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Original Paper

Exploring the Use of Multiple Mental Health Apps Within a Platform: Secondary Analysis of the IntelliCare Field Trial

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Abstract

Background: IntelliCare is a mental health app platform with 14 apps that are *elemental*, *simple and brief* to use, and *eclectic*. Although a variety of apps may improve engagement, leading to better outcomes, they may require navigation aids such as recommender systems that can quickly direct a person to a useful app.

Objective: As the first step toward developing navigation and recommender tools, this study explored app-use patterns across the IntelliCare platform and their relationship with depression and anxiety outcomes.

Methods: This is a secondary analysis of the IntelliCare Field Trial, which recruited people with depression or anxiety. Participants of the trial received 8 weeks of coaching, primarily by text, and weekly random recommendations for apps. App-use metrics included frequency and lifetime use. Depression and anxiety, measured using the Patient Health Questionnaire-9 and Generalized Anxiety Disorder-7, respectively, were assessed at baseline and end of treatment. Cluster analysis was utilized to determine patterns of app use; ordinal logistic regression models and log-rank tests were used to determine if these use metrics alone, or in combination, predicted improvement or remission in depression or anxiety.

Results: The analysis included 96 people who generally followed recommendations to download and try new apps each week. Apps were clustered into 5 groups: Thinking (apps that targeted or relied on thinking), Calming (relaxation and insomnia), Checklists (apps that used checklists), Activity (behavioral activation and activity), and Other. Both overall frequency of use and lifetime use predicted response for depression and anxiety. The Thinking, Calming, and Checklist clusters were associated with improvement in depression and anxiety, and the Activity cluster was associated with improvement in Anxiety only. However, the use of clusters was less strongly associated with improvement than individual app use.

Conclusions: Participants in the field trial remained engaged with a suite of apps for the full 8 weeks of the trial. App-use patterns did fall into clusters, suggesting that some knowledge about the use of one app may be useful in selecting another app that the person is more likely to use and may help suggest apps based on baseline symptomology and personal preference.

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KEYWORDS

mobile apps; depression; anxiety; mobile phone

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Introduction

Background

Depression and anxiety are common mental health problems [1,2] and are among the leading causes of morbidity and disability worldwide [3]. The vast majority of people experiencing these common mental health problems are unable to access treatment due to a variety of actual or perceived barriers including the lack of availability of services, time constraints, transportation problems, and cost [4,5]. A wide variety of Web-based treatments have been developed and shown to be highly effective in the treatment of depression and anxiety, particularly when coupled with some human support to promote adherence and enhance outcomes [6,7]. These programs, leveraging the strengths of computer-accessed Web programs in providing information, have strong psychoeducational components along with some interactional components that function much like worksheets [8].

More recently, mobile apps have been developed and evaluated for the treatment of depression [9,10]. Mobile apps have a number of advantages. Because people keep their phones with them, app-based interventions can fit more seamlessly into the fabric of people's lives. Smartphones are becoming ubiquitous in developed countries and are increasingly common in developing nations [11].

The design of mobile apps for mental health has posed an interesting challenge compared with in-person and Web-based treatments. There are many potential psychological and behavioral strategies that can be used to target specific concerns associated with mental health problems [12,13]. Psychological treatments should be flexible and adaptive, providing treatment elements that best meet the needs and preferences of the patient [14]. Web-based treatments designed to be delivered via a computer can offer a wide variety of treatment approaches, which sometimes require a few layers of navigation. Often, these programs require longer periods of engagement with psychoeducational material, with recommended access every week or few days. However, this design may not be well suited to mobile apps. People tend to use apps in very short bursts of time, sometimes frequently [15,16]. Thus, popular apps tend to be designed for use through simple interactions with limited navigation. A single app tends to focus on a narrow set of objectives. For example, most people do not use one app for transportation needs. Rather, they often use a variety of apps to manage flights on different airlines, manage train transportation and buses, or map driving routes and check traffic. In short, different apps are used flexibly to meet the changing moment-to-moment needs. Thus, there are a large number of behavioral strategies that may be useful for people with common mental health problems, but mobile apps that are used and useful tend to be narrow in focus and quick to use.

The observation of the incongruity between the large variety of potentially useful psychological strategies and the narrow, efficient design requirements for mobile apps has led our team to question the "app for that disorder" approach that has been common in digital mental health design.

IntelliCare addresses this issue by creating a suite of apps, each of which addresses a single psychological or behavioral strategy rather than attempting to address the full theoretical framework for a mental health problem [17]. Thus, each app is elemental, allowing the user to select which strategies are the most useful to them, consistent with the US Institute of Medicine report recommending that app-based treatments combine therapeutic elements as well as consider how people tend to use apps. Each app is simple to use, most requiring less than a minute per engagement [18]. Most of the apps focus on supporting learning or implementing a skill, and not on psychoeducation, thus helping people with an immediate problem. The IntelliCare suite of apps, which has more than 85,000 downloads from the Google Play Store, generally experienced good engagement. A field trial that provided 8 weeks of coaching showed significant reductions in depression and anxiety symptoms.

As we move from a single app that addresses a disorder to a platform of apps that each supports discrete treatment strategies, the management of those apps poses a new challenge. As a mental health app platform such as IntelliCare includes a growing number of apps, user reliance on the trial-and-error method to select apps will make the platform harder to use in a meaningful way. To address this issue, IntelliCare includes a Hub app, which, if downloaded, can help organize users' experience by making recommendations about which apps to select. Users who download this Hub app use more apps and use the apps for longer periods of time [17]. Receiving a recommendation from the Hub app to use a specific app increases the likelihood that the app will be downloaded and used [19]. However, it is unclear at this point how to recommend these apps in a way that ensures users are presented with options that are likely to meet their preferences and needs.

Objective

The aim of this study was to investigate the patterns of app use across the IntelliCare platform over time. Specifically, we characterized the general platform use, specific apps use, and use of multiple apps (ie, clusters). We then examined the relationship between general, app, and cluster use and depression or anxiety symptom improvement. Lastly, we explored if there were optimal patterns of general, specific, or cluster of app use in terms of predicting improvement in depression or anxiety symptoms. This study aimed at not only understanding the possible utility of apps but also examining whether outcomes are driven more by user engagement around a construct (or app cluster) or simply by individual app use. Understanding these use patterns could improve our ability to recommend apps that users may engage with or that will be more helpful to them personally.

Methods

Participants

This is a secondary analysis of a single-arm field trial of IntelliCare. Details on the methods are reported in the primary paper [18] (trial registration: Clinicaltrials.gov NCT02176226). Briefly, participants were recruited from a variety of sources, including online, a health care system, community advertising, and research registries. Participants were included in this

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single-arm field trial if they exhibited depressive symptoms indicated by a score of 10 or higher on the Patient Health Questionnaire-9 (PHQ-9) [20] or anxiety symptoms indicated by a score of 8 or higher on the Generalized Anxiety Disorder-7 (GAD-7) questionnaire [21]; were 18 years of age or older (19 years if in Nebraska, given the age of consent); could speak and read English and lived in the United States; and owned and were familiar with using an Android smartphone with data and text plans. Participants were excluded if they had any visual, hearing, voice, or motor impairments that would prevent completion of study procedures; reported having a severe psychiatric disorder (eg, bipolar disorder, psychotic disorder, or dissociative disorder) or any other diagnosis for which this trial was either inappropriate or dangerous; exhibited severe suicidality including a plan and intent; had initiated or changed antidepressant or antianxiolytic pharmacotherapy in the previous 14 days; or had used any of the IntelliCare apps for more than 1 week in the past 3 months. Participants could earn up to US $90 for completion of assessments but were not paid for using the apps or engaging with the coach.

Procedures

People who met the inclusion criteria based on online questionnaires and signed an online consent approved by the Northwestern University institutional review board were offered 8 weeks of coaching aimed at helping them use the IntelliCare app suite, detailed in the IntelliCare section below. Outcome assessments, which included the PHQ-9 and GAD-7, were administered at baseline and weeks 4 and 8.

IntelliCare

At the time of this trial, the IntelliCare platform consisted of 14 apps (Multimedia Appendix 1). This included 13 clinical apps, each of which was designed to target a specific behavioral or psychological treatment strategy (eg, goal setting, behavioral activation, and social support) and improve symptoms of depression and anxiety through efficacious treatment strategies [17]. The user's experience with the clinical apps was coordinated through a Hub app that, among other functions, made weekly recommendations for new apps. Recommendations were made at random, as there was no basis at the time of this trial to select specific apps. Although users were asked to at least try the newly recommended apps, they were encouraged to use the apps they found most helpful.

Coaching Protocol

Coaching was guided by the IntelliCare Coaching Manual [22], which is based on aspects of the Efficiency Model of Behavioral Intervention Technologies Support [23] and supportive accountability [24]. Coaching was aimed primarily at encouraging participants to try the apps recommended to them through the Hub app. Coaches also answered questions about how to use the tools found in the apps and the rationale behind the skills taught by the apps, encouraged application of the skills in daily life, and provided some technical support as needed. Coaching began with an initial 30- to 45-minute engagement phone call to establish goals for mood and anxiety management, ensure the participant could download the Hub app from the Google Play store, introduce the suite of available smartphone apps, build rapport, and set expectations for the coach-participant relationship. Some participants also received an additional 10-minute call around midtreatment. After the initial engagement call, participants received 2-3 text messages per week from their coach to provide support in using apps, offer encouragement, reinforce app use, and check in on users' progress or challenges. Coaches also responded to all participant-initiated text messages within 1 working day. The coaches had a dashboard that provided information about the IntelliCare apps on each participant's phone, including which apps were installed, when they were downloaded, each time an app was used, and which apps were selected as "primary" in the Hub app. The dashboard also included a short message service tool, a section for brief notes, and an alert indicating when no IntelliCare app had been used for 3 days, prompting coaches to check in. Coaches had at least a bachelor's degree in psychology or a related field and were trained and monitored by one of the authors of the coaching manual.

App-Use Metrics

Although apps were available for download at any time during the trial, app recommendations were made randomly over the course of 8 weeks, and the time that any individual app was on a participant's phone could vary substantially. Therefore, in addition to total apps used, other use metrics needed to be defined in relation to the time that the app was on a phone and available to the participant. Accordingly, we created two metrics: *frequency of use* and *lifetime use*. *Frequency of use* was measured as the percentage of days the app was used, calculated as the number of days the app or set of apps was launched divided by the number of days in the study after the app was downloaded by a participant and available for use. For instance, since the trial lasted 8 weeks, or 56 days, if the participant downloaded the app on day 14, the possible number of days it could have been used was 56 minus 14, or 42 days; if they launched the app on 21 of those days, the *frequency of use* would be 50%. We made an *a priori* decision to measure app-use frequency based on the number of days of use rather than the number of times an app was launched, as we were concerned about the numerous potential sources of variability for app use within a day, such as interruptions, or differences in app design that might encourage differential use. *Lifetime use* was defined as the time between the first launch and the last launch. However, we recognized that not every app was designed to be used every day, so we allowed for censoring if the app was still being used in the last week of the trial. For instance, if the app was first launched on day 14 and last launched on day 22, the *lifetime use* of the app would be 8 days. However, if the app was first launched on day 14 and last used in the last week of the study (between days 49 and 56), the *lifetime use* would be censored at 56 minus 14, or 42 days.

Outcome Assessment

Depression was measured using the PHQ-9 [20] and anxiety was measured using the GAD-7 [25], two commonly used self-report measures. Outcomes were categorized using standard cutoffs [26,27]. For depressed patients, we defined remission as PHQ-9 scores < 5 (typically indicating minimal depression), improvement as 5 ≤ PHQ-9 < 10 (indicating mild-moderate

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depression), and no improvement as PHQ-9 score ≥ 10 (moderately severe-severe depression). For participants with anxiety, remission was determined as GAD-7 score < 5 (minimal anxiety), improvement as 5 ≤ GAD-7 < 8 (mild anxiety), and no improvement as GAD-7 score ≥ 8 (moderate or severe anxiety).

Statistical Analyses

We describe app use using visual informatics and descriptive statistics. Additionally, we performed a cluster analysis on the total number of launches by app using a centroid approach with the Spearman correlation to determine if the use of any of the apps was clustered together.

Analyses relating app use to outcome were conducted separately for participants who met the PHQ-9 score ≥10 entry criterion for depression and participants who met the GAD-7 score ≥ 8 criterion for anxiety. We fit ordinal logistic regression models, modeling proportional odds of improvement or remission (I/R) to determine if frequency of use, for any apps combined, individual apps, and clusters of apps varied by outcome. To assess if the use of multiple apps within a cluster was more effective in treating depression or anxiety, we "scored" apps if they had 25% or more frequency of use and then examined if there was a trend between the number of scored apps within a cluster and outcome. Lastly, we employed stepwise selection to determine which apps or combination of apps was most predictive in a model on our ordinal outcomes concerning the I/R of symptoms. All odds ratios (ORs) and 95% CIs are presented for a 10% increase in the number of days used. To examine lifetime use by outcome, we fit Kaplan-Meier plots and used log-rank tests.

All analyses were performed using SASv9.4 (Cary, NC); graphs were created in SASv9.4 or Rv3.4.3 [28]. The type I error was set at .05 for all analyses, but we caution that any findings should be further investigated, as this is a secondary analysis and therefore subject to increased type I errors.

Results

Participants

A detailed description of the participants and primary outcomes has been published elsewhere [18]. Briefly, 99 participants were enrolled and began the 8-week field trial. A flow diagram is available in the main outcome paper [18]; only 3 participants were lost to follow-up, leaving 96 participants with at least two outcome assessments, who are the focus of this secondary analysis. Among those participants, the median age was 36 (interquartile range: 27-52) years, 74 (77%) were women, 80 (84%) were non-Hispanic white individuals, 60 (63%) were on medication for anxiety or depression, and 24 (25%) were currently receiving psychotherapy. At the start of the field trial, the depression criterion of PHQ-9 score ≥10 was met by 78 (81%) participants, the anxiety criterion of GAD-7 score ≥ 8 was met by 77 (80%) participants, and the criteria for both depression and anxiety were met by 59 (61%) participants. Using our classification of treatment response, among the 78 participants meeting the entry criterion for depression, by the end of treatment, 26 (33%) were in remission, 30 (38%) had improved symptoms, and 22 (28%) remained symptomatic. Of the 77 participants who met the criteria for anxiety, 28 (36%) were in remission, 23 (30%) had improved symptoms, and 26 (34%) remained symptomatic.

General App Use

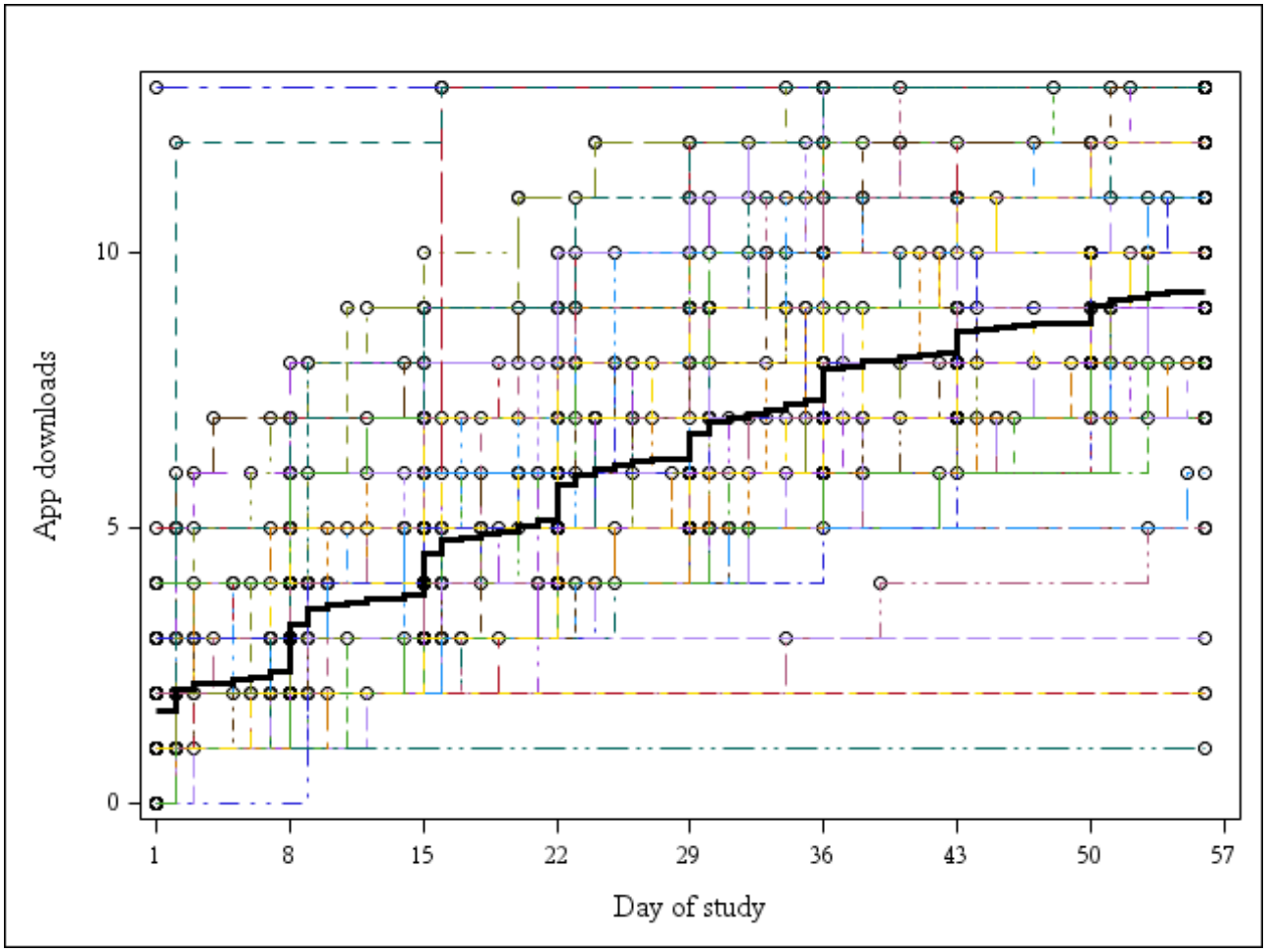
Participants downloaded an average of 9.3 apps (SD 2.6) over 8 weeks; half of the participants used over 9 apps. Overall, participants tended to download the apps in the suite gradually over the 8 weeks, rather than download all the apps at the start of the trial. There was an immediate launch of a few apps in the first week (average number downloaded 2.4; SD 2.0), which tapered gradually over the length of the study, with average increases of 1.4 apps/week for weeks 2 and 3, and roughly 1 app/week for weeks 4-6, down to 0.5 apps/week for weeks 7 and 8 (Figure 1). The apps were used throughout the trial, with a median lifetime use of 55 (interquartile range: 53-55) days for the suite.

Individual App Use

Half of the participants used at least one IntelliCare treatment app for 49 (88%) of the 56 days, with an interquartile range of 35 (63%) to 53 (95%) days. Median percent of days used for specific apps ranged from 2% (Me Locate) to 41% (Daily Feats) (Table 1). The lifetime use for specific apps ranged from 0 days (Me Locate) to 21 days (Daily Feats). Kaplan-Meier plots for each app's lifetime use over the trial period are shown in Figure 2.

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Figure 1. Cumulative downloads of apps by study day.



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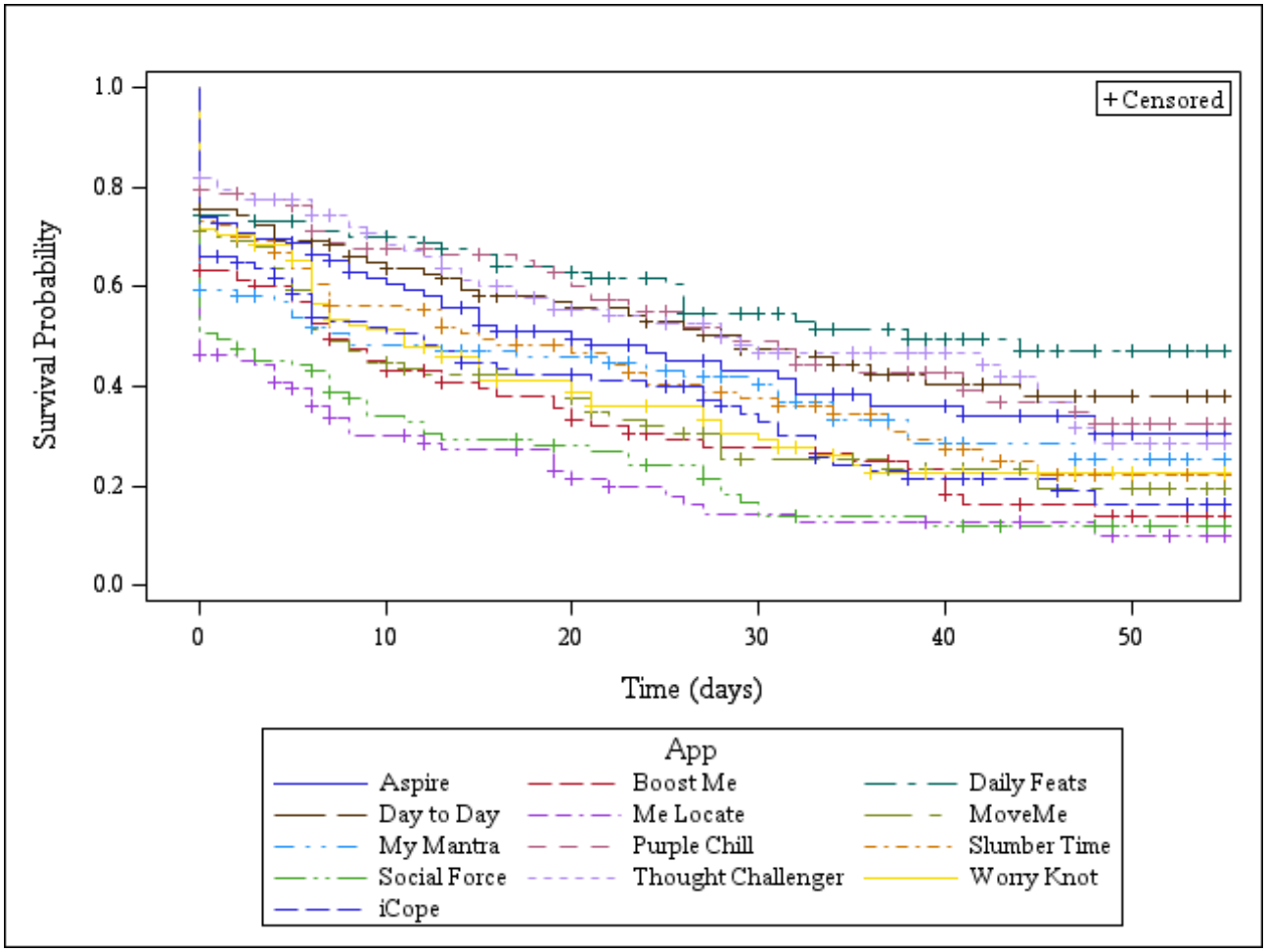
Table 1. Usage of all Intellicare apps.

Usage pattern and apps	Overall use		Use by participants who downloaded the app		
	Frequency of Use, median (25th, 75th)	Lifetime Use[a], median (25th, 75th)	Number downloaded (%)	Frequency of Use, median (25th, 75th)	Lifetime Use[a], median (25th, 75th)
Individual app use					
Aspire	19 (3, 50)	13 (0, 32)	73 (76)	30 (16, 62)	20 (8, 35)
Boost Me	12 (0, 25)	7 (0, 22)	65 (68)	19 (12, 33)	13 (6, 33)
Daily Feats	41 (1, 75)	21 (0, 39)	72 (75)	54 (33, 88)	27 (16, 45)
iCope	11 (0, 25)	6 (0, 30)	69 (72)	17 (10, 42)	20 (5, 33)
My Mantra	16 (0, 58)	6 (0, 30)	59 (61)	43 (18, 78)	25 (7, 37)
Me Locate	2 (0, 17)	0 (0, 8)	50 (52)	17 (12, 31)	8 (4, 20)
Day to day	26 (4, 57)	16 (0, 36)	76 (79)	41 (21, 67)	25 (9, 41)
MoveMe	16 (2, 33)	6 (0, 23)	73 (76)	21 (12, 38)	11 (5, 27)
Purple Chill	24 (5, 62)	19 (3, 40)	79 (82)	34 (17, 68)	23 (8, 41)
Slumber Time	25 (0, 57)	13 (0, 34)	71 (74)	41 (22, 67)	22 (7, 37)
Social Force	5 (0, 22)	1 (0, 15)	54 (56)	17 (9, 35)	12 (6, 27)
Thought Challenger	21 (5, 56)	17 (4, 37)	80 (83)	30 (14, 65)	21 (10, 42)
Worry Knot	13 (1, 29)	7 (0, 28)	72 (75)	19 (12, 46)	15 (6, 32)
Cluster use					
Thinking	54 (30, 83)	45 (29, 55)	93 (97)	55 (32, 83)	46 (33, 55)
Calming	45 (20, 66)	34 (13, 48)	87 (91)	48 (26, 71)	37 (19, 49)
Checklists	48 (26, 83)	37 (16, 49)	84 (88%)	52 (34, 86)	41 (25, 50)
Activity	25 (12, 43)	28 (7, 41)	83 (86%)	29 (14, 47)	33 (13, 44)
Other	15 (2, 32)	6 (0, 23)	73 (76%)	21 (12, 37)	11 (5, 27)

[a]Lifetime Use is defined as the time between the first launch and the last launch.

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Figure 2. Lifetime use of each individual app.



Clusters of Apps

A cluster analysis revealed 5 groups of apps that tended to be used together. The average within-cluster R^2 ranged from .34 to .61, whereas the average R^2 to the nearest cluster was .03 to .33. In total, the 5 clusters explained 59% of the variability of correlations between launches. The five clusters identified could best be described as follows: “Thinking” - Thought Challenger, MyMantra, Day to Day, and iCope; “Calming” - Purple Chill and Slumber Time; “Checklists” - Aspire and Daily Feats; “Activity” - Boost Me and MoveMe; and “Other” - Me Locate, Social Force, and Worry Knot, which appeared unified only in the lack of engagement relative to other apps.

The Thinking and Checklist clusters were used most often and for a longer period of time than the other clusters, with median lifetimes over 5 weeks in the 8-week trial. The Calming and Activity clusters were also used fairly often, with a median use of just over 4 weeks. The Other cluster was used the least, with a median lifetime of a week (Table 1). The number of apps scored (≥25% frequency of use) in each cluster was fairly diverse for the Thinking, Calming, and Checklist clusters, where there were participants who did not use any of the apps much as well as participants who used all the apps within the cluster. The Activity and the Other clusters were more prone to have individuals who did not use any of the apps often (Table 2).

Table 2. Number of apps with more than 25% frequency of use within each app cluster.

Number of apps with ≥25% use	Thinking, n (%)	Calming, n (%)	Checklist, n (%)	Activity, n (%)	Other, n (%)
0	25 (26)	29 (30)	23 (24)	52 (54)	49 (51)
1	21 (22)	36 (38)	40 (42)	32 (33)	31 (32)
2	22 (23)	31 (32)	33 (34)	12 (13)	12 (13)
3	17 (18)	N/A[a]	N/A	N/A	4 (4)
4	11 (11)	N/A	N/A	N/A	N/A

[a]N/A: not applicable.

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Table 3. Ordinal odds ratios for improvement or remission of depression/anxiety by app use.

Item	Depression	Anxiety
Univariate odds ratio (95% CI) for suite		
Number of apps downloaded	1.07 (0.91-1.25)	1.20 (1.01-1.43)
Percent days of app use	1.26 (1.05-1.52)	1.19 (0.99-1.43)
Univariate odds ratio (95% CI) for individual apps		
Aspire	1.15 (1.00-1.32)	1.19 (0.99-1.43)
Boost Me	1.27 (1.00-1.61)	1.37 (1.06-1.77)
Daily Feats	1.09 (0.97-1.22)	1.05 (0.94-1.18)
Day to day	1.11 (0.98-1.27)	1.18 (1.03-1.35)
iCope	1.00 (0.86-1.16)	1.01 (0.86-1.17)
My Mantra	1.02 (0.91-1.15)	1.13 (0.99-1.28)
Me Locate	1.15 (0.93-1.41)	1.82 (1.25-2.63)
MoveMe	1.15 (0.99-1.34)	1.17 (0.99-1.37)
Purple Chill	1.17 (1.02-1.34)	1.16 (1.01-1.34)
Slumber Time	1.04 (0.92-1.18)	1.07 (0.94-1.23)
Social Force	1.05 (0.89-1.25)	1.16 (0.96-1.42)
Thought Challenger	1.07 (0.93-1.22)	1.15 (1.01-1.31)
Worry Knot	1.04 (0.90-1.21)	1.06 (0.91-1.23)
Univariate odds ratio (95% CI) for clusters		
Thinking	1.16 (1.01-1.33)	1.17 (1.02-1.35)
Calming	1.17 (1.02-1.35)	1.18 (1.02-1.36)
Checklist	1.18 (1.04-1.34)	1.14 (1.00-1.30)
Activity	1.08 (0.92-1.27)	1.26 (1.05-1.52)
Other	1.17 (0.99-1.37)	1.16 (0.99-1.36)
Multivariate models		
Boost Me	1.31 (1.02-1.67)	—[b]
Lifetime Purple Chill[a]	1.25 (1.07-1.47)	—
Me Locate	—	1.74 (1.19-2.55)
Lifetime Thought Challenger[a]	—	1.20 (1.02-1.43)

[a]As lifetime is measured in days, and 1 extra day of use is clinically meaningless, odds ratios are based on a unit difference of 1 week.

[b]Not available.

Relationship Between Suite Use and Outcome

The total number of apps used was not associated with I/R in depression (OR=1.07; 95% CI=0.91-1.25), but was associated with I/R in anxiety (OR=1.20; 95% CI=1.01-1.43). Conversely, the frequency of use of any app use was associated with the odds of I/R of depression (OR=1.26; 95% CI=1.05-1.52), but it was not associated with I/R of anxiety (OR=1.19; 95% CI=0.99-1.43) (Table 3).

Relationship Between App Use and Outcome

For depression outcomes, frequency of use of Aspire was associated with increased odds of I/R (OR=1.15; 95% CI=1.00-1.32), and the frequency of use of Purple Chill was associated with increased odds of I/R, but the assumption of proportional odds was not met and increased odds of remission was seen only among those who showed improvement (OR=1.39; 95% CI=1.11- 1.72). For anxiety outcomes, frequency of use of Boost Me (OR=1.37; 95% CI=1.06-1.77), Day to Day (OR=1.82; 95% CI=103-1.35), Me Locate (OR=1.82; 95% CI=1.25-2.63), Purple Chill (OR=1.16; 95% CI=1.01-1.34), and Thought Challenger (OR=1.15; 95% CI=1.01-1.31) were associated with increased odds of I/R (Table 3).

There were significant differences in the lifetime use for iCope, MoveMe, and Purple Chill between participants who had remission, improvement, or no improvement for depression (Log-rank *P*=.02, .04, and .02, respectively) (Figure 3). Among those with anxiety, lifetime use of Boost Me, My Mantra, Me

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Locate, MoveMe, Thought Challenger, and Worry Knot varied across remission, improvement, and no improvement statuses (*P*=.001, .02, .001, .04, .008, and .04, respectively) (Figure 3).

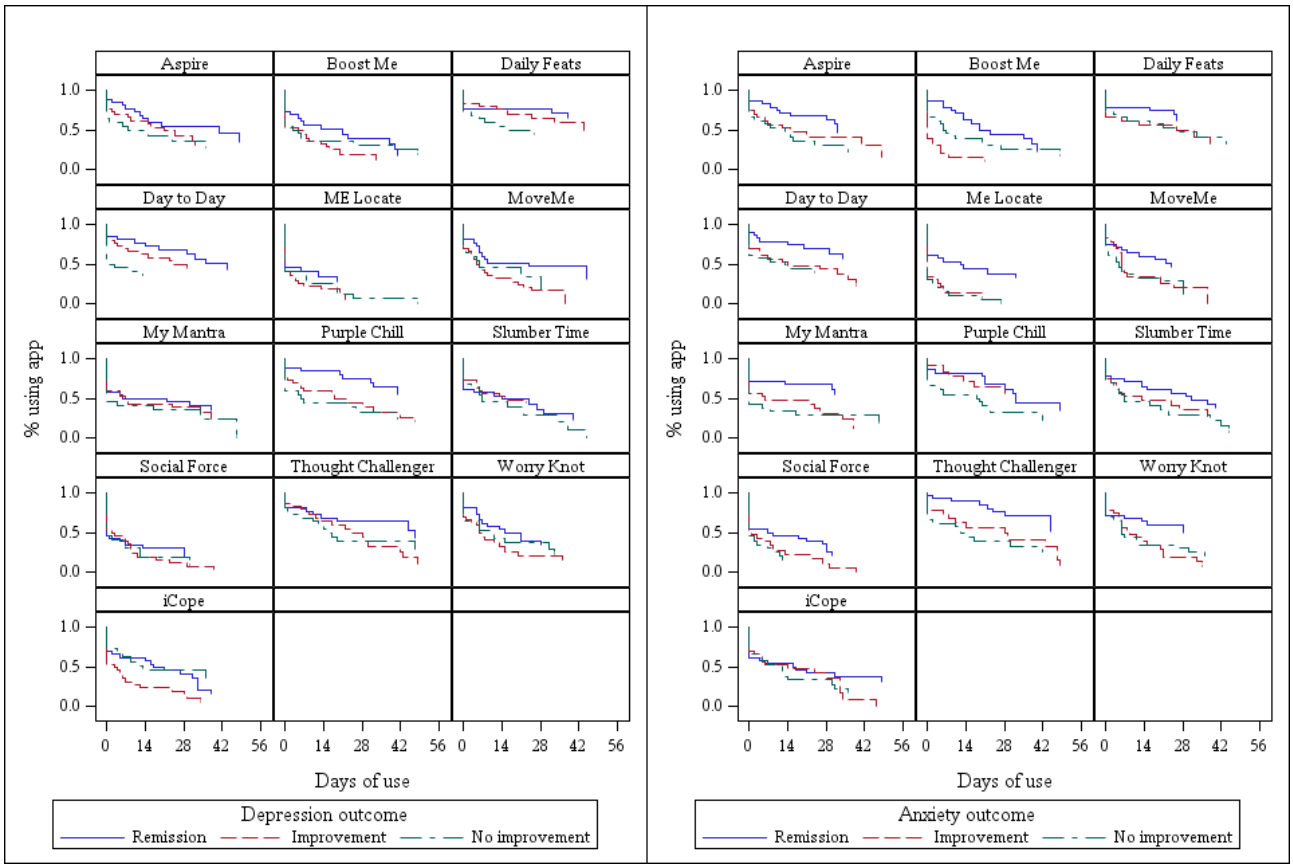
Relationship Between Cluster Use and Outcome

Among participants entering the study with high levels of depressive symptoms, the odds of I/R were significantly greater for participants with a higher frequency of use for apps in the Thinking cluster (OR=1.16; 95% CI=1.01-1.33), the Calming cluster (OR=1.17; 95% CI=1.02-1.35), and the Checklist cluster (OR=1.18; 95% CI=1.04-1.34) (Table 3). We also examined whether the number of apps used within a cluster was related to outcome. There was a significant trend in I/R when multiple apps were used in the Checklist cluster (OR=1.96; 95% CI=1.12-3.44) as well as the Activity cluster (OR=1.81; 95% CI=1.00-3.26). However, in stepwise multivariable ordinal regression models, after adjusting for frequency of use in the Checklist cluster, no other cluster use or number of apps used within a cluster increased the odds of I/R.

Among participants with high levels of anxiety symptoms, the odds of I/R were significantly greater for those with a higher frequency of use in the Thinking cluster (OR=1.17; 95% CI=1.02-1.35), the Calming cluster (OR=1.18; 95% CI=1.02-1.36), the Checklist cluster (OR=1.14; 95% CI=1.00-1.30), and the Activity cluster (OR=1.26; 95% CI=1.05-1.52) (Table 3). Additionally, there was a significant trend in I/R, as the number of apps used increased within the Thinking cluster (OR=1.47; 95% CI=1.07-2.02)), the Checklist cluster (OR=1.79; 95% CI=1.03-3.13), the Activity cluster (OR=1.87; 95% CI=1.03-3.39), and the Other cluster (OR=2.19; 95% CI=1.24-3.89). After adjusting for frequency of use in the Activity cluster, no other cluster or number of apps used within a cluster increased the odds of I/R in multivariable ordinal regression models.

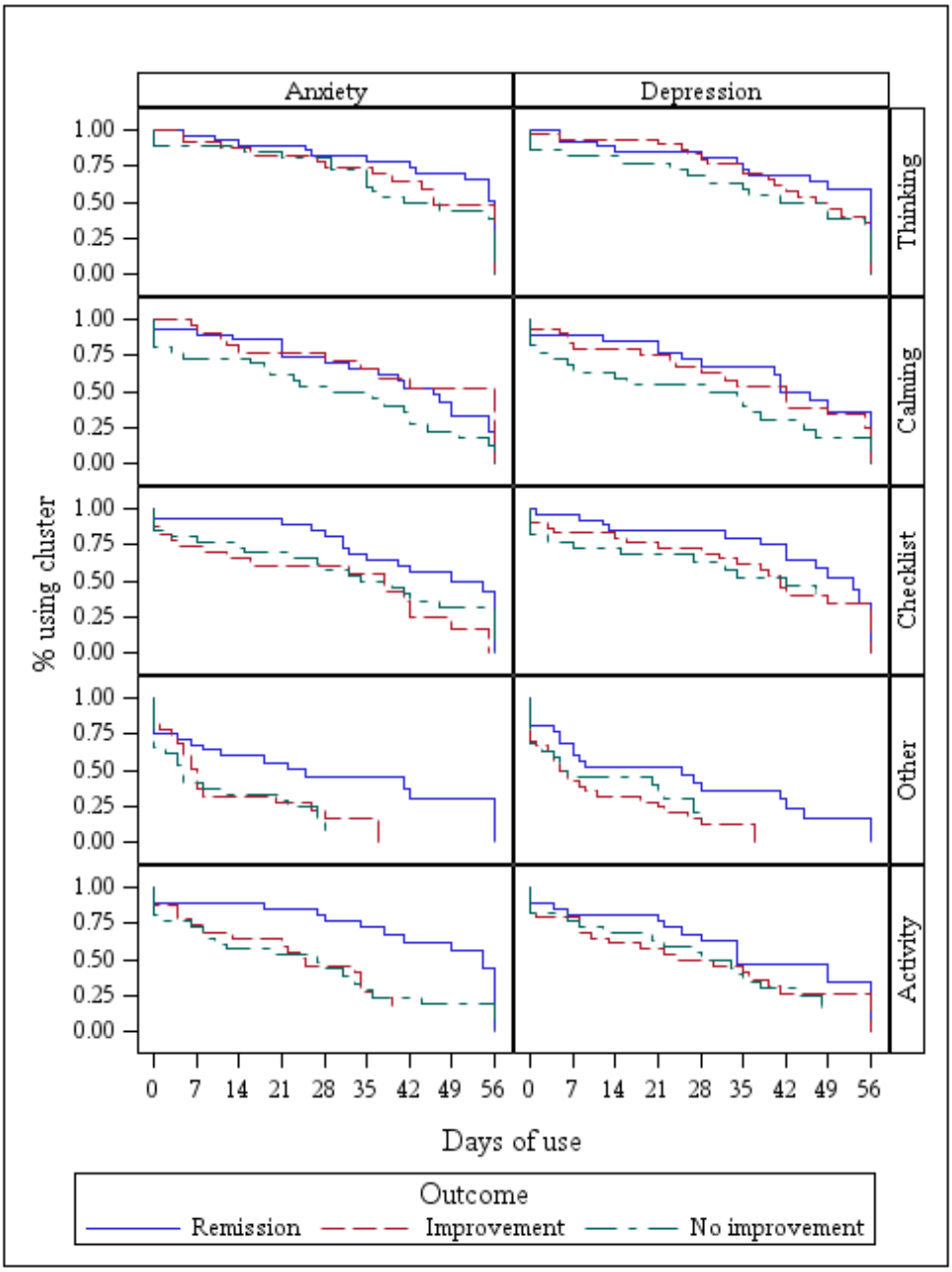
For depression, longer lifetime use of the Activity cluster was significantly associated with better outcomes (Log-Rank *P*=.02). For anxiety, longer use of the Calming, Activity, and Other clusters was associated with better outcomes (Log-Rank *P*=.01, .03, and .002, respectively) (Figure 4).

Figure 3. Lifetime use of individual apps by depression and anxiety outcomes.



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Figure 4. Lifetime use of each cluster of apps by anxiety and depression outcomes.



Optimal Use Patterns

For participants with depression, the frequency of use of Boost Me in combination with lifetime use of Purple Chill was the most predictive combination for response. After adjusting for the frequency of use of Boost Me and the lifetime use of Purple Chill, no other app or cluster use metric was significantly associated with I/R. For participants with anxiety, the frequency of use of Me Locate and lifetime use of Thought Challenger were the most predictive use combination of apps for I/R. After adjusting for these, no other app or cluster use metric was significantly associated with I/R (Table 3).

Discussion

Principal Results

Determining the definition of "use" for apps can be challenging. Here, we defined two metrics: *frequencyof use* (percent of days used) and *lifetime use* (time between initial and last launch). Additionally, we examined clusters of app use based on correlations between the total number of launches and were able to identify groups of apps that could be defined based on behavioral strategy and user interaction style. This revealed five clusters. The Thinking cluster included apps that prompt or rely on a person to use cognitive processes. The Calming cluster provided tools for relaxation and strategies to improve sleep. The Checklist cluster was defined by the type of interaction people had with the app—the use of checklists—rather than by a psychological strategy. This underscores that the design and

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interaction features used in apps may be as important to people's preferences as the psychological goal or behavioral strategies. The Activity cluster was defined by apps that targeted behavioral activation and physical activity. A fifth cluster, which we called Other, consisted of apps that may need further development. Two of the three had the lowest use, and the third—Worry Knot—had an interaction design that was often not well received, based on user feedback. Nonetheless, the fact that the clusters based on use were well defined suggests that recommendation systems could be useful in getting apps to people that are more likely to be used.

We explored the relationship between individual apps and outcome. For depression, Purple Chill (relaxation) and Aspire (living one's values) were predictive of improvement, while Boost Me (behavioral activation), Day to Day (psychoeducation), Me Locate (used geofencing), Purple Chill, and Thought Challenger (cognitive restructuring) were associated with improvement in anxiety. Given that app use was in the context of a suite, it is difficult to interpret these findings. It is likely that improvement is not necessarily due to the use of "an app," but rather a mix of apps.

One hypothesis we proposed was that targeting a construct (eg, Thinking or Calming) through use of a set of apps may be more beneficial than the use of any individual app. Indeed, the Thinking, Calming, and Checklist clusters were all related to improvement in depression, and those three clusters, along with Activity, were associated with improvement in anxiety. However, our stepwise models did not conform to this hypothesis. When individual apps and clusters were analyzed together, the frequency of Boost Me and lifetime use of Purple Chill were associated with improvement in depression, while the frequency of Me Locate and lifetime use of Thought Challenger were associated with improvement in anxiety. Thus, our hypothesis regarding the use of clusters for improvement received partial support, but was not robust in the presence of all app-use data.

Finally, we note that engagement remained high throughout the study. We have noted previously that in the public deployment of IntelliCare through the Google Play Store, providing recommendations, even randomly, as was done in the field trial, increases the likelihood that an individual will download an app [19]. However, it was unclear how people would use apps in the context of a treatment where all apps were available from the start. In this study, we see that people tended not to download all the apps at once, but rather wait for the weekly recommendations to download and initiate use.

This study provides the first view of how digital mental health platforms that provide a variety of apps or treatments may be optimized. These findings suggest that some knowledge about a person's use of one app may be helpful in selecting the next app to recommend. There is some support for the idea that use of clusters may also be helpful in improving symptoms, although these findings were not robust. Together, these findings support the idea that recommendation engines may be useful in promoting use in platforms with multiple apps such as IntelliCare and promoting symptom improvement. This will be critical since, to maintain engagement with an app platform, it will be important to quickly connect people to apps that they want to use. For instance, a recommender system would be helpful in that someone with depression might have Purple Chill and Boost Me recommended first. If the person did not engage with those apps, perhaps other apps in similar clusters could be recommended, like Slumber Time or MoveMe. In a broader perspective, a clinician might recommend apps focused on relaxation or apps geared towards living one's values for depressed patients.

Limitations

There are limitations to this study that should be considered when interpreting these findings. Chief among them is that we have performed a large number of analyses for the sample size. Thus, some of findings may be spurious, and in other cases, we were likely underpowered for the number of variables included in analyses. Additionally, the sample size was restrictive; therefore, we could not account for baseline demographics which may also cluster with app use.

As in any secondary analysis, data obtained were from a field trial that restricted participation in order to assess the effectiveness of the apps in changing symptoms of depression and anxiety. Our findings may reasonably apply to English-speaking adults living in the United States, owing to ownership of an internet-ready Android mobile phone with data and text plans and without any visual, hearing, voice, or motor impairments; severe psychiatric disorders; or suicidality exhibition.

Conclusions

We found that a suite of apps was engaging to participants in a field trial for treatment of depression or anxiety. Despite all apps being available for immediate download, participants gradually downloaded and engaged with various apps throughout the trial. App-use patterns fell into clusters, suggesting that some knowledge about the use of one app may be useful in helping select another app that the person is more likely to use. This could provide the basis for making more targeted recommendations based on app-use data.

Although the use metrics of different apps in the suite are correlated, a stepwise analysis showed that the use of Boost Me (an Activity-focused app) and sustained use of Purple Chill (a Calming app) were most effective at improving depression, while the use of Me Locate and sustained use of Thought Challenger (a Thinking app) were most effective at improving anxiety.

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Conflicts of Interest

DCM has accepted consulting fees from Optum Behavioral Health and has an ownership interest in Actualize Therapy. EL has accepted consulting fees from Actualize Therapy. None of the other authors have any conflicts of interest to declare.

Multimedia Appendix 1

Description of the IntelliCare apps.

[PDF File (Adobe PDF File), 35KB - mental_v6i3e11572_app1.pdf]

References

1. Baxter AJ, Scott KM, Vos T, Whiteford HA. Global prevalence of anxiety disorders: a systematic review and meta-regression. Psychol Med 2013 May;43(5):897-910. [doi: 10.1017/S003329171200147X] [Medline: 22781489]
2. Ferrari AJ, Somerville AJ, Baxter AJ, Norman R, Patten SB, Vos T, et al. Global variation in the prevalence and incidence of major depressive disorder: a systematic review of the epidemiological literature. Psychol Med 2013 Mar;43(3):471-481. [doi: 10.1017/S0033291712001511] [Medline: 22831756]
3. GBD 2015 Disease Injury Incidence Prevalence Collaborators. Global, regional, and national incidence, prevalence, and years lived with disability for 310 diseases and injuries, 1990-2015: a systematic analysis for the Global Burden of Disease Study 2015. Lancet 2016 Dec 08;388(10053):1545-1602 [FREE Full text] [doi: 10.1016/S0140-6736(16)31678-6] [Medline: 27733282]
4. Mohr DC, Ho J, Duffecy J, Baron KG, Lehman KA, Jin L, et al. Perceived barriers to psychological treatments and their relationship to depression. J Clin Psychol 2010 Apr;66(4):394-409 [FREE Full text] [doi: 10.1002/jclp.20659] [Medline: 20127795]
5. Mohr DC, Hart SL, Howard I, Julian L, Vella L, Catledge C, et al. Barriers to psychotherapy among depressed and nondepressed primary care patients. Ann Behav Med 2006 Dec;32(3):254-258. [doi: 10.1207/s15324796abm3203_12] [Medline: 17107299]
6. Richards D, Richardson T. Computer-based psychological treatments for depression: a systematic review and meta-analysis. Clin Psychol Rev 2012 Jun;32(4):329-342. [doi: 10.1016/j.cpr.2012.02.004] [Medline: 22466510]
7. Arnberg FK, Linton SJ, Hultcrantz M, Heintz E, Jonsson U. Internet-delivered psychological treatments for mood and anxiety disorders: a systematic review of their efficacy, safety, and cost-effectiveness. PLoS One 2014;9(5):e98118 [FREE Full text] [doi: 10.1371/journal.pone.0098118] [Medline: 24844847]
8. Renton T, Tang H, Ennis N, Cusimano MD, Bhalerao S, Schweizer TA, et al. Web-based intervention programs for depression: a scoping review and evaluation. J Med Internet Res 2014;16(9):e209 [FREE Full text] [doi: 10.2196/jmir.3147] [Medline: 25249003]
9. Firth J, Torous J, Nicholas J, Carney R, Pratap A, Rosenbaum S, et al. The efficacy of smartphone-based mental health interventions for depressive symptoms: a meta-analysis of randomized controlled trials. World Psychiatry 2017 Oct;16(3):287-298 [FREE Full text] [doi: 10.1002/wps.20472] [Medline: 28941113]
10. Firth J, Torous J, Nicholas J, Carney R, Rosenbaum S, Sarris J. Can smartphone mental health interventions reduce symptoms of anxiety? A meta-analysis of randomized controlled trials. J Affect Disord 2017 Aug 15;218:15-22 [FREE Full text] [doi: 10.1016/j.jad.2017.04.046] [Medline: 28456072]
11. Poushter J. Smartphones are common in advanced economies, but digital divides remain. 2017. Pew Research Center URL: http://www.pewresearch.org/fact-tank/2017/04/21/smartphones-are-common-in-advanced-economies-but-digital-divides-remain/ [accessed 2018-07-11] [WebCite Cache ID 70qCs74sY]
12. Michie S, Richardson M, Johnston M, Abraham C, Francis J, Hardeman W, et al. The behavior change technique taxonomy (v1) of 93 hierarchically clustered techniques: building an international consensus for the reporting of behavior change interventions. Ann Behav Med 2013 Aug;46(1):81-95. [doi: 10.1007/s12160-013-9486-6] [Medline: 23512568]
13. Chorpita BF, Daleiden EL. Mapping evidence-based treatments for children and adolescents: application of the distillation and matching model to 615 treatments from 322 randomized trials. J Consult Clin Psychol 2009 Jun;77(3):566-579. [doi: 10.1037/a0014565] [Medline: 19485596]
14. Committee on Developing Evidence-Based Standards for Psychosocial Interventions for Mental Disorders, Board on Health Sciences Policy, Institute of Medicine. In: England MJ, Butler AS, Gonzalez ML, editors. Psychosocial Interventions For Mental And Substance Use Disorders: A Framework For Establishing Evidence-based Standards. Washington DC: National Academies Press; 2015.

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15. Oulasvirta A, Tamminen S, Roto V, Kuorelahti J. Interaction in 4-Second Bursts: The Fragmented Nature of Attentional Resources in Mobile HCI. In: Proceedings of SIGCHI Conference on Human Factors in Computing Systems. 2005 Presented at: Conference on Human Factors in Computing Systems; 2005; Portland, OR p. 919-928.
16. Vaish R, Wyngarden K, Chen J, Cheung B, Bernstein M. Twitch Crowdsourcing: Crowd Contributions in Short Bursts of Time. In: Proceedings of SIGCHI Conference on Human Factors in Computing Systems. 2014 Presented at: Conference on Human Factors in Computing Systems; 2014; Toronto, ON, Canada p. 3645-3654.
17. Lattie EG, Schueller SM, Sargent E, Stiles-Shields C, Tomasino KN, Corden ME, et al. Uptake and Usage of IntelliCare: A Publicly Available Suite of Mental Health and Well-Being Apps. Internet Interv 2016 May;4(2):152-158 [FREE Full text] [doi: 10.1016/j.invent.2016.06.003] [Medline: 27398319]
18. Mohr DC, Tomasino KN, Lattie EG, Palac HL, Kwasny MJ, Weingardt K, et al. IntelliCare: An Eclectic, Skills-Based App Suite for the Treatment of Depression and Anxiety. J Med Internet Res 2017 Jan 05;19(1):e10 [FREE Full text] [doi: 10.2196/jmir.6645] [Medline: 28057609]
19. Cheung K, Ling W, Karr CJ, Weingardt K, Schueller SM, Mohr DC. Evaluation of a recommender app for apps for the treatment of depression and anxiety: an analysis of longitudinal user engagement. J Am Med Inform Assoc 2018 Apr 06. [doi: 10.1093/jamia/ocy023] [Medline: 29659857]
20. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. J Gen Intern Med 2001 Sep;16(9):606-613 [FREE Full text] [Medline: 11556941]
21. Spitzer RL, Kroenke K, Williams JBW, Löwe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. Arch Intern Med 2006 May 22;166(10):1092-1097. [doi: 10.1001/archinte.166.10.1092] [Medline: 16717171]
22. Noth K, Bardsley L, Lattie E, Mohr D. Northwestern Medicine. 2018. IntelliCare Study Coaching Manual URL: https://digitalhub.northwestern.edu/files/00fa4294-5b9f-4afc-897a-7fffceae8f3f [accessed 2019-01-27] [WebCite Cache ID 75kXBM0qZ]
23. Schueller SM, Tomasino KN, Mohr DC. Integrating Human Support Into Behavioral Intervention Technologies: The Efficiency Model of Support. Clin Psychol Sci Pract 2016 Nov 17;24(1):27-45. [doi: 10.1111/cpsp.12173]
24. Mohr DC, Cuijpers P, Lehman K. Supportive accountability: a model for providing human support to enhance adherence to eHealth interventions. J Med Internet Res 2011;13(1):e30 [FREE Full text] [doi: 10.2196/jmir.1602] [Medline: 21393123]
25. Spitzer RL, Kroenke K, Williams JB. Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire. JAMA 1999 Nov 10;282(18):1737-1744. [Medline: 10568646]
26. Kroenke K, Spitzer RL, Williams JBW, Löwe B. The Patient Health Questionnaire Somatic, Anxiety, and Depressive Symptom Scales: a systematic review. Gen Hosp Psychiatry 2010;32(4):345-359. [doi: 10.1016/j.genhosppsych.2010.03.006] [Medline: 20633738]
27. Depression Management Tool Kit. 2009. URL: https://www.integration.samhsa.gov/clinical-practice/macarthur_depression_toolkit.pdf [accessed 2018-07-12] [WebCite Cache ID 70ri1TTfp]
28. R Development Core Team. R Project for Statistical Computing. Vienna, Austria: R Foundation for Statistical Computing; 2008. R: A language and environment for statistical computing URL: http://www.r-project.org/ [accessed 2019-01-27] [WebCite Cache ID 75kXTL1W7]

Abbreviations

GAD-7: Generalized Anxiety Disorder-7
I/R: improvement or remission
N/A: not applicable
OR: odds ratio
PHQ-9: Patient Health Questionnaire-9

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Original Paper

Cocreative Development of the QoL-ME: A Visual and Personalized Quality of Life Assessment App for People With Severe Mental Health Problems

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Abstract

Background: Quality of life (QoL) is a prominent outcome measure in mental health. However, conventional methods for QoL assessment rely heavily on language - based communication and therefore may not be optimal for all individuals with severe mental health problems. In addition, QoL assessment is usually based on a fixed number of life domains. This approach conflicts with the notion that QoL is influenced by individual values and preferences. A digital assessment app facilitates both the accessibility and personalization of QoL assessment and may, therefore, help to further advance QoL assessment among individuals with severe mental health problems.

Objective: This study focused on the development of an innovative, visual, and personalized QoL assessment app for people with severe mental health problems: the QoL-ME.

Methods: This study targeted 3 groups of individuals with severe mental health problems: (1) people with psychiatric problems, (2) people treated in forensic psychiatry, and (3) people who are homeless. A group of 59 participants contributed to the 6 iterations of the cocreative development of the QoL-ME. In the brainstorming stage, consisting of the first iteration, participants' previous experiences with questionnaires and mobile apps were explored. Participants gave their feedback on initial designs and wireframes in the second to fourth iterations that made up the design stage. In the usability stage that comprised the final 2 iterations, the usability of the QoL-ME was evaluated.

Results: In the brainstorming stage, participants stressed the importance of privacy and data security and of receiving feedback when answering questionnaires. Participants in the design stage indicated a preference for paging over scrolling, linear navigation, a clean and minimalist layout, the use of touchscreen functionality in various modes of interaction, and the use of visual analog scales. The usability evaluation in the usability stage revealed good to excellent usability.

Conclusions: The cocreative development of the QoL-ME resulted in an app that corresponds to the preferences of participants and has strong usability. Further research is needed to evaluate the psychometric quality of the QoL-ME and to investigate its usefulness in practice.

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KEYWORDS

mobile app; quality of life; mental health; homeless persons; medical informatics

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Introduction

Background

Quality of life (QoL) has risen to prominence as an outcome in mental health care. Still, many authors agree that there is further room for improvement in the field of QoL assessment, especially regarding the instruments used to assess QoL [1,2]. Several possibilities for advancement have been pointed out in the literature. First, it is important that instruments are frequently updated to maintain their applicability in our fast-paced society. Examples of developments that may influence the meaning of QoL for people with severe mental health problems include an increasing emphasis on empowerment [3-5] and the advancing digitalization of society [6]. Second, research has indicated the need for personalization of QoL instruments, as QoL differs within groups and between individuals [7,8]. This notion calls for a QoL instrument that enables respondents to select and answer questions on domains of QoL that are relevant for them personally. Third, traditional language-based QoL assessment, which relies heavily on people's verbal and cognitive abilities, might be less appropriate for people with severe mental health problems [9,10]. Visual communication may provide a suitable alternative as it does not require the mastery of a certain language. In addition, visual information may be easier to process by people with severe mental health problems than verbal information [11,12]. Several characteristics of digital technologies make them potentially useful for tackling the aforementioned issues in QoL assessment. A digital instrument has the flexibility to allow for the increased personalization of QoL assessment. In addition, digital technologies facilitate the use of audio and visual multimedia such as images and video, which may improve the accessibility of a digital QoL instrument and help circumvent language-based communication. Furthermore, a digital instrument can easily be updated to incorporate new aspects of QoL that become important as a function of societal changes.

Over the last few years, many digital electronic health (eHealth) technologies for use in mental health care have been developed [13]. People with severe mental health problems use eHealth to obtain information, for Web-based treatment, and as a source of support [13,14]. eHealth for people with severe mental health problems initially focused on the design and development of websites used for treatment, for communication, and to provide information [15-17]. Recently, the rising popularity of mobile devices such as smartphones and tablets has facilitated a shift from websites to mobile health apps for mobile devices such as smartphones and tablets. These mobile health apps have been developed for a variety of psychiatric problems, including anxiety [18], bipolar disorder [19], and schizophrenia [20], and serve a number of purposes, such as treatment, providing information, self-assessment, and self-management [21-25].

Previous studies reveal that websites and apps that are well designed for the general public may not be appropriate for people with severe mental health problems [26-29]. In response to these findings, several authors have reported best practices and guidelines for the design and development of eHealth apps for people with severe mental health problems [21,29-31]. Ben-Zeev et al [30] list a number of specific recommendations for how eHealth apps may best be developed. They stress the importance of working in multidisciplinary teams and involving intended users in the development [30]. Furthermore, Rotondi et al [31] developed the Flat Explicit Design Model (FEDM) to guide the design of eHealth for people with severe mental illness. The model contains 18 variables, grouped into 3 usability dimensions: (1) page complexity, (2) navigational simplicity, and (3) comprehensibility. Examples of variables include minimizing potential distractors, limiting navigational elements, fixing the location of navigational elements, and minimizing page length. Empirical evidence for the usefulness of the FEDM in reducing the cognitive effort for users has been found [31]. These design recommendations are likely to benefit the usability of eHealth technologies for people with severe mental health problems.

Objectives

This research covers the cocreative development of a QoL assessment app that does not rely solely on language-based communication, facilitates personalization, and is useful for both patients and clinicians: the QoL-ME. The aforementioned design recommendations will be taken into account, but the development of the QoL-ME will primarily be based on the input of end users, which continues to be the standard in design in general [32,33] and in the design for people with severe mental health problems in particular [21,30,34-37]. This study aimed to describe the development of the QoL-ME, with special attention to patients' design-related preferences.

Methods

Participants

This study targeted 3 groups of individuals with severe mental health problems: (1) people with psychiatric problems, (2) people treated in forensic psychiatry, and (3) people who are homeless. Homeless individuals were included in this study because of the high prevalence of severe mental health problems in this group [38-40]. There are several reasons for suspecting that these groups may have difficulty with traditional language-based QoL assessment. First, they experience fewer educational opportunities [38,41,42]. Second, mild intellectual disabilities occur relatively frequently in these groups [38,43,44]. Third, psychopathology itself may compromise individuals' ability to engage in QoL assessment [9,10].

Participants were recruited with the help of 6 societal institutions that collaborated in a consortium to facilitate this research project, including a mental health institution; a hospital for forensic psychiatry; a multimodal day treatment center for multiproblem young adults; a day center for people who are homeless; and 2 research institutions focusing on lifestyle, homelessness and addiction.

Development of the QoL-ME

The QoL-ME was cocreatively developed in an iterative development process in which the 3 aforementioned groups of people with severe mental health problems played an essential and indispensable role. The process consisted of 6 iterations divided over 3 stages: (1) brainstorming stage, (2) design stage,

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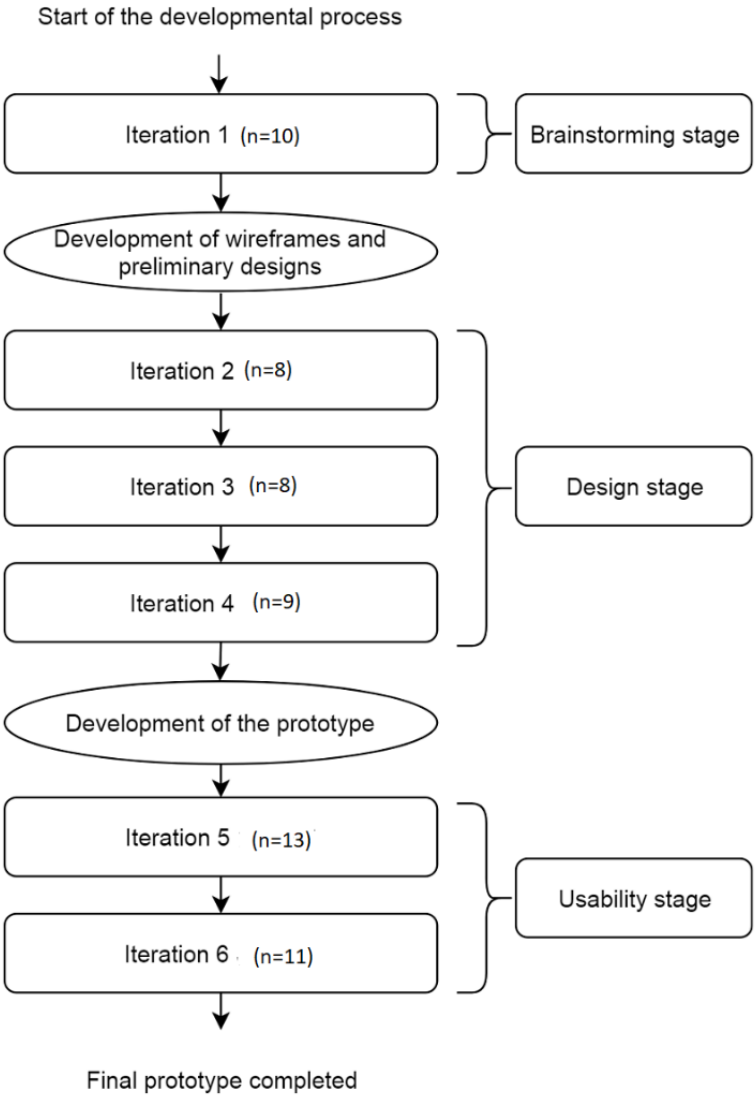
and (3) usability stage. Theoretically, the development process fits in the *explore*, *approximate*, *refine* framework as part of participatory design [45]. A study by Ben-Zeev et al [20] employs a similar approach consisting of 3 steps that correspond to this framework. A schematic overview of the developmental process is provided in Figure 1.

