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Original Paper

A Web-Based Intervention for Users of Amphetamine-Type Stimulants: 3-Month Outcomes of a Randomized Controlled Trial

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Abstract

Background: Among illicit drugs, the prevalence of amphetamine-type stimulant (ATS) use is second only to cannabis. Currently, there are no approved pharmacotherapies for ATS problems, but some face-to-face psychotherapies are effective. Web-based interventions have proven to be effective for some substance use problems, but none has specifically targeted ATS users.

Objective: The objective of the study was to evaluate the effectiveness of a Web-based intervention for ATS problems on a free-to-access site compared with a waitlist control group.

Methods: We used a randomized controlled trial design. The primary outcome measure was self-reported ATS use in the past three months assessed using the Alcohol, Smoking, Substance Involvement Screening Test (ASSIST). Other measures included quality of life (EUROHIS score), psychological distress (K-10 score), days out of role, poly-drug use, general help-seeking intentions, actual help-seeking, and "readiness to change". The intervention consisted of three fully automated, self-guided modules based on cognitive behavioral therapy and motivation enhancement. The analysis was an intention-to-treat analysis using generalized estimating equation models, with a group by time interaction as the critical assessment.

Results: We randomized 160 people (intervention n=81, control n=79). At three months, 35/81 (43%) intervention and 45/79 (57%) control participants provided follow-up data. In the intervention group, 51/81 (63%) completed at least one module. The only significant group by time interaction was for days out of role. The pre/post change effect sizes showed small changes (range d=0.14 to 0.40) favoring the intervention group for poly-drug use, distress, actual help-seeking, and days out of role. In contrast, the control group was favored by reductions in ATS use, improvements in quality of life, and increases in help-seeking intentions (range d=0.09 to 0.16).

Conclusions: This Web-based intervention for ATS use produced few significant changes in outcome measures. There were moderate, but nonsignificant reductions in poly-drug use, distress, days partially out of role, and increases in help-seeking. However, high levels of participant attrition, plus low levels of engagement with the modules, preclude firm conclusions being drawn on the efficacy of the intervention and emphasize the problems of engaging this group of clients in a fully automated program.

Trial Registration: Australian and New Zealand Clinical Trials Registry: ACTRN 12611000947909; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=12611000947909 (Archived by WebCite at http://www.webcitation.org/6SHTxEnzP).

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KEYWORDS

amphetamine related disorders; Internet; World Wide Web; randomized control trial; cognitive therapy; online; Web-based; motivational enhancement; intervention

Introduction

Global Assessment of Amphetamine Type Stimulant

Global assessments of illicit drugs place the prevalence of amphetamine type stimulant (ATS) use second only to cannabis, with an estimated 0.6% of the adult population thought to have used ATS in the last year [1]. In 2010, about 2.2% of Australian adults used methamphetamine/amphetamines and 3.1% used "ecstasy" in the last year, which are the main drugs encompassed by ATS [2]. This use translates into ATS being listed as the primary drug of abuse for more than 20% of those in treatment in Asia, 12% in North America, and 9% in Europe [3]. Even though the consumption of more potent types of ATS, such as crystalline methamphetamine, and utilization of more rapidly absorbed routes of administration (ie, smoking, injecting) have a high potential for developing dependence [4], most users do not reach diagnostic criteria. Therefore, interventions are needed across the spectrum from harm reduction for irregular "recreational" use through to treatment of stimulant use disorders [5].

Although ATS use is widespread, there is currently a lack of cost-effective scalable interventions that can be used to address dependence and other harms from ATS use [6], and no pharmacotherapy has yet been approved as a treatment of ATS dependence [7]. Currently, the treatment of ATS disorders relies on psychosocial interventions, with positive outcomes reported for the intensive application of psychological interventions such as contingency management, cognitive behavior therapy (CBT) and motivational interviewing (MI) [8]. Behavioral interventions can be extremely resource intensive; with some interventions requiring 156 weeks of treatment [8], so there have been attempts to develop shorter programs. Brief CBT based interventions, requiring up to four sessions, have resulted in significant reductions in amphetamine use and greater likelihood of abstinence than in control participants who just received a self-help booklet [9]. In Australia, it is estimated that 33% of dependent ATS users receive treatment for their ATS use in any year [10], and the high prevalence of lifetime comorbidity means that ATS users access health services more than those with other substance use disorders or other mental health disorders [11]. Nevertheless, traditional behavioral treatment options are not generally accessed by ATS users, who frequently report their needs are not being met in these settings [5].

Evidence Base for eHealth Interventions

In the light of evidence that psychological interventions can reduce the use of ATS [8,9,12], there is potential to develop Web-delivered, mobile telephone or computer-based (henceforth referred to generically as "eHealth") treatments for ATS users, an approach that has been effective with other conditions. The evidence base for the effectiveness of eHealth interventions for illicit drug use is limited, and we are not aware of any eHealth treatment interventions that currently exist specifically for ATS users. A review of interventions for cannabis use found only 10 studies that reported outcomes on cannabis consumption with an overall effect size of g=0.16 [13]. A review of eHealth interventions for drug use more broadly identified programs developed for specific drugs (eg, opiates) or interventions covering a range of illicit drugs including amphetamine, cannabis, cocaine, hallucinogens, inhalants, and opiates [14]. However, this review did not synthesize an overall outcome for their effectiveness, but concluded that there was evidence for their initial efficacy compared with control conditions [14].

Although not specifically ATS, one intervention has been evaluated among consumers of cocaine [15]. Having recruited 196 participants, the percentage who completed follow-up at 4, 6, and 26 weeks was 17%, 15%, and 6%, illustrating the difficulty of retaining this population in fully automated interventions [15]. Unsurprisingly, given the small sample retained (n=11 at 26 weeks) in the eHealth study, there were no significant time by group interactions on the key outcome measures, severity of dependence and craving [15]. Web-based or computer-based interventions can also be delivered as an adjunct to in-person treatment, which may serve to improve retention. Data from a mixed cohort of substance dependent individuals that received computer delivered (eg, at a clinic) CBT in addition to in-person treatment retained 72% at three months and 65% of participants at six months [16]. By comparison, a review of in-person interventions reported retention at three months ranging from 37% to 90% [6].

The aim of the current study was to evaluate a fully automated, self-guided Web-delivered intervention, derived from established psychological approaches (ie, CBT, MI), to reduce the use of ATS and associated problems at three months post intervention.

Methods

Design

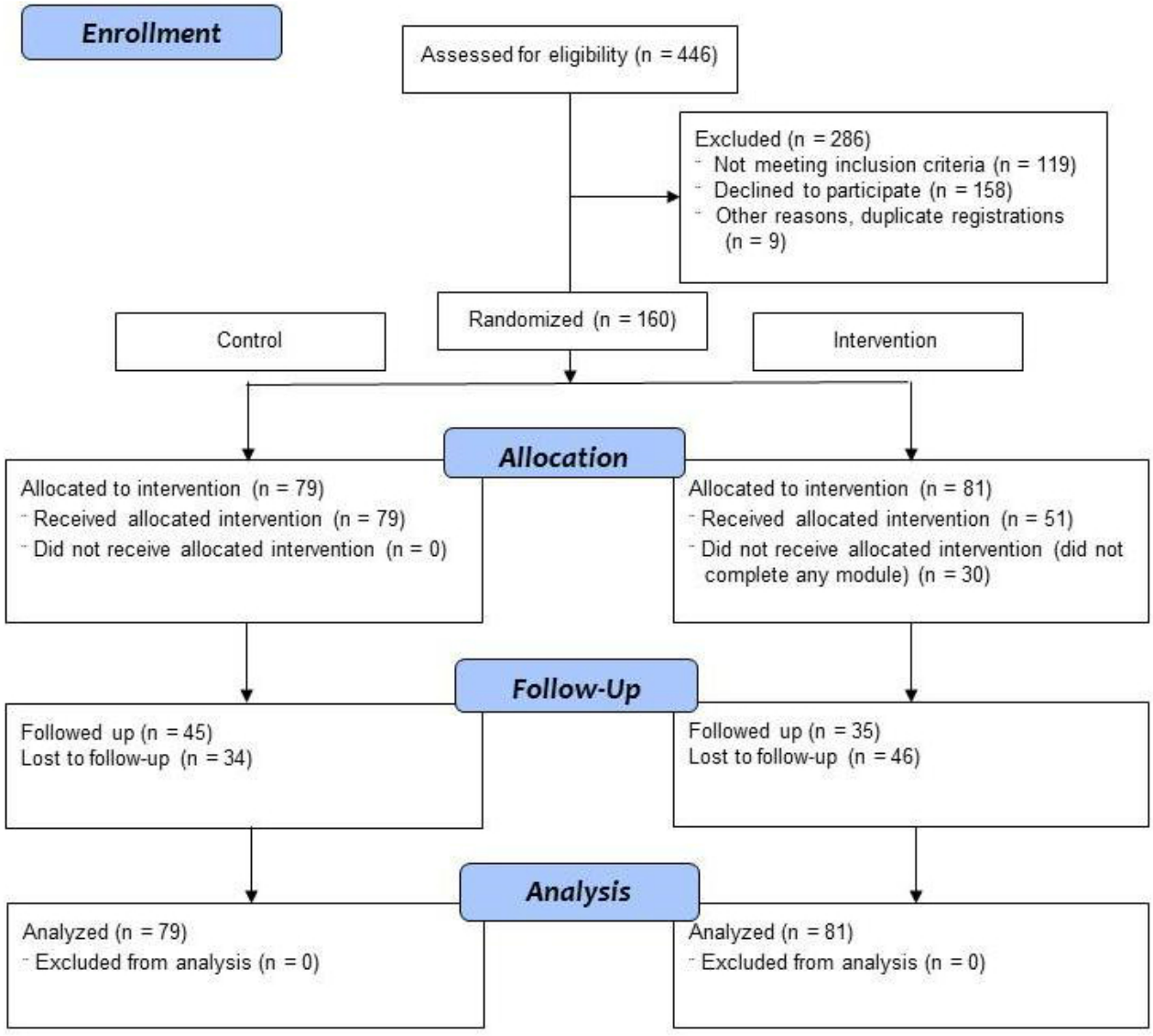
We used a two-group randomized controlled trial, with the intervention group receiving a Web-delivered intervention comprised of three modules, which are described below. The wait-list control group received the same assessment procedures as the intervention group, but they were only able to access the intervention resources after six months. We also provided all participants with contact details for emergency services, such

as Lifeline Australia. The full methodology has been described previously in detail [17].

Sample

We recruited participants by advertising on social networking sites and posters in local clinics. To be eligible, participants had to be a resident of Australia, age 18 years or older, and to report use of ATS (eg, meth/amphetamine, ecstasy, nonmedical use of prescription stimulants) in the last three months. Given the nature of the intervention, participants required access to the Internet and a valid email address. We excluded those who were currently receiving any treatment for stimulant abuse/dependence or pharmacotherapy such as methadone, naltrexone, or buprenorphine for a substance use disorder (nicotine replacement therapy was permitted), or who reported a lifetime diagnosis of schizophrenia, schizoaffective, or bipolar disorder. In addition, nine cases were excluded as duplicate registrations (eg, duplicate Internet protocol addresses/email addresses/payment addresses. Inspection of log files by AB also indicated that these were likely to be repeated registrations). Figure 1 shows the flow of participants through the study. Recruitment opened in January 2013 and closed in July 2013. Of the 446 people assessed, 160 of 446 (35.8%) fulfilled the study criteria.

Figure 1. CONSORT flow diagram.



Procedure

All stages of enrollment and screening were performed via the free study website. Eligible participants provided active consent by “clicking” on a box for each element of the consent form (see Multimedia Appendix 1). A personalized link to access the study was sent to verify their email address and to allow them to create a username and password. Participants were directed to a Web baseline survey before being randomized. We used a simple randomization process that was fully automated with permuted blocks of four with a one to one allocation ratio. Participants who were not eligible for the study were provided with information about other potentially useful websites and resources.

Those in the intervention group were given immediate access to the first module. Participants were advised to allow one week between modules, but could progress at their own pace, although each page in a module had to be opened in sequence to complete the module and obtain access to the next one. Reminder emails were sent three days after the scheduled start date if it had not been commenced, and at day seven when the next module was due. This was repeated for the third module. An email invitation to complete the follow-up assessment was sent after three months. Participants received AU$20 for baseline and follow-up assessments. The study received approval from The Australian National University Human Research Ethics committee and was registered with the Australian and New Zealand Clinical Trials Registry ACTRN 12611000947909.

Modules

In developing the intervention, we drew on motivational interviewing and CBT methods that had been used in clinical practice with amphetamine users [18]. The approach was one of harm minimization, with participants able to decide on the most appropriate goals for themselves, for example, quitting completely, reducing their drug use, and using in a less hazardous manner. Module one explores the typical problems which ATS users incur, including: (1) relationships with family and friends, (2) health, (3) finances, (4) work/study, (5) legal issues, (6) mental health, and (7) specific drug use problems. The last page provides a summary of the endorsed problems, and guides the participant to generate a "map" of the interconnections between these issues. The second module requires participants to think about the pros and cons of their stimulant use, and the likely good and bad things related to changing their behavior, and draws on the Miller and Rollnick model [19]. To aid in their "decision balance" for each element that they select, participants rate its importance. The last module focuses on behavioral change, including techniques such as: (1) setting clearly specified goals, (2) actions on specific dates, (3) strategies to help with controlling and overcoming cravings, (4) refusal skills, (5) managing a "slip", and (6) an action plan to deal with high risk situations. Sample images from the intervention are available elsewhere [17] and in Multimedia Appendices 2-5.

Measures

All the study measures were self-report. The primary outcome measure was ATS use evaluated with the Alcohol, Smoking, Substance Involvement Screening Test (ASSIST) [20]. The ASSIST assesses lifetime and last three month use of nine drug categories (ie, tobacco, alcohol, cannabis, cocaine, ATS, inhalants, sedatives, hallucinogens, opioids, other). Data include frequency of use, cravings, problems (health, social, legal, or financial), failure to fulfill roles, concern expressed about their drug use, and if the person has ever tried and failed to control their drug use. Finally, injection of drugs was assessed. The standard ASSIST scoring algorithm was used to calculate a score for ATS use (range 0-39) [20].

We assessed secondary outcomes in terms of: (1) help-seeking intentions (general help-seeking questionnaire, GHSQ) [21]; (2) actual help-seeking questionnaire (AHSQ) [22,23]; (3) readiness to change, modified to assess ATS rather than alcohol (Readiness to Change Questionnaire, RTCQ) [24]; (4) psychological distress (Kessler-10 questionnaire, K-10) [25]; (5) poly-drug use measured by the ASSIST [20]; (6) days out of role [26]; and (7) quality of life (European Health Interview Survey, EUROHIS, Quality of Life scale) [27]. We also collected demographic information (eg, age, sex, marital status), drug use history (eg, age of first use of ATS), and severity of dependence (Severity of Dependence Scale, SDS) [28].

The RTCQ has four items relating to each of the stages, "precontemplation"; "contemplation"; and "action". The five point scales were summed to obtain scores for each stage, with participants designated to their highest scoring stage, or in the event of tied scores, the higher stage [24]. Psychological distress was indexed as the total score (range 10-50) on the K-10 [25]. Poly-drug use was the sum of ASSIST classes of drugs endorsed, excluding ATS use [20]. The GHSQ asked, "How likely is it that you would seek help from each of the following people for any amphetamine or other drug use problems during the next 4 weeks?", and provided a list of nine potential sources of help (eg, friend, mental health professional, other). The seven point scale ranged from extremely unlikely (1) to extremely likely (7). The AHSQ asked, "Which of the following people have you gone to for advice or help in the past 2 weeks for any amphetamine or other drug use problems?", and listed the same nine sources as the GHSQ. "Days out of role" was based on Kessler's questions, but referencing "ATS drug use (eg, methamphetamine, ecstasy, ice)" rather than "depression" [26], and quality of life was the total EUROHIS score [27].

Sample Size

The study was designed to detect a medium effect (eg, d=0.5) [29] with power of 0.8, which requires a sample of 60 people per group; to allow for 20% attrition, we recruited 80 people per group. In estimating the sample size, we drew on findings for stimulant users who were recruited in primary care settings and received a brief intervention in the ASSIST development study [20]. That group may be less heterogeneous than the current sample.

Analysis

The primary analysis was an intention-to-treat (ITT) analysis and used generalized estimating equation (GEE) models. This approach overcomes many of the limitations of standard repeated measures analysis of variance. It uses all available data without requiring substitution or estimation of missing independent variables to avoid the exclusion of cases with noncomplete data and does not assume homogeneity of correlations over waves of measurement [30,31]. For continuous data, an unstructured correlation matrix was used together with a normal distribution and identity link. Categorical outcome measures were evaluated using GEE models with a multinomial distribution and cumulative logit link. After inspection of the data, days out of role, intended help-seeking, and number of people actually sought help from, were assessed using a Poisson distribution with a log link due to the positively skewed distribution. Outcomes were tested as the group (intervention, control) by time (baseline, three months) interaction. Due to significant differences in baseline data (see Table 1), actual help-seeking was included as a covariate, along with SDS, due

to its importance in predicting attrition (see “Follow-Up” section). The primary outcome measure was the ASSIST ATS score, with other measures deemed as secondary outcomes.

A sensitivity analysis was conducted using multiple imputation of missing data using fully conditional specification with an iterative Markov chain Monte Carlo method. Maximum and minimum values were logically constrained, for example, to the possible range of scores on questionnaires. Baseline outcomes, plus demographic variables were used as predictors; three month outcomes were dependent and predictor variables in generating the 25 datasets. Effect sizes were calculated as the difference in pretest posttest means for the two conditions, divided by their common pretest standard deviation, multiplied by a bias correction factor ($1-(3/4(N_{treatment}+ N_{control}-2)-1)$, Monte Carlo modeling shows that this provides the best estimate of the population effect from the commonly used effect size measures [32]. In addition, attrition was modeled with logistic regression to investigate the characteristics of those lost to follow-up. Baseline predictors were study group, RTC group, age, age of first ATS use, gender, SDS, K-10, ASSIST ATS, poly-drug use scores, actual help-seeking scores, and intended help-seeking scores. Finally a “per protocol” analysis was conducted to evaluate the effect of completing at least one module of the intervention. The ITT and imputed analyses were conducted blind to study condition by RJT.

Results

Group Characteristics

The characteristics of the two groups and overall sample at baseline are shown in Table 1. On all measures, the two groups reported similar baseline scores, except actual help-seeking, where the control had significantly higher levels. There were (38/60) 23.8% of the participants that were female; the mean age was 22.4 (SD 6.3). About 1/3 of users only consumed ATS occasionally (1-2 times in the last three months), with (62/160) 38.8% using ATS weekly or more frequently. Based on a SDS threshold score of five or more, (57/160) 35.6% participants were classified as “dependent”. The large majority had never injected drugs (137/160, 85.6%).

Table 1. Baseline characteristics by study group and sample.

Variable		Control n=79, n (%) or mean (SD)	Intervention n=81, n (%) or mean (SD)	Total N=160, n (%) or mean (SD)	Statistic
Sex					
	Female	21 (27)[a]	17 (21)	38 (24)[a]	χ^2_1=1.80; *P*=.41
Age		22.5 (7.1)	22.2 (5.5)	22.4 (6.3)	t_{158}=0.34; *P*=.74
Education					
	Primary	2 (3)	6 (8)	8 (5)	χ^2_3=3.57; *P*=.31
	Secondary	50 (67)	50 (63)	100 (65)	
	Trade/technical	13 (17)	9 (11)	22 (14)	
	University	10 (13)	15 (19)	25 (16)	
Employment					
	Full-time	13 (17)	15 (19)	28 (18)	χ^2_3=0.60; *P*=.90
	Part-time	17 (22)	14 (18)	31 (20)	
	Unemployed	17 (22)	16 (21)	33 (21)	
	Student	30 (39)	33 (42)	39 (41)	
Amphetamine Type Stimulants (ATS) frequency last 3 months					
	1-2	27 (34)	20 (25)	47 (29)	χ^2_3=6.41; *P*=.09
	Monthly	18 (23)	33 (41)	51 (32)	
	Weekly	23 (29)	21 (26)	44 (28)	
	Daily/almost daily	11 (14)	7 (9)	18 (11)	
Age 1st ATS use		18.6 (4.2)	17.7 (2.6)	18.1 (3.5)	t_{158}=0.08; *P*=.93
ATS score		16.8 (11.1)	17.0 (10.1)	16.9 (10.6)	t_{158}=1.72; *P*=.09
Poly-drug use		4.6 (1.6)	4.8 (1.8)	4.7 (1.7)	t_{158}=0.95; *P*=.34
Intended help-seeking		20.4 (10.9)	19.7 (11.2)	20.1 (11.0)	t_{158}=0.40; *P*=.69
Actual help-seeking		0.8 (1.3)	0.3 (0.7)	0.6 (1.1)	t_{113}=2.83 [b]; *P*=.01
Kessler-10 (K-10) score		22.3 (8.3)	22.2 (8.4)	22.2 (8.3)	t_{158}=0.02; *P*=.98
Injected any drug					
	Never	69 (87)	68 (84)	137 (86)	χ^2_2=0.58; *P*=.75
	Yes, not last 3 months	4 (5)	4 (5)	8 (5)	
	Yes, last 3 months	6 (8)	9 (11)	15 (9)	
Days out of role		2.9 (5.9)	3.5 (5.6)	3.2 (5.7)	t_{158}=0.63; *P*=.53
Days part out of role		3.2 (4.8)	3.9 (5.3)	3.6 (5.3)	t_{158}=0.79; *P*=.43
Quality of life		28.2 (5.8)	27.2 (6.3)	27.7 (6.1)	t_{158}=0.99; *P*=.32
Readiness to Change Questionnaire (RTCQ)					
	Precontemplation	32 (41)	27 (33)	59 (37)	χ^2_2=2.83; *P*=.24
	Contemplation	24 (30)	35 (43)	59 (37)	
	Action	23 (29)	19 (24)	42 (26)	
Severity of Dependence (SDS)		3.8 (3.3)	3.7 (3.5)	3.7 (3.4)	t_{158}=0.17; *P*=.86
SDS >5		33 (42)	24 (30)	57 (36)	χ^2_1=2.57; *P*=.11

[a]One person reported sex as "other"

[b]Levene's correction for inequality of variances

[b]Missing data, education n=5, employment n=5

Engagement

From the 81 intervention participants, 51/81 (63%) completed, 13/81 (16%) started, and 17/81 (21%) did not attempt the first module. The second module was completed by 45/81 (56%) participants and started by another 2/81 (2%); the respective figures for the third module were 39/81 (48%) and 4/81 (5%). Thus, 39/81 (48%) completed all the modules, 6/81 (7%) completed two modules, and six completed one module.

