

Participatory Design of an Online Therapy for Youth Mental Health

Greg Wadley¹, Reeva Lederman¹, John Gleeson², Mario Alvarez-Jimenez³

¹The University of Melbourne
Parkville, Victoria 3010
greg.wadley, reeva.lederman
@unimelb.edu.au

²Australian Catholic University
115 Victoria Parade
Fitzroy, Victoria 3065
john.gleeson@acu.edu.au

³Orygen Youth Health
35 Poplar Rd
Parkville, Victoria 3052
malvarez@unimelb.edu.au

ABSTRACT

Online therapy has the potential to extend existing face-to-face support for mental health, but designers face challenges such as lack of user engagement. Participatory design could improve outcomes but is difficult to pursue in the mental health context. By working with a research-focused clinic we have been able to employ participatory design methods over a period of three years to develop and test an online therapy for young people with psychosis. This paper discusses our methods and results in the light of existing design frameworks for youth mental health, and reports experiences which will be useful for other researchers in the field. We have found that participatory approaches are indeed challenging in the mental health context, but can result in technology that is efficacious and acceptable to young people.

Author Keywords

online social therapy, mental health, participatory design

ACM Classification Keywords

H5.m. User interfaces (e.g., HCI): Miscellaneous.

J.3 Life and Medical Sciences: Health.

INTRODUCTION

Mental illness comprises an extraordinary 30% of the non-fatal disease burden in Australia (Mathers et al., 2000). Half of psychiatric disorders develop before the age of 14, and three quarters before 25, leading some researchers to conclude that “mental disorders are the chronic diseases of the young” (McGorry et al., 2008). Yet most young people who acquire a mental health problem do not receive adequate early intervention (Bhugra, 2010). This is a major social challenge to which, because of the high rate of technology use among young people, HCI might make a significant contribution.

There are specific obstacles to youth involvement in adult clinical services, concerning stigma and access. Major predictors of non-attendance at clinical appointments include young age, transport problems and distance from clinic (Mitchell and Selmes, 2007). The disconnect

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between young people and face-to-face (F2F) services, combined with young people’s enthusiasm for technology, suggests that researchers should explore the utility of ICT for supporting youth mental health and wellbeing (Burns and Morey, 2008). Computer-supported therapy has the potential to extend existing treatments because it can be delivered easily and anonymously and reduces the need to visit a clinic (Griffiths et al., 2007). Yet technological interventions for mental health have had mixed success (Christensen et al., 2009). Engagement in these technologies might improve if design better matched the needs and desires of users, including hedonic preferences (Coyle et al., 2007, p. 560) and there has been a call for participatory design in the youth mental health context (Hagen et al., 2012). This reflects a broader concern that consumers should be involved in the design and evaluation of mental health services (James, 2007). Yet established approaches to technology design are difficult to implement in this context because of ethical considerations and difficulty accessing settings and users, especially youth (Coyle et al., 2007).

This paper describes our design and evaluation of what we believe is the world’s first online social therapy for young psychosis sufferers. Psychotic disorders are among the most disabling of conditions. Symptoms include hallucinations, unusual thought disorder, conceptual disorganization, and suspiciousness (Gleeson et al., 2009). While most people who receive treatment for a first episode recover in the short term, many relapse within 2-5 years (Gleeson et al., 2013), thus there is a need to find ways to keep people engaged in treatment longer to reduce the risk of relapse and improve recovery.

We are fortunate to be working with a research-supportive clinic which has a culture of consulting with clients in the design of new initiatives (Monson and Thurley, 2011). The clinic services young people aged 15 to 25 in a metropolitan region which includes areas of socioeconomic disadvantage (McGorry et al., 1996). The clinic has afforded us (constrained) access to clients and staff over a period of several years.

We began by conducting co-design with clients and clinicians. We implemented a prototype web-based therapy and refined it through client consultation and usability trials. We conducted a 6-week safety and acceptability trial with 23 clients and staff, interviewing participants and analysing usage statistics. We are now refining our design ahead of a 4-year clinical trial.

In a previous publication (Alvarez-Jimenez et al., 2013) we situated our project within the mental health literature. In this paper we discuss our design and evaluation processes and key results in the light of existing frameworks for designing for mental health (Coyle et al., 2007; Doherty et al., 2010). We first review prior work on technology for mental health. Then we describe our design workshops and report on the hopes and concerns reported by clients and clinicians. We describe the technology we implemented and our evaluation of it. Finally we discuss the experiences reported by trial participants and how these are influencing our ongoing work and might inform the work of others.

