Enriching Social Sharing for the Dementia Community: Technological Opportunities

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For my maternal grandparents who braved years of dementia and caregiving despite their lack of access to the community supports described in this thesis.

Abstract

Dementia affects cognition, behaviour, and physical ability, posing serious challenges for maintaining active social interactions. Community-based activities are well-positioned to leverage the strengths and capacities of people with dementia and support social inclusion. A growing body of human-computer interaction (HCI) research is exploring technological opportunities for social activities at home and care facilities; however, comparatively less work has focused on community settings. This thesis helps fill this critical gap in HCI research on supporting community-based social sharing for people with dementia, both in-person and virtual. Through on-site fieldwork, virtual fieldwork, and methodological self-reflection, this thesis makes empirical contributions to dementia-related HCI research, as well as methodological contributions to HCI research in dementia and broader accessibility settings.

Situating our on-site fieldwork in Tales & Travels, a storytelling and socializing program in the Montreal dementia community, we interviewed dyads of people living with early-middle stage dementia and their primary family caregivers, individual caregivers, and Tales & Travels facilitators (librarians and Alzheimer Society coordinators). Concurrently, we observed Tales & Travels sessions. Through thematic analysis on the interview transcripts and observation notes, this work identifies factors that aid in achieving positive outcomes and proposes new avenues for social technologies to diversify the range of social spaces in community settings.

Building upon our on-site fieldwork, our virtual fieldwork investigates remote social activities explored by the same community in response to the impacts of the COVID-19 pandemic. We conducted follow-up interviews with a subset of caregivers and facilitators who participated in our previous study. Then, we reflected on our volunteering and facilitation experience at virtual Tales & Travels. Through thematic analysis on the interview transcripts and reflexive facilitation notes, this work deepens the understanding of virtual social sharing for the dementia community and proposes new avenues for reimagining community social spaces, affirming agency in people with dementia and caregivers, and diversifying HCI support across communities.

Critically reflecting on our on-site fieldwork, we re-analyzed our interview transcripts and observation notes, as well as the process of study design, data collection, and data analysis. We examined how we succeeded and failed to capture the perspective of people with dementia while involving proxies (i.e., caregivers and facilitators). Through qualitative content analysis, this work contributes practical approaches to effective inclusion of proxy stakeholders in qualitative HCI work in sensitive settings. We further propose a set of guidelines recommending 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.

Résumé

La démence affecte la cognition, le comportement et les capacités physiques, ce qui pose de sérieux problèmes pour le maintien d'interactions sociales actives. Les activités communautaires sont bien placées pour tirer parti des forces et des capacités des personnes atteintes de démence et pour favoriser leur inclusion sociale. Alors que la recherche sur l'interaction personne-machine (IPM) explore de plus en plus les possibilités technologiques permettant aux activités sociales de se dérouler à domicile et dans les établissements de soins, les travaux portant sur l'IPM dans les milieux communautaires sont plutôt rares. Cette thèse contribue à combler cette lacune importante de la recherche sur l'IPM en se penchant sur le partage social communautaire, en présentiel et en virtuel, pour les personnes atteintes de démence. Grâce à un travail sur place et en virtuel et à l'autoréflexion méthodologique, cette thèse apporte des contributions empiriques et méthodologiques à la recherche sur les IPM dans les contextes de démence et d'accessibilité élargie.

En situant notre recherche sur le terrain de Contes et voyages, un programme de contes et de socialisation pour la communauté montréalaise de personnes atteintes de démence, nous avons interrogé des personnes atteintes de démence au stade intermédiaire, des aidants naturels et des animateurs de Contes et voyages (bibliothécaires et coordonnateurs de la Société Alzheimer). Parallèlement, nous avons observé les séances de Contes et voyages. Grâce à une analyse thématique de nos notes d'observation et transcriptions d'entrevues, nous avons identifié les facteurs qui aident à obtenir des résultats positifs et proposons de nouvelles voies pour les technologies sociales afin de diversifier l'éventail d'espaces sociaux dans les communautés.

Notre recherche virtuelle, qui s'appuie sur notre recherche sur le terrain, porte sur les activités sociales à distance explorées par la même communauté en réponse à la pandémie de COVID-19. Nous avons mené des entrevues de suivi avec un sous-ensemble d'aidants et d'animateurs ayant participé à notre première étude. Nous avons ensuite réfléchi à notre expérience de bénévolat et de facilitation dans le cadre de Contes et voyages. Grâce à l'analyse thématique des transcriptions des entrevues et des notes de facilitation réflexives, ce travail approfondit la compréhension du partage social virtuel pour la communauté de personnes atteintes de démence et propose de nouvelles voies pour réinventer les espaces sociaux communautaires, affirmer l'autonomie des personnes atteintes de démence et des aidants naturels, et diversifier le soutien offert via les IPM entre différentes communautés.

En réfléchissant de façon critique à notre travail sur le terrain, nous avons réanalysé nos transcriptions d'entrevues et nos notes d'observation, ainsi que le processus de conception de l'étude, de collecte des données et d'analyse des données. Nous avons examiné comment nous avons réussi et échoué à capturer la perspective des personnes atteintes de démence tout en impliquant des mandataires (c'est-à-dire des soignants et des facilitateurs). Grâce à l'analyse qualitative du contenu, ce travail suggère des approches pratiques pour inclure efficacement des parties prenantes dans le travail qualitatif d'IPM dans des contextes sensibles. Nous proposons également un ensemble de lignes directrices recommandant 1) un engagement élargi avec la communauté et une conception de recherche à facettes multiples dans les travaux préliminaires; 2) des milieux de recherche ouverts et flexibles, la gestion de et l'intervention dans les dynamiques de pouvoir, et la communication verbale et non verbale dans la collecte de données; et 3) la sensibilisation aux voix déséquilibrées et à la triangulation entre les sources dans l'analyse des données.

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I am profoundly grateful to my supervisor, Dr Karyn Moffatt, a passionate and exemplary scholar whose work and lectures inspired me to take this academic journey. She provided the academic freedom that every PhD student dreams of while shaping my research skills through concrete, actionable guidance. She always offers timely and insightful feedback, encouraging me to explore research directions with confidence and security, even when I am in doubt. She has been my rock, supportive with no reservations, through thick and thin. With her expertise and warm heart, she has mentored me through trying moments, academic and personal. Everything I have achieved I owe to Dr Moffatt. Our journey together has truly been a privilege.

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Finally, I thank my parents for their indulgence.

Contribution to original knowledge

This thesis makes empirical and methodological contributions to three main areas in human-computer interaction (HCI):

- Empirical contributions to dementia-related HCI work in in-person settings:

This work identifies four factors that aid in achieving positive outcomes in community-based social programs for people with dementia: effective agencies for social interaction, normalized and friendly environments, collaboration and teamwork, and mediating social cues and communication.

This work offers insights for designing new social technologies to diversify the range of social spaces in community settings. We propose to expand peer collaboration and leverage physical and virtual spaces. We call for creating dynamic experiences through richer content, more open-ended structures, synchronized creating and sharing processes, and more diversified participant roles. We further suggest developing more flexible social platforms to offer person-centered yet inclusive activities.

- Empirical contributions to dementia-related HCI work in virtual settings:

This work expands design opportunities to virtual social sharing for the dementia community. We uncover complexities in virtual social engagements in terms of more challenging social lives with more complicated caregiving situations, as well as individual resilience and collective support in the dementia community. We reveal the positive and negative roles of technology in the much-needed online activities, highlighting the corresponding additional demands on caregiver support. We offer new insights into re-building social experiences as a virtual community, such as leveraging physical objects and environments, enhancing open and flexible experiences, and expanding collaborative space.

This work proposes to reimagine community social spaces, deepening the understanding of placemaking in physical/virtual and public/private environments. We suggest affirming agency in people with dementia by creating collaborative group dynamics and supporting active in-the-moment sharing. We call for promoting agency in caregivers through their extended collaborator roles in the new virtual contexts of social experiences. We further discuss diversifying HCI support across communities and stakeholders by developing collaborative approaches, attending to usability, security, and privacy, and building specialized prompting systems.

- Methodological contributions to HCI work in accessibility settings:

This work contributes practical approaches to effective inclusion of proxy stakeholders in qualitative HCI work in sensitive settings such as dementia care. The key strategies include 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.

This work further proposes a set of guidelines for better engaging participants by

effectively involving proxies. These guidelines recommend 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. These guidelines can benefit researchers and practitioners working with vulnerable populations, leading to further discussion and critique to strengthen and improve research practices in the domain of dementia care.

Contribution of Authors

All the research reported in this thesis has been published. Chapter 3 has been published in the Proceedings of the 2020 ACM CHI Conference on Human Factors in Computing Systems;[1] Chapter 4 has been published in the ACM Transactions on Accessible Computing;[2] Chapter 5 has been published in the Proceedings of the 2021 ACM CHI Conference on Human Factors in Computing Systems.[3]

I, Jiamin Dai, am the primary author in all the above published manuscripts forming Chapters 3, 4, and 5. For each manuscript, I was responsible for the idealization, research design, data collection, and qualitative analysis. I wrote all sections of all the manuscripts.

Dr Karyn Moffatt, as my supervisor, provided high-level guidance across all stages of the research behind all three manuscripts. She directed me through the conceptualization and design of the studies and gave critical, timely feedback to my questions along the way. She was actively involved in the regular debriefs during my on-site and virtual fieldwork, as well as the interpretation of the data throughout the data analysis process. She reviewed all the drafts as they were evolving and offered valuable insights.

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[1] Jiamin Dai and Karyn Moffatt. 2020. Making space for social sharing: Insights from a community-based social group for people with dementia. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*, ACM, 1–13. https://doi.org/10.1145/3313831.3376133.

[2] Chapter 4 is a preprint version of the article published in the ACM Transactions on Accessible Computing which was accepted with minor revisions following the initial submission of this thesis: Jiamin Dai and Karyn Moffatt. 2023. Enriching social sharing for the dementia community: Insights from in-person and online social programs. *ACM Transactions on Accessible Computing* 16, 1 (2023), 1–33. https://doi.org/10.1145/3582558.

[3] Jiamin Dai and Karyn Moffatt. 2021. Surfacing the voices of people with dementia: Strategies for effective inclusion of proxy stakeholders in qualitative research. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*, ACM, 1–13. https://doi.org/10.1145/3411764.3445756.

As collaborative manuscripts, Chapters 3, 4, and 5 are written in the voice of first-person plural. Although I am the sole author of Chapters 1, 2, 6, and 7, the first-person plural is used throughout the thesis for consistency.

Contents

List of Tables

List of Acronyms

AAC: Augmentative and Alternative Communication

AI: Artificial Intelligence

CSCW: Computer-Supported Cooperative Work

HCI: Human-Computer Interaction

LIS: Library and Information Science

Chapter 1

Introduction

This research explores technological opportunities to better support community-based social sharing in dementia care. It examines both in-person and virtual social settings, followed by methodological considerations for involving proxy stakeholders in human-computer interaction (HCI) research.

1.1 Motivation

1.1.1 Community settings

This research conceptualizes the *dementia community* as a group of people affected by dementia and those working in dementia-related areas within a larger society. It encompasses people with dementia, along with their families and friends, and a diverse group of professionals who provide care and facilitate activities. The social experiences in community activities often include various above members as stakeholders.

Dementia affects cognition, behaviour, and physical ability [1], but perceptions of self or identity have been found persistent throughout the course of dementia [2] and personhood has been highlighted in dementia care [9]. In addition to the universal need for social interaction [11], social elements are prominent among the recognized non-pharmacological interventions (e.g., art therapy and cognitive stimulation) in dementia [6]. Indeed, social relationships have been identified as an essential component of health-related quality of life for people with dementia and their families [16], 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. People with dementia and their families often wish to remain in their own homes as much as possible, rather than relocating to care facilities. Government directives, such as those proposed by the Public Health Agency of Canada [14], have encouraged these interests by providing healthcare-related services that meet daily needs at home and create socialization opportunities and stimulating activities in the broader community.

Community settings can provide the familiarity of the social and physical environment, which has been found to promote involvement in activities and a sense of continuity for people with dementia, benefiting their personhood and quality of life [13]. Community social programs have proven effective in engaging individuals with dementia both socially and cognitively and improving caregivers' perceptions about people with dementia [15]. Organizations with close ties to local communities (e.g., public libraries) endeavour to meet the rising needs for dementia-related social initiatives and services [4]. Given these well-documented needs and benefits, community-based approaches are well-positioned to leverage the strengths and capacities of people with dementia in public space to support social inclusion [17].[1]

1.1.2 HCI opportunities

HCI research has explored new technological tools designed for the dementia community. A wide range of technologies have been mobilized to support various aspects of dementia care, e.g., from locator devices [12] to virtual reality exergames [7]. A branch of HCI research has explored digital tools for social sharing[2] within families and care facilities. For example, personalized ambient displays have been developed for reminiscence and conversations among family members [3]; print media devices have been built to prompt quizzes for interactive group activities in care homes [5]. However, comparatively less HCI work has considered community settings, thus missing opportunities for designing new community-based social technologies for dementia care.

In addition to in-person social activities, the needs and challenges of virtual settings have been highlighted by the prolonged physical distancing measures due to the COVID-19 pandemic. In co-located community contexts, emerging social programs in cultural establishments such as libraries (e.g., [4]) and museums (e.g., [8]) have proven effective in

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[1] More successes of community-based approaches are reviewed in Chapter 2 (2.5.3 Community-based HCI research).

[2] Social sharing: "sharing for the purpose of communicating with social contacts and fulfilling relational goals" [10].

creating positive experiences for both people with dementia and their caregivers. However, comparatively little work has focused on the design of community-based social technologies for virtual settings.

These gaps and emerging challenges motivate our fieldwork in the dementia community, the on-site followed by the virtual, to identify opportunities for technology design. Our motivations for studying community and online settings echo the Alzheimer's Association's most recent call for better supporting families living with dementia through community-based long-term programs while recognizing technological and accessibility challenges during the transition to remote care delivery [1]. The current technological toolbox has not yet reached its full potential for improving the quality of life for families living with dementia. A better understanding of how to provide in-person and online community-based 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. The pandemic has heightened recent demands on, and shifts to, virtual socialization, but the valuable insights from these new community initiatives can benefit HCI research and practice in the long run, integrating co-located and virtual activities and exploring holistic social computing approaches to enriching social sharing in the dementia context.

In the context of dementia care, scholarly and professional fieldwork increasingly involves multiple stakeholders and incorporates 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 of stakeholders is currently lacking. This gap in research and practice motivates a self-reflexive analysis of our methods and fieldwork data so that the lessons of our successes and setbacks can help advance HCI practices for both academics and information professionals. To that end, valuable empirical and methodological insights can be gained from a nuanced understanding of how people with dementia successfully interact with others and with multisensory materials in a community setting.

1.2 Research Context

The present thesis research examines broader social experiences and one community program, Tales & Travels (adapted from [15]). We hereby briefly introduce the program and its evolution throughout our fieldwork to provide an overview of our research context.

Tales & Travels is a storytelling-oriented social program for people with dementia (usually in the early to middle stages) at the Westmount Public Library[3] in greater Montreal, Canada, in collaboration with the Alzheimer Society of Montreal. It 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.

Tales & Travels was a physically co-located series before the COVID-19 pandemic. Our

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[3] https://westlib.org/iguana/www.main.cls

onsite fieldwork, conducted in 2019, involved non-intrusive observations of Tales & Travels and 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).

Due to the pandemic, in-person Tales & Travels has been paused since March 2020. Since February 2021, it has been offered in an adapted online format. Our virtual follow-up study, conducted in 2020 and 2021, involved online interviewing a subset of caregivers and facilitators who participated in the original fieldwork, followed by reflecting on volunteering and facilitation experiences at virtual Tales & Travels.

1.3 Thesis Goals

This thesis pursues three goals (G1–G3), with two to three research questions (RQs) per goal, through three manuscripts published at top HCI venues.

The first manuscript (Chapter 3) explores the first thesis goal through on-site fieldwork:

G1: To identify opportunities and barriers for technologies that meet the needs of people with dementia in community-based social sharing in in-person settings.

- G1-RQ1: What challenges do people with dementia encounter when sharing stories and socializing within a small group in a community setting?

- G1-RQ2: What materials and prompts are effective in supporting people with dementia in social sharing in this setting?

The second manuscript (Chapter 4) explores the second thesis goal through virtual fieldwork:

G2: To identify opportunities and barriers for technologies that meet the needs of people with dementia in community-based social sharing in virtual settings.

- G2-RQ1: What are the emerging challenges in virtual social engagements for the dementia community from the perspectives of caregivers and professionals?
- G2-RQ2: What strategies and materials are effective in supporting the dementia community in virtual social engagements?
- G2-RQ3: What usability features of the technological tools enable or hinder virtual social engagements for the dementia community?

The third manuscript (Chapter 5) explores the third thesis goal through methodological self-reflection:

G3: To reflect and provide methodological guidance for qualitative work in dementia settings.

- G3-RQ1: How did we, as researchers, balance power dynamics among stakeholders and ensure that the voices of people with dementia are heard and prioritized?

- G3-RQ2: How might we improve this practice in future projects?

1.4 Thesis Outline

The remaining chapters of this thesis are structured as follows:

Chapter 2 presents background information about dementia care and related HCI work for dementia care through a comprehensive literature review.

Chapter 3 explores avenues for designing new technologies for in-person social sharing through on-site fieldwork.

Chapter 4 investigates opportunities for designing new technologies for remote social sharing through virtual fieldwork.

Chapter 5 focuses on methodological lessons from the fieldwork through self-reflexive analyses.

The "**Preface**" sections of Chapters 3, 4, and 5 present bridging texts that explain how each manuscript relates to others and fit within the bigger picture of the thesis research.

Chapter 6 consolidates common threads from previous chapters, discusses limitations and directions for future work, and offers additional reflections.

Chapter 7 summarizes the thesis research and highlights its contributions.

Appendices A–B provide the list of publications and copyright information.

Appendices C–F provide supplementary materials including ethics approvals, consent forms, interview guides, and observation guides.

Bibliography

[1] Alzheimer's Association. 2022. 2022 Alzheimer's disease facts and figures. *Alzheimer's & Dementia* 18, 4 (Apr. 2022), 700–789. `https://doi.org/10.1002/alz.12638`

[2] Lisa S Caddell and Linda Clare. 2010. The impact of dementia on self and identity: A systematic review. *Clinical psychology review* 30, 1 (2010), 113–126. `https://doi.org/10.1016/j.cpr.2009.10.003`

[3] Masashi Crete-Nishihata, Ronald M. Baecker, Michael Massimi, Deborah Ptak, Rachelle Campigotto, Liam D. Kaufman, Adam M. Brickman, Gary R. Turner, Joshua R. Steinerman, and Sandra E. Black. 2012. Reconstructing the Past: Personal Memory Technologies Are Not Just Personal and Not Just for Memory. *Human–Computer Interaction* 27, 1-2 (Apr. 2012), 92–123. `https://doi.org/10.1080/07370024.2012.656062`

[4] Timothy J Dickey. 2020. Programming for Dementia and Dementia Caregivers. In *Library Dementia Services*. Emerald Publishing Limited. `https://doi.org/10.1108/978-1-83867-691-920201006`

[5] Sarah Foley, Daniel Welsh, Nadia Pantidi, Kellie Morrissey, Tom Nappey, and John McCarthy. 2019. Printer Pals: Experience-Centered Design to Support Agency for People with Dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 1–13. `https://doi.org/10.1145/3290605.3300634`

[6] Serge Gauthier, Claire Webster, Stijn Servaes, José A Morais, and Pedro Rosa-Neto. 2022. World Alzheimer Report 2022-Life after diagnosis:Navigating treatment, care and support. (2022). `https://www.alzint.org/u/World-Alzheimer-Report-2022.pdf`

[7] Sukran Karaosmanoglu, Sebastian Rings, Lucie Kruse, Christian Stein, and Frank Steinicke. 2021. Lessons learned from a human-centered design of an immersive exergame for people with dementia. *Proceedings of the ACM on Human-Computer Interaction* 5, CHI PLAY (2021), 1–27. `https://doi.org/10.1145/3474679`

[8] Debbie Kinsey, Iain Lang, Noreen Orr, Rob Anderson, and Daisy Parker. 2021. The impact of including carers in museum programmes for people with dementia: a realist review. *Arts & Health* 13, 1 (2021), 1–19. `https://doi.org/10.1080/17533015.2019.1700536`

[9] Pia C Kontos. 2005. Embodied selfhood in Alzheimer's disease: Rethinking person-centred care. *Dementia* 4, 4 (2005), 553–570. `https://doi.org/10.1177/1471301205058311`

[10] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. Supporting People with Dementia in Digital Social Sharing. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (Denver, Colorado, USA) *(CHI '17)*. Association for Computing Machinery, New York, NY, USA, 2149–2162. `https://doi.org/10.1145/3025453.3025586`

[11] David G Myers. 2003. Close relationships and quality of life. *Well-being: Foundations of hedonic psychology* (2003), 374–391.