Every iteration involved 3 separate user test sessions, and the total number of test sessions was 18. A new group of participants was recruited in every test session. The 3 target groups were involved in every single iteration. In addition, the age distribution of participants was roughly the same in every iteration. Between 2 and 5 individual participants contributed in every test session. The feedback, tips, and insights of end users gathered during test sessions were of vital importance and were fed back to the professional designers who took care of the technical side of the development. In between iterations, the researchers and professional designers discussed the feedback gathered during the previous iteration. If the end users' opinions and preferences contradicted each other, an attempt at a synthesis was made during this discussion. If necessary and possible, 2 rivaling preferences were tested in the next iteration. In all stages of the development, the input and opinions of end users were instrumental and were used to expand and refine the initial designs and early versions of the app.

The brainstorming stage involved iteration 1. In this stage, participants were invited to share their past experiences with apps, share ideas regarding the improvement of QoL assessment, and comment on basic initial designs. The topic list that was used during the brainstorming stage is available in Multimedia Appendix 1. On the basis of the ideas that were gathered in this stage, combined with design-related recommendations found in the scientific literature [21,31,35], a number of designs and interaction mechanisms were developed for testing.

The design stage covered iterations 2, 3, and 4. Initially, paper sketches (wireframes) were used to test alternative navigational structures, various possible page-layouts, and possible forms of interaction for the app. In the remainder of the design stage, digitalized versions of these wireframes were gradually refined, expanded, and made functional. Finally, the first prototype was developed.

Figure 1. Schematic overview of the development of the QoL-ME, involving 3 stages and 6 iterations.



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In iterations 5 and 6, which together formed the usability stage, the prototype was subjected to usability testing. Participants were invited to complete a single task: to fill out the QoL-ME. To test if participants were able to use the prototype independently, no explanation regarding the QoL-ME was provided. The usability of the prototype was systematically assessed using a modified Dutch version of the System Usability Scale (SUS) [46-48].

Measures

In 7 of the 12 test sessions, participants consented to audio recordings. In the other 5 test sessions, the researchers took extensive notes. The researchers made an elaborate summary of every test session of the first 4 iterations, based on either the recordings or the notes. The summaries included all the participants' insights, ideas, and feedback and were discussed together with the designers. On the basis of these discussions, the designers elaborated, adjusted, and polished the QoL-ME.

The English version of the SUS was developed by Brooke [47] and has since been used frequently to assess the usability of a variety of technologies such as websites, operating systems, and hardware [48]. The SUS contains 10 items, scored on a 5-point Likert scale ranging from *strongly disagree* (1) to *strongly agree* (5). Its psychometric properties have been investigated by Bangor et al [46], who analyzed the SUS data of 2324 participants and found a Cronbach alpha of .911. In addition, the authors report strong face validity, high sensitivity, and good concurrent validity [46]. The SUS has been translated into several languages, including Dutch [48]. To facilitate people with severe mental health problems, all the items of the Dutch SUS were worded positively in this study, as advised by Sauro and Lewis [49]. In addition, 3 items that contained complex terms were modified slightly without altering their content. Total SUS scores range between 0 and 100. On the basis of the analysis of a large amount of SUS data, scores above 73 are considered to indicate *good* usability, whereas scores above 85 are considered *excellent* [50].

Procedure

At the start of every test session, the researcher explained the goal of the research project and how participants were invited to contribute. Next, participants gave their informed consent and were asked if they consented to the audio recording of the test session. To prevent acquiescence bias, the researcher emphasized that they did not create the designs or prototypes themselves. In addition, the researcher stressed that there were no right or wrong answers but that participants' opinions, ideas, and insights counted. In the brainstorming stage, participants were asked a number of questions, after which they were invited to comment on a number of basic initial designs. In the design stage, participants were invited to comment on the layout of the wireframes and to test various forms of interaction and navigation. In the usability stage, participants were invited to use the QoL-ME and to fill out the SUS afterward. At the end of a session, participants were asked if they had any additional feedback, tips, or questions. Moreover, the researchers explained that participants' feedback was used to refine the designs, and participants received a 10 Euro gift voucher.

All designs and prototypes were tested using an Apple iPad Air 2, which had a 9.7-inch touchscreen display. The researcher provided this iPad.

Ethical approval was obtained from the Ethics Committee of the Tilburg School of Behavioural and Social Sciences at Tilburg University (EC-2015.44). Informed consent was obtained from each participant. All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional and national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Structure and Content of the QoL-ME

The results of the development of the QoL-ME app are difficult to interpret without additional knowledge of the structure and content of the QoL-ME. To enable an adequate understanding of the results of this study, the conceptual framework underlying the QoL-ME is described in this section.

The QoL-ME consists of 2 main components: a core version and additional modules. The core version comprises a fixed set of universal QoL domains, and every respondent is required to answer questions on these domains. Research indicates that having meaning in life is especially important for people who are homeless [51,52]. The QoL-ME, therefore, encompasses 2 separate core versions. The first core version targets people with psychiatric problems and people treated in forensic psychiatry and includes 3 domains of the Lancashire Quality of Life Profile (LQoLP) [53]: *safety*, *living situation*, and *finances*. A recent study indicates that these 3 LQoLP domains are universal for people with psychiatric problems and people treated in forensic psychiatry [54]. The LQoLP uses a 7-point Likert scale, ranging from *cannot be worse* (1) to *cannot be better* (7). The second core version is tailored to people who are homeless and comprises the Dutch version of the Meaning in Life Questionnaire, a 10-item measure that assesses both the presence of meaning in one's life and the search for meaning in life [55]. The Meaning in Life Questionnaire also uses a 7-point Likert scale, ranging from *completely disagree* (1) to *completely agree* (7).

The additional modules serve to ensure the personalization of the QoL-ME. Every module corresponds with a domain of QoL, and users are free to select any combination of the 8 modules. The following 8 domains of QoL are included: (1) Support and Attention, (2) Social Contacts, (3) Happiness and Love, (4) Relaxation and Harmony, (5) Leisure, (6) Lifestyle, (7) Finances, and (8) Health and Living. These domains were identified in a visual concept mapping study of the QoL of people with severe mental health problems [56]. Domains are assessed using 2 to 4 visual items. Every visual item contains 3 pictures that together denote an aspect of QoL. Users respond to these items using a visual analog scale (VAS) with visual anchors.

This structure, involving both a core version and additional modules, makes for a flexible QoL assessment app. The core version is useful in contexts where group-level data are of interest, such as comparisons of the QoL of different client

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populations. The additional modules are especially suitable for use in individual care planning.

Results

Participants

A total of 59 participants contributed to the development of the QoL-ME. Their mean age was 40.8 years (SD 15), and over 80% were male (see Table 1). The mean age of the 10 participants who engaged in the brainstorming stage was 34.2 years (SD 12.8), 7 of whom were male. In the design stage, a group of 25 people with severe mental health problems participated. Their mean age was 37.7 years (SD 14.3), and 88% were male. In the usability stage, 79% of the participants (19/24) who contributed were male. Their mean age was 46.8 years (SD 14.4). The number of participants who contributed to the development process is displayed in Table 1.

Development of the QoL-ME

Participants in the brainstorming stage reported using apps primarily for communication and maintaining social relations. In addition, 4 younger participants treated in forensic psychiatry reported using apps for services such as internet banking and Web-based shopping. The single most important factor for why participants used certain apps over others was their confidence in the trustworthiness of the apps. The majority of participants indicated having privacy concerns when using apps, but this did not seem to deter them from using apps frequently.

All participants had prior experience with questionnaires, primarily in the context of professional care or research. Participants reported several annoyances regarding their previous experiences with questionnaires, 2 of which were relevant for the development of the QoL-ME: (1) lack of feedback and (2) lack of transparency regarding data use. These considerations were fed back into the development of the QoL-ME. In practice, a feedback module that provided users with insight into their scores was implemented, and special consideration was given to the issue of data ownership, leading to the decision that users retain the ownership of their data.

The participants in the brainstorming stage had a number of ideas regarding the QoL-ME. Some participants indicated a preference for the personalization of the app's appearance by selecting a personal background or by changing the colors of the app. In addition, participants pointed out that not every patient has their own device and therefore advocated a multiplatform app. Furthermore, a combination of visual- and language-based communication was proposed, and some participants even indicated a preference for audio. Whenever possible, these ideas were incorporated into the initial designs of the QoL-ME that were tested in the subsequent iterations.

As displayed in Table 2, the feedback received on the designs that were tested in the 3 iterations of the design stage covers 4 main categories: (1) functionality of the QoL-ME, (2) navigation, (3) personalization, and (4) appearance.

First, participants commented on the functionality of the QoL-ME. Specifically, these comments were related to different forms of interaction, operating the app, and receiving feedback. Several mechanisms for selecting the additional modules of the QoL-ME were tested. Figure 2 displays 4 of these possible modes of interaction. Please note that as the QoL-ME is developed for use in the Netherlands, it contains some Dutch text. To improve the clarity of the screenshots that are part of Figure 2 and other figures, any Dutch text has been translated to English.

Table 1. Basic demographic characteristics of participants per iteration of the development of the QoL-ME.

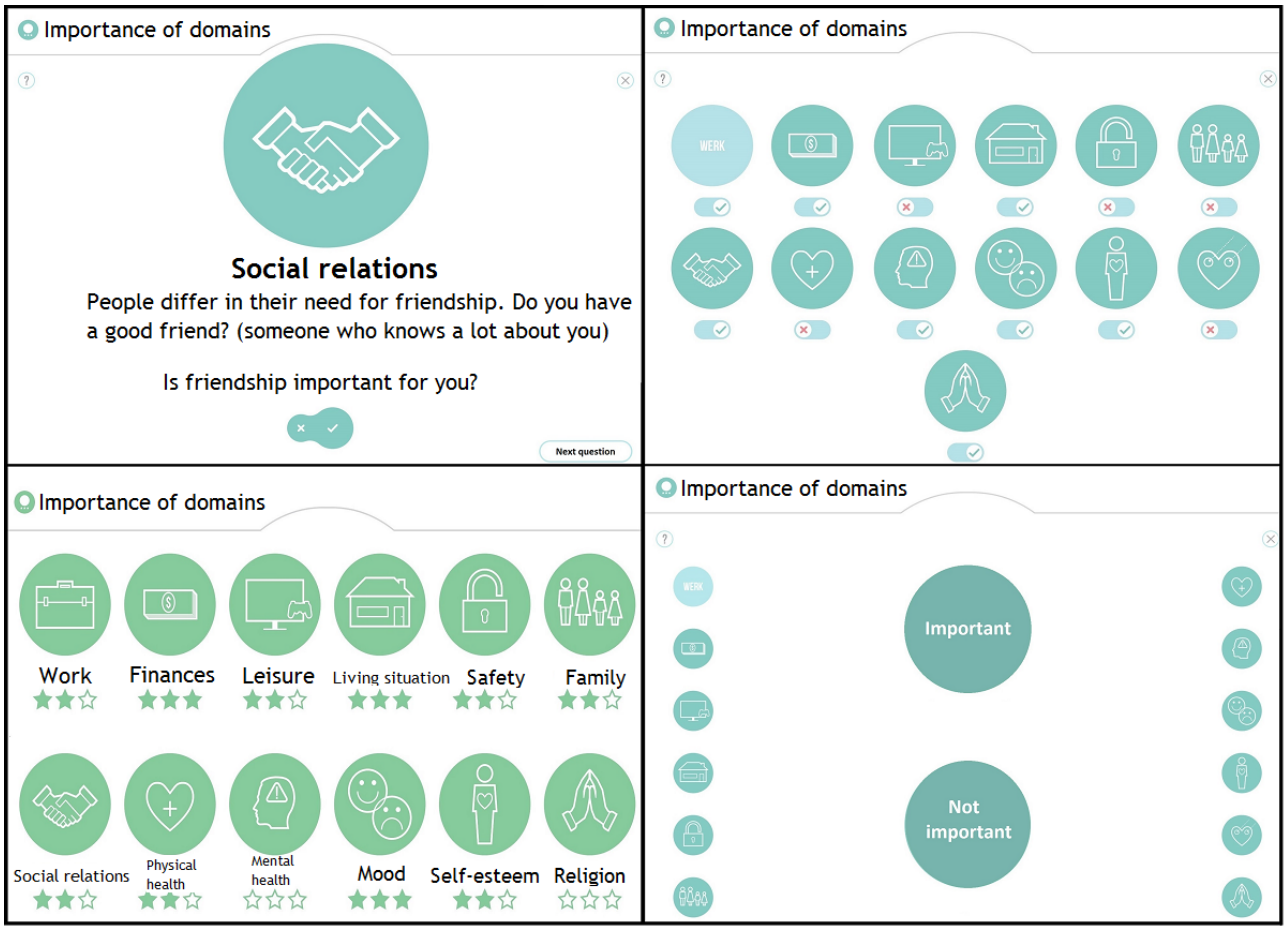
Stage of development and iteration number	Participants (n)	Male participants, n (%)	Age, mean (SD)
Brainstorming stage			
Iteration 1	10	7 (70)	34.2 (12.8)
Design stage			
Iteration 2	8	7 (88)	32.8 (13.6)
Iteration 3	8	7 (88)	38.9 (12.8)
Iteration 4	9	8 (89)	41 (14.9)
Total	25	22 (88)	37.7 (14.3)
Usability stage			
Iteration 5	9	6 (67)	42 (17.5)
Iteration 6	15	13(87)	49.7 (11.3)
Total	24	19 (79)	46.8 (14.4)
Total entire development	59	48 (81)	40.8 (15)

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Table 2. Overview of the feedback obtained during the 3 iterations of the design stage of the development of the QoL-ME.

Category and subcategory	Feedback
Functionality	
Interaction: selecting additional modules	Swiping icons preferred in domain selection
Interaction: items additional modules	Visual analog scale preferred to answer questions of additional modules
Input	Most participants had no difficulty with the touchscreen, but some did: enable alternative options such as a keyboard and mouse
Feedback	Simple visualization of results, avoiding graphs
Navigation	
Linear structure	Inevitable choices in hierarchical structure were confusing: preference for linear structure
Confirming choices	Confirmation of choices (next and previous) was appreciated
Size and position of buttons	Large buttons with fixed sizes (bottom left and bottom right of screen)
Personalization	
Creating user profiles	Too much effort and no added value
Personalization of background and colors	No added value
Appearance	
Layout	Calm and professional layout was evaluated positively
Font size	Large font was advised
Contrasts	Sufficient contrast between text and background

Figure 2. Four mechanisms for selecting additional modules. In the top-left mechanism, users rate the importance of every domain individually. In the top right corner, the same mechanism is displayed for every domain at the same time. In the bottom left panel, every domain is rated by giving it one to three stars. In the bottom right panel, the icons on the left and right have to be swiped or dragged to one of the two circles.



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Participants indicated a strong preference for the option in which icons had to be swiped (see the bottom right panel in Figure 2). In addition, multiple forms of interaction for use in the items of the additional modules of the QoL-ME were tested. Figure 3 provides an overview of 3 interaction mechanisms. As participants indicated a preference for VAS, VAS was used in the prototype. The majority of participants had little to no difficulty with the touchscreen, even though some participants initially described themselves as computer illiterate and reported never having used a touchscreen before. Some participants did indicate that it would be a good idea to also enable the use of a keyboard and mouse to operate the QoL-ME.

Second, initial versions of the QoL-ME allowed participants to select the order in which they wanted to progress through the app. Participants had the opportunity to choose 1 of the 4 menu items (see Figure 4).

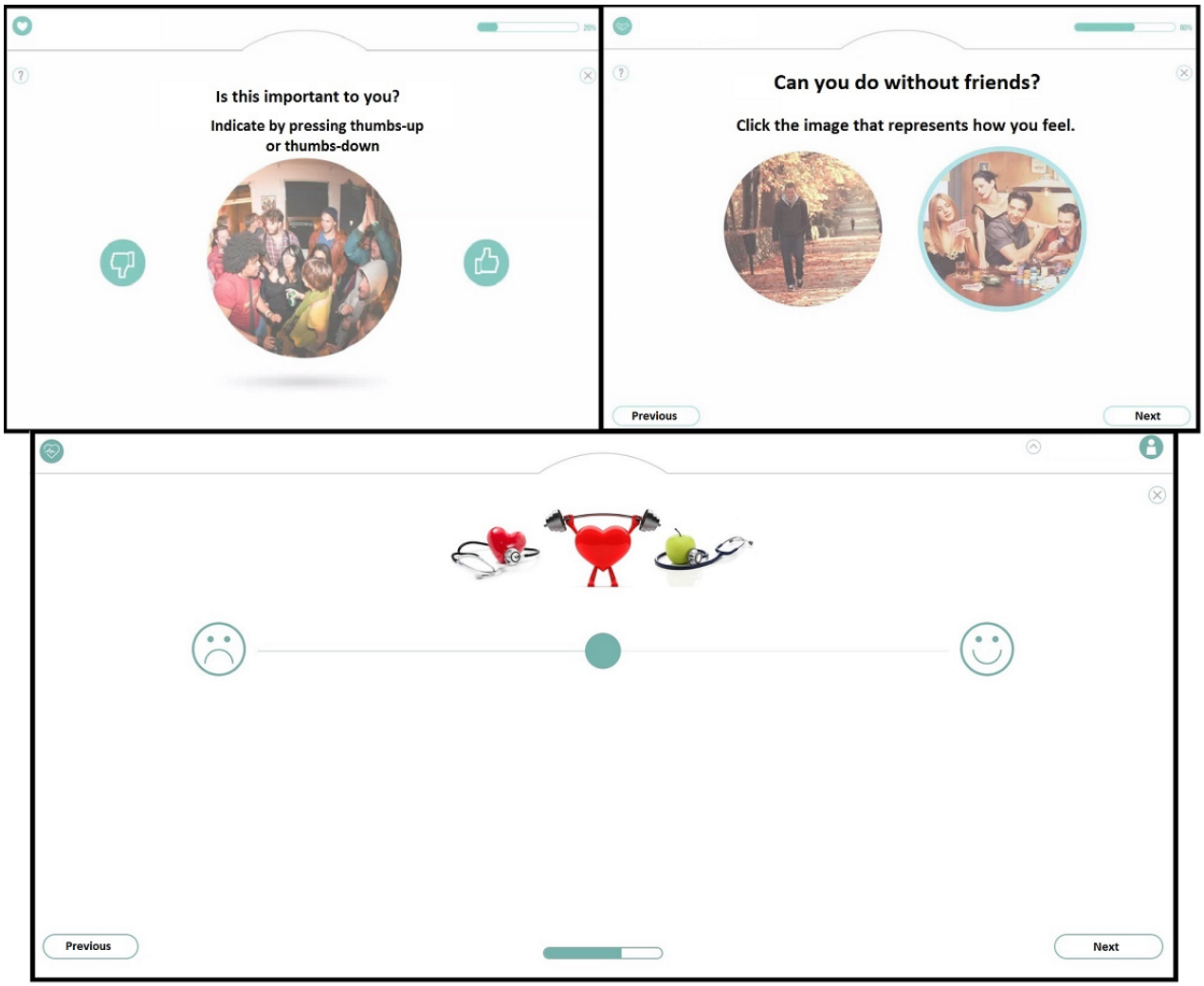
Most of the participants in the design stage were unsure which of the 4 options to select and preferred a linear navigational structure, which was adopted in later versions of the QoL-ME. The QoL-ME requires participants to navigate the app explicitly by selecting buttons at the bottom of the screen (see Figure 5). Participants saw this as a valuable feature, as it allowed them to correct possible mistakes before progressing to the next item or part of the app and because it introduces predictability. In addition, participants indicated a preference for large navigation buttons with a fixed location.

Third, possibilities for the personalization of the QoL-ME were explored. Versions of the QoL-ME that were tested in this stage allowed participants to create a user profile (see Figure 6) and to select 1 of the several colors for the layout of the app (see Figure 7). However, participants were not enthusiastic about these features, and they were dropped in later versions of the QoL-ME.

Fourth, throughout the design stage, participants had a fondness for the calm and clean layout of the QoL-ME (see Multimedia Appendices 2 and 3). Several participants noted that the layout of the QoL-ME made it look professional and added to its credibility and trustworthiness. However, 2 participants found the QoL-ME's appearance to be a little dull. In addition, participants preferred large fonts and sufficient contrast between text and background.

The average SUS score was 76.8 (SD 14.9; median=76.3), and scores ranged between 35 and 97.5. According to the classification reported by Bangor and Kortum [50], a SUS score of 76.8 indicates good to excellent usability.

Figure 3. Three possible mechanisms for interaction in the items of the additional modules.



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Figure 4. Earlier versions of the QoL-ME required users to select 1 of 4 menu options.

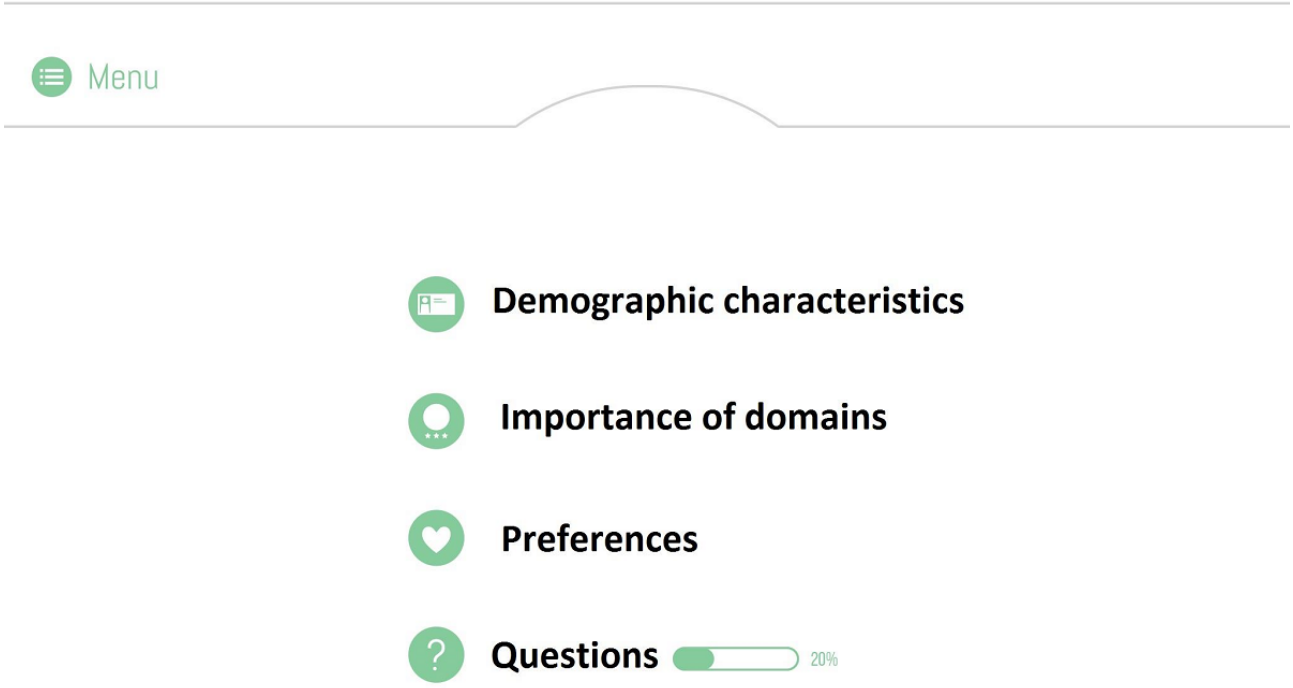
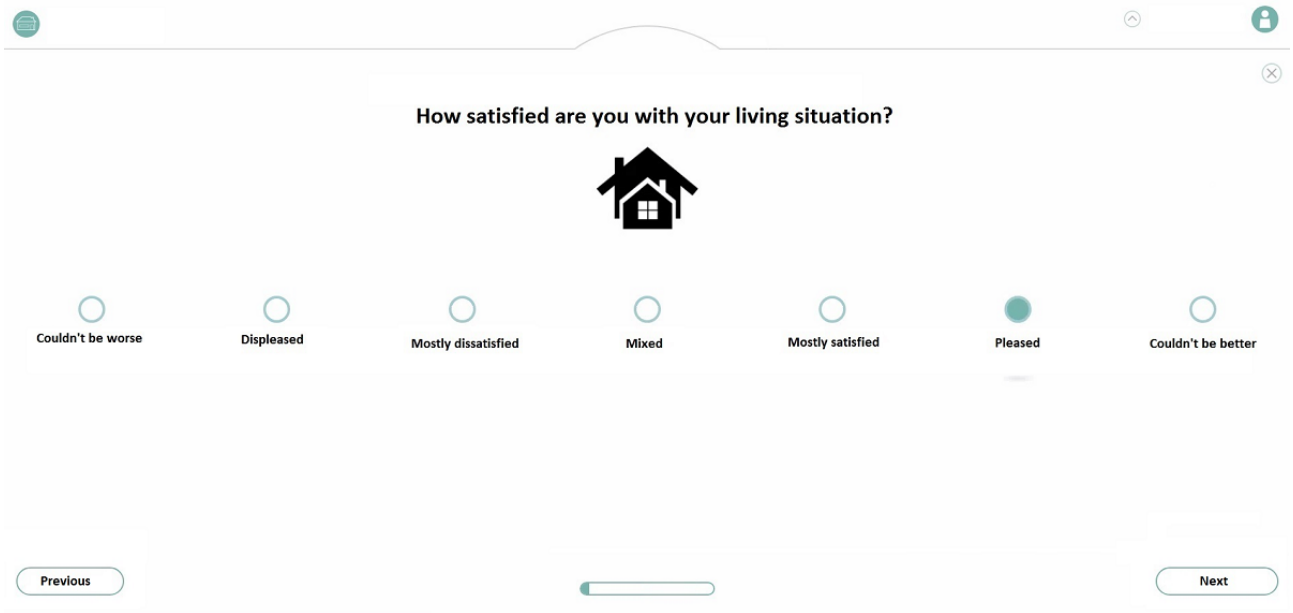


Figure 5. Users are required to navigate explicitly by selecting 1 of the 2 buttons at the bottom left and bottom right of the screen.



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Figure 6. Early versions of the QoL-ME included the possibility to create a user profile.

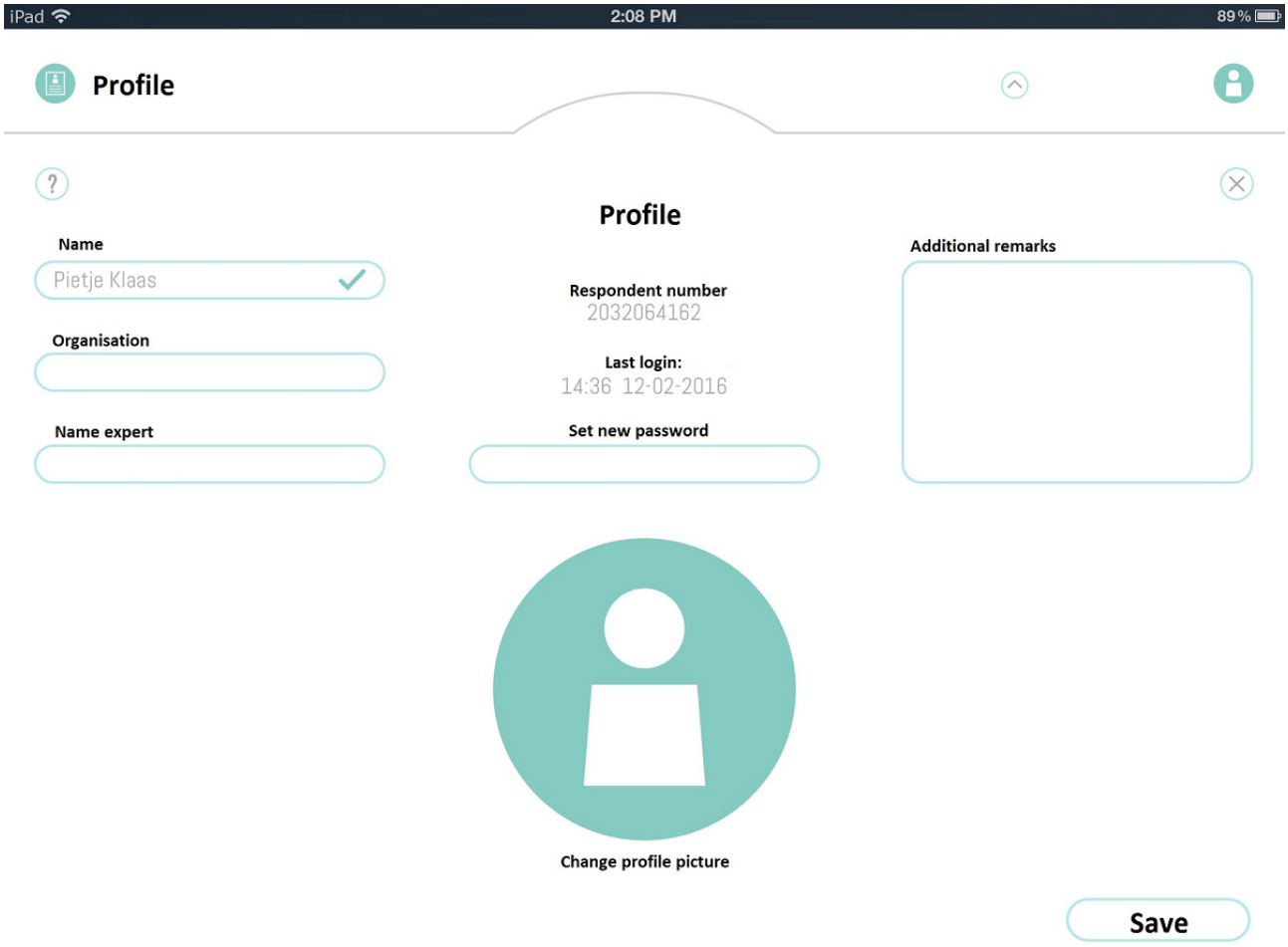
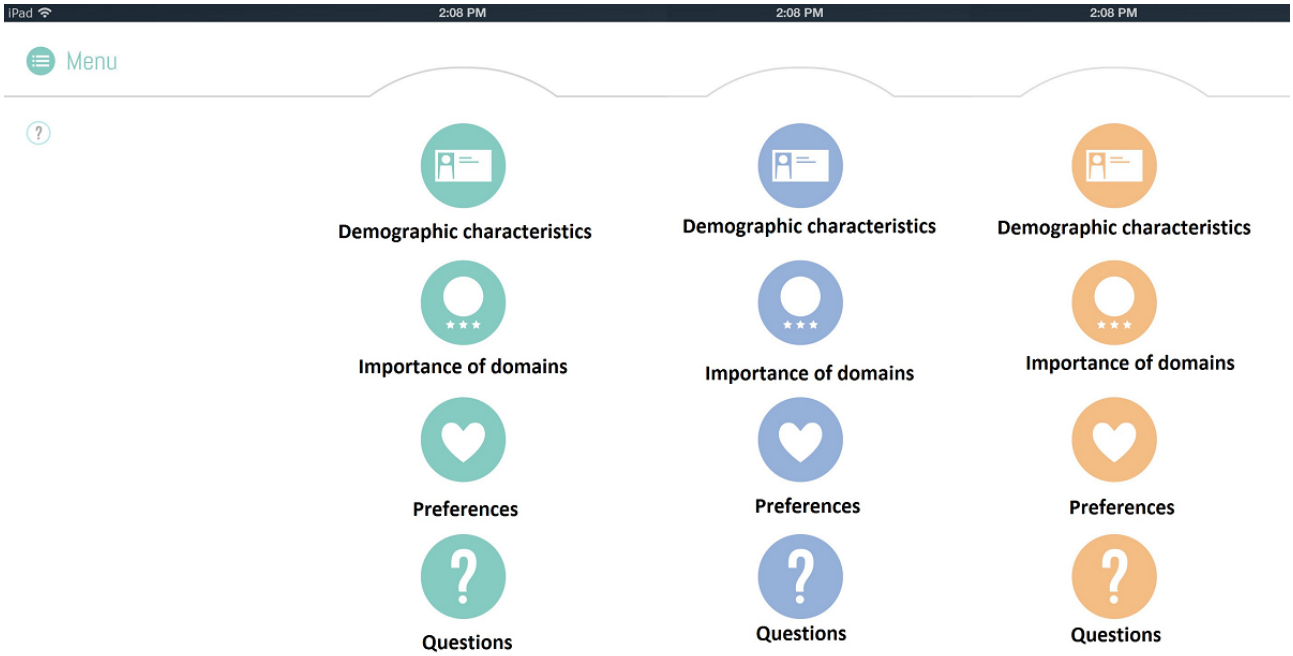


Figure 7. Earlier versions of the QoL-ME allowed users to customize the colors of the QoL-ME.



After filling out the SUS, participants were invited to share any additional feedback. Most of the participants in the usability stage did not have any additional feedback and found the QoL-ME to be easy to use, as reflected by their SUS scores. Some participants wanted more explanation on how to select the content of the additional modules of the QoL-ME. Others

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had difficulty in placing the VAS exactly at the halfway point. These minor remarks were taken into consideration, and some slight modifications to the prototype were made, resulting in the QoL-ME that is described in the following section.

Final QoL-ME

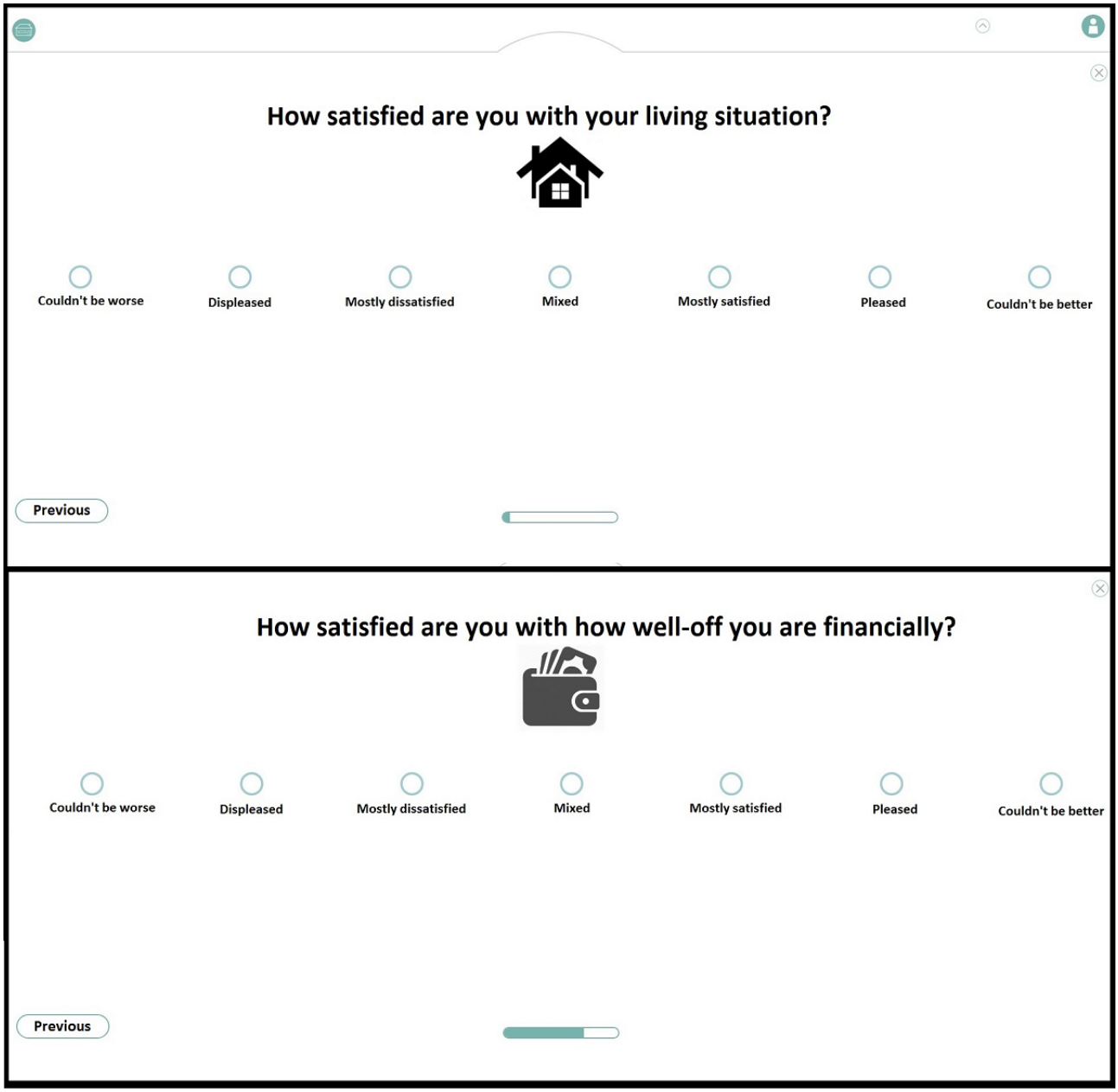
The following section contains a brief walkthrough of the QoL-ME. An accompanying video is provided in Multimedia Appendix 2. After logging into the QoL-ME app using their email address and a personalized password, users arrive at the home screen, which includes a brief explanation of the goal and structure of the app. Users have the opportunity to view a short video tutorial in which the structure and operating mechanisms of the QoL-ME are explained (see Multimedia Appendix 2). After pressing the *start* button on the homepage, users arrive at the core version of the QoL-ME. To determine which of the 2 core versions is applicable to the user, users are first requested to indicate whether they consider themselves as being homeless or not. An affirmative answer will lead the user to the core version for people who are homeless. Alternatively, users are invited to fill out the core version for people with psychiatric problems. Having selected the appropriate core version, users arrive at an explanation of the core version. Examples of 2 items of the core version are presented in Figure 8.

Having completed the core version, users are asked to indicate which domains of the additional modules are important to them. A screenshot of the mechanism used to select add-on modules is available in Figure 9. To ensure that the correct domains have been selected, users are asked to confirm their choice (see Figure 9).

Next, users answer questions corresponding to their selection of additional modules. Figure 9 provides examples of 2 visual items of the additional modules. Once all questions have been answered, users have the option to review their answers on the results page (see Figure 10).

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Figure 8. Examples of 2 items of the QoL-ME's core version.

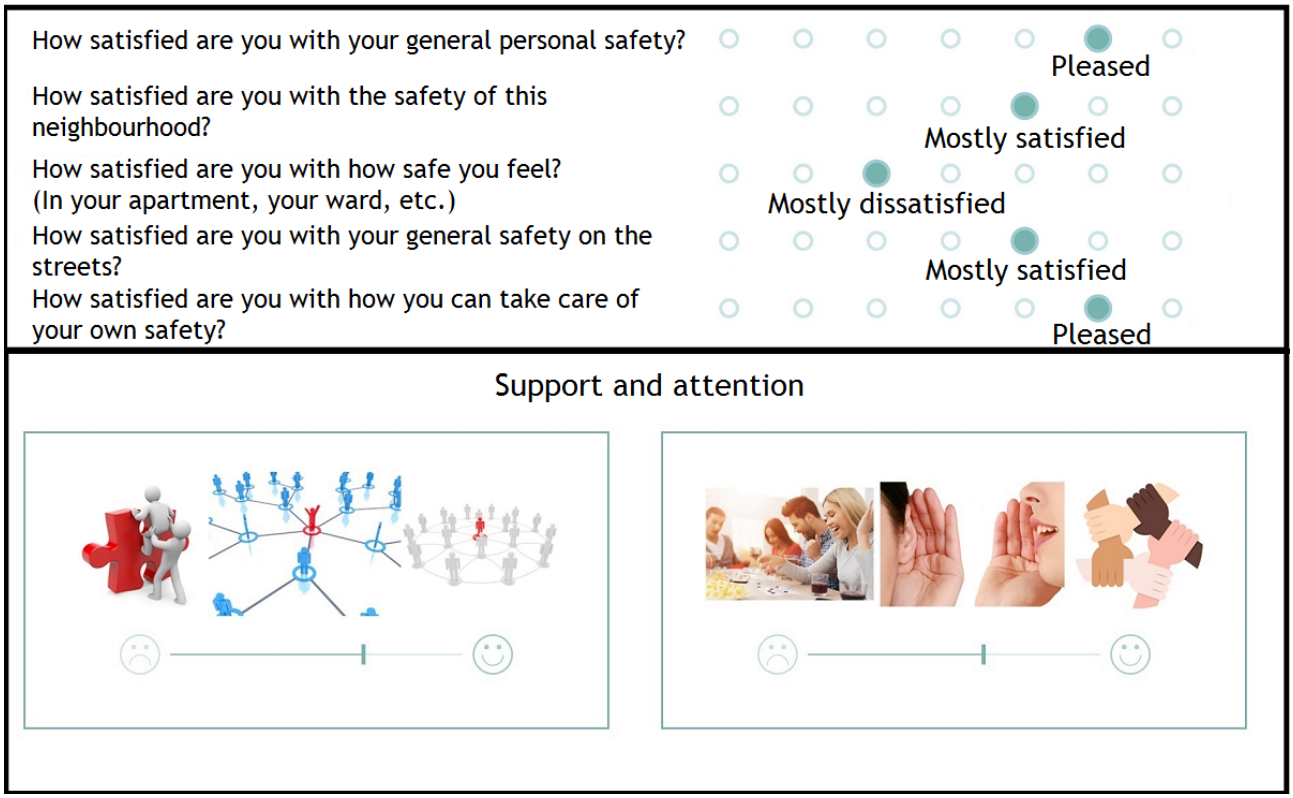


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Figure 9. Four screenshots depicting the additional modules of the QoL-ME. The top left panel displays the mechanism for selecting additional modules. Respondents are invited to drag 8 icons, corresponding to the 8 modules, to either a circle that says important or a circle that says not important. The top right panel shows how respondents are asked to confirm their choice of additional modules. The 2 remaining panels provide examples of items of the additional modules.



Figure 10. Results section of the QoL-ME. The top panel displays how the results of the core version are displayed, whereas the bottom panel demonstrates the results of the additional modules.



Discussion

Principal Findings

This study pertains to the cocreative development of the QoL-ME: an innovative, personalized, and visual QoL assessment app. A diverse group of people with severe mental health problems contributed to every iteration of the development. The feedback regarding the design and functionality of the QoL-ME that was provided by participants played an essential and central role in the development. The usability evaluation using the SUS revealed good to excellent usability of the QoL-ME.

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The feedback gathered during the development of the QoL-ME can be split into 3 categories: (1) feedback that corresponds to previous design recommendations [21,28,31], (2) feedback that deviates from these recommendations, and (3) findings specific to the QoL-ME and its function as a visual QoL assessment app. First, some of the feedback received in the design stage corresponds to existing recommendations reported by Rotondi et al [28] as part of their FEDM and by Bernard et al [21] in their review of factors that facilitate the Web usage of people with mental disorders. The majority of participants had little difficulty in operating the touchscreen. However, some participants recommended enabling the use of a keyboard and mouse. These findings correspond to the results by Bernard et al [21], who recommend providing multiple, alternative ways to operate a technology. Moreover, the fixed position of the navigation buttons made using the QoL-ME predictable and clear, which was in line with recommendations included in the FEDM [28]. In addition, participants were positive regarding the appearance of the QoL-ME and experienced it as calming, pleasant, and professional. Furthermore, participants stressed the importance of using sufficient contrasts between important elements and the background of the apps and of using large fonts. These findings regarding the layout, font size, and contrasts of the QoL-ME confirm existing recommendations [21,28].

Second, some feedback deviated from the design guidelines found in the literature. Of the main recommendations of the FEDM 1 covers the navigational structure of a digital technology. The FEDM advocates a shallow hierarchical structure, whereas participants in this study strongly preferred a linear structure, as it removed the need for making navigational choices. Furthermore, the FEDM promotes scrolling down a page for additional content over paging: having to go to another page for additional content. However, in this study, participants indicated a clear preference for paging over scrolling. The fact that the FEDM primarily targets websites, whereas the QoL-ME is an app, may explain this deviation. General guidelines that target smartphone apps specifically do recommend minimizing navigational choices and advise against scrolling [57]. An alternative explanation for the deviating findings lies in the increasing importance and usage of digital technologies, which may cause shifts in user preferences. In addition, Bernard et al [21] identified the personalization of the appearance of a digital technology, including color and font size, as a facilitating factor. In this study, participants did not welcome the possibilities for personalization included in earlier versions of the QoL-ME. Possibly, the personalization of the appearance of the QoL-ME was seen as a distraction as it was unrelated to the function of the QoL-ME.

Third, 2 preferences indicated by participants are specific to the functionalities of the QoL-ME and are, therefore, unrelated to existing design recommendations. First, participants preferred the use of VAS scales over the Likert scale to answer the items of the additional modules. This finding confirms earlier research [58]. Second, participants preferred a mechanism that involved swiping or dragging icons for the selection of the additional modules. Both mechanisms were tested on a touchscreen device, which may have enhanced their popularity. Prior research confirms the accessibility of a touchscreen-based interaction [59,60].

Usability evaluations of the QoL-ME using the SUS reveal good to excellent usability. The average SUS score of 76.8 obtained in this study is similar to SUS scores gathered in usability evaluations of comparable apps. Kooistra et al [61] evaluated the usability of a blended cognitive behavioral therapy for people with depression and found an average SUS score of 73.2. Furthermore, Fiorillo et al [62] obtained an average SUS score of 81.8 when evaluating the usability of a Web-based acceptance and commitment therapy intervention for people with trauma-related psychological difficulties. In addition, Kobak et al [63] reported an average SUS score of 83.5 in their evaluation of computerized cognitive behavior therapy for people with obsessive-compulsive disorder.

Strengths and Limitations

The diversity of the study population is an important strength. Participants from diverse age groups and care backgrounds shared their insights regarding the QoL-ME. This diverse sample ensures that the QoL-ME appeals to a large and diverse group of potential users and may enhance the generalizability of the results to people with severe mental health problems. The strong emphasis on collaboration with people with severe mental health problems can be seen as another strength [36]. People with severe mental health problems were heavily involved in the development of the QoL-ME, and their feedback, tips, and insights strongly influenced the direction of the development.

Apart from these strengths, several limitations ought to be taken into account when interpreting the results of this study. First, the sample was not selected randomly but by a combination of convenience sampling and stratified sampling. This sampling strategy may negatively affect the generalizability of the results. At the same time, the aforementioned diversity of the sample indicates that the negative consequences of the sampling strategy are minimal. Second, the results may be biased by a selection effect. It is likely that clients who were interested in this study had at least some affinity and experience with digital technology and apps. If this is the case, potential issues in the design of the QoL-ME may not have been uncovered. However, a number of participants described themselves as digital illiterates and some even indicated never having used apps or touchscreen devices before. This anecdotal evidence appears to indicate that no major selection effect occurred. Nevertheless, participants' previous experience with digital technologies was not investigated systematically, and therefore, no firm conclusion can be drawn. Third, the group of participants who evaluated the usability of the QoL-ME using the SUS was rather small. However, a study by Tullis and Stentson [64] revealed a sample of 12 to 14 participants is sufficient to obtain reliable results using the SUS. A fourth limitation concerns the dearth of available information regarding the background of participants. However, in this study, we strove to include a broad group of participants so that the QoL-ME suits a sample of people with severe mental health problems with diverse vulnerabilities and problems. Therefore, no conclusions regarding the appropriateness of the QoL-ME for groups with specific cultural backgrounds, psychopathology, or socioeconomic status can

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be drawn on the basis of this study. Further research will have to reveal whether the cocreative development has resulted in an app that is suitable for specific groups.

Conclusions

The cocreative development of the QoL-ME resulted in an innovative, personalized, and visual app for QoL assessment. Overall, participants had little difficulty in operating the QoL-ME and were positive regarding its usability. Participants indicated a preference for paging over scrolling, linear navigation, a clean and minimalist layout, and the use of touchscreen functionality in various modes of interaction. Further research is needed to evaluate both the validity and reliability of the QoL-ME. In addition, it is important to investigate the usefulness of the QoL-ME for both clients and care professionals in practice. Moreover, for the QoL-ME to be of use in clinical practice, its sensitivity to change in QoL ought to be examined.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Topic list used during the brainstorming stage of the development of the QoL-ME.

[PDF File (Adobe PDF File), 215KB - mental_v6i3e12378_app1.pdf]

Multimedia Appendix 2

Short video introducing the QoL-ME. Users may choose to watch the video directly after logging into the QoL-ME.

[MP4 File (MP4 Video), 4MB - mental_v6i3e12378_app2.mp4]

Multimedia Appendix 3

Video walkthrough of the QoL-ME.

[MP4 File (MP4 Video), 7MB - mental_v6i3e12378_app3.mp4]

References

1. Awad AG, Voruganti LN. Measuring quality of life in patients with schizophrenia: an update. Pharmacoeconomics 2012 Mar;30(3):183-195. [doi: 10.2165/11594470-000000000-00000] [Medline: 22263841]
2. Boyer L, Baumstarck K, Boucekine M, Blanc J, Lançon C, Auquier P. Measuring quality of life in patients with schizophrenia:an overview. Expert Rev Pharmacoecon Outcomes Res 2013 Jun;13(3):343-349. [doi: 10.1586/erp.13.15] [Medline: 23763531]
3. Tambuyzer E, Pieters G, van Audenhove C. Patient involvement in mental health care: one size does not fit all. Health Expect 2014 Feb;17(1):138-150 [FREE Full text] [doi: 10.1111/j.1369-7625.2011.00743.x] [Medline: 22070468]
4. Tambuyzer E, Van Audenhove C. Is perceived patient involvement in mental health care associated with satisfaction and empowerment? Health Expect 2015 Aug;18(4):516-526 [FREE Full text] [doi: 10.1111/hex.12052] [Medline: 23425015]
5. van Gestel-Timmermans H, Brouwers EP, van Assen MA, van Nieuwenhuizen C. Effects of a peer-run course on recovery from serious mental illness: a randomized controlled trial. Psychiatr Serv 2012 Jan;63(1):54-60. [doi: 10.1176/appi.ps.201000450] [Medline: 22227760]
6. Lehdonvirta V. A history of the digitalization of consumer culture. In: Molesworth M, Denegri-Knott J, editors. Digital Virtual Consumption. New York: Routledge; 2012:11-28.
7. de Maeyer J, van Nieuwenhuizen C, Bongers IL, Broekaert E, Vanderplasschen W. Profiles of quality of life in opiate-dependent individuals after starting methadone treatment: a latent class analysis. Int J Drug Policy 2013 Jul;24(4):342-350. [doi: 10.1016/j.drugpo.2012.09.005] [Medline: 23127664]
8. Priebe S, Reininghaus U, McCabe R, Burns T, Eklund M, Hansson L, et al. Factors influencing subjective quality of life in patients with schizophrenia and other mental disorders: a pooled analysis. Schizophr Res 2010 Aug;121(1-3):251-258. [doi: 10.1016/j.schres.2009.12.020] [Medline: 20483566]
9. Ogden J, Lo J. How meaningful are data from Likert scales? An evaluation of how ratings are made and the role of the response shift in the socially disadvantaged. J Health Psychol 2012 Apr;17(3):350-361. [doi: 10.1177/1359105311417192] [Medline: 21824896]

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10. Reininghaus U, McCabe R, Burns T, Croudace T, Priebe S. The validity of subjective quality of life measures in psychotic patients with severe psychopathology and cognitive deficits: an item response model analysis. Qual Life Res 2012 Mar;21(2):237-246. [doi: 10.1007/s11136-011-9936-1] [Medline: 21667228]
11. Unnava H, Burnkrant R. An imagery-processing view of the role of pictures in print advertisements. J Mark Res 1991;28(2):226-231. [doi: 10.2307/3172811]
12. Winn W. Learning from maps and diagrams. Educ Psychol Rev 1991;3(3):211-247. [doi: 10.1007/BF01320077]
13. Naslund JA, Marsch LA, McHugo GJ, Bartels SJ. Emerging mHealth and eHealth interventions for serious mental illness: a review of the literature. J Ment Health 2015 Aug 19:1-12. [doi: 10.3109/09638237.2015.1019054] [Medline: 26017625]
14. Price M, Yuen EK, Goetter EM, Herbert JD, Forman EM, Acierno R, et al. mHealth: a mechanism to deliver more accessible, more effective mental health care. Clin Psychol Psychother 2014;21(5):427-436 [FREE Full text] [doi: 10.1002/cpp.1855] [Medline: 23918764]
15. Ferron JC, Brunette MF, McHugo GJ, Devitt TS, Martin WM, Drake RE. Developing a quit smoking website that is usable by people with severe mental illnesses. Psychiatr Rehabil J 2011;35(2):111-116. [doi: 10.2975/35.2.2011.111.116] [Medline: 22020840]
16. Titov N, Andrews G, Schwencke G, Drobny J, Einstein D. Shyness 1: distance treatment of social phobia over the internet. Aust N Z J Psychiatry 2008 Jul;42(7):585-594. [doi: 10.1080/00048670802119762] [Medline: 18612862]
17. Valimaki M, Anttila M, Hatonen H, Koivunen M, Jakobsson T, Pitkanen A, et al. Design and development process of patient-centered computer-based support system for patients with schizophrenia spectrum psychosis. Inform Health Soc Care 2008 Jun;33(2):113-123. [doi: 10.1080/17538150802127207] [Medline: 18604755]
18. Firth J, Torous J, Carney R, Newby J, Cosco TD, Christensen H, et al. Digital technologies in the treatment of anxiety: recent innovations and future directions. Curr Psychiatry Rep 2018 May 19;20(6):44. [doi: 10.1007/s11920-018-0910-2] [Medline: 29779065]
19. Matthews M, Voida S, Abdullah S, Doherty G, Choudhury T, Im S, et al. In Situ Design for Mental Illness: Considering the Pathology of Bipolar Disorder in mHealth Design. In: Proceedings of the 17th International Conference on Human-Computer Interaction with Mobile Devices and Services. New York: ACM; 2015 Presented at: MobileHCI'15; August 25-28, 2015; Copenhagen, Denmark p. 86-97. [doi: 10.1145/2785830.2785866]
20. Ben-Zeev D, Kaiser SM, Brenner CJ, Begale M, Duffecy J, Mohr DC. Development and usability testing of FOCUS: a smartphone system for self-management of schizophrenia. Psychiatr Rehabil J 2013 Dec;36(4):289-296 [FREE Full text] [doi: 10.1037/prj0000019] [Medline: 24015913]
21. Bernard R, Sabariego C, Cieza A. Barriers and facilitation measures related to people with mental disorders when using the web: a systematic review. J Med Internet Res 2016 Dec 9;18(6):e157 [FREE Full text] [doi: 10.2196/jmir.5442] [Medline: 27282115]
22. Doherty K, Barry M, Marcano-Belisario J, Arnaud B, Morrison C, Car J, et al. A mobile app for the self-report of psychological well-being during pregnancy (BrightSelf): qualitative design study. JMIR Ment Health 2018 Nov 27;5(4):e10007 [FREE Full text] [doi: 10.2196/10007] [Medline: 30482742]
23. Nicholson J, Wright S, Carlisle A, Sweeney M, McHugo G. The WorkingWell mobile phone app for individuals with serious mental illnesses: proof-of-concept, mixed-methods feasibility study. JMIR Ment Health 2018 Oct 25;5(4):e11383 [FREE Full text] [doi: 10.2196/11383] [Medline: 30361199]
24. Sevilla-Llewellyn-Jones J, Santesteban-Echarri O, Pryor I, McGorry P, Alvarez-Jimenez M. Web-based mindfulness interventions for mental health treatment: systematic review and meta-analysis. JMIR Ment Health 2018 Sep 25;5(3):e10278 [FREE Full text] [doi: 10.2196/10278] [Medline: 30274963]
25. Tulbure B, Rusu A, Sava F, Sălăgean N, Farchione T. A web-based transdiagnostic intervention for affective and mood disorders: randomized controlled trial. JMIR Ment Health 2018 May 24;5(2):e36 [FREE Full text] [doi: 10.2196/mental.8901] [Medline: 29798831]
26. Brunette MF, Ferron JC, Devitt T, Geiger P, Martin WM, Pratt S, et al. Do smoking cessation websites meet the needs of smokers with severe mental illnesses? Health Educ Res 2012 Apr;27(2):183-190 [FREE Full text] [doi: 10.1093/her/cyr092] [Medline: 21987478]
27. Ferron JC, Brunette MF, Geiger P, Marsch LA, Adachi-Mejia AM, Bartels SJ. Mobile phone apps for smoking cessation: quality and usability among smokers with psychosis. JMIR Hum Factors 2017 Mar 3;4(1):e7 [FREE Full text] [doi: 10.2196/humanfactors.5933] [Medline: 28258047]
28. Rotondi AJ, Eack SM, Hanusa BH, Spring MB, Haas GL. Critical design elements of e-health applications for users with severe mental illness: singular focus, simple architecture, prominent contents, explicit navigation, and inclusive hyperlinks. Schizophr Bull 2015 Mar;41(2):440-448. [doi: 10.1093/schbul/sbt194] [Medline: 24375458]
29. Rotondi AJ, Sinkule J, Haas GL, Spring MB, Litschge CM, Newhill CE, et al. Designing websites for persons with cognitive deficits: design and usability of a psychoeducational intervention for persons with severe mental illness. Psychol Serv 2007 Aug;4(3):202-224 [FREE Full text] [doi: 10.1037/1541-1559.4.3.202] [Medline: 26321884]
30. Ben-Zeev D, Schueller SM, Begale M, Duffecy J, Kane JM, Mohr DC. Strategies for mHealth research: lessons from 3 mobile intervention studies. Adm Policy Ment Health 2015 Mar;42(2):157-167. [doi: 10.1007/s10488-014-0556-2] [Medline: 24824311]

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RenderX

31. Rotondi AJ, Spring MR, Hanusa BH, Eack SM, Haas GL. Designing eHealth applications to reduce cognitive effort for persons with severe mental illness: page complexity, navigation simplicity, and comprehensibility. JMIR Hum Factors 2017 Jan 5;4(1):e1 [FREE Full text] [doi: 10.2196/humanfactors.6221] [Medline: 28057610]
32. Endsley MR. Designing for Situation Awareness: An Approach to User-Centered Design. Boca Raton: CRC press; 2011.
33. Garrett JJ. The Elements of User Experience: User-centered Design for the Web. London: Pearson Education; 2010.
34. de Beurs D, van Bruinessen I, Noordman J, Friele R, van Dulmen S. Active involvement of end users when developing web-based mental health interventions. Front Psychiatry 2017;8:72 [FREE Full text] [doi: 10.3389/fpsyt.2017.00072] [Medline: 28515699]
35. Doherty G, Coyle D, Matthews M. Design and evaluation guidelines for mental health technologies. Interact Comput 2010;22(4):243-252. [doi: 10.1016/j.intcom.2010.02.006]
36. Torous J, Nicholas J, Larsen ME, Firth J, Christensen H. Clinical review of user engagement with mental health smartphone apps: evidence, theory and improvements. Evid Based Ment Health 2018 Jun 5;21(3):116-119. [doi: 10.1136/eb-2018-102891] [Medline: 29871870]
37. Hardy A, Wojdecka A, West J, Matthews E, Golby C, Ward T, et al. How inclusive, user-centered design research can improve psychological therapies for psychosis: development of SlowMo. JMIR Ment Health 2018 Dec 5;5(4):e11222 [FREE Full text] [doi: 10.2196/11222] [Medline: 30518514]
38. van Straaten B, Schrijvers C, van der Laan J, Boersma S, Rodenburg G, Wolf J, et al. Intellectual disability among Dutch homeless people: prevalence and related psychosocial problems. PLoS One 2014;9(1):e86112 [FREE Full text] [doi: 10.1371/journal.pone.0086112] [Medline: 24465905]
39. Fazel S, Geddes J, Kushel M. The health of homeless people in high-income countries: descriptive epidemiology, health consequences, and clinical and policy recommendations. Lancet 2014 Oct 25;384(9953):1529-1540 [FREE Full text] [doi: 10.1016/S0140-6736(14)61132-6] [Medline: 25390578]
40. Fazel S, Khosla V, Doll H, Geddes J. The prevalence of mental disorders among the homeless in western countries: systematic review and meta-regression analysis. PLoS Med 2008 Dec 2;5(12):e225 [FREE Full text] [doi: 10.1371/journal.pmed.0050225] [Medline: 19053169]
41. Mercier C, Picard S. Intellectual disability and homelessness. J Intellect Disabil Res Apr 2011;55(4):441-449. [doi: 10.1111/j.1365-2788.2010.01366.x] [Medline: 21241395]
42. Schindler V, Kientz M. Supports and barriers to higher education and employment for individuals diagnosed with mental illness. J Vocat Behav 2013;39(1):29-41. [doi: 10.3233/JVR-130640]
43. Einfeld S, Ellis L, Emerson E. Comorbidity of intellectual disability and mental disorder in children and adolescents: a systematic review. J Intellect Dev Disabil Jun 2011;36(2):a. [doi: 10.1080/13668250.2011.572548] [Medline: 21609299]
44. Morgan V, Leonard H, Bourke J, Jablensky A. Intellectual disability co-occurring with schizophrenia and other psychiatric illness: population-based study. Br J Psychiatry Nov 2008;193(5):364-372. [doi: 10.1192/bjp.bp.107.044461] [Medline: 18978313]
45. Spinuzzi C. The methodology of participatory design. Technical communication 2005;52(2):163-174 [FREE Full text]
46. Bangor A, Kortum P, Miller J. An empirical evaluation of the system usability scale. Int J Hum Comput Interact 2008;24(6):574-594. [doi: 10.1080/10447310802205776]
47. Brooke J. SUS-a quick and dirty usability scale. Usab Eval Indust 1996;189(194):4-7 [FREE Full text]
48. Brooke J. SUS: a retrospective. J Usability Stud 2013;8(2):29-40 [FREE Full text]
49. Sauro J, Lewis J, editors. When designing usability questionnaires, does it hurt to be positive? In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. New York: ACM; 2011 Presented at: CHI'11; May 7-12, 2011; Vancouver.
50. Bangor A, Kortum P, Miller J. Determining what individual SUS scores mean: adding an adjective rating scale. J Usability Stud 2009;4(3):114-123 [FREE Full text]
51. Barendregt C, van Straaten B, Wits E. Meaning of life among former homeless substance users. In: Decorte T, Fountain J, editors. Pleasure, Pain and Profit: European Perspectives on Drugs. Lengerich: Pabst Science Publishers; 2010:101-119.
52. van der Laan J, Boersma S, van Straaten B, Rodenburg G, van de Mheen D, Wolf J. Personal goals and factors related to QoL in Dutch homeless people: what is the role of goal-related self-efficacy? Health Soc Care Community 2017 Dec;25(3):1265-1275. [doi: 10.1111/hsc.12429] [Medline: 28122408]
53. van Nieuwenhuizen CH, Schene A, Koeter M, Huxley P. The Lancashire Quality of Life Profile: modification and psychometric evaluation. Soc Psychiatry Psychiatr Epidemiol 2001 Jan;36(1):36-44. [doi: 10.1007/s001270050288] [Medline: 11320806]
54. Buitenweg DC, Bongers IL, van de Mheen D, van Oers HAM, van Nieuwenhuizen C. Subjectively different but objectively the same? Three profiles of QoL in people with severe mental health problems. Qual Life Res 2018 Aug 13;27(11):2965-2974. [doi: 10.1007/s11136-018-1964-7] [Medline: 30105493]
55. Steger M, Frazier P, Oishi S, Kaler M. The meaning in life questionnaire: assessing the presence of and search for meaning in life. J Couns Psychol 2006;53(1):80-93. [doi: 10.1037/0022-0167.53.1.80]

XSL•FO
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56. Buitenweg DC, Bongers IL, van Nieuwenhuizen MD, van Oers HAM, Van Nieuwenhuizen C. Worth a thousand words? Visual concept mapping of the quality of life of people with severe mental health problems. Int J Methods Psychiatr Res 2018 Sep;27(3):e1721. [doi: 10.1002/mpr.1721] [Medline: 29797745]
57. Ahmad N, Rextin A, Kulsoom U. Perspectives on usability guidelines for smartphone applications: An empirical investigation and systematic literature review. Inf Softw Technol 2018 Feb;94:130-149. [doi: 10.1016/j.infsof.2017.10.005]
58. Hasson D, Arnetz B. Validation and findings comparing VAS vs Likert scales for psychosocial measurements. Int Electron J Health Educ 2005;8:178-192 [FREE Full text]
59. Chinman M, Young A, Schell T, Hassell J, Mintz J. Computer-assisted self-assessment in persons with severe mental illness. J Clin Psychiatry 2004 Oct;65(10):1343-1351. [doi: 10.4088/JCP.v65n1008] [Medline: 15491237]
60. Carbonell N, Stephanidis C. Finger instead of mouse: touch screens as a means of enhancing universal access. In: Universal Access: Theoretical Perspectives, Practice, and Experience. New York: Springer Publications; 2007.
61. Kooistra LC, Ruwaard J, Wiersma JE, van Oppen P, van der Vaart R, van Gemert-Pijnen JE, et al. Development and initial evaluation of blended cognitive behavioural treatment for major depression in routine specialized mental health care. Internet Interv 2016 May;4:61-71 [FREE Full text] [doi: 10.1016/j.invent.2016.01.003] [Medline: 30135791]
62. Fiorillo D, McLean C, Pistorello J, Hayes S, Follette V. Evaluation of a web-based acceptance and commitment therapy program for women with trauma-related problems: a pilot study. J Context Behav Sci 2017 Jan;6(1):104-113. [doi: 10.1016/j.jcbs.2016.11.003]
63. Kobak K, Greist R, Jacobi D, Levy-Mack H, Greist J. Computer-assisted cognitive behavior therapy for obsessive-compulsive disorder: a randomized trial on the impact of lay vs. professional coaching. Ann Gen Psychiatry 2015;14:10 [FREE Full text] [doi: 10.1186/s12991-015-0048-0] [Medline: 25722737]
64. Tullis T, Stetson J. A comparison of questionnaires for assessing website usability. 2004 Presented at: Usability Professionals' Association Conference; June 7-11, 2004; Minneapolis, Minnesota, USA URL: http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.396.3677&rep=rep1&type=pdf

Abbreviations

eHealth: electronic health
FEDM: Flat Explicit Design Model
LQoLP: Lancashire Quality of Life Profile
QoL: quality of life
SUS: System Usability Scale
VAS: visual analog scale

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Original Paper

Technological Interventions for Medication Adherence in Adult Mental Health and Substance Use Disorders: A Systematic Review

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Abstract

Background: Medication adherence is critical to the effectiveness of psychopharmacologic therapy. Psychiatric disorders present special adherence considerations, notably an altered capacity for decision making and the increased street value of controlled substances. A wide range of interventions designed to improve adherence in mental health and substance use disorders have been studied; recently, many have incorporated information technology (eg, mobile phone apps, electronic pill dispensers, and telehealth). Many intervention components have been studied across different disorders. Furthermore, many interventions incorporate multiple components, making it difficult to evaluate the effect of individual components in isolation.

