

# Empowering People with Dementia to Share and Socialize

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## ABSTRACT

People with dementia face major challenges in maintaining active social interaction. This work aims to develop a social sharing platform consistent with the needs and preferences of people with early-middle stage dementia and integrated with common caregiving practices. Situated in a local storytelling and social program, the ongoing fieldwork involves semi-structured interviews and observations to identify challenges that people with dementia face in their social lives, along with best practices for supporting their storytelling and socializing. The identified challenges and best practices will guide the upcoming system design and evaluation. We will explore opportunities for information and communication technologies to address existing challenges, mobilize effective prompting materials, and better support people with dementia in social sharing.

## Author Keywords

User-centered design; dementia; social interaction; sharing.

## ACM Classification Keywords

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

## INTRODUCTION

Active social interaction is an essential component of quality of life, but people with dementia (PwD) face major challenges in their social lives due to deterioration in mental functions including memory, communication, attention, and behaviour regulation. Sharing stories can engage PwD in conversations and strengthen interpersonal relationships, which, in turn, can ease caregiving burdens [3]. Existing tools often provide passive sharing opportunities, but PwD can engage more actively to improve social interaction. Especially lacking are tools that focus on PwD's social communication and support the sharing of original content created by PwD [8].

This study is situated in the Tales & Travels program, a storytelling and social series for PwD in Greater Montreal, Canada. The Tales & Travels program was initiated at the Gail Borden Public Library District in Illinois and offers toolkits for librarians and caregivers under Creative Commons licensing [12,13]. In collaboration with the Alzheimer Society of Montreal, the Westmount Public Library has adapted the program and held structured weekly sessions since 2016. This program encourages participation, conversation, and expression by inviting PwD to explore a country through books and images, sharing stories and memories, tasting featured snacks, and watching travel guide videos [15]. It provides a friendly group setting for PwD

(usually in the early-middle stages) to share stories and socialize with each other, caregivers, and facilitators.

## RELATED WORK

Recent frameworks such as *critical dementia* and *technology narrative* help reposition research approaches to interaction design for and with people living with cognitive impairments. By positioning PwD 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 [7]. 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 [11].

To date, the HCI community has mobilized a variety of technologies, such as ambient displays [3], multimedia systems [1], mobile applications [14], interactive frames [8], and virtual reality environments [5], to facilitate PwD's creating and sharing. Person-centered design approaches accommodate PwD's diverse needs, preferences, and responsive behaviours. PwD have been appropriating media content [4] and personalizing interactive media for their preference and enjoyment [6]. Many tools draw materials from PwD's life stories and focus on positive memories and feelings, instead of asking for the correct answers and recollections. Reminiscence materials are carefully chosen to avoid triggering distress or unpleasant memories [10]. Similarly, generic prompts are found effective in avoiding possible frustration or tension when PwD fail to recognize some personal items [1].

Sharing stories and experiences within a group could be challenging for both PwD and facilitators, and technology can help relieve some facilitation burdens. For example, conversation aids make it easier to facilitate a shared interaction with PwD, with no need for caregivers to prompt one question after another to keep the conversation going [1]. Interactive group activities, such as quizzes with the help of print media devices, prove to be enjoyable and successful in fostering co-created experiences [4].

From recent work on *making as expression* in art therapy [9], we can explore how collaborative design engagements empower PwD. We can investigate through creating space for expression, further personalization with better-tailored experiences, and more group-oriented, multisensory activities. PwD can create original content and enjoy

communicating with other people, and the lack of personally tailored social sharing tools opens an opportunity to develop a collaborative platform for families and communities to aid in caregiving and social integration.

## METHODS

We have adopted a human-centered approach consisting of an iterative process of fieldwork, design, and evaluation. Before starting the fieldwork in March 2019, the doctoral candidate was a registered volunteer for the Alzheimer Society of Montreal and volunteered for 9 Tales & Travels sessions from February 2018. This preliminary work helped in understanding the procedures and activities, getting to know the participants, and becoming a part of the community.

