

Health Technologies ‘In the Wild’: Experiences of Engagement with Computerised CBT

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ABSTRACT

The widespread deployment of technology by professional health services will provide a substantial opportunity for studies that consider usage in naturalistic settings. Our study has documented experiences of engaging with technologies intended to support recovery from common mental health problems, often used as a part of a multi-year recovery process. In analyzing this material, we identify issues of broad interest to effective health technology design, and reflect on the challenge of studying engagement with health technologies over lengthy time periods. We also consider the importance of designing technologies that are sensitive to the needs of users experiencing chronic health problems, and discuss how the term sensitivity might be defined in a technology design context.

Author Keywords

Health technology; CCBT; mental health; user experience

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI)

INTRODUCTION

The design and evaluation of technologies intended to support recovery or management in relation to chronic health conditions has become a significant strand of HCI research. Much of this prior work has been structured around the design of prototype technologies which have been evaluated through relatively small-scale, controlled deployments. However, Blandford [8] has argued for research that engages with health technologies in a realistic context of use, and prior experience suggests that the study of deployments “in the wild” will reveal complex and unexpected phenomena that can only emerge in naturalistic settings [7]. Some health technologies have reached a

sufficient level of maturity that they are being deployed on a wide-scale by national health services, and this should provide a broad range of opportunities for research studies that consider usage in naturalistic settings. In the case of chronic health conditions, these might need to consider engagement across a multi-year period; how to study such engagements effectively is then a challenging question.

The focus of this paper is on Computerised Cognitive Behavioural Therapy (CCBT), a class of technology which has been deployed by major health services for a number of years, and which has been designed to support recovery from common mental health conditions such as anxiety or depression. Though a substantial amount of quantitative research into CCBT has been conducted, research that documents the experience of engaging with CCBT as part of a broader treatment process is much more limited. So as to obtain a rich understanding of this experience, we have worked with a group of participants with extensive prior experience of using CCBT, who have contributed a detailed set of reflections on their usage. To allow us to contextualize interactions as part of the broader experience of recovery, this material was captured through two reflective workshops. These were carefully structured to collect rich and detailed recollections of experience, and to discuss participants’ current understanding of these.

Our analysis draws attention to some important phenomena that can only be fully understood when specific experiences are contextualized as part of a multi-year recovery process. Examples include the profound impact of cognitive difficulties associated with mental illness on early interactions with technologies, and the challenge of designing technology for users who are experiencing deep and pernicious levels of despair. Our work also draws attention to the challenges encountered during the early stages of engagement with CCBT and the need to provide effective support for disengagement at the end of a period of treatment. The latter two issues are both highly relevant to the design of effective health technologies more generally, and we discuss them in detail.

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We conclude by discussing the need to design technologies that are sensitive to the needs of users who are experiencing chronic health problems, and consider how to define the term sensitivity in a technology design context. We also reflect on our use of “reflective workshop” structure to develop knowledge about the experience of engaging with a health technology as part of a multi-year recovery process.

What is Computerised CBT?

Computerised CBT refers to a set of technologies which are linked by a common approach to providing support for recovery from mental health problems. The over-arching approach is to present interactive features that teach selected conceptual elements drawn from the professional practice of Cognitive Behavioural Therapy (CBT), a popular approach to the treatment of mental illness that was first formulated in full in the 1960s and 70s [40]. Typically, conceptual elements presented in these packages include a selection of “cognitive distortions” which have previously been identified by CBT practitioners, and which are postulated to contribute to mental distress [5]. Specific implementations of CCBT have then been tailored to support recovery from specific conditions such as anxiety, depression or Obsessive Compulsive Disorder (OCD). Popular examples include Beating the Blues, FearFighter, Living Life to the Full and MoodGYM [4,16,26,28] (BtB, FF, LLF and MG).

CCBT has been deployed by the health services of a number of countries, including the UK and Australia. There are a wide variety of documented institutional motivations at play in relation to the provision of access. These include speeding provision of access to psychological therapies, especially given a shortage of trained professionals [37], opening up access to psychotherapy for those in rural locations [19], opening up access to those with social phobia [37] (for whom traditional psychotherapy may be difficult to engage with) and, potentially, providing a more cost-effective form of treatment. The latter can be related to a popular model of provision known as “Stepped Care” [36], in which a low-intensity intervention is given first, with a higher-intensity intervention only being provided once the former has proven ineffective. Stepped care is an important topic in health services research, and has been implemented through large-scale programmes such as IAPT (Improving Access to Psychological Therapies) [22].

In the UK, where the study presented in this paper was conducted, the provision of access to BtB and FF was first recommended by a regulatory body known as the National Institute of Clinical Excellence (NICE) in 2009 [33], informed by a body of clinical trials providing evidence for their efficacy. This formal recommendation effectively meant that doctors working for the UK National Health Service (NHS) could “prescribe” access to these technologies following a consultation. A prescription then amounts to an electronic account, paid for by the NHS, and allowing a doctor to track progress through the system.