Our contribution is twofold: an illustration of how participatory methods can be employed in designing technology for youth mental health, and a set of outcomes that can inform researchers working in a field in which it is difficult to access users. As online therapy becomes mainstream, the results of early experiments like this will contribute to the success of future implementations.

TECHNOLOGY FOR MENTAL HEALTH

Technology provides candidate approaches for extending and enhancing face-to-face mental health treatments (Griffiths et al., 2007). Computer-based psychoeducation is acceptable to consumers and can be as effective as F2F methods (Walker, 2006). Key motivations for employing technology are access and engagement (Coyle et al., 2007). Young people in particular are comfortable with technology and may prefer it over F2F interaction with therapists (Abeles et al., 2009).

While the popularity of social media has made these particularly attractive in a range of contexts, there are specific advantages that might accrue when they are used to support health (Merolli et al., 2013). Mediated interaction with health workers can be convenient for patients who are geographically distant from health services, or busy re-engaging with normal life (Beattie et al., 2009). Given that social disconnection contributes to negative health outcomes (Holt-Lunstad et al., 2010), social media might improve connectedness for people who are isolated because of a health condition (Vetere et al., 2012). Sharing experiences can be therapeutic (Pennebaker and Seagal, 1999) and may generate useful advice (Ploderer et al., 2013). Social media can be used to promote healthier behaviour (Morris et al., 2011). Social interaction can motivate use, and might address the high dropout rates that have plagued some online therapies (Christensen et al., 2009; Doherty et al., 2012)

Self-help forums have been effective for conditions such as eating disorders (Celio et al., 2000) and depression (Dyer and Thompson, 2000). Online discussion reduces users' sense of dependency on a therapist and allows clients to exchange coping strategies (Hartzler and Pratt, 2011) and form supportive bonds (Castelnuovo et al., 2003). Social support protects against relapse and is one of the strongest predictors of long-term recovery from psychosis (Norman et al., 2012). It has been suggested that online systems should emulate the social interaction that occurs within clinic-based services (Bickmore et al.,

2010). Online community can be especially valuable to stigmatized groups (Baams et al., 2011), though careful management of identity may be required (Barratt, 2011).

However implementing online social therapy presents challenges. Users may be unwilling to discuss health problems (Morris et al., 2011). Designers must balance the need to make user data visible with the need for privacy (Purpura et al., 2011) and must decide whether to leverage existing social media or create new "walled gardens" (Newman et al., 2011). Young users may need behavioural guidelines (Webb et al., 2008). Moderation by staff might be required, since support from clinicians increases adherence to online therapies, and client motivation is influenced positively when they are accountable to trusted moderators (Mohr et al., 2011). In treatment for depression without moderation, only about 1 in 8 participants demonstrated benefits (Andersson and Cuijpers, 2009). However the limited cues available in text-based communication mean that careful consideration must be paid to how messages are presented by moderators.

OUR DESIGN PROCESS

Our research has followed the two-stage process advocated by Coyle et al. (2007) in which a design and usability/acceptability testing stage involving HCI and mental health professionals is followed by a trial of clinical efficacy. This paper describes stage 1: design and initial testing. We have secured funding for a 4-year clinical trial, which will constitute stage 2.

We began our project with the premise that ICT could be used to extend existing face-to-face therapy for psychosis. From this we generated four design sketches which we used to seed discussions with clients and clinicians. The sketches illustrated the following options:

- Deliver therapy content via the web
- Deliver therapy content via mobile phones and SMS
- Deliver therapy content via existing social media
- Deliver web-based wellbeing questionnaires to replace paper forms currently filled at clinic.

Co-design workshop with mental health clients

We held a workshop with 6 current and former mental health clients from the clinic's client advocacy team. We presented our sketches for them to consider and asked about their use of and access to technology, whether they would like to use a technology-mediated therapy, and what features they would like it to offer.

We found that clients lived in a variety of situations: alone, with a partner, with friends or with their parents, and accessed the Internet with varying degrees of privacy, through devices that were often not their own. Privacy and security are critical issues for a therapy targeted to these clients. All participants had mobile phones, though they frequently ran out of credit, and felt it was very important that we ensure that access to the service was cost-free. Most clients had received cognitive behaviour therapy or knew what it was: they agreed this style of therapy was useful, if not always enjoyable, and that it

could be delivered online. However one client claimed that an existing online therapy for depression had triggered a psychotic episode by making him anxious. Others had experienced anxiety upon reading about psychosis on the Internet: “That’s the danger about the Internet, if you look up conditions on Google and get freaked out.” We concluded that trusted advice from the clinic was valued by clients but that therapy should be sensitive to the possibility of anxiety and not force clients to focus negatively on their condition.

