

The Challenge of Technology Research in Sensitive Settings: Case Studies in ‘Sensitive HCI’

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ABSTRACT

A growing proportion of human-computer interaction research now takes place in sensitive settings with participants who might be considered vulnerable, such as the chronically ill, older adults, and people living with mental health issues. Alongside this move into complex “real life” settings there is growing interest in the ethical challenges HCI researchers encounter, the emotional impact research can have on participants and researchers, and the risk that new technologies might exacerbate, rather than ameliorate, existing vulnerabilities. Some authors have called for researchers to openly reflect about ethical challenges so we can learn from shared experiences. Others have warned that HCI researchers may not be sufficiently equipped to understand and respond to the needs of vulnerable participants. This paper documents cases of “sensitive HCI,” drawing on research conducted in diverse sensitive settings. By reflecting on common challenges and discussing possible responses we contribute to growing discourse that promotes reflexive practice in sensitive HCI.

Author Keywords

Sensitive HCI; HCI research; Sensitive settings;

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI); Miscellaneous.

INTRODUCTION

There is growing interest in the HCI community in how to best conduct research in sensitive settings with participants who might be considered “vulnerable.” Recent workshops held at the CHI conference have questioned whether HCI researchers are sufficiently equipped to respond to the needs of vulnerable participants (Vines et al., 2013) and called for researchers to communally reflect on the ethical challenges faced when conducting HCI research in sensitive settings

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(Waycott, Davis, et al., 2015). Other authors have explored appropriate methodologies for designing in sensitive settings, such as using cultural probes in psychiatric hospitals, care facilities, and the home (Crabtree et al, 2003). In this paper, we respond to calls to promote reflexivity in HCI and to share experiences in order to inform future good practice. We document some of the challenges faced in five case studies of HCI research in sensitive settings. By sharing and discussing these challenges we aim to contribute to the growing dialogue about key issues for researchers to consider when conducting “sensitive HCI”. We use the term “sensitive HCI” to communicate two key ideas: firstly, the sensitive and complex nature of the setting in which this type of research takes place and, secondly, the need for researchers to tread cautiously – or to be sensitive – when working in these settings. We explain these concerns below, before describing the challenges we faced, and our responses to each challenge, in five multidisciplinary projects conducted in diverse sensitive settings.

BACKGROUND

HCI is increasingly concerned with designing and evaluating technologies for health and wellbeing (Hayes & Reddy, 2011). In addition, over the past decade interest has grown in conducting HCI research with disadvantaged or marginalised communities, or with specific populations, such as the “oldest old” (e.g., Neves et al., 2015), young children (e.g., Bonsignore et al., 2013), people who are homeless (e.g., Woelfler et al., 2011) and adults with low literacy (e.g., Munteanu et al., 2014). As HCI has moved from the laboratory into these highly complex “real-world” settings, researchers are recognising the inherent sensitivities involved in designing and evaluating technologies to address difficult health and social challenges.

Common challenges for all research in sensitive settings include building rapport with participants who are experiencing complex emotional issues, maintaining boundaries around the research, and ensuring participants do not experience harm or stigma through the research process (Dickson-Swift et al, 2008). Challenges particular to HCI include ensuring empathetic approaches in the design of new technologies (Thieme et al., 2014) and managing the negative impact new technologies might bring (e.g., McNaney & Vines, 2015).

Institutional ethics approval processes provide a valuable and rigorous check to ensure that research can only proceed if it is of sound design and adheres to core ethical principles – such as minimising harm and being respectful towards participants. These formal procedures, however, cannot fully guard against all ethical challenges that researchers might face. While safeguards can be put in place to mitigate against anticipated risks, social interactions cannot be fully controlled, and any research involving human participants may encounter unpredicted ethical challenges. Guillemin and Gillam (2004) called these challenges “ethically important moments” – difficult, sometimes subtle dilemmas where there may be no clear right or wrong choices (Guillemin & Gillam, 2004). In sensitive settings, researchers’ responses to unexpected challenges can change the course of the research and may have consequences for participants. It is important, therefore, that researchers are sensitive to the “situational ethics” (Munteanu et al., 2015) or “ethics in practice” that arise “in the doing of research” (Guillemin & Gillam, 2004, p. 264).

Sensitive HCI can involve conducting research with participants who might be marginalised or at risk of health, social, or political disadvantage. Participants in this category are often labelled “vulnerable,” although this is recognised as a problematic label that can, in itself, be stigmatising (Vines et al, 2014). By designing and evaluating technologies that aim to address particular vulnerabilities, there is a danger that HCI researchers could inadvertently expose or exacerbate participants’ vulnerability.