Objective: The aim of this study was to conduct a systematic scoping review to develop a literature-driven, transdiagnostic taxonomic framework of technology-based medication adherence intervention and measurement components used in mental health and substance use disorders.

Methods: This review was conducted based on a published protocol (PROSPERO: CRD42018067902) in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses systematic review guidelines. We searched 7 electronic databases: MEDLINE, EMBASE, PsycINFO, the Cochrane Central Register of Controlled Trials, Web of Science, Engineering Village, and ClinicalTrials.gov from January 2000 to September 2018. Overall, 2 reviewers independently conducted title and abstract screens, full-text screens, and data extraction. We included all studies that evaluate populations or individuals with a mental health or substance use disorder and contain at least 1 technology-delivered component (eg, website, mobile phone app, biosensor, or algorithm) designed to improve medication adherence or the measurement thereof. Given the wide variety of studied interventions, populations, and outcomes, we did not conduct a risk of bias assessment or quantitative meta-analysis. We developed a taxonomic framework for intervention classification and applied it to multicomponent interventions across mental health disorders.

Results: The initial search identified 21,749 results; after screening, 127 included studies remained (Cohen kappa: 0.8, 95% CI 0.72-0.87). Major intervention component categories include reminders, support messages, social support engagement, care team contact capabilities, data feedback, psychoeducation, adherence-based psychotherapy, remote care delivery, secure medication

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storage, and contingency management. Adherence measurement components include self-reports, remote direct visualization, fully automated computer vision algorithms, biosensors, smart pill bottles, ingestible sensors, pill counts, and utilization measures. Intervention modalities include short messaging service, mobile phone apps, websites, and interactive voice response. We provide graphical representations of intervention component categories and an element-wise breakdown of multicomponent interventions.

Conclusions: Many technology-based medication adherence and monitoring interventions have been studied across psychiatric disease contexts. Interventions that are useful in one psychiatric disorder may be useful in other disorders, and further research is necessary to elucidate the specific effects of individual intervention components. Our framework is directly developed from the substance use disorder and mental health treatment literature and allows for transdiagnostic comparisons and an organized conceptual mapping of interventions.

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KEYWORDS

systematic review; mental health; substance-related disorders; mHealth; psychiatry; medication adherence; medication compliance

Introduction

Background

Medication adherence—the set of behaviors relevant to taking one's medication as directed—is critical to the effectiveness of pharmacologic therapies and improvement of patient outcomes. Psychiatric and substance use disorders are no exception to this rule; studies have repeatedly demonstrated the association between different measures of medication adherence and a wide variety of psychiatric outcomes. Medication nonadherence among individuals with schizophrenia has been shown to be associated with violence [1], hospital admission [2], and mortality [3]. Among those with mood disorders (eg, major depressive disorder and bipolar disorder), nonadherence is associated with hospitalizations, suicide risk, and slower initial recovery [4,5]. Nonadherence can be particularly problematic when treating those with opioid use disorders, as it is associated with treatment dropout [6], which is in turn associated with continued use of illicit drugs [7] and increased mortality [8]. Such studies strongly suggest the important role played by medication adherence across psychiatric disorders. The prevalence of nonadherence in these disorders is also quite high; studies estimate that 41% to 50% of patients with schizophrenia [9], 13% to 52% of those with depression [10], 57% of those with anxiety [11], and 68% of those with opioid use disorder [12] are not fully adherent to their medication. Outside of clinical practice, nonadherence and inaccurate adherence measurement stymie research studies of new interventions; clinical trials must recruit more participants, spend more money, and may even produce erroneous results because of nonadherence [13,14].

Clinicians have been struggling to solve the medication adherence problem for decades; the body of research conducted across a wide variety of medical disorders is large and continues to grow rapidly [15]. The etiologies of nonadherence are complex and multifactorial; perhaps the most common framework includes 5 major categories—socioeconomic factors, health system–related factors, condition-related factors, treatment-related factors, and patient-related factors [16]. In psychiatry, the Perceptions and Practicalities Approach classifies modifiable risk factors of nonadherence into a " *perceptual* category (relating to patient beliefs, eg, about the presence and severity of their disorder, medication efficacy, and side effect profile) and a *practical* category (eg, resources necessary to acquire medication and cognitive capacity to adhere despite adequate motivation)—suggesting 2 broad targets for intervention [17]. Somewhat parallel to this is the distinction between *voluntary* nonadherence (eg, due to lack of insight or desire) and *involuntary* nonadherence (eg, due to cognitive limitations, poor understanding, or simply forgetting) [18].

Mental health and substance use disorders present unique challenges to adherence owing to the nature of the symptoms associated with these disorders. The delusional belief systems and poor insight often found in schizophrenia appear to be associated with lower levels of adherence [9,19]. The street value of opioid partial agonists (the cornerstone of modern office-based opioid treatment for opioid use disorders) raises the specter of medication diversion and provides a strong incentive for nonadherence. Patients with posttraumatic stress disorder (PTSD), in particular PTSD induced by *medical* events, are more likely to be nonadherent to medication regimens—it has been proposed that the medications may serve as aversive reminders that trigger avoidant behaviors [20]. Depressed patients are much less likely to adhere to medication regimens [21], likely mediated through a decreased motivation for self-care [22]. At least one study has linked anxiety disorders to increased medication nonadherence [23], though other studies have found mixed results [24]. Across all psychiatric disorders, the self-stigma associated with receiving treatment for mental illness has also been shown to contribute to nonadherence [25]. In particular, these challenges may motivate an increased emphasis on adherence *monitoring* in addition to adherence motivation, relative to nonpsychiatric disorders.

In the past few decades, information technology and related fields have enabled a wide variety of new approaches and modalities to improve medication adherence and adherence monitoring. The near-ubiquity of mobile phones [26], the relative ease of app development, the boom in Internet of Things devices capable of recording and transmitting real-time biological data, and the steady improvement of artificial intelligence (AI) and machine learning systems have all contributed to this increase in technology-based interventions for medication adherence.

The field of technological interventions for medication adherence in psychiatric disorders is quite young and expanding

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in scope, with multiple new trials each year in each disorder context. Many intervention types have been studied only in pilot studies, or in randomized controlled trials (RCTs) with small sample sizes. Furthermore, many interventions consist of multiple components used in conjunction, which complicates the study of the efficacy of individual intervention components. Significant additional research needs to be done before we can determine which technology-based interventions are most promising.

Recent related research in summarizing the vast and diverse field of psychiatric medication adherence technologies includes systematic reviews focusing on particular disorders such as mood disorders [27], schizophrenia and other psychotic disorders [28,29], and substance use disorders [30]. Other reviews evaluate specific technologic intervention types, including automated reminders [31], adherence monitoring [32], and virtual reality technologies [33]. However, given the breadth, size, and expansion rate of this field, little research has been done to compare and contrast feasibility and effectiveness of various interventions *across* disorder contexts, or to provide a transdiagnostic framework of adherence intervention components. Although the efficacy of specific interventions may ultimately prove to differ between diagnoses, we believe that the etiologies of nonadherence and the frequently studied intervention components are similar enough to justify such a transdiagnostic approach. In this review, we also evaluate this assumption formally.

Objective

Here, we conduct a systematic scoping review of the literature concerning technology-based solutions for medication nonadherence among those with psychiatric disorders. The review is designed to provide a broad transdiagnostic overview of research themes and intervention types, with an eye toward developing a data-driven conceptual framework of technology-based adherence interventions for mental health and substance use disorders. We believe that such a framework would aid researchers in evaluating new literature, create promising directions for future research, and provide a summary of this vast field for the busy clinician who may be overwhelmed by the panoply of available options. In the long term, new multicomponent interventions might be built quickly and effectively by sampling promising components from this framework, based on domain-specific knowledge from a researcher or clinician's area of study.

Methods

Overview

This is a systematic scoping review of technological interventions designed to improve medication adherence in mental health and substance use populations. We define technology broadly, including software, hardware, algorithms, and biosensors. This review was conducted based on a published protocol (PROSPERO: CRD42018067902). We conducted a qualitative synthesis of themes in the included literature, constructed graphical concept maps and graphed topic area popularity over time in different psychiatric disorder contexts. We aimed to provide a comprehensive transdiagnostic framework with which to think about and categorize components of technological interventions for medication adherence in mental health and substance use populations.

Search Strategy

To obtain relevant scientific literature, we searched 7 electronic bibliographic databases: MEDLINE, EMBASE, PsycINFO, the Cochrane Central Register of Controlled Trials (CENTRAL), Web of Science, Engineering Village, and ClinicalTrials.gov. Study records identified from ClinicalTrials.gov were used to search for related published articles and conference proceedings. Reference lists from the included studies as well as reviews on related topics were searched for additional relevant articles. Authors were contacted to answer specific questions when necessary.

Using the Population-Intervention-Comparison-Outcome (PICO) framework [34], 3 core thematic concepts were used to build the search strategy: mental health and substance use disorders (population), technology (intervention), and medication adherence or compliance (outcome); all 3 of which were necessary for article inclusion. We constructed the final search strategy through an iterative collaborative process, which included reading related review articles, building a tree of relevant MeSH terms, and testing searches against a growing corpus of "must-include" articles identified through a preliminary search. Furthermore, we consulted with multiple research librarians to ensure our strategy was comprehensive and database-specific.

We searched by title or keyword, using MeSH terms for MEDLINE and analogous terms for other databases when applicable (eg, Emtree). We initially included English language articles published between January 2000 and January 2018; articles from before 2000 were unlikely to be relevant from a technological perspective. Reviews, letters, case reports, editorials, and other forms of nonprimary research were excluded. Journal articles, conference proceedings, and abstracts were included if they represented primary research. Given the broad scope and heterogeneity of the topic, we included all study designs, ranging from RCTs to pilot feasibility studies to provide a comprehensive concept map. For completeness, a search for any updated manuscripts was rerun on MEDLINE, EMBASE, PsycINFO, CENTRAL, and Web of Science during September 2018. The full search strategies are listed in Multimedia Appendix 1.

Inclusion Criteria

Adherence

Much of the literature around technological adherence interventions relates to improving the accuracy of adherence *measurement* (eg, ingestible biosensors, smart pill bottles, and directly observed remote medication ingestion). Accurate adherence measurement is critical for evaluating the efficacy of interventions both in clinical practice and in research studies, it and is a critical part of many multicomponent interventions. We therefore considered a study to meet the *adherence* criteria of inclusion if the intervention was designed to improve either medication adherence or the accuracy of adherence measurement. We excluded articles which evaluated participant

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adherence to the intervention as a whole, or a component of the intervention other than adherence to pharmacologic therapy (for instance, a study evaluating whether participants were adherent to a Web-based psychoeducational program). Articles that did not directly measure medication adherence or medication adherence measurement accuracy as an outcome (eg, pilot feasibility or usability studies) were included if medication adherence was a key motivating factor for development of the intervention, as assessed by the abstract, introduction, and discussion sections of the article.

Technology

Given the aim of the scoping review, we defined technology as broadly as possible. We wanted to include all forms of modern information technology such as mobile phones, mobile apps, websites, and computer vision-based (CV) AI systems, as well as interactive voice response (IVR) technology. Furthermore, physical technology such as smart pill bottles and ingestible sensors, as well as studies of novel biomarkers or biological measurement methods, were considered to meet the *technology* criterion for inclusion. Many of the multicomponent interventions found throughout the course of the search contained some technological components while also containing other components that did not meet our definition of technology-based; we included these studies and will describe the technological components therein to provide the most comprehensive map of the space.

Other Exclusions

We excluded articles that did not exclusively study a psychiatric or substance use population (although we did include articles in which all the participants had an additional nonpsychiatric condition—eg, patients with HIV and opioid use disorder). We excluded epidemiologic studies that only examined the prevalence of nonadherence. We excluded studies which provided only financial incentive for medication adherence with no other components. We excluded protocol-only articles if outcome articles were available for the same study. We excluded articles focusing on pediatric populations, as their caretakers are often responsible for their adherence behaviors. Similarly, we excluded studies of patients with dementia disorders, as they often have caretakers who are responsible for adherence behaviors.

Study Selection and Extraction

We used the Cochrane Covidence tool [35] to assist in conducting most of the systematic review. To be included, an article had to be deemed relevant at 2 stages—1) title and abstract screen and 2) full-text screen. Overall, 2 reviewers (JMS and NG) independently screened each abstract and full-text article. Conflicts were resolved via discussion until consensus was reached; a third reviewer (JB) was on hand to resolve disagreements, but this was not needed for this review. Interrater reliability was calculated for both the title-abstract stage and the full-text screening stage using Cohen kappa.

Included articles were then extracted using a charting tool developed iteratively by the authors. Both reviewers (JS and NG) performed extraction on each of the articles and compared the extracted results. Extracted data fields included the following: author's name, year of publication, study objectives (primarily targeted at improving adherence, measurement accuracy, or both), population (eg, opioid use disorder or bipolar disorder), study type (eg, RCT or pilot feasibility), study size, components of intervention delivered technologically (eg, reminders, education, support, or monitoring), and technological modality when applicable (eg, app, website, or IVR). We did not assess risk of bias or study quality given the large amount of heterogeneity in study populations, study designs, intervention types, and outcome measures as well as the goal to conduct a systematic scoping review.

Before starting the review, we chose to make a top-level distinction between *data collection components* (system components designed to collect data or improve the accuracy of adherence measurement) and *interventional components* (system components designed to directly increase medication adherence).

Results were labeled as including a data collection component if the study either (1) evaluated the accuracy of a measurement method (for instance, a study which compared clinician ratings of adherence to electronic pill monitors) or (2) evaluated an interventional system which periodically assessed participant adherence as *part of the intervention*, not merely a *study endpoint* (eg, a mobile phone app which notifies clinicians in real time of nonadherence events and encourages them to intervene would count as a "data collection" intervention, but an RCT which evaluated the effects of a psychoeducational program on adherence using electronic pill monitors merely as an *endpoint* would not fall under this category).

Synthesis

For this scoping review, we performed a qualitative synthesis of the included studies. We categorized the studies by study type, intervention type, population studied, and technological modality. We created a hierarchical taxonomy of intervention components.

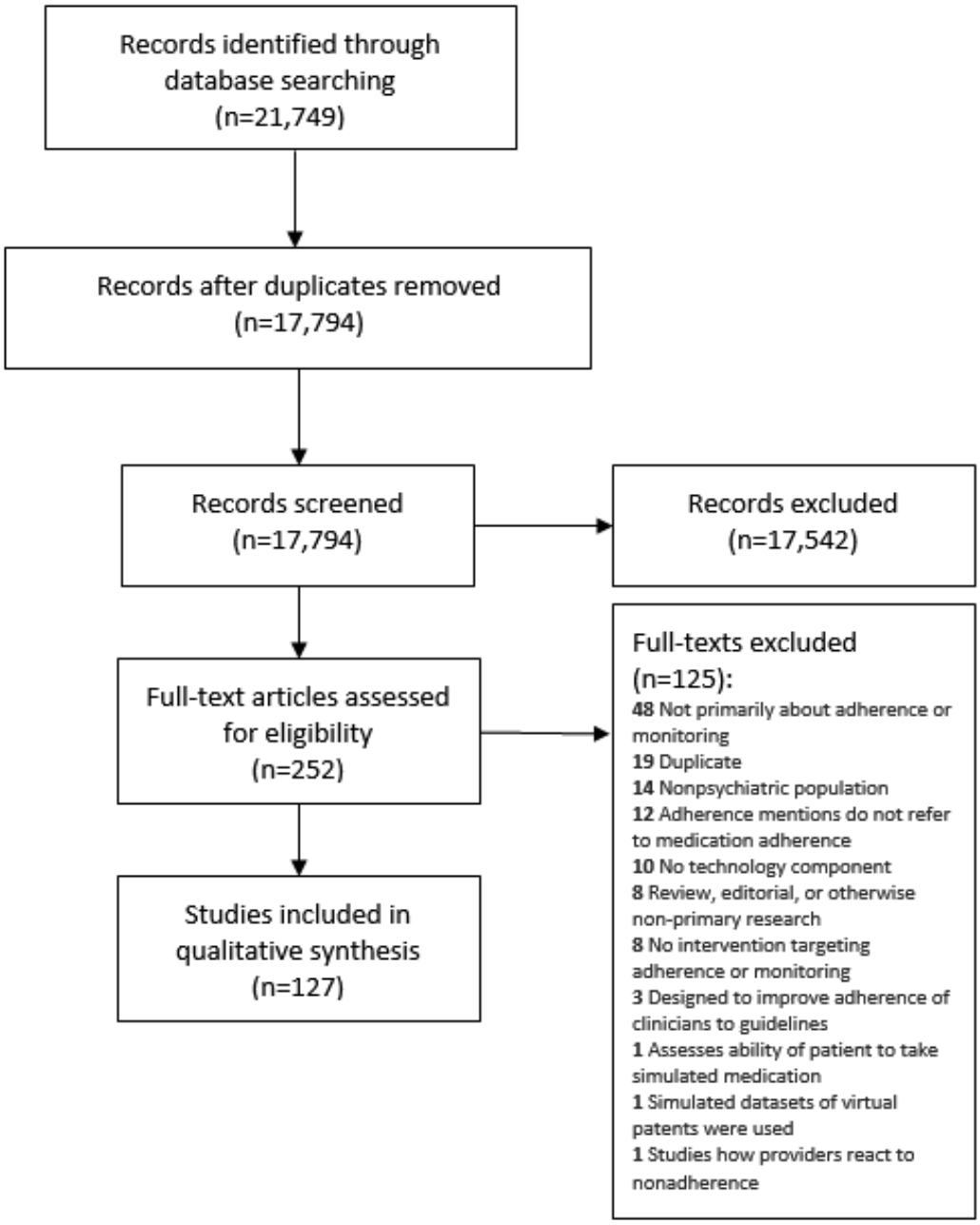
Results

Study Selection and Extraction

The literature search identified 21,749 results. A search of related reviews and references in relevant articles did not find any additional results. Of these, 3955 duplicates were removed, and 17,542 results were excluded based on the title and abstract, yielding 252 results (Cohen kappa before reconciliation=0.82, 95% CI 0.78-0.86). These were screened based on their full texts, and 125 were excluded (Cohen kappa before reconciliation=0.80, 95% CI 0.72-0.87). This left a total of 127 articles and conference proceedings that met the inclusion criteria (Figure 1). In the final rerun of the search in September 2018, 3 indexed manuscripts were found that replaced conference proceedings describing the same studies. All included studies are provided in Multimedia Appendix 2.

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Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses Diagram of included studies.



There was an increase over time (2000-2018) in the prevalence of included articles. The graph showing the number of included articles per year is given in Figure 2. As the amount of total published research has also increased over this same time span, we provide in Figure 3, a graph relative to the total amount of published research in MEDLINE. Each data point is calculated by dividing the number of included articles from a given year by the number of total MEDLINE articles published during that same year (based on MEDLINE's "Publication Date" field).

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Figure 2. Included articles by year.

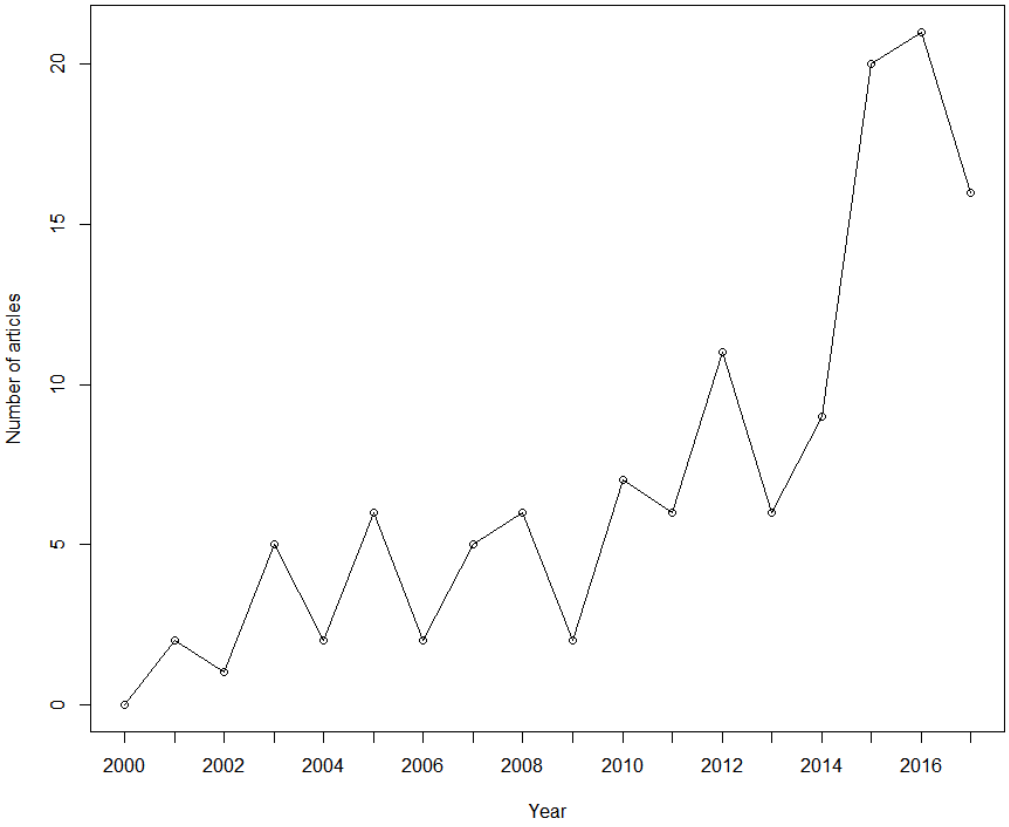
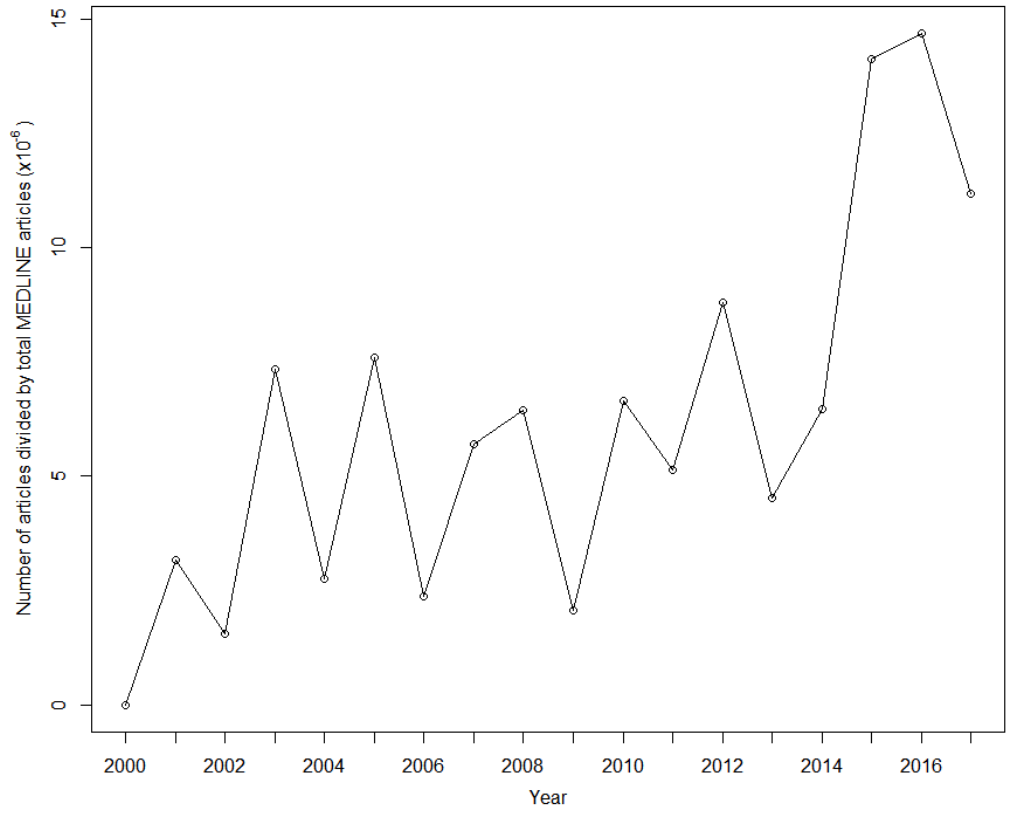


Figure 3. Included articles by year, divided by total number of MEDLINE articles published during that same year.



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Characteristics of Included Studies

Of the included studies, 40.2% (51/127) were RCTs; 56.7% (72/127) implemented nonrandomized interventions (eg, nonrandomized multiarm studies, single-arm studies, pilot feasibility studies, comparison of multiple measurement methods in 1 group, etc). The remaining 4 [36-39] were surveys or focus groups of potential participants evaluating participant willingness to use specific interventions.

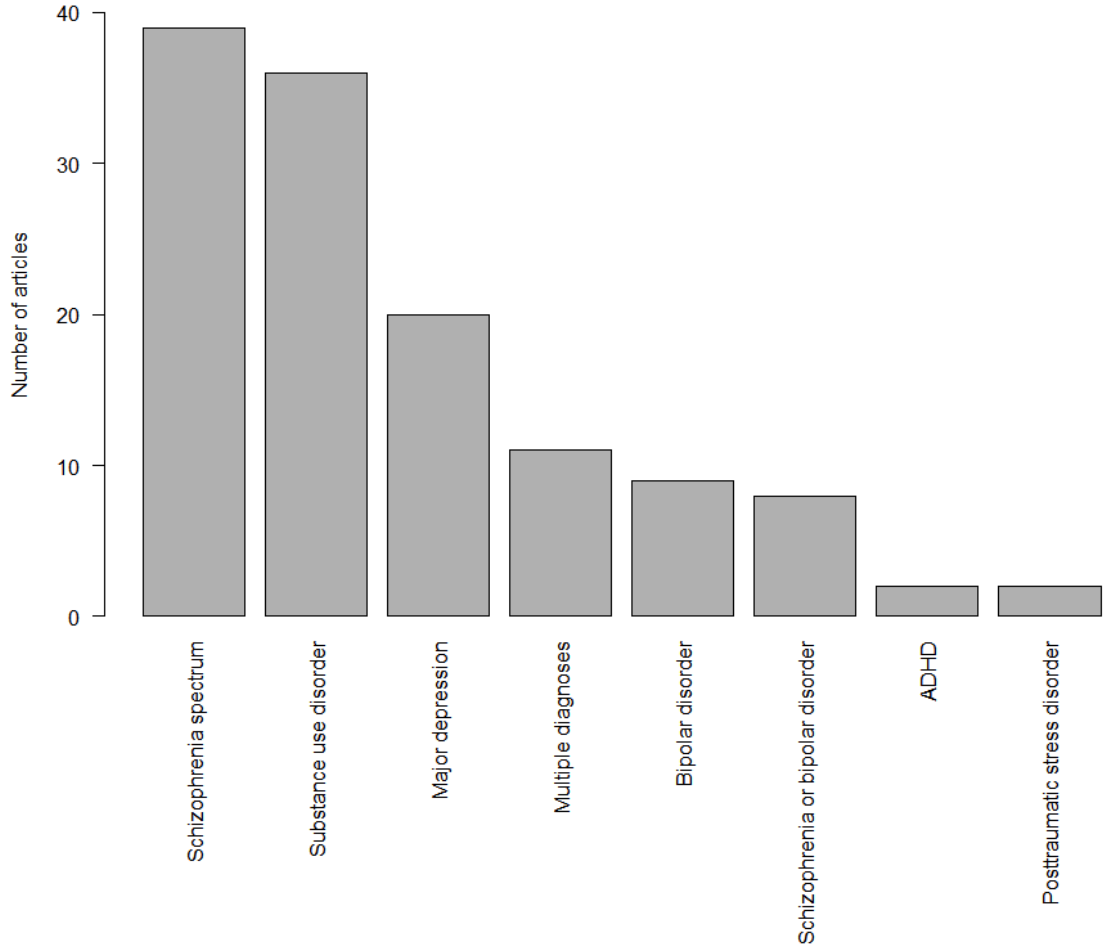
Many psychiatric populations were studied (Figure 4): primary psychotic disorders (n=39), substance use disorders (n=36), major depression (n=20), bipolar disorder (n=9), attention deficit hyperactivity disorder (ADHD; n=2), and PTSD (n=2). Common transdiagnostic populations included "schizophrenia or bipolar disorder" (n=8), dual diagnosis (substance use disorder comorbid with a primary psychiatric disorder, n=3), and pandiagnostic, that is, any psychiatric disorder (n=6). The remaining studies evaluated all patients taking aripiprazole [40] or pooled data from multiple clinical trials of medications for schizophrenia and ADHD [41]. Among the substance use disorders, tobacco was studied most (n=15), followed by opioids (n=11), alcohol (n=5), cannabis (n=2), amphetamines (n=2), and all substance use disorders (n=1).

Studied outcomes included intervention feasibility (n=29), system usability (n=12), and participant satisfaction or acceptability (n=38). Furthermore, 94 studies included some measure of medication adherence, and 32 evaluated or compared the accuracy of one or more medication adherence measurement methods. Many studies evaluated other outcomes, including change in symptoms over time, reduction in substance use, or physiologic metrics such as sleep duration or step count.

Synthesis

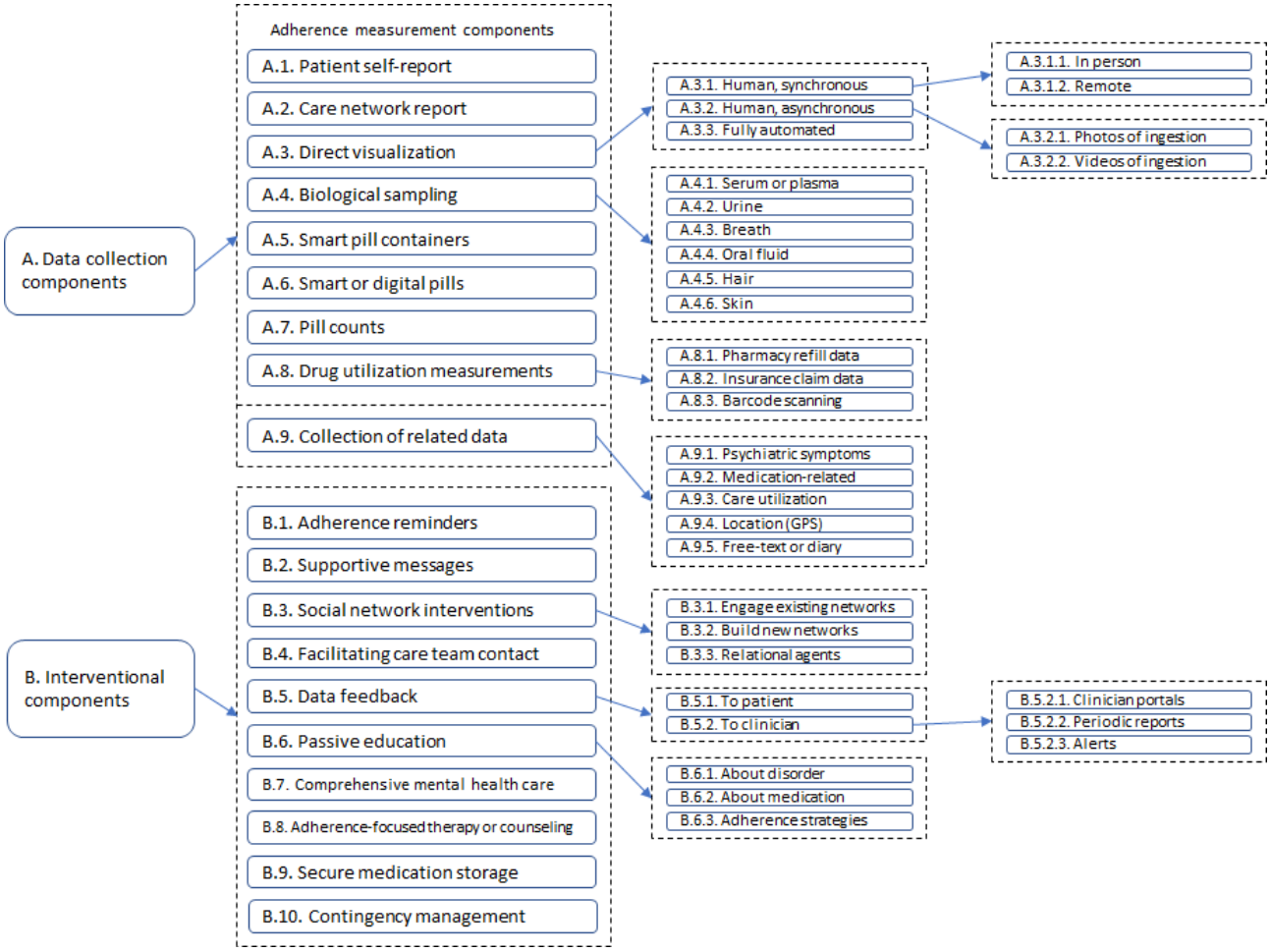
On the basis of the included articles, we constructed a taxonomy of components of the studied technological systems, broken down into the 2 major categories of "data collection components" and "interventional components." Note that any particular study or technological system may include components from one or both categories. A concept map of the full taxonomy is provided in Figure 5.

Figure 4. Number of articles by diagnosis. ADHD: attention deficit hyperactivity disorder.



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Figure 5. Visual concept map of components of studied technological systems. GPS: global positioning system.



A. Data Collection Components

Adherence measurement and monitoring are critical components of adherence enhancement in many ways, from accurately evaluating the efficacy of interventions designed to improve adherence to identifying patients who would benefit from adherence interventions. The majority of studies collected only adherence data, however, we also included a collection of *related* data within this category (A.9.). This reflects the group of technological systems that collect data other than adherence for downstream use in interventional components.

A.1. Patient Self-Report

By far, the most commonly studied method (n=54) for measuring medication adherence was patient self-report. Many multicomponent apps or websites included daily or weekly surveys filled out by the participants; self-report of medication adherence was frequently included in these surveys [42-48]; IVR, telephone, text messaging, and videoconferencing interventions similarly included questions evaluating medication adherence [49-55]. Furthermore, self-report was frequently used as a baseline adherence assessment method with which other, more objective measures were compared [56-59].

A.2. Care Network Report

Some studies evaluated the subjective overall adherence report by individuals other than the participant (eg, treating clinicians or participant's friends, family, or other social support). These reports were not based on direct observation, but rather on subjective, retrospective assessments of a patient's adherence history or an overall perception of their likelihood to be adherent. This method was rarely used; none of the included studies included it as part of an adherence intervention. However, 6 studies evaluated its accuracy compared with other measurement methods [56-58,60-62]. All 6 studies evaluated 1-time subjective clinician rating scales, and 2 also evaluated reports from a "relative" or a "close informant" [58,62].

A.3. Direct Visualization of Medication Ingestion

Many interventions attempted to confirm adherence by *directly visualizing* the process of medication administration. Although there were many types of direct visualization methods, all of them involved observation of the patient during the process of physically ingesting the medication.

A.3.1: Human Observation, Synchronous

Direct visualization of medication ingestion in real time by a human observer was studied in 4 interventions. A total of 2 studies used direct in-person observation as a gold standard to evaluate the accuracy of other measurement systems (A.3.1.1) [63,64], whereas 2 other studies used mobile videoconferencing technology to observe dosing remotely (A.3.1.2) [65,66]. Both of these studies had a standardized protocol for observed dosing, ostensibly to ensure adherence; the participants kept the pill container on camera while removing the medication and showed

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their open mouth following pill ingestion to prevent hiding the medication in the cheek.

A.3.2. Human Observation, Asynchronous

A related method of visual adherence measurement, studied by 4 included articles, involved the participant capturing static photos or videos of the medication dosing process, to be evaluated in nonreal time (n=4). One study [38] evaluated the acceptability of static photos of pill counts (A.3.2.1) among a population of patients on buprenorphine. A total of 2 other studies discussed daily photographs of individual medication doses taken at the time of ingestion, either as the only intervention [67] or as part of a multicomponent intervention app [68]. Moreover, 1 study discussed nonreal-time video footage (A.3.2.2) captured on mobile phones as an adherence measurement method [69].

A.3.3. Computer Observation (Fully Automated)

Overall, 2 included studies evaluated the feasibility, usability, and measurement efficacy of AICure (AICure, LLC), an automated form of direct observation using CV algorithms to confirm pill ingestion in real time without a human observer [41,64]. The platform worked by automatically identifying the patient and drug in real-time video footage taken on mobile devices to confirm ingestion.

A.4. Biomarkers and Metabolites

In current clinical practice, measurements of concentrations of medications or medication metabolites in body fluids such as urine or serum are frequently used to assess compliance with the medication. A total of 15 of the included studies either included such measurements as part of a multicomponent intervention [70,71], used serum (A.4.1) or urine (A.4.2) measurements as a gold standard comparator for other adherence measurement approaches [58,64,72], or evaluated a novel system for biological confirmation of adherence. Such systems included measurements from breath (A.4.3) [73,74], oral fluid (A.4.4) [75,76], hair (A.4.5) [77-79], and skin (A.4.6) [80]. Overall, 1 study evaluated the accuracy of urine systems for an experimental cannabinoid [81]. Another study proposed a system of quantitative serum drug monitoring for all psychiatric medications to track adherence and better achieve therapeutic levels [82].

A.5. Smart Pill Containers

"Smart" pill containers using digital information technology to measure adherence (eg, Medication Event Monitoring System [MEMS]) were well-represented among the included studies. Most of these systems used electronic components in the cap to detect the opening of the pill bottle. Data were either wirelessly transmitted to a central server periodically or were retrieved from the bottle at clinic visits. A total of 34 studies directly used such a pill container as part of an intervention or evaluated the accuracy of adherence measurement through such a system [56-62,67,70,71,83-106]. The MEMS was by far the most widely used, but variations on it, including a nasal spray monitor [86], were also used. A total of 19 included studies examined antipsychotic medication adherence, 10 studied substance use disorders, and the remaining 3 studied mood disorders. Many more studies used the MEMS as the endpoint measure for an adherence-enhancing intervention.

A.6. "Smart" or Digital Pill

A total of 5 studies evaluated the efficacy of a "digital pill" or "digital medicine system" which, upon gastric activation, transmitted a signal to a wearable sensor which then uploaded data to a central server. All of the studies were conducted with antipsychotics meant to be used long term [40,63,107-109].

A.7. Pill Counts

One common low-cost method of medication adherence measurement involved single-time counting of pills remaining in a container, either in-person or remotely over videoconferencing software. Pill counts were used (n=12) either as one component of a multicomponent adherence-enhancing intervention or in comparisons of adherence measurement methods [56-59,66,67,70,71,89,96,104,110]. We did not include studies that merely used pill counts to evaluate a study endpoint.

A.8. Drug Utilization Measurements

Finally, objective measurements such as pharmacy refills (A.8.1) or insurance claims (A.8.2), which do not directly capture medication administration data but may provide indirect indices of medication possession and adherence, have been used to assess adherence behaviors over the long term (n=3). Overall, 2 studies calculated medication possession ratios and used them in feedback interventions to enhance as well as measure adherence: one with antipsychotics [111] and one with PTSD medications [112]. Another study incorporated barcodes attached to pill containers (A.8.3). Participants scanned these codes with their mobile devices upon receiving the pill containers, allowing for another form of pickup-level verification [68]. Pill count (eg, observing how many pills were left in the container) was another commonly (n=12) used component either in multicomponent adherence-enhancing interventions or in comparisons of adherence-monitoring methods.

A.9. Collection of Adherence-Related Data

It was common (n=46) for interventions to collect and track adherence-related data other than medication adherence itself (eg, symptoms and health care utilization) for a variety of downstream uses. As with adherence measurement, we excluded interventions that tracked other data for the purposes of evaluating study endpoints but did not *use* the data in the intervention itself. Data collection modalities included mobile apps, Web forms, phone calls, IVR, one-way text messages, and smart pill dispensers [90]. Most of the data were used in clinician monitoring or alert systems, but some were used to tailor patient-specific motivational therapy (eg, in handling specific drug use triggers in substance use disorders) [113,114]. By far, the most commonly collected data were basic psychiatric symptom assessments (A.9.1), for example, early warning signs of psychosis [105], illicit drug cravings [115], withdrawal symptoms [70,90], mood [107,116], or PTSD symptoms [112]. Other studies tracked attitudes toward medication [117] or medication side effects [118,119] to guide motivational interventions (A.9.2). Others tracked potential triggers or indices for relapse likelihood including stress, anxiety, sleep, and social support [42,44,120]. Some tracked health care utilization

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metrics, such as primary care visits attended, specialty care referrals followed, and medication changes made (A.9.3) [121,122]. A total of 3 studies [42,116,123] collected real-time global positioning system information through mobile phones (A.9.4); in one of the studies, redirection alerts were provided when patients entered previously assigned high-risk areas [123]. Some studies allowed for free text entry by the participant in the form of online journals which could later be viewed and correlated with adherence and symptomatic data (A.9.5) [42,47].

B. Adherence-Enhancing Interventions

Any technological component not designed directly to improve medication adherence monitoring accuracy was classified as an "adherence-enhancing" intervention. Generally speaking, these components were designed to enhance a participant's motivation (eg, motivational intervention or psychoeducation) or ability (eg, reminders or social support engagement) to adhere to pharmacologic therapy.

B.1. Reminders

Reminders directed participants to take their medication as prescribed (n=25). Most of these studies (n=14) used short messaging service (SMS) messages sent to a participant's mobile phone [36,37,39,54,87,124-132]. Usually, these were prespecified reminder messages programmed to be sent at specific times, but some studies examined the use of personalized SMS reminder messages sent by another person, either a "treatment partner" from the community [36] or a social worker [54]. Other messages included reminders delivered as programmatic app notifications, which functioned similarly to SMS reminders [43,52,68,91,118] and often comprised one aspect of multicomponent app interventions. Still other interventions used smart pill containers as the vehicle for reminder delivery—one smart dispenser uses visual and sound alarms to alert the participant when it is time to take medication [95,98], and another similarly uses audio alarms which can be silenced by pressing a button on the pill dispenser [96,105]. Email [45] and an unspecified social media reminder [133] have also been used.

B.2. Supportive Messages

Some interventions (n=21) included supportive one-way messages delivered through SMS, IVR, telephone call, or mobile app, which encouraged or motivated the participant. Some used inspirational quotes such as "The journey of a thousand miles starts with a single step" [49], whereas others displayed the length of successful adherence [68], encouraged continued engagement with the platform [113], or provided encouraging health facts, for example, "Today your blood pressure has been reduced to that of a nonsmoker" [134]. Most were generated and sent or displayed automatically [37,114,123,127,133,135-137], but others were sent as part of a standardized protocol by care team members [53] or lay health support persons [138], or in response to specific behaviors such as persistently elevated adherence [54,118,139] or positive responses to therapeutic questions [55]. Automated relational agents performed this behavior as part of a larger conversation [140,141]. One focus-grouping study found that participants would like to receive personalized self-efficacy messages [39].

B.3. Social Enhancement Interventions

This general category focused on leveraging existing social support or building new social support networks for participants.

B.3.1. Engaging Existing Social Support

Technological interventions focused on engaging patients' social support systems (friends, family, etc) in their care were prevalent (n=9). One study focus-grouped an intervention involving a lay "treatment partner" sending SMS antipsychotic adherence reminders to keep the participant engaged in care [36] . Another study used an online social network intervention to allow former smokers to support current smokers in adhering to their nicotine replacement therapy and promoting cessation [142]. An automated "conversational agent" encouraged participants in a study of individuals with schizophrenia to recruit a specific member of their social network to provide reminders and logistical support (eg, transportation problems) and later referenced this social support in future conversations [140], whereas a telephone and Web-based intervention encouraged participants to find and contact social supports [142]. Other interventions incorporated a lay health supporter as a *recipient* of other technological interventions such as psychoeducation [143] or adherence reminder systems and data-gathering surveys [125]. Still others [125,138,144,145] looped social support into the intervention by sending them automated periodic progress reports on adherence and symptomatic control and encouraging the social support to reach out to the participant depending on the gathered data. One study allowed participants to choose weekly support phone calls with a family member or friend [145] versus a trained peer support specialist and compared outcomes.

B.3.2. Building New Social Support

A total of 6 studies focused instead on building new social support structures for participants. All 6 included online discussion forums or groups where participants could discuss a variety of treatment or adherence-related issues [42,47,123,142,146,147], and all were part of multicomponent interventions. One study [142] included a complete social network of former and current smokers with member profiles and private messaging in addition to public forum posts.

B.3.3. Relational Agent

A total of 2 studies evaluated the use of "embodied relational agents" as adherence aids [140,141] in schizophrenia treatment. These relational agents were computer-generated animated humanoid figures who interacted through scripted modules and programmed response trees, allowing for limited bidirectional communication with the participant. The included studies that evaluated relational agents used the agents as a general purpose treatment delivery modality, incorporating psychoeducation, adherence measurement, symptom assessment, behavioral counseling, encouragement, and general purpose social support.

B.4. Facilitating Care Team Access

Some adherence interventions (n=13), in particular mobile phone and Web apps, included functionality for the participant to initiate contact with a care team representative at any time. Some [118] allowed the sending of prespecified messages regarding side effects or symptoms or had the study staff screen

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messages meant for the clinical care team [128,129], whereas others allowed for general purpose two-way messaging through SMS, email, or a messaging system designed separately for the app [42,45,53,65,114,139,147]. Another stored care team contact information within a multicomponent app to enable one-button contact, and displayed this button based on certain user responses [68]. One study collecting adherence data via IVR allowed participants to be transferred to a case manager during the IVR call [148], and another evaluating text message content preferences among potential participants receiving buprenorphine maintenance treatment found that they would prefer frequent provider contact to be available [39].

B.5. Data Feedback

This component of interventions was designed to present collected data on medication adherence or adherence-related data to users of the system, including participants, clinicians, or both. Participant feedback was designed to enhance self-knowledge and accountability, whereas clinician feedback enabled monitoring of patient adherence, as well as early and targeted intervention in the case of nonadherence or other treatment concerns.

B.5.1. Patient-Directed Feedback

Medication adherence feedback directed toward patients was used in 25 studies. This category included any intervention component which enabled the participant to view their own adherence data, either in real time through a mobile phone or website interface or via periodically generated reports. Frequently, this was one part of multicomponent interventions, but some studies evaluated the effect of feedback alone as an adherence-enhancing intervention [84,85,88,102,103]. Other systems included feedback on more than just adherence data (eg, symptomatic progression as assessed by self-report) [44,46,120]. Note that accurate medication adherence feedback rests on the assumption of an accurate measurement method.

B.5.2. Clinician-Directed Feedback

Various systems were developed to keep treating clinicians informed about medication adherence and other related data, to enable earlier and more accurate identification of potential issues for intervention. The data given to the clinician was sourced from many of the previously listed medication measurement components (direct visualization, smart pill dispenser, self-report, etc). Multiple studies (n=31) explicitly mentioned such systems [40,42,44-46,49,51,53,63,65,91,93,95,104,105,107,108,111,112,114,116,118-120,123,125,138,139,144,145,147], which fell under 3 major categories (not mutually exclusive): "portal" real-time monitoring (n=15), periodic reporting (n=9), and alerts (n=16). Real-time monitoring (B.5.2.1) allows the clinician to, at any time they choose, examine their participants' medication adherence data, almost always through Web portals [40,44-46,63,65,95,104,105,107,108,116,118,120,147]. Periodic reporting (B.5.2.2) involves standard adherence reports sent at regular intervals, most often through emails [49,51,91,93,111,125,139,144,145]. Alerts (B.5.2.3) are "push" notifications sent to notify clinicians in circumstances that require immediate response, such as suicidal ideation, hospitalization, and life disturbances such as housing eviction, physical side effects (eg, chest pain), or relapse to drug use [42,44,51,53,65,104,105,108,111,112,114,119,123,138,144,145]. In some studies, patients' social support as well as the clinical care team was able to receive reports or alerts [53,125,138,144,145].

B.6. Passive Education

Educational interventions were present in 39 included studies [42,45,47,51,64,68,70,71,84,88,91,93,102,105,113,114,118,123,127,130,134,136,137,139-142,146-157]. Modalities included websites, mobile apps, telephone calls, SMS messages, IVR calls, relational agents, and smart pill dispensers. Frequently presented educational topics included the studied disorder (eg, chronicity, symptom management, triggers, and warning signs), the studied medications (eg, purpose, onset of action, and possible side effects), strategies to improve medication adherence (eg, routines and planning for potential barriers), the importance of medication adherence, coping strategies for setbacks, and the importance of social support. In the vast majority of studies, education was one component of a multicomponent intervention.

B.7. Comprehensive Mental Health Care

Many studies (n=22) evaluated medication adherence in the context of remotely delivered psychiatric or mental health care—defined for the purposes of this study as when normal components of mental health care visits (cognitive behavioral therapy [CBT], symptomatic check-ins, and medication adherence counseling) were delivered remotely, through phone calls or videoconferences, by members of the care team including psychiatrists, nurses, pharmacists, and specialized coaches. Some of the studies compared medication adherence (and other outcomes) between telecare and care as usual [158-161], whereas others evaluated the effects on adherence of novel standardized intervention protocols delivered over telephone or videoconference [50,53,65,96,112,115,119,122,127,143,146,149,152,154-157,162]. The content of novel protocols varied widely, but frequently focused on disease or medication education, symptomatic assessment, and motivational enhancement around medication adherence. Overall, 6 explicitly referenced motivational interviewing [65,112,127,146,149,156] and 3 drew from CBT [127,143,149]. Frequency ranged from daily to monthly. Some were part of multicomponent technological interventions [65,96].

B.8. Adherence-Targeted Interactive Psychotherapy or Counseling

Some interventions used technology to deliver adherence-focused psychotherapy or counseling, either remotely as part of remote care or as part of a standardized intervention delivered through an app or a website. One major modality which emerged was motivational intervention around medication adherence (n=9). This was used in remote psychiatric care in the aforementioned 6 studies [65,112,127,146,149,156], but it was also used without a human clinician in 3 mobile phone apps or Web-based interventions [42,47,118]. In one study, the patient was queried about their reasons for nonadherence and, based on the reasons, was provided with tailored motivational feedback [118]. In the others, the cost-benefit framework was used within the website to encourage the participant to evaluate strategies, solve problems, and set goals [42,47]. The other major

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framework which emerged (n=12) was CBT, which is used as a major component of psychotherapy in many of the studied disorders and can help restructure maladaptive thoughts about psychoactive medication. In the included studies, strategies from CBT were used as part of tele-mental health care [127,143,149], as the comparator [84], or as part of Web or mobile phone app–delivered curricula [42,45,47,123,134,136,137]. Another study used CBT strategies in a tailored text messaging intervention to probe for unhelpful behaviors or thought patterns, using information collected from the patient [55].

B.9. Secure Medication Storage

Some studies used a "security" component designed to prevent overuse or diversion, or prevent theft, of medication (n=3). All 3 of these studies were in opioid use disorder populations receiving buprenorphine [65,70,71] and used a secure locked pill dispenser. In 2 studies, doses were only available during a 3-hour window each day and were taken under the supervision of a nurse. In one study, the dispenser released a daily dose of medication via an access code transmitted during a remote check-in with a mobile recovery coach [65].

B.10. Contingency Management

Finally, some studies (n=6) included a contingency management or incentive system which involved prizes or rewards [67-69,93,118,125]. We did not count studies as having a "contingency management" component if the payment or rewards were given merely for study participation; the incentives had to be built into the overall system and specifically incentivize adherence behaviors or comply with adherence-monitoring protocols. Most of these systems took the form of virtual points which were earned based on specific behaviors, tracked through mobile or Web apps, and could be redeemed for cash. In 3 of these, points were earned for scanning a barcode or sending photos or videos for adherence monitoring purposes [67-69], whereas others were earned by completing education materials, responding to messages, or checking in to adherence enhancement systems [93,118,125].

Multicomponent Interventions

Multicomponent interventions were those that used multiple intervention components in tandem. Below are tables (Tables 1-4) for the 4 most common disorder contexts (substance use disorder, depression, schizophrenia spectrum, and bipolar disorder) which show the multicomponent apps with at least 4 separate components. We use our framework to categorize and decompose the interventions based on which components they include.

Table 1. Comparison of multicomponent interventions for schizophrenia spectrum disorders with 4 or more components, by presence or absence of particular components.

Source	System components[a]												
	A.1-8	A.9	B.1	B.2	B.3	B.4	B.5.1	B.5.2	B.6	B.7	B.8	B.9	B.10
Aschbrenner (2016) [54]	✓[b]	✓	✓	✓	—[c]	—	—	—	—	—	—	—	—
Beebe (2014) [50]	✓	✓	—	—	—	—	—	—	—	✓	✓	—	—
Ben-Zeev (2014) [139]	✓	—	—	✓	—	✓	—	✓	✓	—	—	—	—
Bickmore (2010) [140]	✓	—	—	✓	✓	—	✓	—	✓	—	—	—	—
Granholm (2012) [55]	✓	✓	—	✓	—	—	—	—	—	—	✓	—	—
Kane (2013) [63]	✓	✓	—	—	—	—	✓	✓	—	—	—	—	—
Kreyenbuhl (2016) [12]	✓	✓	✓	✓	—	✓	✓	✓	✓	—	✓	—	✓
Ruskin (2003) [105]	✓	✓	✓	—	—	—	—	✓	✓	—	—	—	—
Stentzel (2016) [53]	✓	✓	—	✓	—	✓	—	✓	—	✓	—	—	—
Xu (2016) [125]	—	✓	✓	—	✓	—	—	✓	—	—	—	—	✓

[a]A.1-8: Adherence data collection. A.9: Collection of related data. B.1: Adherence reminders. B.2: Supportive messages. B.3: Social network interventions. B.4: Facilitating care team contact. B.5.1: Data feedback to patient. B.5.2: Data feedback to clinician. B.6: Education. B.7: Comprehensive mental health care. B.8: Adherence-targeted psychotherapy. B.9: Secure medication storage. B.10: Contingency management.

[b]✓: Component is present.

[c]—: Component is not present.

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Table 2. List of multicomponent interventions for bipolar disorder with 4 or more components, by presence or absence of particular components.

Source	System component[a]												
	A.1-8	A.9	B.1	B.2	B.3	B.4	B.5.1	B.5.2	B.6	B.7	B.8	B.9	B.10
Faurholt-Jepsen (2014) [44]	✓[b]	✓	—[c]	—	—	—	✓	✓	—	—	—	—	—
Lauder (2017) [42]	✓	✓	—	—	✓	✓	✓	✓	✓	—	✓	—	—
Sajatovic (2015) [93]	✓	—	—	—	—	—	✓	✓	✓	—	—	—	✓
Wenze (2014) [136]	✓	✓	—	✓	—	—	—	—	✓	—	✓	—	—

[a]A.1-8: Adherence data collection. A.9: Collection of related data. B.1: Adherence reminders. B.2: Supportive messages. B.3: Social network interventions. B.4: Facilitating care team contact. B.5.1: Data feedback to patient. B.5.2: Data feedback to clinician. B.6: Education. B.7: Comprehensive mental health care. B.8: Adherence-targeted psychotherapy. B.9: Secure medication storage. B.10: Contingency management.

[b]✓: component is present.

[c]—: component is not present.

Table 3. Comparison of multicomponent interventions for substance use disorder with 4 of more components, by presence or absence of particular components.

Source	System component[a]												
	A.1-8	A.9	B.1	B.2	B.3	B.4	B.5.1	B.5.2	B.6	B.7	B.8	B.9	B.10
Gordon (2017) [68]	✓[b]	✓	✓	✓	—[c]	✓	✓	—	✓	—	—	—	✓
Gustafson (2016) [123]	—	✓	—	✓	✓	—	✓	✓	✓	—	✓	—	—
McClure (2016) [114]	—	✓	—	✓	—	✓	—	✓	✓	—	—	—	—
Mooney (2007) [84]	✓	—	—	—	—	—	✓	—	✓	—	✓	—	—
Schuman-Olivier (2018) [65]	✓	✓	—	—	—	✓	—	✓	—	—	✓	✓	—
Sigmon (2015) [71]	✓	✓	—	—	—	—	—	—	✓	—	—	✓	—
Swan (2012) [146]	—	✓	—	—	✓	—	✓	—	✓	✓	✓	—	—
Tseng (2017) [127]	—	—	✓	✓	—	—	—	—	✓	✓	✓	—	—

[a]A.1-8: Adherence data collection. A.9: Collection of related data. B.1: Adherence reminders. B.2: Supportive messages. B.3: Social network interventions. B.4: Facilitating care team contact. B.5.1: Data feedback to patient. B.5.2: Data feedback to clinician. B.6: Education. B.7: Comprehensive mental health care. B.8: Adherence-targeted psychotherapy. B.9: Secure medication storage. B.10: Contingency management.

[b]✓: component is present

[c]—: component is not present.

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Table 4. Comparison of multicomponent interventions for major depressive disorder with 4 or more components, by presence or absence of particular components.

Source	System component[a]												
	A.1-8	A.9	B.1	B.2	B.3	B.4	B.5.1	B.5.2	B.6	B.7	B.8	B.9	B.10
Aikens (2015) [138]	✓[b]	✓	—[c]	✓	✓	—	—	✓	—	—	—	—	—
Fortney (2007) [157]	✓	✓	—	—	—	—	—	—	✓	✓	—	—	—
Gervasoni (2010) [119]	✓	✓	—	—	—	—	—	✓	—	✓	✓	—	—
Lauritsen (2017) [46]	✓	✓	—	—	—	—	✓	✓	—	—	—	—	—
Meglic (2012) [147]	—	✓	—	—	✓	✓	✓	✓	✓	—	—	—	—
Mohr (2015) [91]	✓	✓	✓	—	—	—	✓	✓	✓	—	—	—	—
Pfeiffer (2017) [145]	✓	✓	—	—	✓	—	—	✓	—	—	—	—	—
Piette (2013) [144]	✓	✓	—	—	✓	—	—	✓	—	—	—	—	—
Rickles (2005) [152]	✓	✓	—	—	—	—	—	—	✓	✓	—	—	—
Robertson (2006) [45]	✓	✓	✓	—	—	✓	✓	✓	✓	—	✓	—	—
Rusche-Skolarus (2015) [51]	✓	✓	—	—	—	—	—	✓	✓	—	—	—	—

[a]A.1-8: Adherence data collection. A.9: Collection of related data. B.1: Adherence reminders. B.2: Supportive messages. B.3: Social network interventions. B.4: Facilitating care team contact. B.5.1: Data feedback to patient. B.5.2: Data feedback to clinician. B.6: Education. B.7: Comprehensive mental health care. B.8: Adherence-targeted psychotherapy. B.9: Secure medication storage. B.10: Contingency management.

[b]✓: component is present.

[c]—: component is not present.

Discussion

Principal Findings

Our study is the first to create a literature-driven taxonomy of the components of adherence-monitoring methods and adherence-enhancing interventions used across adult psychiatric disorders. There is a proliferation of frameworks used to discuss these technological interventions, some of which are borrowed from nonpsychiatric adherence studies. We hope that this study will build on existing frameworks to provide a definitive framework for this specific context; in particular, we hope to capture the breadth of studied interventions, and provide a uniform vocabulary with which to discuss and compare them. This taxonomy may prove useful during the design phase of a new intervention, where investigators or clinicians may choose to include relevant components from the framework to suit their population or outcome of interest.

Although the framework was constructed bottom-up from the literature, it does ultimately appear to parallel existing frameworks of nonadherence behaviors. Reminders to take medication primarily address *involuntary* nonadherence concerns, whereas security and monitoring interventions often address *voluntary* nonadherence [20]. Educational interventions often aim to provide information and correct misconceptions about disorders, medications, and side effects (addressing *perceptual* nonadherence factors), whereas supportive interventions such as social support engagement and online community building attempt to address the well-studied association between perceived social support and medication nonadherence [163]. It is perhaps not surprising that adherence interventions parallel perceived causes of nonadherence, but it is reassuring nonetheless.

Many of the intervention types have been delivered using various *modalities*. It is useful to draw a distinction between the intervention *type* or *component* (eg, educational, reminder, supportive, feedback, etc) and the *modality* by which it is delivered (SMS, IVR, app, website, etc). Although certain modalities of delivering certain interventions may ultimately prove to have advantages over others (for instance, navigating a mobile app may well be more acceptable than waiting for IVR dialogues when filling out an adherence survey), it is not yet clear from the literature whether this is the case. As technology continues to evolve, there will no doubt be new modalities of intervention delivery (for instance, the once prevalent studies of IVR and telephonic interventions have largely been supplanted in recent years by SMS text messaging, website, and mobile phone app studies). One notable exception: the distinction between *modality* and *intervention type* does not apply to most data collection components (smart pill dispensers, body fluid sampling, and digital pills) as the two are inextricably tied.

