

Making Space for Social Sharing: Insights from a Community-Based Social Group for People with Dementia

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ABSTRACT

People with dementia face major challenges in maintaining active social interaction. Designing digital tools for social sharing within families and care facilities has been well explored by HCI research, but comparatively less work has considered community settings. Situated in a community-based program for storytelling and socializing, our field observations and semi-structured interviews with people living with early-middle stage dementia, family caregivers, and program facilitators illustrate both positive and challenging aspects of social activities. We contribute a nuanced understanding of participants' social lives and identify four factors that aid in achieving positive outcomes: effective agencies for social interaction, normalized and friendly environments, collaboration and teamwork, and mediating social cues and communication. Finally, we examine our findings through the lens of past HCI work and offer insights for designing new social technologies to diversify the range of social spaces in community settings, through expanding peer collaboration, leveraging physical and virtual spaces, creating open-ended experiences, and developing flexible platforms.

Author Keywords

Dementia; community; social sharing; social interaction.

CCS Concepts

• Human-centered computing~Empirical studies in HCI

INTRODUCTION

Social relationships have been identified as an essential component of health-related quality of life for people with dementia and their families [31], but maintaining a fulfilling social life is often challenging due to the nature and progression of dementia, as well as structural and social factors that impede the active inclusion of people with dementia. Sharing stories can engage individuals living with dementia in conversations and strengthen interpersonal relationships, which, in turn, can ease caregivers' burdens [8]. To aid people with dementia in storytelling and sharing,

the HCI community has mobilized a variety of technologies, including ambient displays [8], multimedia systems [3], mobile applications [37], interactive art frames [16], and virtual reality environments [11]. These efforts demonstrate the potential for technology to support people with dementia in more actively engaging in and contributing to social activities [16]. Most work has focused on family and care facility settings, but few studies have explored community-based programs and interactions. We posit that individuals with dementia enjoy communicating with peers, and the lack of community-oriented social platforms further opens an opportunity to create more spaces for their social sharing (i.e., "sharing for the purpose of communicating with social contacts and fulfilling relational goals" [16]).

This study is situated in Tales & Travels (adapted from [29]), a storytelling and social program for people with dementia (usually in the early to middle stages) in a local public library. The program invites participants to explore various countries, one per session, by browsing books and images, tasting featured snacks, and watching travel guide videos. This friendly group setting encourages people with dementia to share stories and memories, while socializing with each other, caregivers, and facilitators. Each session lasts about two hours, starting with a one-hour story time with three to four tables of individuals with dementia, facilitators, and caregivers. Then, during a 25-minute coffee break, everyone enjoys snacks related to the theme country. The session ends with a 25-minute video time when the whole room watches video clips about the country. The library also has three suitcase kits with similar materials to be loaned out.

We present findings from our recent qualitative fieldwork with the Tales & Travels program as a case study, painting a rich picture of social sharing from detailed accounts of people with early-middle stage dementia, family caregivers, and program facilitators. These accounts touched on broader community-based interactions than Tales & Travels and enriched our findings substantially. This paper makes two main contributions: (1) a nuanced understanding of the social lives of people with dementia and key factors to help achieve positive outcomes in various community settings; and (2) a set of reflections on design avenues to diversify social sharing spaces, in terms of expanding community-based peer collaboration and co-located and technology-mediated activities, supporting more open-ended experiences, and building more flexible social platforms.

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RELATED WORK

Empowering People with Dementia in HCI Research

The HCI literature on designing for and with people with dementia is growing. Recent frameworks such as *critical dementia* and *technology narrative* help reposition research approaches to interaction design for people living with cognitive impairments. By positioning people with dementia as competent, engaged, and capable of expressing themselves in meaningful ways, HCI researchers engage with them in an empathic and empowering way, encouraging their perspective, creativity, engagement, and rich emotional expression [15]. Researchers also aim to understand the lived experience of people with cognitive impairments and change the emphasis from suffering the impacts of impairments to enjoying life with the support of technology [20].

Inclusive design practices engage people with dementia and expand design spaces, enabling researchers to build empathic relationships and co-create with participants [9, 17, 19]. Experience-centered design keeps participants' experiences alive in the design process and helps researchers turn from solutionist thinking to explorative thinking, focusing on engaging with and responding to experience [24]. For example, when exploring props and music to inform design, researchers find ways to enable people with dementia and unpack participation through feeling, moving, voicing, playing, and nestling [25]. Similarly, using probes to design personal artefacts opens a way of posing questions through which the researchers, people with dementia, and caregivers make sense of and construct the experiences, which also helps shift from a limited focus on functionality [35]. Probes can be co-designed with participants assuming the roles of co-researchers and collaborators [4]. Prolonged fieldwork proves to be an effective approach, e.g., leading to design implementations that acknowledge participants' preferred media and the lack of internet access in care facilities [9].

Personalizing Technologies for People with Dementia

To aid people with dementia in reminiscing, storytelling, and sharing, person-centered design approaches are widely adopted, from drawing materials from participants' life stories to accommodating their diverse needs and preferences. Developing digital life storybooks helps with person-centered care [32], and personally tailored design can be integrated with existing routines of participants' everyday lives [19]. Moreover, people with dementia are involved in appropriating media content [9] and personalizing interactive media for their preference and enjoyment [11, 12].