The research process can also have a negative impact on researchers. Authors in other social science disciplines have long acknowledged the “emotional labour” involved in doing research in sensitive settings (e.g., Warr, 2004), but the topic is just emerging as a concern within the HCI community (e.g., Moncur, 2013; Thieme et al., 2014; Waycott et al., 2015). In a recent CHI paper that focused on the emotional wellbeing of researchers, Moncur (2013) argued that university departments undertaking HCI research (often computer science or engineering departments) typically have insufficient procedures in place to support researchers working in sensitive settings. This issue would benefit from more open dialogue and the sharing of experiences to ensure our discipline takes seriously the need to protect researchers’ emotional wellbeing when undertaking sensitive research.

This paper aims to contribute a body of case studies to support an improved understanding of the issues that arise in sensitive settings and to generate dialogue, foster shared learning, and promote reflexive practice. The cases support the argument that HCI researchers need to be attuned to situational ethics and highlight key challenges, such as managing the social context when designing/introducing technologies in group settings, and responding to different stakeholders’ preferences and expectations for the design and use of new technologies.

CASES OF SENSITIVE HCI

In this section we present five case studies drawn from the authors’ recent research. All the projects reported here

underwent rigorous review by the relevant university’s ethics committee and were given ethics approval to proceed. During each project, however, researchers encountered a number of challenges that had the effect of exposing participants’ (and sometimes researchers’) vulnerabilities, creating ethical dilemmas that required us to adapt the research process. For each case study below we provide an overview of the research aims and methods, describe the specific challenges encountered, and discuss our responses.

Designing for Socially Isolated Older Adults

The first case study is drawn from a three-year project that trialled a specially designed social networking tool for older adults who are socially isolated. The system has been described as a “sociotechnical intervention”, or a program designed with consideration for both social and technological features (Waycott, Morgans, et al, 2015).

Project aims and methods

Social isolation occurs when people have limited contact with others. As people age, their social networks often diminish and they can experience limited mobility due to physical impairments or lack of suitable transport. This can make it difficult to engage in regular social interactions, putting many older adults at risk of social isolation. This project aimed to develop, implement, and evaluate a new iPad application to connect older adults experiencing, or at risk of experiencing, social isolation.

The project was conducted in collaboration with an aged care organisation. During each field study a group of five to eight older adults – aged care clients, who lived independently in their own homes – used the iPad app, *Enmesh*, to share photographs and messages with each other and with their care managers, who also participated in the project. A researcher visited participants to conduct interviews and help them learn how to use *Enmesh*. Participants were invited to attend regular social events so they could meet each other in person.

The project achieved a number of positive outcomes. Sharing photographs and messages worked well for fostering creative self-expression, building connections between participants, and creating a sense of belonging to a group (Waycott et al, 2013). In addition, the system supported care managers’ communication with their clients, augmenting their provision of psychosocial care (Waycott et al, 2014). Developing and trialling a technology-based social isolation intervention, however, required careful consideration of technical, social, and ethical issues. Below, we reflect on three key challenges.

Challenge 1: Investigating social isolation

Introductory interviews were conducted to find out about participants’ use of technology and their experiences of social isolation. In one field study, social isolation was measured using two established instruments – the Friendship Scale (Hawthorne, 2006) and the Lubben Social Network Scale (Lubben et al, 2006). For the purposes of this study the questionnaires were incorporated into the interview process. Asking participants directly about their experience of social isolation, however, was quite confronting. Some

participants became emotional or were reluctant to respond, which was difficult for both participants and researchers. The researcher assured participants they did not have to answer any questions they did not want to, but a concern remained that this process may have inadvertently exacerbated participants' vulnerability and heightened their sensitivity to the issues discussed. The research process was modified in response. Instead of directly asking questions from the social isolation scales, participants were left a copy of the questionnaires to complete in their own time. Participants were encouraged to contact their care manager if they experienced distress when answering the questions on their own. In a later field study a specially designed questionnaire was used to assess different dimensions of social isolation, which participants found much easier to complete.