Cost-free access to these two technologies without a prescription, is also facilitated by third-sector organisations, who may also provide facilities such as collections of PCs for those who have no home access, or who prefer to access in a communal environment (see [10] for a case-study). Access to BtB and FF can also be purchased privately, and access to LLtF and MG is currently free to all, worldwide, through the browser. There is evidence that medical practitioners are routinely recommending access to these latter services as part of structured treatment programs [20], potentially in response to the cost of providing access to BtB or FF which, though less than a typical six-session period of psychotherapy, is still estimated at several hundred pounds sterling [33] (this estimate takes into account a broad variety of associated institutional costs).

Because access to these technologies has been available for a number of years, and a substantial body of research has emerged in relation to their usage. Much of this has been quantitative, and has revealed that drop-out rates from CCBT are a consistent problem [27]. Some qualitative analyses of the experience of engagement are present, but are currently quite limited. Knowles et al [24] have reviewed the user experience literature, and have concluded that user attitudes to CCBT are often strongly dichotomous, with users expressing both strongly positive and negative attitudes. Kaltenhaler et al [23] have reviewed a variety of sources of information about the acceptability of CCBT treatments, and uncovered wide disparities between reported attitudes towards acceptability. Morrison et al [32] have provided evidence that clinicians’ perceptions of CCBT technologies might limit uptake, through a study suggesting that some clinicians viewed a particular technology as too restrictive to recommend to their clients.

CCBT has received some attention within core HCI literature. Coyle et al [12] have provided an in-depth review of foundational HCI issues around mental health technologies, which considers CCBT in detail. Doherty, Coyle and Sharry [14] have identified a set of four tactics for addressing the causes of drop-out (*interactive, personal, supportive* and *social*), and also described SilverCloud, a more recent CCBT offering which incorporates these. Technologies derived from SilverCloud have then been the subject of a range of experimental deployments [31][32].

CCBT collectively represents an attempt to design interactive technologies informed by concepts drawn from psychotherapeutic practice. As such, there are connections to HCI work exploring how to design health technologies informed by psychological concepts [11] (with the latter typically being the outcome of experiments and studies, and the former being derived from reflections on practice).

METHOD

Recovery from mental illness is frequently a multi-year process. The deployment of CCBT by health services across the world has then provided an opportunity to obtain a holistic understanding of the usage of these technologies

that contextualizes specific interactions within a larger treatment process. To help us understand the experience of engaging with CCBT “in the wild”, we recruited fifteen participants, all of whom had used CCBT outside of a research context (e.g. usage was naturalistic, not part of a clinical study). We then organized two linked workshops, which were carefully structured to provide an opportunity to reflect on this experience in detail. To support this work, the research team incorporated expertise in both HCI and health-services research. As noted by Coyle et al [12], the combined skills of this kind of interdisciplinary team are essential when studying a real-world technological treatment experience, especially given the sensitivity and stigma that can be associated with a mental illness. Because of the sensitivity of this study, no photographs were taken.

Before organizing workshops, we first sought and received ethical support from a Research Ethics Committee approved by the UK NHS. Recruitment was through posters displayed in collaborating mental health charities, which asked participants to contact the research team if interested. To provide an opportunity to consider their engagement more fully, and to consult others if necessary, interested participants were provided with written information by post, and were then contacted by telephone to verify that they had understood the nature of the study and still wished to engage. At this point, we explicitly excluded participants who stated that they had experienced post-natal depression, bipolar disorder, schizophrenia or any form of psychosis, as these conditions were, at the time, not amongst those recommended to receive interventions such as CCBT. Participants were then sent a workshop invitation, and were asked to confirm in writing their consent for engagement at the start of each workshop.

In designing structures for the two workshops, our central challenge was to support participants in reflecting in detail on their experiences, taking into account the range of CCBT packages which had been used, and the possibility that several years might have passed in between participants finishing treatment and engaging in our research. Our central approach was to select structures intended to encourage rich and specific *recollections* of experiences, and also to promote discussions that revealed participants’ current and prior *attitudes* and *beliefs* in relation to these. Our hypothesis was that these recollections, attitudes and beliefs would collectively provide useful insights relevant to healthcare technology design, and we reflect on our choices at the end of this paper.

Our chosen structure, described below, incorporates elements of the “future workshop” [18], which has been frequently used to structure participatory design activities, but which we repurposed to support an understanding of an existing technology. The workshop process was managed by a single facilitator. Selected elements of the proceedings were recorded and transcribed. This produced twenty-two thousand words / sixty-seven pages of textual material.

Workshop one (4 hours): This began with a presentation to describe the intention and scope of the research, also used to motivate the importance of collecting reflections on prior engagements with CCBT. Written consent for engagement was collected. Participants were split into three small groups of five (groupings were selected in advance).