Many projects have emphasized the importance of focusing on positive memories and feelings while avoiding pressure to produce a correct answer or recollection. Reminiscence materials need to be carefully chosen to avoid triggering distress or unpleasant memories [18]. Likewise, generic prompts have been found effective in avoiding possible frustration or tension when people with dementia fail to recognize personal items [3]. Regional materials have proven effective in helping people with dementia to reminisce and

engage in storytelling (e.g., CIRCA [3, 28]). Other strategies include prompting reminiscences through non-personalized materials covering all life periods [27] and mitigating negative memories through playful design [30].

Social Sharing as a Design Context in Dementia

HCI work in art therapy for dementia has explored sharing as a social process, demonstrating its empowering values and the benefits of having a visible audience [7]. For people with complex communication needs, artmaking can create a space for expression and communication [17], which calls for careful reinterpretation and contextualization to avoid misinterpretation or criticism [13]. The digital artwork sharing process benefits from a material workspace and its customized use, and gifting artwork to others has been found to be a valuable form of social sharing [16].

In a broader context, technology can serve as a social agency for people with dementia, offering opportunities to create and maintain social connections [9]. For example, digital storytelling in the form of short videos can enable people with dementia to share stories in a meaningful way [26], and conversation tools connecting different generations within a family can increase participants' agency in social settings [37]. Interactive group activities, such as quizzes prompted by print media devices, have proven successful in fostering co-created experiences and encouraging people with dementia to make social contributions [9]. Sharing can be challenging for both people with dementia and facilitators, and technology can help relieve facilitation burdens. Conversation aids like CIRCA make it easier to facilitate a shared interaction with no need for caregivers to prompt question after question to keep the conversation going [3].

Dementia is characterized by cognitive impairments, including difficulties with memory and language, as well as neuropsychiatric symptoms such as apathy and a lack of inhibition [2]. However, prior HCI work shows the ability of people with dementia to enjoy the process of creating and sharing art and stories. Further research is needed to diversify social sharing spaces for people with dementia, especially in community-based group settings. The primary social occasions of prior work have aimed at families and care facilities, where group activities build upon familiarity and trust between people with dementia and families, friends, or long-term care staff. To fill in the gap for probing community contexts (i.e., public activities outside of home and clinical settings), more work is needed to better understand how socializing is established in public events.

METHODS

This study is guided by two research questions: (1) What challenges do people with dementia encounter when sharing stories and socializing within a small group in a community setting? And (2) what materials and prompts are effective in supporting people with dementia in social sharing in this setting? Tales & Travels was of particular interest due to its tailored design but not our sole focus. A broader orientation would provide richer insight by allowing participants to

compare and contrast their social experiences in various community activities. Before starting the data collection in March 2019, the first author was a registered volunteer for the Alzheimer Society and volunteered for nine Tales & Travels sessions from February 2018. This preliminary work helped in understanding the procedures and activities, getting to know the participants, and joining the community. It further minimized the impact of the researcher's presence during data collection, as the first author became a familiar and friendly face to regular participants at Tales & Travels.

This study consists of three parts. **We conducted semi-structured dyadic interviews with people with early-middle stage dementia and their primary family caregivers** (e.g., the spouse) **and individual interviews with primary family caregivers** (where the person with dementia was unavailable) to understand the experience of sharing stories and attending social activities as or with a person with dementia. These interviews helped characterize the ways in which communication and socializing change over the progression of dementia. As adopted by previous HCI research involving persons with cognitive impairments (e.g., [20]), interviewing dyads gave voice to both care-recipients and caregivers. The semi-structured approach allowed for a consistent set of data, while maintaining flexibility for a deeper understanding of participants' traits and perspectives. **We conducted semi-structured interviews with facilitators of the Tales & Travels program.** We looked into the facilitators' perspectives on participants' preferences and challenges when sharing stories and socializing, as well as the use of prompting materials. **We observed the Tales & Travels sessions** to focus on participants' verbal and nonverbal cues as an indication of their preferences and challenges when socializing, examining the effectiveness of multimedia and multisensory materials. We also observed how facilitators maintain conversations and mediate emerging challenges.

Procedure

Our research was reviewed and approved by our institutional research ethics board. As exact diagnosis was less relevant to our research goals than an ability to participate in a small group social context, we did not seek confirmation of diagnosis but rather relied on facilitators to help identify suitable participants with dementia. The dementia conditions were provided by the caregivers (see Table 1); however, given the small sample size relative to the range of conditions reported, along with the limitations of self-reported data, we do not consider this data in our analyses.

Participation in our interviews was confidential. For dyad 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 the first author to a table (without identifying to the first author which tables, if any, declined participation).

Data Collection and Analysis

The interviews and observations were run concurrently from March to July 2019. We conducted 5 dyadic interviews and 3 individual caregiver interviews (C4, C5, and C8). C4's spouse was present but did not participate in the interview. All the couples interviewed (including C4 and her spouse) were living together at home; C5 and C8 were primary caregivers of parents with dementia living at facilities.