Follow-Up

At three months, 45/79 (57%) participants from the control and 35/81 (43%) from the intervention completed follow-up surveys (Figure 1) (χ^2_1=3.03 *P*=.08). The proportion who submitted follow-up data in the intervention group varied with the number of modules completed, 7 (23%) who completed no modules, 2 (33%) who completed one module, 4 (67%) who completed two modules, and 22 (56%) who completed all three, Fisher's exact test 9.21, *P*=.02. Logistic regression showed that "loss to follow-up" was not significantly related to group allocation. However, higher depression scores increased the odds of completing follow-up (odds ratio, OR) 1.06, 95% CI 1.00-1.11), while the odds were reduced with higher baseline poly-drug use OR 0.75 (95% CI 0.60-0.93), or higher baseline SDS OR 0.82 (95% CI 0.67-0.99).

Intention-to-Treat Analyses

The results of the ITT analyses showed that there was only one significant group by time interaction for the outcome measures (Table 2). Those in the intervention group had a reduction in days out of role relative to the control group (estimated marginal mean, EMM, baseline 3.3, standard error, SE, 1.6; three months 0.70, SE 0.43; vs control EMM 3.1, SE 1.6; 2.9, SE 2.0). Table 2 also shows the scores on the outcome measures at three months together with the effect sizes. To facilitate the interpretation of the effect sizes, the group favored by the change is noted in the Table, because "improvements" constitute increases on some measures (eg, EUROHIS) and decreases on others (eg, ATS use). The majority of effect sizes favored the intervention group. We observed that actual help-seeking was lower for the intervention group at both time points, but their mean level increased while the mean decreased for the controls. With respect to RTC category, the proportion in the "precontemplation" stage fell in the intervention group (27/81, 33% to 8/34, 24%) and remained stable in the control group (32/79, 41% to 19/45, 42%). Changes in the proportions in the "action" and "contemplation" stages were similar for the two groups. The results for the pooled data after multiple imputations showed similar outcomes to the main analyses with only one significant group by time interaction. The intervention group showed improved outcomes relative to the control group for actual help-seeking (*P*=.02; intervention EMM baseline 0.32, SE.09; three months 0.84, SE 0.22; vs control EMM 0.74, SE 0.20; 0.87, SE 0.23.

Table 2. OR for group by time interaction plus posttest outcomes and pre/posttest effect sizes. Group by time interaction is adjusted for the SDS score at baseline and time varying actual help-seeking. Effect size is the difference in pre/post means/common pretest SD with bias correction factor [32]

Variable	OR (95% CI) group * time, mean (SD) or n (%)	Control n=45, mean (SD) or n (%)	Intervention n=35, mean (SD) or n (%)	Effect *d*	*P* value	Group favored
ATS score	0.70 (0.02, 24.64)	13.5 (10.0)	15.3 (9.3)	-0.16	.84	Control
Poly-drug use	0.51 (0.24, 1.09)	4.6 (1.7)	4.2 (1.8)	0.40	.08	Intervention
Intended help-seek	0.91 (0.72, 1.16)	19.5 (9.1)	18.1 (7.3)	0.09	.46	Control
Actual help-seek	1.90 (0.82, 4.39)	0.69 (.95)	0.57 (.92)	-0.33	.14	Intervention
K-10 score	0.15 (0.01, 1.97)	21.6 (7.7)	20.3 (7.4)	0.15	.15	Intervention
Days out of role	0.22 (0.07, 0.68)	2.2 (5.1)	1.1 (2.1)	0.29	.01	Intervention
Days part out of role	0.45 (0.15, 1.33)	3.0 (5.5)	2.9 (6.1)	0.14	.15	Intervention
Quality of life	1.99 (0.31, 12.82)	29.8 (5.4)	28.2 (5.0)	0.11	.47	Control
RTCQ						
Precontemplation	0.55 (0.21, 1.42)	19 (42)	8 (24)	-	.22	Intervention
Contemplation	-	7 (16)	9 (27)			
Action	-	19 (42)	17 (50)			

"Per Protocol" Analysis

The final analysis compared those who completed one or more modules (n=28), zero modules (n=7), or who were in the control group (n=45). Of the outcome measures, only actual help-seeking showed a significant interaction effect (OR 2.90, 95% CI 1.10-7.62). Actual help-seeking increased in those who undertook at least one module (baseline mean 0.22, SE 0.08;

three months 0.59, SE 0.21), whereas for both the control group (baseline 0.72, SE 0.22; three months 0.67, SE 0.25) and the zero module group (baseline 0.42, SE 0.15; three months 0.14, SE 0.15) actual help-seeking decreased. Note, analysis of "per protocol" data does not represent randomized outcomes.

Discussion

Principal Results

To the best of our knowledge, this is the first Web-based intervention developed specifically for users of ATS. There was only one (time by group) significant change on any of the key outcome measures, with an improvement in the number of days out of role for the intervention group. Further, the effect sizes for the intervention were smaller than those estimated in the design phase. The findings of the multiple imputations analysis reinforce the conclusion that the study was "insufficiently powered" to detect small effects. Nevertheless, to put these outcomes into perspective, the effects were larger than those recently reported for eHealth interventions for cannabis use [13] and similar to those for brief face-to-face interventions for alcohol use problems [33]. Thus, there is the potential that this intervention could be of benefit to users of ATS, at least among those with similar characteristics to this cohort. Nevertheless, the high level of attrition and low level of engagement limit the conclusions that can be drawn from these data. Improving engagement is a critical goal for interventions with substance using groups.

Moving beyond the ITT analysis, the effect size analysis and the per-protocol analysis (eg, those completing one or more modules) suggest that the intervention increases actual help-seeking behavior in participants. A recent review has found that it is difficult to change help-seeking, even where this is a specific aim of the intervention, at least among samples with common mental health disorders (eg, depression, anxiety) [34]. Brief interventions can result in small increases in help-seeking in those with alcohol use problems, but are more effective in those without comorbid mental health disorders [35]. This reinforces the above review, which found effect sizes ranging from $d = -.02$ to .24 for changing help-seeking [34]. Therefore, the significant effects found in the per-protocol and multiple imputed data analyses of the current study are an important outcome for a low intensity intervention. Further research is required to evaluate if this type of Web-based intervention can be effectively integrated into a stepped-care program for ATS users as previously recommended [5].

Given that the intervention specifically targeted and was designed for users of ATS, it is surprising that the control group had a greater decline in ATS use than the intervention group, especially as the latter showed a greater reduction than the control in poly-drug use, as indexed by the number of different categories of drugs used in the last three months (excluding ATS). The mean number of drug types used by participants was four to five in addition to ATS. That the participants appear to be opting to change other drug use, as shown by reduced poly-drug scores, rather than their ATS use is of concern, as even low frequency of exposure (ie, greater than five) to ATS is associated with the development of stimulant use disorders [11].

Limitations

There are a number of limitations that need to be acknowledged in the interpretation of these findings. The sample would be regarded as having less severe substance use problems, with the large majority having never injected any drug and their severity of dependence scores being low compared with ATS treatment seeking groups (eg, 75% injecting ATS, mean severity of dependence score approximately 9.0) [36]. Thus, care should be taken in extrapolating beyond this type of ATS user. Nevertheless, 57 participants scored five or more on the SDS and, on the basis of this screening measure, are likely to be ATS dependent [37]. The loss to follow-up of a significant proportion of participants threatens the internal validity of the study. Although this was not related to group allocation in a logistic model, the association with increased severity of dependence and poly-drug use reinforces the caveat that this type of low intensity intervention may not be suitable for those with more severe drug use problems, consistent with the broader literature on brief interventions for substance use [33,38]. Indeed, the small effect sizes reported for eHealth interventions with cannabis users [13] could imply that more intensive interventions are required for most illicit drug users. Other eHealth interventions with illicit drug users (cocaine) have encountered more extensive attrition [15], but the results obtained in the current study are comparable with in-person interventions for ATS [6] and consistent with the broader literature from fully automated Internet interventions [39]. Differences between the groups in the proportion followed-up may also threaten the internal validity.

A further concern is the low level of engagement with the intervention (30/81) 37% of participants randomized to the intervention did not complete the first module, and future research is required to investigate ways to encourage intervention completion. Although in a radically different sample (adolescent girls), recruiting mother-daughter dyads has achieved remarkable retention rates [13]; recruiting "user-significant other" dyads might improve retention in other drug use groups. This is particularly important given previous findings that completion of at least one in-person module of a four-session intervention for ATS was associated with greater ATS reductions than those who did not return for any sessions [9], in addition to our finding here that actual help-seeking increased for people completing at least one module of the Internet intervention. Similar findings have also been reported for Internet support interventions where completion of a greater number of modules following residential treatment was associated with better posttreatment outcomes [40]. Finally, the low level of engagement diminishes any potential difference between the study groups.

Conclusions

The impact of eHealth treatment interventions for ATS drug use remains open to question due to the small effects associated with their application and their potential clinical relevance. However, the impact of an intervention relates both to the prevalence of the condition and its consequences. Thus, brief

interventions by primary care physicians have a net benefit of only 1%-3% in the cessation of smoking, but are still cost effective and recommended [41,42]. The potential of eHealth interventions to reach those unable or unwilling to access conventional facilities means that they should be further evaluated in large scale trials, including effectiveness trials to determine if people will use them without research incentives. It also seems warranted to evaluate their effect as an adjunct to conventional treatment. Ways to further increase engagement with Internet-based treatment programs require research attention, particularly given the current debate as to whether or not "supported" or "guided" eHealth interventions (ie, involving some input from a therapist) are more effective than unguided programs [43,44]. Including an easy means of providing feedback at the end of each module could elicit data to modify the intervention and, hence, improve the experience for users. Without dramatic improvements in retention, substantially larger studies will be required to detect small differences between groups, but which will still leave results with questionable internal validity.

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Conflicts of Interest

The team who evaluated the intervention were also involved in its development.

Multimedia Appendix 1

Online information and consent form.

[PDF File (Adobe PDF File), 26KB - mental_v1i2e1_app1.pdf]

Multimedia Appendix 2

Breakingtheice introduction page.

[JPG File, 54KB - mental_v1i2e1_app2.JPG]

Multimedia Appendix 3

Module 1.

[JPG File, 70KB - mental_v1i2e1_app3.JPG]

Multimedia Appendix 4

Module 2.

[JPG File, 69KB - mental_v1i2e1_app4.JPG]

Multimedia Appendix 5

Module 3.

[JPG File, 65KB - mental_v1i2e1_app5.JPG]

Multimedia Appendix 6

CONSORT-EHEALTH checklist V1.6.2 [45].

[PDF File (Adobe PDF File), 985KB - mental_v1i2e1_app6.pdf]

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Abbreviations

AHSQ: actual help-seeking questionnaire
ASSIST: Alcohol, Smoking, Substance Involvement Screening Test
ATS: amphetamine-type stimulants
CBT: cognitive behavior therapy
EMM: estimated marginal mean
EUROHIS: European Health Interview Survey
GEE: generalized estimating equation
GHSQ: general help-seeking questionnaire

ITT: intention-to-treat
K-10: Kessler-10 questionnaire
MI: motivational interviewing
NHMRC: National Health and Medical Research Council
RTCQ: Readiness to Change Questionnaire
SDS: Severity of Dependence Scale
SE: standard error

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Original Paper

Randomized Comparison of Mobile and Web-Tools to Provide Dementia Risk Reduction Education: Use, Engagement and Participant Satisfaction

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Abstract

Background: Encouraging middle-aged adults to maintain their physical and cognitive health may have a significant impact on reducing the prevalence of dementia in the future. Mobile phone apps and interactive websites may be one effective way to target this age group. However, to date there has been little research investigating the user experience of dementia risk reduction tools delivered in this way.

Objective: The aim of this study was to explore participant engagement and evaluations of three different targeted smartphone and Web-based dementia risk reduction tools following a four-week intervention.

Methods: Participants completed a Web-based screening questionnaire to collect eligibility information. Eligible participants were asked to complete a Web-based baseline questionnaire and were then randomly assigned to use one of the three dementia risk reduction tools for a period of four weeks: (1) a mobile phone application; (2) an information-based website; and (3) an interactive website. User evaluations were obtained via a Web-based follow-up questionnaire after completion of the intervention.

Results: Of 415 eligible participants, 370 (89.16%) completed the baseline questionnaire and were assigned to an intervention group; 200 (54.05%) completed the post-intervention questionnaire. The average age of participants was 52 years, and 149 (75%) were female. Findings indicated that participants from all three intervention groups reported a generally positive impression of the tools across a range of domains. Participants using the information-based website reported higher ratings of their overall impression of the tool, $F_{2,191}$=4.12, P=.02; how interesting the information was, $F_{2,189}$=3.53, P=.03; how helpful the information was, $F_{2,192}$=4.15, P=.02; and how much they learned, $F_{2,188}$=3.86, P=.02. Group differences were significant between the mobile phone app and information-based website users, but not between the interactive website users and the other two groups. Additionally, participants using the information-based website reported significantly higher scores on their ratings of the ease of navigation, $F_{2,190}$=4.20, P=.02, than those using the mobile phone app and the interactive website. There were no significant differences between groups on ratings of ease of understanding the information, $F_{2,188}$=0.27, P=.76. Most participants from each of the three intervention groups indicated that they intended to keep using the dementia risk reduction eHealth tool.

Conclusions: Overall, results indicated that while participants across all three intervention groups reported a generally positive experience with the targeted dementia risk reduction tools, participants using the information-based website provided a more favorable evaluation across a range of areas than participants using the mobile phone app. Further research is required to investigate whether targeted dementia risk reduction tools, in the form of interactive websites and mobile apps, can be improved to provide benefits above those gained by providing static information alone.

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KEYWORDS

dementia; Alzheimer; engagement; health communication; Internet; intervention; mobile phone; risk reduction behavior; user perceptions; mhealth

Introduction

Background

With increasing life expectancy, the global burden of dementia is rapidly increasing, with numbers expected to almost double every 20 years from the 35.6 million people affected in 2010 [1]. Currently, no effective treatments exist to stop or reverse progression of dementia. However, several modifiable health and lifestyle factors have consistently been found to be associated with the risk of developing dementia [2-5]. Factors that may increase the risk of dementia include high blood pressure, midlife high total cholesterol, diabetes, midlife obesity, and smoking; while factors that may decrease the risk include regular physical exercise, mental and social activity, and the Mediterranean diet [2-5]. There is compelling evidence that managing vascular risk factors and remaining mentally and physically active from midlife may reduce the risk or delay the onset of dementia or cognitive decline in late life for individuals, and reduce the future incidence in the population [5-8].

A significant international research effort is currently aimed at developing and evaluating targeted dementia risk reduction interventions. Because the prevalence of dementia increases exponentially with age (from approximately 1-2% at age 65 to 20% at age 85 [1]), most of this research focuses on older people. However, as the underlying pathology and resulting brain damage precede the symptoms of dementia by years or decades [9] and many risk and protective factors have the strongest effect in midlife [10], developing late life interventions is only one part of the required preventative health approach.

While the direct impact of late life interventions on dementia incidence can be assessed by clinical trials conducted over a few years, this is impractical for midlife interventions due to the long interval before the outcome of interest (dementia diagnosis) could be assessed. However, existing epidemiological evidence suggests it is likely that encouraging people to change their behavior and maintain their physical and cognitive health in midlife can have a significant impact on reducing the prevalence of dementia in the future [6,8]. Despite this potential, a large number of Australian adults have limited knowledge about dementia risk factors [11,12].

eHealth Tools

Over 80% of Australians are Internet users [13]. eHealth interventions (health care using the Internet; eg, websites and mobile phone apps) are increasingly being utilized to promote health behavior change [14,15]. eHealth interventions are advantageous because they offer convenience and anonymity to the user [16-18], they allow for individualized, tailored feedback [15], and they have the potential to reach large audiences at a low cost [19,20].

eHealth interventions have been reported to be an effective method for increasing knowledge and/or enabling healthy behavior change [21]; for example, in areas such as physical activity [22], and overweight and obesity prevention [23]. This suggests that eHealth interventions are efficacious for the promotion of healthy lifestyles. However, to date there has been limited high quality research evaluating eHealth intervention programs designed to target multiple behaviors [24,25].

Alzheimer's Australia's Dementia Risk Reduction Program

Alzheimer's Australia (Australia's national dementia association) developed a community education program designed to inform people about what they can do to reduce their risk of dementia (Your Brain Matters). It is based on the scientific evidence and focuses on ten health and lifestyle behaviors that have been identified as modifiable risk and protective factors: alcohol use, blood pressure, body weight, cholesterol, diabetes, diet, mental activity, physical activity, smoking, and social activity. The program initially focused on community education forums and printed resources, but now includes eHealth tools such as a website and mobile phone app. In designing the eHealth tools, the aim was to disseminate the current evidence for modifiable risk and protective factors associated with dementia risk to the Australian community using accessible and engaging modalities. To aid development of these eHealth tools, Alzheimer's Australia reviewed the relevant literature and sought expert advice on the recommendations being made. Alzheimer's Australia staff and consumer advisors provided feedback about the appropriateness of the content for the general public.

The original website developed for this program was evaluated in a previous study [25]. Results indicated that while participants found the website to be interesting, informative, and helpful, additional personalized and interactive resources were desired. Resources to assess and address individual risk factors were rated as potentially very useful [25]. Further resources were developed with the aim of enhancing the website and providing resources on a mobile platform in order to better assist people to implement behavior change, rather than providing static information alone. These personalized and interactive resources include: a brain health survey with results indicating how brain healthy users' current lifestyles are, tailored activity suggestions, tools for recording weekly goals and activities, and brief progress surveys for each health behavior.

While evaluation of the effectiveness of the dementia risk reduction eHealth tools will require assessment of outcomes such as improved knowledge and behavior change, an important first step is evaluating whether the tools are acceptable to intended users. An evaluation of user experiences and perceptions of these eHealth tools was therefore the focus of the present study. The Alzheimer's Australia dementia risk

reduction resources are continually being updated and revised, and an important aspect of these revisions is to ensure they remain relevant and useful for the user, while being easy to access and navigate. Thus, an evaluation which focuses on the user experience of each of these resources is essential.

Current Study

eHealth tools may present a feasible method for providing dementia risk reduction resources to the Australian community, particularly to those in midlife. However, there has been limited research, to date, examining the user experience. The aim of the present study was to explore participant preferences regarding three eHealth interventions. It was hypothesized that participants would provide a more positive evaluation of the interactive eHealth tools (an interactive mobile phone app or an interactive Web-based program) than for a static information-only website.

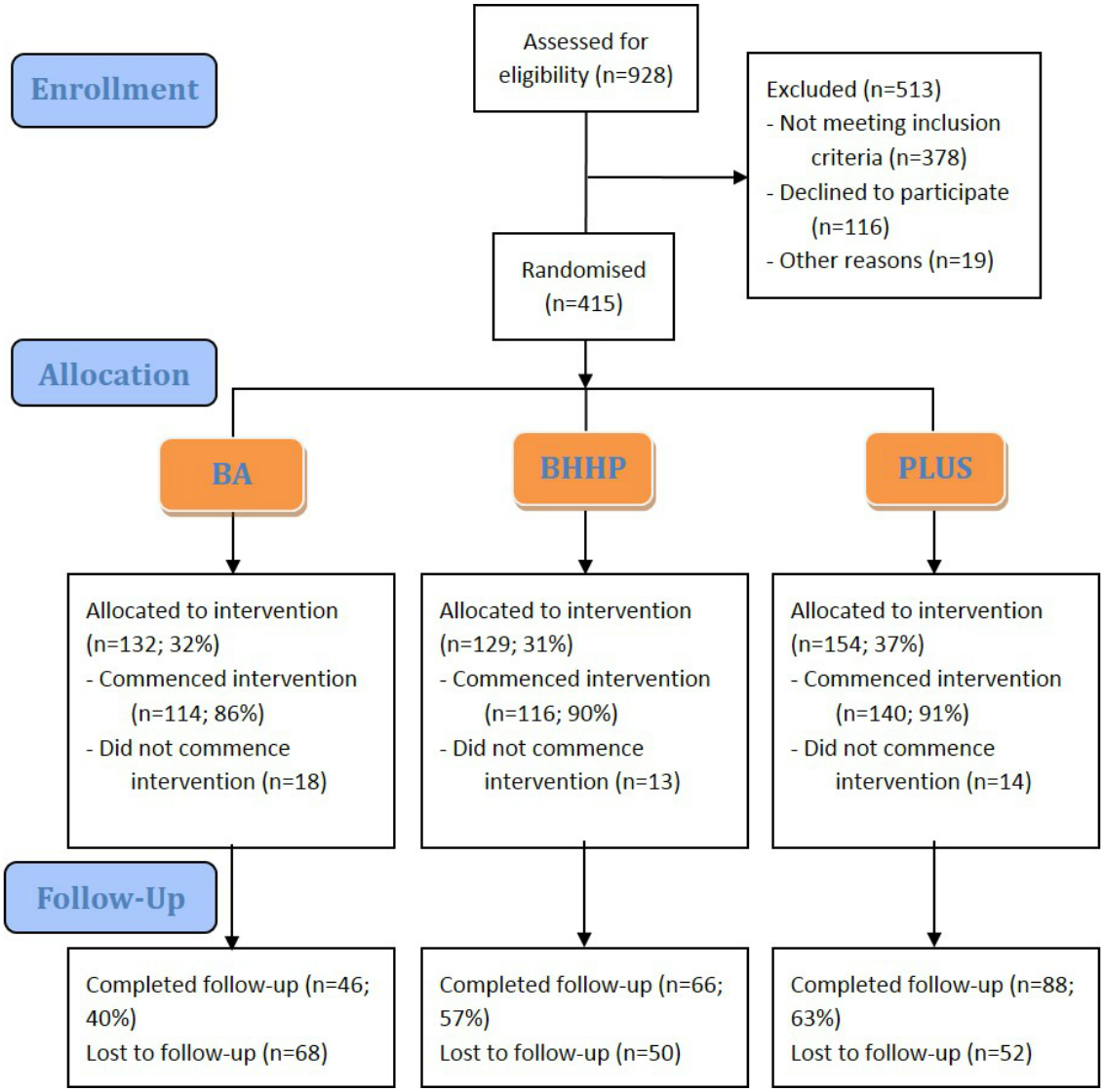
Methods

Participants

Participants were recruited through a range of targeted online and media promotions, including newspaper advertisements, radio interviews, online forum advertising and social media posts. A total of 928 people provided online consent to participate in the research project and completed a screening questionnaire. Of these, 135 (14.6%) had invalid screening tools (eg, withdrew prior to completing the screen or had duplicate entries). Of the 793 valid screens, 415 (44.7%) were eligible. The primary reason for ineligibility was not having an Apple device (n=346, 91.5%; an Apple device being required to use the mobile phone app/tablet tool). Additional eligibility criteria included being 18 years of age or older, fluent in English, healthy enough to undertake physical exercise, and not having a psychiatric or neurological condition. Figure 1 details a flow diagram for participants.