Clients reported that they sometimes experience states of mind in which dealing with people face-to-face is difficult and online communication is preferable. “People sitting at home on their computers accessing this sort of thing – it’s a very comfortable place where they can speak their mind and [...] say these things that they really feel.” They appreciated that online therapy would reduce the need for commuting, which could be challenging in terms of time and cost and because public transport made them anxious. But clients did not want to receive “corny” computer-generated messages. They were not especially enthusiastic about unsolicited reminders of psychological techniques, but suggested this could be an opt-in feature. They wanted to control when and where they used the system, and did not want it to randomly push content to them. Some warned against delivering content via SMS if the recipient was in a psychotic state. “When you’ve got anxiety, someone’s harassing you, having SMS is a scary thing to deal with.” They especially did not want machine-generated SMS. However it might be acceptable to push non-threatening information such as appointment reminders. They felt that while using a PC might also be problematic, a PC user at least chooses when to log in. Clients felt that having access to their medical records could be useful, and they noted that an online system could store diagnostic data and visualize their progress. However they were concerned that evidence of poor progress might provoke anxiety and make a client’s condition worse.

Most participants were enthusiastic users of social media, and the idea of using these platforms to communicate with fellow clients was raised. Some felt that online connectedness was helpful. “I have a lot of friends from [the clinic] on Facebook. We chat about stuff. We don’t necessarily need to chat about our time at [the clinic] but just to know we all went through the same thing, and we’re recovering at the same speeds, or at different speeds, but I think that’s really helpful.” Because of such experiences clients were enthusiastic that the therapy should afford social interaction, and felt this would be a source of advice and connectedness. However they felt strongly that the service should not be delivered via public social media, as they did not want to share their status as mental health clients with friends other than those they had met at the clinic. (This is congruent with the suggestion of Jamison-Powell and Garbett (2012) for online “safe spaces” for discussing health problems.) Furthermore, clients felt that if we implemented user interaction it would need to be moderated, to prevent abuse. “When I was an in-client at [a clinic] there was a lot of people in-fighting, so you wouldn’t want people

getting on there, creating flame-wars and stuff”. They noted that people with mental health conditions would be especially vulnerable to online bullying. They felt also that the system should scan client input for signs of symptom relapse or suicidal intention. Online safety will clearly be important for social therapy.

Upon being asked whether they would want to fill in online questionnaires, clients offered unfavourable assessments of the paper- and web-based forms they were already asked to fill in. They vigorously opposed being asked to fill in long questionnaires, complaining that these often didn’t make sense and caused fatigue and anxiety. A daily online quiz would be too much, though a lower frequency of delivery might be acceptable.

In summary, clients asked for a system that was sensitive to their social and psychological situation and offered:

- help and information about psychosis,
- a social platform through which clients could communicate with each other.
- moderation by and communication with clinical staff,

Co-design workshop with clinicians

We presented the outcomes of our client workshop to a workshop consisting of 8 clinicians at the same clinic, in order to compare their views and concerns. Design for mental health technology must consider these users too (Coyle et al., 2007). Clinicians were cautiously optimistic about the possibilities for an online therapy, but warned of two potential pitfalls. First, they felt that young mental health consumers do not necessarily have the access, experience and expertise with technology that is typical of other young people. Second, they feared that an online therapy might tempt clients to disengage from F2F therapy and spend too much time at home.

Clinicians discussed a range of content ideas such as psychoeducation, information directories, discussion forums, online client records, and an online history of communication between client and case-manager. Some felt that relatively mundane technologies “could be employed to make a real big difference in complementing the things that we do”. However clinicians warned that some psychosis sufferers would find it difficult to engage with an online service. “There are people with high prevalence disorders who might have mild depression, through to people with extreme schizophrenia who are sitting at home. If you want a one size fits all thing, you’re going to lose a lot of people.” This echoed the finding of González-Blanch et al. (2007) that cognitive impairment can be severe in people with first-episode psychosis. Clinicians were concerned whether clients would be sufficiently motivated to use an online therapy, a problem also identified in previous research (Hall and Tarrier, 2003): ‘You have to have a level of motivation, wellness and organization.’

Clinicians felt that socioeconomic factors would restrict some clients’ access to technology, particularly if drug use meant that disposable income was minimal. They cautioned that technical faults or a lack of response from staff would discourage use of an online therapy. They

wondered whether they could successfully assess a client’s status when interacting online, and suggested that a video chat feature might reduce this risk. They feared that computer mediation could damage their relationships with clients and add to their workloads, echoing a major theme of Coyle et al. (2007).