ID	Gender (Age)	Relationship	Dementia condition	Experience with Tales & Travels
P1	M (84)	Spouses	Mid-stage Alzheimer's	Attended regularly
C1	F (74)			
P2	M (90)	Spouses	Mid-stage Alzheimer's	Attended once
C2	F (78)			
P3	F (80)	Neigh- bours	Mid-stage vascular	Attended regularly
C3	F (52)		Attended occasionally	
C4	F (75)	Spouse: Mid-stage vascular		Attended regularly
C5	F (61)	Father: Diagnosis unclear; Mother: Late-stage Alzheimer's (C5 reported on both parents.)		Volunteered regularly
P6	M (76)	Spouses	Mid-stage frontal temporal	None
C6	F (70)			
P7	F (81)	Friends & de- facto family	Early-middle stage Alzheimer's	Attended regularly
C7	Atypical (56)			
C8	F (54)	Father: Mid-stage Alzheimer's		None

Table 1. Dyad and caregiver background

As the interviewer, the first author paid close attention to how participants framed their answers and any differences of opinion; to avoid triggering arguments, follow-up questions were framed carefully to sidestep direct contradictions. Caregivers talked more during the interview, but their comments did not override those of the people with dementia. Some nonverbal cues from participants during interviews were also noted. Because of the difficulty of recruiting people with dementia, varied manifestations of dementia (e.g., different types of dementia and various individual symptoms), and the diverse situations of the people with dementia and their primary caregivers, we did not reach data saturation for the dyadic interviews, nor did we expect to. But we were able to triangulate these findings with the facilitator interviews and observations.

We interviewed 4 facilitators (F1–F4), aged 27–32, two males and two females. Two were Alzheimer Society coordinators with degrees in psychology and special care counseling, and two were librarians with master's degrees in library and information studies. At the time of the interview,

the most experienced facilitator had run 43 sessions, and others had facilitated 9, 15, and 24 sessions. We interviewed all the regular facilitators available, and we observed and interacted with all four facilitators during preliminary work and data collection.

Interviews were conducted in a library meeting room or the participant's home, according to their preference. Each interview took 1–2 hours. Each participant was compensated with \$30 or a gift of approximately the same value. All interviews were audio-recorded and fully transcribed with Amazon Transcribe, and then proofread manually.

We observed 11 people with dementia across 8 Tales & Travels sessions (O1–O8). The first author took an observer-participant role, greeting participants and sitting at a table with them as she did during preliminary work. She did not actively engage in the conversations but politely responded when asked a question. She used a pen-and-paper-based observation guide and took detailed field notes in a non-intrusive manner and without collecting any identifying information. Some still images were taken of the room and table configuration, with care taken to avoid capturing any identifying information. After each session, the field notes were promptly expanded both descriptively and reflectively.

We conducted a thematic analysis [5] on the interview transcripts and observational field notes with NVivo 12. The first author performed inductive open coding in an evolving way throughout interviews and observations. The authors met regularly and discussed the codes as they emerged, which helped the first author reflect on and revise them. The initial codes were later developed into themes and subthemes through axial coding. After the data collection was completed and the initial codebook was developed, the second author helped finetune the themes and interpreting the quotes and examples.

FINDINGS

Five main themes emerged from our analysis. The first explores the challenges of keeping socially active and the importance of community programs. The other four themes and their subthemes detail key factors to answer our research questions: (1) “Mature and intellectual activities” and “normalized and friendly environments” show positive examples of community settings, while “collaboration and teamwork” and “mediating social cues and communication” point out challenges and opportunities. (2) “Positive and inclusive topics”, “person-centered stimuli”, and “tangible, multimedia, and multisensory materials” speak to effective prompts and materials.

Active Social Lives and Community Programs

Aging and dementia changed the social lives of our participants and introduced a wide range of constraints related to cognition, mobility, health, and logistics. Dyads described how it was beneficial and enjoyable for participants with dementia to remain socially active despite the burden it placed on their caregivers to manage these

activities. For example, P6 and C6 tried to maintain social contacts and invite people over, “*trying to not have dull moments*” (C6) and keeping their lives “*colourful*” (P6).

Dyads described going to social events together and shifting to more flexible activities such as short-distance trips and events easy to arrange or without a rigid timeframe. C1 mentioned she could not go out on her own as she used to. P2 and C2 always went to events together, but now it was harder for them to get ready on time. The same applied to C4, who arranged more short and quick trips.

C1: I would say most of the social events we have done together now. I used to go to more things on my own previously. But things have changed. So, we tend to go more together.

C2: We always went to everything together, pretty well. Uh, but now ... it's harder for me to get him ready on time. ... I have to keep reminding him that we're going out and so that he has to get ready. So, it's become much harder to be able to do that together.

C4: Not like before, like we used to go far away ... no more. It's really kind of ... quick, quick. Everything has to be short distance.

Some participants used to travel extensively and independently but have had to adjust to mainly taking cruises where everything is centralized and arranged as a package. Some once frequented cultural events (e.g., art festivals and comedy shows) but could no longer continue these routines. Meanwhile, day programs became an important part of many participants' social lives, in some cases their only structured routine. Typical programs included Alzheimer Society's meetups, Parkinson's dance classes, day centres, art therapy, specialized museum guided tours and art workshops, home visits from recreational therapists, and activities in facilities.

Although the range of events was somewhat limited, they served an important role for the participants with dementia, providing an opportunity to be part of something. C6 described these engagements as offering “*more than taking enjoyment from the activity per se. It's more the idea of going ... to something, being part of activity.*” The appreciation of being socially connected was prevalent among the participants, as in P3's remarks on the pleasure she takes in making other people happy.

P3: I go there, and they're so happy that I come ...