The body of literature on this topic is growing, as reflected by the increasing number of studies included from recent years. However, looking at the literature from any individual psychiatric or substance use disorder highlights the fact that the field remains young, and most studies conducted are small-n pilot studies. Furthermore, large RCTs are necessary to elucidate the impact of particular interventions.

We found that most components are used transdiagnostically, that is, they have been studied in schizophrenia spectrum disorders, mood disorders, multiple substance use disorders, and PTSD (ie, most psychiatric disorders which have a pharmacologic component to therapy). Data collection components (including smart pill dispensers, periodic self-report,

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and body fluid testing), reminders, educational interventions, tele-health–driven counseling, and multicomponent disease management apps have been explored in most or all psychiatric disorders. This suggests that despite the differences in the mental state between different disorders, and perhaps even different primary reasons for nonadherence, there is still much to be learned and transferred from one domain to the others. Particularly, when designing a new intervention for clinical or research use, investigators would do well to peruse the literature from different psychiatric disorders for ideas and related work. It is possible that transdiagnostic interventions (perhaps with disorder-specific education or support modules) might ultimately improve medication adherence in a general psychiatric population. However, as of yet, very little transdiagnostic research has been conducted in this field.

Multicomponent interventions, including comprehensive disease management apps, have been studied in the majority of psychiatric disorders. These interventions present a challenge from a research standpoint, as it is difficult to assess the impact of any individual component without large, factorial-design studies. However, there may be synergistic adherence effects from comprehensive disease management apps, in the same way that standard psychiatric care visits address a wide variety of adherence concerns and motivational factors. Furthermore, if these interventions are to one day be used regularly in clinical practice, multicomponent interventions are more practical from an implementation standpoint.

One surprising fact is that many studies which evaluated the effect of adherence-enhancing interventions used *self-reported* adherence, or adherence as measured by a smart pill dispenser, as the endpoint. Studies have shown that self-reported adherence frequently overestimates true adherence [58,65,164,165]; this fact may compromise or blur results from many of these studies. Biological measurements and directly observed ingestion provide far better adherence assessment, but are costly, inconvenient, and often impractical to implement. Novel adherence measurement systems, such as digital pills, automated adherence monitoring, and remote direct observation, may ultimately provide a better compromise between accuracy and practicality in future trials. In fact, some of these novel methods have been evaluated and used in clinical trials already. Accurate assessment of adherence is crucial to evaluating the efficacy of any of these interventions, and future investigators would do well to select their adherence measurement endpoint wisely.

Strengths and Limitations

The strengths of our study include the breadth of the topic area and the comprehensive coverage of all types of interventions, as well as the literature-guided taxonomic framework. Our tables of multicomponent interventions further show the utility of this transdiagnostic framework to decompose and categorize interventions across all adult mental health and substance use disorders. However, our study is limited by this same breadth; we were unable to conduct a quantitative synthesis or formal meta-analysis of all included studies given the wide variety of interventions, populations, and outcomes. In the future, we plan to build off of this study and conduct more focused comparisons of specific topic areas.

Conclusions

In conclusion, we provide a systematic review of the literature on technological interventions for medication adherence and monitoring in mental health and substance use disorders; we then use the included studies to develop a literature-driven transdiagnostic framework of intervention components. We hope this will help guide future research in the field and ultimately lead to further clinical applications.

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Conflicts of Interest

JMS, JTB, ZS-O, and LAM are affiliated with MySafeRx, a nonprofit organization that supports the development, implementation, and dissemination of technological solutions for medication adherence in mental health and substance use disorder treatment. From 2017 to 2018, JMS received a salary as a software developer for MySafeRx. No other conflicts of interest are declared.

Multimedia Appendix 1

Search strategies for included databases.

[PDF File (Adobe PDF File), 78KB - mental_v6i3e12493_app1.pdf]

Multimedia Appendix 2

Details of included studies.

[XLSX File (Microsoft Excel File), 129KB - mental_v6i3e12493_app2.xlsx]

References

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1. Witt K, van Dorn R, Fazel S. Risk factors for violence in psychosis: systematic review and meta-regression analysis of 110 studies. PLoS One 2013;8(2):e55942 [FREE Full text] [doi: 10.1371/journal.pone.0055942] [Medline: 23418482]
2. Higashi K, Medic G, Littlewood KJ, Diez T, Granström O, de Hert M. Medication adherence in schizophrenia: factors influencing adherence and consequences of nonadherence, a systematic literature review. Ther Adv Psychopharmacol 2013 Aug;3(4):200-218 [FREE Full text] [doi: 10.1177/2045125312474019] [Medline: 24167693]
3. Cullen BA, McGinty EE, Zhang Y, Dosreis SC, Steinwachs DM, Guallar E, et al. Guideline-concordant antipsychotic use and mortality in schizophrenia. Schizophr Bull 2013 Sep;39(5):1159-1168 [FREE Full text] [doi: 10.1093/schbul/sbs097] [Medline: 23112292]
4. Gonzalez-Pinto A, Mosquera F, Alonso M, López P, Ramírez F, Vieta E, et al. Suicidal risk in bipolar I disorder patients and adherence to long-term lithium treatment. Bipolar Disord 2006 Oct;8(5 Pt 2):618-624. [doi: 10.1111/j.1399-5618.2006.00368.x] [Medline: 17042834]
5. Meyers BS, Sirey JA, Bruce M, Hamilton M, Raue P, Friedman SJ, et al. Predictors of early recovery from major depression among persons admitted to community-based clinics: an observational study. Arch Gen Psychiatry 2002 Aug;59(8):729-735. [Medline: 12150649]
6. Warden D, Subramaniam GA, Carmody T, Woody GE, Minhajuddin A, Poole SA, et al. Predictors of attrition with buprenorphine/naloxone treatment in opioid dependent youth. Addict Behav 2012 Sep;37(9):1046-1053 [FREE Full text] [doi: 10.1016/j.addbeh.2012.04.011] [Medline: 22626890]
7. Zhang Z, Friedmann PD, Gerstein DR. Does retention matter? Treatment duration and improvement in drug use. Addiction 2003 May;98(5):673-684. [Medline: 12751985]
8. Clausen T, Anchersen K, Waal H. Mortality prior to, during and after opioid maintenance treatment (OMT): a national prospective cross-registry study. Drug Alcohol Depend 2008 Apr 01;94(1-3):151-157. [doi: 10.1016/j.drugalcdep.2007.11.003] [Medline: 18155364]
9. Haddad PM, Brain C, Scott J. Nonadherence with antipsychotic medication in schizophrenia: challenges and management strategies. Patient Relat Outcome Meas 2014;5:43-62 [FREE Full text] [doi: 10.2147/PROM.S42735] [Medline: 25061342]
10. Stein-Shvachman I, Karpas DS, Werner P. Depression treatment non-adherence and its psychosocial predictors: differences between young and older adults? Aging Dis 2013 Sep 20;4(6):329-336 [FREE Full text] [doi: 10.14336/AD.2013.0400329] [Medline: 24307966]
11. Stein MB, Cantrell CR, Sokol MC, Eaddy MT, Shah MB. Antidepressant adherence and medical resource use among managed care patients with anxiety disorders. Psychiatr Serv 2006 May;57(5):673-680. [doi: 10.1176/ps.2006.57.5.673] [Medline: 16675762]
12. Tkacz J, Volpicelli J, Un H, Ruetsch C. Relationship between buprenorphine adherence and health service utilization and costs among opioid dependent patients. J Subst Abuse Treat 2014 Apr;46(4):456-462. [doi: 10.1016/j.jsat.2013.10.014] [Medline: 24332511]
13. Shiovitz TM, Bain EE, McCann DJ, Skolnick P, Laughren T, Hanina A, et al. Mitigating the effects of nonadherence in clinical trials. J Clin Pharmacol 2016 Sep;56(9):1151-1164 [FREE Full text] [doi: 10.1002/jcph.689] [Medline: 26634893]
14. Czobor P, Skolnick P. The secrets of a successful clinical trial: compliance, compliance, and compliance. Mol Interv 2011 Apr;11(2):107-110 [FREE Full text] [doi: 10.1124/mi.11.2.8] [Medline: 21540470]
15. Kronish IM, Moise N. In search of a "Magic Pill" for medication nonadherence. JAMA Intern Med 2017 Dec 1;177(5):631-632. [doi: 10.1001/jamainternmed.2016.9658] [Medline: 28241306]
16. Sabaté E. World Health Organization. 2003. Adherence to Long-Term Therapies: Evidence for Action URL: http://www.who.int/chp/knowledge/publications/adherence_report/en/ [WebCite Cache ID 7379gHG1y]
17. Chapman SC, Horne R. Medication nonadherence and psychiatry. Curr Opin Psychiatry 2013 Sep;26(5):446-452 [FREE Full text] [doi: 10.1097/YCO.0b013e3283642da4] [Medline: 23880592]
18. Farooq S, Naeem F. Tackling nonadherence in psychiatric disorders: current opinion. Neuropsychiatr Dis Treat 2014;10:1069-1077 [FREE Full text] [doi: 10.2147/NDT.S40777] [Medline: 24966677]
19. Jónsdóttir H, Opjordsmoen S, Birkenaes AB, Simonsen C, Engh JA, Ringen PA, et al. Predictors of medication adherence in patients with schizophrenia and bipolar disorder. Acta Psychiatr Scand 2013 Jan;127(1):23-33. [doi: 10.1111/j.1600-0447.2012.01911.x] [Medline: 22900964]
20. Taggart WL, Shaffer JA, Edmondson D, Bring R, Brondolo E, Falzon L, et al. Posttraumatic stress disorder and nonadherence to medications prescribed for chronic medical conditions: A meta-analysis. J Psychiatr Res 2018 Jul;102:102-109. [doi: 10.1016/j.jpsychires.2018.02.013] [Medline: 29631190]
21. Grenard JL, Munjas BA, Adams JL, Suttorp M, Maglione M, McGlynn EA, et al. Depression and medication adherence in the treatment of chronic diseases in the United States: a meta-analysis. J Gen Intern Med 2011 Oct;26(10):1175-1182 [FREE Full text] [doi: 10.1007/s11606-011-1704-y] [Medline: 21533823]
22. Egede LE, Osborn CY. Role of motivation in the relationship between depression, self-care, and glycemic control in adults with type 2 diabetes. Diabetes Educ 2010;36(2):276-283 [FREE Full text] [doi: 10.1177/0145721710361389] [Medline: 20179250]
23. Bautista LE, Vera-Cala LM, Colombo C, Smith P. Symptoms of depression and anxiety and adherence to antihypertensive medication. Am J Hypertens 2012 Apr;25(4):505-511 [FREE Full text] [doi: 10.1038/ajh.2011.256] [Medline: 22258334]

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24. DiMatteo MR, Lepper HS, Croghan TW. Depression is a risk factor for noncompliance with medical treatment: meta-analysis of the effects of anxiety and depression on patient adherence. Arch Intern Med 2000 Jul 24;160(14):2101-2107. [doi: 10.1001/archinte.160.14.2101] [Medline: 10904452]
25. Livingston JD, Boyd JE. Correlates and consequences of internalized stigma for people living with mental illness: a systematic review and meta-analysis. Soc Sci Med 2010 Dec;71(12):2150-2161. [doi: 10.1016/j.socscimed.2010.09.030] [Medline: 21051128]
26. Badawy SM, Kuhns LM. Economic evaluation of text-messaging and smartphone-based interventions to improve medication adherence in adolescents with chronic health conditions: a systematic review. JMIR Mhealth Uhealth 2016 Oct 25;4(4):e121 [FREE Full text] [doi: 10.2196/mhealth.6425] [Medline: 27780795]
27. Rootes-Murdy K, Glazer KL, van Wert MJ, Mondimore FM, Zandi PP. Mobile technology for medication adherence in people with mood disorders: a systematic review. J Affect Disord 2018 Dec;227:613-617. [doi: 10.1016/j.jad.2017.11.022] [Medline: 29172054]
28. Barkhof E, Meijer CJ, de Sonneville LM, Linszen DH, de Haan L. Interventions to improve adherence to antipsychotic medication in patients with schizophrenia--a review of the past decade. Eur Psychiatry 2012 Jan;27(1):9-18 [FREE Full text] [doi: 10.1016/j.eurpsy.2011.02.005] [Medline: 21561742]
29. Killikelly C, He Z, Reeder C, Wykes T. Improving adherence to web-based and mobile technologies for people with psychosis: systematic review of new potential predictors of adherence. JMIR Mhealth Uhealth 2017 Jul 20;5(7):e94 [FREE Full text] [doi: 10.2196/mhealth.7088] [Medline: 28729235]
30. Marsch LA, Carroll KM, Kiluk BD. Technology-based interventions for the treatment and recovery management of substance use disorders: a JSAT special issue. J Subst Abuse Treat 2014 Jan;46(1):1-4 [FREE Full text] [doi: 10.1016/j.jsat.2013.08.010] [Medline: 24041749]
31. Kauppi K, Välimäki M, Hätönen HM, Kuosmanen LM, Warwick-Smith K, Adams CE. Information and communication technology based prompting for treatment compliance for people with serious mental illness. Cochrane Database Syst Rev 2014 Jun 17(6):CD009960. [doi: 10.1002/14651858.CD009960.pub2] [Medline: 24934254]
32. Swift R, Oslin DW, Alexander M, Forman R. Adherence monitoring in naltrexone pharmacotherapy trials: a systematic review. J Stud Alcohol Drugs 2011 Nov;72(6):1012-1018. [Medline: 22051215]
33. Välimäki M, Hätönen HM, Lahti ME, Kurki M, Hottinen A, Metsäranta K, et al. Virtual reality for treatment compliance for people with serious mental illness. Cochrane Database Syst Rev 2014(10):CD009928. [doi: 10.1002/14651858.CD009928.pub2] [Medline: 25300174]
34. Huang X, Lin J, Demner-Fushman D. Evaluation of PICO as a knowledge representation for clinical questions. AMIA Annu Symp Proc 2006:359-363 [FREE Full text] [Medline: 17238363]
35. Covidence. Melbourne, Australia: Veritas Health Innovation URL: https://www.covidence.org/home [accessed 2018-09-25] [WebCite Cache ID 72hcwuKyg]
36. Mall S, Sibeko G, Temmingh H, Stein DJ, Milligan P, Lund C. Using a treatment partner and text messaging to improve adherence to psychotropic medication: a qualitative formative study of service users and caregivers in Cape Town, South Africa. Afr J Psychiatry (Johannesbg) 2013 Sep;16(5):364-370. [doi: 10.4314/ajpsy.v16i5.49] [Medline: 24051670]
37. Krebs P, Tseng T, Pham H, Wong S, Sherman SE, Shelley D, et al. Formative evaluation of a text messaging intervention to promote varenicline adherence among tobacco-dependent persons with HIV. J Health Commun 2015;20(9):1021-1025. [doi: 10.1080/10810730.2015.1018595] [Medline: 26132516]
38. Welsh C. Acceptability of the use of cellular telephone and computer pictures/video for "pill counts" in buprenorphine maintenance treatment. J Opioid Manag 2016;12(3):217-220. [doi: 10.5055/jom.2016.0334] [Medline: 27435442]
39. Tofighi B, Grossman E, Bereket S, D Lee J. Text message content preferences to improve buprenorphine maintenance treatment in primary care. J Addict Dis 2016;35(2):92-100. [doi: 10.1080/10550887.2015.1127716] [Medline: 26670868]
40. Peters-Strickland T, Hatch A, Adenwala A, Atkinson K, Bartfeld B. Human factors evaluation of a novel digital medicine system in psychiatry. Neuropsychiatr Dis Treat 2018 Feb;14:553-565 [FREE Full text] [doi: 10.2147/NDT.S157102] [Medline: 29497299]
41. Shafner L, Hanina A, Kalali A. Using artificial intelligence on mobile devices to measure and maximize medication adherence in CNS trials. 2016 Presented at: ACNP 55th Annual Meeting: Poster Session III; December 4-8, 2016; Hollywood, Florida. [doi: 10.1038/npp.2016.242]
42. Lauder S, Cosgrove VE, Gliddon E, Grimm D, Dodd S, Berk L, et al. Progressing MoodSwings. The upgrade and evaluation of MoodSwings 2.0: an online intervention for bipolar disorder. Contemp Clin Trials 2017 Dec;56:18-24 [FREE Full text] [doi: 10.1016/j.cct.2017.02.008] [Medline: 28257919]
43. Hammonds T, Rickert K, Goldstein C, Gathright E, Gilmore S, Derflinger B, et al. Adherence to antidepressant medications: a randomized controlled trial of medication reminding in college students. J Am Coll Health 2015;63(3):204-208. [doi: 10.1080/07448481.2014.975716] [Medline: 25338175]
44. Faurholt-Jepsen M, Vinberg M, Frost M, Christensen EM, Bardram J, Kessing LV. Daily electronic monitoring of subjective and objective measures of illness activity in bipolar disorder using smartphones--the MONARCA II trial protocol: a randomized controlled single-blind parallel-group trial. BMC Psychiatry 2014;14:309 [FREE Full text] [doi: 10.1186/s12888-014-0309-5] [Medline: 25420431]

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45. Robertson L, Smith M, Castle D, Tannenbaum D. Using the internet to enhance the treatment of depression. Australas Psychiatry 2006 Dec;14(4):413-417. [doi: 10.1111/j.1440-1665.2006.02315.x] [Medline: 17116083]
46. Lauritsen L, Andersen L, Olsson E, Søndergaard SR, Nørregaard LB, Løventoft PK, et al. Usability, acceptability, and adherence to an electronic self-monitoring system in patients with major depression discharged from inpatient wards. J Med Internet Res 2017 Dec 21;19(4):e123 [FREE Full text] [doi: 10.2196/jmir.6673] [Medline: 28432040]
47. Lauder S, Chester A, Castle D, Dodd S, Gliddon E, Berk L, et al. A randomized head to head trial of MoodSwings.net.au: an internet based self-help program for bipolar disorder. J Affect Disord 2015 Jan 15;171:13-21. [doi: 10.1016/j.jad.2014.08.008] [Medline: 25282145]
48. Tully L, de Leon E, Motoru S, Wahba K, Smith P, Singh K, et al. Using a novel mobile health application to monitor symptoms and functioning in an early psychosis program: Preliminary data on feasibility and acceptability. 2014 Presented at: 69th Society of Biological Psychiatry Annual Meeting 2014; May 8-12, 2014; New York City, New York URL: https://f1000research.com/posters/1095564
49. Stuart GW, Laraia MT, Ornstein SM, Nietert PJ. An interactive voice response system to enhance antidepressant medication compliance. Top Health Inf Manage 2003;24(1):15-20. [Medline: 12674391]
50. Beebe L, Smith KD, Phillips C. A comparison of telephone and texting interventions for persons with schizophrenia spectrum disorders. Issues Ment Health Nurs 2014 May;35(5):323-329. [doi: 10.3109/01612840.2013.863412] [Medline: 24766166]
51. Skolarus LE, Piette JD, Pfeiffer PN, Williams LS, Mackey J, Hughes R, et al. Interactive voice response-an innovative approach to post-stroke depression self-management support. Transl Stroke Res 2017 Dec;8(1):77-82 [FREE Full text] [doi: 10.1007/s12975-016-0481-7] [Medline: 27394917]
52. Krzystanek M, Krzeszowski D, Jagoda K, Krysta K. Long term telemedicine study of compliance in paranoid schizophrenia. Psychiatr Danub 2015 Sep;27 Suppl 1:S266-S268 [FREE Full text] [Medline: 26417777]
53. Stentzel U, Grabe H, Strobel L, Penndorf P, Langosch J, Freyberger HJ, et al. Tecla: a telephone- and text-message based telemedical concept for patients with severe mental health disorders--study protocol for a controlled, randomized, study. BMC Psychiatry 2015 Nov 04;15:273 [FREE Full text] [doi: 10.1186/s12888-015-0659-7] [Medline: 26537570]
54. Aschbrenner KA, Naslund JA, Gill LE, Bartels SJ, Ben-Zeev D. A qualitative study of client-clinician text exchanges in a mobile health intervention for individuals with psychotic disorders and substance use. J Dual Diagn 2016;12(1):63-71 [FREE Full text] [doi: 10.1080/15504263.2016.1145312] [Medline: 26829356]
55. Granholm E, Ben-Zeev D, Link PC, Bradshaw KR, Holden JL. Mobile assessment and treatment for schizophrenia (MATS): a pilot trial of an interactive text-messaging intervention for medication adherence, socialization, and auditory hallucinations. Schizophr Bull 2012 May;38(3):414-425 [FREE Full text] [doi: 10.1093/schbul/sbr155] [Medline: 22080492]
56. Remington G, Kwon J, Collins A, Laporte D, Mann S, Christensen B. The use of electronic monitoring (MEMS) to evaluate antipsychotic compliance in outpatients with schizophrenia. Schizophr Res 2007 Feb;90(1-3):229-237. [doi: 10.1016/j.schres.2006.11.015] [Medline: 17208414]
57. Yang J, Ko YH, Paik JW, Lee MS, Han C, Joe SH, et al. Symptom severity and attitudes toward medication: impacts on adherence in outpatients with schizophrenia. Schizophr Res 2012 Feb;134(2-3):226-231. [doi: 10.1016/j.schres.2011.11.008] [Medline: 22133906]
58. Brain C, Sameby B, Allerby K, Lindström E, Eberhard J, Burns T, et al. Twelve months of electronic monitoring (MEMS®) in the Swedish COAST-study: a comparison of methods for the measurement of adherence in schizophrenia. Eur Neuropsychopharmacol 2014 Feb;24(2):215-222. [doi: 10.1016/j.euroneuro.2013.11.013] [Medline: 24359935]
59. Schaefer MR, Wagoner ST, Young ME, Rawlinson AR, Kavookjian J, Shapiro SK, et al. Subjective versus objective measures of medication adherence in adolescents/young adults with attention-deficit hyperactivity disorder. J Dev Behav Pediatr 2019 Jan;40(1):54-59. [doi: 10.1097/DBP.0000000000000602] [Medline: 30001262]
60. Byerly MJ, Thompson A, Carmody T, Bugno R, Erwin T, Kashner M, et al. Validity of electronically monitored medication adherence and conventional adherence measures in schizophrenia. Psychiatr Serv 2007 Jun;58(6):844-847. [doi: 10.1176/ps.2007.58.6.844] [Medline: 17535946]
61. Byerly M, Fisher R, Whatley K, Holland R, Varghese F, Carmody T, et al. A comparison of electronic monitoring vs clinician rating of antipsychotic adherence in outpatients with schizophrenia. Psychiatry Res 2005 Feb 28;133(2-3):129-133. [doi: 10.1016/j.psychres.2004.11.002] [Medline: 15740989]
62. Acosta FJ, Bosch E, Sarmiento G, Juanes N, Caballero-Hidalgo A, Mayans T. Evaluation of noncompliance in schizophrenia patients using electronic monitoring (MEMS) and its relationship to sociodemographic, clinical and psychopathological variables. Schizophr Res 2009 Feb;107(2-3):213-217. [doi: 10.1016/j.schres.2008.09.007] [Medline: 18849150]
63. Kane JM, Perlis RH, DiCarlo LA, Au-Yeung K, Duong J, Petrides G. First experience with a wireless system incorporating physiologic assessments and direct confirmation of digital tablet ingestions in ambulatory patients with schizophrenia or bipolar disorder. J Clin Psychiatry 2013 Jun;74(6):e533-e540. [doi: 10.4088/JCP.12m08222] [Medline: 23842023]
64. Bain EE, Shafner L, Walling DP, Othman AA, Chuang-Stein C, Hinkle J, et al. Use of a novel artificial intelligence platform on mobile devices to assess dosing compliance in a phase 2 clinical trial in subjects with schizophrenia. JMIR Mhealth Uhealth 2017 Feb 21;5(2):e18 [FREE Full text] [doi: 10.2196/mhealth.7030] [Medline: 28223265]
65. Schuman-Olivier Z, Borodovsky JT, Steinkamp J, Munir Q, Butler K, Greene MA, et al. MySafeRx: a mobile technology platform integrating motivational coaching, adherence monitoring, and electronic pill dispensing for enhancing

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buprenorphine/naloxone adherence during opioid use disorder treatment: a pilot study. Addict Sci Clin Pract 2018 Sep 24;13(1):21 [FREE Full text] [doi: 10.1186/s13722-018-0122-4] [Medline: 30249279]
66. DeWorsop D, Creatura G, Bluez G, Thurnauer H, Forselius-Bielen K, Ranganathan M, et al. Feasibility and success of cell-phone assisted remote observation of medication adherence (CAROMA) in clinical trials. Drug Alcohol Depend 2016 Dec 1;163:24-30. [doi: 10.1016/j.drugalcdep.2016.02.045] [Medline: 27068252]
67. Galloway GP, Coyle JR, Guillén JE, Flower K, Mendelson JE. A simple, novel method for assessing medication adherence: capsule photographs taken with cellular telephones. J Addict Med 2011 Sep;5(3):170-174 [FREE Full text] [doi: 10.1097/ADM.0b013e3181fcb5fd] [Medline: 21844832]
68. Gordon JS, Armin JS, Cunningham JK, Muramoto ML, Christiansen SM, Jacobs TA. Lessons learned in the development and evaluation of RxCoach™, an mHealth app to increase tobacco cessation medication adherence. Patient Educ Couns 2017 Apr;100(4):720-727. [doi: 10.1016/j.pec.2016.11.003] [Medline: 27839891]
69. Oyama M, Hillhouse MP, Thomas C, Annon J, Hasson A, Mooney L, et al. Using cellphone technology to monitor and increase dosing adherence. Drug Alcohol Depend 2015 Nov;156:e168. [doi: 10.1016/j.drugalcdep.2015.07.457]
70. Sigmon SC, Meyer AC, Hruska B, Ochalek T, Heil SH, Higgins ST, et al. Interim buprenorphine treatment: leveraging technology to bridge waitlist delays. Drug Alcohol Depend 2015 Nov;156:e204. [doi: 10.1016/j.drugalcdep.2015.07.550]
71. Sigmon SC, Meyer AC, Hruska B, Ochalek T, Rose G, Badger GJ, et al. Bridging waitlist delays with interim buprenorphine treatment: initial feasibility. Addict Behav 2015 Dec;51:136-142 [FREE Full text] [doi: 10.1016/j.addbeh.2015.07.030] [Medline: 26256469]
72. Kim E, Chocron SE, Ben-Yoav H, Winkler TE, Liu Y, Glassman M, et al. Programmable “Semismart” sensor: relevance to monitoring antipsychotics. Adv Funct Mater 2015 Feb 23;25(14):2156-2165. [doi: 10.1002/adfm.201403783]
73. Fletcher K, Stone E. New technology to support abstinence from alcohol, predict relapse and reduce outpatient costs. Eur Psychiatry 2015 Mar;30:1084. [doi: 10.1016/S0924-9338(15)30855-5]
74. Carlsson S, Olsson R, Lindkvist I, Beck O. Application of drug testing using exhaled breath for compliance monitoring of drug addicts in treatment. Scand J Clin Lab Invest 2015 Apr;75(2):156-161. [doi: 10.3109/00365513.2014.993336] [Medline: 25562730]
75. Patteet L, Maudens KE, Morrens M, Sabbe B, Dom G, Neels H. Determination of common antipsychotics in quantisal-collected oral fluid by UHPLC-MS/MS: method validation and applicability for therapeutic drug monitoring. Ther Drug Monit 2016 Feb;38(1):87-97. [doi: 10.1097/FTD.0000000000000242] [Medline: 26349083]
76. Guinan TM, Neldner D, Stockham P, Kobus H, della Vedova CB, Voelcker NH. Porous silicon mass spectrometry as an alternative confirmatory assay for compliance testing of methadone. Drug Test Anal 2017 May;9(5):769-777. [doi: 10.1002/dta.2033] [Medline: 27364015]
77. Gottardo R, Fanigliulo A, Sorio D, Liotta E, Bortolotti F, Tagliaro F. Monitoring compliance to therapy during addiction treatments by means of hair analysis for drugs and drug metabolites using capillary zone electrophoresis coupled to time-of-flight mass spectrometry. Forensic Sci Int 2012 Mar 10;216(1-3):101-107. [doi: 10.1016/j.forsciint.2011.09.004] [Medline: 21945303]
78. Larabi IA, Abe E, Etting I, Alvarez J. Dosage de naltrexone dans les cheveux : intérêt comme marqueur de l’observance des patients au cours du traitement de l’alcoolo-dépendance (Naltrexone hair analysis as a tool to assess patient compliance in alcohol withdrawal treatment). Toxicologie Analytique et Clinique 2016 Dec;28(4):303-310. [doi: 10.1016/j.toxac.2016.06.001]
79. Binz TM, Williner E, Strajhar P, Dolder PC, Liechti ME, Baumgartner MR, et al. Chiral analysis of amphetamines in hair by liquid chromatography-tandem mass spectrometry: compliance-monitoring of attention deficit hyperactivity disorder (ADHD) patients under Elvanse® therapy and identification after controlled low-dose application. Drug Test Anal 2018 Feb;10(2):254-261. [doi: 10.1002/dta.2208] [Medline: 28440070]
80. Leboulanger B, Aubry JM, Bondolfi G, Guy RH, Delgado-Charro MB. Lithium monitoring by reverse iontophoresis in vivo. Clin Chem 2004 Nov;50(11):2091-2100 [FREE Full text] [doi: 10.1373/clinchem.2004.034249] [Medline: 15192031]
81. Kevin RC, Allsop DJ, Lintzeris N, Dunlop AJ, Booth J, McGregor IS. Urinary cannabinoid levels during nabiximols (Sativex®)-medicated inpatient cannabis withdrawal. Forensic Toxicol 2016 Aug 4;35(1):33-44. [doi: 10.1007/s11419-016-0330-0]
82. Sutherland JJ, Morrison RD, Daniels JS, Milne SB, Ryan TP. Managing psychotropic medications in complex, real-world patients using comprehensive therapeutic drug monitoring. ACS Chem Neurosci 2017 Dec 16;8(8):1641-1644. [doi: 10.1021/acschemneuro.7b00209] [Medline: 28640591]
83. Dunn KE, King VL, Brooner RK. Comparison of methods to assess psychiatric medication adherence in methadone-maintained patients with co-occurring psychiatric disorder. Drug Alcohol Depend 2016 Mar 1;160:212-217 [FREE Full text] [doi: 10.1016/j.drugalcdep.2016.01.016] [Medline: 26851987]
84. Mooney ME, Sayre SL, Hokanson PS, Stotts AL, Schmitz JM. Adding MEMS feedback to behavioral smoking cessation therapy increases compliance with bupropion: a replication and extension study. Addict Behav 2007 Apr;32(4):875-880. [doi: 10.1016/j.addbeh.2006.06.022] [Medline: 16839698]

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85. Schmitz JM, Sayre SL, Stotts AL, Rothfleisch J, Mooney ME. Medication compliance during a smoking cessation clinical trial: a brief intervention using MEMS feedback. J Behav Med 2005 Apr;28(2):139-147. [doi: 10.1007/s10865-005-3663-4] [Medline: 15957569]
86. Schneider M, van Melle G, Uldry C, Huynh-Ba M, Fallab SC, Iorillo D, et al. Electronic monitoring of long-term use of the nicotine nasal spray and predictors of success in a smoking cessation program. Nicotine Tob Res 2003 Oct;5(5):719-727. [doi: 10.1080/14622200310001608545] [Medline: 14577988]
87. Stoner SA, Arenella PB, Hendershot CS. Randomized controlled trial of a mobile phone intervention for improving adherence to naltrexone for alcohol use disorders. PLoS One 2015;10(4):e0124613 [FREE Full text] [doi: 10.1371/journal.pone.0124613] [Medline: 25909320]
88. Cramer J, Rosenheck R, Kirk G, Krol W, Krystal J, VA Naltrexone Study Group 425. Medication compliance feedback and monitoring in a clinical trial: predictors and outcomes. Value Health 2003;6(5):566-573 [FREE Full text] [doi: 10.1046/j.1524-4733.2003.65269.x] [Medline: 14627063]
89. Feinn R, Tennen H, Cramer J, Kranzler HR. Measurement and prediction of medication compliance in problem drinkers. Alcohol Clin Exp Res 2003 Aug;27(8):1286-1292. [doi: 10.1097/01.ALC.0000080670.59386.6E] [Medline: 12966323]
90. Tacke U, Uosukainen H, Kananen M, Kontra K, Pentikänen H. A pilot study about the feasibility and cost-effectiveness of electronic compliance monitoring in substitution treatment with buprenorphine-naloxone combination. J Opioid Manag 2009;5(6):321-329. [Medline: 20073406]
91. Mohr DC, Stiles-Shields C, Brenner C, Palac H, Montague E, Kaiser SM, et al. MedLink: a mobile intervention to address failure points in the treatment of depression in general medicine. In: Proceedings of the 9th International Conference on Pervasive Computing Technologies for Healthcare. 2015 May Presented at: PervasiveHealth'15; May 20-23, 2015; Istanbul, Turkey p. 100-107 URL: http://europepmc.org/abstract/MED/26640740
92. Sajatovic M, Levin JB, Sams J, Cassidy KA, Akagi K, Aebi ME, et al. Symptom severity, self-reported adherence, and electronic pill monitoring in poorly adherent patients with bipolar disorder. Bipolar Disord 2015 Sep;17(6):653-661 [FREE Full text] [doi: 10.1111/bdi.12326] [Medline: 26529124]
93. Sajatovic M, Davis MS, Cassidy KA, Nestor J, Sams J, Fuentes-Casiano E. A technology-enabled adherence enhancement system for people with bipolar disorder: results from a feasibility and patient acceptance analysis. Patient Prefer Adherence 2015;9:753-758 [FREE Full text] [doi: 10.2147/PPA.S81724] [Medline: 26089652]
94. Acosta FJ, Ramallo-Fariña Y, Bosch E, Mayans T, Rodríguez CJ, Caravaca A. Antipsychotic treatment dosing profile in patients with schizophrenia evaluated with electronic monitoring (MEMS®). Schizophr Res 2013 May;146(1-3):196-200 [FREE Full text] [doi: 10.1016/j.schres.2013.02.016] [Medline: 23474024]
95. Stip E, Vincent PD, Sablier J, Guevremont C, Zhornitsky S, Tranulis C. A randomized controlled trial with a Canadian electronic pill dispenser used to measure and improve medication adherence in patients with schizophrenia. Front Pharmacol 2013 Aug;4:100 [FREE Full text] [doi: 10.3389/fphar.2013.00100] [Medline: 23950746]
96. Velligan D, Mintz J, Maples N, Xueying L, Gajewski S, Carr H, et al. A randomized trial comparing in person and electronic interventions for improving adherence to oral medications in schizophrenia. Schizophr Bull 2013 Sep;39(5):999-1007 [FREE Full text] [doi: 10.1093/schbul/sbs116] [Medline: 23086987]
97. Fervaha G, Teo C, Mann S, Hahn M, Foussias G, Agid O, et al. Poster#195: examining levels of antipsychotic adherence to better understand nonadherence in patients with schizophrenia. Schizophr Res 2012 Apr;136(Suppl 1):S161 [FREE Full text] [doi: 10.1016/S0920-9964(12)70509-1]
98. Guevremont C, Sablier J, Lum M, Vincent P, Tranulis C, Marcotte FN, et al. Dopill, an electronic pill dispenser, helping evaluate and control medication adherence in patients with schizophrenia. Schizophr Res 2010 Apr;117(2-3):278. [doi: 10.1016/j.schres.2010.02.450]
99. Zhao Y, Moriwaki M, Kinoshita Y, Kawashima K, Ohga H, Tabuse H, et al. Maintaining favourable adherence by consistent self-administration of medication-medication event monitoring system (MEMS) trial to evaluate the compliance of patients with schizophrenia in Japan. Schizophr Res 2010 Apr;117(2-3):269 [FREE Full text] [doi: 10.1016/j.schres.2010.02.429]
100. Byerly MJ, Nakonezny PA, Rush AJ. The Brief Adherence Rating Scale (BARS) validated against electronic monitoring in assessing the antipsychotic medication adherence of outpatients with schizophrenia and schizoaffective disorder. Schizophr Res 2008 Mar;100(1-3):60-69 [FREE Full text] [doi: 10.1016/j.schres.2007.12.470] [Medline: 18255269]
101. Nakonezny PA, Byerly MJ, Rush AJ. Electronic monitoring of antipsychotic medication adherence in outpatients with schizophrenia or schizoaffective disorder: an empirical evaluation of its reliability and predictive validity. Psychiatry Res 2008 Jan 15;157(1-3):259-263 [FREE Full text] [doi: 10.1016/j.psychres.2007.05.001] [Medline: 17935793]
102. Kozuki Y, Poupore E, Schepp K. Visual feedback therapy to enhance medication adherence in psychosis. Arch Psychiatr Nurs 2005 Apr;19(2):70-80. [doi: 10.1016/j.apnu.2005.02.008] [Medline: 15902676]
103. Kozuki Y, Schepp KG. Visual-feedback therapy for antipsychotic medication adherence. Int Clin Psychopharmacol 2006 Jan;21(1):57-61. [doi: 10.1097/01.yic.0000177016.59484.ce] [Medline: 16317318]
104. Frangou S, Sachpazidis I, Stassinakis A, Sakas G. Telemonitoring of medication adherence in patients with schizophrenia. Telemed J E Health 2005 Dec;11(6):675-683. [doi: 10.1089/tmj.2005.11.675] [Medline: 16430387]
105. Ruskin PE, van der Wende J, Clark CR, Fenton J, Deveau J, Thapar R, et al. Feasibility of using the Med-eMonitor system in the treatment of schizophrenia: a pilot study. Drug Inf J 2016 Aug 28;37(3):283-291. [doi: 10.1177/009286150303700304]

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106. Diaz E, Levine HB, Sullivan MC, Sernyak MJ, Hawkins KA, Cramer JA, et al. Use of the medication event monitoring system to estimate medication compliance in patients with schizophrenia. J Psychiatry Neurosci 2001 Sep;26(4):325-329 [FREE Full text] [Medline: 11590972]
107. Peters-Strickland T, Pestreich L, Hatch A, Rohatagi S, Baker RA, Docherty JP, et al. Usability of a novel digital medicine system in adults with schizophrenia treated with sensor-embedded tablets of aripiprazole. Neuropsychiatr Dis Treat 2016;12:2587-2594 [FREE Full text] [doi: 10.2147/NDT.S116029] [Medline: 27785036]
108. Kopelowicz A, Baker RA, Zhao C, Brewer C, Lawson E, Peters-Strickland T. A multicenter, open-label, pilot study evaluating the functionality of an integrated call center for a digital medicine system to optimize monitoring of adherence to oral aripiprazole in adult patients with serious mental illness. Neuropsychiatr Dis Treat 2017;13:2641-2651 [FREE Full text] [doi: 10.2147/NDT.S143091] [Medline: 29089771]
109. Profit D, Rohatagi S, Zhao C, Hatch A, Docherty JP, Peters-Strickland TS. Developing a digital medicine system in psychiatry: ingestion detection rate and latency period. J Clin Psychiatry 2016 Dec;77(9):e1095-e1100 [FREE Full text] [doi: 10.4088/JCP.16m10643] [Medline: 27379966]
110. Thompson N, Nazir N, Cox LS, Faseru B, Goggin K, Ahluwalia JS, et al. Unannounced telephone pill counts for assessing varenicline adherence in a pilot clinical trial. Patient Prefer Adherence 2011;5:475-482 [FREE Full text] [doi: 10.2147/PPA.S24023] [Medline: 22003285]
111. Patel UB, Ni Q, Clayton C, Lam P, Parks J. An attempt to improve antipsychotic medication adherence by feedback of medication possession ratio scores to prescribers. Popul Health Manag 2010 Oct;13(5):269-274. [doi: 10.1089/pop.2009.0053] [Medline: 20879908]
112. Rosen CS, Azevedo KJ, Tiet QQ, Greene CJ, Wood AE, Calhoun P, et al. An RCT of effects of telephone care management on treatment adherence and clinical outcomes among veterans with PTSD. Psychiatr Serv 2017 Dec 1;68(2):151-158. [doi: 10.1176/appi.ps.201600069] [Medline: 27745535]
113. Guarino H, Acosta M, Marsch LA, Xie H, Aponte-Melendez Y. A mixed-methods evaluation of the feasibility, acceptability, and preliminary efficacy of a mobile intervention for methadone maintenance clients. Psychol Addict Behav 2016 Feb;30(1):1-11 [FREE Full text] [doi: 10.1037/adb0000128] [Medline: 26618796]
114. McClure JB, Anderson ML, Bradley K, An LC, Catz SL. Evaluating an adaptive and interactive mHealth smoking cessation and medication adherence program: a randomized pilot feasibility study. JMIR Mhealth Uhealth 2016 Aug 3;4(3):e94 [FREE Full text] [doi: 10.2196/mhealth.6002] [Medline: 27489247]
115. Beebe LH, Smith K, Crye C, Addonizio C, Strunk DJ, Martin W, et al. Telenursing intervention increases psychiatric medication adherence in schizophrenia outpatients. J Am Psychiatr Nurses Assoc 2008 Jun;14(3):217-224. [doi: 10.1177/1078390308318750] [Medline: 21665767]
116. Niendam TA, Tully LM, Iosif A, Kumar D, Nye KE, Denton JC, et al. Enhancing early psychosis treatment using smartphone technology: a longitudinal feasibility and validity study. J Psychiatr Res 2018 Jan;96:239-246. [doi: 10.1016/j.jpsychires.2017.10.017] [Medline: 29126059]
117. Manuel JM, Maurino J, Diez T, Saiz-Ruiz J. Factors associated with the effectiveness of a telephone-based nursing strategy for enhancing medication adherence in schizophrenia. Clin Pract Epidemiol Ment Health 2011;7:117-119 [FREE Full text] [doi: 10.2174/1745017901107010117] [Medline: 21760832]
118. Kreyenbuhl J, Record EJ, Himelhoch S, Charlotte M, Palmer-Bacon J, Dixon LB, et al. Development and feasibility testing of a smartphone intervention to improve adherence to antipsychotic medications. Clin Schizophr Relat Psychoses 2016 Jul 25. [doi: 10.3371/CSRP.KRRE.070816] [Medline: 27454213]
119. Gervasoni N, Legendre-Simon P, Aubry J, Gex-Fabry M, Bertschy G, Bondolfi G. Early telephone intervention for psychiatric outpatients starting antidepressant treatment. Nord J Psychiatry 2010 Aug;64(4):265-267. [doi: 10.3109/08039480903528641] [Medline: 20166864]
120. Faurholt-Jepsen M, Frost M, Ritz C, Christensen EM, Jacoby AS, Mikkelsen RL, et al. Daily electronic self-monitoring in bipolar disorder using smartphones-the MONARCA I trial: a randomized, placebo-controlled, single-blind, parallel group trial. Psychol Med 2015 Oct;45(13):2691-2704. [doi: 10.1017/S0033291715000410] [Medline: 26220802]
121. Chang TE, Jing Y, Yeung AS, Brenneman SK, Kalsekar ID, Hebden T, et al. Depression monitoring and patient behavior in the Clinical Outcomes in MEasurement-Based Treatment (COMET) trial. Psychiatr Serv 2014 Aug 1;65(8):1058-1061. [doi: 10.1176/appi.ps.201300326] [Medline: 25082605]
122. Bhat S, Chow Z, Heath L, Billups S, Trinkley K, Loeb D. Springer Link. 2017. A collaborative telehealth antidepressant monitoring program involving pharmacists in primary care URL: https://link.springer.com/content/pdf/10.1007%2Fs11606-017-4028-8.pdf [WebCite Cache ID 72hfXl3Rj]
123. Gustafson DH, Landucci G, McTavish F, Kornfield R, Johnson RA, Mares M, et al. The effect of bundling medication-assisted treatment for opioid addiction with mHealth: study protocol for a randomized clinical trial. Trials 2016 Dec 12;17(1):592 [FREE Full text] [doi: 10.1186/s13063-016-1726-1] [Medline: 27955689]
124. Montes JM, Medina E, Gomez-Beneyto M, Maurino J. A short message service (SMS)-based strategy for enhancing adherence to antipsychotic medication in schizophrenia. Psychiatry Res 2012 Dec 30;200(2-3):89-95. [doi: 10.1016/j.psychres.2012.07.034] [Medline: 22901437]

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125. Xu DR, Gong W, Caine ED, Xiao S, Hughes JP, Ng M, et al. Lay health supporters aided by a mobile phone messaging system to improve care of villagers with schizophrenia in Liuyang, China: protocol for a randomised control trial. BMJ Open 2016 Jan 20;6(1):e010120 [FREE Full text] [doi: 10.1136/bmjopen-2015-010120] [Medline: 26792221]
126. Applegate B, Raymond C, Collado-Rodriguez A, Riley W, Schneider N. Improving adherence to nicotine gum by SMS text messaging: a pilot study (RPOS3-57). 2007 Presented at: Society for Research on Nicotine and Tobacco 13th Annual Meeting; February 20-24, 2007; Austin, Texas p. 21-24 URL: https://cdn.ymaws.com/srnt.site-ym.com/resource/resmgr/Conferences/Past_Annual_Meetings/2007_Annual_Meeting_Abstract.pdf
127. Tseng T, Krebs P, Schoenthaler A, Wong S, Sherman S, Gonzalez M, et al. Combining text messaging and telephone counseling to increase varenicline adherence and smoking abstinence among cigarette smokers living with HIV: a randomized controlled study. AIDS Behav 2017 Jul;21(7):1964-1974 [FREE Full text] [doi: 10.1007/s10461-016-1538-z] [Medline: 27605365]
128. Kannisto KA, Adams CE, Koivunen M, Katajisto J, Välimäki M. Feedback on SMS reminders to encourage adherence among patients taking antipsychotic medication: a cross-sectional survey nested within a randomised trial. BMJ Open 2015;5(11):e008574 [FREE Full text] [doi: 10.1136/bmjopen-2015-008574] [Medline: 26553830]
129. Välimäki M, Kannisto KA, Vahlberg T, Hätönen H, Adams CE. Short text messages to encourage adherence to medication and follow-up for people with psychosis (Mobile.Net): randomized controlled trial in. J Med Internet Res 2017 Jul 12;19(7):e245 [FREE Full text] [doi: 10.2196/jmir.7028] [Medline: 28701292]
130. Nye I. Local NGO/government partnership addresses medication non-adherence in psychiatric outpatients: Results from a reminder and support pilot intervention. 2014 Jul 29 Presented at: National Congress of South African Society of Psychiatrists (SASOP); September 3-7, 2014; Durban, South Africa p. 112. [doi: 10.7196/SAJP.664]
131. van Gent E, van der Klein E. Taylor & Francis Online. Improving compliance and treatment outcome in bipolar and schizophrenic patients by using short message text service (SMS) URL: https://www.tandfonline.com/doi/abs/10.3109/13651501.2010.527734?scroll=top&needAccess=true&journalCode=ijpc20 [accessed 2018-09-25] [WebCite Cache ID 72heodgJX]
132. Pijnenborg GH, Withaar FK, Brouwer WH, Timmerman ME, van den Bosch RJ, Evans JJ. The efficacy of SMS text messages to compensate for the effects of cognitive impairments in schizophrenia. Br J Clin Psychol 2010 Jun;49(Pt 2):259-274. [doi: 10.1348/014466509X467828] [Medline: 19735607]
133. Vora A, Smalligan R, Chandra R, James S, Frost J, Basinger R, et al. A smoking cessation model that integrates social media in hospitalized patients post-discharge. In: Pharmacotherapy. 2014 Presented at: Annual Meeting of the American-College-of-Clinical-Pharmacy (ACCP); October 12-15, 2014; Austin, Texas.
134. Brendryen H, Kraft P. Happy ending: a randomized controlled trial of a digital multi-media smoking cessation intervention. Addiction 2008 Mar;103(3):478-484. [doi: 10.1111/j.1360-0443.2007.02119.x] [Medline: 18269367]
135. Yuhongxia L. The compliance of varenicline usage and the smoking abstinence rate via mobile phone text messaging combine with varenicline: A single-blind, randomised control trial. 2011 Presented at: 16th Congress of the Asian Pacific Society of Respirology; November 3-6, 2011; Shanghai, China. [doi: 10.1111/j.1440-1843.2011.02071.x]
136. Wenze SJ, Armey MF, Miller IW. Feasibility and acceptability of a mobile intervention to improve treatment adherence in bipolar disorder: a pilot study. Behav Modif 2014 Jan 8;38(4):497-515. [doi: 10.1177/0145445513518421] [Medline: 24402464]
137. Wenze SJ, Armey MF, Weinstock LM, Gaudiano BA, Miller IW. An open trial of a smartphone-assisted, adjunctive intervention to improve treatment adherence in bipolar disorder. J Psychiatr Pract 2016 Dec;22(6):492-504 [FREE Full text] [doi: 10.1097/PRA.0000000000000196] [Medline: 27824786]
138. Aikens JE, Trivedi R, Heapy A, Pfeiffer PN, Piette JD. Potential impact of incorporating a patient-selected support person into mHealth for depression. J Gen Intern Med 2015 Jun;30(6):797-803. [doi: 10.1007/s11606-015-3208-7] [Medline: 25666218]
139. Ben-Zeev D, Kaiser SM, Krzos I. Remote "hovering" with individuals with psychotic disorders and substance use: feasibility, engagement, and therapeutic alliance with a text-messaging mobile interventionist. J Dual Diagn 2014;10(4):197-203 [FREE Full text] [doi: 10.1080/15504263.2014.962336] [Medline: 25391277]
140. Bickmore TW, Puskar K, Schlenk EA, Pfeifer LM, Sereika SM. Maintaining reality: Relational agents for antipsychotic medication adherence. Interact Comput 2010 Jul;22(4):276-288. [doi: 10.1016/j.intcom.2010.02.001]
141. Puskar K, Schlenk EA, Callan J, Bickmore T, Sereika S. Relational agents as an adjunct in schizophrenia treatment. J Psychosoc Nurs Ment Health Serv 2011 Aug;49(8):22-29. [doi: 10.3928/02793695-20110705-01] [Medline: 21766736]
142. Graham AL, Papandonatos GD, Cha S, Erar B, Amato MS, Cobb NK, et al. Improving adherence to smoking cessation treatment: intervention effects in a web-based randomized trial. Nicotine Tob Res 2017 Mar 1;19(3):324-332. [doi: 10.1093/ntr/ntw282] [Medline: 27836982]
143. D'Souza R. Improving treatment adherence and longitudinal outcomes in patients with a serious mental illness by using telemedicine. J Telemed Telecare 2002;8 Suppl 2:113-115. [doi: 10.1177/1357633X020080S251] [Medline: 12217162]
144. Piette JD, Aikens JE, Trivedi R, Parrish D, Standiford C, Marinec NS, et al. Depression self-management assistance using automated telephonic assessments and social support. Am J Manag Care 2013 Nov;19(11):892-900 [FREE Full text] [Medline: 24511987]

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145. Pfeiffer PN, Valenstein M, Ganoczy D, Henry J, Dobscha SK, Piette JD. Pilot study of enhanced social support with automated telephone monitoring after psychiatric hospitalization for depression. Soc Psychiatry Psychiatr Epidemiol 2017 Dec;52(2):183-191. [doi: 10.1007/s00127-016-1288-2] [Medline: 27783130]
146. Swan GE, McClure JB, Jack LM, Zbikowski SM, Javitz HS, Catz SL, et al. Behavioral counseling and varenicline treatment for smoking cessation. Am J Prev Med 2010 May;38(5):482-490 [FREE Full text] [doi: 10.1016/j.amepre.2010.01.024] [Medline: 20409497]
147. Meglic M, Furlan M, Kuzmanic M, Kozel D, Baraga D, Kuhar I, et al. Feasibility of an eHealth service to support collaborative depression care: results of a pilot study. J Med Internet Res 2010;12(5):e63 [FREE Full text] [doi: 10.2196/jmir.1510] [Medline: 21172765]
148. Castle T, Cunningham MA, Marsh GM. Antidepressant medication adherence via interactive voice response telephone calls. Am J Manag Care 2012 Sep 1;18(9):e346-e355 [FREE Full text] [Medline: 23009333]
149. Cook PF, Emiliozzi S, Waters C, el Hajj D. Effects of telephone counseling on antipsychotic adherence and emergency department utilization. Am J Manag Care 2008 Dec;14(12):841-846 [FREE Full text] [Medline: 19067501]
150. Yakirevitch J, Marchevsky S, Abramovitch Y, Kotler M. P03-153-Special informative internet site for schizophrenic patients: its feasibility and contribution to pharmacotherapy. Eur Psychiatry 2010;25(Suppl 1):1134 [FREE Full text] [doi: 10.1016/S0924-9338(10)71123-8]
151. Atherton-Naji A, Hamilton R, Riddle W, Naji S. Improving adherence to antidepressant drug treatment in primary care: a feasibility study for a randomized controlled trial of educational intervention. Prim Care Psych 2001;7(2):61-67 [FREE Full text] [doi: 10.1185/135525701750384473]
152. Rickles NM, Svarstad BL, Statz-Paynter JL, Taylor LV, Kobak KA. Pharmacist telemonitoring of antidepressant use: effects on pharmacist-patient collaboration. J Am Pharm Assoc (2003) 2005;45(3):344-353. [Medline: 15991756]
153. Perahia DG, Quail D, Gandhi P, Walker DJ, Peveler RC. A randomized, controlled trial of duloxetine alone vs. duloxetine plus a telephone intervention in the treatment of depression. J Affect Disord 2008 May;108(1-2):33-41 [FREE Full text] [doi: 10.1016/j.jad.2007.08.023] [Medline: 17905442]
154. Fortney JC, Pyne JM, Kimbrell TA, Hudson TJ, Robinson DE, Schneider R, et al. Telemedicine-based collaborative care for posttraumatic stress disorder: a randomized clinical trial. JAMA Psychiatry 2015 Jan;72(1):58-67. [doi: 10.1001/jamapsychiatry.2014.1575] [Medline: 25409287]
155. Ruetsch C, Tkacz J, McPherson TL, Cacciola J. The effect of telephonic patient support on treatment for opioid dependence: outcomes at one year follow-up. Addict Behav 2012 May;37(5):686-689. [doi: 10.1016/j.addbeh.2012.01.013] [Medline: 22348921]
156. Gong J, Baker CL, Zou KH, Bruno M, Jumadilova Z, Lawrence D, et al. A pragmatic randomized trial comparing telephone-based enhanced pharmacy care and usual care to support smoking cessation. J Manag Care Spec Pharm 2016 Dec;22(12):1417-1425 [FREE Full text] [doi: 10.18553/jmcp.2016.22.12.1417] [Medline: 27882838]
157. Fortney JC, Pyne JM, Edlund MJ, Williams DK, Robinson DE, Mittal D, et al. A randomized trial of telemedicine-based collaborative care for depression. J Gen Intern Med 2007 Aug;22(8):1086-1093 [FREE Full text] [doi: 10.1007/s11606-007-0201-9] [Medline: 17492326]
158. Ruskin PE, Silver-Aylaian M, Kling MA, Reed SA, Bradham DD, Hebel JR, et al. Treatment outcomes in depression: comparison of remote treatment through telepsychiatry to in-person treatment. Am J Psychiatry 2004 Aug;161(8):1471-1476. [doi: 10.1176/appi.ajp.161.8.1471] [Medline: 15285975]
159. Hungerbuehler I, Valiengo L, Loch AA, Rössler W, Gattaz WF. Home-based psychiatric outpatient care through videoconferencing for depression: a randomized controlled follow-up trial. JMIR Ment Health 2016 Aug 3;3(3):e36 [FREE Full text] [doi: 10.2196/mental.5675] [Medline: 27489204]
160. Grady BJ, Melcer T. A retrospective evaluation of telemental healthcare services for remote military populations. Telemed J E Health 2005 Oct;11(5):551-558. [doi: 10.1089/tmj.2005.11.551] [Medline: 16250818]
161. Farabee D, Calhoun S, Veliz R. An experimental comparison of telepsychiatry and conventional psychiatry for parolees. Psychiatr Serv 2016 Dec 1;67(5):562-565. [doi: 10.1176/appi.ps.201500025] [Medline: 26725291]
162. Beebe LH, Smith K, Phillips C. Effect of a telephone intervention on measures of psychiatric and nonpsychiatric medication adherence in outpatients with schizophrenia spectrum disorders. J Psychosoc Nurs Ment Health Serv 2017 Jan 1;55(1):29-36. [doi: 10.3928/02793695-20170119-04] [Medline: 28135389]
163. Scheurer D, Choudhry N, Swanton KA, Matlin O, Shrank W. Association between different types of social support and medication adherence. Am J Manag Care 2012 Dec 1;18(12):e461-e467 [FREE Full text] [Medline: 23286676]
164. Grymonpre RE, Didur CD, Montgomery PR, Sitar DS. Pill count, self-report, and pharmacy claims data to measure medication adherence in the elderly. Ann Pharmacother 1998;32(7-8):749-754. [doi: 10.1345/aph.17423] [Medline: 9681089]
165. Daniels T, Goodacre L, Sutton C, Pollard K, Conway S, Peckham D. Accurate assessment of adherence: self-report and clinician report vs electronic monitoring of nebulizers. Chest 2011 Aug;140(2):425-432. [doi: 10.1378/chest.09-3074] [Medline: 21330381]

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Abbreviations

AI: artificial intelligence
ADHD: attention deficit hyperactivity disorder
CBT: cognitive behavioral therapy
CENTRAL: Cochrane Central Register of Controlled Trials
CV: computer vision
IVR: interactive voice response
MEMS: Medication Event Monitoring System
PTSD: posttraumatic stress disorder
RCTs: randomized controlled trials
SMS: short messaging service

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Original Paper

Gender Moderates the Partial Mediation of Impulsivity in the Relationship Between Psychiatric Distress and Problematic Online Gaming: Online Survey

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Abstract

Background: Research has shown that some individuals can develop problematic patterns of online gaming, leading to significant psychological and interpersonal problems. Psychiatric distress and impulsivity have been suggested to contribute to problematic online gaming (POG).

Objective: This study aimed to investigate the potential mediating or moderating mechanisms of impulsivity and gender-related differences in possible associations between psychiatric distress and POG.

Methods: A total of 596 matched female and male participants, ranging in age from 14 to 38 years (mean 21.4, SD 4.5), were chosen from a large cross-sectional, nationwide Hungarian online gaming sample. Participants completed online questionnaires about self-reported impulsivity, psychiatric distress, and POG.

Results: Psychiatric distress directly predicted POG, and impulsivity partially mediated the relationship between psychiatric distress and POG. However, this mediation effect was found only for the impatience factor of impulsivity. Impulsivity did not moderate the relationship between psychiatric distress and POG. A moderating effect of gender was not found in the direct relationship between psychiatric distress and POG. However, a moderated mediation analysis revealed that impatience mediated the association between psychiatric distress and POG in males, whereas the indirect effect of impatience was not significant in females.

Conclusions: The results of this work highlight gender-related difference among online gamers in the mediation effect of impulsivity between psychiatric distress and POG and provide novel insights regarding clinical implications for preventing or treating POG.

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KEYWORDS

internet; video games; addictive behavior; psychopathology; impulsivity; gender

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Introduction

Background

Problematic online gaming (POG) may be defined as the persistent and recurrent use of the internet to play video games, leading to clinically significant impairment or distress. Internet gaming disorder was included as a "condition for further study" in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, section 3 [1]. Furthermore, gaming disorder, including online gaming, has been formally included along with gambling disorder as a disorder because of addictive behaviors in the recently released listing of conditions in the International Classification of Diseases 11th Revision [2]. Some have considered POG to be a global public health problem because of its relevant high prevalence and significant negative outcomes in worldwide populations, particularly among adolescents [3,4]. A recent review suggested that the overall prevalence of POG ranged from 0.7% to 15.6% in studies of naturalistic populations, with an average percentage of 4.7% [5].

Psychiatric symptoms such as depression have been associated more broadly with POG and problematic internet use [6,7]. POG has been positively correlated with psychiatric symptom dimensions including depressed mood, loneliness, social anxiety, and negative self-esteem [8-11]. Individuals (particularly females) may engage in potentially addictive behaviors to escape from negative mood states or other psychiatric distress (negative reinforcement motivations), and this may lead to problematic or addictive engagement. Although previous research has focused primarily on the direct association between psychiatric distress and POG, fewer studies have examined how specific factors may moderate relationships between psychiatric distress and POG or how the relationships between psychiatric distress and POG may operate through intervening variables via mediation effects. To address these gaps, this study constructed a moderated mediation model to test the mediating role of impulsivity and the moderating role of gender in the relation between psychiatric distress and POG. Such studies could advance our understanding of how and when psychiatric distress might lead to greater POG and may have implications for the prevention and treatment of POG.

Impulsivity as a Mediator or Moderator

Impulsivity has been described as being characterized by "actions that are poorly conceived, prematurely expressed, unduly risky, or inappropriate to the situation and that often result in undesirable outcomes" [12]. Although impulsivity is a multidimensional construct, impatience is an important component of impulsiveness that may result from relative disregard of future outcomes and oversensitivity to immediate rewards [13]. Impulsivity has been related to substance use, gambling, and gaming [14]. Impulsivity has been proposed to contribute significantly to the development and/or maintenance of addictions [3,15]. It has also been linked to poor addiction treatment outcomes [16]. Furthermore, impulsivity has been associated with problematic internet use and POG. For instance, adolescents with internet addiction exhibited more impulsivity than those without [17], and the severity of internet addiction was positively correlated with the level of impulsivity in individuals with internet addiction [18]. Greater impulsivity among internet users was associated with poorer control over the use of the internet [19]. Similarly, individuals with POG have been found to score high on measures of impulsivity [20].

Psychiatric symptoms may relate to impulsivity. Negative emotional states may lead individuals to focus more on their feelings, which may trigger poor self-control [21]. Semple et al [22] found that depression scores could best discriminate between substance users with high and low impulsivity. Depression and loneliness scores have also correlated with low self-control and problematic internet use [6].

Previous studies have shown that impulsivity may mediate the relation between psychiatric distress and addictive behaviors. For example, impulsivity has been shown to mediate the influence of life stress on pathological gambling [23] and the relationship between depression and problematic gambling [24]. However, mixed findings have been reported in moderation analyses. Although a moderating effect of impulsivity was also observed in a study by Tang and Wu [23], in which a positive association between life stress and pathological gambling was significant among those with low impulsivity only, and pathological gambling remained high regardless of the stress level among those with high impulsivity, this moderating effect was not supported in the study by Clarke [24]. Although studies have examined the relationship between impulsivity and problematic internet use [17,18], and the mediating and/or moderating effects of impulsivity on psychiatric distress and pathological gambling [23,24], few studies have examined a role for impulsivity in relationships between psychiatric distress and POG. Internet addiction has been reported to have comparable levels of impulsivity compared with pathological gambling [18], and POG may be characterized by high impulsivity such as other addictive disorders including gambling disorder [20]. Therefore, previous studies of pathological gambling may shed light on mechanisms of how psychiatric distress may relate to POG. Thus, this study investigated the extent to which impulsivity would mediate and/or moderate a hypothesized relationship between psychiatric distress and POG. On the basis of the findings above, we proposed the following hypotheses (denoted H#):

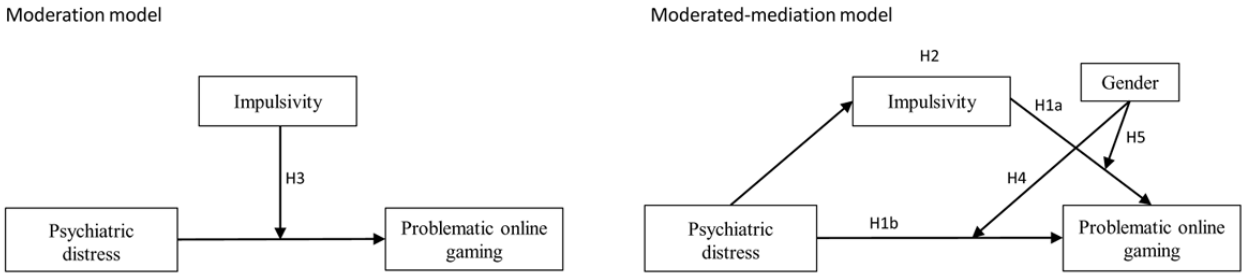
- **H1:** POG would correlate positively with impulsivity with a moderate effect size (H1a) and psychiatric distress with a large effect size (H1b).
- **H2:** According to the mediation model, impulsivity would mediate the relationship between psychiatric distress and POG. Psychiatric distress would relate to POG directly as well as indirectly through impulsivity.
- **H3:** According to the moderation model, impulsivity would moderate the relation between psychiatric distress and POG, with the relationship being stronger for individuals with lower impulsivity.