[12] Noelannah Neubauer, Christa Spenrath, Serrina Philip, Christine Daum, Lili Liu, and Antonio Miguel-Cruz. 2022. Identifying adoption and usability factors of locator devices for persons living with dementia. *Dementia* 21, 3 (2022), 862–881. `https://doi.org/10.1177/14713012211065381`

[13] Alison Phinney, Habib Chaudhury, and Deborah L O'connor. 2007. Doing as much as I can do: The meaning of activity for people with dementia. *Aging and Mental Health* 11, 4 (2007), 384–393. `https://doi.org/10.1080/13607860601086470`

[14] Public Health Agency of Canada. 2021. A Dementia Strategy for Canada: Together We Achieve - 2021 Annual Report.

[15] Mary Beth Riedner, Karen Maki, and Miriam Lytle. 2018. Becoming a dementia-friendly library. In *The Relevant Library: Essays on Adapting to Changing Needs*, Carol Smallwood Vera Gubnitskaia (Ed.). McFarland, Jefferson, NC, 187–194.

[16] Sarah C Smith, Joanna Murray, Sube Banerjee, Beth Foley, Joanna C Cook, Donna L Lamping, Martin Prince, Rowan H Harwood, Enid Levin, and Anthony Mann. 2005. What constitutes health-related quality of life in dementia? Development of a conceptual framework for people with dementia and their carers. *International Journal of Geriatric Psychiatry: A journal of the psychiatry of late life and allied sciences* 20, 9 (2005), 889–895. `https://doi.org/10.1002/gps.1374`

[17] Jodi Sturge, Mirjam Klaassens, C Allyson Jones, France Légaré, Marie Elf, Gerd Weitkamp, and Louise Meijering. 2021. Exploring assets of people with memory problems and dementia in public space: A qualitative study. *Wellbeing, Space and Society* 2 (2021), 9. `https://doi.org/10.1016/j.wss.2021.100063`

Chapter 2

Background and Related Work

This literature review chapter lays the foundation of our work by exploring broad care and HCI contexts for designing social technologies for people with dementia. First, an overview of dementia care foreshadows the needs and challenges for designing digital technologies in dementia contexts, followed by an examination of HCI efforts for improving the quality of families living with dementia and three conceptual frameworks. Then, we delve deep into HCI work for empowering people with dementia in social activities, involving other stakeholders in the research and design process. Finally, we discuss methodological consideration in dementia-related HCI work, in particular researcher reflexivity and community-based research.

2.1 Overview of Dementia Care

Dementia is a group of syndromes characterized by difficulties with memory, language, and other cognitive skills, impairing a person's ability to perform everyday activities. Alzheimer's disease is the most common cause of dementia, accounting for 60-80% of cases. Early symptoms include difficulties in remembering recent conversations, names, or events, as well as apathy and depression. Its progression leads to impaired communication, disorientation, confusion, poor judgment, behaviour changes, and difficulties in speaking, swallowing, and walking. Other common causes include cerebrovascular disease, Lewy body disease, frontotemporal lobar degeneration, Parkinson's disease, hippocampal sclerosis, and mixed pathologies. Mild cognitive impairment, demonstrated by a noticeable yet measurable decline in thinking abilities, is a potential precursor to dementia [3].

With an aging population in many parts of the world, chronic and progressive syndromes such as dementia are affecting increasing numbers of people. The number of people with dementia worldwide is projected to increase from 57.4 million in 2019 to 152.8 million in 2050 [87]. Currently, no treatment is available to cure dementia or alter its progressive course, and dementia is one of the major causes of older adults' disability and dependency. The impact of dementia is overwhelming for both people with dementia and their families [121]. As a result, dementia care has become an emerging healthcare issue in many countries.

Dementia care requires considerable monetary and caregiving resources. For example, in the United States, the total healthcare cost for people with dementia is estimated to reach US$321 billion in 2022, in addition to the US$271.6 billion of unpaid caregiving provided by families and friends [3]. The Alzheimer Society of Canada details the need for care in its most recent report [2]: family members and friends of people with dementia provide 26 hours of care per week on average in Canada. An estimated 350,000 informal caregivers provide 470 million hours of care in a year, which equals 235,000 unpaid full-time jobs. Common areas of care include assistance with everyday activities, support for medical care, accommodating changes in mood, personality, and behaviour, and providing psychological support, companionship, and advocacy.

Communicating with and caring for people with dementia takes a lot of effort and requires a learning curve. Each individual with dementia has a unique personality, preferred ways of communication, various responsive behaviours, and different remaining abilities depending on which parts of the brain are affected. Taking into account various cultural and social contexts, we do not have one model fits all in dementia care, and person-centered care has become a widely recognized approach. Meanwhile, family caregivers, typically the spouse or adult children, are more and more likely to become older adults themselves due to the aging of the population, often overburdened or less familiar with technology. These characteristics of dementia care pose a wide range of challenges for designing digital technologies for in dementia contexts, which will be elaborated with a focus on HCI literature in the following sections.

2.2 HCI Challenges and Frameworks

2.2.1 Improving quality of life

Digital technologies can improve the quality of life for people with dementia in various aspects, such as helping with their complex communication needs and engaging them in enjoyable activities. The World Health Organization defines quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."[1] Quality of life for older adults with cognitive impairment is a multidimensional and subjective concept, and various frameworks and instruments have identified the key factors in play. For example, a conceptual framework for health-related quality of life in dementia identified five domains: daily activities and looking after yourself, health and wellbeing, cognitive functioning, social relationships, and self-concept [101]. Similarly, the Quality of Life in Alzheimer's Disease (QOL-AD) questionnaire invites people with dementia and family members to assess (by assigning a value of "poor", "fair", "good", or "excellent") 13 aspects of their life, including physical health, energy, mood, living situation, memory, family, marriage, friends, self as a whole, ability to do chores around the house, ability to do things for fun, money, and life as a whole [71].

As dementia's progression could not be altered, designing technologies for people with dementia is not about improving their physical or cognitive scores. Instead, the focus is on

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[1] https://www.who.int/tools/whoqol

the perceived psychosocial effects, with improved quality of life as a primary outcome (e.g., [88]). Assessing the quality of life outcomes of assistive technologies in dementia is an evolving topic, and the need for such evaluation frameworks has caught researchers' attention [91].

Enhancing quality of life for dementia caregivers is another focus for technology design. Prior work has engaged caregivers in meaningful dialogues and other activities with people with dementia, which benefits caregiving routines and caregivers' feelings. For example, personal memory technologies could support families in telling their life stories and thus strengthen interpersonal relationships between people with dementia and family members [21]. Current digital tools are found to help relieve some caregiving burdens in various ways. Conversation aids such as CIRCA[2] could make it easier for caregivers to facilitate a shared interaction with people with dementia, no need for caregivers to prompt one question after another to keep the conversation going [6]. When people with dementia are able to engage with the devices or applications unsupervised, technologies could provide caregivers with some reprieve from the constant care and attention (e.g., [69]).

Take for example, the wide factors identified in the previously mentioned quality of life in dementia framework [101]. Facilitating communication and social interaction for people with dementia has been a focus in HCI research. Many projects also share a common devotion to assisting them in getting around and maintaining their sense of independence.

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[2] "CIRCA is a multimedia computer system developed to support and promote communication between people with dementia and caregivers" through "a broad range of stimuli to prompt reminiscing among people with dementia, both in group and one-to-one sessions" [6].

When helping people with dementia enjoy life and connect with people, prior work has emphasized their safety and self-esteem. Except for getting around, the majority of daily activities are less supported. Assistive technologies have been developed for daily routines, e.g., automatic task assistance in brushing teeth and washing hands for people with cognitive impairments [42, 93]. These projects have focused on artificial intelligence (AI) challenges such as sensors and decision processes, instead of interface issues. As it has a positive impact on people with dementia to maintain a sense of normality and keep up appearances [101], these everyday routines are worth investigating further. By facilitating such daily tasks as eating, shopping, housekeeping, and keeping personal hygiene, the design outcomes could help to improve the autonomy and sense of independence for people with dementia, in turn reducing the caregiver burden.

The quality of life in dementia framework points to another research challenge related to the emotions and the mental status of people with dementia, increasing positive feelings while reducing the negative ones. People with dementia value emotions as part of their wellbeing, but they might have to express their feelings in a concrete way of describing activities they enjoyed [101]. Therefore, it requires creative thinking and a keen eye to capture these subtle feelings in future study design, field observation, and data analysis. For example, a preliminary study on developing a smartwatch prototype for evaluating the emotional responses of people with dementia is a good start in this direction [48]. Overall, HCI researchers have focused on participants' positive memories and feelings, instead of asking for right or wrong answers or the correct recollections. Not all memories are pleasant, and reminiscence materials have been carefully chosen to avoid triggering distress [65]. One of the reasons why the CIRCA systems use generic prompts is to avoid possible frustration or tension when people with dementia fail to recognize personal items [31].

Echoing the framework, personhood and autonomy rise from HCI discussions together with safety and independence, while technology could step in to balance the conflicts between those components [70, 73]. The privacy and ethical issues of involving this vulnerable user group are noticed and respected. The case studies situated in the context of art therapy have expanded the horizons of designing for dementia by promoting entertaining, creative, and aesthetically-pleasing activities. These papers contribute to understanding the complex nature of sharing for people with dementia, designing novel and customizable tools for art therapy sessions, exploring a model of empathy and empowerment, and reflecting on epistemological perspectives for dementia and design [20, 42, 59, 62, 63]. Creativity has been approached differently by exploring how to support creative thinking and problem solving by caregivers through a mobile application from the angle of providing novel care in residential homes [123].

2.2.2 Considerations for technology use and participant access

Therapeutic and assistive technologies mobilize people with dementia's remaining abilities, and technology design for people with dementia needs to build upon their current technological abilities and preferences. A possible oversight might come from the assumption that people with dementia do not use technology at all. In fact, individuals with cognitive impairment are engaging in various devices and activities such as iPads, iPhones, Kindles, social media, photos, videos, and games [73]. As everyday technology adoption evolves, we could anticipate more people with dementia being comfortable with digital technologies as they might already be exposed to these tools before their cognitive impairment.

Previous work has investigated participants' everyday technology use, including home appliances such as remote controls and microwave ovens, but not specifically digital technologies. Family caregivers see the technology in daily activities as a means to exercise people with dementia's retained abilities, asking for flexible technology to be integrated into existing habits [98]. Regarding computer use, people with dementia usually require technical assistance and tailored computer activities appropriate to their needs and functioning [107]. In general, participants' technology use data has been collected at small scales in different studies to provide background or baseline information.

The uniqueness of dementia context requires researchers build a profound understanding of users and engage in direct interaction with people with dementia and caregivers, but access to participants is another challenge. It would be difficult to recruit dozens of participants for a single study as people with dementia are restricted by various impairment and caregivers are overwhelmed by caregiving workloads. In the course of a study, participants might have to drop out due to reasons beyond their control, including the progression of dementia making participants no longer fit for the project, people with dementia moving from home to care facilities or moving from one facility to another, and changes in people with dementia's family situations (e.g., [60]). Recruitment difficulties might also be caused by the study's narrow inclusion criteria, e.g., looking for participants with cognitive impairment but able to engage in lengthy discussions and still living at home instead of care facilities (e.g., [73]).

2.2.3 Conceptual frameworks

The three waves or paradigms of HCI drive design from different perspectives. The first paradigm emphasizes human factors to optimize the interaction between humans and machines. The second paradigm focuses on cognition and information processing, abstracting a real-world phenomenon or problem to form a general model. The third paradigm views interaction as phenomenologically situated, aiming to support situated action and meaning-making in specific contexts [38]. Aligning with the third-wave HCI, assistive technology research increasingly focuses on empowering people with diverse accessibility needs through frameworks such as *critical dementia*, *technology narrative*, and *interdependence for assistive technology design* that help reposition research approaches to designing for and with people living with various impairments.

Critical dementia

Critical dementia positions people with dementia as competent, engaged, and capable of expressing themselves meaningfully. It inspires new design directions and helps researchers engage with people with dementia in an empathic and empowering way, encouraging their perspective, creativity, engagement, and rich emotional expression. It reframes dementia through interactive technology and resonates with the epistemological shifts in HCI [62].

The key perspectives of critical dementia (e.g., context, embodiment, and experiences) have resonated with a wide range of research and design projects. Researchers have explored various technical interventions (e.g., art-making and storytelling tools) to put actions into context, rebuilding them from just individual activities to social or family events. Such systems aim to provide a friendly space and a pleasant experience for people with dementia to engage as they wish and to socialize with family and friends locally or remotely (e.g., [59, 119, 122]). People with dementia have been competent contributors in building the systems such as creating virtual environments from their life experiences and to their field of view [39]. Researchers have interpreted participants' interactions with technologies in contexts, e.g., making sense of the digital jewellery probes and the participants' personhood and relationships [116] and co-creating art pieces from furniture to bring a home-like feeling in a hospital setting [115]. Non-verbal indicators such as pointing to draw attention, singing, laughter, and direction of eye gaze have caught researchers' attention in conversation aid research [6]. Movements such as touching, holding, and giving have been discussed as expressions for intimacy or connection in studying prompts during music sessions [80]. Multimedia materials have been explored to enhance multisensory experiences, e.g., an in-home ambient multimedia display cycling through personal music, photographs, movies, and narratives creates an occasion for families to remember and benefits their relationships and communication [75]. A touchscreen computer offering similarly rich personal multimedia materials highlights using the voices of loved ones to make announcements and recount stories [52].

Meanwhile, critical dementia reveals some limitations of current research, including the emerging challenges of personalization, updating, and sharing. Social sharing has emerged as a context for design, but very few systems are designed for social sharing [63]. A digital technological tool could become a "common artefact" to be shared within families living with dementia, encouraging shared interaction and participation of multiple users. The design may bring together technologies, experiences, and users across domains, allowing people to participate, make meaning, create stories and interactions, and develop their personalized use of the system [9].

Technology narrative

Technology narrative aims to understand the lived experiences of people with cognitive impairments and emphasize the enjoyment of life with technological support over traditional narratives of suffering from impairments (i.e., the illness narrative). It could serve as a model for framing the design of home-based technology, especially for those with cognitive impairment and their family caregivers [73].

Researchers have investigated the full picture of living with dementia in the design process, not only about the difficulties caused by dementia but also about finding pleasure. The case studies situated in art therapy have addressed this by promoting entertaining, creative, and aesthetically-pleasing activities (e.g., [20, 43, 59]). Instead of playing a mere supporting role, technology could become an integral part of an engaging and enjoyable interaction. For example, CIRCA supports easy maintenance and engaging interaction and provides the opportunities for people with dementia to choose, control, and become an equal part of the interaction [6, 92]. Producing digital stories in the form of short films in workshops has offered people with dementia an enjoyable and creative experience that fosters a sense of accomplishment [89]. Positioning people with dementia as storytellers and advice givers, a mobile application providing media cues about life stories could potentially prompt and maintain conversations among family members while bridging intergenerational communication gaps between people with dementia and their grandchildren [119].

Technology narrative sheds lights on opportunities to shape greater relationship support for care recipients and caregivers through mutually supportive technologies. Specifically, it calls for further attention on how to mitigate the conflicts between autonomy and safety [73]. As cognitive impairment changes the relationship between people with dementia and their caregivers, compromises are often unavoidable. When caregivers try to look after their loved ones every step of the way and keep them safe every hour of the day, it often costs the autonomy of both parties. In developing a personally tailored digital aid to facilitate safe walking, some researchers have demonstrated the possibility of designing digital technologies to provide tracking and emergency alarm functions while protecting the feelings and sense of identity of people with dementia [70]. Technology has the potential to balance the senses of independence and security and support the autonomy of both care recipients and caregivers, but more details are to be uncovered.

Interdependence for assistive technology design

In broader accessibility contexts, the *interdependence for assistive technology design* framework advances the traditional goal of independence in assistive technologies, which aims at bridging the perceived gaps caused by disabilities between people and environments. The interdependence framework emphasizes the relationships between people with or without disabilities, assistive technologies, and environments. Drawing from disability studies, it interprets the roles of people with disabilities in the collective process to improve accessibility [8].

Recent HCI work in dementia settings has leveraged the interdependence framework in understanding and engaging people with dementia, examining ethical challenges, and positioning researchers in the process of interpreting qualitative data. Learning from practitioner approaches, HCI researchers have advocated respectful approaches and challenges viewing people with dementia solely as recipients of care and help [27]. By studying the lived experiences of ethical use of assistive technologies in dementia care facilities, researchers have highlighted engagement, as opposed to dependence, and promoted communal living and social aspects with the notion of interdependence [57]. The notion of interdependence has shaped the analysis of interviews with people with mild to moderate dementia, centering people's agency in accessing resources and facilitating self-management [28, 29].

The interdependence framework can potentially have broader implications for HCI methodologies and applications. As it advocates for disability rights, the interdependence framework has inspired a dedicated human rights-based approach to design for and with people with dementia [15]. When examining the attitudes and perspectives of older adults regarding robot companions, a recent study has pointed out the concerns for senses of autonomy and dignity [17], which resonates with interdependence and could contribute to further work on age-associate cognitive accessibility.

Framework summary

In sum, the *critical dementia*, *technology narrative*, and *interdependence* frameworks are particularly applicable to guiding HCI research in dementia contexts. Critical dementia inspires contextualized meaning-making, physical and embodied interaction, experiential and sensory perceptions, and emotion without rationalization when designing for and with people with dementia. Shifting from the predominant illness narrative, the technology narrative helps to understand the lived experience and offers a guiding lens to change the emphasis from suffering the impacts of dementia to enjoying life with the support of technology. It can inspire new narrative-led design directions such as creating a space where technology enriches daily life and improves home care, eventually elevating the autonomy and personhood of people with dementia to enhance their quality of life. The interdependence frame stresses the collective work of all parties in accessibility settings and equal rights of people with disabilities, guiding HCI research and practice in the dementia community. All three frameworks have guided the research presented in this thesis. From the beginning of this research, critical dementia shaped the ways in which we positioned participants with dementia and ourselves as researchers, and the technology narrative motivated us to explore technological opportunities for quality-of-life goals. The interdependence framework played a bigger part in virtual fieldwork as we deepened our investigation into supporting various stakeholders and fostering community connectedness.

2.3 Empowering People with Dementia in HCI Research

2.3.1 Personalizing technologies for people with dementia

Prior work has highlighted personalized design for people with dementia, with a variety of devices and technologies (e.g., ambient display, life-logging, touchscreens, websites, and virtual reality) being mobilized and multimedia materials drawn from the life experiences of people with dementia. Personalization could come in various forms, one of which is weaving personal information and materials into the system. It could facilitate stimulation and make technological interventions more meaningful for people with dementia and their family, well worth the additional effort of customizing for every family [18]. Creating and sharing life stories are fundamentally personal processes, and some ambient biographical displays or life story works are personalized products due to their biographical nature (e.g., [21]). This approach has been explored in multimedia biographies and reminiscence applications that enable participants to select personalized photographs, videos, sounds, and music (e.g., [36]). Digital storytelling[3] has been commonly used to support memory, reminiscence, identity, and self-confidence, but technical challenges remain in clinical and home settings, notably the high demand for video editing to create digital stories [95].

Other than personal content and life stories, some technological interventions attend to individual care needs. People with dementia's symptoms and needs cover wide-ranging issues concerning behaviour, mood, sleep, eating, hydration, communication, social life, and difficulties with daily activities. Finding the most pressing problems faced by each family lays the foundations for addressing these through design (e.g., [52]). Personalization also means matching the level of dementia and remaining sensitive to each user, aiming for familiar and self-directed interactions with artefacts. Previous work reminds researchers to consider cultural differences, exploit context, and support social aspects [90].

With personalization widely supported, only several tools allow users to edit materials and update the system easily and freely on their own after deployment. Some types of technology require high-level technical skills to modify, such as virtual reality environments (e.g., [39]) and 3D virtual worlds (e.g., [100]). Some systems mobilize everyday cues to assist daily routines and could be updated frequently, either manually or automatically. For instance, a life-logging system supports daily activities and reminiscence by incorporating cameras, audio recorders, GPS, Bluetooth sensors, computers, and mobile assistants [53]. Another system draws on social media or website content about life experiences to send memory triggers by emails or text messages [90]. These multi-functional systems tend to

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[3] Digital storytelling: using digital technology to create and tell stories [95].

be complicated and require more hardware and software maintenance.

2.3.2 Engaging people with dementia in design

Inclusive design practices engage people with dementia and expand design spaces, enabling researchers to build empathic relationships and co-create with participants [34, 64, 70]. 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 [79].

HCI researchers have explored diverse fieldwork strategies to empower people with dementia and engage them in design, e.g., exploring props and music [80] and using probes to design personal artefacts [116]. Prolonged fieldwork has proven to be an effective approach to uncovering design requirements, e.g., by yielding implementations that acknowledge participants' preferred media and the lack of internet access in care facilities [34]. Prior work has shown that participants can strengthen their engagement in the co-design process as co-researchers and collaborators [7]. More recently, the collective efforts of HCI researchers working in dementia care contexts have revealed higher-level considerations. For example, ethical complexities have been examined through the lenses of situated practice, emotion, and everyday experiences, drawing attention to research impact and clarity, as well as assistive products' technological end-of-life [40]. A human rights-based approach has further been proposed to create a respectful environment that actively engages people with dementia throughout the design process [15]. Empowering people with dementia can have broad impacts, e.g., through self-authored content that effectively reduces the stigmas surrounding dementia [58].