Challenge 2: Managing stakeholders' expectations and misunderstandings about the technology

The iPad is a popular consumer device. Participants, their family members, and care managers often had expectations about how the iPads would be used which could not always be supported within the confines of the project. Some family members and care managers believed the main aim of the project was to teach older adults how to use an iPad; while this was one positive outcome, it was not the key aim, which was to explore how well Enmesh addressed participants' experiences of social isolation. Participants sometimes expressed misunderstandings about the technology, which needed to be carefully managed in order to ensure they gained benefit from the project and did not lose confidence. When this happened, the researchers provided extra training and support. In addition, researchers helped participants learn to use other features of the iPad, such as email and the Internet, although this was outside the scope of the project.

Challenge 3: Managing group dynamics

This project involved not only introducing and evaluating a new technology, but also creating the social network in which it was used. Each field study involved bringing together a group of aged care clients who did not previously know each other, and supporting them to build friendships by sharing photographs and messages. There was no guarantee that participants would enjoy communicating with each other. For the most part, participants were courteous and respectful when communicating on Enmesh and attending the social gatherings. However, one client was clearly unpopular with other members of the group during a social event, when he dominated the conversation; the other clients asked not to be connected to him on Enmesh. In addition, there was no way of guaranteeing that other people would respond to participants' photographs and messages, or that other members of the group would create and share interesting content. Each field study involved a small group of participants; a range of factors (such as health difficulties) affected participation levels, leaving some members of the group wondering why nobody was responding to them. Over the course of a day, one participant sent several messages asking for a response, culminating in a message that said: "That's it. I knew I

was just talking to a plastic thing. I feel silly." This example raises questions about how to effectively design a sociotechnical intervention that supports timely and engaging communication between people. When expectations about communication are not met, feelings of isolation and loneliness might be exacerbated.

This challenge was partly mitigated by the inclusion of care managers as co-participants – they contributed content and responded to their clients' messages as often as possible. In addition, the research protocol was modified to include more input from the researcher. The third iteration of Enmesh included an "activity page," used to share regular prompts that encouraged participants to take photographs or share stories in relation to a particular theme. This helped to ensure there was always activity on Enmesh. Managing group dynamics, however, is an ongoing challenge for the development of social isolation interventions.

Designing mental health support tools for young people

The second case study describes research conducted with participants at a very different stage of life: young people who have experienced mental illness. It is drawn from a project conducted in collaboration with a youth mental health clinic that aims to iteratively develop and trial an online tool to provide social and therapeutic support to young clients (Lederman et al, 2014; Wadley et al, 2013).

Project aims and methods

Serious mental illnesses such as psychosis are devastating and stigmatising conditions which usually have their onset before the age of 25 when young people are at a critical stage of their social and intellectual development (McGorry et al., 2008). Previous work has shown that people with psychosis have significant potential for recovery if they remain engaged in effective treatment (Gleeson et al., 2013). However, public health systems are insufficiently resourced to provide adequate long-term face-to-face care. This project aims to examine the effectiveness of an online tool, as an adjunct to traditional face-to-face services. The project has been running since 2009, with trials underway including pilot studies covering different condition cohorts and an extended randomized control trial involving up to 100 mental health clients which will end in 2018. This is a highly multidisciplinary collaboration involving psychologists, technologists, professional writers, graphic artists, youth workers and mental health clients. The project employs participatory design methods; thus clients and clinicians are significantly involved in designing the therapy.

Challenge 1: Privacy and protection vs sharing

Because of the stigma attached to mental health conditions, user privacy is important. Yet this project asks clients to share their experiences online. Thus the researchers must ask how a social therapy can balance the need for privacy with the need for open discussion. In addition, some of the experiences that clients share could potentially put other clients at risk. For instance, it is foreseeable that expressions of suicidal thoughts could be distressing and trigger dangerous behaviour in others. Care needs to be taken, then, to ensure that such thoughts

are not made visible to other clients. Many conversations might be on the borderline of acceptable risk, yet such conversations may be of great benefit to those seeking help, making both automatic detection and human moderation difficult.

Responses to these concerns were built in to the design of the system. Firstly, privacy is supported through the use of pseudonymous usernames. The system also allows users to delete their prior input, and users are able to “hide” or “unhide” themselves at any time to deal with temporary states of psychosis such as paranoid beliefs. Secondly, users can report psychosis or paranoia posts that worry them; these are flagged to moderators. Thirdly, the therapy’s positive focus, using psycho-education modules and a positive psychology approach (Seligman et al., 2006), aims to avoid detrimental effects of over-exposure to deficit-focused content.

