

Surfacing the Voices of People with Dementia: Strategies for Effective Inclusion of Proxy Stakeholders in Qualitative Research

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Best practices for conducting HCI research on dementia care increasingly involve multiple stakeholders and incorporate diverse viewpoints. When done effectively, involving proxy stakeholders such as family members and professionals can help bring forward the voices of people with dementia. However, concrete practical guidance for navigating the challenges of integrating different perspectives is lacking. We critically reflect on our own recent qualitative fieldwork involving participants with dementia, family caregivers, and facilitators at a local social program for people with dementia, re-examining our interview transcripts and observation notes through content analysis. We illustrate practical approaches to prioritizing participants' voices through concrete excerpts that demonstrate strategies for better managing dynamics, intervening effectively, and engaging all stakeholders in the research process. Our reflections and proposed guidelines can benefit HCI researchers and practitioners working with vulnerable populations. We hope this work will spur further discussion and critique to strengthen and improve research practices in this domain.

CCS Concepts: • **Human-centered computing** → **Empirical studies in HCI**.

Additional Key Words and Phrases: dementia, proxy, stakeholder, reflections on practice

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1 INTRODUCTION

As research on designing for and with people with dementia has matured, the HCI community's framing of dementia has likewise evolved. People with dementia are increasingly recognized as competent, engaged, and capable of expression [42], and the focus of research has shifted from mitigating the impacts of impairments to supporting the enjoyment of life [47]. Inclusive design practices have enabled researchers to build empathetic relationships with participants [24, 43, 46] and co-create technological solutions that prioritize dignity and respect [19]. Multiple stakeholders are commonly involved in designing assistive technologies to mitigate the social and communication challenges associated with dementia and enable researchers to uncover design requirements (e.g., [59]). In this paper, we use the term "proxy" to refer to secondary stakeholders in HCI research. We acknowledge that "proxy" can carry legal meanings as an authorized representative, but our scope here encompasses other stakeholders (e.g., family members, practitioners, and domain experts) acting as surrogates to help primary stakeholders (e.g., people with dementia) express thoughts and opinions. Proxies can bring different strengths to research; for example, dyadic interviewing of care recipients and caregivers paints a rich picture of their lived experience, while the use of domain experts incorporates external

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professional views. Mentis et al. reinforce the practice of involving proxies and point to several references from healthcare domain suggesting that caregiver presence helps people with cognitive impairment to articulate their views [50].

However, if the perspectives of proxies are not integrated with care, they risk overshadowing the voices of people with dementia. Researchers involving multiple stakeholders in their work should carefully consider how this practice can introduce different interests and expectations in their research [1] and conflicting views between primary stakeholders and proxies [9]. Further reflections on proxies' roles and ways to prioritize participants' voices are needed to guide future design for dementia care. While there have been many notable examples of projects that have successfully incorporated multiple perspectives in their data collection (e.g., [23, 43, 54]), detailed accounts of how to manage power dynamics and ensure that the voices of persons with dementia are privileged remain scarce.

We critically reflected on our own recent qualitative fieldwork, reanalyzing our data to examine how we succeeded and failed to capture the perspective of people with dementia. This data was originally collected to explore opportunities for designing new technologies to empower people with dementia to share and socialize, especially in community settings. The research, published at CHI 2020 [14], studied the ways that Tales & Travels, a community-based storytelling and social program, supports people with early–middle stage dementia in social sharing. Tales & Travels (adapted from [55]) is a physically co-located social series held at a local public library in collaboration with the Alzheimer Society. It invites people with dementia, as well as their caregivers, to the library to explore countries through stories and print materials, featured snacks, and travel guide videos. Our fieldwork involved non-intrusive observations of Tales & Travels and semi-structured interviews with dyads of people with dementia and their primary family caregivers, individual caregivers, and Tales & Travels facilitators (librarians and Alzheimer Society coordinators).

In deconstructing our experience, we contribute a data point for understanding how to navigate challenges and avoid potential pitfalls when involving proxies. We further propose a set of actionable guidelines for uncovering and prioritizing the voices of people with dementia in research practices. As people with dementia are more likely to have higher health risk and lower comfort with remote participation, our findings may help support research in situations where access to participants is restricted. Remote access can be useful for reaching a broader, more geographically spread set of participants, including those who live in more remote communities, and increasing the accessibility of research participation by reducing travel overhead. At present, it bears additional applicability in addressing COVID-19 related physical distancing requirements. Meanwhile, this context might bring increased motivations and availability for a wider range of proxies (e.g., younger caregivers) to participate in research. The practice and nuanced reflections of our fieldwork can provide immediate benefit to HCI researchers and practitioners currently working with vulnerable populations and potentially lead to future discussion and critique for HCI work in dementia and broader contexts.

2 RELATED WORK

2.1 Proxies in Assistive Technology Research

In the context of designing for dementia, HCI researchers have involved proxies connected to people with dementia. This includes participants' family members (informal caregivers) [64], as well as a variety of professionals, including formal (professional) caregivers [63], art, speech, occupational, or recreational therapists [11], and staff and volunteers at care facilities [40]. It is common practice to pair a participant with a proxy (e.g., a person with dementia and a caregiver) in interviews or design activities (e.g., [4]). Proxies have played various roles in research, such as direct sources of information [42], supporters of participants in activities [24], providers of contextual or supplementary

information [27], and validators of the research findings [44]. Proxies enable researchers to mitigate communication difficulties, learn stakeholder viewpoints, and paint a fuller picture of the lived experience in dementia care. In cases of exploring new or understudied design spaces, proxies are often well-positioned to provide initial inputs. For example, researchers have successfully sought additional help from a variety of practitioners in probing sensory changes and everyday technology use by people with dementia [20]. On the other hand, involving proxies is challenging and might risk replacing or supplanting the participants' voices with the proxies' opinions, as noted in previous works such as [4, 13, 46].

Similarly, proxies have been widely used for user groups with other cognitive or sensory impairments, including people with aphasia, Parkinson's, or children with communication disorders (e.g., [9, 25, 26]). Participatory design projects drew insights from proxies such as teachers and speech-language pathologists and noted their indirect representation of actual users [26]. Domain experts' roles and dynamics with researchers and primary stakeholders require careful navigation in matching experts and expertise to projects, communicating, and managing interference between different roles [1].