Person-centered design approaches have been widely adopted to aid people with dementia in reminiscing and sharing, e.g., developing digital life storybooks to improve person-centered care [105] and integrating personally tailored design with existing routines of participants' everyday lives [70]. People with dementia can be involved in appropriating media content [34] and personalizing interactive media [39, 41] for their preference and enjoyment. In particular, it has proven effective to focus on positive memories and feelings and avoid triggering distress or unpleasant memories [65] while reducing the pressure to produce a correct answer or recollection. Generic prompts, e.g., regional materials adopted by CIRCA [6, 92], have shown effectiveness in avoiding possible frustration or tension when people with dementia fail to recognize personal items [6]. Other successful strategies include prompting reminiscences through non-personalized materials covering all life periods [90] and mitigating negative memories through playful design [100].

A wide range of technologies has been explored to support the diverse communication needs of people with dementia. Individualized interactive sound players can mobilize everyday sounds to evoke meaningful social and reminiscing cues and experiences at home [46]. AI-driven personalization can potentially support the fluctuating accessibility needs of people with dementia, particularly in terms of adaptive interfaces for changes in various types of memory [72]. Notably, robotic pets have been developed as functional household appliances to facilitate playful interaction in daily practice in residences [74], and low-cost robot pets have been examined in terms of usability and impact in varied use contexts [55].

2.3.3 Social sharing as a design context in dementia

Empowering creating and sharing has been explored in the art therapy context for older adults with cognitive impairments. In some cases, people with dementia like to tell stories through their artwork or sharing their experience of creating. During this process, people with dementia are entitled and capable of being competent individuals [59]. These concepts of empowerment and expression are also applicable in digital storytelling and sharing processes. Older adults are found to be competent digital content producers through creating and sharing photographs and messages, facilitating self-expression and social engagement [118]. Studies of older adult bloggers have shown blogging is viewed as a source of valuable engagement, which helps older adults create meaningful work and regular posting schedules [13]. Such routines and engagements could benefit people with dementia as well.

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 [20]. For people with complex communication needs, artmaking can create a space for expression and communication [64], which calls for careful reinterpretation and contextualization to avoid misinterpretation or criticism [59]. 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 [63].

Recent design work has enhanced technological aids to better support shared social experiences for people with dementia and their families. For example, a tablet app provides opportunities for meaningful and pleasurable joint activities through cooperative games for family visits to care centres [81]. A communication system integrates digital messages with printed postcards to promote lasting social contact and inclusive social dynamics within families [112]. More broadly, technology can enable social agency for people with dementia, offering opportunities to create and maintain social connections [34] and share stories in a meaningful way [89]. Conversation tools can connect different generations within a family and increase participants' agency in social settings [119]. 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 [34]. Moreover, social technology can help relieve facilitation burdens, e.g., conversation aids like CIRCA make it easier to facilitate a shared interaction with no need for caregivers to prompt question after question to sustain the conversation [6].

As an under-investigated area, social sharing of people with dementia has the potential to reach beyond art therapy and blogging. The nature of sharing for people with dementia is complex and dynamic, and the sharing itself could become a social process. Beyond face-to-face reminiscing, digital storytelling and sharing (e.g., through online systems) could form an asynchronous interaction[4] and introduce a different rhythm with the audience [20].

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[4] Asynchronous interaction: online communication that takes place independent of time or location, or at anytime, anywhere (https://www.igi-global.com/dictionary/).

The use of technologies does not mean to replace visits and conversations in person or to promote online socialization exclusively. On the contrary, sharing with the help of digital technologies could become a process to kindle meaningful dialogues and build an engaging family space. We could also draw on projects aiming at older adults in general (e.g., [78, 110]) to inform and inspire future efforts in designing for people with dementia's social sharing. There is room for improvement in facilitating sharing and socializing around the materials or within the systems. Most tools only provide passive sharing opportunities as a by-product (e.g., possible conversations between people with dementia and family members when they view the display together), while people with dementia could engage in sharing more actively and more frequently as a way of social interaction.

2.3.4 Supporting remote interaction in accessibility contexts

With the recent shift to remote interaction during the pandemic, accessibility research has addressed the complex communication needs of vulnerable populations in virtual environments, e.g., for people with vision impairments [68] and hearing impairments [99]. One study investigated the videoconferencing experiences of the aphasia community and uncovered their unique and creative adjustments to augmentative and alternative communication (AAC) strategies (including nonverbal utterances, props, and gestures) [86]. In senior residence settings, HCI research has facilitated immersive virtual reality and drawn attention to benefits, risks, and challenges in full immersion through an ethic of care perspective [117]. A wide range of literature from fields including geriatrics and nursing has revealed the benefits and limitations of using videoconferencing to foster social connectedness among older adults [109], echoed by HCI research findings on older adults forming a community of practice to tackle usability issues of online conferencing tools [94].

Meanwhile, recent HCI work in dementia covers a variety of virtual elements, e.g., online platforms for dementia information [26], self-management systems adopted by people with mild to moderate dementia [29], and interaction between sensory changes and everyday technology use [28]. Studies have also examined the impacts of the pandemic through the lenses of residence staff perceptions [54] and multi-stakeholder teamwork in designing virtual reality exergames [82]. The increased need for virtual interaction has prompted the development of best practices for remote summative usability testing involving people with dementia [120].

2.4 Involving Proxies in HCI research

2.4.1 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) [116], as well as a variety of professionals, including formal (professional) caregivers [115], art, speech, occupational, or recreational therapists [20], and staff and volunteers at care facilities [60]. 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., [5]). Proxies have played various roles in research, such as direct sources of information [62], supporters of participants in activities [34], providers of contextual or supplementary information [39], and validators of the research findings [65]. 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 [28]. 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 [5, 21, 70].

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., [12, 35, 37]). Participatory design projects drew insights from proxies such as teachers and speech-language pathologists and noted their indirect representation of actual users [37]. 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].

2.4.2 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 [61], enabling self and personhood of people with dementia [115, 116], and co-creating personas with participants to build a more engaging and accessible design process [85]. Artistic and creative ways have been explored to study embodiment in the lived experiences of people with dementia [56]. 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 [51]. Attention has been paid to the power of different stakeholders in decision-making, especially in participatory design research (e.g., [11]). 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., [113]) or where their perspectives and experience make them equally valuable stakeholders (e.g., [45]).

More broadly in collaborative system design, uncovering all aspects of different stakeholders' needs and perceptions has been recognized as essential for problem formulation [111], and the importance of balancing stakeholder perspectives has long been noted [76]. Interacting directly with stakeholders, researchers have advanced from mitigating stakeholder conflicts to creating shared understanding [4]. Bringing stakeholders together to explore a design space can reveal issues and opportunities but pose challenges in choosing engaging activities and methods [114]. Stakeholder voices have been recommended to be considered throughout the research process and reported in stakeholders' own choice of words [22], and hearing participants' voices directly and faithfully can help attend to power differences [10].

2.5 Methodological Considerations

2.5.1 Overview of research methodologies in dementia-related HCI work

Relying on qualitative methods, sometimes supplemented by quantitative methods, HCI researchers endeavour to paint a full picture of living with dementia and hear the voices of people with dementia, caregivers, and other stakeholders. To understand the nuanced expressions and emotions of people with dementia, researchers need to focus on human inquiry and empathetic interaction, investigating in participants' natural settings and social contexts. Thus, HCI work in dementia contexts widely adopts qualitative approaches, notably ethnographic methods (e.g., [18, 62, 79]). These approaches usually involve researchers going to long-term care facilities or participants' homes to observe and interact with individual or group activities, as well as conducting in-depth interviews and design workshops. Such studies might face geographic constraints, only analyzing a limited number of cases within a local community. Nevertheless, the small sample size is not always a problem as researchers have reported reaching data saturation after several interviews (e.g., [73]).

Purely quantitative studies are less seen in this line of work, but sometimes quantitative methods are mobilized to provide additional insights. A few examples include questionnaires [69], computer logs [106], and instruments [67], frequently followed by descriptive statistical analyses. As guided by the third-wave HCI and the critical dementia framework, common user performance or eliminating pure usability errors is not usually the goal of designing for people with dementia. Therefore, quantitative methods alone do not serve the purpose of using technology to support the relationships and quality of life for people with dementia and their caregivers. Studies have combined qualitative and quantitative methods, such as questionnaires paired with focus groups [78] and observations and interviews plus instruments [60].

2.5.2 Researcher reflexivity and ethics

To address the socio-technical gap and develop personal solutions, instead of universal ones, HCI work has drawn on ethnography that emphasizes the two-way relationship between participants and researchers and permits the integration of researchers' voices to strengthen their insight into the data and their ability to use it for design [96]. HCI researchers have reflected on their roles in the field, recounting their first-hand experience through reflexivity [96] and examining power dynamics between various fields involved in inherently interdisciplinary HCI studies [30]. 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 [47].

Ethical challenges have been well recognized and negotiated in HCI research and reflections, including a series of ethics panels at CHI[5] and CSCW[6] conferences (e.g., [23, 83]). When involving complex spaces and vulnerable populations, HCI communities have discussed the dynamic nature of ethics requirements and reassessed a situational approach [84], as well as proposing ethics frameworks stemmed from fieldwork in sensitive settings such as hospice [32]. In dementia-related studies, ethics considerations and participant consent procedures have been approached with extra care and well documented in publications (e.g., [34, 39, 45]).[7] Researchers have been cognizant of the ethical implications of new systems, ranging from the levels of engagement (e.g., [33]) to the use of monitoring technologies (e.g., [27]). 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 [40].

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 [103], as well as studying accounts of a hard-of-hearing traveler during 2.5 years [49]. 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 [50]), as well as collaboration among three accessibility researchers and a disability studies scholar to connect contexts and expertise [44]. Moreover, autobiographical design research has been

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[5] The ACM CHI Conference on Human Factors in Computing Systems

[6] The ACM Conference On Computer-Supported Cooperative Work and Social Computing

[7] Our approaches are detailed in each manuscript.

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 [24]. 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 [49, 50].

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 [96]. 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 are needed to provide concrete guidance on effectively collaborating with proxies and prioritizing participants' voices in assistive technology research.

2.5.3 Community-based HCI research

Community-collaborative approaches to HCI research have been widely adopted in the past decade for a wide range of populations (e.g., first nations, people of colour, people with disabilities, older adults, rural/urban/low-income communities), as reported by a recent systematic review [19]. Such approaches have allowed for designing for and with traditionally marginalized communities in diverse settings through qualitative, quantitative, and design methodologies. For example, a mixed-methods study has adopted longitudinal surveys, followed by interviews with all stakeholders (members, mentors, and coaches), to delve into a community-based mentorship program for adults experiencing poverty [25]. Another project has examined older adults' participation through questionnaires, interviews, and focus groups to redesign a resident-led, internal website in partnership with residents and staff [108]. In rural settings, the contextual design of a computer-supported cooperative work (CSCW) portal for a farmers' market has advocated for creating a network of civilly-engaged stakeholders [14], and a community-based co-design project has uncovered nuanced community needs for managing water supplies and developed a locally relevant technological intervention [102].

HCI researchers have created productive partnerships in community-based research, highlighting institutional histories and personal relationships that guided the research conceptualization and methods and reflecting on their diverse roles (e.g., researcher, confidant, advocate, interloper, invader, and collaborator) [66]. A community-based design approach has been successfully adopted in socially engaged arts projects involving artists, collaborators, and researchers. These case studies have characterized the notion of critical openness in community engagements by responsibility and care, valuing relationships, and working openly with complexity [16].

In accessibility settings, community-based research has been adopted as a participatory mapping method to evaluate assistive technology interaction devices [97]. In dementia communities, researchers have engaged in a six-month robot design collaboration with caregiver support groups to contextualize the roles of robots in family caregiving [77].

Leveraging the strengths and capacities of people with dementia in public spaces to contribute to their wellbeing, community-based approaches help highlight physical, social, and institutional assets to navigate public space and support social inclusion and encounters [104].

Bibliography

[1] Meghan Allen, Rock Leung, Joanna McGrenere, and Barbara Purves. 2008. Involving domain experts in assistive technology research. *Universal Access in the Information Society* 7, 3 (Jan. 2008), 145–154. `https://doi.org/10.1007/s10209-008-0112-5`

[2] Alzheimer Society of Canada. 2022. Navigating the Path Forward for Dementia in Canada: The Landmark Study Report 1. (2022). `https://alzheimer.ca/sites/default/files/documents/Landmark-Study-Report-1-Path_Alzheimer-Society-Canada_0.pdf`

[3] Alzheimer's Association. 2022. 2022 Alzheimer's disease facts and figures. *Alzheimer's & Dementia* 18, 4 (Apr. 2022), 700–789. `https://doi.org/10.1002/alz.12638`

[4] Ernesto Arias, Hal Eden, Gerhard Fischer, Andrew Gorman, and Eric Scharff. 2000. Transcending the individual human mind—creating shared understanding through collaborative design. *ACM Transactions on Computer-Human Interaction (TOCHI)* 7, 1 (Mar. 2000), 84–113. `https://doi.org/10.1145/344949.345015`

[5] Arlene Astell, Norman Alm, Gary Gowans, Maggie Ellis, Richard Dye, and Phillip Vaughan. 2009. Involving older people with dementia and their carers in designing computer based support systems: some methodological considerations. *Universal Access in the Information Society* 8, 1 (May 2009), 49–58. `https://doi.org/10.1007/s10209-008-0129-9`

[6] Arlene J Astell, Maggie P Ellis, Lauren Bernardi, Norman Alm, Richard Dye, Gary Gowans, and Jim Campbell. 2010. Using a touch screen computer to support relationships between people with dementia and caregivers. *Interacting with Computers* 22, 4 (2010), 267–275. `https://doi.org/10.1016/j.intcom.2010.03.003`

[7] Jeanette Bell and Tuck Wah Leong. 2019. Collaborative futures: Co-designing research methods for younger people living with dementia. In *Proceedings of the 2019 chi conference on human factors in computing systems.* 1–13. `https://doi.org/10.1145/3290605.3300582`

[8] Cynthia L. Bennett, Erin Brady, and Stacy M. Branham. 2018. Interdependence as a frame for assistive technology research and design. *ASSETS 2018 - 20th International ACM SIGACCESS Conference on Computers and Accessibility*, 161–173. `https://doi.org/10.1145/3234695.3236348`

[9] Susanne Bødker. 2015. Third-wave HCI, 10 years later—participation and sharing. *interactions* 22, 5 (2015), 24–31. `https://doi.org/10.1145/2804405`

[10] Alan Borning and Michael Muller. 2012. Next steps for value sensitive design. In *Proceedings of the SIGCHI conference on human factors in computing systems*. ACM, 1125–1134. `https://doi.org/10.1145/2207676.2208560`

[11] Tone Bratteteig and Ina Wagner. 2012. Disentangling power and decision-making in participatory design. In *Proceedings of the 12th Participatory Design Conference: Research Papers - Volume 1*. ACM, 41–50. `https://doi.org/10.1145/2347635.2347642`

[12] Margot Brereton, Laurianne Sitbon, Muhammad Haziq Lim Abdullah, Mark Vanderberg, and Stewart Koplick. 2015. Design after design to bridge between people living with cognitive or sensory impairments, their friends and proxies. *CoDesign* 11, 1 (Mar. 2015), 4–20. `https://doi.org/10.1080/15710882.2015.1009471`

[13] Robin Brewer and Anne Marie Piper. 2016. "Tell It Like It Really Is": A Case of Online Content Creation and Sharing Among Older Adult Bloggers. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*. 5529–5542. `https://doi.org/10.1145/2858036.2858379`

[14] Alan Chamberlain, Andy Crabtree, and Mark Davies. 2013. Community engagement for research: contextual design in rural CSCW system development. In *Proceedings of the 6th International Conference on Communities and Technologies*. 131–139. `https://doi.org/10.1145/2482991.2483001`

[15] Shaan Chopra, Emma Dixon, Kausalya Ganesh, Alisha Pradhan, Mary L. Radnofsky, and Amanda Lazar. 2021. Designing for and with People with Dementia using a Human Rights-Based Approach. In *Extended Abstracts of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–8. `https://doi.org/10.1145/3411763.3443434`

[16] Rachel Clarke, Jo Briggs, Ann Light, and Pete Wright. 2016. Situated encounters with socially engaged art in community-based design. In *Proceedings of the 2016 ACM conference on designing interactive systems*. 521–532. `https://doi.org/10.1145/2901790.2901882`

[17] Simon Coghlan, Jenny Waycott, Amanda Lazar, and Barbara Barbosa Neves. 2021. Dignity, autonomy, and style of company: dimensions older adults consider for robot companions. *Proceedings of the ACM on human-computer interaction* 5, CSCW1 (2021), 1–25. `https://doi.org/10.1145/3449178`

[18] Tira Cohene, RM Baecker, Elsa Marziali, and Simona Mindy. 2007. Memories of a life: a design case study for Alzheimer's disease. *Universal Usability: Designing Computer Interfaces for Diverse User Populations* (2007), 357–387. `http://ron.taglab.ca/papers/B14.pdf`

[19] Ned Cooper, Tiffanie Horne, Gillian R Hayes, Courtney Heldreth, Michal Lahav, Jess Holbrook, and Lauren Wilcox. 2022. A Systematic Review and Thematic Analysis of Community-Collaborative Approaches to Computing Research. In *CHI Conference on Human Factors in Computing Systems*. 1–18. `https://doi.org/10.1145/3491102.3517716`

[20] Raymundo Cornejo, Robin Brewer, Caroline Edasis, and Anne Marie Piper. 2016. Vulnerability, Sharing, and Privacy: Analyzing Art Therapy for Older Adults with Dementia. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*. ACM, 1572–1583. `https://doi.org/10.1145/2818048.2819960`

[21] Masashi Crete-Nishihata, Ronald M. Baecker, Michael Massimi, Deborah Ptak, Rachelle Campigotto, Liam D. Kaufman, Adam M. Brickman, Gary R. Turner, Joshua R. Steinerman, and Sandra E. Black. 2012. Reconstructing the Past: Personal Memory Technologies Are Not Just Personal and Not Just for Memory. *Human–Computer Interaction* 27, 1-2 (Apr. 2012), 92–123. `https://doi.org/10.1080/07370024.2012.656062`

[22] Janet Davis and Lisa P. Nathan. 2013. Value Sensitive Design: Applications, Adaptations, and Critiques. In *Handbook of Ethics, Values, and Technological Design: Sources, Theory, Values and Application Domains*, Jeroen van den Hoven, Pieter E. Vermaas, and Ibo van de Poel (Eds.). Springer Netherlands, Dordrecht, 1–26. `https://doi.org/10.1007/978-94-007-6994-6_3-1`

[23] Melissa Densmore, Casey Fiesler, Cosmin Munteanu, Michael Muller, Janet C. Read, Katie Shilton, and Özge Subaşı. 2020. Research Ethics Roundtable. In *Conference Companion Publication of the 2020 on Computer Supported Cooperative Work and Social Computing*. ACM, 195–198. `https://doi.org/10.1145/3406865.3419015`

[24] Audrey Desjardins and Aubree Ball. 2018. Revealing Tensions in Autobiographical Design in HCI. In *Proceedings of the 2018 Designing Interactive Systems Conference*. ACM, 753–764. `https://doi.org/10.1145/3196709.3196781`

[25] Tawanna R Dillahunt, Alex Jiahong Lu, Aarti Israni, Ruchita Lodha, Savana Brewer, Tiera S Robinson, Angela Brown Wilson, and Earnest Wheeler. 2022. The Village: Infrastructuring Community-based Mentoring to Support Adults Experiencing Poverty. In *CHI Conference on Human Factors in Computing Systems*. 1–17. `https://doi.org/10.1145/3491102.3501949`

[26] Emma Dixon, Jesse Anderson, Diana Blackwelder, Mary L. Radnofsky, and Amanda Lazar. 2022. Barriers to Online Dementia Information and Mitigation. In *CHI Conference on Human Factors in Computing Systems*. 1–14. `https://doi.org/10.1145/3491102.3517554`

[27] Emma Dixon and Amanda Lazar. 2020. Approach Matters: Linking Practitioner Approaches to Technology Design for People with Dementia. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. ACM, 1–15. `https://doi.org/10.1145/3313831.3376432`

[28] Emma Dixon and Amanda Lazar. 2020. The Role of sensory changes in everyday technology use by people with mild to moderate dementia. In *The 22nd International ACM SIGACCESS Conference on Computers and Accessibility*. 1–12. `https://doi.org/10.1145/3373625.3417000`

[29] Emma Dixon, Anne Marie Piper, and Amanda Lazar. 2021. "Taking care of myself as long as I can": How People with Dementia Configure Self-Management Systems. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–14. `https://doi.org/10.1145/3411764.3445225`

[30] Paul Dourish. 2006. Implications for design. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 541–550. `https://doi.org/10.1145/1124772.1124855`

[31] Deborah I Fels and Arlene J Astell. 2011. Storytelling as a model of conversation for people with dementia and caregivers. *American Journal of Alzheimer's Disease & Other Dementias®* 26, 7 (2011), 535–541. `https://doi.org/10.1177/1533317511429324`

[32] Robert Ferguson, Emily Crist, and Karyn Moffatt. 2016. A Framework for Negotiating Ethics in Sensitive Settings: Hospice as a Case Study. *Interacting with Computers* 29, 1 (2016), 10–26. `https://doi.org/10.1093/iwc/iww018`

[33] Sarah Foley, Nadia Pantidi, and John McCarthy. 2019. Care and Design: An Ethnography of Mutual Recognition in the Context of Advanced Dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 1–15. `https://doi.org/10.1145/3290605.3300840`

[34] Sarah Foley, Daniel Welsh, Nadia Pantidi, Kellie Morrissey, Tom Nappey, and John McCarthy. 2019. Printer Pals: Experience-Centered Design to Support Agency for People with Dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 1–13. `https://doi.org/10.1145/3290605.3300634`

[35] Julia Galliers, Stephanie Wilson, Abi Roper, Naomi Cocks, Jane Marshall, Sam Muscroft, and Tim Pring. 2012. Words are not enough: empowering people with aphasia in the design process. In *Proceedings of the 12th Participatory Design Conference: Research Papers - Volume 1*. ACM, 51–60. `https://doi.org/10.1145/2347635.2347643`

[36] Aideen Gibson, Claire McCauley, Maurice Mulvenna, Assumpta Ryan, Liz Laird, Kevin Curran, Brendan Bunting, Finola Ferry, and Raymond Bond. 2016. Assessing usability testing for people living with dementia. In *Proceedings of the 4th Workshop on ICTs for improving Patients Rehabilitation Research Techniques*. 25–31. `https://doi.org/10.1145/3051488.3051492`

[37] Foad Hamidi, Melanie Baljko, and Isabel Gómez. 2017. Using Participatory Design with Proxies with Children with Limited Communication. In *Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility*. ACM, 250–259. `https://doi.org/10.1145/3132525.3132527`

[38] Steve Harrison, Deborah Tatar, and Phoebe Sengers. 2007. The three paradigms of HCI. In *Alt. Chi. Session at the SIGCHI Conference on human factors in computing systems San Jose, California, USA*. 1–18.

