, a longer duration of engagement with digital health interventions is associated with older age [47]. However, such findings must be interpreted cautiously in light of this sample's relatively young mean age (mean 37 years, SD 12 years).

Across prior literature, the most consistent predictor of digital health literacy is the frequency of electronic device and internet use [27,34,41,44,45,48-50]. In this study, the frequency of app

use was not associated with eHEALS scores, although the use of a BD-related self-management app (operationalized as apps used to support/monitor mood or sleep) predicted higher literacy. Similarly, one study found that the use of digital health resources specifically, not the time spent on the internet in general, predicts digital health literacy [27]. Future studies should test such potential mediators along with the directionality of these relationships, as it is unclear whether patients with lower digital health literacy draw on alternative information sources (eg, health care providers and peers) or whether increased use of digital platforms leads to higher knowledge and skills.

Finally, this study highlights the value of exploring condition-specific predictors of digital health literacy: not meeting diagnostic criteria for BD-I or -II (either owing to a diagnosis of BD not otherwise specified or lack of formal diagnosis) was associated with lower eHEALS scores. Potentially, this may be reflective of lower health literacy skills in general, as people need to navigate complex health care systems and medical insurance to receive appropriate care and diagnosis. Together, demographic, clinical, and behavioral variables explained only a small proportion of variance in self-reported digital health literacy in BD (5.3%); cognitive difficulties, complexity of health information needs, or lack of knowledge about BD are potential predictors that warrant investigation in future research [21].

Although our findings suggest that digital health literacy among people with BD is on par with that among the general population, we note that the web-based context is rapidly transforming in a way that further complicates the search for and evaluation of health information/resources. The dynamic and rapidly expanding mental health smartphone apps marketplace, for example, is particularly challenging to navigate:

there are over 10,000 publicly available offerings [51], app store search algorithms lack transparency and may be influenced by paid advertising [52], turnover in apps is high [53], and app descriptions often make scientific claims regarding effectiveness despite lack of appropriate high-quality evidence [54,55]. Furthermore, apps collect large amounts of potentially identifying data that may be compromised by data breaches or sold to third parties; to make informed choices, users must be aware of and able to understand the implications of unclear or nonexistent privacy policies common to existing health and wellness apps [24,56,57].

A number of projects have been initiated to support people in selecting safe and credible apps for mental health concerns, including the development of a framework with which to appraise the quality, useability, data protections, and evidence base of an app [58]. This has been used as the foundation of a public, web-based database of app ratings [59] to support clinicians and patients in the selection of apps that best suit their mental health needs. Government and health organizations are similarly curating libraries of recommended apps; however, these resources lack public visibility and users often report unsatisfactory search experiences that prompt them to turn to commercial app stores [60]. Likewise, the present analysis found that among people with BD, government/research websites were least commonly endorsed as a source of information on health apps. These findings are in line with those of studies suggesting that people primarily rely on word of mouth or app store ratings and reviews to identify and select mental health apps [61-63]. Further, our survey results suggest that first-hand experience of using digital tools to live well with BD lends credibility to app recommendations. This expertise may be formalized in the creation of “digital navigator” roles (a position often held by people with lived experience) in mental health clinics; such specialists could support patients to identify and use apps to support their recovery goals [64,65].

A second initiative to upskill patients in the technical and health literacy skills required to use mental health apps is the Digital Opportunities for Outcomes in Recovery Services (DOORS) group education program [31]. Skills taught range from basic smartphone functions (eg, accessing Wi-Fi, sending SMS text messages, and making calls), navigating the app store and downloading apps, to making informed decisions about health apps. The 4-week program was reported to numerically improve eHEALS scores in individuals with schizophrenia-spectrum diagnoses, although the significance of this change was not statistically tested owing to the small sample size. The DOORS curriculum is freely available to encourage health services, and peer support groups improve and expand on the program; web-based training modules will shortly be released [66]. Future studies should evaluate the efficacy of such programs in improving digital health literacy in BD populations. Furthermore, qualitative research is required to identify ways to tailor content to the specific needs, interests, and vulnerabilities among people with BD. For example, impulsivity and risk taking is characteristic of hypomanic/manic states in BD [67]; as such, modules may need to provide education and strategies addressing how evaluation of privacy/financial risks of health apps can be impacted by BD symptoms.

## Limitations

Limitations related to the sample were present. Participants self-reported a diagnosis of BD; diagnosis was not confirmed with a structured clinical interview, which may have allowed individuals who did not meet diagnostic criteria for BD to complete the survey. There is limited research to describe the clinical characteristics of people who self-identify as having BD, and as such, the generalizability of present findings should be interpreted with caution. However, we note that reassuringly, an analysis of a random sample (n=100) of people applying to join a BD case registry found that 93% had a lifetime Diagnostic and Statistical Manual of Mental Disorders (fourth edition) bipolar spectrum diagnosis as confirmed by a face-to-face structured clinical interview [68]. Additionally, the survey itself was web-based and primarily related to app use; the self-selected sample may have had higher levels of familiarity and interest in eHealth. Only a small proportion of respondents (n=10) reported using neither a smartphone nor tablet device; limiting our ability to draw inferences regarding the eHealth literacy of this subgroup. Research using paper-based surveys and nondigital methods of recruitment (eg, letters and face-to-face or telephone-based strategies) will provide valuable information regarding the eHealth literacy levels of people with BD impacted by the digital divide. Although a bias in favor of higher levels of eHealth literacy cannot be ruled out, we note that smartphone ownership is increasing amongst people with SMI [69], and rates of smartphone ownership in the present sample were comparable to those of another large-scale survey on BD [20].

Limitations to the measurement of digital health literacy should also be noted. First, eHEALS reflects perceived, rather than demonstrated knowledge and skills; in practice, these may have small to moderate correlations [45,70]. As such, there is a risk that digital health literacy levels reported by survey respondents may not translate to real-world behaviors. Clinicians should therefore remain curious and enquire about the kinds of digital health resources used by their patients and seek to promote credible offerings where available. Researchers should similarly consider dissemination plans to increase the visibility and uptake of evidence-supported digital health tools for BD. However, we note some complementary evidence from this study: a forthcoming analysis of the quality and safety of the most commonly used self-management apps (n=9) utilized by survey respondents in accordance with a standardized framework [71] found that these largely had appropriate data security measures, and half had evidence to support their efficacy at improving mental health outcomes in general population samples (E Morton, PhD, unpublished data, June 2021).

A second limitation related to measurement is that the eHEALS was developed in 2006, prior to widespread availability of smartphones and uptake of social networking. As such, it may not fully reflect how individuals access web-based health information in the present day. For example, the ability of this instrument to account for how social networking interacts with eHealth knowledge and behaviors has been questioned [72,73]; this is important to consider in the context of BD, where peer interactions are often characterized by seeking and sharing advice [74-76]. Despite limitations, eHEALS is the most widely used digital health literacy scale [28,73], and its use permits

comparison with the wider literature. However, we note that conceptual and methodological advancements in the measurement of digital health literacy are ongoing [73], particularly in light of rapid changes to the web-based context, and as such, future research should reassess the presence of this construct as modernized measures are developed and validated in SMI populations.

Finally, it is important to consider potential impacts of the COVID-19 pandemic on familiarity and confidence with technology. The vast majority of respondents (81%) completed the survey between June and July 2020. By this stage, most countries worldwide had recommended or mandated some form of physical distancing; for people with BD, these measures may have increased their exposure to telepsychiatry or digital health resources [77]. As such, the eHEALS scores described in this sample may not be directly comparable to those in studies conducted prior to 2020. Research with contemporary samples

is required to directly compare digital health literacy in BD to that in the general population.

## Conclusions

People with BD may need to seek out information or self-management supports on the internet to respond to new, changing, or ongoing symptoms, or in response to barriers to accessing treatment. However, the quality of existing web- and mobile-based resources is variable; digital health literacy is required to identify, understand, appraise, and use eHealth resources. The present large-scale, international survey offers reassuring findings, with self-reported digital health literacy levels in BD on par with or higher than that in community samples. Future studies should evaluate the concordance between self-reported digital health literacy and real-world applications of knowledge in people with BD, as well as the potential for educational interventions to support the skill development of less digitally literate groups, including those impacted by the digital divide.

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## Authors' Contributions

EM conceptualized and designed the study, conducted the data analysis, and drafted the manuscript. KH contributed to the overall study design. SJB contributed to overall study design. EEM contributed to the overall study design. All authors provided a critical revision of the manuscript for important intellectual content. All authors read and approved the final manuscript.

## Conflicts of Interest

EM, KH, and SJB declare no potential conflicts of interest with respect to the research, authorship, or publication of this article. EEM has received funding to support patient education initiatives from Otsuka.

## Multimedia Appendix 1

Survey Items.

[DOCX File, 66 KB - [mental\\_v8i10e29764\\_app1.docx](#)]

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## Abbreviations

**BD:** bipolar disorder

**CREST.BD:** Collaborative RESearch Team to study psychosocial issues in Bipolar Disorder

**DOORS:** Digital Opportunities for Outcomes in Recovery Services

**eHEALS:** e-Health Literacy Scale

**SMI:** serious mental illnesses

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Original Paper

# Passive Sensing of Preteens' Smartphone Use: An Adolescent Brain Cognitive Development (ABCD) Cohort Substudy

Natasha E Wade<sup>1</sup>, PhD; Joseph M Ortigara<sup>2</sup>, BA; Ryan M Sullivan<sup>3</sup>, MSc; Rachel L Tomko<sup>4</sup>, PhD; Florence J Breslin<sup>5</sup>, MSc; Fiona C Baker<sup>6</sup>, PhD; Bernard F Fuemmeler<sup>7</sup>, PhD; Katia Delrahim Howlett<sup>8</sup>, PhD; Krista M Lisdahl<sup>3</sup>, PhD; Andrew T Marshall<sup>9</sup>, PhD; Michael J Mason<sup>10</sup>, PhD; Michael C Neale<sup>7</sup>, PhD; Lindsay M Squeglia<sup>4</sup>, PhD; Dana L Wolff-Hughes<sup>8</sup>, PhD; Susan F Tapert<sup>1</sup>, PhD; Kara S Bagot<sup>11</sup>, MD; ABCD Novel Technologies Workgroup<sup>12</sup>

<sup>1</sup>University of California, San Diego, La Jolla, CA, United States

<sup>2</sup>University of Vermont, Burlington, VT, United States

<sup>3</sup>University of Wisconsin-Milwaukee, Milwaukee, WI, United States

<sup>4</sup>Medical University of South Carolina, Charleston, SC, United States

<sup>5</sup>Laureate Institute for Brain Research, Tulsa, OK, United States

<sup>6</sup>SRI International, Menlo Park, CA, United States

<sup>7</sup>Virginia Commonwealth University, Richmond, VA, United States

<sup>8</sup>National Institutes of Health, Bethesda, MD, United States

<sup>9</sup>Children's Hospital Los Angeles, Los Angeles, CA, United States

<sup>10</sup>University of Tennessee, Knoxville, TN, United States

<sup>11</sup>Icahn School of Medicine at Mount Sinai, New York, NY, United States

<sup>12</sup>See Acknowledgments,

**Corresponding Author:**

Natasha E Wade, PhD

University of California, San Diego

9500 Gilman Drive

La Jolla, CA, 92093

United States

Phone: 1 (858) 280 6398

Email: [nwade@health.ucsd.edu](mailto:nwade@health.ucsd.edu)

## Abstract

**Background:** Concerns abound regarding childhood smartphone use, but studies to date have largely relied on self-reported screen use. Self-reporting of screen use is known to be misreported by pediatric samples and their parents, limiting the accurate determination of the impact of screen use on social, emotional, and cognitive development. Thus, a more passive, objective measurement of smartphone screen use among children is needed.

**Objective:** This study aims to passively sense smartphone screen use by time and types of apps used in a pilot sample of children and to assess the feasibility of passive sensing in a larger longitudinal sample.

**Methods:** The Adolescent Brain Cognitive Development (ABCD) study used passive, objective phone app methods for assessing smartphone screen use over 4 weeks in 2019-2020 in a subsample of 67 participants (aged 11-12 years; 31/67, 46% female; 23/67, 34% White). Children and their parents both reported average smartphone screen use before and after the study period, and they completed a questionnaire regarding the acceptability of the study protocol. Descriptive statistics for smartphone screen use, app use, and protocol feasibility and acceptability were reviewed. Analyses of variance were run to assess differences in categorical app use by demographics. Self-report and parent report were correlated with passive sensing data.

**Results:** Self-report of smartphone screen use was partly consistent with objective measurement ( $r=0.49$ ), although objective data indicated that children used their phones more than they reported. Passive sensing revealed the most common types of apps used were for streaming (mean 1 hour 57 minutes per day, SD 1 hour 32 minutes), communication (mean 48 minutes per day, SD 1 hour 17 minutes), gaming (mean 41 minutes per day, SD 41 minutes), and social media (mean 36 minutes per day, SD 1 hour 7 minutes). Passive sensing of smartphone screen use was generally acceptable to children (43/62, 69%) and parents (53/62, 85%).

**Conclusions:** The results of passive, objective sensing suggest that children use their phones more than they self-report. Therefore, use of more robust methods for objective data collection is necessary and feasible in pediatric samples. These data may then more accurately reflect the impact of smartphone screen use on behavioral and emotional functioning. Accordingly, the ABCD study is implementing a passive sensing protocol in the full ABCD cohort. Taken together, passive assessment with a phone app provided objective, low-burden, novel, informative data about preteen smartphone screen use.

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## KEYWORDS

preadolescents; smartphone use; passive sensing; screen use; screen time; mobile phone

## Introduction

### Background

Considerable neuromaturation [1,2] and cognitive development [1,3] occur during childhood and adolescence. Screen use, including a myriad of behaviors displayed using or in front of a digital device, may relate to cognitive and neurodevelopmental outcomes even in young children and preadolescents, especially among those who report high use (5 or more hours per day of screen use; [4,5]). For example, previous research suggests that childhood screen use may be associated with both positive and negative neurodevelopmental correlates, depending on individual differences [6]. Studies in older adolescents and adults indicate that smartphone screen use may be associated with deficits in attention, memory, reward processing, and overall functioning, although the extant literature is limited and conflicting [7]. For instance, general technology use in adults has a positive relationship with brain health, such as higher visual attention performance in video game players or greater use of the internet being related to more complex thinking abilities [8], although there is a dearth of studies on positive associations between screen use and brain health in children. Accurate assessment of brain-behavior relationships with screen use requires the accurate measurement of screen use, which is currently understudied.

One challenge to understanding the potential influence of screen use on brain development is that the measurement of screen use has typically relied on self-report [9-11] and parental report of the child's screen use [12]. Self-reported screen use reports tend to underestimate actual use; for example, self-report data suggested that adults were using their smartphone for an average of 4.12 hours per day, whereas objective measurement indicated that the actual number was closer to 5.05 hours per day [9]. A recent meta-analysis of adults also found that fewer than 10% of self-reported screen use times by participants were within 5% of objective measurements [13]. It has been argued that current concerns about youth smartphone use and its consequences cannot be validated due to errors in self-report [13]. However, precise measurement may improve estimates of the impact of both quantity and type of smartphone-based screen use on psychological functioning and brain development in youth [14]. As such, new methods of measurement are needed to directly examine the quantity and quality of smartphone screen use to capture screen time-related behaviors (as in, the ways in which individuals use their screens) and potential associated screen-related pathology [15-17]. To date, data from objective assessment methods have been primarily limited to

adults and older adolescents [16,17], parents of children [18], and young children [19], despite many children owning smartphones beginning in midchildhood [20,21]. Notably, a recent study in older children (aged 10-14 years) found passive monitoring combined with ecological momentary assessment (EMA) notifications to be feasible and acceptable [22]. However, the app used by Domoff et al [22] did not calculate exact app use, leaving a gap in the literature regarding which types of apps are most commonly used among children and adolescents.

Passive sensing via smartphones is promising in its potential to unobtrusively collect objective data on screen use [15]. Admittedly, even passive monitoring may elicit some form of demand characteristics, Hawthorne-type effect, or a novel way of thinking about queried items that then elicits new or different responses [23]. Some studies have theorized that knowledge of tracking of activity on a mobile device alone likely influences the behavior of research participants [24]. Consistent with this, studies using accelerometer data for physical activity [25] and smartphone use in youth [22] show differences in participant engagement during monitoring, although the real-world significance of these changes may be minimal [22]. Furthermore, a recent meta-analysis suggested that these methods can still more accurately inform correlates of screen use, purportedly doing so more accurately than participant report alone [13], making them a valuable contribution to scientific methodology.

The Adolescent Brain Cognitive Development (ABCD) study is a landmark longitudinal study of nearly 12,000 children aged 9-10 years who are being followed for at least 10 years. The design of the ABCD study investigates the impact of environmental exposures (such as screen use) throughout development on behavior and brain structure and functioning. Since its inception, this study has implemented various novel technological subjective and objective methods to assess and track behaviors [26]. An early target was the use of a passive monitoring smartphone app to assess smartphone screen use [26].

Acquisition of high-quality smartphone screen use data in children is a significant contribution to the field. Although research has demonstrated increasing screen use in children and adolescents in recent years [4], less is known about smartphone screen use specifics, such as when smartphones are used most, which apps or platforms are used, and for how long. Existing objective smartphone data are limited to largely adult and college-aged samples [16] and occasional preschool populations [27], with a recent addition of one study of older children and young adolescents [22]. However, a recent systematic review

found that only 3 studies had investigated specific app use [16]. As the level of engagement with specific types of apps may be an important influence on mental health and other outcomes [28], research is greatly needed to refine passive (without direct participant engagement) and objective (rather than perceived) smartphone assessment approaches in children.

## Objectives

Accordingly, a pilot substudy within the ABCD study was designed to passively capture objective smartphone screen use data from preteen ABCD participants. These data were used to inform the acceptability and feasibility of the implementation of passive, objective assessment on a large scale across the ABCD cohort. In this study, we describe the development of an ABCD study passive monitoring app downloaded to participants' phones, descriptive results from both self- and parent reports, and passive sensing of smartphone screen use among children. Beyond the novel descriptive information of children's smartphone screen use, the primary aim is to assess the correspondence between self-report and passive sensing. We hypothesized that (1) child participants would underreport the amount of time they spent on their smartphones, relative to passive, objective measurement, and (2) the degree of child underreporting smartphone use would diminish with participation in a substudy focused on device use, with higher levels of self-reported screen use in the post- than in presensing periods. In addition, we aimed to assess the acceptability of passive sensing methods in a child population, expecting that children and parents would find passive sensing of the child's smartphone to be acceptable.

## Methods

### Participants

Four ABCD study sites that were roughly geographically dispersed among all ABCD study sites participated in this pilot substudy project. Full details regarding the larger ABCD study design are provided elsewhere [29]. All ABCD study participants who were at a substudy site for their 2-year follow-up and had a study-compatible Android smartphone were invited to participate in the substudy between August 2019 and January 2020. Eligible ABCD study participants were invited to install the ABCD-specific Effortless Assessment of Risk States (EARS) [30] app on their phones for at least 4 weeks. Several weeks after the substudy launch, data were collected regarding the number of participants invited and reasons for declining substudy participation, if relevant. Of those invited, approximately 40% were ineligible due to having an iPhone, 31% did not have their own smartphone device, and 8% had other incompatible devices. Of those eligible with compatible devices, 4% of the invited sample (around 20% of those eligible with compatible devices) declined to enroll in the substudy. A total of 71 participant-parent dyads assented and consented to participate, respectively; 4 participants did not complete the full substudy protocol, and therefore, their data were not included in the present analyses. Thus, a total of 67 participants were enrolled in the study, and they downloaded the EARS app onto their phones. Participant-parent dyads

provided written informed assent and consent. All study protocols were approved by the institutional review board.

## Measures

### Demographics

The ABCD study collects full demographic data, including age, sex, parental income, race, and ethnicity [31]. In addition, participants were queried as to their self-identified gender; no participants identified as being transgender.

### Screen Time Questions

Before participating in the substudy, participants and their parents independently completed a questionnaire specific to the child's smartphone device use (presensing). The questionnaire included a 20-item screen time self-report measure modified from previous research [32,33] that assessed how much time participants spent on their phone over the past 4 weeks ("How much of [the time on a weekday/weekend] do you/does your child spend on their mobile device specifically?") and other health and behavior questions (eg, concerns about time spent on the phone). Weekday and weekend averages were reported for both overall time on media on their smartphone and specific types of media use on any device (ie, streaming television or movies, streaming videos, playing single-player or multi-player video games, texting, on social media, editing videos or pictures for social media, browsing the internet, and total time). At the end of the 4-week data collection period, participants and parents were asked the same questions about the child's smartphone use and about times when they were without their phone during the 4 weeks they had the EARS app installed on their mobile device (postsensing). For both presensing and postsensing assessments, average daily self- and parent-reported smartphone use was calculated by adding weekday hours multiplied by 5 and weekend day hours multiplied by 2, then dividing by 7.

### EARS App

Given prior research indicating concerns of battery life, acceptability, and privacy [34], and participant ages 11-12 years, a relatively brief window of 4 weeks of passive sensing data collection was selected. Although commercial or operating system-specific apps (eg, Digital Wellbeing, Apple Health) were considered [26], an app previously used in pediatric research and customized for ABCD was chosen for its optimal function and safety. A collaborative relationship was entered with Ksana Health, creator of the EARS app [30]. Ksana Health customized their passive sensing app for download onto ABCD participants' smartphones for data collection. Owing to potential privacy concerns, this customized version of the EARS app for the ABCD study only collects smartphone data on the duration and time of day of specific apps' use. Tools such as language capture and semantic categorization, geolocation, music or mood profiles, and EMA are available in EARS but were not incorporated into the current ABCD study version.

The ABCD study research assistants helped participants download the ABCD study version of the EARS app from the Google Play Store. On opening the EARS app, the research assistant scanned a code that linked the participant's ABCD study unique participant number to their device and EARS app

data. This approach allowed for a completely confidential conveyance of data and the participant's identification remained confidential. The EARS app ran continuously in the background of the participant's phone, scraping the operating system every few minutes to collect information on (1) screen on and off and (2) which app was in the foreground. Date and time were logged for each app use instance. In addition to individual app use information (data not presented here; accessible through [35]), Ksana Health reviewed each individual app used by a participant and computed summaries across composite app categories: communication (eg, Discord; Facebook), gaming (eg, Temple Run 2, Mario Kart Tour), music (eg, Shazam, Google Play Music), news (eg, Weather Forecast, HuffPost News), reading (eg, WebComics, Amazon Kindle), social media (eg, Twitter, Facebook, TikTok), and streaming (eg, Twitch, Hulu). Certain apps were listed in multiple categories because of the multiple ways in which they can be used (eg, Facebook in both communication and social media). This was done to make more comprehensive categories, although consequently no category is mutually exclusive or independent of one another. In addition, 2 stand-alone categories were created from popular apps: SMS messages (basic texting) and YouTube. Stand-alone categories were not mutually exclusive from composite categories (eg, YouTube was also counted within streaming). Although Google Play Store category summaries are available in ABCD Annual Release 3.0 through National Institute of Mental Health Data Archive (NDA), here we limited analyses to newly created categories that better fit types of apps of interest at this age (eg, social media, gaming). All collected data were encrypted before being uploaded to a secure cloud server. Neither identifiable information (such as participant's name, age, or phone number) nor content regarding what participants were doing was collected. If a participant stopped the EARS app from running in the background, once function resumed, EARS then queried the operating system to collect overall screen use information. This allowed for collection of all screen use, although some finer details (eg, time of day) may not have always been obtained. Raw participant file data accessed via National Institute of Mental Health Data Archive [35] were reviewed to assess for any full days of missing data; no participants had a full-day gap in data collection, indicating no missing passively sensed data.

Participants were not asked to interact with the EARS app, and if they opened it, they would see the message, "You are changing the future of health and wellness." If data were not being received from the phone, the app would push a notification to the participant to open the app, allowing for continuous data collection with minimal intervention. If a participant did not respond to notifications for several days, an ABCD staff member contacted the participant to ensure they still had their phone and the EARS app and troubleshooted, as necessary.

The EARS app for the pilot substudy was limited to use on Android phones with operating systems 6.0 or newer. Although Apple products were considered, the iOS operating system does not allow passive scraping (collecting) of app use information, precluding the inclusion of Apple smartphones from being included in this pilot. In the ABCD data release NDA 3.0, for the 6571 participants at year 2 follow-up (when the substudy

occurred), 36.95% (2428/6571) of the participants had no smartphone, 37.79% (2483/6571) had an iPhone, 23.07% (1516/6571) had an Android, and 2.19% (144/6571) either had another type of smartphone or refused to answer.

## Statistical Analysis

Analyses were run in R 3.6.1 [36] using RStudio [37]. Summary descriptive statistics were calculated for total app use time, total app category time, and self- and parent-reported smartphone use. Analysis of variance evaluated potential differences in the most commonly used app categories (streaming, communication, and social media) by demographic factors (age, sex, household income, race and ethnicity, and geographic location). To assess self-report relative to passive, objective sensing data, Pearson correlations were run to assess relationships between passive, objective sensing daily smartphone use and postsensing self- or parent reports. Postsensing reports were used, as these better reflected the sensing period when objective data were collected. Significant correlations between objective and self-report measurements were then tested using paired sample two-sample *t* tests and chi-square tests. For our second aim, paired samples *t* tests were also used to test mean differences in self-report of pre- and postsensing and self- and parent-report. Finally, to assess the acceptability of passive, objective sensing data collection, the total percentage of child and parent participants' willingness to have the app on the child's phone for longer was reviewed. All *P* values <.05 were interpreted as significant.

## Results

### Overview

The substudy participants (36 men and 31 women; 23/67, 34% White; 5/67, 8% Black; 20/67, 30% Hispanic; 1/67, 2% Asian; and 18/67, 27% *Other*) were at their ABCD year 2 follow-up (mean age 11.88, SD 0.7 years; range 10.75-13.17 years). The annual household income was <US \$50,000 for 35% (23/65), US \$50,000-\$99,999 per year for 34% (22/65), and >US \$100,000 per year for 31% (20/65) of the participants. Comparison of demographics between the full baseline ABCD study cohort and the present sample is presented in [Multimedia Appendix 1](#).

At presensing, 53% (35/66) of the children reported that their parents limit their screen use, with 42% (28/66) of the parent participants restricting smartphone use specifically. Overall, 32% (31/66) of the children reported that their parents installed device monitoring apps on their phone. Similarly, 32% (31/66) of the parents reported having a parental monitoring app on their child's phone and 29% (19/66) reported restricting their child's screen use every day, whereas 42% (28/66) reported rules for weekdays but not weekends, 15% (10/66) reported no rules, and 14% (9/66) said they had not yet made rules. Passive sensing data collection spanned an average of 33.91 (SD 22.20) days to collect the requisite 4 weeks of data, of which 24.22 were weekdays and 9.69 were weekend days, on average. Participants used an average of 2.25 (SD 1.25) unique apps per day, with a total average of 62.48 (SD 22.45) unique apps over the course of sensing. Specific app use is listed in [Table 1](#).

**Table 1.** Average app use (total time) sensed by Effortless Assessment of Risk States from child's smartphone during the 4-week passive sensing period (N=67)<sup>a</sup>.

| Category           | Use time, mean (SD)     |
|--------------------|-------------------------|
| Streaming          | 1 h 57 min (1 h 32 min) |
| YouTube            | 1 h 18 min (1 h 23 min) |
| Communication      | 48 min (1 h 17 min)     |
| Gaming             | 41 min (41 min)         |
| Social media       | 36 min (1 h 7 min)      |
| SMS messages       | 6 min (11 min)          |
| Reading            | 3 min (10 min)          |
| Music <sup>b</sup> | 2 min (5 min)           |
| News               | 1 min (2 min)           |

<sup>a</sup>Categories are composites of specific apps, with the exception of SMS messages and YouTube. Multifunctional apps were listed in multiple categories (eg, Facebook in both communication and social media), so no category is mutually exclusive. SMS messages and YouTube were not mutually exclusive from composite categories (eg, YouTube was also counted within streaming).

<sup>b</sup>Music frequently runs in the background and is only in the foreground when actively selecting songs or turning the app on and off (measured here).

### Relationship Between Objective and Self-report Data

Responses for self- and parent-reports of average daily smartphone screen use before and during the sensing period are reported in Table 2, along with the average daily use as measured by the EARS app. Passive, objectively sensed, and self-reported daily smartphone screen use were significantly correlated ( $P<.001$ ;  $r=0.49$ ; 95% CI 0.28-0.66; Figure 1). Retrospective self-report for the weeks of the sensing did not significantly differ from passive, objective data ( $P=.32$ ), with a nonsignificant tendency for children to show lower and more variable (ie, wider range) self-report than passively collected objective data. However, self-report data collected at presensing about use over the 4 weeks before the sensing period were

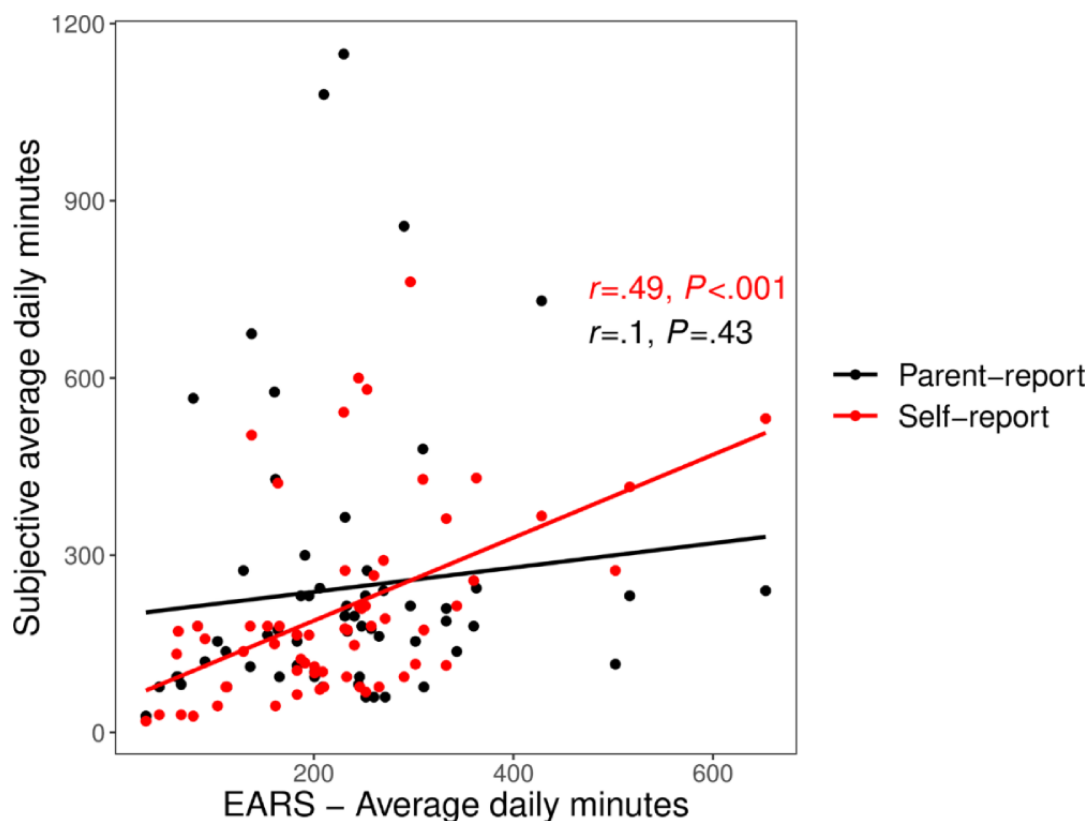
significantly less than passive, objective data ( $P<.001$ ). Overall, 79% (53/66) of children reported less smartphone screen use than indicated by passive sensing, and 21% (14/66) reported more smartphone screen use ( $X^2_1=21.8$ ;  $P<.001$ ). Parent report of their child's smartphone screen use at both pre- ( $r=0.22$ ) and postsensing ( $r=-0.06$ ) did not significantly correlate with objective measurement or with children's self-report ( $P>.05$ ). In the postsensing report, 58% (39/67) of the parents reported less screen use than indicated by passive, objective sensing, and 42% (28/67) reported more ( $X^2_1=1.6$ ;  $P=.20$ ). As parent report varied widely, with some parents reporting their child using their smartphone for more than half the day, results were reanalyzed excluding reports that were 3 SD above the mean; results remained unchanged.

**Table 2.** Child- and parent-report compared with Effortless Assessment of Risk States (EARS) app data for total average daily smartphone screen use, before and after the 4-week passive sensing period (N=67).

|               | Daily device use (4 weeks before sensing), mean (SD) | Daily device use (during 4 weeks of sensing), mean (SD) |
|---------------|--|---|
| Self-report   | 2 h 45 min (2 h 31 min)                              | 3 h 28 min (2 h 43 min)                                 |
| Parent report | 4 h 3 min (3 h 3 min)                                | 4 h 4 min (3 h 51 min)                                  |
| EARS app use  | N/A <sup>a</sup>                                     | 3 h 45 min (1 h 55 min)                                 |

<sup>a</sup>N/A: not applicable.

**Figure 1.** Scatterplot of average daily smartphone use by Effortless Assessment of Risk States and postsensing self-report (in red) and postsensing parent-report (in black). Best-fit simple regression lines are represented for parent report (black) and self-report (red). EARS: Effortless Assessment of Risk States.



### Pre-and Postsensing Behavior Changes

Child self-report of daily average device use pre- and postsensing were correlated ( $r=0.41$ ;  $P<.001$ ; 95% CI 0.19-0.60) and showed an increase (Table 2) from the pre- to postsensing period ( $t_{1,65}=-2.48$ ;  $P=.02$ ; 95% CI -93.97 to -10.06). Parents' pre- and postsensing reports of their child's smartphone screen use were also correlated ( $r=0.61$ ;  $P<.001$ ; 95% CI 0.43-0.74), with no difference between their pre- and postsensing reports ( $P=.63$ ). Most participants reported changing their smartphone screen use behavior during the 4-week sensing period *a lot* (33/62, 55%) or *a little* (28/62, 42%), with only 3% (1/62) reporting *not at all*. Most parents reported no change in monitoring their child's smartphone screen use (42/62, 67%), whereas 25% (15/62) reported closer monitoring and 8% (5/62) did not know; only 8% (5/62) reported a change in their child's smartphone screen use (which was typically an increase). Before sensing, 21% (14/66) of the children reported using the phone more than others their age, which reduced to 13% (8/62) at the postsensing assessment, and children with higher passive, objective screen use tended to perceive that they used their smartphone more than their peers before ( $r=0.33$ ) and after ( $r=0.54$ ) passive sensing.

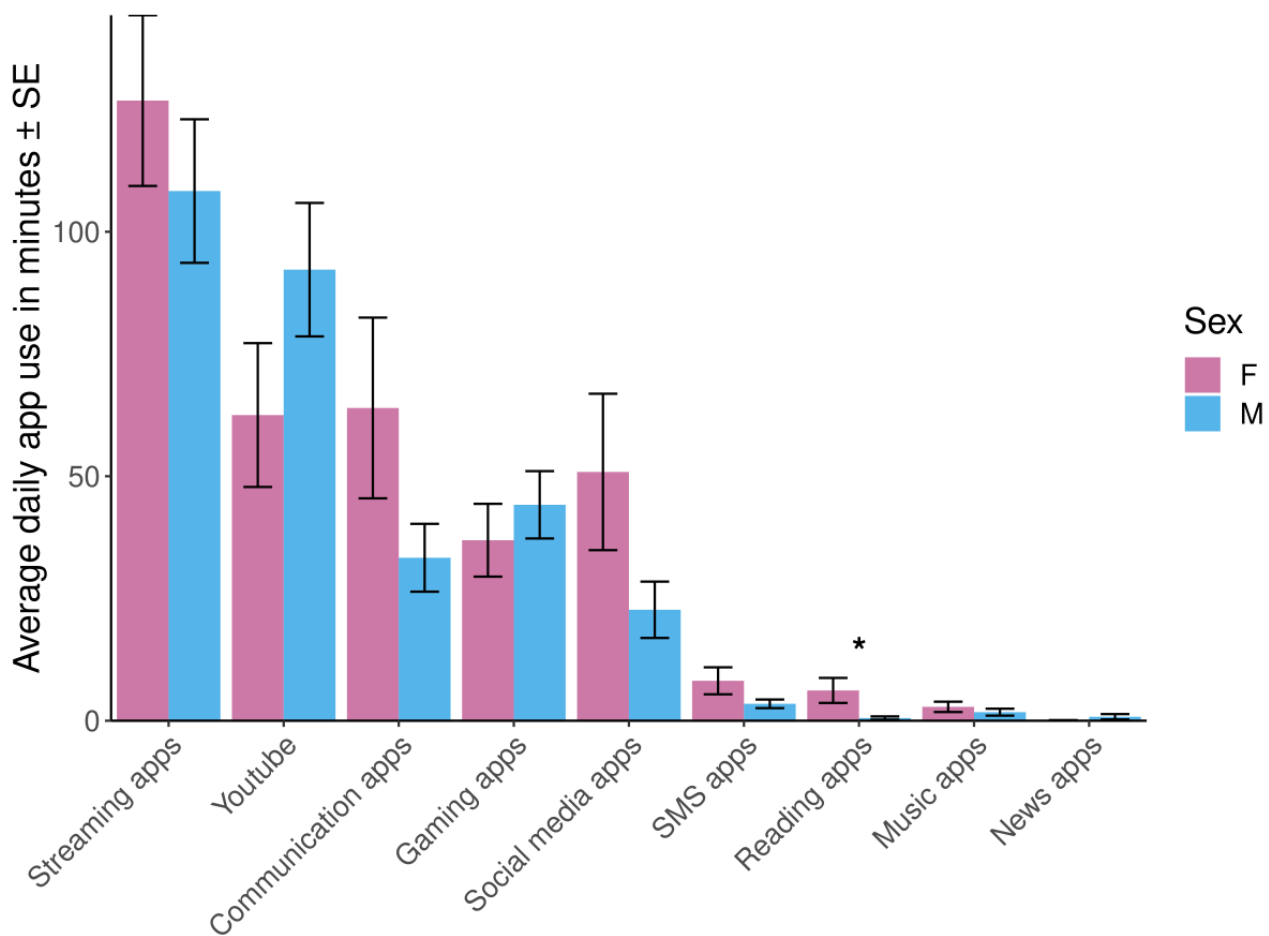
### Feasibility and Acceptability of Passive Assessment of Smartphone Screen Use

Children reported not accessing their phones for a mean of 4.94 (SD 5.04) cumulative days, and parents reported that their child did not use their phone for 4.42 (SD 5.15) days during the 4-week sensing period; however, even in instances when the participant may not have actively used their phone, the EARS app still scanned the device for screen use. Most participants (43/62, 69%) and their parents (53/62, 85%) reported willingness to have a monitoring app such as EARS on the child's phone for a longer period, with 18% (11/62) of child participants unsure.

### Demographic Differences in Smartphone Screen Use

Girls showed more average daily passive, objectively sensed smartphone screen use than boys (4 hours 17 minutes vs 3 hours 19 minutes, respectively;  $F_{1,65}=4.48$ ;  $P=.04$ ) and showed a higher average daily use of reading apps (6 minutes vs <1 minute, respectively;  $F_{1,65}=5.55$ ;  $P=.02$ ; Figure 2). No other demographic differences (age, sex, household income, race and ethnicity, or geographic location) were observed for passive, objectively sensed use of the smartphone overall or for app types. There were also no differences according to demographics for postsensing self-report (sex,  $P=.16$ ; age,  $P=.35$ ; race and ethnicity,  $P=.82$ ; income,  $P=.48$ ; geographic location,  $P=.35$ ) or parent-report (sex,  $P=.51$ ; age,  $P=.92$ ; race and ethnicity,  $P=.72$ ; income,  $P=.06$ ; geographic location,  $P=.14$ ).

**Figure 2.** Average daily app category use sensed by Effortless Assessment of Risk States for girls and boys in minutes. The only significant difference between girls and boys was in reading apps ( $F_{1,65}=5.55$ ;  $P=.02$ ). All other app comparisons were not significant at  $P>.05$ . F: female; M: male.



## Discussion

### Principal Findings

Longitudinal objective smartphone screen use data from a large cohort of children are needed to assess trajectories of smartphone screen use with regard to time spent in total and on specific apps, as well as to map changes in types of information accessed and behaviors displayed across platforms. These data can further be linked to changes in behavior, brain development, psychopathology, and health outcomes across development. In this study, novel data suggests that this type of information is feasible to collect within the ABCD cohort and reveals important information regarding how children are using their smartphones.

Descriptive data from these analyses indicate a wide variety of app use in children. Novel passively sensed data suggest streaming as the most common use of smartphone devices. As defined within the composite category, streaming includes apps such as Netflix and Hulu, as well as others such as Twitch, TikTok, and YouTube. Although streaming is often thought of as a more passive activity, the inclusion of apps with social properties (such as TikTok) also allows for more active engagement. The next most common app categories were communication, gaming, and social media. Thus, it appears that a combination of entertainment and social connection are the primary drivers of smartphone screen use, as most included

apps have the dual capability of passive viewing and active socializing (eg, commenting, posting videos). Previous reports of adolescent and young adult screen use, and particularly social media use, indicate that teens are motivated by social needs [38,39], entertainment [39,40], communication with peers and group members [41-43], complying with perceived social norms [44], feeling a sense of belonging [41], and agency and identity formation [45]. Social motivators are particularly important in adolescence, as teens are likely to seek social approval even at risk of other harm or negative outcomes [46]. The current use patterns may then map well onto reasons for use, as suggested by the literature, despite the young age range of the present sample. In addition to motivations for use, types of screen use and levels of engagement have previously been suggested to be important in screen use outcomes [47,48] and warrant further research.

Perhaps unsurprisingly given their age, other app categories such as *News* were minimally used by this sample. Children may also rely on nontraditional sources of news, such as social media. In addition, although it appears that *Music* apps were used at similarly low rates, this is likely a limitation of the measurement methodology. The EARS app measures apps in the foreground; however, many music-based apps are now able to continue playing music in the background once an album, artist, or playlist are selected. Thus, the *Music* category is likely an underestimate of actual listening time and *Music* in general



appears to be a more passive form of engagement, as children are not frequently actively selecting songs or artists. Together, the wide range of category-based data is informative for the basic description of preadolescent children's smartphone habits, although it also raises many more questions, such as the influence of background apps that require more sophisticated analyses and methods to elucidate.

One of the primary findings of this study is that, assuming relative stability in amount of screen use over time, children underreported smartphone use on presensing, with a stronger correlation (though still moderate in strength) between perceived and measured screen use after the month-long monitoring period. Notably, however, without data from the presensing period, we cannot confirm that participants underreported use rather than actually used their smartphones less. Furthermore, parental report of their child's smartphone screen use was not significantly correlated with passive, objective measurement of use, or with self-reported data. Consistent with concerns from previous research [9-12,49], these findings suggest that reliance on self- or parent-reported estimates of smartphone screen use is likely inaccurately assessing the effects of screens and smartphone use in children and adolescents. Notably though, children appear to be more accurate reporters than their parents. Thus, the collection of passive, objective data of smartphone screen use, rather than reliance on either parent or self-report alone, may contribute more accurate and informative data for understanding how smartphone screen use shapes brain-behavior and pathology relationships in children.

Descriptive data from parent report indicate that parents generally overreported their child's average daily smartphone screen use when looking at the overall mean use reported. On balance, 58% (39/67) of parents underreported their child's smartphone screen use when comparing parent report with passive, objectively sensed data. Similarly, one study found that parents may overreport, relative to their children, screen use [50], although others have found underreporting by parents that they suspect was due to a social desirability bias [49]. As found here, parents are likely unaware of the extent and ways their preteen children use smartphones, as manifested here through inaccurate reporting that is both above and below actual screen use. Together, this suggests decreased ability to adequately monitor their child's behaviors. This is concerning as decreased parental monitoring has been implicated in increased problematic behavior in adolescents [51,52].

Interestingly, children's self-report became more consistent with the objective data after completing the passive sensing protocol (postsensing) and a majority endorsed their phone use behaviors changed *a lot* during the study period. This finding may indicate that, despite the passivity of app-based smartphone measurement, any type of monitoring could influence behavior. It also may be that perceived screen use may fall in line more with passively collected metrics given that participants' attention was drawn to their screen use after being queried about it. A study of passively collected physical data using an accelerometer similarly found participant-reactivity to monitoring [25]. In another study of children and young adolescents, Domoff et al [22] found passive sensing of smartphone use to statistically, but not meaningfully (approximately 11 minutes per day),

increased smartphone screen time. Other research indicates that knowledge of being observed alone can change behavior [23]. Although ABCD and this substudy were designed to be purely observational, the pilot nature of app development may have required additional intervention from the study team (ie, app notifications; calls from research assistants to query whether the app was still installed on the phone). Even if data collection is modestly influencing behavior, the combination of objective and postsensing self-report data is likely more accurate than reliance on presensing self-report alone, as has been supported by a meta-analysis [13]. In addition, although moderately correlated, there is still great variability in self-report in relation to objective report. Although retrospective self-report may be less accurate, it is also possible that app use measurement may not always reflect actual use, as with music apps, and better app measurement is desirable. A combination of passive sensing and real-time self-report, such as through EMA, may provide more accurate and robust app use data.

Notably, the vast majority of children and their parents reported openness to extending the amount of time the EARS app was on their phone, indicating that the use of passive assessment of smartphone screen use is highly feasible and acceptable even in children. This is consistent with previous research on passive mobile sensing in parents and young children (aged 3-5 years) [18,19] and in similarly aged youth [22]. The types of data collected through the EARS app meet most of the recent recommendations for passive sensing smartphone research [16], including collecting data on general use time, screen on and off time, most used apps, and length of app use. Furthermore, raw data can be accessed through the National Institute of Mental Health Data Archive, allowing for the investigation of specific apps or creation of new researcher-derived composite categories outside of those provided by ABCD and Google Play Store categories. New composite categories created by individual investigators or research groups may be more informative than the included categories that are not mutually exclusive included apps. Summary data for daily, weekday, and weekend use are already provided within the NDA 3.0 data release, and combining composites with raw data could be used to further break down use patterns into the time of day that an app was used. Thus, the level of detail available within this subsample and, soon, the full ABCD cohort is uniquely rich and valuable for investigating smartphone screen use. On balance, the depth of available data suggests that further innovation is needed to process the amount of data, and best practices for using such fine-grained data should be outlined.

## Limitations

The data presented in this study are from a small subsection (62/11,875, 0.52%) of the overall ABCD participants and only includes Android users, significantly reducing generalizability from the full ABCD cohort. The ABCD-specific EARS app sensing design is only compatible with non-iOS devices because of Apple blocking app scraping programs, although additional components of EARS (eg, EMA) that are not used by ABCD can be implemented in iOS. Future ABCD passive sensing data collection with the EARS app include methods to calculate a proxy variable for time on Apple phones, which can be validated in comparison to Android data in future ABCD time points.

App categories were created by adults, which may not directly translate to how children and adolescents actually use apps. Categories on their own may not be accurate. For example, although YouTube is generally viewed as a streaming app, it also has means for communicating with others, suggesting it may further be categorized as a communication or social media app. In addition, the youth only reported their overall smartphone screen use time, preventing assessment of the correlation between self-reported specific categories of app use (eg, social media apps) with objective measurement of that same category. Beginning in ABCD follow-up year 4, youth self-report categories of smartphone screen use so that this can be assessed. The methods used here only consider smartphone screen use, not capturing screen time from other platforms (eg, TV, tablets, computers, gaming systems). Some information can also not be derived, such as the frequency of download and removal rate of apps, despite the large range of unique apps used by children. As discussed above, passive monitoring may not have been as passive as desired because of phone notifications and research assistant troubleshooting contact. For the year 4 follow-up in the full cohort, processes are being further automated to attempt to reduce any potential intervention from reminders regarding app monitoring. In addition, participants reported perceived changes in smartphone screen use and greater time spent on their phone, and additional research is needed to determine whether their perceived increase in use was accurate and, if so, how and why they changed their

use. App data use available in NDA 3.0 is rich and detailed, providing many potential avenues of investigation; given the nascent area of research, we limited our analyses to general overall findings. Future research should take a more fine-grained approach to investigate questions such as patterns of use (eg, do children use the same apps and app categories day after day; time of use). Finally, although the EARS app generally uses minimal battery [30], particularly in the ABCD version with fewer sensors activated, participants may still have noticed and been bothered by the battery or data drain, potentially further changing behavior.

## Conclusions

In summary, using passive, objective sensing of app use revealed novel information regarding the types and duration of app use by children. The monitoring system was generally viewed favorably by participants and their parents, and child-parent dyads reported willingness to continue to have the limited electronic passive sensing system on their personal smartphone for research purposes. The results suggested that child report was consistent with objective measurement, though only at a moderate level and with greater variability. Given the sparsity of high-quality data on smartphone use in this developing age group, more objective, longitudinal research in this domain would be beneficial for delineating how amount of time and types of engagement with smartphones impact physical, neurological, and mental health development, as will be assessed in the ABCD study.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Demographics for both the full Adolescent Brain Cognitive Development study cohort at baseline and the present subsample of participants at Year 2.

[DOCX File, 13 KB - [mental\\_v8i10e29426\\_app1.docx](#)]

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## Abbreviations

**ABCD:** Adolescent Brain Cognitive Development

**EARS:** Effortless Assessment of Risk States

**EMA:** ecological momentary assessment

**NDA:** National Institute of Mental Health Data Archive

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Original Paper

# Predictors of Booster Engagement Following a Web-Based Brief Intervention for Alcohol Misuse Among National Guard Members: Secondary Analysis of a Randomized Controlled Trial

Lara N Coughlin<sup>1,2</sup>, PhD; Frederic C Blow<sup>1,3</sup>, PhD; Maureen Walton<sup>1,2\*</sup>, MPH, PhD; Rosalinda V Ignacio<sup>4\*</sup>, MSc; Heather Walters<sup>3</sup>, MS; Lynn Massey<sup>2</sup>, MSW; Kristen L Barry<sup>1</sup>, PhD; Richard McCormick<sup>5</sup>, PhD

<sup>1</sup>Addiction Center, Department of Psychiatry, University of Michigan, Ann Arbor, MI, United States

<sup>2</sup>Injury Prevention Center, University of Michigan, Ann Arbor, MI, United States

<sup>3</sup>VA Center for Clinical Management Research, Department of Veteran Affairs Healthcare System, Ann Arbor, MI, United States

<sup>4</sup>Department of Biostatistics, School of Public Health, University of Michigan, Ann Arbor, MI, United States

<sup>5</sup>Center for Healthcare Research and Policy, MetroHealth/Case Western Reserve University, Cleveland, OH, United States

\*these authors contributed equally

**Corresponding Author:**

Lara N Coughlin, PhD  
Addiction Center  
Department of Psychiatry  
University of Michigan  
2800 Plymouth Rd  
Ann Arbor, MI, 48109  
United States  
Phone: 1 734 615 4774  
Email: [laraco@med.umich.edu](mailto:laraco@med.umich.edu)

## Abstract

**Background:** Alcohol misuse is a major health concern among military members. Reserve component members face unique barriers as they live off base with limited access to behavioral health services. Web and app-based brief interventions are a promising means to improve access to treatment for those who misuse alcohol, with the use of booster sessions to enhance effectiveness, solidify gains, and reinforce changes. However, little is known about who will engage in booster sessions.

**Objective:** This study aims to evaluate booster engagement across booster delivery modalities (Web and Peer) and identify participant-specific factors associated with booster session engagement.

**Methods:** Following a brief web-based alcohol misuse intervention in National Guard members (N=739), we examined engagement in a series of three booster sessions. Using unadjusted and adjusted models, demographic and clinical characteristics that may serve as predictors of booster session engagement were examined across the 2 arms of the trial with different types of booster sessions: peer-delivered (N=245) and web-delivered (N=246).

**Results:** Booster session completion was greater for Peer than Web Booster sessions, with 142 (58%) service members in the Peer Booster arm completing all three boosters compared with only 108 (44%) of participants in the Web Booster arm ( $\chi^2_3=10.3$ ;  $P=.006$ ). In a model in which the 2 groups were combined, socioeconomic factors predicted booster engagement. In separate models, the demographic and clinical predictors of booster engagement varied between the 2 delivery modalities.

**Conclusions:** The use of peer-delivered boosters, especially among subsets of reserve members at risk of lack of engagement, may foster greater uptake and improve treatment outcomes.