The fieldwork aims to answer two research questions: (1) What challenges do PwD encounter when sharing stories and socializing within a small group? (2) What materials and prompts are effective in supporting PwD's social sharing? Semi-structured **dyad interviews** with people with early-middle stage dementia and their primary family caregivers (e.g., the spouse) are aimed at understanding the dyads' experience of sharing stories and attending social activities, giving voice to both care-recipients and caregivers. These interviews also help reveal how communication and socializing change over the progression of dementia. **Individual caregiver interviews** are considered in cases where PwD are not available for a joint interview. Semi-structured **interviews with facilitators** of the Tales & Travels program provide their perspectives on PwD's preferences and challenges when sharing stories and socializing, as well as the use of prompting materials. Finally, **observations** of the Tales & Travels sessions focus on PwD's verbal and nonverbal cues as an indication of their preferences and challenges in social sharing, providing insight into the effects of the multimedia and multisensory materials as prompts for social sharing. We conduct **thematic analysis** on the interview transcripts and observational field texts [2].

On the basis of the fieldwork findings, we will carry out **user-centered design** with PwD and caregivers. An iteration of design and testing will include prototyping, observing participants' interaction with the prototypes, conducting further interviews as needed, developing a suitable platform, and running usability tests. We will integrate testing and feedback into every stage to allow for timely adjustments. Once the platform is developed, we will run an **empirical evaluation** involving users to assess its effectiveness in promoting social interaction. After a period of deployment, we will collect system log data to statistically analyze its usage. We will also combine interviews with scales and questionnaires to concretely establish the usefulness of our platform.

## PRELIMINARY FINDINGS

As of the end of July 2019, we have completed 5 dyad interviews, 3 individual caregiver interviews, 4 facilitator

interviews, and 8 observation sessions. The initial findings from our observations and facilitator interviews highlight the strengths of a normalized environment in which PwD can engage in spontaneous or unsupervised communications in a public venue. Without dementia being mentioned, PwD enjoy sharing travel experiences, life stories, news, knowledge, and humour. It is often a collaborative working and mutual learning process to explore a country's nature, culture, fun facts, and cuisines, with well-received large prints of images and maps, music and videos, and themed food and objects. Facilitators manage to bond with PwD and build upon previously told stories to discover new layers of experiences, turning repetitions into opportunities. Due to limited resources and number of facilitators, the program has a waitlist for participants. Interactive technologies could help relieve some facilitation burdens, and, additionally, offer more activities and richer materials that can make the program more engaging and successful.

We expect to find that collaborative and inclusive applications will engage PwD and caregivers by respecting the roles of both storytellers and listeners and inviting everyone to become a contributor. We will support both one-on-one and group discussions and mobilize multimedia and multisensory materials to promote interaction and social sharing. We will explore artefacts and tangible user interfaces (e.g., 3D-printed items, interactive maps or videos, and touch projectors) to offer more engaging prompts than paper-based materials. Such digital toolkits can be widely used in both private and public settings, expanding the existing limited number of 'suitcase' kits on loan from the library for family gatherings and residential facilities.

## CONTRIBUTIONS

This research will probe storytelling as a form of social sharing and characterize PwD's sharing and socializing with each other in a group setting. The developed person-centered, socialization-enabled platform could find widespread use for PwD as an aid to stimulating their memories, enhancing self-esteem, and improving social interaction. The implementation of our platform has a strong potential to enhance the quality of life for both PwD and caregivers, as well as advance the system design guidelines and evaluation methods relevant to PwD. Further developing the established collaborations with our organizational partners (the Alzheimer Society of Montreal and the Westmount Public Library), we will actively communicate our findings to bridge accessibility research, community outreach, and caregiving practice.

The doctoral candidate is in the third year of the PhD program and is hoping to receive feedback on better interpreting the fieldwork findings and translating the knowledge into the upcoming design. She also looks forward to refining the initial design ideas.

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