Challenge 2: Anytime, anywhere access

Clinics normally interact with clients in person during business hours and at appointed times. An online system potentially creates contact at random times and with the client’s whereabouts unknown. This creates difficult duty-of-care issues. The system is moderated by trained clinicians who monitor clients’ activity and respond to their messages. However what should happen if a client indicates a problem while no clinician is logged on? Responses to messages may not be immediate, and most critically, extreme events such as suicidal ideation may not be noticed immediately. Researchers and designers need to be certain that asynchronous online communication will not add to the workload of clinicians, who are already overworked and under-resourced. Some moderators have indicated that they check the system at night before going to sleep. This could become a burden if it were to become expected of them; furthermore, such use cannot be reliably expected, and moderators may not be able to work effectively at such times.

This challenge is addressed through the design of the system and the research protocol. Each post is searched for words relating to abuse or self-harm. Problematic posts are blocked and flagged to moderators for immediate action, while the author of the post receives a message with the phone number of an emergency mental health service. A further response to this challenge has been careful selection of trial participants. The trial is only available to clients currently in remission, reducing the likelihood that emergency care will be required. All clients are known to the moderation team, who have access to client health histories. The site clearly explains that it is only moderated at certain times and provides contact details for alternative out-of-hours care.

Researching the Impact of a Technology Club for Young People with Autism

The third case study draws on research aiming to evaluate the impact of a technology-based social club for children with high-functioning autism (Wadley & Schutt, 2013). Unlike the first two case studies, this setting did not involve the design of a novel technology; rather it involved technology use and learning in a social setting. Although the challenges described here are specific to

this context, they point to a wider need for HCI researchers to adapt their protocols when it becomes apparent the research process could expose participants’ vulnerability. This theme was common in all five cases.

Project aims and methods

Many young people with high-functioning autism (HFA) are socially isolated yet share common interests related to digital technologies (Wang & Spillane, 2009). The Lab (www.thelab.org.au) provides weekly after-school social spaces where young people aged 10-16 with HFA can meet, make friends through the sharing of interests, and learn new technology skills from expert IT mentors based on those interests (Schutt et al, 2015). Parents and guardians meet in a separate but nearby space during Lab sessions. A Participatory Action Research (Baum et al., 2006) framework informs the operations of the Lab, including ongoing feedback on activities and structure from mentors, participants and families. A year-long evaluation program was launched at The Lab in 2012 to better understand its impact on participants and their families. The program planned to collect data from participants at baseline and 4-6 month intervals through a range of validated instruments.

Challenge 1: Potential impact of interview questions

A number of Lab participants had been experiencing bullying, isolation and other social impacts at school, as well as the effects of transition from childhood to puberty, and from primary school to high school. When parents and guardians were consulted at the research planning stage, some suggested that one of the instruments selected, the Beck Self Concept Inventory (Beck et. al., 1990) could detrimentally impact their children’s mental wellbeing due to the children’s repetitive thinking patterns and tendency to focus on details. Parents were particularly concerned that statements in the Inventory such as ‘People want to be with me’, ‘I like myself’ and ‘I like my body’ could lead to negative rumination. As a result, the research team chose to not use the Beck Self Concept Inventory or similar instruments.

Challenge 2: Participant anxiety

Research interviews for the project took place during Lab sessions in an office adjacent to the main Lab space. Children and families had been notified of the interview time in advance. Present at the interview were the interviewer (with whom the child was by then somewhat familiar), the child, and, if requested by the child or family, a parent or guardian. The interviewer noted that participants reacted to the interview situation in a variety of ways. Some seemed confident and at ease; others did not. Two interviewees exhibited signs of heightened anxiety, causing the interviewer to end one interview early, even though the child’s mother was present to calm the child. The reasons for this were discussed with the parents and the Lab research and mentoring teams. A theme emerged of a ‘fear of looking foolish’. These children prided themselves on their knowledge and ability to answer questions correctly, and the formal interview situation made them feel as if they were lacking in control and unable to provide ‘right’ answers, even though the researchers stressed that there were no right or wrong

answers. A related theme was interviewees' dislike of being taken out of the Lab, where they felt comfortable and accepted, into an interview room, where they did not.

As a result, the team decided that the research program as it was represented an unacceptable ethical risk to the wellbeing of participants, and prematurely curtailed their evaluation. An alternative plan was devised to bring in a particular external evaluator and educator who had demonstrated experience in working with young people and technology. An alternative qualitative methodology was developed in consultation with the evaluator, which involved the evaluator visiting the Lab, building trust with participants through the sharing of technology interests and devices, and asking evaluation questions within the context of the main Lab room itself.

