Asking about Health: Enabling Empathy in Research with Homeless Young People

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Abstract

Questioning people about health can be difficult, calling for empathy on the part of HCI researchers. This short paper begins with a discussion of empathy and moral internalization. Then, I present an experience from a study with homeless young people, highlighting how attention to research setting, preparation and method can set conditions where empathy can be expressed.

Author Keywords

Empathy; moral internalization; homeless young people

ACM Classification Keywords

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

Introduction

Empathy has been defined and theorized since at least the time of Aristotle, with a proliferation of definitions and theories regarding empathy and its development in human beings. Indeed, empathy and its related response, sympathy, are so much a part of our daily experiences and commonsense understanding of the world that they are difficult to approach conceptually. In order to make a start on discussing empathy and HCI research into health and care, I begin with theory

developed by empathy scholar, Martin L. Hoffman [1]. Empathy, Hoffman says, is "an affective response more appropriate to another's situation than one's own" and develops starting in early childhood. Empathy is fully realized if *moral internalization* is achieved and a person's actions towards others arise from an internal moral motive that "(a) has a compelling, obligatory quality, (b) is experienced as deriving from within oneself, (c) makes one feel guilty when one acts or considers acting in ways that harm others, [and] (d) disposes one to consider another's needs even when they conflict with one's own."

Moral internalization, then, provides a working concept of empathy useful when formulating HCI studies of any kind and which may be particularly useful when contemplating a study of health and care. Importantly, moral internalization points out the tensions and potential conflicts that arise when we attempt to balance our own needs as researchers with participants' needs for physical and emotional welfare. Taking this view, we see empathy is not just about what we do during research interactions, but extends to how we approach our work and set conditions for our participants. Accordingly, this paper takes the stance that *empathic* conditions can be put in place through careful attention to research setting, preparation and method.

Background

Moral internalization can vary widely from person to person. Furthermore, a researcher's stance is informed by belief systems, training and experience, influencing approach and method, which in turn influence a researcher's take on empathy toward participants. Consider, as an extreme example, the well-known study of obedience by Stanley Milgram [2]. Although no one was physically harmed, subjects believed they were delivering increasingly lethal electrical shocks to an unseen person. Although results built knowledge useful for psychology, the emotional health of the people who participated, many of whom believed that they had gravely injured or killed an unseen stranger, was not given due consideration. Returning to Hoffman, we can see Milgram's study as an example case where the researcher's need to increase understanding outstripped the participants' needs for emotional safety. In fact, Milgram's study is now commonly cited in human subjects training materials as a negative example and, partly in reaction, present-day researchers are often required to get prior approval in order to assure that the benefits and risks of research are balanced.

Indeed, one potential upside of participating in the human subjects' approval process may be that it goes some distance in ensuring that empathy is given its due. For HCI, however, this purely procedural requirement is further enhanced by belief that design is improved when users participate and are given due consideration in the design process. This belief, dating back to, among others, Rittel and Webber's 1973 paper, *Dilemmas in a General Theory of Planning* [6], which argued that citizens should be engaged in urban planning processes and Norman's seminal 1988 book, *The Psychology of Everyday Things* [3], which called for a user-centered perspective, has given rise to the development within, or appropriation by, HCI of a number of methodological frameworks and approaches, (e.g., participatory design, performance studies, user-centered design, human-centred design, value sensitive design, experience-centred design, to name a few). It perhaps goes without saying that there is also a belief that health-related HCI research requires a heightened

For years Maria struggled with depression and cutting herself. She was very shy and often tried to hide her scars. Besides music, cutting herself was the only way she would feel better when times got hard and she was feeling frustrated, depressed or lonely. One day, Maria's sister Audrey, who was very concerned for Maria's life stumbled across a device called cutatune. It sparked her interest because it was a sleeve MP3 player, so she bought it knowing music was theraputic for Maria. When Audrey got home she gave her sister her new gift, immediately Maria put it on. Later that night Maria was very upset because she got into a argument with her mother. She felt as if no matter what she did, it was never good enough. As usual she had the urge to pull out her razor but then when she pulled up her sleeve she discovered the unique form of the "Cutatune" there was a pocket with a rubber stylus that fit perfectly into the three slots located at the top of the device. This was interesting to Maria because that was the spot where she most frequently cut. She removed the stylus from the pocket and ran it thru the slot, immediately music began to play and the music continued to flow, she was soothed and lost the urge to cut herself. Before Maria had never realized the effect her self-harm had on anyone else or the fact that anyone even cared. To this day Maria is truly grateful for "Cutatune" and works as a counselor, for a teen health clinic that helps low-income/at-risk youth, sponsored by the creator of the "Cutatune". This clinic gives away "Cutatune" to those youth at risk for suicide and self harm for free.

