

Moderated Online Social Therapy: Designing and Evaluating Technology for Mental Health

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While the use and prevalence of web-based mental health applications has grown over the last decade, many of these services suffer high rates of attrition. This is problematic as face-to-face support for mental health is limited. To determine appropriate design guidelines for increasing engagement we conducted a study of First Episode Psychosis (FEP) patients and reviewed theories on the use of existing online services. We produced a set of design goals, developed an online application that combined social networking and online therapy within a clinician moderated site and conducted a six week trial with a group of young FEP patients. The design goals, based on existing theory including Supportive Accountability and Positive Psychology are operationalised through a model we call MOST (Moderated Online Social Therapy). The trial results indicate that our implementation achieved the design goals and that the MOST model can inform the development of more effective and engaging online therapies.

ACM Classification Keywords:

H.5.3. Group and Organization Interfaces: Theory and models.

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General terms: Human Factors, Design, Theory

Keywords: Mental Health Interventions; Online Therapy; Supportive Accountability; Positive Computing; User Experience; User-appropriate Design;

1 INTRODUCTION

The development of online therapies for mental health is a growing field that presents challenges both for mental health researchers and technology designers [1, 2]. It has proven complex to develop systems that deliver effective therapy, are non-harmful for users, and encourage ongoing use. In the case of young people diagnosed with psychotic illness - the focus of this paper – technology design should address their special needs for long-term support, ongoing recovery and social connectedness. This paper discusses a project to design, build and trial an online therapy for young people recovering from a first episode of psychosis (FEP) in terms of specific theoretical models. The project aims to produce a user-driven platform which responds to the specific needs of the target population. We have proposed the MOST (Moderated Online Social Therapy) model, combining moderated social networking and therapy components into a novel, fully-integrated system. These components reinforce each other, creating a dynamic environment that promotes ongoing participation and engagement. We locate our work within the field of Positive Computing [3], aimed at advancing human wellbeing.

Drawing from previous research and from focus group interviews conducted with patients and clinicians at a youth mental health clinic, our multi-disciplinary team of psychologists, human-computer interaction (HCI) experts and system designers developed a design for an online therapy and social networking website for FEP. To inform the design we used research tools from both HCI and the social sciences to develop a rich description of the target group.

In prior work we discussed some aspects of our results for a psychiatric audience [4] in terms of usage data and reduction in psychiatric symptoms. In this paper we discuss the user experience

of our therapy. We apply theories from HCI to understand how people interact with therapy, focusing in particular on how the principles of Supportive Accountability can be implemented to encourage user engagement in online therapy. We conclude with reflections on the adequacy of our system, and discuss implications for how the high rates of attrition currently experienced in the use of online therapies [5] can be reversed through design that takes user characteristics into account.

2 BACKGROUND

Significant effort has been devoted to developing effective online therapies for mental illnesses. This is motivated by a number of factors:

- Mental illnesses have a devastating effect on many people [6].
- Young adults in particular are susceptible to mental illness and are thereby at risk of severe disruption during a critical period of social and intellectual development [7].
- Young adults are enthusiastic users of Internet technologies and social networking [8, 9] and might more easily be reached via an online treatment.
- Mental illness carries a significant stigma, so that young people do not want to be identified as mental health clients [10].
- There is a need to supplement existing ‘face-to-face’ therapies, which are time-consuming, expensive and require leave from school or work to travel to a clinic [11] at a stage when patients are trying to re-engage in society.
- In particular, lack of early remedial and preventive treatment for psychosis can lead to burdensome hospitalization later. Currently, patients with schizophrenia, the most common form of psychosis, occupy approximately 25% of all psychiatric hospital beds in Australia and represent 50% of admissions [6].
- Studies have shown that after recovering from a first psychotic episode, most patients relapse within 2-5 years, suggesting that current interventions should be extended to target this critical period [12].

It is currently the case in Australia that many government-funded services can only provide 18-24 months of face-to-face care. No doubt similar services are limited in cash-strapped health systems across the world. Thus solutions need to be found urgently for interventions that supplement face-to-face care during the full period of relapse risk. Prior research indicates that the Internet can be a powerful source of information and support for patients. This has the potential to significantly influence health-related behaviours and decisions as well as engagement with mental health services [13] to provide long-term maintenance of treatment effects.

To be effective, Internet-based interventions for psychosis will need to take account of the characteristics and needs of patients. These include:

- Possible cognitive deficit [14]. Patients with FEP may suffer impairment in speed of processing ranging up to severe [15] and this could indicate a broader diversity of cognitive deficits. However, the severity and pattern of cognitive deficits is unclear, and varies between individuals.
- Lack of engagement [16, 17]. Patients with psychotic illness are often difficult to engage. Additionally, many teenagers are protective of their privacy and reluctant to open up to an adult therapist [17].
- Experience of stigma [18, 19]. Many people who would benefit from mental health services opt not to pursue them, or fail to fully participate once they have begun, in order to avoid the label of mental illness and the social harm it can bring [18, 19]. Stigmatised mental health consumers are more likely to avoid interaction with people outside their family [18, 19] and to avoid seeking help from psychiatric services. This problem is particularly severe amongst vulnerable social groups such as adolescents and the socially disadvantaged [20].
- Responsiveness to treatment. Patients with first-episode psychosis are more responsive to treatment compared to patients with more enduring forms of psychosis, and so it is important to develop specific interventions for this phase of the disorder [21].

Additionally, the needs and experiences of young technology users in general need to be considered in order to prevent the high rates of attrition that have been evident in other online therapy use [5].

In the following section we briefly summarize prior efforts to implement online psychotherapeutic interventions. Because of extensive adoption of “social computing” [22] which increasingly creates the expectation that connections will be enabled and facilitated online, we apply theories to investigate the benefits of integrating social networking sites (SNS) and web-based psycho-education with expert moderation. We consider the principles by which moderation should be designed. Finally we describe our implementation of the MOST model in a therapeutic website, and discuss the results of a 6 week trial of the site.

3 EXISTING ONLINE SERVICES FOR YOUNG PEOPLE WITH MENTAL ILLNESS

A number of types of online service have been used in the treatment of mental illness:

3.1 Online Therapy and Psycho-education

Because of the dearth of work on therapy sites for psychosis, we take some guidance from depression management sites (some of which we discuss further in later sections of this paper),

which have common issues. Benefits from focusing on personal strengths, for example, have been found to be relevant to both first-episode psychosis [21] as well as depression. Problems of demotivation are common in both psychosis and depression. Thus previous attempts to offer online cognitive behaviour therapy (CBT) for depression provide a number of lessons for researchers wishing to implement similar treatment for psychosis. In depression studies researchers have found that: a system should be interactive so that users can respond to CBT content through exercises; a system should allow the user to share personal information with a therapist; positive results can be achieved by combining therapy with moderation; a system is preferred by young people when they can see that there are other users, even if they are not connecting directly with them [1].

A substantial body of research has provided evidence that psycho-education improves medication compliance, reduces relapse rates, promotes social functioning, and increases satisfaction with mental health services [7]. Computer-based psycho-education can be acceptable and in some cases as effective as face-to-face or paper-based methods [12, 23]. Online interventions which provide clear and engaging information and cater for cognitive deficits and levels of insight about their condition, are also likely to produce improved outcomes [2, 15].

Psycho-education delivered via the web has been found to be effective when patients spend enough time on the website to complete required modules. However a drawback of online treatments is that many users do not persist in viewing all the available material, and many sites have high dropout rates [5]. In self-guided treatments, with no human moderation, only about 1 in 8 participants have demonstrated clear benefits [2].

3.2 Online Community Forums

Research into user-led services has found robust associations between peer support, empowerment and recovery in people suffering from psychosis [19]. Online self-help forums providing peer support health networks have evolved as a strong Internet presence for both mental and physical health. These may be unstructured discussion groups or may be led by an individual, usually a non-professional, who shares the problem that the group addresses [24]. The efficacy of online self-help groups and community forums has been supported in studies of eating disorders [25] and depression [26]. These have proved a valuable adjunct to traditional psychotherapy, allowing patients to form supportive bonds with others [24]. Recent surveys have further shown that age can be a factor in participation: young people are more likely to trust mental health information websites and perceive them as helpful compared with their older counterparts [27].