C3: You happy? What about you? You say ...

P3: I'm happy, too. I'm happy when I make other people happy! This is me!

Effective Agencies for Social Interaction

Our participants emphasized the importance of building mature, positive, and person-centered social settings. The tangible, multimedia, and multisensory materials and activities at the Tales & Travels program provided insights into effective prompts for social sharing.

Mature and intellectual activities

To accommodate cognitive impairments does not imply planning activities for people with dementia similar to those for children. It is an unintentional mistake to fall into the trap of communicating with persons with dementia in a childish manner. Speaking from her experience as a long-term caregiver and volunteer, C5 pointed out that treating people with dementia as adults was essential for Tales & Travels' success. She articulated it was critical to respect participants' maturity and intelligence, instead of belittling them.

C5: It's an adult activity. ... You're not treating them as children. ... It respects their intelligence. ... It's going to a conference. It's going to lecture in a way, and you participate and you're learning something new. ... whether they have early stages of Alzheimer's or mid stage, they're still adults, you know. They know the difference between being treated like a child or being treated like an adult, and activities where they're treated like adults are successful. ... some of the participants in Tales & Travels have been there since the beginning ... and it's because we're not belittling them.

Participants expressed their interests in sharing skills and expertise, bringing their life experiences to the table and contributing in their own way. Mature and intellectual activities can help create such appealing and engaging opportunities. For example, P1 is good at explaining how things work and helping others when he can.

C1: I think P1 likes to share his skills. He was a very good teacher. And if there was a young person or someone who needed help. And he had expertise. He would certainly help them. He's a very helpful, you know, he likes to explain how things work to people.

P1: ... I know quite a bit about machines and cars and things like that. I'm interested in maps. I travelled a fair bit with C1...

Caregivers also mentioned intellectual social events presenting opportunities for them to share interests and hobbies with people with dementia, as well as learning together. For example, C7 taking P7 to science fiction events and Tales & Travels:

C7: I'm a science fiction fan. And if I want to go to something science fiction-y, I just take P7 with me. She learns new things.

P7: That's right. ...

C7: Well, if we were going to choose a social event to go to... what would make it attractive to us. Something where we learned something. So, we learned about countries when we go to Tales & Travels.

At Tales & Travels, we observed mutual learning processes to explore a country's nature, culture, fun facts, and cuisines. In particular, talking about one's home country encouraged more storytelling and stronger motivations for active sharing.

Similarly, pronouncing foreign words was a way of sharing expertise, resembling a teaching and learning scenario.

O5: At the session about Slovenia, a participant from Slovenia was more talkative than usual. He delightedly pronounced many locations on the Slovenian map and showed another participant where he was born. When asked, he explained the diacritics in Slovenian as "*it economizes letters*" and gave an example of interpreting "Š" as "Sh". The caregiver at his table commented, "*He is the facilitator today. He knows all the pictures and places.*"

Positive and inclusive topics

Tales & Travels showed that topics such as traveling and animals are positive and attractive, enabling participants to follow easily and express their opinions at any point. As C2 mentioned, it was easier for P2 to follow facts and documentaries since the discussions around such topics did not require remembering everything said previously.

C2: He likes to watch nature programs, factual things like history things, geography ... documentaries ... things that he can, doesn't have to follow the trend so much that you could just get the facts as they are. So those are easier to follow.

C3 confirmed that the concept of travelling through historical periods or geographical locations with images and videos allowed for an appealing excursion beyond the boundaries of everyday life.

C3: I like the concept ... of travelling through these pictures and through the video. ... it's a great concept for someone who can't necessarily travel. That's a great concept. ... There's always an element in there that will appeal to every, you know, everyone will have one.

In contrast, facilitators pointed out the negative impacts of disturbing or unpleasant topics. F1 mentioned a participant becoming uncomfortable with chaotic situations on the streets in the materials, and F3 once saw a participant losing interest in eating lunch upon the holocaust being brought up.

Person-centered stimuli

Caregivers respected the personalities, interests, and experiences of people with dementia, trying to find effective, person-centered stimuli. For example, C5 found out that music from her mother's youth stimulated her mother while her father was delighted by his favourite comedian.

C5: Around 2011, my brother ... downloaded some Spanish music from her youth. Oh my god, she became alive. She just started singing the song. She started dancing. She started remembering happy times. Um, that's how, from about I guess the middle stages of Alzheimer's till about two years ago, music had an instantaneous happy, um, reaction. ... With my father, the music doesn't seem to work. But I remember he had a favourite comedian and a humourist. So, I found on YouTube ... [my brother] sent me a video of my father

listening to these, this man telling, you know, his comedy routine, and he's smiling. And my brother said that he actually laughed out loud at some of the jokes.

At Tales & Travels, the facilitators made efforts get to know each participant, e.g., who is interested in what, who likes his coffee black, who would like to take printed maps home, etc. Thus, they managed to tailor materials and topics to the needs of different participants, as reflected in this quote detailing how F1 chose materials to spark individual interests.

F1: You would know the interest of some of the participants as well. ... one lady ... really loved animals. So, [I] make sure to include some. ... some guys like, really like history. ... they would "Wow", you know, when things were thousands of years old. That's what kind of sparked something in them. So, I kind of adjusted to when I started to know them better and know what the what they responded to, I guess.