[39] James Hodge, Madeline Balaam, Sandra Hastings, and Kellie Morrissey. 2018. Exploring the Design of Tailored Virtual Reality Experiences for People with Dementia. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. ACM, 1–13. `https://doi.org/10.1145/3173574.3174088`

[40] James Hodge, Sarah Foley, Rens Brankaert, Gail Kenning, Amanda Lazar, Jennifer Boger, and Kellie Morrissey. 2020. Relational, Flexible, Everyday: Learning from Ethics in Dementia Research. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. ACM, 1–16. `https://doi.org/10.1145/3313831.3376627`

[41] James Hodge, Kyle Montague, Sandra Hastings, and Kellie Morrissey. 2019. Exploring Media Capture of Meaningful Experiences to Support Families Living with Dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 3300653, 1–14. `https://doi.org/10.1145/3290605.3300653`

[42] Jesse Hoey, Pascal Poupart, Axel von Bertoldi, Tammy Craig, Craig Boutilier, and Alex Mihailidis. 2010. Automated handwashing assistance for persons with dementia using video and a partially observable Markov decision process. *Computer Vision and Image Understanding* 114, 5 (2010), 503–519. `https://doi.org/10.1016/j.cviu.2009.06.008`

[43] Jesse Hoey, Krists Zutis, Valerie Leuty, and Alex Mihailidis. 2010. A tool to promote prolonged engagement in art therapy: design and development from arts therapist requirements. In *Proceedings of the 12th international ACM SIGACCESS conference on Computers and accessibility*. 211–218. `https://doi.org/10.1145/1878803.1878841`

[44] Megan Hofmann, Devva Kasnitz, Jennifer Mankoff, and Cynthia L. Bennett. 2020. Living Disability Theory: Reflections on Access, Research, and Design. *ASSETS 2020 - 22nd International ACM SIGACCESS Conference on Computers and Accessibility*, 1–13. `https://doi.org/10.1145/3373625.3416996`

[45] Maarten Houben, Rens Brankaert, Saskia Bakker, Gail Kenning, Inge Bongers, and Berry Eggen. 2020. The Role of Everyday Sounds in Advanced Dementia Care. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. ACM, 1–14. `https://doi.org/10.1145/3313831.3376577`

[46] Maarten Houben, Rens Brankaert, Gail Kenning, Inge Bongers, and Berry Eggen. 2022. Designing for Everyday Sounds at Home with People with Dementia and their Partners. In *CHI Conference on Human Factors in Computing Systems*. 1–15. `https://doi.org/10.1145/3491102.3501993`

[47] Dorothy Howard and Lilly Irani. 2019. Ways of Knowing When Research Subjects Care. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 1–16. `https://doi.org/10.1145/3290605.3300327`

[48] Stephan Huber, Jan Preßler, Nam Ly Tung, and Jörn Hurtienne. 2017. Evaluating interaction-triggered emotions in people with dementia. In *Proceedings of the 2017 CHI Conference Extended Abstracts on Human Factors in Computing Systems*. 2659–2667. `https://doi.org/10.1145/3027063.3053251`

[49] Dhruv Jain, Audrey Desjardins, Leah Findlater, and Jon E. Froehlich. 2019. Autoethnography of a Hard of Hearing Traveler. In *The 21st International ACM SIGACCESS Conference on Computers and Accessibility*. ACM, 236–248. `https://doi.org/10.1145/3308561.3353800`

[50] Dhruv Jain, Venkatesh Potluri, and Ather Sharif. 2020. Navigating Graduate School with a Disability. In *The 22nd International ACM SIGACCESS Conference on*

Computers and Accessibility. ACM, Article 8.
https://doi.org/10.1145/3373625.3416986

[51] Jazette Johnson, Rebecca W. Black, and Gillian R. Hayes. 2020. Roles in the Discussion: An Analysis of Social Support in an Online Forum for People with Dementia. *Proc. ACM Hum.-Comput. Interact.* 4, CSCW2 (2020), Article 127. https://doi.org/10.1145/3415198

[52] Chantal Kerssens, Renu Kumar, Anne E Adams, Camilla C Knott, Laura Matalenas, Jon A Sanford, and Wendy A Rogers. 2015. Personalized technology to support older adults with and without cognitive impairment living at home. *American Journal of Alzheimer's Disease & Other Dementias®* 30, 1 (2015), 85–97. https://doi.org/10.1177/1533317514568338

[53] Basel Kikhia, Josef Hallberg, Johan Bengtsson, Stefan Sävenstedt, and Kåre Synnes. 2010. Building digital life stories for memory support. *International journal of Computers in Healthcare* 1, 2 (2010), 161–176. https://doi.org/10.1504/ijcih.2010.03746

[54] Julia Kirkham, Carrie L Shorey, Andrea Iaboni, Hannah Quirt, Alisa Grigorovitch, Arlene Astell, Esther Lin, and Colleen J Maxwell. 2022. Staff perceptions of the consequences of COVID-19 on quality of dementia care for residents in Ontario long-term care homes. *International journal of geriatric psychiatry* (2022). https://doi.org/10.1002/gps.5725

[55] Wei Qi Koh, Sally Whelan, Pascale Heins, Dympna Casey, Elaine Toomey, and Rose-Marie Dröes. 2022. The Usability and Impact of a Low-Cost Pet Robot for Older Adults and People With Dementia: Qualitative Content Analysis of User Experiences and Perceptions on Consumer Websites. *JMIR aging* 5, 1 (2022), e29224. https://doi.org/10.2196/29224

[56] Pia Kontos and Wendy Martin. 2013. Embodiment and dementia: Exploring critical narratives of selfhood, surveillance, and dementia care. *Dementia* 12, 3 (2013), 288–302. https://doi.org/10.1177/1471301213479787

[57] Thomas Kosch, Thomas Grote, Albrecht Schmidt, and Paweł W Woźniak. [n.d.]. Engagement, not Dependence: Ethically Designing Assistive Systems for Users with Cognitive Impairments. In *Proceedings of Nordic Human-Computer Interaction Conference (NordiCHI '22)*. 1–13.

[58] Amanda Lazar, Robin N Brewer, Hernisa Kacorri, Jonggi Hong, Mary Nicole Dugay Punzalan, Maisarah Mahathir, Olivia Vander Hyde, and Warren Ross III. 2021. How Content Authored by People with Dementia Affects Attitudes towards Dementia.

Proceedings of the ACM on Human-computer Interaction 5, CSCW2 (2021), 1–32. `https://doi.org/10.1145/3479542`

[59] Amanda Lazar, Raymundo Cornejo, Caroline Edasis, and Anne Marie Piper. 2016. Designing for the third hand: Empowering older adults with cognitive impairment through creating and sharing. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems*. 1047–1058. `https://doi.org/10.1145/2901790.2901854`

[60] Amanda Lazar, George Demiris, and Hilaire J. Thompson. 2016. Evaluation of a multifunctional technology system in a memory care unit: Opportunities for innovation in dementia care. *Informatics for Health and Social Care* 41, 4 (Jan. 2016), 373–386. `https://doi.org/10.3109/17538157.2015.1064428`

[61] Amanda Lazar and Emma E. Dixon. 2019. Safe Enough to Share: Setting the Dementia Agenda Online. *Proc. ACM Hum.-Comput. Interact.* 3, CSCW (Nov. 2019), 1–23. `https://doi.org/10.1145/3359187`

[62] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. A Critical Lens on Dementia and Design in HCI. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM, 2175–2188. `https://doi.org/10.1145/3025453.3025522`

[63] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. Supporting People with Dementia in Digital Social Sharing. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (Denver, Colorado, USA) *(CHI '17)*. Association for Computing Machinery, New York, NY, USA, 2149–2162. `https://doi.org/10.1145/3025453.3025586`

[64] Amanda Lazar, Jessica L. Feuston, Caroline Edasis, and Anne Marie Piper. 2018. Making as Expression: Informing Design with People with Complex Communication Needs through Art Therapy. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. ACM, 1–16. `https://doi.org/10.1145/3173574.3173925`

[65] Amanda Lazar, Hilaire J. Thompson, and George Demiris. 2016. Design Recommendations for Recreational Systems Involving Older Adults Living With Dementia. *Journal of Applied Gerontology* (Apr. 2016), 1–25. `https://doi.org/10.1177/0733464816643880`

[66] Christopher A Le Dantec and Sarah Fox. 2015. Strangers at the gate: Gaining access, building rapport, and co-constructing community-based research. In *Proceedings of the 18th ACM conference on computer supported cooperative work & social computing*. 1348–1358. `https://doi.org/10.1145/2675133.2675147`

[67] Fong Yoke Leng, Donald Yeo, Stacey George, and Christopher Barr. 2014. Comparison of iPad applications with traditional activities using person-centred care approach: impact on well-being for persons with dementia. *Dementia* 13, 2 (2014), 265–273. `https://doi.org/10.1177/1471301213494514`

[68] Barbara Leporini, Marina Buzzi, and Marion Hersh. 2021. Distance meetings during the COVID-19 pandemic: are video conferencing tools accessible for blind people?. In *Proceedings of the 18th International Web for All Conference*. 1–10. `https://doi.org/10.1145/3430263.3452433`

[69] Fabian S Lim, Tim Wallace, Mary A Luszcz, and Karen J Reynolds. 2013. Usability of tablet computers by people with early-stage dementia. *Gerontology* 59, 2 (2013), 174–182. `https://doi.org/10.1159/000343986`

[70] Stephen Lindsay, Katie Brittain, Daniel Jackson, Cassim Ladha, Karim Ladha, and Patrick Olivier. 2012. Empathy, participatory design and people with dementia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 521–530. `https://doi.org/10.1145/2207676.2207749`

[71] Rebecca G Logsdon, Laura E Gibbons, Susan M McCurry, and Linda Teri. 2002. Assessing quality of life in older adults with cognitive impairment. *Psychosomatic medicine* 64, 3 (2002), 510–519. `https://doi.org/10.1097/00006842-200205000-00016`

[72] Hanuma Teja Maddali, Emma Dixon, Alisha Pradhan, and Amanda Lazar. 2022. Investigating the Potential of Artificial Intelligence Powered Interfaces to Support Different Types of Memory for People with Dementia. In *CHI Conference on Human Factors in Computing Systems Extended Abstracts*. 1–7. `https://doi.org/10.1145/3491101.3519858`

[73] Galina Madjaroff and Helena Mentis. 2017. Narratives of Older Adults with Mild Cognitive Impairment and Their Caregivers. In *Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility*. ACM, 140–149. `https://doi.org/10.1145/3132525.3132554`

[74] Emanuela Marchetti, Sophie Grimme, Eva Hornecker, Avgi Kollakidou, and Philipp Graf. 2022. Pet-Robot or Appliance? Care Home Residents with Dementia Respond to a Zoomorphic Floor Washing Robot. In *CHI Conference on Human Factors in Computing Systems*. 1–21. `https://doi.org/10.1145/3491102.3517463`

[75] Michael Massimi, Emma Berry, Georgina Browne, Gavin Smyth, Peter Watson, and Ronald M Baecker. 2008. An exploratory case study of the impact of ambient biographical displays on identity in a patient with Alzheimer's disease.

Neuropsychological rehabilitation 18, 5-6 (2008), 742–765. `https://doi.org/10.1080/09602010802130924`

[76] Deborah J. Mayhew and Todd J. Follansbee. 2012. User Experience Requirements Analysis within the Usability Engineering Lifecycle. In *Human Computer Interaction Handbook: Fundamentals, Evolving Technologies, and Emerging Applications* (3rd ed.), Julie A. Jacko (Ed.). CRC Press, Boca Raton, 945–954.

[77] Sanika Moharana, Alejandro E Panduro, Hee Rin Lee, and Laurel D Riek. 2019. Robots for joy, robots for sorrow: community based robot design for dementia caregivers. In *2019 14th ACM/IEEE International Conference on Human-Robot Interaction (HRI)*. IEEE, 458–467. `https://doi.org/10.1109/HRI.2019.8673206`

[78] Luca Morganti, Giuseppe Riva, Silvio Bonfiglio, and Andrea Gaggioli. 2013. Building collective memories on the web: the Nostalgia Bits project. *International Journal of Web Based Communities* 9, 1 (2013), 83–104. `https://doi.org/10.1504/IJWBC.2013.051373`

[79] Kellie Morrissey, John McCarthy, and Nadia Pantidi. 2017. The value of experience-centred design approaches in dementia research contexts. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. 1326–1338. `https://doi.org/10.1145/3025453.3025527`

[80] Kellie Morrissey, Gavin Wood, David Green, Nadia Pantidi, and John McCarthy. 2016. 'I'm a rambler, I'm a gambler, I'm a long way from home' The Place of Props, Music, and Design in Dementia Care. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems*. 1008–1020. `https://doi.org/10.1145/2901790.2901798`

[81] Diego Muñoz, Stu Favilla, Sonja Pedell, Andrew Murphy, Jeanie Beh, and Tanya Petrovich. 2021. Evaluating an App to Promote a Better Visit Through Shared Activities for People Living with Dementia and their Families. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–13. `https://doi.org/10.1145/3411764.3445764`

[82] John Muñoz, Samira Mehrabi, Yirou Li, Aysha Basharat, Laura E Middleton, Shi Cao, Michael Barnett-Cowan, Jennifer Boger, et al. 2022. Immersive Virtual Reality Exergames for Persons Living With Dementia: User-Centered Design Study as a Multistakeholder Team During the COVID-19 Pandemic. *JMIR Serious Games* 10, 1 (2022), e29987. `https://doi.org/10.2196/29987`

[83] Cosmin Munteanu, Amy Bruckman, Michael Muller, Christopher Frauenberger, Casey Fiesler, Robert E. Kraut, Katie Shilton, and Jenny Waycott. 2019. SIGCHI

Research Ethics Town Hall. In *Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, Paper panel05. `https://doi.org/10.1145/3290607.3311742`

[84] Cosmin Munteanu, Heather Molyneaux, Wendy Moncur, Mario Romero, Susan O'Donnell, and John Vines. 2015. Situational Ethics: Re-thinking Approaches to Formal Ethics Requirements for Human-Computer Interaction. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*. ACM, 105–114. `https://doi.org/10.1145/2702123.2702481`

[85] Timothy Neate, Aikaterini Bourazeri, Abi Roper, Simone Stumpf, and Stephanie Wilson. 2019. Co-Created Personas: Engaging and Empowering Users with Diverse Needs Within the Design Process. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 1–12. `https://doi.org/10.1145/3290605.3300880`

[86] Timothy Neate, Vasiliki Kladouchou, Stephanie Wilson, and Shehzmani Shams. 2022. "Just Not Together": The Experience of Videoconferencing for People with Aphasia during the Covid-19 Pandemic. In *CHI Conference on Human Factors in Computing Systems*. 1–16. `https://doi.org/10.1145/3491102.3502017`

[87] Emma Nichols, Jaimie D Steinmetz, Stein Emil Vollset, Kai Fukutaki, Julian Chalek, Foad Abd-Allah, Amir Abdoli, Ahmed Abualhasan, Eman Abu-Gharbieh, Tayyaba Tayyaba Akram, et al. 2022. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. *The Lancet Public Health* 7, 2 (2022), e105–e125. `https://doi.org/ttps://doi.org/10.1016/`

[88] Roger Orpwood, James Chadd, Deborah Howcroft, Andrew Sixsmith, Judith Torrington, Grant Gibson, and Garuth Chalfont. 2010. Designing technology to improve quality of life for people with dementia: user-led approaches. *Universal Access in the Information Society* 9, 3 (2010), 249–259. `https://doi.org/10.1007/s10209-009-0172-1`

[89] Elly Park, Hollis Owens, David Kaufman, and Lili Liu. 2017. Digital storytelling and dementia. In *International conference on human aspects of IT for the aged population*. Springer, 443–451. `https://doi.org/10.1007/978-3-319-58536-9_35`

[90] S Tejaswi Peesapati, Victoria Schwanda, Johnathon Schultz, Matt Lepage, So-yae Jeong, and Dan Cosley. 2010. Pensieve: supporting everyday reminiscence. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 2027–2036. `https://doi.org/10.1145/1753326.1753635`

[91] Carrie Beth Peterson, Neeli R Prasad, and Ramjee Prasad. 2012. Assessing assistive technology's quality of life outcomes with dementia. *Gerontechnology* 11, 2 (2012), 195. `https://doi.org/10.4017/gt.2012.11.02.414.00`

[92] Barbara A Purves, Alison Phinney, Wendy Hulko, Gloria Puurveen, and Arlene J Astell. 2015. Developing CIRCA-BC and exploring the role of the computer as a third participant in conversation. *American Journal of Alzheimer's Disease & Other Dementias®* 30, 1 (2015), 101–107. `https://doi.org/10.1177/1533317514539031`

[93] Kirsten Rassmus-Gröhn and Charlotte Magnusson. 2014. Finding the way home: supporting wayfinding for older users with memory problems. In *Proceedings of the 8th Nordic Conference on Human-Computer Interaction: Fun, Fast, Foundational.* 247–255. `https://doi.org/10.1145/2639189.2639233`

[94] Hirak Ray, Ravi Kuber, and Adam J Aviv. 2022. Investigating older adults' adoption and usage of online conferencing tools during COVID-19. In *Proceedings of the 19th International Web for All Conference*. 1–11. `https://doi.org/10.1145/3493612.3520447`

[95] Adriana Maria Rios Rincon, Antonio Miguel Cruz, Christine Daum, Noelannah Neubauer, Aidan Comeau, and Lili Liu. 2022. Digital storytelling in older adults with typical aging, and with mild cognitive impairment or dementia: A systematic literature review. *Journal of Applied Gerontology* 41, 3 (2022), 867–880. `https://doi.org/10.1177/07334648211015456`

[96] Jennifer A. Rode. 2011. Reflexivity in digital anthropology. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 123–132. `https://doi.org/10.1145/1978942.1978961`

[97] Andreia Sias Rodrigues, AS Rodrigues, Marcelo Bender Machado, Ana Margarida Pisco Almeida, Jorge Ferraz de Abreu, and Tatiana Aires Tavares. 2019. Evaluation methodologies of assistive technology interaction devices: a participatory mapping in Portugal based on community-based research. In *Proceedings of the 18th Brazilian Symposium on Human Factors in Computing Systems*. 1–9. `https://doi.org/10.1145/3357155.3358458`

[98] Lena Rosenberg, Anders Kottorp, and Louise Nygård. 2012. Readiness for technology use with people with dementia: the perspectives of significant others. *Journal of applied gerontology* 31, 4 (2012), 510–530. `https://doi.org/10.1177/0733464810396873`

[99] Matthew Seita, Sarah Andrew, and Matt Huenerfauth. 2021. Deaf and hard-of-hearing users' preferences for hearing speakers' behavior during

technology-mediated in-person and remote conversations. In *Proceedings of the 18th International Web for All Conference*. 1–12. `https://doi.org/10.1145/3430263.3452430`