Both outside and within the health community certain general factors can affect engagement in on-line forums: for example applications designed for use by a group may not support the level of improvisation that can characterize group activity [28]. Poor design can also occur because intuition in development tends to be poor for multi-user systems [28]. Certain types of user input

are more likely to encourage a response from other members of an online community, such as posts that express either negative or positive emotions or which describe feelings or personal testimonials [29]. Millen and Patterson, studying a local community forum, found that encouraging members of a community to observe the activities of the community promoted use of the forum, as did notification processes such as emails which alerted users to new posts [30].

Engagement can be engendered through belonging to a specific patient group. A number of organizations run online forums that provide specific support for mental health issues or simply an outlet for young people to discuss youth-centred issues which may involve mental health. Webb et al have studied design guidelines and the role of moderators in these communities [31]. These forums provide a safe environment for discussion; however they are not paired with online therapies and moderators are encouraged to emphasize that forums are a secondary form of support, designed to encourage users to seek help in face-to-face counseling [31, p.111].

Research with members of online health communities (OHC) shows that members engage in very different levels of disclosure when they are communicating with fellow members of their health community than with their Facebook friends [32]. Newman et al interviewed 14 participants who belonged both to an OHC for weight loss and to Facebook. Participants felt embarrassed to talk about weight issues or discuss their exercise regime with their social group on Facebook and felt their concerns would be met with sarcasm or dismissiveness. However, they found the OHC supportive and positive. Online forums are especially useful for stigmatized populations [33, 34] where careful management of online identity is required [35]. Newman et al supported the creation of separate “non-judgemental spaces” and concluded that for therapeutic purposes users needed “greater control over their communication partners” [32,p.348] and should at least be in “custom groups” if using applications like Facebook, to deal with stigmatized conditions.

3.3 What has been missing so far in online psychotherapy for psychosis?

While the work detailed above illustrates robust attempts to use the Internet to support mental health in a variety of ways, there is no prior published research providing a theoretical basis to the use of online therapist-moderated social networking in combination with psychotherapy for treating psychosis. This approach has never been evaluated for FEP patients, and the work described in this paper provides a unique contribution in this area. Previous research has shown that many young people with psychosis have difficulty interacting face-to-face with similarly diagnosed peers [36] and that there are overwhelming push factors away from engagement in services, such as stigma and low motivation [37]. It is interesting to consider how motivation to engage might translate to the online context. The literature on social networking led us to hypothesize that social networking sites (SNS) supported by moderation may be useful in supplementing the success of websites that have so far provided psycho-education alone, by providing the support of peers in addition to professional therapists. We propose that clinician-moderated social networking will provide the additional motivation for users to engage. The

questions we are investigating are: **What user-appropriate system designs can be developed to combine moderator supported psycho-education and social networking in a web-based service? What principles should underlie the moderation?**

The premise of our research is that appropriately designed and moderated social networking may be both therapeutic and sufficiently attractive to consolidate use of psycho-education online. Studies examining the connection between adolescent wellbeing and online interaction show that online behaviour can stimulate wellbeing by reinforcing existing relationships [38]. It cannot be presumed, however, that enthusiasm by young people in general for social networking will necessarily translate to this particular user group or to the context of an online therapy. Patients with FEP may in fact avoid services that force them to acknowledge their connection to this illness group. Because of their low levels of motivation [16] they may also be disinclined to participate in anything new or untried.

4 THEORY AND REQUIREMENTS GATHERING: WHAT MIGHT MOTIVATE SITE USAGE?

Theories on how and why people use social networking can provide some guidance for design that addresses these motivational issues:

4.1 Online Social Networking and Identity

Research suggests that people using a lean medium such as text-based computer mediated communication are more likely to disclose personal information than when using a rich medium such as a face-to-face conversation [39]. Young people have been found to spend almost as much time involved in text-based communication as they do in face-to-face or telephone communication [40] and so are less likely than older people to be dismissive of the legitimacy of such means of communication.

While the success of Facebook hinges upon people knowing each other, a website can allow users to hide their identity through pseudonyms and this can encourage higher rates of personal disclosure, which can be therapeutically beneficial. Research suggests that psychosis sufferers like using the Internet because of its anonymity and absence of a hierarchy and its potential to assist in overcoming difficulties with social interaction [13]. The possibility of being anonymous or pseudonymous can allow a person to express their true self [41] while when forced to use their name they may be concerned about being punished or ridiculed [41]. In SNS environments where users are identified they tend to express the “possible self” or a socially desirable identity [42]. Thus the option for pseudonymity can have a significant positive impact on the way users impart information to others in the SNS and what information they are willing to share. However, because not all social computing is positive in tone [43] there is a further argument for moderated interventions, even where the opportunity for anonymity exists.

4.2 Social Networking, Self-esteem and Positive Psychology

Young people with psychosis often suffer from lowered self-esteem. Research suggests that self-esteem may be malleable [33], and this may particularly be the case for young people who not only have long entrenched feelings of low self-esteem but may have been affected by their sudden self-perception as sufferers of mental illness. Thus social network sites which aim to provide positive reinforcement of therapeutic behaviors, or involve therapists using Positive Psychology methods [44] should work against an inclination toward low self-esteem. Positive Psychology focuses on building positive psychological traits, positive experiences, positive relationships and positive institutions [44]. Emphasizing the positive can be particularly constructive for patients with only one psychotic episode whose poor self-esteem is not well entrenched. Thus they may be willing to engage with an SNS that has this focus. Using Positive Psychology, individuals whose negative self-concept is refuted in face-to-face therapy have been found to move some way toward changing a negative self-image [33]. Individuals can have a stable self-concept as well as a working self-concept which may be situationally relevant [45]. Thus if individuals are in a social network with others who have the same condition they may not feel as marginalized, as the context mediates a higher level of both self-acceptance and sense of belonging to the group. So while it is possible that low self-esteem may discourage involvement in social networking, it is also possible that patients may still be inclined to join social networks with people they see as being like them. Joining a network of people with the same condition allows patients to enter into what Dwyer et al [46] call an “anchored relationship”. Social contact and the development of social skills bring benefits to patients with psychosis [47] and may be advanced through “anchoring” in online social networking in a less stressful environment than face to face contact.

4.3 Making sense of Illness and Affiliating with an Illness Group

Research has shown that people with serious illnesses of any kind try to find ways to make sense of the illness [48]. Leventhal et al call this the Common Sense Model (CSM) of illness representation [48]. It suggests that as a way of coping, sufferers find lay interpretations that help them understand their condition. Many self-management groups for chronic illnesses are built around the notion that individuals use the experiences of others with a similar condition to make sense of their illness [49]. A need to make sense of one’s illnesses by using the lay knowledge of fellow sufferers may work against the inclination to dissociate from others with mental health problems and instead be an attractor to communication.

Research by Hartzler et al [50], outside the mental health context, suggests that fellow patients offer substantial support and expertise that can be quite different to that obtained from professionals. Patients value the expertise of other patients who have had the same illness experience as them. Using sources from on-line message boards it was found that cancer survivors valued opportunities to share patient expertise using health related social software [50].

Long before the advent of online communities, Festinger showed that people with a serious medical condition are inclined to engage in affiliative behaviours which promote attachment to a group or the seeking of support from the group [51]. These can be either downward comparisons (someone else is suffering more) or upward comparison that provide hope or inspiration. Others suggest that belonging to a health community can provide opportunities for disclosure, empathic connection, shared goals, and psychological adjustments to life challenges [52]. Thus the opportunity to affiliate and make sense of what can be a very confronting and confusing condition could be a compelling pull factor for young people with psychosis to join an SNS of other people in the same situation.

4.4 Supporting Strengths and Accountability

Previous work emphasizes the value of providing therapist support in on-line therapy sites. Bickmore et al [53] stress that social support from a therapist is an important factor in positive outcomes for schizophrenia. In this work they used a relational agent who has access to several thousand programmed utterances to provide counseling support. They found positive results in maintaining medication adherence and increasing physical activity in participants and regard these electronic agents as a possible inexpensive solution for extending care, while still regarding human clinicians as representing the “gold standard”.

Doherty et al have designed systems which include support from human moderators. They found that interventions for depression where the moderator encourages users to take account of their existing strengths and resources are most likely to be effective [1] as is treatment tailored to meet the individual interests of the patient [1]. These features are also relevant for psychosis patients [21]. While the system Doherty et al designed did not allow for communication between patients, and so was not an SNS, it allowed patients to communicate with therapists and recorded whether other patients had liked particular parts of the program, giving them a sense of the presence of others and reducing feelings of isolation. Doherty et al reported higher levels of ongoing engagement with their system compared to systems that had no therapist support [1].