Challenge 3: Trade-off between participant comfort and reliability and validity of data

The original research program began with the collection of baseline data. After consulting with parents, the research team chose to undertake this data collection two and three weeks into young people's involvement with the Lab, rather than in the first week, so that they would be more familiar with the interviewer and Lab in general, thereby minimising their anxiety. Although this strategy worked, some parents pointed out in later focus groups that they had already seen significant impacts on their children's wellbeing by their second or third week of Lab involvement. This meant that the baseline data collected may not have reflected true pre-involvement states.

Supporting Social Connectedness for Children in Hospital

The fourth case study is drawn from a project that aimed to design technology to enable children in hospital to remain socially connected with their classmates. This setting is again very specific, and raises particular challenges associated with conducting research with children and families in a hospital setting. Links can be drawn, however, with the other cases, particularly in the desire to consider the needs of multiple stakeholders in technology design and the difficulty of managing stakeholders' expectations about the technology.

Project aims and methods

Children who spend significant time in hospital can experience social dislocation at a time when engagement with family and friends is critical. Losing touch with classmates in particular can lead to isolation, loss of motivation to study while in hospital, anxiety about returning to school, and ultimately disengagement with education, and undesirable life outcomes. Some parents and schools use off-the-shelf technology to connect with children in hospital, and a few researchers have designed bespoke technologies for this context. However, little work has been done on the use, effects and challenges of mediated connection for hospitalized children.

The project involved design workshops with parents, teachers and hospital staff to gather insights to inform the design and trial of a tablet-based technology. The researchers found it was inappropriate to set up audio-visual "media spaces" or even text-messaging in schools and hospitals. To respect the need for privacy and order in

these settings, they chose instead an unobtrusive medium. The technology offered three modalities: a colour-sharing feature, visualization of remote ambient activity, and asynchronous photo-sharing. This choice represented a compromise between the desire for rich social presence and the need to avoid disrupting sensitive settings or breaching children's privacy (Wadley et al, 2014).

Challenge 1: Involving children in the research process

The children in this project were young (7 to 12) and very sick, some with potentially fatal illnesses. These concerns as well as restrictions imposed by the hospital meant the children could not participate in the design workshops. Instead workshops were held with adults close to the children, such as parents, teachers and hospital staff. Vulnerability thus directly impacted the research and forced a compromise that was not entirely satisfactory.

The researchers were, however, able to conduct the field trial in hospitals and schools. Working with very sick children can be emotionally confronting for HCI researchers, who, it should be noted, do not have the training and experience that medical staff have. It is not uncommon for a patient to die during a hospital research project; thankfully this did not occur here.

Challenge 2: Balancing the needs of different stakeholders

The project involved consulting with different stakeholders (parents, teachers, and hospital staff) who sometimes had conflicting desires. For example parents of hospitalised children wanted video connections between hospital and classroom, but teachers rejected this as they feared the technology might "take over". Teachers were balancing the vulnerability of the hospitalised child to isolation against the needs of classmates who might be affected by disruption and breach of privacy. There were also concerns about school children being disturbed by hospital scenes. In another example of mismatched stakeholders, some parents asked for a vital-signs monitor, but hospital staff strongly disagreed it be provided, for fear of alarming parents if the device failed.

Different family members sometimes had quite different needs. Some parents already spent a lot of time at the hospital with the child and thus did not strongly desire mediated connection, and in fact could have become exhausted and require time *without* a connection. Parents must maintain family routines despite their child's hospitalisation, especially if there are siblings, while other relatives may rarely see the hospitalised child. So while one might assume that all stakeholders want maximum connectivity, in practice this is impractical. This is a difficult point for a stakeholder to make; teachers, parents, nurses, etc. do not want to appear to be unconcerned with the hospitalised child. Yet for practical reasons they cannot maintain constant connection. Acknowledging this in research can be discomfoting.

Challenge 3: Managing expectations about the technology

Ethical concerns meant audio-visual media had to be avoided as they could potentially expose not only the child communicating but other, perhaps unrelated children in the vicinity. However some trial participants felt that video should have been implemented, and were

dissatisfied with the technology and unconvinced by its design logic.