The first activity was a *critique* of existing technologies, intended to seed discussions and help to develop a common language of analysis [18]. Participants were presented with screenshots of features in existing technologies, and scenarios describing usage of these by fictional personas. They were then asked to develop a critique these in light of their own experiences. At an appropriate point (as decided by the facilitator), each small group presented their critique, which was then discussed at length, with discussions allowed to run until complete. We found that discussions frequently incorporated reflections on personal experiences, e.g. when considering the need for social support:

“I don’t think you can just have that [CCBT] on its own, I think, you do need the backup, so you have got someone that you can relate to and help solve what you don’t understand, *I mean, that’s what happened to me, I did an online course and I had a phone call every week and when I first started the course, I couldn’t even understand it, I couldn’t take in what it meant until it was explained to me* “

An example of a specific and informative recollection of a personal experience has been highlighted in italics.

For a second activity, participants were asked to *imagine* the features that they might want in an ideal mental health / CCBT technology, drawing on their own expertise as prior users, and working as a single large group. Although this was nominally a design session, our intention was to elicit a discussion of specific features of the technologies which participants had used, and which had either worked well or badly (and why).

Workshop two (2 hours): This took place one week later, and was attended by thirteen or the original fifteen participants. It was conducted as a detailed reflective discussion. The primary feature was a traditional focus group, providing time for a more detailed reflection on issues of importance to our participants which had emerged in workshop one. We also considered a small paper prototype, constructed by the research team, and inspired by the “ideal” mental health technology discussion. These provided an opportunity to discuss specific implementation challenges in relation to mental health technologies.

Throughout the workshop process, we found that participants were incredibly enthusiastic about reflecting on their own experiences in a very substantial amount of detail, explicitly motivated by an altruistic desire to improve the experiences of future users of mental health technologies. This means that the transcripts of workshop proceedings were a very rich resource for analysis, providing sufficient material to allow for the construction of a publication.

FINDINGS

Drawing on reflections contributed through the two workshops, analytical work has focused on selecting and characterizing a set of interactional issues which seemed important to participants, and which should be of interest to HCI and health technology researchers. Presented issues have been structured into seven topics, and specific implications are discussed later in the paper.

1. Reflections on attitudes towards CCBT

CCBT is a relatively new addition to the range of treatment options for mental health problems, especially in comparison to traditional psychotherapy, which has had a widespread influence for more than a hundred years, and the provision of psychoactive drugs such as antidepressants, which have been widespread use since the 1960s [17]. As such, understanding the range of real-world attitudes that are present in relation to it is an important exercise, since strongly-held attitudes, whether positive or negative, might influence the experience of engaging with a technology. As noted above, work by Knowles et al [24] indicates the possibility of a wide range of attitudes being present in users of mental health technologies. Our workshop transcripts embed a substantial amount of interesting information about participants' recollections of their initial attitudes to CCBT, and how they changed during the treatment process.

At the point of initial contact with CCBT, some participants recalled attitudes which were starkly negative, which included statements such as "it's a cost-cutting exercise to avoid paying for therapist" or that "nothing tackles the problem like a real practitioner ... it's only a stop gap, they can never be a complete cure". One participant described how, early on in their engagement, they were "very against the course of treatment that I was moved into and ... fought against it, fought really hard for years". The same participant described how, early in their treatment, they had thought that "the NHS [UK health service] must be looking at this problem of mine in a very simplistic way" and that they were being offered what they felt was a very basic computer package for a very serious illness, which they then found profoundly insulting.

A number of participants talked about the increasingly technological nature of modern society, and the possibility that this might cause members to be more prone to mental health problems, through mechanisms such as reducing social contact time. They then raised a question of whether a technological solution was appropriate, if the problem itself was a symptom of excessive technological change. Some negative attitudes seemed to be linked to a quirk of the UK regulatory environment. Essentially, because the NICE recommendation for provision of access was linked to successful but expensive clinical trials of BtB and FF, then updating these offerings would invalidate the results of these trials. This has contributed to a situation in which the interfaces to these technologies appear somewhat dated.

Recollections of attitudes were not universally negative, and positive or neutral attitudes were also present. A number of participants described being unhappy with the format of traditional "talking therapies", which are often rigidly structured around engagements that last a fixed amount of time, and which take place at the same time every week. One participant described feeling much better engaging with a technology that allowed them to work at their own pace, in contrast to traditional one-to-one therapy constructed around what they described as "long sessions". The fact that technology was available immediately, rather than requiring a lengthy (e.g. multi-month) wait for traditional treatments, was seen by a benefit by some.

There was also some evidence that attitudes and beliefs about the technology could change substantially during the course of usage. The participant who had conceptualised a technology as being a "stepping stone" found that it worked so effectively that she did not need to take up any further sessions. A participant who had become a volunteer at a CCBT-orientated self-help group at the conclusion of his own treatment described how he regularly saw people making substantial improvements over the course of an eight-week periodic interaction. As such, he was convinced of the benefit that could be provided to some, in that he had "seen it turn people's lives around". One participant described being initially dubious about a technology, but having changed his mind on presentation of clear factual information that highlighted recovery rates. This then made him feel less like "a guinea pig" [colloquialism for someone who is the subject of an experiment], and more like someone who had a choice in how to engage in treatment. This participant repeatedly expressed an opinion that the provision of objective information around the evidence base and professional consensus regarding treatment options would be an important approach in engendering more positive attitudes in relation to technology usage.