Hartzler’s work [50], discussed above, suggested that patients value both the support they get from peers and the support they get from professionals. In mental health applications, an important role for professional moderation has likewise been found to exist alongside the value given to peer support in areas such as OHC.

The “Supportive Accountability” model of e-health interventions involving human support proposes that patients be made accountable for their level of online participation, through processes such as goal setting, expectation setting and monitoring. [39]. In this approach the co-responsibilities of therapist and client are emphasized with a focus on the individuals’ personal resources. A moderator establishes their legitimacy by illustrating expertise and showing trustworthiness and benevolence. Particularly important is the shared role of the patient and moderator in determining expectations. Moderation designed according to these principles could

be effective in motivating on-going use. While Supportive Accountability offers promising ideas by examining the association between intrinsic motivation and goal setting [39,p.43] and trust and therapeutic alliance [39, p. 41] it has only been published as a theoretical model and has not been previously operationalised.

In sum, prior research suggests that despite the possible stigma attached to joining an SNS of fellow psychosis patients, young people may still be willing to engage if the site supports the following design goals aimed at enabling an effective and positive user experience for this unique group:

1. A secure and safe environment which promotes a sense of co-belonging
2. Incorporation of therapist-supported Positive Psychology
3. Incorporation of Supportive Accountability principles,
4. Opportunities for learning about one's condition through the experiences of others.
5. Appealing content presented in a user-appropriate manner

These goals align with the specific characteristics of young mental health patients, detailed earlier, such as problems of stigmatization and the need for a presentation format which creates engagement and is easy and compelling to use for users with a range of cognitive abilities. Additionally, they are based on relevant psychological principles and theories. So far no research has examined this combination of features in one system.

In our work we consider how to apply these ideas to an on-line system for young people who have experienced a first episode of psychosis. This cohort is a unique user group not previously considered in the HCI literature, and requires a design based not just on the present condition of these users but on the need to prevent and potentially deal with future psychotic episodes. Work by Goldberg and Agget [16] stresses the need to “keep the problem alive” in the treatment of psychosis so that patients who have had some reduction in symptoms don't lose vigilance in monitoring for signs of future relapse.

In this work we revisit Doherty et al's guidelines to provide an extended focus on safety, and the detection of early warning signs of possible future illness. This extended focus includes an enriched understanding of the role of moderators/therapists, particularly with regard to Supportive Accountability. Doherty specifically suggests that designers “consider the dynamic of client and therapist together”, without suggesting a specific model that should be implemented to achieve this. We illustrate ways in which we have operationalized the Supportive Accountability model to design for the prevention of psychosis. We provide the first documented test of elements of this model and identify the practical features that can be used to support its theoretical base. In this way we distinguish our approach from previous work on online moderation, such as that

reported by Webb et al [31], by adding an analysis of the theoretical basis for the moderation and suggesting that it works in tandem with a program of online therapy and social networking.

One element of the Supportive Accountability model is promotion of motivation: an intermediate outcome en route to recovery. HCI theory suggests users are intrinsically motivated to engage with technologies that are fun and interesting [54]. In the health domain in particular, engagement is differently motivated: it can arise from the ability of a system to address a problem that the patient identifies or finds important. We specifically consider in design the patient's intrinsic goal of preventing future illness: a significant concern of people who have had a psychotic episode [55]. It is a particular challenge for system designers to create motivation and a sense of control over a possible future condition.

5 METHODOLOGY

Our methodology conforms to a framework initially proposed by Campbell et al [56] for the evaluation of any complex health interventions and which has subsequently been adapted in research on computer supported mental health applications [57]. This framework proposes an initial stage to review theories which might provide a basis for intervention design, such as those described in the preceding section, followed by a “modelling” stage such as is described below in Design (section 6.1), which can involve elements such as research with users to help define relevant components, followed by an exploratory trial stage such as we describe in Evaluation (section 6.3), and finally a long term implementation such as we discuss in our Conclusion.

5.1 Design

The identification of the issues discussed above in the Theory and Requirements Gathering section led to the development of a set of design sketches for online delivery of therapy. These ideas were tested in focus groups in the first stage of the project. The use of focus groups follows both Campbell's model as well as Doherty, Coyle and Matthew's suggestion that one should design in the mental health setting with users and mental health professionals as well as usability and HCI experts [52]. This follows Coyle et al.'s earlier conclusion [17] that ethical considerations relating to privacy and security, arising from the sensitivity and stigma associated with mental illness, necessitate collaborative research which involves mental health professionals working closely with HCI professionals. To this end we conducted focus groups involving patients, clinicians and usability experts.

The first focus group was conducted with 6 prospective system users who were current and former patients of a youth mental health service and members of a client advocacy and advisory service there (Focus Group 1). We asked for comment on appropriate media for delivery as well as the kinds of functionality and support they would like to experience in a mediated psychological intervention. The clients explored possibilities for delivering content via media such as web sites, mobile phones, and existing popular social media platforms. Potential designs were presented as paper sketches to seed discussion about what a system should deliver

and what would be acceptable and safe. A summary of the outcomes of this focus group was taken to a second focus group consisting of 8 clinicians who worked at the same clinic. The focus of this session was on whether the intervention might facilitate, replicate, or disrupt staff-patient communication.

Clients expressed disdain for automated feedback and SMS messaging, which they felt they would find disconcerting on days that they were unwell. However they were positive about a web based design with human moderation. They expressed a desire to engage in social networking with other patients of the clinic, though they did not want their therapy or their status as patients to be visible on existing SNS such as Facebook. They indicated they would be open to completing therapy units and being involved in a moderated site. Clinicians supported the general concept but were concerned about impacts on staff workload and that the system would need to be simple to use to account for cognitive deficit in patients.

Using the insights gained at these workshops we designed a web-based system and refined it via a series of prototypes and usability and acceptability trials. Two tests for usability and functionality issues were conducted with an expert panel comprising a graphic designer and usability researcher, a web developer, a software developer and social networking researcher, an educational developer and researcher, and a usability practitioner and researcher. They provided feedback as to style and navigability which was incorporated into subsequent design. Two usability tests were conducted with an expert usability panel to test general functional issues of ease of use to ensure they did not mediate against other non-functional characteristics of the system.

A prototype web application was presented to a subsequent patient workshops conducted at the clinic. Participants found the design appealing and useable and saw value as a therapeutic support. Our approach of offering self-directed home use and social networking was quite different to the questionnaire software and informational websites typically provided to these patients. The testers were optimistic and expressed a desire to trial the finished version.

5.2 Initial Design Guidelines

Based on HCI and mental health literature and on our workshop results, we developed a set of guidelines to be followed in order to achieve the design goals previously listed:

1. The system needs to help users make sense of their illness through discussion with a cohort to which they feel affiliated or anchored in some way (goal 4).
2. A crucial factor is the capability of patients who have suffered FEP to use the technology. As stated above, people with disorders like schizophrenia can suffer interpersonal and cognitive deficits that affect their daily functioning [18]. Ease of use principles such as Nielsen's usability heuristics are especially important in designing for this group [58].

Doherty et al.'s guidelines on design for users with cognitive deficits stress the need to observe the user group in interaction with the system as part of the design process [52] (goal 5).

3. The system needs feedback that reinforces that there is a clinician actively moderating as engagement can be effected by concerns about safety and threats from the outside world [16]. Communication should not appear to be automated as this can be distressing for paranoid patients. This was reinforced in the patient focus groups and is interesting to contrast with Bickmore's earlier discussed work on relational agents[53] (goals 2 and 3).
4. Moderation should be guided by two models:
 - a. Positive Psychology which promotes self-esteem, focuses on solutions instead of problems, and creates opportunities to identify positively with the group.
 - b. Supportive Accountability which proposes that patients need to-
 - i. be self-reflective in nominating goals and proactive in addressing them
 - ii. progress through the therapy modules and commit to the therapeutic activity
 - iii. meet monitored goals and expectations (proven features of face-to-face therapy)

while moderators should establish trust and behave benevolently (goals 2 and 3).

5. The system needs to cater for patients with both high and low insight into their condition, and should use psycho-education to improve insight (goal 5).
6. The system should be interesting and engaging (goal 5).
7. The system should provide support from other clients and enable pseudonymity. It should allow sharing of experiences of the condition in a private custom space, through tools such as text chat, bulletin boards or social networking. The social networking style is recommended as it is popular in the target group (goals 1 and 4).