[100] Panote Siriaraya and Chee Siang Ang. 2014. Recreating living experiences from past memories through virtual worlds for people with dementia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 3977–3986. `https://doi.org/10.1145/2556288.2557035`

[101] Sarah C Smith, Joanna Murray, Sube Banerjee, Beth Foley, Joanna C Cook, Donna L Lamping, Martin Prince, Rowan H Harwood, Enid Levin, and Anthony Mann. 2005. What constitutes health-related quality of life in dementia? Development of a conceptual framework for people with dementia and their carers. *International Journal of Geriatric Psychiatry: A journal of the psychiatry of late life and allied sciences* 20, 9 (2005), 889–895. `https://doi.org/10.1002/gps.1374`

[102] Fiona Ssozi-Mugarura, Edwin Blake, and Ulrike Rivett. 2016. Supporting community needs for rural water management through community-based co-design. In *Proceedings of the 14th Participatory Design Conference: Full papers-Volume 1*. 91–100. `https://doi.org/10.1145/2940299.2940311`

[103] Kate Stephens, Matthew Butler, Leona M Holloway, Cagatay Goncu, and Kim Marriott. 2020. Smooth Sailing? Autoethnography of Recreational Travel by a Blind Person. In *The 22nd International ACM SIGACCESS Conference on Computers and Accessibility*. ACM, Article 26. `https://doi.org/10.1145/3373625.3417011`

[104] Jodi Sturge, Mirjam Klaassens, C Allyson Jones, France Légaré, Marie Elf, Gerd Weitkamp, and Louise Meijering. 2021. Exploring assets of people with memory problems and dementia in public space: A qualitative study. *Wellbeing, Space and Society* 2 (2021), 9. `https://doi.org/10.1016/j.wss.2021.100063`

[105] Ponnusamy Subramaniam and Bob Woods. 2016. Digital life storybooks for people with dementia living in care homes: an evaluation. *Clinical interventions in aging* 11 (2016), 1263. `https://doi.org/10.2147/CIA.S111097`

[106] Sunghee H Tak, Hongmei Zhang, and Song Hee Hong. 2015. Preferred computer activities among individuals with dementia: a pilot study. *Journal of Gerontological Nursing* 41, 3 (2015), 50–57. `https://doi.org/10.3928/00989134-20141029-01`

[107] Sunghee H Tak, Hongmei Zhang, Hetal Patel, and Song Hee Hong. 2015. Computer activities for persons with dementia. *The Gerontologist* 55, Suppl_1 (2015), S40–S49. `https://doi.org/10.1093/geront/gnv003`

[108] Barsa Tandukar, Pooja Vazirani, and Aqueasha Martin-Hammond. 2021. Advocacy Through Design: Partnering to Improve Online Communications and Connections in a Life Plan Community. In *Designing Interactive Systems Conference 2021*. 1695–1709. `https://doi.org/10.1145/3461778.3462009`

[109] Kong Saoane Thach, Reeva Lederman, and Jenny Waycott. 2021. Adoption of Videoconferencing for Social Connectedness among Older Adults: A Systematic Review. In *ACIS 2021 Proceedings, 15*. `https://doi.org/acis2021/15`

[110] Elizabeth Thiry, Siân Lindley, Richard Banks, and Tim Regan. 2013. Authoring personal histories: Exploring the timeline as a framework for meaning making. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 1619–1628. `https://doi.org/10.1145/2470654.2466215`

[111] John C. Thomas and John T. Richards. 2012. Achieving Psychological Simplicity: Measures and Methods to Reduce Cognitive Complexity. In *Human Computer Interaction Handbook: Fundamentals, Evolving Technologies, and Emerging Applications* (3rd ed.), Julie A. Jacko (Ed.). CRC Press, Boca Raton, 491–514.

[112] Myrte Thoolen, Francesca Toso, Sebastiaan TM Peek, Yuan Lu, and Rens Brankaert. 2022. LivingMoments: Bespoke Social Communication for People living with Dementia and their Relatives. In *CHI Conference on Human Factors in Computing Systems*. 1–18. `https://doi.org/10.1145/3491102.3517430`

[113] David Unbehaun, Konstantin Aal, Daryoush Daniel Vaziri, Peter David Tolmie, Rainer Wieching, David Randall, and Volker Wulf. 2020. Social Technology Appropriation in Dementia: Investigating the Role of Caregivers in Engaging People with Dementia with a Videogame-based Training System. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. ACM, 1–15. `https://doi.org/10.1145/3313831.3376648`

[114] John Vines, Peter C. Wright, David Silver, Maggie Winchcombe, and Patrick Olivier. 2015. Authenticity, Relatability and Collaborative Approaches to Sharing Knowledge about Assistive Living Technology. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing*. ACM, 82–94. `https://doi.org/10.1145/2675133.2675222`

[115] Jayne Wallace, Anja Thieme, Gavin Wood, Guy Schofield, and Patrick Olivier. 2012. Enabling self, intimacy and a sense of home in dementia: an enquiry into design in a hospital setting. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 2629–2638. `https://doi.org/10.1145/2207676.2208654`

[116] Jayne Wallace, Peter C. Wright, John McCarthy, David Philip Green, James Thomas, and Patrick Olivier. 2013. A design-led inquiry into personhood in dementia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 2617–2626. `https://doi.org/10.1145/2470654.2481363`

[117] Jenny Waycott, Ryan M Kelly, Steven Baker, Barbara Barbosa Neves, Kong Saoane Thach, and Reeva Lederman. 2022. The Role of Staff in Facilitating Immersive Virtual Reality for Enrichment in Aged Care: An Ethic of Care Perspective. In *CHI Conference on Human Factors in Computing Systems*. 1–17. `https://doi.org/10.1145/3491102.3501956`

[118] Jenny Waycott, Frank Vetere, Sonja Pedell, Lars Kulik, Elizabeth Ozanne, Alan Gruner, and John Downs. 2013. Older adults as digital content producers. In *Proceedings of the SIGCHI conference on Human Factors in Computing Systems*. 39–48. `https://doi.org/10.1145/2470654.2470662`

[119] Daniel Welsh, Kellie Morrissey, Sarah Foley, Roisin McNaney, Christos Salis, John McCarthy, and John Vines. 2018. Ticket to talk: Supporting conversation between young people and people with dementia through digital media. In *proceedings of the 2018 CHI conference on human factors in computing systems*. 1–14. `https://doi.org/10.1145/3173574.3173949`

[120] Rachel Wood, Emma Dixon, Salma Elsayed-Ali, Ekta Shokeen, Amanda Lazar, and Jonathan Lazar. 2021. Investigating Best Practices for Remote Summative Usability Testing with People with Mild to Moderate Dementia. *ACM Transactions on Accessible Computing (TACCESS)* 14, 3 (2021), 1–26. `https://doi.org/10.1145/3460942`

[121] World Health Organization and others. 2017. Global action plan on the public health response to dementia 2017–2025. (2017). `https://www.who.int/publications/i/item/global-action-plan-on-the-public-health-response-to-dementia-2017---2025`

[122] Aaron Yurkewich, Anita Stern, Rushmita Alam, and Ron Baecker. 2022. A field study of older adults with cognitive impairment using tablets for communication at home: Closing technology adoption gaps using InTouch. In *Research Anthology on Supporting Healthy Aging in a Digital Society*. IGI Global, 904–939. `https://doi.org/10.4018/978-1-6684-5295-0.ch050`

[123] Kos Zachos, Neil Maiden, Kristine Pitts, Sara Jones, Ian Turner, Malcolm Rose, Kevin Pudney, and Julie MacManus. 2013. A software app to support creativity in dementia care. In *Proceedings of the 9th ACM Conference on Creativity & Cognition*. 124–133. `https://doi.org/10.1145/2466627.2466637`

Chapter 3

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

Jiamin Dai and Karyn Moffatt. 2020. Making space for social sharing: Insights from a community-based social group for people with dementia. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*, ACM, 1–13. https://doi.org/10.1145/3313831.3376133.

Preface

This chapter grounds the thesis research in community settings through prolonged on-site fieldwork, achieving empirical contributions and building strong collaboration with community partners. Our goals were to uncover positive and challenging factors in community social experiences, as well as effective materials and prompts. Our interviews involved multiple stakeholder views from people with early to middle stage dementia, their primary family caregivers, and professionals, covering broad community social programs. Our observations of Tales & Travels offered a focused lens into an exemplary program, examining the details and uncovering a range of factors in social sharing. Tales & Travels was of particular interest due to its tailored design for socializing as it encouraged but was not restricted to reminiscing and storytelling. It was also distinctive in its non-clinical settings, outside home or care facilities, filling in a critical gap in community-oriented HCI work.

This chapter builds upon and adds to my long-term engagement in the local dementia community. Before, during, and after this fieldwork, in addition to my involvement in Tales & Travels, I have engaged in a variety of volunteering, training, and lecturing activities through the Alzheimer Society of Montreal as follows:

- I actively participated in the Alzheimer Cafés held at the Atwater Library and the Art Links program (guided tours and art-making workshops) held at the Montreal Museum of Fine Arts from 2016 to 2019.

- I completed two training sessions on dementia care held at the Alzheimer Society of Montreal in May 2018.
- I gave talks on "*Technology for Everyone: Designing for Aging and Dementia*" at two Alzheimer's Cafés in October and November 2018.
- I presented a webinar "*Empowering People with Dementia to Socialize*" upon invitation by the Huddol caregiver network in October 2019.
- I led a workshop "*Inspirations and Resources: A Conversation on Technologies for Promoting Social Interaction in Dementia Care*" at the Alzheimer Society Colloquium on Innovations & Assistive Technologies in Dementia Care in November 2019.

I was initially motivated to pursue this research topic by my experiences two decades ago interacting with my grandparents as they navigated living with dementia without access to community support or programming. In this research, I have adopted an interpretivist approach and an empathetic interaction methodological stance. Over the course of the work, I have evolved from an outsider to an insider in the Montreal dementia community. I view and presented myself to the participants as an engaged observer, learner, helper, and researcher. Indeed, my interpretations of the data have been informed by my interactions with stakeholders both within and beyond the research. Meanwhile, to the best of my ability, I sought to minimize my influence on participants and programs, especially during observations by, for example, conducting extensive preliminary work to familiarize participants with my presence. My research evolved in response to my engagement with the community as well as to the broader social context of the pandemic. Under constant self-examination and reflection, my positionality evolved throughout the research process. Different aspects of my identity and background (e.g., female, speaking English as a second language, a first-generation immigrant from mainland China, and redirecting from an industry job to graduate studies after settling in Canada in my early 30s) might have also influenced my interactions with participants and my interpretation of the data.

In addition to its contributions to in-person HCI work in dementia settings, this chapter lays the foundation for the following two chapters. It provides contextual knowledge and establishes partnerships for the follow-on virtual fieldwork presented in Chapter 4. It offers the groundwork and the dataset for the methodological self-reflections presented in Chapter 5.

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.

3.1 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.

3.2 Related Work

3.2.1 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].

3.2.2 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].

3.2.3 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.

3.3 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.

3.3.1 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 3.1.); 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.

Table 3.1 Dyad and caregiver background

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

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).

3.3.2 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.

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.

3.4 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.

3.4.1 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!

3.4.2 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).

3.4.3 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 continues 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.

3.4.4 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.

3.4.5 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.

3.5 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.

3.5.1 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].

3.5.2 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].

3.5.3 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.

3.5.4 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.

3.6 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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Bibliography

[1] Sarah Alsawy, Sara Tai, Phil McEvoy, and Warren Mansell. 2020. 'It's nice to think somebody's listening to me instead of saying "oh shut up"'. People with dementia reflect on what makes communication good and meaningful. *Journal of psychiatric and mental health nursing* 27, 2 (2020), 151–161. `https://doi.org/10.1111/jpm.12559`

[2] Alzheimer's Association. 2019. 2019 Alzheimer's disease facts and figures. *Alzheimer's & Dementia* 15, 3 (2019), 321–387. `https://doi.org/10.1016/j.jalz.2019.01.010`

[3] Arlene J Astell, Maggie P Ellis, Lauren Bernardi, Norman Alm, Richard Dye, Gary Gowans, and Jim Campbell. 2010. Using a touch screen computer to support relationships between people with dementia and caregivers. *Interacting with Computers* 22, 4 (2010), 267–275. `https://doi.org/10.1016/j.intcom.2010.03.003`

[4] Jeanette Bell and Tuck Wah Leong. 2019. Collaborative futures: Co-designing research methods for younger people living with dementia. In *Proceedings of the 2019 chi conference on human factors in computing systems*. 1–13. `https://doi.org/10.1145/3290605.3300582`

[5] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3 (1 2006), 77–101. Issue 2. `https://doi.org/10.1191/1478088706qp063oa`

[6] Sharon Lynn Chu, Brittany Garcia, Taylor Quance, Lisa Geraci, Steven Woltering, and Francis Quek. 2016. Understanding storytelling as a design framework for cognitive support technologies for older adults. In *Proceedings of the International Symposium on Interactive Technology and Ageing Populations*. 24–33. `https://doi.org/10.1145/2996267.2996270`

[7] Raymundo Cornejo, Robin Brewer, Caroline Edasis, and Anne Marie Piper. 2016. Vulnerability, Sharing, and Privacy: Analyzing Art Therapy for Older Adults with Dementia. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*. ACM, 1572–1583. `https://doi.org/10.1145/2818048.2819960`

[8] Masashi Crete-Nishihata, Ronald M. Baecker, Michael Massimi, Deborah Ptak, Rachelle Campigotto, Liam D. Kaufman, Adam M. Brickman, Gary R. Turner, Joshua R. Steinerman, and Sandra E. Black. 2012. Reconstructing the Past: Personal Memory Technologies Are Not Just Personal and Not Just for Memory. *Human–Computer Interaction* 27, 1-2 (Apr. 2012), 92–123. `https://doi.org/10.1080/07370024.2012.656062`

[9] Sarah Foley, Daniel Welsh, Nadia Pantidi, Kellie Morrissey, Tom Nappey, and John McCarthy. 2019. Printer Pals: Experience-Centered Design to Support Agency for People with Dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 1–13. `https://doi.org/10.1145/3290605.3300634`

[10] Steve Harrison and Paul Dourish. 1996. Re-place-ing space: the roles of place and space in collaborative systems. In *Proceedings of the 1996 ACM conference on Computer supported cooperative work*. 67–76. `https://doi.org/10.1145/240080.240193`

[11] James Hodge, Madeline Balaam, Sandra Hastings, and Kellie Morrissey. 2018. Exploring the Design of Tailored Virtual Reality Experiences for People with Dementia. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. ACM, 1–13. `https://doi.org/10.1145/3173574.3174088`

[12] James Hodge, Kyle Montague, Sandra Hastings, and Kellie Morrissey. 2019. Exploring Media Capture of Meaningful Experiences to Support Families Living with Dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 3300653, 1–14. `https://doi.org/10.1145/3290605.3300653`

[13] Amanda Lazar, Raymundo Cornejo, Caroline Edasis, and Anne Marie Piper. 2016. Designing for the third hand: Empowering older adults with cognitive impairment through creating and sharing. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems*. 1047–1058. `https://doi.org/10.1145/2901790.2901854`

[14] Amanda Lazar and Emma E. Dixon. 2019. Safe Enough to Share: Setting the Dementia Agenda Online. *Proc. ACM Hum.-Comput. Interact.* 3, CSCW (Nov. 2019), 1–23. `https://doi.org/10.1145/3359187`

[15] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. A Critical Lens on Dementia and Design in HCI. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM, 2175–2188. `https://doi.org/10.1145/3025453.3025522`

[16] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. Supporting People with Dementia in Digital Social Sharing. In *Proceedings of the 2017 CHI Conference on*

Human Factors in Computing Systems (Denver, Colorado, USA) *(CHI '17)*. Association for Computing Machinery, New York, NY, USA, 2149–2162. `https://doi.org/10.1145/3025453.3025586`

[17] Amanda Lazar, Jessica L. Feuston, Caroline Edasis, and Anne Marie Piper. 2018. Making as Expression: Informing Design with People with Complex Communication Needs through Art Therapy. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. ACM, 1–16. `https://doi.org/10.1145/3173574.3173925`

[18] Amanda Lazar, Hilaire J. Thompson, and George Demiris. 2016. Design Recommendations for Recreational Systems Involving Older Adults Living With Dementia. *Journal of Applied Gerontology* (Apr. 2016), 1–25. `https://doi.org/10.1177/0733464816643880`

[19] Stephen Lindsay, Katie Brittain, Daniel Jackson, Cassim Ladha, Karim Ladha, and Patrick Olivier. 2012. Empathy, participatory design and people with dementia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 521–530. `https://doi.org/10.1145/2207676.2207749`

[20] Galina Madjaroff and Helena Mentis. 2017. Narratives of Older Adults with Mild Cognitive Impairment and Their Caregivers. In *Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility*. ACM, 140–149. `https://doi.org/10.1145/3132525.3132554`

[21] Fabian Mertl, Nadine Meißler, Lena Wiek, Alina Fröhlich, and Alina Huldtgren. 2019. "Traumreise"-Exploring the use of multisensory digital media in dementia groups. In *Proceedings of the 13th EAI International Conference on Pervasive Computing Technologies for Healthcare*. 189–197. `https://doi.org/10.1145/3329189.3329199`

[22] Luca Morganti, Giuseppe Riva, Silvio Bonfiglio, and Andrea Gaggioli. 2013. Building collective memories on the web: the Nostalgia Bits project. *International Journal of Web Based Communities* 9, 1 (2013), 83–104. `https://doi.org/10.1504/IJWBC.2013.051373`

[23] Kellie Morrissey, Andrew Garbett, Peter Wright, Patrick Olivier, Edward Ian Jenkins, and Katie Brittain. 2017. Care and Connect: exploring dementia-friendliness through an online community commissioning platform. In *Proceedings of the 2017 CHI conference on human factors in computing systems*. 2163–2174. `https://doi.org/10.1145/3025453.3025732`

[24] Kellie Morrissey, John McCarthy, and Nadia Pantidi. 2017. The value of experience-centred design approaches in dementia research contexts. In *Proceedings of*

the 2017 CHI Conference on Human Factors in Computing Systems. 1326–1338. `https://doi.org/10.1145/3025453.3025527`

[25] Kellie Morrissey, Gavin Wood, David Green, Nadia Pantidi, and John McCarthy. 2016. 'I'm a rambler, I'm a gambler, I'm a long way from home' The Place of Props, Music, and Design in Dementia Care. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems*. 1008–1020. `https://doi.org/10.1145/2901790.2901798`

[26] Elly Park, Hollis Owens, David Kaufman, and Lili Liu. 2017. Digital storytelling and dementia. In *International conference on human aspects of IT for the aged population*. Springer, 443–451. `https://doi.org/10.1007/978-3-319-58536-9_35`

[27] S Tejaswi Peesapati, Victoria Schwanda, Johnathon Schultz, Matt Lepage, So-yae Jeong, and Dan Cosley. 2010. Pensieve: supporting everyday reminiscence. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 2027–2036. `https://doi.org/10.1145/1753326.1753635`

[28] Barbara A Purves, Alison Phinney, Wendy Hulko, Gloria Puurveen, and Arlene J Astell. 2015. Developing CIRCA-BC and exploring the role of the computer as a third participant in conversation. *American Journal of Alzheimer's Disease & Other Dementias®* 30, 1 (2015), 101–107. `https://doi.org/10.1177/1533317514539031`

[29] Mary Beth Riedner, Karen Maki, and Miriam Lytle. 2018. Becoming a dementia-friendly library. In *The Relevant Library: Essays on Adapting to Changing Needs*, Carol Smallwood Vera Gubnitskaia (Ed.). McFarland, Jefferson, NC, 187–194.