Three hundred and seventy (89.16%) eligible participants completed the online baseline questionnaire and thus entered the study. Of these, 200 (54.05%) continued through to completion of the online four-week post-intervention questionnaire, with the remaining 170 not responding to follow-up reminder emails.

Figure 1. Flow diagram detailing the involvement of participants in the study. BA: BrainyApp (mobile phone/tablet app); BHHP: Brain-Heart Health Program (information only website); PLUS: Brain-Heart Health Plus Program (interactive Web-based program).



Procedure

In this study, participants made contact initially through an advertisement which provided a link to an online screening tool. Eligible participants were then randomly allocated to use BrainyApp (an app available on Apple devices; BA group), or the Brain-Heart Health Program (an information-based website; BHHP group), or the Brain-Heart Health Plus Program (an interactive website; PLUS group) and invited, via email, to complete a baseline questionnaire and then engage with the app, information-based website, or interactive website for a period of four weeks. During this time, participants' use of the eHealth tool was monitored by automatic logging of the frequency and duration of their use of the app or website. A reminder email was sent halfway through the four week intervention, encouraging participants to continue using the eHealth tool. At the conclusion of the intervention period, participants were asked to complete a post-intervention questionnaire online. All participants were offered a $20 Woolworths (major supermarket chain) voucher as compensation for their time and effort. Ethical approval was obtained from the Australian National University Human Research Ethics Committee.

Interventions

BrainyApp is a mobile device application for iPhone, iPad, and iPod Touch. Figures 2 and 3 illustrate two screenshots from BrainyApp. This tool allows users to complete a brain health survey, which asks questions about current physical, social and mental activity, cardiovascular health, diet, smoking and drinking habits. The brain-heart health score achieved indicates how brain healthy the users' current lifestyle is and particular areas for improvement are highlighted. Users can then engage in activities to improve in areas that may be increasing their dementia risk. If users record sufficient activities according to recommendations for dementia risk reduction, their brain-heart health score improves over time. Users can also read and share facts about dementia, the brain and how to keep their brain healthy. BrainyApp is publicly available (and has been downloaded over 300,000 times since its release in 2011), but participants in this study used a research version of the app that allowed monitoring of their usage.

The Brain-Heart Health Program is an information-based website. Figures 4 and 5 illustrate two screenshots from the information-based website. This site provides static information

only, and the information about risk and protective factors is presented in three sections–Brain, Body, and Heart. These sections explain the current evidence and provide some practical advice on how users can be brain healthy and reduce their risk of dementia, with links to additional relevant resources. Users can also learn about dementia, the brain, and how to keep their brain healthy. The information-based website was created specifically for this study, and was only accessible to participants with a log-in account.

The Brain-Heart Health Plus Program is an interactive Web-based brain health program. Figures 6 and 7 illustrate two screenshots from the interactive website. The information about risk and protective factors is presented in three sections–Brain, Body, and Heart. The interactive website also allows users to complete a brain health survey, which asks questions about current physical, social and mental activity, cardiovascular health, diet, smoking and drinking habits. Survey results indicate how brain healthy users' current lifestyle is. Users are then provided with information about which areas could be improved to boost their brain health, and are given the opportunity to engage in recommended activities to improve in these areas. They are provided with links to additional relevant resources, research snapshots, planners for recording weekly goals and activities, and brief progress surveys. Additional health information, practical tips, and resources, were emailed to users halfway through the intervention. Users can also learn about dementia, the brain, and how to keep their brain healthy. The interactive website was created specifically for this study, and was only accessible to participants with a log-in account.

Figure 2. Screenshot of the BrainyApp "Brain-Heart Health points" page.

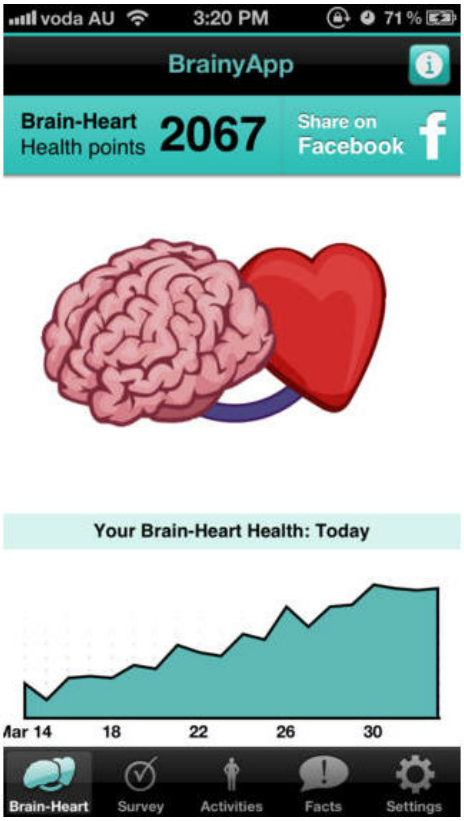


Figure 3. Screenshot of the BrainyApp "Brain Health Survey: Your Results" page.

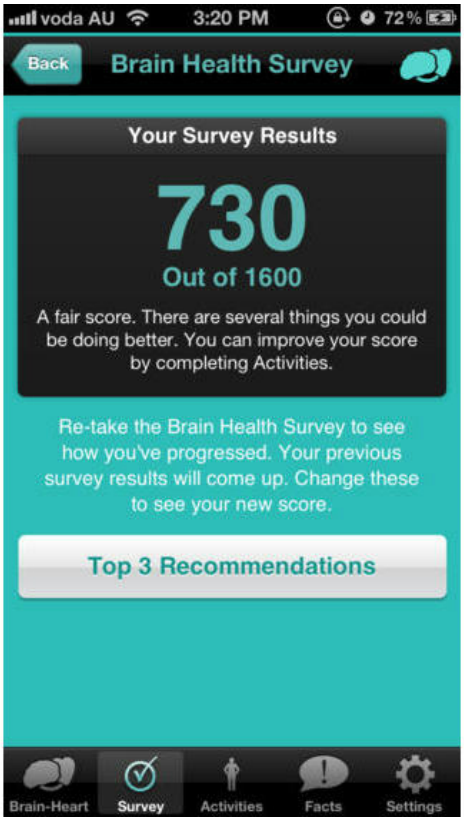


Figure 4. Screenshot of the Brain-Heart Health Program "About Alzheimer's Australia" page.

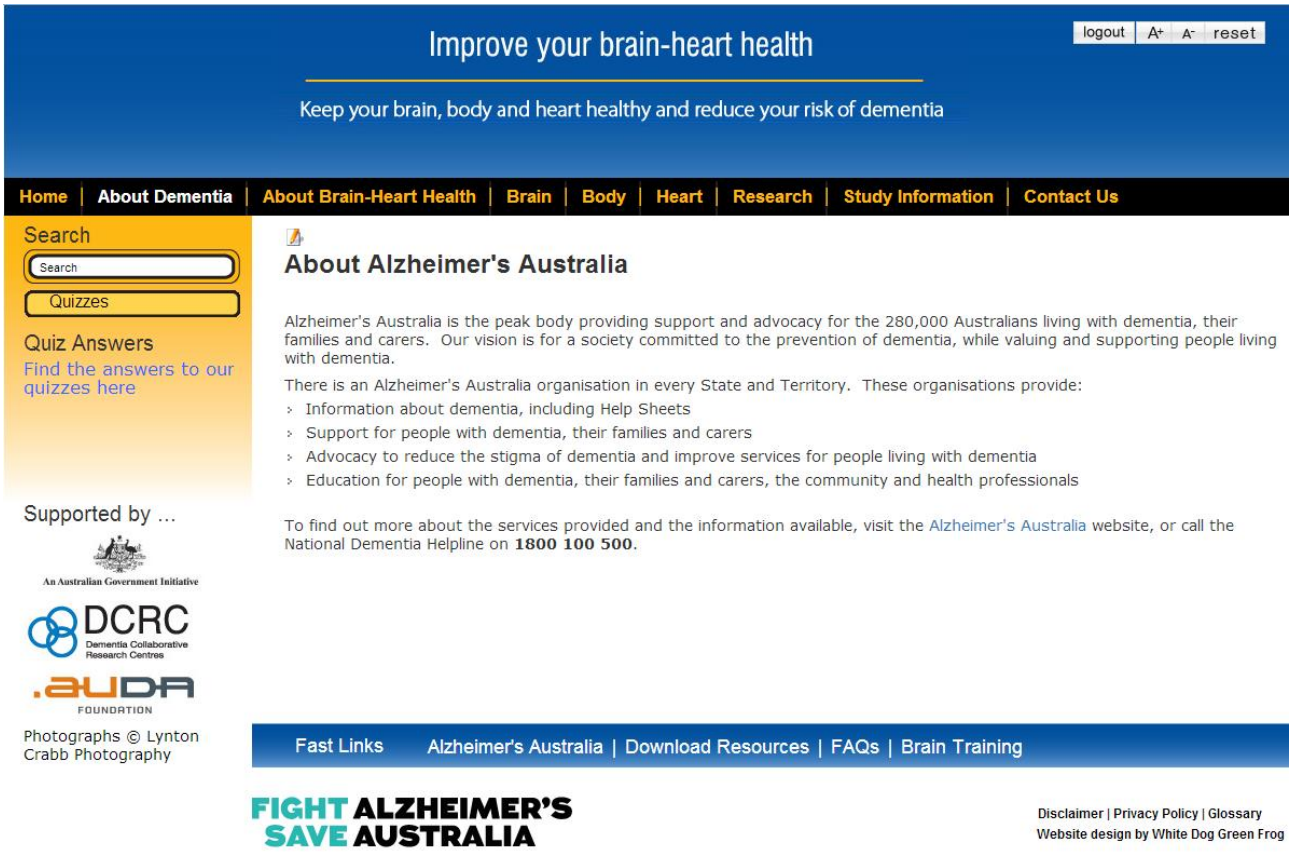


Figure 5. Screenshot of the Brain-Heart Health Program "Keep your body fit and healthy" page.

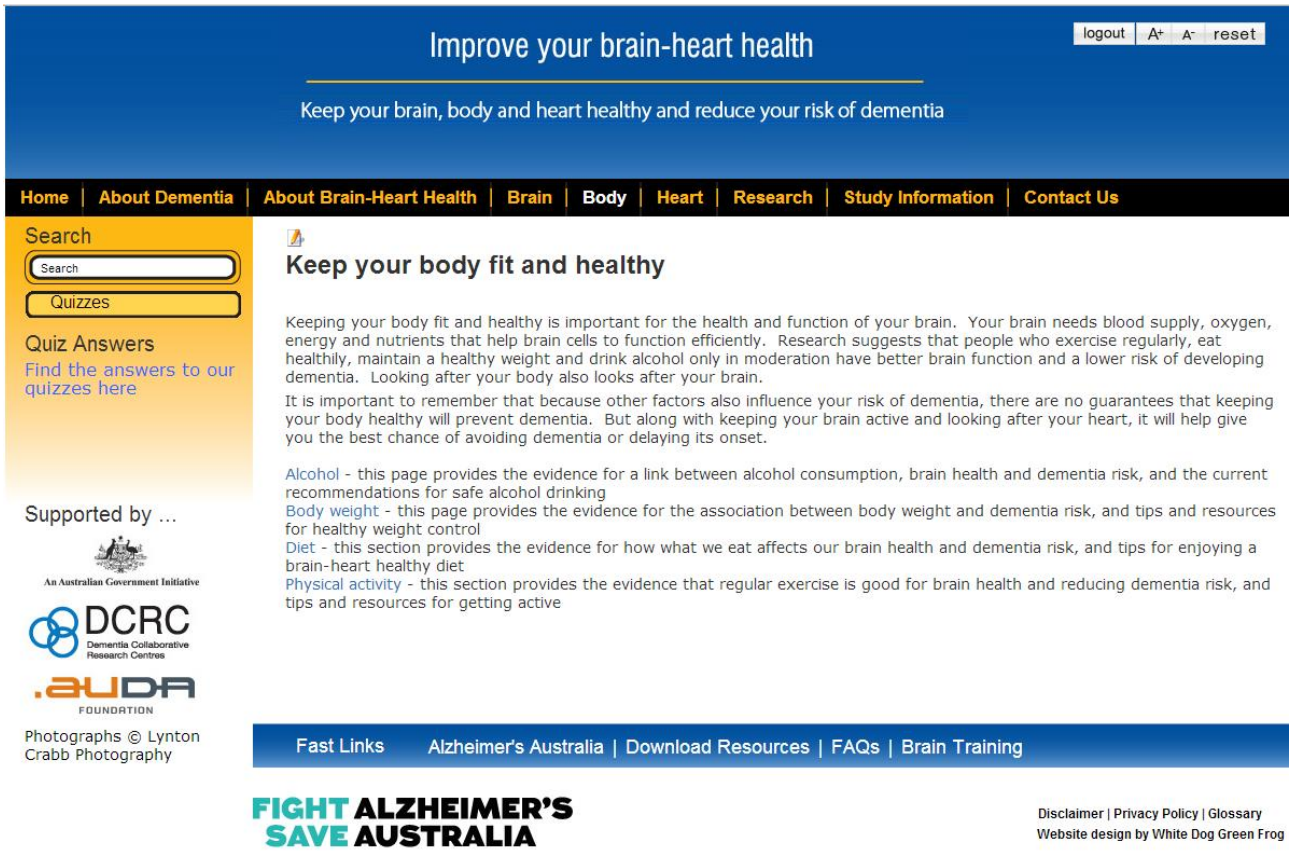


Figure 6. Screenshot of the Brain-Heart Health Plus Program "Your Brain Health Survey" page.

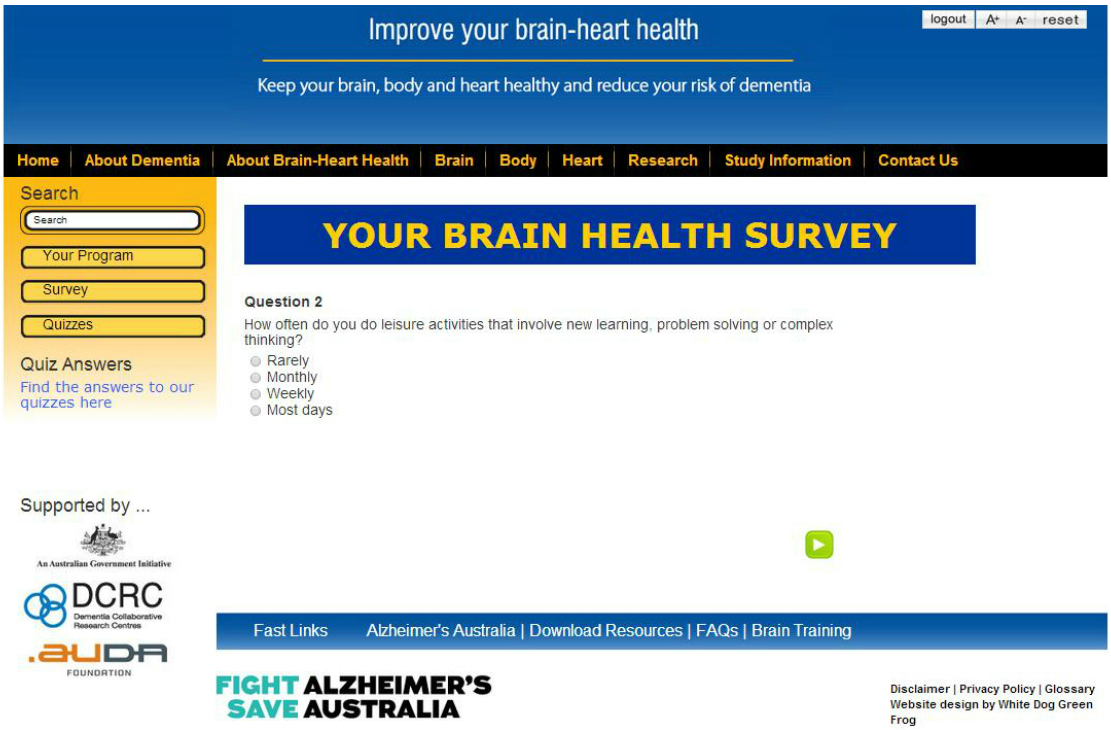
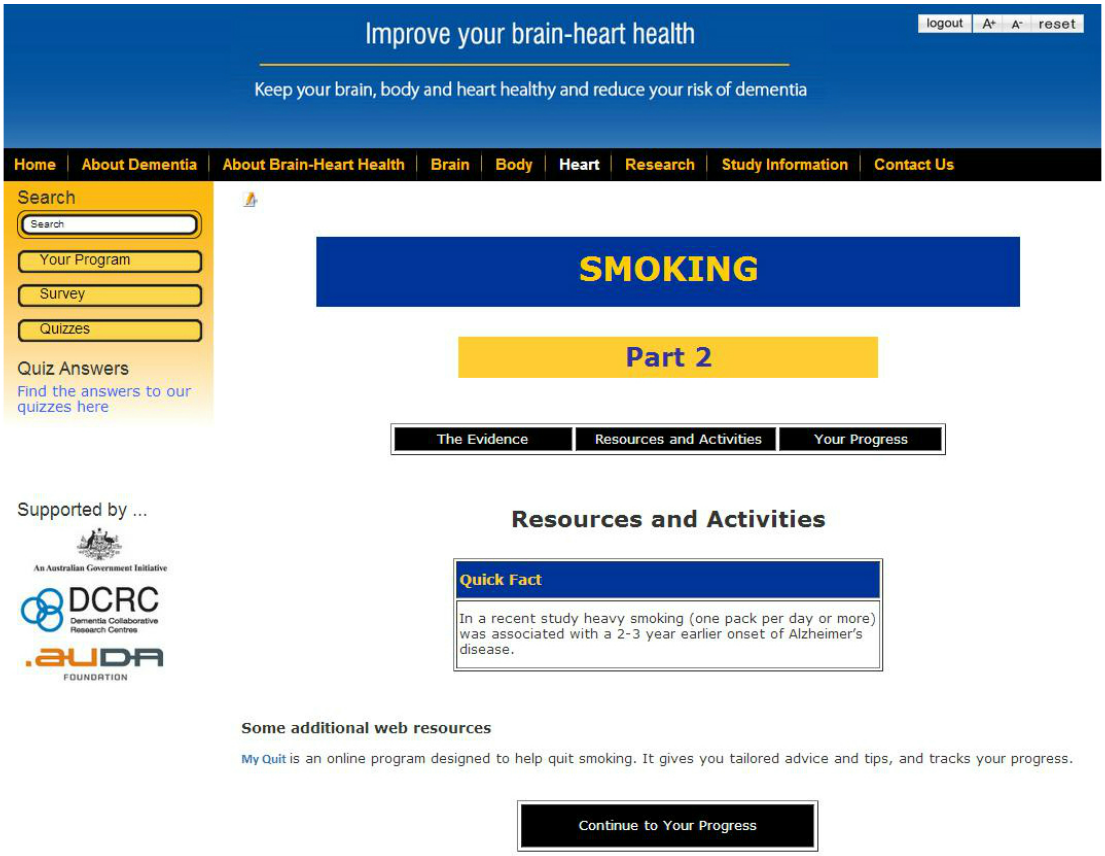


Figure 7. Screenshot of the Brain-Heart Health Plus Program "Smoking: Part 2" page.



Measures

Demographic Information

Participants were asked about their age, gender, country of birth, current living situation, and highest level of education. They were also asked about their current employment status, current occupation, whether they had ever worked as a health professional, and their annual household income (before tax). Finally, they were asked how often they download and use a new general app or health-related app on their Apple device, and how often they use the Internet to search for general and health-related information, on a five-point scale (from 1=never to 5=daily).

Evaluation Information

Overview

Participants were asked a series of questions about their use and evaluation of the tools during the four-week intervention. Questions were tailored specifically to each of the three intervention tools.

Use of eHealth Tools

Participants were asked whether they had heard of or used Alzheimer's Australia's Your Brain Matters or BrainyApp prior to the study, how they accessed the current intervention tool, how often they used it, how long they used it for each time, whether they were ever unable to access it, and whether they intended to keep using it. For the BA and PLUS groups, they were also asked whether they were surprised by their scores on the survey. Participants' use of the eHealth tool was tracked throughout the four-week intervention; data included frequency and duration of use.