Moreover, facilitators managed to bond with participants and build upon their previously told stories to discover new layers of experiences, turning repetitions into opportunities and becoming part of the conversation. As Tales & Travels is like a "*conversation group*", sometimes "*the leading is implicit. ... We're just facilitating the conversations, but we were also in the conversation*" (F4). We witnessed the facilitators adopt different strategies in various scenarios.

O1–O8: The facilitators encouraged and followed when participants were comfortable taking the lead in storytelling and reading materials; they prompted and explored when the table became quiet; they redirected and regrouped when participants were trapped in unpleasant thoughts or difficult discussions.

Tangible, multimedia, and multisensory materials

The Tales & Travels program mobilizes many materials to engage participants in storytelling and socializing, including books, fact sheets, large print images and maps, objects and artefacts, clothing and textile, food, music, and videos. People with dementia and caregivers are free to engage with their preferred media and materials, e.g., maps for P1 and artefacts for C1. "*I love maps. ... When I have nothing to do, I read a map. Everything I learned ... Read a map, a very good map, it will tell you a lot*" (P1). "*Artefacts. ... I'm a textile person, I love clothing, I love fabric stuff. So, if I've been somewhere, if I have an object that I feel that I could bring it into ... Show and tell, I guess we would call it*" (C1).

Facilitators reported their efforts in exploring prompts to fit various themes, as F3's successful use of tropical clothing as a visual cue to spark interests and conversation demonstrates:

F3: [I] changed into a tropical theme shirt to fit the Jamaican setting. ... a change in clothing, a visual cue to put in with where you're traveling also, the more ridiculous it is, sometimes the more you get a rise out of people. ... a large shamrock hat for St Patrick's Day, people will notice, right? It initiates interactions.

Although we noticed minimal technology use among our participants with dementia, they were happy to engage with technology when guided by caregivers such as joining in on a video call or selfie. Technologies were used selectively at Tales & Travels and a memorable example was one participant excited to revisit his hometown via Google Street View projected on a large screen. It not only brought back childhood memories for this participant but also enabled him to share the place with others in the group.

C1: [The facilitator] was able to pull up East London. And for [this participant], that was so exciting, because he could see where he grew up. ... It brought back for him lots of memories. So, I think Google Map is a wonderful way of being able to bring people back to a previous period that they remember. ... I just remember ... how excited he was. Because he could relate exactly to that street and that area. ... It enabled us to sort of get a feeling of where he came from.

Such a wide range of multisensory materials helped with communication and enhanced participants' experience. Themed snacks, such as Jamaican patties, a Swiss cheese platter, and Armenian treats, were well-received. Several facilitators and caregivers also confirmed the advantages of tangible objects and themed artefacts. For example, a globe can be held and passed around, inviting participants to join in. Such materials also provided a "*frame of reference*" (F3) for facilitators and participants to fill in the memory or knowledge gaps without anxiety or embarrassment. At the session for Australia, P7 and C7 brought a stuffed koala and a kangaroo from their previous trip to Australia. These toys "*were quite popular. They made their rounds of the tables and hopped around a little bit*" (C7).

Normalized and Friendly Environments

Caregivers described public spaces and open environments as bringing a sense of normality, sparking spontaneous expressions, and offering opportunities for social interaction. C2 detailed how P2 once joined children playing soccer in a park, and describes in this quote how a cafe environment spurred spontaneous philosophical observations.

C2: ...He was sitting at the [cafe] and he was facing the street... "See, all those people going by," he says, "some are skinny, some are fat, some are ugly, some are nice, and, you know, in a while, all those people are gonna be dead, you know." he says, "But they're just walking like this. Nothing. No thinking. They just think they're gonna be here forever."

P2: With deadly guys (laugh).

C2: ... It was really quite astounding because he usually, nowadays, doesn't philosophize. But he did.

Similarly, C8 described the casual and serendipitous opportunities the public market afforded to her father.

C8: He likes if we go to the ... market where there's ice cream. And just there's a lot of people... He looks at

people. There's people with dogs. That's great. Yeah, I've bumped into a friend once or twice. So then he got to talk to my friend, and then he'll talk. ... he talks a lot.

P3 expressed her affection for day programs because of their friendliness and hospitality, stressing the importance of social connections, especially for vulnerable individuals.

P3: People are wonderful. You go in there and everybody's smiling and happy and become friends. ... I like them all. For the people that are sick, they need help. They need cooperation. They need friends. And they got it here and there.

C3: Yeah. P3 is very social. ... She needs people.

Regarding Tales & Travels, in particular, caregivers stressed how its location, a public library in an attractive historical building, affirmed the experience of normal life and provided a sense of belonging to the community.

C3: The setting at the Tales & Travels, beautiful, you know, big, open space. That's wonderful. You know, I think that adds something to the activity, the fact that you're in an old building. ... So, it's a significant, ... an impressive place to be in. You feel it, walking in, you know, if you look at details. It's just fantastic.

C4: For us, for example, to come here, across the park and come is like, not a picnic, but a beautiful... enjoyment, first of all. And the library is so attractive.

C4 continues by describing the role facilitators played in creating this experience, which we also observed.

C4: When we come in, the hospitality that you show, your kindness that you show, also attracts. It's very important. So it's not like a dogmatic... you feel you are welcome, which is very important. ...I could feel that I was, I had an attachment. I'm sure [my husband] felt the same thing.