**Trial Registration:** ClinicalTrials.gov NCT02181283; <https://clinicaltrials.gov/ct2/show/NCT02181283>

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**KEYWORDS**

alcohol use; National Guard; brief intervention; boosters; engagement

## Introduction

### Background

Alcohol misuse is a major health concern among military members. A Department of Defense Health Related Behaviors Survey of active duty personnel, conducted in 2015-2016, found high rates of hazardous drinking (35%) and binge drinking (30%) [1]. Previous national surveys have found similarly high rates of alcohol misuse [2,3], and these rates were higher among deployed reserve component members, including the National Guard, than among deployed active duty members [4]. Alcohol misuse adversely affects the psychological health and well-being of service members and their families and has a direct impact on their resilience and military readiness [5].

Reserve components have been used heavily during the recent wars, accounting for 28% of all deployments [6]. The approximately 336,000 Army National Guard members nationwide make up 41% of the operational Army forces [7]. They are projected to be an integral part of the fighting force going forward [6]. Maintaining the resilience and readiness of military members, including addressing alcohol misuse, is a particular challenge for reserve component members who do not live and train on military bases where many support services are available, and who spend most of their time in their civilian roles.

Stigma and confidentiality concerns are significant barriers to seeking help with alcohol-related problems in the military [8-10]. Reserve component members face additional unique barriers to seeking help. Unlike active duty members who live on or near military bases where many services are readily available, reserve component members generally attend scheduled training activities only 1 weekend per month, and often live in rural areas remote from their home armory or unit. Web-based and mobile apps can help ameliorate these challenges [11].

The use of computers to screen and deliver brief intervention (BI) has been shown to be effective for a variety of health behaviors, including alcohol use [12,13]. The eHealth interventions for alcohol use seem to be especially useful for older, nonstudent populations [14]. Patients often evaluate computer interactions positively [15,16], and participants may more accurately record sensitive information on computers because of fewer concerns about judgment [17,18].

Few studies of web-based approaches have been reported with military populations, and controlled trials have been hampered by low follow-up rates [19,20]. The Department of Defense is committed to expanding the use of mobile and web-based approaches, but the development and testing of these interventions is needed [21]. A small body of research indicates that the use of booster sessions can enhance effectiveness, solidify gains, and reinforce changes after an initial BI [22-24], including after a computerized intervention, but results are mixed [25-28].

Increasing engagement positively impacts health-related behavior change, including reducing alcohol misuse [29,30], but there is limited understanding of the factors that are

associated with engagement [31]. Initial evidence suggests that older age, higher educational attainment, and being female are associated with greater engagement in app- and web-based interventions [31-34], potentially reflecting characteristics that are also broadly associated with greater study adherence.

Despite their potential importance, booster sessions create a number of logistical challenges. They are resource-intensive, and sessions are difficult to deliver when participants are at a distance from their provider. Furthermore, boosters may have limited benefits for some individuals, while being essential for sustained outcomes in others. To date, limited research has sought to identify the characteristics of individuals who are likely to engage in booster sessions following BIs for alcohol and other substance use. In a recent study, Hatch-Maillette et al [35] found that people receiving a BI targeting reduced substance misuse during a visit in the emergency department were more likely to engage in phone-based booster sessions during the month following the BI if they were older, regularly employed, and if they believed substance use was related to the emergency department visit. There is also limited research on the impact of various booster delivery systems on engagement with booster sessions, as measured by the number of booster sessions completed by the participant. Given that in many studies, gains in reducing alcohol misuse dissipate over time, more information on factors associated with booster engagement is needed. Furthermore, the optimal delivery modality for delivery boosters is uncertain.

For example, research indicates that peer support is useful in the treatment of individuals with substance use disorders [36,37]. The use of peer-to-peer interactions has expanded in recent years in Veterans Health Administration facilities and other health care systems and has been widely accepted. The military has recognized the unique value of harnessing the power of peer support and identification with a military peer group to overcome stigma and enhance participation in resilience building and help seeking. For example, the Army's Comprehensive Soldier and Family Fitness Program heavily used unit-based noncommissioned officers as trained trainers who teach and work with soldiers to increase their resilience and overcome stigma for seeking help [38,39]. Numerous *grassroots* peer programs have also been implemented within the military and National Guard, using fellow veterans trained for a range of counseling and support functions. For example, the Buddy-to-Buddy program [40] has been implemented in the Michigan National Guard and in other states but does not focus on alcohol misuse. Peer counselors benefit from the acceptance and trust afforded to men and women who have also served and have the potential to boost adherence to plans created in a web-based intervention; however, research to verify their efficacy for alcohol misuse is needed.

Alternatively, there is also some evidence that eHealth interventions for hazardous alcohol use that include human contact are more effective [13]. A telephone app intervention for alcohol reduction has been modified and tailored for use with veterans receiving treatment in a primary care setting [41], but there has been no research on the impact of eHealth interventions among military or veteran populations as part of the National Guard.

## Objective

In this paper, we examine two modes of booster delivery, web-based and peer-based, to explore modality-specific differences in booster engagement and predictors of booster engagement by delivery modality. Given the paucity of information on boosters, the study is exploratory, and no specific a priori hypotheses have been made. There is strong evidence in the civilian literature on the efficacy of BIs for adults with at-risk or harmful levels of drinking [42-44], but this approach has not been well studied in military populations. Therefore, the aim of this study is to gain a better understanding of booster session engagement among specific populations. This can inform future intervention approaches in two ways. First, by identifying those who are likely to engage with boosters, limited resources can be allocated to those who are likely to use the services. Second, those who are unlikely to engage in booster sessions may constitute a hard-to-reach subpopulation of National Guard service people for whom more intensive engagement approaches are needed.

## Methods

### Study Design

The randomized controlled study, Mission Strong, was approved by the University of Michigan Institutional Review Board and conducted with members of the Michigan Army National Guard attending weekend training drills (NCT02181283). Participants were randomly assigned to the Intervention + Web Booster (N=246) or Intervention + Peer Booster interventions (N=246), or to a control that did not contain intervention content (N=248).

All intervention participants, regardless of booster modality, initially completed a 30-40 minutes web-based BI based on motivational interviewing, which was tailored for each participant (by sex, deployment history, and baseline drinking pattern) using the FRAMES format [45]: personalized *feedback* (regarding substance use, risk factors), emphasis on *responsibility* for change, *advice*, *menu* of options, *empathic* clinical behaviors, and support of *self-efficacy* regarding making changes. The intervention included a review of participants' goals and strengths, feedback regarding their present alcohol or drug use patterns and the consequences of their drinking, a decisional balance exercise developing the discrepancy between their alcohol use and ability to meet their goals, an assessment of their readiness to change, and the formulation of a plan with strategies for change. The intervention was designed in a virtual therapist interactive style, with a personally selected military or nonmilitary avatar guiding the participant on his or her *mission* to navigate through the program. The content of the BI protocol was built on existing intervention content in place from previous work by the investigators, but the content was modified to be appropriate within a reserve component military context [46,47].

The overall study included participants who misused alcohol only (N=711) misused only prescription drugs (N=18), and those who misused both alcohol and prescription drugs (N=28). Only participants who misused alcohol alone or alcohol plus prescription drugs were included in the current analyses

(N=739). Individuals were eligible to participate if they had an Alcohol Use Disorders Identification Test–Consumption score of 5 or more for men and 4 or more for women, indicating that they met the criteria for at-risk drinking or alcohol misuse [48]. Participants were excluded if they reported receiving substance use treatment in the past 4 months. All participants were provided access to a resource brochure with relevant information for treatment and crisis services. For participants who had an AUDIT [49] score of 19 or more, indicative of a likely alcohol use disorder, the resource brochure was reviewed with the participant with the recommendation to look into treatment options. Following the baseline assessment, participants were randomized using a computer-generated algorithm and stratified by gender and recent alcohol, prescription opiate or sedative misuse into either the web-based intervention plus web administered boosters, the web-based Intervention plus Peer Boosters, or the enhanced usual care (EUC) control arm.

At the end of the BI, participants in the Intervention + Web Booster arm were reminded that they would receive emails once a month for three months, instructing them to log in to complete booster sessions. Those assigned to the Intervention + Peer Booster arm were informed that they would be contacted by peer support veterans at least once a month for three months for follow-up support. If a participant missed a scheduled booster, regardless of the arm, contact attempts were made 1-2 times per week (via preferred means of contact, eg, phone, text, email) until the participant completed the booster or the date of the next appointment arrived. Participants were remunerated US \$20 for completion of the baseline assessment, US \$15 for completing the BI, US \$5 for each of the 3 booster sessions, US \$35 for the 4-month follow up, US \$40 for the 8-month follow-up, and US \$45 for the 12-month follow-up.

Sample sizes were determined using power analysis for the primary outcome study. Sample sizes were chosen to allow the comparison of each treatment arm against the usual care arm.

### Booster Types

#### Web Boosters

The Web Booster content mirrored the last three sections of the BI. Messages were tailored based on whether the participant misused only alcohol or both alcohol and prescription medication. Like the BI, boosters were structured as a mission, including different points on a map that the participant had to navigate. They also included video message that provided testimonials that were tailored based on alcohol and prescription opioids as indicated and were based on deployment history (yes or no). Web and Peer Boosters were structured to require approximately 15 minutes to complete, but because they were done independently, no exact data on the time it took to complete them for each participant was available.

#### Peer Boosters

Peer Boosters, a type of person-delivered booster that uses people with similarities to the target population, were delivered by veterans and were conducted over the phone or in person (414/466, 88.8% delivered by phone), lasting approximately 15-20 min. The Peer Boosters had content parallel to that of the Web Boosters, albeit with some differences. At the first booster,



peers shared the purpose of the session and asked about the experiences with the first BI session. Survey data were not shared with peers, and peers did not directly ask about the level of alcohol consumption or level of prescription drug use. However, the participants' individual goals established in the BI were reviewed, which tailored the booster sessions for those who also misused prescription drugs. The booster session

meetings started with a discussion of health habits, proceeding to choices, and concluding with the next steps (sections 4-6 of Table 1). The topics discussed at each booster were identical to those of the web sessions, namely finances and reasons for use, physical fitness and mood, and getting places (driving under the influence) and social influences. Table 1 summarizes the contents of the three booster sessions for each treatment arm.

**Table 1.** Web Booster session content.

| Booster 1   | Booster 2   | Booster 3   |
|---|---|---|
| <b>Finances and reasons for use</b>   | Physical fitness and mood                             | Getting places: driving under the influence and social influences |
| 1. Review past session (strengths, goals, strategies)   | 1. Review past session (strengths, goals, strategies) | 1. Review past session (strengths, goals, strategies)             |
| 2. Current health habits (use and guidelines)   | 2. Current health habits (use and guidelines)         | 2. Current health habits (use and guidelines)                     |
| 3. Calculator of money spent on alcohol   | 3. Calculator of alcohol calories                     | 3. Calculator of BAC <sup>b</sup> + how to get home safely        |
| 4. What could I spend money on instead? How use affects activities and spending?  | 4. Exercise, mood, and drinking                       | 4. Social influences on drinking                                  |
| 5. Video of a peer message and strategies (eg, coping, leisure activities, use reduction strategies, safe rides home, pain or stress or sleep management) | N/A <sup>a</sup>                                      | N/A   |
| 6. Summary and plan with one next step  | N/A   | N/A   |

<sup>a</sup>N/A: not applicable.

<sup>b</sup>BAC: blood alcohol concentration.

## Measures

Demographic, military, and clinical characteristics were assessed at baseline. Military-specific measures included their military rank and the number of previous deployments, including both international and domestic deployments. Clinical characteristics included past 4-month cannabis or other illicit drug use (cocaine, methamphetamines, hallucinogens, inhalants, heroin, or prescription amphetamines [eg, Ritalin, Adderall]) using the Alcohol, Smoking, and Substance Involvement Screening Test [50]. Alcohol misuse was measured using the 10-item AUDIT [49]. How often the participant drove while drinking in the past 4 months was assessed using a single-item Likert scale ranging from 0 (never) to 4 (10+ times).

Mental health measures included depression, measured using a 9-item depression screen, the Patient Health Questionnaire (PHQ-9) [51]; anxiety, measured using the 7-item General Anxiety Disorder Questionnaire (GAD) [52]; and a history of exposure to trauma, measured using the Mini International Neuropsychiatric Interview (MINI) PTSD module [53].

The current motivation to change alcohol use was measured using a motivation for change ruler scaled from 1 (not ready) to 10 (very ready); the degree of confidence that you can change in the next 4 months was measured with a similar ruler [54]. Motivation for drinking or drug use was assessed using questions from the Drinking Motives Questionnaire-Revised [55]. Drinking Motives Questionnaire-Revised items measuring all 5 subscales were included: Enhancement (eg, drinks or uses drugs to get high, because they like the feeling); coping with

anxiety (eg, drinks or uses drugs when anxious); coping with depression (eg, drinks or uses drugs when depressed); conformity (drinks or uses drugs so will not feel left out), and social (eg, what my friends do when get together). Items from the Washington University Risk Behavior Assessment for Club Drugs [56] were used to create an additional subscale assessing motivation to drink or use drugs to obtain physical effects (eg, to function better physically or for pain). The Short Index of Problems (SIP) version of the Drinker Inventory of Consequences Impulsivity Scale was used to measure problems with impulsivity associated with drinking [57].

## Analyses

All analyses were performed using the SAS software (version 9.4, SAS Institute) [58]. General linear modeling (GLM) and chi-square tests were used to examine the unadjusted associations between booster session engagement and follow-up assessment adherence and demographic and clinical characteristics separately for those randomized to Intervention + Peer Booster and intervention + Web Booster arms. Because of the lack of information currently in the literature regarding the effect of booster delivery format on engagement and to stimulate further research in this area, we conducted an exploratory analysis on the univariate relationship between delivery method (Web vs Peer) on booster engagement for variables identified as meaningful based on the previous within-arm analyses. The relationship between the modality of booster delivery (Web vs Peer) and booster session engagement was evaluated using the chi-square test.

Finally, stepwise regression analyses were conducted for each treatment arm separately and for the combined sample from both treatment arms, including the treatment arm as a predictor of booster session engagement. The stepwise regression procedure uses a series of alternating forward and backward selection steps to identify variables to include and maintain in the model. The criterion for a variable to be entered and maintained in the model at each step was  $P \leq .3$ , which is the default criterion in SAS and balances the risk of including unnecessary predictors with overly stringent inclusion criteria that can exclude meaningful predictors [59,60]. As such, predictors could be retained in a model because they were below the  $P \leq .3$  threshold even though they were not statistically significant at the  $P < .05$ . Stepwise regression was chosen because of the limited previous information to inform the selection of predictors of booster session engagement in the general population and the absence of any information in military populations. Given the limited information to guide theory driven variable selection, the data driven stepwise variable selection approach, and the criteria for inclusion and retention in the stepwise process were preferred for this initial, exploratory study of predictors of booster engagement using demographic and clinical variables in a military sample. Of note, for this exploratory regression analysis, the depression (PHQ>4) and anxiety (GAD>9) scales were dichotomized based on clinical cutoffs indicative of positive screening [51,52]. This was done because these are the cutoffs clinically recommended for mild depression when the PHQ is used as a screening instrument in nonclinical samples, such as our National Guard sample.

## Results

### Overview

The study consort diagram is shown in [Multimedia Appendix 1](#). For the purposes of this study, all analyses focused on the two active treatment arms: Intervention + Peer Booster and intervention + Web Booster. Almost all participants randomized to these two arms completed the BI (227/246, 92.3% for Intervention + Web Booster and 228/245, 93.1% for Intervention + Peer Booster). In the Intervention + Web Booster arm, 56.5% (139/246), 53.7% (132/246), and 48.8% (120/246) completed each specific booster session (ie, booster sessions 1, 2, or 3). In the Intervention + Peer Booster arm, 68.9% (169/245), 63.3% (155/245), and 57.9% (142/245) completed booster 1, 2, or 3, respectively. In the Web Booster arm, 61.4% (151/246) completed at least 1 booster, and 68.9% (169/245) completed at least one booster session in the Peer Booster arm. [Table 2](#) presents booster session engagement by the Web and Peer Booster treatment arms. Of the participants randomized to the Peer Booster arm, 142 (58%) completed all 3 booster sessions compared with only 108 (44%) in the Web Booster arm. In both study arms, of the participants who engaged in any booster sessions, most went on to complete all three. In other words, a relatively small portion of participants who engaged in boosters completed only 1 or 2 boosters. Participants randomized to the Peer Booster delivery format were significantly more likely to engage in boosters than participants in the Web Booster arm ( $\chi^2_3=10.3$ ;  $P=.006$ ).

**Table 2.** Number of booster sessions completed by delivery modality.<sup>a</sup>

| Booster sessions | Web Booster, n (%) | Peer Booster, n (%) |
|------------------|--------------------|---------------------|
| 0                | 95 (39)            | 76 (31)             |
| 1                | 19 (8)             | 14 (6)              |
| 2                | 24 (10)            | 13 (5)              |
| 3                | 108 (44)           | 142 (58)            |

<sup>a</sup> $\chi^2_3=10.3$ ;  $P=.006$ .

### Unadjusted Outcomes

[Tables 3](#) and [4](#) present the unadjusted associations for the Web and Peer Booster arms between the number of booster sessions completed and demographic and clinical characteristics. In both treatment arms, those who completed more boosters were significantly more likely to be older. Because of the relatively small number of participants completing either 1 or 2 booster sessions, the participants were combined into a category of those

completing either 1 or 2 boosters. In the Web Booster arm, there was a significant relationship between more booster engagement and higher rank, more education, and higher income, as well as trauma history. In the Peer Booster arm, men, people with more education, higher income, deployment history, current employment, married or living together, and experiencing more severe depression or anxiety symptoms were more likely to engage in the booster sessions.

**Table 3.** Unadjusted association between baseline characteristics and Web Booster engagement.

| Predictors                             | Web Boosters |               |             | Test statistic ( <i>df</i> ) | <i>P</i> value | Effect size <sup>a</sup> |
|--|--------------|---------------|-------------|------------------------------|----------------|--------------------------|
|  | 0 (n=95)     | 1 or 2 (n=43) | 3 (n=108)   |                              |                |                          |
| <b>Follow-up completion, n (%)</b>     |              |               |             |                              |                |                          |
| 4 months                               | 31 (17.61)   | 37 (21.02)    | 108 (61.36) | $\chi^2_2=118.0$             | <.001          | .69                      |
| 8 months                               | 35 (20.00)   | 34 (19.43)    | 106 (60.57) | $\chi^2_2=94.1$              | <.001          | .62                      |
| 12 months                              | 37 (21.14)   | 36 (20.57)    | 102 (58.29) | $\chi^2_2=79.8$              | <.001          | .57                      |
| <b>Baseline characteristics</b>        |              |               |             |                              |                |                          |
| Sex (male), n (%)                      | 86 (41.55)   | 34 (16.07)    | 87 (42.03)  | $\chi^2_2=4.7$               | .09            | .14                      |
| Age, mean (SD)                         | 27.4 (7.5)   | 27.9 (7.4)    | 30.5 (7.7)  | $F_{1,244}=8.54$             | .004           | .03                      |
| <b>Race, n (%)</b>                     |              |               |             | $\chi^2_2=1.1$               | .57            | .07                      |
| White                                  | 77 (40.10)   | 34 (17.71)    | 81 (42.19)  |                              |                |                          |
| Other                                  | 18 (33.33)   | 9 (16.67)     | 27 (50.00)  |                              |                |                          |
| Hispanic (yes), n (%)                  | 13 (48.15)   | 3 (11.11)     | 11 (40.74)  | $\chi^2_2=1.4$               | .48            | .08                      |
| <b>Marital status, n (%)</b>           |              |               |             | $\chi^2_6=2.4$               | .87            | .07                      |
| Married                                | 25 (33.33)   | 13 (17.33)    | 37 (49.33)  |                              |                |                          |
| Living together                        | 16 (38.10)   | 7 (16.67)     | 19 (45.24)  |                              |                |                          |
| Widowed, divorced, or separated        | 10 (35.71)   | 5 (17.86)     | 13 (46.43)  |                              |                |                          |
| Never married                          | 44 (43.56)   | 18 (17.82)    | 39 (38.61)  |                              |                |                          |
| <b>Highest grade completed, n (%)</b>  |              |               |             | $\chi^2_4=26.1$              | <.001          | .23                      |
| High school or less                    | 30 (58.82)   | 9 (17.65)     | 12 (23.53)  |                              |                |                          |
| Some college                           | 54 (40.60)   | 25 (18.80)    | 54 (40.60)  |                              |                |                          |
| College or more                        | 11 (17.74)   | 9 (14.52)     | 42 (67.74)  |                              |                |                          |
| <b>Rank, n (%)</b>                     |              |               |             | $\chi^2_4=19.1$              | <.001          | .20                      |
| E1-E4                                  | 60 (45.11)   | 29 (21.80)    | 44 (33.08)  |                              |                |                          |
| E5-E9                                  | 31 (32.98)   | 14 (14.89)    | 49 (52.13)  |                              |                |                          |
| WO1-WO5/O1-O9                          | 4 (21.05)    | 0 (0)         | 15 (78.95)  |                              |                |                          |
| Employed (yes), n (%)                  | 81 (36.99)   | 40 (18.26)    | 98 (44.75)  | $\chi^2_2=2.4$               | .22            | .10                      |
| <b>Household income (US \$), n (%)</b> |              |               |             | $\chi^2_6=19.1$              | .004           | .20                      |
| 25,000 or less                         | 29 (46.48)   | 10 (15.38)    | 26 (40.00)  |                              |                |                          |
| 25,000-50,000                          | 33 (24.49)   | 12 (16.90)    | 26 (36.62)  |                              |                |                          |
| 50,000 or more                         | 24 (24.49)   | 19 (19.39)    | 55 (56.12)  |                              |                |                          |
| Refused                                | 9 (75.00)    | 2 (16.67)     | 1 (8.33)    |                              |                |                          |
| Ever deployed (yes), n (%)             | 45 (37.19)   | 23 (19.01)    | 53 (43.80)  | $\chi^2_2=0.4$               | .80            | .04                      |
| Trauma exposure (yes), n (%)           | 21(26.25)    | 17 (21.25)    | 42 (52.50)  | $\chi^2_2=7.6$               | .02            | .18                      |
| Illicit drug use (yes), n (%)          | 7 (26.92)    | 8 (30.77)     | 11 (42.31)  | $\chi^2_2=3.9$               | .14            | .13                      |
| Cannabis use (yes), n (%)              | 14 (50.00)   | 5 (17.86)     | 9 (32.14)   | $\chi^2_2=2.0$               | .36            | .09                      |
| AUDIT <sup>b</sup> , mean (SD)         | 9.4 (5.4)    | 9.3 (5.8)     | 9.6 (5.8)   | $F_{1,244}=0.08$             | .77            | <.01                     |
| PHQ <sup>c</sup> , mean (SD)           | 5.1(6.0)     | 6.0 (5.4)     | 5.1 (5.8)   | $F_{1,244}=0.00$             | .99            | <.01                     |

| Predictors                               | Web Boosters |               |           | Test statistic ( <i>df</i> ) | <i>P</i> value | Effect size <sup>a</sup> |
|--|--------------|---------------|-----------|------------------------------|----------------|--------------------------|
|  | 0 (n=95)     | 1 or 2 (n=43) | 3 (n=108) |                              |                |                          |
| GAD <sup>d</sup> , mean (SD)             | 5.7 (5.5)    | 6.7 (5.3)     | 5.1 (5.3) | $F_{1,244}=0.71$             | .40            | <.01                     |
| Drink and drive, mean (SD)               | 0.3 (0.7)    | 0.3 (0.8)     | 0.3 (0.7) | $F_{1,244}=0.09$             | .77            | <.01                     |
| Readiness to change, n (%)               | 4.1 (3.0)    | 3.9 (2.9)     | 3.9 (2.9) | $F_{1,244}=0.23$             | .63            | <.01                     |
| Confidence reduction, n (%)              | 5.1 (3.0)    | 4.5 (2.9)     | 4.4 (3.3) | $F_{1,244}=2.19$             | .13            | .01                      |
| SIP <sup>e</sup> -Impulse control, n (%) | 1.0 (1.5)    | 1.2 (1.6)     | 1.1(1.6)  | $F_{1,244}=0.24$             | .63            | <.01                     |
| <b>Motives to drink, mean (SD)</b>       |              |               |           |                              |                |                          |
| Social                                   | 4.6 (2.3)    | 5.4 (2.3)     | 5.1 (2.4) | $F_{1,244}=2.01$             | .16            | .01                      |
| Coping with anxiety                      | 3.7 (2.1)    | 4.0 (2.1)     | 3.9 (2.3) | $F_{1,244}=0.36$             | .55            | <.01                     |
| Coping with depression                   | 4.8 (2.8)    | 5.3 (2.1)     | 5.3 (3.0) | $F_{1,244}=1.32$             | .25            | .01                      |
| Enhancement                              | 4.1 (2.3)    | 4.5 (2.0)     | 4.1 (2.0) | $F_{1,244}=0.00$             | .96            | <.01                     |
| Conformity                               | 2.6 (1.6)    | 2.6 (1.6)     | 2.7 (1.5) | $F_{1,244}=0.21$             | .65            | <.01                     |
| Physical                                 | 4.4 (2.3)    | 4.6 (1.9)     | 4.5 (2.1) | $F_{1,244}=0.15$             | .70            | <.01                     |

<sup>a</sup>Effect size reported as Cramer *V* for chi-square tests and as *R*-square for *F* tests.

<sup>b</sup>AUDIT: Alcohol Use Disorders Identification Test.

<sup>c</sup>PHQ: Patient Health Questionnaire.

<sup>d</sup>GAD: General Anxiety Disorder Questionnaire.

<sup>e</sup>SIP: Short Index of Problems.

**Table 4.** Unadjusted association between baseline characteristics and Peer Booster engagement.

| Predictors                             | Peer Boosters |               |             | Test statistic ( <i>df</i> ) | <i>P</i> value | Effect size <sup>a</sup> |
|--|---------------|---------------|-------------|------------------------------|----------------|--------------------------|
|  | 0 (n=76)      | 1 or 2 (n=27) | 3 (n=142)   |                              |                |                          |
| <b>Follow-up completion, n (%)</b>     |               |               |             |                              |                |                          |
| 4 months                               | 31 (17.42)    | 17 (9.55)     | 130 (73.03) | $\chi^2_2=65.6$              | <.001          | .52                      |
| 8 months                               | 36 (19.57)    | 20 (10.87)    | 128 (69.57) | $\chi^2_2=48.4$              | <.001          | .44                      |
| 12 months                              | 33 (18.97)    | 16(9.20)      | 125 (71.84) | $\chi^2_2=49.9$              | <.001          | .45                      |
| <b>Baseline characteristics</b>        |               |               |             |                              |                |                          |
| Sex (male), n (%)                      | 57 (27.80)    | 22 (10.73)    | 126 (61.73) | $\chi^2_2=6.9$               | .03            | .17                      |
| Age, mean (SD)                         | 26.8 (6.2)    | 26.9 (8.1)    | 28.6 (6.9)  | $F_{1,244}=4.08$             | .04            | .02                      |
| <b>Race, n (%)</b>                     |               |               |             | $\chi^2_2=6.1$               | .05            | .16                      |
| White                                  | 68 (32.38)    | 19 (9.05)     | 123 (58.57) |                              |                |                          |
| Other                                  | 8 (22.86)     | 8 (22.86)     | 19 (54.29)  |                              |                |                          |
| Hispanic (yes), n (%)                  | 11 (31.43)    | 4 (11.43)     | 20 (57.14)  | $\chi^2_2=0.0$               | .99            | .01                      |
| <b>Marital status, n (%)</b>           |               |               |             | $\chi^2_6=17.3$              | .008           | .19                      |
| Married                                | 16 (25.00)    | 3 (4.69)      | 45 (70.31)  |                              |                |                          |
| Living together                        | 16 (6.53)     | 7 (21.88)     | 9 (28.13)   |                              |                |                          |
| Widowed, divorced, or separated        | 8 (25.00)     | 4 (12.50)     | 20 (62.50)  |                              |                |                          |
| Never married                          | 36 (30.77)    | 13 (11.11)    | 68 (58.12)  |                              |                |                          |
| <b>Highest grade completed, n (%)</b>  |               |               |             | $\chi^2_4=7.7$               | .10            | .13                      |
| High school or less                    | 18 (40.91)    | 4 (9.09)      | 22 (50.00)  |                              |                |                          |
| Some college                           | 45 (31.91)    | 19 (13.48)    | 77 (54.61)  |                              |                |                          |
| College or more                        | 13 (21.67)    | 4 (6.67)      | 43 (71.67)  |                              |                |                          |
| <b>Rank, n (%)</b>                     |               |               |             | $\chi^2_4=4.2$               | .37            | .09                      |
| E1-E4                                  | 45 (33.09)    | 18 (13.24)    | 73 (53.68)  |                              |                |                          |
| E5-E9                                  | 29 (29.90)    | 7 (7.22)      | 61 (62.89)  |                              |                |                          |
| WO1-WO5/O1-O9                          | 2 (16.67)     | 2 (16.67)     | 8 (66.67)   |                              |                |                          |
| Employed (yes), n (%)                  | 69 (33.82)    | 19 (9.31)     | 116 (56.86) | $\chi^2_2=6.5$               | .04            | .16                      |
| <b>Household income (US \$), n (%)</b> |               |               |             | $\chi^2_6=12.0$              | .06            | .16                      |
| 25,000 or less                         | 28 (37.33)    | 9 (12.00)     | 38 (50.67)  |                              |                |                          |
| 25,000-50,000                          | 27 (36.00)    | 8 (10.67)     | 40 (53.33)  |                              |                |                          |
| 50,000 or more                         | 18 (21.18)    | 7 (8.24)      | 60 (70.59)  |                              |                |                          |
| Refused                                | 3 (30.00)     | 3 (30.00)     | 4 (40.00)   |                              |                |                          |
| Ever deployed (yes), n (%)             | 30 (25.00)    | 10 (8.33)     | 80 (66.67)  | $\chi^2_2=7.3$               | .03            | .17                      |
| Trauma exposure (yes), n (%)           | 26 (27.08)    | 10 (10.42)    | 60 (62.50)  | $\chi^2_2=1.4$               | .50            | .08                      |
| Illicit drug use (yes), n (%)          | 4 (33.33)     | 1 (8.33)      | 7 (58.33)   | $\chi^2_2=0.1$               | .95            | .02                      |
| Cannabis use (yes), n (%)              | 10 (30.30)    | 5 (15.15)     | 18 (54.55)  | $\chi^2_2=0.6$               | .71            | .05                      |
| AUDIT <sup>b</sup> , mean (SD)         | 8.9 (5.1)     | 9.4 (5.5)     | 10.2 (6.1)  | $F_{1,244}=2.75$             | .10            | .01                      |
| PHQ <sup>c</sup> , mean (SD)           | 4.4 (4.9)     | 6.0 (4.9)     | 6.2 (6.0)   | $F_{1,244}=4.72$             | .03            | .02                      |

| Predictors                                   | Peer Boosters |               |           | Test statistic ( <i>df</i> ) | <i>P</i> value | Effect size <sup>a</sup> |
|--|---------------|---------------|-----------|------------------------------|----------------|--------------------------|
|  | 0 (n=76)      | 1 or 2 (n=27) | 3 (n=142) |                              |                |                          |
| GAD <sup>d</sup> , mean (SD)                 | 4.8 (4.9)     | 6.9 (4.5)     | 6.7 (5.9) | $F_{1,244}=5.43$             | .02            | .02                      |
| Drink and drive <sup>e</sup> mean (SD)       | 0.3 (0.6)     | 0.1 (0.4)     | 0.3 (0.7) | $F_{1,244}=0.84$             | .36            | <.01                     |
| Readiness to change, mean (SD)               | 3.9 (3.0)     | 3.9 (3.2)     | 3.5 (2.9) | $F_{1,244}=0.98$             | .32            | <.01                     |
| Confidence reduction, mean (SD)              | 4.5 (3.1)     | 4.4 (3.5)     | 4.0 (3.0) | $F_{1,244}=1.09$             | .30            | <.01                     |
| SIP <sup>e</sup> -Impulse control, mean (SD) | 1.0 (1.3)     | 1.2 (1.2)     | 1.0 (1.6) | $F_{1,244}=0.24$             | .96            | <.01                     |
| <b>Motives to drink, mean (SD)</b>           |               |               |           |                              |                |                          |
| Social                                       | 5.4 (2.4)     | 5.3 (2.2)     | 5.4 (2.5) | $F_{1,244}=0.02$             | .88            | <.01                     |
| Coping with anxiety                          | 3.8 (2.1)     | 4.4 (2.5)     | 4.1 (2.2) | $F_{1,244}=1.19$             | .28            | <.01                     |
| Coping with depression                       | 5.0 (2.5)     | 5.8 (3.4)     | 5.1 (2.9) | $F_{1,244}=0.02$             | .89            | <.01                     |
| Enhancement                                  | 3.8 (2.1)     | 5.1 (2.2)     | 4.3 (2.3) | $F_{1,244}=2.01$             | .16            | .01                      |
| Conformity                                   | 2.6 (1.5)     | 2.9 (1.5)     | 2.8 (1.7) | $F_{1,244}=0.47$             | .49            | <.01                     |
| Physical                                     | 4.5 (1.9)     | 4.9 (2.1)     | 4.6 (2.4) | $F_{1,244}=0.04$             | .83            | <.01                     |

<sup>a</sup>Effect size reported as Cramer *V* for chi-square tests and as *R*-square for *F* tests.

<sup>b</sup>AUDIT: Alcohol Use Disorders Identification Test.

<sup>c</sup>PHQ: Patient Health Questionnaire.

<sup>d</sup>GAD: General Anxiety Disorder Questionnaire.

<sup>e</sup>SIP: Short Index of Problems.

## Adjusted Outcomes

Table 5 presents the results of the 3 multinomial logistic models of the candidate predictors of booster session engagement. A Web Booster model, Peer Booster model, and Combined model with treatment arm (Web or Peer) entered as a candidate predictor of the number of booster sessions completed (0, 1, 2, or 3) are presented. All models used a stepwise variable selection routine to identify predictors of engagement where candidate predictors were entered sequentially, and variables were retained at either step if they were below the threshold of  $P \leq .30$  level. The Web Booster model retained 9 candidate predictors of

booster engagement: gender, education level, rank, being deployed, having experienced trauma, anxiety, frequency of alcohol use, social motives for drinking, and income. In the final Web Booster model, participants who had completed high school or lower (adjusted odds ratio [aOR] 0.21, 95% CI 0.07-0.64;  $P=.006$ ) and those who had completed any college-level education (aOR 0.39, 95% CI 0.16-0.93,  $P=.03$ ) were significantly less likely to complete all three boosters when compared with those with higher education (Table 5 for summary of models; Multimedia Appendix 2 for all adjusted odds ratios of model predictors).

**Table 5.** Model-adjusted stepwise models of predictors of engagement in Combined, Web, and Peer Booster arms.

| Selected candidate predictors              | Combined                     |         | Web Boosters    |         | Peer Boosters  |         |
|--|------------------------------|---------|-----------------|---------|----------------|---------|
|  | $\chi^2$ (df)                | P value | $\chi^2$ (df)   | P value | $\chi^2$ (df)  | P value |
| Treatment arm                              | <i>10.0</i> (2) <sup>a</sup> | .01     | NA <sup>b</sup> | NA      | NA             | NA      |
| Education                                  | <i>17.9</i> (4)              | .001    | 9.6 (4)         | .047    | 8.7 (4)        | .07     |
| Income                                     | <i>12.5</i> (4)              | .02     | 5.9 (4)         | .20     | — <sup>c</sup> | —       |
| Employed                                   | 3.3 (2)                      | .19     | —               | —       | 6.2 (2)        | .04     |
| Rank                                       | <i>6.0</i> (2)               | .049    | <i>10.5</i> (2) | .005    | —              | —       |
| Anxiety (GAD <sup>d</sup> )                | 4.6 (2)                      | .10     | 3.7 (2)         | .16     | —              | —       |
| Alcohol use severity (AUDIT <sup>e</sup> ) | 2.6 (2)                      | .27     | —               | —       | —              | —       |
| Confidence can reduce alcohol use          | 3.5 (2)                      | .18     | —               | —       | —              | —       |
| Gender                                     | —                            | —       | 4.2 (2)         | .12     | 8.2 (2)        | .02     |
| Motive: social                             | —                            | —       | 3.4 (2)         | .18     | 3.6 (2)        | .16     |
| Deployed                                   | —                            | —       | 3.9 (2)         | .14     | —              | —       |
| Binge drinking frequency                   | —                            | —       | 4.1 (2)         | .13     | —              | —       |
| Traumatic event                            | —                            | —       | 5.7 (2)         | .06     | —              | —       |
| Marital status                             | —                            | —       | —               | —       | 13.4 (6)       | .02     |
| Depression (PHQ <sup>f</sup> )             | —                            | —       | —               | —       | 6.0 (2)        | .049    |
| Motive: enhancement                        | —                            | —       | —               | —       | 10.1 (2)       | .01     |
| Motive: coping with depression             | —                            | —       | —               | —       | 2.9 (2)        | .23     |
| Drink and drive                            | —                            | —       | —               | —       | 3.8 (2)        | .15     |

<sup>a</sup>Italicized values indicate statistical significance at the  $\alpha < .05$  threshold.

<sup>b</sup>NA indicates that the predictor (ie, treatment arm) was not included as a candidate predictor in the model. All variables selected in each model were reported.

<sup>c</sup>—: Indicates that candidate variable was not retained in the model.

<sup>d</sup>GAD: General Anxiety Disorder Questionnaire.

<sup>e</sup>AUDIT: Alcohol Use Disorders Identification Test.

<sup>f</sup>PHQ: Patient Health Questionnaire.

The Peer Booster model retained 9 predictors: employment status, marital status, gender, education level, enhancement, social, and coping with depression motives for drinking, drinking while driving, and depression symptoms. Those who were employed were significantly less likely to complete 1 or 2 boosters than those who were unemployed (aOR 0.19, 95% CI 0.05-0.71;  $P=.01$ ), although this relationship was not statistically significant for engagement in all three boosters (aOR 0.40, 95% CI 0.14-1.11;  $P=.08$ ). Men were significantly more likely to complete all 3 boosters than women (aOR 3.53, 95% CI 1.47-8.48  $P=.005$ ). Those who were living together were significantly less likely to complete all three booster sessions than those who were married (aOR 0.23, 95% CI 0.08-0.68;  $P=.008$ ). Those who were depressed were significantly more likely to complete all three boosters (aOR 1.11, 95% CI 1.02-1.20;  $P=.01$ ). Finally, those who reported drinking to enhance positive feelings were significantly more likely to complete 1 or 2 booster sessions (aOR 1.59, 95% CI 1.18-2.16;  $P=.003$ ) and complete all 3 sessions (aOR 1.27, 95% CI 1.04-1.56;  $P=.02$ ) than people with lower enhancement

motives (Multimedia Appendix 3 for all adjusted odds ratios of model predictors).

The combined model retained 8 of the candidate predictors of booster engagement: treatment arm (Web or Peer), education level, income, military rank, anxiety, confidence in ability to reduce alcohol use, and alcohol use severity. Treatment arm, education, income, and rank were statistically significant in the final model. People randomized to the Peer Booster arm were more likely to engage in booster sessions overall; however, neither contrast between some sessions (aOR 0.63, 95% CI 0.34-1.15;  $P=.13$ ) nor all sessions (aOR 1.51, 95% CI 0.99-2.32;  $P=.06$ ) was statistically significant. Those who had completed high school or lower (aOR 0.24, 95% CI 0.12-0.47;  $P<.001$ ) and those who had completed some college (aOR 0.44, 95% CI 0.25-0.76;  $P=.004$ ) were significantly less likely than those who had completed college to complete all boosters. Those who reported incomes greater than US \$50,000 were more likely to complete all boosters than those who made US \$25,001 to US \$50,000 (aOR 2.11, 95% CI 1.23-3.63;  $P=.007$ ) and to complete 1 or 2 boosters than no boosters (aOR 2.19, 95% CI 1.03-4.70;  $P=.04$ ). Finally, those of lower rank were more likely to

complete 1 or 2 boosters than no boosters (aOR 2.09, 95% CI 1.05-4.15;  $P=.03$ ; [Multimedia Appendix 4](#) for all adjusted odds ratios of model predictors).

## Discussion

### Principal Findings

This study provides novel findings regarding engagement in boosters delivered through the web or peer modality. Results showed that 65.2% (320/491) of participants attended at least 1 booster session, most people who attended one booster session attended all three boosters, and engagement was higher when boosters were delivered by peers than via an interactive website. Previous analyses of engagement in boosters have generally used emergency room populations and have reported difficulty maintaining engagement after the initial BIs, in part because of low rates of cell phone ownership and high rates of homelessness [25,35]. In contrast, our sample of adults actively enrolled in the National Guard is different in that nearly all participants had access to a phone or had a home address, all had income from their guard duties, and most were also employed in their civilian role. The Peer Booster delivery format was more successful in fostering engagement in the booster sessions. This may be related to the effect of human-to-human peer interactions. Peer Boosters may have been further enhanced compared with simple person-delivered boosters since military veterans conducted Peer Booster sessions. There is generally a strong sense of camaraderie between those active in the reserve components, most of whom are also officially veterans and have previously served in the active military. The percentage of reserve component members who have official veteran status has markedly increased in the past 15 years since reserve component members have been activated for overseas deployment in the ongoing wars in the Middle East. It is also notable that once the initial contact was made with the peer during the first booster session, a higher percentage of these participants (142/169, 84%) completed all 3 boosters than was the case with the Web Booster sessions (108/151, 71.5%; despite the fact that it was interactive and tailored;  $\chi^2_1=7.3$ ;  $P=.007$ ). This finding is a potential additional indicator that peer alliances drove continued booster engagement. It has been suggested that the characteristics of the person delivering the booster may be important. For example, Longabaugh et al [25] reported on the wide variation of success among their in-person boosters in getting participants to do a single booster in their study and recommended more studies on the characteristics of the persons delivering the boosters.

Future research should identify whether general factors related to human interaction as opposed to military-specific factors such as camaraderie or other characteristics of similarity between service members were the primary drivers of greater engagement in the Peer compared with Web Booster sessions.

Research on web- and app-based BIs is increasing because of their potential cost effectiveness and scalability to increase the reach of interventions for those historically underserved through traditional health models of health care. Similarly, there is a need to assess the possible combination of web- and peer-based delivery systems for boosters following BIs. The case may be

that combining web- with person-based delivery can be optimized to balance cost and scalability benefits of web-delivered boosters with increased engagement from person-delivered boosters. This balance can take into account the inherent increased cost of a peer delivery format, where a staff member must be paid and where the length of the booster session may be longer because the peer may spend time, particularly initially, building a relationship of trust and respect with the participant.

Few previous studies, which included boosters following a web-delivered BI, have examined the predictors of booster engagement. Longabaugh et al [25] reported that for an alcohol misuse BI presented in person in the emergency room, with the booster also in person, 69% of participants completed the booster, and those who completed the booster had reduced alcohol-related consequences and injuries, whereas those without the booster did not. Hatch-Maillette et al [35] reported details of booster engagement for a drug misuse BI presented in person in an emergency department followed by two in-person booster sessions; 57.3% did the first booster and 39.1% completed both boosters. Our findings fit within the context of previous studies. The Peer Booster group engaged in a single booster session at a rate comparable with those reported previously [25] and completed all 3 boosters at a much higher rate than in the study by Hatch-Maillette et al [35]. The Web Booster participants performed only moderately worse than those in the Longabaugh study and slightly better in completing the full course of boosters than participants in the study by Hatch-Maillette et al [35]. These findings suggest that largely phone-based Peer Boosters may increase booster engagement compared with in-person booster delivery, and that web-delivered boosters may be associated with similar engagement as in-person boosters.

A number of factors potentially affect whether a booster is optimally impactful, including the content of the booster, the dosage of the booster delivered, the timing of the booster following the BI, and whether the booster is sufficient to motivate the participant to continue to engage. When considering wide-scale dissemination, delivering boosters in person is expensive compared with web or phone delivery options. The cost effectiveness of booster delivery could be potentially addressed by using multiple options for delivery of boosters and identifying subsets of individuals who require more labor-intensive and expensive personal delivery approaches. VA has invested heavily in hiring peer counselors. Nevertheless, the number of counselors is likely to be insufficient to meet the needs of all patients. VA has begun to assess whether peer counselors can be more effective than web- or app-based eHealth interventions when integrated into primary care clinics [41]. A natural extension of this work is to identify additional settings, such as armories, to integrate peer counselors to connect with service members and provide ongoing support. The military mental health and resilience building systems also use fellow enlisted and noncommissioned members as health technicians. In both systems, it would be useful to be able to identify subsets of veterans and military members who would most benefit from eHealth interventions that include a peer support component.

In this reserve component military population, the combined model indicates that those with relatively higher socioeconomic



status engaged more often in boosters. Those with higher rank, higher income, and more education all engaged more. All three of these characteristics were intercorrelated in the military population. The results from the separate models for web and peer delivery modes suggest that participant characteristics had differential effects on booster engagement.

The finding that participants who report more depression are more likely to engage in boosters in the Peer Booster arm is notable given the high prevalence of mental health comorbidities in people who misuse alcohol. Not surprisingly, depression symptoms were high in this alcohol-misusing sample. People experiencing depression represent a considerable and clinically meaningful subset of the total study population and could be a meaningful target for identifying those service members that may improve booster engagement if provided with a peer delivery format.

Web Boosters have many practical advantages. It is noteworthy that older participants were more likely to complete Web Boosters. Although one might expect younger participants to be more drawn to computer interaction, our sample was somewhat age restricted, reflecting the age demographics of the military, including the guard. The constellation of variables predicting booster engagement in the web format (higher rank, higher socioeconomic status, higher age) suggests that whatever greater affinity younger participants might have for computer interaction, it is likely to be secondary to the tendency of older, higher ranked individuals with better socioeconomic status who may be more willing to adhere to the intervention.

### Limitations

These findings should be considered in the context of several limitations. The nature of the sample (members of the National Guard of a single state) potentially limits the generalizability of the results. Although we screened a substantial proportion of the total population of the Guard members in Michigan (about one-third), randomly selected the units to assure broad

representation of all military occupational categories (eg, infantry, logistics, military police) in the sample, and the Michigan National Guard is largely comparable with the National Guard nationally, future work is needed to identify the generalizability of booster engagement in other National Guard populations. Women were underrepresented based on the general population, but adequately represented relative to their prevalence in the Michigan National Guard. This is generally consistent with military populations, although the percentages of women in the military, and in most occupational categories within the military, are increasing [61]. The study was not designed to be powered to detect head-to-head differences between the 2 booster delivery formats. These findings are exploratory in nature and require further investigation in studies powered to detect key indicators of booster engagement across delivery modalities.

In summary, the use of telephone or in-person peer support to provide encouragement and lived experience in helping individuals make behavioral changes has been successfully employed in a number of settings. The inclusion of peers to provide booster follow-ups with National Guard members experiencing issues related to alcohol use promotes engagement and fits well with the goals of this and other organizations that work toward maintaining and improving the health of their members so that they do well at work and in their personal lives. These exploratory analyses suggest promising directions for future research aimed at identifying subsets of individuals who require more intensive booster delivery modalities, such as peer delivery, to optimally facilitate engagement. Additional work to replicate the predictors of booster engagement noted here, in addition to considering other possible indicators of engagement, are needed. In addition, exploration of combining web-delivered boosters with some person-delivered components of booster sessions may balance pragmatic concerns around cost and scalability with the need to foster booster engagement, especially among at-risk subsets of service members who misuse alcohol.

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### Conflicts of Interest

None declared.

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#### Multimedia Appendix 1

Mission Strong Consort Diagram for participants that misuse alcohol.

[\[DOCX File, 210 KB - mental\\_v8i10e29397\\_app1.docx\]](#)

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#### Multimedia Appendix 2

Model-adjusted odds ratios and 95% confidence limits for web-delivered booster condition.

[\[DOCX File, 15 KB - mental\\_v8i10e29397\\_app2.docx\]](#)

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#### Multimedia Appendix 3

Model-adjusted odds ratios and 95% confidence limits for peer-delivered booster condition.

[[DOCX File , 14 KB - mental\\_v8i10e29397\\_app3.docx](#) ]

#### Multimedia Appendix 4

Model-adjusted odds ratios and 95% confidence limits for both booster conditions.

[[DOCX File , 14 KB - mental\\_v8i10e29397\\_app4.docx](#) ]

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## Abbreviations

**aOR:** adjusted odds ratio  
**BI:** brief intervention  
**EUC:** enhanced usual care  
**GAD:** General Anxiety Disorder Questionnaire  
**GLM:** General linear modeling  
**MINI:** Mini International Neuropsychiatric Interview  
**PHQ-9:** Patient Health Questionnaire  
**SIP:** Short Index of Problems

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Original Paper

# Social Semiotics of Gangstalking Evidence Videos on YouTube: Multimodal Discourse Analysis of a Novel Persecutory Belief System

Andrew Lustig<sup>1\*</sup>, MD, MSc; Gavin Brookes<sup>2\*</sup>, PhD; Daniel Hunt<sup>3\*</sup>, PhD

<sup>1</sup>Department of Psychiatry, Faculty of Medicine, University of Toronto, Toronto, ON, Canada

<sup>2</sup>ESRC Centre for Corpus Approaches to Social Science, Department of Linguistics and English Language, Lancaster University, Lancaster, United Kingdom

<sup>3</sup>School of English Studies, Faculty of Arts, University of Nottingham, Nottingham, United Kingdom

\* all authors contributed equally

**Corresponding Author:**

Andrew Lustig, MD, MSc  
Department of Psychiatry  
Faculty of Medicine  
University of Toronto  
1051 Queen Street West  
Crisis and Critical Care Building  
Toronto, ON, M6J1H3  
Canada  
Phone: 1 4165185878  
Email: [andrew.lustig@camh.ca](mailto:andrew.lustig@camh.ca)

## Abstract

**Background:** Gangstalking refers to a novel persecutory belief system wherein sufferers believe that they are being followed, watched, and harassed by a vast network of people in their community who have been recruited as complicit perpetrators. They are frequently diagnosed as mentally ill, although they reject this formulation. Those affected by this belief system self-identify as targeted individuals (TIs). They seek to prove the veracity of their persecution and dispute the notion that they are mentally ill by posting videos online that purport to provide evidence of their claims.

**Objective:** The objective of the study was to characterize the multimodal social semiotic practices used in gangstalking evidence videos.

**Methods:** We assembled a group of 50 evidence videos posted on YouTube by self-identified TIs and performed a multimodal social semiotic discourse analysis using a grounded theory approach to data analysis.

**Results:** TIs accomplished several social and interpersonal tasks in the videos. They constructed their own identity as subjects of persecution and refuted the notion that they suffered from mental illness. They also cultivated positive ambient affiliation with viewers of the videos but manifested hostility toward people who appeared in the videos. They made extensive use of multimodal deixis to generate salience and construe the gangstalking belief system. The act of filming itself was a source of conflict and served as a self-fulfilling prophecy; filming was undertaken to neutrally record hostility directed toward video bloggers (vloggers). However, the act of filming precipitated the very behaviors that they set out to document. Finally, the act of filming was also regarded as an act of resistance and empowerment by vloggers.

**Conclusions:** These data provide insight into a novel persecutory belief system. Interpersonal concerns are important for people affected, and they construe others as either sympathetic or hostile. They create positive ambient affiliation with viewers. We found that vloggers use multimodal deixis to illustrate the salience of the belief system. The videos highlighted the Derridean concept of différance, wherein the meaning of polysemous signifiers is deferred without definitive resolution. This may be important in communicating with people and patients with persecutory belief systems. Clinicians may consider stepping away from the traditional true/false dichotomy endorsed by psychiatric classification systems and focus on the ambiguity in semiotic systems generally and in persecutory belief systems specifically.

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**KEYWORDS**

internet; discourse analysis; psychosis; delusion; semiotics; linguistics; computer-mediated communication; schizophrenia; eHealth; video; communication; YouTube; social media; discourse; mental health

**Introduction**

Gangstalking refers to a persecutory belief system wherein those affected believe they are being followed, watched, and harassed by many people in their community who have been recruited into a network of complicit perpetrators [1]. In contrast to traditional forms of stalking that are usually organized by a single person [2], sufferers of gangstalking are unable to identify a responsible individual and experience it as a widely distributed and coordinated effort of co-conspirators.