Evaluation of Intervention

Using a five-point scale, participants were asked about their overall impression of the intervention (from 1=terrible to 5=excellent), whether the information provided was interesting (from 1=not at all interesting to 5=very interesting), and easy to understand (from 1=very complex to 5=very simplistic), whether the intervention was easy to navigate (from 1=very difficult to 5=very easy), how helpful they found the intervention (from 1=not at all helpful to 5=very helpful), and how much they felt they learned (from 1=nothing at all to 5=a great deal).

Analysis

IBM SPSS Statistics Version 21 was used to conduct the analyses. The average rate of missing data across the variables was low (no more than 3.0%); as a result, pairwise deletion was utilized for all analyses. A threshold of $P<.05$ was used for reporting statistical significance.

The analyses are presented in four parts. First, significant differences between completers and non-completers were explored. Next, the sample characteristics were described, including levels of eHealth usage prior to the study. Third, usability and access data were examined across the intervention groups, including both self-report data and user tracking. Finally, differences in evaluation scores between the intervention groups were examined using a series of one-way between-groups ANOVAs.

With power set at .80 and alpha=.05, the required sample size for each group in order to observe a medium effect was 52 [26]. Thus, the sample size for BHHP and PLUS groups was adequate, while the sample size for the BA group was limited.

Results

Comparison of Completers and Non-Completers

A series of independent *t* tests and chi-square tests for independence indicated the following significant differences between the 200 completers of the four-week follow-up and the 170 non-completers: education level, χ^2_5=17.2, n=370, *P*=.004, Cramer's *V*=.22, (95% CI 0.07-0.30); and employment status, χ^2_6=12.9, n=369, *P*=.045, Cramer's *V*=.19, (95% CI 0-0.26). Those who completed the follow-up were more likely to have an undergraduate degree (n=64, 32.0% vs n=32, 18.8%) and be retired or looking for work (n=59, 29.5% vs n=25, 14.8%), while those who did not complete the follow-up were more likely to have a postgraduate degree (n=65, 38.2% vs n=56, 28.0%) and working full-time (n=69, 40.8% vs n=63, 31.5%).

There were no significant differences found between completers and non-completers for age, t_{368}=1.59, *P*=.11, mean difference=2.53 years, (95% CI -0.60 to 5.67); gender, χ^2_2=2.8, n=366, *P*=.24, Cramer's *V*=.09, (95% CI 0-0.18); country of birth, χ^2_1=0.02, n=369, *P*=.99, phi=-.01, (95% CI 0-0.04); living situation, χ^2_3=5.7, n=368, *P*=.13, Cramer's *V*=.13, (95% CI 0-0.21); occupation, χ^2_{12}=10.9, n=364, *P*=.53, Cramer's *V*=.17, (95% CI 0-0.19); work as a health professional, χ^2_1=0.9, n=369, *P*=.27, phi=-.06, (95% CI 0-0.16); or household income, χ^2_3=4.1, n=360, *P*=.25, Cramer's *V*=.11, (95% CI 0-0.19).

Demographic Characteristics

Demographic characteristics of the participants are detailed in Table 1. Three-quarters of participants were female, with an average age of 52 years. Most participants were born in Australia, and lived with their partner and/or children. More than half of all participants had an undergraduate or postgraduate degree; the majority were employed either full-time or part-time. A wide range of occupations were represented; 19% (38 of 200) had worked as a health professional; and the vast majority had a household income of more than AUD$52,000 per annum.

A series of one-way between-groups ANOVAs and chi-square tests for independence indicated that there were no significant differences between intervention groups for the demographic characteristics: age, $F_{2,197}$=0.28, *P*=.78; gender, χ^2_4=7.9, n=198, *P*=.10, Cramer's *V*=.14, (95% CI 0-0.22); country of birth; χ^2_2=1.8, n=200, *P*=.41, Cramer's *V*=.10, (95% CI 0-0.22); current living situation, χ^2_6=3.8, n=199, *P*=.71, Cramer's *V*=.10, (95% CI 0-0.14); education, χ^2_{10}=8.2, n=200, *P*=.61, Cramer's *V*=.14, (95% CI 0-0.17); employment status, χ^2_{12}=9.6, n=200, *P*=.65, Cramer's *V*=.16, (95% CI 0-0.17); occupation, χ^2_{24}=21.1, n=198, *P*=.63, Cramer's *V*=.23, (95% CI 0-0.29); work as a health professional, χ^2_2=1.8, n=200, *P*=.41, Cramer's *V*=.10, (95% CI 0-0.22); or income, χ^2_6=5.1, n=193, *P*=.53, Cramer's *V*=.12, (95% CI 0-0.17).

Table 1. Demographic characteristics for all participants who completed the four-week follow-up.

Characteristics	BA (n=46) Mean (SD) or n (%)	BHHP (n=66) Mean (SD) or n (%)	PLUS (n=88) Mean (SD) or n (%)
Age, mean (SD)	52.26 (15.81)	53.18 (13.75)	51.35 (15.48)
Gender, n (%)			
Male	16 (34.80)	9 (14.10)	23 (26.10)
Female	30 (65.20)	55 (85.90)	64 (72.70)
Other	0 (0.00)	0 (0.00)	1 (1.10)
Country of birth, n (%)			
Australia	36 (78.30)	45 (68.20)	67 (76.10)
Other	10 (21.70)	21 (31.80)	21 (23.90)
Living situation, n (%)			
Alone	6 (13.30)	8 (12.10)	8 (9.10)
Partner and/or children	32 (71.10)	51 (77.30)	73 (83.00)
Parents	4 (8.90)	3 (4.50)	5 (5.70)
Other adults	3 (6.70)	4 (6.10)	2 (2.30)
Education, n (%)			
Primary	0 (0.00)	0 (0.00)	1 (1.10)
Secondary	13 (28.30)	7 (10.60)	14 (15.90)
Trade/Apprenticeship	2 (4.30)	4 (6.10)	4 (4.50)
Diploma	7 (15.20)	14 (21.20)	14 (15.90)
Undergraduate	12 (26.10)	23 (34.80)	29 (33.00)
Postgraduate	12 (26.10)	18 (27.30)	26 (29.50)
Employment, n (%)			
Full-time	13 (28.30)	19 (28.80)	31 (35.20)
Part-time	9 (19.60)	17 (25.80)	18 (20.50)
Looking for work	3 (6.50)	4 (6.10)	4 (4.50)
Studying full-time	3 (6.50)	1 (1.50)	5 (5.70)
Retired	9 (19.60)	17 (25.80)	22 (25.00)
Home duties	4 (8.70)	1 (1.50)	2 (2.30)
Other	5 (10.90)	7 (10.60)	6 (6.80)
Occupation, n (%)			
Managers	4 (8.70)	11 (16.70)	7 (8.10)
Professionals	13 (28.30)	18 (27.30)	28 (32.60)
Other occupation	6 (13.00)	10 (15.10)	11 (12.90)
Home duties or carer	4 (8.70)	2 (3.00)	2 (2.30)
Self-employed	3 (6.50)	3 (4.50)	5 (5.80)
Retired	10 (21.70)	17 (25.80)	23 (26.70)
Looking for work	3 (6.50)	4 (6.10)	4 (4.70)
Student	3 (6.50)	1 (1.50)	6 (7.00)
Health professional, n (%)			
Yes	8 (17.40)	16 (24.20)	14 (15.90)
No	38 (82.60)	50 (75.80)	74 (84.10)

Characteristics	BA (n=46) Mean (SD) or n (%)	BHHP (n=66) Mean (SD) or n (%)	PLUS (n=88) Mean (SD) or n (%)
Household income, n (%)			
Less than $15,600	2 (4.50)	2 (3.20)	1 (1.20)
$15,600-$52,000	13 (29.50)	16 (25.40)	16 (18.60)
$52,000-$104,000	19 (43.20)	31 (49.20)	41 (47.70)
More than $104,000	10 (22.70)	14 (22.20)	28 (32.60)

Table 2 indicates that, on average, participants downloaded and used a new app rarely or monthly, and downloaded and used a new health-related app never or rarely. Further, participants used the Internet to search for general information weekly or daily on average, while they used the Internet to search for health-related information monthly or weekly. A series of chi-square tests for independence indicated that there were no significant differences found between intervention groups (see Table 2).

Table 2. Mean ratings of eHealth and general app/Internet usage (rated on a five-point scale from 1=never to 5=daily).

	BA (n=46) Mean (SD)	BHHP (n=66) Mean (SD)	PLUS (n=88) Mean (SD)	Chi-square tests (95% CIs for V)
New app	2.82 (0.94)	2.68 (0.81)	2.76 (0.91)	χ^2_8(n=199)=8.5, *P*=.39, *V*=.15, (0-0.19)
New health-related app	1.82 (0.94)	1.88 (0.73)	1.75 (0.68)	χ^2_6(n=199)=4.0, *P*=.67, *V*=.10, (0-0.15)
General Web search	4.54 (3.07)	4.73 (0.54)	4.72 (0.61)	χ^2_8(n=200)=9.2, *P*=.33, *V*=.15, (0-0.20)
Health-related Web search	3.07 (0.90)	3.36 (0.87)	3.18 (0.96)	χ^2_8(n=199)=7.5, *P*=.49, *V*=.14, (0-0.18)

Use of eHealth Tools

The majority of participants had not previously heard of or used BrainyApp or Alzheimer's Australia's Your Brain Matters program, and this did not differ between groups (see Table 3). Very few BA participants used an iPod Touch to access the intervention, with the vast majority using either an iPhone or iPad. BHHP and PLUS participants primarily used a desktop computer or laptop, so there was a significant association between intervention group and mode of access.

The majority of both BA and PLUS participants indicated that they were not surprised by their score on the Brain Health Survey (see Table 3; participants in the BHHP group did not have access to the survey and so were not asked this question). Across all three groups, most participants indicated that they intended to keep using the eHealth tool.

As indicated in Table 3, there were significant associations between intervention group and frequency and duration of eHealth tool use. Most BA participants reported using the app a few days a week, while BHHP participants tended to use the website weekly, and PLUS participants tended to use the program fortnightly. BA participants reported using their eHealth tool mostly for 5 to 10 minutes at a time, while most BHHP participants used their eHealth tool for 15 to 30 minutes at a time, and PLUS participants reported using their eHealth tool mostly for 5 to 20 minutes at a time. Few participants reported that they were ever unable to access the eHealth tool (eg, due to a crash).

User tracking indicated that BA participants used the app for an average of 20.5 sessions (SD 17.3, range 1-62). The average duration per session was 5.2 minutes (SD 3.5, range 0.5-13.6). BHHP participants used the website an average of 3.0 times (SD 2.4, range 1-12), for an average duration of 22.2 minutes (SD 27.2, range 0.5-137.2) per session. Finally, PLUS participants used the program an average of 2.3 times (SD 1.4, range 1-7), for an average duration of 16.6 minutes (SD 14.7, range 1.9-83.6) per session. Comparison of the self-reported frequency and duration of use with the user tracking indicated that, while broadly consistent, there was a tendency for participants to over-report their use of the eHealth tools.

Table 3. Use of eHealth tools.

	BA[a] (n=46) n (%)	BHHP (n=66) n (%)	PLUS (n=88) n (%)	Chi-square tests (95% CIs for V)
Heard of BA/YBM [b]				χ^2_2(n=196)=0.9, *P*=.63, *V*=.07, (0-0.18)
Yes	10 (21.7)	11 (16.7)	21 (23.9)	
No	35 (76.1)	52 (78.8)	67 (76.1)	
Used BA/YBM				χ^2_2(n=195)=3.0, *P*=.22, *V*=.12, (0-0.25)
Yes	8 (17.4)	8 (12.1)	7 (8.0)	
No	36 (78.3)	55 (83.3)	81 (92.0)	
Mode of access				χ^2_8(n=196)=113.5, *P*<.001, *V*=.54, (0.42-0.62)
Mobile phone	23 (50.0)	3 (4.5)	2 (2.3)	
Tablet device	20 (43.5)	13 (19.7)	11 (12.5)	
Desktop computer or laptop	0 (0.0)	37 (56.1)	61 (69.3)	
iPod Touch	2 (4.3)	0 (0.0)	0 (0.0)	
Multiple devices	0 (0.0)	11 (16.7)	13 (14.8)	
Surprised by score				χ^2_2(n=128)=0.4, *P*=.82, *V*=.06, (0-0.18)
Yes, higher than expected	9 (19.6)	N/A	13 (14.8)	
Yes, lower than expected	8 (17.4)	N/A	16 (18.2)	
No	28 (60.9)	N/A	54 (61.4)	
Intend to keep using				χ^2_2(n=190)=3.7, *P*=.16, *V*=.14, (0-0.27)
Yes	30 (65.2)	51 (77.3)	56 (63.6)	
No	15 (32.6)	12 (18.2)	26 (29.5)	
Ever unable to access				χ^2_2(n=194)=0.8, *P*=.66, *V*=.07, (0-0.18)
Yes	7 (15.2)	9 (13.6)	9 (10.2)	
No	38 (82.6)	54 (81.8)	77 (87.5)	
Self-reported frequency of use				χ^2_{12}(n=195)=40.6, *P*<.001, *V*=.32, (0.16-0.38)
Everyday	2 (4.3)	0 (0.0)	1 (1.1)	
Most days	12 (26.1)	4 (6.1)	5 (5.7)	
A few times a week	15 (32.6)	14 (21.2)	9 (10.2)	
Weekly	8 (17.4)	15 (22.7)	22 (25.0)	
Fortnightly	4 (8.7)	13 (19.7)	27 (30.7)	
Monthly	2 (4.3)	13 (19.7)	16 (18.2)	
Not at all	1 (2.3)	4 (6.1)	8 (9.1)	
Self-reported duration of use				χ^2_8(n=191)=26.0, *P*=.001, *V*=.26, (0.11-0.33)
5 minutes or less	4 (8.7)	5 (7.6)	4 (4.5)	
5 to 10 minutes	22 (47.8)	8 (12.1)	30 (34.1)	
15 to 20 minutes	12 (26.1)	21 (31.8)	29 (33.0)	
25 to 30 minutes	3 (6.5)	20 (30.3)	11 (12.5)	
More than 30 minutes	3 (6.5)	9 (13.6)	10 (11.4)	

[a]BA=BrainyApp

[b]YBM=Alzheimer's Australia's Your Brain Matters program

Evaluation of Intervention

The majority of participants from all three groups reported a generally positive overall impression of the eHealth tools. They also reported that the information provided was interesting, easy to understand, and easy to navigate. Again, the majority reported that the information provided was helpful, and that they learned a substantial amount from the eHealth tool.

A series of one-way between-groups ANOVAs were conducted to explore differences between intervention groups on each aspect of the evaluation. Table 4 details participants' average responses to each of the evaluation items, and results of each of the ANOVAs.

There were statistically significant differences between groups on the variables concerning participants' overall impression of the intervention, how interesting the eHealth tool was, how easy it was to navigate, how helpful participants found the information provided, and the amount learned, but not how easy the information was to understand. Post-hoc comparisons using the Tukey HSD test indicated that the mean rating for the BA group was significantly lower than the BHHP group's rating on the variables concerning participants' overall impression (*P*=.02), how interesting the information was (*P*=.03), how helpful participants found the information provided (*P*=.02), and the amount learned (*P*=.02); the PLUS group did not differ significantly from the other two groups on these variables. For the variable concerning how easy the eHealth tool was to navigate, post-hoc comparisons indicated that the mean rating for the BHHP group was significantly higher than the ratings of both the BA group (*P*=.03) and the PLUS group (*P*=.04); however, the mean score for the BA group did not significantly differ from the PLUS group.

Table 4. Mean ratings (rated on a scale from 1 to 5) for participants' evaluations of the interventions.

Participants' Evaluations	BA (n=46)	BHHP (n=66)	PLUS (n=88)					
	Mean (SD)	Mean (SD)	Mean (SD)	*F*	Degrees of Freedom	*P*	eta^2	90% CIs for eta^2
Overall impression	3.56 (0.84)	4.03 (0.87)	3.75 (0.89)	4.12	2,191	.02[a]	.04	(0.004-0.09)
Interesting information	3.89 (0.86)	4.31 (0.80)	4.06 (0.82)	3.53	2,189	.03 [a]	.04	(0.002-0.08)
Easy to understand	3.52 (0.82)	3.40 (0.96)	3.44 (0.83)	0.27	2,188	.76	.003	(0-0.02)
Ease of navigation	3.64 (1.11)	4.17 (0.96)	3.74 (1.11)	4.20	2,190	.02 [a]	.04	(0.004-0.09)
Helpful information	3.87 (0.76)	4.33 (0.90)	4.02 (0.91)	4.15	2,192	.02 [a]	.04	(0.004-0.09)
Amount learned	3.29 (0.76)	3.79 (1.02)	3.53 (0.92)	3.86	2,188	.02 [a]	.04	(0.003-0.09)

[a]*P*<.05

Discussion

Principal Findings

In order to address the growing number of people affected by dementia, increased efforts to provide a preventative health strategy are essential [5-7,27-29]. This study aimed to explore participant engagement in targeted dementia risk reduction eHealth interventions, and to determine whether interactive eHealth tools might be more effective at engaging middle-aged members of the public than a static information-only environment. Results indicated that the majority of participants reported a generally positive experience with the eHealth tools and intended to continue using them following the intervention. However, compared to participants who used the mobile phone app (BA group), participants using the information-based website (BHHP group) reported a more positive evaluation across a range of domains.

Use of eHealth Tools

User exposure, in terms of visiting, using, and revisiting, is an important component of examining the impact of eHealth interventions [20]. Self-reported usage of the eHealth tools indicated that BA participants were more likely to use the eHealth tool regularly, for shorter periods of time, as expected for an app (able to be used anywhere) compared to a Web-based tool (primarily available when in front of a computer). Alternately, BHHP and PLUS participants were more likely to use the eHealth tool less frequently but for longer periods of time. These differences in frequency and duration of use between the app and Web-based tools were expected due to the inherent differences in the way the two modalities are used. User tracking confirmed this pattern of frequency and duration of use, while also highlighting the tendency for participants to over-report their use of the eHealth tools.

Most participants indicated that they intended to keep using the eHealth tool following the intervention. These findings suggest that there is community interest in understanding what can be done to reduce dementia risk, and that the resources were perceived to be useful even beyond the scope of the study. It has been proposed that the primary difficulty for eHealth interventions is to engage the community for long enough so that they obtain exposure to at least the most important aspects of the program [30]. Further, previous research has indicated that continued use of eHealth programs over time is more likely to occur when earlier visits result in positive feelings [20]. Results from the present study revealed that most participants used the eHealth tool for long enough to process the information provided, and were engaged enough to use the tools on multiple

occasions, highlighting the potential public health impact of these interventions. However, it is important to note that results are only available for the participants who completed the evaluation. There were quite high rates of drop-out in the present study, and there is no data available for those participants who did not complete the follow-up evaluation. It may be the case that these participants had very different experiences in terms of visiting, using, and revisiting the eHealth tools. Non-completers were more likely to be in full time employment, while completers were more likely to be retired, so time constraints may have contributed to drop-out.

Mode of Delivery

Previous research has established that overall usability and easily accessible information are important aspects of a successful eHealth intervention [31]. In the present study, participants reported an overall positive impression of the three eHealth tools. Each of the eHealth tools were generally reported to be interesting, easy to understand, easy to navigate, as well as providing helpful information, and enabling participants to learn a substantial amount about the topic of dementia risk reduction.

All three groups had similar ratings on ease of understanding the information provided, with mean ratings falling between "just right" and "somewhat simplistic". Further, the only significant difference between the BHHP and the PLUS groups was that participants rated the information-based website significantly easier to navigate than the interactive website. Thus, while it was hypothesized that PLUS participants would provide a more positive evaluation of the interactive tool compared to those who accessed the static information-only website, results indicated that, overall, the two versions of the website were rated equivalently. This is at odds with prior research which has indicated a strong user desire for interactive components of an eHealth intervention [25,31,32] and may indicate shortcomings with the design of the interactive website tools for those participating in this study.

There were, however, a number of significant differences between the BA and BHHP groups, with the BHHP group rating the information-based website more interesting, helpful, and favorable overall, reporting that they learned more, and finding their eHealth tool easier to navigate. While the popularity of using mobile phone apps to deliver health information is growing rapidly [33,34], as yet there is limited evidence as to their effectiveness [35] and the current findings suggest that traditional modes of eHealth delivery may be more appropriate for middle-aged populations. Specifically, as most participants were in their fifties, and downloaded and used a new app rarely, the limitations of BrainyApp may have had more to do with the mode of delivery than the app itself; as participants appeared to have limited experience using apps. In addition, there was no specific instruction provided on how to use the app, or how to make the most of the interactive components (such as the survey, apart from some basic instructions included in the app itself). As a result, participants may have experienced some confusion around how to access the relevant information.

Strengths and Limitations

The evaluation of publicly available dementia risk reduction resources represents a major strength of the present study, as it promotes a greater understanding of the features that contribute to user engagement with these resources. The results of this study have the potential to inform future developments in dementia prevention initiatives for the Australian and international communities.

However, there were a number of methodological limitations to the present study. Firstly, the results may not be generalizable to the Australian population as a whole, as the sample consisted predominantly of older, female, highly educated participants. There were also large drop-out rates, particularly for the BA group. Additionally, there were significant differences in education level and employment status between those who completed the follow-up, and those who dropped out, which may also limit the generalizability of findings. However, participants were randomly allocated into groups in an effort to limit the impact of these issues. Previous research has indicated that people who are highly motivated to live a healthy lifestyle are more likely to use the Internet for health-related information, and that older, highly educated people are more likely to revisit these information sources over time [20,30]. This highlights the importance of targeting interventions such as the ones evaluated here for a broad range of demographic groups. More work is needed to determine how to attract less motivated, younger, and less educated people to use online dementia risk reduction resources.

A further limitation is that apps are designed to be used differently and can offer very different features compared to Web-based tools. As a result, the user experience may not be directly comparable between these two modalities. All groups engaged with their eHealth tool as expected, such that frequency and duration of use differed between modalities. BA participants used the app more frequently but for shorter durations, compared to BHHP and PLUS participants less frequent but longer duration use of the Web-based tools. However, the app and interactive website were designed to provide similar information and resources within the parameters of each modality, while the information-based website was used to compare interactive and static tools. The findings of this study provide important information about user preferences within and across the different modes of delivery of dementia risk reduction information.