Clinicians recognized that mediated contact might be easier for clients than travelling to the clinic, but felt that this convenience might tempt clients to skip consultations: “People who are stuck at home, completely isolated from regular social contact and their friends because of various issues they’ve faced NEED to get up out of their rooms.” On the other hand, one clinician felt that online therapy could help people with mild problems who may never present to a clinic.

Clinicians agreed that a system in which clients exchanged messages could be useful and that it should be moderated. They wondered whether there were sufficient human resources to do this. Would moderators need to be online at all times? How many would be required? Would they receive a large number of messages? They pointed out that most of a clinician’s day is spent with clients, yet their workload was increasingly augmented with administrative duties which could not be performed during client contact. Some felt that online interaction was simply the way of the future and would inevitably be part of therapy programs.

We responded to concerns about the impact of symptoms on system use by restricting our design to clients not currently experiencing severe psychotic symptoms. We responded to concerns about clinician workload by specifying that only specific staff would be appointed as moderators, and that time for moderation would be set aside from existing duties. As development and testing of our system has progressed, clinical staff have become increasingly supportive of the project and see it as a useful adjunct to their work.

Design decisions

Our work with clients and clinicians led us to the conclusion that an online therapy was feasible and that it should offer three functions:

- Psychoeducation: Clients access, at times and places and at a pace convenient to them, therapy content which is focused on positive constructs such as problem solving and self-efficacy;
- Peer-to-peer social interaction: Clients interact with each other via group therapy and discussion pages, using UI elements modelled on popular social media;
- Advice and moderation from staff: Client interaction is moderated by professional clinical staff to ensure online safety. Clients communicate with staff through public or one-to-one messages according to preference.

The therapy should be available via any Internet-enabled computer and in particular via mobile devices, so that clients can gain help when and where it is needed. It should be positive in tone, solution-oriented, and carefully designed not to cause anxiety (we have drawn inspiration from the Positive Psychology framework of

Seligman et al., 2006). Moderation should be by trained staff and should integrate with and not impose a burden on existing work routines.

IMPLEMENTATION AND TESTING

Prototyping

Through iterative prototyping we implemented an online therapy website that embodied our design decisions. We considered combining existing software for online learning and social networking; however this limited our flexibility and we decided on a bespoke design. This has allowed us to tightly integrate therapy, social networking and moderation components. We are using web standards and open-source technologies, and to promote reuse, keeping therapy content decoupled from software.

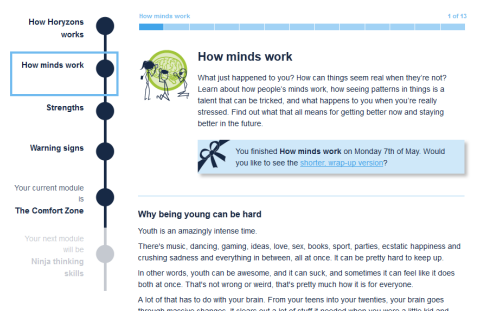


Figure 1: Psychoeducation module

Clients access a series of therapy modules designed to promote understanding and recovery (Figure 1). Each module consists of one or more pages of text and graphics prepared by a professional author experienced in writing for young people, working in conjunction with psychology researchers and practitioners (cf. Coyle et al., 2007, section 3.5). The modules are integrated with social networking via “talking points”: questions embedded in the therapy text that invite asynchronous discussion among users.

In the version trialled, therapy modules were prescribed on the basis of a diagnostic quiz administered upon the client’s first login: modules were then consumed in the order prescribed. The modules were presented as a menu (Figure 1, left of screen) designed to resemble a railway map in order to give the sense of a journey taken.

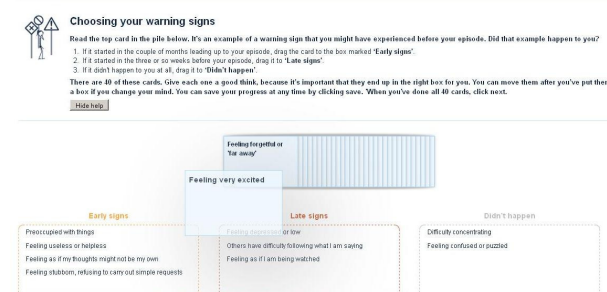


Figure 2: Card-sort for identifying early warning signs

In addition to being presented with information and strategies, clients are offered a number of interactive exercises which allow them to identify a set of personal

strengths, create a check-list of “early warning signs” that preceded their episode of psychosis, and create and update their personal “comfort zone” (lists of social situations in which they do or do not yet feel comfortable) (Figure 2). These interactives were modelled on face-to-face card-sort exercises already in use at the clinic, where decks of cards showing pre-printed material are used to prompt clients to create their own lists. We emulated card-sorting using JQuery drag-and-drop.