2. Varied routes to accessing technology

There are a variety of tools for formally screening for or diagnosing particular mental illnesses, but data from our focus groups illustrates some interesting routes by which users might engage with CCBT technology without ever being formally screened or diagnosed. One example was provided by a participant who had had such a positive experience with CCBT that he had become a volunteer with a self-help group that offered access to Beating the Blues. He described an individual who had approached them in despair, and who had nowhere else to go:

"I work with prisoners as well, and one of them came out of prison recently and was suffering from depression, has been suicidal in prison, and they just kicked him out and got nobody to care, and so he came to us"

As described earlier in this paper, direct access is available to all of the major CCBT technologies, either for free (e.g. MoodGYM) or on an individual payment basis (e.g. Beating the Blues). As such, we would expect a substantial

cohort of users who are effectively referring themselves to these technologies. Interview transcripts then suggest that doctors may also be taking a role in encouraging self-referral:

“ ... when I went to the doctor he didn't refer me at all although I was suicidal, he just said that you'll have to look online ... so that was it”

Both of these cases involve potential users who are experiencing suicidal thoughts; whether it is possible to design a technology that is appropriate for such individuals is a challenging question for research.

Even when a diagnosis of mild or moderate depression has been made by a medical professional, this does not then guarantee that a particular technology is suitable to a user, and the possibility of misdiagnosis is always present, especially in the context of an illness which is not defined by directly observable physical symptoms (e.g. work by Hirschfield, Lewis and Vornik [21] suggests a misdiagnosis rate of 69% for bipolar disorder, with a substantial proportion of these individuals being misdiagnosed with unipolar depression, making them eligible for a prescription of access to CCBT). The participant who was a volunteer at a self-help service described how:

“ ... doctor's don't have a lot of time and we quite often get referrals which are just not suitable for the service ... when somebody sits down and talks to them in great detail about the problem, they realise they shouldn't have been referred to that service in the first place”

Here, at least, the structure of the self-help service seems to have provided a second level of screening that may have at least helped to filter out users for whom interaction with a technology is an inappropriate route to treatment; this kind of screening might be an important component of an effective social support structure around a technology.

3. The impact of cognitive impairments on usage

There was an essentially universal agreement during the two workshops that the nature of mental illness made interaction with a technology difficult, and often profoundly so. This is graphically illustrated by one participant who described a first technological contact taking place in the context of a support-group session provided by a charity:

“... they gave me the password and everything and I went on it and I mean I'm computer literate, but I couldn't even understand what they were trying to say to me and I just thought, this is not for me ... I just couldn't take the information in. Half of the time they don't speak in English when your brains in Double Dutch [colloquialism for language that is impossible to understand] “

This kind of difficulty was echoed in contributions from many other participants. It clearly had a profound impact on their usage of technologies, especially early in the process of interaction. One participant described it as follows:

“well you're intellect actually closes down [when you develop a mental illness], it did for me anyway and I know a lot of people I've spoken to their intellect or their want to take things on board is stopped, they don't really want to take much on board, because they've got too much going on.”

An interesting aspect of this phenomenon was that the debilitating effects of mental illness meant that participants own reactions become unpredictable to them, meaning that they were less able to anticipate their own needs:

“I never would have thought I could be so blank minded, I really couldn't, because I had a terrific memory [previously], but now I can't remember hardly anything ... the brain just shuts off ... totally shut down and didn't want to know anything”

For some, the onset of cognitive problems seems to have been very rapid, which potentially creates a challenging context for effective technology design work.

Cognitive difficulties associated with mental ill health have been discussed previously in the HCI literature, e.g. by Lederman et al [25], who have considered their impact in relation to on-line treatments intended to support the management of psychosis. Psychosis is typically a symptom of a variety of serious and chronic conditions which only affects a relatively small proportion of the population [2].

In contrast, participants in our study had experienced forms of mental illness (e.g. anxiety and depression) that are highly prevalent, and frequently co-morbid with other conditions [30]. The profound impact on their interactional capabilities is therefore important to understand in the broader context of efforts to design effective health technologies, given that users of a broad range of health technologies might experience anxiety or depression at some stage of their engagement.

4. Motivations for engagement with technology

Balaam et al [3] have observed the importance of designing health technologies in light of an understanding of users' motivation for engagement. In the case of our workshops, participants reported a variety of motivations for engaging with technology. Interestingly, lengthy waiting lists for traditional talking therapies, combined with a desperate need for recovery, were a motivating factor for one participant, who described how:

“ ... I knew I had to persist with it, there was nothing else on offer ...