Those affected gather in online communities to support each other and co-construct, develop, and contest the gangstalking belief system. The community members use a specialized lexicon to describe their experiences and to signal membership in the community of those affected. For example, the term “gangstalking” is used to describe the system of persecution, a “targeted individual (TI)” denotes the subject of the harassment, while those who participate in the intimidation are known as “perpetrators” or “perps” [3].

People affected by gangstalking report that the experience is extremely distressing. The campaign of harassment is frequently experienced as the accumulation of numerous otherwise innocuous acts, such as people clearing their throat, muttering under their breath, or giving lingering glances as they pass on the street. Because each of these acts may individually be passed off as unremarkable and mundane, TIs find it difficult to prove the existence of the harassment. When they come to clinical attention, they are frequently diagnosed with psychiatric illness and their belief systems are labeled as persecutory delusions

[4]. However, TIs interpret such diagnoses as part of a gangstalking plan; by making them appear mentally ill, they are further discredited and stigmatized.

Our previous work found that concerns about being believed and procuring and presenting proof of their systematic victimization are prime concerns of TIs in online fora [3]. For this study, we identified a genre of YouTube videos wherein TIs have posted videos to provide irrefutable evidence of their persecution and harassment. Figure 1 depicts a typical title screen of a video from this genre. YouTube provides a democratic and accessible medium where those affected can post videos to advance their point of view. In contrast to other social media platforms that are primarily text or image based, YouTube is a video-sharing platform. More than other media, video has an air of authority and legitimacy. Photography (and video) are often thought of as reproducing rather than representing reality [5], although, in reality, photographs and videos are often the product of a significant amount of arrangement and editing by their creators. These modes, in contrast, for example, to drawings or illustrations, possess a high degree of visual modality [6], presented as a seemingly “naturalistic, unmediated, uncoded representation of reality” [7]. Several culturally significant videos have demonstrated the evidentiary power of videographic evidence, such as the Zapruder video documenting the assassination of JFK and the Holliday video documenting the assault of Rodney King. Pop cultural artifacts, such as the British TV show *Caught on Camera*, highlight the role of the video camera as an apparently dispassionate and truthful observer of reality.

**Figure 1.** Gangstalking evidence video title screen.



Previous studies have examined linguistic data in online communities regarding mental health concerns, including depression and anorexia [8], self-injury [9], the role of social media in construing subjectivity [10], and contested conditions, including diabulimia and gangstalking.

Previous studies have examined Google search activity in early psychosis [11] and the use of social networks in the diagnosis and treatment of psychotic disorders [12]. Previous research

has also examined social media as a tool for family support [13] and as a diagnostic tool [14]. However, to date, there is no research examining multimodal semiotic content produced by people experiencing persecutory belief systems. This is the first study to examine social media content produced by people experiencing persecutory belief systems.

Table 1 summarizes recent research on computer-mediated communication by people with psychiatric illness.

**Table 1.** Recent research on computer-mediated communication by people with psychiatric illness.

| Study                   | Year | Population  | Finding   |
|-------------------------|------|---|---|
| Kirschenbaum et al [11] | 2020 | Google search history prior to first admission for psychosis                                    | People searched for information about symptoms prior to admission.  |
| Birnbaum et al [14]     | 2020 | Search history prior to diagnosis of psychiatric illness  | Differences in search history were identified between healthy volunteers and people diagnosed with psychiatric illness. |
| Westermann et al [12]   | 2020 | Internet-based intervention for people with psychosis   | Psychotic symptom severity decreased in the internet-based intervention.  |
| Barbetio et al [13]     | 2020 | Systematic review of online interventions for families of patients with severe mental disorders | Perceived stress decreased in families.   |
| Valentine et al [15]    | 2020 | People's experience of a social media-based intervention for first-episode psychosis            | The intervention fostered connection and understanding.   |
| Jakubowska et al [16]   | 2019 | Systematic review of online social networking use among people with psychosis                   | People with psychosis appear to use online social networking frequently.  |

The objective of this study is to characterize the multimodal semiotic practices used in gangstalking evidence videos. We examine how these resources are deployed in order to construct the discourse of gangstalking, as well as how they are used to accomplish interpersonal tasks. To do this, we use a multimodal social semiotic theoretical framework to identify the semiotic resources used by TIs to construct and develop the gangstalking belief system in these evidence videos. In keeping with this framework, we identify social and interpersonal tasks accomplished by TIs in the videos, including constructing their own identity, creating distance with some groups, and fostering closeness and intimacy with other ones.

This analysis begins by describing and defining the genre of gangstalking evidence videos. We then describe how TIs use deictic strategies to create salience in the videos. First, we describe linguistic practices, and then we move on to visual strategies, including the gaze of the camera, intertitles, and text and image overlay. Next, we describe several interpersonal dynamics at work in the videos.

## Methods

### Collecting Videos

For this study, we assembled a corpus of videos posted on YouTube by self-identified TIs. For this, we used the YouTube Application Programming Interface (API) to search for videos. We used Python 3.0 to access the API and search the snippet object of videos. We searched for videos that contained the terms “gang stalking” or “gangstalking” AND “caught on video” or “caught on tape” or “proof” or “evidence” in the video title, description, or category. We sorted the search results by relevance using the YouTube API. We manually reviewed the

search results to identify videos posted as proof or evidence of the gangstalking phenomenon. To be included in the analysis, a video had to be posted by a self-identified TI and purport to depict gangstalking activity. We identified other types of videos concerning gangstalking that were not germane to the analysis. These included first-person descriptive accounts of gangstalking, slideshow-type informational content about gangstalking, excerpts of news stories about gangstalking, original musical performances about gangstalking, and others. These videos were excluded from our analysis. We assembled a corpus of 50 videos meeting our inclusion criteria and achieved consensus by the authors regarding the suitability of the videos for inclusion.

### Multimodal Discourse Analysis

We then conducted a multimodal discourse analysis to identify the social semiotic resources mobilized by content creators posting YouTube videos presented as evidence of the gangstalking phenomenon.

To do this, we imported the videos into the NVivo software package (QSR International) [17], which allowed us to view the videos and annotate and code them. We applied a grounded theory approach to data analysis [18,19]. We viewed and transcribed the videos. We subsequently reviewed the transcripts and coded them. We grouped the codes into themes. We applied a qualitative multimodal discourse analysis to the video data, as described by Hansen and Machin [20].

We coded the videos and transcripts for paralinguistic and multimodal features of the videos, such as gestures, intertitles, text and image overlay, camera angles, and visual effects such as close-ups, time lapse, and slow motion. We considered linguistic and paralinguistic resources as well as the



technologically mediated visual frame [21]. We captured these features in memos. We used a constant comparison approach, moving between the codes, memos, conceptual framework, and primary data until theoretical saturation was achieved.

All the data used for the analysis were posted in a public forum available to any internet user. Our analysis constitutes what Eysenbach and Till refer to as passive analysis [22].

The institutional research ethics board at the Centre for Addiction and Mental Health reviewed the proposed study design and opined that it did not require formal approval.

## Results

### Defining the Genre

Gangstalking evidence videos can be considered a subgenre of a video blog (vlog). A genre is a conventionalized form associated with a conventionalized purpose or occasion and is characterized by a schematic structure [23]. The videos contain several functional stages: an introductory section setting the stage, the body where the evidence is presented, and a coda that summarizes the evidence presented. To tell their story, authors rely on previously established genre conventions and tropes, in the process evidencing syntagmatic intertextuality, which has to do with how texts build on texts with which they are related sequentially [24].

As mentioned before, each video can be viewed as having three functional components (introduction, evidence, and coda), two of which are optional and one of which is essential to this genre.

### Introduction

During the optional introductory component of the video, the TI addresses the viewer directly and orients them to the purpose and content of the video. As described later, TIs also use this section of the video to establish positive ambient affiliation with the viewer. Ambient affiliation is a concept proposed by Zappavigna [25] to describe the realization of social bonds in language and on the internet. Typical excerpts from the introductory section are as follows:

*This is what a targeted individual experiences all day long.*

*All right, everyone. Looks like gangstalking is at hand. You guys wanted to see some video. Well. It's about to happen.*

### Evidence

This is the essential functional component of the video that presents the first-hand evidence of gangstalking. Much of the video is displayed in real time. However, two main temporal techniques are used to de-emphasize portions of the video deemed less significant or to highlight salient parts. Specifically, TIs use time lapse in parts that are deemed less important, while slow motion is used to mark particular moments in the video as important. We discuss these in more detail later.

### Coda

During this optional component, the TI once again directly addresses the viewer, summarizes the contents of the video, and re-establishes affiliation with the viewer.

*So there you go. There is a full-blown, orchestrated, uh, you know, I call it street theater—planned event, whatever. There it is broken down. All right, guys. Catch ya later. Bye.*

In part, this generic structure derives its meaning from paradigmatic associations that the viewer establishes between the content of the video and other culturally available videos [26]. For instance, the use of the introduction and coda components to establish rapport with the viewing audience reflects similar practices in more conventional vlogging genres, while the use of introductory remarks to frame the subsequent evidence footage also reflects genres such as the *Caught on Camera* reality TV show or a nature documentary.

### Multimodal Deixis

A frequent and recurrent theme in the videos is that evidence of the gangstalking behaviors is obvious and self-evident; the actions of the people captured in the evidence videos are presented as incontrovertible evidence that they are gangstalkers. However, video creators also communicate that to pick up on the relevant cues, an observer must be oriented or initiated as to what cues to look for and be inducted into the group that is able to detect relevant signs. To bridge the gap between seemingly benign actions of people filmed by TIs and the gangstalking conspiracy, TIs use features of multimodal deixis to draw attention to salient features of the videos.

Deixis refers to linguistic features that encode information about the personal, spatial, and temporal situation in which they are used [27]. For example, successfully decoding and interpreting deictic expressions such as “here,” “this,” “that,” and “yesterday” requires some knowledge of the circumstances in which such expressions are used. In the case of video, the concept of deixis has been expanded beyond language to also include the visual mode. We consider how the video creators draw on both linguistic and visual deixis.

### Linguistic Deixis

Most of the videos used some form of voice-over narration to describe their contents, put the depicted events in context, and create salience. This practice exemplifies discourse simultaneously being constructed by and constructing social reality; creators use deixis to draw attention to features and events that they observe and perceive as salient and, in so doing, construct the salience of these features for their viewers. In one video, a narrator claims:

*There's a Honda Odyssey that always be following me, so.*

The creator uses the deictic determiner *there* to direct the viewer's attention to an otherwise unremarkable car in the video footage. The remainder of the sentence consists of a noun phrase (*a Honda Odyssey*), coupled with a relative clause that highlights the relevance or salience of this particular vehicle.

*I see the neighbor who does not, uh, light up the front of his driveway with a security light. However, what he does do is he lights up the driveway of this house, which is 50 to 60 feet away. Now that's called targeting. That's called harassment.*

In this example, the creator uses the deictic *that* as a demonstrative determiner to refer anaphorically to their prior description of the light. This gloss imbues the description with semiotic salience, highlighting the connotative significance of the scene. If this were absent, some uncertainty or confusion may exist regarding the relevance or significance of the light. These deictic phrases serve to definitively resolve this ambiguity.

*Look at this guy. He is intentionally blocking me from moving.*

The first sentence of this example serves to index the salient portion of the video. The second sentence then provides the connotative salience assigning malicious intent to the subject. In this way, seemingly normal elements in the video footage are verbally marked out for the viewer and then described as definitive evidence of gangstalking.

**Figure 2.** Still image illustrating the use of zoom.



For example, one video is shot in a shopping mall and the evidentiary portion of the video depicts people walking around and shopping. A portion of the video depicts this in time lapse and then returns to normal speed to display [Figure 3](#), which

### **The Camera's Gaze**

The visual frame itself constitutes a type of deixis. By pointing the camera in a direction, at a particular scene, the image creator is effectively pointing at the scene and indicating that there is something relevant or noteworthy about it. In other words, image creators use the gaze of the camera to direct attention to salient content. The point-of-view (POV) shot is a shot in which the camera assumes the position of a subject to show us what that subject sees [28]. The POV shot also means that the TI's and the audience's gaze is conflated [21]. Within a shot, various other techniques are used to indicate salience: zoom, slow motion/time lapse, and repetition of salient sections of footage ([Figure 2](#)). The video bloggers (vloggers) in our data use zoom to highlight features and indicate their salience. This tactic is applied to the faces of perps. Vloggers used time lapse to speed up footage that was deemed of lesser importance, thereby de-emphasizing the salience of such segments. In contrast, slow motion was applied to highlight segments that were purported to be salient.

appears to be a caretaker pushing a garbage bin. The salience of the image is indicated by slowing the video from time lapse to real time and highlighting the salient feature with text overlay and a red circle.

**Figure 3.** Image depicting visual deixis.



### **Verb Transitivity**

Systemic functional linguistics (SFL) uses the concept of transitivity to identify how speakers use language to describe their experience. It groups all processes, expressed by verbs, into six categories: material, behavioral, mental, existential, verbal, and relational [29]. Our analysis revealed that TIs frequently use material and behavioral processes to describe the activities of purported gangstalking.

In a video of a TI at a store, he says:

*Literally look at 'em all come over here.*

Later in the same video:

*Ha ha ha. It's so obvious. Absolute madness. Look at the whole store. Look at it. Barely anyone. Couple people here, and then wham, look at that. They just all came and flooded me like that, eh.*

In this example, the TI uses the transitive material verb *flooded* with the direct object *me* to indicate that the malicious activity is being directed toward him. This lexical choice also invokes a water metaphor to equate the experience of being gangstalked to that of being flooded. Metaphor is pervasive in the language used to reify mental states and forms of distress [30]. This particular trope applies to gangstalking qualities that we may associate with flooding, such as it being excessive, uncontrollable, and overwhelming.

In contrast to material processes, which involve physical actions, behavioral processes exist at the border of material and mental processes and represent an external manifestation of cognitive processes [31]. Behavioral processes have only one participant, the behavior [32]. Additional information regarding the circumstances of the action is communicated by prepositional phrases. In this way, describing the actions of people in gangstalking evidence videos using behavioral processes at once allows video producers to mark their actions as ordinary *and* as evidence of more malicious thinking.

In this example, a vlogger documents his harassment at a gas station. Referring to a woman standing at the station, he says:

*She's going to be constantly staring at me and no doubt running what happens in that store and who comes out of it and at what time.*

By describing the woman's behavior—"staring at me"—as constant, the video producer is able to represent this woman's actions as suspicious, supporting the subsequent claim that she is "no doubt running what happens" in the store. Staring therefore becomes evidence of widespread, orchestrated harassment.

Behavioral processes such as this lie in the hinterland between thought and outward behavior. This is fertile ground for projection of the persecutory belief system. If the processes inferred were entirely mental, typically denoted by such verbs as *believe*, *hate*, or *know*, they would create no outward manifestation to document in the vlogs. In contrast, if the processes were entirely material, the observable behavior would not have the polysemous property that leaves it open to multiple interpretations. Occupying the middle ground between a physical and a mental process thus leaves these processes open to interpretation and hence open to classification as gangstalking.

### **Intertitles and Text Overlay**

Vloggers make extensive use of text in apposition to video footage to create salience and construct the gangstalking narrative. Figure 4 depicts an urban scene with a shopping cart laying on its side in a park. This image is unremarkable on its own. The vlogger uses two follow-up images with text to construct this image as relevant to gangstalking. Figure 5 has the following text: A "red" "target" on its "side". The use of quotation marks and red text highlights that these words are imbued with connotative meaning, although it remains unclear just what this meaning is. Figure 6, from the same video, attempts to definitively resolve the ambiguity with the text = *A dead targeted individual*. This gloss indicates that the

apparently unremarkable scene is actually specifically about gangstalking and that the overturned cart represents a deceased TI. The connotation of death is intensified, and even rendered more explicit, by the image of a cemetery in the background onto which the shopping cart is overlaid.

In another example, an image depicts an outdoor urban neighborhood with people walking and cars being driven. As [Figure 7](#) shows, a subtitle focuses attention on an otherwise

unremarkable detail; a car depicted in the scene appears to be missing a hubcap. The subtitle urges viewers to *Note the missing hub cap*, thereby indexing this as salient. The text goes on to state *This same white car comes back two more times*. This combination of text and image allows the vlogger to tie together temporally disparate events and imbue them with salience, supporting the position that the driver of this car is engaged in gangstalking.

**Figure 4.** Unmarked image of a shopping cart.



**Figure 5.** Title card suggests a deeper connotative meaning of the image.

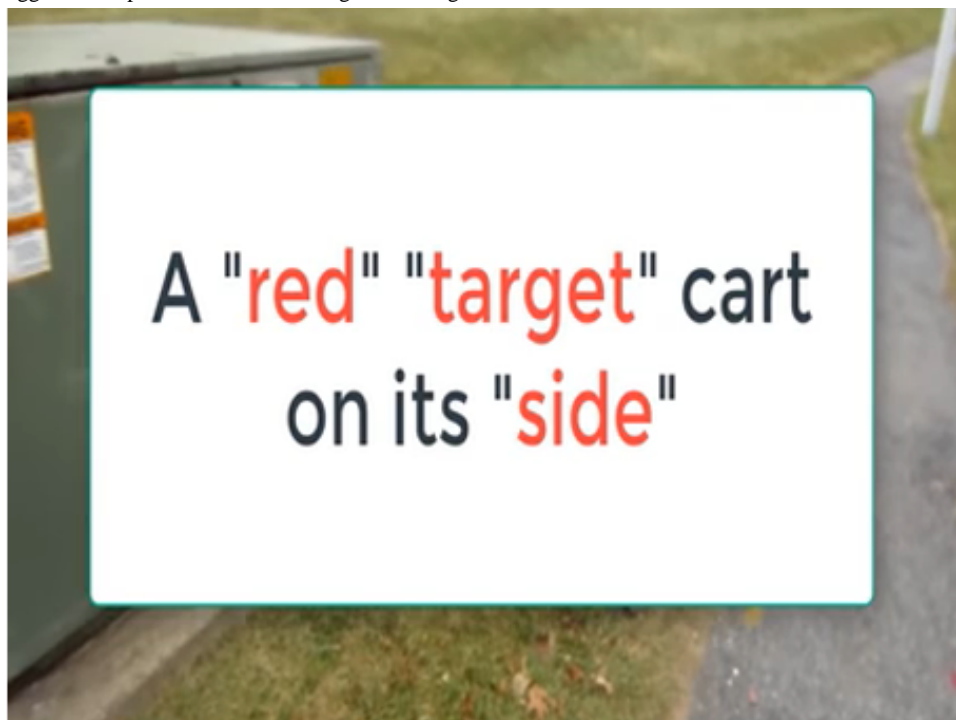


Figure 6. Third image in the series attempting to definitely define the significance of the image.



Figure 7. Combination of text and image assigns connotative significance.



A third example (Figure 8) depicts a street as viewed from the vantage point of the driver's seat. The dashboard and steering wheel of the TI's car frame the scene. The image is overlaid with the text *He a low life gangstalker*, followed by two emoji, one grinning and one laughing. Here, once again, the unindexed scene is unremarkable and does not itself suggest persecution

or gangstalking. Rather, this interpretation is added by the overlaid text, which uses the deictic *He* to point out a participant in the scene and the phrase *a low life gangstalker* to functionalize the represented participant as engaged in gangstalking and to assign salience and significance to them.

**Figure 8.** Use of text and emoji to construe salience of image.



### Ambient Affiliation With the Viewer

When posting videos on YouTube and other social media sites, a creator may direct them to a specific audience. More commonly, however, videos are merely “out there” for any other internet user to find and consume. They are meant for “anybody and everybody, or possibly nobody” [33]. This phenomenon has been called *context collapse*, referring to the numerous contrasting possible audiences and settings in which the vlogs may be viewed, including among audiences who may be skeptical of or hostile to the vloggers’ claims regarding gangstalking. TIs therefore use the videos to advance a discourse about the nature of gangstalking while simultaneously accomplishing interpersonal tasks relating to their audiences. They use one set of rhetorical techniques to generate affiliation with viewers of the videos and a contrasting set to promote disaffiliation and hostility with represented participants, which we term “representational disaffiliation.”

TIs can choose between shots that depict them speaking to the camera and shots in which the camera assumes the position of a subject to show us what they see and to invite us to experience it contemporaneously with them. These compositional choices define the relationship between vlogger and viewer in a process called subjectification [10]. The main choice regarding subjectification is between positioning the viewer in an *as photographer* or a *with photographer* position. In our data, during the evidentiary portion of the videos, vloggers construct the former position and merge with the viewer, thereby achieving social affiliation. In some instances, a portion of the TI’s body is included in the shot, as in Figure 9.

Creators of the videos also use the introductory portion as an opportunity to affiliate with viewers. They gaze directly into the camera and arguably seek to establish a relationship with their viewers by looking directly at them. Such an image is known as a *demand image* [34] because the represented participants (in this case, the TIs themselves) engage the

audience directly through their eye gaze and posture to request a relationship with them.

When addressing viewers directly, vloggers uniformly adopt a friendly, helpful, and explanatory tone as one might expect in an instructional video. TIs generally address viewers as equals; they do not use formal language or speak disrespectfully.

*All right, everyone. Looks like gangstalking is at hand. You guys wanted to see some video. Well. It's about to happen.*

In this example, the TI uses the politeness strategy [35] of recognizing the presumptive wants of their audience [27] to promote affiliation while also positioning themselves as part of a community of people interested in gangstalking.

*What's up YouTube? It's your boy [redacted] coming at you with another one. You know what I'm sayin'?*

In this instance, the TI adopts a friendly, conversational tone and informal forms of address that would not be out of place in more mainstream YouTube vlogs aimed at a young audience.

*Yeah, guys, what's going on? Yeah, so something really crazy happened to me today.*

*Hey, guys. I've got some footage here of me filling up at a service station, and it shows just how the handlers orchestrate things.*

Similarly, in the coda section of the vlogs, vloggers adopt a similar register with viewers:

*Peace and love and light to all. I'm out.*

*Thank you. I'm [redacted], and I'm out in Oklahoma. September 15th, 2:05 pm. Have a good day.*

*But anyways, guys I'm gonna get off here for now. Um, enjoy your day. Unfortunately, it's rainy. Cloudy and rainy here today, but it's still a beautiful day, you guys. Stay happy. Stay peaceful. And yeah, just keep the hope going. Everything's gonna be good. Love you, guys. Bye.*

**Figure 9.** POV shot conflates the identity of the viewer and the targeted individual. POV: point of view.



### Representational Disaffiliation

In contrast to the affiliation construed with viewers, TIs use a different set of multimodal discursive strategies to construct others as being hostile and malicious and to increase interpersonal distance between themselves and the perps they claim are represented in the videos.

In contrast to the generally positive regard creators demonstrate toward viewers, they use a variety of discursive strategies to express negative affect—primarily anger and hostility—toward

other people present in the videos. They also use compositional strategies to distance themselves from those represented as engaged in gangstalking.

In the evidentiary portion of the vlogs, depictions of perps of gangstalking use long-distance shots, as shown in [Figure 10](#). This generates interpersonal distance between perps on the one hand and the vloggers and viewers on the other [34]. As [Figure 11](#) demonstrates, TIs also make extensive use of framing to disconnect themselves from the perps represented in the videos.

**Figure 10.** Long-distance shots create distance between perps and the vlogger/viewer dyad. vlogger: video blogger.



**Figure 11.** Use of framing disconnects perps from TIs. TI: targeted individual.



### Uses of Impoliteness Strategies

TIs engage in a variety of face-threatening acts with others in their videos. “Face” is a sociological concept, originating in the work of Goffman [36], which broadly denotes individuals’ public self-image. Politeness strategies can be used to preserve but also to attack or harm another’s face [37]. The latter are known as face-threatening acts, and there is evidence of these in the data. In one video, a creator confronts a perp in a parking lot and says:

*Why are you gangstalking? Why are you gangstalking me? Why are you gangstalking me? Why are two cars pulled up with their headlights facing me? Are you doing a psyop?*

This utterance is face threatening in that it includes direct questioning but with no attempts at softening or redressing its direct, pointed nature. The formulation “Why are you gangstalking?” presupposes that the interlocutor is in fact engaged in gangstalking and leaves no room for a version of events in the way that the question “Are you gangstalking me?” would. Further, repeating the question several times in rapid succession lends a sense of urgency and even aggression to the interrogation.

In another video, a TI enters a Walmart store and confronts a group of people smoking cigarettes at the store entrance:

*Aye, my god, you know there's, like, a cigarette place you can smoke over there? It's right there to the left. You feel me? So, like, you smoke a lot right here, that shit, like, that's fucked up. You know what I'm saying? But you could smoke right there, though.*

In this example, the TI enacts impoliteness by calling out the behaviors of the interlocutors, who were apparently not known to him previously, and using expletives in pointedly criticizing

their behavior [37]. He also uses message enforcers (*You feel me, You know what I'm saying*), which intensify the impoliteness of the utterance.

Immediately after disengaging from the group, the vlogger turns to the camera and says, “*That's provoking. That's provoking.*” to justify the hostility he demonstrated toward the smokers. He goes on to reiterate his high regard for viewers of the video and especially those who leave supportive comments:

*I'm tired of this shit, boy. But I'm not gonna feed into it. Imma keep doing my thing. I appreciate you all up in my motherfucking comments, talking about some “Oh, don't feed into it.” But I've been ignoring this shit for too long.*

This abrupt change of tone signals to viewers that although the TI is angry with those portrayed in the video, viewers are exempt from this and are in fact valued. Taken together, these strategies function to establish in- and out-groups around the vlogs. Although viewers are addressed using the language of social intimacy and as part of a shared community, perps who appear in the videos are explicitly confronted, interrogated, and sworn at. Despite engaging in such socially proscribed behavior, the way in which gangstalking vloggers explicitly justify their impoliteness toward perps also serves to present themselves as generally reasonable and polite; they mark their rudeness as an acceptable way to treat their purported harassers but also as a deviation from the otherwise genial register with which they address their intended audience. Nevertheless, such confrontational behavior creates a spectacle in the videos themselves, allowing the audience to vicariously experience direct altercations with apparent perps.



## Filming as an Act of Resistance

Throughout our data, and as indicated in the extant literature regarding gangstalking [1,3], TIs express that the persecutory system is so pervasive, persistent, and widely distributed that they feel powerless to effectively intervene or protect themselves. They note that law enforcement and other figures of authority are complicit, so the usual forms of redress are not available. The important caveat to this sense of futility and nihilistic outlook is that vloggers describe that perps are frightened of being recorded and of having their behaviors exposed publicly.

*And it's to a point where I'm, like, OK. Cool. You all wanna be about that life, I be about it too. I'll record all your all ass . . . you try to provoke me, I'll put your ass on this camera.*

*Faces turned. They know that they're being filmed now. Look, they turn away. They shy away.*

*Tell you y'all. These damn demons won't stop. And I ain't gonna stop recording them.*

By using the notion of perps being caught unawares and being unwillingly publicly exposed, the TIs can offset the power differential to some degree and partially restore a sense of agency. Creators frequently refer to perps as being frightened of exposure. The power of the videos, or more specifically the act of filming, to strike fear in perps is thus presented as helping TIs to redress the perceived power imbalance inherent in the persecutory belief system, wherein it is otherwise the perps who maliciously wield their collective power over TIs.

## Filming Perceived as an Aggressive Act

In some instances, community members appear unnerved by vloggers filming them, and the act of filming itself forms the basis of hostile interactions between vloggers and participants in the evidence videos.

In this instance, a vlogger confronts shoppers at a grocery store. He films them and accuses them of gangstalking him. He demands to see the manager, and when the manager arrives, the following exchange ensues, highlighting the act of filming as a source of conflict.

*TI: Ah, here you are, mate. How are you? Good?*

*Manager: I'm good. How are you?*

*TI: Yeah, not bad. What's your name?*

*Manager: Why are you filming everyone?*

*TI: Oh, don't worry, man. I will . . . I won't post this on YouTube, I just want . . .*

*Manager: No, no. I'm just asking why you're filming everyone.*

*TI: I'm not filming people. I just wanna ask you a question.*

*Manager: No, no. You are filming, innit?*

*TI: No, no. Uh. No, no. Uh. Uhm. Can I ask you a quick question?*

*Manager: Can you stop that, please?*

*TI: Yeah, yeah. Of course.*

TIs regard their filming as gathering evidence in an objective manner about activities that occur, regardless of whether they are being filmed. However, perps regard the process of filming itself as aggressive, hostile, and unnerving and respond with their own face-threatening acts by insisting that the filming cease. The act of filming, which is designed to capture hostility, appears to elicit the very phenomenon it attempts to document, thereby serving as something of a self-fulfilling prophecy.

## Discussion

### Summary of the Findings

Semiotics, the study of signs, defines a sign as composed of a signifier and a signified [38]. A sign is anything that can stand for something else. In semiotics, a *floating* or an *empty signifier* is one with a vague, highly variable, unspecifiable, or non-existent specifier [39]. The behaviors and interactions that form the subject of the gangstalking evidence videos analyzed in this study can be productively viewed as floating signifiers. They are polysemous in that different people may form distinct interpretations of the same observations. The scenes depicted appear to be unremarkable depictions of people going about their quotidian routines. The denotative meanings of these scenes are straightforward, but the connotative meanings are contested. The connotative significance of signs is used to signify the discursive content [40], in this case that gangstalking is real.

Our analysis revealed that the vloggers, who identify as individuals targeted by gangstalking, use a variety of multimodal strategies to indicate the salience of the acts depicted, thereby construing the gangstalking narrative. These included linguistic deictic features, paralinguistic features, and features operating through the visual frame.

Although the stated purpose of the videos is to document and disseminate evidence of the gangstalking phenomenon, vloggers also accomplish interpersonal tasks in the videos. On the one hand, they generate intersubjective ambient affiliation with viewers of the videos. On the other, they create hostility and reinforce animus with people depicted in the videos—a process we termed “representational disaffiliation.” This may serve to strengthen community building with viewers by projecting authenticity and intimacy [41]. People experiencing psychosis are likely to experience loneliness and social isolation at higher rates than the general population [42]. Our study is consistent with previous observations that people experiencing persecutory belief systems are more likely to perceive ambiguous social situations as hostile [43]. As predicted by interpersonal theory, this perceived hostility begets further hostility, leading to a positive feedback loop of ever-increasing hostility [44]. Pervasive hostility in the social milieu of TIs may frustrate the capacity to form strong, supportive interpersonal bonds in their offline lives. The need to have such bonds and to belong is a powerful, fundamental, and extremely pervasive motivation [45]. By forming affiliative bonds with hypothetical viewers of these videos, TIs may therefore offset the isolation induced by hostility and work toward meeting needs for belonging.

The videos use the rhetorical trope of synecdoche, where a part is used to stand in for the whole. Gangstalking is described as

a widely distributed and pervasive system, but videos must be limited in scope in time and space due to practical constraints. The scenes depicted in the videos are meant to stand in for the pervasive nature of gangstalking. TIs are asking viewers of these videos to generalize the specific instances depicted.

The videos highlight the Derridean concept of *différance*. Derrida argued that “the signified concept is never present in and of itself, in a sufficient presence that would refer only to itself. Every concept is inscribed in a chain or in a system within which it refers to the other, to other concepts, by means of a systematic play of differences” [46]. In this study’s data, vloggers attempt to assign meaning through deixis. However, these efforts merely serve to defer meaning. When a vlogger points to a car and claims that it is being used for their persecution, a new question arises. Namely, what about that car signifies persecution? The vlogger may respond that it is some aspect of the car, such as its color, position, direction of travel, or the facial expression of the driver. However, this merely invites a new question: what is it about that attribute that signifies persecution? This cycle of deictic signifiers, each one pointing to the next, continues in an infinite chain and never arrives at its destination or definitively resolves the question.

### Clinical Implications

This observation may have important clinical ramifications. Traditionally, psychiatrists define delusions as fixed beliefs that are not amenable to change, considering conflicting evidence [47]. An alternative definition is that delusions are beliefs that

are demonstrably untrue or not shared by others [48]. However, these and other definitions of delusions fall short, and arriving at a definitive definition may be impossible [49]. The prospect of a clinician definitively establishing the truth or falsity of a delusional belief system is often impractical or impossible. Often when a clinician states that a belief system is untrue or impossible, they are relying on their own beliefs, biases, and cultural referents. By shifting, instead, to a linguistic or semiotic understanding of delusions as belief systems that are unresolvable or that defer understanding *ad infinitum*, clinicians may sidestep the difficulties inherent in existing definitions. Ultimately, all users of semiotic systems—patients and clinicians alike—are subject to the same fundamental limits on communication and understanding inherent in language and all symbolic systems. Such a humbling realization may help to promote empathy and understanding and reduce stigma affecting people afflicted by persecutory belief systems.

### Conclusions

Our findings provide insight into a novel persecutory belief system. Interpersonal concerns are important for people affected, and they construe others as either sympathetic or hostile. They create a positive ambient affiliation with viewers. Vloggers use multimodal deixis to illustrate the salience of the belief system. Clinicians may consider stepping away from the traditional true/false dichotomy endorsed by psychiatric classification systems and focus on the ambiguity in semiotic systems generally and in persecutory belief systems specifically.

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### Conflicts of Interest

None declared.

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## Abbreviations

**API:** Application Programming Interface

**POV:** point of view

**SFL:** systemic functional linguistics

**TI:** targeted individual

**vlog:** video blog

**vlogger:** video blogger

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Review

# Use of Automated Thematic Annotations for Small Data Sets in a Psychotherapeutic Context: Systematic Review of Machine Learning Algorithms

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Alexandre Hudon<sup>1,2</sup>, BEng, MD; Mélissa Beaudoin<sup>1,2</sup>, MSc; Kingsada Phraxayavong<sup>3</sup>, BSc; Laura Dellazizzo<sup>1,2</sup>, MSc; Stéphane Potvin<sup>1,2</sup>, PhD; Alexandre Dumais<sup>1,2,3,4</sup>, MD, PhD

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<sup>1</sup>Centre de recherche de l'Institut Universitaire en Santé Mentale de Montréal, Montréal, QC, Canada

<sup>2</sup>Department of Psychiatry and Addictology, Faculty of Medicine, Université de Montréal, Montréal, QC, Canada

<sup>3</sup>Services et Recherches Psychiatriques AD, Montréal, QC, Canada

<sup>4</sup>Institut national de psychiatrie légale Philippe-Pinel, Montréal, QC, Canada

**Corresponding Author:**

Alexandre Dumais, MD, PhD

Centre de recherche de l'Institut Universitaire en Santé Mentale de Montréal

7331, rue Hochelaga

Montréal, QC

Canada

Phone: 1 (514) 251 4000

Email: [alexandre.dumais@umontreal.ca](mailto:alexandre.dumais@umontreal.ca)

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## Abstract

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**Background:** A growing body of literature has detailed the use of qualitative analyses to measure the therapeutic processes and intrinsic effectiveness of psychotherapies, which yield small databases. Nonetheless, these approaches have several limitations and machine learning algorithms are needed.

**Objective:** The objective of this study is to conduct a systematic review of the use of machine learning for automated text classification for small data sets in the fields of psychiatry, psychology, and social sciences. This review will identify available algorithms and assess if automated classification of textual entities is comparable to the classification done by human evaluators.

**Methods:** A systematic search was performed in the electronic databases of Medline, Web of Science, PsycNet (PsycINFO), and Google Scholar from their inception dates to 2021. The fields of psychiatry, psychology, and social sciences were selected as they include a vast array of textual entities in the domain of mental health that can be reviewed. Additional records identified through cross-referencing were used to find other studies.

**Results:** This literature search identified 5442 articles that were eligible for our study after the removal of duplicates. Following abstract screening, 114 full articles were assessed in their entirety, of which 107 were excluded. The remaining 7 studies were analyzed. Classification algorithms such as naive Bayes, decision tree, and support vector machine classifiers were identified. Support vector machine is the most used algorithm and best performing as per the identified articles. Prediction classification scores for the identified algorithms ranged from 53%-91% for the classification of textual entities in 4-7 categories. In addition, 3 of the 7 studies reported an interjudge agreement statistic; these were consistent with agreement statistics for text classification done by human evaluators.

**Conclusions:** A systematic review of available machine learning algorithms for automated text classification for small data sets in several fields (psychiatry, psychology, and social sciences) was conducted. We compared automated classification with classification done by human evaluators. Our results show that it is possible to automatically classify textual entities of a transcript based solely on small databases. Future studies are nevertheless needed to assess whether such algorithms can be implemented in the context of psychotherapies.

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**KEYWORDS**

psychotherapy; artificial intelligence; automated text classification; machine learning; systematic review

## Introduction

The intrinsic effectiveness of psychotherapies is generally measured through semistructured interviews or self-reported questionnaires [1-3]. However, these instruments have limitations in relation to constructs that can be set a priori, for which there are standardized measures available. To assess the intrinsic effectiveness of psychotherapies (the psychotherapeutic process itself), an increasing number of research teams have started to use qualitative methods. Although these approaches have inherent biases (eg, data analysis subjectivity), mathematical algorithms can be used to reduce such biases. Furthermore, assessment of a psychotherapy's intrinsic effectiveness usually refers to an assessment of a patient's characteristics and the therapeutic process [4]. Studies often use therapy session transcripts to qualitatively evaluate psychotherapies [5]. For in-person therapies, transcriptions are often time-consuming and classifying therapeutic interactions under various themes (labels) for analysis is even more demanding. Machine learning is a potential solution to reduce the amount of labor-intensive work required [6]. With the increasing development of new psychotherapies for various psychopathologies, there is a higher need for tools to measure and understand their effectiveness.

Text mining is one of the few techniques used in psychiatry to derive data from the large number of interactions that occur during therapy sessions [7]. One such technique is the use of artificial intelligence by means of machine learning. It is currently being used in many areas in the medical field, ranging from surgical procedure analyses to medical diagnostics [8]. When attempting to classify textual entities from medical fields into various categories, the text is often classified into a few categories. This can be done by applying a set of rules to an algorithm to be used for classification and is usually facilitated by the nature of the entity being classified (eg, signs and symptoms relating to a particular diagnosis or treatment) [9]. Classification of therapeutic interactions can be tricky considering the vast array of information associated with the therapy itself, the ability of the patient to communicate, and the context in which the therapy is being conducted [10]. This leads to transcripts that may vary widely from patient to patient; therefore, the information is less directly interpretable than medical records or results. In relevant fields where such data is usually used for research, such as psychiatry and psychology, the use of machine learning in the context of text mining in psychotherapy has been limited [11]. Many algorithms are readily available to conduct automated text classification [12]. Simple probabilistic mathematical algorithms (ie, naive Bayesian probability algorithms) as well as more complex ones (ie, neural networks) are available via open access libraries on the web [13]. Machine learning algorithms often need large databases to adequately classify new data by creating training sets and testing sets [14-16]. Large databases, such as some seen in the field of internet-enabled cognitive behavioral therapy, are required for complex machine learning algorithms to adequately learn and classify new information [1]. However, in-person therapies often yield databases that are smaller than the ones generated by internet-enabled cognitive behavioral therapy

because of the need for human-driven transcriptions. This creates a need to find potential algorithms that can operate on small databases [17,18]. A machine learning algorithm applicable for small databases is therefore needed for such cases.

The objective of this study is to conduct a systematic review of the use of machine learning for automated text classification for small databases in the fields of psychiatry, psychology, and social sciences to determine the best algorithm for automatically classifying the content of psychotherapy transcripts. This would provide an interesting solution for automated therapy annotations in the context of qualitative analysis and could generate data to enable the evaluation of therapeutic processes.

## Methods

### Search Strategies

A systematic search was performed in the electronic databases of Medline, Web Of Science, PsycNet (PsycINFO), and Google Scholar from their inception dates until 2021 using text words and indexing (MeSH) terms with keywords that were inclusive for the fields of psychiatry (eg, psychiatric, psychiatry), psychology (eg, psychology, psychotherapy, neuropsychology) and social sciences (eg, social science) and machine learning. Additional records identified through cross-referencing were used to find other studies. The fields of psychiatry, psychology, and social sciences were selected as they include a vast array of textual entities in the domain of mental health that can be reviewed. A complete electronic search strategy is available in [Multimedia Appendix 1](#). The search methodology was developed by the corresponding author and a librarian specialized in mental health at the Institut universitaire en santé mentale de Montréal. Searches were completed by AH and cross-validated by MB in May 2021. No setting, date, or geographical restrictions were applied. Searches were limited to English- or French-language sources.

### Study Eligibility

Studies were included if they met the following criteria: (1) classification in various data categories of textual entities (eg, medical records, letters, transcripts); (2) the study was conducted in the fields of psychiatry, psychology, or social sciences; (3) automated classification of text was conducted in more than 2 data categories (text was classified in more than two features); (4) automated text classification was conducted by machine learning (either supervised or unsupervised algorithms); and (5) the number of elements in the database used was less than 10,000, which corresponds to a small database. Although there is no consensus on what a small database is, we defined a small database as one that had a maximum of 10,000 items since 5000-10,000 items have been referred to as small samples in prior studies [19-21]. Studies that use a combination of many algorithms, instead of a single algorithm, were also included. Unpublished literature was excluded as well as studies using artificial intelligence algorithms outside the scope of machine learning.

### Data Extraction

Data were extracted with a standardized form and cross-verified for consistency and integrity by two authors, AH and MB.

Information such as size of the database, number of classification categories, algorithms used, prediction success rate (in %), and interjudge agreement were recorded.

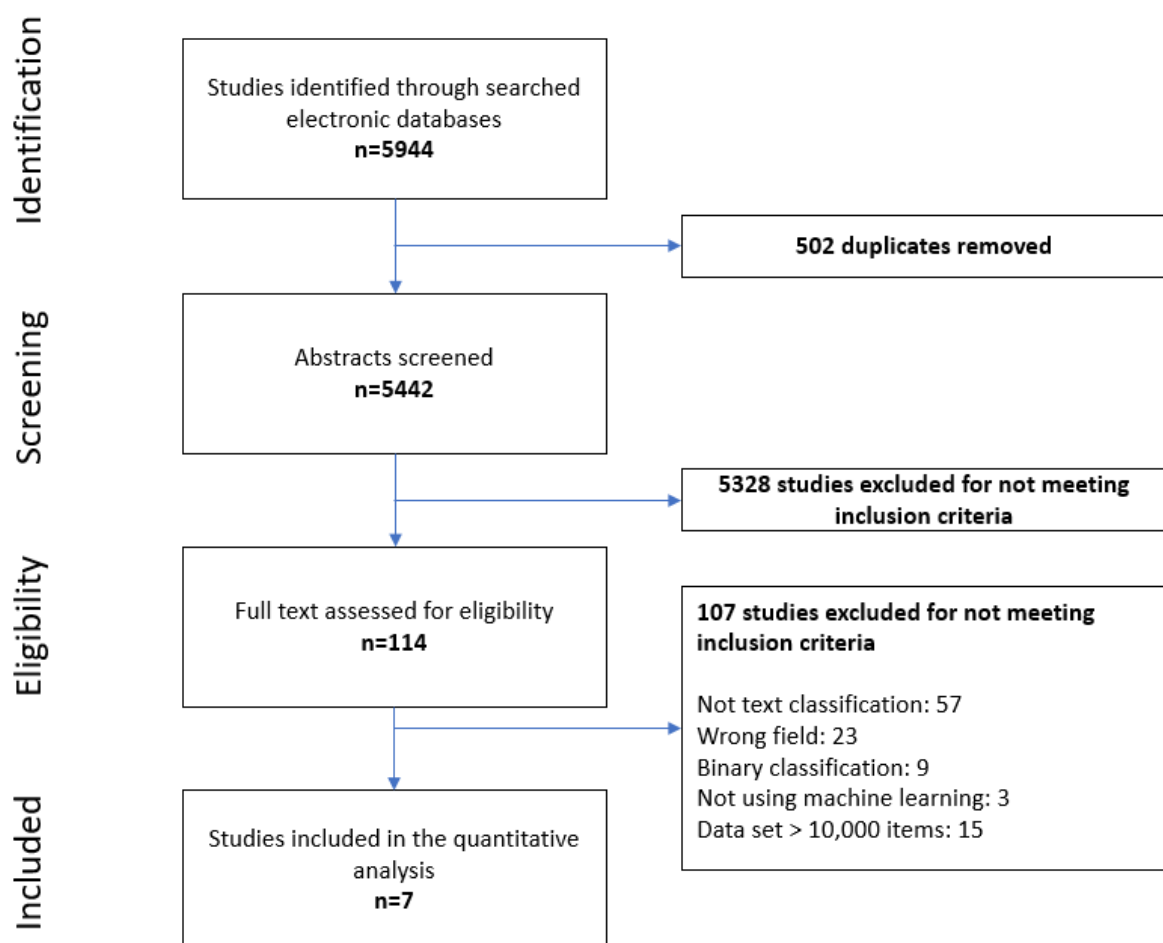
## Results

### Description of Studies

Our systematic review assessed studies that used machine learning to classify text in the fields of psychiatry, psychology, and social sciences. This literature search identified 5442 articles that were eligible for our study after the removal of duplicates. Following abstract screening, 114 full articles were assessed in their entirety, of which 107 were excluded. The remaining 7 studies were analyzed. The flowchart for the inclusion of studies

in this systematic review is found in Figure 1. The details of the studies are provided in Multimedia Appendix 2. Notably, a limited number of articles on automated text classification with small databases were found. Studies that met inclusion criteria reported different types of documents used for automated annotation. Social medical content, such as forum posts in the study by Yu et al [22] and Twitter entries in the study by Balakrishnan et al [23] generated the largest data sets (5000 and 5453 items, respectively). Those textual entities consisted of complete or partial sentences manually written by users and were annotated in their entirety. The remaining types of documents were mainly medical records completed by physicians or health science professionals. No image or mathematical data were classified by the algorithms as part of these studies.

**Figure 1.** Flowchart depicting the process of study selection.



### Algorithms

#### Overview

Several algorithms have been used on the presented textual entities. Naive Bayes classifier, decision tree-based algorithms, support vector machine (SVM) classifiers, and combinations of multiple algorithms were the main strategies used by the included studies. The number of categories for text classification ranged from 4-7 and overall precision classification ranged from 77.0%-91.8%. For the studies that included multiple algorithms,

SVM-based algorithms demonstrated the best accuracy in 5 of 7 studies.

#### Naive Bayes Classifier

A naive Bayes classifier is a probabilistic-based classifier that makes use of Bayes' theorem to classify items into different categories [12]. This type of classifier achieves average performance in the context of supervised learning [24]. This type of algorithm is advantageous when little data is available as it can be optimally parameterized in the event of a small data set [25]. This algorithm assumes that there is independence

between the predictors. For text classification, Balakrishnan et al [23] outlined that this algorithm works best when using each word as a variable that needs to be classified.

### **Decision Tree–Based Classifiers**

Decision tree–based classifiers are nonparameterized; they are supervised learning methods that can be used to classify items [26]. Observations about an item are represented as branches and conclusions about an item's value (score) are represented as leaves [27]. Splitting across the different branches is based on defined rules according to the categories used to classify the items. In text classification, the general idea is that every piece of text being classified is split across the branches until it reaches a leaf (category) based on probabilistic rules set by the designer of the tree [27].

### **SVM Classifiers**

SVM classifiers can be used in both supervised and unsupervised learning contexts. In simple terms, these classifiers use the concept of a hyperplane that divides a data set into classes. A hyperplane in an  $n$ -dimensional Euclidean space is a flat,  $n-1$  dimensional subset of that space that divides the space into two disconnected parts [28]. The items in the data set are considered as data points on the hyperplane. The item being classified is therefore categorized in one of the disconnected parts.

### **Outcomes**

In the 7 identified studies, SVM classifiers and algorithms combined with SVM classifiers tended to achieve the best prediction score (in %) as compared to other algorithms for small data sets. Studies by Zolnoori et al [29], Singh et al [30], and Yu et al [22] reported prediction scores of SVM classifiers that were superior to other classifiers for their data sets. Their precision scores ranged from 77%-90%. Only 3 studies attempted to compare the classification done by the classifiers with human annotators. The statistics used to assess these automated annotations were  $\kappa$  and pairwise agreements. The interrater agreement of these studies was comparable to interrater agreements for annotation done by human annotators; the  $\kappa$  scores were 0.84 [23], 0.67 [30], and 0.86 [29], respectively.

## **Discussion**

### **Review of Findings**

In this study, we conducted a systematic review to identify potential algorithms that could be useful for small databases for the automatic annotation of unannotated interview transcripts from the field of psychotherapy. The systematic review we conducted demonstrated that limited literature exists on the subject. However, few algorithms displayed sufficient accuracy when performing text classification on small databases. SVM classifiers tended to display the best accuracy in the context of small databases.

Compared to other reviews on the subject, this study highlights algorithms being used in the context of small data sets, which is consistent with the reality of studies of therapies [31], as transcribing therapy sessions is time-consuming and demanding. Regarding novel therapy developments, such as virtual

reality–based therapy, this is even more needed considering the small number of patients that have received these treatments so far [32]. Therapy usually involves a wider range of words and contextual sentences compared to other areas of medicine where specific words (eg, symptoms, signs) can be used to facilitate classification. Therefore, it is not surprising to see that this systematic review identified algorithms that differ from those that are widely used in other medical fields. For example, Srivastava et al [33] reviewed the efficiency of different text classifiers in the context of social media posts referring to medical content. They found that a multilayer perceptron–based neural network performed best in their study as compared to a SVM classifier. Another study, conducted by Visveswaran and colleagues [34], identified convolutional long short-term memory neural networks as the best at predicting vaping habits. This can be explained by the fact that most classifiers are combined with a vectorizer when used to classify textual entities. A vectorizer transforms text into a meaningful number vector that can then be used by classifiers [35]. Considering that classification of textual entities to identify a specific diagnosis or medical condition usually requires specific terms that pertain to the diagnosis or condition, vectors tend to discriminate better between the textual entities of these fields [36]. This is usually not the case with therapy transcripts in the context of analysis of the psychotherapeutic process as this analysis often requires a larger array of categories that can sometime overlap.

In contrast with other types of medical data—such as imagery or numerical entities (eg, laboratory results)—where neural networks seem to be the most used class of algorithms for classification, textual classification appears to be performed with a more restricted number of classifiers [37]. This can be explained by the fact that text classification requires additional considerations. Automated classifications lack the ability to interpret a sentence out of a given context (eg, a therapeutic session), while the meaning of a sentence could change based on the context. Another complexity is that words can refer to different entities based on the sociocultural context. Therefore, considering such complexities can require further parameterizations and considerations, which may also explain why, in the identified studies, the same algorithm used on data sets of a similar size could have a diverging predictive score.

Consistent with our findings, linear SVM classifiers tend to be regarded as one of the best text classifying algorithms in the literature [38]. Many types of classifiers are available, but it appears that only a few are consistently used for the classification of textual entities [26]. This is consistent with our review, as the identified studies tended to use similar strategies when classifying textual entities. A recent literature review on data classification of clinical text data explains this phenomenon by the fact that there is a bottleneck of annotations in the context of supervised learning [39].

### **Limitations**

This systematic review of literature focuses on the fields of psychiatry, psychology, and social sciences to reflect the type of textual entities usually found in therapy transcripts. A limitation of this study is the small number of classification algorithm studies published in these fields. As this is an



emerging domain, the number of studies on the topic should increase in the future.

### Conclusions

Machine learning can be beneficial for the field of psychiatry. Automated text classification for psychotherapy is a promising avenue to generate quantitative and qualitative data in an efficient way to make the data readily available for analyses.

SVM classifiers appear to be preferred over other types of classifiers in the context of small databases. Using such classifiers could be useful in the evaluation of therapeutic processes of novel therapies where data are limited. Nevertheless, the limited number of articles found on the subject outlines the need for more development in this field, especially regarding the use of such classifiers in the domain of mental health.

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### Authors' Contributions

The study was designed by AH, SP, and AD. Statistical analyses were performed by AH and MB. All the authors have made substantial contributions and have revised, edited, and approved the manuscript.

### Conflicts of Interest

None declared.

#### Multimedia Appendix 1

Electronic search strategy for the systematic review conducted.

[[DOCX File, 14 KB - mental\\_v8i10e22651\\_app1.docx](#)]

#### Multimedia Appendix 2

Detailed results of the systematic review study selection.