Figure 1: Anna's Cutatune drawing and story.

emphasis on empathy toward participants, [e.g., 4]. One could make the case that each design approach above is more or less likely to set conditions where empathy is manifest. Space does not allow for this analysis at the present time, and so I will turn to an example of moral internalization and empathy in practice, from a study where homeless young people answered health-related questions.

The Study and Anna[1]

The study was an investigation of music with homeless young people, aged 15-25 [8]. Drawing on value sensitive design, the study consisted of three research components: a survey, one-on-one interviews, and a design activity. In order to gauge associations between music-listening and health, the survey had questions about drug use, sex and mental health which had been tested in a previous study [5] and approved for use in the current study. Participants were informed that they could skip questions or end their participation at any time. Also, data was collected anonymously and the survey was given via laptop computer, eliminating the need for participants to respond out loud, reducing potential embarrassment. In the end, over 200 people completed the survey without incident. Some even laughed and said that some questions (e.g., about sex) were funny. A single exception to this was Anna.

Anna took part in the study during drop-in at one of the two collaborating service agencies. This means that she was in a large common room with both agency staff and other youth nearby but was screened from view by some moveable walls. During the consent process, Anna asked questions about the study indicating that

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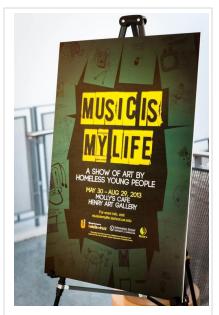1 Participants did not give their names. Anna is a pseudonym.

she knew her participation was voluntary and she could skip questions. She began the survey then asked for a Kleenex while she was answering the health-related questions. When I returned with a tissue, I saw that Anna had a tear running down her cheek. I asked if she was OK or wanted to stop. Anna said she wanted to continue as the survey was reminding her of things to talk about with her case manager during a meeting scheduled to start in 30 minutes. Once Anna completed the survey she said that, after her meeting, she wanted to do the design activity, which involved making a drawing and writing a story. Anna returned and created the drawing and story of the Cutatune (Fig. 1) a music device that helps a young woman overcome her urge to harm herself with a razor. When finished, Anna said the research had been a big help to her.

Much can be said about this, but I will focus on three practical aspects that turned what could have been a problematic situation into a constructive engagement: research setting, preparation, and method.

Research Setting

Anna's crisis during the survey took place in a setting where she felt safe. This is the very reason why the study took place at a service agency. Since my training and responsibility do not include counseling homeless youth, by situating the study at a service agency, I was able to rely on staff expertise if young people requested help or if problems arose. In Anna's case, her previously scheduled meeting with her caseworker acted as the support she needed to work through the survey, and whatever was discussed in her meeting may have led to the catharsis that she seemed to feel as she was completing the drawing activity. So, rather than trying to eliminate all possibility of problems

Figure 2: Poster for the Music is My Life exhibit. (Photo by Robert Wade.)

Anna's drawing and story of the Cutatune (Fig. 1), along with 128 others, are included in the Music is My Life exhibit. Subsequently, her drawing and story have been viewed by over 4,000 people. More details are available at http://www.facebook.com/MusicIsMyLifeProject and http://musicismylife.ischool.uw.edu/wordpress/

While I cannot currently gauge if viewers of the Music is My Life exhibit experience empathic distress or anger, two pre-cursors to empathy [1], I can say anecdotally that seasoned agency staff, with no direct knowledge of Anna, have cried when reading the Cutatune story. Further research is planned to in-vestigate whether drawings and stories, like the Cutatune, invoke empathy towards homeless young people.

during my study, an impossible task, I fulfilled my obligation by engaging homeless young people in a setting where their needs could be met.

Preparation
Careful preparation went in to the design of the study, including review of all procedures and questions by independent review boards in Canada and the US and close collaboration with staff at two service agencies. Furthermore, the study built on my experience working with homeless young people since 2007, which helped me foresee where conflicts and tensions might arise between my need to complete a large-scale exploratory study and participants' needs for emotional safety. Finally, by using questions that had been tested in other research, I felt more confident that homeless youth would feel comfortable when taking the survey.

Method
Method also played a role in giving due consideration to homeless young people's circumstances by focusing on different forms of expression [7]. In Anna's case, the survey was difficult but the drawing activity, which was perhaps no less personal, posed no problem. Also, like many other participants, Anna chose to anonymously share her drawing and story in a public exhibit (see details in Fig. 2) providing viewers with a unique perspective on the lives and skills of homeless youth.

Conclusion
This paper has made a start on discussing practical actions that HCI researchers can take to meet internal moral motives and thereby enable empathy in studies dealing with health and care. Although limited to a particular health-related example, I believe the approach toward research setting, preparation and

method outlined in this paper may be applicable and useful for any HCI study.

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