Social interaction takes place within therapy modules, on interactive pages designed to facilitate group problem-solving discussions, and through user-to-user conversation on pages such as the “newsfeed” (Figure 3: note that for confidentially reasons screenshots do not show actual trial data). These “social features” are listed in a menu on the right hand side of each screen.

All user-to-user interaction is asynchronous and follows the style of familiar social media. Notifications are generated by user-generated events such as users commenting on other user’s input, and by system-generated events such as availability of therapy modules. Notifications are delivered within the website and via email.

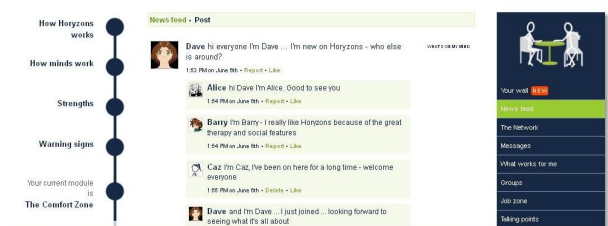


Figure 3: Social interaction on the “newsfeed”

However while we have borrowed the look-and-feel of social media, we have not implemented a social graph. All users are “friends of” all other users. This decision was taken to prevent social anxiety related to friending. Our system is not envisaged as a public website but will be specifically prescribed to clients at an appropriate stage of recovery, and be used by relatively small groups of the order of a few hundred per server.

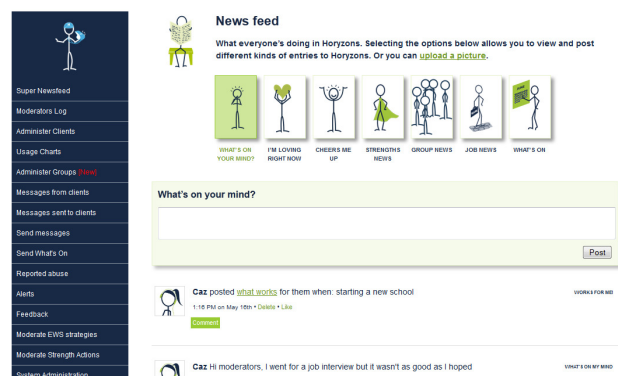


Figure 4: Moderator view

Though moderators have a range of user- and site-management features (left-hand menu, Figure 4), they use the same underlying database as clients, are part of the same social network and share the same social tools

(visible in Figure 4). Moderators not only guard against misuse of the system, but look out for non-use and for opportunities to enhance use through acting as a model of use. Our design recognizes that moderators must effect responsible oversight of a large number of users within a small amount of time (cf. Doherty et al., p. 248).

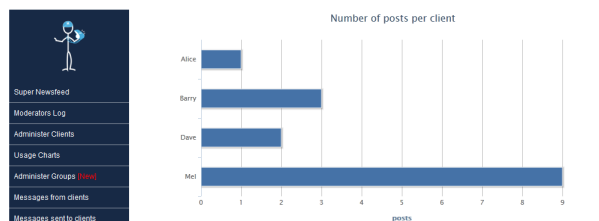


Figure 5: Example usage chart

We devised a moderation protocol to guide staff through the tasks they need to perform. We also built a suite of software tools which includes the ability to individually message clients, and a staff-only newsfeed so that moderators can discuss issues across shifts. Moderators can view real-time charts of usage data drawn from system logs (e.g. Figure 5). These allow moderators to identify problematic usage and are also used by the research team to evaluate the system (cf. the suggestion of Doherty et al., p. 250).

The clinic offers a vocational therapy designed to support clients’ return to work (Killackey et al., 2008). We implemented an online version of this called the “Job Zone” within our website. This offers static information as well as both public and private communication with the clinic’s vocational therapist (Figure 6).



Figure 6: "Job Zone" (vocational therapy)

Client safety was a major concern during co-design and we included a number of features to support this. A key danger in including user-generated content in a mental health therapy is that a user may post content that endangers others. For this reason a primary task of moderators is to inspect what is being posted. In response to concerns that clients might express suicidal ideation we included a mechanism to block posts that contain particular keywords and to redirect the poster to an emergency help page. False positives and negatives are a concern with a keyword approach but it appears to be a useful adjunct to human moderation. Also, a button is displayed beside each post which allows clients to report content which makes them uncomfortable, is abusive, or indicates that the poster is distressed: this is flagged to moderators for investigation and, if necessary, removal.

