
Reflections on Using Proxies in Supporting the Voice of People with Dementia in HCI Research

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Abstract

The HCI literature on designing for dementia care is evolving, and strategies for using proxies will help better support the voice of people with dementia. We reflected on our recent qualitative fieldwork involving people with dementia, family caregivers, and social program facilitators, analyzing how we navigated the emerging challenges of involving proxies. We examined our practice of building rapport, seeking intermediaries, and balancing power dynamics between participants and proxies. We further discussed better interpreting participants' voice through enhancing verbal and non-verbal communication, as well as verifying across multiple sources. Our reflections helped to reveal potential directions for future discussion and critique.

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Dementia; design; reflections on practice.

CCS Concepts

• **Human-centered computing** ~ **Empirical studies in HCI**

Introduction

In this paper, we critically reflect on our experiences designing social technologies for people with dementia. As research on designing for and with people with dementia has matured, the HCI research community's framing of dementia has likewise evolved. People with dementia are increasingly recognized as competent, engaged, and capable of expression [5], and the focus of research has shifted from mitigating the impacts of impairments to supporting the enjoyment of life [8]. Inclusive design practices have enabled researchers to build empathic relationships and co-create with participants [4, 6, 7]. Involving multiple stakeholders is a common practice in designing assistive technologies but not without well-documented challenges (e.g., [1]). As the evidence for how to use proxies in the dementia context is still sparse and anecdotal, our experience can serve as an additional data point in understanding how to navigate challenges and center participants' voice.



Figure 1: Story session settings at Tales & Travels



Figure 2: Video session settings at Tales & Travels

Context

Our project aims to support people with early-middle stage dementia in social sharing in community settings. To date, we have completed an initial phase of qualitative fieldwork involving non-intrusive observations of a community-based storytelling and social program, Tales & Travels, and semi-structured interviews with 5 dyads of people with dementia and their primary family caregivers, 3 individual caregivers, and 4 Tales and Travels facilitators (see Table 1). Tales & Travels (adapted from [9]) invites people with dementia, as well as their caregivers, to the local library to explore countries through stories and print materials (see Figure 1), featured snacks (e.g., Brazilian sweets and Jamaican patties), and travel guide videos (see Figure 2). A thematic analysis on interview transcripts and observation notes revealed insights for diversifying the range of social spaces available to people with dementia in community settings [3]. A second phase of research to use these findings to design and evaluate a set of new social tools is underway.

The Pros and Cons of Using Proxies

Reflecting on our process, we mainly sought proxies from caregivers in the presence of people with dementia in dyadic interviews. Together with individual caregiver and facilitator interviews, the viewpoints of participants with dementia were not the sole source of our data. We mitigated the drawbacks by involving participants as much as we could and cross-referencing multiple informants. Keeping in mind that each stakeholder might have different blind spots or biases, we included observations and spent substantial time with the community before and after the data collection to enable a deeper understanding of the context.

Rapport and trust

The first author volunteered for 9 Tales & Travels sessions before collecting data and helped to facilitate 10 sessions afterwards, as well as giving public lectures. This prolonged engagement with the community helped us to build rapport and trust with participants, in many cases through proxies. Caregivers and facilitators aided in acquainting us with participants in preliminary work, thus minimizing the researcher's interference during observations and enabling us to develop tailored interview questions. Proxies also helped us to add a personal touch in choosing tokens of gratitude for participation as we realized that cash often did not resonate well with participants. For example, a caregiver suggested writing the recipient name on the bookstore gift card cover, and it was greatly appreciated by the participant as a reminder of their contribution to research. However, we recognized the risks of potential biases and losing our external standpoint as the long-term involvement led us to regard the proxies as respective colleagues, which risks prioritizing their viewpoints over the participants'.

Intermediaries and power dynamics

Interacting with people with dementia requires close attention to various responsive behaviours and preferred ways of communication, as well as neuropsychiatric issues such as apathy and a lack of inhibition [2]. As a way of mitigating these challenges in dyadic interviews, caregivers acted naturally as intermediaries, e.g., reassuring the interviews' friendly and stress-free nature, restating the goals of the interviews, and relaying or rephrasing the questions. It was inspiring to witness some caregivers took advantage of props at hand to get more engaging responses from participants with dementia, e.g.,

