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USING ON-LINE TECHNOLOGIES TO IDENTIFY AND TRACK EARLY WARNING SIGNS OF PSYCHOSIS

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Research-in-progress

Abstract

This research in progress examines ways to design on-line applications that help young people suffering from psychosis to identify and act on the early warning signs that indicate a potential relapse in their condition. It examines how proven treatments from face-to-face therapy can be incorporated in information systems design to create effective on-line or mobile therapy tools. It uses a multi-disciplinary approach to propose a design and testing program based on both psychological and usability principles.

Keywords: Early warning Signs; participatory design; on-line therapy

1 Introduction

Psychosis is one of the most costly mental health disorders in terms of human suffering and presents a complex psychosocial problem. Conventional therapies for psychotic disorders involving face-to-face counselling are labour-intensive, and supply rarely meets demand. In recent years, attempts to provide more cost-effective and accessible services has seen a growth in the development of online therapies and peer support for mental illnesses such as depression. Psychotic disorders including schizophrenia have not been as well serviced although there have been some early efforts to establish web-based treatments. Online treatments have generally been one-dimensional websites that offer only therapy and have suffered high rates of attrition.

This paper proposes design guidelines for therapy modules for early warning signs (EWS) of psychotic relapse in an on-line therapy website built to support young people recovering from a first episode of psychosis (FEP). People who have suffered an initial episode of a psychotic disorder typically achieve remission from acute symptoms, which include hallucinations and delusions, but remain at risk of suffering further episodes, with consequent problems for participation in regular work and education. Consequently, treatments that focus on relapse prevention for sufferers of FEP are important in reducing the long-term impact of psychosis. However, even with the best quality treatments, relapse cannot always be prevented (Birchwood, Spencer et al. 2000). One approach to prevention is to focus on identifying the individual patient's EWS and personal strengths.

2 Work to date

In initial work (Alvarez-Jimenez, Bendall et al. 2013) we have built a prototype system which adheres to a novel model of integrated support which we call MOST for "Moderated On-line Social Therapy". We conducted a six-week safety and acceptability trial of MOST with members of a youth mental health support service. Twenty subjects aged 15-25 years participated in the use of a website that integrated the use of therapy modules with professional moderator support and social networking among users. Features included group problem solving, discussion threads linked to therapy modules, and a job zone providing vocational training and rehabilitation support. A "wall" function organised discussion under headings such as "what cheers me up". Therapy modules included a module on "How Minds Work" which helps users come to terms with the experience of psychosis. Over the six weeks patients logged on an average of 13.2 times with 70% considering the system to be a useful long-term treatment option beyond discharge and considered safe and acceptable by users.

The trial produced encouraging results in terms of engagement and therapeutic value and the attractiveness of integrating social networking with therapy. However, the limited extent of the pilot trial means that we are unsure whether the system encourages long term use and provides the type of support required to play a significant role in preventing psychotic relapse. Consequently, we are planning a longer controlled trial which involves exploring additional features designed to enhance usage and therapeutic effectiveness.

In the next stage of this research, we plan to extend our technology to monitor (EWS) and strengths using web-based technologies. This plan will provide users with a constantly available facility for tracking their individualised EWS and responding in a timely fashion. This is an innovative approach in balancing EWS tracking (which can be stressful) with an affirming and positive focus on strengths. Our challenge is in how to use web-based technologies and individualised prompting to achieve this balance. In the next sections we describe previous research on EWS, personal strengths and self-monitoring and consider how it can inform the design of therapy modules for monitoring EWS and strengths. We address the following research question: **What design features should underpin an**

online intervention to detect Early Warning Signs of relapse in young people who have experienced a first episode of psychosis?

3 Early Warning Signs of Psychosis Relapse

Previous research shows that vigilance in monitoring for EWS can prevent relapse in people diagnosed with schizophrenia (Spaniel 2008). This is of significant interest to psychosis patients who fear relapse (Yung and McGorry 1996) and who thus may be motivated to engage with a system that seeks to monitor EWS. For individuals who have previously suffered an acute psychotic episode there are typical early warning signs that precede relapses, although these vary across individuals (Swan 2009). These “relapse prodrome” signs include depressed mood, disrupted sleep or appetite, attenuated psychosis-like symptoms such as mild suspicion, and clear psychotic symptoms such as auditory hallucinations which may not have reached frequency or duration criteria for a full-threshold episode.