2.2 Stakeholder Voices

As dementia care settings involve various stakeholders, researchers have explored approaches to giving voice through design, including prioritizing the genuine voices of people with dementia in space for sharing through dementia diaries [41], enabling self and personhood of people with dementia [63, 64], and co-creating personas with participants to build a more engaging and accessible design process [54]. Artistic and creative ways have been explored to study embodiment in the lived experiences of people with dementia [39]. Regarding platforms that host diverse voices (e.g., an online forum), a recent study has examined different types of support sought by different roles, such as people with dementia, people experiencing dementia-like symptoms but undiagnosed, family, friends, and caregivers, to analyze interaction dynamics and develop moderation models [37]. Attention has been paid to the power of different stakeholders in decision-making, especially in participatory design research (e.g., [8]). It has also been recognized that caregivers and practitioners could be the research focus, instead of proxies, in the contexts where their mediator roles in design and use of technology are prominent (e.g., [61]) or where their perspectives and experience make them equally valuable stakeholders (e.g., [31]).

More broadly in collaborative system design, uncovering all aspects of different stakeholders' needs and perceptions has been recognized as essential for problem formulation [60], and the importance of balancing stakeholder perspectives has long been noted [48]. Interacting directly with stakeholders, researchers have advanced from mitigating stakeholder conflicts to creating shared understanding [3]. Bringing stakeholders together to explore a design space can reveal issues and opportunities but pose challenges in choosing engaging activities and methods [62]. Stakeholder voices have been recommended to be considered throughout the research process and reported in stakeholders' own choice of words [16], and hearing participants' voices directly and faithfully can help attend to power differences [6].

2.3 Researcher Reflexivity and Ethics

Researchers have reflected on their roles in the field, recounting their first-hand experience through reflexivity [56] and examining power dynamics between various fields involved in inherently interdisciplinary HCI studies [21]. Recent discussion includes how participants' interest and investment in the research topics bring interpersonal, institutional, and discursive difficulties and impacts on the use, application, and sustainability of research [33].

Ethical challenges have been well recognized and negotiated in HCI research and reflections, including a series of ethics panels at CHI and CSCW conferences (e.g., [17, 52]). When involving complex spaces and vulnerable populations, HCI communities have discussed the dynamic nature of ethics requirements and reassessed a situational approach [53], as well as proposing ethics frameworks stemmed from fieldwork in sensitive settings such as hospice [22]. In dementia related studies, ethics considerations and participant consent procedures have been approached with extra care and well documented in publications (e.g., [24, 27, 31]). Researchers have been cognizant of the ethical implications of new systems, ranging from the levels of engagement (e.g., [23]) to the use of monitoring technologies (e.g., [19]). Ethical complexities in sensitive settings have been further examined as a part of the community reflections on practice, touching upon rethinking design impact and research clarity [28].

Notably, recent works have demonstrated a growing recognition of researchers' self-study in accessibility and design research. Auto-ethnography has been adopted to capture a blind person's experience during a recreational cruise trip [58], as well as studying accounts of a hard-of-hearing traveler during 2.5 years [35]. This reflexive method has been extended to multiple auto-ethnographers (e.g., a trio-ethnography from three authors reflecting on their graduate school experiences as students with disabilities [36]), as well as collaboration among three accessibility researchers and a disability studies scholar to connect contexts and expertise [30]. Moreover, autobiographical design research has been adopted and reexamined to uncover nuances in long-term relationships between human and technology, as a way of offering new perspectives into otherwise hard-to-approach topics [18]. Meanwhile, the challenges of first-person research have been surfaced in terms of extra care required to achieve rigour and quality, tensions between privacy and transparency, and potential difficulties in balancing authority among authors [35, 36].

Such an increasing number of self-reflexive studies have provided a first-person lens into lived experiences with impairments and emerging design avenues for assistive technologies. More researcher reflexivity in participative forms of research has been highlighted in studying socio-technical gaps [56]. Yet, current reflective work falls short with respect to strategically navigating the challenges of involving proxies in diverse contexts to mitigate the concerns and potential risks of overshadowing participants' viewpoints. Critical reflections on practice, such as the one we present in this paper, are needed to provide concrete guidance on effectively collaborating with proxies and prioritizing participants' voices in assistive technology research.

3 METHODS

3.1 Revisiting the Data Collected

Our self-reflection involved re-examining the interview transcripts and fieldnotes collected from the original study [14]. The transcripts of audio-recorded interviews included five dyads of participants with early-middle stage dementia (hereinafter referred to as participants) and their primary family caregivers (P1/C1, P2/C2, P3/C3, P6/C6, and P7/C7), three individual caregivers (C4, C5, and C8), and four Tales & Travels facilitators (F1–F4), as detailed in Table 1 and Table 2. The observation notes (ON) included eight Tales & Travels sessions, both the descriptive notes taken in situ and the reflective notes expanded in a timely manner after each session.

The first author (FA) conducted all the interviews and observations. Interviews were held in a library meeting room or the participant's home, according to their preference. Each interview took 1–2 hours, and each participant, caregiver, and facilitator was compensated with \$30 or, if preferred by the participant, a gift of approximately the same value. During observations, FA took an observer-participant role, not actively engaging in the conversations but responding

Table 1. Dyad and caregiver backgrounds

ID (Gender/Age)	Relationship	Dementia conditions	Tales & Travels Exper.
P1 (M/84) & C1 (F/74)	Spouses	Mid-stage Alzheimer's	Both attended regularly
P2 (M/90) & C2 (F/78)	Spouses	Mid-stage Alzheimer's	Both attended once
P3 (F/80) & C3 (F/52)	Neighbours	Mid-stage vascular	P3 attended regularly; C3 attended occasionally
P6 (M/76) & C6 (F/70)	Spouses	Mid-stage frontal temporal	None
P7 (F/81) & C7 (Atypical ¹ /56)	Common-law ²	Early-middle stage Alzheimer's	Both attended regularly
C4 (F/75)	Spouse	Mid-stage vascular	Attended regularly
C5 (F/61)	Daughter	Father: diagnosis unclear; Mother: late-stage Alzheimer's	Volunteered regularly
C8 (F/54)	Daughter	Father: mid-stage Alzheimer's	None

¹ Self-described.