A photo-sharing feature was intended as a workable compromise between presence and privacy. However research ethics for working with school-children demanded that photos be moderated in case unsuitable images were sent. Again not everyone was happy with this decision: for example a peer reviewer for a previous publication suggested children should have been trusted not to misuse the feature. There was also the question of who should be the moderator, both during the trial and later if the technology were to enjoy routine use, as this choice can impact privacy.

Although teachers felt text-messaging would be disruptive in class and this feature was not included, some users subverted this design by hand-writing messages and sending them through the photo-sharing feature. This forced the researchers to consider whether to block these photos or instruct users not to continue this practice; we decided in fact to allow it to continue.

Designing a Mindfulness App for Women with Chronic Pelvic Pain

The final case study is drawn from the beginning stages of a doctoral project that will design a mobile application to provide therapeutic support for people with chronic pelvic pain (CPP). Although this project is in its very early stages, challenges that are similar to those described above have already begun to emerge. These relate to the specific research context and highlight the difficulties of group-based design research in a sensitive setting.

Project aims and methods

One in five women and men will experience intense and debilitating pain that can last months or even decades (Blythe et al., 2001). While CPP is the single most common cause of referral to women's health services (Lathe et al., 2006), often the physical causes are unclear, in which case the therapeutic focus must be on coping with, rather than curing, the pain. Some doctors believe that such cases are at least partly psychological, and some believe CPP may be linked to earlier trauma such as abuse during childhood. CPP is often comorbid with anxiety, depression and personality disorders.

This project aims to design and trial a smartphone app to help people cope with incurable pain by using a mindfulness technique. While the technology design is still under way, the therapy is likely to involve a one-month mindfulness course (which allows people to distance themselves from their perception of pain) as well as a psycho-education module (which provides education about pain). Mediating the therapy allows a more intensive, daily engagement, which could not be delivered in a clinical setting due to resource constraints and because of the limited mobility some patients experience.

The early stage of this research involves asking focus groups about their experiences of CPP, how it impacts their lives, the treatments they have already tried, their existing use of and access to technology, whether they find mindfulness and psycho-education acceptable, and whether it would be acceptable to learn these via an app.

Subsequent phases are likely to involve developing and trialling an app. Design decisions include: which therapies to include in the app, through which modalities to deliver the therapy (e.g. voice, video, text, interactivity), and how to keep users engaged with the app for the length of the course (e.g. using reminders, narratives, or gamification).

Challenge 1: Managing focus group discussions

The focus group is a standard way to efficiently gain an understanding of a cohort of users. It has a number of advantages and is widely used in requirements gathering and design. However it may be problematic in this project. The focus group format exposes participants to each other's personal stories, and possibly, personality disorders. Stories about pelvic pain often involve sex and relationships with intimate partners, as was discovered during a focus group session for this project. People in chronic pain can easily become agitated or upset. If such interactions arise during focus groups they may affect both participants and researchers. Furthermore, people with CPP are likely to find sitting for long periods of time uncomfortable, which may prime them to respond in a negative manner and confound the data. Thus, researchers need to regularly check in with participants, and if necessary encourage movement and stretches.

Challenge 2: Reliving or exposing trauma

Because chronic pelvic pain often has no clear medical explanation, some doctors attribute it to psychological processes. Patients in these situations often feel that their doctors do not believe they are suffering real pain or have a real medical problem. Some participants have reported arguing with unsympathetic doctors, an experience which can be traumatic. It is therefore possible that participants might feel that being asked to design or trial a psychological therapy implies that members of the research team, also, do not believe they have "real" pain. In addition, since pain may be linked to past trauma, asking patients about their condition or asking them to sample a therapeutic intervention may trigger an adverse or unexpected reaction in the workshop.

Challenge 3: Exposing vulnerability through design

Adding a social component to technology-mediated therapy can boost engagement, and be therapeutic in itself, especially if users are immobile, socially isolated or suffer psychological problems such as anxiety (Lederman et al, 2014). Thus the technology to be developed in this project will likely include a social component. However this raises potential problems. Should users be able to communicate with each other, or is this too risky? Is there a way to create a degree of social presence without enabling potentially harmful communication?

Likewise gamification may increase engagement and motivation to complete a course of therapy. Some participants have already suggested features that can be considered forms of gamification. But would competitive features (e.g. usage or pain leader-boards) create performance anxiety and tension exacerbating pain symptoms? Finally, to what extent is it paternalistic or patronising for the researchers to make such decisions on behalf of people with CPP?