Research has shown that people are often able to detect early signs of likely relapse (Birchwood, Spencer et al. 2000) and that 63% of sufferers maintain awareness that their condition is deteriorating up until the time of complete relapse (Birchwood, Spencer et al. 2000). Thus a patient may be responsive to therapy based on EWS because they acknowledge these symptoms. This prior research was however completed on patients who had had more than one psychotic episode: rates of awareness may be less for those who have had only one. Medication use can also mean that symptoms after a first episode differ from those that preceded the original episode. Thus patients who have disengaged from continuing care after remission of symptoms may need assistance detecting EWS and in monitoring them in an on-going fashion.

3.1 Self-Monitoring for EWS with Moderator Support

The availability of medical advice on-line and the use of monitoring technologies have begun to shift thinking from an understanding that the medical profession controls the detection and evaluation of illness to one where patients are involved in detecting and monitoring disorders.

Self-monitoring is becoming increasingly popular as governments try to redistribute the responsibility for individual health (Johansen, Henriksen et al. 2012). Enthusiastic use of the Internet and mobile phones makes self-monitoring with new technologies an obvious pathway for future treatments and fits with the new model of healthcare which is “co-care” (Wolf 2010) between patients, physicians and carers. Trends toward self-monitoring in many areas of personal health such as weight loss and diabetes indicate that people are willing to self-monitor and it can in fact become a compelling and self-perpetuating practice (Pina, Ramirez et al. 2012).

Previous work on self-monitoring by psychosis sufferers has employed home tele-monitoring via Internet enabled devices (Granholtm 2011). This work showed that automated prompting with electronic devices created some improvements in medication adherence, socialization and reduction in hallucinatory symptoms (Granholtm 2011).

Our MOST model proposes that online systems for self-monitoring of early warning signs should be supplemented with human support by online mediators. This follows a model known as Supportive Accountability (Mohr, Cuijpers et al. 2011) where the patient is made accountable for their level of on-line participation through processes such as goal setting and monitoring and the moderator establishes legitimacy by showing expertise, trustworthiness and benevolence. Thus both parties need to be active in their engagement. Because of the individual nature of EWS this moderator-supported approach is considered to have a greater likelihood of success than automated prompting, although some individuated prompts can also be built in to the system.

Previous work suggests that there is some suspicion of self-monitoring and concern about some of the feelings it engenders. Self-monitoring can have a range of negative impacts including the promotion of

self-criticism (Wolf 2010). It can lead to feelings of negativity and failure when results do not positively reflect the self. Young patients with psychotic illness are particularly vulnerable to negative thoughts, are often difficult to engage and are self-conscious about their illness. Consequently, models and tools for self-monitoring that have been successful in areas such as weight loss and diabetes do not necessarily transfer to the domain of youth mental health. It is possible however, that moderators acting either as observers or direct participants can assist in controlling these negative effects and encouraging open disclosure of EWS. There is a need to examine the unique requirements of this particular user group and consider how self-monitoring can be used in tailored systems to promote feelings of positivity, without exacerbating pre-existing paranoia or low self-esteem.

3.2 Positive Psychology and Strengths

In regard to attracting and retaining users for depression management websites, it has been found that interventions that take account of the patient's existing strengths and resources are most likely to be effective, as is treatment tailored to meet the patient's individual interests (Doherty, Coyle et al. 2012).

Research suggests that a focus on strengths identification can also be valuable in relapse prevention if done in conjunction with EWS monitoring. The rationale for this is derived from positive psychology principles (Seligman and Csikszentmihalyi 2000) and focuses on encouraging patients to put strengths into practice.

Identifying strengths can be effectively used as a relapse prevention strategy in itself, and as a way to cope with EWS. This practice-based approach requires an interface design that involves not merely reading about strengths but encouraging patients to engage with the system in identifying their own personal strengths as well as active strategies to implement strengths (Schueller and Parks 2012).