ID	Gender (Age)	Relationship
P1	M (84)	Spouses
C1	F (74)	
P2	M (90)	Spouses
C2	F (78)	
P3	F (80)	Neighbours
C3	F (52)	
C4	F (75)	C4 reported on her spouse.
C5	F (61)	C5 reported on both parents.
P6	M (76)	Spouses
C6	F (70)	
P7	F (81)	Friends & de-facto family
C7	Atypical (56)	
C8	F (54)	C8 reported on her father.
ID	Profession	
F1	Librarian	
F2	Coordinator, Alzheimer Society	
F3	Coordinator, Alzheimer Society	
F4	Librarian	

Table 1: Dyad, caregiver, and facilitator background

bringing a participant’s favourite teddy bear or board game into the discussion. Meanwhile, we were aware that the caregivers talked more than the participants in dyadic interviews, bringing a risk of the proxies’ voice overshadowing the participants’. We trod carefully to ensure the proxies’ account reflected the dyads’ experiences via confirming with participants and paying attention to participants’ reactions. We further reflected that potential conflicts between participants and proxies could arise due to the differences in recollections, opinions, and emotional reactions. We mitigated such emerging disagreements by empathizing with both parties and avoiding taking sides, so as to balance power dynamics between participants and proxies.

Lessons learned from the proxies

We learned a variety of approaches to verbally engage people with dementia from the proxies in our fieldwork. The caregivers and facilitators offered participants options and acted as a neutral guide in conversations, sometimes filling in gaps but not imposing opinions. We witnessed a range of communication strategies, such as encouraging, following, prompting, exploring, redirecting, and regrouping. Speaking animatedly, as well as using humour, often lead to positive responses among participants (e.g., the scenario in Table 2). We came to understand the benefits of using concrete examples or comparisons and connecting to participants’ experience or expertise. Various materials helped the facilitators start and maintain conversations, e.g., discussing images and maps, browsing books and commenting, bringing and introducing featured snacks to the table, and offering souvenirs to be taken home. We further reflected that facilitators and caregivers leave participants space to enjoy themselves, instead of pushing for responses.

When participants were having difficulties with words, caregivers and facilitators adopted rich body language and eye-contacts to communicate alternatively. Other effective non-verbal approaches included gesturing, nodding, and pointing to materials. Laughing and smiling were especially well received, as one participant commented: “*Laughter is the best therapy for me.*”

Overall, we paid close attention to verbal and non-verbal expressions and constantly verified our interpretation across different cues. We reflected that working with people with dementia required recognizing the relative importance of non-verbal cues might be greater than in other contexts. For example, smiling while leaning towards materials could indicate enjoyment even in the absence of comments. Furthermore, we triangulated the findings from one source with others. As the example shown in Table 3, P1’s responses to C1’s apparently leading questions were verified through our observations of the dyad that P1 does love maps and enjoy Tales & Travels.

Conclusion

Looking back, the use of proxies helped us with getting access, understanding the context, and improving interaction with participants. We recognized the potential pitfalls of involving proxies, such as risking overshadowing participants’ voice. Moving forward, we are taking the following effective approaches that emerged from using proxies, e.g., actively seeking support from caregivers and professionals but carefully balancing power dynamics between participants and proxies, cross-referencing to uncover and stay true to participant feedback in design sessions, and mobilizing a set of probing questions, printed materials, objects, audio-visual clips, and body language cues.

A to B: *You also look young. You look like in your 70's, as me.* (Both participants are almost 90 years old.)
A (on hearing B used to be in the shipping business):
Shipping? Do you build ships?
B laughed: *No, I travel in ships!*
<Although it was hard to tell if A was joking or confused about shipping, this conversation made everyone at the table laugh. It was likely the first time that A and B met. The spontaneous jokes helped them to break the ice and enjoy each other's company.>

Table 2: Excerpts from observation notes

C1: *As much as we can, we attend because we love Tales & Travels. We love the way it's presented. Am I right? You like Tales & Travels?*
P1: *Yes.*
C1: *You love the maps.*
P1: *Yes, I do.*
C1: *You love meeting the people and chatting.*
P1: *Of course.*

Table 3: Excerpts from interview transcripts

The voice of people with dementia is essential in HCI research in the dementia context. It is often an unavoidable situation to bring in other stakeholders, sometimes involving domain experts as co-researchers. We reflected on our prolonged fieldwork involving people with dementia, family caregivers, and facilitators, as well as the interactions between these stakeholders. Examining our use of proxies, we shared our thoughts on building rapport and improving verbal and non-verbal communication with participants. We also discussed better interpreting participants' voice by verifying across multiple channels while seeking intermediaries and balancing power dynamics. This case study pointed out potential directions for discussion and critique in future work, where more structured examinations can provide deeper insights into using proxies and supporting the voice of people with dementia.

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