
Caring for Design: Engaging with People with Dementia Through Research and Recognition.

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Abstract

The person-centered approach to care has highlighted the psycho-social needs of people with dementia and influenced HCI research with regards to designing for experience. However, due to the emphasis placed on responding to the needs of people with dementia, supporting and acknowledging them as agentic beings has been somewhat under-emphasized in the literature. In this paper, we introduce the social theory of recognition as a framework for engagement and design with people with dementia. Recognition theory highlights the need for positive social engagement between equal agents, which has relational, cultural and political implications. Drawing on ethnographic examples from the current doctoral research project, we illustrate the bearing of recognition theory for HCI and suggest ways that it can inform research and design practices with people with dementia.

Author Keywords

Dementia; Person-centered care; Recognition; communicative engagement.

ACM Classification Keywords

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

Introduction

In the past two decades, our understanding of dementia care has significantly advanced from the traditional medical model of the illness, towards a person-centered approach to care and design. The shift to person-centered care [8] has highlighted the importance of responding to the psycho-social needs of people with dementia [2,13] resulting in significant improvements in the care provided [3,4]. Further, this shift has motivated the inclusion of people with dementia in research practices, which in the case of HCI research, has resulted in design responses that enrich the lives of those living with dementia and expand our understanding of how to better design for life with dementia [11,12,14].

Despite the huge benefits the person-centered care approach has offered and continues to offer, it has been suggested that it overemphasizes the needs most closely associated with the disease [8], rather than acknowledging the person with dementia as an active, free-willed agent [2]. This can result in people with dementia experiencing a lack of opportunity to engage as equal, mutual actors in the lives of others [3,10]. To respond to this reported experience, we need to extend our types of engagement with people with dementia and fully acknowledge them as active agents, with respect to care, research and design. This position paper proposes the social theory of recognition as a way of understanding and addressing the importance of mutually beneficial engagement for people with dementia [6]. Through briefly introducing the theory of recognition and using examples from ethnographic engagements with people with dementia in residential care as examples of recognition in practice, we wish to

highlight the ways in which engagement with people with dementia can be experienced and supported as part of both the research process and output.

Recognition Theory and Dementia

The theory of recognition has its foundations in the works of Hegel, Fichte, Rousseau, and Ricoeur, and continues to be developed by contemporary theorists, calling for the need for recognition amongst individuals and groups in modern society [5]. The theory emphasizes the importance of mutuality in the realization of the self, based around positive social engagements [6]. Recognition theory also examines the ways in which recognition is achieved, and the different aspects of the self that can be recognized through social processes. For example, one is recognized through engaging in mutual loving relationships, for one's individual merits and achievements, and one's ability to contribute positively to the social world [6]. In contrast, failure to be recognized by others, or society as a whole, results in misrecognition. The concept of misrecognition has been used to highlight the ways in which minority groups experience discrimination at both subtle and systemic levels [5]. In this sense, there are moral and political implications of recognition, which state that the struggle for recognition is a 'fundamental struggle' of the human condition [6]. Within the context of dementia care, the concept of recognition highlights the importance of mutuality between people with dementia and those who engage with them. With an emphasis on mutuality, the theory suggests that the passive role in which people with dementia are often cast, can lead to a form of misrecognition, as we may fail to recognize the way in which they communicate and contribute to their social world. This research is interested in the ways in which

recognition can occur and be facilitated, within the dementia care context. We propose that the theory of recognition can enable us to understand the ways in which people with dementia communicate both the need for-and ability to give- recognition, as well as the challenges that emerge within this context in terms of achieving recognition. Further, the suggested framework has implications with respect to design ideation, and the research process itself.

Applying Recognition in Practice.

Using the theory of recognition to inform our approach to ethnographic and design work with people with dementia has highlighted the ways in which recognition in care is possible, as well as the opportunities to better support recognition through design. Through our ethnographic work, we have come to understand the importance of embodied communicative action as a means of engaging in moments of recognition with the residents we work with [7]. This allows us to not only better acknowledge and respond to the experience of the person with dementia, but also better understand their embodied expressions of self. For example, the following excerpt details the importance of responding to the expressions of the other as a means of embodied communication:

She starts to pull her blankets off her, asking me to help. 'I'm too hot' she says. She pulls them off... her legs are so thin. 'I'm too hot, I can't breathe'... I'm watching her closely and she is breathing normally, but also holding her hands up, reaching out for something. 'I'm dying' she says repeatedly. 'No you're not.' I try to reassure her. I take her hand and she strokes mine gently. Her fingers are so thin. She might be dying,

how would I know? She starts to run her fingers over my watch. She asks me what time it is. 'Three'. 'I'll be dead by four' she tells me. Does she believe this? Is it correct? She seems physically relaxed once I have her hand. She says I'm very good to sit with her. I wonder does she think this is her death bed? After a while, she says her legs are sore, could I help her move them. 'If I could just stand up' she states, as if this is the answer to all her problems. Her legs have been badly ulcerated and are crossed over each other. I uncross them gently and she makes a sound that expressed some relief. She seems better now...

The need for comfort, reassurance and understanding are often primary needs expressed through the embodied actions of people with dementia. Recognition theory suggests that giving and receiving human comfort is a form elementary recognition, and can be achieved through our respectful and thoughtful engagement with people with dementia in care settings.

Within the care context, it is also important to support and encourage opportunities for people with dementia to actively contribute to the social world. In the following excerpt, we can see the importance of respecting the agency of the individual with dementia, supporting them to engage in tasks that speak to their need to give and receive recognition:

When I get to her room, she asks me do I mind if she gets a glass of water before we go. I tell her to take her time, there is no hurry. She pours herself a glass of water and I think about asking does she need me to do it but then decide not to, as she is clearly able. She offers me a glass too but I tell her I'm fine, I just had

my lunch after all. She says she'll just sit down in her chair to drink it and tells me I should sit down too. I sit on the end of her bed, mostly because I don't want to rush her and we chat for a few minutes until she decides she's ready to get up.

Supporting people with dementia in their acts of agency, such as allowing the resident to set the pace of the interactions, are subtle yet all-important ways of recognizing the active role people with dementia play in their engagements with others. In terms of recognition, approaching engagements with people with dementia as collaborative interactions allows for greater appreciation of their sense of agency. Designing for collaborative interactions can therefore further support one's sense of agency in care. While design for agency can improve moments of engagement with people with dementia, approaching the design process itself as a collaborative engagement fosters a greater sense of mutual recognition.

From the ethnographic examples, we can see that recognition in action occurs in the subtle engagements, which communicate to people with dementia that their actions are recognized as worthy of response. In the next section we will discuss the ways in which the early stages of the research have informed our design practices and approach to engagement.

The Role of Recognition in Research and Design

Through our current research, we wish to highlight the following points in relation to the use of recognition theory in HCI design approaches:

Designing for recognition- There are many aspects of recognition that can be supported through design interventions, particularly honoring the agency of the individual with dementia. By understanding both the importance of contributing positively to one's social world, as well as the unique experiences of people with dementia, we can aim to support these acts of agency through design. For example, with the aid of design probes and technologies, designing for experiences which draw on the unique abilities and local knowledge of the people we are working with can create more meaningful experiences.

Recognition based design- Reconsidering our engagements with people with dementia as acts of mutual recognition creates opportunities for researchers to approach the design process as an opportunity to give and receive recognition through collaborative actions. This helps us to move away from the concept of people with dementia as being passive actors, drawing on the ways in which people with dementia engage with their social world. Supporting people with dementia to engage in the research process as peers with fellow researchers and members of the community can result in more mutually beneficial engagement.

Further Evaluation

In the current research project, we wish to emphasize and draw on the communicative abilities of people with dementia, supported by the design and use of probes, which not only support people with dementia in their struggle for recognition, but also emphasize the ways in which people with dementia give recognition to others. We are currently in the process of designing probes that support collaborative engagement with people with dementia, with a view to increasing moments of recognition in residential care [9]. Designing for recognition, will also encourage a more holistic approach to the needs of people with dementia, as recognition incorporates the need to receive positive regard for different aspects of one's self, such as positive contribution to one's social world, and respect for the universal human condition [1]. It is also important to highlight that the research process itself can be an act of recognition, which supports the positive contribution of people with dementia. In this regard, HCI research is well positioned to further contribute to achieving greater recognition for people with dementia.

Conclusion

The experience of engaging with people with dementia is the basis of understanding and supporting better quality of care. In this paper, we have discussed the ways in which working towards recognition for and with people with dementia creates an approach to research that acknowledges the person with dementia as an equal agent. Moving forward with this research, we aim to further highlight the possibilities of increasing recognition through the design process.

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