There were also a number of technical issues across the eHealth interventions. The user tracking was limited in that it was unable to record BA participants' final session, and was unable to record the duration of the last page visited for BHHP and PLUS participants if they did not log out of the session; thus, the user tracking information is somewhat incomplete. Further, the large drop-out rate for BA participants (following randomization to that group) may have been due in part to the technical requirements for installing the app on their device (participants had to sign up to a third-party app in order to install the research version of BrainyApp, rather than downloading it from the App store). While necessary to facilitate user tracking, the process proved difficult for some participants and the majority of

drop-outs happened at this stage. Some participants reported difficulties with the lack of guidance provided on how to use the app. While this is an inherent feature of apps which are meant to be intuitive, the unfamiliarity with using apps of the demographic group involved in this study may have contributed to the higher drop-out rate in the BA group.

Implications and Future Research

Previous research identified that, while an information-based dementia risk reduction website was reported to be useful and relevant, users wanted more interactive and personalized resources [25]. Research into other eHealth interventions has also reported a user desire for interactivity (eg, physical activity interventions [31]). However, the results of the present study indicate that the information-based website received a more positive evaluation than the two interactive learning environments. Thus, it may be the case that information-based resources are more appropriate for some groups of people than interactive resources. For example, participants in the present study likely volunteered because they had an existing interest in brain health, and thus may have been seeking more detailed information than an app can provide. Interactive resources may be more beneficial to people who have little prior interest or knowledge about brain health and dementia risk reduction, as a means to engage them with the topic.

Nevertheless, the results of the present study provide an important platform from which to improve public health dementia risk reduction resources. Further research is required to determine whether there are specific interactive components that can be used to improve and enhance the way information is provided to the general community, above those gained by providing static information alone. Future research should also determine whether resources such as the ones evaluated here have the potential to improve dementia risk reduction knowledge and motivation, and to change people's behaviors toward a more brain healthy lifestyle.

Conclusions

The results of the present study demonstrated that, overall, participants from each of the three intervention groups reported a generally positive experience with the targeted dementia risk reduction eHealth tools. In particular, participants who used the information-based website reported a more positive evaluation, across a range of domains, than participants who used the mobile phone app. These findings will inform future developments of Alzheimer's Australia's dementia risk reduction resources.

Acknowledgments

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Conflicts of Interest

The authors are employees of Alzheimer's Australia, the trademark and copyright owner of the Your Brain Matters program and website and BrainyApp smartphone application.

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Abbreviations

AUD: Australian dollar
BA: BrainyApp (mobile phone/tablet application) group
BHHP: Brain-Heart Health Program (information-based website) group
PLUS: Brain-Heart Health Plus Program (interactive website) group

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Original Paper

Patient Smartphone Ownership and Interest in Mobile Apps to Monitor Symptoms of Mental Health Conditions: A Survey in Four Geographically Distinct Psychiatric Clinics

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Abstract

Background: Despite growing interest in mobile mental health and utilization of smartphone technology to monitor psychiatric symptoms, there remains a lack of knowledge both regarding patient ownership of smartphones and their interest in using such to monitor their mental health.

Objective: To provide data on psychiatric outpatients' prevalence of smartphone ownership and interest in using their smartphones to run applications to monitor their mental health.

Methods: We surveyed 320 psychiatric outpatients from four clinics around the United States in order to capture a geographically and socioeconomically diverse patient population. These comprised a state clinic in Massachusetts (n=108), a county clinic in California (n=56), a hybrid public and private clinic in Louisiana (n=50), and a private/university clinic in Wisconsin (n=106).

Results: Smartphone ownership and interest in utilizing such to monitor mental health varied by both clinic type and age with overall ownership of 62.5% (200/320), which is slightly higher than the average United States' rate of ownership of 58% in January 2014. Overall patient interest in utilizing smartphones to monitor symptoms was 70.6% (226/320).

Conclusions: These results suggest that psychiatric outpatients are interested in using their smartphones to monitor their mental health and own the smartphones capable of running mental healthcare related mobile applications.

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KEYWORDS

psychiatry; mobile health; smartphone

Introduction

The utility of mobile mental health has become a topic of increasing interest to psychiatric researchers, industry, and the public. Furthermore, the role of smartphones for clinical monitoring and care of psychiatric patients is receiving significant attention. Recent research has investigated the feasibility and potential of smartphone applications in the care

of patients suffering from major depressive disorder [1], bipolar disorder [2], anxiety disorders [3], substance abuse disorders, [4,5] and psychotic disorders [6,7]. However, one fundamental question remains largely unanswered despite such research advances: do patients with psychiatric conditions actually own smartphones and, if so, are they interested in using their personal devices to run clinical monitoring or treatment applications?

The only previous study addressing this question suggested that psychiatric outpatients at a university outpatient clinic in Boston owned smartphones at a rate of 72% [8], greater than the current United States average ownership rate of 58% in January 2014 [9]. In this expanded study, we sought to perform the same survey and protocol as in the Boston-based study in four new psychiatric clinics located across the country in each of the four distinct US census districts.

We aimed to capture opinions from a broad range of psychiatric patients by studying different clinic settings. Patients with serious and chronic mental illness are an important population to include, given the unique challenges in caring for this population. Patients with private insurance may also be very ill, but have different resources available to them and thus represent another important population to study. Finally, those patients with more variable resources are also important to consider, given that many psychiatric patients may not qualify for state level of care but also not have private insurance. County clinics often serve these patients and feature sliding scale payments to meet patients' ability to pay. Clinic type has also been used as a proxy for patient socioeconomic status [10]; thus, including multiple clinic sites helps ensure that a diverse population is captured.

We hypothesized that those patients with serious and chronic mental illness would have a lower prevalence of ownership than those patients in hybrid or county clinics, and that patients at a private insurance clinic would have the highest prevalence of ownership. Based on prior research, we expected that all patient groups would demonstrate high levels of interest in running smartphone applications to monitor their mental health on their personal devices. Finally, we hypothesized that younger patients would have both higher ownership and interest in utilizing their smartphones for monitoring than older patients.

Methods

A total of four study sites conducted the survey. The first study site included a state-run outpatient psychiatric clinic with a partial hospital program, and a 40-bed transitional residential program for those with largely serious and chronic mental illness in Boston, Massachusetts. The second site was a system of two county-run community outpatient psychiatry clinics that serves largely independently functioning patients in Sacramento, California. The third site was a hybrid clinic that treats a majority of patients with public insurance but also sees roughly one third of patients with private insurance in New Orleans, Louisiana. The fourth site was a university outpatient psychiatry clinic that serves a largely privately insured population in Madison, Wisconsin.

Identical paper-and-pencil surveys assessing patients' smartphone ownership and interest in using personal smartphones phones to monitor mental health were distributed to each of the four study clinics. A copy of the survey questions are displayed in Textbox 1. The surveys were made available to all patients in clinic who voluntarily filled them out before or during appointments, and submitted completed forms to the clinic. Surveys, along with handouts explaining the purpose, mental health focus, and voluntary nature of the study, were offered and provided to patients by clinic staff at all sites while patients were waiting for appointments. All surveys were completed in the clinic setting. All clinic patients were eligible. The survey was made available for 4 weeks at each study site, with all sites completing the data collection in either July or August 2014.

Patients received no compensation or incentives to complete surveys, and study personnel collected completed surveys at least weekly. Results were entered into password-protected spreadsheet software, and all analyses and graphs were completed in the R programming language. We used Pearson chi-squared goodness of fit tests to compare distributions of groups. The Institutional Review Boards at each of the respective study sites approved the study, and a waiver of informed consent was obtained for each site.

Textbox 1. Questions from the paper survey used for the study.

1) Do you currently have daily access to the Internet? Yes or No

2) Do you currently own a mobile phone? Yes or No

3) Can your phone receive and send text messages? Yes or No

4) Can your phone browse the Internet? Yes or No

5) Can your phone download applications or "apps"? Yes or No

6) Does your phone have GPS built in? Yes or No

7) Do you own smartphone? Yes or No

8) What is the brand and type of your mobile phone (eg Apple iPhone).

9) How many applications or "apps" do you have on your phone?

10) How many applications or "apps" do you put on your phone each month?

11) How many health care related applications or "apps" to you have on your phone?

12) In the last six months, have you used your smartphone to access general health care information? Yes or No

13) In the last six months, have you used your phone to access your personal health care information such as for example test results or to schedule appointments? Yes or No

14) Would you want to be able to access general information related to your health via your smartphone? Yes or No

15) Would you want to receive text messages on your phone related to your health from your doctor's office? Yes or No

16) Would you want to use your phone to help track your medical condition via an application or "app" on your smartphone? Yes or No

17) Would you download an application or "app" to your phone to help monitor your health condition? Yes or No

18) Would you be willing to use an application or "app" on your phone on a daily basis to help monitor your health condition? Yes or No

Results

A total of 320 patients completed the survey at all study sites. This comprised of 106 (33.1%; 50/106, 47.2% female) patients at the state clinic in Boston, 50 (15.6%; 28/50, 56% female) at the hybrid clinic in New Orleans, 56 (18%; 36/56, 64% female) at the county clinics in Sacramento, and 108 (33.8%; 51/108, 47.2% female) at the university clinic in Madison. In total, 52% of total respondents were female. The mean age of respondents was 43.7 years. The mean age at the state clinic in Boston was 43.9 years, 39.6 years at the Sacramento county clinic, 44.7 years at the New Orleans hybrid clinic, and 36.2 years at the private clinic in Madison.

As the survey was not monitored, it was difficult to know exactly what percentage of patients chose to complete it. Based on estimates of patient volume, we believe that roughly 10% of patients at each clinic site took the survey. Although we were not able to physically examine patients' phones, of the 184 patients who answered question 7—indicating that they owned a smartphone—all 184 also responded affirmatively to questions 3 through 6, indicating that features of their phones included the ability to send text messages, browse the Internet, download apps, and track location using GPS.

The total average for smartphone ownership, question 7, was 62.5% (200/320) for all study sites. The overall willingness to use a smartphone app to monitor their mental health was 70.6% (question 16; 226/320).

We analyzed results for each of the 4 sites. At the state-run clinic, 38.7% (41/106) of patients reported owning a smartphone and 57.5% (61/106) were willing to use a smartphone to monitor their mental health. At the hybrid clinic, the smartphone ownership was 66% (33/50) and willingness to use was 70% (35/50). At the county clinic system, smartphone ownership was 79% (43/56) and willingness to use was 71% (40/56). Finally, ownership at the university clinic was 76.9% (83/108), and willingness to use was 88.0% (95/108). Details of the results by study site are displayed in Figure 1.

We also analyzed results by age groupings in a similar fashion to prior studies [8]. To further study age effects, we categorized patients into age buckets of those less than 30 (n=85), between age 30 and 45 (n=120), between age 45 and 60 (n=72), and those older than 60 (n=31). Twelve patients did not include their age and were not included in this analysis. Of note, there was a significant difference between these age groupings, with a *P* value of .002 (χ^2_9=26.09).

For patients under thirty years of age, percent ownership was 78% (66/85) and willingness to use to monitor mental health was 89% (76/85). For patients between ages 30 and 45, ownership was 68.3% (82/120) and willingness to use was 75.0% (90/120). For patients between ages 45 and 60, ownership was 40% (29/72) and willing to use was 54% (39/72). Finally, for patients over 60, ownership was 39% (12/31) and interest was 51% (16/31). Details of results by age are shown in Figure 2. Responses to other survey questions, stratified by age, are shown in Table 1.

Table 1. Response to other survey questions, stratified by age.

Question	Under 30 years (n=85) n (%)	31-45 years (n=120) n (%)	46-60 years (n=72) n (%)	Over 60 years (n=31) n (%)	Average Response (n=308) n (%)
Q1: Daily Access to Internet?	85 (88.2)	96 (80.0)	53 (73.6)	22 (71.0)	246 (79.9)
Q2: Owning any Mobile Phone? (not necessarily a Smartphone)	76 (89.4)	109 (90.8)	58 (80.6)	23 (74.2)	266 (86.4)
Q12: Used a Smartphone in Last Six Months to Access General Health Information?	57 (67.1)	68 (56.7)	18 (25.0)	9 (29.0)	152 (49.4)
Q13: Used a Smartphone in Last Six Months to Access Personal Health Information?	39 (45.9)	33 (27.5)	12 (16.7)	5 (16.1)	89 (28.9)
Q15: Want to Receive Text Messages Related to Your Health?	67 (78.8)	85 (70.8)	39 (54.2)	18 (58.1)	209 (67.9)
Q18: Would you use an App to Monitor Your Health on a Daily Basis?	53 (62.4)	73 (60.8)	32 (44.4)	16 (51.6)	174 (56.5)

Figure 1. Percent ownership of smartphones (question 7) and interest in using a smartphone to monitor mental health conditions (question 16) by clinic.

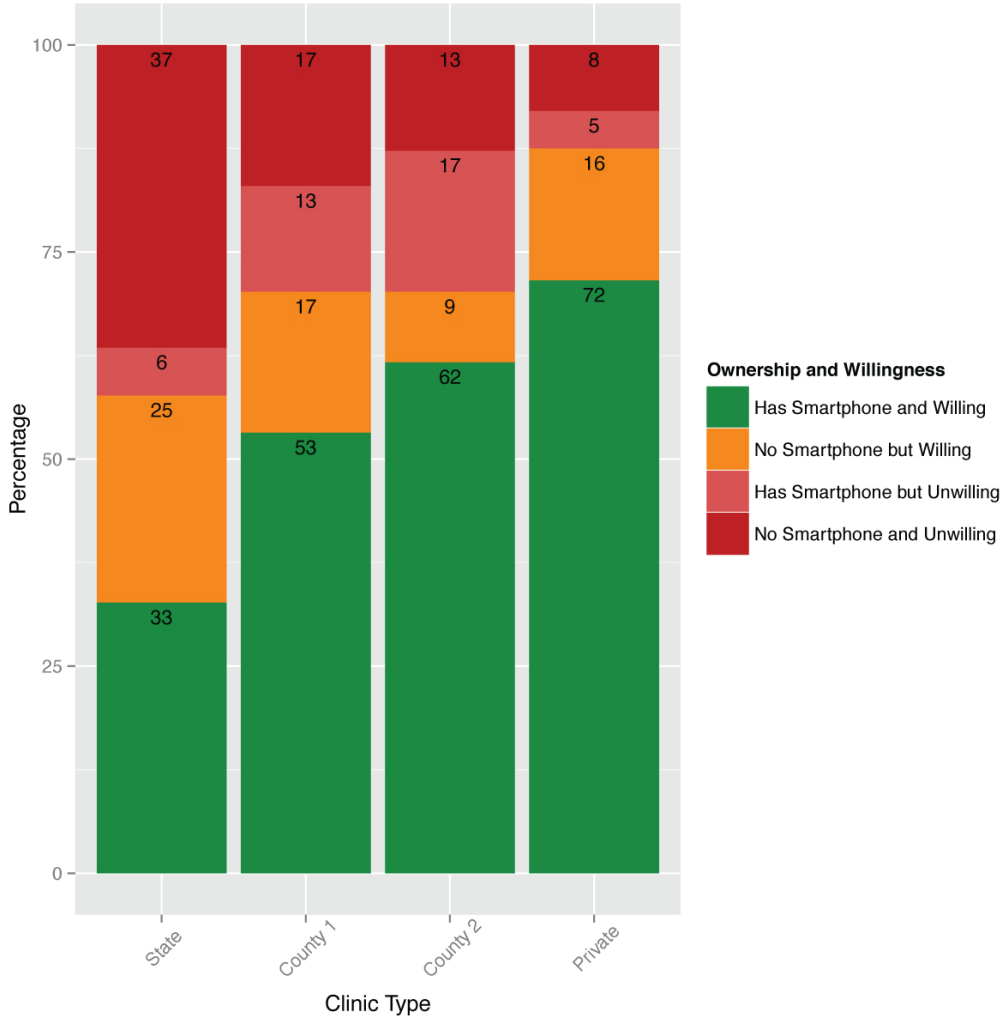
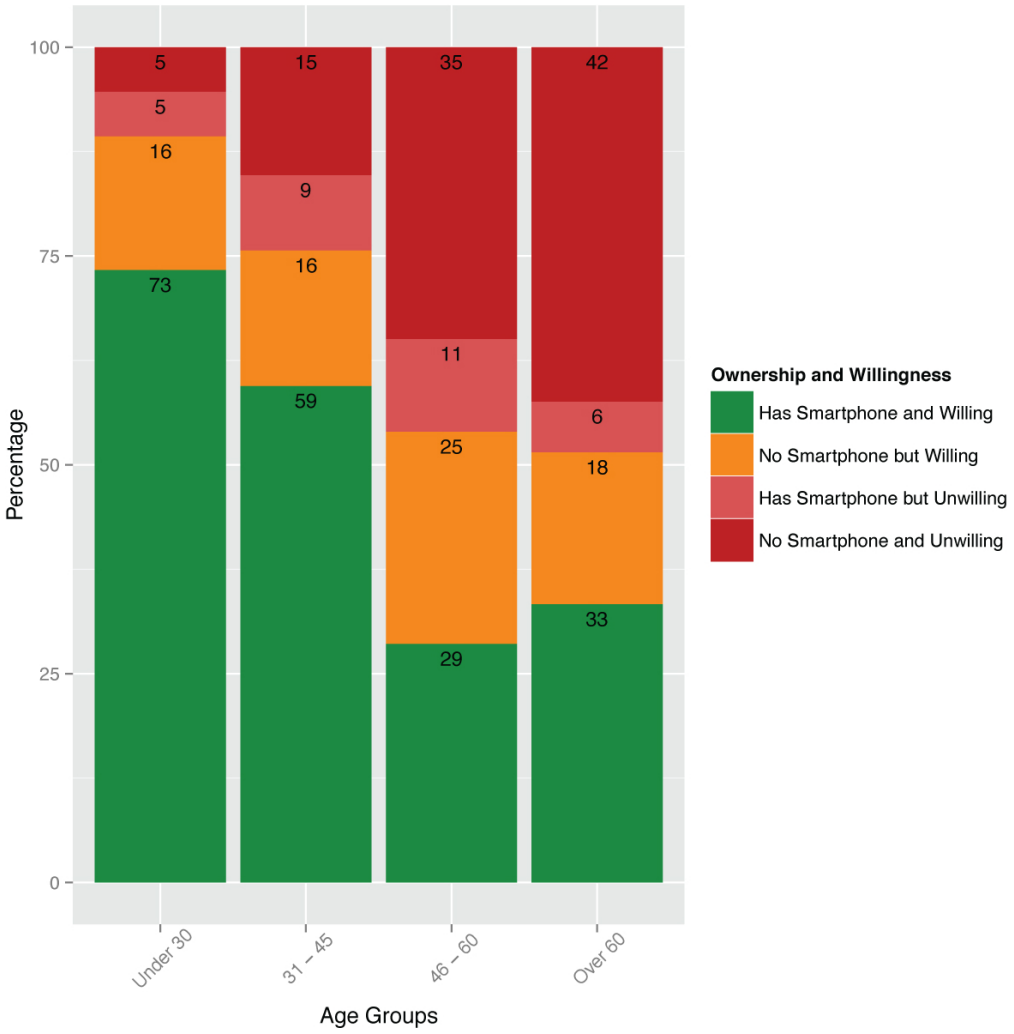


Figure 2. Percent ownership of smartphones (question 7) and interest in using a smartphone to monitor mental health conditions (question 16) by age.



Discussion

Principal Findings

Our results confirmed the hypothesis that psychiatric outpatients' ownership and interest in utilizing smartphones varied by clinic setting and age. Across all sites, average smartphone ownership was 62.5%, which is similar to the United States national average of 58% as of January 2014 [9]. Our results also suggest that, overall, psychiatric outpatients are favorable to the idea of using their own smartphones to run applications to monitor their mental health, with 70.6% favoring this assessment modality. Even in the state-run clinic, which had the lowest rates of both patient ownership and interest, the results were positive: 39% reported owning a smartphone, and 58% expressed a willingness to use a smartphone to monitor their condition. However, contrary to our first hypothesis, patients in the county clinic system, and not the private clinic, had the highest average rate of smartphone ownership, although the results only differed by 1% between these two clinics.

Such results are important as they suggest that implementing smartphone application based clinical monitoring and treatment protocols may involve fewer patient obstacles and less resistance than commonly thought. The results are also important as they underscore the potential to implement digital interventions or monitoring at a lower implementation cost, given that patients are willing to use their own personal smartphones. Mirroring national trends for smartphone ownership, our data also suggests that the youngest generation, represented by those less than 30 years of age in our study, had the highest rates of ownership and willingness to engage in this modality.

Our results also suggest areas of opportunity and growth for mobile mental health. As smartphones become cheaper in price and progress towards ubiquity, it is likely that those patients in our survey who indicated that they do not currently own a smartphone but would be willing to use such to monitor their health will soon have that opportunity. In our study, the number of patients who owned a smartphone but were unwilling to use this modality to monitor their health was relatively small. This suggests that while some patients will remain resistant to mobile mental health technologies, it is likely that overall patient interest and engagement in such will continue to grow.

Taken together, these results suggest that smartphone monitoring and intervention studies targeting younger patients with private insurance may be easier to implement than in other patient environments, such as with elderly patients in state-based clinics. Thus, when interpreting the results of feasibility studies for mobile mental health, it may be important to understand that

both age and socioeconomic demographics are likely independent variables that must also be taken into account.

Looking at patient connectivity beyond smartphones, our data suggests that, on average, 80% of patients have access to the Internet and that 86% own a mobile phone. Thus, to reach those patients currently without smartphones or Internet access, text messaging apps remain a viable solution. Interestingly, while 72% of patients in our study were willing to use an app to monitor their mental health, only 68% wanted to receive text messages related to their health. While we did not collect data on why patients may prefer apps to text messaging, the dynamic interactivity and visual format of apps may be easier to use and respond to than text messaging, comprised of static text with strict character limits.