[30] Panote Siriaraya and Chee Siang Ang. 2014. Recreating living experiences from past memories through virtual worlds for people with dementia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 3977–3986. `https://doi.org/10.1145/2556288.2557035`

[31] Sarah C Smith, Joanna Murray, Sube Banerjee, Beth Foley, Joanna C Cook, Donna L Lamping, Martin Prince, Rowan H Harwood, Enid Levin, and Anthony Mann. 2005. What constitutes health-related quality of life in dementia? Development of a conceptual framework for people with dementia and their carers. *International Journal of Geriatric Psychiatry: A journal of the psychiatry of late life and allied sciences* 20, 9 (2005), 889–895. `https://doi.org/10.1002/gps.1374`

[32] Ponnusamy Subramaniam and Bob Woods. 2016. Digital life storybooks for people with dementia living in care homes: an evaluation. *Clinical interventions in aging* 11 (2016), 1263. `https://doi.org/10.2147/CIA.S111097`

[33] Elizabeth Thiry, Siân Lindley, Richard Banks, and Tim Regan. 2013. Authoring personal histories: Exploring the timeline as a framework for meaning making. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 1619–1628. `https://doi.org/10.1145/2470654.2466215`

[34] David Unbehaun, Konstantin Aal, Daryoush Daniel Vaziri, Rainer Wieching, Peter Tolmie, and Volker Wulf. 2018. Facilitating collaboration and social experiences with videogames in dementia: results and implications from a participatory design study. *Proceedings of the ACM on Human-Computer Interaction* 2, CSCW (2018), 1–23. `https://doi.org/10.1145/3274444`

[35] Jayne Wallace, Peter C. Wright, John McCarthy, David Philip Green, James Thomas, and Patrick Olivier. 2013. A design-led inquiry into personhood in dementia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 2617–2626. `https://doi.org/10.1145/2470654.2481363`

[36] Jenny Waycott, Frank Vetere, Sonja Pedell, Lars Kulik, Elizabeth Ozanne, Alan Gruner, and John Downs. 2013. Older adults as digital content producers. In *Proceedings of the SIGCHI conference on Human Factors in Computing Systems*. 39–48. `https://doi.org/10.1145/2470654.2470662`

[37] Daniel Welsh, Kellie Morrissey, Sarah Foley, Roisin McNaney, Christos Salis, John McCarthy, and John Vines. 2018. Ticket to talk: Supporting conversation between young people and people with dementia through digital media. In *proceedings of the 2018 CHI conference on human factors in computing systems*. 1–14. `https://doi.org/10.1145/3173574.3173949`

Chapter 4

Enriching Social Sharing for the Dementia Community: Insights from In-person and Online Social Programs

Jiamin Dai and Karyn Moffatt. 2023. Enriching social sharing for the dementia community: Insights from in-person and online social programs. *ACM Transactions on Accessible Computing* 16, 1 (2023), 1–33. https://doi.org/10.1145/3582558

Preface

This chapter moves forward from the work introduced in the previous Chapter 3. In the community my research is situated, in-person activities used to heavily outweigh the virtual probably due to community preferences and minimal technology use among people with dementia and some of their caregivers. Thus, the technological opportunities identified in Chapter 3 mainly stem from and add to co-located programs and activities.

The COVID-19 pandemic has severely disrupted the community programs appreciated by families living with dementia. To support social interactions in a sudden, urgently-needed shift to virtual environments, we must expand the scope to examine online social activities and critically contrast in-person and virtual contexts. Thanks to the community rapport established in the previous on-site fieldwork, we have distinctive opportunities to expand to virtual settings by follow-up interviewing caregivers and facilitators and reflecting on the newly adapted virtual Tales & Travels. Contrary to previous experiences and perceptions that largely preferred in-person settings, members of the local dementia community adapted to virtual activities unexpectedly well. However, more nuances need to be uncovered in the recent transition to remote deliveries of social programs. Building upon the findings from this virtual fieldwork, this chapter offers a set of approaches to opening new design opportunities in a timely response to the design spaces changed by the pandemic. Insights from online activities can have a prolonged impact on community-based social programs and HCI research in the dementia context.

The format of this chapter is a journal article ([19]) as an extended version of the published conference full paper ([17]), a common practice in the field of HCI. While incorporating summaries from the previous chapter, this chapter makes stand-alone contributions with approximately 80% new content. More specifically, this chapter presents a new Introduction section, an extended Related Work section, a new Methods section including a summary of the previous on-site fieldwork methods for context, a new Findings section including a small portion of cross-references to previous findings for contrast, a new Discussion section including several relevant points from the previous chapter, and a new Conclusion section. This chapter is a preprint version of the article published in the ACM Transactions on Accessible Computing after the initial thesis submission.

Abstract

The dementia community faces major challenges in social engagements, which have been further complicated by the prolonged physical distancing measures due to the COVID-19 pandemic. Designing digital tools for in-person social sharing in family and care facility settings has been well explored, but comparatively little HCI work has focused on the design of community-based social technologies for virtual settings. We present our virtual fieldwork on remote social activities explored by one dementia community in response to the impacts of the pandemic. Building upon our previously published on-site fieldwork in this community, we expand on our initial publication by follow-up interviewing caregivers and facilitators and reflecting on a virtual social program. Through thematic analysis and contrasting in-person and online formats of the program, we deepened the understanding of virtual social engagements of the dementia community, examining their efforts to leverage physical objects and environments, enhance open and flexible experiences, and expand collaborative space. We propose to open new design opportunities through holistic approaches, including reimagining community social spaces, rethinking agency in people with dementia and caregivers, and diversifying HCI support across communities and stakeholders.

4.1 Introduction

The dementia community encompasses people with dementia along with their families and friends and a diverse group of professionals who provide care and facilitate activities. Prolonged physical distancing measures due to the COVID-19 pandemic have further complicated the delivery of social programming for people with dementia. Within face-to-face family and care settings, HCI research has explored digital tools for social sharing ("sharing for the purpose of communicating with social contacts and fulfilling relational goals" [46]). For example, personalized ambient displays have been developed for reminiscence and conversations among family members [15]. Print media devices have been built to prompt quizzes for interactive group activities in care homes [27]. In co-located community contexts, emerging social programs in cultural establishments such as libraries (e.g., [22]) and museums (e.g., [37]) have proven effective in creating positive experiences for both people with dementia and their caregivers. However, comparatively little work has focused on the design of community-based social technologies for virtual settings.

These gaps and emerging challenges motivate our fieldwork in the dementia community, the on-site followed by the virtual, to identify opportunities for technology design. Our motivations for community and online settings echo the Alzheimer's Association's most recent call for better supporting families living with dementia through community-based long-term programs while recognizing technological and accessibility challenges during the transition to remote care delivery [3]. The current technological toolbox has not yet reached its full potential for improving the quality of life for families living with dementia. A better understanding of how to provide virtual community-based 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. The pandemic has heightened recent demands on and shifts to virtual socialization, but the valuable insights from these new community initiatives can benefit HCI research and practice in the long run, integrating co-located and virtual activities and exploring holistic social computing approaches to enriching social sharing in the dementia context.

This article presents our virtual fieldwork, reported for the first time here, focusing on remote social activities explored by the dementia community in response to the impacts of the COVID-19 pandemic. It builds upon our on-site fieldwork, originally published at ACM CHI 2020 [17], focusing on in-person social activities in the dementia community. We expand on our initial publication by adding new materials from follow-up interviews of three caregivers and two facilitators from the first study and reflections on 35 sessions of a virtual social program. Revisiting the themes from the first study, we broaden the scope of our work to online settings and correspondingly offer an expanded spectrum of opportunities for technology design. This article contributes (1) a deepened understanding of virtual social engagements of the dementia community by comparing and contrasting in-person and online settings and (2) a set of considerations to expand design space through holistic approaches, including reimagining community social spaces, rethinking agency in social experiences, and diversifying HCI support across communities and stakeholders.

4.2 Related Work

4.2.1 Empowering People with Dementia in HCI Research

HCI research increasingly focuses on empowering people with dementia, leading to frameworks such as *critical dementia* and *technology narrative* that help reposition research approaches to designing for and with people living with cognitive impairments. *Critical dementia* positions people with dementia as competent, engaged, and capable of expressing themselves meaningfully, and HCI researchers interact with them in an empathic and empowering way, encouraging their perspective, creativity, engagement, and rich emotional expression [45]. *Technology narrative* aims to understand the lived experiences of people with cognitive impairments and emphasize the enjoyment of life with technological support over traditional narratives of suffering from impairments [54]. Inclusive design practices engage people with dementia and expand design spaces, enabling researchers to build empathic relationships and co-create with participants [27, 47, 51]. 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 [60].

HCI researchers have explored diverse fieldwork strategies to empower people with dementia and engage them in design, e.g., exploring props and music [61] and using probes to design personal artefacts [77]. Prolonged fieldwork has proven to be an effective approach to uncovering design requirements, e.g., by yielding implementations that acknowledge participants' preferred media and the lack of internet access in care facilities [27]. Prior work has shown that participants can strengthen their engagement in the co-design process as co-researchers and collaborators [5]. More recently, the collective efforts of HCI researchers working in dementia care contexts have revealed higher-level considerations. For example, ethical complexities have been examined through the lenses of situated practice, emotion, and everyday experiences, drawing attention to research impact and clarity, as well as assistive products' technological end-of-life [33]. A human rights-based approach has further been proposed to create a respectful environment that actively engages people with dementia throughout the design process [11]. Empowering people with dementia can have broad impacts, e.g., through self-authored content that effectively reduces the stigmas surrounding dementia [42].

4.2.2 Personalizing Technologies for People with Dementia

Person-centered design approaches have been widely adopted to aid people with dementia in reminiscing and sharing, e.g., developing digital life storybooks to improve person-centered care [72] and integrating personally tailored design with existing routines of participants' everyday lives [51]. People with dementia can be involved in appropriating media content [27] and personalizing interactive media [32, 34] for their preference and enjoyment. In particular, it has proven effective to focus on positive memories and feelings and avoid triggering distress or unpleasant memories [48] while reducing the pressure to produce a correct answer or recollection. Generic prompts, e.g., regional materials adopted by CIRCA [4, 67]), have shown effectiveness in avoiding possible frustration or tension when people with dementia fail to recognize personal items [4]. Other successful strategies include prompting reminiscences through non-personalized materials covering all life periods [66] and mitigating negative memories through playful design [71].

A wide range of technologies has been explored to support the diverse communication needs of people with dementia. Individualized interactive sound players can mobilize everyday sounds to evoke meaningful social and reminiscing cues and experiences at home [35]. AI-driven personalization can potentially support the fluctuating accessibility needs of people with dementia, particularly in terms of adaptive interfaces for changes in various types of memory [53]. Notably, robotic pets have been developed as functional household appliances to facilitate playful interaction in daily practice in residences [55], and low-cost robot pets have been examined in terms of usability and impact in varied use contexts [39].

4.2.3 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 [14]. For people with complex communication needs, artmaking can create a space for expression and communication [47], which calls for careful reinterpretation and contextualization to avoid misinterpretation or criticism [43]. 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 [46].

Recent design work has enhanced technological aids to better support shared social experiences for people with dementia and their families. For example, a tablet app provides opportunities for meaningful and pleasurable joint activities through cooperative games for family visits to care centres [62]. A communication system integrates digital messages with printed postcards to promote lasting social contact and inclusive social dynamics within families [75]. More broadly, technology can enable social agency for people with dementia, offering opportunities to create and maintain social connections [27] and share stories in a meaningful way [65]. Conversation tools can connect different generations within a family and increase participants' agency in social settings [81]. 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 [27]. Moreover, social technology can help relieve facilitation burdens, e.g., conversation aids like CIRCA make it easier to facilitate a shared interaction with no need for caregivers to prompt question after question to sustain the conversation [4].

4.2.4 Supporting Remote Interaction in Accessibility Contexts

With the recent shift to remote interaction during the pandemic, accessibility research has addressed the complex communication needs of vulnerable populations in virtual environments, e.g., for people with vision impairments [49] and hearing impairments [70]. One study investigated the videoconferencing experiences of the aphasia community and uncovered their unique and creative adjustments to AAC communication strategies (including nonverbal utterances, props, and gestures) [64]. In senior residence settings, HCI research has facilitated immersive virtual reality and drawn attention to benefits, risks, and challenges in full immersion through an ethic of care perspective [78]. A wide range of literature from fields including geriatrics and nursing has revealed the benefits and limitations of using videoconferencing to foster social connectedness among older adults [73], echoed by HCI research findings on older adults forming a community of practice to tackle usability issues of online conferencing tools [68].

Meanwhile, recent HCI work in dementia covers a variety of virtual elements, e.g., online platforms for dementia information [23], self-management systems adopted by people with mild to moderate dementia [26], and interaction between sensory changes and everyday technology use [25]. Studies have also examined the impacts of the pandemic through the lenses of residence staff perceptions [38] and multi-stakeholder teamwork in designing virtual reality exergames [63]. The increased need for virtual interaction has prompted the development of best practices for remote summative usability testing involving people with dementia [82].

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]. Prior HCI work shows the ability of people with dementia to enjoy the process of creating and sharing art and stories. The primary social occasions of previous studies 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), our previous work contributes to understanding socialization in public events and diversifying social sharing spaces for people with dementia, especially in community-based group settings [17]. However, remote interactions necessitated by the COVID-19 pandemic pose extra challenges and demand an extension of our work to virtual settings.

4.3 Methods

4.3.1 Research Settings: The In-person and Virtual Tales & Travels Program

Our fieldwork was situated in the Tales & Travels program (adapted from [69]), which provides an exemplary case of effective community programs for people with dementia. This storytelling-oriented social program for people with dementia (usually in the early to middle stages) is hosted by the Westmount Public Library,[1] Greater Montreal, Canada, in collaboration with the Alzheimer Society of Montreal. In its in-person format prior to the COVID-19 pandemic, the program invited people with dementia, as well as their caregivers, to the library to explore various countries by browsing books and print materials, tasting featured snacks, and watching travel guide videos. Each session had one theme country and lasted about two hours. Our on-site fieldwork in 2019 involved non-intrusive observations of Tales & Travels and semi-structured interviews with dyads of people with early-middle stage dementia and their primary family caregivers, individual

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[1] https://westlib.org/iguana/www.main.cls?surl=home

caregivers, and Tales & Travels facilitators (see Table 4.1, Column 1–4).

Since February 2021, Tales & Travels has been adapted to an online format to accommodate social distancing restrictions. 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. Our virtual fieldwork, conducted in 2020 and 2021, involved online interviews (prior to the launch of virtual Tales & Travels) with a subset of caregivers and facilitators who participated in the original fieldwork (see Table 4.1, Column 5), followed by reflections on volunteering and facilitation experiences at virtual Tales & Travels.

In both the in-person and virtual iterations, Tales & Travels creates a friendly group setting and encourages people with dementia to share stories and memories while socializing within the group. This program was of particular interest due to its tailored design but not our sole focus. In our on-site and virtual fieldwork, a broader orientation offered richer insight by allowing participants to compare and contrast their social experiences in various community activities. Investigating the in-person and remote versions of the same social program also provided opportunities to uncover the common and distinctive challenges in physical and virtual social settings.

Table 4.1 Participant backgrounds

ID[1] (Gender/Age)	Relationship	Dementia conditions	Professions	Participated in both studies
P1 (M/84)	Spouses	Mid-stage Alzheimer's		
& C1 (F/74)				C1
P2 (M/90)	Spouses	Mid-stage Alzheimer's		
& C2 (F/78)				
P3 (F/80)	Neighbours	Mid-stage vascular		
& C3 (F/52)				
P6 (M/76)	Spouses	Mid-stage frontal temporal		
& C6 (F/70)				C6
P7 (F/81) & C7 (Atypical[2]/56)	Common-law[3]	Early-middle stage Alzheimer's		
C4 (F/75)	Spouse	Mid-stage vascular		
C5 (F/61)	Daughter	Father: diagnosis unclear; Mother: late-stage Alzheimer's		C5
C8 (F/54)	Daughter	Father: mid-stage Alzheimer's		
F1			Librarian	
F2			Coordinator, Alzheimer Society	F2
F3			Coordinator, Alzheimer Society	
F4			Librarian	F4

[1] P – People with dementia, C – Caregivers, F – Facilitators.
[2] Self-described.
[3] Since the publication of [17], the legal status of P7 and C7 was retroactively changed from friends forming a de-facto family to common-law companions.

4.3.2 Study 1: On-site Fieldwork

Study design

Our on-site fieldwork was 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? More methodological details are described in our previous publication at ACM CHI 2020 [17].

This study consists of three parts:

(1) 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., [54]), interviewing dyads could hear the voices of both care-recipients and caregivers.

(2) 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.

(3) 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 multisensory materials. We also observed how facilitators maintain conversations and mediate emerging challenges.

Before starting the data collection in March 2019, the first author was a registered volunteer for the Alzheimer Society of Montreal 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.

Data collection and analysis

This study was reviewed and approved by our institutional research ethics board. The interviews (see Table 4.1, Column 1–4) 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. 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.[2] At the time of the interview, the most experienced facilitator had run 43 sessions, and others had facilitated 9, 15, and 24 sessions.

Each interview took 1–2 hours, and 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. The first author took an observer-participant role, greeting participants and sitting at a table with

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[2] To protect the anonymity of the facilitators, we reported their backgrounds collectively, instead of detailing on the individual level.

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 [8] on the interview transcripts and observational field notes with NVivo 12.[3] 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 interpret the quotes and examples.

4.3.3 Study 2: Virtual Fieldwork

As we concluded the on-site fieldwork (published at ACM CHI 2020 [17]), the COVID-19 pandemic severely disrupted the community programming like Tales & Travels. To support social interactions in a sudden, urgently-needed shift to virtual environments, the organizers of Tales & Travels rapidly developed an online version of their program. To better understand virtual social sharing, we must expand the scope to examine online

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[3] https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home

social activities and critically contrast the findings from in-person and virtual settings. Insights from online activities can have a prolonged impact on community-based social programs and HCI research in the dementia context.

Study design

Our virtual fieldwork is guided by three research questions (RQs):

- RQ1: What are the emerging challenges in virtual social engagements for the dementia community from the perspectives of caregivers and professionals?
- RQ2: What strategies and materials are effective in supporting the dementia community in virtual social engagements?
- RQ3: What usability features of the technological tools enable or hinder virtual social engagements for the dementia community?

This virtual fieldwork consists of two parts:

(1) We conducted semi-structured online interviews with a subset of caregivers and facilitators who participated in the previous study in 2019. The interview questions focused on how physical distancing changed the social lives of people with dementia and their caregivers in the first year of the pandemic, as well as how professionals adjusted their work to continue helping them stay socially active and navigate emerging challenges in virtual settings. Building upon direct the input of people with dementia from our on-site study and prior work (e.g., [46, 27]), these interviews aimed to add caregiver and

professional perceptions on supporting the broader dementia community in virtual social engagements. The semi-structured approach allowed for a consistent set of data, while maintaining flexibility for a deeper understanding of participants' perspectives.

(2) After the conclusion of our interviews, the Tales & Travels social program for people with dementia was adapted to an online format, and the first author was invited to join as a volunteer facilitator. We reflected on the first author's volunteering and facilitation experiences at the virtual Tales & Travels. Our reflections aimed to analyse the strengths and challenges of virtual social programs inclusive of people with dementia and their caregivers, exploring technological opportunities to better support the dementia community in social activities.

Procedure

This study was approved by our institutional research ethics review board. Interview invitations were sent via email or text to the caregivers and the facilitators in our previous study. Due to the additionally challenging nature of virtual conversations, we did not approach people with dementia directly but encouraged caregivers to relay comments from their loved ones. The interviews were about daily life and work, with minimal privacy concerns and very low risk for our participants. Participation in the interviews was confidential.

Participants could choose to be interviewed via email, telephone, or Zoom. We advised participants not to include sensitive or identifiable information in emails. As they all chose telephone or Zoom, the interviews were only audio-recorded. When using Zoom, we sent meeting links directly to each participant, created a waiting room, set a password to gain entry, locked the meeting once started, informed participants that they could log in with only their first name or pseudonym for further confidentiality and that they had the option of turning their video off. We turned off the cloud recording feature and recorded the audio directly to our own device. After the participants expressed their interest in the interview, we provided an informed consent form via email (or another remote means preferred by the participant). Before we presented our questions, we asked participants to confirm that they had read the form and consented to participate via email or text or verbally.

Invited by F4, the first author joined the virtual Tales & Travels as a volunteer and later a facilitator, including the pre- and post- session facilitator debriefs. With the permission of the facilitators, she took reflexive notes after each session.

Data collection and analysis

Five interviews with three caregivers and two facilitators (see Table 4.1, Column 5) were held via Zoom between November 2020 and March 2021. Each interview lasted 30–55 minutes, and each participant received a $30 honorarium.

Our reflections included 35 virtual Tales & Travels sessions from April to December 2021. Of these sessions, the first author joined 26 as a volunteer and 9 as a facilitator. After each session, she took reflexive notes on informative incidents, including both the positive experiences and the challenges encountered. She also recapped pre- and post-session debriefs with the other facilitators, highlighting their strategies and comments. These reflective notes enabled us to learn from the first author's participant-observer role without recording any personal information.

We conducted a thematic analysis on the interview transcripts and reflexive facilitation notes within MAXQDA2022.[4] The first author performed inductive open coding, and both authors discussed the codes and themes as they emerged and evolved. The initial results from facilitation reflections were presented to F4 for member checking to ensure accurate interpretation of the data and respect for participants' privacy. Any information that might potentially compromise the privacy of any participants, caregivers, or facilitators was removed or rephrased. The member checking process, increasingly recognized as essential in accessible computing research (e.g., [6]), provided additional validation and feedback on our reflections.

4.4 Findings

In this section, we detail the findings from our virtual fieldwork, reporting them here for the first time. We analyzed this dataset independently from our earlier data but drew from the previously published on-site fieldwork to aid interpretation. This was particularly important because all participants in the virtual fieldwork also participated in the on-site fieldwork. Thus, the follow-on interviews and reflections were built upon a shared understanding established in the earlier work. This influenced how participants framed

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[4] https://www.maxqda.com/

their responses and how we contextualized our interpretations of the new dataset. In detailing our new results, we selectively present prior results where they add depth or contrast to the virtual fieldwork findings.