4 Design Guidelines and Tool Development

We designed some initial guidelines for EWS monitoring and development of Strengths. Work by Doherty, Coyle and Matthews (Doherty, Coyle et al. 2012) provides guidelines for mental health technologies, although they do not specifically envisage a site that combines therapy with moderation and social networking. Their work is directed generally at mental health, not specifically psychosis, although much of their previous work examines depression. Nonetheless many of the suggestions that they make are appropriate for psychosis patients: for example, to design with specific outcomes and a specific context in mind, to collaborate with mental health professionals, to be user centred, and design for engagement. The validity and usefulness of the guidelines that follow is underpinned by the literature discussed so far as well as the results of our early trials:

1. Use self-monitoring to identify individual EWS
2. Provide moderator support to control the negative effects of self-monitoring
3. Allow users to identify individual strengths using positive psychology principles
4. Use personally tailored materials to cater for the characteristics of patients with FEP. That is:
 - a) simple and uncomplicated to cater for possible cognitive deficits
 - b) interesting enough to attract those who resist participation and are difficult to engage.
 - c) Relevant, perceived as helpful, supportive and non-stigmatising, dynamic as a way of attracting a young cohort
5. Utilise usability principles and engage in participatory design (Kensing 1998) through iterative acceptance testing.

6. Utilise learnings from established successful face-to-face programs relevant to EWS and Strengths identification

After arriving at these design guidelines we have developed two modules which we intend to roll-out for both personal computer and smart-phone use. In the *Early Warning Signs* module we have implemented a card-sorting technique which has proved engaging in face-to-face therapy to help patients to discover their own unique set of EWS (as indicated in guideline 1). Using the JQuery 'draggable' and 'sortable' plugins, the user selects cards with symptoms printed on them, and places these into piles marked "early signs", 'late signs' and 'not applicable' as illustrated in Figure 1. Usability testing during development indicated that this UI technique worked well and was liked by users.

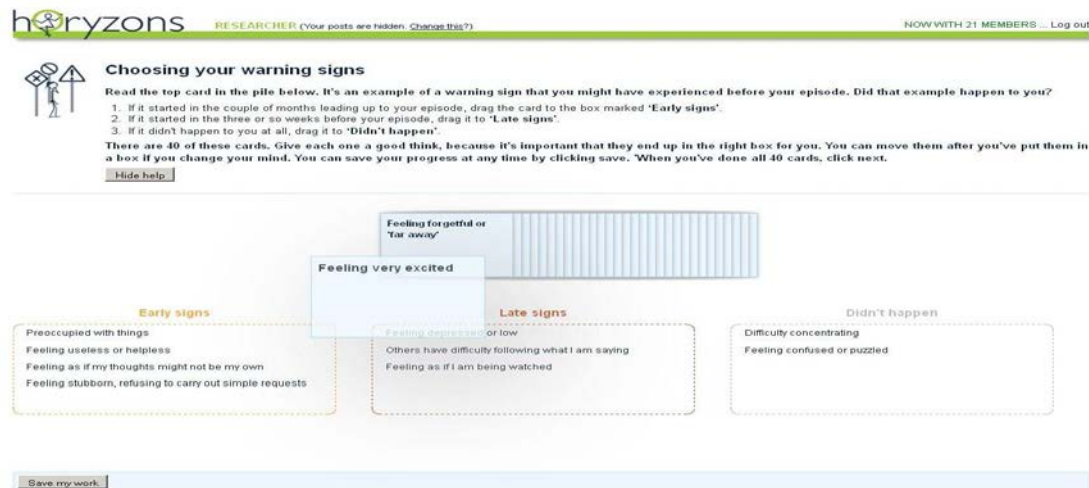


Figure 1: Early Warning Signs card sort

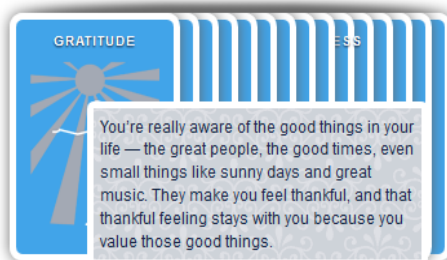
All materials in the Strengths and EWS modules have been produced by an experienced writer who has worked previously in adolescent fiction and are designed to be upbeat and fun to read and use positive psychology, as indicated in guidelines 3 and 4.

The *Strengths* module starts with the following introduction.

Everyone has strengths. That doesn't just mean lifting heavy things (although good for you if you can). It means there are sides to your personality that are strong and good. When you use those strengths, you do better and feel better. In this module you can find out what your strengths are, and build on them.

It sounds a bit weird, doesn't it? We rarely talk about being unusually good in some way, but we can all find something about ourselves we don't like. Well this is the reverse of that: here you have official permission to think about where you're talented.