² Since the publication of [14], the legal status of P7 and C7 was retro-actively changed from friends forming a de-facto family to common-law companions.

Table 2. Facilitators' professional backgrounds

ID	Professions
F1	Librarian
F2	Coordinator, Alzheimer Society
F3	Coordinator, Alzheimer Society
F4	Librarian

when approached. Using a pen-and-paper-based observation guide, FA took notes in a non-intrusive manner and without collecting any identifying information.

The original study was approved by our institutional research ethics board, and care was taken during the participant recruitment and data collection to ensure the privacy and confidentiality of participation, especially for the observations which occurred in a group setting. For dyadic and caregiver interviews, we mainly recruited through word of mouth, especially at Tales & Travels. For facilitator interviews, we contacted each facilitator in person and via email. For observations, we discussed the details with the library director and the librarian in charge of the program. The librarian introduced the project to attendees and identified which tables were open to observation and then assigned FA to a table (without revealing which tables, if any, declined participation).

3.2 Self-reflection Through Content Analysis

Our reflections are guided by two research questions: 1) *How did we, as researchers, balance power dynamics among stakeholders and ensure that the voices of people with dementia are heard and prioritized?* 2) *How might we improve this practice in future projects?* We adopted a qualitative content analysis with a deductive, directed approach [34]. Our initial motivation to engage with this process was inspired by the CHI 2020 workshop, "Rethinking Notions of 'Giving Voice' in Design", which called on researchers to describe the successes and challenges they have experienced around the topic of 'giving voice' in their research [65]. Directed by two initial categories, "our successes" and "our setbacks," our first round of reflection revealed the following three categories: "rapport and trust," "intermediaries and power dynamics," and "lessons learned from the proxies" [15]. In this process, we came to realize that our practice and the original data could offer more insights into involving proxies in HCI research. Thus, we continued to reflect on our

practice and reanalyze the relevant data sections to refine and expand the categories with vignettes through axial and selective coding. The authors met on a weekly basis during the initial coding, and then periodically in the later stages, to cross-check the coding.

We continuously revisited our self-reflection approach before and during the data analysis and reporting with the goal of ensuring its validity and reliability. As a valid—albeit different—way of knowing, the self-reflective nature of this work has inherent challenges in establishing rigour and transparency, as described in Section 2.3. However, there is also strength in the opportunities it provides for deep investigation. Over a year of preliminary work and five months of data collection, FA built a profound understanding of the research context and rapport with multiple stakeholders representing a range of viewpoints. Echoing the guidelines for reliability in qualitative HCI and CSCW research practice [49], FA's unique expertise and experience embedded in a social context for long periods enabled us to bring great value out of the introspection. While an outside coder would have brought more objectivity to the analysis, they would not have had access to these nuances. In addition to triangulation and prolonged field observations, we followed other validity procedures standard in qualitative inquiry, including the use of thick descriptions, transparent disclosure of researchers' roles and positions, and peer debriefing [12].

Our self-reflection process included three concurrent activities: 1) reexamining the process of study design, data collection, and data analysis, 2) iteratively reanalyzing the interview transcripts and fieldnotes with a focus on proxies' roles and researchers' practice, and 3) engaging in a series of discussions among the authors about effective approaches and emerging challenges. The final categories are presented as strategies for effectively involving proxies in the following section.

4 STRATEGIES FOR EFFECTIVELY INVOLVING PROXIES IN QUALITATIVE WORK

Our self-reflection and reanalysis includes diverse data sources (dyadic and individual interviews as well as observations) and first-hand experience of working with participants and various types of proxies over an extended period. Our reflections and meta-observations draw from concrete examples in our practice and identify the following key strategies to answer our research questions: prioritizing participants' voices in collaboration with proxies, triangulating findings across multiple sources, learning from proxies and cross-referencing multiple cues, and extending engagement with the community.

4.1 Prioritizing Participants' Voices in Collaboration with Proxies

4.1.1 Ensuring that proxies amplify rather than suppress participants' voices. Our reexamination of the dyadic interviews revealed that ensuring that participants' voices are heard requires active intervention on the part of the interviewer (FA). Interacting with people with dementia demands 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]. To mitigate these challenges, the proxies in our study were generally well intentioned and tried to help participants express their opinions. For example, the caregivers acted naturally as intermediaries, restating the goals of the interview and reassuring its friendly and stress-free nature (as in the example below).

P3: My, my, my, my brain is ... You remember the time somebody [a social worker] came here, and I was, that was ... When he was here, I was, I just couldn't talk.

C3: Well, yeah, P3 stutters when she's very nervous. ... But [FA] is not here to [criticize or inspect], you know, it's not a negative thing. It's a positive thing.

Caregivers often relayed or rephrased the questions and expanded on participants' answers (as in the example below), as well as redirecting the conversation if the participant was stuck in negative thoughts or went off-topic for too long.

P7: What are we doing?

C7: [FA] is asking what we like to do to socialize and what aspects of socialization would make us go. Either choose to go to something or choose to leave something.

P7: When you see the people.

C7: Yeah, yeah, yeah. I think that's a very simple one-sentence answer, but I think that encompasses it very well. ... I don't think P7 means 'see' in the sense of, you know, do they look ugly or hideous ... I think P7 has just used a very good and apt sentence. I think it really would depend on the people.

We found ourselves walking a fine line between proxies expanding on and deviating from participants' thoughts. FA trod carefully to ensure that the caregivers' accounts reflected the dyads' experiences via confirming with the participants and paying close attention to the dyads' reactions when possible. In the above example of C7 explaining P7's short response at length, P7 remained silent and showed no clear nonverbal hints for FA to confirm C7's explanation. The excerpt below provides a contrasting example: even though P2 asked C2 to be "*quiet*" about them sitting in parks, the tone and flow of their conversation, together with their facial expressions and body language, suggested relaxed and humorous feelings, instead of embarrassment or offence. FA thus adopted a positive tone and encouraged them to share their experiences in the parks.