[[DOCX File, 17 KB - mental\\_v8i10e22651\\_app2.docx](#)]

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## Abbreviations

**SVM:** support vector machine

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Original Paper

# Examining the Preliminary Effectiveness and Acceptability of a Web-Based Training Program for Australian Secondary School Teachers: Pilot Study of the BEAM (Building Educators' Skills in Adolescent Mental Health) Program

Belinda L Parker<sup>1,2\*</sup>, PhD; Melissa Anderson<sup>1\*</sup>, MCouns&PsychTh; Philip J Batterham<sup>1,3\*</sup>, PhD; Aimee Gayed<sup>1,2\*</sup>, PhD; Mirjana Subotic-Kerry<sup>1,2\*</sup>, PhD; Melinda R Achilles<sup>1\*</sup>, BBSoc; Cassandra Chakouch<sup>1\*</sup>, BSc; Aliza Werner-Seidler<sup>1,2\*</sup>, PhD; Alexis E Whitton<sup>1,2\*</sup>, PhD; Bridianne O'Dea<sup>1,2\*</sup>, PhD

<sup>1</sup>Black Dog Institute, Randwick, NSW, Australia

<sup>2</sup>Faculty of Medicine, University of New South Wales Sydney, Kensington, NSW, Australia

<sup>3</sup>Centre for Mental Health Research, Australian National University, Canberra, ACT, Australia

\* all authors contributed equally

**Corresponding Author:**

Bridianne O'Dea, PhD

Black Dog Institute

3 Hospital Rd

Randwick, NSW, 2031

Australia

Phone: 61 29382 8509

Email: [b.odea@blackdog.org.au](mailto:b.odea@blackdog.org.au)

## Abstract

**Background:** Secondary schools are increasingly supporting adolescents' mental health and well-being, yet many teachers report that they lack the skills and confidence to do so. Building Educators' skills in Adolescent Mental Health (BEAM) is a web-based training program developed to improve secondary school teachers' knowledge and confidence in caring for students' mental health.

**Objective:** This pilot study examined the preliminary effectiveness and acceptability of the BEAM program for improving mental health knowledge, attitudes, confidence, helping behaviors, and psychological distress among secondary school teachers.

**Methods:** A single-arm pilot trial was conducted from July to December 2019 among secondary school teachers located in New South Wales, Australia, who were employed in leadership positions responsible for managing student well-being (ie, Year Advisors). Participants had access to the BEAM program for 6 weeks. Self-report surveys, delivered at baseline, postintervention (6-weeks post baseline) and 3-month follow-up (19 weeks post baseline) were used to measure changes in training outcomes. Acceptability was assessed by program use, barriers, satisfaction, and participants' perceptions of program effectiveness.

**Results:** A total of 70 secondary school teachers took part (mean age 36.5 years, SD 9.41 years, range 24–60 years). Significant improvements in confidence were reported at postintervention and 3-month follow-up. Significant improvements in helping behaviors were reported at 3-month follow-up only. There was also a significant reduction in psychological distress at postintervention. Participants agreed that the program content was easy to understand and relevant, but program completion was challenged by lack of time, competing priorities, and forgetfulness.

**Conclusions:** Findings indicated that a web-based training program may be beneficial for improving secondary school teachers' abilities to care for students' mental health; however, program modifications are required to increase training completions.

**Trial Registration:** Australian New Zealand Clinical Trials Registry (ANZCTR) ACTRN12619000821190, Universal Trial Number U1111-1232-7680; <https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=377529>

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**KEYWORDS**

mental health; training; high school teachers; youth; mental health programs; secondary schools

## Introduction

### Background

Adolescence is a key period for the development of mental illness, with over half of all mental health problems first emerging before the age of 18 years [1]. Secondary schools are increasingly providing mental health care and support to adolescent students, primarily owing to the accessible nature of educational settings for service provision and the functional impacts of mental illness on social development and academic achievement. There are over 2800 secondary schools in Australia, enrolling over 2 million young people and employing more than 140,000 full-time teachers. One-third (n=830) of these schools are in New South Wales (NSW), where the average school size is 700 students with 58 teachers [2,3]. Population surveys in Australia and the United States [4] have confirmed the use of school services for mental health problems among youth, with service utilization rates similar to those of traditional health care settings [5]. Secondary schools can enable the early identification of mental illness, [6-9] as many Australian teachers are the first to identify emotional problems in students and initiate help-seeking [5]. However, many teachers report a lack of skills and confidence in recognizing and responding to students' mental health needs [10,11] and few have received specialized training in this domain [8,12]. Many teachers have reported that additional management of student well-being has led to greater workload and stress [8,13,14]. In 2020, specialized mental health training was mandated for all NSW teachers [15], further confirming the need for these skills. Workplace learning and development opportunities may improve teachers' abilities to care for students' mental health and reduce the associated stress [16,17]. However, there are limited evidence-based training programs currently available.

Three recent systematic reviews on youth mental health training for secondary school teachers have indicated a lack of evidence-based programs [18-20]. Anderson et al [18] found that only 6 programs had been evaluated, and while all improved the mental health knowledge of the participating teachers, none increased actual helping behavior toward students (eg, referring or recommending a student seek professional help). Four of the reviewed training programs were delivered through didactic instruction (the remaining 2 were a combination of face-to-face and web-based components) and required teachers to be absent from school duties, likely limiting the uptake [18]. Furthermore, only 1 program was evaluated within the Australian context [21,22]. Similarly, Yamaguchi et al [19] noted that while most programs observed an improvement in knowledge, attitudes,

confidence, and behavior, the quality of studies was low [19]. These findings were further confirmed by Ohrt et al [20]. Taken together, these reviews suggest that a focus on mental health literacy alone is unlikely to elicit behavior change. There is a clear need for high quality programs that are evidence-based, flexible in delivery, and effective for improving teachers' confidence and skills in the domain of student mental health. Web-based mental health training has been shown to be effective in workplace settings [23], and may provide a delivery model that is scalable and accessible for school settings.

The Black Dog Institute has developed a web-based training program that aims to improve secondary school teachers' knowledge, confidence, and skills in recognizing and supporting students with mental health problems. Delivered over 6 weeks, the Building Educators' skills in Adolescent Mental Health (BEAM) program combines self-directed content with in-person peer coaching activities and printable resources. The program consists of 5 topics that include educational information, quizzes, blog-style story-sharing, and case studies (Figure 1). Each topic is complemented by a peer coaching component that aims to help teachers contextualize the program, build professional relationships, self-reflect, and learn from those with different expertise and experience [24,25]. Topics are completed in sequential order and are not unlocked until the peer coaching activities are completed. However, topics can be completed at any pace during the 6 weeks with no limit on topics completed per week.

BEAM was developed in partnership with a lived experience advisory group of 12 teachers [12], and the delivery format was adapted from the evidence-based manager-training program HeadCoach [23,26]. HeadCoach is designed to help managers to better understand and support the mental health needs of their staff [23]. An evaluation of HeadCoach demonstrated positive effects on managers' confidence and workplace practices for mental health, with significant improvements in responsive and preventative behaviors toward staff [23]. BEAM includes similar persuasive techniques (eg, reminders, feedback, theory, and practical advice) to target engagement [27] and tunneling (eg, program modules are presented in a structured and sequential manner) to guide program completion [28,29]. As such, the BEAM program can be completed at a time and place that is convenient for teachers. However, this web-based training model for student mental health is the first of its kind to be delivered in Australian secondary schools. It is unclear whether teachers are open to this type of training, and whether a self-directed program is effective for improving outcomes and behavior related to student mental health.

**Figure 1.** Overview of the Building Educators' skills in Adolescent Mental Health (BEAM) training program.

## Objectives and Hypotheses

This study examined the preliminary effectiveness and acceptability of the BEAM program for improving mental health knowledge, attitudes, confidence, and helping behaviors among secondary school teachers in NSW, Australia. It was hypothesized that participating teachers would report improvements in knowledge, attitudes, confidence, and helping behaviors at postintervention. This study also examined teachers' psychological distress to determine whether the training program was associated with positive improvements in the mental health of teachers themselves. Program acceptability was examined by measures of program use, barriers to use, and training satisfaction. Our results provide important information about the feasibility of using a training platform that combines web-based and offline learning to address shortages in teachers' professional development in student mental health.

## Methods

### Design

An uncontrolled, single-arm pilot study was conducted with outcome measures assessed at baseline, postintervention (6 weeks after baseline), and 3-month follow-up (19 weeks after baseline). The study was approved by the University of New South Wales (UNSW) Human Research Ethics Committee (HC190047), the NSW State Education Research Advisory Process (SERAP 2019048), and the Sydney, Parramatta, and Maitland-Newcastle Catholic Dioceses. This trial was registered with the Australian New Zealand Clinical Trials Registry (ACTRN12619000821190) and assigned a Universal Trial Number (U1111-1232-7680).

### Participants

The current study targeted secondary school teachers from NSW, who were employed in a teaching role with increased responsibility for the mental health of students aged between 12 and 18 years (eg, Year Advisor or equivalent, Student Coordinator, Head of Year). These teachers were identified as

requiring significant skills in student mental health as they acted as informal case managers for students by offering support when needed and liaising with others about school performance. Secondary school teachers were eligible to participate in the current study if they were (1) employed full-time for the duration of the study in a teaching role that had responsibility for student well-being, (2) able to obtain support and signed consent from their school principal, and (3) able to participate alongside at least 1 other equivalent colleague from their school to enable completion of the peer coaching.

### Recruitment and Consent

Recruitment was undertaken between June 17 and July 19, 2019, in NSW. The study was advertised in 9 School-Link newsletters (ie, a state government service that connects schools with local mental health services). The study was also advertised on the Black Dog Institute's website and Facebook page. Teachers were directed to the study website where they completed the eligibility screening and registered with their name, school, and email address, and downloaded the participant information statement and consent forms (PISCFs). Eligible teachers were advised to consult with their school principal and colleagues and email the completed PISCFs to the research team.

### Procedure

Once eligibility was confirmed and consent forms were returned, participants were invited to complete the baseline survey. Participants who did not attempt or complete the baseline survey within 7 days were withdrawn from the study. Upon completion of baseline, participants were given access to the BEAM program for 6 weeks. The BEAM program was accessible on internet-enabled computers only. Modules were completed sequentially, and all activities were mandatory. The program provided automatic feedback on incorrect responses and this content was not reviewed by the researchers. Responses to the peer coaching activities were submitted to the research team through the program and researchers provided feedback via email within 3 days of submission. Participants were sent 4 reminders to use the program. At 6 weeks post baseline, participants were invited to complete the postintervention survey. At 3-month follow up (ie, 19 weeks post baseline),

participants were invited to complete the follow-up survey, and those who completed it were reimbursed with an Aus \$50 (US \$36.26) e-gift voucher, irrespective of whether they completed the BEAM program.

## Measures

### *Demographics and Background Characteristics*

At baseline, participants reported their gender and age, teaching experience, duration in current role, and employment at current school (all reported in years). Participants also reported the location of their current school (metropolitan, regional, or rural/remote), the school funder (government or nongovernment), and gender type (single-sex or coeducational). Participants reported their current level of training in student mental health (none, limited, moderate, or extensive). Participants were asked to rate the importance of receiving mental health training and their confidence in web-based programs for satisfying their training needs. Items were answered using a 5-point Likert scale ranging from not at all (1) to extremely (5).

### *Mental Health Knowledge*

A 6-item adapted subscale of the Mental Health Knowledge Schedule (MAKS) [30] scale was used to measure mental health knowledge. The first 6-item subscale assessed literacy (eg, “most students with mental health problems want to complete their schooling”) and were answered on a 5-point Likert scale ranging from strongly disagree (1) to strongly agree (5). Items were summed to yield a total score ranging from 6 to 30. Higher scores indicated greater mental health literacy. As the MAKS consists of multidimensional items that examine different mental health-related domains, calculating and reporting the subscale Cronbach  $\alpha$  has been considered inappropriate [30].

### *Mental Health Attitudes*

A modified version of the Depression Stigma Scale–Personal Stigma subscale [31] was used to measure teachers’ attitudes toward students with mental health problems. Participants were asked to rate how much they agreed with 9 statements (eg, “students with a mental illness could snap out of it if they wanted”) using a 5-point Likert scale ranging from strongly disagree (1) to strongly agree (5). Items were summed to yield a total score, ranging from 9 to 45. Higher scores indicated greater levels of stigma. In this study, Cronbach  $\alpha$  = .82.

### *Confidence in Helping Behaviors*

An adapted version of the Confidence in Helping subscale [32] was used to measure participants’ self-confidence in their ability to recognize, refer, and support students with mental health problems. Participants were asked to rate their confidence in dealing with 15 mental health scenarios (eg, “recognizing a student with mental health problems”). Items were answered using a 5-point Likert scale ranging from not at all confident (1) to very confident (5). Items were summed to yield a total score ranging from 15 to 75. Higher scores indicated greater levels of confidence. In this study, Cronbach  $\alpha$  = .95.

### *Frequency of Helping Behaviors*

A 14-item adapted version of the Help Provided to Students questionnaire [21] was used to measure the frequency of helping behaviors for mental health among teachers. Participants were asked to indicate how often, in the past 2 weeks, they had engaged in 14 helping behaviors (eg, “reached out to a student with mental health problems”). Items were answered using a 4-point scale (never, once, occasionally, or frequently). Items were summed to yield a total score ranging from 14 to 56. Higher scores indicated more frequent helping behaviors. In this study, Cronbach  $\alpha$  = .89.

### *Psychological Distress*

The self-report 5-item Distress Questionnaire-5 (DQ5) [33] was used to measure teachers’ psychological distress. Items were answered using a 5-point Likert scale ranging from never (1) to always (5). Items were summed to yield a total score ranging from 5 to 25. Higher scores indicated greater psychological distress with a score of 14 indicating the possibility of a mental health condition [33]. Completion of the DQ5 was optional, since it was not a primary outcome of the training program. The DQ5 has high internal consistency and convergent validity [33,34]. In this study, Cronbach  $\alpha$  = .84.

### *Perceived Effectiveness*

At postintervention, participants were asked to rate (using 4 separate items) the extent to which they believed the BEAM program increased their confidence, skills, and approach to students’ mental health needs, and whether the program met their training needs. Items were answered using a 5-point Likert scale ranging from not at all (1) to entirely (5).

### *Program Use and Barriers*

Program use was measured by the number of topics completed. As topics were sequential, participants could not progress through the program without completing the peer coaching. Therefore, topics were deemed completed when a participant submitted the corresponding peer coaching activity. Barriers to program use were assessed at postintervention. Participants were asked to report whether they had experienced any items from a list of 11 barriers to program use (eg, “forgot about the program” and “the program wasn’t a priority,” answered with “yes” or “no”).

### *Program Acceptability and Satisfaction*

Acceptability was measured at postintervention using a 13-item questionnaire that was adapted for the BEAM program [35,36]. Participants were asked to rate the extent to which they agreed with 13 statements (eg, “the content was easy to understand” and “the program activities were engaging”). Items were rated on a 5-point Likert scale ranging from strongly disagree (1) to strongly agree (5). Satisfaction was measured at postintervention using 3 items. Participants were asked to rate how satisfied they were with the program, the likelihood of future use, and the likelihood of recommending the program to others. Items were rated on a 5-point Likert scale ranging from not at all (1) to entirely (5).

### Data Collection and Analysis

Program and study data were collected and stored securely using the Black Dog Institute Research Engine hosted on the University of New South Wales servers in Australia. Data was then downloaded into Microsoft Excel and exported into SPSS (version 27.0, SPSS Inc) for analysis. The final sample for analysis consisted of the participants who completed the baseline assessment. At postintervention and 3-month follow-up, participants' responses were included in the analyses regardless of whether they completed all questionnaires. Basic descriptive statistics, including means and standard deviations were calculated and reported for participant and school characteristics, and acceptability items. To estimate the pre- and postintervention effects of the program on participants' mental health knowledge, confidence, attitudes, helping behaviors, and psychological distress, mixed models repeated measures analysis of variance were conducted, with time as a main effect. Statistical significance was set at  $P < .05$  (2-tailed). We conducted *t* tests to compare mean differences in acceptability, satisfaction, and perceived effectiveness scores between program completers

(ie, participants who completed the entire program) and noncompleters.

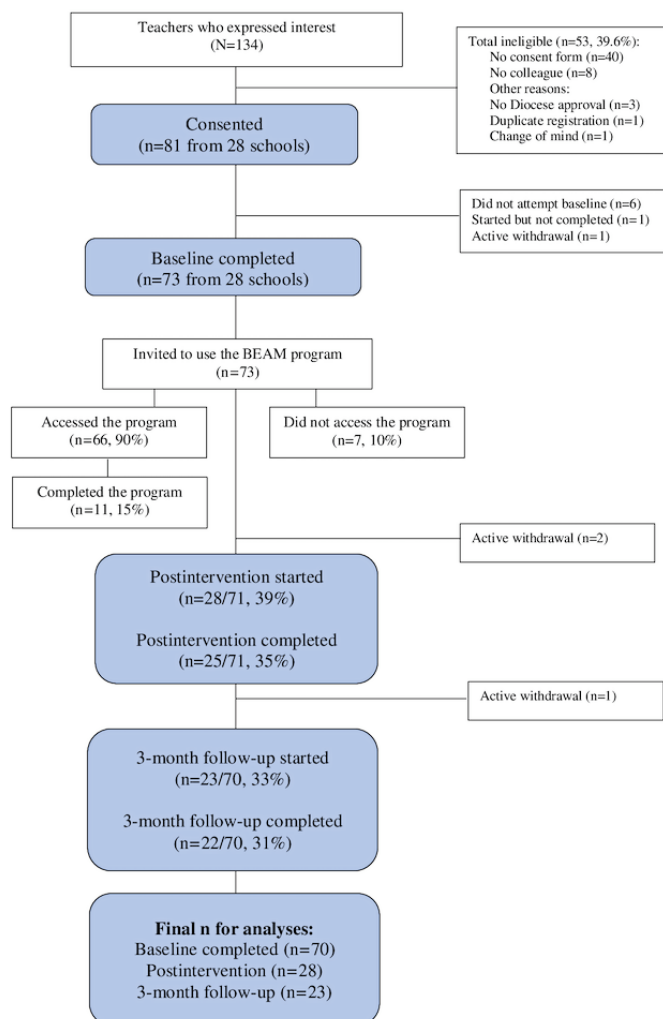
## Results

### Participants

A total of 134 teachers expressed interest in the study. Of these, 81 (60.4%) teachers from 28 schools obtained consent from their principal and were invited to complete the baseline survey (Figure 2). Table 1 presents the participant characteristics for the final sample at baseline (N=70).

At baseline, 40% (28/70) of the sample reported having had "nil" or "limited" prior training in student mental health and 60% (42/70) reported having had "moderate" or "extensive" prior training. All participants believed that mental health training was "moderately" (5/70, 7%) or "extremely" (65/70, 93%) important. The majority (51/70, 73%) felt "moderately" or "extremely confident" that a web-based program could meet their mental health training needs: 19% (13/70) were "neutral" and 9% (6/70) were "somewhat confident."

**Figure 2.** CONSORT (Consolidated Standards of Reporting Trials) diagram of study recruitment and flow. BEAM: Building Educators' skills in Adolescent Mental Health.





**Table 1.** Sample characteristics at baseline (N=70).

| Characteristics   | Values              |
|---|---------------------|
| Females, n (%)  | 49 (70)             |
| School funder: government, n (%)  | 68 (97)             |
| School type: coeducational, n (%)                                       | 63 (90)             |
| <b>School location, n (%)</b>   |                     |
| Metropolitan  | 21 (30)             |
| Regional  | 29 (41)             |
| Rural/remote  | 20 (29)             |
| Age (years), mean (SD); range   | 36.47 (9.41); 24-60 |
| Experience in current role (ie, Year Advisor) (years), mean (SD); range | 3.33 (2.97); 0-15   |
| Experience as a secondary school teacher (years), mean (SD); range      | 9.62 (6.82); 2-36   |
| Duration of employment at current school (years), mean (SD); range      | 6.23 (4.40); 1-23   |

### Preliminary Effectiveness

There were no significant changes in mental health knowledge or attitudes at postintervention or 3-month follow-up (Tables 2 and 3). Significant increases in confidence were found at postintervention (Cohen  $d=0.60$ ) and 3-month follow-up (Cohen  $d=0.53$ ). There was also a significant increase in the frequency of helping behaviors at 3-month follow-up and a significant

reduction in participants' psychological distress at postintervention (Cohen  $d=0.33$ ). [Multimedia Appendix 1](#) provides further information regarding each measure.

When asked about their perceptions of training effectiveness at postintervention, the mean scores indicated that on average, participants rated the training program as "somewhat" (ie, score of 3) effective for improving their confidence, skills, and approach to student mental health (Table 4).

**Table 2.** Outcome measures at each time point.

| Measures <sup>a</sup>          | Baseline score, mean (SD) | Postintervention score, mean (SD) | 3-month follow-up score, mean (SD) |
|--------------------------------|---------------------------|-----------------------------------|------------------------------------|
| Mental health knowledge        | 23.14 (2.27)              | 23.50 (2.24)                      | 24.48 (2.71)                       |
| Mental health attitudes        | 13.67 (4.01)              | 13.71 (3.75)                      | 14.86 (7.43)                       |
| Confidence in helping behavior | 52.04 (10.68)             | 58.44 (9.23)                      | 63.32 (6.37)                       |
| Frequency of helping behavior  | 35.37 (7.37)              | 36.46 (7.77)                      | 41.68 (7.42)                       |
| Psychological distress         | 11.25 (3.78)              | 10.00 (3.39)                      | 10.71 (3.23)                       |

<sup>a</sup>Owing to attrition, the number of participants at postintervention varied: mental health knowledge, n=28; mental health attitudes n=28; confidence in helping behavior, n=27; frequency of helping behaviors, n=26; and psychological distress, n=21. Similarly, at follow-up: mental health knowledge, n=23; mental health attitudes, n=22; confidence in helping behavior, n=22; frequency of helping behaviors, n=22; and psychological distress, n=21.

**Table 3.** Estimates of change in outcomes at postintervention and 3-month follow-up based on mixed model repeated measures analysis of variance.

| Outcomes                       | Postintervention vs baseline |                             |                    |             | 3-month follow-up vs baseline |                             |                    |             |
|--------------------------------|------------------------------|-----------------------------|--------------------|-------------|-------------------------------|-----------------------------|--------------------|-------------|
|                                | Estimate (SE)                | <i>t</i> test ( <i>df</i> ) | <i>P</i> value     | Cohen $d^a$ | Estimate (SE)                 | <i>t</i> test ( <i>df</i> ) | <i>P</i> value     | Cohen $d^a$ |
| Mental health knowledge        | 0.41 (0.29)                  | 1.45 (38.03)                | .16                | 0.2         | 0.59 (0.38)                   | 1.58 (31.04)                | .13                | 0.4         |
| Mental health attitudes        | 0.14 (0.61)                  | 0.23 (23.35)                | .82                | 0.01        | 1.25 (1.37)                   | 0.91 (23.99)                | .37                | 0.3         |
| Confidence in helping behavior | 6.83 (1.54)                  | 4.44 (30.24)                | <.001 <sup>b</sup> | 0.6         | 9.79 (1.29)                   | 7.54 (33.22)                | <.001 <sup>b</sup> | 0.5         |
| Frequency of helping behavior  | 1.09 (1.00)                  | 1.09 (28.62)                | .28                | 0.2         | 4.98 (1.34)                   | 3.73 (23.90)                | .001 <sup>b</sup>  | 0.7         |
| Psychological distress         | -1.09 (0.41)                 | -2.66 (21.66)               | .01 <sup>b</sup>   | 0.3         | 0.08 (0.45)                   | 0.17 (19.97)                | .87                | 0.1         |

<sup>a</sup>Cohen  $d$  effect sizes were calculated as the difference between observed means at postintervention (or follow-up) and baseline, divided by the SD at baseline.

<sup>b</sup>Significant at  $P<.05$ .

**Table 4.** Participants’ perceived effectiveness of the training program for increasing confidence, skills, approach, and meeting training needs at postintervention (n=25).

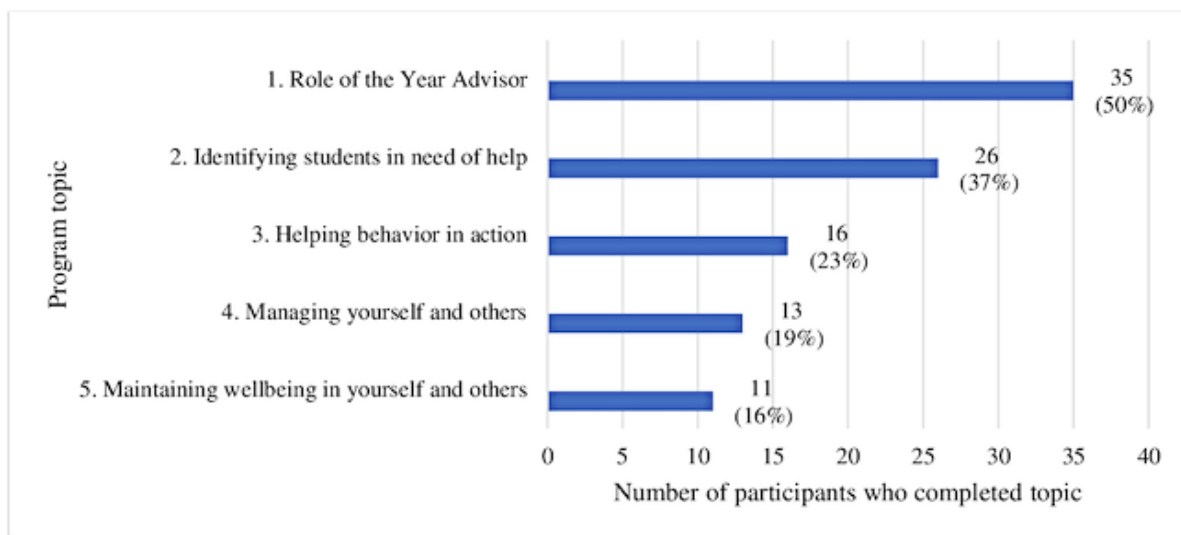
| Measures   | Values, mean (SD) |
|--|-------------------|
| The extent to which the program increased your confidence to support students’ mental health | 3.24 (0.88)       |
| The extent to which the program increased your skills to support students’ mental health     | 3.32 (0.90)       |
| The extent to which the program improved your approach to supporting students’ mental health | 3.28 (0.90)       |
| The extent to which the program met your mental health training needs                        | 3.28 (0.84)       |

**Program Use and Barriers**

A total of 94% (66/70) of the baseline sample accessed the first topic and 50% (35/70) completed it. There was a steady decrease in topic completions over time: 16 (23.9%) participants completed half the program (ie, ≥3 topics) and 11 (16%)

completed the entire program (Figure 3). Lack of time, competing priorities, and forgetfulness were reported as the common barriers to program completion. Lack of engagement with content, disruptions to working relationships, and taking leave were the least common barriers to program use (Table 5).

**Figure 3.** Program use: Sequential topic completion among participants (N=70). Note: Topics were sequential and locked. New topics could not be started unless the peer coaching activity was submitted to the program.



**Table 5.** Barriers to program use (n=26).

| Barriers   | Yes, n (%) |
|--|------------|
| I didn’t have enough time to complete the program                    | 22 (85)    |
| The program wasn’t a priority  | 15 (58)    |
| I forgot about the program   | 14 (54)    |
| I had problems with my Internet connection or device access          | 4 (15)     |
| I didn’t have another colleague to complete peer coaching activities | 3 (12)     |
| I had problems with accessing the program                            | 2 (8)      |
| I had concerns about the privacy and security of my data             | 2 (8)      |
| Other reasons not listed   | 2 (8)      |
| I went on leave from school/role                                     | 1 (4)      |
| Program was disruptive to my working relationships                   | 1 (4)      |
| Program wasn’t engaging  | 1 (4)      |

**Program Acceptability and Satisfaction**

Most participants rated the program content as easy to understand, relevant, practical, realistic, and helpful (Table 6). Participants gave lower ratings to the peer coaching and

feedback components. Overall, participants were “somewhat” to “moderately” satisfied with the training program. *t* tests indicated no significant differences in the mean scores of acceptability, satisfaction, and perceived effectiveness between

participants who completed the entire program (n=9) and those who did not (n=17) ( $P=.08-.98$ ).

**Table 6.** Measures of program acceptability and satisfaction (n=26).

| Measures  | Score, mean (SD) |
|---|------------------|
| <b>Program acceptability</b>                                      |                  |
| The content was easy to understand                                | 4.35 (0.56)      |
| The content was relevant to my current role                       | 4.27 (0.45)      |
| The program content matched the learning objectives               | 4.23 (0.51)      |
| The learning objectives were clear and realistic                  | 4.19 (0.40)      |
| The program structure was logical                                 | 4.15 (0.46)      |
| The examples and suggestions were practical and realistic         | 4.12 (0.52)      |
| The content was helpful for my current role                       | 4.08 (0.56)      |
| I had opportunities in the program to practice the skills learned | 4.04 (0.72)      |
| The program activities were engaging                              | 3.65 (0.69)      |
| The feedback I received throughout the program was constructive   | 3.62 (0.80)      |
| The peer coaching activities were helpful                         | 3.58 (0.76)      |
| I enjoyed the opportunity to complete the Share my Story activity | 3.08 (0.94)      |
| The content was confronting or distressing                        | 2.12 (1.07)      |
| <b>Satisfaction (n=25)</b>  |                  |
| Overall, how satisfied were you with the program?                 | 3.60 (1.00)      |
| How likely are you to use the program again in the future?        | 3.56 (1.00)      |
| How likely are you to recommend the program to others?            | 3.84 (1.03)      |

## Discussion

### Principal Findings

This study examined the preliminary effectiveness and acceptability of a web-based training program for improving mental health knowledge, attitudes, confidence, and helping behaviors among secondary school teachers in NSW. Our findings indicate that the BEAM program may be beneficial for improving teachers' confidence in, and the frequency of, helping behaviors toward their adolescent students with mental health problems, when measured with self-report scales. The BEAM program did not appear to be associated with improvements in mental health knowledge or attitudes, although this may be owing to the high baseline levels of experience and training within this cohort. The BEAM program may also be associated with a reduction in teachers' psychological distress, although this would need to be replicated within a randomized controlled trial. Given that past evaluations of teacher training programs for mental health have not observed improvements in helping behavior or teachers' well-being [18,19], these initial findings are promising. However, study attrition was high and program completion rates were low. Modifications to the training program and associated study design are needed for future trials.

### Program Acceptability

Program acceptability was high among the teachers who remained in the study at postintervention. These teachers viewed the training content as relevant, helpful, and engaging but were less favorable toward the peer coaching activities. Only half of

all participants continued beyond the first topic, suggesting that the compulsory completion of the peer coaching activity may have halted progress for many participants. While there was no evidence to suggest that program completion was associated with greater acceptability and satisfaction, it is difficult to examine overall levels owing to the high study attrition rate. Future trials may benefit from removing the mandatory completion of the peer coaching activities to encourage more training completions. This would allow participants to complete the program at their own pace and lead to greater exposure to training content. While it is not yet clear which persuasive techniques are associated with better outcomes for web-based programs [37], engagement with the BEAM program may also be enhanced by greater tailoring of content (eg, message personalization and topic recommendations based on experience and interest), thus improving the quality and relevance of the feedback, increasing interactivity, and removing the sequential format. These changes may improve completion rates, perceived effectiveness, and overall acceptability [38].

A key aim of this project was to create a mental health training program for secondary school teachers, which was highly accessible, easily disseminated, and scalable but also engaging and effective. The use of a web-based platform enabled these goals; however, this study shows that 1 in 4 teachers were not confident that this type of program could meet their training needs. Some teachers may have felt that the skills needed to care for students' mental health could not be taught (or learnt) via a self-directed web-based program. Given that other web-based workplace mental health training programs have

been shown to be effective [23], some teachers may require additional messaging to address these attitudes prior to commencing the training. Embedding acceptance facilitation techniques (eg, video explainers, provision of research findings, and feedback on the changes in participants' outcomes) may help increase confidence and uptake of this training format [39,40]. Additional feedback from peers, students, and parents about improvements in participants' helping behavior may also help strengthen perceptions of training effectiveness. The results may also indicate some discordance between participants' improvements on the self-report outcome scales and their ratings of perceived training effectiveness. This may suggest that teachers did not perceive the training to be immediately beneficial and instead require more time to transition their new skills into practice and reflect on these changes. This would suggest that future study designs should carefully examine the outcomes measures used and ensure that suitable follow-up periods are used.

### Limitations

The study was impacted by high attrition, for both survey completion and program use, thus limiting firm conclusions about program effectiveness and acceptability. It remains unclear whether participants' attitudes towards the program or other external factors influenced dropout. A larger sample size, with a control group, would allow for these analyses. Of the 11 participants who completed the program, 9 (82%) also completed the postintervention. This may suggest that improvements in program completions may also improve study retention. Future studies would likely benefit from using

incentives for all study assessments, thus increasing the study duration to give participants more time to access and complete the program, and modifying the program in accordance with the user feedback to sustain engagement [41]. The high number of teachers expressing interest demonstrates the need for this type of training program; however, the requirement of signed principal consent and a coparticipating colleague likely hindered recruitment. Future trials may benefit from revising the consent process, eligibility criteria, and study dissemination process to enable greater participation. Different results may also be found when the program is evaluated among teachers who have not received prior mental health training or are not currently in self-selected roles delegated to caring for student well-being.

### Conclusions

This study indicates that the BEAM program may improve teachers' confidence in caring for students' mental health and increase the frequency of helping behaviors. The training program may also reduce teachers' psychological distress. The program content was easy to understand and relevant, although barriers related to time, competing priorities, and forgetfulness inhibited program use. The results have indicated that some program modifications are necessary to increase completion. Taken together, the findings demonstrate the potential of a web-based training program for improving helping behavior and related outcomes among Australian secondary school teachers. A randomized controlled trial of the BEAM program will help determine genuine effects.

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### Acknowledgments

BOD and MA conceived and designed the study. BOD and MA prepared the protocol, and MA initiated the trial. MA and BP coordinated the trial. PB contributed to the statistical analyses. All authors contributed to the refinement of the protocol, and all authors read and approved the final manuscript.

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### Conflicts of Interest

BOD is a Section Editor for JMIR Mental Health. No other authors have a conflict of interest.

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### Multimedia Appendix 1

Mean (SD) values for all outcome measure items.

[DOCX File, 24 KB - [mental\\_v8i10e29989\\_app1.docx](#) ]

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## Abbreviations

**BEAM:** Building Educators' skills in Adolescent Mental Health

**DQ5:** 5-item Distress Questionnaire

**MAKS:** Mental Health Knowledge Schedule

**NSW:** New South Wales

**PISCF:** Participant Information Sheet and Consent Form

**UNSW:** University of New South Wales

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Original Paper

# Understanding University Students' Experiences, Perceptions, and Attitudes Toward Peers Displaying Mental Health–Related Problems on Social Networking Sites: Online Survey and Interview Study

Taewan Kim<sup>1</sup>, MSc; Hwajung Hong<sup>1</sup>, PhD

Department of Industrial Design, Korea Advanced Institute of Science and Technology, Daejeon, Republic of Korea

**Corresponding Author:**

Hwajung Hong, PhD

Department of Industrial Design

Korea Advanced Institute of Science and Technology

291 Daehak-ro

Yuseong-gu

Daejeon, 34141

Republic of Korea

Phone: 82 42 350 4502

Email: [hwajung@kaist.ac.kr](mailto:hwajung@kaist.ac.kr)

## Abstract

**Background:** College students' mental health is at an all-time low. Students are increasingly disclosing their vulnerable, stigmatizing experiences on online social networking sites (SNSs). Peer support facilitated by SNSs can play a crucial role for the students in coping with mental health–related problems. Thus, it is imperative to understand how university students form perceptions, attitudes, and behaviors toward their peers who are dealing with mental health problems.

**Objective:** This study aimed to provide a better understanding of how college students recognize, perceive, and react to signs of mental health problems in their peers on SNSs. Our ultimate goal in this study was to inform the design of SNSs that can facilitate online peer support.

**Methods:** We conducted surveys with 226 students as well as semistructured interviews with 20 students at six universities in South Korea.

**Results:** Of the 226 survey respondents, 150 (66.4%) reported that they recognized signs of a mental health problem on their friends' SNS posts. However, a considerable number of respondents (62/150, 41.3%) were reluctant to offer support, even when they had identified friends who were at risk; this reluctance was due to a lack of knowledge or confidence and their desire to maintain a distance from at-risk peers to save their identity from stigmatization and to avoid emotional contagion online.

**Conclusions:** Drawing on these results, we provide implications that could explain the construction of students' perceptions regarding their peers' mental health problems. We also provide design proposals for SNSs to serve as platforms that facilitate just-in-time and adaptive support exchanges among peers while mitigating stigma-related concerns.

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**KEYWORDS**

mental health; social media; social support; peers; peer support; self-disclosure

## Introduction

**Background**

College students' mental health is at an all-time low because they are now exposed to a wide variety of stressors and pressures [1]. These students are also at a vulnerable life stage, which is

frequently when the first episodes of serious mental health problems appear [2]. According to a 2018 World Health Organization survey of students in eight countries, 1 out of 3 students screened positive for a mental health illness and approximately 20%-35% of students might need treatment for mental health [3]. On the other hand, college is a place that provides students with an important opportunity to access a



variety of mental health care resources, from clinical services to social support [4].

Social support and peer support—meaningful interactions that provide some sort of support, including emotional and instrumental support among fellow students who are of similar age and social status (ie, members of the same student population)—play a key role for coping with mental illness and maintaining well-being [5]. These peers may or may not have experienced similar mental health challenges. In this context, peer support includes a variety of interpersonal behaviors, including providing informational support (eg, providing advice and tips) and emotional support (eg, communicating care, confidence, and esteem) that can help fellow students with their mental health problems [6].

Social networking sites (SNSs) have served as a technology-mediated support system that facilitates the exchange of peer support [7,8]. Students are turning to SNSs to relieve their distress or to seek help from others by disclosing their vulnerable, stigmatizing experiences related to mental health problems [8]. A large body of research has addressed supportive online interactions with peers, which have been shown to help individuals who suffer from mental health problems attain improved mental well-being [9,10]. However, most of the research on peer support has focused on those who seek help and has not taken into account the potential benefits and risks of social support from the perspectives of those who are expected to provide support. Few empirical studies have examined how nonprofessional individuals—those who are susceptible to other people's emotions and experiences—perceive online signals from at-risk friends. Thus, we need a better understanding of the experiences and challenges that these individuals face when identifying someone displaying signs of mental health problems on SNSs.

Furthermore, it is important to understand perceptions of the student population toward their friends experiencing mental health problems to tackle peer exclusion, lessen stigmatization, and further foster social support [11]. Public stigma [12] negatively affects those who could benefit from various mental health care resources, as they are reluctant to seek both personal and professional help [13]. Regarding the situation in which SNSs are used as a primary means of social interaction [14], we elucidate students' perceptions toward their peers who they believe are experiencing mental health problems based on observing a variety of social interactions displayed on SNSs.

In summary, understanding peers' viewpoints regarding mental health problems is crucial to empowering SNSs to serve as digital mental health support systems. The aim of this study is to investigate how college students perceive and react to their peers who display mental health-related challenges on SNSs and to identify factors that interfere with peer support. This paper documents the findings from online surveys and interviews conducted in six universities in South Korea. Note that we do not limit the term “mental health” to refer only to medically diagnosed illnesses. Rather, we consider all kinds of negative emotions and experiences, including those that make people feel vulnerable, including stress, loneliness, and minor depression.

## Related Work

### *Online Social and Peer Support for Mental Health*

Individuals benefit from online social media as they interact [15], gain access to shared and tailored advice [10], and receive informational and/or emotional support from social network members [16]. Online social media can also provide useful resources for individuals with particular personality traits (eg, self-esteem issues [15]) as well as those who are affected by mental illness [17]. Individuals who experience mental health challenges often struggle to seek help because they feel embarrassed or have a fear of stigma and rejection [18]. Online social media platforms provide space for disclosing mental health issues with the benefits of convenience, privacy, and anonymity [19,20]; they also allow users to share difficulties and seek emotional support [21]. Social media helps college students, in general [22], and those who are suffering to attain improved mental well-being, in particular [9,10]. Thus, researchers have identified numerous factors that drive online social support [23] and have proposed computing platforms that would promote online mental health support from peers [17,24]. Despite the demonstrated importance of online social support, researchers have yet to empirically study the motives and challenges behind such support from the perspective of the peers who are expected to provide it.

### *Sensitive Disclosure and Responses on SNSs*

SNSs allow users opportunities to address their mental health problems. Increasingly, college-aged people, who are the largest cohort of SNS users, have been posting sensitive disclosures on SNSs to relieve their psychological distress or to ask for help from others when they are in need [8]. A large body of research has addressed supportive online interactions with peers, which have been shown to improve the mental well-being of individuals who are suffering [9,10,21]. Earlier studies have addressed aspects of mental health-related SNS disclosures, including negative emotions [7], experiences of feeling stigmatized or vulnerable [25], depressive symptoms [26], curated self-harm images [27], the sharing of pro-eating disorder content [28], and even suicidal ideation [29]. Researchers have also revealed that sensitive disclosures garner supportive interactions between the discloser and the audience. For instance, due to their personal and intimate nature, sensitive disclosures (eg, personal narratives or references to an illness) have been shown to elicit more positive comments from peers on an SNS, as compared to less sensitive disclosures [25]. However, excessive negative expressions, such as statements about enduring loneliness, aversively affected the likelihood of both responses and likes [30]. Although a large number of previous studies have discovered the impact that sensitive disclosures have on general responses, few empirical studies have examined the holistic procedures and mechanisms through which the audience of a disclosure identifies, perceives, responds to, and even takes action for at-risk contacts on SNSs.

In summary, we found that a systematic investigation to determine how university students form perceptions, attitudes, and behaviors toward their fellow students' mental health-related activities on SNSs was crucial in the study of

human-computer interaction and health informatics. More specifically, we explored the following research questions:

- Research Question 1: Experiences—How do students discern their peers' mental health problems through SNS content and activities? In other words, what kinds of SNS content and activities are considered by the viewers to be signals of mental health problems?
- Research Question 2: Attitudes—How do students react to the SNS activities of the peers who they believe are displaying mental health-related problems? What are the factors influencing these reactions?
- Research Question 3: Consequences—What are the consequences of viewing posts that are perceived as mental health-related issues on SNSs?

## Methods

### Overview

We conducted a two-phase study: Phase I involves a large-scale survey, and Phase II comprises semistructured interviews. Through an online survey of current students (N=226), we wanted to probe (1) the respondents' experiences with friends who had signaled mental health issues on SNSs, (2) the perceived influence of such posts and activities, and (3) the types of support and responses the peers provided, along with their perceptions of the expected helpfulness of that support. We then conducted semistructured interviews with 20 of the participants to investigate why and how they decided to support or ignore their friends. We have limited our scope of analysis to semiprivate SNSs, such as Facebook, Instagram, and Twitter. We excluded private messenger services and public group forums.

### Recruitment

We targeted participants from various universities to overcome the limitations of the referral sampling method, in which students from various universities spread the word to individuals via SNSs and in which the gatekeepers of the universities' online communities posted the study's recruitment flyer. All undergraduate or graduate students were eligible to participate, provided that they were currently seeking a degree or would be matriculating into a degree program soon. We originally contacted 10 individuals at various domestic universities, and we eventually collected survey responses from 226 participants from six universities in South Korea. The recruitment posts featured links to an online survey and a consent form. We also added the participants to a raffle for a ₩5000 (US \$5) gift card as compensation for their efforts. For the interview, we first sampled 102 participants from the group of survey participants who showed interest in participating in the interview session. Out of these 102 participants, 67 were initially selected based on the selection criteria. Of these, the final 20 interview participants were selected through random sampling. We selected interview participants with the following criteria: (1) participants who have detected mental health-related problems in others on SNSs, (2) participants who explicitly described details of the experience, and (3) participants who were determined that the researchers needed additional information to understand the experience in detail.

### Phase I: Online Survey

All survey participants were provided both demographic questions and semi-open-ended questions, the latter of which allowed them to select multiple responses and to enter text if necessary ([Multimedia Appendix 1](#)). In this way, the participants answered questions about (1) whether they had witnessed a person signaling mental health problems on SNSs, (2) why they were concerned about that person's mental health, (3) what their relationship was to that person, and (4) what type of response they provided. We also asked the participants to answer several questions about their perceptions of closeness, responsibility, susceptibility, and helpfulness using a 5-point Likert scale. We iteratively developed these questionnaire items based on the existing literature; our intent was to examine the factors that influenced the participants' degree of willingness to respond to mental health-related disclosures [31]. In turn, we determined the following four factors that could influence students' perceptions and attitudes toward individuals who signaled mental health issues on SNSs:

1. Closeness [32]: "To what extent did you feel that you were close with the person you mentioned above?" Studies have revealed that the degree of relationship closeness between two individuals influences the extent to which intimate disclosures between them are positively received [23]. In the same vein, disclosing intimate information to a stranger can be seen as socially unacceptable behavior; such disclosures are often thought of as inappropriate [33]. As previous studies have shown that closeness affects the acceptance and recognition of such disclosures, we sought to investigate whether this factor also affects the willingness to support the discloser.
2. Responsibility [34]: "To what extent did you feel that you should respond to that person?" Because we focused on publicly shared content for which no recipient was specified, no particular person was obligated to respond [7]. We examined the extent to which the participants felt responsible for reacting to mental health-related disclosures.
3. Susceptibility [35]: "How did that person's disclosures or other activities influence your emotions?" According to Forgas [35], a discloser reveals more intimate information when in a negative mood. However, little research has been done to examine how these intimate disclosures affect the viewers' emotions or attitudes. Thus, we investigated how viewers' emotional susceptibility affected their willingness to respond to disclosures.
4. Helpfulness [34]: "To what extent did you feel that your response or support would be helpful to that person?" We considered how confident the participants were in responding to the disclosure or in providing support for the discloser, as well as whether the perceived helpfulness of their actions would impact their willingness to respond.

### Phase II: Semistructured Interviews

We conducted follow-up interviews with 20 of the survey participants to elucidate the perceptions and conception of social support from the viewers' perspectives. Of the 226 respondents in the Phase I survey, 20 participants were selected. Specifically, we wanted to elicit detailed and accurate narrative accounts of

students' experiences. These interviews lasted from 40 to 60 minutes. To help them recall past experiences, we asked the participants to browse their own SNS accounts. We asked them to tell us about some posts and activities that may have signaled that an individual was facing mentally challenging situations, such as Facebook messages or Instagram images that reflected unstable mental health conditions (eg, depressive states, suicidal ideations, or requests for help). We then asked the participants how they reacted to the posts, how that experience impacted their perceptions of the poster, and about their chosen methods of support. Our interview protocol and questionnaires were reviewed by three clinical psychologists working in a university's health care center. Based on the interview guide ([Multimedia Appendix 2](#)), two researchers who conducted the interviews ran two rehearsal sessions. The interviews were conducted in a face-to-face format in a quiet lab where only an interviewer and an interviewee could talk privately.

### Analysis

We analyzed the survey questions, which contained single-selection, multiple-selection, and Likert-scale responses, using descriptive statistics and Mann-Whitney *U* tests. For quantitative analysis, we used Prism (version 8; GraphPad Software). We also examined the responses to the open-format survey questions and the interview transcripts using the qualitative data analysis software ATLAS.ti (version 7; Scientific Software Development GmbH) for inductive thematic analysis [36]. Interviews and surveys were conducted and transcribed in Korean, and analyses were also conducted in Korean. This process allowed us to analyze the original responses as accurately as possible. For the responses cited in the paper, an English-Korean bilingual-speaking researcher first translated interview responses into English and then revised them through consultation with a proofreading expert. Two researchers independently coded the responses and transcripts to iteratively formulate possible themes and then compared their codes. The coding process was recursive; it ended when the researchers considered the themes to have stabilized, and a set of distinct themes emerged.

### Ethical Considerations

We acknowledge that this study addresses several ethical concerns, even though the researchers' institutional review board approved it in March 2017. In this study, we did not investigate the "posters," those who produced the references to mental health issues, because our primary research focus was on understanding the perspective of the "viewers," those who were concerned about the posters. Thus, we did not directly interact with highly vulnerable individuals who might have mental illness diagnoses. However, we acknowledge that mental health

problems are very common among students. Thus, it is quite likely that some of the participants have also struggled with undiagnosed disorders (eg, depression), given the crisis regarding such disorders that has struck college campuses nationwide [37]. Note that during the interviews, 3 participants indicated that they had been diagnosed with major depressive disorder. To reduce the chances that our participants would identify the original posters, we asked the participants not to show or tell us any identifying information about the posters (eg, their names or SNS accounts).

## Results

### Survey Results

#### Overview

The survey participants comprised 226 students from six institutions of higher education in South Korea. The collection of survey answer data was conducted from March 27 to April 15, 2017. [Table 1](#) shows the overall survey participant demographics. The participant sample included undergraduate students (n=178, 78.8%), master's students (n=26, 11.5%), and doctoral students (n=22, 9.7%). Regarding gender, 91 (40.3%) participants were male, 133 (58.8%) were female, and 2 (0.9%) did not specify gender. Respondents were between 19 and 30 years old (mean 22.4, SD 2.6). The survey began with the question, "Have you ever seen a person whom you know displaying signs of a mental health problem on his/her SNS?" The majority of survey respondents (n=150, 66.4%) reported that they had seen such activities. Some participants (n=18, 8.0%) referenced friends who had been diagnosed with mental illnesses, including major depressive disorder (n=9, 50%), schizophrenia (n=1, 6%), eating disorder (n=1, 6%), posttraumatic stress disorder (n=1, 6%), anxiety disorder (n=2, 11%), and unspecified (n=4, 22%).

The interview participants comprised 20 students from among the survey participants: 11 (55%) female and 9 (45%) male. All 20 interviewees were born and raised in South Korea. Their knowledge and awareness of mental health problems varied. During the interview process, 3 (15%) participants voluntarily disclosed having a past diagnosis of mental illness. In addition, 1 (5%) participant noted that his former girlfriend had diagnosed him with depression, and another participant (n=1, 5%) had a family member who had been diagnosed with a mental illness. In total, 3 (15%) of the interviewees were graduate students—2 were in a master's program and 1 was in a doctoral program—and the rest were undergraduate students. Interviews were conducted from April 12 to July 26, 2017.

**Table 1.** Demographic information about survey participants.

| Demographic          | Participants (N=226), n (%) |
|----------------------|-----------------------------|
| <b>Gender</b>        |                             |
| Male                 | 91 (40.3)                   |
| Female               | 133 (58.8)                  |
| Not specified        | 2 (0.9)                     |
| <b>Age in years</b>  |                             |
| 22-24                | 163 (72.1)                  |
| 25-27                | 46 (20.4)                   |
| 28-30                | 17 (7.5)                    |
| <b>Degree course</b> |                             |
| Undergraduate        | 178 (78.8)                  |
| Master's student     | 26 (11.5)                   |
| Doctoral student     | 22 (9.7)                    |

### *Types of SNS Content and Activities Displaying Mental Health Issues*

A total of 150 respondents out of 226 (66.4%) reported that they had seen a person displaying signs of a mental health problem on his or her SNS. These respondents found that the media the posters used were mostly text messages (n=132, 88.0%), with some images (n=7, 4.7%) and other types of content, such as shared links (n=11, 7.3%). These posts reflected each poster's negative feelings, stigmatized experiences, or moods, and they made him or her appear to be suffering. For instance, Participant #77 perceived a friend's Facebook post, which contained a photograph of a celebrity who had died by suicide, as implicit suicidal ideation. In addition, 18.7% (n=28) of the respondents identified signs of mental health problems by tracing a poster's activities over time, such as a constant liking of content mentioning depression (Participant #59) or a sudden burst of Facebook updates (Participant #29). The detailed reasons for how and why these respondents became concerned about the posters' mental health conditions are reported in the Qualitative Analysis section.