Users then work through another card-sort listing 24 clearly-explained strengths and choose the ones that apply most closely to them. The materials encourage users to think of themselves at their best, not necessarily as they might have felt during recent times when they were unwell. As well as using approaches that have been successful in face to face therapy, the unit uses an interface that encourages activity rather than passive reading of materials.



Users can click on strength and a description appears. They then drag and drop the "strength" into a pile. An example appears in Figure 2, at left:
Figure 2: Strengths Card

We have engaged a graphic designer to ensure the interface is colourful and engaging. The modules feature fictitious cartoon characters such as Caz who tells her story and The Coach who provides advice and guides the user through the module.

5 Proposed Implementation of Tracking

The system described above allows patients to identify and record a list of recognized symptoms that preceded their first episode of psychosis, as well as a list of strategies that they might employ if the symptoms were to re-emerge. This collection of signs and strategies is called the patient's "relapse prevention plan". The system allows the patient to view their relapse prevention plan at any subsequent time by merely choosing it from a menu. What we are now planning is a system which allows the patient to track their symptoms over time. We are currently designing how EWS tracking should work; it raises a number of interesting design issues.

At its most basic, tracking of EWS involves presenting the patient at various times with the set of signs that they identified, and asking them which, if any, have reoccurred. Their answers can be tracked over time so that the patient (and their clinician and the system moderator – as indicated by Guideline 2)) could be provided with a graph of symptom reoccurrence over time. This could be displayed along with life events, use of strengths identified in the Strengths module, use of therapy or other system features, to allow exploration of correlations. A sudden preponderance of symptoms within a short period of time indicates that a relapse may be imminent: this can be flagged to the patient and other stakeholders – so changes in behaviour or medication regime can be reviewed.

A design question that immediately arises is when to prompt patients to check their EWS and enter data. Doing this too infrequently might mean that imminent relapse events are missed. Doing it too frequently might annoy, fatigue or overly worry the patient. The literature on experience sampling (Csikszentmihalyi M 1987) and "quantified self" (Wolf 2010) will inform our decision. As well as frequency we need to decide whether to prompt users for data at regular intervals or at random times and whether to record the occurrence of symptoms as a binary quantity (symptom either happened or it didn't) or a scalar value (e.g. 0 for no occurrence through to 10 for severe occurrence).

Not all warning signs have equal weight: for example "hearing voices" is more likely to indicate relapse of psychosis than "reduced appetite". Furthermore, for usability reasons it might be advantageous to reduce a patient's vector of tracked symptoms to a single numerical quantity for display. This number would therefore be a weighted sum of the occurrence values for the collection of signs. Tracking a single number in this way would allow charts to be displayed in a more straightforward way. However there may be particularly relevant signs that need to be acted upon immediately and should not be swamped within an average. By using an experience-sampling approach and regularly prompting patients to track their symptoms on-line, we not only capture the situation as it happens - instead of recording a memory of it - but can deliver an immediate response.

However, along with usability issues we must consider the user-experience of tracking early warning signs online, particularly through a mobile interface, which is the next logical development. While frequent prompting might lead to more accurate data and a higher likelihood of identifying an impending relapse, equally it might annoy or frighten a young person who is trying to re-establish routines at work or school, and might create anxiety about the development of EWS. We need to track the interaction of Strengths and EWS to see how encouraging and focussing on Strengths impacts on these possible negative impacts of tracking EWS and helps in encouraging positive behaviours to control EWS.

The research team involved in this work is a multidisciplinary team involving HCI and usability experts and psychologists. It is proposed that this tracking facility can be tested in our on-going trial by current and former clients of youth mental health facilities to which some of the researchers are attached. There will be an 18 month recruitment and trial phase where two measures will be assessed: Firstly, on-going usability and acceptability of the system will be assessed using qualitative interviews. Appropriate delivery platforms such as smart-phones and tablets will, in the final stages of the project, be compared to home-based use on PC's. Secondly, the success of the system in assisting users to identify EWS and Strengths will be assessed using established psychological measures.

6 Conclusion

This research-in-progress paper describes a plan for an online therapy that aims to help identify and address early warning signs to prevent relapse in patients who have experienced a first episode of psychosis. It shows how an understanding of patient characteristics, therapies for detecting EWS and encouraging a focus on Strengths, and usability techniques to encourage engagement, can be combined into an innovative design targeted to this unique user group. Future work requires extended testing of the proposed design.

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