C2: ... there's like free parks around here. So, we are sitting in the park. [P2] loves watching the birds flying and the children playing.

P2: You have to be quiet. Not gonna tell anybody about that.

C2 (laughing): No?

P2: Silly. No. We are sitting in the park, watching the kids, birds go by...

FA: That's a beautiful life. Why not?

C2: What's wrong with sitting in the park? We used to ... when we walked along the river and we went and sat in the rock garden. It was so lovely.

At times, FA needed to intervene and navigate the interviews to allow proxies to facilitate communication without overshadowing participants' voices. Even though everyone was generally working towards the same goal to uncover participants' opinions, it was important for FA to remain vigilant about caregivers unintentionally shifting towards their own viewpoints. For example, during a discussion about what attracted them to Tales & Travels, P7 seemed confused and asked, "*What are you talking about?*" and "*What are we doing?*" Naturally, C7 talked a lot about what they liked about the program, but these accounts could very likely reflect C7's personal view only. Thus, FA cautiously redirected to find new ways for P7 to express her thoughts (as below). Although P7 still had difficulties understanding FA's questions, this redirection shifted C7's focus from her own thoughts to explain to P7 and confirm P7's remarks.

FA: Did you tell stories at the library when we talk about travels or countries? Or [do] you prefer to listen to other people's travel stories?

P7: I'm sorry but I don't understand what you mean.

C7: When we go to the library to talk about different countries, do you contribute? Yes, on Fridays. When we go on Fridays to talk about different countries, you often talk about countries you've been to? Or do you prefer to listen to other people talk?

P7: No, I prefer to listen to other people.

C7: I would agree with. I don't mean for me, because I've traveled a lot and I like to talk about it, but I would concur that P7's self-evaluation there is accurate.

While accepting caregivers' accounts to maintain the conversational flow, FA often encouraged the participants with prompts such as "*How about you?*" or "*We want to hear the voices of both of you.*" Yet, we noted that the caregivers talked more than the participants (as in the example below), raising a risk of the proxies' voices overshadowing those of the participants.

P6 (pointing to C6): That's her. She does the talking. I do the listening. Yeah.

C6 (smiling and gesturing zipping her mouth): Now you talk. ... I've always talked a lot. But I used to say you would talk to a telephone pole, so he did like to talk as well. But I always talk more.

Therefore, we remained cognizant of this imbalance of voices and took care that the greater quantity of comments from caregivers did not bias our interpretation of the results. Similarly emphasizing interaction among participants to share and compare as dyadic interviews, focus groups can offer some guidance on avoiding taking one person's more persistent voices for opinions shared by all participants [51]. Common strategies might not be directly feasible in this context, e.g., FA could hardly ask the caregivers to yield the floor in a diplomatic way, which would be an acceptable moderating technique in usual focus groups [45]. Additionally, our reexamination of dyadic interviewing people with early-middle stage dementia and their caregivers revealed different scenarios from previous studies involving people with mild cognitive impairment, where the caregivers were found to fill in gaps but did not dominate the conversation [47, 50]. Nonetheless, we kept being mindful, especially during data analysis, that allowing one type of voice more airtime did not mean their views were more substantial or representative of a consensus.

4.1.2 Managing disputes and power dynamics. Our experience showed that potential conflicts between participants and proxies could arise due to the differences in recollections, opinions, and emotional reactions. For example, C1 recounted an unpleasant incident in which P1 misunderstood an artist's talk and made some inappropriate comments. While C1 showed some signs of frustration about this incident, P1 felt accused of unfriendliness or wrongdoing and went on the defensive. To be supportive of both sides and navigate through this dispute, FA acknowledged this as a good example, assured the dyad these situations were common, and redirected the conversation.

FA: Very good example.

C1: Anyway.

P1: I wasn't unfriendly, though.

C1: You weren't unfriendly, but you didn't... For [the artist], he didn't understand you, because you have not picked up things that he had said during the presentation. So, we spoke with him afterwards. And then you asked him something, but he just didn't understand why you were saying that.

FA: Yeah, these things happen. It's Okay. Maybe we can talk about Tales & Travels. How often have you attended the Tales & Travels here?

Reexamining our practice of mitigating disagreements, we adopted strategies such as empathizing with both parties and avoiding taking sides, as shown in the example below. FA used similar expressions such as "*I understand both of you*" and "*Yes, it's a very difficult situation*" in cases of disputes between the dyad.

C1: There was another time at the cross-country ski centre when P1 decided that the person in charge of the centre was behaving inappropriately. So...

P1: Who's that?

C1: I don't know.

P1: You don't remember his name?

C1: I do.

FA: Yeah. I know people could be very difficult...

We found it challenging to balance power dynamics between participants and proxies, partly because the proxies talked more than the participants and remembered more details of their experiences. In the example below, C1 described one of their cruise itineraries, while P1 was confused about the trips and details. FA prompted and encouraged P1 to elaborate on his general feelings towards social experiences when they were taking cruises. Thus, P1 had the chance to lead this part of the discussion and shared his passion for ships and socializing, preventing C1 from dominating the conversation but leaving it open for C1 to fill in some additional details.

C1: We went to Bermuda, Cape Canaveral, and Florida. So...

FA: That was a lot of social, 11 days.

P1: Yeah, just... it's easy when people are on a trip that they all talk, you know.

FA: Okay. What part of this cruise did you enjoy?

P1: The ship.

FA: The ship? What kind of room did you guys get?

P1: Yes, I love ships. With... a little balcony. On a ship, I want to see, I want to see the ocean, you know. It's a little more expensive. You see where you are going. You see when you come into the harbour. All that type of thing, interesting.

FA: Good reasons. Did you talk to anyone that you never knew before?

P1: Yes. On the ship, you usually start talking to people next to you. Or they are eating at the table with you, you chat with them. Everybody tends to be in a good mood on a holiday.

FA: What did you talk about to those people that you don't know?

P1: What they do. How they like the ship. Where they, you know, where they travel to. All that sort of thing... sometimes get into what they do.

