Walk a mile in my shoes: reflecting on studies with people with chronic pain

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Abstract

In invisible illness, like chronic pain, often people encounter a lack of empathy because others cannot see what is 'wrong' with them. This can lead to feelings that their condition is disregarded or minimised. In this paper, we reflect on the empathic aspect of some of our encounters when doing qualitative studies with people with chronic pain, and how they affected the study and the researcher.

Author Keywords

Chronic pain; qualitative study; empathy

ACM Classification Keywords

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

Introduction

In this paper we reflect on the role and effect of empathy in HCI studies, specifically the studies we conducted while investigating the needs of people with chronic pain to motivate and support physical activity through technology (*www.emo-pain.ac.uk*). Our reflections are based on a set of multifaceted qualitative studies with people with chronic pain (CP), physiotherapists and psychologists in pain management [9].

To ground our reflections, we start with a definition of empathy. According to the online Oxford dictionary, empathy is *"the ability to understand and share the feelings of another*." There are three key attributes to empathy [5]: "(*a) knowing what another is feeling, (b) feeling what another is feeling, and (c) responding compassionately to another person's distress"*.

By using these attributes, empathic qualitative research allows the researcher a deeper grasp of how people make sense of their experiences and can help to engage with the user, gather reliable data and be a validating device when presenting the research [10]. Empathy is important in HCI, to facilitate the understanding of people's needs, values and emotions leading to better technology design [11]. It requires the researcher to immerse him/herself in the topic (barriers and enablers of physical activity in people with CP in this case). Findings are interpreted, with the formation of socially and experientially based mental constructions. These experiences are grounded in the information provided by the participant but also inevitably influenced by the researcher undertaking the study. Researchers' empathic emotional involvement and reactions to narratives of participants can help to build a trusting relationship, and also influence the interpretation of information they provide. At the same time, researchers can feel a gamut of emotion, from feeling worthwhile, to feeling frustration to elements in participants' stories or guilt at contributing to emotional distress in the participant [7].

In many HCI case studies like ours, feelings and emotions are the direct focus of attention and what we aim to design for. In the case of physical rehabilitation for CP, fear of movement, further damage and pain are just some of the barriers that technology aims to overcome [7] by helping to regulate them. This means that empathy is at the core of the investigation. In the next section, we reflect on the role of empathy when studying the needs of people with CP.

Chronic pain (CP): an invisible illness
CP is pain that persists past healing (around 3 months) after injury or with no identified lesion or pathology[8]. People with CP may encounter a lack of empathy because others cannot see what is 'wrong' with them: they may not show any external or even internal signs of illness. For example, a lady who had CP related such an instance when earlier that day someone had joked about what she had done to get a disabled badge as there was '*nothing the matter with her*'. This little vignette illustrates what people with CP can encounter on a regular basis, leading to feelings that their condition is disregarded or minimised [2] and they often feel stigmatized. People with CP can become socially withdrawn from friends and relatives and feel like a burden to them[1], may feel misunderstood by healthcare professionals and in many cases are not able to get the help they need to manage their condition.

Against this backdrop, when talking to CP people about their experiences, it was important to communicate empathy to make them comfortable. However the researcher's 'empathic horizon' [6] was far removed from that of the participants, having no experience of CP. It was important to learn how to show empathy.

Affective state of people with CP: People often expressed frustration and anger about the things they had to do just to 'maintain' mobility. Sometimes at the time of the study, a person may be in a very negative

mood or be feeling low and behave negatively towards the researcher. We had an instance of such behaviour and empathising with the affective state of the individual helped to cope with it, stay calm and facilitate the situation and remain positive. In other cases, participants enjoyed the opportunity to talk about their condition and often thanked the researcher for talking to them. Many seemed to find insights in their lived experiences while talking to the researcher.

Understanding he Context of CP: Assuming an understanding of CP purely on the basis of having experience of some pain can oversimplify the factors that affect a person with CP who may be living with pain for an extensive period of time leading to a long term change of life. Knowledge of our users health condition, vulnerabilities and emotions developed through accounts in books, papers and briefings from psychologists on our team helped us frame an initial empathic reference in this context, which was useful for dealing with people with CP. However as we met more people and gained more experience, we found it easier and more natural to delve deeper into their words, derive a deeper empathic understanding of the condition and resolve implied meanings.

Communicating empathy, the use of language: Empathy plays a role in building trust and a rapport with potential study participants. We also learnt that language was important. For example, it was important that the researcher communicated that she regarded CP as a *real* disease. Further, language for questions and later discussions or even writing up was carefully chosen: e.g., words such as "sufferer" were not used in questions or presentation of the research as they can be depersonalising. Words convey unintended attitudes that can be hurtful to participants. But this kind of information can be elusive for HCI researchers so it was very helpful to obtain inputs of pain specialist psychologists before starting field research and also at regular intervals thereafter. E.g., the researcher was challenged for saying, 'I understand' by a participant who said '*you cannot understand what it felt like to wake up with pain every morning.'* This incident demonstrated to us the need to be careful of easy empathy, where researchers assume they understand the participant, and become complacent (e.g. through projecting our understanding on user accounts rather than being objective) and render the research unethical [10].

Staying objective and focused: The focus of our study was on CP peoples' experiences with physical activity. In the context of the emotional nature of learning about the impact of CP on their lives, it could be very challenging to adhere to the pre-set course of the interview. Some of the vulnerabilities that were shared made the researcher feel a bond to the participant as they were intimate aspects of the person's life. For participants as well some of the discussions brought up uncomfortable and painful memories. To regain perspective, the studies were distributed over a longer time; the researcher also made time between conducting studies and doing analysis to reflect on practices [3] and stay objective about the research.

Impact on researcher: Undertaking emotion-laden and sensitive research can have benefits but also potential challenges and burdens for the researcher, which they need to be aware of and willing to work through. Interviews could be emotionally draining and at times forthcoming interviews were viewed with dread. Engaging in difficult emotional discussions with

participants is not something that HCI researchers are typically trained to do. The researcher could also feel out of his/ her depth when engaging with such issues and was aware that she could cause real harm. E.g. more than once, people interviewed expressed that they had felt like ending their lives in the past because they felt unable to cope with pain on a daily basis. In such cases it was necessary for the researcher to think about an exit strategy to minimise distress and next steps (e.g. discussing with advisor). Further, constant reflection on the stories narrated by participants provided a good opportunity to immerse the researcher in the data but could cause deep emotional responses, causing them to examine their own lives more closely, both in terms of the positive and negative experiences. Support from the advisory team (including a psychologist) and peers helped the researcher to cope and share the burden.

Conclusion
Empathy is vital to the qualitative researcher to develop a rapport with the user. However, empathy in HCI needs more definition and frameworks like [4] but with more support for the researcher and for research involving vulnerable populations. As researchers, we need to balance empathy by applying scientific rigour to our attitudes, challenging assumptions and ensuring that we are not patronising, stereotyping or biasing our participants or research through our words or approach. More discussions like this in the HCI community can help create guidelines and regulate such research.

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