The desperation of living with a mental illness was a common theme, and participants discussed how desperation could easily motivate experimentation with technologies that were inappropriate or poorly-designed, especially given the availability of freely-accessible technologies marketed as being intended for the treatment of individuals experiencing mental health problems:

“you know, with severe depression, would be willing to try anything”

In parallel, however, an absolute desire for recovery was described by many of our participants, described in the case of one participant as:

“you ... look around and you keep your eye out and if something comes up and you .. see it .. you think, oh my God, there’s something there which might help, I’m going to bloody take it, this might be my chance, it might be an opportunity”

An ability to leverage this desire for recovery then seems like an essential capability for an effective technology.

5. The importance of support for engagement

A substantial body of prior HCI research has considered the importance of providing support for health technology engagement [39], and Doherty et al [14] have argued that support facilities should be a core element of effective mental health technology design. Discussion in our workshops generally echoed the importance of providing support; a substantial proportion of participants persevered with treatment programmes, and obtained positive results, and professional support seems to have been instrumental in most of these cases. For some participants, help was provided by in-person support, either co-located or at a distance (with the later generally being provided over the telephone). Other methods included meetings at self-help centres run by charities, or telephone help-lines that could be used if they were experiencing difficulties.

An interesting issue to note is that those participants who accessed CCBT technologies through community doctors (known in the UK as General Practitioners), received very little support at all, and seemed to have a consequently more difficult experience. The NICE guidance for prescribing access to CCBT [33] has been constructed on the assumption that users will have regular debriefing sessions with GPs. This guidance does not seem to have been implemented in the case of some of our participants. This situation seems to have been rooted in typical patterns of access to GPs, which are traditionally structured around short appointments. It is possible that these might not be amenable to the discussion of complex issues around engagement with a treatment technology, leading to a situation in which this group of users receives inadequate support during their engagement.

6. Desire for social engagement in technology usage

Social isolation is a common element of the experience of mental illness, and may be a contributing factor to its development [9]. Doherty et al have argued that social interaction should be supported through mental health technologies, and have highlighted specific challenges, such as avoiding “negatively reinforcing discussions” between users [14]. However, an interesting feature of the core CCBT offerings described in the background section to this paper is that they do not support social interaction between

users. Instead, the experience is essentially a single-user one, although in Beating the Blues users are at least indirectly exposed to other individuals through a mechanism of carefully-selected recorded videos.

As a research team, we were therefore interested in the decision of technology designers to exclude social interaction as a strategy in their offerings, and specifically asked our participants to reflect on the impact of this decision during the final phase of the second workshop. Several participants indicated that, during their treatment programme, they had in fact been given the option of getting in touch with others on the programme through on-line forums, which then appears to be an attempt to bolt-on social interaction onto an existing technology on the part of some health providers. However, as part of this discussion, one participant stated very strongly that:

“I closed down and I was just doing the course and I didn’t want to know about anything [i.e. anyone outside of her own experience]”

Which clearly indicates that social interaction through technology would not be appropriate for all participants, or at all stages of the treatment process. It would also need to be sensitively handled.

Discussions then focused on identifying points in the general trajectory [6] of treatment through a health technology where these interactions might take place; a stated motivation for this was the value of:

“just finding someone that is in the same situation that you can relate to and kind of support each other really.”

Suggestions present in the workshop then included being introduced to someone around the mid-point of the course, when the user had developed some confidence, or being introduced to someone as the course concluded, so that they could provide each other with ongoing support after interaction with a technology was complete. The latter then hints at the value of reflecting with others on what could be an intense and life-changing experience. One participant stated that they:

“would like to go back and see how other people developed after they have done the course, perhaps when I did it was too far...”

Another participant, talking about her own experience, stated that:

“I was too much down my own anus that I just had to get it done and try and build things up, but now I feel, yes I would like to share that now and find out how other people are managing that, so now I’m in a bigger group and talking about different issues”.

These long term support groups, accessed after the discrete, time limited intervention, were also considered beneficial through providing rewarding social engagement for the participants:

“And there is something about groups in some ways like all the stuff that you do for a programme on this can feel like theory maybe until you actually put it into practice and actually in a group then you have, you are engaging with other people for real, it’s quite a challenging situation to actually try some of the things you have learnt out there, but fundamentally can be quite rewarding.”

A central issue to consider in relation to the introduction of social interaction as a mechanism was considered to be the length of time that recovery can take; how best to schedule interaction in the context of either a life-long chronic illness or a multi-year recovery period, potentially involving multiple technological interactions, was considered to be a difficult one, but one that was important to get right.

7. The use of characterisation in teaching CBT

A common interactional theme across the design of Beating the Blues, FearFighter, OCDFighter and MoodGYM is the use of characters as part of the process of teaching CBT concepts. Characters are placed into real-life settings, and used to help the process of linking concepts to practical reality. The use of characters is then a design choice which shapes the experience of use. Participants’ reflections on this choice can then be useful in identifying future design possibilities for mental health technologies. Positive observations about characterisation included the ease with which a participant could identify with a character:

“ ... if you’re a young mother, for instance, and you’ve got two children and you’re bringing them up on your own, and you see this girl there with two children, and actually showing the film, you actually see the children, don’t you, and that seems pretty reasonable to me ”

MoodGYM presents a set of cartoon-style, clearly fictional characters. One choice, to name a character with apparently severe mental health problems Mr. Creepy Angry was heavily critiqued as being inappropriate, as was a choice to set up a mentally healthy character called ‘Noproblemo’ as an ideal for MoodGYM users to work towards.