C1: Or what we did during the day because we only see them for dinner at night. We don't have lunch with them or breakfast, so.

P1: And you're talking to all sorts of people... you know, they might be millionaires, they might be... They are all happy... They all want to chat... (laughing)

As we drew the above examples from a married couple to illustrate the challenges of managing disputes and power dynamics, we found different types of existing relationships between a dyad would bring various dynamics and interactions. Among the five dyads we interviewed, three were married couples with decades-long relationships. The other two dyads were neighbours (P3/C3) and friends becoming common-law companions (P7/C7). Even though both pairs had known each other for more than two decades, they only formed closer connections in recent years when P3 and P7 needed help due to their dementia conditions and C3 and C7 took on a primary informal caregiver role. We found that P3 and P7 were less likely to interrupt or contradict their caregivers than other participants were with their spouses. Meanwhile, C3 and C7 would not have known the participants' families and personal histories as well as spousal caregivers and thus might not have been as able to fill in gaps. As our understanding of this tension only emerged from our analysis after the data collection, FA had to navigate these situations on the spot as the interviews unfolded. Although we encountered examples of very successful navigation, it was not always consistent. When we

pursue this kind of fieldwork in the future, we plan to assess the dyadic dynamics before each interview to prepare potential intervention strategies.

4.2 Triangulating Findings Across Multiple Sources

In our reexamination, as well as reported in previous studies (e.g., [46]), it was common to see participants agree with proxies when asked for opinions on the same matter. To further validate proxies' accounts, we triangulated the findings from one source with others when possible. In the following example, C1's questions and comments appear to be leading P1. When combined with P1's simple and total agreement, this seems to be a classic example of the sort of pitfalls researchers should beware of when interviewing dyads.

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.

However, in this case, FA was able to mitigate this concern by independently verifying that these accounts reflected the dyad's mutual satisfaction of Tales & Travels through the observation sessions attended by P1 and a later part of the interview. For example, P1 later elaborated his love for maps with convincing details: *"I love maps. ... When I have nothing to do, I read a map. Everything I learned ... I got a map, I started ... the countries like this, they have mountains, rivers. Picture it. ... Read a map, a very good map, it will tell you a lot."* These testimonies demonstrated that P1's agreement with C1 was true to his preference.

FA further confirmed through observations that P1 frequently attended Tales & Travels, read maps, chatted with others, and enjoyed himself (ON below), noting that he had commented while reading maps and that like many participants he had often interacted with print materials and run his fingers on maps.

ON: P1 when reading maps: *"I'm used to maps. I always enjoy maps. I love geography at school. The cities and the mountains..."* Participants often browsed, touched, held, or pointed to the materials, e.g., P1 ran his fingers along the coastline or borderline when reading maps.

In contrast, we were not always able to fully verify participants' accounts or expressions. While FA knew P1 and C1 well through Tales & Travels, she only met P2 and C2 for the interview. As in the following example, even though FA encouraged P2 to share his thoughts, it was hard to unpack his feelings towards "quiet" Mondays and "less quiet" Tuesdays and Thursdays to tell if he enjoyed the recreational therapy. With hindsight, it would have been worthwhile to bring up recreational therapist visits again later in the interview to provide P2 with an additional opportunity to share his thoughts, creating a possible triangulation point.

FA: So, you mentioned on Tuesdays and Thursdays, there's recreational therapy. Monday?

C2: That's right. OK, Monday, Monday we have nobody that comes in, so we'll do our own thing. Well, depending upon what the weather's like if we're going to go outside or not.

P2: Monday's quiet.

FA: Monday's quiet. Do you like quiet?

P2: I like Monday.

FA: Tuesdays? You don't like Tuesdays? How about Tuesdays?

P2: What?

C2: That's the day that girls [recreational therapists]...

P2: ... less quiet.

C2: Less quiet. That's good.

P2: No... we [are] quiet at [the] start of the week. The end of the week is more... more hilarious than the front of the week.

The above scenarios with two dyads further demonstrated that a multifaceted study design allowed for the validation of participants' voices across multiple channels (as in the case of P1/C1). While it was feasible to only meet with participants for a single research activity, it could be difficult to verify certain information or clarify some doubts (as in the case of P2/C2).

Moreover, when cross-referencing different sources, we acknowledged the possibility of contradictions in the data. Even though we were not faced with dramatic conflicts among our data from different sources, we occasionally found subtle differences that required further analysis to uncover the nuances in that particular scenario and context. In the following case, F1 expressed the preference for short travel guide videos at Tales & Travels, and C2 mentioned that dementia limited P2's attention span.

F1: We usually try to pick short videos from four to six minutes top. ... They are very good at giving information about these countries, and... landscapes of some of the countries with music.

C2: [P2's] ability to read is intact. It's just the attention and being able to follow after a few minutes [become challenging].

These accounts aligned with common difficulties with concentration caused by dementia [2], but we once observed a roomful of participants captivated and attentive through a 15-20 minutes' video clip (ON below). This contrast prompted us to delve deeper into the characteristics of this unusual but successful session (e.g., immersive first-person narrative and interesting topics recurring at different points).

ON: The first-person narration video was a bit longer than usual clips, but the participants kept focused on it. A hint for immersive activities. Armenian folk musical instrument, duduk, the playing and the making of it. Also, the carving of khachkar, the Armenian cross-stone, which we've just seen in one of the images during the story session. Making a subtle connection between the story and the video sessions, whether the participants noticed it or not.

Overall, a multifaceted study design aided us in bridging gaps and eliciting inputs from participants and proxies, as well as triangulating findings across multiple sources. In dyadic interviews, caregivers were sought as proxies in the presence of participants to surface the voices of both care recipients and care providers. Together with individual caregiver and facilitator interviews, the viewpoints of the participants were not the sole data source. Potential drawbacks were mitigated by involving the participants as much as possible and cross-referencing multiple informants. As each stakeholder might have different blind spots or biases, the non-intrusive observations of Tales & Travels provided an outsider view of the events and interactions between stakeholders. With information sources extending to participants, families, and professionals, we adjusted the study design to each family's situations and our ways of communication to professionals from different backgrounds.