Our thematic analysis of the virtual fieldwork data reveals three themes, all of which interrelate in addressing our RQs (see Table 4.2). First, "complexities in social engagements for the dementia community" highlights how the pandemic magnified and shifted caregiving and socializing challenges, including the individual resilience and the collective effort in navigating hard times as a community. Second, "roles of technology in new social engagements" focuses on the strengths and challenges of technological tools in new social engagements explored by the dementia community. Third, "re-building social experiences as a virtual community" learns from the successes and setbacks of recently adapted online social programs, particularly Tales & Travels, to investigate system features in fostering community connectedness in virtual settings. Most summaries of the Study 1 results were cross-referenced in the third theme.

4.4.1 Complexities in social engagements for the dementia community

More challenging social lives with more complicated caregiving situations

The sudden yet prolonged physical distancing restrictions resulted in complex caregiving situations for each family, as reported by all caregivers. C1 and C6 were caring for their husbands at home, and both families' daily lives were further complicated by the

Table 4.2 Theme overview

Themes and subthemes	Definitions	Relation to RQs
Complexities in social engagements for the dementia community - More challenging social lives with more complicated caregiving situations - Individual resilience and collective support	Highlighting how the pandemic magnified and shifted caregiving and socializing challenges, including the individual and the collective effort in navigating hard times as a community	Addressing RQ1 in caregiving and community contexts
Roles of technology in new social engagements - Much-needed online activities - Additional demands on caregiver support	Focusing on the strengths and challenges of technological tools in new social engagements explored by the dementia community	Addressing RQ2 and RQ3 in technological contexts
Re-building social experiences as a virtual community - Leveraging physical objects and environments - Enhancing open and flexible experiences - Expanding collaborative space - Technological accommodations	Learning from the successes and setbacks of recently adapted online social programs, particularly Tales & Travels, to investigate system features in fostering community connectedness in virtual settings	Addressing RQ2 and RQ3 in social programming practice

pandemic. C1 described how they were “fortunate” to receive home visits from various care professionals, even with several disruptions along the way due to the changing pandemic restrictions. Being more confined at home amplified the household maintenance needs and conflicting attitudes towards outside assistance.

> C1: [My husband] really likes [those visits] although he keeps saying, ‘I don’t need a babysitter. . . ’ . . . he’s still somewhat negative about people coming to help me. . . . probably being home [makes me] very aware I live in a very big house. There’s a lot needs to be done that isn’t getting done.

Similarly, C6 appreciated the occasional assistance with daily tasks, but she had to run errands quickly: “I can’t really leave him [at home alone].” She stressed how the cancellation of her husband’s usual community programs partly contributed to his significant physical and mental decline, which required accommodations to their living space.

> C6: It's been very, very, very difficult. [He] has gone from being pretty much autonomous to being almost totally dependent because there's no more outings. He used to go three times a week to the Alzheimer Society. He used to go to the day center. So, there's been nothing ... no socialization. ... I had major renovations. ... I have a shower that ... he can go in with a walker... And he barely walks ... for the last week or so, he hasn't even been very hungry, which is unusual for him. *[Later]* He sleeps most of the day. He's more incontinent than he was ... He's had a couple of falls.

People with dementia living in care facilities were extremely vulnerable in a healthcare crisis, with both their physical and mental wellbeing at risk. Their family caregivers faced additional challenges with respect to the rapidly changing restrictions at the residence and in the home area. C5 recounted the intense strain on her mother and their family, as well as the facility's "lack of communication:"

> C5: [In] the early months of COVID, my mother was diagnosed as being positive but asymptomatic... [After] a few months... she was negative. And so, I was able to go see her, dressed like an astronaut. ... The residence she was at, 50% of the residents died. ... [Those] months were extremely stressful because the staff was sick... you'd call, and nobody would answer...

Caregivers and their loved ones faced less structured social lives and reduced social circles. C1 described how they missed dining with guests, travelling, and socializing with the sailing club, all of which used to be their routine for years.

> C1: [My husband] does miss the fact that we're not entertaining people, . . . 'Why isn't anyone coming to eat with us?' *[Later]* [He] is missing some of the exterior people that we socialized with quite a bit.

C6 explained the nuanced effects of being isolated, especially in winter, and excluded from the community. Such changes of routine and disconnection from their children and extended social circles made her feel trapped and much less motivated:

> C6: . . . ever since the weather has changed, we're in the house all the time . . . nowhere to go, and no one to see. . . . it's very hard to be included . . . when you can't participate when you can't actively contribute anything. *[Later]* We don't do anything. . . . I don't feel like doing anything. . . . I feel like I'm in a cage . . . I know I need to be grateful because we have a nice big house and everything, [but] it's still a cage.

C5 highlighted the lack of "spontaneity of a leisure activity," including her efforts to reduce the risks of exposing her mother to the virus and missing unplanned leisure time out of their house.

> C5: . . . everything has to be planned [and] calculated . . . one thing that I'm missing [is] being able to just [go somewhere] . . . I try to restrict doing

> anything with others until after I see my mother ... because I don't want the risk of catching anything and passing it on to her.

This subtheme deepened the understanding of the Study 1 theme "Active Social Lives and Community Programs," as summarized below:

> 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. Day programs became an important part of many participants' social lives, in some cases their only structured routine. Typical programs included Alzheimer Society 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 [the] activity."*

Individual resilience and collective support

Participants endured many frustrations throughout the pandemic with the loss of socialization on which they depended for emotional support. As C6 summarized, "the

COVID, it has taken the *joie de vivre...*" She described the sudden deprivation of social contacts leading to depressing thoughts:

> C6: I overthink everything . . . something in my head . . . goes around and around and around. . . what we miss [is] the contact. . . I'm very social. . . . Every Sunday I [used to] have [a] minimum of 10, 11 people. . . . I took a real dive. . . so sudden.

Caregivers demonstrated prominent resilience by staying positive and taking comfort in reciprocal help. C6 coped by baking, reading, knitting, and playing puzzles, and she appreciated the opportunity to open her swimming pool to the neighbourhood and receive help with groceries.

> C6: Over the summer, it was fun. . . I set up a tent in the. . . backyard, and the kids [in the neighbourhood] would come and swim. . . . I got to know people better. . . They phone and say: 'You need anything at the grocery store. . . ?' *[Later]* I'm hopeful that we'll get through it. . . I'm doing my best, but it is difficult. . . I used to always say no to help, but now I'm saying yes.

Similarly, C1 showed her resilience through optimism and reconciliation, "trying to think the positives" and "come to terms with it" despite going "through some real downers." In addition to extra efforts with holiday decorations to lighten the mood, she took pleasure in getting newspaper deliveries and supporting local restaurants.

> C1: [One] of the positives is the Gazette comes six days a week. So, I am very thankful to have that little routine... we're trying to help the local businesses . . . I can phone [the restaurants], and they have it ready and they write on the bag: 'Have a good meal...'

Tenacious professionals adapted to sudden, drastic changes in the workplace, including temporary furlough for one of the facilitators. Both facilitators tried to rebalance work and life while remaining mindful of their clients' challenges. F2 described how she built some symbolic divide between work and life and how the Alzheimer Society team diligently provided caregiving support.

> F2: [The] physical. . . limit between work and. . . private life [pre-pandemic] just doesn't exist anymore now. . . . I had to find ways of. . . having these new. . . symbolic limits [like] changing when I stopped working. . . *[Later]* . . . it's really hard for the people we're working for at the Society. They're having a very, very difficult time. And it's important to do our best to make them feel better, even though . . . we can't do things the way they were before. . . . on the team, everyone's doing their best.

Members of the dementia community navigated the emerging challenges collectively by relying on each other to cope with changes, uncertainties, and losses. When Tales & Travels resumed online, the facilitators often observed the returning participants' deterioration, offering each other facilitation hints and emotional support. Through support groups or other personal connections, caregivers inevitably heard about the decline of others in their network, including speech loss and dramatic personality change: "another one that [we] will be losing [at Tales & Travels]. Very sad" (C1). C5 described how she missed a previous participant at Tales & Travels who passed away.

> C5: ... you get very attached to them, and you know that they're vulnerable ... I was really, really saddened to hear that [this participant] had passed... I know you're not supposed to have favourites, but she was my favourite. ... I just loved her, and she was always so positive and so inquisitive.

Professionals had always been cognizant of participants' deterioration, which was the nature of dementia but now worsened by the pandemic. F4 described "bracing" himself when preparing to reach out to participants whose physical, mental, and social conditions were possibly affected during the lockdowns.

> F4: [Deterioration] happens even before the pandemic, where we'd come back from the summer, and someone would... have advanced a lot in their disease...[Now,] physical mobility may have been reduced... social interactions reduced, mental health for caregivers and the people with [dementia] ... we're talking about people in the age group that are ... affected more likely by COVID... I'm bracing myself a little bit for that.

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. In C1's words, "all of that physical space… was so necessary to us." C5 and C6 noticed how the pandemic shifted people's attitudes towards each other, sometimes frustrated by discrimination against their loved one with dementia.

> C5: I find the world is angry… People… don't acknowledge you… the world has become rude… people see [each other] as a walking virus… you'd walk down the sidewalk and people would, like, go to the opposite sidewalk. … this sense that human beings are a danger to each other…

> C6: Part of my frustration is… it's disrespectful… It's a weird, weird, weird world. … I see some discrimination [against us]. I've never felt that before. [I] see… people avoid [us].

Theme summary

The first theme brought forward the nuanced effects of the pandemic and remote interactions on families living with dementia. Our findings revealed 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. We delved deep into the individual and collective efforts from members of the dementia community to reconcile with the dramatic changes throughout the pandemic. These findings explored nuanced losses, social and emotional connections, and space for mutual support, highlighting the interdependence between the dementia community and the broader social landscape of shifting interpersonal interactions and physical space.

4.4.2 Roles of technology in new social engagements

Much-needed online activities

As families living with dementia tackling complex social engagements, professionals echoed their clients' difficult loss of routine due to the cancellation of in-person programs. They worked hard to adjust to the shifting social and technological environments by being much more active on social platforms such as Facebook and Instagram. F2 further stressed the Alzheimer Society's urgent efforts to switch to virtual activities and offer any support possible, despite having limited resources.

> F2: It's very difficult because ... people don't have their usual routines ... we're really doing our best at the Society to ... maintain contact and ... offer our support. ... it definitely isn't the same as what we used to have ... like Tales & Travels [which] was a really big part of their weeks. We managed to ... do some little things ... like the Laughter Yoga. ... it's just an hour [per] week ... they're still in their living room in their home that they don't get out of.

F2 described their awareness of technological challenges when adapting in-person programs to virtual formats:

> F2: ... online activities for people living with dementia, ... it really depends

> on their abilities. But for people who are in more moderate stages… it's hard for them to do several things at the same time. And focusing on the screen is already a lot. … a lot of our clients… don't even have Internet at home. [Some] have a tablet at home, but honestly, they just don't know how to turn it on. [Some] can use their email, but outside of that… it's just unknown territory… [for those] who are technologically challenged… it's really the main way we have now to reach out to people.

F4 echoed their devotion to the program, being mindful of clients' urgent need for socialization.

> F4: Tales & Travels was… on my mind… I was in contact with everyone... [I] was mindful of the fact that people are already in difficult situations when they're at home, not receiving as many services as they need... they are probably on one of the top lists of… our patrons that could use some support… So, I reached out to the Alzheimer Society… about how we would move the Tales & Travels to Zoom.

Such timely adjustments towards virtual programming were greatly appreciated by caregivers, yet C1 highlighted her appreciation of close interactions in the community and pointed out that virtual social programs might need more planning.

> C1: Part of what was such fun [at Tales & Travels] was the coming together, and [the librarian] and the snack… Yes, we can watch the videos [online], but

> it was more that interaction... we can show each other the maps and the pictures. We could hold them up. But it was that human coming together. *[Later]* The socialization is not the same. Spontaneity is less as we do not have access to all the materials which used to be on the tables. ... I find Zoom meetings have to be more formally organized.

Virtual visits facilitated by care facilities were deeply appreciated: "[The staff] would bring the iPad to her room... we would be able to see her, so that was really nice" (C5). With her husband at home and his brother also living with Alzheimer's in a residence, C1 faced the combined challenge of two caregiving scenarios. She described her brother-in-law as being "very restricted" at the residence and feeling "very upset about [lockdowns]" while frequent video calls helped:

> C1: He does have a [web] portal. So, we do have video chats, probably every day, sometimes three or four times a day.

All three caregivers took on new engagements themselves with the help of technologies. For example, C6 enjoyed online games with her family, such as interactive treasure hunts and virtual escape rooms. C1 managed to continue her previous in-person yoga classes virtually but lacked the bandwidth to find the similar replacement for the Zumba she enjoyed. She had to balance keeping her husband company and engaging with virtual activities, in addition to managing screen fatigue.

> C1: … I haven't joined in all of the things [the Society] is offering. I think it's fatigue of being on the screen... *[Later]* I'm missing … Zumba … I just haven't taken the time to look for [a virtual alternative] … because [my husband] gets angry with me being on the screen too long.

More positively, C5 appreciated that "technology allowed a certain level of normalcy," and she was enthusiastic about new virtual activities, "completely tied to [her] laptop." Regularly via Zoom, she started morning stretch exercises with a local trainer and learning ukulele through a local women's centre. She also took a statistics course to complete her sociology degree and enjoyed family time online. Her accounts highlighted positive roles of technology in remote interactions with respect to emotional satisfaction and control.

> C5: I'm connecting to you emotionally [over Zoom] on the same level as if I was in at the library with you... *[Later]* [Learning] ukulele, that I may have not done in person. … if you feel a bit embarrassed, you just turn your video off [or mute] … social distancing provides us the opportunity to control our feelings in a way through technology that we can't in person.

Additional demands on caregiver support

In finding new social activities for their loved ones, caregivers explored new technological tools, both tangible and virtual, to help with specific needs. For example, a robot dog provided C1's husband with a much-needed source of focused interaction and social stimulation.

> C1: [My husband] doesn't seem able to focus, and I think that's the hard part for him now. ... we have bought . . . a robot dog. . . . It's so big and it's like a golden colour and has a little red white neck and it barks and it whines and it breathes deeply, and then it closes its eyes. [He] has a dog, and his brother has a dog. And sometimes when we're on video chat . . . with the two dogs and they're barking at each other, and this seems to bring a lot of [joy] . . . [My husband] talks to that dog every single day for about half an hour . . . he's occupied because he gives the dog the life history of dogs and his life [and] interacts with that dog.

C1 deemed the robot pet "a lifesaver" that can keep her husband entertained and provide her with some short respite. Other technological tools, however, required additional caregiver attention. Zoom enabled C6's husband to continue his art therapy remotely, but C6 had to provide technical and procedural support because his cognitive decline prevented him from navigating the virtual environment and physically drawing on his own. C6's accounts on caregiver support were later echoed in virtual Tales & Travels as we observed that many caregivers were needed in setting up Zoom and accompanying their loved ones in virtual sessions.

> C6: . . . he can't handle [Zoom]. . . . [the art therapist] sends me the link every week. . . . I set him up. Some days he cooperates. Some other days he doesn't

> want to … at least he sits there and talks to her. … he can't really [paint by] himself anymore. So, she sent me photocopies of [drawings] and carbon paper. And I trace it onto a canvas, and then he paints it. … I have to be sitting almost next to him. … I have the one that I've traced. … when they discuss a colour, I write it on the copy … so that I know what he's supposed to be doing because I'm not artistic. … when he first started, he would just … look at the picture and … draw it freehand.

C5 and her family members worked together to stimulate her mother as much as possible during 30-minute virtual visits arranged by the residence. However, the conditions of late-stage Alzheimer's required more tangible interactions than the virtual:

> C5: … through WebEx … we would connect through different computer, so [my nephew] would be on his computer; my brother on his; I would be on mine. … we would be trying to stimulate her. … when I visit, I bring my phone, and so my brother visits virtually, and vice versa. I don't think she reacts very much to the phone or the iPad. I think it's more the touch … She's very, very low functioning… there's no communication. … if she had been younger or at an earlier stage of her Alzheimer's… it would have been a different experience.

Theme summary

This theme highlighted the timely adjustments to virtual social activities, a collective effort of the dementia community. A prominent burden fell on the caregivers to explore and support new activities for them and their loved ones. Participants reported positive roles of technologies in facilitating new engagements, e.g., video chats, robot dogs, online classes and games, and social media, while facing challenges such as access, fatigue, distraction, and the lack of physical interactions.

4.4.3 Re-building social experiences as a virtual community

Leveraging physical objects and environments

The facilitators built upon the previous in-person experiences and elements to adapt the Tales & Travels community to virtual settings. The librarian prepared an online folder with the materials mirroring those used during the in-person sessions, e.g., fun facts, images, Google map links, and YouTube travel video links. The facilitators met 30 minutes before the session to discuss how to arrange breakout rooms based on participant inscriptions, like the way they discussed table arrangements in the in-person sessions.

The following summary of the Study 1 theme ”Effective Agencies for Social Interaction – Tangible, multimedia, and multisensory materials” provided more background information of diverse materials in the in-person format:

> Tales & Travels mobilizes many materials to engage participants in storytelling

> and socializing, including books, fact sheets, large print images and maps, objects and artefacts, clothing and textiles, food, music, and videos. People with dementia and caregivers are free to engage with their preferred media and materials. Facilitators reported their efforts at tailoring prompts to various themes, e.g., F3's successful use of tropical clothing as a visual cue to spark interest and conversation. Technologies were used selectively at Tales & Travels. In a memorable example, a participant was excited to revisit his hometown via Google Street View projected on a large screen. The wide range of multisensory materials improved communication and enhanced participants' experiences. 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.

However, as F2 articulated in the interview before the launch of virtual Tales & Travels, losing the physical ambiance and interactions was a significant challenge for such a social program:

> F2: It was just… nice being there… sitting in the room and the ambiance. It was… something in itself, the beautiful room [and] the furniture… the voices around of people laughing and being happy to be here… shaking hands. … [Switching to virtual is] better than nothing... [but] it's definitely sad to think about Tales & Travels online.

The Study 1 theme ”Normalized and Friendly Environments” contrasted the loss of physical ambiance in virtual settings:

> Caregivers described public spaces and open environments as bringing a sense of normality, sparking spontaneous expressions, and offering opportunities for social interaction. 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. Though targeted at 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 sharing travel experiences, life stories, news, knowledge, and humor. As a dynamic and open-ended program, Tales & Travels increases participants' experience of normalcy and ease with telling, discussing, listening to, and responding to stories.

Nonetheless, the facilitators tried to connect to the physical space as much as they could and create an “intimate” experience. For example, F4 showed participants around the original Tales & Travels library room through his camera whenever he could. When planning the virtual Tales & Travels, F4 carefully considered his position at the library when running Zoom in accordance with public health safety measures.

> F4: . . . this will be a very intimate, . . . intense Zoom experience, . . . it will be

> better for me to be at the library than at home. . . . I have to choose where I'll place myself, too. But I think it would be nice ... The library is empty right now. . . . like nine employees sharing this huge space and we're encouraged to spread out. . . I found a spot on the third floor. . . like a wall of books behind me. It's kind of cool.

In the planning stage, F4 learned from other librarians running virtual programs to explore ways to enhance participants' experiences, e.g., by offering program-specific objects within the library's loan services.

> F4: [One colleague said] that we could potentially have items at the library ready for people to pick up and then use those items in the session. . . . it could be . . . images we've typically had in Tales & Travels. . . . I have to search and find which items would actually be interesting to have, and then there would be the element of coordinating the pick-up... The library already has a system in place for picking items up. . . I may put it on the back burner.

Such offerings could potentially improve the experience, as echoed by a caregiver's interest in pulling out the maps of countries explored in previous Tales & Travels. Facilitators found ways to introduce physical senses, including presenting the virtual background of landmarks as a poster behind us. This explanation also helped quietly resolve possible confusion about virtual background among participants.

As F4 ran the program from the library, other facilitators and participants joined from their homes, creating opportunities to bring items in front of the camera to share with the group. For example, a caregiver found their photo albums of the Alps in the 1950s. Facilitators showed various souvenirs from the theme country, such as fridge magnets, a huge beer glass from Munich, a Swiss watch, and a Swiss army knife. Themed clothing was easier to arrange, e.g., the first author wore a Japanese traditional happi shirt for the Japan sessions, which then inspired a caregiver to show her happi bought from her trip to Japan. All these physical elements might need more logistical planning to be shared in the in-person sessions, yet remote delivery afforded easy and spontaneous communal sharing of objects. This demonstrated one of the few advantages of remote settings, i.e., the ability to pull in personal artefacts was better supported as attendees were at home and could share personal possessions as the need arose.

In the virtual sessions, however, minor profanity and dress issues (e.g., attending in a bathrobe) occasionally occurred while this was never observed in the in-person sessions at the library. These incidents may result from lowered inhibitions at the participants' own residences than in public or new cognitive requirements to perceive their home as a public space via Zoom. Being mindful that the casualness of these private settings could be conducive to inappropriate dress or language, the facilitators resorted to mediating strategies such as advance reminders, conversational redirection, and rearranging of breakout rooms. The facilitator debriefs also touched on the subtle impacts on the participation from the positioning of participants and their caregivers. Possibly due to their personalities or stages of dementia, some participants chose to sit further away from the screen and the camera, leaving their caregiver in charge of the meeting controls or relaying conversations.