In the case of Beating the Blues, workshop participants seemed divided on whether the characters presented (through recorded videos) had actually suffered mental health problems or not. The interface claims that they are actually real people, and that they had suffered mental health problems. Some workshop participants believed that the acting present in the videos was of a sufficiently low quality that the characters could not be real. Whether they were indeed real or not, and whether this had an impact on the effectiveness on the technology was then an issue of contention between participants. Several felt profoundly angry that they may have been deceived by the presence of actors, whilst for others the reality of the characters was irrelevant to their perceptions of the technology.

DISCUSSION

The previous section has documented participants’ reflection on their experience with CCBT, by presenting a

set of findings which are specifically relevant to interactions with these technologies “in the wild”. Given that the existing literature on user experiences of CCBT is currently quite limited, then this should be seen as a contribution that supports an understanding of this category of technology. It therefore represents an incremental contribution in relation to work by Knowles et al [24] and Kaltenhaler et al [23], and complements more experimental work published in core HCI venues by Coyle et al [12] and Doherty et al [14].

Some of our findings can also be seen as contributions that advance a more general understanding of how to design interactions with health technology. Our discussion of attitudes to characterization, for example, is relevant to any health technology that uses this as a teaching device. Our discussion of attitudes to CCBT has some elements that are specific to the UK health service, but also some elements that support an understanding of how to introduce health technologies as an acceptable alternative to more traditional forms of treatment.

In seeking to make as broad a contribution as possible, we now seek to discuss in more detail the most generally applicable elements of our findings. In selecting topics to discuss, we have been guided by an observation that mental health problems such as depression and anxiety are frequently co-morbid with other chronic illnesses [30], and are also highly prevalent in the general population as a whole [2]. This implies that a substantial proportion of users of healthcare technologies of all kinds might also be experiencing mental health problems. A key implication of our findings is that the needs of these users need to be accounted for, as their experiences might substantially disrupt their interactions with technologies that might otherwise provide substantial benefits to their health.

How best to design effective healthcare technologies which are also robust in the presence of mental health problems is then a challenging question to address, which should be of interest to researchers interested in HCI and interaction design. Informed by our findings, we would suggest that the following three topics are worthy of attention. Each of these then implicates a set of research questions in its own right, so this should be seen as a contribution which can guide the process of future research.

Topic 1: Careful design of early interactions

One issue that is clear from our findings is that early interactions with healthcare technologies can be very difficult for users experiencing mental ill health. This then suggests a need to pay careful attention to the design of these interactions. The following are a set of considerations that have emerged from our study. These are likely to only be a partial picture; we would argue for further research which specifically considers early engagement with healthcare technologies as a distinctively challenging experience, and which seeks to document the various considerations at play during this phase of engagement.

Unduly negative attitudes towards healthcare technologies

Technology as a vehicle for delivering therapeutic benefits is likely to be a relatively novel concept for a substantial part of the population and therefore unlikely to be fully understood. During early interactions with a technology, this situation could lend itself to perceptions of technology that are unfairly negative, and which may preclude or damage the usage of such technologies by individuals who might actually benefit from them. This hints at the value of directly challenging unfairly negative perceptions, though how best to do this, and whether it is an issue for technology design or social support is an open question.

In topic 1, we reported on a participant whose initially negative attitudes towards CCBT were successfully challenged through the provision of accurate information which highlighted recovery rates in relation to these offerings. This is just one available strategy; the persuasive technology literature presents a broad range of general strategies that could be used to manage perceptions of services (e.g. [1]) but how and when it is reasonable and ethical to attempt to manage user perceptions of a health technology is an intriguing question.

This implicates a consideration of users who really do need to work with a human rather than a technology, or who have been misdiagnosed prior to obtaining access. A consideration of the former may also need to take into account the limited resources for human engagement that may be present in a health services context [38]; as noted in topic 4, one of the motivations for engaging with CCBT was the limited availability of traditional talking therapies, and hence interaction with a technology may be the only option available to some users.

How to present technologies in a manner that encourages engagement despite unduly negative attitudes is then an interesting challenge. The health services community has already developed resources and delivery mechanisms for material that educates people about their condition¹. Potentially, these could also be used to deliver information designed to address such attitudes. This kind of work might encompass approaches such as designing and presenting “experience trailers” [35]. These could provide a glimpse of what interactions with a treatment programme might look like, and therefore allow users to move beyond an initial concern about how a technological treatment might work.