4.3 Learning from Proxies and Cross-referencing Multiple Cues

Reexamining the dyadic interview process provided valuable lessons learned from the proxies as they supported the participants through attention to various prompts and cues. As our original study focused on the dyads' social lives, we invited the caregivers to bring their calendars and planners to help recount their recent social events. Most dyads chose to be interviewed in their own homes, and caregivers were able to make participants comfortable and take advantage of props at hand to prompt more engaging responses from participants. For example, C7 introduced P7's favourite teddy bear and the board games they played. When P3's physical discomfort began to impede her speech, C3 noticed right away and offered coffee and juice to keep P3 hydrated and refreshed; later in the interview, C3 helped P3 stand up and take a short walk to improve her circulation.

In one notable scenario, C6 showed the paintings that P6 had created in art therapy sessions to help P6 recount the stories about his artistic process and interactions with his audience. The following extract showed how P6's paintings on the table prompted a conversation about paintings as his favourite topic. However, when discussing a similar art program for people with dementia held at a local art museum, P6 only commented "so so" and did not show the same enthusiasm. Both FA and C6 tried to find out the reason for this and P6's perceived difference between the two art-making workshops, but failed. FA had volunteered at this museum program, understood its setting and procedure, and accompanied the dyad a couple of times during preliminary work. If FA were better prepared with pictures of the setting and P6's artwork created at the museum, they might have helped P6 collect his memories and thoughts, potentially expanding the findings.

FA: ... in recent years, if you're going out and meet people, what will you talk about with them?
 P6: I don't remember.
 C6: I do. Just look to your right. Look to your right (on the table where P6's paintings were). What you talk about when you tell, when you meet people.
 P6: To my right... Art?
 C6: You ask them if they've got one of your paintings, will they like one, what colours would they like. That's usually the conversation.

Reviewing our fieldnotes and reflecting on our engagement with the community revealed that the proxies demonstrated a variety of approaches to verbally engage participants. Caregivers and facilitators offered participants options and acted as a neutral guide in conversations, sometimes filling in gaps but not imposing opinions. Speaking animatedly, as well as using humour, often led to positive responses among participants. We witnessed effective communication strategies such as encouraging, following, prompting, exploring, redirecting, regrouping, as well as connecting to participants' experience or expertise and using concrete examples or comparisons (as in the example below).

ON: F4 introduced a picture of sea cow: "*They are very, very big... the size of this table.*" Comparing with something in front of them could give participants a concrete idea of the size of the animal in the picture. It didn't even need to be accurate.

The facilitators chose a range of materials to 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. As shown in the fieldnotes below, facilitators and caregivers made sure to leave participants space to enjoy themselves and follow their own pace, instead of insisting on one topic or pushing for responses.

ON: Carnival picture: colour patterns similar to a participant's eyeglass frames. She took off the glasses and showed it to others. Then, they compared each other's eyeglass frames and discussed shades of pink and blue. It was a spontaneous and interesting discussion among the participants. Even though it was a little bit off-topic, F3 didn't interrupt but joined instead. This was an example that the program was effective in providing prompts and a group setting for participants to share their thoughts and socialize with each other.

The reexamination of observations showed that caregivers and facilitators adopted rich body language and eye-contact to communicate alternatively when participants were having difficulties with words. Other effective nonverbal approaches included gesturing, nodding, and pointing to materials. Laughing and smiling were especially well received, as a participant commented: "*Laughter is the best therapy for me*" (ON). Nonverbal cues from participants were often illustrative of their mood and enjoyment, helping researchers interpret the situation, as in the example below.

ON: Participants greeted each other no matter they've met before or it was the first time they saw each other. Sometimes with touching, hugging, or shaking hands. All these nonverbal cues demonstrated participants were relaxed, feeling safe and cheerful, enjoyed other people's company.

Our reanalysis suggested that it was essential to pay close attention to verbal and nonverbal expressions and constantly verify interpretations across different cues. From the discussions among the authors, we understood better that working with people with dementia required recognizing that the relative importance of nonverbal cues might be greater than in other contexts. For example, smiling while leaning towards materials could indicate enjoyment even in the absence of comments. Moreover, we found a recurring strategy of supporting sensory needs and pleasure in caregiver and facilitator interviews. For example, C4 mentioned that homemade cakes helped her husband socialize with a neighbour; F3 stressed that food and drinks aided in engaging participants over longer sessions and keeping participants' refreshed; F4 tried to mobilize a range of senses (touch, taste, smell, vision, and auditory) to stimulate participation and start conversation at Tales & Travels.

C4: [My husband] goes daily, almost daily, with the friend, our neighbour... for an hour and a half. And they spend time together. ... They talk. They have coffee, and I make cakes. Yeah. He gets the cake box, always with him. ... They have a good quality time together.

F3: Food is an important component to animating longer sessions, period. It's such a nice break, and it's such a normal thing to do with people. ... It's a perfect time to socialize, right? Like you're relaxing, but at the same time you're discussing... Sometimes we're casual, like it switches the mood. [Food is] an element I wouldn't take out. And then the fact that you greet people with coffee at the beginning or water... They can boost up the energy a little bit. Whatever it is, that's a nice touch.

F4: I would like to have more items in the room. I think that the touching and carrying an item... country props like a hat or a piece of cloth or a statue or an instrument or beads or anything. ... If you're talking about all the senses, we're doing the visual; we're doing the auditory; we're doing the taste and smell, the touch is kind of missing. ... People did engage with [the items]. ... And it was just another conversation starter. But just like having an image in front of you and talking about it is very stimulating. Having something in your hand and talking about it is also very stimulating.

Upon further reflection of our study, we noted that more extensive recording of nonverbal cues would have provided richer data, as it proved challenging for FA to write down dyads' body language while conducting interviews. As

an alternative to video recording, bringing in a second researcher to take detailed notes on nonverbal cues and communications might be worth considering. Previous ethnographic fieldwork has found that the pairing of researchers itself has been fruitful, especially with complementary pairings of experienced and novice researchers [57]. Yet, we remain mindful that the presence of cameras or multiple researchers might place more pressure on participants and proxies and would need to be approached with care.