The system gives clients control over self-presentation. They can delete their own prior posts at any time, and can toggle between 'visible' and a 'hidden' status which hides all of that client's prior posts: this permits clients to cope with temporary paranoia without mass deletion of their data. Clients can at any time click on a "feeling distressed?" button which displays emergency contacts and strategies. These features are simple and usable in line with a suggestion of (Yeratziotis et al., 2012).

Usability testing and refinement of design

We refined our design through a series of usability tests. Following a heuristic from Doherty et al. (2010), most of these involved usability experts, though on some occasions we were able to access groups of clients for one-hour sessions. Experts focussed on interaction design, while clients mostly critiqued therapy content and visual design. When we felt the prototype was sufficiently mature we proceeded with a safety and acceptability trial.

Safety and acceptability trial

We conducted a six-week trial of our therapy with 20 clients and 3 clinicians acting as moderators. Clients used the system for about 4 weeks each. They were given a short one-on-one training session as well as a tutorial and online help (cf. Doherty et al., 2010, p. 246). They could access the system at their convenience, 24 hours a day, 7 days a week, through any Internet-enabled computer. Moderators logged in at regular times each weekday to supervise and interact with clients. The researchers monitored system use and social interaction.

No safety incidents occurred. While not all participants were strongly engaged, our results compared favourably to previous work, with 70% of client participants logging in at least weekly and 75% reporting a positive experience. Regarding therapy content, 95% of clients completed at least one module, and 60% at least three. Social features were well received by clients, with 95% of participants using these and 70% finding them useful. 90% reported moderation as supportive. 90% said they would recommend the service to others, and no participants reported negative or unpleasant experiences. 100% felt the site was safe to use. 55% felt empowered in their own recovery process, and 70% considered the system to be a useful long-term treatment option beyond discharge.

Though clinical efficacy was not the focus of this brief trial, analysis revealed improvement in participants' depressive symptoms. We believe this was due to the extra social interaction experienced, as 60% of participants reported that using the system had significantly increased their social connectedness: this can be compared with findings that loneliness decreases with use of social network sites (Burke et al., 2010).

YOUNG PEOPLE'S EXPERIENCES OF ONLINE SOCIAL THERAPY

We conducted a structured post-trial interview with each participating client in order to understand their experiences of using online social therapy. Thematic analysis revealed the following results.

Online therapy is acceptable to young people

Online delivery divorces therapy from its normal physical and social context and we were unsure whether clients would accept this. However consuming therapy online was viewed favourably by a majority of clients.

Specific aspects of our design were commented on. Some praised being able to access the content in short, manageable pieces: "Because it wasn't one chunk, like study. It's split over the time and I could go into it when it was ready, click on the link and I read the [therapy] while I'm on the train." Our positive psychology approach was praised: "It was nice to think about the positive side of myself." Clients liked being prompted to consider their personal strengths: "I just thought picking out your strengths and that was a really great idea. Once you know all your strengths and weaknesses you can practically overcome anything."

Presentation of therapy as a personalised sequence of modules that must be completed in order was controversial. The sequence made sense to some participants: "Things were related to the next thing. It wasn't all over the place. It's like one thing – oh we talked about depression, so the next one is how the mind deals with depression ... there's a correlation." But others found it restricting not to have random access to content. We have responded in ongoing design by making access more flexible.

Echoing a warning from Doherty et al. (2010; p. 247), a participant reminded us that therapy should not be too complex: "There are ... too many What Works For Me, Groups, like just too many things." One participant did not engage with the content at all: "Personally none of this stuff is useful to me. It doesn't help me mentally or anything. But I suppose the younger crowd it might". One participant found the therapy emotionally challenging: "The more I read, the more upset I feel about myself. ... It is very constructive, very good, I strongly support it, but – ". These comments illustrate the difficulty of targeting pre-written material to a broad audience.

Social interaction highly valued

Most participants responded very positively to being able to interact socially within online therapy: "It's a place where you can feel comfortable just talking about what's going on, and what you've been through, and you can feel secure and not feel scared that people will judge you, because they've been through the same thing and will be supportive. It's a comfortable environment." Clients felt the design was suited to: "people who need to talk their problems, and need to sort things out." They enjoyed discussing therapy with peers: "I thought it was a really great idea. A bunch of people get together, they talk about it, it really helps them out." Advice from peers was considered valuable: "It's kind of like social networking but like learning from other people's experiences." Shared experience made advice more credible: "Because they know what you've gone through and it's someone to relate to. There's not a lot of people who understand what it's like." Empathy was enhanced by online interaction: "You know a bit more about the person, and you can ask

or check in on them, ‘Hey, how’s everything going’”. Clients felt they had helped each other: “it makes you feel good about yourself when you help other people”. Clients suggested the site should support a large number of users.