Comparison With Other Studies

Our results are in line with and supported by previous research. A similar study of psychiatric outpatients at a different university clinic that accepts largely private insurance reported 72% smartphone ownership and 68% willingness to use such to monitor their mental health [8], while in this study, the university clinic patients had 77% ownership and 88% willingness to use such apps. A study of schizophrenia patients with chronic illness noted that 28% owned a smartphone [7], which is slightly lower than our rate of 39% ownership in the state clinic that treats largely those with serious mental illness. A recent study of 189 psychiatric outpatients in an inner-city community psychiatric clinic reported that 85.7% of patients in that study owned a mobile phone [11]; similarly, in our study, the average rate of mobile phone ownership was 86%.

Limitations

Our study has several limitations. First, our results are based on survey data and responses about using an app are hypothetical and not verified in practice. While 70.6% of patients reported interest in using an app to monitor their mental health, only 49% indicated they had used a smartphone to look up general health information in the six months preceding the survey, and only 29% had used such to look up personal health information. Second, we did not collect data on those who chose not to partake in the survey, and this may have skewed our results to be more positive. Third, we did not collect data related to individual diagnoses, so we are not able to further analyze and compare between patients with specific disorders such as, for example, patients with depression versus anxiety versus bipolar disorder. Fourth, we did not control for potential differences in smartphone ownership rates in each community where the study clinics were located.

Conclusions

In conclusion, our results suggest that psychiatric outpatients may own smartphones at near the national average and that overall patient interest in using smartphones to monitor their mental health is high. Our results varied based on age and clinic type, suggesting that both are important factors to consider when designing a study or implementing a treatment intervention. Many psychiatric outpatients have smartphones and are interested in using them regarding their mental health. The next challenge is whether psychiatry can meet that interest with clinically valid and effective apps.

Conflicts of Interest

Steven Chan writes for iMedicalApps, evaluates news posts for Doximity, and evaluates technologies at Kaiser Innovation, but receives no financial compensation. None of the remaining authors declare any conflict of interest related to this work.

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Review

Assessing the Evidence for e-Resources for Mental Health Self-Management: A Systematic Literature Review

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Abstract

Background: In a climate which recognizes mental health as a key health improvement target, but where mental health services are increasingly over-stretched, self-management e-resources can play a potentially important role in helping to ensure people get the care and support they need. They have the potential to enable individuals to learn more about, and to exercise active involvement in, their care, and thus we see a growing interest in this area for both research and practice. However, for e-resources to become important adjuncts to clinical care, it is necessary to understand if and how they impact on patients and care outcomes.

Objective: The objective of this study was to review systematically the research evidence for theory-driven and evidence-based mental health self-management e-resources; and make recommendations about strengthening the future evidence base.

Methods: A comprehensive literature search in MEDLINE, EMBASE, AMED, PsycINFO, Scopus, and Cochrane Library was conducted. No limits to study design were applied. We did not restrict the types of Web-based technologies included, such as websites and mobile applications, so long as they met the study inclusion criteria. A narrative synthesis of data was performed to elaborate both the development and effectiveness of online resources.

Results: In total, 2969 abstracts were identified. Of those, 8 papers met the inclusion criteria. Only one randomized controlled trial was identified. The e-resources were aimed at self-management of bipolar disorder, depression, or general mental health problems. Some of the e-resources were intended to be used as prevention aids, whereas others were recovery orientated.

Conclusions: Mental health self-management e-resources have the potential to be widely effective, but our review shows it is early days in terms of development of the evidence base for them. To build robust evidence, clear guidelines are needed on the development and reporting of e-resources, so that both developers and researchers maximize the potential of a new, but rapidly evolving area.

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KEYWORDS

self-management; mental health; depression; bipolar disorder; eHealth; e-resources; digital technology; systematic review

Introduction

Digital Technology and Self-Management of Mental Health

Digital technology has become part of nearly everyone's lives, with 74% of households having access to the Internet, and the average user spending about 14 hours per week on it [1]. Health services are adapting to new initiatives and are progressively using information and communication technologies (ICT) in health care [2]. The Internet can be used as a cost-effective method for providing large-scale delivery of resources and interventions with the aim of enabling people to manage their

own health better. Thus, there is a clear opportunity of using ICTs to help address global resource challenges, such as costs of service delivery, workforce issues, access to services, and continuity of care [2,3].

E-mental health refers to the use of ICTs for supporting and improving mental health, via online resources, social media, and smartphone applications. (In this paper, we use the term "e-resources" as an umbrella term covering the variety of media available to support self-management of mental health problems). There is a great potential for e-mental health to enable a move toward a social model of health by empowering patients to control, effectively manage, and ultimately exercise greater choice in matters related to their health and illness. This is in line with the UK Department of Health's "No Health Without Mental Health" strategy [4] that sets out the need for a new relationship between mental health services and service users. In particular, the report stresses that service users should be offered an active role in shaping the support that is available to them.

E-mental health is a rapidly evolving area and has the potential to be delivered to large numbers of people worldwide. In addition, research shows that individuals prefer Internet-enabled health care for mental health problems [5,6]. Thus, self-management approaches, and interventions could find, a useful platform in eHealth, utilizing e-resources to support self-management of mental health and well-being.

There is no global consensus on what self-management is. Interventions, and especially e-resources, tend to use the term "self-management" rather vaguely, often confusing it with "self-help", and only a few provide descriptions of what self-management actually means. The World Health Organization (WHO) describes self-management as "putting patients or service users in direct control of managing their conditions by enabling them to cope in one or more of the following areas; problem solving, goal setting, identifying triggers, and indicators of deteriorating health; and responding to these themselves before relying on clinician-led intervention" [7]. We have used the WHO definition as the basis for this review. On the other hand, self-help can be defined as a standardized psychological treatment that a participant can work through independently [8]. Self-management is an activity that helps people identify the need for clinical intervention and/or self-help in the first place, and which then guides them through a process of self-led management intervention, which may or may not involve the use of a specific self-help e-tool. Even though there are a burgeoning number of self-help e-resources [9], growth in self-management e-resources for common mental health problems does not appear to have happened at the same pace. In addition, even though some self-help e-tools may also include self-management components, most often than not these components are incorporated in the self-help intervention. And as we see a growing need and demand for self-management support across the range of mental health problems experienced both by people already receiving care services, and among those who are not, self-management tools deserve more individual attention, with the evidence base for self-management e-tools needing to be established independently and disentangled from the evidence base for self-help e-tools. For this reason, this review focuses on the evidence of e-resources for the self-management of mental health.

Aim of the Study

Self-management e-resources have been used successfully in medical conditions. There are some emerging new tools in the area of mental health, however the evidence base is unclear. Specifically, little is known about the quality of the processes used in developing the e-resources or about the scientific evaluation of their effectiveness. This review aims to address this. Therefore, the aim of this study is to review the available literature systematically to identify theory-driven and evidence-based mental health and/or well-being self-management e-resources. Specifically, this paper will: (1) describe the evidence-based self-management e-resources, (2) describe the available published evidence about the e-resources' development and effectiveness, (3) assess their methodological quality, and (4) recommend future directions for strengthening the evidence base underpinning self-management e-resources in mental health.

Methods

Search Strategy

We searched 6 bibliographic databases for relevant articles published between January 1990 and November 2013: (1) MEDLINE, (2) EMBASE, (3) AMED, (4) PsycINFO, (5) Scopus, and (6) Cochrane Library. The interest in and development of e-resources is a recent phenomenon and searching papers from 1990 onward guarantees inclusion of all possible e-resources (for example, the launch date of the first mobile application, app, was 2008). Terms (subject headings and MeSH terms) relevant to e-resources (smartphone, digital technology, telehealth, app, mobile phone, Internet, eHealth, mHealth, e-source, e-tool, online, Web, and tablet), self-management (self-management and self care), and mental health (mental illness, mental health, mental disorders, anxiety, depression, mood, well-being, personal safety, and risk) were used to search the electronic databases. The terms were adapted for the individual databases as needed. Limits to "humans" and "English" were applied. Further limits were applied to exclude papers with focus on physical illness, physical activity, weight management, and phobias (eg, spider phobia). Phobias were excluded, as there are a vast number of self-management e-resources, and so this should be examined separately. Study authors were contacted if further information was required. Hand searching of references in the included papers was also performed.

Selection Process

Paper titles and abstracts were screened for eligibility. There were two reviewers that independently screened the first 30.1% of all eligible abstracts (50/166). There was 90% initial agreement, with disagreements resolved by consensus. Both reviewers further independently screened full text papers, reaching 83% agreement. Again, disagreements were resolved by consensus.

We included papers about e-resources aimed at users concerned with their mental health or well-being. We applied strict

inclusion criteria in order to investigate self-management e-resources only. Self-help and/or therapeutic e-resources were excluded. Tools also had to be interactive for inclusion, so that e-resources that contained static information or which were simply educational were also excluded. E-resources could have the form of Web-based technologies such as websites, decision support systems, or mobile applications. There was no restriction on end user age. The focus of this review forms a rather new area of research and development. Developing and testing the effectiveness of an intervention is a lengthy process and needs to go through a number of steps before a definitive trial is possible. For this reason, we did not exclude papers based on study design (papers presenting outcome data, description of e-resources and/or e-resources concepts were eligible for inclusion).

Data Extraction and Synthesis

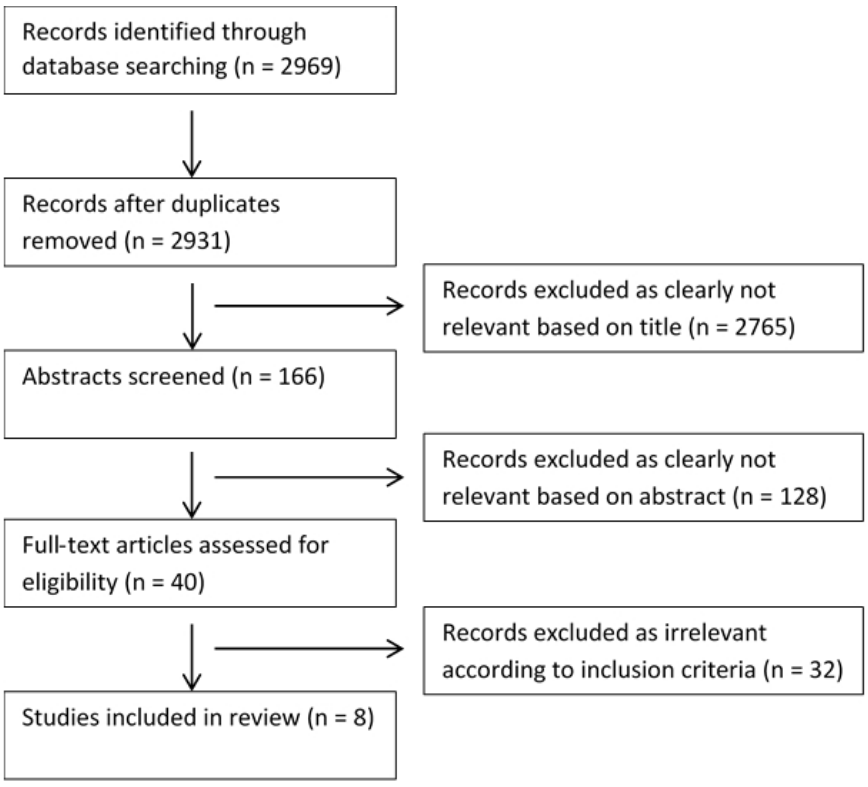
The first reviewer (EK) extracted data from relevant publications using a Data Extraction Form specifically developed for this systematic review and according to the Centre for Reviews and Dissemination guidance [10]. A Quality Assessment Checklist was also developed taking into consideration publication-specific contextual, pragmatic, and methodological issues [10]. The checklist assessed both the studies and e-resources reported according to 13 criteria grouped as; clear description of purpose, appropriateness of study design, main methods, e-tool development process, and theoretical frameworks used. No publications were excluded based on quality. Both reviewers independently tested both forms. Due to the variability in study designs, a narrative synthesis of data was conducted.

Results

Study Selection

A total of 2969 abstracts were identified from the electronic searches. There were thirty-eight of these that were removed after accounting for duplicates, leaving 2931 abstracts for further consideration. Screening the titles excluded a further 2765 records. The abstract screening process reduced the potential studies to 38. A particular abstract was based on a conference presentation; the full study was later published and picked up by our search, so the conference abstract was removed. Another abstract was excluded, as the full paper was not available (the authors of the paper were contacted, however, a copy was not sent for consideration in the review). There were four additional papers that were obtained by contacting authors of conference abstracts. In total, 40 full text papers were potentially eligible for inclusion. Of these, 32 papers were excluded, as they did not meet our inclusion criteria, identifying 8 papers suitable for the review (a sample list of excluded studies is provided, see Multimedia Appendix 1). A further screening for potentially relevant references in included studies did not reveal any additional studies. Figure 1 shows the screening process.

Figure 1. Flow diagram illustrating the study selection process.



Characteristics of Included Studies and e-Resources

The 8 papers identified described 2 mobile apps (Mobiletype and PHIT for Duty) [11,12], 5 interactive websites (eCHAT; SUMMIT; MyRecoveryPlan; Buddy; and Living with Bipolar) [13-17], and 1 personal digital assistant (PDA) programme (PRISM) [18]. Of the 8 included papers, successful management of bipolar disorder was described as the primary focus for 3 of the e-resources included in the review (PRISM, MyRecoveryPlan, and Living with Bipolar), depression

management was the primary focus for 2 e-resources (Mobiletype and SUMMIT), and 3 papers described e-resources addressing multiple issues such as stress, anger, anxiety, and depression (PHIT for Duty), unhealthy behaviors and negative mood states (eCHAT), and general mental health problems (Buddy). In each case, the aim of the e-resource is to support the end user in achieving a reduction in the conditions and negative behaviors measured. Table 1 provides an overview of the included papers (see Multimedia Appendix 2 for a longer list).

The included papers describe e-resources addressing the needs of varied end-user populations at different stages along the care pathway; with variable degrees of integration with existing clinical service provision; and representing different degrees of progress toward generating evidence to support their efficacy and effectiveness. An e-resource targeted adolescents (Mobiletype), and 4 targeted adults (eCHAT, PHIT for Duty, SUMMIT, and Living with Bipolar). An e-resource was designed for military personnel (PHIT for Duty), 2 were designed for primary care populations (eCHAT and Mobiletype), and 2 were designed specifically for mental health service users (SUMMIT and Living with Bipolar). There were three e-resources that were intended to be used at early stages of symptoms, as prevention aids (Mobiletype, PHIT for Duty, and eCHAT), whereas, three others were recovery-orientated (SUMMIT, Living with Bipolar, and MyRecoveryPlan). There were four self-management interventions that were designed to be delivered as a stand-alone e-resource (eCHAT, Mobiletype, PHIT for Duty, and Living with Bipolar), 2 were designed to be used in conjunction with online contact either with clinicians (SUMMIT) or peer specialists (MyRecoveryPlan), 1 was designed to be accompanied by text messages (Buddy), and another one was designed as a companion to clinic-based sessions (PRISM). In terms of evidence of efficacy and effectiveness, two papers provided a general e-resource description (eCHAT and PHIT for Duty), 1 paper used mixed-methods (Buddy), and another paper described a pilot study (MyRecoveryPlan). A paper described a randomized controlled trial (RCT) protocol (Living with Bipolar), while 2 papers provided RCTs design descriptions (PRISM and SUMMIT). Only 1 paper presented a full RCT (Mobiletype).

Table 1. Included studies and e-resources characteristics (abridged version).

References; E-resource name	Study design	Primary outcome measures	Delivery type
Depp 2010 [18], *PRISM*	RCT (study design description)	Bipolar disorder	PDA + clinic-based sessions
Goodyear-Smith 2013 [13], *eCHAT*	General e-resource description	Unhealthy behaviors and negative mood states	Website
Kauer 2012 [11], *Mobiletype*	RCT	Depression	Mobile app
Kizakevich 2012 [12], *PHIT for Duty*	General e-resource description	Stress, depression, anger, anxiety, alcohol use, sleep quality	Mobile app
Kordy 2013 [14], *SUMMIT*	RCT (study design description)	Depression	Website; website + online chat
Simon 2011 [15], *MyRecoveryPlan*	Pilot study	Bipolar disorder	Website; website + online coaching
Treanor 2012 [16], *Buddy*	Mixed-methods	Mental health problems	Website + text messages
Todd 2012 [17], *Living with Bipolar*	RCT (protocol)	Bipolar disorder	Website

Quality Assessment

The quality of the papers varied (see Multimedia Appendix 2). There were two papers providing only a description of e-resources that achieved a relatively high quality assessment score in the range of 4-6 out of a total possible score of 6, with a mean of 5, and standard deviation of 1.41. The 6 papers describing both evaluation studies and the prior development of e-resources achieved scores ranging from 1-13 out of a total possible score of 13, with mean of 7.7, and standard deviation of 4.55. The majority of the papers lacked information about the development process and theoretical underpinnings used to support the design of their e-resources [11,12,14-16,18]. Some papers did not provide sufficient information on how the e-resources can be accessed by users [12,14,16,18]. Finally, a few papers did not include a description of the e-resource features and components [14,16,18].

Given the lack of evidence about the efficacy and effectiveness of the mental health self-management e-resources exposed by this review, we present available evidence about the reported e-resources development processes, focussing on a number of key topics: (1) the theoretical underpinnings of the e-resources, (2) service user involvement in the development process, and (3) evaluation of acceptability and usability among the target end-user population.

e-Resources Development Process

There were five of the publications that presented a theoretically driven approach to the development process, drawing on diverse

theories related to clinical practice and work organization, education, health behavior change, and patient activation. Specifically, eCHAT builds on the self-efficacy theory of behavior change [19]. Whereas, PHIT's approach is similar to the "subjective, objective, assessment, and plan" notes workflow model that is often used in primary care settings [20]. Living with Bipolar uses evidence-based techniques for managing mood imbalance. Theoretically, it draws on the cognitive behavioral model of mood experience [21], but also on the recovery model [22]. PRISM incorporates experience sampling [23], with aspects of an evidence-based brief psycho-educational intervention for bipolar disorder [24]. Finally, Mobiletype was developed based on the concept that self-monitoring can lead to a positive change in behavior [25-27]. Mobiletype was based on emotional self-awareness (ESA), which is hypothesized to predict depressive symptomatology [28-30].

Most of the publications did not present information on service user involvement during the development stage. Only two papers presented clear evidence of the design of the e-resources being informed by a service user perspective; those describing MyRecoveryPlan and Living with Bipolar. Service users had input into designing the content of the interventions and the Web-based formats. Early acceptability and usability testing was sometimes presented in the included publications. Papers describing both Living with Bipolar and PRISM reported previously conducted pilot studies during the development process. The PHIT paper reported that this resource was being evaluated in usability and other validation studies at the time of the review. Mobiletype's acceptability and usability evaluation has already been published [31], and so have assessments of eCHAT [32,33].

Use of e-Resources for Self-Management

Before going on to consider the limited available results about the efficacy and effectiveness of e-resources for mental health self-management, we present a description of the available information on the e-resources. There was marked variability in the types of content, the amount and type of user input, and method of use of the e-resources. The description of both the publications and the e-resources was also varied with respect to the details provided. To illustrate these points, we present information from the reviewed papers about the e-resources, grouped according to the mental health problems they address.

Self-Management for Bipolar Disorder

The use of PRISM requires collaboration between users and clinicians in identifying personal mental health symptoms, illness triggers, and adaptive responses. PRISM is then personalized to prompt engagement in self-management based on real-time data. Users respond to a mood chart, and reported exacerbation of symptoms triggers the preselected self-management strategy.

Living with Bipolar is aimed at increasing access to psychological support. Users may access worksheets; record their thoughts and any symptoms; schedule activities; and create staying well plans. Living with Bipolar is expected to support users to learn about their condition, how to manage it, and increase their self-esteem. An online forum for peer support is also available.

MyRecoveryPlan may be used as a stand-alone e-tool or with the addition of online peer coaching (both in real-time and not). The e-tool uses a number of interactive sections for self-monitoring and self-management of both illness and treatment triggers. Its educational and recovery plan modules comprise of information, slide shows, and personal videos, whereas the self-monitoring modules comprise of customizable tools for tracking wellness and/or warning signs. Finally, social networking may be accessed via discussion boards, chat rooms, and peer-to-peer messaging.

Self-Management for Depression

SUMMIT (inclusive of access to an Internet forum for peer-support) may be used as a stand-alone tool, or in combination with contact with a clinician in an online chat environment and individualized crisis management when the monitoring process signals a crisis. SUMMIT is intended for use for patients who had been treated for (at least) their third depressive episode. The primary aim of the e-resource is the promotion of self-management skills by providing continuous monitoring and supportive feedback, and allowing early detection of critical developments, as well as timely provision of clinical support.

With Mobiletype, self-monitoring data may be uploaded to general practitioners and used to guide further high-intensity interventions if needed.

Self-Management for Mental Health in General

PHIT for Duty is aimed at those exposed to psychological trauma and showing symptoms of distress, but with subclinical findings. The e-resource is designed as a prevention aid to psychological health problems through self-monitoring and self-assessing unhealthy behaviors and negative mood states. This is the only tool in this review that builds in physiological and behavioral sensors (eg, for assessing arousal, stress reactivity, and sleep quality). It also incorporates an intelligent advisor that analyses assessments and recommends self-help interventions.

eCHAT is an e-tool designed for use as an early detection and management for lifestyle and mental health issues. It claims to focus on the whole person rather than the disease. It allows the identification of unhealthy behaviors and negative mood states so that appropriate help may be discussed with primary care clinicians. Health care professionals are able to access users' assessment results with the aim that users play a more active role in decision-making and engagement in self-management. eCHAT may be accessed as part of a number of possible interventions, using a stepped care model.

Finally, Buddy uses a text service for Internet mood monitoring. This allows users to be able to track their moods, thoughts, and feelings. The e-tool is designed with the aim that self-reflection can help users understand the relationship between their mental health state and their daily actions. Between clinical sessions, users receive daily text messages that prompt them to record their activities and feelings. The Treanor et al [16] study does

not specify if clinicians can access users' results, or how structured the user input may be.

