

Enriching Social Sharing for the Dementia Community: Identifying Opportunities for Technology Design

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ABSTRACT

We present two qualitative studies to identify technological opportunities for designing effective socializing activities for engaging people with dementia. Our completed on-site fieldwork involved interviewing people with dementia, their families, and professionals and observing an in-person social program, leading to insights for designing new social technologies to diversify the range of social spaces in community settings. Our virtual fieldwork includes follow-up interviews with a subset of caregivers and professionals in our first study and reflections on the virtual adaptation of the social program, exploring the positive and negative roles of technology in virtual social engagements. Our preliminary findings from ongoing analysis lead to design considerations for re-building social experiences as a virtual community. We hope this work will enrich social sharing space and inspire future HCI work in dementia settings.

Index Terms: Human-centered computing—Accessibility—Empirical studies in accessibility

1 INTRODUCTION

The dementia community encompasses a diverse group of people with dementia, their families, and various professionals who provide care and facilitate activities. The community faces major challenges in social engagements, which are further complicated by the prolonged physical distancing measures due to the COVID-19 pandemic. HCI research has explored digital tools for social sharing (“sharing for the purpose of communicating with social contacts and fulfilling relational goals” [4]) within families and care facilities. Personalized ambient displays have been developed for reminiscence and conversations among family members [1]. Print media devices have been built to prompt quizzes for interactive group activities in care homes [3]. However, comparatively less HCI work has focused on community settings, thus missing opportunities for designing new community-based social technologies for dementia care.

These gaps and emerging challenges motivate our fieldwork in the dementia community, the on-site followed by the virtual (both approved by the university ethics board), to identify opportunities for technology design. The current technological toolbox has not yet reached its full potential to improve the quality of life for families living with dementia. A dedicated community-based approach to technology design for social programming could positively impact a greater number of people while using fewer resources, with the added benefit of creating interactions and collaborations for the dementia community.

2 CONTEXT: ON-SITE FIELDWORK

To explore an exemplary case of effective community programs, our on-site fieldwork was situated in Tales & Travels (adapted from [5]).

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It is a storytelling-oriented social program for people with dementia (usually in the early to middle stages) held by the Westmount Public Library, Greater Montreal, Canada, in collaboration with the Alzheimer Society of Montreal. The program invites people with dementia, as well as their caregivers, to the library to explore various countries, one per session, by browsing books and print materials, tasting featured snacks, and watching travel guide videos. It creates a friendly group setting and encourages people with dementia to share stories and memories while socializing within the group. Our on-site fieldwork in 2019 involved non-intrusive observations of eight Tales & Travels sessions and twelve semi-structured interviews with dyads of people with early-middle stage dementia and their primary family caregivers, individual caregivers, and Tales & Travels facilitators (librarians and Alzheimer Society coordinators).

Published at CHI’20 [2], this fieldwork contributes a nuanced understanding of the social lives of people with dementia and their family caregivers. We 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. We offer insights for designing new social technologies to diversify the range of social spaces in community settings by expanding peer collaboration, leveraging physical and virtual spaces, creating open-ended experiences, and developing flexible platforms.

3 VIRTUAL FOLLOW-UP

To support the dementia community in the transition to online social engagements due to the pandemic, our virtual follow-up study investigates how the pandemic impacted the social lives of families living with dementia, as well as the work of professionals and social programs, and reexamines the themes from the on-site fieldwork.

3.1 Methods

We started with semi-structured online interviews with a subset of caregivers and facilitators who participated in our previous on-site fieldwork. These interviews focused on how physical distancing changed the social lives of people with dementia and their caregivers, as well as how professionals adjusted their work to continue helping their clients maintain socially active and navigate emerging challenges in virtual settings. Five interviews (three caregivers and two facilitators) were held via Zoom. Each interview lasted 30–55 minutes, and each participant received a \$30 honorarium.

After the conclusion of our interviews, the first author was invited to join the newly adapted virtual Tales & Travels as a volunteer facilitator. Each session lasts about 45 minutes via Zoom, starting with 5-minute greetings and a brief introduction of the theme country. Then, a 30-minute story time is held in 2–3 breakout rooms. The session ends with a 10-minute video time for the whole group. We reflected on the first author’s volunteering and facilitation experiences at the virtual Tales & Travels, aiming at a detailed understanding of virtual social programs inclusive of people with dementia and their caregivers. Our reflections included 35 virtual Tales & Travels sessions, among which the first author joined 26 sessions as a volunteer and 9 sessions as a facilitator.