DISCUSSION

The five cases we have documented are drawn from projects conducted in diverse sensitive settings, with participants who face a range of health and social difficulties. The challenges sometimes emerged directly from the particular setting in which the research was conducted (e.g., the difficulty of subjecting children with autism to a research interview, and the privacy and disruption issues that occur in classrooms). When reviewed together, however, these challenges highlight key issues that HCI researchers need to be aware of when conducting research in sensitive settings. Of course, these issues are not unique to HCI. However, the particularities of HCI research – which involves designing, implementing or evaluating new technologies that may cause unexpected disruptions to participants – mean it is important to discuss these issues in the context of our research discipline. Here, we identify and discuss five lessons that can be drawn from our case studies.

Responding to Situational Ethics

The cases highlight the highly contextualised nature of ethically-charged scenarios that emerge in sensitive HCI. Challenges arise from the setting in which the research is conducted, the particularities of the research participants, the problem that the technology seeks to address, the values and expectations of multiple stakeholders, and so on. Despite careful planning and review before projects like these proceed, researchers will inevitably face dilemmas that emerge during the research process, where there may not be a clear right or wrong response. Researchers need to be able to recognise and respond in an agile manner to challenges as they arise.

Munteanu and colleagues referred to these emergent, unanticipated ethical issues as “situational ethics” (Munteanu et al., 2015). The experiences we have described above lend support to Munteanu et al.’s argument that there needs to be greater recognition of situational ethics within formal ethics review procedures, particularly in the context of HCI research. However, while they called for improvements to *anticipatory* ethics review, we suggest in addition a need for training to ensure that HCI researchers are sensitised to these issues and are fully aware that their research processes may need to be adapted over time. In all the cases we have presented above, modifications needed to be made either to the research process or to the technology design (or both) in response to unexpected ethical challenges.

Being able to adapt and respond to situational ethics is important not just in the sensitive settings we have highlighted but in any HCI research that involves dealing with people. Researchers in HCI have noted ethical challenges that emerged in ethnographic research conducted to understand distributed collaboration (MacColl et al, 2005) and, more recently, in HCI’s “turn to the cultural” which increasingly involves research conducted in public spaces and centred on the performing arts (Benford et al, 2015). Ethical practices in HCI have to be agile not only during individual projects but over time, as both the research discipline and society’s relationship with digital technologies evolves. Benford et

al (2015) demonstrated this in their recent discussion of the ethical implications of the growing interest within HCI in digital arts, performance, and public spaces.

Exposing Vulnerability

The ethical dilemmas described above often emerged because of concerns that the research process or the technologies being designed and evaluated may have exposed or exacerbated participants’ vulnerability. Difficulties, anxieties, and constraints that participants were grappling with came to the surface, making researchers and project stakeholders acutely aware of the personal challenges participants were facing. In two cases (“Designing for socially isolated older adults” and “Researching the impact of a technology club for young people with autism”) some participants showed signs of distress when being interviewed, leading us to modify the research protocol. In another case (“Designing a mindfulness app for women with chronic pelvic pain”) a focus group discussion led some participants to disclose intimate and confronting personal information in front of strangers. Meanwhile, the danger of exposing participant’s vulnerability was a key consideration in the design of mental health support tools for young people, and technology to support social connectedness for children in hospital. In both of these cases, the privacy of young people using the system was a key concern. We responded to these challenges by embedding constraints within the technology to prevent or overcome privacy transgressions. However, these design decisions inevitably involved compromising functionality; sometimes this meant not including features that could potentially be of great value to participants.

HCI researchers need to take into consideration how a technology design – and the evaluation process – might expose vulnerabilities, putting participants or users at risk of negative effects. We need to reflect on the possibility that the technologies we design could, in fact, “be more disruptive or harmful than the circumstances they are meant to improve” (Baumer & Silberman, 2011). In addition, researchers, participants, and other stakeholders may have different perspectives and values, which will affect how they view and respond to the research. In sensitive HCI, many of the conditions we design for carry social stigma and we must try to ensure the technology we design is empowering. There is a danger, however, that by aiming to address vulnerabilities, the technologies we design could be disempowering; the label “vulnerable” therefore needs to be used with caution (Vines et al, 2014), and we need to acknowledge that sometimes the best course of action is to *not* design technology-based solutions (Baumer & Silberman, 2011).

Recognising the Impact on the Researcher

HCI researchers are likely to have been educated in computing, social science, design or a related field; they are less likely to have received the skills for encountering vulnerable participants that a medical doctor, clinical psychologist or counsellor receives during training (Moncur, 2013). Such skills would have been helpful in all of our cases, particularly when we encountered participants who became upset during the research.