5.2.1 Safety protocol Design

While broadband technologies have the benefit of being able to bring therapeutic services out of the clinic to the home, they have the disadvantage of removing the safety and privacy controls inherent in face-to-face treatments. Amongst other things, the design of a therapy system needs to take account of the potential for personal information to be disclosed, or for users to take on false identities: common problems for web-based applications. While all social software must take security into account, the potential for stigma and paranoia in this cohort makes security particularly important. This relates to a very specific usability principle: that "users should not

feel apprehensive about the technology” [59 p.322] which is particularly salient for this user group. We designed the following safety protocol with reference to security best practice as defined by the Open Web Application Security Project [60] as well as requirements specific to our user group. These safety guidelines should work in tandem with the trust engendered by the Supportive Accountability model to reinforce perceptions of safety, since trust and perceived safety have been found to be related [61].

1. Access to the site should be password-protected and all users identified on the site by a pseudonym of their choice.
2. In line with Supportive Accountability, users should be encouraged to take responsibility for their own and each other’s safety and consider carefully what information they are posting.
3. Opportunity for “fake” member sign-ups should be eliminated by users being invited to join through the health service.
4. All user input should be able to be deleted or hidden later by the posting user.
5. Users should be able to “hide” and “unhide” themselves as desired, in order to deal with temporary episodes of paranoia.
6. Users should be able to easily report misuse of the site (such as abusive posts) by other users: these are flagged to moderators.
7. Moderators should be able to easily delete any user input they deem inappropriate, with the relevant users receiving an explanatory message. Moderators must be able to temporarily suspend any user from the site at any time, for example if they show signs of a deteriorating mental state or repeatedly post inappropriate content.
8. Users should be carefully selected to exclude participants at high risk.
9. All user input should be subject to an automated check for keywords relating to suicide or self-harm (sent to moderators for immediate action).

5.2.2 System Design

Based on our design guidelines we built a prototype combining two functional sub-systems:

- Web-based delivery of therapy modules
- Moderated online social interaction among patients and clinicians.

Users access the system through any web-enabled device and must first log on with their chosen pseudonym and password. Though this iteration was not designed for smartphone access, in the

trial some patients successfully used the system through their phones. The system offers a number of features that integrate therapy and social interaction. The therapy and social subsystems are integrated and share a common database so that the events that occur in one are reflected in the other. Figure 1 shows a user's "home page". It illustrates the screen layout used, with the user's therapy modules listed in a menu on the left, and other site features including those involving social interaction listed on the right.

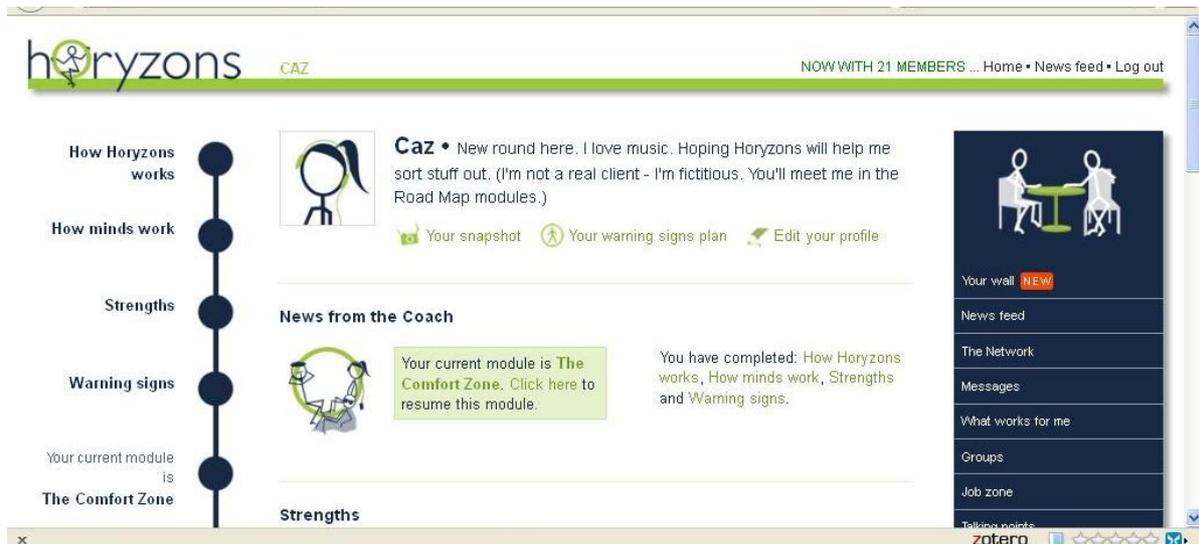


FIGURE 1: CLIENT HOMEPAGE

Patients are introduced to the therapy via an introductory module accessible through the Home Page (see Figure 1) Patients then proceed with a course of modules involving CBT, psycho-education and Positive Psychology interventions. Users are presented with a named, personalised letter setting out their goals and achievements to date. The system provides warnings and progress reports to staff so that they can intervene if necessary. These measures are informed by previous work done by our research team [21] .

Patients may use the system as often and at any time they like. As patients progress through their therapy the system keeps track of which modules have been completed as well as use of the social networking features, so that moderators can check on the current status of patients and their use of the system. A user's list of modules are presented as a menu designed to look somewhat like a railway map, to suggest a journey taken (left hand side of figure 1). Therapy materials are made interesting and engaging by integrating stories and self-appraisal exercises. We implemented an innovative interface feature based on card-sorting (figure 2) which emulated a therapeutic technique in use at the outpatient program [21]. In face-to-face sessions in the outpatient program, clinicians help patients to discover their own unique set of symptoms ("early warning signs") that precede and predict psychotic episodes. To do this the clinician presents, one at a time from a deck, cards with symptoms printed on them, and the patient places these into piles marked 'early signs', 'late signs' and 'not applicable'. This technique is valued by clinicians

for its cognitive simplicity and clarity [21]. We implemented card-sorts using the JQuery ‘draggable’ and ‘sortable’ plugins, enhanced aesthetically with CSS and connected to the site’s database using Ajax. Usability testing during development indicated that this UI technique worked well and was liked by users. Therefore we implemented it also in two other pages that involved patient self-analysis.

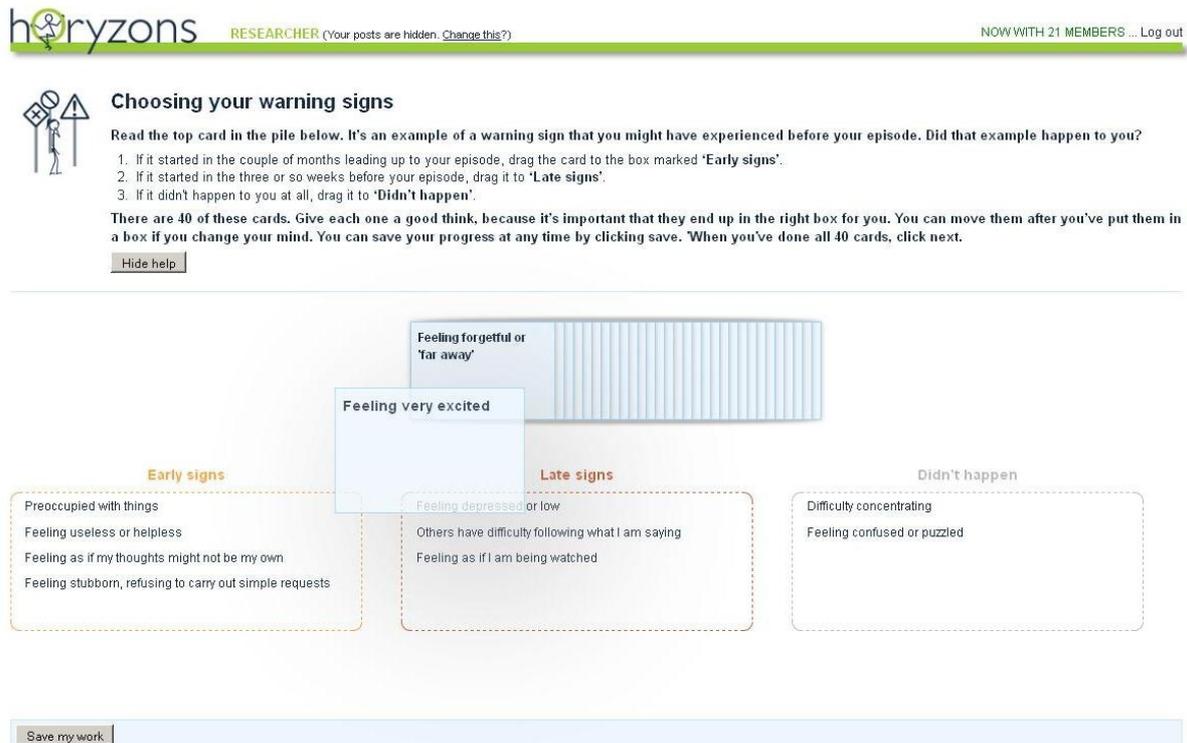


FIGURE 2: IDENTIFYING EARLY WARNING SIGNS USING CARD-SORTING

5.2.3 Social networking and the “news feed”

The design of much of the website’s user-interface is intended to appear familiar to users through emulating the look and feel of popular social networking sites: A newsfeed (figure 3) allows free-form conversation on any topic. Users (patients or moderators) can post text, photos, videos, and links to other sites.