4.4 Extending Engagement with the Community

Looking back, we found that FA's prolonged engagement with the community played an instrumental role in the study. Volunteering for Tales & Travels before and after collecting data and volunteering and giving public lectures at Alzheimer Society events allowed her to spend meaningful time with the community and to develop a deeper understanding of the context. This helped FA build rapport and trust with participants, in many cases through proxies. The trust between participants and researchers was especially important in dyadic interviews. For example, we were lucky that P2 was welcoming and actively engaged in conversations even though it was the first time FA met with the pair. In another case, P7 and FA attended many of the same Tales & Travels sessions and greeted each other but never talked much prior to the interview. At the end of their interview, C7 mentioned that P7 was quieter than usual and would have opened up more if FA had regularly come to afternoon tea at their place beforehand. This again highlighted the importance of relationship building. While FA did spend extensive time with the Tales & Travels group, more attention could have been paid to individual relationships, by for example, seeking out less outgoing participants like P7. Had FA taken the opportunity to chat more with P7 like she did with other participants in the group, this interview may have better surfaced P7's opinions and yielded stronger data.

Caregivers and facilitators aided in acquainting FA with participants in preliminary work, thus minimizing FA's interference during observations and enabling tailored interview questions. In terms of procedures, this engagement facilitated recruiting by word of mouth, easing the common access issues such as recruitment difficulties [47] and participants dropping out halfway [40]. Proxies also helped add a personal touch in choosing tokens of gratitude for participation as cash often did not resonate well with participants. For example, C3 suggested writing the recipient name on the bookstore gift card cover, which was greatly appreciated by P3 as a reminder of their contribution to research.

In sum, our self-reflection analyzed our successes and missed opportunities in the fieldwork and led to a set of strategies for effective inclusion of proxies. We explored avenues of prioritizing participants' voices by ensuring that proxies amplify rather than suppress participants' voice, as well as managing delicate dynamics and emerging disputes. We took advantage of a multifaceted study design to triangulate findings across interviews and observations. We summarized lessons learned from proxies in mobilizing verbal and non-verbal communication cues. We also benefited from the prolonged involvement with the community, increasing the chances of a successful fieldwork. These reflections and strategies opened up opportunities for further developing explicit guidelines for future HCI studies in dementia context.

5 GUIDELINES

Retroactively examining our fieldwork and referencing previous works, we take a first step towards developing guidelines for strategically collaborating with proxies to surface the voices of people with dementia. As dyadic interviews with participants and proxies shed light on power dynamics and intervention strategies, individual proxy interviews and observations triangulate these findings and offered additional insights on diversified ways of communicating with

participants. Combining these lessons with our first-hand interactions with participants and proxies in the field, we summarize our reflections with the following guidelines (G1–G12), at three stages of research, for engaging participants by effectively involving proxies.

5.1 Guidelines for Preliminary Work and Research Design

- G1 Engage with the community extensively to establish trust and rapport with participants and proxies, as well as allowing for deeper understanding of the context;
- G2 Involve relevant proxies and choose appropriate approaches for the research context and the spectrum of dementia;
- G3 Explore multiple information sources and facets of research design;
- G4 Assess the power dynamics among participants and proxies and develop concrete redirection plans;
- G5 Prepare multisensory probes and personalized prompts in collaboration with proxies.

The first group of guidelines stem from our strategy of prolonged fieldwork and extended engagement with the community. Our successes with acquainted participants and setbacks due to less-established raptports suggest that preliminary work is irreplaceable and carries considerable weight in this domain. Thus, we propose that researchers build a deeper understanding of the context through sustained involvement with related events and programs. This process will help with recruiting participants and relevant proxies and building trust (G1), as well as developing suitable approaches corresponding with participants' dementia conditions (G2).

Prior work has shown the attention to healthcare and social contexts, e.g., designing for lifelogging and reminiscing within families [13] would require different contextual approaches from engaging care staff in technology-mediated activities in facilities [4]. In a case of implementing an interactive cushion to be used together with families or caregivers in a dementia care home, a wide range of proxy perspectives (e.g., from entrepreneurs, policymakers, healthcare professionals, and relatives) were consulted and contrasted directly in design workshops [32]. As advancing HCI work for dementia care inevitably touches upon the whole spectrum of dementia, researchers should choose different approaches and levels of engagement when engaging participants with different stages of dementia. For example, previous studies involving people with more advanced dementia relied more on long-term ethnography with a participant-observer approach [23], took into account the different nature of participation according to different stages of dementia [24], or focused on technologies that fit better with daily care context and nonverbal responses from participants [31].

Implementing G1 and G2, together with our triangulation strategies, will allow for a comprehensive study design involving multiple informants and data sources (G3). While our fieldwork yielded rich data as we navigated the emerging challenges along the way, our reflections reveal what could be improved in future work. Drawing on our experience in managing disputes and dynamics, we recommend that future research assess the existing relationships and power dynamics between participants and proxies to prepare more concrete and personalized plans for redirecting conversations, especially for dyadic interviews (G4). FA had prepared a list of generic follow-up questions and tailored the interview guides to each dyad and proxy beforehand, but context-specific and diversified prompts may have further helped to elicit more details of the interviewees' experiences and balance the dynamics (G5), echoing the strategies for enhancing communications adopted by the proxies. This approach aligns with the use of photo, audio, and artefact diaries, in combination with interviews, to support the voices of people with dementia (e.g., [5]).

5.2 Guidelines for Data Collection

- G6 Create an open and flexible research setting to provide private and comfortable space for participants and proxies;
- G7 Enable proxies to facilitate communication and prepare to intervene if necessary (even when proxies are trying to be supportive);
- G8 Empathize with both participants and proxies to avoid potential disputes among them;
- G9 Pay close attention to verbal and nonverbal communications (possibly involving video recording or multiple researchers to collect detailed nonverbal data) and cross-reference across multiple cues;
- G10 More communication tips: connect to participants' expertise and experiences; speak animatedly (and humourously if possible) and use concrete examples and body language to enhance communication; attend to participants' physical and mental status and offer breaks and refreshments once needed.