Impact of e-Resources on Mental Health Self-Management

The review identified only one completed RCT. Kauer et al [11] assessed the effectiveness of Mobiletype after 2 to 4 weeks of usage. Both intervention and control groups used Mobiletype; the intervention group used an extended version of Mobiletype with additional modules on ESA, whereas the attention comparison group used an abbreviated version of the e-resource without ESA modules. The study found an indirect effect of the intervention on depressive symptoms via the mediator ESA (beta = -.610, 95% CI -5.596 to -0.003).

Discussion

Summary of Results

The papers included in this systematic review varied in design and purpose, ranging from descriptions of the e-resource concept and development process, through early evaluation of acceptability and usability of e-resources, to operationalized RCT protocols, and one full RCT testing the efficacy of an e-resource. The available e-resources have mixed mental health foci, with some targeting specific conditions such as bipolar disorder, while others were targeting depression, and others more general mental health issues, such as anxiety, anger, etc. Due to the limited availability of RCTs, an outcome assessment was not possible. Instead, this systematic review serves as a mapping review, presenting the available evidence about e-resources supporting self-management of mental health issues. In general, the papers lacked sufficient description of their e-resources, notably descriptions of the development process and of the built-in modules comprising the self-management intervention. The theoretical underpinnings for the approaches used were also not always clear.

Efficacy and Effectiveness of e-Resources

The review has pointed that while e-resources addressing self-help in mental health show promising results [9], there is a dearth of studies clearly describing theoretically driven and evidence-based e-resources in mental health self-management. While new e-resources emerge daily, the evidence base supporting their use remains in its infancy. The current review found only one completed RCT [11], with a further three RCT protocols/study plan descriptions [14,17,18]. Systematic, evidence-based reporting on the development of e-resources for mental health self-management was also found to be lacking. The availability of numerous e-resources that can easily be accessed by the public without evidence of their effectiveness or of any possible harm is a worry. This is a concern across all e-health areas [34], and it necessitates the development of quality control guidelines [35].

In the absence of widely accepted guidelines for the development and evaluation of e-resources for mental health, it is advisable that the general guidelines recommended by the Medical Research Council (MRC) for complex interventions [36] are followed. There is a recent movement toward establishing guidelines for Internet intervention research that builds on the MRC's report, but with greater relevance to the field of interest, see [37]. Both guidelines highlight the importance of testing the feasibility of interventions prior to testing their effectiveness. Testing e-resources' usability and acceptability is especially important, as there are obvious concerns that users rarely adhere to using an e-resource for longer that just a couple of times. Qualitative research has a place in this stage so that users' experiences in using the e-resources are explored with particular emphasis on identifying features that may or may not work for the targeted populations. Only one of the studies [16] included in this review used qualitative interviews in a mixed-methods approach, however, it is unclear at which stage of the development or evaluation process of the e-resource the study was placed, or what the study's aims were.

Strengths and Limitations of the Review

To our knowledge, this is the first systematic review of e-resources aimed at mental health self-management. The review presents a clear picture of the available evidence-based e-resources and highlights the need for more rigorous description and evaluation of them. Although all well-defined self-management e-resources were identified, some self-help e-resources may also incorporate some self-management components, and these would not have been identified by the review unless the self-management component was described in the study as an important element of the self-help package. No study design criteria were applied due to the low number of available studies, so outcomes cannot be summarized.

Research and Clinical Implications

More theoretically driven and evidenced-based e-resources are needed, where the theoretical basis for developing the e-resource, together with evidence about its acceptability, usability, and effectiveness, is established in well-designed and well-reported studies. Clear guidelines to aid this process should also be implemented, so that both developers and researchers follow clear procedures.

By ensuring the rigorous evaluation of e-resources, health care professionals may then recommend the use of e-resources for self-management with confidence. They can also use self-management interventions in parallel with other health care plans, thus enabling the fulfilment of key policy visions, for example, [2,4].

Conclusions

The area of e-health has great potential to reach wide and diverse populations, and digital technologies have huge potential for the development of effective mental health self-management e-resources. The findings of this systematic review suggest some promising developments, but they also highlight important gaps that future research should address. This is a new, but rapidly evolving, field, and while this systematic review shows plans of some good quality research currently underway, more work is needed to improve the standard of reporting of development and evaluation processes.

Acknowledgments

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Conflicts of Interest

AA is codeveloper of the Galatean Risk and Safety Tool (GRiST), a tool to support self-assessment and management of risks associated with mental health problems. GRiST is not cited in the paper.

Multimedia Appendix 1

Sample list of excluded studies with reasons.

[PDF File (Adobe PDF File), 35KB - mental_v1i1e3_app1.pdf]

Multimedia Appendix 2

Included studies and e-resources characteristics (Table 1 full version).

[PDF File (Adobe PDF File), 62KB - mental_v1i1e3_app2.pdf]

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Abbreviations

app: mobile application
ESA: emotional self-awareness
GRiST: Galatean Risk and Safety Tool
ICT: information and communication technologies
MRC: Medical Research Council
PDA: personal digital assistant
RCT: randomized controlled trial
WHO: World Health Organization

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Original Paper

Implementation and Outcomes of a Collaborative Multi-Center Network Aimed at Web-Based Cognitive Training – COGWEB Network

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Abstract

Background: Cognitive care for the most prevalent neurologic and psychiatric conditions will only improve through the implementation of new sustainable approaches. Innovative cognitive training methodologies and collaborative professional networks are necessary evolutions in the mental health sector.

Objective: The objective of the study was to describe the implementation process and early outcomes of a nationwide multi-organizational network supported on a Web-based cognitive training system (COGWEB).

Methods: The setting for network implementation was the Portuguese mental health system and the hospital-, academic-, community-based institutions and professionals providing cognitive training. The network started in August 2012, with 16 centers, and was monitored until September 2013 (inclusions were open). After onsite training, all were allowed to use COGWEB in their clinical or research activities. For supervision and maintenance were implemented newsletters, questionnaires, visits and webinars. The following outcomes were prospectively measured: (1) number, (2) type, (3) time to start, and (4) activity state of centers; age, gender, level of education, and medical diagnosis of patients enrolled.

Results: The network included 68 professionals from 41 centers, (33/41) 80% clinical, (8/41) 19% nonclinical. A total of 298 patients received cognitive training; 45.3% (n=135) female, mean age 54.4 years (SD 18.7), mean educational level 9.8 years (SD 4.8). The number enrolled each month increased significantly (r=0.6; P=.031). At 12 months, 205 remained on treatment. The major causes of cognitive impairment were: (1) neurodegenerative (115/298, 38.6%), (2) structural brain lesions (63/298, 21.1%), (3) autoimmune (40/298, 13.4%), (4) schizophrenia (30/298, 10.1%), and (5) others (50/298, 16.8%). The comparison of the patient profiles, promoter versus all other clinical centers, showed significant increases in the diversity of causes and spectrums of ages and education.

Conclusions: Over its first year, there was a major increase in the number of new centers and professionals, as well as of the clinical diversity of patients treated. The consolidation of such a national collaborative network represents an innovative step in

mental health care evolution. Furthermore, it may contribute to translational processes in the field of cognitive training and reduce disease burden.

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KEYWORDS

cognitive training; neurorehabilitation; eHealth systems; memory clinic; collaborative network; stroke; dementia; schizophrenia; mental health services

Introduction

Professional Collaborative Networks and Cognition Care

The evolution of health systems is increasingly dependent on professional collaborative networks [1,2]. This type of solution has been thoroughly explored in social, governmental, commercial, and enterprise competitive settings [3,4]. Nonetheless, in the health care setting, there is a limited understanding of the network dynamics, internal processes, key structural features, or how to evaluate their outcomes [5-7].

In general, professionals see collaboration as necessary, and their main expectations are to establish interprofessional relations that would lead to greater efficiency, better knowledge of other institutions, and professional support [8]. However, most health care settings are prone to generate isolated clusters, like professional groups, medical specialties, organization departments, and units [9]. They usually are kept apart due to physical, cultural, cognitive, or trust barriers [10].

The mental health sector, mainly due to demographic and economic constraints on health resources, is under increasing pressure to self-reshape and implement new sustainable approaches [11-13]. This situation has been enlightening groups and key players, at several hierarchic levels of decision, to the advantages of working together in search of synergies and more effective ways to deliver mental care [2,11,14].

Cognitive deficits associated with the most prevalent neurologic and psychiatric diseases represent 11.2% of the global burden of disease worldwide, accounting each year for 30 new cases per 1000 inhabitants [15]. Nowadays, treatment of cognitive deficits largely relies on specialized human mediated interventions (eg, cognitive rehabilitation, training, stimulation, or remediation), with pharmacological options far from playing an important role [16]. The combination of these factors renders most mental health systems worldwide largely unable to meet cognitive rehabilitation needs, either in due time after injury or adequate intensities [2]. To adequately meet these new demand patterns without increasing health care costs, sustainable organizational changes are necessary [2,17]. In addition, the clinical use of information technology based systems is known to improve cognitive interventions, namely their intensity, patient adherence, and quality of professional monitoring [18-21].

An Innovative Web-Based Cognitive Training System

With this global scenery in mind, starting in 2005 in a memory clinic setting, we developed an innovative Web-based cognitive training system, named COGWEB and described elsewhere [22-24]. Over time, the system evolved to address the needs of patients, professionals, and organizations in the field of cognitive rehabilitation [22,25]. It was designed to: (1) improve the efficiency of home-based cognitive training procedures; (2) increase patient access to care; (3) shift the therapeutic footprint from hospital to patient comfort zones; and most importantly, (4) to foster collaborative work between professionals from geographically distributed centers [24,25]. This set of characteristics made the COGWEB system especially suited to be the promoter of a new collaborative network, sharing specialized knowledge, improved procedures, innovative tools, and connecting professionals and institutions dedicated to cognitive rehabilitation.

The aim of this paper is to describe the implementation, early outcomes, and sustainability, over its first year of functioning, of a nationwide multi-organizational cognitive interventional network, taking advantage of the characteristics of an innovative Web-based cognitive training system.

Methods

National Setting

Cognitive Interventions

The Portuguese mental health sector has some specificities [26], nevertheless most of its organization is comparable to Western European models of care [15,27]. Neuropsychological rehabilitation is performed in different and almost unrelated settings in Portugal [28]. If we consider all forms of cognitive intervention provided (rehabilitation, training, stimulation, or remediation) along mental health services, as defined by the World Health Organization [15,27] and the National mental health plan [26,29], we may group them in the following ways.

Referral Institutions With Medical Supervision or Integrated in Multi-disciplinary Clinical Departments

The adult outpatient memory clinics in neurology and psychiatry departments are mainly dedicated to neuropsychological assessment, but some of them are also interested in providing rehabilitation care.

The day centers within psychiatric clinics and departments are dedicated to patients with schizophrenia, major depression, or bipolar disorder. Some of them provide social and cognitive remediation programs.

The referral rehabilitation hospitals are chiefly dedicated to traumatic brain injury patients and young patients with anoxic damage, stroke, multiple sclerosis, encephalitis, and postneurosurgery.

The outpatient rehabilitation clinics are largely run by rehabilitation medicine specialists and dedicated to motor rehabilitation of neurologic diseases, but they are developing a growing interest for cognitive rehabilitation.

The developmental clinics in pediatric departments are primarily concerned with early detection of motor and mental delays, and psychosocial interventions, a few of them having specialized human resources dedicated to cognitive rehabilitation.

Community Services, Supervised by Allied Health Professionals Including Psychologists, Occupational Therapists, Social Workers, or Rehabilitation Nurses

The community day centers and residential facilities dedicated to neurodegenerative diseases and providing cognitive care are mainly focused in cognitive stimulation and training of activities of daily living.

The community day centers and residential services are dedicated to children and adults with cerebral palsy and other inborn causes of intellectual disability.

Community Services Related With the Educational System, Not Included in the Health System

There are psychology and special education services at schools of the National Ministry of Education. There are also study centers dedicated to the compensation of learning difficulties. Additionally, there are adult and senior learning services.

Academic Centers Dedicated to Basic and Clinical Neurosciences

These centers are generally in partnership with institutions from the above categories.

Patient Care Limitations

In spite of the variety of services, patient access to care is limited by several important factors: (1) the location of patients' home (urban vs suburban or rural), (2) socioeconomic status, (3) mobility, and (4) the level of education of patients and families [26,27]. Furthermore, National Health Service standards of care do not include global access to cognitive interventions [29]. This leads to great heterogeneity on the level of service available, and the type of providers (private vs governmental) between regions [28]. The standards of professional care and practices, certification and training, and how those standards are maintained over time are also not perfectly established [27,28]. Outside of hospitals or other medical institutions, the clinical responsibility for cognitive interventions or local multi-disciplinary teams' coordination is difficult to understand solely based on professional certification and specialized training [26,28,29].

Promoter Center Setting

The clinical center where the initial research and development of COGWEB took place was an outpatient memory clinic. This was based in a neurology department in a tertiary hospital that provided care to 400,000 inhabitants. The resident clinical staff included neurologists and neuropsychologists. Patients with suspected cognitive deficits, irrespective of their cause, were referred to this clinic for diagnosis and rehabilitation by other neurologists, neurosurgeons, psychiatrists, rehabilitation medicine physicians, pediatricians, internists, or general practitioners [23].

Development and Main Functionalities of COGWEB

The COGWEB system is a Web-based working tool that allows for the implementation of personalized cognitive training programs remotely, in the hospital, or patient's living environment, under continuous supervision by experienced neuropsychologists [24]. Its development started in 2005, and the first clinical center initiated its use in 2007 (promoter center). Then, the system underwent a five-year period of further technological development, refinement, and thorough clinical testing [24]. Over the last three years, this Web-based cognitive training system was integrated into regular clinical practice at the promoter center. This option led to a threefold increase in patient access to supervised cognitive training and, on average, a sevenfold increase in rehabilitation training time, while maintaining human resources expenditures [23]. More recently, a cohort study provided data on patient adherence and intensity of training obtained using this instrument over long periods of time in a common outpatient memory clinic setting [25]. The version used for this study was composed of 30 independent exercises in a computerized game format. They were developed to train various degrees of impairments in specific cognitive domains, such as attention, executive functions, memory, language, praxis, gnosis, and calculus [23,24]. The training sessions were individually prescribed on the Internet by a therapist, just after thorough cognitive assessment and according to personalized plans discussed face-to-face with each patient, as previously described [25]. Internet activities performed by the patients were summarized in several progress graphs (eg, right answers vs wrong answers, levels completed, global training time, or accesses) that were revised weekly by the professional in charge. This information was used to monitor patient's evolution, as well as to elaborate progress reports or to aid motivation [23,24].

Network Implementation Procedures

In March 2012, the most important clinical actors and institutions in the field of cognitive impairment assessment, diagnosis, and treatment in Portugal were invited to join the COGWEB network. The institutions included psychiatry, neurology, and rehabilitation medicine departments, as well as more specialized units within these structures like memory and dementia clinics, schizophrenia clinics, day hospitals, and residential facilities. At the time two national workshop meetings were organized to present the COGWEB system and the results of the first clinical studies. Additionally, actors were invited to talk about their clinical settings and difficulties to implement cognitive intervention programs in everyday practice. During the meetings all were allowed to experiment with the COGWEB system, and were formally invited to participate in a collaborative network, due to start in the near future, and with the main purposes of: (1) democratize patient access to specialized Web-based cognitive stimulation, training, or rehabilitation services; (2) putting Web-based cognitive intervention knowledge into routine practice; (3) further develop and tailor the COGWEB system to the needs and requirements

of all professionals that use it in their clinical settings, and patients in their communities; (4) foster multi-center research studies in the field of cognitive rehabilitation; and (5) create the environment necessary to foster translational pathways in the field of cognitive neuroscience. The centers that initially accepted to participate in the network were considered as the baseline group. As the network operated as an open system, all centers that joined thereafter were considered new centers for the analysis.

Network Maintenance Procedures

All centers that decided to adopt the COGWEB system were visited in person by the network founders (VTC and JP), and received the COGWEB training manuals and in-house formation on how to use the system [23,30]. The first visit had an average duration of 2 hours, and included a session with all the clinical staff enrolled in activities with patients having cognitive deficits (eg, physicians, psychologists, therapists, and nurses). This was followed by a practical workshop with the local responsible neuropsychologist and other team staff such as therapists. During this visit, a second encounter was scheduled to discuss the treatment plans of the first patients to enroll in Web-based cognitive training activities.

The final decision to include patients was the responsibility of the local professionals that selected who could benefit the most from the Web-based cognitive training. There were no restrictions related with medical diagnosis or severity of deficits.

Between visits, all centers were regularly updated on new functionalities of the system (eg, an automatic report tool, performance and assiduity alerts, tutorial videos, and Internet manual), availability of new cognitive training exercises (number went from 17 to 34 during the first year of functioning), the results of quality assessment questionnaires to patients and caregivers, and the results of research study protocols and scientific presentations at national and international meetings. This information was passed in newsletter format by email to the local responsible, and also in part diffused in the blog at the project Web page [22], and at the Facebook page. To incorporate professionals' points-of-view toward the COGWEB system, these actors were challenged to fill opinion Web-questionnaires using Google Docs. The founders' efforts to improve quality of use of the system by the professionals in active centers included regular in person visits or webinars using Skype and Google Hangouts to discuss patients and methods, with the centers that were comfortable with this type of communication. Web presentations were also used (eg, good practice advice on how to program daily sessions, information on how to use COGWEB materials in exercise book format, and clinical vignettes).

Ethical Issues

All professionals signed a specific written informed consent. All patients and caregivers also provided written informed consent. This study was approved by the hospital review board and local ethics commission at Hospital São Sebastião, Centro Hospitalar de Entre o Douro e Vouga, Santa Maria da Feira, Portugal (chair, Rui Carrapato, MD, PhD) and Portuguese National Data Protection Commission.

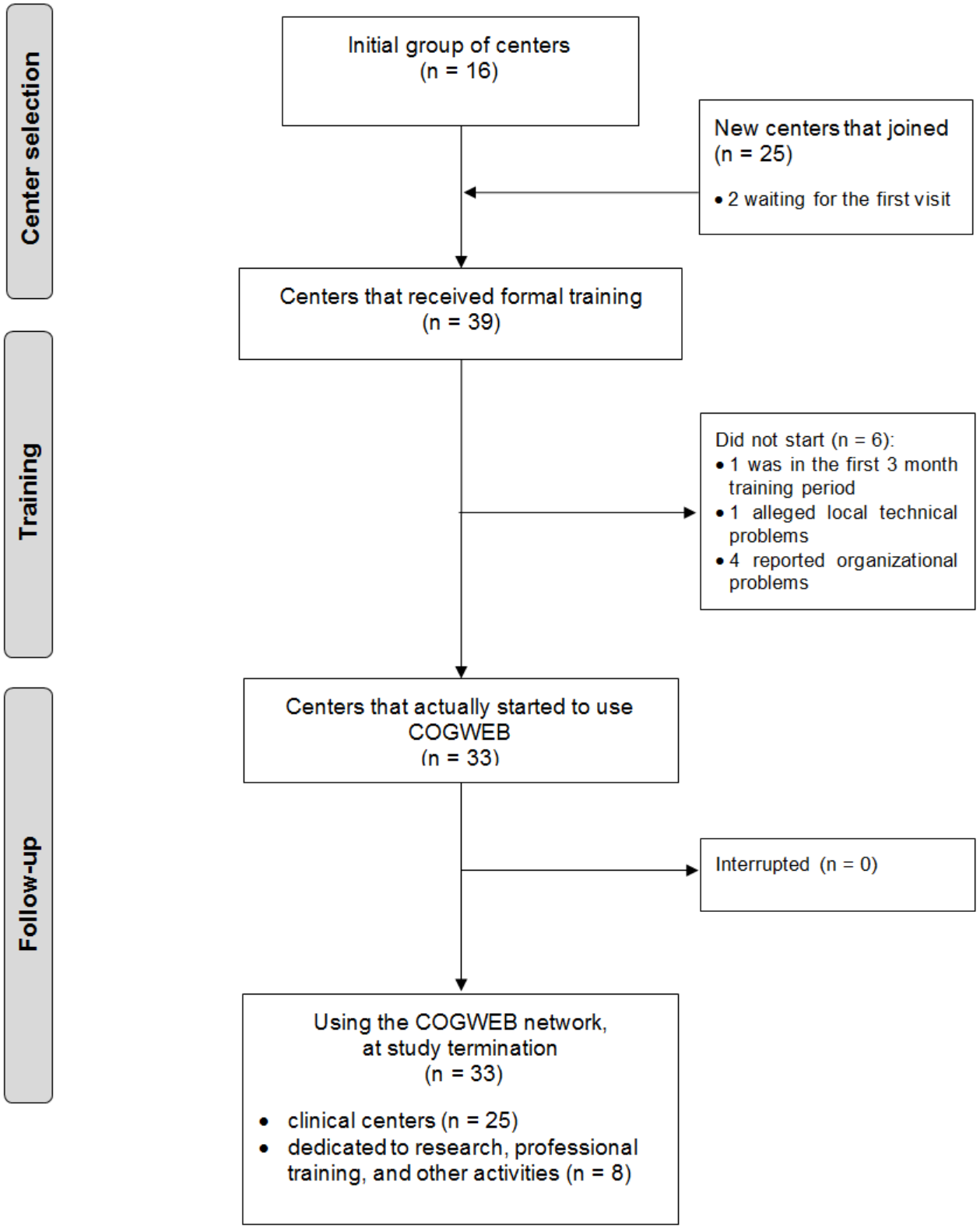
Financial Issues

Each center that was enrolled in the COGWEB network paid an annual fee to cover training costs, materials, and development of the system. These fees were supported by the centers themselves, research funding, or by third party sponsors listed in the Conflicts of Interest section. The average cost of using the system amounted to US $8.05 per patient and per month (taxes included). Human resources to manage the system locally were the responsibility of the centers.

Study Flow

There were 68 professionals from 41 centers that received formal training on the COGWEB system during the first year of functioning of the COGWEB network (Figure 1 shows this). The network behavior of these centers was analyzed between August 2012 and September 2013, according to the variables defined for the study.