Accounting for differing routes to access

A core strategy for overcoming difficulties in early interactions might be the provision of effective support structures incorporating social elements. How to design integrated support structures around a technology has been considered in detail in the HCI community (e.g. see [27]). However, as noted in topic 2, the reality of a naturalistic engagement with a health technology is that access may be

acquired through a broad variety of routes, some of which may not have been anticipated by service designers, meaning that such users may be using a technology without any social support. Additionally, where a specific solution is licensed to multiple service providers (as is the case for Beating the Blues and Fear Fighter) then technology designers may also have no control over how support is provided for use of their technology. This then raises a question of how much support should be directly built into a technology itself, and how much support should be provided by surrounding structures.

At a minimum, we wonder whether an ethically-designed technology might attempt to:

- identify usage by individuals whose conditions mean that they are not at all suited for treatment by it
- identify deteriorations in the mental health of its users, and embed mechanisms to respond effectively to this, as discussed above

How best to respond to these conditions is then a challenging question for research.

Tailoring the presentation of information

Doherty et al [14] have argued for the need to tailor elements of healthcare technologies to the needs of specific users, and the argument above suggests the need to tailor the presentation of information to the needs and abilities of specific users. Existing CCBT offerings typically present information in a static manner which is not personalized to the user. Arguably, elements of this presentation are inappropriate for those with temporary limitations on their cognitive capacity; MoodGYM, for example, opens with a four-page disclaimer presented in extremely dense text.

The use of characterization, as considered in topic 7, could potentially provide a mechanism for supporting engagement from users experiencing cognitive difficulties (in that it may help to make a link between an abstract concept and the lived experience of the user), but the specific usage of characterization in MoodGYM was roundly criticized by participants as being too cartoon-like, and sometimes dismissive of the reality of living with a mental illness.

Recent HCI work focused on automatically detecting the “reading age” of a user [29] might offer a hint about how to proceed; it might be possible to design technologies that rapidly detect the presence of cognitive difficulties, and which respond by automatically adjusting the manner in which information is presented. Such technologies might offer a mechanism for identifying deteriorations in the mental health of a user occurring during the course of a technologically-assisted treatment process (e.g. by considering cognitive capacity as a proxy); a user who appeared to be developing more profound difficulties could then be re-assessed, and potentially shifted to a more appropriate form of treatment.

¹ e.g. <http://www.healthtalk.org/>

2. Supporting effective disengagements

CCBT packages are typically designed around treatment programmes with a temporal structure, often nominally designed to be accessed over several months, though users can generally engage at their own pace. The broader context in which access has been provided may limit the duration of engagements; if a user has paid for access themselves, then this is generally on a time-limited basis, and prescribed access, in the example of the UK National Health Service, is generally on a time-limited basis as well.

What this means is that the experience of engaging with these packages cannot continue indefinitely, and that at some point a user will need to disengage. Interactions with CCBT are inherently intended to be life-changing if successful, in that they are presented in an attempt to promote recovery from a debilitating condition. As such, the process of disengagement seems important to consider, as disengagement has the potential to be an emotionally-charged process. How to effectively manage disengagement so as to maximize the benefits to an individual is then an interesting question for those interested in human interaction with health technologies.

Topic 6 – which considers the question of whether social interaction should be integrated into technology usage – hints at a potential beneficial usage of the process of disengagement, in that it offers an opportunity to introduce users to others who have experienced similar conditions, and who may then be able to offer mutual support. Service providers may need to consider carefully how to manage this process, potentially by seeking to match up individuals or groups who can appropriately assist each other.

There is also a broader question of how to use interactive technologies to ethically support a wider-scale distribution of what is effectively expert knowledge that has been developed through engaging with a process of treatment. What seems clear from our workshops is that there are significantly more barriers to introducing social interaction early in the experience of engagement, where individuals may be experiencing substantial cognitive and emotional difficulties; it may be that, early in the process of treatment, a substantial proportion of users may not be ready for any kind of social interaction at all.

Workshop discussions also hint at a need for users to be able to reflect on their experience so as to obtain maximum benefit, with reflection potentially happening years after the engagement. Partly, this then requires organizational structures that ensure that access to records of interaction can be maintained, so that individuals can return to interfaces so as to revisit and reflect on content. There is, however, an interesting research question of whether technology can specifically support personal reflection. This may touch on recent HCI work around digital souvenirs of experience [15], the design of which has been explicitly motivated in terms of the support that can be provided for reflection on experiences.

3. Despair and its relevance to health technology design

The nature of despair, as experienced by many of our participants during the course of their illness, underpinned much of the discussions in our workshops, and had a profound influence on the experience of engaging with technology. Despair on the part of users has not been considered in any detail within the HCI literature. Given the societal prevalence of mental health problems, it is a phenomenon that will affect many technological interactions, and deserves to be better understood.

In the context of this discussion, despair has been picked out as a topic because of its frequent occurrence in the natural language of many of the workshop participants, who described how they had “been in despair” or “had been despairing”. As used in these workshops, despair generally described an emotional state that was unbearably uncomfortable, and for which participants could see no way out. Designing technologies for despairing users therefore presents a very significant challenge, which hints at an extreme level of caution needed on the part of designers.