Gender as a Moderator

Although psychiatric distress may relate to impulsivity and POG, it is possible that not all individuals are equally influenced. This study examined whether the direct effect of psychiatric distress on POG and the indirect effect of impulsivity would be moderated by gender.

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Figure 1. Conceptual model of hypotheses. H1a: Hypothesis 1a; H1b: Hypothesis 1b; H2: Hypothesis 2; H3: Hypothesis 3; H4: Hypothesis 4; H5: Hypothesis 5.



Gender may relate importantly to internet gaming behaviors. First, boys have been found to be more likely than girls to report having played video games [25-27] and to report more problematic gaming than girls [28]. Second, being male was a strong predictor of problematic game use [26], and POG was strongly associated with being male [29]. Third, gender-related differences may extend to gaming motivation. Female gamers scored significantly higher on fantasy, escape, social, and recreation motives, whereas male gamers reported significantly higher scores on competition motives [9]. Male players also reported a greater need for gaming-related friendships than did females [30].

Gender-related differences may also exist in impulsivity's relationship to addictive behaviors. Gender was found to moderate the relationship between sensation seeking/impulsivity and alcohol use; in particular, males and females were found to have comparable alcohol use frequencies under conditions of low sensation seeking/impulsivity, and males were found to have a higher frequency of alcohol use than females under conditions of high sensation seeking/impulsivity [31]. A moderating effect of gender on the association between impulsivity and alcohol-use problems was also found in the study by Stoltenberg et al [32]. Similarly, impulsivity was found only to associate with levels of alcohol use in males [33]. Given that urges/cravings in POG and substance-use disorders may share similar neurobiological mechanisms [34], gender-related differences in previous studies of alcohol use may extend to POG, and this possibility should be tested directly.

Together, both the association between psychiatric distress and POG and the association between impulsivity and POG may be moderated by gender. Furthermore, if impulsivity were to mediate the relation between psychiatric distress and POG, and gender were to moderate the association between impulsivity and POG simultaneously, the mediating effect of impulsivity would be moderated by gender. In other words, there would be a moderated-mediation model involving impulsivity and gender in the relation between psychiatric distress and POG. We sought to test this model. Thus, we put forward the following hypotheses (see Figure 1).

- **H4:** Gender would moderate the relationship between psychiatric distress and POG, with the relation being stronger for males.
- **H5:** Gender would moderate the mediating effect of impulsivity in the relationship between psychiatric distress and POG, with the mediating effect only being significant among males.

Methods

Participants and Procedure

We used data from a nationwide Hungarian online gaming sample. Participants were recruited via gaming-related websites and Facebook pages. A total of 3 calls containing the link to the questionnaire were posted on a popular gaming magazine's (ie, GameStar) website and Facebook page in August and September 2014. The magazine's Facebook page had approximately 65,000 followers at the time of the data collection. The post was liked more than 800 times and shared more than 130 times during this period, reaching a wide circle of Hungarian gamers. A shopping voucher of approximately 300 Euro was drawn and offered to 1 study participant as an incentive to boost participation. For more details of the data collection process, see the study by Király O et al [35]. Participants were informed about the aim of the study, the time necessary for completion, and confidentiality of the data. Every participant included in this analysis provided informed consent by ticking a checkbox indicating agreement before starting the questionnaire. Participants aged between 14 and 17 years needed to indicate the approval of their parents with an affirmative response from the parent to the question stating, "I allow my child to participate: parent." This study was approved by the Institutional Review Board of Eötvös Loránd University, Budapest, Hungary. The Institutional Review Board of Yale University approved the use of deidentified data in these analyses. This study was performed in line with the Helsinki Declaration. We used the larger sample in 2 previous studies, which did not include data analysis findings reported in this study [35,36].

A total of 7757 gamers started the survey. To verify unique entries (ie, emanating from different individuals), email addresses were checked for uniqueness, and cases having the same email address were removed from the dataset. Furthermore, we checked for invalid answer patterns (eg, the impulsivity scale had several reversed items—if a person gave the same values for all items, the answers were considered as invalid). We deleted responses from individuals with invalid answer patterns. After excluding cases reflecting duplicate submissions, severe incompleteness or inconsistencies on the variables from this study, 5222 online gamers remained in the sample from this study (4830 males and 384 females). Due to

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the overrepresentation of males that is frequent in specific video gamer samples, we identified a matched sample of males based on the female participants (298 males and 298 females) for further analysis. The matching method is described in the Statistical Analysis section. In the sample from this study, the mean age was 21.4 years (SD 4.5, age range 14-38). Most participants were either single (41.6%, 248/596) or in a relationship but living separately (39.3%, 234/596), and most were students (68.9%, 409/594). For further details on sample demographics, see Table 1.

Measures

Problematic Online Gaming Questionnaire

The Problematic Online Gaming Questionnaire (POGQ) is an 18-item scale assessing POG [37], showing good psychometric properties in both adult and adolescent samples (Pápay et al). The scale comprises 6 factors: social isolation, interpersonal conflicts, overuse, withdrawal, immersion, and preoccupation. Participants responded on a 5-point Likert scale (1="never" and 5="almost always/always") to each item (eg, "How often do you get irritable or upset when you cannot play?" and "How often do you neglect other activities because you would rather be gaming?"), with higher scores indicating greater POG. The scale was originally developed in the Hungarian context and showed good psychometric properties in other cultures as well, for example, the study by Ballabio et al [10]. The internal consistency of this scale was 0.89 in this study.

Brief Symptom Inventory

The Brief Symptom Inventory assesses psychiatric distress with 53 items on 9 self-reported clinically relevant psychological symptoms: somatization, obsession-compulsion, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism [38]. Respondents rank the distress level of each item (eg, "Having to check and double check what you do," "Feeling fearful," and "Trouble falling asleep") on a 5-point Likert scale (0="not at all" and 4="extremely") during the past 7 days. Rankings characterize the intensity of distress during the past 7 days. In this study, a global index of *Global Severity Index (GSI)*, namely the mean for all 53 items, was used to assess the level of general distress. Higher GSI scores indicate stronger psychiatric distress. The scale was previously adapted to the local (Hungarian) culture and showed good psychometric properties [39]. The internal consistency of this scale was 0.96.

Table 1. Demographics and weekly gaming time of sample participants.

Demographics	Male (n=298)	Female (n=298)
Age in years, mean (SD)	21.4 (4.5)	21.4 (4.5)
Education (years completed), mean (SD)	13.0 (2.6)	13.0 (2.6)
Marital status, n (%)		
Single	124 (41.6)	124 (41.6)
In a relationship but living separately	117 (39.3)	117 (39.3)
Living in a partnership	51 (17.1)	51 (17.1)
Married	6 (2.0)	6 (2.0)
Divorced	0 (0.0)	0 (0.0)
Widowed	0 (0.0)	0 (0.0)
Currently a student[a], n (%)	203 (68.6)	206 (69.1)
Working status, n (%)		
Does not work	165 (55.4)	165 (55.4)
Has a part-time job	58 (19.5)	58 (19.5)
Has a full-time job	75 (25.2)	75 (25.2)
Weekly gaming time[b], n (%)		
Less than 7 hours	48 (16.2)	57 (19.2)
7-14 hours	52 (17.5)	78 (26.3)
15-28 hours	109 (36.7)	100 (33.7)
29-42 hours	57 (19.2)	49 (16.5)
More than 42 hours	31 (10.4)	13 (4.4)

[a]2 missing values in males.

[b]2 missing values (1 male and 1 female, respectively).

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Barratt Impulsiveness Scale

The Barratt Impulsiveness Scale (BIS)-21, revised from the original BIS [40], has been tested in 3 different Hungarian adult samples, including a representative one, and assesses impulsivity with 21 items comprising 3 components of impulsivity: self-control, impulsive behavior, and impatience [41]. Participants indicated their responses on a 4-point Likert scale (1="rarely/never" and 4="almost always/always") to each item (eg, "I am future oriented," "I do things without thinking," and "I am restless at the theater or lectures,"), with higher scores indicating greater impulsivity. The internal consistency (Cronbach alpha) was .74 for the self-control subscale, .78 for the impulsive behavior subscale, and .63 for the impatience subscale, whereas it was .80 for the whole scale.

Statistical Analysis

We used the case-control matching tools in Medcalc v17.8 (MedCalc Software bvba) to obtain matched data from the sample pool (N=5222). Female status was set to be the matching target group, and male cases were chosen from the pool to match each female case by case. The matching condition was set to include a maximal allowable difference in age of 1 year and required both paired individuals to be the same on measures of education, marital relationship, and work status. This approach generated 298 pairs of cases satisfying the matching conditions.

Description analysis, correlation analysis, and *t* tests were performed with SPSS 19. Internal consistencies were assessed by Cronbach alpha coefficient. Cohen *d* was used to measure the effect size.

Mediation and moderation effects were tested using SPSS PROCESS (v3.0) for bootstrapping as described by Hayes [42]. PROCESS is a computational tool for path analysis–based moderation and mediation analysis as well as for their combination [42]. We first tested a mediation model (model number 4 in PROCESS) for H2 using the total score of the BIS-21; we then tested a moderation model (model number 1 in PROCESS) for H3. If positive mediation and/or moderation effects of impulsivity were observed, then a series of post hoc analyses were used to examine specific subscales of the BIS-21 separately. We further tested the moderated mediation model (model number 15 in PROCESS) for H4 and H5. Values of variables were standardized before calculating the models in PROCESS for the purpose of obtaining the standardized regression coefficient. Age, education, and working status were included as covariates in all models. Significant interactions in the moderated-mediation model were followed-up with simple slopes analysis at high (+1 SD) and low (−1 SD) values of the moderator variable [42]. Indirect mediating effects were evaluated with 95% CIs using the percentile method based on 5000 bootstrap samples. If the CI did not contain zero, then the indirect effect was considered statistically significant [42]. If the presence of such an indirect effect depended on the value of a moderating variable, then it was considered an indication of moderated mediation.

Results

Sample Description

Given the matching process, males and females in the subsample had precisely the same demographic characteristics with respect to age, education, marital status, and working status. Student status was also largely similar. Chi-square testing revealed that a higher percentage of males played games for more than 14 hours per week compared with females (χ^2_4=14.3; *P*=.006, odds ratio=1.64).

The descriptive statistics and zero-order correlations for demographic variables and psychological measures are presented in Table 2. GSI was positively and strongly correlated with POG (*r*=0.52, *P*<.001), whereas impulsivity was moderately related to POG (*r*=0.33, *P*<.001); thus, H1 was confirmed.

Gender-Related Differences

We examined gender-related differences using *t* tests (see Table 3). Statistically significant gender-related differences were not observed in impulsivity. Females scored higher in immersion (t_{565}=−3.52; *P*<.001, Cohen *d*=0.30) but lower in overuse (t_{563}=2.10; *P*=.04, Cohen *d*=−0.18) than males on subscales of the POGQ. GSI scores were higher in females than males (t_{491}=−5.40; *P*<.001, Cohen *d*=0.49), but males spent more weekly time gaming than did females (t_{592}=3.14; *P*=.002, Cohen *d*=−0.26).

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Table 2. Mean, SD, and Spearman's correlation matrix with *P* values of overall variables.

Variables	1	2	3	4	5	6	7	8	9
1. Age	1.00	__[a]	—	—	—	—	—	—	—
2. Education	0.66 (<.001)	1.00	—	—	—	—	—	—	—
3. Working status[b]	.64 (<.001)	.42 (<.001)	1.00	—	—	—	—	—	—
4. Problematic online gaming	−0.18 (<.001)	−0.16 (<.001)	−0.18 (<.001)	1.00	—	—	—	—	—
5. Global Severity Index	−0.20 (<.001)	−0.21 (<.001)	−0.15 (<.001)	0.52 (<.001)	1.00	—	—	—	—
6. BIS[c] self-control	−0.06 (=.17)	−0.06 (=.18)	−0.08 (=.07)	0.19 (<.001)	0.16 (<.001)	1.00	—	—	—
7. BIS impulsive behavior	−0.09 (=.03)	−0.12 (=.006)	−0.04 (=.38)	0.25 (<.001)	0.13 (<.001)	0.37 (<.001)	1.00	—	—
8. BIS impatience	−0.06 (=.14)	−0.03 (=.43)	−0.03 (=.44)	0.36 (<.001)	0.33 (<.001)	0.22 (<.001)	0.43 (<.001)	1.00	—
9. BIS total score	−0.09 (=.04)	−0.09 (=.047)	−0.06 (=.15)	0.33 (<.001)	0.27 (<.001)	0.78 (<.001)	0.76 (<.001)	0.70 (<.001)	1.00
Mean (SD)	21.38 (4.48)	13.00 (2.55)	1.70 (0.85)	0.74 (0.66)	12.8 (3.76)	17.37 (4.40)	9.96 (3.06)	12.56 (3.43)	39.70 (8.02)

[a]The correlation coefficient was not shown as it was shown in the asymmetrically diagonal position of the table.

[b]Working status: it was coded as 1="does not work," 2="has a part-time job," and 3="has a full job."

[c]BIS: Barratt Impulsiveness Scale (version 21).

Table 3. Gender differences in overall variables.

Variables	Male, mean (SD)	Female, mean (SD)	*t* test(df)	*P* value	Cohen *d*
Impulsivity					
Self-control	17.15 (4.34)	17.60 (4.46)	−1.18(*539*)	.24	0.10
Impulsive behavior	9.82 (3.11)	10.09 (3.00)	−1.03(*547*)	.30	0.09
Impatience	12.42 (3.43)	12.69 (2.43)	−0.89(*545*)	.37	0.08
Total score	39.22 (7.99)	40.18 (8.04)	−1.38(*526*)	.17	0.12
Problematic online gaming					
Preoccupation	5.24 (1.83)	5.33 (2.03)	−0.56(*572*)	.57	0.05
Immersion	11.87 (3.51)	12.93 (3.65)	−3.52(*565*)	<.001	0.30
Withdrawal	6.89 (3.24)	6.85 (3.44)	0.16(*566*)	.87	−0.01
Overuse	6.05 (2.67)	5.58 (2.72)	2.10(*563*)	.04	−0.18
Social isolation	5.08 (2.40)	5.09 (2.70)	−0.03(*570*)	.98	0.00
Total score	39.22 (11.15)	39.73 (11.74)	−0.53(*540*)	.60	0.04
Global Severity Index	0.58 (0.55)	0.89 (0.73)	−5.40(*491*)	<.001	0.49
Weekly game time[a]	2.90 (1.19)	2.61 (1.10)	3.14(*592*)	.002	−0.26

[a]6-point scale: 0="none," 1="less than 7 hours," 2="7-14 hours," 3="15-28 hours," 4="29-42 hours," and 5="more than 42 hours."

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Figure 2. Results of models testing for mediating effects of impulsivity and its dimensions in the relationship between measures of global severity index and problematic online gaming (N=5000 bootstrapping resamples). Path c=total (nonmediated) effect; Path c'=direct (controlling mediator) effect; all paths are quantified with standardized regression coefficients.

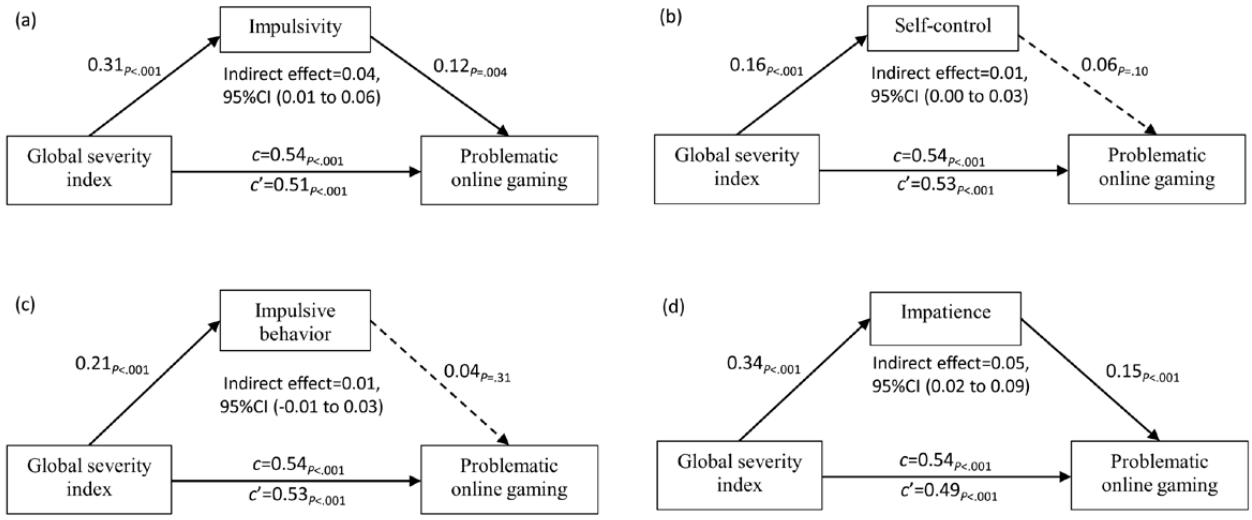


Table 4. Summary of multiple regression analyses for the moderated analysis.

Predictors[a]	Beta	*SE*	*t* test(*df*)	*P* value	95% bootstrap CI
Age[b]	−.06	0.06	−1.04(*492*)	.30	−0.18 to 0.06
Education[b]	−.06	0.05	−1.25(*492*)	.21	−0.16 to 0.04
Work status[b]	.03	0.05	0.60(*492*)	.55	−0.07 to 0.13
GSI[c]	.53	0.04	12.52(*492*)	<.001	0.44 to 0.61
Impulsivity	.12	0.04	3.02(*492*)	.003	0.04 to 0.20
GSI×Impulsivity	−.06	0.04	−1.64(*492*)	.10	−0.13 to 0.01

[a]Dependent variable is POG (problematic online gaming).

[b]Covariate variables; N=5000 bootstrapping resamples.

[c]GSI: Global Severity Index.

Impulsivity

To test the hypothesis regarding a mediating role for impulsivity (H2), the mediating effect of impulsivity as well as indirect effects and direct effects of psychiatric distress on POG was calculated with 5000 bootstrap samples. Age, education, and working status were controlled as covariates. The bootstrap results showed that impulsivity partially mediated the effect of GSI on POG. In particular, the total (nonmediated) effect of GSI was significant and strong (beta=.54, SE 0.04, t_{465}=13.95, P<.001). After controlling for impulsivity, the direct effect of psychiatric distress was weakened but remained significant and strong (beta=.51, SE 0.04, t_{464}=12.50, P<.001). The indirect effect of GSI through impulsivity was significant, with a small effect size estimate (0.04 with a 95% bootstrap CI of 0.01 to 0.06; see model a in Figure 2).

In post hoc analyses, we examined the specific subscales of the BIS-21 in mediation analyses. In the model of self-control and impulsive behavior (see model b and c in Figure 2), the 95% bootstrap CI of the indirect effect included zero, so the mediation effect was not significant. However, the mediation effect of impatience was significant with an effect size estimate of 0.05 with a 95% bootstrap CI of 0.02 to 0.09 (see model d in Figure 2).

To test the moderation effect of impulsivity (H3), a multiple regression analysis was conducted to determine main and interaction effects of impulsivity and GSI on POG. As shown in Table 4, main effects of GSI (beta=.53, P<.001) and impulsivity (beta=.12, P=.003) were both significant, but their interaction term (GSI×Impulsivity) was not significant (P=.10). Thus, the moderation effect of impulsivity was not supported in the study.

Test of Moderated Mediation

As only the impatience subscale of BIS-21 was significant in the mediation model, we further tested H4 and H5 with respect to impatience by adding gender as a moderator into the model. The result revealed that gender significantly moderated the relationship between impatience and POG (beta=.19, P=.02), but its moderation effect in the direct path between GSI and POG was not significant (beta=.08, P=.34; see Table 5).

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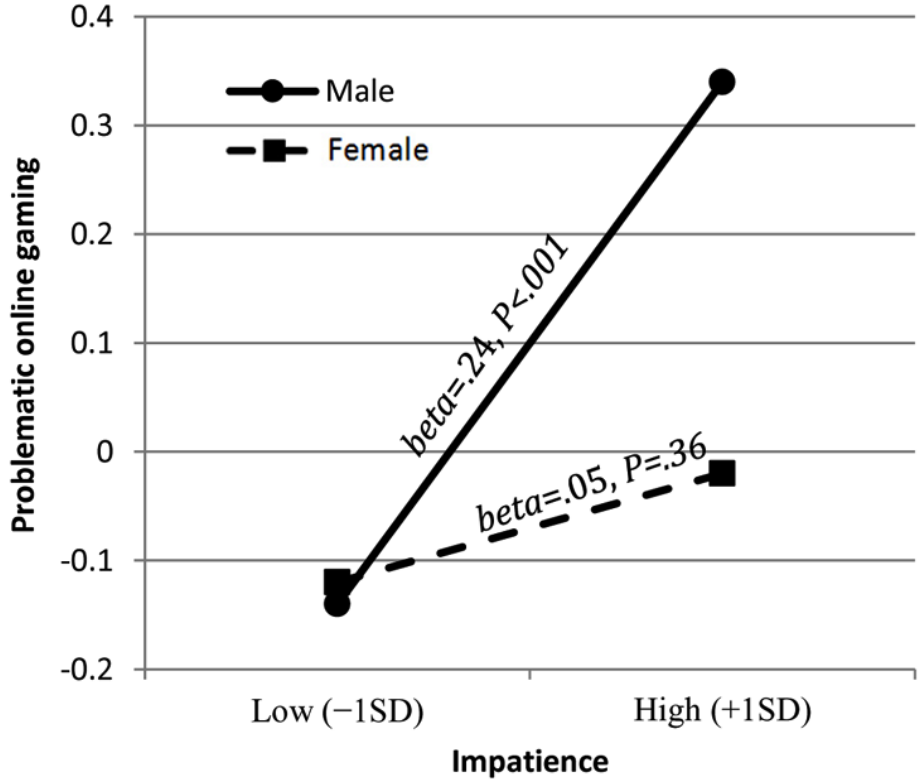
Table 5. Summary of multiple regression analyses for the moderated mediation analysis.

Dependent variables	Beta	*SE*	*t* test(*df*)	*P* value	95% bootstrap CI
Impatience					
Age[a]	−.02	0.07	−0.23(*464*)	.82	−0.15 to 0.12
Education[a]	.02	0.06	0.27(*464*)	.79	−0.10 to 0.13
Work status[a]	.04	0.06	0.69(*464*)	.49	−0.07 to 0.15
GSI[b]	.34	0.04	7.52(*464*)	<.001	0.25 to 0.42
Problematic online gaming					
Age[a]	−.04	0.06	−0.73(*460*)	.47	−0.16 to 0.07
Education[a]	−.07	0.05	−1.50(*460*)	.14	−0.17 to 0.02
Work status[a]	.02	0.05	0.32(*460*)	.75	−0.08 to 0.11
GSI	.53	0.04	12.32(*460*)	<.001	0.44 to 0.61
Impatience	.14	0.04	3.64(*460*)	<.001	0.07 to 0.22
Gender	.17	0.08	2.25(*460*)	.03	0.02 to 0.32
Gender×GSI	.08	0.08	0.96(*460*)	.34	−0.08 to 0.25
Gender×Impatience	.19	0.08	2.35(*460*)	.02	0.03 to 0.34

[a]Covariate variables; N=5000 bootstrapping resamples.

[b]GSI: Global Severity Index.

Figure 3. Simple slopes probing the interaction between gender and impatience in the prediction of problematic online gaming (Z score).



Graphs of the interaction (Gender×Impatience) are presented in Figure 3 with simple slopes, derived from the regression equations, where high and low values of impatience were specified as 1 SD above and below the mean. Results indicate a significant positive association between impatience and POG for males (beta=.24, *P*<.001) but not for females (beta=.05, *P*=.36). In females, impatience and POG were not associated. Testing the indirect effect of psychiatric distress on POG via impulsivity revealed that impatience scores mediated the association between GSI and POG but only in males and not in females (see Table 6).

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Table 6. Conditional direct and indirect effects of Global Severity Index (independent variable) on Problematic Online Gaming (outcome variable) via impatience (mediator) and gender (moderator).

Values of the moderator	Direct effects				Indirect effects		
	Beta	SE	*t* test(*df*)	*P* value	Effect (bootstrap estimate)	SE (bootstrap estimate)	95% bootstrap CI
Male	.57	0.07	8.41(*496*)	<.001	0.08	0.02	0.04 to 0.13
Female	.49	0.05	9.42(*496*)	<.001	0.02	0.02	−0.02 to 0.06

Discussion

Principal Findings

Although several studies have examined links between psychiatric distress and POG [8-11], this study is the first to provide empirical evidence investigating the extent to which impulsivity and facets thereof may mediate and/or moderate this relationship in a gender-sensitive fashion. Our a priori hypotheses were partially supported in which impulsivity mediated the relationship between psychiatric distress and POG. However, this relationship seemed most relevant for impatience and was moderated by gender such that the mediating relationship was evident in males but not females. These findings provide insight into possible mechanisms by which psychiatric distress may influence POG.

The finding that POG was related to psychiatric distress supported H1 and is consistent with previous findings in POG [8-10,43], as well as findings in other behavioral addictions [44,45]. The findings from this study expand upon previous ones through exploration of a role for impulsivity. As hypothesized (H2), the relationship between psychological distress and POG was mediated partially through impulsivity, consistent with studies of problematic gambling [23,24]. However, the hypothesized moderation effect of impulsivity was not observed, consistent with findings from the study by Clarke [24] but not from the study by Tang et al [23]. For POG, psychological distress and impulsivity did not interact to account for POG beyond the main effects. As distress increased, the likelihood of experiencing POG symptoms increased, partially through impulsivity. The results resonate with the pathways model of problematic gambling described by Blaszczynski et al [46]. According to the third path in the model, the effect of impulsivity may be increased when experiencing negative emotions or when feeling pressured or stressed, and impulsivity is proposed to mediate the effects of emotional disturbances on problem and pathological gambling symptoms through an interactive process [46]. Further analysis revealed that this mediation effect only appeared in the dimension of impatience. Previous studies have found that impatience is related to increased substance use [47], pathological gambling [48], and POG [49]. The findings from this study suggest an important role of psychiatric distress that may influence POG indirectly through impatience; therefore, helping to develop skills in specific impatience-related domains (emotion regulation and behavioral control) may be important when treating patients with POG.

Earlier studies have reported that boys were more likely to play online games than girls and also more likely to be problematic players [11,28]. Our results indicate that males did spend more time online playing games compared with females; however, there was no gender-related difference in overall POG (as assessed by POGQ total scores) in the sample from this study. Possible reasons may be related to the sample from this study, which was recruited from gaming-related websites and Facebook pages; therefore, both gender groups may have comprised highly engaged gamers [50]. In this study, females had higher psychological distress than males, but the groups did not differ in levels of impulsivity. Moreover, results provided some support for gender as a moderator among the association between impatience and POG in the mediation model. Specifically, as predicted in H5, the indirect effect of impatience was significant in males but not in females. The result is consistent with previous findings in alcohol-use behaviors, in which impulsivity was correlated with alcohol use in males but not in females [33]. The findings from this study suggest that males may be more vulnerable to POG triggered by impulsivity. However, gender did not moderate the direct effect of psychological distress and POG as hypothesized in H4, which suggests both males and females may exhibit POG symptoms in relation to psychiatric distress.

Limitations and Implications

This research should be viewed in light of several limitations. First, male players are overrepresented (92.5%) in the original sample of gamers (N=5222) recruited online. Therefore, a new matched sample based on the female cohort was used for this study, and the results may not extend to the general population. Second, this study involved cross-sectional survey data. Thus, it does not permit identification of cause-and-effect associations. For example, we could not determine whether psychiatric distress increased POG or whether POG led to distress. It is also possible that there was a reciprocal influence between distress and POG. Future studies should utilize longitudinal methods to examine the directionality of relationships among POG, psychiatric distress, and impulsivity. Third, despite the advantage of a larger sample size, the self-selected data collected online from a Hungarian sample are derived from a convenience sample, thus limiting the generalizability of our findings. The sample likely overrepresents active and highly engaged gamers, as suggested elsewhere [50]. Nevertheless, data from this sample have both limitations and strengths and may be particularly suitable for examining potential roles of impulsivity and psychiatric distress in problematic gaming. The use of different anchor points for Likert scales across instruments in the study also has both strengths and limitations, with strengths including the use of values employed in the originally described and validated instruments and weaknesses including potential complexities in comparing findings internally across

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instruments. Finally, the self-report nature of the data may introduce certain biases (eg, memory recall bias and social desirability bias) that should be considered.

Despite the above limitations, the results have significant clinical implications. Cooccurring features of POG (eg, depression and impulsivity) should be considered in its treatment [51]. The findings in this investigation suggest that because distress affects impulsivity, it may thus be appropriate to treat emotional distress experienced by problematic gamers in addition to treating impulsivity, as suggested by Clarke [24]. Moreover, targeting impulsivity, and particularly impatience, may be helpful to weaken the link between psychiatric distress and POG, especially for males. Cognitive-behavioral therapy, by itself or in conjunction with medication, might be helpful in treating associated impatience/restlessness and emotional distress [52]. As video games are attractive to and accepted by those at risk of POG, they may be considered in novel approaches to help control impulsivity and improve emotion regulation. For example, in other disorders, some video games (eg, PlayMancer) may be effective as additional therapy tools to help improve emotional regulation and impulse control in cases with bulimia nervosa [53] and gambling disorder [54]. The potential therapeutic effect of video games in POG may be worth exploring in future studies. However, one should also consider the potential triggering effects of exposing individuals with POG to online games, especially if abstinence is being targeted. As males with high impulsivity may be more vulnerable to POG than females, future interventions for POG should consider gender-related differences in this domain. Furthermore, given that attention-deficit/hyperactivity disorder (ADHD) has been linked to online gaming [55] and greater impatience/restlessness during abstinence from gaming [56], medications that reduce impulsive behaviors (eg, stimulants like methylphenidate or nonstimulants like atomoxetine) may be helpful in reducing POG, particularly in males. As relationships between ADHD and problematic internet use, more broadly, have been observed, especially in young adults [57], the extent to which the findings and corresponding intervention-related considerations are relevant to a broader range of problematic online behaviors (gambling, shopping, and pornography viewing) warrants direct investigation. Among females, the higher GSI scores suggest that psychopathology may be a greater consideration related to POG in females as compared with males. Given that females exhibit anxiety more frequently than males, they receive more mental health treatment and engage in addictive behaviors like gambling for negative reinforcement motivations [58-60]. Future studies should assess these domains as they relate to POG, particularly in females.

Conclusions

In conclusion, this study provides some of the first empirical data investigating the extent to which impulsivity and its dimensions may mediate and/or moderate relationships between psychiatric distress and POG in a gender-sensitive fashion. The study suggests that impulsivity (specifically impatience) acts as a mediator rather than a moderator in the relationship between psychiatric distress and POG. A moderating effect of gender was not found in the direct relationship between psychiatric distress and POG. However, a moderated mediation analysis suggested that impatience mediated the association between psychiatric distress and POG in males, whereas the indirect effect of impatience was not significant in females. The findings suggest important implications for preventing or treating POG in online gamers. Future studies should examine other individual differences (eg, with respect to age or race/ethnicity) that may also help understand different populations and potentially advance prevention and treatment efforts.

Acknowledgments

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Conflicts of Interest

None declared.

References

1. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders (5th-ed). Washington, DC: American Psychiatric Association; 2013:947.
2. World Health Organization (WHO). 2018. ICD-11: Gaming Disorder URL: https://icd.who.int/dev11/f/en [accessed 2018-10-19] [WebCite Cache ID 73HUQE2R9]
3. Petry NM, Rehbein F, Ko C, O'Brien CP. Internet gaming disorder in the DSM-5. Curr Psychiatry Rep 2015 Sep;17(9):72. [doi: 10.1007/s11920-015-0610-0] [Medline: 26216590]
4. Saunders JB, Hao W, Long J, King DL, Mann K, Fauth-Bühler M, et al. Gaming disorder: its delineation as an important condition for diagnosis, management, and prevention. J Behav Addict 2017 Sep 1;6(3):271-279 [FREE Full text] [doi: 10.1556/2006.6.2017.039] [Medline: 28816494]

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5. Feng W, Ramo DE, Chan SR, Bourgeois JA. Internet gaming disorder: trends in prevalence 1998-2016. Addict Behav 2017 Dec;75:17-24. [doi: 10.1016/j.addbeh.2017.06.010] [Medline: 28662436]
6. Özdemir Y, Kuzucu Y, Ak S. Depression, loneliness and internet addiction: how important is low self-control? Comput Human Behav 2014 May;34:284-290. [doi: 10.1016/j.chb.2014.02.009]
7. Yau YH, Potenza MN, White MA. Problematic internet use, mental health and impulse control in an online survey of adults. J Behav Addict 2013;2(2):72 [FREE Full text] [Medline: 24294501]
8. Kim NR, Hwang SS, Choi JS, Kim DJ, Demetrovics Z, Király O, et al. Characteristics and psychiatric symptoms of internet gaming disorder among adults using self-reported DSM-5 criteria. Psychiatry Investig 2016 Jan;13(1):58-66 [FREE Full text] [doi: 10.4306/pi.2016.13.1.58] [Medline: 26766947]
9. Király O, Urbán R, Griffiths MD, Ágoston C, Nagygyörgy K, Kökönyei G, et al. The mediating effect of gaming motivation between psychiatric symptoms and problematic online gaming: an online survey. J Med Internet Res 2015 Apr 7;17(4):e88 [FREE Full text] [doi: 10.2196/jmir.3515] [Medline: 25855558]
10. Ballabio M, Griffiths MD, Urbán R, Quartiroli A, Demetrovics Z, Király O. Do gaming motives mediate between psychiatric symptoms and problematic gaming? An empirical survey study. Addict Res Theory 2017 Mar 27;25(5):397-408. [doi: 10.1080/16066359.2017.1305360]
11. van Rooij AJ, Kuss DJ, Griffiths MD, Shorter GW, Schoenmakers TM, van de Mheen D. The (co-)occurrence of problematic video gaming, substance use, and psychosocial problems in adolescents. J Behav Addict 2014 Sep;3(3):157-165 [FREE Full text] [doi: 10.1556/JBA.3.2014.013] [Medline: 25317339]
12. Evenden JL. Varieties of impulsivity. Psychopharmacology (Berl) 1999 Oct;146(4):348-361. [Medline: 10550486]
13. van den Bos W, Rodriguez CA, Schweitzer JB, McClure SM. Adolescent impatience decreases with increased frontostriatal connectivity. Proc Natl Acad Sci U S A 2015 Jul 21;112(29):E3765-E3774 [FREE Full text] [doi: 10.1073/pnas.1423095112] [Medline: 26100897]
14. Walther B, Morgenstern M, Hanewinkel R. Co-occurrence of addictive behaviours: personality factors related to substance use, gambling and computer gaming. Eur Addict Res 2012;18(4):167-174 [FREE Full text] [doi: 10.1159/000335662] [Medline: 22398819]
15. Gullo MJ, Dawe S. Impulsivity and adolescent substance use: rashly dismissed as "all-bad"? Neurosci Biobehav Rev 2008 Oct;32(8):1507-1518. [doi: 10.1016/j.neubiorev.2008.06.003] [Medline: 18588911]
16. Stevens L, Verdejo-García A, Goudriaan AE, Roeyers H, Dom G, Vanderplasschen W. Impulsivity as a vulnerability factor for poor addiction treatment outcomes: a review of neurocognitive findings among individuals with substance use disorders. J Subst Abuse Treat 2014 Jul;47(1):58-72. [doi: 10.1016/j.jsat.2014.01.008] [Medline: 24629886]
17. Cao F, Su L, Liu T, Gao X. The relationship between impulsivity and internet addiction in a sample of Chinese adolescents. Eur Psychiatry 2007 Oct;22(7):466-471. [doi: 10.1016/j.eurpsy.2007.05.004] [Medline: 17765486]
18. Lee HW, Choi JS, Shin YC, Lee JY, Jung HY, Kwon JS. Impulsivity in internet addiction: a comparison with pathological gambling. Cyberpsychol Behav Soc Netw 2012 Jul;15(7):373-377. [doi: 10.1089/cyber.2012.0063] [Medline: 22663306]
19. Meerkerk GJ, van den Eijnden RJ, Franken IH, Garretsen HF. Is compulsive internet use related to sensitivity to reward and punishment, and impulsivity? Comput Human Behav 2010 Jul;26(4):729-735. [doi: 10.1016/j.chb.2010.01.009]
20. Choi SW, Kim HS, Kim GY, Jeon Y, Park SM, Lee JY, et al. Similarities and differences among Internet gaming disorder, gambling disorder and alcohol use disorder: a focus on impulsivity and compulsivity. J Behav Addict 2014 Dec;3(4):246-253 [FREE Full text] [doi: 10.1556/JBA.3.2014.4.6] [Medline: 25592310]
21. Ward A, Mann T. Don't mind if I do: disinhibited eating under cognitive load. J Pers Soc Psychol 2000 Apr;78(4):753-763. [Medline: 10794378]
22. Semple SJ, Zians J, Grant I, Patterson TL. Impulsivity and methamphetamine use. J Subst Abuse Treat 2005 Sep;29(2):85-93. [doi: 10.1016/j.jsat.2005.05.001] [Medline: 16135337]
23. Tang CS, Wu AM. Impulsivity as a moderator and mediator between life stress and pathological gambling among chinese treatment-seeking gamblers. Int J Ment Health Addict 2011 Aug;10(4):573-584. [doi: 10.1007/s11469-011-9355-0]
24. Clarke D. Impulsivity as a mediator in the relationship between depression and problem gambling. Pers Individ Dif 2006 Jan;40(1):5-15. [doi: 10.1016/j.paid.2005.05.008]
25. Sampasa-Kanyinga H, Lewis RF. Frequent use of social networking sites is associated with poor psychological functioning among children and adolescents. Cyberpsychol Behav Soc Netw 2015 Jul;18(7):380-385. [doi: 10.1089/cyber.2015.0055] [Medline: 26167836]
26. Mentzoni RA, Brunborg GS, Molde H, Myrseth H, Skouverøe KJ, Hetland J, et al. Problematic video game use: estimated prevalence and associations with mental and physical health. Cyberpsychol Behav Soc Netw 2011 Oct;14(10):591-596. [doi: 10.1089/cyber.2010.0260] [Medline: 21342010]
27. Mottram AJ, Fleming MJ. Extraversion, impulsivity, and online group membership as predictors of problematic internet use. Cyberpsychol Behav 2009 Jun;12(3):319-321. [doi: 10.1089/cpb.2007.0170] [Medline: 19445635]
28. Desai RA, Krishnan-Sarin S, Cavallo D, Potenza MN. Video-gaming among high school students: health correlates, gender differences, and problematic gaming. Pediatrics 2010 Dec;126(6):e1414-e1424 [FREE Full text] [doi: 10.1542/peds.2009-2706] [Medline: 21078729]

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29. Király O, Griffiths MD, Urbán R, Farkas J, Kökönyei G, Elekes Z, et al. Problematic internet use and problematic online gaming are not the same: findings from a large nationally representative adolescent sample. Cyberpsychol Behav Soc Netw 2014 Dec;17(12):749-754 [FREE Full text] [doi: 10.1089/cyber.2014.0475] [Medline: 25415659]
30. Huang CL, Yang SC, Chen AS. Motivations and gratification in an online game: relationships among players' self-esteem, self-concept, and interpersonal relationships. Soc Behav Personal 2015 Mar 21;43(2):193-203. [doi: 10.2224/sbp.2015.43.2.193]
31. Baker JR, Yardley JK. Moderating effect of gender on the relationship between sensation seeking-impulsivity and substance use in adolescents. J Child Adoles Subst 2002 Dec;12(1):27-43. [doi: 10.1300/J029v12n01_02]
32. Stoltenberg SF, Batien BD, Birgenheir DG. Does gender moderate associations among impulsivity and health-risk behaviors? Addict Behav 2008 Feb;33(2):252-265 [FREE Full text] [doi: 10.1016/j.addbeh.2007.09.004] [Medline: 17913380]
33. Nagoshi CT, Wilson JR, Rodriguez LA. Impulsivity, sensation seeking, and behavioral and emotional responses to alcohol. Alcohol Clin Exp Res 1991 Aug;15(4):661-667. [Medline: 1928641]
34. Ko CH, Liu GC, Hsiao S, Yen JY, Yang MJ, Lin WC, et al. Brain activities associated with gaming urge of online gaming addiction. J Psychiatr Res 2009 Apr;43(7):739-747. [doi: 10.1016/j.jpsychires.2008.09.012] [Medline: 18996542]
35. Király O, Tóth D, Urbán R, Demetrovics Z, Maraz A. Intense video gaming is not essentially problematic. Psychol Addict Behav 2017 Nov;31(7):807-817. [doi: 10.1037/adb0000316] [Medline: 28956935]
36. Király O, Sleczka P, Pontes HM, Urbán R, Griffiths MD, Demetrovics Z. Validation of the Ten-Item Internet Gaming Disorder Test (IGDT-10) and evaluation of the nine DSM-5 internet gaming disorder criteria. Addict Behav 2017 Jan;64:253-260. [doi: 10.1016/j.addbeh.2015.11.005] [Medline: 26632194]
37. Demetrovics Z, Urbán R, Nagygyörgy K, Farkas J, Griffiths MD, Pápay O, et al. The development of the Problematic Online Gaming Questionnaire (POGQ). PLoS One 2012;7(5):e36417 [FREE Full text] [doi: 10.1371/journal.pone.0036417] [Medline: 22590541]
38. Derogatis LR. Clinical Psychometric Research. Baltimore; 1993. Brief Symptom Inventory URL: https://www.pearsonclinical.com/psychology/products/100000450/brief-symptom-inventory-bsi.html [accessed 2019-02-01] [WebCite Cache ID 75r7kZYSu]
39. Urbán R, Kun B, Farkas J, Paksi B, Kökönyei G, Unoka Z, et al. Bifactor structural model of symptom checklists: SCL-90-R and Brief Symptom Inventory (BSI) in a non-clinical community sample. Psychiatry Res 2014 Apr 30;216(1):146-154. [doi: 10.1016/j.psychres.2014.01.027] [Medline: 24524946]
40. Patton JH, Stanford MS, Barratt ES. Factor structure of the Barratt impulsiveness scale. J Clin Psychol 1995 Nov;51(6):768-774. [Medline: 8778124]
41. Kapitány-Fövény M, Urbán R, Varga G, Potenza M, Griffiths M, Szekely A. The 21-item Barratt Impulsiveness Scale Revised (BIS-R-21): An alternative three-factor model. Manuscript in preparation 2019 (forthcoming).
42. Hayes A. Introduction to Mediation, Moderation, and Conditional Process Analysis. 2nd ed A Regression-Based Approach. New York: Guilford Press; Dec 13, 2017:692.
43. Starcevic V, Berle D, Porter G, Fenech P. Problem video game use and dimensions of psychopathology. Int J Ment Health Addict 2010 Jul 7;9(3):248-256. [doi: 10.1007/s11469-010-9282-5]
44. Jiménez-Murcia S, Granero R, Wolz I, Baño M, Mestre-Bach G, Steward T, et al. Food addiction in gambling disorder: frequency and clinical outcomes. Front Psychol 2017 Apr;8:473 [FREE Full text] [doi: 10.3389/fpsyg.2017.00473] [Medline: 28421009]
45. Maraz A, Urbán R, Griffiths MD, Demetrovics Z. An empirical investigation of dance addiction. PLoS One 2015 May;10(5):e0125988 [FREE Full text] [doi: 10.1371/journal.pone.0125988] [Medline: 25951077]
46. Blaszczynski A, Nower L. A pathways model of problem and pathological gambling. Addiction 2002;97(5):487-499. [Medline: 12033650]
47. Reynolds B, Fields S. Delay discounting by adolescents experimenting with cigarette smoking. Addiction 2012;107(2):417-424. [doi: 10.1111/j.1360-0443.2011.03644.x] [Medline: 21906199]
48. Wiehler A, Peters J. Reward-based decision making in pathological gambling: the roles of risk and delay. Neurosci Res 2015 Jan;90:3-14. [doi: 10.1016/j.neures.2014.09.008] [Medline: 25269860]
49. Wang Y, Wu L, Zhou H, Lin X, Zhang Y, Du X, et al. Impaired executive control and reward circuit in internet gaming addicts under a delay discounting task: independent component analysis. Eur Arch Psychiatry Clin Neurosci 2017 Apr;267(3):245-255. [doi: 10.1007/s00406-016-0721-6] [Medline: 27506757]
50. Khazaal Y, van Singer M, Chatton A, Achab S, Zullino D, Rothen S, et al. Does self-selection affect samples' representativeness in online surveys? An investigation in online video game research. J Med Internet Res 2014;16(7):e164 [FREE Full text] [doi: 10.2196/jmir.2759] [Medline: 25001007]
51. Han DH, Renshaw PF. Bupropion in the treatment of problematic online game play in patients with major depressive disorder. J Psychopharmacol 2012 May;26(5):689-696 [FREE Full text] [doi: 10.1177/0269881111400647] [Medline: 21447539]
52. Schmitz JM. The interface between impulse-control disorders and addictions: are pleasure pathway responses shared neurobiological substrates? Sex Addict Compulsivity 2005 Apr;12(2-3):149-168. [doi: 10.1080/10720160500203641]

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53. Fagundo AB, Santamaría JJ, Forcano L, Giner-Bartolomé C, Jiménez-Murcia S, Sánchez I, et al. Video game therapy for emotional regulation and impulsivity control in a series of treated cases with bulimia nervosa. Eur Eat Disord Rev 2013 Nov;21(6):493-499. [doi: 10.1002/erv.2259] [Medline: 24092598]
54. Tárrega S, Castro-Carreras L, Fernández-Aranda F, Granero R, Giner-Bartolomé C, Aymamí N, et al. A serious videogame as an additional therapy tool for training emotional regulation and impulsivity control in severe gambling disorder. Front Psychol 2015 Nov 12;6:1721 [FREE Full text] [doi: 10.3389/fpsyg.2015.01721] [Medline: 26617550]
55. Stockdale L, Coyne SM. Video game addiction in emerging adulthood: cross-sectional evidence of pathology in video game addicts as compared to matched healthy controls. J Affect Disord 2018 Jan 1;225:265-272. [doi: 10.1016/j.jad.2017.08.045] [Medline: 28841491]
56. Bidwell LC, Balestrieri SG, Colby SM, Knopik VS, Tidey JW. Abstinence-induced withdrawal severity among adolescent smokers with and without ADHD: disentangling effects of nicotine and smoking reinstatement. Psychopharmacology (Berl) 2018 Jan;235(1):169-178. [doi: 10.1007/s00213-017-4753-z] [Medline: 29018894]
57. Ioannidis K, Treder MS, Chamberlain SR, Kiraly F, Redden SA, Stein DJ, et al. Problematic internet use as an age-related multifaceted problem: evidence from a two-site survey. Addict Behav 2018 Jun;81:157-166 [FREE Full text] [doi: 10.1016/j.addbeh.2018.02.017] [Medline: 29459201]
58. Echeburúa E, González-Ortega I, de Corral P, Polo-López R. Clinical gender differences among adult pathological gamblers seeking treatment. J Gambl Stud 2011 Jun;27(2):215-227. [doi: 10.1007/s10899-010-9205-1] [Medline: 20532964]
59. Potenza MN, Steinberg MA, McLaughlin SD, Wu R, Rounsaville BJ, O'Malley SS. Gender-related differences in the characteristics of problem gamblers using a gambling helpline. Am J Psychiatry 2001 Sep;158(9):1500-1505. [doi: 10.1176/appi.ajp.158.9.1500] [Medline: 11532738]
60. Blanco C, Hasin DS, Petry N, Stinson FS, Grant BF. Sex differences in subclinical and DSM-IV pathological gambling: results from the National Epidemiologic Survey on alcohol and related conditions. Psychol Med 2006 Jul;36(7):943-953. [doi: 10.1017/S0033291706007410] [Medline: 16650342]

Abbreviations

ADHD: attention-deficit/hyperactivity disorder
BIS: Barratt Impulsiveness Scale
GSI: Global Severity Index
POG: problematic online gaming
POGQ: Problematic Online Gaming Questionnaire

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Original Paper

Caregiver Daily Reporting of Symptoms in Autism Spectrum Disorder: Observational Study Using Web and Mobile Apps

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Abstract

Background: Currently, no medications are approved to treat core symptoms of autism spectrum disorder (ASD). One barrier to ASD medication development is the lack of validated outcome measures able to detect symptom change. Current ASD interventions are often evaluated using retrospective caregiver reports that describe general clinical presentation but often require recall of specific behaviors weeks after they occur, potentially reducing accuracy of the ratings. My JAKE, a mobile and Web-based mobile health (mHealth) app that is part of the Janssen Autism Knowledge Engine—a dynamically updated clinical research system—was designed to help caregivers of individuals with ASD to continuously log symptoms, record treatments, and track progress, to mitigate difficulties associated with retrospective reporting.

Objective: My JAKE was deployed in an exploratory, noninterventional clinical trial to evaluate its utility and acceptability to monitor clinical outcomes in ASD. Hypotheses regarding relationships among daily tracking of symptoms, behavior, and retrospective caregiver reports were tested.

Methods: Caregivers of individuals with ASD aged 6 years to adults (N=144) used the My JAKE app to make daily reports on their child's sleep quality, affect, and other self-selected specific behaviors across the 8- to 10-week observational study. The results were compared with commonly used paper-and-pencil scales acquired over a concurrent period at regular 4-week intervals.

Results: Caregiver reporting of behaviors in real time was successfully captured by My JAKE. On average, caregivers made reports 2-3 days per week across the study period. Caregivers were positive about their use of the system, with over 50% indicating that they would like to use My JAKE to track behavior outside of a clinical trial. More positive average daily reporting of overall type of day was correlated with 4 weekly reports of lower caregiver burden made at 4-week intervals (r=–0.27, P=.006, n=88) and with ASD symptoms (r=–0.42, P<.001, n=112).

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Conclusions: My JAKE reporting aligned with retrospective Web-based or paper-and-pencil scales. Use of mHealth apps, such as My JAKE, has the potential to increase the validity and accuracy of caregiver-reported outcomes and could be a useful way of identifying early changes in response to intervention. Such systems may also assist caregivers in tracking symptoms and behavior outside of a clinical trial, help with personalized goal setting, and monitoring of progress, which could collectively improve understanding of and quality of life for individuals with ASD and their families.

Trial Registration: ClinicalTrials.gov NCT02668991; https://clinicaltrials.gov/ct2/show/NCT02668991

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KEYWORDS

autism spectrum disorder; ecological momentary assessment; symptom assessment; mobile app; mHealth; affect; patient reported outcome measures

Introduction

Background

Autism spectrum disorder (ASD) is a complex neurodevelopmental disorder with a prevalence rate of approximately 1% that is characterized by social communication impairments and restricted, repetitive patterns of behavior [1,2]. There are no approved medications for the core symptoms of ASD, which is in part related to a lack of sensitive outcome measures available for use in clinical trials evaluating potential medications [3,4]. For example, Loth et al 2016 report the failure to detect efficacy in compounds that have shown preclinical promise. The heterogeneity of the ASD population and difficulties with detection of short-term changes have led to recent attempts to develop more sensitive measures including biomarkers [5-7] and novel caregiver rating scales [8,9].

ASD interventions are frequently evaluated using caregiver-reported measures administered during study visits [10]. Two common caregiver measurements of behavior change in ASD are the Social Responsiveness Scale-2 (SRS-2), which measures symptoms associated with ASD [11], and the Aberrant Behavior Checklist (ABC) [3], which measures general behaviors. These surveys require recall of specific behaviors over periods of time, up to 6 months in the case of the SRS-2, which can reduce accuracy of ratings. For example, it was found that caregivers remembered ASD symptoms as being worse in the past compared with current reporting [12]. In addition to problems with retrospective recall, caregivers' reports can be subject to bias on the basis of context [13]. For example, completing a scale in a clinic context may yield different responses than those provided in settings where the behavior more typically occurs [14]. A respondent's mood during recall can also influence responses [15]. Finally, measures completed retrospectively are commonly administered before and after an intervention, not during the intervention period, which may limit the ability to assess stability or dynamic change over time and impact detection of potential causal relationships [8,9,16]. Shorter recall periods on symptom reporting scales, for example, the Autism Impact Measure [9] (weeks) and the Autism Behavior Inventory (ABI) [8] (1 week) address this to a certain degree, but these scales could still be influenced by most recent behaviors not necessarily representative of the reporting period.

The advent of mobile health (mHealth) technologies has enabled the development of viable alternatives to retrospective reporting that can facilitate naturalistic logging and recording of behaviors in real or near real time [17,18]. Monitoring of ASD symptoms in a naturalistic setting has the potential to improve reporting validity, leading to increased insight into the condition. Moreover, reporting on symptoms in real time holds the potential to improve accuracy and reliability by reducing episodic memory delays and recall bias [19]. In addition, related to the development of biosensor technologies, real-time observation and reports captured by mHealth have the ability to be used in combination with biometric data to enhance the understanding of the relationship of measures such as actigraphy to classify patterns, symptoms, and behaviors of ASD [20-25].

mHealth approaches could also prove useful in recording transitory factors that reflect or impact mental or behavioral states, such as sleep [26] and caregiver affect [27], items that are more likely to change in the short term. In particular, individuals with ASD have a higher level of reported sleep [28] and psychiatric symptoms, primarily anxiety and mood disorders [29], than the general population; increased anxiety [30-32] and sleep problems [33] are associated with an increase in the severity of the core symptoms of ASD. In addition, a bidirectional relationship has been reported between sleep and internalizing and externalizing behaviors in ASD, as well as a relationship between child sleep and caregiver stress [34-37]. Dynamic measures of these changing states in ASD could lead to better understanding of their effects on core ASD symptoms and help identify more personalized and efficacious interventions.

Paper diaries have been used in clinical trials to obtain information from participants on a daily basis. However, 1 major issue with these approaches, which is prevented with electronic reporting systems, is the reliability of the timing of the report. In 2002, Hufford et al compared the use of paper diaries with electronic reporting and found that although the completion rate was the same at 90%, only 11% of the paper diaries were completed in real time despite what participants reported about their compliance [38].

There is also a need for more idiographic approaches than those afforded by generic scales when considering outcomes that might improve quality of life for patients and caregivers [39,40]. Specific symptoms of most concern to caregivers may not be obvious within change scores of multi-symptom scales, and caregiver-reported responsiveness to treatment may not be detected with these measures [41-43]. Assessments can be

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enriched by focusing on identifying and monitoring change in problems that caregivers identify as important [44]. As mHealth apps offer the potential for deep personalization, they are well-placed to provide opportunities for tracking real-world, meaningful outcomes.

Although the use of apps to monitor and track health data is expanding [45-47], adoption of e-tech into clinical trials has been slow [48]. Within the field of ASD, there are limited publications regarding user experiences, including opinions about a wide range of features and technologies that mobile apps are capable of monitoring and tracking [49]. Although there are examples of mHealth apps for ecological momentary assessment (EMA) self-reporting in high functioning adolescents with ASD [50-52], to our knowledge, no studies of regular daily or real-time reporting by caregivers of individuals with ASD have been reported. Caregiver reporting may be particularly important for understanding concordance between self-report and caregiver report in ASD and for tracking behavior in younger children or individuals with greater intellectual impairment that might limit the ability to self-report.

Aims

To address ASD symptom monitoring and tracking needs, the Janssen Autism Knowledge Engine (JAKE), a dynamically-updated clinical research system, was created to provide quantifiable and reproducible measures for use in assessing treatment outcomes, potentially including detection of change in ASD symptoms and behaviors and ASD subgroup identification.

A comprehensive pilot version of JAKE was developed that considered caregiver feedback from focus groups, review of symptoms and symptom descriptions from expert autism clinicians and beta testing [7]. My JAKE is 1 component of the JAKE system and is a Web and mobile app for use by caregivers and clinicians to log symptoms, record treatments, track progress, and gather detailed medical information. Included in My JAKE is the ABI, a Web-based, caregiver-rated scale for assessing ASD core diagnostic symptoms and associated behavior, designed specifically to provide robust and sensitive outcome measures for ASD clinical trials and other interventional studies [8].

One aim of this study was to test the utility of My JAKE as used by caregivers of individuals with ASD who participated in a noninterventional, observational study for a duration of 8 to 10 weeks. In addition, daily ratings of behaviors were compared with the ABI core and associated symptoms of ASD and periodic, retrospectively-collected paper rating scales. Though there was an exploratory component of the study, prespecified hypotheses were created, and they are shown in Table 1.

Table 1. Correlation hypotheses of overall type of day, sleep, and mood with autism spectrum disorder (ASD) symptoms and behaviors.

Measure	Hypothesis
Overall type of day	• Higher average reports of "overall type of day" will correlate negatively with increased symptoms and behaviors: Core ASD symptoms, challenging behavior, mental health, measured on the ABI[a] • Higher average reports of "overall type of day" will correlate negatively with increased reported caregiver burden on the Zarit Burden Inventory
Sleep	• Daily reported sleep quality will correlate negatively with sleep problems reported on the ABI
Mood	• Average valence reported in the mood report will correlate negatively with symptoms and behaviors reported by caregivers: ABI and ABC[b]; Average arousal reported in the mood report will correlate negatively with symptoms and behaviors reported by caregivers: ABI and ABC • Percentage of reports in each quadrant during the course of the study will correlate with symptoms and behaviors: Quadrant 1 (positive valence, positive arousal) negative correlation with behavior; Quadrant 2 (negative valence, positive arousal) positive correlation with behavior; Quadrant 3 (negative valence, negative arousal) positive correlation with behavior; Quadrant 4 (positive valence, negative arousal) no prediction made

[a]ABI: Autism Behavior Inventory.

[b]ABC: Aberrant Behavior Checklist.

Methods

Materials

My JAKE

My JAKE is a Web and mobile app comprising various modules to help caregivers of individuals with ASD and their health care providers log symptoms, record participant activities, medical information and treatments, and track progress and change in behaviors. Self-report by study participants was not supported. My JAKE is accessible through most Web browsers, as well as an app for mobile devices, and it was used throughout the study. Caregivers were encouraged to use their own computer and mobile device to access My JAKE. My JAKE includes the following elements.

Home Page

A dashboard on the home page provides an overview of the participant's appointments, progress, and notifications of My JAKE sections due to be completed (Figure 1). When caregivers log in to the app or the Web version of My JAKE, they will see the "things to do" list, with reminders of what needs to be completed that day.

An external pop up reminder appears outside the app at 8 pm every evening. Clicking on the pop up will take the caregivers to the home page from where they can complete the tasks that had not already been completed for that day. The progress in

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completing the daily tasks is recorded in the green bar (Figure 1).

Medical/Developmental History

A comprehensive medical and developmental history was completed by caregivers during the screening phase of the study. Certain sections, such as developmental milestones, could be completed throughout the study.

The Autism Behavior Inventory

The ABI included a series of 73 items related to core and associated symptoms of ASD (Figure 2) [39]. The ABI was completed by the primary caregiver at baseline, midpoint (week 4), and endpoint. Specifically, caregivers are asked to report on the behavior observed in the past week.

The Daily Tracker

The Daily Tracker was used to measure sleep and overall type of day (Figure 3). It comprised several questions answered by the caregivers of ASD participants. In this study, all caregivers were asked in the morning "How was (participant name)'s sleep last night?" (Sleep) and in the evening "How was (participant name)'s day?" (Overall type of day). Caregivers could choose up to 3 additional behaviors to track. Questions could be answered by dragging a card along an 8-point scale ranging from "troubling" to "encouraging," either in the My JAKE mobile app or through a Web browser. Picture representation of "good weather" and "bad weather" depicted extremes of the scale, and these icons were selected following extensive user testing with caregivers [7]. Text labels "troubling or encouraging" appear when the user begins to move the card on the screen (shown on right hand side image, Figure 3).

Figure 1. Example of the "to do list" and progress completion apps.

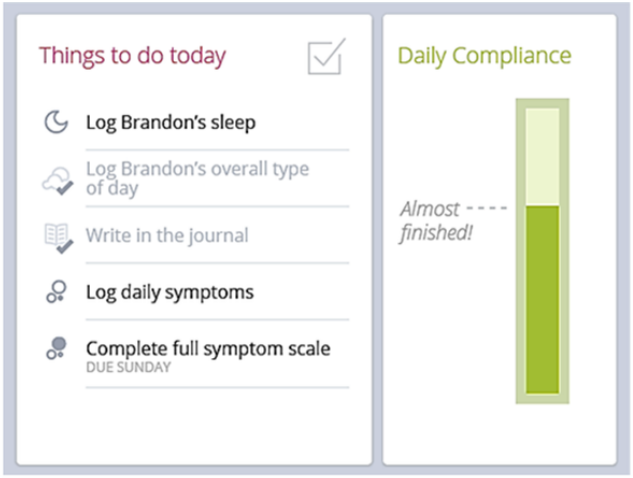
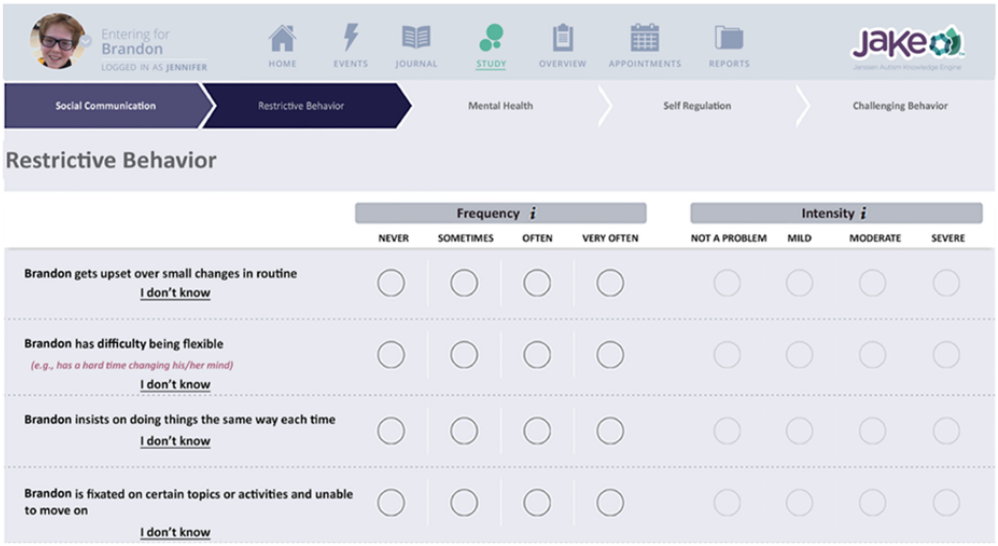


Figure 2. Sample Web-based Aberrant Behavior Checklist to capture autism spectrum disorder symptoms.