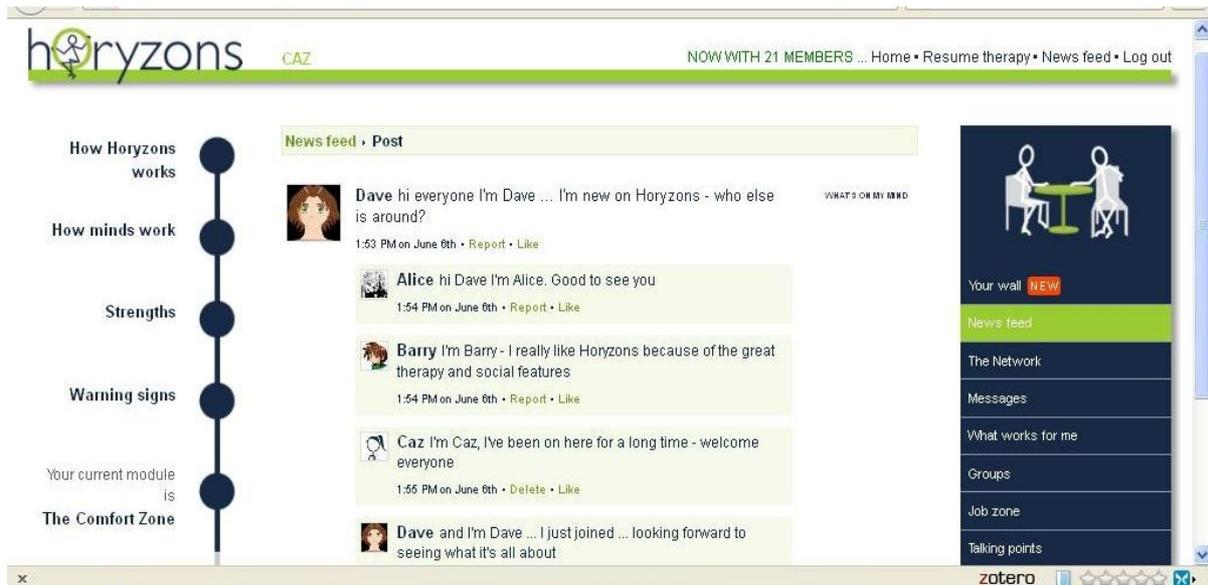


FIGURE 3: THE NEWSFEED

Notifications are generated when a user comments on another user's message: this follows common practice and is intended to motivate repeat visits to the site and promote the sense that the social network is lively. Users maintain profile pages and can read each other's profiles. Personal messages can be sent between staff moderators and patient users.

Structured interactions occur via the "What Works For Me" feature which is a forum for sharing coping strategies, and the Group Therapy feature for social problem-solving. These allow users to post solutions to common problems and to comment on solutions proposed by others.

The features can be seen listed in the menu on the right hand side of Figure 1.

5.2.4 Moderation Protocol

For the trial, the site was moderated for two hours per day on weekdays and one hour per day on weekends so regular and timely feedback could be provided to users to establish an atmosphere of trust. We developed a moderation protocol based on Supportive Accountability principles which aim to make users feel cared about and supported yet responsible for making decisions about how they would manage their condition to prevent future relapse. Example implementations of Supportive Accountability include the following:

- Moderators are to encourage a tone of hope and optimism in the social networking forum.
- Moderators are to create their own profiles so that they present as real people to whom users could relate.
- Moderators in their comments are to encourage users to practice the behavioural and cognitive skills introduced in each therapy module as a means of users taking responsibility for their own wellbeing.

- In moderating discussion, moderators are to encourage activities such as completing the homework in the strengths module (diarizing strengths, using your strengths, noticing other peoples strengths).
- Moderators are to enforce the policies and procedures of the site such as exclusion policies for negative behaviours to enhance the perceived trustworthiness of the site and to encourage users to self-moderate their own behaviours.
- Moderators are to have access to client usage data in order to both provide relevant support and encourage appropriate levels of use and patient responsibility for use .

In our system moderators use the same interface as patients and share the same underlying database, and thus were naturally part of ongoing social interaction such as newsfeed discussions. However moderation was supported by a suite of software tools for monitoring usage, such as a collection of real-time visualizations of system usage (figure 4).

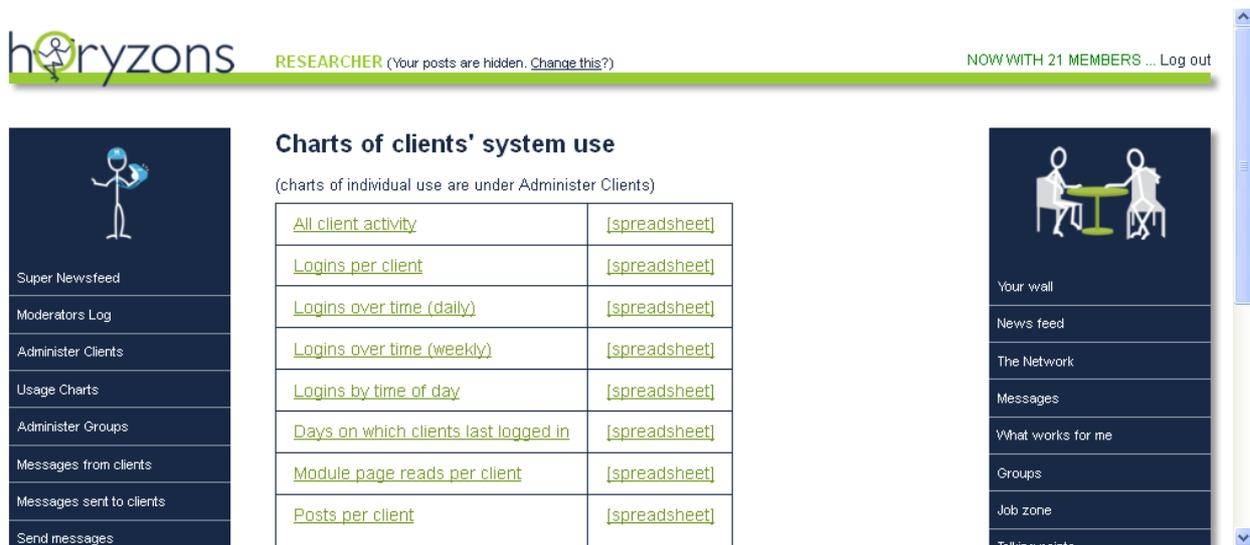


FIGURE 4: TOOLS FOR MODERATORS

The next screen shot illustrates use of the moderation system in the trial. These extracts of the Newsfeed page (Figure 5) show how the system provided an opportunity for the “coach” (moderator) to participate effectively but unobtrusively by contributing to the conversation.

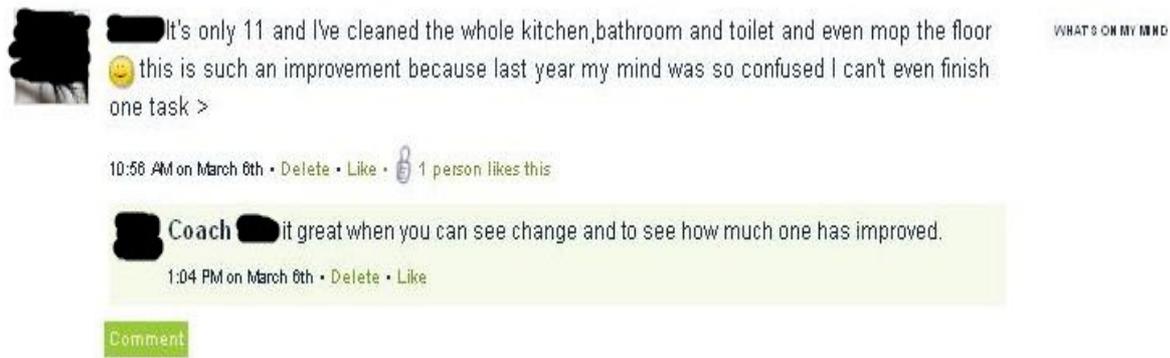


FIGURE 5: COACH (MODERATOR)/CLIENT INTERACTION

In Figure 5 (real names blacked out) the moderator provides positive support for a specific client comment which was part of a longer conversation thread with other users. Figure 1 also shows the role of the moderator as a vehicle for delivering reminder messages about therapy content.