Our case studies demonstrate that the challenges researchers face can extend beyond managing emotional wellbeing. Researchers may struggle to manage overbearing contributors to a group discussion without causing conflict. They may struggle to manage their own responses when hearing confronting or distressing stories from participants. They may struggle to manage personal frustration and maintain a positive demeanour when there is tension or conflict. Targeted research training is one possible response. Another is to include in research protocols the requirement for extra staff members who are trained in relevant counselling or medical skills. Some research settings, such as mental health clinics, already have this requirement. However problematic situations do not only arise in recognised sensitive settings such as clinics, but can occur in any research involving people. Researchers in disciplines such as sociology and anthropology have been aware of these issues for years (e.g., Warr, 2014), but researchers in HCI may not be suitably sensitised.

The Social Context of HCI Research

All five of the cases discussed above involved a significant social element. This was either embedded in the design of the technology – that is, using technology to build social connections – or in the way the research was conducted – for example, using group design workshops. In either case, the research involved bringing a group of people together (physically or virtually) to share experiences. Often, people did not know each other prior to engaging in the research project. This created a significant challenge for managing group dynamics and ensuring the anticipated social benefits of each project were realised. Bringing people together can give rise to conflict or unexpected disclosures, and in our cases we were creating social experiences in sensitive settings with people who were likely to be sharing difficult life experiences. For some vulnerable or socially isolated participants, the research setting might be a rare social encounter, making group dynamics a central concern. Participants might find it uncomfortable to express an opinion, while disrespectful treatment of an opinion by others may be considered a personal slight. Thus researchers may need training in group management, and may need to provide contact details for medical or mental health services for individual participants who are negatively impacted by group dynamics.

In HCI, it is not only the research process but also the resulting technologies that can create uncomfortable social contact. Publications reporting the outcomes of design and evaluation studies typically focus on the social benefits that the technologies provide, with less focus on the challenges encountered when using technology to connect people (see Gerling et al., 2015, for an exception). By documenting our experiences, we hope to encourage other HCI researcher to share and reflect on the challenges of using technology to create social connections in sensitive settings.

Managing Diverse Needs and Expectations

In each of our case studies there were diverse stakeholders with different needs and expectations about

how the technology might benefit them. The difficulty of managing diverse expectations can be seen most clearly in the children’s hospital case, where parents, siblings, staff at the hospital, and teachers brought entirely different perspectives to bear, despite all wanting the best for their charges. Similar tensions are likely to arise in any project in which technology is designed or deployed.

Participants in technology trials bring prior beliefs, values, and expectations about technology with them, especially when off-the-shelf platforms such as phones and tablets are used to deploy the intervention. They are likely to expect the platform to offer features they have already used or heard about, and may be dissatisfied if these expectations are not met, especially if the chosen design represents a *constraint* over existing technologies.

How do designers/researchers manage expectations and values that diverge from the aims of the project? In sensitive settings the stakes may be high, and the possibility of mismatch between expectations and outcomes is likewise high. For example, people experiencing chronic distress are likely to have been actively searching for a solution, and may have unrealistic expectations of what ICT can achieve. Participants who are not used to research protocols may even mistake an invitation to take part in design sessions for an invitation to evaluate a finished design, and be disappointed not to take home a cure: thus the recruitment process must be very clear about what participants can expect.

CONCLUSION

Responding to growing interest in HCI about the need for researchers to communally reflect on the challenges of research in sensitive settings, we have contributed a collection of relevant cases and reflected on the key challenges they have posed. Our aim in developing a body of cases of “sensitive HCI” is to contribute to an improved understanding and refinement of practices for conducting HCI work in sensitive contexts. We have highlighted five key lessons that can be drawn from our cases; that is, the need for researchers to be mindful of: situational ethics; the dangers of exposing vulnerability through the design and evaluation of new technologies; the potential impact of the research on the researcher; managing the social context of sensitive HCI research; and managing diverse needs and expectations about how technologies should be designed and used. This is not intended to be a definitive list; rather, it contributes to ongoing discourse about HCI research in sensitive settings. We acknowledge that building a body of case studies on sensitive HCI means that researchers may be asked to expose problems that are typically left out of research reports, potentially exposing researchers to criticism. However the benefits to the research community and to the community for whom we design should outweigh these risks, and we encourage HCI researchers to continue discussing these issues.

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