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Figure 3. My JAKE Daily Tracker mobile interface: Sleep and overall type of day.



Responses to these questions were tracked and displayed over a 2-week period on the website home page to provide feedback to caregivers and increase engagement in the study.

Mood Report

The circumplex model of affect has a long and widespread history measuring affective or emotional states, including in those with ASD [53,54]. A digital, square version of the classical affective circumplex was created for the My JAKE mobile app for this study (Figure 4). The horizontal axis represents valence, termed "mood," and the vertical axis represents arousal, termed "activity." The model was divided into "Quadrants" of activity and mood relationships. Caregivers were instructed to move the icon representing the participant to a location on the screen that best captured the participant mood at that moment. Caregivers were asked to do this twice a day but could use as many times as desired.

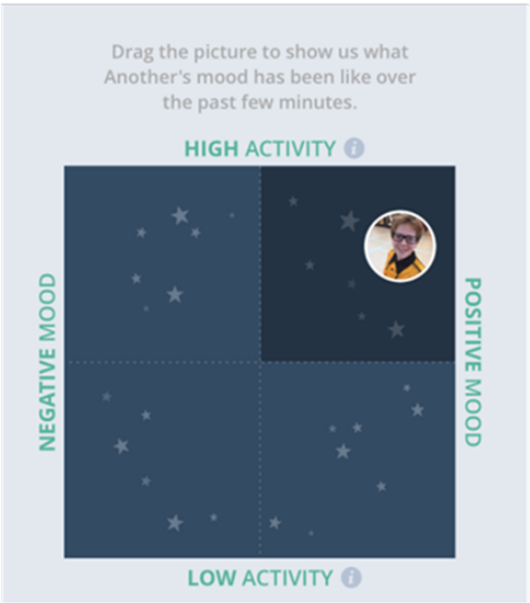
Journal and Event Tracker

Caregivers were able to provide ad hoc free-text entries when tracking both positive and negative events as they occurred, and they were able to track all items of interest, including sleep and diet, on a daily basis. A list of common events for ASD, includes repetitive behaviors and tantrums, allowed real-time and retrospective reporting of specific behavior, which would receive a time stamp, enabling comparison with actigraphy and other biosensor data.

Therapy Tracker

This module allowed tracking of participants' medical treatments or therapies using a calendar-like interface. Caregivers could also optionally export created appointments to a calendaring system of their own choice.

Figure 4. Revised "circumplex" model of affect for the My JAKE mobile app.



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Connection to Microsoft Health Vault

Microsoft HealthVault [55]—a publicly available, Class 1 electronic personal health record system—was used as the storage mechanism for all data created and accessed by My JAKE. All caregivers were required to create an account in Health Vault to enable registration with My JAKE. The use of HealthVault permitted caregivers to own and control their dependent's study data, even after the study ended. In addition, caregivers controlled who, as well as which apps, could access their HealthVault account at any time. As an optional service to reduce caregiver burden, Zweena Health, an external company, entered select medical and developmental history data on behalf of participants into the Microsoft HealthVault account, both directly and through My JAKE.

Standard Instruments for Measuring Change

Caregiver reported rating scales were used to assess ASD symptom change over time. Scales were selected on the basis of their previous use in clinical trials for ASD or recommendations in reviews of scales for use in measuring change in ASD core and associated behavior [56-58].

The ABC, a 58-item behavior rating scale, was used to measure behavior problems across the following 5 subscales: irritability, lethargy (social withdrawal), stereotypy, hyperactivity, and inappropriate speech. Items are rated on a 4-point Likert scale—ranging from 0 (not at all a problem) to 3 (the problem is severe in degree)—with higher scores indicating more severe problems. The ABC has recently been validated for use in ASD [59,60].

The Zarit Burden Interview—Short Version (ZBI) [61]—is a scale with 22 items designed to assess psychological burden experienced by caregivers. Items ask how the caregivers feel, and responses range from 0 to 4 (never to nearly always). The ZBI has been used to assess burden among caregivers of individuals with ASD [62-68]. Using the ZBI, caregivers of individuals with ASD have been found to experience greater burden of care than other caregivers [63] and burden was related to unmet need in young people with ASD, for example, depression, anxiety, and inappropriate behavior [61,69].

The Social Responsiveness Scale 2

Social Responsiveness Scale 2 (SRS-2) identifies presence and severity of social impairment because of ASD. It contains 65 items intended to assess social communication and restricted and repetitive behaviors. A total of 3 forms are available, dependent on the age of the individual with ASD [11].

Participants

The study enrolled males and females aged ≥6 years, between 6.0 and 54.0 years of age, with a confirmed diagnosis of ASD on the basis of Diagnostic and Statistical Manual of Mental Disorders criteria. In addition, participants were required to meet research-determined cut-offs identifying a potential diagnosis of ASD according to the Autism Diagnostic Observation Schedule (ADOS-2). Participants were permitted to receive behavioral and/or pharmacologic interventions for ASD and comorbid disorders during the study, but this was not required. However, study inclusion did require participants to live with a caregiver or if not, to spend at least 3 hours a day for at least 4 days each week or at least 3 weekends a month with a caregiver.

Institutional Review Boards approved the study protocol and its amendments. The study was conducted in accordance with the ethical principles that have their origin in the Declaration of Helsinki, consistent with Good Clinical Practices and applicable regulatory requirements. Participants, their caregivers (for participants <18 years old) or legally authorized representatives provided written informed consent before participating in the study. The study is registered at ClinicalTrials.gov (NCT02668991).

Study Design

This prospective, noninterventional study was conducted from July 06, 2015 to October 14, 2016 at 9 study sites in the United States. The study comprised a 14-day screening phase followed by an 8- to 10-week data-collection phase. Throughout the study, data were collected via My JAKE and additional caregiver report scales were completed on paper.

Procedure

Individuals with ASD and their caregivers were recruited by sites to participate in the study, which involved a screening visit and 3 additional site visits. Participants received a stipend of US $80 to $100 for attendance at each site visit, which lasted around 3 hours. No additional incentives were given for use of My JAKE between visits.

Caregivers were registered to use My JAKE during the baseline visit at the site. The site staff demonstrated the My JAKE app and described requirements for study completion. Caregivers were also provided with a "quick guide" explaining the system and when and how to use it.

The My JAKE home page included an interactive "to do list," which presented and linked required components (Figure 2). Once a required assessment or measure within My JAKE was completed, it was "grayed out" on the list, and progress toward daily completion was updated. A pop-up reminder outside the app appeared daily at 8 pm. After first completing the ABI at the baseline visit, caregivers could select 3 specific behaviors from the ABI item list for regular tracking through the duration of the study. These formed a part of the daily tracker, along with the additional "overall type of day" question. These questions were available for the caregiver to respond from 6 pm until 12 am. The sleep tracker appeared at 5 am each day and a request to complete the mood tracker appeared twice during the day on the "to do list." Caregivers were free to use other components of the app, for example, journal, events tracker, in whichever way they wanted.

Site staff members were able to monitor the caregiver's usage of the app through a clinical dashboard and they had 2 follow up calls (week 1 and week 6) with participants and caregivers at the site visit. Reminders for caregivers to use the app were given at the 4-week midpoint visit, as necessary.

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Exit Interview

Caregivers were asked to provide final feedback on their experience with My JAKE in an exit interview and by completing a 36-question Web-based survey about system functionality. Examples of questions included "Which JAKE components would you like to use outside of a clinical trial?" and "How easy were the following tasks to complete?"

Data Analyses

Correlations between My JAKE daily report measures—for example, 0 to 7 (0=troubling, 7=encouraging) rating on overall type of day, mood report—with ABI and scale domains were calculated using Spearman rank correlations controlling for age and gender.

Features of the mood report analyzed were percentage of time in a given Quadrant—1 to 4 (1=top right, 2=top left, 3=bottom left, 4=bottom right; Figure 4)—percentage of positive valence or arousal, average valence or arousal, and variability of valence or arousal.

All features were averaged over the entire duration of the study and compared with the baseline ABI Core ASD symptoms, associated behaviors, mental health (MH), self-regulation, challenging behavior, and the ZBI. Data were included in these analyses when there were 12 or more reports available.

In addition, the features reported the week before midpoint and the week before endpoint were averaged and compared with scales completed for the corresponding time period. Data were included in analyses for weekly features when there were 3 or more reports available.

Results

Study Population

Participants

A total of 144 participants with a diagnosis of ASD were enrolled; 136 (94.4%) participants completed the study and 8 (5.6%) participants discontinued. The most common reason for discontinuation was self-withdrawal from the study (6; 4.2%). The majority of the ASD study population sample was male (77.8%), consistent with higher male:female ratio in ASD [49]. Mean (SD) age of participants was 14.6 (7.8) years. Mean (SD) ADOS total score of the participants was 7.6 (1.7), and intelligence quotient (IQ) was 99.2 (19.6).

Respondents

A majority of caregivers (41%) were between the ages of 41 to 50 years. Mothers made up 79.9% (115/144) of all caregivers. Most caregivers (32.6%; 47/144) had a bachelor's degree (Table 2).

Table 2. Caregiver demographics (N=144).

Characteristic	n (%)
Age group (years)	
Missing	10 (6.9)
20-30	5 (3.5)
31-40	41 (28.5)
41-50	59 (41.0)
>50	29 (20.1)
Relationship	
Missing	10 (6.9)
Father	12 (8.3)
Grandparent	1 (0.7)
Mother	115 (79.9)
Other caregiver (nonfamily member)	1 (0.7)
Other family member	5 (3.5)
Education level	
Missing	14 (9.7)
Doctorate degree	3 (2.1)
Professional degree	6 (4.2)
Master's degree	23 (16.0)
Bachelor's degree	47 (32.6)
Some college, no degree	41 (28.5)
High School graduate	9 (6.3)
Less than high school	1 (0.7)

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Data Collected

Caregivers were asked about overall type of day and sleep once per day and asked to complete the mood reports twice per day (Table 3). The average number of caregiver reports per caregiver, completed over the 8-week study, was highest for mood. A total of 12 caregivers (8%) elected not to use My JAKE during the study. More reports were given for younger participants (<13 years of age) than for older participants (≥13 years of age) over the study period (Table 3). The frequency of caregiver reports obtained by week across the course of the study for overall type of day, sleep, and mood is shown in Figure 5. A linear mixed-effect model with random intercept, having participant as random factor and time (week) as fixed covariate, was used for modeling of weekly number of reports per participant to test whether there were changes in number of weekly reports as a function of time in the study. The number of weekly "overall day" reports per participant significantly decreases at rate 0.025 reports/week (P<.001, 95% CI–0.20 to –0.11), and the number of weekly "mood" reports per participant significantly decreases at rate 0.23 reports/week (P<.001, 95% CI–0.32 to –0.14). A decrease in reporting of sleep was not significant.

Caregiver ratings were obtained from the exit interview on ease of use and mood report. Most caregivers reported their comfort level using the mobile app as "easy"—37.0 % (40/108)—or "very easy"—37.0% (40/108; Figure 6). Over half of the caregivers responded that they were either likely or very likely to use the mood report outside of clinical trials.

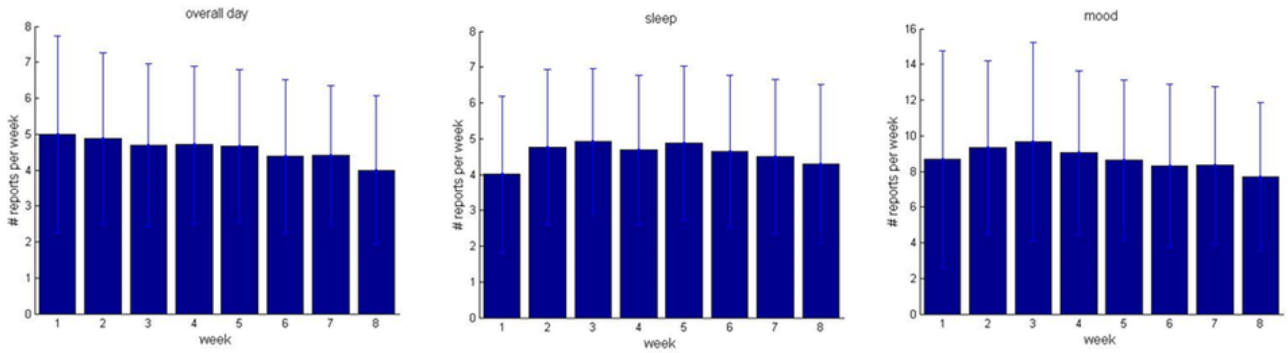
Table 3. Average number of caregiver reports given for age subgroups (N=132).

Variable	Mean (SD)
Mood report	
All participants	61.2 (35.62)
<13 years[a]	67.5 (38.86)
≥13 years[b]	53.5 (30.54)
Overall day	
All participants	29.8 (35.62)
<13 years[a]	31.3 (17.62)
≥13 years[b]	27.9 (16.97)
Sleep	
All participants	28.4 (35.62)
<13 years[a]	32.1 (19.07)
≥13 years[b]	23.9 (18.24)

[a]n=72 for <13 years of age.

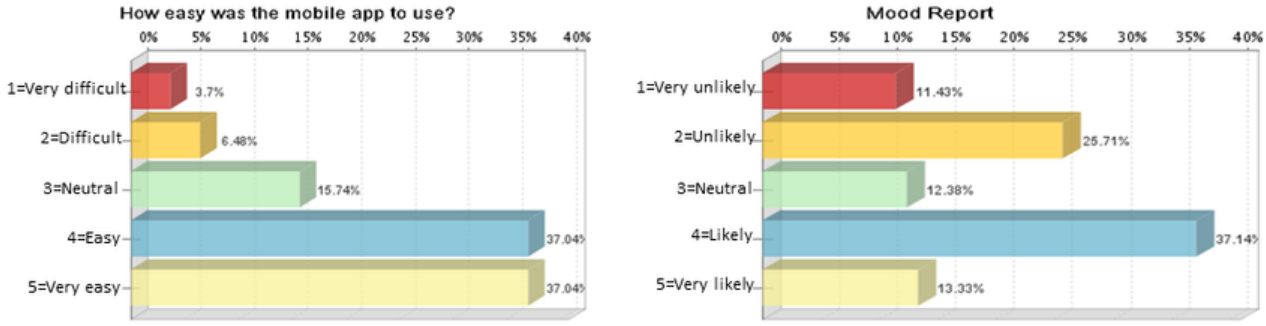
[b]n=60 for ≥13 years of age.

Figure 5. Frequency of caregiver reports over the course of the study, shown as average number of weekly reports with correspondent standard deviations: overall day, sleep, and mood.



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Figure 6. Caregiver rating on the use of the mobile app and the likelihood of using the mood report outside of a clinical trial.



Caregiver Selected Behaviors

Caregivers used the behavior selection component of My JAKE to choose 3 behaviors from the ABI that they wanted to track during the study. The most commonly selected behavior was "sleep problems" (Table 4).

Sleep Tracker

Caregivers' daily reports of sleep displayed a significant negative correlation (P<.001) with retrospective reporting on the ABI sleep domain for average rating for the duration of the study and for averaged ratings in the 7 days before midpoint and endpoint visits (Table 5). A negative correlation was expected because a higher score on the ABI sleep symptoms indicates worse symptoms and vice versa.

Overall Type of Day

Overall type of day rating scores was averaged across all days in the study and then compared with ABI baseline scale scores for core ASD symptoms, challenging behavior, and MH domains a week after baseline, a week before the week 4 visit, and endpoint. Caregiver rating of overall type of day showed correlations with retrospective caregiver report measures (Table 6). As with sleep measures, a negative correlation was expected with ABI core symptoms, challenging behavior, and MH. In addition, the rating of overall type of day across the duration of the study negatively correlated with caregiver reported burden using the ZBI (n=114, r=–0.24, P=.005).

Mood Report

Average Valence

Average valence for the study duration and for the week before midpoint and endpoint was compared with retrospective caregiver reports (Table 7). Average valence was negatively correlated with symptoms and behaviors. In particular, reported negative valence was associated with increased ASD core symptoms (ABI) and increased challenging behaviors across all time points.

Table 4. Summary of most commonly selected Autism Behavior Inventory (ABI) daily tracking items.

Rank	Frequency[a]	ABI item selected for tracking
1	24	Has sleep problems
2	20	Acts without thinking
3	19	Has difficulty being flexible
4	18	Is fixated on certain topics or activities and unable to move on
4	18	Worries about things
4	18	Is tense or anxious
7	16	Is irritable and whiny
8	14	Shows inappropriate affection toward unfamiliar people
9	13	Has sensitivities to certain food textures
9	13	Reacts with aggression when he or she is upset or stressed
11	11	Is able to take turns in conversation
11	11	Is anxious in social situations
11	11	Is excessively active
14	10	Directs facial expression toward other people to communicate feelings
14	10	Insists on saying words and phrases over and over

[a]Number of caregivers selecting the item to track.

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Table 5. Correlation coefficients of daily sleep reports with retrospective reports.

Daily tracker sleep	ABI[a] sleep
Duration (n=104)	–0.62
7 days before midpoint (n=78)	–0.67
7 days before endpoint (n=78)	–0.63

[a]ABI: Autism Behavior Inventory.

Table 6. Overall type of day correlations with Autism Behavior Inventory (ABI) core and other ABI domains, and Zarit Burden Interview (ZBI).

Overall type of day	ABI core symptoms	Challenging behavior	Mental health	ZBI caregiver burden
Study duration (n=112); ZBI (n=114)	–0.42	–0.35	–0.38	–0.24
Midpoint (n=82)	–0.34	–0.42	–0.29	–0.27
Endpoint (n=80)	–0.32	–0.45	–0.26	–0.27

Table 7. Correlations of average valence with Autism Behavior Inventory (ABI) core and other domains and autism spectrum disorder (ASD) behaviors.

Timepoint	ABI core ASD symptom scale score	ABI mental health	ABI self-regulation	ABI challenging behavior	ABC[a] hyperactivity noncompliance	ABC lethargy social withdrawal
Duration (n=111)	–0.26[b]	–0.32[c]	–0.25[b]	–0.29[c]	–0.16	–0.29[c]
Week 4 (n=95)	–0.34[c]	–0.35[c]	–0.21[b]	–0.32[c]	–0.15	–0.25[b]
Endpoint (n=93)	–0.26[b]	–0.12	–0.16	–0.25[b]	–0.06	–0.09

[a]ABC: Aberrant Behavior Checklist.

[b]Significant relationship(P<.05) among average valence and ABI core and other domains and ASD behaviors.

[c]Significant relationship (P<.001) among average valence and ABI core and other domains and ASD behaviors.

Table 8. Correlations of quadrants of activity and mood relationships with Autism Behavior Inventory (ABI) core and other domains, and autism spectrum disorder (ASD) behaviors.

Quadrant	ABI core ASD symptom scale score	ABI mental health	ABI self-regulation	ABI challenging behavior	ABC[a] hyperactivity noncompliance	ABC lethargy social withdrawal
1	–0.12	–0.30	–0.17	–0.25	–0.07	–0.07
2	0.18	0.26	0.27	0.31	0.21	0.21
3	0.19	0.29	0.18	0.23	0.17	0.17
4	–0.01	0.10	–0.01	0.05	–0.04	–0.04

[a]ABC: Aberrant Behavior Checklist.

Average Arousal

Average arousal was also compared for the same time points and no significant correlations were found.

Quadrant Reports

The percentage of reports in each quadrant of the mood report across the duration of the study was compared with caregiver reported scales at study baseline (Table 8). Negative correlations were expected between reports in quadrant 1 and increased severity of behavior (Table 1). Those with the fewest reports in quadrant 1 reported challenging behaviors (r=–0.25, P=.01) and MH (r=–0.30, P=.001). In contrast, positive correlations were expected among reports in other quadrants. In quadrant 2 (low valence, high arousal), significant positive correlations were found with MH (r=0.26, P=.006), challenging behavior (r=0.31, P=.06), and self-regulation (r=0.27, P=.005). In quadrant 3 (low valence, low arousal) significant positive correlations were found with MH (r=0.29, P=.003), challenging behavior (r=0.23, P=.02) and core ASD symptoms (r=0.19, P=.45). There were no significant correlations for quadrant 4 (high valence, low arousal).

Discussion

Principal Findings

To our knowledge, this 8- to 10-week prospective, observational study including caregiver reporting using an mHealth app appears to be the first study of its kind and size in ASD. Caregivers who were using the app, reporting on 4 to 5 days of the week, were able to use My JAKE successfully to report mood, overall type of day, and sleep. There was some decline in reporting over time possibly as caregivers were requested, not mandated, to provide daily reports, but a large proportion

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of caregivers continued to provide regular reports on their child's behavior over the course of the 8-week study. Reminders within the system and native to the phone app were limited to once per day, and missed assessments could not be retroactively completed, which meant that daily reports were guaranteed within real time. A few studies have addressed feasibility and compliance with these types of measures, but in a 2-week smoking cessation EMA study, Shiffman et al reported that responsiveness dropped in half of the participants by day 14 [16]. In comparison, a larger proportion of respondents in this study continued to provide daily reports at midpoint (4 weeks) and endpoint. Our data suggest that those caregivers who were still providing reports were doing so at the same rate as when the study began. It was also not unexpected that caregivers of younger children reported more often than caregivers of adolescents and young adults. Due to the exploratory nature of this study, other than the built-in pop-up reminders and midpoint visit, there were no other specific or consistent attempts to increase adherence and participation. However, clinical teams at sites had access to a dashboard, which enabled real-time viewing of data entry points. It would be possible for reports identified as key outcome measures to be more closely monitored and participation to be reinforced through telephone or text reminders by increased initial training on the use of the app. The current feasibility study had many components, including the use of biosensors in the clinic and at home, meaning potentially less focus was on the reporting in the app. In addition, it is expected that in the absence of an intervention, caregiver motivation to monitor and report behaviors will be less. We are currently implementing My JAKE in a 12-week interventional study. This version has some enhanced features for reminders and reduced, more specific requirements for caregivers. It also has an additional training session for parents on the use of the app, with increased support in selecting behaviors of interest to track. Furthermore, in response to parent feedback, interactive features for monitoring and viewing daily reports have been added to the app (whereas they were previously available on the Web). We will observe the influence that these enhancements have on parent reporting.

The use of daily tracking of symptoms by caregivers could be a useful way of identifying early change in response to intervention. Sleep problems were most commonly prioritized by caregivers to track, and 3 items relating to anxiety also appeared in the top 15 items selected by caregivers, confirming research on the prevalence of these cooccurring problems in ASD and the importance of these behaviors to caregivers [70,71]. Other items were consistent with those commonly described by caregivers in clinical settings such as hyperactivity or impulsivity, rigidity, aggression, and problems with social interaction or interpretation [72,73].

Daily measures of behavior showed significant correlations with the ABI and other scales, suggesting that daily electronic tracking of symptoms by caregivers could be a useful way of identifying early change in response to intervention. In particular, the single question regarding "overall type of day" correlated with caregiver report of core symptom severity. Overall type of day also correlated negatively with caregiver report of burden (ZBI), consistent with research on the impact of ASD symptoms and behavior on caregiver strain [74,75], and it has a possibility, with further validation, for use as a global index for caregiver-reported change. It is difficult to address the validity of a new measure, especially in relation to an existing measure [16]. Some concordance is expected, and it was seen in this study, indicating that similar constructs and concepts were being reported by caregivers in both real time and retrospectively. Further triangulation of data is important, for example, use of biosensor actigraphy information alongside daily sleep reports, and consideration of the relationship between physiological changes, detected by biosensors, and parent daily report as well as retrospective reports. This will be a focus of data analysis in our next clinical trial using My JAKE. In addition, we will be investigating the relationship of daily reports with measures of symptom and behavior change from other informants, such as the Clinician Global Impression of Severity [76].

Caregivers reported that they found My JAKE easy-to-use, which was a likely contributor to their willingness and expressions of interest in using the system outside of a clinical trial. In particular, caregivers made use of the mood report, which allowed them quick and easy reporting on 2 dimensions of valence and arousal with a single action. Although valence correlated with ABI domains, arousal did not. The use of quadrants that combined the 2 features is a potentially useful way to measure and report mood, as it takes into account the second dimension of arousal. Further investigation into the relationship of quadrant reports and behavior will be carried out to establish the value of the 2-dimensional mood report for measuring mood in ASD. In addition, variability in mood or caregiver affect as interpreted by a caregiver or observer is a feature of particular interest when caregivers report regularly over a period of time. It should be noted that no anchor words were provided for reference on any part of the mood report, that is, caregivers were left to provide their own definitions while rating valence and arousal. Thus, the scale may be partly self-referential, and may require other analytic methods to objectively characterize scale performance (ie, operationally defining clinically meaningful change).

Study Limitations

The caregiver burden in this study was considerable. In addition to either filling in or curating a lengthy medical and developmental history, caregivers were expected to use My JAKE to report on their child's behavior several times per day and this led to missing data. A better sampling strategy, including focus on only a few elements, is currently being implemented in an interventional study to prevent data loss and could contribute to keeping caregiver burden low and quality and utility of data high.

We also observed a differential pattern of reporting that included fewer assessments completed for caregivers of adolescents and adults compared with children. This may be because of a lack of awareness of behaviors, less frequent contact or observation opportunity, or other factors, and it should be taken into consideration when selecting completion requirements in future studies.

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Although this was a relatively heterogeneous group of individuals with ASD, it would be helpful to obtain data for participants across the spectrum of severity and IQ to determine whether there are meaningful patterns of differences. This would necessarily require a much larger sample than allowed by this initial study.

Data were generally provided by the primary caregiver. It may be important to have data from other collateral sources such as school or program staff or self-reported data from individuals with ASD who are capable of providing feedback on their own behavior.

Though My JAKE was not used by caregivers for EMA in this study, it does have the capacity to do so with a minor modification. However, the burden of more frequent prompts and reminders for caregivers would need to be considered, in contrast with the need for consistency of many repeated measures over fluctuating periods of time. In addition, caregivers are not always with the child to report behaviors in real time (or the nature of a distracting behavior itself may make reporting difficult). The ability of My JAKE to be used for real-time and retrospective reporting of events increases its flexibility to be used to collect the type of data most relevant to outcomes of interest for a particular intervention while considering what is least burdensome for caregivers. We plan to use the event reporting from our current intervention study to correlate with biosensor data obtained from an actigraphy watch that participants with ASD will wear over the 12-week period. The use of biosensor data will also improve our understanding of the content validity of daily assessments, providing an opportunity for comparison with objective measures alongside the retrospective parent reports.

Next Steps

My JAKE is currently employed in an interventional clinical study in ASD. Learnings from this study relating to frequency and burden of caregiver reporting, specific instructions to caregivers, and ability of study sites to train and support caregivers in regular use of the app have been used to ensure maintenance of quality and useful data for measuring outcomes. The current version of My JAKE is also suitable for multiple raters, including teachers and other health care professionals, enabling the possibility of additional reporting across a broader range of contexts, settings, and perspectives. Finally, with some adaptations, the app has the potential to allow for self-reporting in more cognitively-able and older individuals with ASD. This would add an important dimension to the assessment of change in symptoms over time.

Conclusions

To our knowledge, this study represents the first reported implementation of an mHealth app in a large number of caregivers for electronically tracking behaviors in ASD. Caregivers were successful in using My JAKE to report behaviors, and reported behaviors largely agreed with other more traditional retrospective reports. The study findings will aid in selecting specific outcome measures, leading to fewer and more specific reporting requirements from caregivers, with the expected result of reduced caregiver burden, improved data quality, and potentially more sensitive and meaningful outcomes in monitoring behavior of individuals with ASD.

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Authors' Contributions

AB, NVM, MB, SJ, AS, MC, MSG, GD, BL, RH, FS, SN, and GP were involved in study design, data collection, analysis or interpretation of the results, drafting or revising the manuscript, and final approval of the manuscript. DL was responsible for the statistical analyses. All authors had full access to all study data, and they take responsibility for the integrity of the data and the accuracy of the data analysis. All authors have approved the final manuscript.

Conflicts of Interest

AB, JM, NVM, DL, MB, AS, SJ, MC, SN, and GP are employees of Janssen Research & Development, LLC and may hold company stocks or stock options. GD is on the Scientific Advisory Boards of Janssen Research and Development and Akili, Inc, a consultant to Roche, has received grant funding from Janssen Research and Development, LLC and Perkin Elmer, and receives royalties from Guildford Press and Oxford University Press. MSG has received research and consulting funding from Janssen Research & Development, LLC. RH received reimbursement for consultation from Janssen Research & Development, LLC. BL has received research grant funding from the NIH, is a consultant to Janssen Research & Development, LLC and the Illinois Children’s Healthcare Foundation, and is a board member of the Brain Research Foundation. FS is on the Scientific Advisory

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References

1. Centers for Disease Control and Prevention. 2017. Data & Statistics on Autism Spectrum Disorder URL: https://www.cdc.gov/ncbddd/autism/data.html [accessed 2018-05-10] [WebCite Cache ID 6zJo4l0cm]
2. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders: DSM-5. Arlington, TX: American Psychiatric Publishing; 2013.
3. Aman MG, Novotny S, Samango-Sprouse C, Lecavalier L, Leonard E, Gadow KD, et al. Outcome measures for clinical drug trials in autism. CNS Spectr 2004 Jan;9(1):36-47 [FREE Full text] [Medline: 14999174]
4. Ghosh A, Michalon A, Lindemann L, Fontoura P, Santarelli L. Drug discovery for autism spectrum disorder: challenges and opportunities. Nat Rev Drug Discov 2013 Oct;12(10):777-790. [doi: 10.1038/nrd4102] [Medline: 24080699]
5. Loth E, Charman T, Mason L, Tillmann J, Jones EJ, Wooldridge C, et al. The EU-AIMS Longitudinal European Autism Project (LEAP): design and methodologies to identify and validate stratification biomarkers for autism spectrum disorders. Mol Autism 2017 Jun;8:24 [FREE Full text] [doi: 10.1186/s13229-017-0146-8] [Medline: 28649312]
6. Loth E, Spooren W, Ham LM, Isaac MB, Auriche-Benichou C, Banaschewski T, et al. Identification and validation of biomarkers for autism spectrum disorders. Nat Rev Drug Discov 2016 Jan;15(1):70-73. [doi: 10.1038/nrd.2015.7] [Medline: 26718285]
7. Ness SL, Manyakov NV, Bangerter A, Lewin D, Jagannatha S, Boice M, et al. JAKE® Multimodal Data Capture System: insights from an Observational Study of Autism Spectrum Disorder. Front Neurosci 2017;11:517 [FREE Full text] [doi: 10.3389/fnins.2017.00517] [Medline: 29018317]
8. Bangerter A, Ness S, Aman MG, Esbensen AJ, Goodwin MS, Dawson G, et al. Autism Behavior Inventory: a novel tool for assessing core and associated symptoms of autism spectrum disordera. J Child Adolesc Psychopharmacol 2017 Nov;27(9):814-822 [FREE Full text] [doi: 10.1089/cap.2017.0018] [Medline: 28498053]
9. Kanne SM, Mazurek MO, Sikora D, Bellando J, Branum-Martin L, Handen B, et al. The Autism Impact Measure (AIM): initial development of a new tool for treatment outcome measurement. J Autism Dev Disord 2014 Jan;44(1):168-179. [doi: 10.1007/s10803-013-1862-3] [Medline: 23748386]
10. Lord C. Methods and measures of behavior in the diagnosis of autism and related disorders. Psychiatr Clin North Am 1991 Mar;14(1):69-80. [Medline: 2047333]
11. Constantino JN, Davis SA, Todd RD, Schindler MK, Gross MM, Brophy SL, et al. Validation of a brief quantitative measure of autistic traits: comparison of the social responsiveness scale with the autism diagnostic interview-revised. J Autism Dev Disord 2003 Aug;33(4):427-433. [doi: 10.1023/A:1025014929212] [Medline: 12959421]
12. Jones RM, Risi S, Wexler D, Anderson D, Corsello C, Pickles A, et al. How interview questions are placed in time influences caregiver description of social communication symptoms on the ADI-R. J Child Psychol Psychiatry 2015 May;56(5):577-585 [FREE Full text] [doi: 10.1111/jcpp.12325] [Medline: 25243378]
13. Coyne JC, Gottlieb BH. The mismeasure of coping by checklist. J Pers 1996 Dec;64(4):959-991. [doi: 10.1111/j.1467-6494.1996.tb00950.x] [Medline: 8956519]
14. Rutherford C, Costa D, Mercieca-Bebber R, Rice H, Gabb L, King M. Mode of administration does not cause bias in patient-reported outcome results: a meta-analysis. Qual Life Res 2016 Mar;25(3):559-574. [doi: 10.1007/s11136-015-1110-8] [Medline: 26334842]
15. Heide M, Gronhaug K. Respondents' Moods As a Biasing Factor in Surveys: an Experimental Study, in NA - Advances in Consumer Research. Provo, UT: Association for Consumer Research; 1991. URL: http://www.acrwebsite.org/volumes/7218/volumes/v18/NA-18 [WebCite Cache ID 74OVyoc04]
16. Shiffman S, Stone AA, Hufford MR. Ecological momentary assessment. Annu Rev Clin Psychol 2008;4:1-32. [Medline: 18509902]
17. Stone AA, Shiffman S. Capturing momentary, self-report data: a proposal for reporting guidelines. Ann Behav Med 2002;24(3):236-243. [Medline: 12173681]
18. Woodard CR, Goodwin MS, Zelazo PR, Aube D, Scrimgeour M, Ostholthoff T, et al. A comparison of autonomic, behavioral, and parent-report measures of sensory sensitivity in young children with autism. Research in Autism Spectrum Disorders 2012 Jul;6(3):1234-1246. [doi: 10.1016/j.rasd.2012.03.012]
19. Damiano CR, Mazefsky CA, White SW, Dichter GS. Future directions for research in autism spectrum disorders. J Clin Child Adolesc Psychol 2014;43(5):828-843 [FREE Full text] [doi: 10.1080/15374416.2014.945214] [Medline: 25216048]
20. W Adams Z, McClure EA, Gray KM, Danielson CK, Treiber FA, Ruggiero KJ. Mobile devices for the remote acquisition of physiological and behavioral biomarkers in psychiatric clinical research. J Psychiatr Res 2017 Dec;85:1-14 [FREE Full text] [doi: 10.1016/j.jpsychires.2016.10.019] [Medline: 27814455]
21. Goodwin MS, Intille SS, Albinali F, Velicer WF. Automated detection of stereotypical motor movements. J Autism Dev Disord 2011 Jun;41(6):770-782. [doi: 10.1007/s10803-010-1102-z] [Medline: 20839042]

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22. Großekathöfer U, Manyakov NV, Mihajlović V, Pandina G, Skalkin A, Ness S, et al. Automated detection of stereotypical motor movements in autism spectrum disorder using recurrence quantification analysis. Front Neuroinform 2017;11:9 [FREE Full text] [doi: 10.3389/fninf.2017.00009] [Medline: 28261082]
23. Hossain SM, Ali AA, Rahman M, Ertin E, Epstein D, Kennedy A, et al. Identifying drug (cocaine) intake events from acute physiological response in the presence of free-living physical activity. IPSN 2014;2014:71-82 [FREE Full text] [Medline: 25531010]
24. Kratz A, Braley T, Whibley D, Murphy S. Are nights of poor sleep related to greater next-day fatigue and pain in older adults with symptomatic osteoarthritis? An actigraphy and ecological momentary assessment study. J Pain 2018;19(3):S7-S8. [doi: 10.1016/j.jpain.2017.12.037]
25. Staples P, Torous J, Barnett I, Carlson K, Sandoval L, Keshavan M, et al. A comparison of passive and active estimates of sleep in a cohort with schizophrenia. NPJ Schizophr 2017 Oct 16;3(1):37 [FREE Full text] [doi: 10.1038/s41537-017-0038-0] [Medline: 29038553]
26. Libman E, Fichten C, Bailes S, Amsel R. Sleep questionnaire versus sleep diary: which measure is better? Int J Rehabil Health 2000;5(3):205-209. [doi: 10.1023/A:1012955423123]
27. Wenze SJ, Miller IW. Use of ecological momentary assessment in mood disorders research. Clin Psychol Rev 2010 Aug;30(6):794-804. [doi: 10.1016/j.cpr.2010.06.007] [Medline: 20619520]
28. Malow BA, Connolly HV, Weiss SK, Halbower A, Goldman S, Hyman SL, et al. The Pediatric Sleep Clinical Global Impressions Scale-a new tool to measure pediatric insomnia in autism spectrum disorders. J Dev Behav Pediatr 2016 Jun;37(5):370-376. [doi: 10.1097/DBP.0000000000000307] [Medline: 27244298]
29. Russell AJ, Murphy CM, Wilson E, Gillan N, Brown C, Robertson DM, et al. The mental health of individuals referred for assessment of autism spectrum disorder in adulthood: a clinic report. Autism 2016 Dec;20(5):623-627. [doi: 10.1177/1362361315604271] [Medline: 26471427]
30. Lidstone J, Uljarevi M, Sullivan J, Rodgers J, McConachie H, Freeston M. Relations among restricted and repetitive behaviors, anxiety and sensory features in children with autism spectrum disorders. Res Autism Spectr Disord 2014;8(2):82-92. [doi: 10.1016/j.rasd.2013.10.001]
31. Miller A, Vernon T, Wu V, Russo K. Social skill group interventions for adolescents with autism spectrum disorders: a systematic review. Rev J Autism Dev Disord 2014 Jun 5;1(4):254-265. [doi: 10.1007/s40489-014-0017-6]
32. Spiker MA, Lin CE, Van Dyke M, Wood JJ. Restricted interests and anxiety in children with autism. Autism 2012 May;16(3):306-320. [doi: 10.1177/1362361311401763] [Medline: 21705474]
33. Veatch OJ, Sutcliffe JS, Warren ZE, Keenan BT, Potter MH, Malow BA. Shorter sleep duration is associated with social impairment and comorbidities in ASD. Autism Res 2017 Jul;10(7):1221-1238. [doi: 10.1002/aur.1765] [Medline: 28301091]
34. Adams HL, Matson JL, Cervantes PE, Goldin RL. The relationship between autism symptom severity and sleep problems: Should bidirectionality be considered? Res Autism Spectr Disord 2014;8(3):193-199 [FREE Full text] [doi: 10.1016/j.rasd.2013.11.008]
35. Hollway J, Aman M, Butter E. Correlates and risk markers for sleep disturbance in participants of the Autism Treatment Network. J Autism Dev Disord 2013 Dec;43(12):2830-2843. [Medline: 23624832]
36. Mayes S, Calhoun S, Murray M, Zahid J. Variables associated with anxiety and depression in children with autism. J Dev Phys Disabil 2011;23(4):325-337. [doi: 10.1007/s10882-011-9231-7]
37. Meltzer LJ, Mindell JA. Relationship between child sleep disturbances and maternal sleep, mood, and parenting stress: a pilot study. J Fam Psychol 2007 Mar;21(1):67-73. [doi: 10.1037/0893-3200.21.1.67] [Medline: 17371111]
38. Hufford M, Stone A, Shiffman S, Schwartz J, Broderick J. Paper vs electronic diaries. Appl Clin Trials 2002;11(8):38-43 https://www.researchgate.net/publication/284666042_Paper_vs_electronic_diaries_Compliance_and_subject_evaluations.
39. Barlow DH, Nock MK. Why can't we be more idiographic in our research? Perspect Psychol Sci 2009;4(1):19-21. [doi: 10.1111/j.1745-6924.2009.01088.x]
40. McConachie H, Parr JR, Glod M, Hanratty J, Livingstone N, Oono IP. National Institute for Health Research. 2015 Jun. Systematic review of tools to measure outcomes for young children with autism spectrum disorder URL: https://pure.qub.ac.uk/portal/files/39022827/HTA_MEASURE_Review.pdf [accessed 2018-12-03] [WebCite Cache ID 74ORXEja4]
41. Arnold LE, Huestis RD, Smeltzer DJ, Scheib J, Wemmer D, Colner G. Levoamphetamine vs dextroamphetamine in minimal brain dysfunction. Replication, time response, and differential effect by diagnostic group and family rating. Arch Gen Psychiatry 1976 Mar;33(3):292-301. [Medline: 769721]
42. Arnold LE, Vitiello B, McDougle C, Scahill L, Shah B, Gonzalez NM, et al. Parent-defined target symptoms respond to risperidone in RUPP autism study: customer approach to clinical trials. J Am Acad Child Adolesc Psychiatry 2003 Dec;42(12):1443-1450. [doi: 10.1097/00004583-200312000-00011] [Medline: 14627879]
43. Arnold LE, Wender PH, McCloskey K, Snyder SH. Levoamphetamine and dextroamphetamine: comparative efficacy in the hyperkinetic syndrome. Assessment by target symptoms. Arch Gen Psychiatry 1972 Dec;27(6):816-822. [Medline: 4564954]
44. Weisz JR, Chorpita BF, Palinkas LA, Schoenwald SK, Miranda J, Bearman SK, Research Network on Youth Mental Health. Testing standard and modular designs for psychotherapy treating depression, anxiety, and conduct problems in youth: a

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randomized effectiveness trial. Arch Gen Psychiatry 2012 Mar;69(3):274-282. [doi: 10.1001/archgenpsychiatry.2011.147] [Medline: 22065252]
45. Fox S, Duggan M. Pew Research Center's Internet & American Life Project. 2013. Tracking for health URL: http://www.pewinternet.org/2013/01/28/tracking-for-health/ [accessed 2019-03-08] [WebCite Cache ID 76j3hIXtB]
46. Free C, Phillips G, Watson L, Galli L, Felix L, Edwards P, et al. The effectiveness of mobile-health technologies to improve health care service delivery processes: a systematic review and meta-analysis. PLoS Med 2013 Jan;10(1):e1001363 [FREE Full text] [doi: 10.1371/journal.pmed.1001363] [Medline: 23458994]
47. Woodward B. m-Health Care Models and Applications. In: m-Health: Fundamentals and Applications. Hoboken, New Jersey: Wiley-IEEE Press; 2016.
48. Rosa C, Campbell AN, Miele GM, Brunner M, Winstanley EL. Using e-technologies in clinical trials. Contemp Clin Trials 2015 Nov;45(Pt A):41-54. [doi: 10.1016/j.cct.2015.07.007] [Medline: 26176884]
49. Dennison L, Morrison L, Conway G, Yardley L. Opportunities and challenges for smartphone applications in supporting health behavior change: qualitative study. J Med Internet Res 2013;15(4):e86 [FREE Full text] [doi: 10.2196/jmir.2583] [Medline: 23598614]
50. Chen RY, Feltes JR, Tzeng WS, Lu ZY, Pan M, Zhao N, et al. Phone-based interventions in adolescent psychiatry: a perspective and proof of concept pilot study with a focus on depression and autism. JMIR Res Protoc 2017 Jun 16;6(6):e114 [FREE Full text] [doi: 10.2196/resprot.7245] [Medline: 28623183]
51. Khor AS, Gray KM, Reid SC, Melvin GA. Feasibility and validity of ecological momentary assessment in adolescents with high-functioning autism and Asperger's disorder. J Adolesc 2014 Jan;37(1):37-46. [doi: 10.1016/j.adolescence.2013.10.005] [Medline: 24331303]
52. Kovac M, Mosner M, Miller S, Hanna EK, Dichter GS. Experience sampling of positive affect in adolescents with autism: Feasibility and preliminary findings. Res Autism Spectr Disord 2016;29-30:57-65 [FREE Full text] [doi: 10.1016/j.rasd.2016.06.003] [Medline: 28083073]
53. Kring AM, Barrett LF, Gard DE. On the broad applicability of the affective circumplex: representations of affective knowledge among schizophrenia patients. Psychol Sci 2003 May;14(3):207-214. [doi: 10.1111/1467-9280.02433] [Medline: 12741742]
54. Tseng A, Bansal R, Liu J, Gerber AJ, Goh S, Posner J, et al. Using the circumplex model of affect to study valence and arousal ratings of emotional faces by children and adults with autism spectrum disorders. J Autism Dev Disord 2014 Jun;44(6):1332-1346 [FREE Full text] [doi: 10.1007/s10803-013-1993-6] [Medline: 24234677]
55. Microsoft. International HealthVault. 2018. URL: https://international.healthvault.com/us/en [accessed 2018-05-10] [WebCite Cache ID 6zJnXznqn]
56. Anagnostou E, Jones N, Huerta M, Halladay AK, Wang P, Scahill L, et al. Measuring social communication behaviors as a treatment endpoint in individuals with autism spectrum disorder. Autism 2015 Jul;19(5):622-636. [doi: 10.1177/1362361314542955] [Medline: 25096930]
57. Lecavalier L, Wood JJ, Halladay AK, Jones NE, Aman MG, Cook EH, et al. Measuring anxiety as a treatment endpoint in youth with autism spectrum disorder. J Autism Dev Disord 2014 May;44(5):1128-1143 [FREE Full text] [doi: 10.1007/s10803-013-1974-9] [Medline: 24158679]
58. Scahill L, Aman MG, Lecavalier L, Halladay AK, Bishop SL, Bodfish JW, et al. Measuring repetitive behaviors as a treatment endpoint in youth with autism spectrum disorder. Autism 2015 Jan;19(1):38-52. [doi: 10.1177/1362361313510069] [Medline: 24259748]
59. Aman MG, Singh NN. Aberrant Behavior Checklist Manual. East Aurora, NY: Slosson Educational Publications, Inc; 2017.
60. Kaat AJ, Lecavalier L, Aman MG. Validity of the aberrant behavior checklist in children with autism spectrum disorder. J Autism Dev Disord 2014 May;44(5):1103-1116. [doi: 10.1007/s10803-013-1970-0] [Medline: 24165702]
61. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist 1980 Dec;20(6):649-655. [Medline: 7203086]
62. Cetinbakis G, Bastug G, Ozel-Kizil E. Factors contributing to higher caregiving burden in Turkish mothers of children with autism spectrum disorders. Int J Develop Disabilities 2018 Jun 05:1-8. [doi: 10.1080/20473869.2018.1478630]
63. Ezzat O, Samarkandi OA, Bayoumi M. Quality of life and subjective burden on family caregiver of children with autism. Asian J Neurosurg 2017;6(1):33. [doi: 10.11648/j.ajns.20170601.15]
64. Hartley SL, Barker ET, Seltzer MM, Greenberg JS, Floyd FJ. Marital satisfaction and parenting experiences of mothers and fathers of adolescents and adults with autism. Am J Intellect Dev Disabil 2011 Jan;116(1):81-95 [FREE Full text] [doi: 10.1352/1944-7558-116.1.81] [Medline: 21291312]
65. Javalkar K, Rak E, Phillips A, Haberman C, Ferris M, Van Tilburg M. Predictors of caregiver burden among mothers of children with chronic conditions. Children 2017 May 16;4(5):39. [doi: 10.3390/children4050039]
66. Macedo EC, da Silva LR, Paiva MS, Ramos MN. Burden and quality of life of mothers of children and adolescents with chronic illnesses: an integrative review. Rev Lat Am Enfermagem 2015;23(4):769-777 [FREE Full text] [doi: 10.1590/0104-1169.0196.2613] [Medline: 26444180]

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67. Orsmond GI, Seltzer MM, Greenberg JS, Krauss MW. Mother-child relationship quality among adolescents and adults with autism. Am J Ment Retard 2006 Mar;111(2):121-137. [doi: 10.1352/0895-8017(2006)111[121:MRQAAA]2.0.CO;2] [Medline: 16466284]
68. Pandey S, Sharma C. Perceived burden in caregivers of children with autism spectrum disorder. J Nepal Health Res Counc 2018 Jul 03;16(2):184-189. [Medline: 29983435]
69. Tomasello M, Carpenter M, Call J, Behne T, Moll H. Understanding and sharing intentions: the origins of cultural cognition. Behav Brain Sci 2005 Oct;28(5):675-91; discussion 691. [doi: 10.1017/S0140525X05000129] [Medline: 16262930]
70. Goldman SE, Richdale AL, Clemons T, Malow BA. Parental sleep concerns in autism spectrum disorders: variations from childhood to adolescence. J Autism Dev Disord 2012 Apr;42(4):531-538. [doi: 10.1007/s10803-011-1270-5] [Medline: 21538171]
71. Kerns CM, Kendall PC, Berry L, Souders MC, Franklin ME, Schultz RT, et al. Traditional and atypical presentations of anxiety in youth with autism spectrum disorder. J Autism Dev Disord 2014 Nov;44(11):2851-2861 [FREE Full text] [doi: 10.1007/s10803-014-2141-7] [Medline: 24902932]
72. Kanne SM, Mazurek MO. Aggression in children and adolescents with ASD: prevalence and risk factors. J Autism Dev Disord 2011 Jul;41(7):926-937. [doi: 10.1007/s10803-010-1118-4] [Medline: 20960041]
73. Leyfer OT, Folstein SE, Bacalman S, Davis NO, Dinh E, Morgan J, et al. Comorbid psychiatric disorders in children with autism: interview development and rates of disorders. J Autism Dev Disord 2006 Oct;36(7):849-861. [doi: 10.1007/s10803-006-0123-0] [Medline: 16845581]
74. Al-Farsi OA, Al-Farsi YM, Al-Sharbati MM, Al-Adawi S. Stress, anxiety, and depression among parents of children with autism spectrum disorder in Oman: a case-control study. Neuropsychiatr Dis Treat 2016;12:1943-1951 [FREE Full text] [doi: 10.2147/NDT.S107103] [Medline: 27536117]
75. Schieve LA, Blumberg SJ, Rice C, Visser SN, Boyle C. The relationship between autism and parenting stress. Pediatrics 2007 Feb;119(Suppl 1):S114-S121. [doi: 10.1542/peds.2006-2089Q] [Medline: 17272578]
76. Arnold LE, Aman MG, Martin A, Collier-Crespin A, Vitiello B, Tierney E, et al. Assessment in multisite randomized clinical trials of patients with autistic disorder: the Autism RUPP Network. Research Units on Pediatric Psychopharmacology. J Autism Dev Disord 2000 Apr;30(2):99-111. [Medline: 10832774]

Abbreviations

ABC: Aberrant Behavior Checklist
ABI: Autism Behavior Inventory
ADOS: Autism Diagnostic Observation Schedule
ASD: autism spectrum disorder
EMA: ecological momentary assessment
IQ: intelligence quotient
JAKE: Janssen Autism Knowledge Engine
MH: mental health
mHealth: mobile health
SRS-2: Social Responsiveness Scale 2
ZBI: Zarit Burden Interview

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Review

Social Connection and Online Engagement: Insights From Interviews With Users of a Mental Health Online Forum

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Abstract

Background: Over the past 2 decades, online forums for mental health support have emerged as an important tool for improving mental health and well-being. There has been important research that analyzes the content of forum posts, studies on how and why individuals engage with forums, and how extensively forums are used. However, we still lack insights into key questions on how they are experienced from the perspective of their users, especially those in rural and remote settings.

Objective: The aim of our study was to investigate the dynamics, benefits, and challenges of a generalized peer-to-peer mental health online forum from a user perspective; in particular, to better explore and understand user perspectives on connection, engagement, and support offered in such forums; information and advice they gained; and what issues they encountered. We studied experiences of the forums from the perspective of both people with lived experience of mental illness and people who care for people with mental illness.

Methods: To understand the *experience* of forum users, we devised a qualitative study utilizing semistructured interviews with 17 participants (12 women and 5 men). Data were transcribed, and a thematic analysis was undertaken.

Results: The study identified 3 key themes: participants experienced considerable *social and geographical isolation*, which the forums helped to address; participants sought out the forums to find a *social connection* that was lacking in their everyday lives; and participants used the forums to both find and provide *information and practical advice.*

Conclusions: The study suggests that online peer support provides a critical, ongoing role in providing social connection for people with a lived experience of mental ill-health and their carers, especially for those living in rural and remote areas. Forums may offer a way for individuals to develop their own understanding of recovery through reflecting on the recovery experiences and peer support shown by others and individuals enacting peer support themselves. Key to the success of this online forum was the availability of appropriate moderation, professional support, and advice.

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KEYWORDS

internet; mental health; social stigma; self-help groups; qualitative research; mental health recovery; mental disorders

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Introduction

Background

Web-based interventions for mental ill-health are increasingly becoming a part of policy frameworks for community mental health (eg, by the Australian and Scottish governments [1-3]), and large and well-used forums have been developed in many countries. Internet-based supports and services make sense for governments, given the number of people who incorporate the online into their social worlds and the considerable difficulties services and supports have accessing people face-to-face due to distance and other forms of social isolation. Previous studies have shown that although the rate of people in the general population accessing online mental health forums may be small, the proportion of people with diagnosed mental illness accessing forums is relatively high [4-6]. Yet, we lack essential information about how mental health forums are experienced by people with lived experience and the carers or what motivates their use, particularly for large generalized mental health forums that cater to different diagnoses. To fill this gap, this paper reports on interviews with people who are members of the SANE Forums, a well-used Australian online forum run by the nongovernment mental health organization SANE Australia. The research is part of a wider study exploring experiences of engagement with and use of the SANE Australia online forums with funding provided by the National Mental Health Commission. The aim of this paper is to address gaps in our knowledge about the experiences and motivations of forum use from the perspective of those who are regular users to provide evidence to shape their future development.

To provide a framework for the interviews, a literature review of existing studies was undertaken. The review included only studies that were concerned with online forums focusing on mental health. It did not focus on forums for nonmental health–related illnesses or discussions via social media. This review showed that studies focused primarily on a number of areas, including forums for specific diagnoses [7,8]; clinician-led or medical service–led sites, which are often used as an adjunct to other interventions [9-12]; and sites that focus on specific consumer groups including men and young people [13-15]. Analysis focused on 2 main areas: analyses of the content of forum posts and motivations and impact of forum use, but very little of this research focused on experiences from the forum user perspective. This existing literature is outlined here.

Content-Based Research

Research on the content of mental health–specific online forum postings has attempted to understand *illness* experiences or the construction of online chat rather than the user experience of accessing the forums. This includes, for example, the study of the experience of obsessive-compulsive disorder [7], cannabis addiction [16], dual diagnosis [17], and eating disorders [18]. Other content analysis has sought to determine whether forums help or hinder people's recovery. Kavuluru et al [19] have developed a system to identify the helpfulness of comments on Reddit forums for mental health. Similarly, Cohan et al [13] drew on content from the Australian-based Reachout.com forums for young people to develop a matrix identifying harmful content so that it could be targeted and addressed more easily by forum moderators. Several studies have also attempted to characterize the types of posts that are made [20-22]. For example, a paper by Mazur and Mickel [23] coded content according to purpose and found that 86% of posts in a carer forum were about seeking advice or information on a specific topic and 20% were seeking support for the poster's situation. Other content-based research utilizes forums as a methodological tool to understand naturally occurring chat for groups that may be difficult to engage with through traditional research. In addition, 2 studies, for example, analyzed men's mental health, including a study which focused on depression [15] and another on eating disorders [8].

Impact of Forum Involvement

Existing studies on the "experience" of utilizing forums focus on positive or negative personal behaviors and emotions as a result of forum interactions. The impact of involvement in mental health–related online forums is shown to be largely positive in terms of symptom alleviation [18,24,25]. A small number of studies have warned of an increase in self-harm or mental distress due to forum use [26]. Interviews with people using a postnatal mental health support forum, for example, found that women could sometimes become more unwell because they were talking about the issues more [27]. These effects are viewed as particularly concerning in relation to unmoderated forums [28,29] and those that discuss eating disorders or suicide where techniques for harm are discussed [8]. One study found that negative forum experiences came from poor interactions with other forum members or disagreements with forum moderators [20]. Horgan et al [12] conducted a survey with 118 university students aged from 18 to 24 years with depression, who had been chosen to join a peer support forum. They found no benefit in symptom alleviation from involvement in the forum.

These studies largely focus on the impact of forum interactions on symptoms. However, studies that focus on symptom alleviation may miss the purpose of such forums, which are focused more on peer support for people moving toward recovery [30]. Recovery in this context does not mean to get better but to live a meaningful life with or without the symptoms of mental ill-health [31]. Peer support is an important component of recovery because it allows for modeling of recovery and provides hope for people who may be struggling with their mental ill-health [32]. Several papers reflecting on online forums used the structured recovery framework and determined that the forums did support participants' recovery [20,33].

Motivations for Use

A small number of papers have examined the motivation of participants engaging in peer support via online forums or what they perceive they benefit from involvement. A survey reported by Seward et al [22] characterized the motivations of forum participants into 3 groups—those who sought online professional help, those who sought online anonymous help, and those who sought both online help and friendship. One paper provided a content analysis of posts to determine the utility of an online forum for participants by examining posts that reflected on the forum itself [20]. This study found that users believed that their

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involvement resulted in positive "personal change...social interactions and support." A survey by Jones et al [34] of young people accessing the self-harm forum, *SharpTalk*, found that participants preferred to discuss self-harm anonymously online than with friends and family. An even smaller number of papers has involved qualitative interviews with forum participants. Moore and Ayers [27] drew on interviews with forum users seeking postnatal mental health support in the United Kingdom. They found that many forum users do not seek help in real life because of stigma but found the online forums helpful because they were anonymous, provided connections with others with similar experiences, and were nonjudgmental. This lack of interview-derived data is significant because data from surveys or content analysis of posts do not allow for in-depth exploration, contextualized in an individual's life, of why people are motivated to use forums and what their experiences are.

What emerges from this examination of existing research is that there is a clear lack of in-depth, qualitative accounts of experiences of forum use in the context of an individual participant's life. This paper addresses this gap by offering an understanding of the motivations for ongoing forum involvement among registered users of a large moderated forum for carers and consumers. As shown here, very few studies focus on the large-scale general forums, which are most accessible across a broad population base. Those that do focus on such forums do not focus on the experiences of individuals from their own perspective. Existing forum-based studies on other types of long-term conditions which do this are not fully applicable to the context of mental illness, which have been shown to differ both in the content of posts and the social context of the illness [35].

Methods

Context and Research Aims

The research presented here is part of a wider study exploring experiences of engagement with and use of the SANE Australia online forums.

To understand the *experience* of forum users, a qualitative design utilizing semistructured interviews was adopted to allow for a back-and-forth dialogue to foster and develop an understanding between participant and interviewer [36]. A topic guide was developed to guide the interviews with questions focusing on why participants used the forum, how they used it, what they liked and did not like about it, and how these issues could be addressed in forum design. The interview questions were designed to be as open as possible to provide practical information for the development of the forum. A copy of the topic guide is available from the lead author on request. All interviews were conducted by phone at a time convenient for participants. Each participant received Aus $30 gift card as compensation for their time in participating in the research. Phone interviews were chosen for practical reasons because participants were from across Australia and costs to interview in person would have been prohibitive. All participants were sent their interview transcripts and offered the opportunity to remove any details that they did not want to be included. Ethics approval was gained from the University of Sydney Human Research Ethics Committee (approval no. 2016/717). Interviews were conducted by KM, who is a psychologist and social science researcher and has worked as a postdoctoral qualitative researcher for several years. See Multimedia Appendix 1 for the semistructured interview schedule.

The forums used by participants in this study are operated by SANE Australia, are free to access, and are intended for Australian participants, although, in practice, are accessed by people worldwide. There are separate forums for carers and people with lived experience of mental ill-health, though this does not restrict who can publish on the forums. Within each forum, there are a number of subcategories of posts, with the *Lived Experience* forum including, among others: "our experience and stories," "looking after our wellbeing," "social spaces," "something's not right," and "what's new: services, research and technologies." There are special forum sessions offered each week for discussion around topics that SANE identifies.

The forums operate under the 3 broad principles of respect, safety, and anonymity, and posting guidelines limit the content of posts. Participants are encouraged to "share helpful content, focused on wellbeing, recovery and help seeking behaviours" [37]. There are forum guidelines that require members to not post information about specific harmful behaviors and not provide details of medication. Any information provided must be from personal experience or trustworthy sources with links provided. Participants must use pseudonyms and must not share personal details about themselves. The forums do not offer crisis support but are constantly moderated by mental health professionals who monitor content and offer advice.

Sampling

An initial survey, advertised to forum members by SANE, was conducted to understand who the SANE forum members were and how they used the forums (the survey results will be reported elsewhere). Consumers and carers were able to specify on the survey whether they were interested in participating in an interview. A total of 104 survey participants indicated their willingness to participate in an interview. A purposive sampling strategy was then used to identify a broad, but not statistically significant, range of consumer and carer participants, ensuring that those participants were included who were from both rural and metropolitan areas and a range of Australian states, genders, and ages. Although there were constrictions on the numbers of men sampled, given that all eligible male participants were included, no further female participants were included once the initial coding and theme development (see below) had been conducted because saturation had been reached.

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Table 1. Participant characteristics.

Gender	Age (years)	Location (including state of Australia)	Forum
Female	26-30	Metropolitan South Australia	Lived experience
Female	31-35	Rural New South Wales	Carers
Female	31-35	Metropolitan Queensland	Lived experience
Female	41-45	Rural Victoria	Lived experience
Female	46-50	Rural Queensland	Both
Female	46-50	Rural Victoria	Lived experience
Female	46-60	Metropolitan New South Wales	Both
Female	51-55	Metropolitan Victoria	Both
Female	51-55	Rural Victoria	Lived experience
Female	51-55	Rural Queensland	Lived experience
Female	51-55	Rural Victoria	Carers
Female	56-60	Metropolitan Queensland	Lived experience
Male	26-30	Metropolitan New South Wales	Lived experience
Male	41-45	Rural New South Wales	Lived experience
Male	51-55	Australian Capital Territory	Lived experience
Male	51-55	Metropolitan Victoria	Lived experience
Male	61-65	Metropolitan Victoria	Carers

Participants were excluded if they were not based in Australia, did not provide valid contact details, or did not respond to researcher invitations to participate. Characteristics of the 17 participants are listed in Table 1. Only 12 men offered to participate, so the final number of male participants was lower (the remaining 7 were either not from Australia or did not provide contact details). Several people identified as both a carer and someone with a lived experience of mental ill-health and so used both forums. Only 3 of the participants who indicated they were interested in being interviewed and were aged 61 years and over were contactable. Of the 3, we were able to interview 1. Interviews concentrated on those who used the lived experience forum, but we also interviewed 3 respondents who used the carer's forum and 3 people who indicated they used both forums.

Analysis

Data were transcribed verbatim and entered into NVivo 10, where they were coded by hand.

Analysis of data followed a basic thematic approach to coding derived from that described by Braun and Clarke [38]. This involved the following 6 steps:

1. Step 1: Data familiarization—each interview transcript was initially read through several times to develop an initial sense of the themes that were emerging.
2. Step 2: Development of first set of codes—data were systematically coded in a line-by-line fashion according to the overarching research questions, described above with reference to the interview transcript.
3. Step 3: Theme development—codes were then sorted into draft thematic groups around key findings.
4. Step 4: Review of themes—a thematic map was developed and reviewed in relation to the initial full dataset. Transcripts were reread to check that the themes reflected the corpus as a whole.
5. Step 5: Definition of key themes—each theme was brought together as a set of data and explained to get a sense of its meaning as a whole.
6. Step 6: Reporting—the themes were developed into a narrative, which both explained the themes and provided evidence from the data in the form of quotations. The themes were presented in relation to existing research.