5.3 Evaluation

5.3.1 Six-week trial of prototype system

Recruitment

A six week trial of a prototype system was conducted early in 2012. The participants included 20 patients of an early psychosis prevention program at the mental health service with 3 staff members of the clinic acting as moderators.

Participants were informed that the study was aimed at finding out what young people with psychosis thought of the program. Participants were told that the results from the pilot test would help the researchers to make modifications so that the system could eventually be tested over a longer period of time to assess its impact upon young people's recovery from psychosis.

Once informed consent was obtained from each client the RA administered two psychological tests: the SCID (Structured Clinical Interview for DSM Disorders) and the BPRS (Brief Psychiatric rating Scale). For minors, consent was obtained from a carer or guardian. Following Miles and Huberman's guidelines for reliability [62] it was stated explicitly that the RA was not a member of the clinical treating team, and participants were fully informed that their choice regarding involvement in the study would in no way affect their access to usual treatment. Participants were reimbursed \$30 for the first research interview, \$10 for logging on one or more times per week during each week of the study, and \$20 for the follow-up research interview. Participants were recruited progressively over the six weeks of the trial, and each participated for at least 4 weeks.

Inclusion criteria were: age 15 to 25, experience of a first episode of a psychotic disorder (according to categories established by the American Psychiatric Association), and at least 4-

week remission of positive symptoms of psychosis. (Symptoms are clearly established in the discipline and include confused thinking, delusions, hallucinations and disorganized thoughts.) Exclusion criteria included severe suicidal thoughts and diagnosis of either antisocial or borderline personality disorder. Participants were assessed at baseline and 1-month follow-up.

System Initiation

The RA oriented participants to the website and the terms of use which detailed potential consequences of inappropriate online communication and procedures for sharing information between the researchers and the treating team. Carers or guardians of minors were oriented to the system but in the interests of the young person's privacy were not provided with login details. Participants signed the terms of use and were coached in management of personal privacy on the site, how to report inappropriate use, and what to expect from the online moderators.

System Use

Participants could access the system at their convenience, 24 hours per day, from any Internet-enabled device. At the conclusion of the 6 week trial the RA conducted one-on-one audio-recorded interviews to ascertain each individual participant's experience with the system.

Interview Protocol

Interview protocols were established and questions kept consistent to ensure dependability/reliability across research assistants [62]. Internal validity/authenticity [62] of the findings was cross checked with moderators and other counselors and staff at the youth mental health service post-trial to ensure the account of the trial "rang true".

6 DATA GATHERING AND ANALYSIS

Data analysis included measuring the frequency of posts that were of concern to moderators, posts that triggered reports by other users, and posts that triggered the automated keyword system. Quantitative variables were aggregated into simple descriptives in order to characterise the experiences of the users and reported in a previous publication [4].

The interview data was systematically transcribed, coded and analysed to uncover emergent themes. This was done independently by multiple reviewers. We used accepted theory building approaches to data analysis to ensure we were not selective in choosing data to support a particular view. These approaches recommend multiples parses of the data with different levels of coding and the development of theoretical notes and memos as the data is progressively worked through. We coded the audio-recorded interviews through three cycles [63, 64] using the software NVivo, version 9. The open and axial coding cycles were used to induce propositional statements [64] from which the themes were developed.

7 RESULTS

The trial produced two sets of results. In a previous paper we identified and discussed results relevant to system usage and specific psychological measures such as depressive symptoms [4]. These results illustrated promising usage for a short term trial. They do not allow us to claim long term engagement, but indicate positive newcomer participation and initial engagement and uptake.

Only a brief summary of the results previously published will be offered in this paper, to give context to the current analysis, with the most salient quantitative indicator of usage being that 60% of participants utilized the system over 4 weeks and 70% for at least 3 out of 4 weeks, with a total of 275 logins during the trial. Importantly, analysis of symptom rating measures revealed an improvement in participants' depressive symptoms at 1-month follow-up. Moreover, 60% reported that using our system significantly increased their social connectedness, 55% felt empowered in their own recovery process, and 70% considered the system to be a useful long-term treatment option beyond discharge.

In the current paper we build on this analysis by using the data from patient interviews to better understand the effects identified and to relate these to the design goals stated earlier in this paper.

7.1 Interview Results

Each trial participant was interviewed about their experience of using our online therapy. Four categories emerged under the broader theme of user experience. These results provide support for our design goals.

The data suggest that users experienced the site in four significant ways:

Theme 1. It helped give them a sense of belonging and identification with the group, which led to feelings of security and safety

Theme 2. It helped them to understand their condition better

Theme 3. It helped to engender positive thoughts, accountability and a focus on individual strengths.

Theme 4. It was visually appealing and engaging to use

7.1.1 Theme 1- Belonging and Security

Data samples that support theme 1 included the following:

Participants commented on feeling safe “Because I knew no-one else could access it. I knew that only people from (Youth Mental Health Centre) could see it.” (participant 7).

Anonymity was appreciated ‘...even though it was social networking, it was quite private- you didn’t really have any information about yourself in the profile apart from your name, and like say a photo. But you didn’t have to worry about coming in and walking around and someone recognizing you..’

When asked if they felt supported by the moderators one participant said: “...yes, because (they) are from (Youth Mental Health Centre) and I trust (Youth Mental Health Centre)” (participant 18).

Participant 3 said: “.. It’s a peer-support thing. It’s a place where you can feel comfortable just talking about what’s going on, and what you have been through, and you can feel secure and not feel scared people will judge you, because they have been through the same thing and will be supportive. It’s a comfortable environment.”

On the idea of belonging and feeling secure participant 15 commented “ it made it easier to discuss things that you wouldn’t normally talk to people about. It was good because everyone was in the same boat.” Similarly, participant 4 said “...you can say what you wanted. You wouldn’t be judged.” Participant 5 commented that they found the site helpful “because they (other users) know what you have gone through and its someone to relate to... There’s not a lot of people who understand what its like.”

Participant 9 commented that he liked getting lots of incoming email notifications ...”There’s a connection. 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.”

Some felt that there was a benefit in not being connected offline: “I didn’t feel like I was being judged or anything, because I didn’t know any of them personally.” However some expressed some discomfort in networking with people whom they did not know offline. “You’re on a social network level, not on a personal level, so it always makes it a bit more strange.”

7.1.2 Theme 2- Better understanding of condition

Example data that supported theme 2 were as follows: Participant 16 said he would recommend the site to “people who have been having a bit of trouble with mental health issues and stuff like that because it gives you more of an understanding of things and I think if you understand what is happening to you, it makes it a little bit easier.” Participant 15 echoed the informational value of the site in providing opportunities to share information with others in the same situation: “it’s useful and straightforward and gives you the option to discuss it with people.”

In stressing the help the system provided in understanding their condition, one participant said it was helpful to get in touch with afflicted others as “ it also made me feel better about my situation because I’m assuming a lot of people would have been through it worse than me.” Other

participants also alluded to this idea of the site providing information and knowledge about the condition through a comparison upward, or downward, with their own experience.

The “What works for me” section was cited as particularly useful in providing lay help from the group: “It has other people’s suggestions as well, not just the ones I think might work but other stuff I never thought of before” (participant 3) and simply “because it has tips on it” (participant 14). Similarly, the Early Warning Signs module was well supported with comments such as “you know what can happen as well, not that it all happens to you, but you know what happens to other people as well. And you can actually help them too, if you use warning signs.” Overall the site was seen to help users understand their condition better in reference to others experiences and to empower them to help themselves and others.

7.1.3 Theme 3- Engendering Positive Thoughts, Being Accountable and Focusing on Strengths

Regarding theme 3, the site was seen to help engender positive thoughts and to encourage individuals to focus on their personal strengths. For example comments such as the following were common: “it also made me feel better about my situation because I’m assuming a lot of people would have been through it worse than me” (participant 14).