Though targeted to people with dementia, Tales & Travels does not dwell on the disease; it simply invites everyone to join the community and public space. Without dementia being mentioned, we observed participants joyfully share travel experiences, life stories, news, knowledge, and humor. Below F1 and F2 reflect on this aspect of the program and how it contributes to a positive experience for participants.

F2: The point is to provide ... an environment where they're safe and you know their difficulties won't show too much, which is why it's a program adapted for them. ... it's also in the library in a public place. It's meant to make it look like ... normal life, actually, and I think that's when they actually enjoy about it. Well, I believe because it looks like they're just going ... somewhere like you would go to a reading club or anything. And it doesn't look like it's labelled dementia ... I think that's what people probably enjoy about this, too.

F1: I think it's kind of the elephant in the room, but at the same time, you kind of want to give the moment to

like, not think about that. I'm sure they go to lots of programs or doctor's appointments and things like that. You just want to make it seem like it at the library, too. So, it's not in a hospital or, uh, in [the] Alzheimer Society building. It's just in the community. It's an event to discuss ... I think it's a good thing that we don't talk about [dementia] during the program. ... it makes it more light, maybe more like lightly, light-spirited.

F1 continue by noting that though caregivers are welcome to participate in the program, the library setting also provides the opportunity for respite from caregiving duties.

F1: And some caregivers stay at the library when the participants are in the room. They didn't sit in the room, but they just go read somewhere else ... It's what they do. They just come. This is the place. ... you can just walk around, sit, move whenever you feel like it.

Tales & Travels is a dynamic and open-ended program, increasing participants' experience of normalcy and ease with telling stories, commenting, discussing, and listening. We often observed them playfully ask, "*Where are we going today?*" to which facilitators would cheerfully respond, "*Today we'll visit ...*" For instance, P1 described that he would like to keep an open mind about telling his stories and listening to others.

P1: I really enjoyed travel. I want to find out more about these places and so on. ... I tell stories if I've been to places. Otherwise, I'm listening to find out something. ... Got to be open. While learn things, got to be open.

F3 confirmed the advantage of an open structure without fixed steps to follow and the challenge of managing the flow in facilitation.

F3: It's much more open than some other activities that I've seen done with clients with dementia where there's like steps. Let's say, like, let's do an art activity, but these are the steps to do it, right? This is an open-ended thing. ... So it's dynamic. It's moving, you know, it means you have to surf that wave. But it, yeah, it's fun.

Collaboration and Teamwork

Participants valued the group setting. Here, P3 describes her social groups as a team and C3's support for these activities.

P3: All those wonderful people. They're with me. They all realized we were a team. ... we are a team there. And C3, she joins in with that team and she regulates the [activities] ...

C3: I'm P3's social director, really (laugh).

[And then later] P3: ... I devoted myself to them because we're all a team. Everybody. I treat each and every place that we go to. ... They're very friendly. ... Very compassionate. They know me very well. And make me feel at home.

C3: ... I think P3 is very well appreciated in the groups.

When asked about expanding the Tales & Travels, C4 proposed additional ways for participants to work collectively, new opportunities for social interaction, and the mutual benefit of collaboration, as below.

C4: If they can make together, something together. ... They speak with each other most of the time, right? ... Something they can make together, you know. Like collectively. ... Something they can construct. Like a puzzle but not a puzzle. Something like when they can work when they interact together. That will be good. That's interesting. ... They can help each other.

F1 was likewise positive about the role of collaboration, proposing "*more interactive group activities*" and "*teamwork*" for completing activities like quizzes. In this next quote, she further describes how collaboration provided opportunities for people to take on different roles through the example of a participant in the earlier stage of dementia helping someone at a more advanced stage.

F1: There was one new person that came for the first time. And we set her with another patron [who was more advanced]. And this new person was really early (stage), and they just got along so well. The person was really acting as an animator, almost, with that person, one on one. So showing things and being very nice and patient and even helping the person to go get coffee or go get like food and stuff. So it was nice ...

Facilitators explained how Tales & Travels, as a social program, helped build friendships and expand social circles, for both participants and caregivers, as F4 explains here.

F4: ... participants with dementia do befriend each other, and seek each other out at the beginning of the sessions. ... And caregivers who maybe have been quite isolated, haven't reached out for help yet, haven't reached out for additional services, meet other caregivers or meet someone from the Alzheimer Society. So they start to build their network of support.

Connecting with facilitators over time, participants demonstrated their attachment and appreciation towards the program through heartfelt responses and comments. For example, when F3 informed two participants that it was the end of his practicum at Tales & Travels, they expressed sincere gratitude and a close bond.

F3: They were people I've worked with quite a bit and don't participate in other programs. ... like it was kind of a goodbye in a sense. ... So I mentioned that to them and, ah, one of the participants ... offered to give me a hug. And then when she was going, walking, and stopped. And then it's like, "Come on, come on, say goodbye to me again, give me a kiss", you know? So we kissed each other on both cheeks and said, you know, "Be well. Thank you." And similar again. The gentleman I was with, had left, uh, but then realized ... He came back, shook hands. It was a pleasure.

Mediating Social Cues and Communication

People with dementia can have difficulty interpreting social cues. Self-awareness of these limitations can prevent them from engaging in public settings, as it did for C8's father.