Throughout the data collection and analysis process, the researcher collecting data (KM) engaged in personal reflective practice by exploring her own emotional reactions to the experiences shared by participants. Given the nature of the research topic, participants often shared very difficult aspects of their lives, including suicidal ideation, hospitalization for mental ill-health, and the ongoing experience of social isolation and loneliness. It was felt important to acknowledge that hearing about and analyzing these experiences was not a neutral experience for this researcher. KM took care to make note of her emotional reactions to explore how these might impact the interactions during interview and subsequent analysis of data. Data analysis was primarily conducted by KM, but an independent cross-analysis of coding and theme development and reporting was conducted by JSM at steps 2, 4, and 6. This confirmed the initial coding. Both KM and JSM have extensive postdoctoral experience in qualitative research and teaching in universities. All authors checked the data and its analysis once an initial draft was complete. This allowed the expertise of the other authors (in cyber-psychology, media, and communication) to be used as a reflective tool. As a team, we worked through

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areas of analysis that were questioned from these alternative research standpoints.

Results

Overarching Themes Emerging From the Data

Analysis of the data revealed findings clustered around the following 3 key themes:

1. Participants experienced considerable *social and geographical isolation*, which the forums helped to address
2. Participants sought out the forums as a way to find a *social connection* that was lacking in their everyday lives
3. Participants sought out the forums to both find and provide *information and practical advice.*

Experience of Mental Illness: Social Isolation and Geographical Isolation

Social Isolation

Participants described their lives in a variety of negative terms including loneliness, social isolation, stigma, exclusion, and workplace discrimination. This is noted by C08 who stated "Yeah, you know, you have the loneliness, you don't know where to go, don't have support...those stories just keep popping up. It's scary how consistent it is." Many participants felt unable to discuss mental illness in their everyday lives and communities because they felt that people were not interested, did not understand, or might hold prejudices and stigmatizing attitudes toward them. Several participants described feeling unable to leave the house due to their mental health symptoms or how these symptoms might appear to others.

They felt that people in their lives who had not experienced mental ill-health could not understand their experiences and, therefore, could not offer support:

> *...other than professionals, I haven't had many people I can have conversations about mental illness with in my life, because unless they've been through it, they don't reallythey can't relate to it at all.* [C11]

> *You can't just talk to anyone about mental health issues. They just don't get it...They just don't get it because their lives are so full.* [C03]

For others, this was related to stigma in their own communities or workplaces (C01, C05, and C15):

> *...after they find out I had a mental illness, they don't want to be friends anymore.* [C15]

> *I get really upset about it because where I previously worked, they knew what happened to me while I was in hospital and they said, we don't care, we're not interested, we should have sacked you.* [C01]

The consequence of the isolation caused by a lack of understanding was profound, leading to loneliness and further mental distress. For these participants, the forums were a space where they could step out of the stigmatization and loneliness that they experience in their everyday lives into a community where mental health was accepted and understood. This is discussed further below.

Social isolation and inability to talk about mental illness appeared to be compounded for participants who lived in rural communities (C02, C05, C06, and C07). One participant spoke about the necessity to "hide" their illness and the lack of resources available to address mental ill-health in their own community:

> *When you're in a country town you have to sort of hide it because people are not tolerant...I don't have access to a lot of stuff and there's nothing really out there to communicate with other people about your mental health.* [C05]

For this participant, the forums offered an alternative space for connection that helped to reduce the social isolation they experienced in their rural community:

> *I think it's helped me because it's a connection...I'm in a restricted country area and I've hurt my back so I don't work in nursing. So I'm home all day. It's just company to know that there's other people out there.* [C05]

Rural participants faced additional barriers in accessing supports in their area. This was true for carers as well as those with a lived experience of mental illness (C06). In 1 instance, a participant mentioned that although services were available in her area, she knew all the psychiatrists because she used to work in mental health so did not feel comfortable accessing them (C04). She, therefore, had to travel to a capital city to access support. Another mentioned that the only face-to-face social support groups in his area were for people with specific needs and did not cater to chronic mental illness (C02). Another said that in their rural area, there was only 1 support group and timing was not appropriate for those with young children (C06). For these participants, the forums offered a support group that they could access when they wanted and for their own specific needs.

Social Connection

As the following quotations demonstrate, for participants who were socially isolated and unable to speak about mental illness or connect with anyone with similar experiences in their own communities, the forums offered an important opportunity for social connection:

> *...I can always get online and so that's the beauty of it.* [C05]

> *...for me it's a real connection. I'm not the only one with bipolar disorder.* [C07]

The forums also provided an opportunity to reframe experiences, receive support, and give back or help others who were struggling with the same issues.

Participants described accessing the forums in an attempt to ameliorate their social isolation. The forums presented an opportunity to discuss the reality of their situation when it was not possible or appropriate to discuss their experiences with others. They spoke of "struggling" (C12) to speak to family members or worried about "pestering" their relatives and friends (C14). In addition, 1 participant spoke about the forums being an antidote to their social isolation but that they were less important when they were able to speak to their friends in person

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(C10). For these participants, the forums played a powerful role in their lives by allowing them to speak and connect with people how and when they needed it most.

For some participants, the opportunity to connect with others provided a context in which they could understand or reframe their own experiences and develop hope for the future (C01 and C10):

> *I remember there was one guy that used to say, it does get better. It gets a lot better and I know that this is an awful feeling now, but it does get better and that was really big. That was life-changing.* [C10]

Participants also described others offering new skills or perspectives that they could then put to use in their own recovery and contextualize their experiences (C09 and C11). This practical support is discussed in detail in a later section of the Results.

Similar Experience

A strong theme reported among the respondents was the ability to connect with others who shared similar experiences. All but 1 of the participants (who did not speak about the topic) spoke about the utility of the forums being tied to the feeling that others had the same experiences as themselves. The participants felt that there was a large group out there that they could connect with, which made them feel less alone and allowed them to share with others who would understand their experiences—something that was rare in their everyday lives (C03, C04, and C07). This can be seen in the following quotation:

> *I wanted to be surrounded by people that know my experience rather than don't know but want to help...Not therapists, not my best friends who has understanding but doesn't have experience of it.* [C04]

This shared experience was a strong motivator for initial engagement with the forums. Ongoing engagement came from a sense of personal connections being made and a shared community around these experiences, which alleviated loneliness, developed a sense of belonging, and contributed a range of experiences and coping strategies. Moreover, 1 person went as far as to liken the connections they felt with people on the communities to the connections they had with their own family members (C12). Seeking out those with similar experience was also a means to normalize the experience of having a mental illness:

> *...it's more the sense of other people relate to what you are saying and they can say yeah, I know exactly how you feel because this happened to me. You feel better about it all of a sudden.* [C11]

> *When I first went to hospital...I was feeling very isolated and pretty dysfunctional. Just like I was the only one and I just couldn't cope or function as an adult. I went on there [the forums] and I had people say, you know what, we've been through this too and we're better and it does get better.* [C10]

To find others with similar experiences, participants searched through forum threads to identify those that they most related to and which they could draw on for comfort, strategies, or a sense that someone understands (C01 and C08). Although many of these accounts spoke about receiving support from others, participants also spoke about the importance of providing support. This offered a way to use one's experiences and knowledge to give back to others who supported them (C07, C08, and C12). It was also viewed as being "therapeutic" (C02) for the person providing the support.

For some, it was the connecting that was important rather than the content of what was discussed. The forums provided an opportunity to have a chat or socialize online with people who had something in common for people whose social isolation in the physical world meant that this type of day-to-day interaction was not otherwise possible. Participants spoke about forum events or get-togethers such as themed chat, "fun Fridays" (C15) or a "party" (C04) among online friends. In addition, 1 participant spoke about treating the forum as if they were chatting with friends or family over coffee:

> *...if you were living with somebody you would just say hi and here's a coffee, whatever, so I feel like [the forum has] become that for me. If I sit down and have a coffee I'll log on and that might be four times a day. Just the talking every day helps...chatting. Lifeline [a telephone based support service] isn't always terribly helpful and they're always in a rush.* [C03]

For this participant, this type of human, informal, interaction was not available from formal mental health services, which are more oriented to outcome and pressured for time. Another participant contrasted these types of interactions with in-person support groups, who they described in negative terms:

> *I used to go to pity parties, which are better known as support groups. They sit there and compare each other's scars...I actually prefer the computer forum.* [C09]

Such interactions on the forums contributed to the connectedness of participants in their wider, offline communities (C04 and C10):

> *It's been a big help in motivating me when you see people post tomorrow I'm going to go down and have a coffee. What are you doing tomorrow...I think I've learnt to speak better to people and that of course creates better relationships.* [C04]

> *Being able to actually articulate those experiences within that [online] community makes me more able to go out and talk about it to the broader community...It was a lot easier with something like bipolar to articulate it to the forums first before going out and talking to other people that really don't understand it.* [C10]

As these quotations show participants spoke not only of an increased community connectedness but also a strength in communicating about the experience of mental illness and greater compassion for others in the community who may also have mental illness.

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Boundaries, Anonymity, and Authenticity

Although the forums offered an opportunity for meaningful social connection, participants also recognized the need for boundaries. More than half of the participants mentioned that reading about other people's circumstances could, on occasions, be difficult and could potentially "trigger" (C03 and C04) their own mental ill-health.

This meant that participants might need to establish and negotiate boundaries around how they used the forums, including allowing others to respond to certain posts rather than responding themselves or even staying off the forums, especially if they were feeling unwell:

> *I do self-regulate, because if it's a similar situation sometimes it can be really beneficial and other times you're just not in the headspace to hear someone else's story the same.* [C01]

Participants also negotiated boundaries around what they were either prepared to discuss or were able to discuss due to restrictions on the posting of certain types of content by the site moderators. Moreover, 1 carer participant (C17) mentioned setting boundaries around what he would post because he was unsure if people should hear it.

Another participant described her inability to share suicidal ideation with someone in her community and then reflected that she could also not share this information with people on the forums. She reflected that having to negotiate the boundaries on what could be shared had the potential to be "tiring" and restricted her ability to be "open":

> *You have to really think about how you share it. It gets a bit tiring when you're not well.* [C03]

In addition to negotiating boundaries around difficult content, the requirement for anonymity imposed another boundary on participants. One participant called the requirement for anonymity a "double-edged sword" because it allowed them to "let a lot more out" but they had "to be a lot more careful about who knows who you are" (C08).

A sense of connection and community was both enabled and constrained by the need for anonymity. This was closely linked to the concept of authenticity. For some participants, the sense of being part of a genuinely supportive community was still authentic, despite anonymity. Moreover, 1 participant indicated that although she did not know people's real names, she still felt like they were her friends (C04). Participants described the anonymity of the forums as "useful" (C10) and facilitating somewhere they could be more "real" (C03) and described impersonal nature of online social connection helpful for sharing personal information (C06).

Although anonymity made some feel they could be more real, it conversely made others feel that the connection to others was less real and the online anonymous format limited the extent to which they experienced a sense of connection and community (C02, C08, C14, and C17). This can be seen in the following quotations:

> *I don't find it overly helpful to post there or talk there because it is remote. So something I've been looking for recently is a group in my town that we can go and even if we just go and have a cup of coffee and you've got people in front of you to talk to.* [C02]

> *I've never really counted people I've met on the internet as people in my life...That's not [the forum's] fault. That's just how I think about the world.* [C08]

For these people, the forums played an important role but did not supplant their need for offline social support.

Practical Advice and Information

Participants were directly asked about the importance of practical advice and information received via the forums. In addition to seeking social connection from people with similar experiences, participants stated that they accessed the forums to seek or provide practical information and advice (C01, C02, C03, C04, C08, C10, C11, and C14). C14 notes:

> *I would rather, because of the face to face factor, take the advice of [my] case manager...But, as I say, real life people and real life set ups like that, aren't always available. In those circumstances in particular, [the] Forum can be excellent.* [C14]

The forum helped individuals with answering specific questions, developing a greater understanding of mental illness and by providing peer support.

Receiving Help for Specific Questions

The forums were used to ask or provide advice on specific questions. These questions were often practical in nature and related to how to navigate the mental health system, private health care (C01), or how to navigate other bureaucratic systems (C02). People also asked advice about other practical issues, which were impacted because of their mental ill-health, such as finding employment or housing:

> *At one stage I was investigating the concept of moving to Supported Residential Service Accommodation. I asked people on the forum if they had any experience...I got interesting feedback and useful feedback from that. The long and the short of it was that I didn't end up moving.* [C14]

Greater Understanding of Mental Ill-Health Beyond Their Own Experiences

Participants mentioned that the forums had given them a greater understanding of mental illness, symptom management, and about where to get help (C03, C04, C08, C10, and C11). This came from reading other people's posts, information and links posted by moderators, and information or discussion sessions linked to the forums:

> *I've got my two brothers are unwell. Just listening to how [people with] schizophrenia talk about their experiences. It just helps me understand my brothers a bit.* [C03]

> *I think it's given me better insight into the diversity of experiences that can come under one diagnosis.* [C10]

> *I read people's experiences across the board. I also look at links people have posted. That can be really*

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> *educational. That's made me do broader research on the internet, reading articles about mental health and all that kind of thing.* [C11]

This knowledge was often not directly relevant to their own personal experience but developed a valuable wider understanding of mental illness (C04 and C08). This breadth of knowledge helped with understanding others' experiences and could be used to put one's own experience into perspective.

However, others indicated that they already knew a great deal about mental illness and about the types of help available (C02). For these participants, the responses to their posts were supportive but not of much practical use. For some individuals, who had sought advice about specific issues, this could be disappointing, but for others, social connection was more important than advice, and involvement in the forums fulfilled other support roles in their lives (C11, C13, and C15):

> *What's useful is mainly just knowing people are out there and they are compassionate...who can relate to what you are going through, that is supportive within itself...I don't know if I really need advice as such.* [C11]

Professional Versus Peer Advice

In discussing the quality of advice and information provided through the forums, participants set up a distinction between peer advice and the advice provided by moderators. The forum moderators were viewed as a very important part of the forum experience by providing oversight and more "professional" support (C04, C07, and C08). One participant felt reassured that she could call on the moderators when she felt that another forum user might need more professional advice or a user had overdisclosed:

> *I love the fact that when I have concerns about a person...I can instantly send an email message and one of the [moderators] will then handle that. I can just say so and so, I'm concerned about their post, have a look...We know that there is someone professional out there that will get straight on and [remove their] phone number and their real name.* [C04]

However, some participants found the involvement of moderators or the posting guidelines too restrictive, which they felt limited the utility of the forums (C02 and C05), for example:

> *You can't talk about this or that or treatment or anything like that. So there is quite a restrictive - I find it constricted but at least it's an avenue for people to communicate to each other.* [C05]

Another participant reflected on the limits of boundary setting on the forums, which they felt had not gone far enough after a bad experience where moderators did not step in when needed (C07).

For another participant, the professional advice offered by one of the moderators was one of the highlights of the forum (C08). However, for this participant, it was important that the forum retains its function as a community of peers rather than as a site on which people could access advice from professionals:

> *I think if you have too many people doing it you'll just turn people away a little bit, it's meant to be a community for like-minded people. So you don't want psychologist after psychologist in there.* [C08]

Several participants were concerned that the advice offered by peers was incorrect and felt that people with mental illness were not the best people to be giving advice on how to live well (C03, C05, C07, and C09).

Moreover, 1 participant mentioned that she did not like it when people "play doctor" (C09) and another was concerned that advice might be confusing because it was offered by "everyday people" with mental illnesses rather than professionals (C07). One participant (C05) wished to connect with individuals on the forum with a similar diagnosis but was concerned about the ability of someone who was unwell to offer support:

> *Because we are really isolated sometimes, and I guess that's when we're unwell and probably [when] we shouldn't be communicating to another unwell person [laughs]. I don't know.* [C05]

This shows that despite the use of the forums for social support, a number of the participants demonstrated a mistrust of lived experience and expressed stereotypical views about the ability of people who are mentally unwell to provide advice.

Discussion

Main Findings and Their Implications

This paper has developed our understanding of the experiences of engagement with general mental health forums in several key areas: (1) forum use by people living in rural and regional areas, (2) the value of peer support and peer education, (3) the experiences of carers in forums, and (4) the use of moderators. Each of these findings is discussed here in turn.

The study offers crucial insights into rural and remote mental health consumers and their motivations and experiences in using online forums. This study is based in Australia—a country which is highly urbanized but includes a large minority of people living in very sparsely populated regions where distances of hundreds of kilometers often separate people from support services for mental health. The interviews underscore that many participants experience considerable *social isolation and stigmatization* associated with their experiences of mental ill-health. This sense of isolation was especially acute for those participants in nonmetropolitan locations. The isolation compounded the pain, marginalization, exclusion, and other challenges that these participants experienced in relation to their mental ill-health. This isolation also cut participants off from the crucial social connection they felt that they needed and, which research has shown, will promote recovery [39].

The arguments for forums addressing social isolation arising from stigma have been well rehearsed elsewhere [17,20,25,40] but in only a very limited way in relation to people in rural and regional areas, for whom the issues of isolation and stigmatization are often more acute [21,41,42]. Although Australia has, in general, an adequate standard of mental health service provision through universal health care, in rural areas,

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services and supports are provided over long distances to small numbers of people, which means that all but the most essential medical services rarely operate outside of urban areas or major regional centers. These interviews show that it is not just a lack of appropriate services that leads to social isolation but both stigma and the "close-knit" context of small rural communities that stop people from connecting and receiving face-to-face support. An anonymous forum made sense to these participants because it was not place-based, and they were free to speak without people knowing who they were. The strong sense expressed by participants of sharing recognizably similar experiences with other participants in the forums was key to this sense of connection. Our findings support the findings of a relatively small, preliminary study of forum users in Australia, which found that online connections were able to address the isolation felt by people with mental ill-health in rural and regional areas [41]. More focused research on the experience of rural and remote forum participants is needed to confirm the findings presented here, but these results do provide preliminary support for forums as part of a national framework for rural and remote health.

The overwhelming message that emerged from the data was that for all the groups that accessed them—consumers and carers and urban and rural participants—the functioning of the forums as a site of connectedness was based on the value of peer support. There were 3 key components of this connection. As discussed in the previous sections, participants experienced considerable *social isolation*, which the forums helped to address as a way to find a *social connection* that was lacking in their everyday lives. Participants utilized the online social connections to both find and provide *support*, *information*, *and practical advice.* These are fundamental processes that have been identified strongly elsewhere in research on online forums more generally [24,35,43]. Our research adds to this by identifying the mechanisms by which forum involvement can enhance an understanding of the principals of recovery in the context of mental illness and enhance offline social inclusion.

Peer support is a core part of the recovery journey for many people experiencing mental ill-health [44]. This study revealed that peer support provided through the forums had 3 components: (1) individuals reflecting on the modeling of recovery or hope given by others sharing their stories (support of other to self); (2) the provision of support to others (support of self to other); and (3) visualizing individuals providing help to others on the forums (support of other to other). Several participants stated that the online community of the forums helped them to be more involved with their own communities in the offline world. For these participants, the "practice" of online discussion allowed them to develop a more powerful discourse of themselves and their mental ill-health, which they could use to counter perceived discourses of stigma that had hitherto stopped them from speaking. A similar finding has been noted previously in a study on forum use in postnatal mental ill-health, which found that the "virtual 'voice'" which participants were able to express online "empowered them to disclose offline" [27]. This shows that the peer support provided by these forums may promote social inclusion in new and unexpected ways and, as such, should continue to be promoted as a key element of recovery-oriented mental health policy.

Previous research has largely ignored the inclusion of carers or family members in online support forums for mental health, except with some notable studies in the area of suicide bereavement support forums [45] and parenting children with mental ill-health [14,23]. Our results offer insights into why carers of people with mental illness engage with online forums, why they persist in doing so, and what benefits and issues they report that it brings them. When analyzing our results, we found that carer experiences largely mirrored those of participants in the mental illness "lived-experience"–focused forums and that half of the carers utilized both forums at the same time as they had a dual identity of both person with a lived experience of mental illness and carer. Although issues of stigma were noted less, the issues related to social isolation and need for connectedness were equally felt. Issues related to forum use more generally, including anonymity and boundary setting, were also equally felt among carer and lived experience forum users. These results demonstrate the necessity of including carer experiences in forum design. Large, general forums such as the one studied here, which focus on all types of diagnoses, as opposed to diagnosis-specific forums, makes it more likely that a large enough cohort of carers will be able to gather for a meaningful online community to develop.

The nature of the way information is circulated and advice is proffered raises issues for participants, especially in terms of accuracy, relevance, and appropriateness. Here, the availability, deployment, and intervention of experts—for instance, in the form of the moderators, specific advice from trained professionals, and opportunities for information sessions (such as webinars)—were often mentioned as important. The interviews show that such authoritative and trusted experts play a crucial role in the architecture, success, and sustainability of the forums, precisely because they provide a well-supported, welcome way to leaven and balance peer discussion with professional advice. Several international studies have also pointed to moderation as an important factor in maintaining a positive culture on forums [18]. Research that focuses on forums without moderation have emphasized the need for moderation to assist with participants who overdisclosed, broke forum posting rules, or were unkind to other participants [27,46]. However, content analysis of posts has also shown that participants were sometimes unhappy about moderator influence on their posts [20]. This demonstrates a need for moderation but in a form that is carefully crafted so that participants perceive it as a facilitator of support rather than a burden.

The participants expressed a range of views on anonymity and how it helped or detracted from their experience in the use of and attitudes toward the forums. For the majority, anonymity allowed them to express themselves in ways they were not able to do elsewhere—to be more "real" or "authentic." This perception aligns with previous systematic reviews that have focused on the benefits of anonymous online self-disclosure [25,46]. For some, however, the anonymity, especially with an online platform, meant that they felt that the experience was less "real." Previous research has also highlighted these 2 faces of anonymity [27,47]. Moreover, one antidote to this is to see

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the forums as one important element within a broader set of physical, virtual, and mixed environments of support [15]. Although it may be tempting to move all services online for this isolated community, online forums are not a panacea and services must complement rather than replace face-to-face services.

Another concern commonly raised by participants was the need to manage boundaries. Given the nature of online peer support, the burden falls upon consumers to manage themselves in various ways to make the best of the space while minimizing the potential negative implications of sharing their experiences. Several participants spoke of how they needed to ensure they were able to cope with what can be distressing communication or information from others, especially at times when they felt particularly vulnerable. It may be appropriate for forums to provide increased guidance for participants on this difficult balancing act, perhaps in the form of collaborative advice provided by other forum users and staff. "Peer knowledge" was not accepted uncritically by all. Although not a common theme, the comments that criticized the advice provided by others on the forums destabilized the idea of a peer support forum by restigmatizing people with mental illness as potentially inappropriate sources of information, advice, or social support more generally. Self-stigma has been noted in several other studies of online forums [21,48].

However, overall participation in the SANE forums was an important way for participants to learn about mental ill-health and, in doing so, challenge self-stigma. In addition, 2 other studies have also noted this benefit to participation [27,47]. Commentary that does engage in self or other stigmatizing can be addressed through explicit advice in forum rules or "pinned" posts, which explain stigma and provide advice on how it can be handled [21].

Limitations

The findings of this study must be considered in relation to several limitations. These results relate to 2 specific forums, and therefore, participant responses relate to the structure and internal culture of those forums. Readers should peruse the forums to understand the context in which the study was written. Those that we spoke to were all registered users of the forums, as they had indicated their willingness to participate via a survey only sent to forum members. It is likely that those people who received the survey invitation were those that were motivated to become members rather than just read occasionally. Interview content may, therefore, be positively biased toward forum use and does not represent the views of those who only "lurk" or "listen" to the forum conversations.

Conclusions

This research has offered important insights into the support- and information-seeking preferences and habits of mental health consumers and carers. It shows that online peer support provides a critical, ongoing role in providing social connection for mental health consumers. The online forums also provided crucial information and advice for many participants in this study, especially those living in rural and remote areas, who could not access this in their day-to-day lives.

There are important directions for future research that emerge from this qualitative study. Further work is needed to explore and understand the experiences of mental health forum participants living in rural and remote settings and to understand how online forums can be designed, promoted, maintained, and moderated to complement other available support, information, and interventions available offline or in other online formats.

Acknowledgments

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Conflicts of Interest

At the time the research took place, author CB was employed by SANE Australia. She was no longer employed by SANE Australia at the time the paper was drafted. The remaining authors declare no conflicts of interest.

Multimedia Appendix 1

Semi-structured interview schedule. Approved by ethics committee.

[PDF File (Adobe PDF File), 55KB - mental_v6i3e11084_app1.pdf]

References

1. The Department of Health. Australia: Australian Government E-Mental Health Strategy for AustraliaE-Mental Health Strategy for Australia URL: http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-e-emstrat [accessed 2019-02-07] [WebCite Cache ID 760IwTMdw]
2. Australian Government. 2018. 6 ways Head to Health can help you URL: https://headtohealth.gov.au/ [accessed 2018-05-18] [WebCite Cache ID 6zV0yJKn3]
3. Scottish Government. Edinburgh; 2017. Mental Health Strategy 2017-2027 URL: https://www.gov.scot/publications/mental-health-strategy-2017-2027/ [accessed 2019-02-07] [WebCite Cache ID 760JT4VnQ]
4. DeAndrea DC, Anthony JC. Online peer support for mental health problems in the United States: 2004-2010. Psychol Med 2013 Nov;43(11):2277-2288 [FREE Full text] [doi: 10.1017/S0033291713000172] [Medline: 23410539]

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5. Thomas N, Foley F, Lindblom K, Lee S. Are people with severe mental illness ready for online interventions? Access and use of the internet in Australian mental health service users. Australas Psychiatry 2017 Jun;25(3):257-261. [doi: 10.1177/1039856217689913] [Medline: 28139947]
6. Kalckreuth S, Trefflich F, Rummel-Kluge C. Mental health related internet use among psychiatric patients: a cross-sectional analysis. BMC Psychiatry 2014;14:368 [FREE Full text] [doi: 10.1186/s12888-014-0368-7] [Medline: 25599722]
7. Campbell R, Longhurst R. Obsessive-compulsive disorder (OCD): gendered metaphors, blogs and online forums. N Z Geog 2013 Aug 01;69(2):83-93 [FREE Full text] [doi: 10.1111/nzg.12011]
8. Wooldridge T, Mok C, Chiu S. Content analysis of male participation in pro-eating disorder web sites. Eat Disord 2014;22(2):97-110. [doi: 10.1080/10640266.2013.864891] [Medline: 24359281]
9. Giles DC, Newbold J. 'Is this normal?' The role of category predicates in constructing mental illness online. J Comput-Mediat Comm 2013 Jun 11;18(4):476-490 [FREE Full text] [doi: 10.1111/jcc4.12022]
10. Carli V. Preventing suicidality through online tools: The SUPREME project. In: Courtet P, editor. Understanding Suicide: From Diagnosis to Personalized Treatment. London: Springer; 2016:281-289.
11. Sin J, Henderson C, Norman I. Usability of online psychoeducation for siblings of people with psychosis. Int J Technol Assess Health Care 2014 Oct;30(4):374-380. [doi: 10.1017/S0266462314000488] [Medline: 25394550]
12. Horgan A, McCarthy G, Sweeney J. An evaluation of an online peer support forum for university students with depressive symptoms. Arch Psychiatr Nurs 2013 Apr;27(2):84-89. [doi: 10.1016/j.apnu.2012.12.005] [Medline: 23540518]
13. Cohan A, Young S, Yates A, Goharian N. Triaging content severity in online mental health forums. J Assoc Inf Sci Technol 2017 Sep 25;68(11):2675-2689 [FREE Full text] [doi: 10.1002/asi.23865]
14. Terbeck S, Chesterman LP. Parents, ADHD and the internet. Atten Defic Hyperact Disord 2012 Sep;4(3):159-166. [doi: 10.1007/s12402-012-0081-7] [Medline: 22736404]
15. Gough B. Men's depression talk online: a qualitative analysis of accountability and authenticity in help-seeking and support formulations. Psychol Men Masc 2016;17(2):156-164. [doi: 10.1037/a0039456]
16. Greiner C, Chatton A, Khazaal Y. Online self-help forums on cannabis: a content assessment. Patient Educ Couns 2017 Oct;100(10):1943-1950. [doi: 10.1016/j.pec.2017.06.001] [Medline: 28602568]
17. Edward KL, Robins A. Dual diagnosis, as described by those who experience the disorder: using the internet as a source of data. Int J Ment Health Nurs 2012 Dec;21(6):550-559. [doi: 10.1111/j.1447-0349.2012.00833.x] [Medline: 22830579]
18. Kendal S, Kirk S, Elvey R, Catchpole R, Pryjmachuk S. How a moderated online discussion forum facilitates support for young people with eating disorders. Health Expect 2017 Dec;20(1):98-111 [FREE Full text] [doi: 10.1111/hex.12439] [Medline: 26725547]
19. Kavuluru R, Williams AG, Ramos-Morales M, Haye L, Holaday T, Cerel J. lassification of helpful comments on online suicide watch forums. ACM BCB 2016 Oct;2016:32-40 [FREE Full text] [doi: 10.1145/2975167.2975170] [Medline: 28736770]
20. Griffiths KM, Reynolds J, Vassallo S. An online, moderated peer-to-peer support bulletin board for depression: user-perceived advantages and disadvantages. JMIR Ment Health 2015;2(2):e14 [FREE Full text] [doi: 10.2196/mental.4266] [Medline: 26543919]
21. Barney LJ, Griffiths KM, Banfield MA. Explicit and implicit information needs of people with depression: a qualitative investigation of problems reported on an online depression support forum. BMC Psychiatry 2011;11:88 [FREE Full text] [doi: 10.1186/1471-244X-11-88] [Medline: 21592335]
22. Seward AL, Harris KM. Offline versus online suicide-related help seeking: changing domains, changing paradigms. J Clin Psychol 2016 Jun;72(6):606-620. [doi: 10.1002/jclp.22282] [Medline: 26928393]
23. Mazur E, Mickle CL. Online discourse of the stressors of parenting children with mental health disorders. J Child Fam Stud 2017 Oct 16;27(2):569-579 [FREE Full text] [doi: 10.1007/s10826-017-0912-4]
24. Marchant A, Hawton K, Stewart A, Montgomery P, Singaravelu V, Lloyd K, et al. Correction: a systematic review of the relationship between internet use, self-harm and suicidal behaviour in young people: the good, the bad and the unknown. PLoS One 2018;13(3):e0193937 [FREE Full text] [doi: 10.1371/journal.pone.0193937] [Medline: 29494676]
25. Ali K, Farrer L, Gulliver A, Griffiths KM. Online peer-to-peer support for young people with mental health problems: a systematic review. JMIR Ment Health 2015;2(2):e19 [FREE Full text] [doi: 10.2196/mental.4418] [Medline: 26543923]
26. Dunlop SM, More E, Romer D. Where do youth learn about suicides on the internet, and what influence does this have on suicidal ideation? J Child Psychol Psychiatry 2011 Oct;52(10):1073-1080. [doi: 10.1111/j.1469-7610.2011.02416.x] [Medline: 21658185]
27. Moore D, Ayers S. Virtual voices: social support and stigma in postnatal mental illness Internet forums. Psychol Health Med 2016 May 24;22(5):1-6. [doi: 10.1080/13548506.2016.1189580] [Medline: 27218265]
28. Birnbaum ML, Candan K, Libby I, Pascucci O, Kane J. Impact of online resources and social media on help-seeking behaviour in youth with psychotic symptoms. Early Interv Psychiatry 2016 Oct;10(5):397-403. [doi: 10.1111/eip.12179] [Medline: 25200743]
29. Dosani S, Harding C, Wilson S. Online groups and patient forums. Curr Psychiatry Rep 2014 Nov;16(11):507 [FREE Full text] [doi: 10.1007/s11920-014-0507-3] [Medline: 25273668]

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30. Naslund JA, Aschbrenner KA, Marsch LA, Bartels SJ. The future of mental health care: peer-to-peer support and social media. Epidemiol Psychiatr Sci 2016 Apr;25(2):113-122 [FREE Full text] [doi: 10.1017/S2045796015001067] [Medline: 26744309]
31. Mead S, Copeland ME. What recovery means to us: consumers' perspectives. Community Ment Health J 2000 Jun;36(3):315-328. [Medline: 10933247]
32. Deering K, Williams J. What activities might facilitate personal recovery for adults who continue to self-harm? A meta-synthesis employing the connectedness/hope and optimism/identity/meaning/empowerment framework. Int J Ment Health Nurs 2018 Apr;27(2):483-497. [doi: 10.1111/inm.12387] [Medline: 28929615]
33. Anthony W. Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. Psychosoc Rehabil J 1993;16(4):11-23 [FREE Full text] [doi: 10.1037/h0095655]
34. Jones R, Sharkey S, Ford T, Emmens T, Hewis E, Smithson J, et al. Online discussion forums for young people who self-harm: user views. Psychiatrist 2018 Jan 2;35(10):364-368 [FREE Full text] [doi: 10.1192/pb.bp.110.033449]
35. Kvale SS. InterViews: An Introduction to Qualitative Research lnterviewing. Thousand Oaks: Sage Publications; 1996.
36. SANE Australia. 2017. About the forum, including feedback and news: Community guidelines URL: https://saneforums.org/t5/About-the-forum-including/Forum-Guides/m-p/105960 [accessed 2018-05-18] [WebCite Cache ID 6zV0bp1y5]
37. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
38. Davidson L, O'Connell M, Tondora J, Styron T, Kangas K. The top ten concerns about recovery encountered in mental health system transformation. Psychiatr Serv 2006 May;57(5):640-645. [doi: 10.1176/ps.2006.57.5.640] [Medline: 16675756]
39. Highton-Williamson E, Priebe S, Giacco D. Online social networking in people with psychosis: a systematic review. Int J Soc Psychiatry 2015 Feb;61(1):92-101. [doi: 10.1177/0020764014556392] [Medline: 25381145]
40. Baylosis C. Isolated connections: re-writing the self and social support within online communities. 2015 Presented at: 7th Australian Rural and Remote Mental Health Symposium; October 26-28, 2015; Creswick, Victoria.
41. Parish MB, Yellowlees P. The rise of person-centered healthcare and the influence of health informatics and social network applications on mental health care. Ment Health Infor 2014;491:17-39. [doi: 10.1007/978-3-642-38550-6_2]
42. Pavalanathan U, De Choudhury M. Identity management and mental health discourse in social media. Proc Int World Wide Web Conf 2015 May;2015(Companion):315-321 [FREE Full text] [Medline: 27376158]
43. Solomon P. Peer support/peer provided services underlying processes, benefits, and critical ingredients. Psychiatr Rehabil J 2004;27(4):392-401. [Medline: 15222150]
44. Kramer J, Boon B, Schotanus-Dijkstra M, van Ballegooijen W, Kerkhof A, van der Poel A. The mental health of visitors of web-based support forums for bereaved by suicide. Crisis 2015;36(1):38-45. [doi: 10.1027/0227-5910/a000281] [Medline: 25410257]
45. Balani S, De Choudhury M. Detecting and characterizing mental health related self-disclosure in social media. In: Proceedings of the 33rd Annual ACM Conference Extended Abstracts on Human Factors in Computing Systems. 2015 Presented at: the 33rd Annual ACM Conference; April 18-23, 2015; Seoul, Korea p. 373-375. [doi: 10.1145/2702613.2732733]
46. Nguyen M, Bin YS, Campbell A. Comparing online and offline self-disclosure: a systematic review. Cyberpsychol Behav Soc Netw 2012 Feb;15(2):103-111. [doi: 10.1089/cyber.2011.0277] [Medline: 22032794]
47. Deetjen U, Powell JA. Informational and emotional elements in online support groups: a Bayesian approach to large-scale content analysis. J Am Med Inform Assoc 2016 May;23(3):508-513. [doi: 10.1093/jamia/ocv190] [Medline: 26911815]
48. Lawlor A, Kirakowski J. Online support groups for mental health: a space for challenging self-stigma or a means of social avoidance? Comput Human Behav 2014 Mar;32:152-161 [FREE Full text] [doi: 10.1016/j.chb.2013.11.015]

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Original Paper

Relationship Between Sleep Quality and Mood: Ecological Momentary Assessment Study

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Abstract

Background: Sleep disturbances play an important role in everyday affect and vice versa. However, the causal day-to-day interaction between sleep and mood has not been thoroughly explored, partly because of the lack of daily assessment data. Mobile phones enable us to collect ecological momentary assessment data on a daily basis in a noninvasive manner.

Objective: This study aimed to investigate the relationship between self-reported daily mood and sleep quality.

Methods: A total of 208 adult participants were recruited to report mood and sleep patterns daily via their mobile phones for 6 consecutive weeks. Participants were recruited in 4 roughly equal groups: depressed and anxious, depressed only, anxious only, and controls. The effect of daily mood on sleep quality and vice versa were assessed using mixed effects models and propensity score matching.

Results: All methods showed a significant effect of sleep quality on mood and vice versa. However, within individuals, the effect of sleep quality on next-day mood was much larger than the effect of previous-day mood on sleep quality. We did not find these effects to be confounded by the participants' past mood and sleep quality or other variables such as stress, physical activity, and weather conditions.

Conclusions: We found that daily sleep quality and mood are related, with the effect of sleep quality on mood being significantly larger than the reverse. Correcting for participant fixed effects dramatically affected results. Causal analysis suggests that environmental factors included in the study and sleep and mood history do not mediate the relationship.

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KEYWORDS

sleep; affect; ecological momentary assessment; smartphone; depression; causality

Introduction

Background

Sleep disturbances and poor sleep quality are common and are associated with a wide variety of physical and mental health difficulties [1]. Mood disturbances are often viewed as the hallmark symptoms of mental health disorders such as depression and anxiety. Symptoms of depression and anxiety include disturbances in sleep and poor sleep quality, which are often viewed by patients as being among the more troubling symptoms experienced [2,3]. and are frequently cited as worsening one's mood. There have been multiple studies demonstrating that sleep disturbances and insomnia relate to the course of depression, including increased prevalence of suicidal ideation and risk of suicide [4-6]. As such, the relationships between sleep and mood have long been examined.

Early investigations of the relationships between mood and sleep typically used retrospective self-report data. For example,

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Rodin et al [7] conducted 8 interviews over the course of 3 years with participants to determine longitudinal, positive associations between depressed mood and disturbed sleep. As technologies evolved, it became increasingly convenient for researchers to obtain more frequent and accurate assessments of mood and sleep quality. Initially, ecological momentary assessment (EMA) of participants required that participants carry a study-prescribed device such as a personal data assistant. As mobile phones continue to gain popularity, they provide a relatively noninvasive method for collecting data from users. Mobile apps that notify users to complete mood and sleep ratings are often more convenient than paper-and-pencil tracking, and the resulting ratings are more reliable than those in paper-and-pencil charts [8]. Mobile phone data can also provide Global Positioning System (GPS) information on the participants' daily life that are predictive of their daily mood [9]. Thus, EMA using mobile phones is the state of the art for collecting self-report data.

The increased ease with which we can collect daily assessment data has led to increased focus on the intricate relationships between mood and sleep. Sleep is considered predictive of next-day mood [10-14]. The findings about the effect of mood on sleep are less clear. Some found no significant relations [10], and others found positive affect to be correlated with subsequent sleep quality [12,13]. Most of these studies collected data for 2 weeks or less. Blaxton et al [14] collected data for 6 weeks but did not report results on the relationship between mood and subsequent night sleep. Furthermore, only 1 of these studies included individuals with significant mood symptom variation: Bower et al (2010) compared groups of individuals with major depression and minor depression with healthy controls. Other studies did not report on mood symptoms, whereas Totterdell et al [10] explicitly recruited participants without clinically significant symptoms of depression. A detailed review of the relationship of affect and sleep can be found in the study by Watling et al [15]. Clearly, there have been limitations to past research on the topic as most studies of the relationship of everyday mood and sleep are short and do not differentially assess the mood states of individuals with mood and anxiety disorders. In this work, we attempt to address these shortcomings by using a collection of data over a long period (6 weeks), using mobile phones for reliable data collection, and assessing the differential relationships of sleep and affect in individuals with mood and anxiety disorders as well as in healthy controls.

Objective

Ultimately, we are asking a causal question. We do not want to know if people with a positive mood sleep better; we want to know if helping them sleep better would improve their mood. The answer to this question can directly inform psychotherapeutic intervention efforts. To ask such causal questions, we can look to statistics for methods that allow correcting for confounders. One popular technique for correcting for confounders is propensity score matching (PSM; [16]). In that approach, we compare days when people are equally likely to engage in a specific behavior (eg, sleep well) based on other measured characteristics. Causal inference from observational data promises to improve the estimation of the causal relationship between sleep and mood.

The aim of this study was to examine the relationship between self-reported sleep quality and self-reported mood in a national sample of adults in the United States, who completed daily ratings via a mobile phone app over 6 weeks. By including roughly equal sizes of depressed, anxious, both depressed and anxious, and control participants, we compared the magnitude of this relationship in these groups. By controlling for a number of possibly confounding factors, we inferred the strength of the *causal* relationship between sleep quality and mood.

Methods

Recruitment

Participants were recruited between October 28, 2015, and February 12, 2016, by Focus Pointe Global, a company specializing in participant recruitment [17]. Focus Pointe Global used internet panels of participants as a primary means of recruitment. They sent out emails to these panels with links to the screener questionnaire and made phone calls to potential participants in their in-house registries.

Individuals were eligible for our study if they were aged at least 18 years, able to read and understand English, owned a personal mobile phone with Android 4.4 through 5.1, and had access to Wi-Fi for at least one 3-hour period a day for our data collection software to transfer the data.

To minimize the likelihood of interruption in data collection, we excluded individuals who reported they had been diagnosed with any psychotic disorders or had positive screens for alcohol abuse (Alcohol Use Disorders Identification Test score ≥16; [18]), drug abuse (Drug Abuse Screening Test-10 score ≥6; [19]), suicidal ideation (Patient Health Questionnaire-9 item [PHQ-9] rating ≥1; [20], and Beck Depression Inventory-II item 9 rating ≥2; [21]), or bipolar disorder (Mood Disorder Questionnaire question 1 score ≥7, an endorsement of question 2, and a response of 2 or 3 for question 3 [22]). Potential participants meeting any of these criteria were excluded both for safety reasons, as study staff could not manage problems arising from these conditions in an automated way and to focus the study on depression and anxiety.

Eligible participants consented using procedures approved by the Northwestern University Institutional Review Board, which included descriptions of the data to be gathered along with data security and privacy policies. We selected roughly equal numbers of participants in 4 groups, such that there were wide ranges of depression and anxiety symptoms in the sample. We defined the groups as depressed and anxious (PHQ-9≥10; Generalized Anxiety Disorder-7 item [GAD-7]≥10), depressed only (PHQ-9≥10; GAD-7<10), anxious only (PHQ-9<10; GAD-7≥10), and control (PHQ-9<10; GAD-7<10). These cut-off values for PHQ-9 and GAD-7 were chosen as they have been shown to maximize the sensitivity and specificity for the diagnosis of major depression [20] and GAD (Spritzer et al, 2006), respectively. Table 1 shows the distribution of age, gender, PHQ-9 scores, and GAD-7 scores among groups.

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Table 1. Distribution of age, gender, Patient Health Questionnaire-9 item (PHQ-9) scores, and Generalized Anxiety Disorder-7 item (GAD-7) scores within the 4 groups of participants.

Group	Age, mean (SD)	Gender (male, female, other), n	PHQ-9[a], mean (SD)	GAD-7[b], mean (SD)
Depressed	38.10 (10.30)	6, 43, 2	13.40 (2.90)	5.94 (2.43)
Anxious	36.30 (9.35)	10, 33, 1	7.11 (1.69)	13.36 (2.88)
Depressed and anxious	37.12 (9.56)	8, 44, 0	14.19 (3.45)	14.33 (3.06)
Control	41.42 (11.06)	11, 48, 0	4.47 (3.05)	3.80 (2.95)

[a]PHQ-9: Patient Health Questionnaire-9 item.

[b]GAD-7: Generalized Anxiety Disorder-7 item.

Each participant was enrolled for a period of 6 weeks. Participants were compensated from US $25 up to US $270.40 depending on how long they stayed in the study and how many of the daily questionnaires they answered.

Data Collection

We collected EMA data to assess the daily mood and sleep quality of the participants. Every day, at 9 am local time, a brief set of questions was launched on the participant's mobile phone assessing their sleep quality and affect states. A single item prompted participants to rate their sleep quality from 0 to 8 on a 9-point–labeled Likert scale. Mood, stress, energy, and focus levels were also assessed on similar 9-point–labeled Likert scales. The participants also reported the day type (working, day off, half day). In addition to the morning assessments, mood, stress, energy, and focus were assessed 2 more times throughout the day, at 3 pm and 9 pm. Participants could respond immediately to the questions or delay the response until later that day. They were also able to adjust the survey times within a 2-hour window. If they did not answer the questions before midnight, the questionnaire disappeared; on the next day, a new questionnaire was launched asking about the next-day states.

In addition to EMA data, phone sensor data were collected from a range of sensors including GPS, accelerometer, light, microphone, call and short message service events, and Wi-Fi. We used an open-source Android app, *Purple Robot* [23], to collect both sensor and EMA data and to transmit them to our data servers. The data were transmitted via encrypted, password-protected tunnels and then deleted from the phone. The data residing on the server were only accessible to individuals with the proper credentials.

For this study, we included data from sensors known to be related to daily mood and sleep quality. These included physical activity provided by Android's Activity Recognition application programming interface (API) and the daily weather conditions using the Weather Underground [24].

Measured Variables

Sleep Quality

Sleep quality was reported on a labeled Likert scale: 0 (extremely poor), 1 (very poor), 2 (poor), 3 (a bit poor), 4 (adequate), 5 (a bit rested), 6 (rested), 7 (very rested), and 8 (extremely rested).

Mood, Stress, Energy, and Focus

The 3 self-reported ratings for mood, stress, energy, and focus were averaged for every person and every day. The variables were reported on the following labeled Likert scales:

- Mood: 0 (extremely poor), 1 (very poor), 2 (poor), 3 (a bit poor), 4 (neither), 5 (a bit good), 6 (good), 7 (very good), and 8 (extremely good).
- Stress: 0 (extremely stressed), 1 (very stressed), 2 (stressed), 3 (a bit stressed), 4 (normal), 5 (a bit calm), 6 (calm), 7 (very calm), and 8 (extremely calm).
- Energy: 0 (extremely tired), 1 (very tired), 2 (tired), 3 (a bit tired), 4 (average), 5 (a bit energetic), 6 (energetic), 7 (very energetic), and 8 (extremely energetic).
- Focus: 0 (extremely distracted), 1 (very distracted), 2 (distracted), 3 (a bit distracted), 4 (neither), 5 (a bit focused), 6 (focused), 7 (very focused), and 8 (extremely focused).

The average scores were used in all subsequent analyses. Mood was used in all models to estimate its effect on subsequent sleep quality or to estimate the effect of sleep quality on next-day mood. Stress, energy, and focus were used as possible confounders of mood and subsequent sleep quality and of sleep quality and next-day mood as they are known to be related with both [25].

Physical Activity

Physical activity was used as a possible confounder of mood and sleep quality as there is a body of work relating physical activity to well-being [26,27]. The activity of each participant was classified as 1 of the following by the Android's Activity Recognition API: "in _vehicle," "on _bicycle," "on _foot," "running," "still," "tilting," "walking," and "unknown." The sum of "biking," "running," and "walking" intervals was used as a measure of physical activity.

Weather

Weather is also known to influence affect [28], and is therefore used as a possible confounder. For each participant, the weather report closest to the time the participant visited each location was downloaded from the Weather Underground service. The reports provide a number of attributes, including sky condition and mean temperature. As a measure of weather conditions, we used the mean temperature and the sum of intervals when the sky was clear.

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Day of the Week and Type of Day

We also included the day of the week (Monday to Sunday) and the type of day (normal [normal work day], partial [partial work day], off [not a work day]) as possible confounders for mood and sleep quality.

Statistical Analysis

Daily Interplay Between Sleep Quality and Mood

Our goal was to examine how sleep quality is related to subsequent mood and also how daily mood affects subsequent sleep quality. To do so, each day's average mood was paired with (1) sleep quality the following night, to estimate the effect of mood on sleep quality, and (2) sleep quality the previous night, to estimate the effect of sleep quality on mood. All analyses were then performed on both datasets 1 and 2. To estimate the effect of mood on sleep quality, we used dataset 1, with sleep quality as the dependent variable. To estimate the effect of sleep quality on mood, we used dataset 2, with mood as the dependent variable. This allows us to evaluate if the effect of sleep on mood is higher than the effect of mood on sleep. To account for both across-subject and within-subject effects, we used mixed effects models.

Within-Subject Normalization

People may respond to self-report scales very differently, in a manner that is consistent for each individual and independent of the specific self-report question [29].

Although mixed effects models use random intercepts to model different baselines, they do not take into account the different ranges used in the personal reports. Therefore, to examine the relationships between the relative personal mood and sleep quality, we normalized the within-person data using the *z*-score of each variable. We then used mixed effects models with varying slopes and fixed (=0) intercepts to calculate the corresponding fixed and random effects. By normalizing within-subject data and using mixed effects models, we tried to quantify the relationship of the *relative personal* mood and sleep quality, defined on the basis of personal variation.

Propensity Score Matching

The relationship between sleep quality and mood could be confounded by a number of other factors such as other measures of daily affect (eg, stress), physical activity, environmental factors, and work status. Compared with pairwise models, controlling for these variables bring us closer to the actual *causal* effect of sleep quality on mood and vice versa.

PSM reduces the confounding bias in the estimated effects by controlling for measured confounders and is mainly used for binary treatments (ie, a participant either receives or does not receive treatment). This is done by matching cases (treatment=1) and controls (treatment=0) based on the confounders and then computing the average outcome on both groups. Matching is done based on the propensity score, which is the probability of treatment given the values of the confounders, and can be estimated with a logistic model. This procedure aims to balance the distribution of possible confounds and, thus, reduce the bias of the effect estimate.

Although sleep quality is not a controllable or prescribable treatment for an individual, this analytic method can reduce the confounding bias of the estimated causal effect of sleep quality on mood and vice versa. We applied PSM on each subject. For both models (sleep quality as treatment and mood as outcome; mood as treatment and sleep quality as outcome), the treatment variable within each subject was binarized with respect to the subject mean value. The personal causal effect is estimated as the difference in average outcomes in the 2 matched groups divided by the pooled SD of the 2 matched groups [30]. To check if controlling for confounders changes the estimated causal effects, we compared with the unmatched effect, which is calculated using all the subjects' data (without matching).

Results

Participation

A total of 208 eligible participants were recruited for the study, of which 2 were removed for insufficient data (1 of them did not install the software on their phone and another had invalid GPS data). Of the 206 remaining participants, 170 (82.5%) were females and 36 (17.5%) were males. Their ages ranged between 18 and 66 years, with a mean of 39.3 (SD 10.3). Geographically, they were from 37 different states. Mean depression score (PHQ-9) of the participants was 9.72 (SD 5.06), and mean anxiety score (GAD-7) was 9.0 (SD 5.36).

Participants had a diverse educational background. A total of 4 participants (4/206, 1.9%) had some high school education, 25 (25/206, 12.1%) had completed high school, 73 (73/206, 35.4%) had some college training, 28 (28/206, 13.6%) completed a 2-year college, 49 (40/206, 23.8%) had a Bachelor's degree, 23 (23/206, 11.2%) had a Master's degree, and 4 (4/206, 1.9%) had a professional Doctorate degree. Regarding employment status, 126 (126/206, 61.2%) were employed; 43 (43/206, 20.9%) were unemployed; 17 (17/206, 8.3%) had disability, which prevented them from working; and 4 (4/206, 1.9%) were retired. A total of 16 participants (16/206, 7.8%) did not specify their employment status.

The planned duration of the study was 6 weeks, corresponding to 42 sleep quality assessments and 126 mood assessments. However, some participants stopped sending data at various stages of the study, whereas others continued sending data after the completion of 6 weeks, resulting in 6 to 134 report days. The mean reported mood across all participants was 5.0 (SD 1.49), and the mean sleep quality was 4.45 (SD 1.83).

Daily Interplay Between Sleep and Mood

Using linear mixed effects models [31], we found a significant effect of mood on sleep quality (Table 2, b_1=.247; P<.001) and sleep quality on mood (b_1=.270; P<.001). Although the effect of sleep quality on mood was slightly larger than the opposite effect, this difference was not significant. We emphasize here that the wording *effect* we use here is from the statistical community, and it only corresponds to causality if there are no confounders outside of the participant's identity.

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Table 2. Mixed effects model results on mood and sleep quality scores and within-person normalized mood and sleep quality scores.

Predictor	Raw scores		Within-person normalized scores	
	Coefficient (SE)	*P* value	Coefficient (SE)	*P* value
Effect of sleep quality on mood: sleep quality	0.270 (0.013)	<.001	0.344 (0.009)	<.001
Effect of mood on sleep quality: mood	0.247 (0.020)	<.001	0.132 (0.019)	<.001

To see whether our results were affected by participants having different subjective scales for rating mood and sleep quality, we normalized these within each subject and fit mixed effects models to them. The results (Table 2) were different compared with non-normalized data. Importantly, the effect of sleep quality on mood (b_1=.344; *P*<.001) was now much larger than the effect of mood on sleep quality (b1=.132; *P*<.001). Thus, using normalized scores indicates that the effect of the relative personal sleep quality on mood is on average larger than the opposite. The fact that the precise definition (relative vs absolute) has such a huge influence shows that individual differences in completing questionnaires [29] may lead to spurious correlations between modeled variables.

Relationship Between Mood and Sleep Quality in the Presence of Confounders

The effect of mood on sleep quality and vice versa can be confounded by other variables that potentially affect both mood and sleep quality, for example, exercise. We used PSM to control for the potential effect of these confounding variables. As possible confounders, we included the following variables: the participant's mood and sleep quality on the previous day; the participant's reported stress, energy, and focus levels on the previous day; the participant's physical activity level on the previous day measured by the phone sensors; weather conditions (mean daily temperature and sky condition); day type (working day, half day, or day off); and the day of the week (calculated based on the EMA data timestamps). Using PSM to control for these variables, we calculated the personal causal effect of mood on sleep quality for each participant, using mood as *treatment* and sleep quality as *outcome*, and the personal causal effect of sleep quality on mood for each participant, using sleep quality as *treatment* and mood as *outcome*. Participants with very low variance in the treatment variable (<0.5) did not admit a reliable treatment discretization and were therefore excluded from the analysis. This setting allows us to correct for confounding bias.

To quantify the effect, we calculated the unmatched scores using all samples from each participant without matching. The effect of sleep on mood quality is significantly (*P*<.001) larger than the effect of mood on sleep quality (Figure 1, left side). This is consistent with the result of the mixed effects models with normalization. For PSM, treatment and control samples for each participant were matched based on the value of confounding variables, and the rest of the samples were discarded. We started by including weather variables, physical activity, stress, focus, energy, day of the week, and day type as confounds. Table 3 describes the confounds used for matching and their correlations with the treatment variable. The results (Figure 1, T=0) did not differ much from the unmatched results. We also included the past values of mood and sleep quality 1 (T=1), 2 (T=2), and 3 (T=3) days before. None of the changes in effect size, as covariates are added, is significant. Therefore, on average, confounds did not affect the relationship between mood and sleep quality in our study.

Relationship Between Mood and Sleep Quality for Different Groups in Terms of Anxiety and Depression

To examine whether the causal effect of mood on sleep and vice versa differs for people with different depression and anxiety profiles, we performed the PSM analysis separately in the 4 groups in our study design: *depressed and anxious*, *depressed only*, *anxious only*, and *control*. We matched the subjects based on the confounders shown in Table 3 as well as mood and sleep quality on the previous day (as shown in Figure 1, T=1). We compared the mean estimated causal effect for each of the groups against the control group. For the effect of mood on sleep, the mean personal causal effect is significantly larger for the anxious group compared with control (*P*<.001; Figure 2). However, there was no difference between the control and the rest of the groups. In contrast, the effect of sleep on mood is significantly smaller for depressed, anxious, and depressed and anxious groups (*P*<.001; Figure 2) compared with control. Thus, sleep quality for people with anxiety appears more sensitive to mood fluctuations; on the other hand, sleep quality seems to have a higher effect on the mood of people without anxiety and depression. Moreover, it seems that the relationship of mood and sleep quality is stronger for people with anxiety compared with people with depression.

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Figure 1. Mean personal causal effect of mood on sleep quality (patterned bar) and sleep quality on mood (empty bar), obtained by 100 bootstraps over participants. Treatment (> mean) and controls (<mean) were matched based on a number of possible confounders, such as weather, stress, focus, energy, day of the week, day type, and activity (T=0, 1, 2, and 3), as well as the mood and sleep quality history (T=1, 2, and 3). Error bars show standard deviations. None of the confounders used seem to confound the effect sizes. Including past sleep quality and mood also does not greatly affect the results. However, the effect of sleep quality on mood was significantly (P<.001) larger than the effect of mood on sleep quality in all cases (unmatched, T =0, 1, 2, 3, 4).

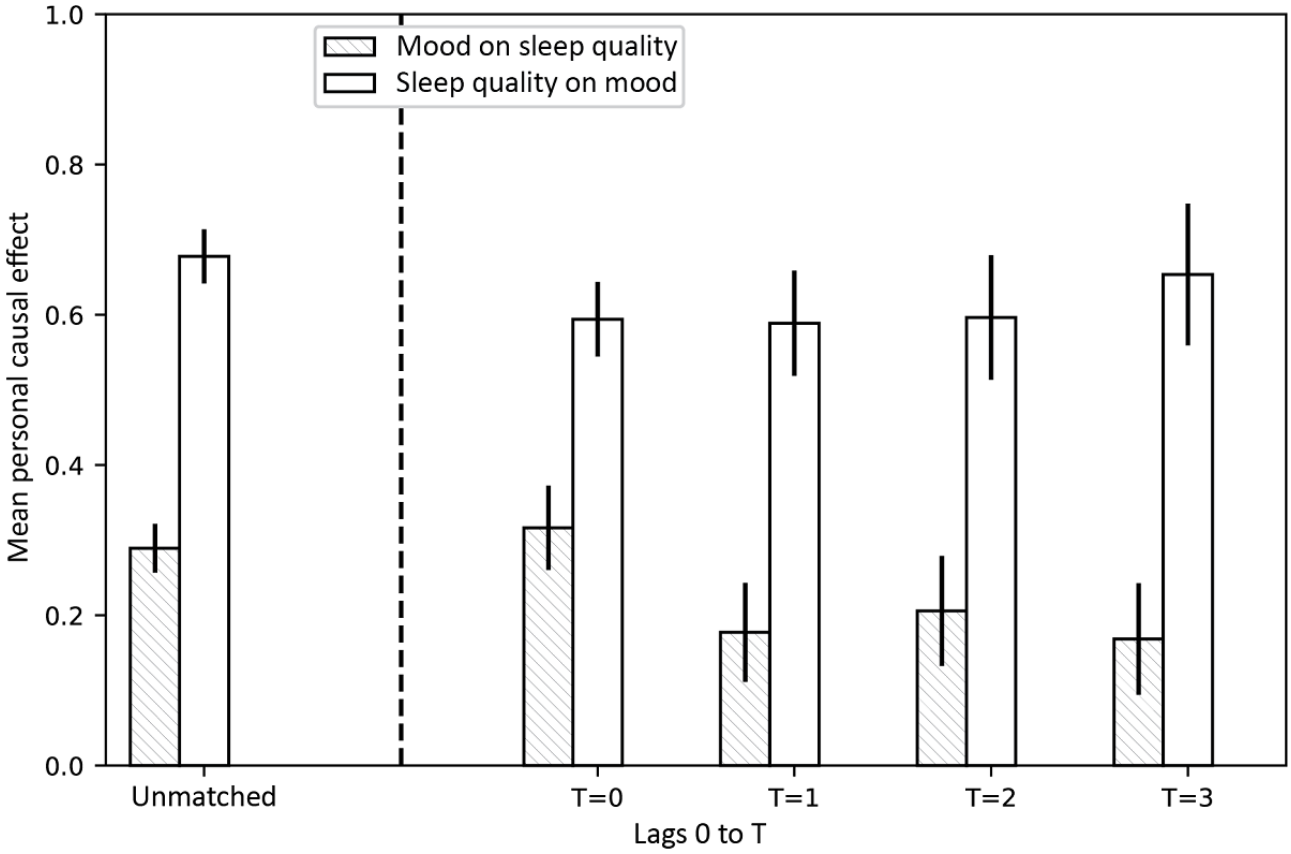
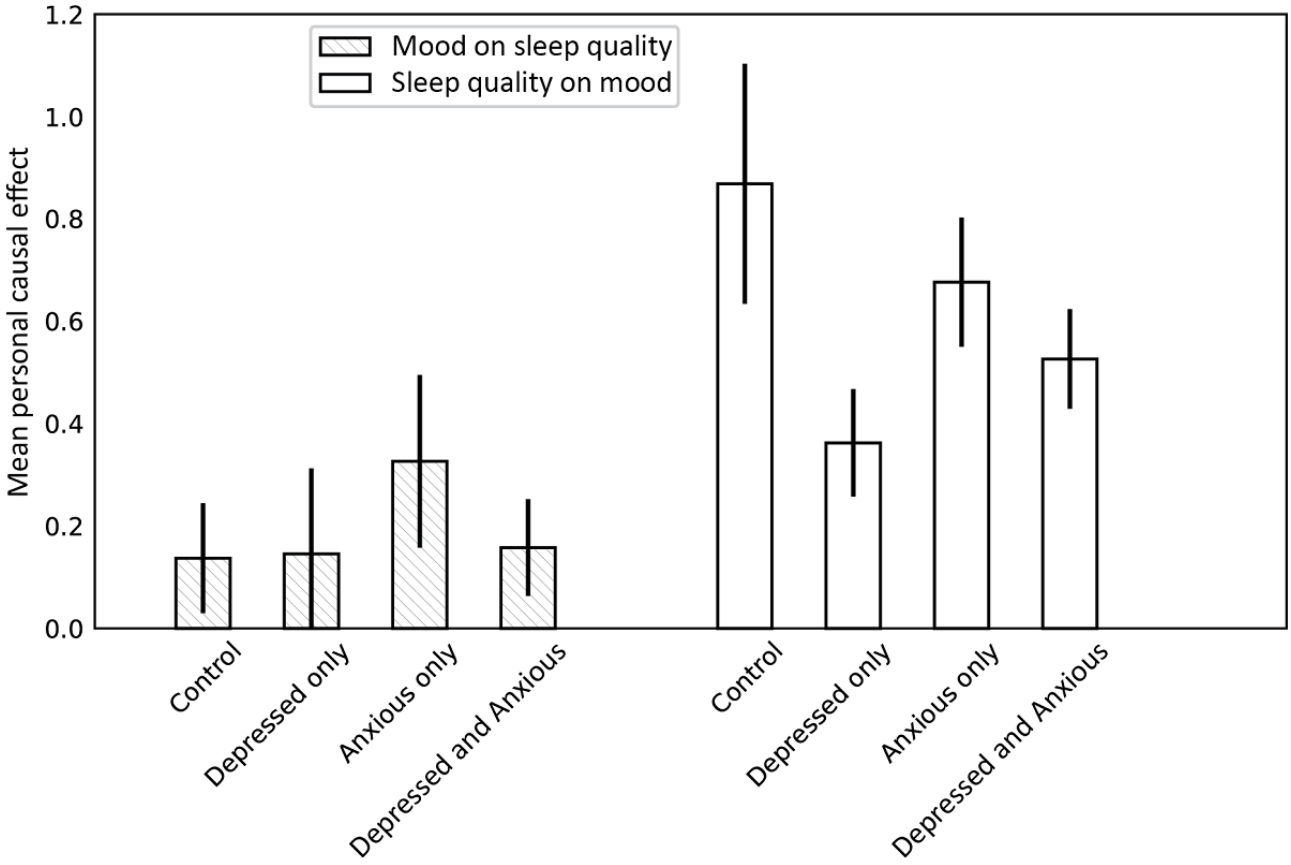


Table 3. Possible confounds and their correlation with treatment, averaged over 206 participants.