Our guidelines for the data collection stage derive from our practice of accommodating participants' diverse situations and collaborating with proxies from various backgrounds. We suggest creating an open and flexible research setting to better engage participants and work with proxies (G6). In our study, the effective and opportune aids from the caregivers when being interviewed at their homes have demonstrated that proxies could offer valuable prompts and timely interventions in a flexible space. Similarly, previous work has shown that private and comfortable settings allowed for access to relevant personal items and welcoming other household members to join in occasionally [10]. In recent works, the research settings have been extended to outdoor walking interviews with people with dementia when examining the impact of GPS location technologies, combining interviewing and participant observation in an inclusive and low-risk environment [7]. Researchers have also joined participants' family day out, recording audios, photographs, and VR videos to capture multimedia, meaningful experiences [29].

Future studies can benefit from researchers preparing to intervene and manage disputes and power dynamics (G7), including empathizing with both participants and proxies (G8). Our approaches to empathizing with and balancing between participants and proxies echo the repositioning and empowerment of participants [42], empathy in design [46], and attention to decision-making power among stakeholders [8, 9]. Previous works have adopted other strategies to ensure participants' voices are heard. In [4], for example, the individual interviews were conducted at the end of technology-mediated sessions; the participants were interviewed first to help retain their experience and opinions as much as possible, and then the caregivers were interviewed to share their thoughts on the session and the participants' responses. Overall, researcher participation in the field will contribute to a better understanding of participant responses and promoting empathy [38].

As we establish the value of nonverbal cues in this research context, we propose to cross-reference multiple cues and better record nonverbal interactions (G9). Additionally, we draw from lessons learned from the proxies to offer practical verbal and nonverbal communication tips (G10). The effective approaches emerged from our fieldwork and reflections include: actively seeking support and inspirations from proxies, cross-referencing multiple cues to uncover and stay true to participant feedback, and mobilizing a variety of probing questions, body language cues, and multisensory materials. In this vein, future work can better incorporate methods such as video recording interviews for systematic analysis of nonverbal cues [47, 50], including nonverbal behaviour as measures of engagement and enjoyment [4], and studying the nonverbal interactions between participants and caregivers [31]. These strategies demonstrate recent findings on stimulating social connections by eliciting nonverbal responses [31] and learning from practitioner approaches such as careful interpretation of actions and expressions [19].

5.3 Guidelines for Data Analysis

- G11 Conduct an additional round of data analysis to explicitly focus on power dynamics and risks of participants' voices being overshadowed;
- G12 Triangulate findings across different sources and delve deeper to interpret both alignments and contradictions in the data.

Our in-depth reflection on prioritizing participants' voices and triangulating findings throughout the research process points to the last pair of guidelines. Enabling proxies to facilitate communication during data collection, we find that ensuring they amplify rather than suppress participants' voices remains essential during data analysis. Researchers need to be mindful about proxies' voices overshadowing or deviating from those of participants and consider adding an explicit pass of the data to reflect on power dynamics (G11). The often inevitable imbalance of voices among participants and proxies calls for cautious navigation in establishing consensus and validating across multiple channels. We also propose to pay close attention to both alignments and contradictions when triangulating findings from multiple sources. The underlying nuances of dramatic or subtle conflicts in the data might point to deeper insights into a particular scenario or broader research context (G12). Other triangulation strategies included talking to stakeholders about the same topics at different times and in different levels of detail and discussing findings with experts from various domains [61].

5.4 Limitations and Considerations for Interpretation

This set of guidelines can be potentially applied more broadly than dementia care settings and benefit researchers, especially junior members of HCI communities, working in sensitive settings and with marginalized populations. For example, multisensory probes and personalized prompts (G5) and concrete examples (G10) could help bridge communication barriers when approaching abstract concepts for people with aphasia [25]. However, as we have drawn insights only from the dementia related work, we remain cautious about directly extending these guidelines to other contexts and welcome further discussions with researchers working in related domains.

As a self-reflective effort, this work is limited by the authors' subjectivity and potential oversights. In conducting the work, we have sought to avoid potential pitfalls as much as we can, cautiously navigating the delicacy of ourselves as researchers interpreting the voices of participants and proxies, as well as FA's dual roles of both researcher and subject of study. In doing so, we have followed approaches such as discussing rapport and iteratively reflecting on participant observation [56]. However, we acknowledge that we can never fully account for our own biases, and we encourage the readers to interpret our findings with a critical eye to these limitations. Though we posit that our account fills a critical gap in practice, we emphasize that these guidelines should not be viewed as a final output but rather a starting place for HCI communities to discuss, critique, and refine them. As we are only reviewing one specific study, our findings are limited to its scope (e.g., participant and proxy backgrounds and community characteristics). Future work can provide additional perspectives and broader reflections across more projects.

Looking back on our analytical process, we resonate with the potential authority issue among authors, as described in previous auto-ethnographic work [35]. As FA is a PhD student co-authoring with her supervisor, the power dynamics could have hindered her revealing the setbacks during data collection and analysis. Fortunately, the two authors have known each other for over five years and built a supportive, collaborative working relationship. The mutual trust and communicative rhythms helped us overcome the difficulties in exposing researcher vulnerability and conducting iterative self-examination.

6 CONCLUSION

The voices of people with dementia are essential for HCI research in the dementia context, and it is often necessary to bring in a variety of proxies. To examine proxies' understudied roles and develop strategies for surfacing participants' voices, we reflect on our prolonged fieldwork involving participants, family caregivers, and facilitators, as well as the interactions between these stakeholders. Integrating self-reflection on practice and content analysis of interview transcripts and observation notes, we propose a set of practical guidelines for effectively collaborating with proxies to engage participants and prioritize participants' voices. These guidelines mainly touch upon 1) extended engagement with the community and multifaceted research design in preliminary work, 2) open and flexible research settings, power dynamics management and intervention, and verbal and nonverbal communication in data collection, and 3) awareness of imbalanced voices and triangulation across sources in data analysis. We hope our reflections will spur future discussion and critique and encourage HCI researchers to likewise reflect and offer their experiences as additional data points, to collectively develop deeper insights into involving proxies and supporting the voices of people with dementia.

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