Figure 1. Study flowchart.



Outcomes Definition and Analysis

To evaluate the network as a whole, the centers included were classified as clinical centers, if they were primarily dedicated to clinical activities, or nonclinical centers, if they were focused in research, professional training, and other activities. Additionally, all centers were classified according to the overall services they provided and positioning on the national mental health system setting (Table 1). The number and type of new centers and professionals that joined during the first year of implementation were the elements used to assess the network growth and degree of diversity.

For the subset of the network primarily concerned with clinical activities, the following outcomes were used: (1) number of patients enrolled in Web-based cognitive training activities; (2)

number of new patients enrolled per month; (3) characteristics of the patients enrolled (age, gender, level of education, profession, and medical diagnosis); (4) time to start enrolling patients after initial training visit (months); and (5) number of active clinical centers after 1 year, defined as those centers that have patients under treatment at 1 year.

The outcomes (1) and (2) evaluated clinical network growth and the impact on patient access to cognitive treatments. Linear regression was used to identify any time trend in the number of new patients recruited per month. The outcome (3) was concerned with characterization of patient profiles at the centers, and used to compare the profile of the patients enrolled in the first clinical center (promoter) with that in other centers of the network primarily focused in clinical activities. This comparison was used to assess the global impact of the COGWEB network on the diversity of patients (spectra of age and level of education) and diseases offered supervised Web-based cognitive training. This analysis was performed using Student's *t* test, chi-square, or Fisher's exact tests.

Finally, the outcomes (4) and (5), combined with outcome (2) were used to obtain knowledge on operative network functioning and long-term sustainability. The median time to start enrolling patients was compared among type of center using the Wilcoxon rank test. All the statistical analysis was performed using the SPSS 20.0 statistical package, considering an alpha = 0.05.

Results

Characteristics of the Baseline Centers

The network was initiated in August 2012 with a membership of 16 institutions and 29 health professionals willing to integrate the COGWEB system in their routine (Table 1). These professionals were mainly neuropsychologists and psychologists; two were occupational therapists. The initial centers were all hospital-based clinics, 14 inserted in neurology or psychiatry departments, one in a rehabilitation medicine department, and another in research academic facilities next to a large tertiary center.

Table 1. Major types of centers in the network at baseline and 1 year of follow-up (number of centers, trained professionals, and patients enrolled per major category of center).

	Baseline		1 year		
Centers	Centers	Professionals	Centers	Professionals	Patients enrolled
Clinical					
1. Outpatient clinics in neurology or psychiatry hospital departments[b]	14	25	19	38	209
2. Outpatient clinics in rehabilitation hospital departments[b]	1	2	1	2	2
3. Outpatient clinics in pediatric hospital departments[b]	-	-	1	1	[a]
4. Community day care[c]	-	-	2	3	10
5. Community private practices run by neuropsychologists[c]	-	-	8	8	42
6. Occupational psychology practice in a major company[c]	-	-	1	1	15
7. Psychology office at a second grade school[c]	-	-	1	1	20
Subtotal	15	27	33	54	298
Nonclinical					
8. Academic clinical research[d]	1	2	3	8	163
9. Academic basic research[d]	-	-	1	2	20
10. Postgraduate professional training[d]	-	-	1	1	NA[e]
11. Adult learning institutes[c]	-	-	3	3	60
Subtotal	1	2	8	14	243
Combined total	16	29	41	68	541

[a]The single center in this category was waiting for the initial training visit at the end of study.

[b]Hospital-based

[c]Community-based

[d]Academic/education-based

[e]NA = Not applicable

Characteristics of the Professionals and Centers at 1 Year of Network Functioning

The number of professionals that received specialized training within the network went from 29 to 68 (60 psychologists or neuropsychologists, 4 occupational therapists, 2 neurology residents, 1 psychiatrist, and 1 neurosciences researcher). The mean age of the professionals was 38.1 years (SD 8.8), 83% (57/68) female.

During the first 12 months of functioning, 25 additional centers joined the COGWEB network, from 16 at baseline. There are two of the new centers that have recently joined and were waiting to receive formal training. A total of 41 centers were part of the final analysis. Furthermore, 33 of these centers were classified as clinical (33/41, 80%), while 8 were considered nonclinical and focused in academic research, postgraduate training, or stimulation of normal adults (8/41, 19%) (Table 1).

Considering the services provided by the 25 new centers, 7 belonged to 2 of the initial existing categories (outpatient clinics in neurology or psychiatry departments and academic clinical research centers), and 18 represented 8 new categories of centers (Table 1). At one year, there were 11 different types of centers that could be additionally grouped by major sector of activity as; hospital-based (21/41, 51%), community-based (15/41, 36%), or academic/education-based (5/41, 12%).

From the 39 centers that received training by the end of the study period, 33 (84%) started to use COGWEB, either developing clinical or research activities. Taking into account all the active centers, the median time from the first on-site training visit to the enrollment of the first patient was 1.5 months (interquartile range, 0.5-3.0; SD 1.08 months; 95% CI 1.33-2.15) without differences between types of center (P=.57). Among all clinical centers that received formal training (n=31), by the end of the study period, 80% (25/31; n=25) remained actively enrolling patients and using COGWEB. The 6 clinical centers that were not active at the end of the study (6/31, 19%), never started to enroll patients after their first visit; 1 center was in the first 3 month training period (1/6, 16%), 4 reported organizational and local human resources problems (4/6, 66%), and 1 alleged major technical problems (1/6, 16%). All of the centers that started to use COGWEB with their patients (n=25) were active at the end of the 12 months follow-up period, with no dropouts.

Characteristics of Patients that Received Treatment in Clinical Centers

Among all the 25 clinical centers that started to use the COGWEB system in their activities, a total of 298 patients were enrolled for cognitive training during the first year. The average age was 54.4 years (SD 18.7), 45.3% (135/298; n=135) were female. The patients had diverse formal educational levels, 22.5% (67/298; n=67) from 1-4 years, 28.5% (85/298; n=85) from 5-9 years, 24.8% (74/298; n=74) from 10-12 years, and 24.1% (72/298; n=72) with more than 12 years of school (Table 2). The major causes for cognitive impairment of all the patients treated were; neurodegenerative diseases (115/298, 38.5%; n=115), static structural brain lesions (63/298, 21.1%; n=63), multiple sclerosis and other immune diseases (40/298, 13.4%; n=40), schizophrenia (30/298, 10.0%; n=30), cognitive dysfunction of functional nature (28/298, 9.3%; n=28), attention deficit hyperactivity disorder (12/298, 4.0%; n=12), and others (10/298, 3.3%; n=10) (Table 2).

During the follow-up period there was a significant increase of the number of patients enrolled every month at the clinical network (r=0.6; P= .031) (Figure 2 shows this). At 12 months, 205 patients remained on active treatment (Figure 3 show this).

Table 2. Description of the patients enrolled at promoter center, other clinical centers, and global clinical network.

	Promoter center	Other clinical centers	Global clinical network
Number of patients	117	181	298
Age, years, average (SD)	45.8 (14.7)	60.1 (19.7)	54.4 (18.7)
Gender			
Female frequency, n (%)	39/117 (33.3)	96/181 (53.0)	135/298 (45.3)
Education, years, average (SD)	8.9 (4.2)	10.6 (5.1)	9.8 (4.8)
Cause of cognitive impairment, n (%)			
Neurodegenerative diseases with dementia	20/117 (17.1)	95/181 (52.4)	115/298 (38.6)
Stroke, TBI[a], and other static structural lesions	23/117 (19.7)	40/181 (22.1)	63/298 (21.1)
Multiple sclerosis and other autoimmune diseases	35/117 (29.9)	5/181 (2.8)	40/298 (13.4)
Cognitive dysfunction of functional nature	10/117 (8.5)	18/181 (9.9)	28/298 (9.4)
Schizophrenia	27/117 (23.0)	3/181 (1.7)	30/298 (10.1)
ADHD[b]	1/117 (0.9)	11/181 (6.1)	12/298 (4.0)
Others	1/117 (0.9)	9/181 (5.0)	10/298 (3.4)

[a]TBI = traumatic brain injury

[b]ADHD = attention deficit hyperactivity disorder

Figure 2. Number of patients enrolled each month in Web-based cognitive training through the COGWEB network.

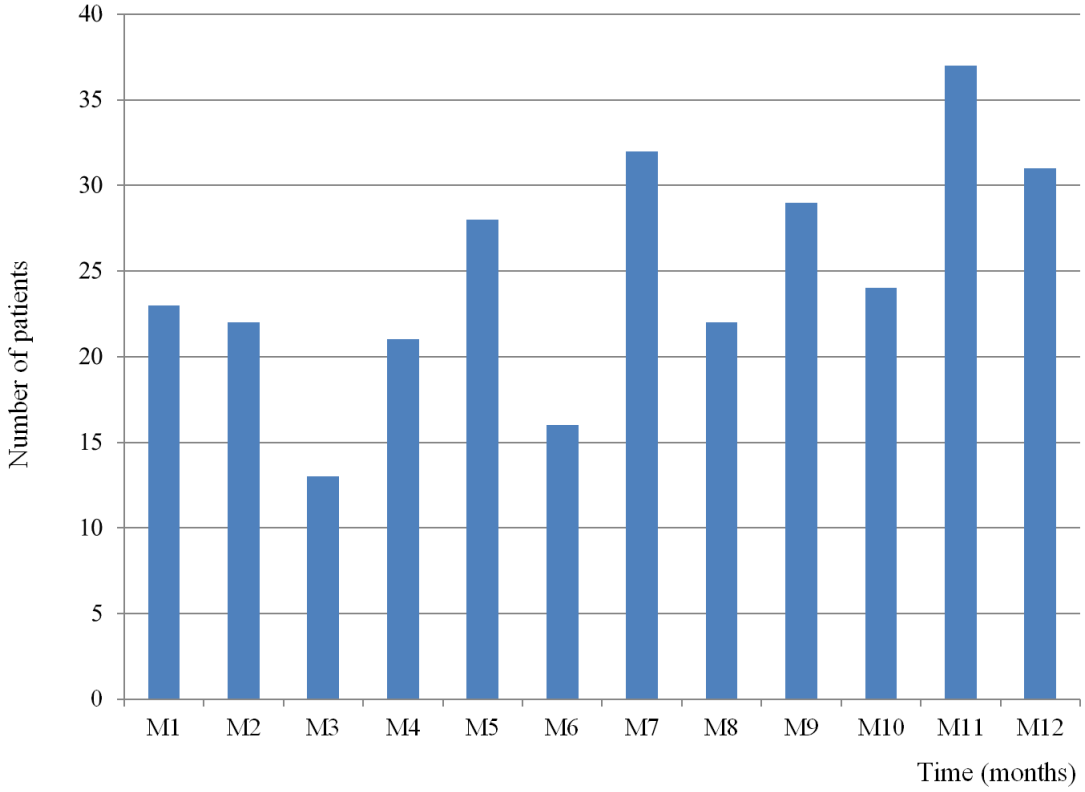
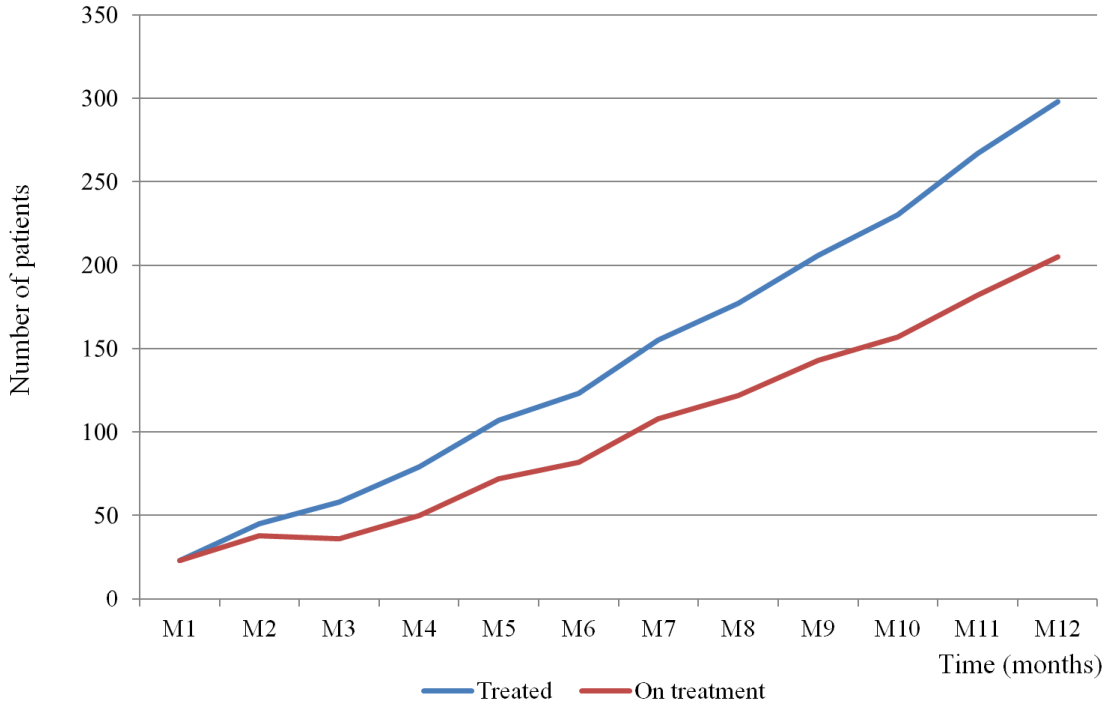


Figure 3. Cumulative number of patients treated during the first year (blue) against the number of patients receiving active treatment trough the COGWEB network each month (red).



Comparison of the First Clinical Center Activity With the Other Network Centers

In Table 2, the patients at the promoter center are compared with the patients at the remaining network, namely: (1) mean age, (2) gender, (3) level of education, and (4) cause of cognitive impairment. The patients recruited at the new network centers were older (P<.001). Nonetheless, the new centers also doubled the proportion of patients with less than 20 years of age 5.6% (10/181) versus 2.6% (3/117) at the promoter center. There was a significant difference in the gender distribution (P=.01), with more males in the promoter center. The patients' educational attainment was higher in the new centers than in the promoter (P=.005). Considering the distribution of the causes of cognitive

impairment, the promoter center enrolled relatively more patients with schizophrenia 23.0% (27/117) versus 1.7% (3/181), $P<.001$, and autoimmune diseases 29.9% (35/117) versus 2.8% (5/181), $P<.001$. Patients with neurodegenerative diseases were the majority of patients enrolled at the new centers (95/181, 52.4%), while their percentage at the promoter center was 17.0% (20/117; $P<.001$). The new centers also enrolled relatively more patients with ADHD, 6.1% (11/181) versus 0.9% (1/117; $P=.04$).

General Description of Activities at Research Centers

Besides the research and development activities occurring at the promoter center, four academic research centers (three clinical and one basic science) participated in the network, using COGWEB in their studies. These centers were dedicated to the study of the effects of cognitive training across several disease models and settings, and looking for molecular, brain imaging, or neuropsychological biomarkers and characterization of neuroplastic processes. Some of the disease models included Alzheimer's dementia, schizophrenia, multiple sclerosis, stroke, and school age learning disabilities. A center was dedicated to epidemiological and public health cohort studies. The total number of patients enrolled in all these research activities during the follow-up period amounted to 417, with 183 (43.9%) coming from studies originating outside the promoter center (Table 1).

Discussion

Principal Findings

Starting from an initial clinical promoter center, integrated in a wider national mental health system setting in Western Europe, it was possible to implement over a 12 month period a collaborative network composed of 41 centers and 68 professionals. This network was dedicated to cognitive intervention and, for its establishment, took advantage of an innovative Web-based cognitive training system, COGWEB [23,24,30]. This tool was developed for clinical and research purposes at the promoter center, and had proved to be proficient in increasing patient access to care and intensity of cognitive training [23-25]. The process of training and sharing a new working tool, and methods, in the field of cognitive training was the cornerstone for the construction of the COGWEB network, and fostered synergies and cooperation between so diverse centers and settings. Health care is a collaborative endeavor, but the degree of collaboration and exchange depends largely on the ability to share and the reciprocity perceived by all the players and stakeholders of a network [10].

The 16 baseline centers that started the network were all based on hospital institutions. Nonetheless, during the first year of functioning, the network was able to attract 25 new centers, and at the end of the study period 11 different categories of centers were identified (Table 1), with 36% (15/41) of them being primarily based on the community. The diversity of centers and institutions enrolled went from referral hospitals and academic centers to day care institutions, schools, adult learning institutes, and companies. All this variety provided us with a wider view on global patient needs, settings, and professional groups interested in improving their standards of care in the field of cognitive intervention. Considering the main characteristics of the national mental health service where the study occurred, namely the range of environments and existing barriers to patient access to cognitive interventions [28,29], this was an important achievement. Only through an inclusive approach is it possible to enhance solutions within a network environment and bridge the gaps between so diverse settings and professionals like those from referral hospital centers, basic and clinical academic centers, or community based institutions [1,8-10]. The needs for cognitive training in the population are very widespread and growing, mostly due to the multiplicity of diseases associated with cognitive deficits, the wide spectrum of ages of onset, and ageing trends in the population [15,27,29]. Altogether, if the aim is a public health impact in the near future, the multiplicity of solutions and settings connected through a cognitive care collaborative network are an important solution to match current and future needs of the population, at the same time improving the sustainability of health services [2,13].

Although the implementation of the clinical network was only a short period of time, the number of patients provided Web-based cognitive training through the network increased steadily, amounting to more than 30 new patients per month in the last two months. Furthermore, the percentage of patients remaining under clinical supervision at the end of the study period was also high (205/298, 68.8%). These multi-center adherence estimates, during a 12 months follow up, may be comparable with adherence data obtained in a previous cohort study at the promoter center (82.8% at 6 months) [25]. Although an indirect quality measure, the reproduction of the adherence data in this study supports the strategy used for the professionals' training at the new centers.

The comparison of the characteristics of patients treated at the promoter center with those enrolled at other centers in the clinical network showed a marked increase, with significant differences, in the diversity of diagnosis, spectra of ages, and education. These findings are in accordance with the different categories of centers and types of services provided within the wider mental health system context [26,29]. The achievement of such a variety of settings and diseases is an important characteristic of the clinical network, namely for the implementation of future research studies and tailoring of the COGWEB system to professional and patient needs. A striking finding was the increase in the number and percentage of patients with neurodegenerative diseases (Table 2), possibly in association with the characteristics of the new centers that adhered to the network, with a great proportion being dedicated to neurodegenerative diseases and elder patients (Table 1). This fact probably reflects the distribution of cognitive impairment in an aging population [31], and the willingness of those centers and professionals to adhere to a network dedicated to Internet cognitive training activities [25].

The strategy defined for professional training, network implementation, and maintenance allowed for a median time to start using the COGWEB system in clinical activities of 1.5 months, with 80% (33/41) of the clinical centers active at 12 months and no dropouts. Nonetheless, 4 institutions reported local organizational and human resources restrictions as reasons for not starting to use the system. These estimates are important for programing further network expansion, anticipating points of tension between individual and organizational goals,

guaranteeing its alignment with financial incentives, and sustainability [9].

Besides clinical activities, it was verified a remarkable growth in research activities over the network. This finding is of utmost importance because studies originating outside the leading promoter center already represented 43.9% (183/417) of patients enrolled in these activities. Research activity is one of the main purposes of this network, and tightly linked to the capacity to generate innovation, processes, and finally patient outcomes [11,32]. This happens in close resemblance with the development of translational research and translational networks in the fields of oncology [6], pediatrics [33], genetics [34], neurodegenerative diseases [35], virology [36], pharmacology [37], big data bioinformatics [38], epidemiology [39], and public health [32], all good examples of the growing efforts being made to fill the gap and speed processes between basic research and clinical outcomes for communities [11].

Limitations

The main limitations of this study are related with the youth nature of the COGWEB network (first year of functioning), being difficult to validate the long term sustainability, outcomes, and impact of the network structure. The differences between center characteristics (41 centers distributed by 11 categories), and the small relative number of patients enrolled at each center prevented us from analyzing patient profiles per type of center and establish comparisons. The aggregation of clinical centers into promoter and others was thus necessary. Data on the severity of patient deficits as well as type, intensity, and quality of cognitive training provided were not analyzed. Additional studies are necessary to evaluate the long term impact of the network on global access of patients to supervised cognitive training at the level of the national health system, quality of care provided, and patient outcomes according to major cause of cognitive impairment. Furthermore, the professional members of the network were not addressed directly through a network survey, nor are data available on key players, ties (indegrees and outdegrees), brokers, or sociograms [6]. These points are very important for translational network analysis, and will be addressed in forthcoming studies on the COGWEB network functioning.

Conclusions

This paper provides insight on the implementation and early outcomes of a large scale multi-organizational cognitive rehabilitation network in a Western European health system environment. Over its first year, there was a major increase in the number, as well as in the clinical diversity, of patients treated and centers, crucial factors for its long term viability. At the beginning of the big data analysis era for neurosciences [40], the consolidation of such a national collaborative network represents an innovative step in mental health care evolution. Furthermore, it may contribute to translational processes in the field of cognitive training and cognitive care, this way providing the foundations for continued innovation, clinical care improvement, and reducing the burden of disease.

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Authors' Contributions

VTC, JP, and PC created the study concept and design. VTC, JP, IA, CM, AS, LR, RB, EC, IAraújo, VB, MC, and COGWEB network collaborators acquired the data. VTC, JP, LR, NR, and PC analyzed and interpreted the data. All authors critically revised the manuscript for important intellectual content. VTC, JP, and PC obtained funding. IA, LR, CM, AS, RB, EC, IAraújo, VB, MC, and COGWEB network collaborators provided administrative, technical, and material support. VTC, JP, VB, MC, NR, and PC provided study supervision.

Conflicts of Interest

VTC and JP have a shareholder position at Neuroinova, Lda, a company that develops and commercializes COGWEB related products. VB and MC received fees for the technological development of COGWEB.

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Abbreviations

COGWEB: Web-based cognitive training system

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