### *Types of Reactions*

After taking a closer look at the types of reactions that the peers provided to the posters, we found that a considerable number

of survey respondents who had seen mental health-related posts on SNSs (62/150, 41.3%) did not respond to the posts or provide any other support, even though some (22/150, 14.7%) still had concerns. Of the 88 respondents who reacted to the posts, 30% (n=26) expressed their emotions using simple communicative features of SNSs (eg, the "like" button options or crying emoticons), 18% (n=16) wrote short comments on the posters' SNS feeds to express support (eg, "It will get better"), 16% (n=14) sent private messages to the posters, 7% (n=6) made appointments to meet with the posters, 2% (n=2) offered specific advice, and 1% (n=1) researched resources on behalf of the posters (eg, by calling a counselor).

### *Students' Perceptions That Can Affect Support*

As we reported above, a considerable number of survey respondents reported that they did not respond to the friends' posts signaling mental health problems. Thus, we wanted to determine how these viewers' perceptions differed from those who did react. The average scores for these perception properties were higher for peers who provided support than for those who did not. To determine whether there were significant differences between the two groups, we conducted a Mann-Whitney *U* test (two-tailed, reported with a *U* score and a *P* value). Table 2 summarizes the results for all assessments.

**Table 2.** Comparison of participants' perceptions.

| Perception               | Participants who provided support (n=88) |              | Participants who did not provide support (n=62) |              | <i>U</i> test | <i>P</i> value |
|--------------------------|--|--------------|---|--------------|---------------|----------------|
|                          | Mean (SD)                                | Median (IQR) | Mean (SD)                                       | Median (IQR) |               |                |
| Perceived closeness      | 2.86 (1.22)                              | 3 (2)        | 1.74 (0.81)                                     | 2 (1)        | 1327          | <.001          |
| Perceived responsibility | 3.28 (1.01)                              | 3 (1)        | 2.24 (0.93)                                     | 2 (2)        | 1316          | <.001          |
| Perceived susceptibility | 3.09 (1.07)                              | 3 (2)        | 2.96 (1.19)                                     | 3 (2)        | 2353          | .14            |
| Perceived helpfulness    | 3.09 (1.07)                              | 3 (2)        | 2.67 (1.27)                                     | 2 (2)        | 1435          | <.001          |

We found that peers were significantly more likely to support others if they felt more responsible ( $U=1316$ ,  $P<.001$ ), were closer to the poster ( $U=1327$ ,  $P<.001$ ), or believed that their support would be helpful ( $U=1435$ ,  $P<.001$ ). Susceptibility did

not affect the likelihood of providing support ( $U=2353$ ,  $P=.14$ ). There was no significant difference between male and female participants. Overall, the viewers' perceived responsibility, their closeness to the posters, and their perceptions of the expected

results of their support all impacted the likelihood that they would provide social support. Keeping these high-level findings in mind, we move on to the interview data, through which we aim to understand the detailed contexts in which these patterns occurred.

## Qualitative Analysis

### Overview

Our findings indicate that the participants based their perceptions of others' mental health conditions on a variety of signals (Table

3). Many participants used the communicative features of SNSs to help their friends who appeared to be suffering from mental health issues. We also identified several challenges that led to most participants refraining from providing such support. We reported participant quotes using identity codes, the type of SNS they mentioned, and the source of the quote.

**Table 3.** Signals that raised participants' concern about others' mental health problems. Codes or categories are not mutually exclusive.

| References to mental health concerns               | Participants, n (%)          |                  | Detailed descriptions  | Examples of quotes or cases reported   |
|--|------------------------------|------------------|--|--|
|  | Survey (n=150 <sup>a</sup> ) | Interview (n=20) |  |  |
| Disclosed mood and diagnostic history              | 121 (80.7)                   | 15 (75)          | <ul style="list-style-type: none"> <li>Negative mood, from depressive symptoms to suicidal feelings</li> <li>Use of swearing or abusive or offensive language</li> <li>Disclosure of mental illness diagnosis (eg, alcohol problems and anxiety disorder) and experiences or desire for treatment, such as counseling or medication</li> </ul> | <ul style="list-style-type: none"> <li>"He wrote he's seeking information about a psychiatric service on campus because he was not getting along well at school." (Participant #140)</li> <li>"My friend's post, 'I'm a loser. I feel I will never be successful,' with no details frightened me." (Participant #34)</li> </ul>  |
| Personal life struggles and stigmatized experience | 53 (35.3)                    | 9 (45)           | <ul style="list-style-type: none"> <li>Description of severe difficulties and challenges that negatively impact a poster's life (ie, family disruption, romantic breakups, interpersonal difficulties, and personal concerns)</li> </ul>   | <ul style="list-style-type: none"> <li>"He considered dropping out of college due to feeling overwhelmed." (Participant #141)</li> <li>"After breaking up with his girlfriend, he expressed how he felt devastated every night." (Participant #88)</li> </ul>  |
| Encoded content implying mental health problems    | 10 (6.7)                     | 4 (20)           | <ul style="list-style-type: none"> <li>Implicit signals, such as the use of literary references or visual images implying mental health problems</li> </ul>  | <ul style="list-style-type: none"> <li>"My 'bro' writes many songs. He often posts very dark and macabre lyrics. Sometimes, he posts a video streaming of himself singing that song. It seems weird." (Participant #51)</li> <li>"It was a poem about death. She kept posting such things on her Instagram." (Participant #69)</li> </ul>  |
| Gaps between offline and online identity           | 22 (14.7)                    | 4 (20)           | <ul style="list-style-type: none"> <li>Gaps between online identity appearing to be at odds with his or her offline identity</li> </ul>  | <ul style="list-style-type: none"> <li>"I felt that it was written by a totally different person. The tone in the post was completely different from what he used to be like." (Participant #115)</li> <li>"It feels like a 'drunken Facebooking.' As far as I know, he's always sober. He never drinks." (Participant #63)</li> </ul>   |
| Social interaction and activity log                | 29 (19.3)                    | 6 (30)           | <ul style="list-style-type: none"> <li>Constant usage of social media as a forum for expressing negative feelings</li> <li>A drastic change in social media activities (eg, a sudden burst of Facebook updates) and unusual communicative patterns</li> </ul>  | <ul style="list-style-type: none"> <li>"He always shares such a depressive thing every day. He is 'liking' a tremendous number of things that are extremely negative." (Participant #29)</li> <li>"He's weird. He writes things that no one cares about. If there's no reply, he then deletes his post. I have seen this [his repetitive posting and deleting activity] happening so many times." (Participant #12)</li> </ul> |

<sup>a</sup>Respondents who reported that they had seen a person displaying signs of a mental health problem on social networking sites.

### ***Experiences: How Do Students Discern Their Peers' Mental Health Problems Through SNS Content and Activities?***

Our participants cited a number of signals that led them to think that their friends might have mental health problems. These ranged from explicit references, such as mood disclosures in SNS content, to implicit references, such as inconsistent offline and online personality traits. Table 3 summarizes these signals, gives a detailed description of each one, and lists examples provided by both survey and interview participants.

The explicit disclosure of negative emotions provided a clear signal that led our participants to become concerned about a poster's mental health. The disclosed moods included feeling exhausted and overwhelmed (37/170, 21.8%), depressed (35/170, 20.6%), lonely (19/170, 11.2%), angry (15/170, 8.8%), hopeless (9/170, 5.3%), and other (6/170, 3.5%). One interview participant responded that a poster's symptoms appeared to be serious if they displayed negative feelings without a detailed explanation of such feelings:

*She [a poster] updated her Facebook like, "I'm useless. There's no reason for why I have to live"...When I saw this post, I felt she was at risk though she never gave a reason for saying this. It seemed like a very conclusive remark. That caused me to be really worried about her. [Participant #67, Facebook, interview]*

Some participants also considered the disclosure of negative experiences as a reliable source for confirming a poster's unstable mental state. They shared examples of experiences that made the poster seem vulnerable, including disclosures of interpersonal strife (18/170, 10.6%), low academic performance (9/170, 5.3%), relationship breakups (3/170, 1.8%), family issues (2/170, 1.2%), financial hardship (2/170, 1.2%), and other challenges (19/170, 11.2%). Disclosures about negative moods, diagnostic history, and stigmatized experiences were often used to recognize the state of a poster's mental health, but some participants cited more implicit signals, such as the use of literary references or visual images [25].

In our survey, most of the participants (129/150, 86.0%) reported having a personal relationship with the suffering individuals in real life (eg, a roommate). Thus, the participants had already constructed an identity for the poster through offline interactions. However, if they recognized that the poster's online identity was at odds with his or her offline identity, they became concerned:

*As far as I know, my friend is a very kind and positive person. He loves his friends. He has often told me that sincere friendships are the most important thing in his life. However, I just found a sudden update on his Facebook saying that his life was meaningless. I felt like he was a totally different person online. [Participant #84, Facebook, interview]*

A series of SNS data can provide a window for understanding an individual's usage pattern and motives for usage [38]. Some participants pointed to an exceptionally high frequency of updates as one source of concern. This finding is consistent

with the results of a prior study that revealed that a depressed user group showed an increased rate of wall posts [39]. In this regard, the participants did not rely on a single post but rather made an inference by observing a poster's usage characteristics over a longer time period:

*He always shares his negative feelings, but no one reacts to him: no likes, no comments. If there's no response for a couple of days, he then deletes the original post. He has done this kind of thing many times as far as I can tell. [Participant #13, Facebook, interview]*

### ***Attitudes: How Do Students React to the SNS Content and Activities of the Peers Displaying Problems? What Are the Factors Influencing These Reactions?***

#### ***Overview***

Our findings show that SNSs were used as a mediating tool to recognize others' mental health problems in various ways. Meanwhile, our survey results reveal that a significant percentage of the peers remained inactive. In this section, we give our attention to identifying reasons for viewers' reactions toward the SNS content and activities of the poster who displayed mental health problems through SNSs.

#### ***Attitudes Toward Social Support and Self-disclosure in SNSs***

Participants reported negative beliefs about the concept of social support using SNSs. Furthermore, they mentioned that mental health issues would not be treated simply by leaving a short comment or pushing the "like" button. A total of 44.7% of the respondents (67/150) in the survey answered that it would be "very unhelpful" and "somewhat unhelpful." Many participants expressed low expectations and even negative feelings regarding reacting to the poster disclosing sensitive matters on SNSs:

*I am not sure these kinds of SNS reactions could make my sister better. [Participant #37, Facebook, survey]*

Participants had a negative perception of self-disclosure associated with stigma in SNSs considered as public places. Therefore, many of the participants were reluctant to react because their reactions would negatively impact the poster. They warned that their reactions might make the poster rely on online interactions rather than seek professional help. In some cases, participants thought that the poster just wanted to draw attention:

*He keeps posting depressed posts to aggregate comments and likes. I think this cycle will make him more depressed. [Participant #11, Facebook, survey]*

#### ***Challenges in Responding to the Poster***

Participants said that they did not want to directly interact with someone who might need mental health care, due to their own lack of expertise and confidence. One participant reported that he had no idea what to say and argued that even an indifferent response would be worse than no response:

*I am still not sure whether I could help others...I don't know anything about mental health. I can't even say*

*something like “hang in there,” because I’m afraid that my naïve response may hurt someone who needs serious care.* [Participant #13, Facebook, interview]

While participants could recognize posters’ signals of being at risk, it was not always easy for them to take action in response. They experienced feelings of guilt about watching another’s social feed reflecting private matters. Thus, one participant decided to remain silent:

*Note that I am neither a stalker nor a lurker. But her unusual social media activities often catch my eye. Seeing what others are doing online is like reading another person’s diary. So, unless requested, I won’t respond. I will be quiet.* [Participant #67, Facebook, interview]

We found that many participants wanted to keep away from the person displaying mental health issues on SNSs. Participants mentioned that they do not add a comment or a “like” because they do not want to be part of the posts. By doing that, they intend to keep some distance from the poster. They also mentioned that the SNS environment where everyone can see their social interaction log (eg, comments, “likes,” and shares) also makes them more careful:

*I think that others will also see me as a similar type of person if I write a comment on his postings...So, I would not respond to such kinds of weird postings.* [Participant #63, Facebook, interview]

Another way of keeping a distance from the poster was to unfollow the poster. One participant who recovered from depression a few years ago reported that she unfollowed her friends who constantly post depressive content. She did so because the posts reminded her of when she was depressed in the past. Another participant reported that he blocked one of his friends who “contaminated” his news feed with all kinds of negative matters. While the previous study showed that the main reason for keeping a distance was because of induced fear (ie, fear that the person will do something violent) [11], four findings show that people wanted to keep a social distance to save their identity from stigmatization and avoid emotional contagion. Thus, many of the participants decided to view their friends’ posts without directly interacting in any way, known as lurking, to maintain distance from the poster.

### **Consequences: What Are the Consequences of Viewing Posts That Reveal Mental Health Issues on SNSs?**

#### **Providing Social Support**

While many participants did not respond for a variety of reasons, some have used SNS features to provide appropriate help. Participants used SNSs to track whether someone they care about might be suffering from a mental health problem and even to provide support in a timely manner. When participants detected a problem, they leveraged their background knowledge about the poster to respond. For instance, one participant, whose friend was struggling with an eating disorder, reported an example of how she could help her friend:

*She looks okay on her Instagram, but I’m the only one who knows that she’s struggling with an eating*

*disorder. So, whenever she posts food images, such as sushi or cakes, I really worry about her. Others would think, “Oh, it looks delicious, and she might want to share her happy moment with others.” But I cannot think that way. So, I call her immediately.* [Participant #67, Instagram, interview]

Some participants acknowledged that it was difficult to talk with a poster about his or her mental health issues even if they were close to the poster. We found that some participants contacted a poster’s family member or close friend if they noticed the poster was at risk. Two of the participants detected an implicit signal of suicide in their friends’ posts. One called the friend’s sister directly, and the other one sent a direct message to a member of the friend’s family. Some participants encouraged their friends to seek help and coping resources. Rather than trying to pressure their friends into treatment, they deliberately approached them with information:

*She posted something that implied suicidal ideation, but I could not say, “You have a problem. You should go to the center.” Instead, I asked her, “Why don’t we go to the counseling center? I feel I am overwhelmed. I want to go there with you.”* [Participant #94, Facebook, interview]

This participant sought to help her friend in a way that would make her feel comfortable. In turn, she was thankful that her friend was able to be diagnosed with depression and began regularly visiting a psychiatrist.

### **Fatigue and Stigma From the Posts**

In contrast to the discerning peers who carefully supported suffering individuals in a timely manner, a considerable number of participants did not proactively provide support, even when they noticed friends at risk due to various reasons. SNS curation features helped our participants identify their peers’ problems. However, constant displays of negative feelings and experiences resulted in audience fatigue. Such fatigue could result in a high threshold for concern, meaning that peers could become less troubled by those who keep expressing problems. Also, an individual’s disclosure of such negative aspects could lead to a negative stereotype or a fixed identity for the person as someone who is always depressed:

*If you know someone who keeps disclosing negative feelings on Facebook, you’ll say, “Well, that is what he always does. A blue guy.” So, no matter how serious he is, [such repetitive behavior] will be likely to mute the signal.* [Participant #72, Facebook, interview]

## **Discussion**

### **Overview**

Our online survey and interview study provided a rich description of students’ attitudes toward, and identification experiences with, peers who display signals of mental health problems on SNSs. In this section, we discuss further implications of the findings by extending previous studies to the research community. We then present design considerations for social media to enhance peer support experiences.

## Synthesis of Multiple Signals to Identify Mental Health Problems

We found that peers identified others at risk on SNSs by synthesizing a variety of signals ranging from explicit disclosures to implicit signals. Our findings confirmed that people identify vulnerable individuals through online content and activities pertaining to interaction patterns [39], social capital [15], emotions [40], and linguistic style [41]. Research on sensitive disclosures has also characterized corpora of text [20] or imagery [2] signaling mental health problems, such as depression [40] or eating disorders [42]. In this study, we identified additional signals, such as inconsistency between online and offline personalities, which are often subtle and are detected only by those who know the poster and the context. Rather than relying on a single signal, our participants synthesized multiple signals via long-term offline and online observation to interpret a peer's state of mind. In many cases, the individuals at risk did not explicitly solicit help or disclose problems [43]. However, their friends were able to notice the individual's vulnerability based on implicit signals. Recognition of the signals motivated some friends to deliberately intervene in problematic situations in a timely manner.

## Attitudinal Social Distance for Identity Management

According to our survey, 66.4% (150/226) of college students said they recognized students who seemed to have mental health problems. However, a significant percentage of the participants remained inactive due to low expectations, negative beliefs about self-disclosure on SNSs, lack of confidence and knowledge, and a desire to maintain social distance from a person displaying mental health problems. While some groups of people were likely to take immediate action to persuade their suffering friends to seek help from experts, others felt fatigue and even unfollowed the poster to keep a social distance from the person displaying mental health problems. These findings align with prior work on stigma that revealed that the public desires to maintain a social distance from individuals with mental health problems [11]. Members of the public are aware of the need to help and to have prosocial reactions; however, they also consider a person with a mental health problem to be unpredictable and dangerous [11,44]. Therefore, the tendency to distance oneself from others with mental health problems was reported in Angermeyer and Dietrich [44]. Although a previous study showed that the main reason for maintaining a distance was due to induced fear (ie, fear that the person will do something violent) [11], our study findings showed that students wanted to maintain a social distance to protect their identities from stigmatization and to avoid emotional contagion. We could assume that people might feel less concerned about this fear in the online SNS context, where they can easily avoid contact from someone via lurking or disconnecting, compared with the offline environment [45], where they cannot predict where and when they will encounter a person with a mental health problem that could make him or her unpredictable and violent [11]. However, the SNS context, where interaction with someone is exposed to everyone [46], makes one more sensitive to one's social distance from the problematic individual viewed by others. Therefore, interacting with the stigmatized content in a place where every interaction is exposed to others is

considered to be careless behavior [47]. Consistent with Link et al [11] and Phelan et al [48], our study participants wanted to maintain a social distance from the content or the person who posted stigmatized issues, to protect their identities [49] and present a "positive" image on SNSs [50].

## Design Implications for SNSs to Serve as Platforms That Facilitate Support Exchanges Among Peers

### Overview

Drawing on the results of this study about students' experiences, perceptions, and attitudes toward peers signaling mental health problems on SNSs, we discuss opportunities for using design to enhance peer support experiences. In this section, we propose the design implications of strengthening the positive aspects of SNS usage for facilitating support and overcoming the challenges and risks that were identified and presented in the Results section.

### Designing Peer-Supported Risk Identification

Research has suggested that computational algorithms can model behaviors of the mental health-challenged population using a variety of signals on SNSs [15,23,39,40,51]. Our study of viewers' perspectives could complement the computational applications by incorporating implicit signals that only another person might recognize and by synthesizing these signals to provide appropriate support specific to the individual involved. We acknowledge that the majority of students might not have received training and have no qualification to diagnose others. Nevertheless, identification is the first step to access both personal support and professional treatment [52]. In addition to recognizing friends at risk, our participants responded to their peers' signals based on context and personality. One participant's persuasive intervention drove her close friend, who was displaying depressive symptoms, to a clinical service. We suggest that students' contextualized sensemaking abilities could provide insight to advance computational models so they can recognize individuals who appear to be experiencing mental health problems. Furthermore, the students' special capabilities, such as persuasive powers, could help their peers at risk become aware of their mental health conditions and could reduce barriers to help-seeking.

### Make the Visibility of Supportive Interactions Adjustable

SNSs make activities visible to many other people [46]. Therefore, the line between public and private communication is blurring [53]. In this study, this broadcasting nature of SNSs makes every interaction transparent and, thus, it causes a reason people to hesitate to interact with or support people who are considered to have mental health problems. Both survey and interview participants reported that they felt uncomfortable responding to posts that displayed mental health problems because of the public nature of SNSs that might negatively affect their identity. For example, an audience group who can see supporters' comments are dependent on the publisher of the original post. In other words, the supporter cannot predict the scope of the people who can see the comments [46]. This means that people sometimes bear the cost of identity management risk in the process of providing supportive comments on posts. Thus, supportive methods of interaction on SNSs need to be



designed to control the likelihood of broadcasting. One can argue that fostering the use of direct communication through private messages or phone calls for the support of individuals signaling mental health problems can be considered as a primary method. However, our survey and interview study results showed that participants felt reluctant to initiate communication with someone displaying a mental health issue because they lacked confidence in their abilities to provide the appropriate support. Instead, we could consider augmenting existing features of SNSs, such as Facebook or Instagram, to be used as supportive platforms. For example, we suggest an audience management feature that enables the person who writes comments to select the audience of these comments. In existing SNS platforms, only the poster can manage this.

### ***Fostering Just-in-Time Adaptive Support***

The timeline and newsfeed are the main features of recent SNSs, such as Facebook, Twitter, and Instagram [54]. These features visualize a person's activity continuously and chronologically [55]. Thus, our study participants often used these features to examine a poster's posting pattern, which allowed them to detect problems in the poster. According to major scales of depression, such as the Center for Epidemiologic Studies Depression Scale, the frequency of depressive symptoms or negative thoughts is a basis for diagnosis [56]. The timeline and newsfeed visualizing the recent activities and thoughts of a poster experiencing mental health issues could help both posters and viewers to be aware of the poster's situation. For those who are willing to support others, this feature also allows them to recognize their friends' statuses and provide just-in-time support. We could consider a computerized risk notification system for those participants who are willing to support others. This system could provide a nudge to a supporter when his or her peers are uploading signals of vulnerability. These features can help to reduce the risk that the supporter will miss out on a friend's dangerous situation. However, monitoring the sensitive SNS posts of others can be ethically problematic, especially if this is done to detect vulnerable states. Therefore, ethical consideration is needed, such as an approval system requiring mutual consent, to activate such a feature. Facebook now offers a feature that reports on users who express behavior that suggests suicide or self-harm [27], which could save a friend in an emergency. However, such a system has limitations when it comes to supporting peers, so recognizing and providing appropriate help for the intermittent

symptoms of mental illness, such as intermittent depressive mood and feelings of frustration and despair, is critical.

### **Limitations and Future Work**

In this study, we were not able to determine whether the posters that our participants mentioned had actually been experiencing mental health issues or whether the reported activities were actual signals of mental illness. Our study did not focus on finding general factors to recognize or predict mental health conditions. Rather, our attention was on characterizing references to mental health concerns regardless of the posters' diagnostic states. We reported empirical evidence regarding the viewers' perceptions of the signals from the posters' disclosures. By acquiring ground-truth data, future studies should address what factors affect the possibility of a viewer's correct detection or false alarm. While our main study target was a student population, we recruited students from different universities to achieve diversity in the participant group. However, we conducted this study in a single country; thus, our study's generalizability could be limited. We acknowledge that cultural background may affect how participants perceive mental health or social support. Nevertheless, the level of awareness, stigma, and literacy that the general public has about mental health issues varies significantly from country to country, which makes it challenging to derive guidelines that can be generalized to all cultural backgrounds. Therefore, it would be worthwhile for future research to compare students' behaviors and thoughts regarding our research topic in various cultures.

### **Conclusions**

The goal of this study was to examine students' perceptions of mental health-related issues displayed on SNSs. The characterization of SNS posts and activities related to negative, sensitive disclosures illuminated the key signals that students perceived as mental health problems. Our student participants synthesized multiple signals gained both offline and online to recognize an individual's mental health condition and, further, to help them in a timely and appropriate manner. However, our study also revealed that a considerably large number of students did not provide support due to practical or emotional challenges resulting from low expectations, negative belief about self-disclosure, lack of confidence and knowledge, and a desire to maintain a social distance. Based on our findings, we provided design implications of strengthening the positive aspects of SNS usage for facilitating support and overcoming the challenges.

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### **Conflicts of Interest**

None declared.

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Multimedia Appendix 1

Survey questions and possible responses.

[[DOCX File, 1431 KB](#) - [mental\\_v8i10e23465\\_app1.docx](#) ]

## Multimedia Appendix 2

Interview guide.

[\[DOCX File , 17 KB - mental\\_v8i10e23465\\_app2.docx \]](#)**References**

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## Abbreviations

**IITP:** Institute for Information & Communications Technology Planning & Evaluation

**MSIT:** Ministry of Science and ICT

**SNS:** social networking site

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Original Paper

# Attitudes About COVID-19 and Health (ATTACH): Online Survey and Mixed Methods Study

Anna M Hood<sup>1</sup>, BA, MA, PhD; Hanne Stotesbury<sup>1</sup>, MSc; Jennifer Murphy<sup>2</sup>, PhD; Melanie Kölbel<sup>1</sup>, MSc; April Slee<sup>3</sup>, MS; Charlie Springall<sup>4</sup>; Matthew Paradis<sup>4</sup>, PhD; Nadia Saraí Corral-Frías<sup>5</sup>, PhD; Azalea Reyes-Aguilar<sup>6,7</sup>, PhD; Alfredo B Cuellar Barboza<sup>8</sup>, MD; Amy E Noser<sup>9</sup>, PhD; Stacey Gomes<sup>9,10</sup>, MS; Monica Mitchell<sup>9,11</sup>, PhD; Sharon M Watkins<sup>12</sup>, BA; Melinda Butsch Kovacic<sup>11</sup>, MPH, PhD; Fenella J Kirkham<sup>1\*</sup>, MD; Lori E Crosby<sup>9,13\*</sup>, PsyD

<sup>1</sup>Developmental Neurosciences Unit and Biomedical Research Centre, University College London Great Ormond Street Institute of Child Health, London, United Kingdom

<sup>2</sup>Department of Psychology, Royal Holloway University of London, London, United Kingdom

<sup>3</sup>Axio Research LLC, Seattle, WA, United States

<sup>4</sup>AirMyOpinion Ltd, Weybridge, United Kingdom

<sup>5</sup>Department of Psychology, Universidad de Sonora, Hermosillo, Sonora, Mexico

<sup>6</sup>Department of Psychobiology, Facultad de Psicología, Universidad Nacional Autónoma de México, Ciudad de México, Mexico

<sup>7</sup>Department of Neuroscience, Facultad de Psicología, Universidad Nacional Autónoma de México, Ciudad de México, Mexico

<sup>8</sup>Department of Psychiatry, Universidad Autonoma de Nuevo Leon, Monterrey, Mexico

<sup>9</sup>Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center, Cincinnati, OH, United States

<sup>10</sup>College of Criminal Justice, Education and Human Services, University of Cincinnati College of Medicine, Cincinnati, OH, United States

<sup>11</sup>Department of Pediatrics, University of Cincinnati College of Medicine, Cincinnati, OH, United States

<sup>12</sup>Cincinnati-Hamilton County Community Action Agency, Cincinnati, OH, United States

<sup>13</sup>James M Anderson Center for Health Systems Excellence, Cincinnati Children's Hospital Medical Center, Cincinnati, OH, United States

\* these authors contributed equally

## Corresponding Author:

Anna M Hood, BA, MA, PhD

Developmental Neurosciences Unit and Biomedical Research Centre

University College London Great Ormond Street Institute of Child Health

30 Guilford Street

London, WC1N 1EH

United Kingdom

Phone: 44 02079052744

Email: [a.hood@ucl.ac.uk](mailto:a.hood@ucl.ac.uk)

## Abstract

**Background:** Behavioral mitigation strategies to slow the spread of COVID-19 have resulted in sweeping lifestyle changes, with short- and long-term psychological, well-being, and quality of life implications. The Attitudes About COVID-19 and Health (ATTACH) study focuses on understanding attitudes and beliefs while considering the impact on mental and physical health and the influence of broader demographic and geographic factors on attitudes, beliefs, and mental health burden.

**Objective:** In this assessment of our first wave of data collection, we provide baseline cohort description of the ATTACH study participants in the United Kingdom, the United States, and Mexico. Additionally, we assess responses to daily poll questions related to COVID-19 and conduct a cross-sectional analysis of baseline assessments collected in the UK between June 26 and October 31, 2020.

**Methods:** The ATTACH study uses smartphone app technology and online survey data collection. Participants completed poll questions related to COVID-19 2 times daily and a monthly survey assessing mental health, social isolation, physical health, and quality of life. Poll question responses were graphed using 95% Clopper–Pearson (exact) tests with 95% CIs. Pearson correlations, hierarchical linear regression analyses, and generalized linear models assessed relationships, predictors of self-reported outcomes, and group differences, respectively.

**Results:** By October 31, 2020, 1405, 80, and 90 participants had consented to participate in the UK, United States, and Mexico, respectively. Descriptive data for the UK daily poll questions indicated that participants generally followed social distancing measures, but worry and negative impacts on families increased as the pandemic progressed. Although participants generally reported feeling that the reasons for current measures had been made clear, there was low trust that the government was doing everything in its power to meet public needs. In the UK, 1282 participants also completed a monthly survey (94.99% [1326/1396] White, 72.22% [1014/1404] female, and 20.12% [277/1377] key or essential workers); 18.88% (242/1282) of UK participants reported a preexisting mental health disorder, 31.36% (402/1282) reported a preexisting chronic medical illness, and 35.11% (493/1404) were aged over 65; 57.72% (740/1282) of participants reported being more sedentary since the pandemic began, and 41.89% (537/1282) reported reduced access to medical care. Those with poorer mental health outcomes lived in more deprived neighborhoods, in larger households ( $P_s < .05$ ), had more preexisting mental health disorders and medical conditions, and were younger than 65 years (all  $P_s < .001$ ).

**Conclusions:** Communities who have been exposed to additional harm during the COVID-19 pandemic were experiencing worse mental outcomes. Factors including having a medical condition, or living in a deprived neighborhood or larger household were associated with heightened risk. Future longitudinal studies should investigate the link between COVID-19 exposure, mental health, and sociodemographic and residential characteristics.

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## KEYWORDS

COVID-19; mental health; international; mitigation strategies; deprivation

## Introduction

### Background

The COVID-19 (SARS-CoV-2 virus) pandemic has placed an overwhelming burden on health systems and public health authorities to respond with effective interventions, policies, and messages [1]. Efforts to develop vaccines began quickly, with the first human clinical trial of a COVID-19 vaccine commencing on March 3, 2020, in the United States [2]. In the UK, the COVID-19 vaccine was authorized for clinical use on December 2, 2020 [3], with Mexico following soon afterward on December 11, 2020 [4]. Even with these pharmacological measures, *behavioral* mitigation strategies (eg, physical distancing, handwashing, face masks) [5] remain critical to slow the spread of COVID-19 [6]. However, the effectiveness of these behavioral strategies is dependent on adherence to policies and guidelines and on a person's ability to perceive risks associated with the virus and adapt accordingly [7].

As the mitigation guidelines change over time and differ between countries and regions, there are many areas of uncertainty, including financial and health concerns, employment, and housing, along with fear about the future and social isolation. These sources of uncertainty may impact coping and increase the risk of developing mental health problems, with implications for quality of life in both the short and long term [8,9]. Families have had to juggle home-schooling children with working remotely or being unable to work at all [10]. Evidence from previous viral disease outbreaks indicates that when the number of stressors is high, there can be a negative effect on mental health, particularly for high-risk persons (eg, survivors and frontline health care workers) [11-15]. Currently, individuals are reporting widespread concerns about the effect of social distancing on well-being. There is evidence of increased anxiety, depression, and stress, along with reports of

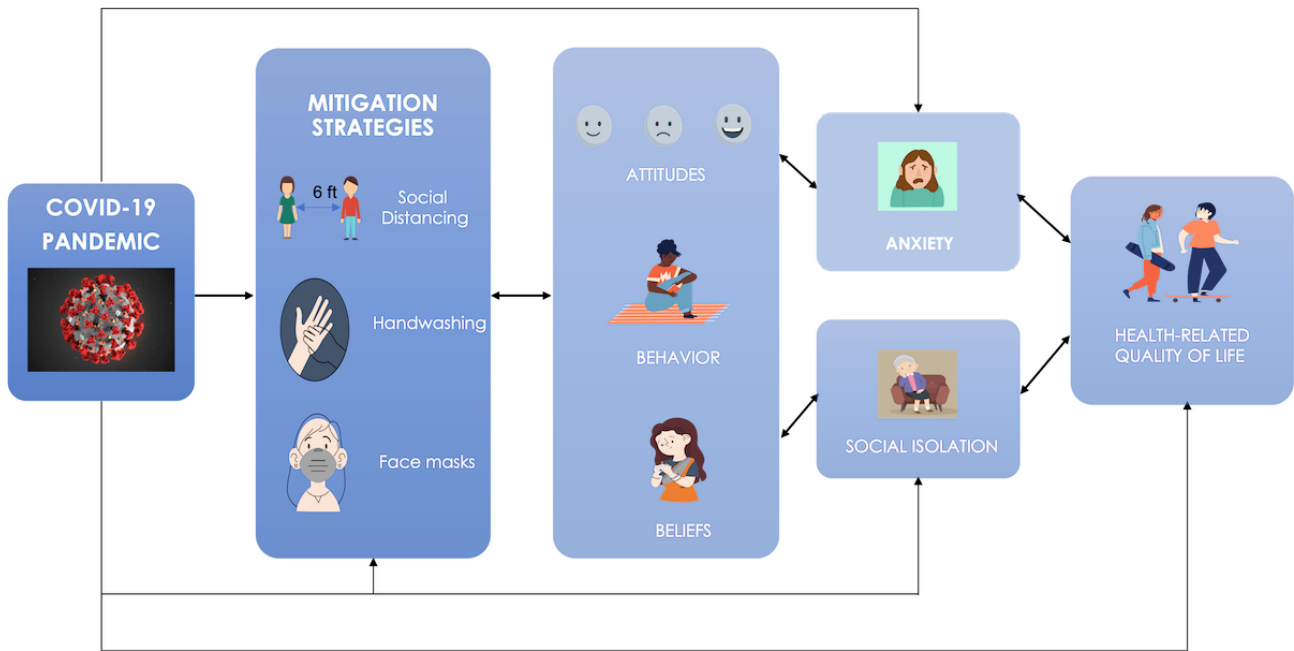
concern about the practical implications of the pandemic response, including for personal finances [9,16].

Social and medical factors play a significant role in COVID-19 exposure and influence the impact on mental health. It has quickly become apparent that these social and medical consequences of COVID-19 do not affect all people equally. Older adults, people with medical conditions (eg, asthma, sickle cell disease), and those facing long-standing societal inequities (ie, Black, Latinx, Indigenous, Asian, and traveler communities) face a disproportionate burden [17]. A report from Public Health England indicated that socioeconomic disadvantage, population density, and household composition may increase the likelihood not only of COVID-19 illness and severe disease [18] but also of poorer mental health outcomes [19,20]. Individuals' concerns about their mental health outcomes will likely result in additional pressure on referral systems. Known barriers to accessing mental health interventions may also increase during the pandemic, such as distance, work commitments, and caring responsibilities.

### Goal of This Study

The Attitudes About COVID-19 and Health (ATTACH) study aims to understand attitudes and beliefs about the COVID-19 pandemic while considering the impact on mental and physical health, along with the influence of demographic and geographic factors. We examine how the pandemic and behavioral mitigation strategies influence attitudes and beliefs, which in turn are predicted to affect mental and physical health (eg, anxiety, social isolation) and therefore influence overall quality of life (see [Figure 1](#) for the theoretical model). Specifically, to assess the impact of COVID-19-related measures (eg, isolation, physical distancing), our study: (1) tracks attitudes and behaviors daily as the pandemic evolves, and (2) longitudinally monitors mental and physical health symptoms using established measures that are reliable and sensitive to change.

Figure 1. Theoretical model.



The ATTACH study uses a smartphone app and online survey data collection. Our goals necessitate oversampling those communities that have been exposed to additional harm during the COVID-19 pandemic to guide the development of effective, and ideally, more person-centered interventions. Data encompass a sample from the United Kingdom (a high-resource country). We also include data from 2 smaller-scale studies from the United States (another high-resource country) and Mexico (a low-resource country). We chose these countries for inclusion because, before the pandemic, the Global Health Security Index ranked the United States and the UK as the first and second most prepared countries to manage a pandemic, but by June 2020, they were the first and second in excess deaths related to COVID-19 [21]. Mexico has Latin America's second highest death toll and had 50% excess deaths when data collection began [22]. As Mexico is a primarily Spanish-speaking country with a similarly challenging COVID-19 response as the United States and the UK, the comparison could help better understand attitudes, behaviors, and mental health during the COVID-19 pandemic. Although behavioral mitigation strategies changed regularly during the study period, all 3 countries used lockdowns (eg, shelter in place), social distancing, and relied on individual compliance with the new rules. Additionally, some form of mask mandate had been introduced in all 3 countries, hospitality venues had been closed or required outdoor dining, and stores limited the number of individuals allowed inside [23-25]. However, COVID-19 vaccines had not been released in any of these countries at the time of data collection.

Data collection for ATTACH is ongoing, and longitudinal aims and specific hypotheses have been preregistered [26]. This paper primarily focuses on a cross-sectional analysis of baseline assessments collected in the UK between June 26 and October 31, 2020. It also considers longitudinal changes in UK daily poll responses through the same period. Descriptive analyses for data from the United States and Mexico are also reported, but we did not conduct statistical analyses. During the first

wave, the sample sizes in those countries were less than 100 participants.

### Aims

The objectives of this study were to (1) describe the baseline characteristics of participants in the ATTACH study in the UK, United States, and Mexico; and (2) describe changes in daily UK poll responses over time in relation to specific policy interventions (eg, mask mandates) and the pandemic's trajectory (eg, a 7-day rolling average of COVID-19 cases).

### Hypotheses

We hypothesized that residential population density, socioeconomic deprivation, and household composition will predict self-reported outcomes (ie, anxiety and depressive symptoms, social isolation, physical health, quality of life) in our UK sample; and there will be baseline differences in our UK sample in self-reported outcomes between (1) participants with and without mental health disorders, (2) participants with and without medical conditions, and (3) participants under and over the age of 65.

### Methods

#### Study Design

ATTACH is a prospective cohort study conducted nationwide during the COVID-19 pandemic with arms in the UK, the United States, and Mexico. Our research team developed the study between March and April 2020. Data collection began on June 26, 2020, in the UK, on July 27, 2020, in the United States, and on October 10, 2020, in Mexico. In the UK, the ATTACH study partnered with Air My Opinion (AMO), a smartphone app that enables organizations to gather longitudinal poll data to interpret trends in attitudes and beliefs.



## Population

The ATTACH study purposely targets individuals with increased susceptibility to adverse health outcomes for recruitment, focusing on 3 priority groups: (1) those with a self-reported mental health disorder, (2) those with a self-reported chronic medical condition, and (3) those over 65 years of age. Participants were at least 16 years of age (18 years in the United States and Mexico), could read in English (UK; does not have to be their first language), Spanish (Mexico), or English or Spanish (United States). Participants had to reside in the country where the study was being completed and have access to a smartphone (UK) and the internet (UK, the United States, and Mexico). Participants provided informed electronic consent before completing daily poll questions and monthly surveys. The ATTACH study received ethical approval from the University College London (UCL) Research Ethics Committee (18177/001), the Cincinnati Children's Hospital Medical Center Institutional Review Board (No. 2020-0465), and the Universidad de Sonora Ethics Committee (CEI-UNISON 010/2020). The study is reported in accordance with the STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) [27] and the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) guidelines [28].

## Materials

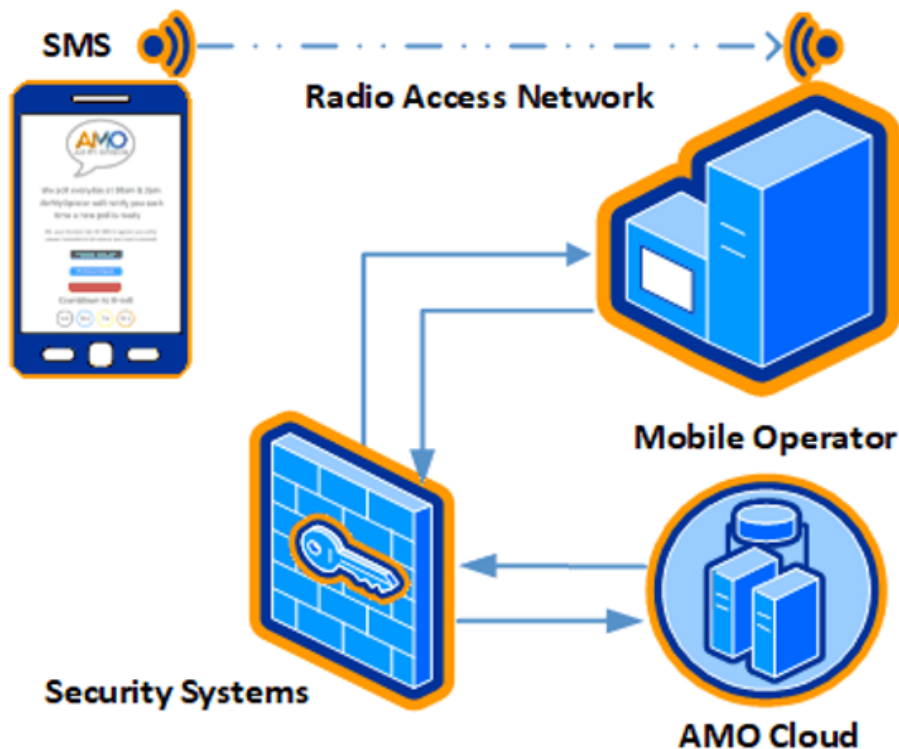
### *Air My Opinion App (UK Data Only)*

The AMO app was customized for the ATTACH study through an iterative design process between the research team and app developer. Before the study launched, the research team

appraised a mock-up design, highlighted their satisfaction and dissatisfaction with the design and format, and provided feedback and suggestions for improvement. The AMO app uses the flutter framework, has embedded encryption, and is General Data Protection Regulation (GDPR) compliant. Participants could freely install the app on an internet-enabled smartphone (Google Play or Apple App Store) running Android or iOS operating systems. Responses to daily poll questions were collected via an SMS text message service-center voting platform. Some participants (n=344) had difficulty sending their first SMS text message (ie, changed the wording, did not realize it had not been sent), which included their registration data (ie, postcode). As such, the app development team made changes so that registration data were incorporated within the app instead of being included in the first SMS text message.

If a participant's phone plan is the traditional pay-as-you-go, they pay for each SMS text message, but if they have a monthly plan or pay-as-you-go bundle, there is no additional cost. Each phone number is associated with a unique 1-way encrypted participant key (eg, 1::747d6f41-2f7a-47fd-a2a0-0cf41b8ca9f2::i2::1::484::), which feeds directly into a secure response firewall-protected database (Figure 2). According to GDPR, age range, sex, postcode, ethnic minority status (yes/no prefer not to say), and parent and chronic medical condition group status were stored in a separate secure firewall-protected database. Data protection registration has been obtained for this study (UCL Data Protection Registration Number: Z6364106/2020/04/110). The data are minimized at the first opportunity, with new keys assigned and the original keys stored separately from the rest of the data on the UCL shared drive.

**Figure 2.** Smartphone survey polling system. AMO: Air My Opinion.



### **Poll Questions (UK Data Only)**

In March and April 2020, the research team conducted a literature review and held several virtual video conference meetings to develop daily poll questions using prior expertise, survey knowledge, group discussion, and reliable sources of COVID-19 information (eg, World Health Organization [WHO]). Given the fast-moving nature of the COVID-19 pandemic, validation or pilot testing of questions externally was not possible. Poll questions track attitudes, beliefs, and behaviors related to the COVID-19 pandemic and fit into broad categories related to health and well-being, personal concerns, worry or hope, compliance or rationale, government trust, and habits. All questions have 3 Likert response options (eg, yes, somewhat, not at all). There are currently 60 poll questions. New questions are added on a flexible schedule to capture changes during the pandemic while maintaining the original questions for longitudinal assessment (see [Multimedia Appendix 1](#) for a complete list of poll questions). Most questions are repeated every 2 weeks. In this study, 6 questions were focused on descriptive analyses (see below). These questions were chosen as they were asked continuously from the beginning of the study, represent a question from each category, and were chosen before any analyses were conducted.

- In the past week, have you followed social distancing measures?
- In the past week, have you felt that COVID-19 has had a negative impact on your family?
- In the past week, how worried have you been about the ongoing COVID-19 pandemic?
- In the past week, have you felt that the reasons for the current pandemic measures have been made clear?
- In the past week, have you trusted the government to do everything in their power to ensure that the basic needs of the public are met?
- In the past week, have you spent more time than usual using social media (eg, Facebook, WhatsApp, Instagram)?

### **Monthly Survey**

Baseline sociodemographic characteristics included age, sex, relationship status, educational level, first language, household composition, and caregiver status. For race and ethnicity, participants could choose from categories (based on census data from each country) or self-identify using a free response. Mental health disorders and medical conditions were identified from free response. Mental health disorders were classified based on the *Diagnostic and Statistical Manual of Mental Disorders*, 5th Edition [29] categories. To capture changes as the COVID-19 pandemic progresses, participants were asked to provide their employment and keyworker status, effects on household income, sources of and trust in COVID-19-related information, and political status on a 100-point scale (“0=left” and “100=right”) at baseline and at months 7 and 12.

Measures included in the study are validated, nonvalidated (developed rapidly during the COVID-19 pandemic), and those designed by our research team. Internal consistency (ie, Cronbach  $\alpha$ ) for this study and the assessment schedule are reported in [Multimedia Appendices 2 and 3](#). When possible, short forms of measures were used to reduce participant burden.

Measures included for analyses in this study were the Patient-Reported Outcomes Measurement Information System (PROMIS) Anxiety-Adult Short Form [30], 9-item Patient Health Questionnaire (PHQ-9) [31], 10-item University of California Los Angeles Loneliness Scale (UCLA-10) [32], PROMIS Global Health [30], the PROMIS Meaning and Purpose-Short Form [30], and the Epidemic-Pandemic Impact Inventory (Physical Health questions) [33] ([Multimedia Appendix 4](#)). PROMIS measures were available in Spanish; for the other measures, a study team member (NC-F) completed the translation.

### **Residential Risk Factors (UK Data Only)**

#### **Overview**

Geographic region, socioeconomic disadvantage, and household composition may influence an individual’s ability to follow COVID-19-related guidelines and restrictions [18]. In our study, 2 measures captured these factors: deprivation and population density. Participants provided the first 5 characters of their UK postcode (ie, postcode sector) on the AMO smartphone app. In 2016, there were 12,381 postcode sectors in the UK. Postcode sectors vary in terms of the number of dwellings but typically range between 200 and 5000 [34].

#### **Socioeconomic Deprivation**

The index of multiple deprivation (IMD; 2017-2020) is an official postcode-based measure of relative deprivation in England [35], Wales [36], Scotland [37], and Northern Ireland [38] and is available as open-source government data. The IMD defines deprivation to encompass income, employment, education, health, crime, barriers to housing and services, and living environment. All neighborhoods are ranked on a relative rather than absolute scale according to their deprivation level relative to other areas. All zones are grouped into 5 bands (quintiles), each containing 20% of the zone, with “1=most deprived, 5=least deprived.” In this study, each participants’ postcode sector was assessed to determine the level of deprivation. IMD quintile scores are combined from all UK countries.

#### **Residential Population Density**

Population density estimates for England and Wales [39], Scotland [40], and Northern Ireland [41] are produced for each country using the cohort component method and cover the “usually resident population” from 2011 Census data. In this study, each participants’ postcode sector was assessed to determine the population density (ie, number of usual residents per hectare), and population density was combined from all UK countries.

#### **Household Composition**

Participants responded to the question, “How many people (adults and children) live in your household?” The 5 response options were “1” through “5 or more.”

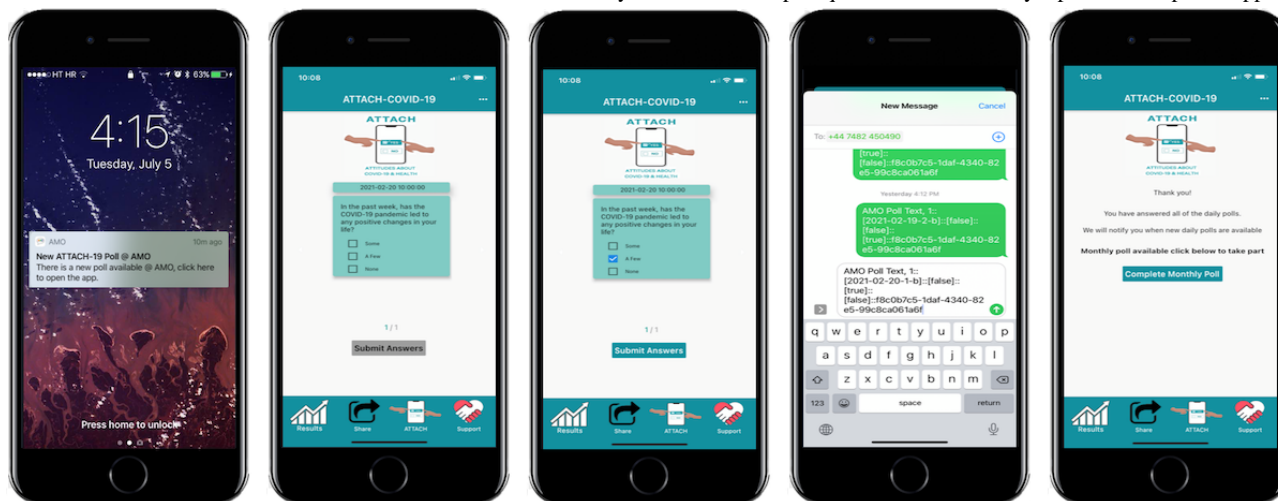
#### **Procedures**

Recruitment strategies for all countries are described in [Multimedia Appendix 5](#). Participants downloaded the smartphone app to complete consent in the UK and then

provided their demographics (in case a participant chose not to complete monthly surveys) and postcode. Participants received push notifications on their smartphones to complete daily 1-minute polls 2 times each day at 10 am and 2 pm. Participants could answer both questions at the same time, but each question

was removed after 24 hours. Once the participant completed the daily poll questions, they could then click on an embedded link (with a unique access code) in the app to complete their monthly survey via Research Electronic Data Capture tools (REDCap) hosted at UCL (see Figure 3 for a schematic) [42,43].

**Figure 3.** Schematic of an Attitudes About COVID-19 and Health study notification and poll question on the Air My Opinion smartphone app.



If responses to survey questions indicated that participants had severe depression or experienced high levels of stigma due to their medical condition, a pop-up message provided mental health resources along with the study email address, which was monitored regularly by a clinical psychologist (AH) to provide additional resources or referrals. After the survey, participants were redirected to the study webpages (located on the UCL Child Health Institute website), which contain links to mental health (eg, Mind), COVID-19 (eg, government), and authoritative medical information (eg, National Health Service [NHS]). Participants could see the results of daily poll questions (as pie charts) by clicking on a link in the app or via the study Twitter account.

In the United States, participants completed poll questions and monthly surveys using REDCap, and in Mexico, participants completed monthly surveys using Qualtrics (Qualtrics International Inc) with open survey links. Participants in the UK and United States who completed the monthly survey were entered into a monthly prize draw (UK £10 [US \$13.75]/US \$10 Amazon card). In Mexico, most participants did not receive any compensation. A subset of the sample (ie, undergraduate students) had the opportunity to receive *culture credits* (obtained through research studies or going to concerts or workshops) for their participation.

### Statistical Analysis

Analyses were conducted using R version 4.0.3 [44] and SAS version 9.4 [45]. Descriptive statistics summarized demographic and clinical characteristics. The PROMIS [30] Anxiety, Physical Health, and the Meaning and Purpose scales were scored using the online HealthMeasures scoring service [46] that utilizes information from each item to calculate a T-score (mean 50 [SD 10]). For the PHQ-9 and UCLA-10 scales, raw scores were calculated in line with published norms. Mean imputation was used when a participant completed at least 80% of items (ie, 8/10 for the UCLA-10 or 8/9 for the PHQ-9) [47,48]. The

frequency of *somewhat* and *yes* poll question responses from July 15, 2020, to October 15, 2020, was graphed based on the timing of response using 95% Clopper–Pearson (exact) tests with 95% CIs, alongside the 7-day average counts of daily COVID-19 cases (per 100 persons) and deaths. Pearson correlations examined the relationship between household composition and self-reported outcomes. Hierarchical linear regression analyses assessed whether residential socioeconomic deprivation and population density independently predicted self-reported outcomes after controlling for age and sex.

Generalized linear models were used to produce adjusted least-square mean scores and differences to compare groups (participants with and without mental health and medical conditions, those under and over 65 years). Analyses controlled for demographic factors (ie, age, sex, level of residential socioeconomic deprivation) and comorbidities (ie, mental health and medical condition). All analyses were conducted using pairwise deletion, as variables generally contained less than 1% of missing data. Adjusted *P* values were based on the model *t*-statistics. Semipartial  $\eta^2$  was used as a measure of effect size to describe the proportion of total variation accounted for by the effect being tested. Statistical significance was determined at an  $\alpha$  level of  $P < .05$  (2 tailed).