3.2 Preliminary Findings

We are conducting a thematic analysis on the interview transcripts and reflexive facilitation notes within MAXQDA2022. Our ongoing analysis reveals three preliminary themes.

Complexities in Social Engagements The first theme highlights how the pandemic magnified and shifted caregiving and socializing challenges, including the positive and negative roles of technology. Our findings reveal complicated and fluid caregiving situations both at home and in residences, as well as less structured and less motivated social lives with a heightened lack of spontaneity. Participants reported positive experiences with technologies in facilitating new engagements, e.g., video chats, robot dogs, and online classes and games while facing challenges such as access, fatigue, distraction, and the lack of physical interactions. A prominent burden fell on the caregivers to explore and support new activities for their loved ones. Some technological tools provided a much-needed source of focused interaction for people with dementia (e.g., playing with a robot dog), which allowed some respite for caregivers. However, other technology-mediated activities required additional caregiver attention. In the case of remote art therapy, caregivers had to provide technical and procedural support because their loved ones were unable to navigate the virtual environment and physically draw or paint on their own.

Interdependence in the Dementia Community The second theme delves deep into the individual and collective efforts of members of the dementia community to reconcile with the dramatic changes throughout the pandemic. These findings explore nuanced losses, social and emotional connections, and space for mutual support. Caregivers demonstrated prominent resilience by staying positive and taking comfort in reciprocal help. For example, while enduring the sudden deprivation of social contacts, one caregiver appreciated the opportunity to open her swimming pool to the neighbourhood and receive help with groceries. Tenacious professionals adapted to sudden, drastic workplace changes, trying to rebalance work and life while remaining mindful of their clients' needs. More broadly, the dementia community was sensitive to the changing physical and mental space for interactions and contributions. Caregivers missed previously frequent visits downtown to cultural establishments such as museums and noticed how the pandemic shifted people's attitudes towards each other, sometimes frustrated by discrimination against their loved one with dementia.

Re-building social experiences as a virtual community The third theme learns from the strengths and challenges of recent online social programs, particularly Tales & Travels, to foster community connectedness in virtual settings. We investigate how these programs could leverage physical objects and environments, enhance open and flexible experiences, and expand collaborative space. The facilitators tried to connect to the physical space and create an "intimate" experience, including showing participants around the original Tales & Travels library room through the camera, presenting souvenirs from the theme country, and wearing themed clothing. Mindful of the challenges of engaging people with dementia remotely, the facilitators made space for spontaneous discussion of topics and materials and encouraged participants to choose which pictures or videos to watch through screen sharing. Caregivers were less likely to take short respite during virtual sessions as they needed to help their loved ones, either with technology or with attention. Thus, virtual Tales & Travels extended the inclusion of caregivers to a more collaborative space for caregivers to reconnect with each other and share their travel stories.

In addition, this theme reveals helpful usability features and technological challenges, together with emerging facilitation strategies, leading to further design considerations. We are exploring preliminary avenues such as:

- How to balance ease of use and privacy and security concerns (e.g., creating an inviting, hands-free environment while remaining mindful of lowered inhibition combined with being situated in private environments leading to inappropriate dresses or languages)?
- How to develop specialized prompting systems to aid participants in meeting controls (e.g., to join, leave, mute, and unmute)?
- How to build more flexible platforms to accommodate personal and group needs and mediate conflicts (e.g., managing several breakout rooms with participants trickling in and making space for some participants who rely on text communication without audio or video)?
- How to enhance positive virtual experiences such as spontaneous sharing of multimedia materials (e.g., listening to national anthems, reading folklore, and exploring landmarks with various map views and interactive features)?
- How to help facilitators manage divided attention during complex multitasking, streamline the communication between them, and handle fluid situations (e.g., disruptions on participants' end, in-person facilitation skills not translating well into virtual settings, and facilitation fatigue)?

4 CONCLUSION

We present two qualitative studies embedded in the dementia community to explore technological opportunities to support social activities. Our completed on-site fieldwork focuses on in-person settings, while our ongoing virtual fieldwork delves deep into online social programs. We hope this work will enrich social sharing space and inspire future HCI work for the dementia community, in both in-person and online settings.

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