C8: Or he'll tell people, ... I see you today, but I might not remember I saw you tomorrow. ... he's very aware of that, is very self-conscious. And he's a proud man. So you know that stops him from doing things ...

Public events add further challenges as strangers may not recognize the condition or know how to respond. For example, C1 recalled an incident in which P1 failed to appreciate some of the nuances in the content and social context of an art panel discussion, and as a result made some inappropriate comments that clearly perplexed the artist.

Nonverbal cues are also easy to misread, and even facilitators struggled sometimes to "*indicate subtly*" (F3) and not to hurt participants' mood or self-esteem. For example, a participant once kept talking to F3 at the coffee stand and failed to read F3's body language and realize his intention of getting back to the table he was facilitating.

Other communication barriers relate to memory, attention, personality, responsive behaviour, and diverse language, cultural, and community backgrounds. These obstacles can cause tension and irritation among participants, leading to aggressive comments, loud and irritating laughter, conflicting behaviour, and inappropriate jokes, as described below. Facilitators try to mediate such difficulties by getting to know participant so that they can better arrange tables and pairings to manage group dynamics and avoid conflicts.

F1: I think it was subtle. ... aggressive things were said and then the person was just overwhelmed and decided to leave the situation. Um, some other person laughs very loudly and that also irritated someone else, so they didn't want to sit together. So you kind of see the dynamics once you start to know the patrons...

F2: I guess it's more challenges for us, because, um, well, we pay very much attention to who will be sitting next to whom. Because some participants will, for example, ask the same questions over and over. And some participants will have difficulty speaking. So, if you put [them next to each other], it will make, like lead to a very uncomfortable situation.

F4: I think when we have a conversation, there's so many different social cues happening ... you can lose the communication route very easily. So it happens very easily. You know, some people are telling jokes that aren't appropriate because their filter is not there anymore and offend someone, not intentionally.

DISCUSSION

Our findings uncover a nuanced understanding of the social lives of people with dementia, revealing both positive and challenging aspects of their social experiences, especially in community events. Case studies of successful programs like

Tales & Travels highlight a number of best practices for supporting social sharing, including the choice of mature and intellectual materials, the careful adoption of technologies to respect participants' minimal technology use, and the proper facilitation of activities. As detailed below, our work further opens up avenues to diversify social sharing spaces, thus creating opportunities to design new social technologies.

Expanding to Community Settings

Our findings show that a public venue is especially helpful to create a normal-life environment in contrast to specialized, healthcare-related contexts. The physical attributes of a public library might be similar to hospital meeting rooms, but they offer different affordances [10]. People perceive these locations differently, and community environments foster distinctive associations and attachments, as reported by our participants. Aligned with current policy of enabling people with dementia to live at home, these normalized, community-based settings can help form a sense of attachment and belonging and extend sharing scenarios to the less explored group and public sessions [7].

Peer collaboration. Community settings offer more channels of sharing among peers, potentially playing a bigger part in the social lives of people with dementia than occasional events such as exhibitions of their artwork (e.g., [7]). In prior work, the collaborative effort is mainly between individuals with dementia and therapists or researchers. A notable example of co-creating knowledge and experience among peers is using print media device for quizzes in care homes [9]. Tales & Travels fosters more collaboration and teamwork among people with dementia, e.g., helping each other get drinks and snacks, answering each other's questions about a country, or reading and finding answers together. Thus, this setting not only creates a distinctive group structure but also signifies a collaborative dynamic among peers. As suggested by caregivers and facilitators, building something together as a team or engaging in group activities will provide more opportunities for interaction and a sense of accomplishment.

Physical and virtual spaces. As a public library program situated in the community, Tales & Travels opens doors to people with dementia living independently at home with caregivers as well as those living at long-term care facilities. The library's downtown location helps many participants to join by foot, car, or public transit, but hinders those with limited mobility. In contrast, virtual spaces can reach more people but risk losing the benefits of a public, normalized environment. Similarly, while co-located Tales & Travels was found helpful for caregivers to reduce isolation and build support network, technology-mediated spaces can connect caregivers in a broader capacity but face other constraints such as technology adoption and access. This tension between physical and virtual spaces calls for prioritizing user needs and preferences when developing co-located or technology-mediated activities in HCI practice.

We envision technology as a part of the collaborative effort to improve community and peer activities. Our findings show that many people with dementia cannot access public venues in person due to mobility and logistic constraints. Thus, a promising avenue is to mobilize technologies to negotiate those physical barriers, e.g., expanding dementia-friendly and online community platforms [23]. The benefits of social collaboration can be extended from virtual spaces to physical ones, as shown in videogame-based systems for dementia daycare centres [34]. Tangible, multisensory, and multimedia materials found effective in co-located activities in our fieldwork can be incorporated into technology-mediated spaces but require careful integration and alignment among senses and media [21]. For programs like Tales & Travels, digital toolkits can be widely used in both private and public settings, expanding the currently limited number of suitcase kits on loan from the library. Future platforms can draw inspiration from research in related areas, such as compiling collective memories online to connect older and younger users [22] and exploring a less linear narrative of personal histories within a timeline [33].

Supporting More Open-Ended Experiences

Our work reveals new avenues for social sharing by people with dementia, extending the range detailed by past research. We argue for the creation of more open-ended social sharing spaces for people with dementia by promoting a richer content of sharing, exploring more open-ended structures, and synchronizing the creating and sharing processes. Through these measures, the roles of people with dementia will be diversified and dynamic.