### Data Exclusion

The smartphone app and online survey data were examined for duplicates by matching unique app identifiers and participant numbers. Through this process, it was determined that 15 participants had downloaded the app more than once. Duplicate data were excluded before analyses.

### Power

The ATTACH study was powered to detect longitudinal effects and not baseline group differences [26], so power calculations were not performed for these largely descriptive first-wave baseline assessments. However, for our longitudinal analyses

with 3 subgroups, 5 covariates, 5 or more repeated measures at 0.80 power, an error probability of 0.05, and an effect size of 0.3, the sample size required for between-participants analyses is 153 and 50 for within-participants analyses.

**Data Sharing**

Data will be shared upon reasonable request and with permission according to the ATTACH Group data release policy.

**Results**

**UK Preliminary Analyses**

By October 31, 2020, 1405 individuals had downloaded the smartphone app and consented to participate in the UK ATTACH study. As of October 31, 2020, the study link that takes participants to the study recruitment page had been clicked on 5068 times, with Facebook and Twitter being the most common referrers. No participants reached out via email or social media to indicate that they had a mental health concern.

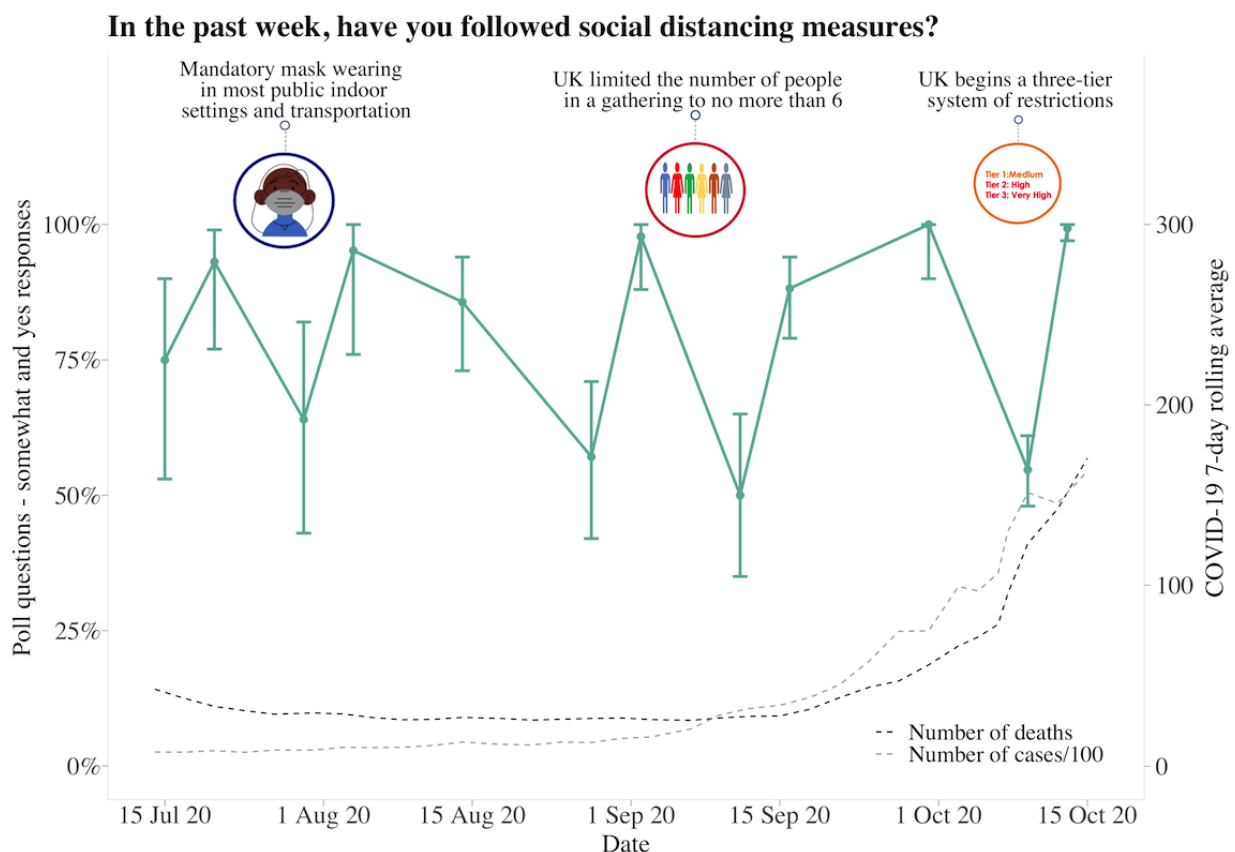
A total of 123/1405 participants (8.75%) answered poll questions on at least one occasion but did not complete the monthly survey. Sensitivity analyses indicated that participants who did and did not go on to complete the survey were similar in age ( $P=.24$ ), sex ( $P=.62$ ), level of deprivation ( $P=.83$ ), and UK country of residence ( $P=.74$ ). However, those who did not complete a monthly survey were significantly more likely to identify as non-White ( $P<.001$ ) and were from a more populated geographic region ( $P=.02$ ) than those who did. Analyses

assessed whether there were differences between participants who did and did not ( $n=344$ ) send their first SMS text message correctly. They did not differ in terms of identified race ( $P=.54$ ), but they were significantly older ( $P<.001$ ) and more likely to be female ( $P=.02$ ).

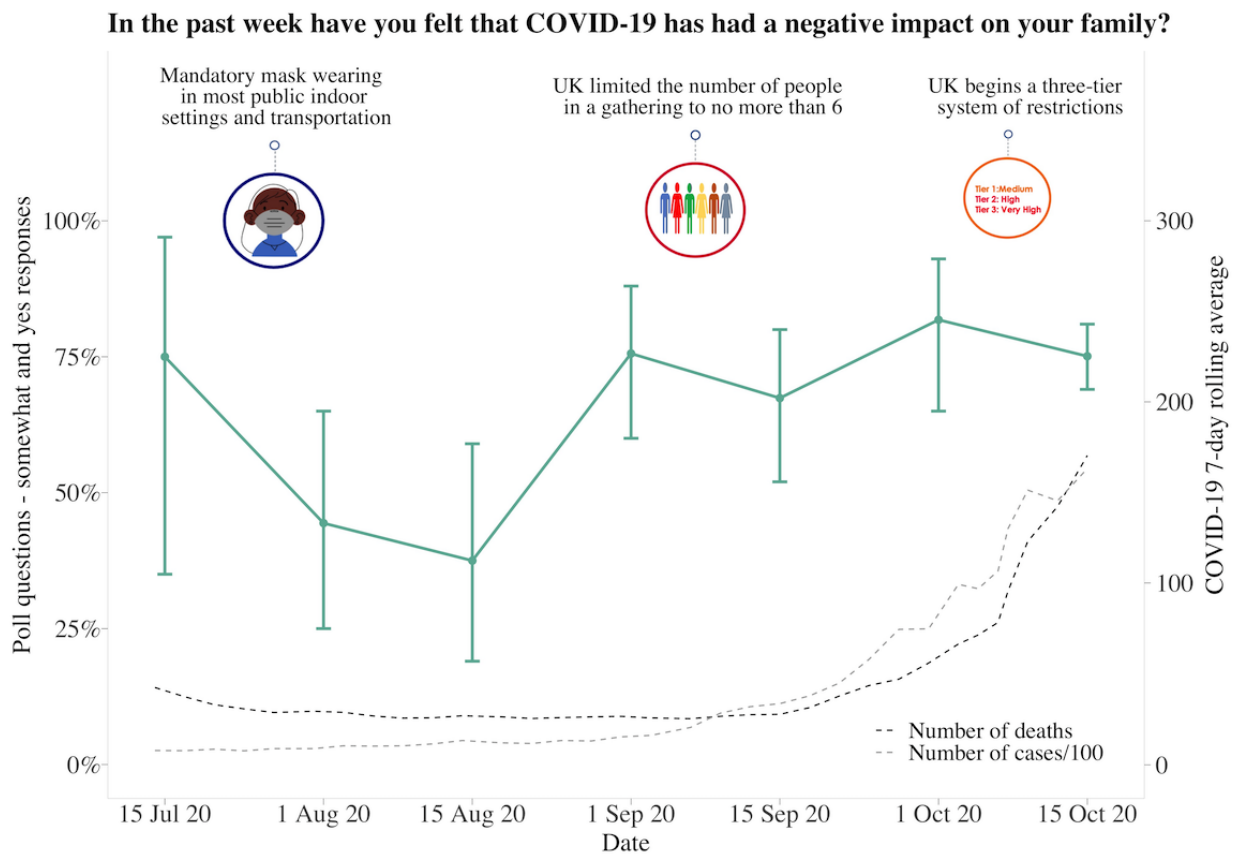
**UK Poll Questions**

About 62.63% (880/1405) of participants answered each poll question separately at 10 am and 2 pm, with the fastest response at 8 seconds and the slowest response at 23 hours and 58 minutes. The average time to answer 1 question was 2 hours and 17 minutes, with 11.88% (167/1405) of participants answering within 10 minutes. Longitudinal data from 6 poll questions indicated that participants had generally followed social distancing measures, although there was variability across time (responses varied between 50% and 99%). Regarding whether the COVID-19 pandemic had a negative impact on the family and whether participants were worried about the pandemic, both increased over time. Over 80% of participants responded “somewhat or yes” as the pandemic progressed and as the 7-day rolling average of cases and deaths increased. Although participants generally reported feeling that the reasons for current measures had been made clear (70%-85% across the study period), there was much less trust that the government was doing everything in their power to meet public needs, with less variability in responses over time (25%-50% across the study period). Increased social media use remained consistent, with 30%-40% of participants reporting spending more time than usual (Figures 4-9).

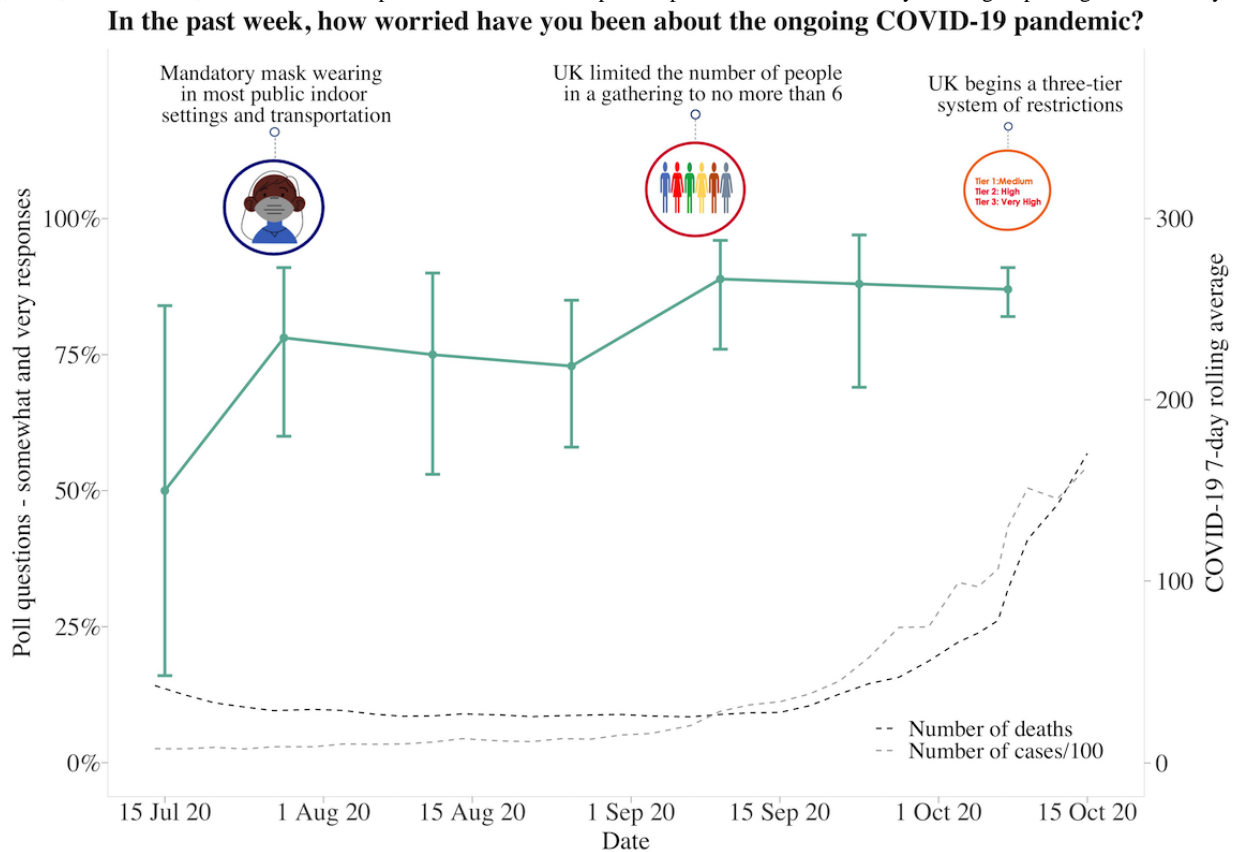
**Figure 4.** Graphs represent United Kingdom longitudinal daily poll responses for COVID-19-related question in the category of health from July 15, 2020, to October 15, 2020. Error bars represent 95% CIs. Participant responses “somewhat” and “yes” are grouped together for analyses.



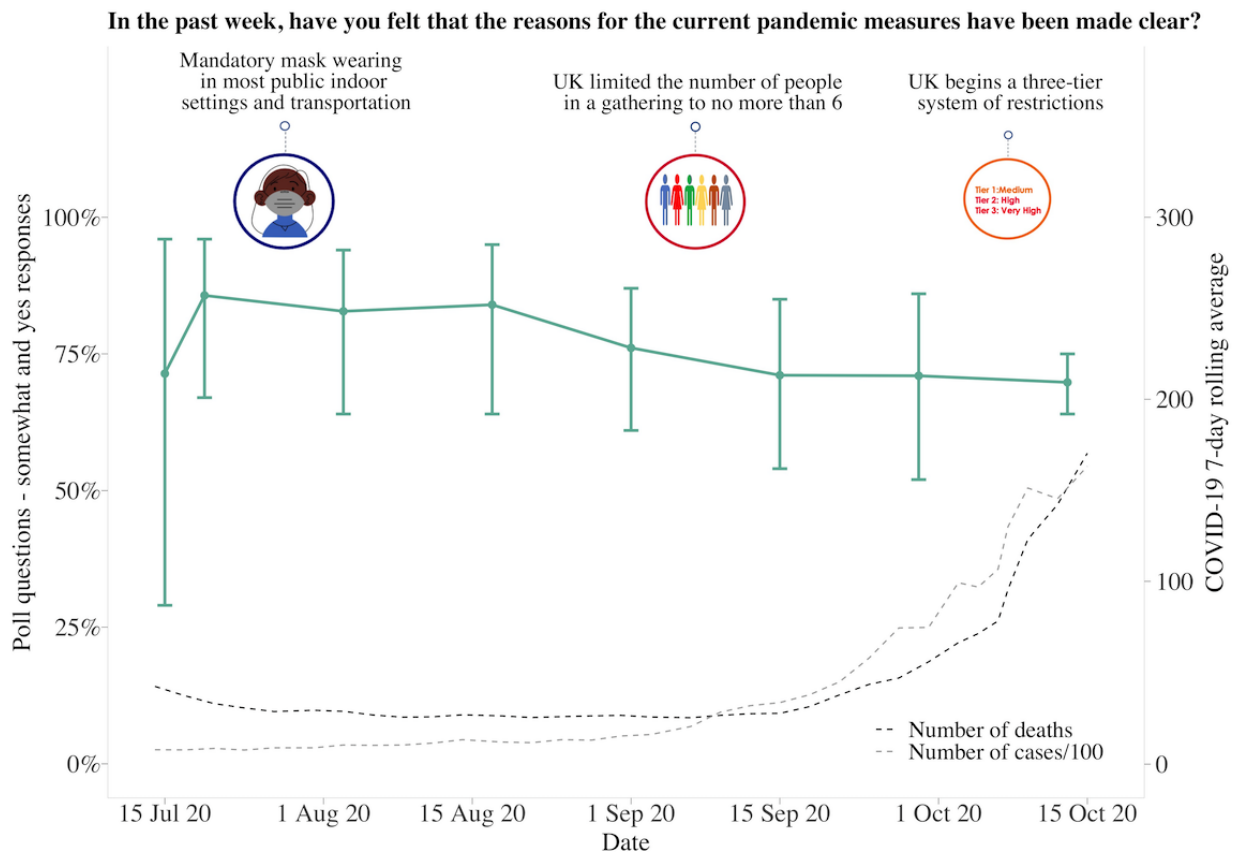
**Figure 5.** Graphs represent United Kingdom longitudinal daily poll responses for COVID-19-related question in the category of personal concerns from July 15, 2020, to October 15, 2020. Error bars represent 95% CIs. Participant responses “somewhat” and “yes” are grouped together for analyses.



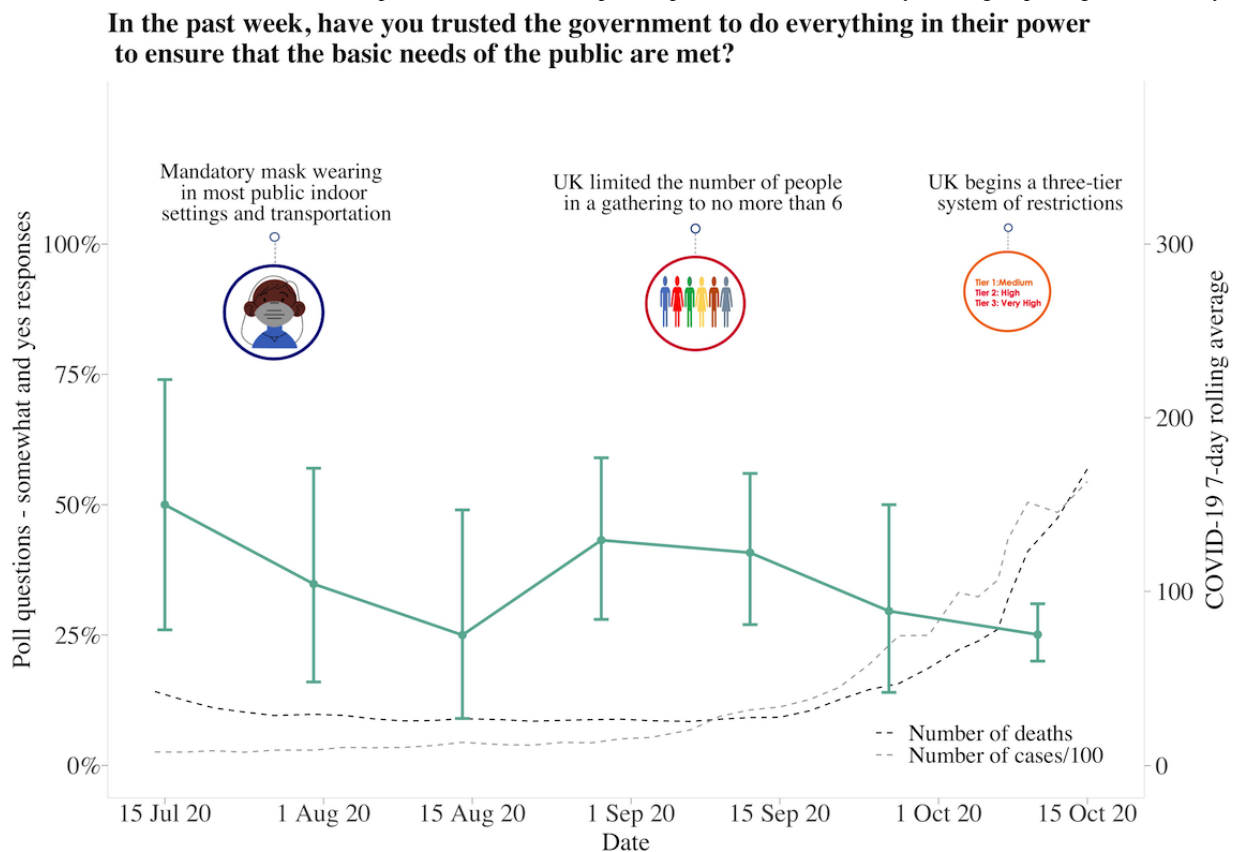
**Figure 6.** Graphs represent United Kingdom longitudinal daily poll responses for COVID-19-related question in the category of worry or hope from July 15, 2020, to October 15, 2020. Error bars represent 95% CIs. Participant responses “somewhat” and “yes” are grouped together for analyses.



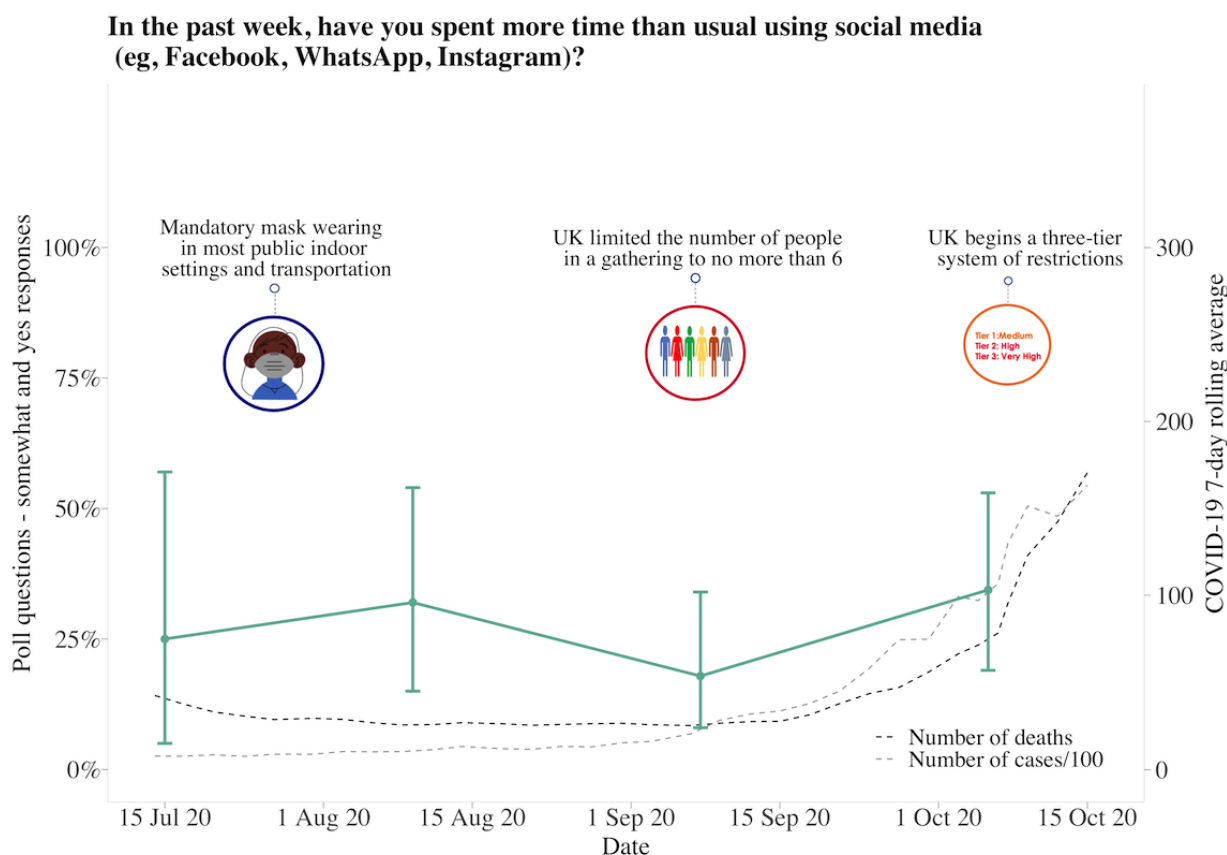
**Figure 7.** Graphs represent United Kingdom longitudinal daily poll responses for COVID-19-related question in the category of compliance or rationale from July 15, 2020, to October 15, 2020. Error bars represent 95% CIs. Participant responses “somewhat” and “yes” are grouped together for analyses.



**Figure 8.** Graphs represent United Kingdom longitudinal daily poll responses for COVID-19-related question in the category of government trust from July 15, 2020, to October 15, 2020. Error bars represent 95% CIs. Participant responses “somewhat” and “yes” are grouped together for analyses.



**Figure 9.** Graphs represent United Kingdom longitudinal daily poll responses for COVID-19-related question in the category of habits from July 15, 2020, to October 15, 2020. Error bars represent 95% CIs. Participant responses “somewhat” and “yes” are grouped together for analyses.



## UK Monthly Survey

### Descriptive Data

Participants at baseline had a mean age of 57 years, with the majority identifying as White (1326/1396, 94.99%), female (1014/1404, 72.22%), married (765/1282, 59.67%), speaking English as a first language (1231/1282, 96.02%), and educated to the college/university level or higher (996/1282, 77.69%). A total of 540/1262 participants (42.78%) were retired, and about one-fifth (277/1377, 20.12%) were key or essential workers. Most lived in a 2-person household (681/1282, 53.12%), and a minority were parents of children under 16 years (139/1282, 10.84%). Less than a quarter (300/1259, 23.83%) reported that their income had been affected by the COVID-19 pandemic, and when reporting where they see themselves on the political spectrum, scores ranged from 0 to 100 (mean 42.3 [SD 22.2]; [Multimedia Appendix 6](#)).

A subgroup of participants reported preexisting mental health disorders (242/1282, 18.88%), with depression and anxiety disorders being the most commonly reported. Just over one-third (402/1282, 31.36%) reported a preexisting chronic medical illness, with asthma, Type 1 and 2 diabetes, and arthritis being the most commonly reported ([Multimedia Appendix 7](#)). Some

participants also had comorbid (ie, more than 1) mental health disorders (94/1282, 7.33%) or chronic medical illnesses (71/1282, 5.54%). Additionally, some participants had at least one mental health disorder *and* at least one chronic medical condition (100/1282, 7.80%; [Multimedia Appendix 8](#)). Scores on self-reported outcome measures indicated that just under one-third of the sample (352/1244, 28.30%) was experiencing moderate-to-severe anxiety symptoms, while just under one-fifth (233/1217, 19.15%) was experiencing moderate-to-severe depressive symptoms. Most of the sample (985/1232, 79.95%) reported feeling some loneliness or social isolation, while 248/1208 (20.53%) participants reported poor-to-fair physical health, and 476/1206 (39.47%) reported poor-to-fair quality of life ([Multimedia Appendix 8](#)).

### Impact of the COVID-19 Pandemic

Participants reported how the COVID-19 pandemic had changed their lives and impacted their household members. Generally, fewer participants reported physical health changes, although many had received less routine or preventative medical care. At least one-third of the sample reported being less physically active and eating less healthy foods. In fact, 57.72% (740/1282) of participants reported being more sedentary since the pandemic began ([Table 1](#)).

**Table 1.** COVID-19 pandemic-related changes for participants and people in their home at baseline in the UK ATTACH study from June 26 to October 31, 2020.

| COVID-19 pandemic-related changes  | Participant, % <sup>a</sup> | Person in home, % <sup>a</sup> |
|--|-----------------------------|--------------------------------|
| Spent more time sitting down or being sedentary                                    | 57.7                        | 30.8                           |
| Got less medical care than usual (eg, routine or preventive care appointments)     | 41.7                        | 23.0                           |
| Less physical activity or exercise   | 40.7                        | 23.7                           |
| Overeating or eating more unhealthy foods (eg, junk food)                          | 31.9                        | 16.8                           |
| Increase in health problems not related to this disease                            | 21.1                        | 12.3                           |
| Important medical procedure cancelled (eg, surgery)                                | 6.9                         | 5.4                            |
| Elderly or disabled family member not in the home/unable to get the help they need | 5.5                         | 6.9                            |
| Unable to access medical care for a serious condition (eg, dialysis, chemotherapy) | 2.3                         | 1.3                            |

<sup>a</sup>n is not reported because it is different for each question as not all participants answered each question. The n ranged from 1280 to 1282 participant responses for each question.

### Residential Risk Factors

Pearson correlations demonstrated that residential socioeconomic deprivation was significantly related to increased population density ( $r=-0.24$ ;  $P<.001$ ) and household composition ( $r=0.07$ ;  $P=.04$ ). Higher household composition (ie, more people residing in the home) was, however, related to *less* residential population density ( $r=-0.06$ ;  $P=.09$ ), although this result did not reach significance.

### Socioeconomic Deprivation

Younger age, female sex, and living in a more deprived neighborhood (ie, quintile 1 vs quintiles 2 through 5) were predictive of reporting more anxiety symptoms,  $F_{8,880}=23.12$ ,  $r^2=0.13$  (95% CI 0.09-0.17;  $P<.001$ ). For our second analysis, younger age and living in a more deprived neighborhood (ie, quintile 1 vs quintiles 2 through 5), but not sex, were predictive of reporting more depressive symptoms,  $F_{6,862}=25.87$ ,  $r^2=0.15$  (95% CI 0.11-0.19;  $P<.001$ ). For our third and fourth analyses, age ( $P=.40$  and  $.17$ , respectively) and sex ( $P=.22$  and  $.34$ , respectively) were not significant predictors, but living in a more deprived neighborhood (ie, quintile 1) compared with living in a less deprived neighborhood (quintiles 2 through 5) was predictive of reporting worse physical health,  $F_{6,860}=2.88$ ,  $r^2=0.13$  (95% CI 0.00-0.04;  $P<.001$ ) and more social isolation (only the least deprived quintile),  $F_{6,872}=11.60$ ,  $r^2=0.08$  (95% CI 0.04-0.10;  $P<.001$ ). For our fifth analysis on quality of life, the overall model was significant,  $F_{6,860}=6.19$ ,  $r^2=0.03$  (95% CI 0.01-0.06;  $P<.001$ ). However, only female sex ( $P=.03$ ) was a significant predictor of worse quality of life. Overall, these analyses indicated that living in the most deprived neighborhoods (quintile=1) predicted worse mental health, increased social isolation, and poorer physical health.

### Residential Population Density

Hierarchical linear regression analyses assessed whether residential population density significantly predicted self-reported outcomes after controlling for the age and sex of participants. We found that age ( $P<.01$ ) but not sex ( $P>.05$ ) was a significant predictor in all 5 regression models, indicating that younger participants were more likely to live in

neighborhoods with higher population density. With regard to self-reported outcomes, the severity of anxiety and depressive symptoms and reporting more social isolation and poorer physical health were not predictive of living in a more populated neighborhood ( $P>.05$ ). By contrast, participants who reported poor quality of life were more likely to live in a more populated area than those who reported excellent quality of life,  $t_{861}=2.21$ ,  $\beta=-.31$  (95% CI  $-0.58$  to  $-0.03$ ;  $P=.03$ ).

### Household Composition

Pearson correlations found small, but significant relationships between higher household composition and more anxiety ( $r=0.07$ ;  $P=.01$ ) and depressive symptoms ( $r=0.07$ ;  $P=.01$ ). Higher household composition was, however, related to *less* social isolation ( $r=-0.06$ ;  $P=.07$ ), although this result did not reach significance. Household composition was not related to physical health or quality of life ( $P>.05$ ).

### Differences Between Groups

We found that participants with mental health disorders reported significantly more anxiety and depressive symptoms, more social isolation, worse physical health, and poorer quality of life than those without a mental health disorder (all  $P<.001$ ) after controlling for age, sex, level of residential socioeconomic deprivation, and comorbid medical conditions (Table 2). Tables 2-4 focus on specific group contrasts; however, the covariates in each model are identical. Thus, the following model-level goodness-of-fit statistics apply to each model: Anxiety (PROMIS 7 T-score),  $R^2=0.224$ ; Depression (PHQ-9 total score),  $R^2=0.298$ ; Social Isolation (UCLA 10-item total),  $R^2=0.114$ ; Social Isolation (UCLA 3-item total),  $R^2=0.111$ ; Physical Health (PROMIS T-score),  $R^2=0.204$ ; and quality of life (PROMIS T-score),  $R^2=0.091$ .

After controlling for age, sex, level of residential socioeconomic deprivation, and comorbid mental health disorders, we found that participants with medical conditions reported significantly more anxiety ( $P=.003$ ) and depressive symptoms ( $P=.002$ ), and worse physical health (all  $P<.001$ ) than those without a medical condition. Social isolation and quality of life were similar for both groups ( $P>.05$ ; Table 3).



After controlling for sex, level of residential socioeconomic deprivation, and comorbid mental health *and* medical conditions, we found that contrary to hypotheses, participants under 65 years of age reported significantly more anxiety and depressive symptoms and more social isolation than those over 65 years

of age (all  $P$ s<.001). They also reported slightly better quality of life ( $P$ =.05), although both groups were in the average range according to the measure classifications. Participants over and under 65 years reported similar physical health ( $P$ =.88; Table 4).

**Table 2.** Differences in self-reported outcomes for those with and without mental health disorders.

| Self-reported outcomes                            | n   | No mental health disorder, LSM <sup>a</sup> (SE) | n   | Mental health disorder, LSM (SE) <sup>b</sup> | LSM difference (CI) | <i>t</i> ( <i>df</i> ) | $\eta^2$ | <i>P</i> |
|---|-----|--|-----|---|---------------------|------------------------|----------|----------|
| Anxiety: PROMIS 7a <sup>c</sup> T-score           | 987 | 52.2 (0.4)                                       | 227 | 60.6 (0.7)                                    | -8.4 (-9.8 to -6.9) | -11.3 (866)            | 0.9      | <.001    |
| Depression: PHQ-9 <sup>d</sup> total score        | 970 | 4.0 (0.2)  | 218 | 10.4 (0.4)                                    | -6.4 (-7.2 to -5.6) | -15.5 (849)            | 0.6      | <.001    |
| Social Isolation: UCLA <sup>e</sup> 10-item total | 978 | 19.4 (0.3)                                       | 224 | 23.4 (0.5)                                    | -4.1 (-5.1 to -3.1) | -8.1 (858)             | 0.9      | <.001    |
| Social Isolation: UCLA 3-item total               | 978 | 6.3 (0.1)  | 224 | 7.6 (0.2)                                     | -1.3 (-1.7 to -1.0) | -7.1 (858)             | 0.9      | <.001    |
| Physical Health: PROMIS T-score                   | 963 | 51.7 (0.4)                                       | 217 | 46.3 (0.7)                                    | 5.4 (4.0 to 6.8)    | 7.4 (847)              | 1.0      | <.001    |
| QOL <sup>f</sup> : PROMIS T-score                 | 961 | 48.9 (0.5)                                       | 217 | 41.6 (0.9)                                    | 7.4 (5.6 to 9.2)    | 8.0 (847)              | 1.0      | <.001    |

<sup>a</sup>LSM: least square mean.

<sup>b</sup>SE: standard error.

<sup>c</sup>PROMIS: Patient-Reported Outcomes Measurement Information System.

<sup>d</sup>PHQ-9: 9-item Patient Health Questionnaire.

<sup>e</sup>UCLA: UCLA Loneliness Scale.

<sup>f</sup>QOL: quality of life.

**Table 3.** Differences in self-reported outcomes for those with and without medical conditions.

| Self-reported outcomes                            | n   | No medical condition, LSM <sup>a</sup> (SE) | n   | Medical condition, LSM (SE) <sup>b</sup> | LSM difference (CI) | <i>t</i> ( <i>df</i> ) | $\eta^2$ | <i>P</i> |
|---|-----|---|-----|--|---------------------|------------------------|----------|----------|
| Anxiety: PROMIS 7a <sup>c</sup> T-score           | 848 | 56.2 (2.0)                                  | 396 | 58.1 (2.1)                               | -1.9 (-3.1 to -0.6) | -2.9 (866)             | 1.0      | .003     |
| Depression: PHQ-9 <sup>d</sup> Total score        | 831 | 8.2 (1.1)                                   | 386 | 9.3 (1.1)                                | -1.1 (-1.8 to -0.4) | -3.1 (849)             | 0.5      | .002     |
| Social Isolation: UCLA <sup>e</sup> 10-item total | 842 | 21.1 (1.4)                                  | 390 | 21.6 (1.4)                               | -0.5 (-1.3 to 0.4)  | -1.5 (858)             | 0.9      | .25      |
| Social Isolation: UCLA 3-item total               | 842 | 6.7 (0.5)                                   | 390 | 6.9 (0.5)                                | -0.3 (-0.6 to 0.02) | -1.9 (858)             | 0.9      | .06      |
| Physical Health: PROMIS T-score                   | 823 | 45.8 (2.0)                                  | 385 | 52.6 (2.0)                               | 6.9 (5.6 to 8.1)    | 11.1 (847)             | 1.0      | <.001    |
| QOL <sup>f</sup> : PROMIS T-score                 | 821 | 43.2 (2.5)                                  | 385 | 42.6 (2.5)                               | 0.7 (-0.9 to 2.2)   | 0.8 (847)              | 1.0      | .40      |

<sup>a</sup>LSM: least square mean.

<sup>b</sup>SE: standard error.

<sup>c</sup>PROMIS: Patient-Reported Outcomes Measurement Information System.

<sup>d</sup>PHQ-9: 9-item Patient Health Questionnaire.

<sup>e</sup>UCLA: UCLA Loneliness Scale.

<sup>f</sup>QOL: quality of life.

**Table 4.** Differences in self-reported outcomes for those over and under 65 years.

| Self-reported outcomes                            | n   | Under 65 years, LSM (SE) <sup>a</sup> | n   | Over 65 years, LSM (SE) <sup>b</sup> | LSM difference (CI) | <i>t</i> ( <i>df</i> ) | $\eta^2$ | <i>P</i> |
|---|-----|---------------------------------------|-----|--------------------------------------|---------------------|------------------------|----------|----------|
| Anxiety: PROMIS 7a <sup>c</sup> T-score           | 800 | 58.6 (2.0)                            | 444 | 55.7 (2.1)                           | 3.0 (1.7 to 4.2)    | 4.7 (866)              | 1.0      | <.001    |
| Depression: PHQ-9 <sup>d</sup> Total score        | 827 | 9.8 (1.1)                             | 454 | 7.8 (1.2)                            | 2.0 (1.3 to 2.7)    | 5.7 (849)              | 0.5      | <.001    |
| Social Isolation: UCLA <sup>e</sup> 10-item total | 827 | 22.2 (1.4)                            | 454 | 20.5 (1.4)                           | 1.7 (0.8 to 2.5)    | 3.9 (858)              | 0.9      | <.001    |
| Social Isolation: UCLA 3-item total               | 827 | 7.1 (0.5)                             | 454 | 6.5 (0.5)                            | 0.6 (0.3 to 1.0)    | 4.1 (858)              | 0.9      | <.001    |
| Physical health: PROMIS T-score                   | 827 | 49.2 (2.0)                            | 454 | 49.3 (1.9)                           | 0.1 (-1.1 to 1.3)   | 0.2 (847)              | 1.0      | .88      |
| QOL <sup>f</sup> : PROMIS T-score                 | 827 | 42.1 (2.5)                            | 454 | 43.6 (2.5)                           | -1.5 (-3.0 to -0.1) | -1.98 (847)            | 1.0      | .05      |

<sup>a</sup>LSM: least square mean.

<sup>b</sup>SE: standard error.

<sup>c</sup>PROMIS: Patient-Reported Outcomes Measurement Information System.

<sup>d</sup>PHQ-9: 9-item Patient Health Questionnaire.

<sup>e</sup>UCLA: UCLA Loneliness Scale.

<sup>f</sup>QOL: quality of life.

## The United States

At baseline, participants in the smaller-scale US ATTACH study ( $n=90$ ) were younger than the UK sample (mean 47.1 [SD 13.1]), more likely to identify as Black/African American (45/90, 50%), be employed (69/90, 77%), be key or essential workers (40/90, 44%), be parents of children under 16 years (34/90, 38%), and be educated at the college/university level or higher (85/90, 94%). Participants in the United States were less likely than those living in the UK to report that they were married (42/90, 47%), have a mental health disorder (12/90, 13%), and when reporting where they see themselves on the political spectrum; scores ranged from 0 to 100 (mean 34.0 [SD 21.6]). The 2 samples were similar in that the majority were female (68/90, 76%), English speakers (78/90, 87%), reported having a medical condition (26/90, 29%), most lived in a 2-person household (33/90, 37%), and less than a quarter (22/90, 24%) reported that their income had been affected by the COVID-19 pandemic ([Multimedia Appendix 9](#)).

## Mexico

During the first wave of baseline assessments, the Mexico ATTACH study ( $n=80$ ) had been collecting data for less than 1 month. Participants were more likely than the UK sample to be younger than 40 years (71/80, 89%), identify as mixed/multiple ethnic groups (40/80, 50%), be single (48/90, 53%), be unemployed or employed without income (ie, furloughed; 42/80, 53%), to live in a 3-person household or larger (58/80, 73%), and be a caregiver to a child under 16 years (17/80, 21%). Similar to the UK sample, most participants were female (59/80, 74%), were educated to the college/university level or higher (48/80, 60%), had a mental health disorder (22/80, 28%), and when reporting where they see themselves on the political spectrum; scores ranged from 0 to 100 (mean 46.9 [SD 25.3]; [Multimedia Appendix 10](#)).

## Discussion

### Principal Findings

This paper offers a description of longitudinal trends in attitudes and behaviors related to the COVID-19 pandemic. Additionally, we report descriptive data from 2 smaller-scale mirror studies conducted in the United States and Mexico for comparison. Descriptive data for the UK daily poll questions indicated that participants generally followed social distancing measures, but worry and negative impact on families increased as the pandemic progressed. Our cross-sectional baseline assessment in a UK adult population indicated that those with poorer mental health outcomes lived in more deprived neighborhoods, in larger households, had more preexisting mental health disorders and medical conditions, and were younger than 65 years.

In terms of the UK pandemic trajectory, cases and deaths were relatively stable for most of this period, with more rapid increases observed only in the final month. UK longitudinal smartphone data from 6 poll questions indicated that as the pandemic progressed and the 7-day rolling average of cases and deaths began to increase rapidly, participants became more worried about the pandemic with a corresponding negative impact on their families. Although most people felt that information about the COVID-19 pandemic had been conveyed clearly, their trust in the government response was much lower. Nevertheless, participants reported generally following social distancing measures (responses varied between 50% and 99%), and 30%-40% of participants also reported spending more time than usual using social media, even though the average age of our UK sample was nearly 60 years.

Cross-sectional data from our first-wave baseline assessments in the UK yielded several important findings. Participants with preexisting mental health disorders reported worse outcomes

across all mental health and psychosocial indicators. Unsurprisingly, those with preexisting mental disorders reported more symptomatology. However, those with medical conditions and younger participants (age < 65) also had increased psychological symptomatology. Specifically, 139/396 (35.1%) and 50/386 (13.0%) of participants with chronic medical conditions reported currently experiencing moderate-to-severe anxiety and depressive symptoms, respectively. Similarly, 285/827 (34.5%) and 93/827 (11.2%) of younger participants (<65 years) reported currently experiencing moderate-to-severe anxiety and depressive symptoms, respectively.

These data parallel other UK cohort studies conducted during the COVID-19 pandemic, as we found that depressive and anxiety symptomatology was higher in our UK sample relative to epidemiological data collected before the COVID-19 pandemic [49-52]. We had hypothesized that older adults (>65 years) in our sample would experience worse mental health outcomes than younger participants because older people are at higher risk for worse COVID-19-related outcomes. However, after controlling for demographic factors and comorbid mental health and medical conditions, this was not the case. Instead, our data suggest chronic medical conditions are a greater risk factor than older age for poor mental health outcomes. The relationships identified between deprivation, population density, and household composition suggest that they may be surrogates for poorer housing, overcrowding, or the need to use public transportation, which increase the risk of COVID exposure.

Consistent with other online surveys assessing mental health outcomes, women were over-represented in our study sample [51]. Although this overrepresentation limits some of our conclusions, women are experiencing a disproportionate economic and employment burden related to COVID-19, along with mothers having increased childcare responsibilities [53]. These factors could have long-term deleterious effects on mental health. As our study moves into longitudinal analysis, we can determine how mental health symptoms are related to attitudes and behaviors associated with COVID-19 and whether robust, rather than uncertain, public health measures ameliorate mental health difficulties [54]. Future interventions will need to be tailored to individual and community needs while tackling entrenched preexisting mental health inequities.

Other notable findings from this study were the relationship between mental health, psychosocial outcomes, and potential risk factors, although they likely existed before the COVID-19 pandemic. Data revealed that those with poor quality of life were more likely than those with excellent quality of life to live in more populated neighborhoods. Further, higher household composition was related to more anxiety and depressive symptoms, but appeared protective with regard to social isolation. Most prominently, living in the most socioeconomically deprived neighborhoods (quintile=1) was predictive of worse outcomes for all indicators, except quality of life. These results are concerning because they indicate the potential for an exacerbation of preexisting inequities, particularly if future interventions are not tailored with a consideration of these factors. Evidence shows that those who live in the most deprived neighborhoods are hospitalized more frequently for COVID-19 infections [55]. Our results indicate

that the impact of neighborhood deprivation may not only encompass physical health but may be more wide ranging and include mental health and quality of life.

Many participants reported physical health changes since the pandemic began. Strikingly, 57.72% (740/1282) of participants reported being more sedentary, and 41.89% (537/1282) reported engaging in less physical activity. These results are in conjunction with 40.95% (525/1282) of participants reporting receiving less preventative or routine medical care. Lockdown measures have reduced physical activity opportunities, and these restrictions to limit the spread of COVID-19 infection may result in a less healthy populace [51]. Given the importance of early detection for many diseases, the impact of reduced preventative care combined with poorer engagement in health-promoting behaviors may be profound. As the risk of infection may remain high for some time, medical providers, administrators, and policymakers should continue to assess procedures to optimize care for all patients as well as identify safe avenues for increasing daily physical activity and reducing time spent sedentary [56].

### Limitations

There are limitations of the findings reported in this study. A potential limitation of our survey study is self-selection bias, as participants may have joined the study because they were particularly interested in the topic. Although we used various recruitment methods, targeted efforts to improve representation, and placed a strong emphasis on anonymity and confidentiality, our UK sample was more likely to be White and from higher educational backgrounds, which is not representative of the UK population and so limits the generalizability of our findings to non-White and lower-income communities. Efforts to engage and form partnerships have begun to increase the representativeness of our sample for future longitudinal analyses. Additionally, data from Mexico ATTACH currently include over 1200 baseline assessments, so diverse between-country analyses will be possible for future waves. However, for the current UK baseline assessment, cultural factors and behavioral strategies specific to the UK, such as strong public messaging to protect the NHS, may mean our results do not generalize outside the UK.

This study began recruiting after the first UK lockdown (March 2020), so we lack real-time data from before the COVID-19 pandemic and cannot know if symptomatology has changed. Further, indicators of preexisting mental health disorders and chronic medical conditions were based on self-report rather than clinical diagnoses. Given the unprecedented nature of the pandemic, we prioritized rapid deployment and data collection and so did not pilot test poll questions. However, many of the questions mirror those of other newly developed studies [57,58]. The fast changes related to the pandemic meant that we could not consider all possible predictors before study initiation, so there are no measures related to quarantine status, fear of COVID-19, duration of exposure to COVID-19-related information, and infection risk perception. Although 87% of the UK population has access to a smartphone, just 53% of those aged 65 or older have internet access via smartphone ownership [59]. Access to digital devices and the internet are also limited

among other marginalized communities. Therefore, those who are digitally excluded are likely to be underrepresented in our sample.

### Strengths

Strengths of our study include the mix of cross-sectional and longitudinal data collection methodology with the ability to assess daily attitudes and behaviors during the rapidly changing COVID-19 pandemic. Through the use of smartphone technology and mHealth, we can capture real-time responses and bridge physical distance. Participants completed most measures with little missing data, indicating that items were not burdensome. Finally, although our UK sample needs to increase representation related to ethnic and racialized identities, our Mexican sample includes a cross-section of communities. Through targeted recruitment, the United States sample includes an overrepresentation of participants who identified as Black or African American.

### Implications

Smartphone apps are increasingly recognized as potentially powerful tools for mHealth studies and interventions [60,61]. They have been utilized successfully in adult and pediatric chronic illness populations [62-65] and in ecological momentary assessment studies and interventions [66,67]. Data from the UK ATTACH study demonstrate that people are also prepared to answer daily questions and provide mental health data in a

longitudinal study using smartphone technology. Optimizing digital approaches and integrating them into the public health response is possible while considering logistical and technological barriers. However, currently, there is limited evidence that mHealth apps and interventions are cost-effective or cost-saving [68,69]. This engagement increases the feasibility of undertaking potentially sensitive longitudinal research and reduces retrospective judgments that tend to be affected by recall bias [67]. Because of this engagement, moving forward, the Mexico ATTACH study will use the Telegram messaging system to collect daily poll data, as they are widely accessible with an encrypted point-to-point connection. As we move forward, it will be necessary to include participants' input early in the research process to engender long- and short-term engagement [70].

### Conclusions

Our data indicate that those with mental health disorders and chronic medical conditions are experiencing increased anxiety and depressive symptoms. Socioeconomic deprivation also appears to be a considerable risk factor for poor mental health. Although these challenges are not new, they could become more deep-rooted and challenging to tackle in this new COVID-19 era and beyond. Along with a renewed focus on mental health, investment to increase access to preventative medical care and messaging to encourage health-promoting behaviors, including physical activity, will be critical.

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### Authors' Contributions

AH, HS, JM, MK, AS, CS, MP, NC-F, AR-A, MM, SW, MK, FK, and LC contributed to the conception and design of the study. AH, HS, JM, MK, AS, CS, MP, NC-F, AR-A, AB, AN, SG, MM, SW, MK, FK, and LC contributed to the organization of the conduct of the study. AH, CS, MP, NC-F, AR-A, AB, AN, and SG carried out the study (including data acquisition). AH and AS analyzed the data. AH drafted the initial output. All authors contributed to the interpretation of data. All authors have read and approved the final version of the manuscript.

### Conflicts of Interest

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#### Multimedia Appendix 1

Complete list of daily poll questions and the assessment schedule.

[[DOCX File, 28 KB - mental\\_v8i10e29963\\_app1.docx](#)]

#### Multimedia Appendix 2

Validated measures and assessment schedule in the ATTACH Study.

[[DOCX File, 17 KB - mental\\_v8i10e29963\\_app2.docx](#)]

## Multimedia Appendix 3

Non-validated measures and assessment schedule in the ATTACH Study.

[\[DOCX File , 15 KB - mental\\_v8i10e29963\\_app3.docx \]](#)

## Multimedia Appendix 4

Measures used in the ATTACH study.

[\[DOCX File , 1442 KB - mental\\_v8i10e29963\\_app4.docx \]](#)

## Multimedia Appendix 5

Recruitment strategies and example Facebook advertisement used in the ATTACH study.

[\[DOCX File , 835 KB - mental\\_v8i10e29963\\_app5.docx \]](#)

## Multimedia Appendix 6

Mental health disorders and medical conditions reported in the ATTACH study.

[\[DOCX File , 16 KB - mental\\_v8i10e29963\\_app6.docx \]](#)

## Multimedia Appendix 7

Participant characteristics at baseline in the UK ATTACH Study from June 26 to October 31, 2020.

[\[DOCX File , 20 KB - mental\\_v8i10e29963\\_app7.docx \]](#)

## Multimedia Appendix 8

Participant clinical classifications and severity on self-reported outcomes at baseline in the UK ATTACH study from June 26 to October 31, 2020.

[\[DOCX File , 15 KB - mental\\_v8i10e29963\\_app8.docx \]](#)

## Multimedia Appendix 9

Participant characteristics at baseline in the USA ATTACH Study from June 26 to October 31, 2020.

[\[DOCX File , 18 KB - mental\\_v8i10e29963\\_app9.docx \]](#)

## Multimedia Appendix 10

Participant characteristics at baseline in the Mexico ATTACH Study from October 6 to October 31, 2020.