When asked about his experience with the system participant 4 replied “....if someone needed cheering up, or needed a way to get around obstacles, they could refer to the website.” He continued “ they helped me feel good because I’d say I don’t feel like going to work today and someone said that’s pretty amazing that you can get up at 5 in the morning. And I thought, yeah, it’s not really amazing but you’ve got to do it. But that stuff cheered me up, so I thought it was really good.” Similarly participant 3 commented “.. Its kind of like: hey, I was like that before, and hey look what I am now, and then I can help them. It makes you feel better that you can help other people too.” In reflecting on their willingness to use the newsfeeds participant 13 said they liked that “everyone was posting positive stuff.” Participant 4 said the newsfeed let you “see how others were going and if you wanted to chat to them or cheer them up, ask them how they were.”

Analysis of comments posted to the social network revealed that the bulk of peer-to-peer interactions were supportive (e.g. ‘YOU can do it! i should say WE CAN because we're in this together’), and focused on recovery-related themes (e.g.‘(...) to be with a group where everyone can relate to each other somehow and with one common goal: to move on’). Moreover, participants frequently shared positive experiences and accomplishments (‘e.g. ‘i feel so happy :) being busy with school work is so much better than staying at home doing nothing :)’ and were positive about the use of the system (e.g. ‘I’m on board, this will be interesting’)

In relation to theme 3 users particularly commented positively on the style of moderation. Users noted that the therapy modules encouraged accountability and self-reflection. “ I just thought picking out your strengths was a really great idea. Once you know all your strengths and weaknesses you can practically overcome anything. It really makes you think more about

yourself and what things you can overcome (participant 4). Another also commented on this realisation of strengths: “Wow, there are all these things that can be strengths actually!” (participant 3).

The positive orientation of the moderators was also noted: “I didn’t feel like someone was bossing me around. It was just guidance, like supervision, to make sure everything works fine and is going well for you (participant 3)” and “they’d always be commenting on things, and being nice (participant 4).” Users appreciated being able to communicate with moderators privately through the message system to remind them about goals and expectations: “It was good because it reminded me I had a new module (participant 15) or “(I’d like to receive) feedback on how I was going , ... or just checking” (participant 16). Users appreciated the positive and caring approach of the moderators which seemed to engender trust and confidence in the moderation: “...It would be really good if they stayed on because they could help a lot more people (participant 4)”. When (name of moderator) asked me how I was going on Horyzons...”that was pretty cool, checking up on me (participant 3). Following on from this idea were further comments such as : “I knew that they would always be there...That they supported us” (participant 6).

Users were also positive about the level of moderation: “.. Because they are always on line, it seems. “You message them, and 15 to 20 minutes later there’ll be a message reply” (participant 12). Participant 15 commented on the value of this. “if you wanted to say something about how you were feeling, within the next couple of hours you’d have a response, ... so it’s really helpful.”

7.1.4 Theme 4- Appealing and engaging presentation

In relation to theme 4, further incentive to use the site came from it being considered helpful, appealing and fun to use. Many patients considered the therapy modules to be helpful (e.g. ‘everything is related to the next thing, everything is progressive, everything is linked, I like reading it and thinking over it’). Many features of the therapy modules were noted as engaging and fun” “ I like how you drag and drop the strengths. I’ve done card sorts before. So I’m like “hey, I’ve done this before” (participant 3).

Some however found the number of features overwhelming. Echoing the warning of Doherty et al. (2010; p. 247), one participant reminded us that a therapy for psychosis sufferers should not be too complex: “There are all kinds of other things as well like ... too many “What Works For Me”, Groups, like just too many things.”

Other comments testified to interest in the story lines in the therapy: “I like the stories of Caz and Raj. I was kind of looking forward to what happened to them as well. I thought it would be like a happy ending as well, but actually there’s the comfort zone stuff first, like how it shrinks and what they will do- it’s kind of exciting to find out” (participant 4) .

However, not all users were able to rally this level of enthusiasm. Some did not participate at a high level, and one participant reminded us that psychosis and depression were 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.”

8 DISCUSSION

Earlier in this paper we proposed a number of theoretically motivated design goals aimed at encouraging engagement. Our results indicate that the design trialed goes some way to achieving the goals. The themes uncovered align with the goals as follows:

- Design goal 1, a secure environment (private and pseudonymous that encourages co-belonging) is supported by the data collected under theme 1, which suggested that an environment that felt secure and provided a sense of belonging was achieved;
- Design goal 2 called for incorporation of Positive Psychology. Theme 3 shows that participants commented enthusiastically about the support and encouragement of moderators, suggesting that the Positive Psychology approach was valued.
- Design goal 3 called for Supportive Accountability. The data collected under themes 2 and 3 illustrates support for the central platforms of Supportive Accountability which emphasizes a co-responsibility between therapist and client, and clients’ use of personal resources for self-monitoring and goal setting within a benevolent counseling environment. Theme 3 data also align with the objectives of Supportive Accountability in encouraging participant responsibility including self-education.
- Design goal 4 proposed provision of opportunities for learning about one’s condition. Data aggregated under theme 2 suggest a positive response to the ways in which the system provided greater understanding by which participants could self-manage their condition.
- Design goal 5 and theme 4 data align in, respectively, advocating and supporting an engaging and interesting design.

The following discussion expands on these relationships, and uses the theories previously discussed to further explain the results of the trial. Although not all users were motivated to engage, usage data previously reported [4] illustrate high and reasonably well sustained rates of use over the testing period. Viewed through the theories discussed earlier in our paper, our interview data helps explain why this was so: Firstly, engagement was facilitated by a clear sense among participants of being in what was described earlier as “anchored relationships” [46] through their membership of the same mental health service. The online community clearly became a secure space where users felt a sense of belonging and connectedness (see responses under theme 1). The comment that they felt safe using the system was repeated by many users who felt confident that the site could only be accessed by (mental Health Centre) clients and, as

stated above, the sentiment “ I trust (Mental Health Centre)” was expressed by several participants, which supports design goal 1.

Overall the sense of belonging to a group of people, “anchored” [46] in the same context and feeling value in belonging was a major theme. Participants affiliated with the group in ways that encouraged them to seek support from it. Participants found it easier to talk about their problems with others who had had the same experience. As Dwyer et al [46] suggested this provides not just connectedness but an opportunity to self-present in a positive way [42] in an environment where users do not feel judged. Participants reported that they felt good about being able to help others. This allowed them to take a role in the group. This converted membership of a problem space where they might feel stigmatized by association, into membership of a support group where they had a role in providing the support and an opportunity to present themselves to the group in a way that increases their own self-worth. This positive focus also fits with design goal 2.

Secondly, the affiliative model suggests that people benefit from “downward comparisons” [51] to others going through a worse experience (see responses under theme 2). This was borne out by participants quoted above who described how reading about the experience of others who had had more severe episodes made them feel less negative about their own experience. This concurs with previously described work on why people with medical conditions participate in self-help websites. Theories of affiliative behavior also suggest that people like to affiliate in different ways. The site provided opportunities for users to either participate actively in the social networking, to merely eavesdrop on the social networking, to post comments on interactive pages like “What works for me”. Usage and interview data suggest that the option to affiliate through these different channels helped maintain usage across the full range of participants.

Thirdly, in line with the Common Sense Model (CSM) [48] the data show that participants appreciated the opportunity to share information and find lay explanations from the group for how they might be feeling or acting. From tips in the “What works for me” section to the more detailed information on early warning signs in the therapy units, the site was seen as helping users develop an understanding of their condition in reference to the experiences of others, and to empower them to help themselves and others (theme 2). Empowerment through sharing information is stressed in the Common Sense model as a way of explaining user participation.

In other health domains, people who use the CSM to help understand their medical condition have been found to be most interested in the effect that their condition has on their everyday life [65, p.904]. This is what compels individuals to stay engaged with online health communities: these provide opportunities to follow the ongoing progress of others. The CSM suggests that “illness representations are linked to the selection of coping procedures, action plans and outcomes [65, p.904] and that users trying to make sense of their condition will keep coming back

to a site that continually provides new options for implementing these strategies. Our data suggests that some participants saw the site as providing continuing opportunities for new action plans. Participant 9, for example, spoke of receiving incoming messages with tips for approaches “he hadn’t thought of” and participant 13 of “stuff I never thought of before”. These and many other examples support the idea that an effective site design which generates longer term engagement will allow users to share common sense or easily understandable coping strategies and actions that they can see have helped other users.