However feedback highlighted the unpredictability inherent in a social therapy. When engagement was strong the user experience was very good: “Because there’s like one question and like twenty different answers from different people.” But when engagement was weak, the experience was poor: “I just felt like I was writing to myself really.” Social therapy, like other social media, relies to a degree upon user input which cannot be designed but only encouraged (Burke et al., 2009).

Few of the participants knew each other personally, but simply knew that they were all clients of the same clinic. Some felt that a degree of social distance was a bonus: “I didn’t feel like I was being judged or anything, because I didn’t know any of them personally.” However some found it unusual to be networking with people they did not know personally. “You’re on a social network level, not on a personal level, so it always makes it a bit more strange.” But interaction was positive: “I feel happy, at least someone talks to me, even if it’s just a greeting”. These experiences illustrate the isolation often suffered by mental health clients and a key benefit of user interaction within online therapy, but emphasize the need to encourage safe positive relationships.

One client reminded us of the degree to which mental illness could be demotivating: “I haven’t been on there that much. I haven’t been on the computer for a while. I lay in bed most of the day.” While this comment serves as a stark reminder of what some clients face in day-to-day life, it also highlights a particular need for therapy to be accessible through mobile devices.

Utility of incorporating familiar social media tools

Our intuition was that implementing familiar social media tools would increase comfort and motivate use. The ‘newsfeed’ was universally approved of: “Yeah, it’s like Facebook. ... It’s very straightforward.” Likewise private messaging between clients and staff was considered useful. “If you wanted to talk about something in private or didn’t feel comfortable talking about something, then you could just message someone.” Notifications were sent not just within the site but via email, to encourage clients to log in. Designing notifications is a trade-off between burdening users and failing to engage them. However participants liked them: “You’d write something, and then you’d get an incoming email saying “oh this person wrote something else” and you’d go “oh wow, I didn’t think of this or that.” No-one complained of receiving too many notifications. We will develop this mechanism further as a way to keep clients engaged and promote site features.

Supportive moderation appreciated

Moderators were perceived as helpful and supportive. “It didn’t feel like someone was bossing you around. It was just guidance, like supervision, to make sure everything works fine and is going well for you.” Clients appreciated

the moderators’ responsiveness: “You message them, and 15 or 20 minutes later there’ll be a message reply, and they’re always replying to posts and everything”. We believe that the positive experience our clients reported was partly due to the willingness of moderators to engage at a social level.

Contributors to perception of online safety

All participants reported feeling safe (cf. Doherty et al., 2010, p. 248) and a number of factors contributed to this. Users supported each other: “No-one was threatening, no-one was mean”. Trust grew from association with the clinic: “It was part of [clinic], and [clinic] I sort of trust.” Access was restricted: “It’s a limited network of users. Not everyone can use it”, and clients were pseudonymous: “It was no real names, and part of your name not your full name.” Clients mentioned that the site’s security features, explicit usage policy, and supervision by staff, inspired confidence. Finally although the technology was a prototype, we aimed for high design quality and this inspired confidence: “It’s an authentic website. It’s professionally done.” Our experience suggests that good design is very important in gaining the interest and confidence of young people.

DISCUSSION

The success of this project to date supports the suggestion of Coyle et al. (2007) that design of computer-supported therapy should be a collaboration between workers in HCI and mental health care (MHC). We affirm that participatory design can be difficult to conduct in the mental health domain. But patience and persistence, and close collaboration with a research-focused clinic, has allowed us to produce a technology which is:

(1) based on accepted theoretical models of MHC, (2) designed in full collaboration with MHC professionals, (3) designed to integrate with existing working methods and (4) used by clients under the guidance of a professional therapist (Coyle et al., 2007, p. 550).

We have found that young mental health clients have clear views on what they require from a computer-supported therapy. They embrace online therapy for much the same reason that young people in general expect interactions with institutions to be online: for convenience and flexibility in structuring their lives. Clinicians are somewhat more cautious as they fear losing contact with clients who are not required to attend a clinic in person, and are concerned that some clients will not be able to access digital technology. However clinicians are increasingly accepting of online therapy as they witness clients adopting it with enthusiasm.