[\[DOCX File , 18 KB - mental\\_v8i10e29963\\_app10.docx \]](#)

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## Abbreviations

**AMO:** Air My Opinion

**ATTACH:** Attitudes About COVID-19 and Health

**GDPR:** General Data Protection Regulation

**NHS:** National Health Service

**PROMIS:** Patient-Reported Outcomes Measurement Information System

**PHQ-9:** 9-item Patient Health Questionnaire

**REDCap:** Research Electronic Data Capture

**STROBE:** STrengthening the Reporting of OBServational studies in Epidemiology

**UCL:** University College London

**UCLA-10:** 10-item University of California Los Angeles Loneliness Scale

**WHO:** World Health Organization



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Original Paper

# Supporting the Mental Health Needs of Military Partners Through the Together Webinar Program: Pilot Randomized Controlled Trial

Laura Josephine Hendrikkx<sup>1\*</sup>, BSc, MScRes, MSc; Dominic Murphy<sup>1,2\*</sup>, MA, PhD, DclinPsy

<sup>1</sup>Combat Stress, Leatherhead, United Kingdom

<sup>2</sup>King's Centre for Military Health Research, King's College London, London, United Kingdom

\* all authors contributed equally

**Corresponding Author:**

Dominic Murphy, MA, PhD, DclinPsy

Combat Stress

Tyrwhitt House

Oaklawn Road

Leatherhead, KT22 0BX

United Kingdom

Phone: 44 01372 587 017

Email: [dominic.murphy@combatstress.com](mailto:dominic.murphy@combatstress.com)

## Abstract

**Background:** Despite an increased risk of psychological difficulties, there remains a lack of evidence-based support for the mental health needs of military partners.

**Objective:** This study aims to investigate whether the Together Webinar Programme (TTP-Webinar), a 6-week structured, remote access group intervention would reduce military partners' experience of common mental health difficulties and secondary trauma symptoms.

**Methods:** A pilot randomized controlled trial was used to compare the TTP-Webinar intervention with a waitlist control. The sample was UK treatment-seeking veterans engaged in a mental health charity. A total of 196 military partners (1 male and 195 females; aged mean 42.28, SD 10.82 years) were randomly allocated to the intervention ( $n=97$ ) or waitlist ( $n=99$ ) condition. Outcome measures were self-reported measures of common mental health difficulties, secondary trauma symptoms, and overall quality of life rating.

**Results:** Compared with the waitlist, military partners in the TTP-Webinar had reduced common mental health difficulties ( $P=.02$ ) and secondary trauma symptoms ( $P=.001$ ). However, there was no difference in quality-of-life ratings ( $P=.06$ ).

**Conclusions:** The results suggest that TTP-Webinar is an effective intervention to support the mental health difficulties of military partners. This study provides promising evidence that webinars may be an appropriate platform for providing group-based support.

**Trial Registration:** ClinicalTrials.gov NCT05013398; <https://clinicaltrials.gov/ct2/show/NCT05013398>

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**KEYWORDS**

mental health support; online group-based support; military partners

## Introduction

Military partners are at an increased risk of developing psychological difficulties, including problematic alcohol use, depression, anxiety, and symptoms resembling posttraumatic stress disorder (PTSD) [1-4]. This risk may partially be understood in the context that many military partners adopt a caregiving role that supports veterans' mental and physical health difficulties [2]. Military partners report increased feelings

of isolation, emotional pressure, and relationship inequality [5], and may perceive limited opportunities to develop their own self-identity within the context of the romantic relationship [6]. Furthermore, many adopt a sense of responsibility to manage stressors that may trigger veterans' PTSD symptoms [7]. Findings suggest that this population may experience greater distress than the public (44.9%) and other caregivers (eg, 29.5% among dementia caregivers) [8,9] and that such increased burden may increase their own risk of developing health difficulties

[3]. Being exposed to the adverse details of veteran military experiences, many partners may also go on to develop symptoms typical of PTSD (*secondary traumatization*) [4]. Finally, additional stressors such as employment status, ex-military status, length of veteran deployment, and veteran treatment stage may also impact military partners' well-being [1,8,10]. Despite the clear need for appropriate support for military partners, there remains a lack of evidence-based treatment for this population's specific mental health needs. Much of the support available for military partners is typically offered in the context of the family unit or in tandem with the veteran [11,12]. Although such interventions do reveal positive improvements in partner well-being [13], they may overlook the unique challenges faced by military partners. A recent review highlighted that there remains a paucity of programs that specifically and appropriately target military partners and their vulnerabilities [13].

Military partners face a range of barriers that may prevent them from seeking or engaging with psychological support, which may contribute to the disparity between the number of those in need of support and those who report being able to access and engage with such support [1,14]. Military families often adopt the concept of toughness and self-reliance promoted in military culture [15], and partners' negative beliefs about support-seeking behaviors and associated feelings of shame may discourage them from seeking support [6,16]. Many partners report concerns that others do not understand the difficulties they face [1]. They may also avoid seeking support for themselves in an attempt to protect veterans from being identified as having psychological difficulties, which in turn may further heighten their own distress [17]. Such concerns reflect the unique challenges faced in military relationships as compared with civilian counterparts. In addition to such stigma-related barriers, military partners face practical barriers to seeking support. Many partners assume responsibility as the family's main financial provider, as chronic psychological difficulties often make it difficult for veterans to maintain a permanent job [6]. In addition to being an additional stressor, this introduces restrictions in partners' time availability, and concerns that requesting time off from work would threaten their job security may prevent them from engaging with support [16]. Similarly, many military partners may also adopt the main caregiving role for children, as veterans with PTSD may demonstrate violent behavior and respond in an aggressive manner within the family home [18]. Veterans' symptoms of PTSD and lack of interest in maintaining social connections may result in partners becoming increasingly isolated from friends and family [19], and they may end up supporting veterans in the absence of any psychological or social support to manage their own distress. Clearly, it is essential to consider how to make evidence-based treatment most accessible to military partners.

The Together Programme (TTP) is a 5-week community-based intervention that was developed to support the mental health needs of partners living alongside veterans with PTSD and other mental health difficulties. TTP is a manualized psychoeducational intervention that aims to provide military partners with an understanding of the mental health difficulties that arise following trauma and to equip them with the practical

tools to empower them in supporting the veteran's management of their symptoms while ensuring their own well-being. When piloted across 9 UK locations, TTP demonstrated promising reductions in military partners' mental health difficulties and secondary trauma symptoms [16]. However, this study revealed that many partners were unable to engage with support because of work responsibilities, a lack of flexibility in working hours, childcare responsibilities, and issues regarding traveling distance to the venue [16]. In an attempt to increase the accessibility of mental health support for military partners, TTP was adapted into a web-based 6-week webinar intervention named the Together Webinar Programme (TTP-Webinar). Previous research comparing web-based and face-to-face support within military contexts has demonstrated similar levels of efficacy and acceptability, as well as potentially lower rates of attrition, among web-based modalities [20-22]. This study is a randomized, waitlist-controlled pilot trial that examines the effectiveness of TTP-Webinar in supporting the mental health needs of military partners. It was hypothesized that the TTP-Webinar would result in significant reductions in general psychological distress and secondary trauma symptoms, as well as improvements in overall quality of life (QoL).

## Methods

### Design and Registration

This study is a pilot randomized controlled waitlist trial (RCT) approved by the research department at the charity through which participants were recruited. The study was not prospectively registered as it was conducted to test the feasibility of offering support to military partners via a remote access group intervention and was administered as a treatment within a mental health treatment center.

### Study Recruitment

The sample of this study is partners of veterans experiencing PTSD or other mental health difficulties. Participants were recruited by writing to veterans who had engaged with Combat Stress seeking support for mental health difficulties between April 2018 and April 2019. Combat Stress is a UK-based charity offering nationwide support for veterans with mental health difficulties and receives a high number of yearly referrals, suggesting that the current sample is likely representative of partners of veterans with mental health difficulties. A total of 2051 veterans were contacted, informed about the study, and asked for consent to reach out to their partners. Once the veterans provided consent, partners were contacted directly by a research assistant and were informed about the study. Participants were screened as eligible if they were currently in an intimate relationship with a veteran who (1) met the criteria for PTSD and (2) was previously or currently engaged with Combat Stress. Of the 285 partners who expressed interest in the study, 196 (age mean 42.28, SD 10.82 years; 195 females and 1 male) provided consent, completed baseline measures that were mailed to them, and were randomly allocated to the study conditions.

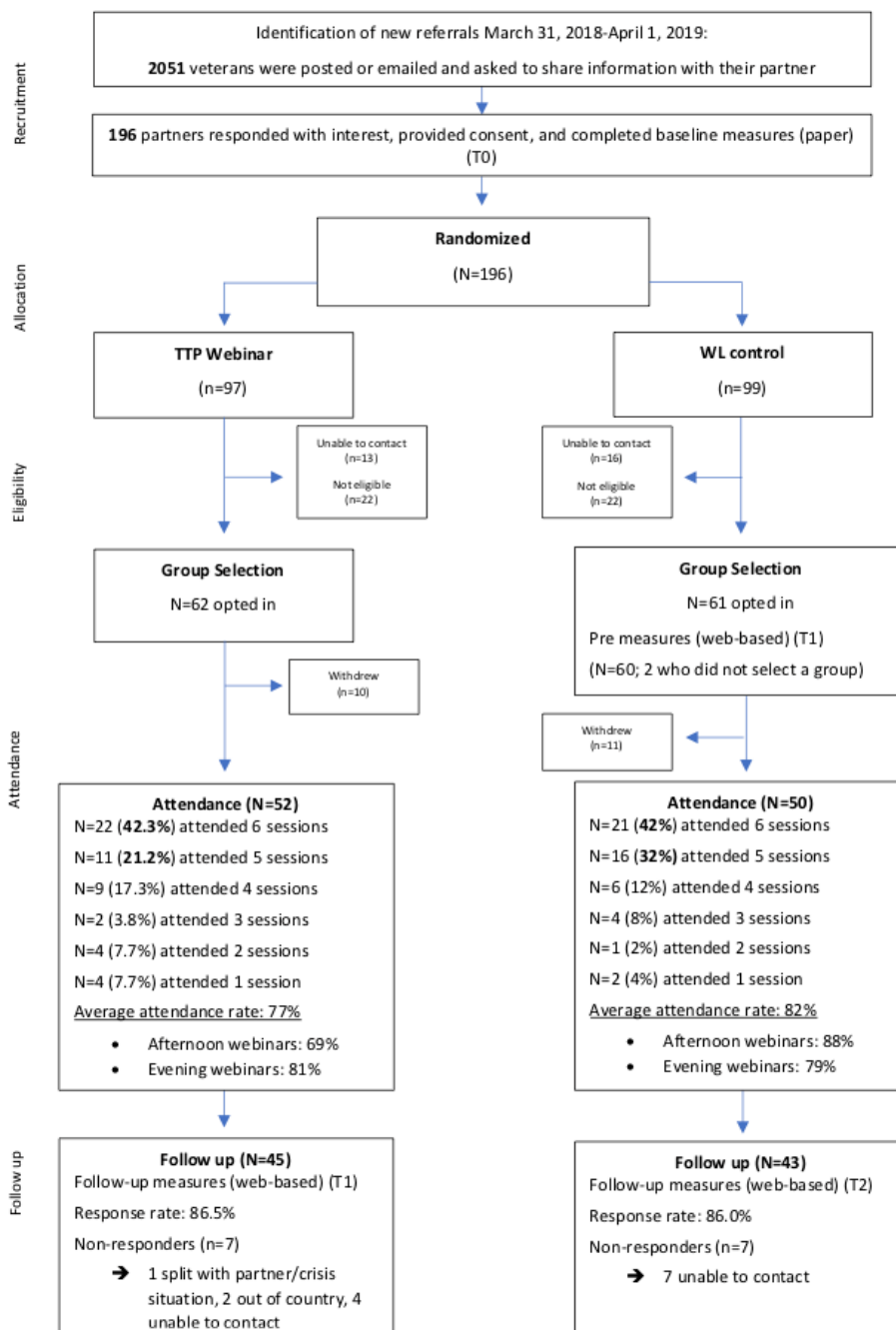
### Participants

An a priori power analysis indicated that the study required a sample size of 24 participants per condition to attain a power of 0.80 to detect a 5-point reduction on the General Health Questionnaire-12 (GHQ-12) with an SD of 6.0, assuming a standard 95% significance level. Assuming a conservative 25% dropout rate, 6 additional participants were calculated per condition, yielding a minimum sample of 60 participants.

The flow of the participants in this study is described in Figure 1. A total of 196 partners provided consent, completed baseline measures, and were randomized to either the TTP-Webinar intervention (n=97) or the waitlist condition (n=99). Following

randomization, 29 participants were not available, 44 were no longer eligible (eg, ended their relationship with a veteran), and 21 withdrew from the study because of difficulties with technology availability and use, previous engagement in the community TTP, childcare responsibilities, etc. As we aim to evaluate the TTP-Webinar for those who used it, these participants were excluded, and analyses included only participants who took part in at least 1 webinar session. The final sample consisted of 102 female partners (age mean 48.59, SD 10.74 years), of which 52 were randomized to the TTP-Webinar intervention and 50, to the waitlist condition. The demographic characteristics of the participants are shown in Table 1.

**Figure 1.** Graphical layout of participant flow in this study. TTP-Webinar: The Together Webinar Programme; WL: waitlist.



**Table 1.** Demographic information of participants who completed baseline measures, were randomized, and registered to a group in the TTP-Webinar intervention and waitlist condition<sup>a,b</sup>.

| Demographics   | Participant characteristics (N=102) |
|--|-------------------------------------|
| Age (years), mean (SD)   | 48.59 (10.74)                       |
| <b>Living with partner, n (%)</b>  |                                     |
| Yes  | 90 (88.2)                           |
| No   | 10 (9.8)                            |
| <b>Length of relationship (years), n (%)</b>   |                                     |
| <9   | 37 (36.2)                           |
| >9   | 64 (62.7)                           |
| <b>Dependents, n (%)</b>   |                                     |
| Yes  | 50 (49)                             |
| No   | 50 (49)                             |
| <b>Ex-military, n (%)</b>  |                                     |
| Yes  | 8 (7.8)                             |
| No   | 93 (91.2)                           |
| <b>Employment status, n (%)</b>  |                                     |
| Full-time  | 46 (45.1)                           |
| Part-time  | 27 (26.5)                           |
| Not working, seeking employment  | 19 (18.6)                           |
| <b>Level of education, n (%)</b>   |                                     |
| Low (A levels or HNDs <sup>c</sup> or NVQ <sup>d</sup> or GCSEs <sup>e</sup> , or lower) | 63 (61.8)                           |
| High (degree or postgraduate)  | 36 (35.2)                           |

<sup>a</sup>Because of missing data, numbers may not add up to the sample size and percentages may not add up to 100%.

<sup>b</sup>For participants who selected two responses, the average of both responses was entered. In the case of level of education and length of relationship, the highest response was considered.

<sup>c</sup>HND: Higher National Diploma.

<sup>d</sup>NVO: National Vocational Training.

<sup>e</sup>GCSE: General Certificate of Secondary Education.

## Procedure

Participants were informed of the study, provided consent, and returned completed baseline measures that were mailed to them. They were then randomized to the intervention or waitlist condition and rescreened for eligibility by the study coordinator via telephone.

Participants in the intervention condition were instructed to sign up to 1 of the 5 intervention groups that ran from June to July 2019. Participants in the waitlist condition were informed that they would receive details regarding the TTP-Webinar at a later point. Participants completed posttreatment measures 1 month after completion of the TTP-Webinar. To reduce nonresponse, they were sent reminder emails and, if necessary, were called by a research assistant up to three times to complete the measures via telephone. Two weeks before the waitlist groups were commenced, participants randomized to the waitlist condition were contacted via email and instructed to complete measures and sign up to 1 of the 4 waitlist groups that ran from August to September 2019.

At the end of the treatment, participants who took part in the TTP-Webinar were provided links to recordings of the 6 webinar sessions and additional self-help literature and were sent a certificate of participation if they completed the program (ie, attended at least four webinar sessions). All participants were reimbursed for their participation in a British £10 (US \$13.9) Amazon voucher.

## TTP-Webinar

TTP-Webinar is a web-based adaptation of the TTP [16]. The development of TTP involved an initial review of existing programs developed to support veterans and their mental health. Two psychoeducational programs, Support and Family Education Programme [23] and Homefront Strong [24] were identified as particularly relevant. The content of the two programs was explored and adapted to meet the needs of UK partners through a process of surveying military partners to understand their needs and relevant content and format. TTP incorporates a range of techniques used in cognitive behavioral therapy (eg, to understand the maintenance of PTSD), dialectical behavioral therapy (eg, to recognize own emotions and maintain

healthy boundaries), compassion focused therapy (eg, to access and develop one's own soothing system), and acceptance and commitment therapy (eg, to help reduce avoidance behaviors and promote meaningful activity engagement).

TTP-Webinar is a live webinar intervention developed to support the mental health needs of partners living alongside veterans with PTSD and other mental health difficulties. It is a manualized program consisting of 6 hour-long weekly sessions. The content of each session encompasses a focus on (1) psychoeducation and self-management strategies for supporting veterans with PTSD or other mental health difficulties, (2) self-management strategies and skills training to enhance their own self-care, and (3) between-session homework to practice using the introduced tools. The focus of each session of the TTP-Webinar can be found in the [Multimedia Appendix 1](#).

TTP-Webinar is delivered on a web-based platform that participants join via a link they receive. Group participants can see the facilitator and the relevant session material and presentation slides but are not able to see or hear other participants. They are encouraged to engage in the sessions by providing feedback, asking questions, and sharing their own experiences via the chat box that is viewed by all participants. During the 6-week program, participants were offered one 1:1 telephone contact, if requested, or if any risk concerns were identified.

### Outcome Measures

Demographic information was collected at baseline. Participants reported their overall QoL on a 5-point scale, ranging from 1 (*very good*) to 5 (*very bad*). Scores were reverse-scored for higher values to indicate a greater QoL.

### Measures for GHQ-12

The GHQ-12 is a self-report measure of psychological distress within the past month [25]. It contains 6 negative (eg, *Loss of sleep over worry*) and six positive (eg, *Able to face difficulties*) items that are scored on a 4-point Likert scale ranging from 0 (*not at all or much less than usual*) to 4 (*much more than usual or more so than usual*). Positive items were reverse-scored before calculating the total score, with higher scores indicating greater psychological distress.

### Measures for Secondary Traumatic Stress Scale

The Secondary Traumatic Stress Scale (STSS) is a self-report measure of secondary trauma symptoms within the past month [26]. The 17 items (eg, *It seems as if I am reliving the traumas experienced by my partner*) are scored on a 5-point Likert scale, ranging from 1 (*never*) to 5 (*very often*). Scores were summed to create a secondary trauma symptom score, as well as avoidance, arousal, and intrusion subscales. Higher scores indicated a greater severity of symptoms.

### Data Analysis

Missing data were inputted in a step-wise manner and were inputted only if 20% or less data on the GHQ-12 and STSS

were missing (across all time points). Inputted means for missing baseline data included all 196 participants who returned baseline measures. The input means for time point 1 only included participants who took part in the program and completed measures at the given time point. The input means were computed for each condition.

Independent sample *t* tests and chi-square tests were conducted on the demographics and main outcome measures to ensure there were no differences between participants who dropped out and those who took part. Similar analyses were conducted to ensure successful randomization between the intervention and waitlist conditions.

The data were then arranged to identify the time points ( $T_0$  and  $T_1$ ).  $T_0$  ratings were used to represent the baseline measures for both conditions.  $T_1$  was used to represent follow-up measures for the intervention condition and preintervention measures for the waitlist condition. Next,  $2 \times 2$  (condition: intervention vs waitlist  $\times$  time:  $T_0$  vs  $T_1$ ) repeated measures analysis of variance (RM-ANOVA) was conducted on the GHQ-12, STSS, and QoL scores, separately. Significant interactions were followed up using paired-sample *t* tests. Additional RM-ANOVAs were then conducted to explore potential differences in the avoidance, arousal, and intrusion STSS subscales.

## Results

### Dropout

Participants who opted out of the study did not significantly differ from those who took part in terms of common mental health difficulties ( $t_{194}=1.62$ ;  $P=.11$ ;  $d=0.23$ ) or secondary trauma symptoms ( $t_{194}=1.10$ ;  $P=.27$ ;  $d=0.16$ ). However, those who dropped out reported significantly poorer QoL (mean 2.97, SD 0.82) than those who opted in (mean 3.27, SD 0.83;  $t_{194}=2.47$ ;  $P=.01$ ;  $d=0.35$ ). In terms of demographic differences, significant differences emerged in terms of education level ( $\chi^2_1=9.5$ ;  $P=.002$ ;  $\phi=0.022$ ) and employment status ( $\chi^2_2=6.5$ ;  $P=.04$ ;  $V=0.08$ ). Although significant, further testing suggested that these differences were modest.

Additional analyses exploring differences in sociodemographic and military factors and mental health outcomes between those who dropped out of the intervention and waitlist condition are shown in Table S1 [Multimedia Appendix 1](#).

### Randomization

Table 2 demonstrates the demographics and mental health outcomes of the intervention and waitlist conditions. As can be noted, significant differences between the 2 groups were only observed in terms of education level ( $P=.03$ ), with a larger proportion of those in the intervention condition reporting lower educational achievement compared with the waitlist condition.

**Table 2.** Randomization of participants across the intervention and waitlist conditions<sup>a</sup>.

| Demographics   | Intervention (n=52) | Waitlist (n=50) | P value          |
|--|---------------------|-----------------|------------------|
| Age (years), mean (SD)   | 49.37 (11.08)       | 47.78 (10.43)   | .46              |
| <b>Living with partner, n (%)</b>  |                     |                 | .46              |
| Yes  | 47 (90.4)           | 43 (86.0)       |                  |
| No   | 4 (7.7)             | 6 (12.0)        |                  |
| <b>Dependents, n (%)</b>   |                     |                 | .23              |
| Yes  | 23 (44.2)           | 27 (54.0)       |                  |
| No   | 29 (55.8)           | 21 (42.0)       |                  |
| <b>Length of relationship (years), n (%)</b>   |                     |                 | .98              |
| <9   | 19 (36.5)           | 18 (36.0)       |                  |
| >9   | 33 (63.5)           | 31 (62.0)       |                  |
| <b>Ex-military, n (%)</b>  |                     |                 | .93              |
| Yes  | 4 (7.7)             | 4 (8.0)         |                  |
| No   | 48 (92.3)           | 45 (90.0)       |                  |
| <b>Employment status, n (%)</b>  |                     |                 | .42              |
| Full-time  | 22 (42.3)           | 24 (48.0)       |                  |
| Part-time  | 12 (23.1)           | 15 (30.0)       |                  |
| Not working, seeking employment  | 12 (23.1)           | 7 (14.0)        |                  |
| <b>Level of education, n (%)</b>   |                     |                 | .03 <sup>b</sup> |
| Low (A levels or HNDs <sup>b</sup> or NVQ <sup>c</sup> or GCSEs <sup>d</sup> or lower) | 37 (71.1)           | 26 (52.0)       |                  |
| High (degree or postgraduate)  | 13 (25.0)           | 23 (46.0)       |                  |
| <b>Mental health outcomes, mean (SD)</b>   |                     |                 |                  |
| QoL <sup>e</sup>   | 3.19 (0.79)         | 3.35 (0.88)     | .36              |
| GHQ-12 <sup>f</sup>  | 19.68 (6.33)        | 18.00 (6.60)    | .19              |
| <b>STSS<sup>g</sup></b>  | 47.51 (12.57)       | 45.40 (14.02)   | .43              |
| Avoidance  | 19.21 (5.06)        | 17.71 (6.56)    | .20              |
| Arousal  | 15.62 (4.33)        | 15.22 (4.33)    | .65              |
| Intrusions   | 12.68 (4.68)        | 12.47 (4.16)    | .81              |

<sup>a</sup>Gender is not presented in the table as all participants were female.

<sup>b</sup>HND: Higher National Diploma.

<sup>c</sup>NVO: National Vocational Training.

<sup>d</sup>GCSE: General Certificate of Secondary Education.

<sup>e</sup>QoL: Quality of Life.

<sup>f</sup>GHQ-12: General Health Questionnaire-12.

<sup>g</sup>STSS: Secondary Traumatic Stress Scale.

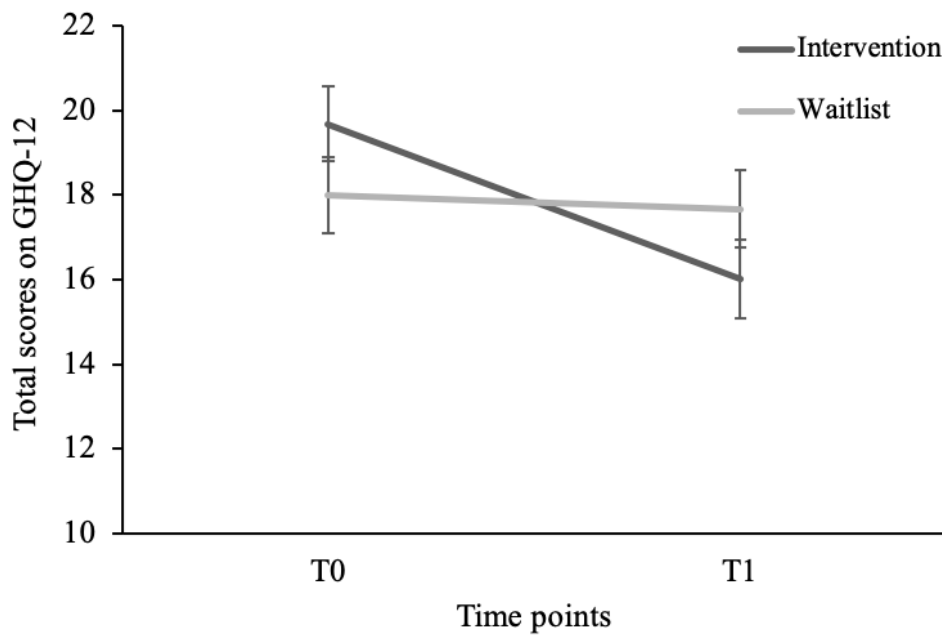
## Outcome Measures

### Measures for GHQ-12

There was a main effect of time ( $F_{1,93}=9.10$ ;  $P=.003$ ;  $\eta_p^2=.09$ ) but not of condition ( $F_{1,93}=0.00$ ;  $P=.96$ ;  $\eta_p^2=.00$ ). There was

also a significant time  $\times$  condition interaction ( $F_{1,93}=6.15$ ;  $P=.02$ ;  $\eta_p^2=.06$ ; **Figure 2**). Further analyses revealed that general psychological distress was reduced in the intervention ( $t_{44}=3.50$ ;  $P=.001$ ;  $d=0.52$ ) but not the waitlist condition ( $t_{49}=0.42$ ;  $P=.67$ ;  $d=0.06$ ).

**Figure 2.** Results of a repeated measures analysis of variance of mean general psychological distress ratings of military partners, per condition (2019). Error bars represent the SEs. GHQ-12: General Health Questionnaire-12.



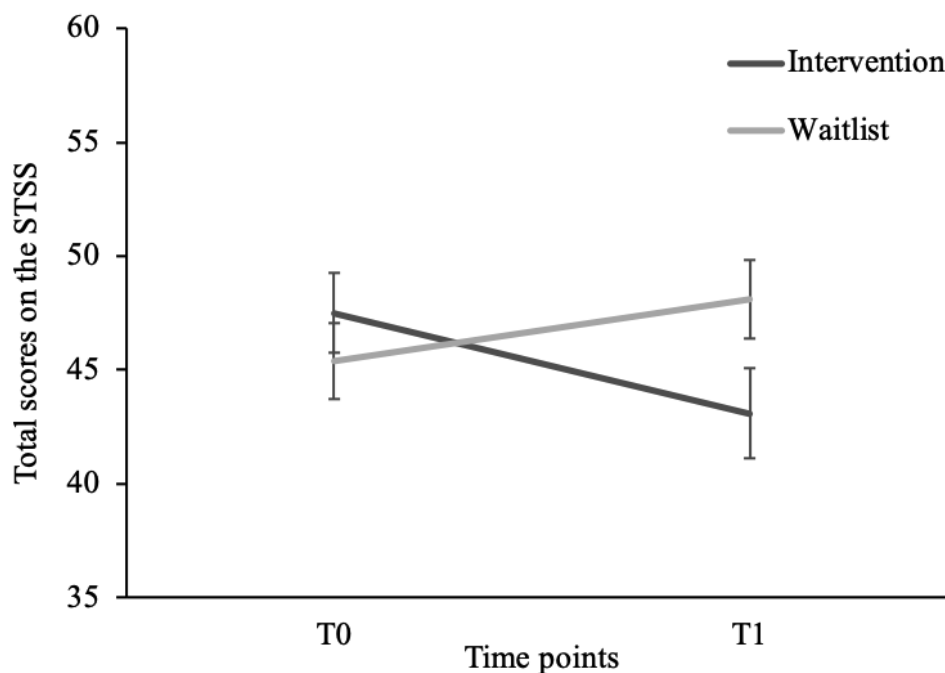
**Measures for STSS**

There was no main effect of time ( $F_{1,93}=1.56; P=.22; \eta_p^2=.02$ ) nor condition ( $F_{1,93}=0.20; P=.66; \eta_p^2=.002$ ). However, there was a significant time  $\times$  condition interaction ( $F_{1,93}=12.56; P=.001; \eta_p^2=.12$ ; **Figure 3**). Further analyses revealed that secondary trauma symptoms decreased in the intervention

( $t_{44}=3.04; P=.004; d=0.45$ ) but not in the waitlist condition ( $t_{49}=-1.82; P=.07; d=0.26$ ).

Exploratory analyses of the STSS subscales demonstrated a significant increase in intrusion symptoms in the waitlist condition ( $t_{49}=-2.09; P=.03; d=0.30$ ) and a decrease in both avoidance ( $t_{44}=3.65; P=.001; d=0.54$ ) and arousal ( $t_{44}=2.05; P=.047; d=0.31$ ) in the intervention condition.

**Figure 3.** Results of a repeated measures analysis of variance of mean secondary trauma symptom scores of military partners, per condition (2019). Error bars represent the SEs. STSS: Secondary Traumatic Stress Scale.





## Measures for QoL

There was no main effect of time ( $F_{1,93}=1.18$ ;  $P=.28$ ;  $\eta_p^2=.01$ ) nor condition ( $F_{1,93}=0.13$ ;  $P=.72$ ;  $\eta_p^2=.00$ ). Furthermore, the time  $\times$  condition interaction was not significant ( $F_{1,93}=3.45$ ;  $P=.07$ ;  $\eta_p^2=.04$ ).

## Discussion

### Principal Findings

This study is one of the first pilot RCTs evaluating a psychoeducational web-based group intervention developed specifically for military partners. This study aimed to examine the impact of TTP-Webinar and to determine the feasibility of offering support via a remote access web-based platform. The findings of this study revealed that partners in the TTP-Webinar intervention condition demonstrated moderate reductions in self-reported general psychological distress and secondary trauma symptoms. However, similar reductions were not observed in self-reported QoL. One potential explanation for this may be that QoL is a complex concept and there may not have been sufficient content validity to identify changes with a single-item measure. Nonetheless, the findings provide promising initial evidence that TTP-Webinar may be an effective, web-based, structured group intervention to support the specific mental health needs of partners of veterans with PTSD and other mental health difficulties.

Although limited, previous research that has investigated support specifically aimed at military partners has focused on the effect of peer support groups on family adaptation [27], or psychoeducational groups on partners' understanding of PTSD and self-reported behaviors of encouraging veterans to seek treatment [28]. Although the mechanisms of change cannot be established in this pilot study, numerous mechanisms are likely involved. One potential mechanism of TTP-Webinar may be the psychoeducational focus of the program. Psychoeducation for families of veterans who are experiencing PTSD and other severe mental health difficulties is a common practice within US Veteran Affairs medical centers [29]. In line with such efforts, this study extends the field by demonstrating that enhancing partner understanding of posttrauma difficulties may result in better mental health outcomes for military partners themselves. In addition to psychoeducation of veteran posttrauma difficulties, the benefits of the program may relate to psychoeducation focusing specifically on helping partners understand and manage their own mental health separate from the well-being of their veteran partner. A second potential mechanism of TTP-Webinar may be the group setting of the program. Previous research has demonstrated the benefits of group therapy for military partners [27]. Many partners experience increased social isolation and resist seeking support because of concerns that others may not be able to understand their unique difficulties [1,19]. TTP-Webinar differs from more traditional forms of group therapy, given the web, remote access delivery, and absence of participant-to-participant interaction. Nonetheless, it remains plausible that the opportunity for normalization of one's own difficulties because of the group format and interactive platform may partially explain the

beneficial effects of TTP-Webinar. Qualitative analyses of participants' experience of TTP-Webinar indicated that psychoeducation and normalization through connecting with other military partners were key aspects of the acceptability of the program [30]. Such findings suggest that the power to develop an understanding of posttrauma difficulties and connecting to other military partners may be offered to partners through the remote, webinar program.

In addition to the importance of TTP-Webinar for supporting military partners with their mental health difficulties, the wider benefits can also be seen when considering that partner distress and poorer family functioning may result in poorer outcomes for veterans undergoing PTSD treatment [31,32]. Research suggests that a lack of partner engagement in the treatment of veterans' PTSD treatment may have negative effects on treatment outcomes [33]. In this regard, the psychoeducational component of TTP-Webinar may be beneficial for equipping military partners with the relevant knowledge and skills to support veterans during their treatment. However, it is important to remain cautious in encouraging military partners' engagement in veteran treatment, as it may increase the level of partner burden [34]. It is worth further investigation to determine the point at which it is most appropriate to offer military partners such a program to ensure that they are able to look after their own well-being adjunct to potentially supporting veterans' treatment.

Military partners may develop PTSD-like symptoms that cluster in a similar manner to PTSD (avoidance, hyperarousal, and reexperiencing) because of vicariously experiencing veterans' traumas and by taking on veterans' feelings and experiences while trying to support them [35,36]. However, there remains a lack of clarity regarding the effects of such symptoms on military partners' well-being, as well as a lack of investigation on how to support partners experiencing these difficulties. Exploratory analyses in this study yielded positive findings demonstrating that TTP-Webinar may be useful in attenuating partners' avoidance and hyperarousal but not reexperiencing symptoms. The psychoeducational material delivered in TTP-Webinar focuses on enhancing the understanding of the symptoms of PTSD and depression and promoting engagement with strategies to manage such symptoms, which may explain the observed reduction in avoidance and hyperarousal. Being the first study to investigate the attenuation of secondary PTSD symptom clusters, further research is necessary to develop further insight.

### Strengths and Limitations

TTP-Webinar is a structured, manualized program developed specifically for military partners. As such, it may be argued that they have high treatment fidelity and are likely to produce similar outcomes upon replication. In line with previous evidence of good follow-up of web-delivered interventions [37], there was a high level of engagement and completion among partners who enrolled and took part in the program. The completion rates of TTP-Webinar are particularly favorable when compared with difficulties in participant retention of longer programs [38]. As military partners tend to face a complex set of demands, the beneficial findings of a short

6-week program provide further support for the appropriateness of such an intervention. Finally, this study was an RCT and thus provides strong evidence of the effectiveness of TTP-Webinar.

Despite these promising findings, this study had a few limitations. Participants were recruited via the consent of veterans. There remains a lack of clarity regarding veterans' attitudes of their partners receiving support, and it remains plausible that veterans may withhold study information or otherwise restrict their partners' engagement. Further dissemination of TTP-Webinar should involve consideration of how to contact military partners to promote the likelihood of engaging. Another limitation is the high dropout rate of partners who did not participate in the study because they were no longer eligible or able to be contacted. Those who dropped out differed in terms of education level, employment status, and QoL. No differences were observed between those who dropped out of the intervention or waitlist condition (Supplementary Table 1). Further dissemination of TTP-Webinar should consider how to further increase accessibility and engagement. The study was also limited in that participants were not screened for mental health difficulties. However, as the study was presented to potential participants with the aim of reducing mental health difficulties, it may be assumed that participants (subjectively) experienced distress and thus expressed interest in taking part in the study. Furthermore, the sample of this study is homogeneous, and it remains unclear whether the findings are generalizable to other groups such as male partners and partners in nonheterosexual relationships.

The smaller limitations of this study include that inferences about the long-term effects of TTP-Webinar cannot be made

because of the single follow-up time point. Furthermore, in an attempt to reduce dropout, not all participants completed the follow-up measures at the 1-month interval, and some participants may have completed the questionnaires via telephone rather than on the web. It is also important to note that the webinar facilitator and research assistant involved in data collection were not blinded to the condition. However, we do not believe that such issues undermine the positive findings observed. A final limitation is that some participants may have received additional 1:1 support from the TTP-Webinar facilitator if it was requested or if any risk concerns were identified. Future replications of the study may wish to provide all partners with one 1:1 telephone call to allow appropriate risk monitoring and to ensure similar levels of support across participants.

### Conclusions

Despite these limitations, the RCT provides tentative support that TTP-Webinar is likely to be an effective, standardized program to support the psychological needs of military partners in terms of general psychological distress and secondary trauma symptoms. Furthermore, military partners are likely to find TTP-Webinar a highly acceptable program [30]. Being a web-administered program, TTP-Webinar may help to increase the accessibility of support for partners who may be unable to attend face-to-face. However, it is important to note that there were still several partners who could not engage in this study because of practical barriers, and future research should consider how to further minimize the disparity between partners in need of support and those engaging in support.

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### Acknowledgments

The authors would like to thank the staff at Combat Stress who supported the project and all clinicians who referred to potential participants for the trial. Funding for the project was provided by the Royal British Legion. Approval for this study was provided by the Combat Stress research committee.

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### Authors' Contributions

LJH and DM contributed to the statistical analysis and preparation of the manuscript.

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### Conflicts of Interest

None declared.

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**Editorial notice:** This randomized study was only retrospectively registered, explained by the authors as follows: "This was not done prospectively as it was conducted to test the feasibility of administering support via a remote-access group intervention, and because it was offered as a treatment within the mental health treatment centre where the study was conducted. This is mentioned within the methods section." The editor granted an exception from ICMJE rules mandating prospective registration of randomized trials because the risk of bias appears low. However, readers are advised to carefully assess the validity of any potential explicit or implicit claims related to primary outcomes or effectiveness, as retrospective registration does not prevent authors from changing their outcome measures retrospectively.

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Multimedia Appendix 1

Webinar outline.

[[DOCX File, 17 KB - mental\\_v8i10e25622\\_app1.docx](#) ]

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Multimedia Appendix 2

CONSORT-eHEALTH checklist (V 1.6.1).

[[PDF File \(Adobe PDF File\), 371 KB - mental\\_v8i10e25622\\_app2.pdf](#) ]

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## Abbreviations

- GHQ-12:** General Health Questionnaire-12  
**PTSD:** posttraumatic stress disorder  
**RCT:** randomized controlled trial  
**STSS:** Secondary Traumatic Stress Scale  
**TTP:** The Together Programme  
**TTP-Webinar:** The Together Webinar Programme  
**QoL:** quality of life

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Original Paper

# Virtual Education Program to Support Providers Caring for People With Intellectual and Developmental Disabilities During the COVID-19 Pandemic: Rapid Development and Evaluation Study

Anupam Thakur<sup>1</sup>, MBBS, MSc, MD; Cheryl Pereira<sup>1</sup>, MPH; Jenny Hardy<sup>1</sup>, OT Reg Ont; Nicole Bobbette<sup>2</sup>, OT Reg Ont, PhD; Sanjeev Sockalingam<sup>1</sup>, MHPE, MD; Yona Lunsky<sup>1</sup>, PhD

<sup>1</sup>Centre for Addiction and Mental Health, Department of Psychiatry, University of Toronto, Toronto, ON, Canada

<sup>2</sup>School of Rehabilitation Therapy, Queen's University, Kingston, ON, Canada

**Corresponding Author:**

Anupam Thakur, MBBS, MSc, MD  
Centre for Addiction and Mental Health  
Department of Psychiatry  
University of Toronto  
1025 Queen Street West  
Toronto, ON, M6J 1H1  
Canada  
Phone: 1 6476185764  
Fax: 1 416 583 1241  
Email: [anupam.thakur@camh.ca](mailto:anupam.thakur@camh.ca)

## Abstract

**Background:** People with intellectual and developmental disabilities are at increased health-related risk due to the COVID-19 pandemic. Virtual training programs that support providers in caring for the physical and mental health needs of this population, as well provide psychological support to the providers themselves, are needed during the pandemic.

**Objective:** This paper describes the design, delivery, and evaluation of a virtual educational COVID-19–focused Extension for Community Healthcare Outcomes program to support providers during the COVID-19 pandemic in caring for the mental health of people with intellectual and developmental disabilities.

**Methods:** A rapid design thinking approach was used to develop a 6-session program that incorporates mindfulness practice, a wellness check, COVID-19–related research and policy updates, a didactic presentation on a combination mental health and COVID-19 related topic, and a case-based discussion to encourage practical learning. We used the first 5 outcome levels of Moore’s evaluation framework—focusing on participation, satisfaction, learning, self-efficacy, and change in practice—which were rated (out of 5) by care providers from health and disability service sectors, as well as additional reflection measures about innovations to the program. Qualitative feedback from open-text responses from participants were analyzed using modified manifest content analysis.

**Results:** A total of 104 care providers from health and disability service sectors participated in the program. High levels of engagement (81 participants per session on average) and satisfaction (overall satisfaction score: mean 4.31, SD 0.17) were observed. Self-efficacy (score improvement: 19.8%), support, and coping improved. Participants also rated the newly developed COVID-19 program and its innovative components highly. Open text feedback showed participants felt that the Extension for Community Healthcare Outcomes program expanded their knowledge and competency and created a sense of being part of a community of practice; provided value for the COVID-19 innovations; supported resource-sharing within and beyond program participants; and facilitated changes to participants’ approaches to client care in practice and increased participants’ confidence in supporting clients and families.

**Conclusions:** The Extension for Community Healthcare Outcomes program is an effective model for capacity-building programs with a shared-learning approach. Future iterations should include targeted evaluation of long-term outcomes such as staff burnout.

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**KEYWORDS**

COVID-19; coronavirus; pandemic; intellectual disability; mental health; community of practice; ECHO, virtual; capacity-building

## *Introduction*

Countries across the world have responded to the COVID-19 pandemic with rapid deployment of public health measures and hospital-based care for the acutely unwell. Various population groups, including people with intellectual and developmental disabilities, are marginalized and underserved in the health care system, both during and prior to COVID-19 [1]. They are at increased risk for poorer outcomes since the start of the COVID-19 pandemic, which includes a higher risk of COVID-19 infection, severe complications, and mortality [1-5]. The COVID-19 pandemic presents twin challenges of (1) addressing clinical vulnerabilities experienced by people with intellectual and developmental disabilities [4], and (2) responding swiftly to ever-evolving information. Social service providers and health care providers play a major role in caring for this marginalized group in the community [6,7]. Effective training programs for health and community service providers are needed because of the increased vulnerability to risk of infections of people with intellectual and developmental disabilities, as well as a lack of information available about supporting the needs of people with intellectual and developmental disabilities.

Experiences from previous pandemics suggest the need to support health care workers by increasing their mental health awareness and encouraging self-care [8]. Health care providers and support staff in the community are facing psychological distress during the COVID-19 pandemic. This has been attributed to high levels of uncertainty about the illness, rising mortality rates [4], lack of effective cure, and risks to personal safety and their loved ones [8,9]. Emerging COVID-19 literature, as well as studies from previous pandemics, have highlighted the risk and negative impacts of moral distress and injury in health care [10,11] and social service providers [7].

Virtual education programs can be used to overcome barriers to healthcare and social service provider training in a pandemic situation arising from physical distancing, quarantine, and other isolation measures [12]. Extension for Community Healthcare Outcomes (ECHO) is a widely used virtual education model that has been implemented globally to build capacity and create virtual communities of practice [13,14]. The model helps to address issues related to complexities in care, disparities in access to care, and rapid diffusion of evidence-based practices [14]. It leverages videoconferencing technology to create a virtual community of practice, whereby primary care and other health care providers (“spokes”) connect with specialist teams (“hubs”) to collaborate, learn, and share best practices through regularly scheduled sessions. Each session typically consists of a brief didactic presentation on a relevant disease-related topic, followed by a spoke-provider presentation about an anonymized complex case of a patient in their care, and then a community discussion to consolidate learning and to work through the case to develop practical recommendations for the provider to take back to their practice [13,14].

Globally, organizations have adapted the ECHO model for their respective COVID-19-specific needs. A recent study [15] reported the use of the ECHO model in supporting health care providers mental well-being and resilience during the COVID-19 pandemic; however, use of the ECHO model to support social service providers and health care providers in caring for people with intellectual and developmental disabilities during the pandemic has yet to be reported.

COVID-19 was declared a pandemic on March 11, 2020. As a result of the pandemic, social service providers and health care providers who support people with intellectual and developmental disabilities faced new and unprecedented challenges in community settings. In response, we leveraged the ECHO model to develop ECHO Ontario Adult Intellectual and Developmental Disabilities: Mental Health in the Time of COVID-19 (ECHO AIDD-COVID), a targeted virtual education program to support care providers, working together, from the disability and health sectors. The purpose of the program was to share best practices in caring for the mental health of the intellectual and developmental disabilities population during the COVID-19 pandemic and to reduce feelings of isolation and burnout by making new connections and sharing resources. In this paper, we aim to describe the rapid development and evaluation of the ECHO AIDD-COVID program. We hypothesized that this program would improve participants’ self-efficacy in supporting and managing the mental health issues of people with intellectual and developmental disabilities during the COVID-19 pandemic.

## *Methods*

### **General Design**

The rampant increase in COVID-19 infections in the winter of 2020, and the subsequent need to enhance and strengthen the skills of care workers, led to the rapid planning and development of a COVID-19-focused ECHO program. This program was an adaptation of an existing 12-session ECHO program launched prior to the COVID-19 pandemic, ECHO Ontario Adult Intellectual and Developmental Disabilities (ECHO Ontario AIDD), which focused on caring for the mental health of people with intellectual and developmental disabilities [16].

A rapid design thinking approach [17] over 2 weeks, similar to plan-do-study-act cycles [18], guided our development process. Design thinking is a step-wise approach that involves observation, collaboration, fast learning, the visualization of ideas, rapid prototyping, feedback gathering, and redesign [19,20]. It is human-centered; incorporates creative problem-solving, co-design, low-fidelity prototyping; has an iterative design; and “bias towards action [19,20].” With the uncertainties related to illness outcomes experienced during the COVID-19 pandemic and ongoing rapidly emerging information, a flexible process that allowed for adjustments to be made quickly when developing and running programs was needed. Design thinking facilitated such adjustments and offers a structure for building creative and innovative solutions to

complex problems that involve uncertainty [17]. The preferred approach has the added advantage of accelerated prototyping and testing; key steps in this approach included inspiration, ideation, and implementation [17].

### Stage 1: Inspiration

The inspiration stage—the problem or opportunity at hand—comprised the challenges created for providers caring for people with intellectual and developmental disabilities by the COVID-19 pandemic, such as the negative impact on mental health, for both clients and providers alike, and the need for rapid capacity building and connection in the community.

### Stage 2: Ideation

This stage involved brainstorming and refining ideas and solutions. We met several times with project leads, hub members, and members of the ECHO program team to explore ways to leverage existing operational structures and the collective expertise of the multidisciplinary ECHO Ontario AIDD team members.

### Stage 3: Implementation

In this stage, potential solutions were developed and shared with target users, who provided feedback. A prototype—a description used in rapid design framework to develop best possible solutions for the identified problems [17,21]—program was developed with COVID-19 pandemic–focused innovations within the existing structure and curriculum of the ECHO Ontario AIDD program. The innovative solutions in our prototype were (1) a curriculum that integrated COVID-19, mental health, and intellectual and developmental disabilities; (2) curated COVID-19 updates; (3) wellness checks and mindfulness sessions for self-care and wellness; and (4) a family member as one of the content experts in the hub. Content experts in the team had identified several unique COVID-19 mental health challenges faced by people with intellectual and developmental disabilities, and it was important to create opportunities that rapidly enhance the skills of care providers in the community. Moreover, the “infodemic” [22] of COVID-19 information highlighted the need to provide authentic, updated, and timely COVID-19 information to care providers. The specially designed curriculum and COVID-19 updates were creative solutions tailored for this purpose. Family members with lived experience, as content experts in the hub, brought an important perspective to the pedagogy of the program, specifically, by providing insight into how knowledge obtained from ECHO discussions could be translated and applied in the realistic care of clients. Early reports [23] from the pandemic highlighted the need to provide wellness tools to care providers to prevent burnout. We integrated wellness checks and mindfulness within the program to address this concern.

### ECHO AIDD-COVID Program

Participation in the ECHO AIDD-COVID program was open to all care providers, both social service providers and health care providers, working with people with intellectual and developmental disabilities in Ontario, Canada. We recruited potential participants by emailing invitation flyers to all previous participants of ECHO programs at the Centre for Addiction and Mental Health, as well to developmental service agencies,

community mental health organizations, professional accrediting colleges, and primary care sites in Ontario. Providers who were interested in participating completed a web-based application form. All applicants independently providing care were accepted in to the program.

We assembled a hub team that comprised a psychiatrist, psychologist, primary care physician, behavior therapist, occupational therapist, nurse, social worker, and family advisor (the parent of an adult with intellectual and developmental disabilities). The strengths of the team included expertise in primary care, mental health, and intellectual and developmental disabilities; experience working directly with people with intellectual and developmental disabilities during COVID-19; and experience managing psychological distress.

The curriculum was developed by triangulating sources, including feedback from a prior needs’ assessment [24], evaluation of the recently piloted ECHO Ontario AIDD cycle, review of COVID-19 literature on evidence-based practices to support health care providers, and consensus discussions within the hub members. Concerns related to the impacts of COVID-19 pandemic on people with intellectual and developmental disabilities were deterioration in mental health, worsening of challenging behaviors, overprescription of medications, and diagnostic overshadowing [25]. Hence, mental health was an important part of this program. Caregiver strain was identified as another area of need [26]. The final list of topics were COVID-19 overview (with relevance to intellectual and developmental disabilities); staff wellness and self-care; advanced care planning and supported health care decision-making during COVID-19; depression, anxiety, and evaluating risk; supporting families during COVID-19 and family interventions; and grief and loss. Because we did not know how long people would be willing and able to participate in an ECHO program during the pandemic, we opted for 6 sessions, which seemed sufficiently long to present key material and form a community of practice while also remaining efficient at spreading information.

Weekly 1.5-hour-long sessions were conducted from April 17, 2020 to May 22, 2020 over 6 weeks, which is half the duration of ECHO Ontario AIDD. Each session included introductions, a mindfulness exercise led by the family advisor, a wellness check, COVID-19–related research and policy updates, a didactic presentation based on the curriculum topic for the day, and a case-based discussion, in which a participant (care provider) presented an anonymized case from their practice, for which they required support, to illustrate the complexities in caring for people with intellectual and developmental disabilities in conjunction with the impact of COVID-19. Additionally, a web-based ECHO AIDD-COVID resource portal, with reference materials related to the ECHO program, was available to the participants for use during and after the sessions. Sessions had a dual focus—participant skill development, for addressing the mental health issues faced by people with intellectual and developmental disabilities, and support for the psychological well-being of participants. The innovations described earlier were integrated in to the ECHO sessions seamlessly. Evidence-based resources were shared with participants and could be accessed after the course.



## Evaluation

### Overview

Our evaluation strategy was informed by the Evaluation framework for continuing professional development, specifically, levels 1 to 5 (participation, satisfaction, learning, self-efficacy and change in practice) [27]. This framework has been used globally to structure evaluations for ECHO [28-30]. We asked additional questions about participation in the program within the context of the COVID pandemic and reflections on innovations to the program.

### Participation

Basic participant demographic information (profession, practice setting, and attendance) was collected throughout the duration of the program.

### Satisfaction

Participant satisfaction was measured weekly using web-based postsession satisfaction questionnaires. Statements were rated on a 5-point Likert scale, from 1 (strongly disagree) to 5 (strongly agree), and focused on expanded knowledge and skills, reduced professional isolation, addressed learning needs, recommend session to others, and overall satisfaction. We obtained qualitative feedback with open-text responses to questions that asked for suggestions (for curriculum topics) and overall comments or feedback.

### Learning and Competency

Perceived self-efficacy was assessed for 4 core program competencies, with respect to providing care for people with intellectual and developmental disabilities during the COVID-19 pandemic, before and after program participation, with a previously established 100-point confidence scale (a higher number indicated higher confidence) [28]. Competencies were developed by the ECHO AIDD-COVID hub team through team discussions on personal experience, review of the literature on care providers' challenges in managing mental health care in the intellectual and developmental disabilities population during the pandemic, and expert consensus.