Possible confounder	Treatment			
	Sleep quality		Mood	
	Mean (SD)	Number of *P* values (*P*<.05)	Mean (SD)	Number of *P* values (*P*<.05)
Day of the week	0.016 (0.176)	16.0	0.058 (0.170)	20.0
Mean temperature (previous day)	0.017 (0.181)	13.0	−0.019 (0.195)	25.0
Clear sky (previous day)	−0.006 (0.191)	15.0	0.003 (0.192)	17.0
Activity (previous day)	0.013 (0.199)	16.0	0.018 (0.189)	15.0
Day type	0.074 (0.199)	25.0	0.066 (0.199)	20.0
Stress (previous day)	0.160 (0.221)	59.0	0.296 (0.233)	110.0
Energy (previous day)	0.113 (0.228)	44.0	0.220 (0.241)	77.0
Focus (previous day)	0.131 (0.225)	40.0	0.248 (0.227)	80.0

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Figure 2. Mean personal causal effect of mood on sleep quality (patterned bars) and sleep quality on mood (empty bars), obtained with propensity score matching by 100 bootstraps over subjects within 4 groups: control, depressed, anxious, and depressed and anxious. Treatment (> mean) and controls (<mean) were matched based on a number of possible confounders, such as weather, stress, focus, energy, day of the week, day type, and activity (T=0, 1, 2, and 3), as well as the mood and sleep quality of the previous day. Error bars show standard deviations. The effect of mood on sleep quality is significantly larger (P<.001) for the anxious group, compared with control. In contrast, the effect of sleep quality on mood is significantly smaller for the depressed (P<.001), anxious (P<.001), and depressed and anxious group (P<.001), compared to control.



Discussion

Principal Findings

We examined the effect of sleep quality on mood and vice versa in a large and diverse sample with a wide range of depression and anxiety symptoms. When we analyzed the data in the full sample, we found these 2 effects to be similar. However, we observed that participants probably used the Likert-type rating scales in different ways. Thus, when individual participant data were normalized and participant data were examined at the individual level, the effect of sleep quality on mood was significantly larger than the effect of mood on sleep quality. This result is consistent with that of previous studies [10-14,32].

We also examined whether the relationship between mood and sleep quality was mediated by other daily variables that can affect both mood and sleep. We examined the roles of daily physical activity, weather conditions, stress, and past mood and sleep quality [26,28,33] and used PSM to obtain a less biased causal effect. We found that the confounders included in the study did not mediate the relationship between sleep quality and mood in either direction. Although we cannot rule out the presence of additional unmeasured confounders, we are confident about these results as this analytic method is known to greatly reduce the bias of the estimated causal effects. These findings suggest that sleep quality has a significant impact on next-day mood, independent of other daily factors, which have valuable clinical implications.

Finally, we examined if the severity of depression or anxiety symptoms affect these relationships. The effect of mood on sleep quality was significantly stronger among anxious participants than among the depressed and control groups. Thus, affect regulation strategies may be effective at improving sleep quality among individuals with elevated symptoms of anxiety [34,35]. However, for the effect of sleep quality on mood, the effect size of the control group was significantly larger than that of the group of individuals with elevated symptoms of anxiety or depression. Overall, these results suggest that the relationship between sleep quality and mood considerably varies depending on the levels of depression or anxiety symptoms.

Limitations

There are limitations to our study that must be mentioned. First, the study sample is not necessarily entirely representative because of the study design (eg, only Android users) and recruitment procedure (eg, use of a data survey company). However, it is worth noting that relationships between mood and sleep quality did not vary by demographic and socioeconomic factors. In addition, a single item of sleep quality measure was used, and thus, we do not have data available on specific types of sleep disturbances (ie, difficulty falling asleep,

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staying asleep, early morning wakening, and waking up not feeling rested).

Second, although the PHQ-9 and GAD-7 are validated tools for screening for depressive and anxiety disorders, we did not conduct formal diagnostic interviews. We, therefore, suggest caution in generalizing these findings to clinically diagnosed diagnostic groups.

Finally, we cannot exclude the possibility of additional unmeasured confounders in our analyses, such as social interactions, drug and alcohol consumption, or receiving mental health care. In addition, physical activity was calculated based on phone sensor data, and therefore, it likely overlooked the intervals during which the participants were mobile without carrying their phone. Thus, including additional putative confounders in future studies could help further elucidate the nature of the causal interplay between sleep quality and mood.

Clinical Implications

Our results indicate that improving sleep quality may have positive outcomes on daily mood. Although the range of sleep quality disturbances is wide, some of them are treatable. Specifically for insomnia, cognitive behavioral therapy for insomnia (CBT-I) has been established as a gold standard treatment [36,37]. Furthermore, past studies have found that the benefits of CBT-I extend beyond sleep to include markers of positive psychological outcomes [38,39] and that these benefits extend to individuals with depression and anxiety [40]. Although CBT-I is unlikely to be prescribed to individuals without diagnosable insomnia, these findings are valuable for elucidating the effect of poor sleep quality on next-day mood. Clinicians should fully assess for sleep disturbances when assessing mood disturbances and are likely to see greater gains in their patients if they address and treat sleep disturbances early in the course of treatment [38,41]. As we found that the effect of sleep quality on mood was significantly greater among control participants compared with participants endorsing elevated levels of depression and/or anxiety, the effect of treating sleep disturbances early in the course of treatment may be particularly relevant for patients endorsing subthreshold mood symptoms.

Conclusions

Overall, our results suggest that the effect of sleep quality on mood is significantly larger than the effect of mood on sleep quality, even when relevant confounds are considered. However, this relationship can vary across individuals with different levels of depression and anxiety. Moreover, our study highlights the importance of analyzing data at the participant level to account for the individual biases in responding to self-report scales over time. Given the strong effect of sleep quality on next-day mood, clinicians may find enhanced treatment gains by focusing on resolving sleep disturbances early in treatment.

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Conflicts of Interest

None declared.

References

1. Foley D, Ancoli-Israel S, Britz P, Walsh J. Sleep disturbances and chronic disease in older adults: results of the 2003 National Sleep Foundation Sleep in America Survey. J Psychosom Res 2004 May;56(5):497-502. [doi: 10.1016/j.jpsychores.2004.02.010] [Medline: 15172205]
2. Pandina GJ, Garibaldi GM, Revicki DA, Kleinman L, Turkoz I, Kujawa MJ, et al. Psychometric evaluation of a patient-rated most troubling symptom scale for depression: findings from a secondary analysis of a clinical trial. Int Clin Psychopharmacol 2010 Mar;25(2):51-59. [doi: 10.1097/YIC.0b013e3283320667] [Medline: 20061962]
3. Zimmermann TM, Clouth J, Elosge M, Heurich M, Schneider E, Wilhelm S, et al. Patient preferences for outcomes of depression treatment in Germany: a choice-based conjoint analysis study. J Affect Disord 2013 Jun;148(2-3):210-219. [doi: 10.1016/j.jad.2012.11.062] [Medline: 23290792]
4. Fawcett J, Scheftner WA, Fogg L, Clark DC, Young MA, Hedeker D, et al. Time-related predictors of suicide in major affective disorder. Am J Psychiatry 1990 Sep;147(9):1189-1194. [doi: 10.1176/ajp.147.9.1189] [Medline: 2104515]
5. Ağargün MY, Kara H, Solmaz M. Sleep disturbances and suicidal behavior in patients with major depression. J Clin Psychiatry 1997 Jun;58(6):249-251. [Medline: 9228889]
6. Turvey CL, Conwell Y, Jones MP, Phillips C, Simonsick E, Pearson JL, et al. Risk factors for late-life suicide: a prospective, community-based study. Am J Geriatr Psychiatry 2002;10(4):398-406. [Medline: 12095899]
7. Rodin J, McAvay G, Timko C. A longitudinal study of depressed mood and sleep disturbances in elderly adults. J Gerontol 1988 Mar;43(2):P45-P53. [Medline: 3346525]
8. Depp CA, Kim DH, de Dios LV, Wang V, Ceglowski J. A pilot study of mood ratings captured by mobile phone versus paper-and-pencil mood charts in bipolar disorder. J Dual Diagn 2012 Jan 01;8(4):326-332 [FREE Full text] [doi: 10.1080/15504263.2012.723318] [Medline: 23646035]

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9. Pratap A, Atkins DC, Renn BN, Tanana MJ, Mooney SD, Anguera JA, et al. The accuracy of passive phone sensors in predicting daily mood. Depress Anxiety 2019 Dec;36(1):72-81. [doi: 10.1002/da.22822] [Medline: 30129691]
10. Totterdell P, Reynolds S, Parkinson B, Briner RB. Associations of sleep with everyday mood, minor symptoms and social interaction experience. Sleep 1994 Aug;17(5):466-475. [doi: 10.1093/sleep/17.5.466] [Medline: 7991960]
11. Sonnentag S, Binnewies C, Mojza EJ. "Did you have a nice evening?" A day-level study on recovery experiences, sleep, and affect. J Appl Psychol 2008 May;93(3):674-684. [doi: 10.1037/0021-9010.93.3.674] [Medline: 18457495]
12. Galambos NL, Dalton AL, Maggs JL. Losing sleep over it: daily variation in sleep quantity and quality in Canadian students' first semester of university. J Res Adolesc 2009;19(4):741-761. [doi: 10.1111/j.1532-7795.2009.00618.x]
13. de Wild-Hartmann JA, Wichers M, van Bemmel AL, Derom C, Thiery E, Jacobs N, et al. Day-to-day associations between subjective sleep and affect in regard to future depression in a female population-based sample. Br J Psychiatry 2013 Jun;202:407-412. [doi: 10.1192/bjp.bp.112.123794] [Medline: 23661764]
14. Blaxton JM, Bergeman CS, Whitehead BR, Braun ME, Payne JD. Relationships among nightly sleep quality, daily stress, and daily affect. J Gerontol B Psychol Sci Soc Sci 2017 May 01;72(3):363-372 [FREE Full text] [doi: 10.1093/geronb/gbv060] [Medline: 26307483]
15. Watling J, Pawlik B, Scott K, Booth S, Short MA. Sleep loss and affective functioning: more than just mood. Behav Sleep Med 2017;15(5):394-409. [doi: 10.1080/15402002.2016.1141770] [Medline: 27158937]
16. Rosenbaum PR, Rubin BD. The central role of the propensity score in observational studies for causal effects. Biometrika 1983 Apr;70(1):41-55 [FREE Full text] [doi: 10.2307/2335942]
17. Focus Pointe Global. 2016. URL: https://www.focuspointeglobal.com/ [accessed 2019-02-27] [WebCite Cache ID 76Ut7bEM3]
18. Bohn MJ, Babor TF, Kranzler HR. The Alcohol Use Disorders Identification Test (AUDIT): validation of a screening instrument for use in medical settings. J Stud Alcohol 2015 Jan 04;56(4):423-432. [doi: 10.15288/jsa.1995.56.423]
19. Skinner HA. The drug abuse screening test. Addict Behav 1982;7(4):363-371. [doi: 10.1016/0306-4603(82)90005-3] [Medline: 7183189]
20. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. J Gen Intern Med 2001 Sep;16(9):606-613 [FREE Full text] [doi: 10.1046/j.1525-1497.2001.016009606.x] [Medline: 11556941]
21. Beck AT, Steer RA, Brown GK. BDI-II, Beck Depression Inventory: Manual. 2nd Edition. San Antonio, Tex: Harcourt Brace; 1996:38p.
22. Hirschfeld RM, Williams JB, Spitzer RL, Calabrese JR, Flynn L, Keck Jr PE, et al. Development and validation of a screening instrument for bipolar spectrum disorder: the Mood Disorder Questionnaire. Am J Psychiatry 2000 Nov;157(11):1873-1875. [doi: 10.1176/appi.ajp.157.11.1873] [Medline: 11058490]
23. CBITs TECH Website. 2015. Purple Robot: Purple Robot is a core component of CBITs mobile offerings URL: https://tech.cbits.northwestern.edu/purple-robot/2015/ [accessed 2019-02-12] [WebCite Cache ID 768kmN4RN]
24. Weather Underground. 2017. URL: https://www.wunderground.com/ [accessed 2019-02-27] [WebCite Cache ID 76UxrPd1I]
25. Guilleminault C, Lugaresi E, editors. Sleep-Wake Disorders: Natural History, Epidemiology, and Long-Term Evolution. New York, NY: Raven Press; 1983.
26. Penedo FJ, Dahn JR. Exercise and well-being: a review of mental and physical health benefits associated with physical activity. Curr Opin Psychiatry 2005 Mar;18(2):189-193. [doi: 10.1097/00001504-200503000-00013] [Medline: 16639173]
27. DeMasi O, Feygin S, Dembo A, Aguilera A, Recht B. Well-being tracking via smartphone-measured activity and sleep: cohort study. JMIR Mhealth Uhealth 2017 Oct 5;5(10):e137. [doi: 10.2196/mhealth.782] [Medline: 28982643]
28. Denissen JJ, Butalid L, Penke L, van Aken MA. The effects of weather on daily mood: a multilevel approach. Emotion 2008 Oct;8(5):662-667. [doi: 10.1037/a0013497] [Medline: 18837616]
29. Austin EJ, Deary IJ, Gibson GJ, McGregor MJ, Dent JB. Individual response spread in self-report scales: personality correlations and consequences. Pers Individ Dif 1998 Mar;24(3):421-438. [doi: 10.1016/S0191-8869(97)00175-X]
30. Austin PC. An introduction to propensity score methods for reducing the effects of confounding in observational studies. Multivariate Behav Res 2011 May;46(3):399-424 [FREE Full text] [doi: 10.1080/00273171.2011.568786] [Medline: 21818162]
31. Lindstrom MJ, Bates DM. Newton-Raphson and EM algorithms for linear mixed-effects models for repeated-measures data. J Am Stat Assoc 1988 Dec;83(404):1014-1022. [doi: 10.1080/01621459.1988.10478693]
32. Bower B, Bylsma LM, Morris BH, Rottenberg J. Poor reported sleep quality predicts low positive affect in daily life among healthy and mood-disordered persons. J Sleep Res 2010 Jun;19(2):323-332 [FREE Full text] [doi: 10.1111/j.1365-2869.2009.00816.x] [Medline: 20374447]
33. DeLongis A, Folkman S, Lazarus RS. The impact of daily stress on health and mood: psychological and social resources as mediators. J Pers Soc Psychol 1988 Mar;54(3):486-495. [Medline: 3361420]
34. Monti JM, Monti D. Sleep disturbance in generalized anxiety disorder and its treatment. Sleep Med Rev 2000 Jun;4(3):263-276. [doi: 10.1053/smrv.1999.0096] [Medline: 12531169]
35. Hoge EA, Bui E, Marques L, Metcalf CA, Morris LK, Robinaugh DJ, et al. Randomized controlled trial of mindfulness meditation for generalized anxiety disorder: effects on anxiety and stress reactivity. J Clin Psychiatry 2013 Aug;74(8):786-792 [FREE Full text] [doi: 10.4088/JCP.12m08083] [Medline: 23541163]

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36. Edinger JD, Wohlgemuth WK, Radtke RA, Marsh GR, Quillian RE. Cognitive behavioral therapy for treatment of chronic primary insomnia: a randomized controlled trial. J Am Med Assoc 2001 Apr 11;285(14):1856-1864. [Medline: 11308399]
37. Morin CM, Vallières A, Guay B, Ivers H, Savard J, Mérette C, et al. Cognitive behavioral therapy, singly and combined with medication, for persistent insomnia: a randomized controlled trial. J Am Med Assoc 2009 May 20;301(19):2005-2015 [FREE Full text] [doi: 10.1001/jama.2009.682] [Medline: 19454639]
38. Manber R, Edinger JD, Gress JL, Pedro-Salcedo MG, Kuo TF, Kalista T. Cognitive behavioral therapy for insomnia enhances depression outcome in patients with comorbid major depressive disorder and insomnia. Sleep 2008 Apr;31(4):489-495 [FREE Full text] [Medline: 18457236]
39. Manber R, Bernert RA, Suh S, Nowakowski S, Siebern AT, Ong JC. CBT for insomnia in patients with high and low depressive symptom severity: adherence and clinical outcomes. J Clin Sleep Med 2011 Dec 15;7(6):645-652 [FREE Full text] [doi: 10.5664/jcsm.1472] [Medline: 22171204]
40. Wu JQ, Appleman ER, Salazar RD, Ong JC. Cognitive behavioral therapy for insomnia comorbid with psychiatric and medical conditions: a meta-analysis. J Am Med Assoc Intern Med 2015 Sep;175(9):1461-1472. [doi: 10.1001/jamainternmed.2015.3006] [Medline: 26147487]
41. Smith MT, Huang MI, Manber R. Cognitive behavior therapy for chronic insomnia occurring within the context of medical and psychiatric disorders. Clin Psychol Rev 2005 Jul;25(5):559-592. [doi: 10.1016/j.cpr.2005.04.004] [Medline: 15970367]

Abbreviations

API: application programming interface
CBT-I: cognitive behavioral therapy for insomnia
EMA: ecological momentary assessment
GAD-7: Generalized Anxiety Disorder-7 item
GPS: Global Positioning System
PHQ-9: Patient Health Questionnaire-9 item
PSM: propensity score matching

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Original Paper

Feasibility and Acceptability of a Mental Health Website for Adults With an Intellectual Disability: Qualitative Evaluation

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Abstract

Background: Electronic mental health (e-mental health) programs for people with an intellectual disability are currently underexplored but may provide a way of mitigating some of the barriers that this population faces in accessing appropriate mental health services.

Objective: The aim of this study was to examine the feasibility and acceptability of Healthy Mind, an e-mental health program for adults with an intellectual disability developed by the Black Dog Institute, focusing on the design and implementation of the website.

Methods: A qualitative research design was used, which involved semistructured interviews and focus groups with people with an intellectual disability, support workers, and allied health professionals. People with an intellectual disability were also observed while using the website. A thematic analysis was used to interrogate the interview transcripts and observational field notes.

Results: Participants found the content of the website informative and appreciated the many ways that the website had been made accessible to users. Participants voiced some differing requirements regarding the way information should be presented and accessed on the website. Acknowledging different types of support needs was identified as an important issue for website dissemination.

Conclusions: The Healthy Mind website promises to provide an excellent tool for people with ID and their supporters. This research has pragmatic implications for the future development and implementation of the program, while contributing to knowledge in the broader fields of e-mental health and inclusive design for people with an intellectual disability.

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KEYWORDS

mental health; internet; intellectual disability; qualitative evaluation; qualitative research; health services accessibility

Introduction

Background

As a clinical term, intellectual disability (ID) denotes a lifelong impairment of cognitive functions that is associated with difficulties in a range of domains including, for example, learning and communication [1]. Approximately 1% of the world population has an ID [2]. ID is highly heterogeneous and must be understood in terms of the degree of support and environmental barriers that a given individual experiences [3].

People with an ID are more likely to experience common mental health problems than the general population [4], although prevalence estimates vary [5]. Despite early concerns regarding the suitability of psychological therapies for people with an ID [6], a recent meta-analysis found that appropriately modified cognitive behavioral therapies (CBTs) were an effective form of treatment [7]

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Nevertheless, individuals with an ID face many barriers to accessing mental health services, from a lack of appropriate services to issues with communication and diagnosis [8]. For instance, many people with an ID find face-to-face interactions with health care professionals daunting, with some individuals opting to avoid doctors and other allied professionals whenever possible [9]. Digital mental health platforms have the potential to mitigate some of these barriers by providing readily accessible tools for both communication and treatment [9,10]. A plethora of such electronic mental health (e-mental health) programs are available for the general population, with substantial evidence to support the clinical effectiveness of many of these programs [11-13]. Despite available guidelines for adapting therapies for people with an ID [14,15], few e-mental health programs have been specifically tailored for users with an ID.

A team in Ireland has recently developed a computerized CBT game called Pesky Gnats, specifically adapted for use by adults with ID in sessions with a trained psychologist. The game was effective in reducing anxiety symptoms compared with treatment as usual for participants in a recent randomized control trial [16]. Similarly, Vereenooghe et al [17,18] found that computerized cognitive awareness training for people with ID improved the ability to identify behaviors and feelings, which is 1 important element of CBT. These studies provide promising evidence that digital mental health interventions can be an effective form of treatment for people with ID.

At another level, in the field of electronic health, there is growing acknowledgement that the usability and accessibility of platforms is a crucial factor that must be accounted for when considering their value and impact [19-21]. For people with ID, digital technologies are sometimes inaccessible [22]. For example, many platforms are not designed to account for the needs of people with cognitive differences. Accessible or inclusive design of digital technologies aims to ensure that digital platforms are readily useable by people with different abilities [23]. The Web Content Accessibility Guidelines 2.1 provide a comprehensive overview of how different features of a website can be optimized to promote accessibility [24].

A small body of research has begun to examine how people with ID interact with digital platforms, adapting methods from user experience and usability research to evaluate the design of websites and mobile apps [25,26-29]. To date, no research has examined the design of e-mental health platforms for people with an ID. Nevertheless, Cooney et al's [30] qualitative study of the experience of participants in the Pesky Gnats randomized controlled trial highlighted some elements of program design, from the use of images to the delivery of a workbook, that affected participants' engagement with the program.

Objectives

The aim of this study was to evaluate the feasibility and acceptability of Healthy Mind, an e-mental health program for adults with IDs, with a focus on the relationship between the design of the platform and how users engage with and understand its content. This study had a pragmatic goal of informing further development of the website, along with strategies for its dissemination and implementation. However, as there is little existing research in the field of e-mental health for people with ID, this study also aimed to contribute to the knowledge base, informing best practices for inclusive design in this domain.

Methods

Study Design

The qualitative research design drew upon the emerging methodology of realist evaluation, which is ideal for evaluating complex interventions. The realist philosophy is positioned between positivist and constructivist paradigms and seeks to answer the questions *What works for whom, in what circumstances and why?* In seeking to answer these questions, realist evaluation enabled us to reflect on 3 fundamental components of the website: context, mechanism, and outcome [31]. The realist theoretical framework methodologically embraces pluralism, while emphasizing the importance of understanding complex social structures and relations when evaluating a given intervention.

Interviews and focus groups following semistructured schedules were conducted with lived experience experts (LEEs), support workers, and allied health professionals (AHPs) with expertise in ID mental health. To gain a deeper understanding of how people with ID interact with the website, LEEs were asked to work through a series of activities on the website, whereas the researchers observed and recorded field notes [28].

LEEs also completed a basic demographic questionnaire to ascertain age, level of experience with technology, and help-seeking strategies.

In focus groups and interviews, all participants were asked to reflect on what they liked and did not like about the website: its content, design, and the process of using the site. They were asked to comment upon any challenges they might have faced or that they believed others might face, elements of the website that they found to be particularly beneficial or otherwise good, and how they imagined the website could be used in day-to-day life, including specific probes for degree of support and context of use. Support workers were also asked to comment on the process of supporting an individual to use the website, and both support workers and AHPs were asked to consider how the website may be integrated into existing services. As the schedule of questions was semistructured, all participants were provided ample leeway to bring their own interests and unique perspectives to the discussions. Audio recordings varied in length between 18 and 70 min (mean 45.25 min). The research received ethical approval from the University of New South Wales (UNSW) Human Research Ethics Committee (approval reference HC180204).

The Website

The Healthy Mind website was developed over an iterative process of consultation with key stakeholders and LEEs. It is an adapted version of the Black Dog Institute's e-mental health platform, myCompass [32]. The target population for Healthy Mind is people with mild to borderline ID who want to build better mental health. In total, 2 key myCompass activities were chosen on the basis of consultation with researchers at UNSW's Department of Developmental Disability Neuropsychiatry (3DN)

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specializing in ID mental health, along with a community advisory group consisting of people with ID, carers, health administrators, special educators, and clinicians who deliver mental health services to people with ID. These modules were chosen because they provide an introduction to 2 different but complementary approaches to better mental health. Please see Multimedia Appendix 1 for indicative screenshots of the website.

In the *Relax, Breathe Easy* activity, users are guided through breathing exercises for relaxation and body visualizations to reduce muscle tension and stiffness. In the CBT-based *Tackling Unhelpful Thinking* activity, users are taught to identify unhelpful thoughts and thinking traps, they are also introduced to the concept of a thought diary and how it might help to tackle unhelpful thoughts.

The content and design of these modules were modified, enhanced, and reconfigured to best suit the needs of the target population. A psychologist with extensive experience in providing and developing mental health services for people with Autism Spectrum Disorder and ID worked on the clinical content of the modules to modify the activities, ensuring strategies were in line with clinical best practice for this audience. An Easy Read Translation expert from the UNSW Centre for Social Impact ensured that all the content was in an accessible form: All the content is delivered in Easy Read English with an option for listening to an audio version of the text; video content also complements some of the tasks.

Additional consultation was sought with LEEs and their support workers at 2 stages during the development of the modules. Focus groups were conducted with 3 LEEs and 2 support workers where they were shown static pages from the website in development and were asked to comment on the look, feel, and design of the website. At the final stage of the development process, a working prototype of the website was shown to 2 people with ID and their support workers for feedback as they worked through the activities. All feedback was incorporated into the development and refinement of the interface.

Participants

In total, 36 people participated in this study. LEEs were identified and recruited by supporting disability service providers in Sydney. The selection criteria for LEE participants were a diagnosis of ID, familiarity with computers, the ability to read and understand simple onscreen text, and the capacity to give informed consent regarding research participation. In total, 13 LEEs participated in the study (see Table 1 for LEE participant characteristics). In total, 9 support workers who accompanied LEEs also consented to participate in the research. These support workers were always present with LEEs while they used the website, providing assistance at their discretion. The ratio of support workers to LEEs varied between sessions; while some LEEs had one-on-one support, during 1 session there was a single support worker accompanying 3 LEEs. LEEs and their support workers all participated in focus groups. There were a total of 5 focus groups with these participants, which ranged from 2 to 7 participants per group (mean 4). In each focus group, at least 1 support worker was present.

In total, 5 AHPs participated in the research: a psychiatrist with specialization in neuropsychiatry and ID mental health, a social worker in a specialist disability health team, a speech pathologist working with children and adults in the disability sector, a community mental health outreach occupational therapist with a background in disability support, and a forensic mental health and cognitive disability expert. The occupational therapist and forensic mental health expert met together with a researcher in a small focus group, whereas the other 3 AHPs participated in one-on-one interviews.

Initially, the research team also hoped to recruit carers or unpaid supporters to participate in the research. Responding to ongoing recruitment difficulties, an advisory group shared by 3DN and the Black Dog Institute with expertise in ID was invited to participate in a focus group discussion. In total, 9 individuals participated in this focus group, including a clinical psychologist, a carer, a self-advocate, 2 psychiatrists, an ID e-mental health project officer, and senior staff from ID health and advocacy organizations.

Data Analysis

All audio recordings of interviews and focus groups were transcribed verbatim for analysis. The final dataset also included observational and reflective field notes and amounted to over 150 pages of textual data. Thematic analysis was used as *a method for identifying, analyzing, and reporting patterns (themes) within the data* [33,34]. A bottom-up or inductive, data-driven approach to analysis was taken, focusing on the interpretation of the explicit or surface meanings of the data. In such a way, the analysis primarily described and summarized participant's perspectives—a process of *giving voice* [35]—rather than deconstructing or critiquing.

CW followed Braun and Clarke's [33] steps for thematic analysis, first familiarizing herself with the data, then embarking upon an iterative process of coding for semantic content, then searching for, reviewing, and naming themes. KB also reviewed potential themes by checking for coherence with selected extracts from the original transcripts. Final theme names and definitions were developed by CW and KB in collaboration as the writing process evolved. Research rigor was established via team analysis, prolonged engagement with the subject matter, and reflexivity.

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Table 1. Lived experience expert participants' demographic, technology use, and help-seeking characteristics (N=13).

Variable	Statistics
Age (years)	
Mean (SD)	31 (10.4)
Range	19-52
Gender, n (%)	
Female	7 (54)
Male	6 (46)
Technology use, n (%)	
Owns a computer	12 (92.3)
Owns a smartphone	10 (76.9)
Uses the internet daily	10 (76.9)
Has used a health app	1 (7.8)
Help-seeking, n (%)	
Has seen a mental health professional	7 (53.8)
If experiencing a personal problem, would seek help	
From family or friend	7 (53.8)
From mental health professional	3 (23.1)
Online	2 (15.4)

Results

The User Experience

We identified 3 overarching themes, subsuming 7 key themes, which are presented in a thematic map (Figure 1): The overarching theme *The user experience* comprises the themes *Learning about mental health, Accessibility of information*, and *Digital Interaction*; the overarching theme *Design Dilemmas* comprises the themes *Repetition as a blessing and a curse* and *Balancing different types of engagement*; and the overarching theme *Reconceptualizing self-help* comprises the themes *Supported self-help* and *Facilitating a conversation*.

The User Experience

Learning About Mental Health

Many participants reflected that a key part of the experience of using the Healthy Mind website was learning about ways to promote and understand mental health. For instance, one LEE noted:

> *It helps me to think things and learn more about mental health.*

Other LEEs also used the word *learn* to describe their experience:

> *I like to learn it;*
>
> *I would love to listen with the voice again. Listen to the things again so I can gain more, so I can learn more.*

LEEs commented on some of the specific skills gained while engaging with the website and how they made them feel. Many noted feeling more relaxed after doing breathing modules:

> *The breathing was good;*
>
> *I do feel more relaxed;*
>
> *5 big breaths, that's all it takes.*

Similarly, a support worker commented:

> *Whether it was because it took a lot of concentration or because it was doing its job incredibly well, there was a level of relaxation that fell over everyone and it was very quiet...I feel like it just had a very calming effect on people.*

LEEs also commented on how the website might help with thinking and feelings:

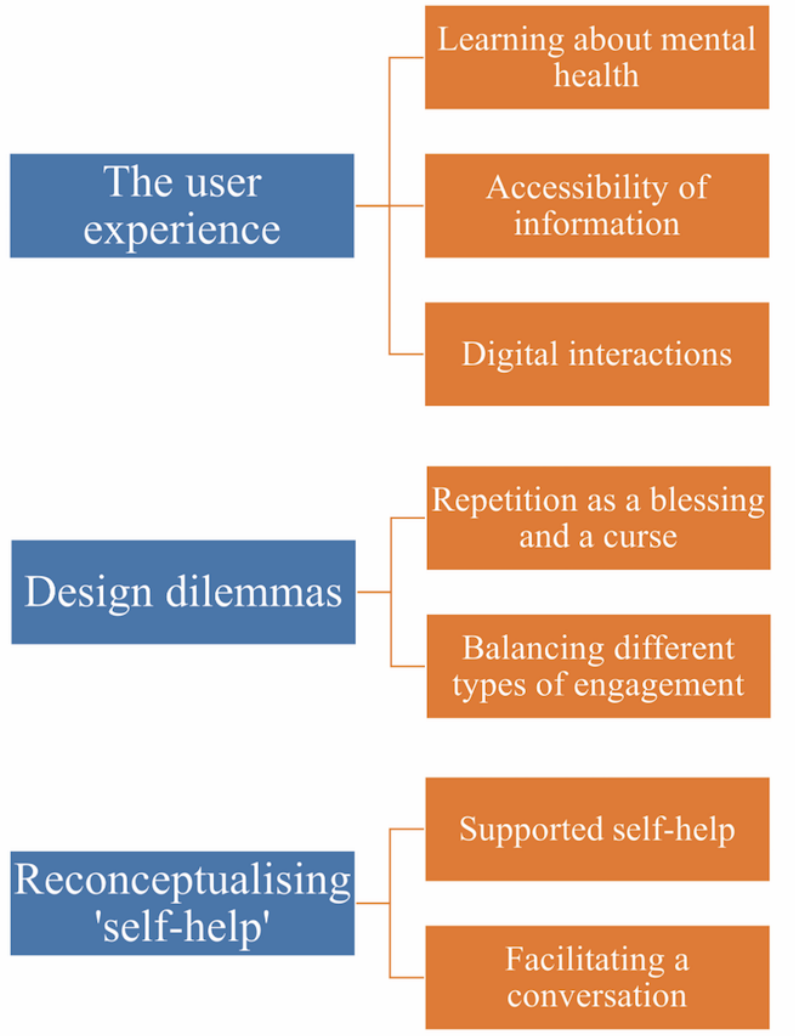
> *It's for your mind, your thinking, and it's for your brains too. It's good for the brains.*

One LEE reflected on how the program had helped her to understand her own thoughts and feelings: "It allowed me to open up how I felt and why I felt like that the other day." However, she also noted that it might be tricky to use the skills in everyday situations: "It all depends on how angry and emotional you are." Overall, she recognized the value of the program but also wondered how she could ultimately use it to fundamentally change her mental health:

> *At the end of the day it's something that is my experience and it's something that is always probably going to be there and that I think I'm going to have to carry for the rest of my life.*

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Figure 1. Thematic map.



Accessibility of Information

Participants provided feedback about the accessibility of information on the website, particularly considering the different types of needs that users may have when engaging with textual and audio-visual information. For instance, AHPs raised some concerns about the accessibility of the website for specific populations, including people with hearing and vision impairments; in its current form, the website is not adaptable to a screen-reader, and the video content is not captioned. AHPs also discussed accessibility issues for culturally and linguistically diverse users.

Easy Read

The use of Easy Read English was appreciated by LEEs:

> *I really liked it that it was very largely in easy read form.*
>
> *I found that I was able to read the format easy because it had the pictures to explain.*

AHPs also valued the use of short sentences accompanied by images. They were particularly positive about the use of *step-by-step* instructions.

Participants commented on the benefits of images within specific sections of the website as a way of elucidating the textual content, for example:

> *The image also shows you, it also gives you how you feel this.* [LEE]

However, LEEs also pointed out places where it would be difficult to understand the relationship between image and text or where people may have trouble interpreting images:

> *There were some pictures that I didn't understand because it didn't make sense and the pictures were the wrong pictures.*

Some AHPs were concerned that users would have difficulty understanding different emotions using the current images on the website, particularly for people on the autism spectrum. Participants provided some conflicting opinions about the types of visual cues that would be helpful for users. Although some suggested using photographs of real human faces, others thought cartoon images or emojis would be more easily identifiable. One AHP suggested drawing upon similar imagery to the picture exchange communication system, which might already be familiar to users. AHPs also raised the issue of the tone of the images. One participant stated that it is important not to portray information "in a childlike manner."

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Audio and Video

During observations of website use, most LEEs accessed the audio function for some, if not all, of the textual content. Many gave positive feedback about the audio:

> *I liked the audio thing. It's good, it helped me to understand more.*

AHPs also noted that this audio function made the website more accessible to people who might not have a high degree of literacy. However, they also highlighted that the home page and some other parts of the website did not have this function, which could pose an access problem for some users.

The video content was appreciated by participants. During observations, all LEEs engaged with at least 1 video and gave feedback that they particularly enjoyed videos within the website. One LEE noted that "video is easier for me." AHPs also responded positively to the videos as a means of promoting an understanding of the website content. Some recommended that videos may provide a more engaging way of introducing concepts or activities:

> *Definitely having more videos and interactive animation upfront before you go into all the detail.*

Digital Interactions

Log In

Setting up a password and logging in to the website was a challenge for many LEEs, the majority of whom needed support to get through this process. Logging in seemed to cause anxiety in some users, who had their hands on their head, sighing, or making exclamations during this process. As a member of the advisory panel, the focus group said:

> *It's basically asking people to do a whole bunch of arbitrary tests before they can actually—they might fail and it's really understandable.*

Remembering a password to log back in with was also a challenge for many LEEs. At another level, people might be deterred by the need to provide personal information during their first interaction with the site:

> *People would necessarily not feel comfortable with putting in their information unless they have probably had a familiarity with the website beforehand.* [LEE]

The log in process poses one of the biggest usability issues for this website. In its current state, it will likely deter many people from accessing the website, particularly if they are seeking to do so independently. However, design solutions need to balance multiple concerns that will be addressed in further sections of this paper.

Navigation

During observations, all LEEs could complete basic navigation tasks on the website, such as starting an activity, scrolling down the page, clicking next to move on to a new part of the activity, and clicking finish to finish an activity, although sometimes they needed prompting or extra assistance from a supporter. Many had difficulty navigating between parts of the second activity via the homepage dashboard, and participants suggested ways that the dashboard could be optimized so that it would be easier to navigate. In addition, participants suggested that progress within the activity should be made clearer, for instance, by including page numbers. Similarly, an LEE proposed:

> *How about instead of just saying next say what happens next in part so on and so on, that way they actually know that it's a stepped activity program layout and if they don't feel like doing it then they can press finish and come back to it when they need to.*

Activities

During observations, many LEEs failed to complete some of the activities within the website despite clicking through the information on the page. For example, some participants did not hold their hand over their stomach to count breaths during the breathing activity or began deep breathing when the activity involved counting a normal breathing rate. Similarly, in a task on unhelpful thinking, participants did not answer questions asking them to reflect on how their thoughts made them feel. These signs of misunderstanding or not engaging with the activities could have been the result of any number of causes, not the least being the unnatural *testing* environment. The role of a support person in fostering engagement with the activities was critical, the implications of which are discussed further below. At another level, participants suggested that including more creative forms of interactivity and positive reinforcement within the website may increase motivation to engage with learning activities.

Design Dilemmas

The current Healthy Mind website is designed so that certain information is repeated in a slightly varied form as a user progresses through the website. For example, information about how the website works is repeated at the beginning of each activity, but other types of information are also repeated, such as the idea of breathing to decrease stress. Participants offered conflicting responses regarding this repetition of content, which presents 1 design dilemma for the development team. On the one hand, some LEEs expressed frustration at points where they encountered information they had already seen:

> *OK, so some of the stuff is being repeated again. Like, I understand it but I got it the first time when I read it.*

On the other hand, some LEEs seemed to appreciate the repetition and even wanted more: "Just recap the end...yeah, just more repeating." AHPs generally approved of the repetition of concepts within the site. For instance, an occupational therapist thought people should be encouraged to learn across multiple modalities:

> *How can you give the same information in a number of different formats so that you're getting repetition and the option of taking it in in all the different ways that we learn?*

The issue of repetition points to a larger issue of designing a single platform to meet the diverse needs of many different users who will have varying levels of literacy, receptive

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vocabulary, and other factors that affect the understanding of content. As one support worker commented:

> *It's almost like different people will have different things that contradict each other, for instance the repetition could have been really helpful for someone else but...everyone is so different. That's its own complication.*

Balancing Different Types of Engagement

A distinct but related design dilemma that participants raised was the issue of how users may want to engage with the website. On the one hand, participants affirmed the importance of a linear, iterative, and personalized process of learning, where people could track their progress through the activities and return to complete them over time. Currently, the website is set up to create this kind of learning experience where users move progressively through the site at their own pace. An advisory group member commented on the importance of people being able to see how much they have completed of the program:

> *I think for people generally they really like a reinforcement. Either I've achieved something, or I've actually completed something.*

This type of reinforcement is fostered by a personalized and step-by-step design.

On the other hand, participants described wanting something to access quickly for help in a crisis or to easily practice skills, for example, with video content or other simple tasks immediately at your fingertips:

> *It needs to be fast and quick, it needs to be like fast food, like a drive through...you need to be able to go and order and get your thing.* [LEE]

The analogy of the drive-through is an apt one when summarizing this kind of approach to website use, where many options are presented to the user who can quickly choose something that may help them at a given moment in time. A support worker similarly described the importance of having quick access to particular exercises:

> *Just say for instance one of the guys was on there and went on there because they were having a bit of a panic attack, maybe instead of having to go through everything, all the steps, if there was like an emergency button where they could click on it straight away and it would have breathing exercises and count downs to go through together with that person would be really good.*

Here, she envisages using the website in response to an immediate need—for example, to calm someone down if they are experiencing a panic attack.

Other participants also mentioned ways of optimizing the home page so that users could more readily choose exercises that respond to how they are feeling in the moment:

> *Instead of all this stuff you have to get through to get to this, just say today I need something to help me to come down, breathing activities it is...and just having some simple go to apps on it or buttons.* [AHP]

Participants also suggested that this type of easy access to exercises would be a way of facilitating practice so that, for example, people could readily work through deep breathing on a daily basis.

Both quick and easy access to certain content, and a linear, accumulative learning experience could be contained within the same site. However, this would require rethinking the design of the website, particularly the homepage/dashboard and the log in process as it currently stands. As already discussed under the theme of digital interactions, requiring people to log in before accessing content creates an immediate hurdle to quick and easy access. However, if people use the site without logging in, then progress cannot be tracked and people will not be able to return to where they have left off during previous sessions. Furthermore, there are ethical dilemmas concerning interactive tasks where users provide personal information if the website is not password protected.

Many participants offered potential solutions to this predicament. Some thought that the log in should be completely discarded and the homepage reorganized so that users could choose between an array of exercises and simply remember where they were up to. Another recurring suggestion was that users' first interactions with the site should not require logging in and that they should only be prompted to create a log-in profile once they proceed to activities that would benefit from collecting personal information and tracking progress.

Reconceptualizing Self-Help

The Healthy Mind website is as an adapted version of the Black Dog Institute's flagship e-mental health platform, myCompass, which has been described as *a personalized self-help tool for your mental health*. However, the notion of *self-help* needs to be clarified when considering the diverse support needs of people with an ID, as well as the way that this program may negotiate existing support systems.

Supported Self-Help

During the analytic process, the concept of *supported self-help* enabled the team to think through the ways that people may use this platform with the support of other people. A key finding during observations of website use was that when LEEs were working together closely with a support worker, they appeared more engaged with the tasks as they were able to talk over content and have assistance in completing activities. In contrast, many individuals who were largely unassisted in using the website were observed to be skipping through content very quickly or not actually completing the interactive tasks. AHPs also noted points in the program where they thought their clients would benefit from support in engaging with the activities. Support workers commented that some of the LEEs appeared overwhelmed or even had their anxiety triggered by not understanding what they were doing on the website. A sensitive supporter guiding someone through the website could perhaps help alleviate some of this anxiety of *not knowing*. For instance, a support worker conveyed the issues that she observed her clients facing as they attempted to negotiate the website by themselves, describing it as an "isolated experience...when you're staring at a screen and being like overloaded with all of

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these words." Instead, she advocated for a social approach to the tasks in a group setting, envisaging the website as a resource for support workers to guide their clients "so it all becomes more familial and more all-encompassing."

Support workers expressed a tension between wanting to enable people to access the website independently as much as possible versus acknowledging and even encouraging people to engage with support as they use the site. For example, one support worker commented: "Sometimes you just want them to learn the way they want to learn." This requires a certain degree of sensitivity on the part of a supporter to at once respect privacy and agency while ensuring that the person is enabled to fully understand the program. The support worker also commented: "[It] should be supportive for them until they really understand that website well." Some users may find that they benefit from a trusted support worker showing them how to use the website and working through some exercises before going off and using it on their own. LEEs articulated differing views about whether they would like to be supported when using the website. Although some said they would want the help, others said:

> *I don't mind using it by myself. I'm capable to do it myself, yeah.*

One LEE with limited computer literacy did not have trouble understanding the website content but did require support to use the mouse, scroll down the page, and other basic navigational tasks. He commented: "You couldn't do it by yourself if you didn't have any computer experience." A *digital divide* does affect the ID population, with many people not having access to computer technologies and/or with limited computer literacy [22]. As one support worker said: "The barrier would be actually the computer literacy skills more than the website itself." Acknowledging this divide, it is important that adequate support and resources are also in place to ensure that the website reaches people who may not be confident using computers.

Unfortunately, there is no clear-cut answer to how the tension between providing independence and support can be navigated. Ultimately, participants suggested that being clear about the many ways that people can use the website is of utmost importance—whether alone, with a friend, family member, or support worker. As one advisory group member commented: "I'm thinking is it a barrier if it's set up as if you're doing it on your own and someone's feeling they need support to do it."

Facilitating a Conversation

One unanticipated benefit of the website is its capacity to initiate communication between people that may not have occurred otherwise—in the words of an AHP: "this is a great way for a conversation to be facilitated." Participants mentioned multiple ways that the website could operate within a broader social network of family members, support workers, and AHPs.

For example, the website was understood as a way of enabling users to discuss difficult to verbalize topics with people in their lives:

> *I think it's a way of that support person getting an understanding as well of where that individual is. Because they might not be able to verbalise I feel really depressed...Even if they are not kind of strictly adhering to the modules, it's that avenue towards communication that I think is really quite helpful.* [AHP]

In a similar way, the website was described as a safe space to "address the possible mental health concern without judgement" [AHP], which is particularly important for people who may be uncomfortable about identifying with either mental health problems or their disability and who may not seek out a counselor or other mental health professional. In this sense, the website was also understood as a potential gateway to other services or forms of help. For instance, an AHP described it as *a soft entry point*. Participants also recommended that the website could include examples of different words and phrases that people could use when they are asking for help—a way of building this process of facilitating conversation into the fabric of the platform. Others suggested that it include links to registered psychologists in the area or other services that may be helpful for mental health.

At another level, the website was frequently framed in response to a scarcity of existing resources—both a lack of training and expertise among AHPs and support workers and a lack of money and/or time to provide services. For example, an AHP commented on how the website might help with:

> *Things that I don't have to do myself because I don't have the capacity...this is—it wouldn't replace kind of—but it's a supplement.*

Similarly, participants considered how the website could be used by supporters who do not have training in psychological interventions:

> *I think that could be filling a nice gap in there for people who maybe don't have too much experience...working with clients on some of those like counselling sort of strategies.* [AHP]

Here, the website is framed as a tool that can help supplement existing services to provide better forms of psychological and behavioral support to clients.

Discussion

This study employed a realist theoretical framework to explore the context, mechanism, and outcomes of the Healthy Mind website [31]. The context is that individuals with ID face barriers to access appropriate mental health services, and there is currently no research that examines the design of e-mental health platforms for people with ID. The mechanisms of website development were elucidated including the model of cocreation that involved people with ID and their networks of support. The outcomes were that website content was informative and accessible to users, although differing requirements vis-à-vis presentation of information were suggested. In addition, different support needs were identified, further clarifying the need to distinguish what works for whom and under what circumstances. The findings of this research have significance for the continuing development and dissemination of the Healthy Mind website,

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while at the same time presenting broader implications for the fields of e-mental health and inclusive design.

As in broader literature on inclusive or universal design, this study demonstrates that flexibility and multiple options for engagement lie at the core of truly accessible digital technologies [36]. Similar principles underpin many of the accessibility standards and guidelines; however, this study provides a uniquely situated insight into how different needs may be accommodated from the users' perspective [37]. Further research could also consider how existing technology acceptance models may be used to evaluate and develop inclusive design projects such as Healthy Mind [38].

It was important to ensure that LEEs were enabled to provide feedback about the website; however, the literature provides few pointers regarding the best way to engage with people with ID in the design process. In general, guidelines suggested drawing upon multiple sources of evidence, including observations during use, while remaining responsive to the particular strengths and needs of participants [25,26,39]. Although some LEEs were very confident providing verbal feedback, during and after website use, others were much less so and this proved a significant challenge in a qualitative study requiring rich textual data. Nevertheless, this was mitigated by drawing upon observational notes and additional feedback from support workers who were present during testing. Similarly, consultations with AHPs and the advisory group added to the completeness of the picture.

However, additional work is certainly needed to develop more inclusive methods for engaging with people with ID in the design and evaluation process, particularly when verbal communication may be a challenge (these papers provide some interesting suggestions [40-42]). This is important for both research and intervention outcomes. For instance, involving users in the development of digital health products can lead to higher levels of engagement with the final platform [43]. However, the extent to which this applies for people with ID would be a fruitful avenue for further research.

The analysis generally treated all groups as a whole and did not attempt to compare and contrast between the perspectives of people with ID, support workers, and AHPs, instead identifying themes that were important in the data generated by all participant groups. In such a way, the points of contradiction in perspective that were identified during analysis occurred within all participant groups and not between them. For example, the contradiction between some participants wanting fast, easy access to resources and others emphasizing the importance of a progressive and step-by-step learning process was something that was highlighted by all participant groups. However, investigating the similarities and differences in perspectives between the different participant groups represented here would be an interesting avenue for future research. Considering potential points of difference in the perspectives of supporters and AHPs may also be important for website development, particularly when developing components of the website that are specifically tailored to supporters.

Despite some evidence of a digital divide affecting people with ID [22], the majority of LEEs did not have difficulties navigating the program or foresee issues with accessing a computer. The inclusion criteria for this study was that LEEs had a familiarity with computers, and the results of the survey show that all LEEs owned either a computer or smartphone and most used the internet on a daily basis, which may explain why the issue of a *digital divide* did not seem to be relevant to this group. Nevertheless, some AHPs and support workers did raise concerns about access to technologies for their clients. This study was limited by the fact that technology use and other demographic data were not collected routinely from the support workers and AHPs who participated in this study. For example, it is possible that these participants' level of experience with technology may have influenced their perspectives. Regardless, it is important to consider how and where people will be able to use this program. For some, it may only be possible to use a computer in a communal or public space, or with the assistance of a supporter.

A key finding from this study is that the feasibility of the website ultimately depends on its ability to negotiate the different support needs and different systems of support that each user will bring to their engagement with the platform. Here, accessibility is reframed as something that can be fostered through both the design of the website *and* its dissemination—processes of knowledge translation and training will need to be developed to ensure that the website is accessible to people regardless of their support needs. Recent studies examining mobile assistive technology for people with ID also highlight the importance of training for users and/or the presence of ongoing support from a significant other [44,45]. Other research into e-mental health for people with ID has focused on the use of computerized therapy *with* psychologists [17,30]. When a platform such as Healthy Mind is intended to be used without the direct assistance of a counselor or psychologist, it is important to consider how linking in with other existing services may ensure that users are supported to engage with the program in a way that best suits their needs.

These findings can be considered in dialogue with broader literature surrounding e-mental health. E-mental health interventions have frequently been framed as a way of providing easy and free/inexpensive accessible services to people who may not otherwise choose to or be able to seek help from mental health professionals [11]. The Healthy Mind platform also seeks to serve this function. Interestingly, the idea that this website may also *facilitate a conversation* between people about mental health deepens our understanding of how e-mental health operates in society—for example, opening avenues to other types of help seeking [46]. Certainly, people with ID have unique support needs, which mean they may be more likely to use e-mental health programs with other people. However, the implications of this insight may also be relevant to a wider population of e-mental health users.

To conclude, this study provides a nuanced picture of the multiple and complex factors affecting how users engage with the Healthy Mind website. Acknowledging the importance of fostering engagement with e-mental health websites to increase their impact on well-being, this study highlights important issues that must be considered when designing and implementing e-mental health platforms for people with ID. The Healthy Mind

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website has the potential to provide an excellent tool for people with ID and their networks of support. We hope that this study will inspire further research into e-mental health programs such as this one.

Acknowledgments

This study was funded by a grant to the Black Dog Institute from New South Wales Health, which also supported the development of the Healthy Mind website.

Conflicts of Interest

All authors were employed by the Black Dog Institute during the evaluation research. CH is the project officer and CR is the project manager responsible for the development of the Healthy Mind website.

Multimedia Appendix 1

Indicative screenshots of the Healthy Mind website.

[PDF File (Adobe PDF File), 1006KB - mental_v6i3e12958_app1.pdf]

References

1. Salvador-Carulla L, Reed GM, Vaez-Azizi LM, Cooper S, Martinez-Leal R, Bertelli M, et al. Intellectual developmental disorders: towards a new name, definition and framework for. World Psychiatry 2011 Oct;10(3):175-180 [FREE Full text] [Medline: 21991267]
2. Maulik P, Mascarenhas M, Mathers C, Dua T, Saxena S. Prevalence of intellectual disability: a meta-analysis of population-based studies. Res Dev Disabil 2011;32(2):419-436. [doi: 10.1016/j.ridd.2010.12.018] [Medline: 21236634]
3. McKenzie JA. Models of intellectual disability: towards a perspective of (poss)ability. J Intellect Disabil Res 2013 Apr;57(4):370-379. [doi: 10.1111/j.1365-2788.2012.01547.x] [Medline: 22458334]
4. Cooper S, Smiley E, Morrison J, Williamson A, Allan L. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. Br J Psychiatry 2007 Jan;190:27-35. [doi: 10.1192/bjp.bp.106.022483] [Medline: 17197653]
5. Buckles J, Luckasson R, Keefe E. A systematic review of the prevalence of psychiatric disorders in adults with intellectual disability, 2003–2010. J Ment Health Res Intellect Disabil 2013 Jul;6(3):181-207. [doi: 10.1080/19315864.2011.651682]
6. Oathamshaw SC, Haddock G. Do people with intellectual disabilities and psychosis have the cognitive skills required to undertake cognitive behavioural therapy? J Appl Res Int Dis 2006 Mar;19(1):35-46. [doi: 10.1111/j.1468-3148.2005.00284.x]
7. Vereenooghe L, Langdon PE. Psychological therapies for people with intellectual disabilities: a systematic review and meta-analysis. Res Dev Disabil 2013 Nov;34(11):4085-4102. [doi: 10.1016/j.ridd.2013.08.030] [Medline: 24051363]
8. Whittle EL, Fisher KR, Reppermund S, Lenroot R, Trollor J. Barriers and enablers to accessing mental health services for people with intellectual disability: a scoping review. J Ment Health Res Intellect Disabil 2017 Dec 18;11(1):69-102. [doi: 10.1080/19315864.2017.1408724]
9. Vereenooghe L, Gega L, Langdon PE. Intellectual disability and computers in therapy: views of service users and clinical psychologists. Cyberpsychology 2017 May 31;11(1). [doi: 10.5817/CP2017-1-11]
10. Sheehan R, Hassiotis A. Digital mental health and intellectual disabilities: state of the evidence and future directions. Evid Based Ment Health 2017 Nov;20(4):107-111. [doi: 10.1136/eb-2017-102759] [Medline: 28947677]
11. Christensen H, Petrie K. State of the e-mental health field in Australia: where are we now? Aust N Z J Psychiatry 2013 Feb;47(2):117-120. [doi: 10.1177/0004867412471439] [Medline: 23297367]
12. Andersson G, Cuijpers P, Carlbring P, Riper H, Hedman E. Guided Internet-based vs. face-to-face cognitive behavior therapy for psychiatric and somatic disorders: a systematic review and meta-analysis. World Psychiatry 2014 Oct;13(3):288-295 [FREE Full text] [doi: 10.1002/wps.20151] [Medline: 25273302]
13. Newby J, Twomey C, Yuan Li SS, Andrews G. Transdiagnostic computerised cognitive behavioural therapy for depression and anxiety: a systematic review and meta-analysis. J Affect Disord 2016 Dec 15;199:30-41. [doi: 10.1016/j.jad.2016.03.018] [Medline: 27060430]
14. Whitehouse RM, Tudway JA, Look R, Kroese BS. Adapting individual psychotherapy for adults with intellectual disabilities: a comparative review of the cognitive-behavioural and psychodynamic literature. J Appl Res Int Dis 2006 Mar;19(1):55-65. [doi: 10.1111/j.1468-3148.2005.00281.x]
15. Hronis A, Roberts L, Kneebone II. A review of cognitive impairments in children with intellectual disabilities: implications for cognitive behaviour therapy. Br J Clin Psychol 2017 Jun;56(2):189-207. [doi: 10.1111/bjc.12133] [Medline: 28397306]
16. Cooney P, Jackman C, Coyle D, O'Reilly G. Computerised cognitive-behavioural therapy for adults with intellectual disability: randomised controlled trial. Br J Psychiatry 2017 Aug;211(2):95-102. [doi: 10.1192/bjp.bp.117.198630] [Medline: 28596245]

XSL•FO
RenderX

17. Vereenooghe L, Gega L, Reynolds S, Langdon PE. Using computers to teach people with intellectual disabilities to perform some of the tasks used within cognitive behavioural therapy: a randomised experiment. Behav Res Ther 2016 Jan;76:13-23. [doi: 10.1016/j.brat.2015.11.002] [Medline: 26600556]
18. Vereenooghe L, Reynolds S, Gega L, Langdon PE. Can a computerised training paradigm assist people with intellectual disabilities to learn cognitive mediation skills? A randomised experiment. Behav Res Ther 2015 Aug;71:10-19. [doi: 10.1016/j.brat.2015.05.007] [Medline: 26004217]
19. Goldberg L, Lide B, Lowry S, Massett HA, O'Connell T, Preece J, et al. Usability and accessibility in consumer health informatics current trends and future challenges. Am J Prev Med 2011 May;40(5 Suppl 2):S187-S197. [doi: 10.1016/j.amepre.2011.01.009] [Medline: 21521594]
20. Wozney L, Baxter P, Newton A. Usability evaluation with mental health professionals and young people to develop an internet-based cognitive-behaviour therapy program for adolescents with anxiety disorders. BMC Pediatr 2015 Dec 16;15:213 [FREE Full text] [doi: 10.1186/s12887-015-0534-1] [Medline: 26675420]
21. Hill C, Martin JL, Thomson S, Scott-Ram N, Penfold H, Creswell C. Navigating the challenges of digital health innovation: considerations and solutions in developing online and smartphone-application-based interventions for mental health disorders. Br J Psychiatry 2017 Aug;211(2):65-69. [doi: 10.1192/bjp.bp.115.180372] [Medline: 28522435]
22. Chadwick D, Wesson C, Fullwood C. Internet access by people with intellectual disabilities: inequalities and opportunities. Future Internet 2013 Jul 17;5(3):376-397. [doi: 10.3390/fi5030376]
23. Dekelver J, Kultsova M, Shabalina O, Borblik J, Pidoprigora A, Romanenko R. Design of mobile applications for people with intellectual disabilities. In: Communications in Computer and Information Science. 2015 Presented at: Creativity in Intelligent Technologies and Data Science; September 15-17, 2015; Volgograd, Russia p. 823-836.
24. W3C. 2018. Web Content Accessibility Guidelines (WCAG) 2.1: W3C Recommendation 05 June 2018 URL: https://www.w3.org/TR/WCAG21/ [accessed 2018-11-28] [WebCite Cache ID 74Fmttsjr]
25. Cáliz D, Gomez J, Alamán X, Martínez L, Cáliz R, Terán C. Evaluation of a usability testing guide for mobile applications focused on people with down syndrome (USATESTDOWN). : Springer; 2016 Presented at: International Conference on Ubiquitous Computing and Ambient Intelligence; November 29-December 2, 2016; Gran Canaria, Spain p. 497-502 URL: https://link.springer.com/chapter/10.1007/978-3-319-48746-5_51
26. Lepistö A, Ovaska S. Usability evaluation involving participants with cognitive disabilities. 2004 Presented at: NordiCHI '04: the third Nordic conference on Human-computer interaction; October 23-27, 2004; Tampere, Finland. [doi: 10.1145/1028014.1028061]
27. George J, Dietzsch N, Bier M, Zirpel H, Perl A, Robra-Bissantz S. Testing the perceived ease of use in social media: Acceptance testing for people with intellectual and cognitive disabilities. : Springer; 2014 Presented at: Computers Helping People with Special needs: 14th International Conference International Conference on Computers for Handicapped Persons; July 9-11, 2014; Paris, France p. 169-176 URL: https://link.springer.com/chapter/10.1007/978-3-319-08596-8_26
28. Williams P, Hanson-Baldauf D. Testing a web information portal for people with learning disabilities. JORSEN 2010;10(1):42-51. [doi: 10.1111/j.1471-3802.2009.01142.x]
29. Karreman J, van der Geest T, Buursink E. Accessible website content guidelines for users with intellectual disabilities. J Appl Res Int Dis 2007 Nov;20(6):510-518. [doi: 10.1111/j.1468-3148.2006.00353.x]
30. Cooney P, Jackman C, Tunney C, Coyle D, O'Reilly G. Computer-assisted cognitive behavioural therapy: the experiences of adults who have an intellectual disability and anxiety or depression. J Appl Res Intellect Disabil 2018 Nov;31(6):1032-1045. [doi: 10.1111/jar.12459] [Medline: 29722919]
31. Kazi M. Realist evaluation for practice. Br J Soc Work 2003 Sep 01;33(6):803-818. [doi: 10.1093/bjsw/33.6.803]
32. Proudfoot J, Clarke J, Birch M, Whitton AE, Parker G, Manicavasagar V, et al. Impact of a mobile phone and web program on symptom and functional outcomes for people with mild-to-moderate depression, anxiety and stress: a randomised controlled trial. BMC Psychiatry 2013;13:312 [FREE Full text] [doi: 10.1186/1471-244X-13-312] [Medline: 24237617]
33. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
34. Virginia B. Successful Qualitative Research: A Practical Guide For Beginners. London: Sage; 2019.
35. Fine M. Disruptive voices: the possibilities of feminist research. Ann Arbor, MI: University of Michigan Press; 1992.
36. Preiser W, Smith KH. Universal Design Handbook, 2e. New York, NY: McGraw-Hill Professional Pub; 2010.
37. Lewthwaite S. Web accessibility standards and disability: developing critical perspectives on accessibility. Disabil Rehabil 2014 Jul;36(16):1375-1383. [doi: 10.3109/09638288.2014.938178] [Medline: 25009950]
38. Holden RJ, Karsh B. The technology acceptance model: its past and its future in health care. J Biomed Inform 2010 Feb;43(1):159-172 [FREE Full text] [doi: 10.1016/j.jbi.2009.07.002] [Medline: 19615467]
39. Petrie H, Bevan N. The evaluation of accessibility, usability and user experience. The Universal Access Handbook: CRC Press; 2009. URL: http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.461.1537&rep=rep1&type=pdf
40. Brown M, Tsai A, Baurley S, Koppe T, Lawson G, Martin J, et al. Using cultural probes to inform the design of assistive technologies. In: Human-Computer Interaction: Theories, Methods, and Tools. 2014 Presented at: International Conference on Human-Computer Interaction; 2014; Crete, Greece p. 35-46 URL: https://link.springer.com/chapter/10.1007/978-3-319-07233-3_4

XSL•FO
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41. Brown S, Silvera-Tawil D, Gemeinboeck P, McGhee J. The case for conversation: A design research framework for participatory feedback from autistic children. In: Proceedings of the 28th Australian Conference on Computer-Human Interaction.: ACM; 2016 Presented at: OzCHI '16; 29 November 2016; Tasmania, Australia p. 605-613.
42. Nakarada-Kordic I, Hayes N, Reay SD, Corbet C, Chan A. Co-designing for mental health: creative methods to engage young people experiencing psychosis. Design for Health 2017 Oct 24;1(2):229-244. [doi: 10.1080/24735132.2017.1386954]
43. Orlowski SK, Lawn S, Venning A, Winsall M, Jones GM, Wyld K, et al. Participatory research as one piece of the puzzle: a systematic review of consumer involvement in design of technology-based youth mental health and well-being interventions. JMIR Hum Factors 2015 Jul 9;2(2):e12. [doi: 10.2196/humanfactors.4361]
44. Darcy S, Green J, Maxwell H. I've got a mobile phone too! Hard and soft assistive technology customization and supportive call centres for people with disability. Disabil Rehabil Assist Technol 2017 Dec;12(4):341-351. [doi: 10.3109/17483107.2016.1167260] [Medline: 27293107]
45. Darcy S, Maxwell H, Green J. Disability citizenship and independence through mobile technology? A study exploring adoption and use of a mobile technology platform. Disabil Soc 2016 May 16;31(4):497-519. [doi: 10.1080/09687599.2016.1179172]
46. Cotten SR, Gupta SS. Characteristics of online and offline health information seekers and factors that discriminate between them. Soc Sci Med 2004 Nov;59(9):1795-1806. [doi: 10.1016/j.socscimed.2004.02.020] [Medline: 15312915]

Abbreviations

AHP: allied health professional
CBT: cognitive behavioral therapy
e-mental health: electronic mental health
ID: intellectual disability
LEE: lived experience expert
UNSW: University of New South Wales
3DN: Department of Developmental Disability Neuropsychiatry

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Addendum

Addendum to the Acknowledgements: Video-Delivered Family Therapy for Home Visited Young Mothers With Perinatal Depressive Symptoms: Quasi-Experimental Implementation-Effectiveness Hybrid Trial

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