Enabling Empathy in Health and Care: Design Methods and Challenges

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Abstract

The role of empathy has come to prominence in HCI as the community increasingly engages with issues in medical, health and emotionally charged contexts. In such settings empathizing with others is crucial in understanding the experience of living with specific conditions, or in being sensitive to the concerns and emotions of potentially vulnerable participants. Researchers in these areas become implicated in designing new tools and technologies that support empathic relations. This workshop therefore aims to build an interdisciplinary community of researchers, designers and practitioners to share and discuss their work and the challenges they encountered when establishing empathic relationships within health or care contexts. We will work towards developing a richer conceptual and practical understanding of empathic engagement and design methods in this context to support and shape an agenda for future research.

Author Keywords

Empathy, Health, Care, Dignity, Vulnerability, Ethics.

ACM Classification Keywords

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

Introduction

The importance of enabling empathic relationships between researchers, including designers and system-

builders, and participants is widely recognized across HCI [12]. Initially, empathy in HCI has been understood as a necessity in moving from a focus on system functionality to a more humanistic perspective on design [6] that acknowledges the subjective experiences, feelings and values of the user [4]. According to Wright and McCarthy [12], empathy evolves through a meaningful emotional encounter between the researcher and participant that involves a rich, holistic understanding of that person's lived and felt life experiences; what it *feels like* to be that person and how they *make sense* of their situation, informed by their personal history and anticipated futures. The formation of intimate relationships that enable a better understanding of the person/user is often valued by researchers for providing important insights for design and for facilitating the interpretation of their research.

The role of empathy becomes all the more important when we consider the growing body of HCI research that engages with particularly sensitive and emotionally challenging contexts such as domestic violence [1], bereavement [3], care for people with dementia [2][11], and other complex mental health conditions [7]. While empathy is considered of great importance in these contexts, or at least is heavily implied, there has been very limited discussion on what it means and how it may be enabled or supported.

HCI researchers are often outsiders to specific health contexts and may not know how to respond appropriately in sensitive situations (e.g. when working with participants who can become emotionally distressed). This can place researchers in situations where they may feel helpless, uncertain and often concerned about their actions. This challenges our ability to understand the perspectives of participants,

who are situated in these contexts and have specific care needs.

In addition, certain health conditions can cause participants to have difficulty in recognizing or articulating their own emotions (e.g. [7]), or result in them experiencing changes to their mental abilities (e.g. [11]). As such participants may perceive and experience the world very differently to the researcher. While such dynamics create unique implications for the whole research design process, they also mean that participants' partial understanding of themselves limits our understanding of their experiences (potentially more so than in other contexts). A fuller understanding may therefore be achieved by including additional perspectives on the person from their health and care professionals as well as family and friends; and this fuller picture can be subsequently mobilized (both formally or tacitly) in the design process.

Aim of the Workshop
This workshop aims to build an interdisciplinary community of researchers, designers and practitioners to share and discuss their work and the challenges they have encountered when establishing empathic relationships within health or care contexts. We aim to develop a richer conceptual and practical understanding of empathic engagement, design methods and technology design for empathy to support and shape an agenda for future research.

Workshop Themes
Understanding Empathy: Concepts and Practice
HCI research within health and care contexts usually employs a variety of ethnographic, in-depth qualitative and participatory design approaches, where researchers tend to work very closely with participants. At the

workshop we will devote time to the sharing of experiences from research and practice and, through discussing empathy, will be better placed to capture nuanced understandings of the term. We will ask what are the different textures and dynamics of empathy, how have we experienced it, and which theoretical descriptions have helped us to articulate our empathic experiences? How do understandings of empathy and the values of being empathically involved with participants vary between different professions and in different health or care settings?

Achieving Empathy: Methods and Skills
Drawing together experiences and practice we aim to consolidate methods that enable empathic engagement and provoke new ideas around design methods. We will be asking what aspects of commonly used design methods for empathic engagement (such as probes [4][10] or theatre [9]) enable us to gain empathy? What are their limitations? How do they support empathy and understanding in contexts where participants are less able to reflect (due to restricted cognitive abilities for example) or have difficulties in communicating their feelings and experiences? How can we actively involve participants in design processes that respond sensitively to their individual abilities, respect their dignity, and allow them to remain advocates of their own experiences?

We will also consider empathy as a skill that can be developed. Unlike in most academic contexts, trainees in medical professions (e.g., nursing or counseling) are required to learn how they can be compassionate and empathic in their care. In fact, empathy training often forms the core part of their course and commonly focuses on increasing self- and other-awareness as well as the effectiveness of their interpersonal communication (e.g., active listening, careful responding) [12]. This perspective acknowledges the importance of considering empathy not only for HCI research but for researcher/designer training and practice, and also highlights its overall commercial relevance. Thus, what is the potential for digital technologies to teach us to develop empathy skills? Moreover, how can we design tools and technologies to promote empathic relations such as online communities where people experience emotional transitions in life can share advice and feelings with one-another (e.g. [3]), or that allow carers to gain a better understanding of the worries and concerns of those they care for?

Empathy through Multiple Perspectives
Often in health and care contexts, our understanding of participants is enriched by multiple perspectives offered by their care-givers, families and friends. However, to negotiate access to these people and to establish relationships with them, involves a lot of time and commitment from a researcher as well as interest, willingness and resources from the other to get empathically engaged with the research. Researchers are also challenged with having to combine and make sense of potentially very different understandings and experiences that are shared by different people. We will ask how do our research encounters prompt involved health and care professionals or family members to engage and empathize with these multiple perspectives? How do we negotiate contexts where the perspectives and values of carers are at odds with those of the researcher? How can our empathic understanding be communicated across design teams?

Emotional Encounters: Researcher Wellbeing
While research commonly considers the health, safety and wellbeing of participants (e.g. as part of stringent

ethical approval processes), the HCI community has only recently begun to take the wellbeing of researchers working in sensitive contexts into account [5][8]. Both in health contexts as well as care settings outside medical contexts (i.e. bereavement [3], transitions in later life [9]), the relationships we build with participants are often more intimate and of longer-term. Thus, it requires more consideration as to how we manage our emotional involvement as researchers when working closely with, at times, very challenging populations (i.e. sick children, participants that engage in self-harm, or are diagnosed with terminal illness), which can be overwhelming, emotionally draining and at times extremely difficult for individual researchers to manage. What are our support and self-care needs? How can we ensure to have access to appropriate formal and informal support?

Intended Audience

This one-day workshop will invite 15-20 participants. It aims to support interdisciplinary discussion around the concept of empathy based on participants shared experiences from research and practice and to work towards a richer theoretical and practical understanding of empathic engagement. It will include the exchange of knowledge and the challenges about developing sensitive design methods and technology that support empathic skills or the formation and maintenance of empathic relations, to promote and shape an agenda for future research. Submissions will be solicited from researchers, designers and practitioners from a wide range of disciplines, including but not limited to healthcare, health informatics, social sciences and interaction design.

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