### Change in Practice

Participants responded, using a binary scale (1, yes; 0, no), to a question that asked whether participation in the program resulted in a change in their practice; participants were also prompted to provide examples with open-text feedback.

### Experiences With the COVID-19 Pandemic

Feedback in this area was collected before and after the program with 2 items—having professional support and being equipped to cope with stressors (ie, fear of contagion; rapid spread of virus; risk to self, client, family, or friends, etc) related to the pandemic—using a 5-point Likert scale from 1 (strongly disagree) to 5 (strongly agree).

Reflection questions about innovations to the program (combining social service providers and health care providers, COVID-19 strategy sharing, including of mindfulness practice, including support from the community of practice, and sharing COVID-19 updates) were asked after the program, with responses captured using a 5-point Likert scale. Participants were also asked to comment on how participation in the ECHO AIDD-COVID program impacted the challenges that they experienced during the COVID-19 pandemic with open-text responses.

Evaluation measures and data sets generated and analyzed in this report were reviewed and deemed to be part of program evaluation at the Centre for Addiction and Mental Health.

### Data Analysis

Quantitative data were analyzed using either Excel (Microsoft Inc) or SPSS software (version 21; IBM Corp). Proportions, frequencies, and percentages were calculated for categorical variables (profession, practice setting, change in practice, and attendance). Means and standard deviations were calculated for continuous variables (satisfaction scores, self-efficacy scores, scores for reflections about innovations to the program, and scores for experiences with COVID-19 pandemic). Pre- and postprogram data about experiences during the COVID-19 pandemic and self-efficacy were analyzed using either paired *t* tests or Wilcoxon signed-rank tests, as appropriate. Statistical tests were 2-sided, with a statistical significance level of 5%.

Preliminary modified manifest content analysis was conducted using NVivo software (version 12, QSR International) to evaluate open-text responses about program participation and the impact to challenges experienced during COVID-19. A project team member uploaded all open-text responses into NVivo, and then reviewed and performed open coding on all text. The project team met on a regular basis to review and discuss coding to develop and refine a coding matrix with definitions. This coding matrix was applied to all text; references for each code were reviewed, and frequencies were calculated. Finally, all codes were summarized and organized for interpretation [31,32].

## Results

A total of 104 care providers, with a variety of professional backgrounds, from 56 organizations (Table 1) attended 1 or more sessions (participants per session: mean 81), and more than 88% of participants (92/104) attended at least half of the sessions.

Weekly satisfaction scores were high, ranging from a mean 4.07 (SD 0.18) to a mean 4.32 (SD 0.14); the overall mean satisfaction score was 4.31 (SD 0.17; Table 2).

**Table 1.** Participant demographics.

| Demographic group   | Value, n (%) |
|---|--------------|
| <b>Participants by profession</b>   | 104 (100)    |
| Access coordinator or service navigator   | 2 (1.9)      |
| Administrator   | 5 (4.8)      |
| Behavior analyst  | 6 (5.8)      |
| Case worker or manager  | 23 (22.1)    |
| Developmental services professional   | 16 (15.4)    |
| Physician   | 8 (7.7)      |
| Nursing professional (registered nurse, registered practical nurse, nurse practitioner) | 8 (7.7)      |
| Occupational therapist  | 2 (1.9)      |
| Other (pharmacist, speech language pathologist)   | 4 (3.8)      |
| Psychologist or psychotherapist   | 2 (1.9)      |
| Social worker   | 19 (18.3)    |
| Support worker  | 9 (8.7)      |
| <b>Organizations by practice setting</b>  | 56 (100)     |
| Academic hospital   | 3 (5)        |
| Community health center   | 3 (5)        |
| Community mental health agency  | 6 (11)       |
| Community mental health and addictions agency   | 1 (2)        |
| Community support services agency   | 10 (18)      |
| Developmental services community agency   | 28 (50)      |
| Family health group   | 1 (2)        |
| Family health team  | 1 (2)        |
| Other   | 1 (2)        |
| Private practice or solo practitioner   | 2 (4)        |

**Table 2.** Ratings for satisfaction survey items.

| Item   | Rating out of 5 (n=228) <sup>a</sup> , mean (SD) |
|--|--|
| The session content expanded my existing skills and knowledge. | 4.07 (0.18)                                      |
| This session has addressed my learning needs.                  | 4.15 (0.07)                                      |
| This session has reduced my professional isolation.            | 4.21 (0.18)                                      |
| I would recommend this session to others.                      | 4.32 (0.14)                                      |
| Overall, I was satisfied with the session.                     | 4.31 (0.17)                                      |

<sup>a</sup>Total number of completed weekly surveys received.

In total, 42 participants completed both pre- and postprogram self-efficacy and experiences with the COVID-19 pandemic questionnaires. Mean self-efficacy scores prior to participation in ECHO were 61.3 (SD 18.2), and after the program, self-efficacy scores were 81.1 (SD 9.8); there was a statistically significant improvement ( $t_{41} = -9.035$ ,  $P < .001$ ;  $d = 1.394$ ). Analysis of individual statements (core program competencies)

also showed statistically significant improvements in mean self-efficacy scores (all  $P < .001$ ). Statistically significant differences were also seen for pre-ECHO to post-ECHO mean scores for both statements on experiences with COVID-19 (ie, professional support and being equipped to cope with stressors related to the pandemic). **Table 3** shows mean self-efficacy scores for individual core program competency statements and mean scores for experience with COVID-19 items.

**Table 3.** Change in change in pre- and postprogram confidence and experience with COVID-19 participation in the ECHO AIDD-COVID program.

| Items  | Score (n=42), mean (SD) |                  |                  | P value            |
|--|-------------------------|------------------|------------------|--------------------|
|  | Pre                     | Post             | Difference       |                    |
| <b>Core program competencies</b>   |                         |                  |                  |                    |
| Communicate effectively and prepare for person and family-centered care for adults with intellectual and developmental disabilities during the COVID-19 pandemic   | 65.38<br>(20.22)        | 81.83<br>(9.79)  | 16.45<br>(17.72) | <.001 <sup>a</sup> |
| Support and manage the mental health of individuals with or suspected of having intellectual and developmental disabilities during the COVID-19 pandemic   | 56.47<br>(20.06)        | 77.88<br>(13.54) | 21.40<br>(16.39) | <.001 <sup>b</sup> |
| Manage burnout and build resilience in myself, other health care and developmental service professionals, and caregivers during the COVID-19 pandemic  | 57.57<br>(22.34)        | 78.52<br>(12.08) | 20.95<br>(21.44) | <.001 <sup>c</sup> |
| Work effectively in/with interprofessional and intraprofessional teams across health and social systems during the COVID-19 pandemic to support the care of clients with intellectual and developmental disabilities | 69.33<br>(18.04)        | 86.07<br>(10.09) | 16.74<br>(15.72) | <.001 <sup>d</sup> |
| <b>COVID-19 experience</b>   |                         |                  |                  |                    |
| I feel I have enough professional support and resources for myself to continue caring for my clients during this time  | 3.45 (0.89)             | 4.10 (0.62)      | 0.64 (0.82)      | <.001 <sup>e</sup> |
| I feel equipped to cope with stressors (ie fear of contagion, rapid spread of virus, risk to self/client/family/friends, etc) related to the COVID-19 pandemic   | 3.17 (0.93)             | 4.10 (0.66)      | 0.93 (0.87)      | <.001 <sup>f</sup> |

<sup>a</sup>The Wilcoxon signed rank test was used ( $Z = -4.728$ ;  $r = 0.730$ ).

<sup>b</sup>A paired  $t$  test was used ( $t_{41} = -8.464$ ;  $d = 1.306$ ).

<sup>c</sup>A paired  $t$  test was used ( $t_{41} = -6.335$ ;  $d = 0.977$ ).

<sup>d</sup>A paired  $t$  test was used ( $t_{41} = -6.902$ ;  $d = 1.065$ ).

<sup>e</sup>A paired  $t$  test was used ( $t_{41} = -5.074$ ;  $d = 0.783$ ).

<sup>f</sup>A paired  $t$  test was used ( $t_{41} = -6.945$ ;  $d = 1.072$ ).

The analysis of 53 open-text responses about the impact of ECHO participation on challenges experienced by participants during the COVID-19 pandemic is summarized in Table 4. Key areas that emerged within the responses included: ECHO expanding participants' knowledge and competency (29/53, 55%); being part of a community of practice in ECHO (25/53, 47%); reflections on the value of the COVID-19 innovations

(21/53, 40%); ECHO supporting the gaining and sharing of resources, not just within the smaller ECHO community, but also with participants' teams and organizations (18/53, 34%); ECHO facilitating changes to participants' practice via their approach to client care (10/53, 19%); and feelings of increased confidence in supporting clients and families (3/53, 6%).

**Table 4.** Key areas that emerged from open-text responses.

| Key areas   | Participants (n=53), n (%) <sup>a</sup> |
|---|---|
| <b>Expanding knowledge and competency</b>               | 29 (55)                                 |
| Benefits of case-based learning                         | 9                                       |
| Improvements to knowledge and awareness                 | 13                                      |
| Increased learning through interprofessional education  | 5                                       |
| <b>Being part of a community of practice</b>            | 25 (47)                                 |
| Supporting and learning from one another                | 9                                       |
| Validation from others                                  | 2                                       |
| <b>Reflections on COVID-19 innovations</b>              | 21 (40)                                 |
| Benefits of mindfulness                                 | 4                                       |
| Increases in COVID-19 knowledge                         | 12                                      |
| Value of family perspective                             | 5                                       |
| <b>Gaining and sharing resources</b>                    | 18 (34)                                 |
| Sharing resources with broader teams and organizations  | 3                                       |
| <b>Facilitating changes to practice</b>                 | 10 (19)                                 |
| Application of knowledge in client care                 | 7                                       |
| Increased confidence in supporting clients and families | 3 (6)                                   |

<sup>a</sup>Percentages do not add to 100%, and only n values are provided for subthemes.

Participants were also asked about participation in ECHO having an impact on practice. Participants reported participation in ECHO AIDD-COVID resulted in a change in their practice and an equal number were in favor of this program being run again (46/53, 87%). Almost all of the participants reported their learning needs were met in the program (51/53, 96%). The reflection questionnaire around prototype innovations in the program was completed by 53 participants. An overwhelming 98% of participants (52/53) agreed ECHO AIDD-COVID made them feel supported and part of a virtual community of practice. One participant commented that it was

*so nice to know that we are not alone in this strange time and share the same challenges*

and that they would

*miss this weekly touch point with professionals.*

A similar percentage of participants (52/53, 98%) reported COVID-19 updates and resources as valuable; a participant shared,

*there were innovative strategies suggested in each session as well as content in the presentations that I believe helped improve my approach day to day with the clients I have been supporting.*

Furthermore, 94% of participants (50/53) agreed or strongly agreed that having both interprofessional health care providers and social service providers enhanced their learning. Most participants (51/53, 96%) also reported that having a family member in the hub enhanced their learning. The impact of the family perspective is best illustrated by a participant who shared that

*...the most powerful experiences I had was whenever the family member spoke. I think we all can hypothetically understand caregivers' perspectives, but we cannot understand the full emotional toll or the personal thoughts and worries that caregivers have.*

A similar percentage (51/53, 96%) of participants appreciated the opportunity to share strategies in the community. The weekly mindfulness exercise led by the family advisor was reported to be helpful by 77% of the participants (41/53) and functioned to

*remind us to take care of ourselves.*

## Discussion

### General

We described the successful development and evaluation of a COVID-19–focused ECHO program for workers caring for people with intellectual and developmental disabilities. A rapid design thinking approach was used to develop the ECHO AIDD-COVID program. Evaluation findings showed high levels of engagement and satisfaction with the program, with the majority of participants reporting changing their practice because of the program. To the best of our knowledge, this paper is the first to document use of the ECHO model and its significant improvement in perceived self-efficacy in caring for people with intellectual and developmental disabilities during the COVID-19 pandemic for a cohort that encompassed both social service providers and health care providers. Improved confidence in all the core program competencies shows the ECHO model is an effective way to improve provider skills for supporting the mental health needs of people with intellectual and developmental disabilities. Additionally, there was a

cascading effect from knowledge shared by participants beyond the program—use of the program can be an effective share-and-spread strategy during the pandemic. Participant feedback from open-text responses shows that the program helped expand knowledge and facilitated changes in practice. The ECHO model was conceptually designed to develop a community of practice. This was validated by the qualitative feedback from participants. The results of the pre- and postprogram evaluations suggest that participants felt that group participation helped to support their own well-being, especially their ability to cope with COVID-19 stressors.

### Rapid Design Thinking and COVID-19

Because of the pandemic, uncertainty and unprecedented challenges arose in social support and health care sectors, and there was a need for the swift deployment of a capacity-building program to support the needs of people with intellectual and developmental disabilities and those of the health and social service providers who work with this underserved population. The rapid design thinking framework was instrumental in incorporating lessons learned from our previous ECHO capacity-building project [16], to adapt to COVID-19-specific needs, develop a purpose-built prototype, and implement the design within a short timeframe. The design thinking principles are helpful in volatile, uncertain, complex, and ambiguous situations [33], and the COVID-19 pandemic presents such conditions. Additionally, there is evidence in medical education literature that supports the use of design thinking [21,34,35]. Other agile methods [36] that are similar to rapid design thinking can be explored in developing similar programs. The attendance rate, high levels of satisfaction, and retention of the program suggest the acceptability of the shortened 6-session program. Interestingly, retention rates were similar to those of the prior 12-week ECHO program targeted toward the same audience. It may be that in a time of intense duress, people are able to commit to a short intervention, with enough support being conveyed over this short period to make a difference. Additional research is necessary to determine if a brief program produces as much change as that from a longer program and whether attendance is better in one program or the other. Rapid prototyping and testing were key aspects of the program; we utilized qualitative and quantitative findings from the previous iteration and introduced several time-sensitive innovations including COVID-19-specific content, such as advance care planning and care provider wellness. The learn-as-you-go aspect of the rapid design thinking framework was evident in the iterative nature of the model [17,34], guided by feedback obtained from weekly satisfaction surveys.

### Innovations That Made a Difference

In contrast to other ECHOs designed to strictly focus on working with a population [37] or addressing worker mental health [15], this course integrated both aspects. High levels of satisfaction with the innovations in the COVID-19 prototype program may have contributed to its success. Participants appreciated the COVID-19-specific content of the program, and almost all questionnaire respondents indicated an intent to apply learning in practice. Curated COVID-19 information and weekly updates, self-care tips, and family perspectives were prominent in

participants' reflections on COVID-19-related innovations in the program. Several participants spoke about the mindfulness exercises and how they helped them to be more aware of their own wellness needs during the pandemic. We recognized that, while it is important to provide practical clinical tools to providers, it is not enough to address clinical needs without recognizing the impacts of moral distress and injury on frontline care providers [7]. The wellness checks and community mindfulness exercises were opportunities to share ideas about coping during the pandemic. Participants also reflected on the program's contribution as a virtual community of practice. "*Feeling connected*" and "*we are not alone*" came out strongly in the reflections, which were indicators of the program bringing professionals from disability and health services sectors together as a community. Sockalingam et al [15] concluded that virtual communities of practice that focus on self-care skills development and support for frontline health care workers are needed to address emerging distress, fatigue, and mental health needs during this pandemic. The curriculum was coproduced and co-delivered with a family advisor hub member. Similar to descriptions in literature [38-40], the family-centered care perspective was deeply valued by participants. Training in partnership with patients and providers helps in developing empathy and desired professional attitudes [40]. At a pedagogical level, this highlights the important role of caregivers as educators and working in partnership to improve provision of care [41,42].

### Limitations

There are some limitations to consider when reviewing our findings. First, the data and measures used in this evaluation are from a single cycle of an ECHO program that was specifically focused on mental health in intellectual and developmental disabilities populations in Ontario during COVID-19; as such, our findings may not be generalizable to other cycles or settings. Future evaluation and research efforts will seek to replicate these findings with other health conditions and settings. Additionally, findings for satisfaction, changes in confidence, and experience with COVID-19 participation were informed by data collected from individuals who completed satisfaction surveys and questionnaires. This may introduce a response bias, whereby those who participated in these data collection activities may have been more engaged and likely to respond with higher scores; however, we recognize this challenge is not unique to our evaluation and exists for anyone collecting data via surveys.

### Future Directions

Future iterations should incorporate targeted outcome measures to evaluate the role of ECHO in addressing the mental health needs of care workers who are supporting people with intellectual and developmental disabilities in the community [15]. The virtual, synchronous nature of the ECHO model was valuable during the pandemic, as the timing and outreach of the capacity-building program was essential, and travel restrictions were major impediments to any in-person training. Future work should also include the perspective of adults with intellectual and developmental disabilities in teaching. Emerging literature has highlighted the importance of people with intellectual and

developmental disabilities in medical education [43,44]. The role of *expert patients* as educators in the ECHO model needs further exploration.

Although this study addressed self-efficacy and the competency of learners, focus on retention and its medium- to long-term effects would be helpful for designing future programs. In addition, the evaluation of implementation outcomes would be helpful to understand the impact of this educational intervention. Ethical implications and dynamics involved in coproducing

educational content are important future considerations [42]. We will continue with this program at a provincial and national level as long as Canada continues to face COVID-19-related restrictions, and we plan to measure long-term outcomes such as staff burnout and COVID-19-related stress in future iterations. Furthermore, by scaling up capacity-building initiatives nationally, a wider community of practice can be built, which has implications for knowledge translation research at a systems level.

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## Conflicts of Interest

None declared.

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## Abbreviations

**ECHO:** Extension for Community Healthcare Outcomes

**ECHO AIDD-COVID:** Extension for Community Healthcare Outcomes Ontario Adult Intellectual and Developmental Disabilities: Mental Health in the Time of COVID-19

**ECHO Ontario AIDD:** ECHO Ontario Adult Intellectual and Developmental Disabilities

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Original Paper

# Acceptance and Use of Telepsychology From the Clients' Perspective: Questionnaire Study to Document Perceived Advantages and Barriers

Beatriz Sora<sup>1</sup>, PhD; Rubén Nieto<sup>2</sup>, PhD; Adrian Montesano del Campo<sup>2</sup>, PhD; Manuel Armayones<sup>3</sup>, PhD

<sup>1</sup>Department of Psychology, Rovira i Virgili University, Tarragona, Spain

<sup>2</sup>Department of Psychology, eHealth Center, Open University of Catalonia, Barcelona, Spain

<sup>3</sup>eHealth Center, Open University of Catalonia, Barcelona, Spain

**Corresponding Author:**

Beatriz Sora, PhD

Department of Psychology

Rovira i Virgili University

Campus Sescelades. Carretera Valls, s/n

Tarragona, 43007

Spain

Phone: 34 977558097 ext 8097

Email: [beatriz.sora@urv.cat](mailto:beatriz.sora@urv.cat)

## Abstract

**Background:** Telepsychology is increasingly being incorporated in clinical practice, being offered in many psychotherapy centers, especially after the impact of the pandemic. However, there seems to be a remarkable discrepancy between the offer, or interest in, and real-world uptake of e-mental health interventions among the population. A critical precondition is clients' willingness to accept and use telepsychology, although this issue has thus far been overlooked in research.

**Objective:** The aim of this study was to examine people's acceptance and use of telepsychology by adopting an extended model of the unified theory of acceptance and use of technology (UTAUT) that integrates perceived telepsychology advantages and barriers, usefulness perceptions, behavioral intention, and telepsychology use.

**Methods:** An online survey was conducted with a convenience sample of 514 participants. Structural equation models were computed to test a mediation model.

**Results:** Results supported the UTAUT model to explain participants' acceptance and use of telepsychology. They showed a causal chain in which perceived telepsychology advantages and barriers were related to telepsychology use through the perceived usefulness of and intention to use telepsychology.

**Conclusions:** Telepsychology use may be explained according to the UTAUT model when coupled with participants' perceptions of telepsychology advantages and barriers. Mental health stakeholders could consider these factors in order to increase the acceptance and use of telepsychology.

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**KEYWORDS**

telepsychology; telepsychology advantages; telepsychology barriers; telepsychology use; telepsychology usefulness; intention to use telepsychology

## Introduction

**Background**

Every year, a high percentage of the population requires mental health services [1]. However, not all people have adequate access to the specialized mental health care they need. Figures illustrating this vary widely between studies and depend on the

definition given to mental health care. For example, a representative European sample evidenced that while 6.5% of people had a need for mental health care, more than 3% of them did not receive the appropriate treatment [2]. The negative consequences of failing to treat these problems are well documented in the literature and include poor health outcomes, suicide, divorce, substance abuse, child neglect and abuse, and

youth delinquency [3-5]. Thus, finding solutions that spread access to mental health care throughout the population is critical.

Information and communication technologies (ICT) have great potential to facilitate access to interventions. In this regard, telepsychology, which the American Psychological Association (APA) defines as “the provision of psychological services using telecommunication technologies,” has appeared in recent years as an alternative to traditional face-to-face interventions, at least for a significant proportion of the population. Telepsychology involves the use of different electronic tools to deliver health care, which may range from telephones and fiber optics to interactive satellite video [6]. This work focuses on videoconferencing technology, which synchronously overcomes geographical barriers, thereby enabling people to see and talk to each other as if they were in the same room despite being apart.

Literature on telepsychology use (especially on the use of videoconferencing technology) has increased exponentially in recent years [7]. In this line, institutions such as the APA have created guidelines for the use of telepsychology [8]. Systematic reviews showing the positive effects of telepsychology have also appeared. For example, Varker et al [9] reviewed published research about the use of synchronous telepsychology to treat anxiety, post-traumatic stress disorder, and adjustment disorder. They found strong evidence pointing to the high-quality nature of this option, as well as to the equivalence between telephone- or videoconference-delivered interventions and face-to-face interventions. Although more research is needed, in general terms, available results suggest that telepsychology could produce equal results when compared to traditional interventions and that therapeutic alliance can be as successfully established in videoconference psychotherapy as in face-to-face interventions [10-12]. In addition, telepsychology is also gaining representativeness in routine clinical practice, especially after the pandemic. For instance, Pierce et al [13] surveyed a national sample of 2619 licensed psychologists in the United States and found that those practicing in outpatient facilities reported a 26-fold increase in telepsychology in response to the pandemic. Moreover, participants stated that 34.96% of their clinical work would be conducted via telepsychology after the pandemic ceases, reflecting an important shift in attitudes toward the use of telepsychology.

For really potentiating the use of telepsychology, a fundamental precondition, as with the implementation of any other new technology or application [14,15], is to study users' willingness to accept and use it. In general, there seems to be a remarkable discrepancy between the interest in and real-world uptake of e-mental health interventions among the population [16,17]. Studies have shed light on the fact that willingness to participate in e-mental health interventions is limited, either because of a low uptake rate among patients or low acceptance by the population in general [18-21].

Unfortunately, research has overlooked this issue. Only 3% of studies on eHealth, in general, focus on people's acceptance, making this an understudied domain [22,23]. Consequently, there is limited knowledge about people's genuine attitudes towards e-mental health and the reasons behind their intention

to use it [14]. A comprehensive understanding of determinant factors for acceptance and use of e-mental health, in general, and telepsychology, in particular, represents an essential first step towards creating successful telepsychology services. This is a pressing issue in the current context of social distancing and the telepsychology revolution [13].

### **Acceptance and Use of Telepsychology: Unified Theory of Acceptance and Use of Technology (UTAUT) Model**

Technology acceptance is a relatively mature area of research, and there is a significant amount of literature on the matter [24]. It presents several models, based mainly on social psychology, to explain people's acceptance and use of new technologies. Some more widely accepted theories on the use behavior of new technologies are the technology acceptance model (TAM) [25], theory of planned behavior (TPB) [26], theory of reasoned action (TRA) [27], motivational model (MM) [28], combined TAM and TPB (C-TAM-TPB) [29], model of personal computer use, theory of innovation diffusion (TID) [30], and social cognitive theory (SCT) [31]. These theories and models have since been fused to create a more complex framework: the unified theory of acceptance and use of technology (UTAUT) [24]. This model was proposed in order to combine the contributions of the mature yet fragmented literature on technology acceptance and to establish a unified theory to explain individuals' use and acceptance of technology. The UTAUT contemplates 4 core determinants of use and intention: (1) performance expectancy, (2) effort expectancy, (3) social influence, and (4) facilitating conditions. In this respect, Koivumäki et al [22] summarized their definitions as follows. Performance expectancy reflects the degree to which using a technology will facilitate the achievement of some goal (ie, technology will enhance quality of life performance). It involves determinants such as perceived usefulness, extrinsic motivation, job fit, relative advantages, and outcome expectations from technology acceptance studies. Effort expectancy represents the degree of ease associated with the use of a technology, such as ease of use and its determinants and complexity. Social influence is defined as the extent to which it is perceived that significant others (eg, family or friends) believe that they should use a technology. It reflects the determinants of social factors, subjective norms, and image from the technology acceptance literature. Facilitating conditions represent perceptions of the external resources and infrastructure that support the use of an information and technology system (eg, perceived behavioral control and compatibility). Finally, behavioral intention was defined as a measure of the strength of one's intention to perform a specific behavior [26]. It reflects the acceptance to use eHealth tools. More specifically, the UTAUT model [24] proposes that performance expectancy, effort expectancy, and social influence are direct predictors of the intention to use an innovative technology and that facilitating conditions and behavioral intention are direct determinants of actual use.

This model has been applied and tested in multiple contexts to provide insight into the forces that motivate individuals to adopt technology. In the case of eHealth, most empirical research singles out performance expectancy (eg, perceived usefulness) as the strongest predictor of technology acceptance [32-37]. Perceived usefulness is defined as the extent to which a person

believes that using a system will help him or her to achieve their objectives [25]. It essentially captures people's cognitive expectations about the performance of the system, which determines the intention of technology use. In other words, if people believe that the new technology, in our case telepsychology, can help them, they will present higher intention to use it compared to those who do not perceive any benefit. In this line, several meta-analyses in the eHealth field show that perceived usefulness has the largest effects on behavioral intention (eg, [38,39]). Likewise, behavioral intention is the main predictor of use behavior (eg, [32,40]). Unfortunately, as mentioned previously, we are not aware of any study that has specifically examined telepsychology; accordingly, people's acceptance and use of psychotherapy through videoconferencing — that is, telepsychology — are still unknown.

### **Additional Determinants of Telepsychology Acceptance and Use: Advantages and Barriers**

The UTAUT model [24] underpins the determinants of technology acceptance and use, making it the most complete model for predicting technology acceptance and use. However, given the complex nature of eHealth acceptance and its determinants, it necessary to extend this model and adapt it to different contexts [14].

A relevant line of research has expanded the UTAUT model by including success factors (eg, advantages) and resistance factors (eg, barriers) that drive people to adopt and use a certain technology (eg, [14,36,41,42]). At the initial stage of adoption of a new ICT, people have limited knowledge and thus struggle to decide whether to use it. There are likely opportunity factors that motivate them to use the new technology, as well as barrier or risk factors (understood as perceptions and not only as actual obstacles) that cause them to hesitate using it. Hence, perceived advantages and barriers represent reasons for or against the use of a technology [43].

Literature on eHealth suggests that the inclusion of ICT in mental health care services may pose several advantages and barriers for patients that conventional face-to-face interventions do not. Ebert et al [41] summarized them as follows. Advantages include the fact that (1) e-mental health interventions are more easily accessible at any time and place, (2) e-mental health interventions facilitate the integration of acquired skills in daily life because of the patients' active roles, (3) participants can work at their own pace and go through materials as often as they want, (4) travel time and costs are removed, and (5) e-mental health interventions may attract people who do not make use of traditional mental health services. The following barriers have been pointed out: (1) low expectancies regarding its effectiveness, (2) reservations regarding data security, (3) low comfort using such programs, (4) influence by important social contacts (eg, family and health professionals), (5) negative attitudes towards seeking psychological help in general, (6) low internet experience, and (7) high internet anxiety. Further studies added low internet orientation in health problems and insufficient knowledge of eHealth interventions [21] as well as worries about impersonal interaction [44].

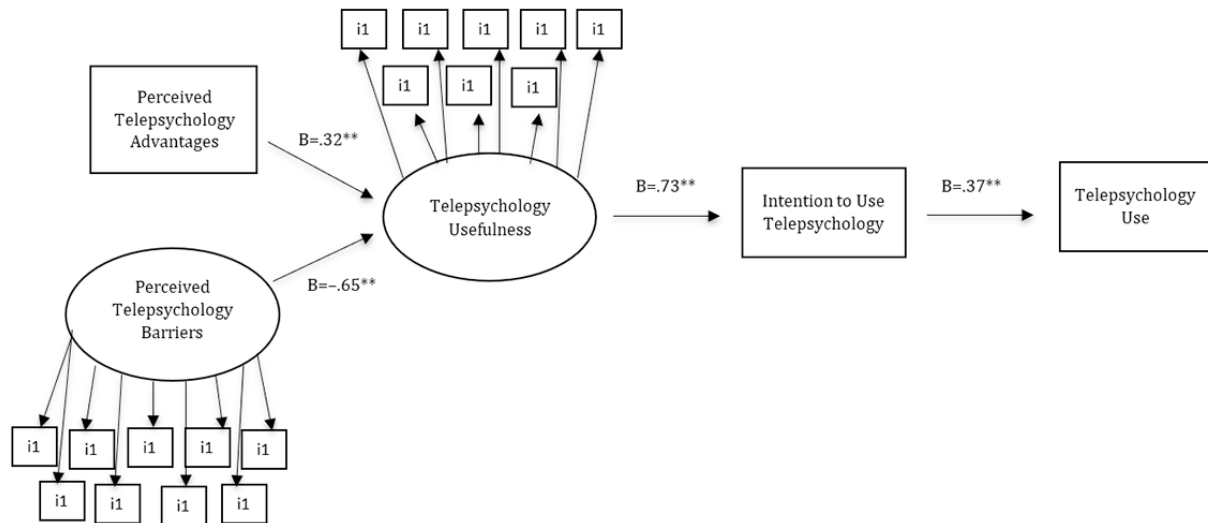
In sum, research has paid special attention to advantages and barriers that may determine e-mental health care services. However, authors such as Henneman et al [14] call for further research, as knowledge about eHealth adoption barriers and advantages remains limited. For example, only a handful of empirical studies have simultaneously examined advantages and barriers [42], indicating that, to facilitate the use of eHealth applications, they need to integrate ease of use and usefulness with a certain level of reliability. Finally, in terms of telepsychology, we are not aware of any study that has specifically focused on psychotherapy through videoconferencing technology. Thus, the advantages of and barriers to adopting telepsychology remain to be studied.

### **Research Purpose and Hypotheses**

This study aimed to obtain a deeper understanding of people's acceptance and use of telepsychology by examining the determinant factors according to an extended UTAUT model that includes perceived telepsychology advantages and barriers. It represents a first step in the study of telepsychology acceptance and use. Thus, our goal was to examine the strongest predictors of technology use in the UTAUT model following eHealth literature (ie, usefulness perceptions and behavioral intention). Our conceptual model is displayed in Figure 1 and integrates telepsychology advantages and barriers as antecedents of usefulness perceptions and behavioral intention. It also considers usefulness perceptions and behavioral intention as key mediating mechanisms for telepsychology use. So, first, this model proposed that perceived telepsychology advantages and barriers may determine telepsychology usefulness. The more advantages and fewer barriers that are perceived, the more useful telepsychology will be perceived. Second, telepsychology usefulness is related to telepsychology use because, when people believe that telepsychology can help them, that is, it is useful, then they will have a higher intention to use it. Third, intention to use is related to use. Intention to use is a natural predictor of technology use. Finally, note that in the UTAUT model, sex and age play a moderator role in the relationship between usefulness and behavioral intention. They have significant effects in the model, so we included them as control variables to take into account their effects on telepsychology acceptance and use. Accordingly, we had the following hypotheses:

- Hypothesis 1 stated that perceived telepsychology barriers are negatively related with telepsychology usefulness.
- Hypothesis 2 stated that perceived telepsychology advantages are positively related with telepsychology usefulness.
- Hypothesis 3 stated that telepsychology usefulness is positively related with the intention to use telepsychology.
- Hypothesis 4 stated that the intention to use telepsychology is positively related to telepsychology use.
- Hypothesis 5 stated that telepsychology usefulness mediates the relationship between perceived telepsychology barriers (H5a) and advantages (H5b) and the intention to use telepsychology.
- Hypothesis 6 stated that the intention to use telepsychology mediates the relationship between telepsychology usefulness and telepsychology use.

**Figure 1.** Results of the structured equation model (SEM) for the hypothesized unified theory of acceptance and use of technology (UTAUT) model applied to telepsychology. All parameters are standardized; results are controlled for sex and age; telepsychology use is a dummy variable: (1) no and (2) yes. \* $P < .05$ , \*\* $P < .01$ .



## Methods

### Procedure and Sample

As we wanted to study the general population perspective, we recruited a convenience sample through an online advertisement published on our university's website. The ad explained the research project, explained its main objective, and asked for volunteers who might be willing to participate in our research by taking an open online survey. The ad also provided the link to the survey, which was implemented using the Qualtrics platform. In order to increase response rates, the researchers sent this link along with a brief summary of the research project to their contacts via email.

All of the surveys implemented in the host institution for research purposes are implemented using the Qualtrics platform, since it guarantees data protection. Qualtrics allows downloading responses in different formats. Once the survey closed, we downloaded data in Excel format and moved it to SPSS.

The survey was responsive to different devices, but we recommended that potential participants complete it using a computer since it was perceived by the research team and users who tested it in advance to be easier. The survey assessed the dimensions (presented in the order used for the survey) that are presented in the following sections. Questions had to be completed to progress in the survey and move to the next screen (if a question was not answered, the system provided an error message). There was a maximum of 10 screens (some of them did not appear if they were not applicable for the specific participant by taking into account his or her previous responses). There was not a specific number of items per screen since it depended on the type of item, but we always tried to avoid excessive scrolling.

The user's IP was not registered to guarantee anonymity; however, the Qualtrics system maintains an opened survey and saves a participant's progress for a week. So, during this period, if participants stopped and restarted the survey, they were

directed to the exact place they were when they left the survey (if they used the same computer and browser). At the bottom of the screen, there was a progress bar.

The only inclusion criterion for participation was being older than 18 years. In the data collection process, anonymity and confidentiality were guaranteed, and participants provided their consent to participate by accessing the survey and accepting the conditions (ie, all responses were anonymous, no personal data were gathered, and participants could stop participating at any time). No incentive was offered to participants. The protocol was previously approved by the university's ethics committee. The final sample was composed of 514 participants. A total of 568 persons entered the system; of these, 54 did not complete the survey and were excluded.

### Measures

The current literature did not offer measures for the specific variables in this study. Accordingly, a specific online survey was created following similar studies and taking into account the available literature. The survey was created and reviewed in an iterative manner by the authors. In addition, before making the survey available to participants, it was tested by 4 volunteers who suggested changes that were implemented. They could judge both the format and functionality of the online survey and the content of the items. Regarding the content of items, they could assess if they were appropriate for the targeted construct and easily understandable. The measures of this study were perceived telepsychology advantages, perceived telepsychology barriers, telepsychology usefulness, intention to use telepsychology, and telepsychology use.

#### Perceived Telepsychology Advantages

The perceived telepsychology advantages were assessed by computing the participants' answers to the statement: "Please indicate the different advantages that might motivate you to use telepsychology." According to the literature (eg, [41]), the possible answer options were: (1) lower economic cost, (2) the possibility of receiving treatment from home, (3) access to

specialized treatment, (4) greater anonymity, (5) as a complement to face-to-face psychotherapy, and (6) none of the above. All “yes” responses were given a value of 1, except for the last option (none of the above), which was given a value of 0. The sum of the marked (“yes”) options was the index that represented perceived telepsychology advantages.

### **Perceived Telepsychology Barriers**

The perceived telepsychology barriers were measured by means of a self-developed scale. It included a general statement: “Please indicate to what extent the following elements would present a barrier to doing online psychotherapy,” with 9 items that reflected the main barriers identified in the literature (eg, [19,41,43]). These items were: (1) it would prevent me from having close or warm contact with my therapist, (2) it would prevent me from expressing my emotions or feelings, (3) I would not be able to pick up on the therapist’s nonverbal language well, (4) the therapist would not understand my nonverbal language well, (5) there would be online confidentiality risks, (6) I would not have enough connection speed or the connection would cut out, (7) there is scarce scientific evidence for the efficacy of telepsychology, (8) there is scarce legal regulation, and (9) I lack the knowledge or resources required to videoconference. The response options varied from 1 (not at all) to 5 (very much so). The mean of the items was the index that represented perceived telepsychology barriers.

### **Telepsychology Usefulness**

Telepsychology usefulness was also measured using a self-developed, 5-point Likert scale. It included the general statement: “Please indicate to what extent you think telepsychology can be effective for the following issues,” with 8 items reflecting the most common presenting problems in psychotherapy. More specifically, the items were: (1) improvement of mood disorders (eg, depression, anxiety), (2) improvement of relational problems (eg, couple or family problems), (3) improvement of work-related stress problems, (4) health problems (eg, chronic pain, diet, fibromyalgia), (5) personal growth issues, (6) mild psychological problems (interfering little with daily life), (7) moderate psychological problems (interfering moderately with daily life), and (8) severe psychological problems (interfering seriously with daily life). The response options ranged from 1 (not at all) to 5 (very much so).

### **Intention to Use Telepsychology**

Intention to use telepsychology was assessed with a mono-item scale asking: “If you had a problem today, how likely would you be to use telepsychology?” The response options ranged from 1 (very unlikely) to 5 (very likely).

### **Telepsychology Use**

Telepsychology use was measured as a dummy variable with the following question: “Have you ever attended any kind of

online psychological therapy?” Two answer options were provided: (1) no and (2) yes.

### **Analysis**

The following preliminary analyses were computed: mean, SD, and correlation. In addition, given that the measures of telepsychology barriers and usefulness were self-developed, we examined their validity and reliability through confirmatory factor analysis (CFA) and Cronbach alpha. Later, structural equation models (SEM) were performed to test our hypotheses on mediation effects. Two models were computed: (1) a full model that included the direct and indirect relationships among all our variables and (2) a hypothesized UTAUT model. Mplus software [43] was used. Maximum likelihood was employed to estimate the parameters of the model. Model adjustment was assessed through chi-squared statistics and fit indices, such as the Tucker-Lewis index (TLI), root mean square error of approximation (RMSEA), and weighted root mean square residual (WRMR). A good fit was defined as values higher than .90 for TLI, values lower than .08 for RMSEA, and values lower than 1 for WRMR [45,46].

## **Results**

### **Sample Characteristics**

Of the 514 participants, 79.8% (410/514) were women, and 20.2% (104/514) were men. The mean age was 36.27 (SD 10.35) years. Only 0.4% (2/514) of the participants had not completed any level of education, while 2.7% (14/514) had studied at elementary school, 27.0% (139/514) had studied at secondary school, 43.2% (222/514) had studied at college, and 26.7% (137/514) had studied a postgraduate course. Up to 61.9% (318/514) of participants reported having undergone face-to-face psychotherapy, and 6.4% (33/514) had experienced telepsychology formats. Finally, 17.1% (88/514) had a monthly salary lower than €600 (US \$708.54), 16.7% (86/514) had a salary between €600 and €999 (US \$1179.71), 26.7% (137/514) earned between €1000 (US \$1180.86) and €1499 (US \$1770.14), 20.6% (106/514) earned between €1500 (US \$1771.32) and €1,999 (US \$2360.58), 10.7% (55/514) had an annual income between €2000 (US \$2361.72) and €3000 (US \$3542.63), 3.5% (18/514) earned more than €3000, and finally 24 participants did not disclose their salary range.

### **Preliminary Analysis**

Table 1 shows our descriptive results. Most of the variables were significantly correlated with the others. Noteworthy is the high correlation between telepsychology usefulness and intention to use telepsychology ( $r=0.50$ ). Table 2 presents our confirmatory factor analysis. Goodness-adjustment indexes pointed out an appropriate adjustment of data to model for telepsychology barriers and usefulness measures (see [46-48]). Cronbach alphas were .83 for telepsychology barriers and .92 for telepsychology usefulness. Thus, it is possible to conclude that the validity and reliability of these scales were appropriate.

**Table 1.** Descriptive analysis and correlations.

| Variable                                   | Sex            | Age <sup>a</sup> | Perceived telepsychology advantages <sup>b</sup> | Perceived telepsychology barriers <sup>c</sup> | Telepsychology usefulness <sup>d</sup> | Intention to use telepsychology <sup>e</sup> | Telepsychology use <sup>f</sup> |
|--|----------------|------------------|--|--|--|--|---------------------------------|
| <b>Sex</b>                                 |                |                  |  |  |  |  |                                 |
| <i>r</i>                                   | 1              | −0.03            | 0.03   | 0.09   | 0.01                                   | 0.05   | −0.03                           |
| <i>P</i> value                             | — <sup>g</sup> | .55              | .54  | .06  | .76                                    | .26  | .45                             |
| <b>Age</b>                                 |                |                  |  |  |  |  |                                 |
| <i>r</i>                                   | −0.03          | 1                | −0.10  | −0.02  | −0.22                                  | −0.03  | 0.01                            |
| <i>P</i> value                             | .55            | —                | .02  | .71  | <.001                                  | .48  | .87                             |
| <b>Perceived telepsychology advantages</b> |                |                  |  |  |  |  |                                 |
| <i>r</i>                                   | 0.03           | −0.10            | 1  | −0.08  | 0.37                                   | 0.32   | −0.04                           |
| <i>P</i> value                             | .54            | .02              | —  | .09  | <.001                                  | <.001  | .36                             |
| <b>Perceived telepsychology barriers</b>   |                |                  |  |  |  |  |                                 |
| <i>r</i>                                   | 0.09           | −0.02            | −0.08  | 1  | −0.38                                  | −0.25  | 0.11                            |
| <i>P</i> value                             | .06            | .71              | .09  | —  | <.001                                  | <.001  | .01                             |
| <b>Telepsychology usefulness</b>           |                |                  |  |  |  |  |                                 |
| <i>r</i>                                   | 0.01           | −0.22            | 0.37   | −0.38  | 1                                      | 0.50   | −0.11                           |
| <i>P</i> value                             | .76            | .00              | <.001  | <.001  | —                                      | <.001  | .01                             |
| <b>Intention to use telepsychology</b>     |                |                  |  |  |  |  |                                 |
| <i>r</i>                                   | 0.05           | −0.03            | 0.32   | −0.25  | 0.50                                   | 1  | −0.18                           |
| <i>P</i> value                             | .26            | .48              | <.001  | <.001  | <.001                                  | —  | <.001                           |
| <b>Telepsychology use</b>                  |                |                  |  |  |  |  |                                 |
| <i>r</i>                                   | −0.03          | 0.01             | −0.04  | 0.11   | −0.11                                  | −0.18  | 1                               |
| <i>P</i> value                             | .45            | .87              | .36  | .01  | .01                                    | <.001  | —                               |

<sup>a</sup>Mean (SD): 36.27 (10.35) years.<sup>b</sup>Mean (SD): 2.61 (1.28).<sup>c</sup>Mean (SD): 3.04 (1.23).<sup>d</sup>Mean (SD): 3.14 (1.14).<sup>e</sup>Mean (SD): 2.69 (1.28).<sup>f</sup>Dummy variable: (1) yes and (2) no.<sup>g</sup>Not applicable.**Table 2.** Fit indices for the structural equation model.

| Variables  | $\chi^2$ | <i>df</i> | <i>P</i> value | $\chi^2/df$ | TLI <sup>a</sup> | RMSEA <sup>b</sup> | WRMR <sup>c</sup> |
|--|----------|-----------|----------------|-------------|------------------|--------------------|-------------------|
| CFA <sup>d</sup> : perceived telepsychology barriers | 75.16    | 18        | <.001          | 4.17        | .93              | .08                | N/A <sup>e</sup>  |
| CFA: telepsychology usefulness                       | 72.20    | 16        | <.001          | 4.51        | .96              | .08                | N/A               |
| Full model: direct and indirect effects              | 291.95   | 10        | <.001          | 29.19       | .89              | .08                | .91               |
| UTAUT <sup>f</sup> model                             | 291.95   | 10        | <.001          | 29.19       | .90              | .08                | .95               |

<sup>a</sup>TLI: Tucker-Lewis index.<sup>b</sup>RMSEA: root mean square error of approximation.<sup>c</sup>WRMR: weighted root mean square residual.<sup>d</sup>CFA: confirmatory factor analysis.<sup>e</sup>N/A: not applicable.<sup>f</sup>UTAUT: unified theory of acceptance and use of technology.

## Hypothesis Testing

Table 2 presents the SEM results. Both the full and UTAUT models indicated an acceptable fit because the adjustment indexes were very similar. However, taking into account the theoretical framework and the fact that the UTAUT model presented a slightly better adjustment compared to the full model, we adopted the UTAUT model results.

Figure 1 displays the model results and supports all hypotheses. Hypothesis 1 was supported, as there was a significant negative relationship between perceived telepsychology barriers and telepsychology usefulness. In other words, the higher the perceived barriers to telepsychology were, the less useful participants perceived it to be. Hypothesis 2 was also supported: Perceived telepsychology advantages were positively related with telepsychology usefulness. This means that the greater the perceived advantages of telepsychology, the more useful participants perceived it to be and the higher their intention of use was. Note that the effect of perceived telepsychology barriers on telepsychology usefulness was stronger than the association between perceived telepsychology advantages and telepsychology usefulness.

Hypothesis 3, which suggested a positive relationship between telepsychology usefulness and the intention to use telepsychology, was supported as well, with results showing a significant positive relationship. In other words, participants that perceived telepsychology as useful tended to show a greater intention to use it.

Hypothesis 4 was supported, as there was a significant positive relationship between the intention to use telepsychology and actual telepsychology use, indicating that participants with higher levels of intention to use telepsychology presented higher telepsychology use than those with low intention.

Finally, all the hypotheses about mediation effects were also supported. Regarding the mediator role of telepsychology usefulness (H5), the results showed that it mediated the relationship between perceived telepsychology advantages ( $B=.23$ ,  $P=.00$ ) and perceived telepsychology barriers ( $B=-.47$ ,  $P=.00$ ) and the intention to use telepsychology.

The results presented a significant indirect effect of telepsychology usefulness on telepsychology use through the intention to use telepsychology (H6), showing that the intention to use telepsychology mediates the relationship between telepsychology usefulness and telepsychology use ( $B=.27$ ,  $P=.00$ ). In sum, perceived advantages and barriers affected participants telepsychology use through their perception of telepsychology usefulness and their intention to use telepsychology.

## Discussion

### Principal Findings

This study is one of few to examine the acceptance and use of telepsychology from participants' perspectives. It draws from the UTAUT model to explain how people accept and use telepsychology, taking into account not only UTAUT factors

(usefulness) but also additional determinants such as perceived telepsychology advantages and barriers.

Our results supported the viability of the UTAUT model in assessing telepsychology acceptance and use. It showed that telepsychology use is predicted by telepsychology usefulness and the intention to use telepsychology. These results are congruent with the extensive literature on the acceptance and use of new technology and on eHealth acceptance and use in particular [22,35,36,38-40].

Perceived advantages and barriers also played a relevant role in explaining telepsychology acceptance and use. These factors determined participants' perceptions of telepsychology usefulness, which affected their intention to use it and, in turn, their actual use of it. A positive perception in the balance between telepsychology advantages and barriers seems to be critical in determining whether people will accept and use this treatment option, with barriers having the strongest effect. These results are also congruent with previous literature on perceived eHealth advantages and barriers [14,36,41,42]. In this respect, it is worthy to mention that this literature has pointed out a discrepancy between low performance expectancy and actual efficacy of eHealth interventions [14,49]. This discrepancy is at least partially supported by our study, as it illustrates the critical role of perceived barriers in explaining telepsychology usefulness. Therefore, the need for further and transparent information and education to clarify misconceptions, especially those related to telepsychology barriers, was clear.

Overcoming barriers and fostering a positive perception of telepsychology has become a central issue since the outbreak of the COVID-19 pandemic. In this new context of social distancing, online psychotherapy has become more a necessity than an option. Many European and American mental health providers and policies relied on using technology to mitigate COVID-19 risks and to respond to elevated mental health demands. Our results can help stakeholders to strategically design ways of facilitating access and readiness to this treatment modality by focusing on the tested UTAUT model. Furthermore, as suggested by Pierce et al [13], telepsychology has come to stay, beyond the response to the pandemic crisis, and, therefore, the maturity of the field needs accelerated development to equal its expected widespread dissemination in routine practice.

Finally, the focus of this study was on the perception of synchronous videoconferencing, which is the most similar form of internet-delivered treatment to face-to-face psychotherapy. Other forms of telepsychology, such as internet-based treatment or self-guided, internet-based psychological interventions, could share some critical aspects with the model presented in our study. However, further research should be carried out to understand specific barriers and perceived usefulness when the intervention involves minimal or nonexistent contact with professionals.

### Limitations

Despite the interesting insight provided by this study, some limitations must be taken into consideration. First, all the measures were self-reported by participants, making common method variance possible. Future research should consider using

additional measures from other sources. Second, the research design of this study was cross-sectional. Thus, it was not possible to infer causal relationships. Further research with longitudinal designs will be necessary to appropriately examine the possible causal effects as well as the stability of the UTAUT model over time.

Third, a convenience sampling method was used to collect data, which may limit the extrapolation of our results, especially to clinical settings. However, as it happens in other studies [50], it is unlikely to jeopardize the validity of our results, and it seems more probable that our results would be similar in other samples. In addition, since more than 60% of participants had used psychotherapy services in the course of their life, restrictions to the generalizability of the results to actual patients are lessened. In any case, further replication studies are needed. Fourth, 79.8% of the sample were women. This composition could have influenced our results, and it can make extrapolating them to a male sample difficult. Nevertheless, psychotherapy services are also more commonly used by women than men. Further research is needed to replicate and validate our results.

### Future Research

This study represents a first step towards applying the UTAUT model to telepsychology. However, we focused on the most important factors to explain participants' acceptance and use of telepsychology, thereby overlooking other factors that are also relevant. In fact, it is congruent with the recent work by Ammenwerth [51], who concluded that the acceptance of a technology depends on multiple additional factors that has been overlooked, such as socio-organizational, workflow, cultural, or emotional aspects as well as differences in user groups (physicians, nurses, patients). For example, a critical personal determinant in telepsychology acceptance and use could be a

previous mental health diagnosis or treatment. Thus, future research is needed to examine these additional factors to gain a deeper understanding of telepsychology acceptance and use. Such factors could be ease of use, facilitators, or moderator variables. Telepsychology is a new field of study that requires further research, especially from the users' perspectives. A promising line of patient-focused research consists of involving users in the development of tools and platforms used to deliver interventions in order to meet their needs and minimize perceived barriers. Optimizing the engagement of participants in interventions is a key aspect for achieving successful treatment outcomes. Finally, it is probable that consumers' and professionals' perceptions about online psychotherapy had shifted as they have been impelled to experience the setting due to the pandemic crisis. Data collection was carried out before the outbreak, and, therefore, we could not take into account the social context when developing the UTAUT model for telepsychology. It is probable that society's perception about telepsychology has changed. Hence, additional research is necessary to better understand telepsychology acceptance by society.

### Practical Implications

This study describes the main factors that must be taken into account to promote acceptance and use of telepsychology among potential clients. Our results provide evidence of the need to foster a positive perception of telepsychology, with a focus on its advantages, and to come up with ways to overcome perceived barriers that do not otherwise hinder conventional face-to-face psychotherapy. In this respect, mental health care stakeholders have a critical role, as van Voorhees et al demonstrated [52], showing that uptake of an e-mental health intervention increased when clinicians adopted a focus on client-centered information aimed at intrinsic motivation.

### Conflicts of Interest

None declared.

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## Abbreviations

**APA:** American Psychological Association

**C-TAM-TPB:** combined technology acceptance model and theory of planned behavior

**CFA:** confirmatory factor analysis

**ICT:** information and communication technology

**RMSEA:** root mean square error of approximation

**SCT:** social cognitive theory

**SEM:** structural equation models

**TAM:** technology acceptance model

**TID:** theory of innovation diffusion

**TLI:** Tucker-Lewis index

**TPB:** theory of planned behavior

**TRA:** theory of reasoned action

**UTAUT:** unified theory of acceptance and use of technology

**WRMR:** weighted root mean square residual

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