Richer content. The content of sharing in prior work tends to concentrate on different forms of personal stories (e.g., [8]) and artwork (e.g., [7, 16]). The accounts of dyads and caregivers, as well as the success of Tales & Travels, demonstrate that people with dementia are able and happy to share their thoughts and opinions (e.g., making observational comments in public places and discussing news or local events), as well as their skills and expertise (e.g., explaining how machines work and pronouncing foreign words). They also enjoy a mutual learning process (e.g., finding out fun facts about a country together). An enriched content increases chances for communication and interaction.

More open-ended structures. The focus of existing work on sharing in dementia care is mainly twofold. On one hand, social sharing is often embedded in therapeutic processes, such as art, reminiscence, occupational, or speech therapies, where people with dementia mainly follow the lead of therapists or care professionals. On the other hand, many activities are designed to produce some piece of work, such as multimedia biographies [8], virtual environments [11], or art pieces [16]. At Tales & Travels, in contrast, each session has a theme but no concrete objectives to meet at the end, similar to some open-structured group artmaking sessions [7]. We saw that this structure enabled participants to focus on materials and conversations freely and effortlessly. Moving forward, we can explore the experience itself as the

end goal, enabling people with dementia to take the lead and interact in the ways they prefer. Meanwhile, as byproducts of social sharing experiences, participants could still keep some souvenirs as a reminder of the event, as previous work has found it important for people with dementia to have a physical cue [9]. For example, we observed that Tales & Travels participants often took home some printed materials, especially the large print maps and images they liked.

Synchronized creating and sharing processes. Our findings suggest bringing creating and sharing processes together, in contrast to the mostly asynchronized processes of creating and sharing in past work. For example, making art first and sharing later through exhibiting or gifting artwork, making digital storytelling videos first and viewing later with family and friends, and capturing photos and videos first and discussing these media cues later. Tales & Travels showcases a shift to real-time creating and sharing, enabling everyone to enjoy socializing in the moment. We observed that participants were encouraged to share their emerging reflections and personal stories. This combined process affirms the ‘in-the-momentness’ felt by people with dementia and establishes a visible, co-present audience, both found beneficial in prior work [7]. A similar “here and now” approach proved effective in a recent diary study, supporting people with dementia in sharing their emerging thoughts immediately via voice messages [14]. Moreover, we uncovered arising challenges in facilitating concurrent creating and sharing, e.g., more pressure on facilitators to mediate emerging social cues and communication problems. More preparation effort might also be needed due to the increasing uncertainty of participants’ reactions to materials and activities as found in other group settings [21].

More diversified and dynamic roles. Expanded social sharing spaces diversify and give greater flexibility to the roles of people with dementia. They can be storytellers and listeners, contributors and audiences, or peer collaborators, switching roles smoothly as the activities evolve. Participants are heard and become equal conversation partners, which contribute to meaningful communications [1]. The dynamic roles can benefit group interactions as previously found in engaging people with dementia as performers or spectators in music sessions [25]. Open-ended activities encourage more active sharing and invite more participants to become content producers, in line with the findings in improving older adults’ self-expression and community-based care [36], as well as self-esteem and sense of usefulness [6].

Building More Flexible Platforms

We further propose to build more flexible social platforms by balancing personal and generic materials and offering person-centered yet inclusive options. Past work has disagreed on whether personal or generic materials are better for supporting storytelling. Personal items can help with reminiscing (e.g., [8]) but risk creating embarrassment when items are not recognized. Generic materials avoid these pitfalls (e.g., [3, 28]) but may be less effective at spurring

meaningful interactions. Our work reveals subtle nuances in the roles of personal and generic materials.

Tales & Travels presents materials in a generic manner, keeping low expectations for remembering. On multiple occasions, the materials were personally relevant to a participant and provided a low-risk opportunity for reminiscence and sharing. In the example of using Google Maps, one participant recognized his hometown and was able to share his experiences there with Street View. However, had he not recognized his hometown that day, the session would have simply continued as any other, with the group exploring and discussing the place together.

Similarly, Tales & Travels illustrates the need to balance person-centered and inclusive approaches. One topic might resonate better with some participants, but others should not be left out of the conversation. Offering both one-on-one and group interactions is another way of increasing flexibility. This mixed setting resembles real-life social scenarios with low pressure, as participants are given sufficient attention yet not obliged to talk all the time. In sum, more flexible social platforms allow for the engagement of people with dementia in their preferred ways in a stress-free environment.

Limitations

Although the dyads and caregivers come from various cultural, educational, and professional backgrounds, most of them have higher education and comfortable socioeconomic status which might contribute to their active involvement in social events and research in the first place. As this study is situated in a populous municipality in North America, some findings might have inherent social and demographic limitations when being applied to other communities.

CONCLUSION

Our recent fieldwork in the Tales & Travels storytelling and social program, distinctive in its community setting, reveals the potential to diversify social sharing spaces for people with dementia, thus informing the design of new social technologies. On the basis of thematic analysis on interview transcripts and observation notes, we propose to further community-based peer collaboration and balance the tension between co-located and technology-mediated spaces. We suggest richer content, more open-ended structures, and synchronized creating and sharing processes, diversifying the roles of people with dementia in social interaction. We further discuss developing more flexible social platforms to offer person-centered yet inclusive activities.

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