The essence of the Common Sense Model is that users look for “labels to identify themselves (albeit not necessarily biomedically correct)” [65,p.904] and this occurred with our sample. Almost no-one in the interviews referred to themselves as having a psychotic illness, yet they knew they had all come from a mental health service, and many spoke of “others in the same boat”... “in this together”.. others “understanding what its like”. In ways that suggest both a CSM and an affiliative approach, users connected with the user group as a form of support separate from the support they gained from medical services, and made sense of their identification with the group in ways they found helpful and positive and non-stigmatizing. The affiliation of most members was self-determining in the sense that they were able to feel a part of the group without having to attach themselves to negative labels.

This outcome also helps us to better understand Newman’s premise, discussed earlier [32], that when users feel stigmatized they prefer to network in a trusted dedicated space as suggested by design goal 1. This assertion was borne out by interview data, even though we worked with a different cohort and in different health context to Newman. There was clear support for Newman’s proposal of a dedicated website which users join understanding each other’s situation and shared everyday experience, and which is not connected to the general social networking applications.

The positive response to the peer interactions and therapy was coupled with an encouraging reaction to the moderation process (see responses under theme 3). As stated earlier, Doherty et al [1] recommended considering the dynamic of the client and therapist together without specifying precisely how this guideline should be implemented. We show here the positive response from users when this dynamic is mediated through the principles of Positive Psychology and Supportive Accountability as suggested by design goals 2 and 3. The Positive Psychology framework was successful in promoting ongoing participation as was borne out by the data from theme 3. Controlling the space so that the output is focused in a positive way is an important addition to design of the online health community. Previously-cited work discussed the benefit of automated filtering out of negative messages [13] but we have extended this in our work where trained moderators filter messages. Having both the therapy modules and the moderators convey positive messages has provided an enhanced solution to this issue, allowing the site to be designed in ways that will encourage long term engagement and be seen as safe and supportive.

This expectation aligns with past research which suggests that interventions which challenge self-stigma are more likely to promote adherence [18] and fits with the Supportive Accountability (SA) approach where moderators are encouraged to be benevolent. That users' perceptions of moderators fitted this model was borne out by the high level of trust in moderators and by users' affirmation of moderators' positive style.

Our work further illustrates the viability of the Supportive Accountability (SA) approach in the ways it helps develop intrinsic motivation in users. We designed the system to engender motivation by encouraging users to focus on future prevention through features such as the identification of early warning signs, and in assisting users to become actively involved in managing their own condition and their own relapse prevention. Increased motivation and belief in the efficacy of the application was clearly exemplified by some users' desire to provide support to help others, which illustrates an extended effort and more significant motivation than is required in simply looking to help themselves.

The style of moderator intervention was regarded as low key - "just guidance, like supervision" - which users found both benevolent and empowering, in line with the SA model. Users expressed appreciation for getting feedback to remind them of positive actions they could take. Additionally, the fact that the application has so many places where users can express themselves, the newsfeed, What Works for Me, Talking Points, the personal profile, personal messages between moderators and users, makes it difficult for users to selectively manage the information and cues conveyed to create a positive profile or bias. The user is encouraged to be open and the moderator has their profile to work with. This further promotes the trust relationship encouraged by SA, as revelation of personal information is known to promote trust [66] and an active user will likely reveal significant information to moderators. Better knowledge of users, in turn, helps alert moderators to early warning signs of relapse so the moderator can take steps to encourage users to initiate preventive measures.

The short term nature of the trial makes it hard to be conclusive about how effective Supportive Accountability, Positive Psychology and our technology design might be at promoting long term engagement. Rather it goes some way to illustrating what features might attract users to a site in the short term, which are worthwhile taking to a longer trial. However, participant comments indicate that a system that encourages users to set goals which are supported by moderators who establish their credentials and create a positive and trusted space goes some way toward promoting the motivation required for the intermediate goals of consistent, ongoing use and the sustained levels of motivation and engagement, required for the overall goal of promoting relapse prevention.

Finally, it must be noted that not only online therapy but traditional face-to-face therapy is subject to drop-out [67] and the problem of getting young people with psychotic illnesses to

engage long term with either form of treatment is not easily solved. As Doherty et al noted, “engagement is more than the converse of attrition” [1, p.8]. Turning up for treatment or signing on to a website does not necessarily denote genuine engagement with an intervention or even real recognition by users that they have a problem. Hence the enthusiasm illustrated by interview data and the indications that users were actively participating, connecting with other users and gaining from this participation are particularly encouraging. We anticipate that in a longer trial where site users experience a more dynamic environment with new users constantly entering and new ideas and solutions being generated, feedback from users will be even more positive. In cases where users did not engage, their comments (such as, “ I haven’t been on the computer for a while”) suggest the value of further pursuing mobile options which may require less motivation for uptake.

9 CONCLUSION

Following the remarkable popularity of Facebook and other social media, system designers in many domains have sought to integrate social networking into online applications as a way of engaging users. However the uniqueness of mental health cohorts means that designers face additional challenges and cannot assume that a one-size-fits-all SNS module can be plugged into bigger therapy based systems to ensure high usage. Consequently in this work we have set out design goals tailored to a specific mental health population, and illustrated the initial success of our design in meeting these goals.

In this paper we explored the utility of Moderated Online Social Therapy (MOST) through an “invitation only” psychotherapy and social networking system for young people who have suffered a first episode of psychosis. We analysed our design and trial of MOST and found that we can claim initial success for a system which combines therapist-moderated social networking with online therapy, judged by qualitative and quantitative measures. We found that the unique combination of peer interaction, clinician support and online therapy provided a level of support which built on the success of previous health based applications which provided either one or two of these features. We found support for incorporation of the Supportive Accountability model and feel it can be used in combination with previous guidelines to design a sociotechnical system that is particularly appropriate for preventing future relapse in this unique user group.

The success of this project to date suggests that there are design opportunities in solving the tension between the inclination to want to present positively on social sites and the support of health-related goals which require honesty and disclosure. We have shown that moderator-supported custom environments in which individuals feel safe and protected and which provide an opportunity to convey strengths and accomplishments within an engaging design can go some way to encouraging greater rates of participation in computer-based therapy for mental health. These are important findings and indicate a constructive design direction for harnessing the

benefits of both social networking and online therapy to create systems that young mental health clients are willing to use and can derive value from.

From the insights gained from the short trial we believe that long-term utilization of the Supportive Accountability model will benefit from extra tools designed to support the moderator such as visualizations of activity to indicate whether users are active or passive, intrinsically motivated or not, autonomous or not, greater use of one-to-one communication between moderators and users, and user modeling to allow moderators to target promoted content to individuals. These features would help provide a more structured application of the Supportive Accountability model.

Our results to date allow us to conclude, at least tentatively, that by acknowledging the specific characteristics of particular user groups and by engaging with previous theories that provide insight into social networking use and therapeutic methods, we can design systems that enjoy greater uptake and sustained usage. As online social networking comes of age, therapeutic frameworks like MOST can help meet the challenge of exploiting this phenomenon for Positive Computing by providing tailored systems to solve unique problems.

10 FUTURE RESEARCH DIRECTIONS AND CONSIDERATIONS

We have secured funding to expand this project in two ways. First, we are preparing to conduct a 4-year randomized controlled trial to test the clinical efficacy of the therapy: during this longer trial we expect to have around 100 users at a given time. Second, we are creating versions of the system for young people with depression and for families and carers of patients. This creates the need to consider scale both in terms of the time the social network exists and the number of people who comprise it.

The first problem that might arise in scaling to more users concerns the number of user inputs (posts, comments, etc) from other users that a given individual can reasonably process. We have implemented and are fine-tuning a salience function that take into account recency and popularity as well as therapy-related factors such as whether a post includes a link to therapy content, and system-specific factors such as whether posts are user or system-generated.

More subtly, a broader user cohort might create problems concerning trust. Our trial participants indicated that a key factor that helped them develop trust in our system was that it is connected to a clinic with which they were already familiar. This raises the question of whether clients attending other clinics, or those who don't have access to a clinic at all, can develop sufficient trust to fully engage.

In rolling out new instances of MOST we plan at this stage to keep networks small - under 100 users per therapy group- and to limit each network to a particular therapy. We are inclined to follow a similar approach and create new social networks if MOST instances are implemented in

other clinics or cities. However we note that when asked how many users our system should support, most of our trial participants responded with very large numbers. Though these were not deeply-considered responses, they suggest that young mental health clients might be comfortable with sharing a therapy website with strangers to a greater degree than we have anticipated.

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