It is the author’s opinion that some existing CCBT offerings do not adequately pay attention to the true nature of despair, and therefore risk rapidly disengaging users. MoodGYM regularly attempts to insert humour into interfaces; this seems entirely inappropriate given the expected despairing state of mind of many of its users. The danger here is that attempts at humour simply appear as flippant to those who are experiencing a very serious and debilitating condition, potentially damaging the effectiveness of the package and leading to early disengagement.

Several of our participants described how they would have quite happily tried anything to improve their situation, regardless of its provenance. This then places a very significant responsibility on the designers of technology to behave ethically, and to always have in mind the best of interests of users. Given that CBT is a family of therapeutic practices with a long and complex history, then there is a danger of CCBT packages presenting an overly-simplified version of this therapy, thereby introducing distortions that could be damaging in their own right. As an example, MoodGYM claim that CBT embeds an assumption that negative emotions are caused by cognitive distortions, whereas an effective CBT practitioner would recognize that negatively-felt emotions such as sadness can actually be a healthy response to situations such as bereavement.

Designing technologies that do not require the intervention of a therapist but which stay true to therapeutic principles presents a substantial challenge, especially since much therapeutic work is inherently confidential. This then makes it difficult to apply traditional approaches to developing an understanding of the work of the therapist (such as design ethnography [13]). It raises a question of how technology designers might best study and understand therapeutic practices, and how design work might effectively respond to understandings developed through this work.

CONCLUSIONS

We have presented an analysis of a rich corpus of material, collected through two reflective workshops attended by users who have previously engaged with CCBT. We have presented specific findings that complement prior work on user experiences of engagement with mental health technologies [23,24], and also documented issues of more general interest to healthcare technology design research, including the challenge of engaging and disengaging with health technologies, and the implications of technology usage by people who are experiencing deep despair. Collectively, our work amounts to an argument for the careful design of healthcare technologies that are sensitive to the specific needs of users who are experiencing chronic health problems, and which therefore avoids discouraging those who might benefit substantially from engagement. How to design sensitive technologies is an under-explored topic in HCI research, and we believe it to be worthy of further consideration by the community.

In this context, material presented in this paper can provide an insight into issues which are worthy of consideration. In particular, we would suggest that sensitivity as a design consideration is particularly important in relation to those health conditions that have a profound impact on interactional abilities, particularly where this results in abilities that change dynamically, leading to interactional capabilities which are unpredictable. This argument certainly implicates a broad range of mental health conditions, as considered in this paper. It also implicates a range of other conditions that affect the brain, including dementia and Alzheimer's disease, or brain injury acquired through a traumatic accident or a stroke. In the case of the latter, prior research suggests that the damage acquired through a stroke can lead to abilities that change unpredictably on a minute-by-minute basis, which can then cause frustration as particular interfaces becoming rapidly unusable as abilities change [34].

We would also argue that sensitive design requires an understanding of the whole trajectory of experience in relation to specific health conditions; this is particularly apparent in relation to technology designed to support recovery from mental health problems, where a successful set of interactions might be associated with a potentially life-changing transition from an uncomfortable to a comfortable mental state. In seeking to understand these broad trajectories, our findings suggest a need to consider issues that pre-date initial technological interactions (such as early engagements with health professionals, or experiences that contribute to excessively negative attitudes to technologies). Research might also consider issues that occur after disengagement, such as reflection, or contributions made to the engagements of others.

As noted in our introduction, these kinds of trajectory might span multiple years, which raises a question of how best to study them. In work presented in this paper, our

approach has been to organize two workshops which were structured to collect specific recollections and associated attitudes and beliefs. These reflections have then constituted the data on which we have built our analysis; we are generally interested in understanding the affordances of reflective workshops as a healthcare research method, and in understanding how best to structure these engagements.

In our experience, the major strength of a reflective workshop structure is that it has allowed for the rapid collection of a rich corpus of material which considers the broad experience of engagement. Some of the insights present in this material would not be fully accessible through methods conducted during the process of engagement itself. As an example, attitudes to technology might continue to develop for years after usage as people reflect on their experience and its impact, and hence a full understanding of this requires an intervention that can consider this time period as a whole. We would note, however, that human memory is limited in accuracy, and this implies that specific issues raised in reflective workshops might then be explored in more detail through alternative methods. As an example precise details of how exactly attitudes evolve through the first month of engagement might be better captured through a questionnaire administered at the time of usage.

Finally, we would note that prior work has documented a phenomenon of groups of individuals who are "hidden" or "hard to reach" in relation to healthcare research (e.g. illegal drug users or migrants) [37]. Understanding the experience of these groups might provide substantial benefits to healthcare technology design, but by definition, they are less likely to be accessible during a period of treatment. Reflective workshops may then be an appropriate a mechanism for collecting useful insights into their experience (working from an assumption that recruitment might be easier after a treatment process has taken place).

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² <https://www.epsrc.ac.uk/files/aboutus/standards/clarificationsofexpectationsresearchdatamanagement/>

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