Benefits and challenges of social therapy

We found that adding social interaction to online therapy motivates engagement and is therapeutic in its own right. Peer interaction was a source of advice (cf. Hartzler and Pratt, 2001) and helped clients overcome social anxiety in a supportive environment. The convenience of an online service is especially important for young people beginning to reengage with work, education and social life following an episode of illness.

However, enabling user interaction within online therapy creates risks and a need for staff moderation. There is a risk that self-exposure will lead to criticism and bullying, or that insufficient interaction occurs so that a request for help goes unanswered or a discussion falters. Users might provide evidence of crisis which needs to be acted upon quickly, possibly outside of clinic hours. Managing a social network is a complex undertaking and our ongoing work is exploring whether it is a feasible project for a resource-stretched clinic.

Challenges of participatory design in this context

We affirm that a number of potential challenges face researchers who wish to conduct participatory design in the youth mental health context.

Mental health research addresses a user cohort which is relatively small and hard to reach. One cannot advertise for participants but must source them via a clinical service. Features such as online interaction between clients, and the ability for clients to input text which might indicate emergency after clinical hours, raised significant concerns for ethics committees. Some of our safety features were designed in response to committee feedback, illustrating the value of the ethics process.

Mental health clients are under considerable stress and cannot always keep appointments. Motivation can be a problem, and travel to a discussion room or usability lab difficult. Many young people do not wish to identify as mental health clients and this can affect their motivation to engage in research. Because so much research is conducted with so few participants, those who are willing to engage may suffer “research fatigue” (Clark, 2008).

Lessons learned

We have learned valuable lessons and are redesigning some aspects of the system in response.

As mentioned above, separate modules of therapy focussed on specific topics worked well, but forced sequential access to them was seen by many as too restrictive. We have devised a different delivery model that links portions of therapy content thematically while permitting random access and browsing.

Online vocational therapy was very popular and we are expanding this model to include other professional and medical advice. What sets this feature apart from informational websites is that clients have a choice not only to consume pre-written material but to engage in personal or open communication with a known expert.

We are adding a new class of user: peer-support clients who have completed the therapy, have significant experience using the site, and have completed a training program. This reflects a popular peer-support program already offered at the clinic (Monson and Thurley, 2011).

We are focusing more resources on designing and understanding the mobile experience, because we have become convinced that this is critical to online therapy. Our aim is to provide help where it is needed most, and to exploit short breaks and moments of “micro-boredom” (Anttila and Jung, 2006) as opportunities to engage in

therapy. Young people feel a greater sense of ownership of their mobile device than, say, a household PC, and this may motivate use. Though clinicians initially expressed concern that clients from socially-disadvantaged backgrounds may not have access to mobile Internet-based devices, our experience is that increasingly our clients own smart phones. We note also research showing that disadvantaged people value mobile technology for its ability to support social ties and access to resources (Roberson and Nardi, 2010).

Future research directions

We have secured funding to expand this project in two ways. First, we are preparing to conduct a 4-year randomized controlled trial which will test clinical efficacy. During this much longer trial we expect to have around 100 users at a given time. This forces us to think at different scales in terms of the size of the network and the length of time it exists.

We are also preparing versions for two new cohorts: young people with mood disorders, and parents and carers of young clients. To support multiple implementations we are keeping the therapy content independent of the software platform, while making some visual presentation parameters customizable: thus new sites can be created at low cost. Maintaining multiple therapies for different user cohorts raises implementation questions such as whether the cohorts should share one social network, or users should join individual networks for each therapy.

CONCLUSION

Moderated online social therapy shows promise as a way to deliver accessible, non-stigmatizing and engaging mental health interventions for young people. Responding to the agenda set down by Coyle et al. (2007) we have designed a therapy through cooperation between HCI and psychology researchers. The experiences we report highlight the complex contextual factors that can impact the use of online therapy. By paying careful attention to these we have arrived at a model which appears to be safe, feasible and acceptable to young people. By focussing not only on clinical efficacy but on user experience (and recognizing that these overlap), we hope that this approach continues to generate useful insights into the successful provision of online social therapy.

This paper makes three contributions. First, responding to the call by Hagen et al (2012) it explores the utility of participatory design in the domain of youth mental health; we conclude that while participatory approaches are challenging, persistence and a supportive clinic can make them feasible and beneficial. Second, following the suggestion of Coyle et al. (2007, p. 550), we describe a technology design which is likely to be useful across a range of mental health scenarios. Finally, the paper contributes experiential data sourced from clients and clinicians who participated in our design and evaluation process: our hope is that this will assist other researchers seeking to design technology to support youth mental health, a context in which research participants and reported experiences can be difficult to access.

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