The Study 1 theme "Mediating Social Cues and Communication" showed that facilitation challenges depended in virtual settings:

> People with dementia can have difficulty interpreting social cues. Self-awareness of these limitations can prevent them from engaging in public settings. Public events add further challenges as strangers may not recognize the dementia conditions or know how to respond. Nonverbal cues are also easy to misread, and even facilitators struggled sometimes to *"indicate [these cues] subtly"* (F3) and not to hurt participants' feelings or self-esteem. Other communication barriers relate to memory, attention, personality, responsive behaviour, and diverse language, cultural, and community backgrounds. Facilitators tried to mediate such difficulties by getting to know participants so that they could better arrange tables and pairings to manage group dynamics and avoid conflicts.

Enhancing open and flexible experiences

Virtual platforms could hold many attendees, and online lectures hosted by the Westmount Public Library for the general public did reach larger audiences than the capacity of their physical lecture hall, as observed by F4. However, programs like Tales & Travels relied on small groups to ensure conversational opportunities. F4 recognized the challenge to aid each participant in “figuring all the logistics out about the social interactions” and reaching as many participants on the lengthy wait list as they could. Before launching the virtual version, he carefully considered how to offer conversational environments suitable for participants’ needs, preparing to make timely adjustments through trial and error.

> F4: I’ll have to experiment with breakout rooms in Zoom [with] the six to eight people split into two groups… in a more conversational… situation… [With] three to four people [per room], you can offer pretty good… almost one on one conversations. … we’re doing two [sessions] back-to-back… because I want to try to reach out to as many people as we can. … both sessions [per week, up to] 16 participants… *[Later]* I [discussed with] the Alzheimer Society [about] how many people work … in a Zoom meeting when there are people [with] dementia. … that number varied when we were in person. … depending on the… attention span or like of individuals. … we’ll have to start from scratch and say, ‘Okay, this group worked well together. This didn’t…’

From the beginning, F4 was mindful of the challenges of engaging people with dementia remotely, as well as additional difficulties such as “missing social cues,” which “could be a bigger obstacle for… people with dementia.” He tried to find mitigating strategies such as offering one-on-one attention and multimedia stimuli.

> F4: … some people may not engage with the screen. [Just] me talking about a

> country… doesn't make it very different from just… with bad sound and video… But if I'm saying someone's name… 'Oh, what do you think?' … that might get someone to engage more... *[Later]* And as you're learning about the music and the history of it, you can play and discuss and then move back... And I hope that that will transfer well to Zoom. … music has been one of the elements that really has had the big reactions in Tales & Travels… I hope that … a screen share with audio [will] be effective.

In addition to the previous summary on mediating social cues, another Study 1 theme ”Effective Agencies for Social Interaction - Person-centered stimuli” helped to ground F4's considerations for remote delivery:

> Caregivers respected the personalities, interests, and experiences of people with dementia, trying to find effective, person-centered stimuli. At Tales & Travels, the facilitators made efforts to know each participant, e.g., who was interested in what topics, who preferred their coffee black, who wanted to take printed maps home, etc. Thus, they tailored materials and topics to the needs of different participants. 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 joining 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).

During debriefs at virtual Tales & Travels, facilitators discussed how to assess whether participants enjoyed the session and agreed that no single measure would suffice. They took participant comments like "interesting" as a good sign. In fact, the virtual delivery saw the same excitement from participants with dementia about the countries they grew up in or were familiar with. Similar questions about the country were discussed, e.g., 'where's the capital?' Pictures of animals, such as Bernese mountain dogs, received the same immediate warm, joyful reactions. It was encouraging for the facilitators to hear some participants delightfully say, "I got my friends back" or "It's nice to have friends on your computer." In another encouraging example, a participant at a care home was initially frustrated and wanted to leave the session, but his mood and attitude changed as he chatted with the facilitator. Mid-session, he started expressing motivations to focus on the positive side and showed enjoyment.

The facilitators carefully arranged breakout rooms to balance the need for one-on-one attention and group interaction, but fewer interactions between participants with dementia were observed than in previous in-person sessions. Nonetheless, participants enjoyed the group setting and sometimes commented, "the more the merrier" when waiting for more people to join.

In addition to a flexible group setting, virtual Tales & Travels offered open experiences through diverse choices of topics and materials. The facilitators would ask, 'Any picture caught your eye?' while browsing pictures or videos through screen sharing, thus giving control to the participants. They adopted spontaneous sharing of multimedia materials, such as recordings of national anthems, folklore for group reading, and interactive maps for exploring landmarks. The facilitators adjusted the handling of these media on the go according to participants' reactions. For example, they usually played only the opening part of a national anthem but kept it playing until the end when a participant appeared to enjoy herself and conduct along with the music.

To establish a concrete connection with the theme country, the facilitators often searched and shared the weather and the time of the notable cities, often comparing them to local conditions as a conversation starter. The first author tried bringing more personal and local materials into the conversation, including travel photos taken in the theme country and pictures of relevant local attractions (e.g., the Japanese garden in the Montreal Botanical Gardens and the Egyptian and Moroccan collections on the Montreal Fine Arts Museum website).

The above choices and presentation of materials and topics echoed two subthemes of the Study 1 theme ”Effective Agencies for Social Interaction:” ”Mature and intellectual activities” and ”Positive and inclusive topics:”

> Participants expressed their interests in sharing skills and expertise, bringing their life experiences to the table and contributing in their own ways. Mature and intellectual activities can help create appealing and engaging opportunities.

> C5 articulated that it was critical to respect participants' maturity and intelligence, instead of belittling them. Caregivers also mentioned intellectual social events presenting opportunities for them to share interests and hobbies with people with dementia, as well as learning together. At Tales & Travels, we observed mutual learning processes to explore a country's nature landscape, culture, fun facts, and cuisine. In particular, talking about one's home country encouraged more storytelling and strengthened the motivations for active sharing.
>
> Tales & Travels showed that topics such as traveling and animals are positive and attractive, enabling participants to follow the discussions easily and express their opinions at any point. C2 mentioned that it was easier for P2 to follow facts and documentaries since the discussions around such topics did not require them to remember all the previous content. 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. In contrast, facilitators pointed out the negative impacts of disturbing or unpleasant topics.

Virtual programs of a more physically engaging nature encouraged participation more effectively. In an email follow-up after first sessions, C1 mentioned: "I find active conversation is more difficult with Zoom as [one] tends to get off topic very easily [or] into repetitive loops, which is hard to change or stop and [another] has difficulty verbalizing especially if he is not familiar with the country." In contrast, she found virtual yoga more enjoyable because the verbal instructions were easier to follow and the exercises were complemented by social opportunities.

> C1: Yoga on Zoom is much more participatory! The teacher is talking and demonstrating at the same time. If you know the poses you do not need the visual presentation but when it is a variation it is helpful. Most of the time I just need the audio to stay on track, but I do enjoy the pre and post chats with other participants.

F2 further explained the advantages of the well-received Laughter Yoga program inclusive of people with dementia and their caregivers, highlighting the accessibility and pleasure of nonverbal participation.

> F2: Laughter Yoga sessions every week for people living with dementia and their caregivers [is] a big hit. . . . we made it really open for people to do either together or [alone]. . . . very accessible to everyone. . . you don't need to be able to talk or. . . even following instructions. . . [At] some point when everyone is laughing, it just makes you laugh as well.

Expanding collaborative space

Although engaging participants with dementia in virtual settings proved challenging, facilitators tried to invite everyone into a collaborative space to create more interaction opportunities by adopting facilitation strategies of conversing rather than presenting. They thoughtfully left long pauses for participants to collect their thoughts and speak up, and sometimes participants would ask about each other's heritages and families. An effective strategy observed was to choose countries and topics related to participants' backgrounds. Facilitators often acknowledged and built upon participant input, as well as sharing participants' insights from the first session with those in the second session. Simple phrases like "as you said" could express confirmation, agreement, and encouragement. When a participant voiced interest in any of the visual materials provided, the facilitator would quickly search online for more detailed illustrations.

In this virtual space, collaborations among facilitators were more frequent, spontaneous, and integrated into the process. Together, they often found fun facts or explained details about the country, e.g., when the participants were curious about a glacier that one facilitator showed on screen, the other searched and explained the term "ice tongue." On another occasion, when F2 was asked about her Zoom background of the Malacca city, F4 went to find Malacca on the Google Maps.

Facilitators often reminded each other about the hobbies and passions of each participant to engage them better in the future. They emphasized learning from the program and each other, expressing a common sense of fulfillment and joy. However, holding such a personal program virtually could be stressful and intense for the facilitators, as F4 anticipated below.

> F4: [It]'s always been the program that I felt was most... effective and... it meant the most... almost on a personal level... It's gonna be [a] really intense Zoom experience with a lot of paying attention and clicking and making sure [of everything]. ... Tales & Travels is always... very, very tiring.

Notably, the inclusion of caregivers played a bigger part in the collaboration to make virtual Tales & Travels successful. When envisioning virtual programs for people with dementia, C5 pointed out that both people with dementia and caregivers would benefit from the activities, and she articulated how virtual programs could create a change of space and interactive rhythm as a form of respite from restrictive routines.

> C5: [People with dementia] are not doing it alone. They have their caregivers to help... It's probably more of a help to the caregivers because it gives them an idea of what to do, ... and they get to do something themselves... [If] they're helping someone do yoga, they might be doing the yoga. With art therapy... they're also involved with doing the art... [Zoom] momentarily pulls you out of your reality into another... you're connecting with someone. You're in a different space... You're not at home alone, just staring at the walls... Tales & Travels... I remember... I would leave there: 1) happy to

> have participated in an activity that that made others feel good and 2) what I learned about all these countries… it was as good for me as what I felt. I was… sharing with others. *[Later]* … it demands [attention]. It's not a respite anymore for the caregiver but …a respite in the sense that they could derive something from it as well… they're interacting with… their loved one or the person they're caring for in a different way.

Caregivers needed to keep their loved ones on track in Zoom sessions, helping them by operating devices or directing their attention. Some participants needed specific assistance, such as the translation or explanation of the ongoing conversation. In the interview before the launch of virtual Tales & Travels, F4 envisioned the need for caregivers' help, highlighting the strength of Tales & Travels to traditionally involve caregivers:

> F4: Tales & Travels series has always been for caregivers and people with dementia… It's not strange for me to ask that the caregiver be there, whether it's to help with the interaction or to participate themselves for their own good or to guide through the technology.

Meanwhile, F2 mentioned that "people miss seeing each other," in particular caregivers lost the opportunities of such social programs to connect with each other in the library:

> F2: [There] was a moment for them, … sitting on the bench at the front door, they would just chat all together during the session like an informal caregivers' meeting.

Later on, when debriefing on the virtual Tales & Travels, the facilitators agreed on several occasions that the caregivers chatting with each other was a good chance for them to connect, even though such scenarios were deemed less preferrable in pre-pandemic in-person sessions, distracting participants with dementia from interacting with each other. Caregivers with living and travel experiences in the theme country shared more, recounting their trips, discussing landmarks, filling the gaps for the facilitators about local features, and sharing their travel pictures in session or via email afterwards. We observed that one caregiver attended many sessions by herself even when her husband did not feel like joining, which showed her appreciation and enjoyment of this community social group.

In the virtual sessions, the increased involvement of caregivers, along with the encouragement from facilitators, expanded the Study 1 theme ”Collaboration and Teamwork,” as summarized below:

> Participants valued the group settings. C4 proposed additional ways for participants to work collectively, new opportunities for social interaction, and the mutual benefit of collaboration. F1 likewise confirmed the positive role of collaboration, proposing *“more interactive group activities”* and *“teamwork”* for completing activities like quizzes. Facilitators explained how Tales & Travels, as a social program, helped build friendships and expand social circles, for both participants and caregivers.

Technological accommodations

Our facilitation experiences and reflections revealed helpful usability features and technological challenges in running social activities in the dementia community (summarized in Table 4.3). We reflected on how the facilitators handled these challenges and their emerging strategies, grouping them under three cross-cutting categories:

(1) Maintaining a virtual environment for individual and group needs. The facilitators successfully enhance the participant engagement through virtual features such as breakout rooms, screen sharing, spotlighting tools, various map views, and zooming in and out. However, technical difficulties like connectivity issues, combined with the participants‘ preferences, added to the challenges of balancing individual and group needs.

(2) Balancing ease of use with privacy and security concerns. The facilitators carefully configured meeting settings for barrier-free, autonomous participation while respecting participants’ self-identification preferences and safeguarding their privacy and security.

(3) Navigating complex multitasking and communication. The facilitators’ attention was divided between monitoring chats, sharing screen, engaging participants, as well as communication difficulties between breakout rooms. Extra care needed to aid participants in meeting controls (e.g., to join, leave, mute, and unmute) added to the facilitation burden and fatigue.

Table 4.3 Summary of technological challenges and considerations at virtual Tales & Travels

Categories	Technological accommodations & usability features	Current strategies & challenges
Maintaining a virtual environment for individual and group needs	Engaged participants when sharing screen. Read fun facts and folklore together. Brought up the map spontaneously. Different views on Google maps to show the proximity of the city and the pyramids. Video captions read better than in-person, on everyone's screen instead of the big screen in the library.	Incorporated spotlight tools to highlight scenic spots and tourist attractions, coastline, borders, as well as World Tour 360. Zoomed in/out on the maps/pictures. Spotlighted a facilitator/participant if they were wearing themed clothing or showing objects to get everyone's attention. Encountered audio connection problems, screen share lagging, and choppy videos.
	Made judgement call on choosing between one big room and two to three breakout rooms	Arranged the rooms according to the participants in each session. Encountered difficulties in managing the room size with participants trickling in.
	One pair of participant and caregiver mostly chose not to turn on their microphone nor camera but relied on text messages in the chat.	Opened up chat function for everyone and allowed copy paste. Encountered difficulties to weave async messages into ongoing conversations.
Balancing ease of use and privacy and security concerns	Considered meeting configuration: Participants entering on mute or not? With or without video? Breakout room options like entering/leaving and mute upon re-entering the main room or not? Allowed attendees change their name display.	Tried to make it hands-free for all. Remained mindful of being inviting but raised privacy/security concerns. Acted cautiously when unnamed device asked to join the meeting. Addressed everyone by their first name.
Navigating complex multitasking and communication	Faced challenges of divided attention in multitasking facilitation (e.g., monitoring chats, sharing screen, explaining materials, keep track of time, etc. Encountered difficulties in communication between facilitators in different breakout rooms. Encountered facilitation fatigue. Missed some social cues.	Prepared materials more thoughtfully, e.g., making filenames more informative to depict the content for easier access when viewing through screen share. Tried texting which might not work as cellphones might be on mute. Tried to address each participant directly and clearly by first name, still with misunderstanding/confusion.
	Encountered disruptions or distractions from participants' surroundings. Encountered background noise on participants' end. Some might talk loudly during video time.	Coordinated with caregivers and residence staff in advance. Reminded everyone to turn off their TV or radio. Muted the participants, risking them being unable to unmute due to cognitive/fine motor skill impairments.
	Participants might not know how to leave the meeting.	Said goodbye and removed them from the meeting one by one.

Theme summary

The third theme examined the virtual adaptation of social programs, especially compared with the previous in-person sessions. Our results highlighted the strengths of virtual activities in terms of more flexible and collaborative social space. Our analysis also revealed the challenges in virtual social sharing such as the changed physical connections and the necessary technological accommodations. These findings inspired design opportunities for enhancing community experiences in virtual settings for the dementia community.

4.5 Discussion

Our findings paint a complex picture of virtual social engagements in the dementia community, uncovering the positive and negative roles of technologies. Our first-hand investigation of virtual programs like Tales & Travels provides opportunities for further examining physical and virtual community-based social sharing. Comparing the in-person and online Tales & Travels, we find underlying similarities in terms of mature and intellectual discussions, positive and inclusive topics, and person-centered approaches. The multisensory materials are heavily adapted for online activities, e.g., showing physical objects or clothes via webcam and using screen sharing for music, videos, images, and maps. However, the virtual group missed the physical ambiance and olfactory/gustatory elements (e.g., themed snacks) that were highly appreciated in the in-person sessions. As detailed below, we advance the nuanced understanding of physical and virtual social sharing and open new design avenues for the dementia community through holistic approaches.

4.5.1 Reimagining community social spaces

The recent shift to online social programs opens up opportunities for placemaking, deepens the understanding of physical and virtual environments, and reveals the tension between public and private spaces. These programs provide an extended social circle inclusive of people with dementia living at home and in residences, as well as their caregivers. As our findings show that families living with dementia faced less structured social lives and reduced social circles, virtual community programs help create more socializing opportunities while inevitably losing the benefits of changing physical surroundings, especially those of public venues.

Our previous on-site fieldwork illustrates 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 [31]. People perceive these locations differently, and community environments foster distinctive associations and attachments, as reported by our participants regarding in-person programs. These normalized, community-based settings can help form a sense of attachment and belonging by extending sharing scenarios to the less explored group and public sessions [14].

In virtual environments, such normalized, familiar feelings of walking into the library are out of reach, but the atmosphere of social programs can remain welcoming and friendly, as created by the virtual Tales & Travels. The facilitators' strategies of leveraging physical objects and environments help bridge the transition from in-person to online activities, recognizing the importance of normalcy during transition states of adopting new tools and conversation channels [68]. Virtual programs can remove some physical barriers (e.g., mobility issues preventing visits to libraries or community centres), but logistical problems with participants' surroundings remain, including environmental distractions from their focus on the screen.

Moreover, our findings reveal layered attributes of virtual environments from varied perspectives of members of the dementia community. Families expressed the feelings of being trapped in their houses, and professionals reconfigured work-life balance during prolonged periods of working from home. Notably, minor dress code and profanity issues emerged in virtual sessions where participants joined from their homes rather than going to public spaces. In addition to the commonly reported issue of screen fatigue, the physical cues of being in virtual public events are difficult to interpret, and social signals appear abstract during communication through a screen.

With the loss or change of physical attributes and the blurring of public and private boundaries, more work is needed to unpack the affordance of virtual community environments. For programs like Tales & Travels, digital toolkits can be widely used in both private/public and physical/virtual settings, building upon the current suitcase kits on loan from the library. Such an approach echoes recent CSCW research that recommends designing for ”complementing the ambiance of private spaces” and ”in-a-box experiences for location-independent scenarios” [52]. Another relevant CSCW work on the psycho-social impact of the work-from-home experience identifies six types of boundary work (spatial, temporal, psychological, sensory, relational/social, and technological) that are enacted ”to reconstruct the sense of place and attachment” and proposes ”an emergent interplay among adapted work practice, reimagined physical (and virtual) spaces, and the establishment and continual re-negotiation of boundaries” [10]. Such discourses connecting physical and virtual interactions, as well as personal and work spaces, can be extended to dementia settings and inspire future HCI design to build virtual community social spaces. Recent reflections on virtual galleries or classrooms using commercially available platforms such as Gather.Town provide more inspirations for leveraging videoconferencing features (e.g., proximity chat, private spaces, spotlighting, and embedded objects) [41] and creating sense of place [40].

4.5.2 Rethinking agency in virtual social experiences

Affirming agency in people with dementia

Our findings demonstrate how social restrictions negatively affect the agency of people with dementia in virtual environments in addition to significantly decreasing their physical and mental health. Even though virtual programs are overall well received by participants and appreciated by caregivers, nuanced challenges surface when we compare the findings from our two studies. We explore opportunities for affirming agency through the lenses of group dynamics in virtual settings and active roles in sharing in the moment.

Group dynamics in virtual settings As observed at the in-person Tales & Travels sessions, physical settings provide more opportunities for peer interaction and collaboration, such as helping each other get drinks and snacks and finding answers in a book or a globe together. In contrast, the online format requires the facilitators to take the control of the overall environment (e.g., arranging breakout rooms) and detailed activities (e.g., screen sharing materials). In most cases, the caregivers operate the meeting interface for their loved ones. The group dynamics are changed especially when some participants chose to position themselves further away from the screen than their caregivers, losing the effects of everyone sitting around the table in the previous physical setting. Thus, at virtual Tales & Travels, we observed fewer interactions among participants and fewer opportunities for collaboration and teamwork than in the in-person format. Sharing experiences and expertise were especially difficult for participants in more advanced stages of dementia. The scenarios for co-creating knowledge and experience among peers are more challenging and less supported than previous notable examples of in-person Tales & Travels and print media devices for quizzes in care homes [27].

More positively, the richer content and greater spontaneity of virtual Tales & Travels make it more open-ended than the in-person delivery. The facilitators explored more impromptu web searches on the spot, continuing the mutual learning tradition without adding to participants' cognitive or technological workload. The facilitators' screen sharing supports both generic and personal prompts, retaining both the person-centered and the inclusive approaches. We observed the facilitators' efforts to provide one-on-one attention and give flexibility and control to participants by offering choices and optional topics as they arise. However, it remains challenging to promote the agency of every participant as community programs require ongoing group participation, unlike more dedicated and controlled scenarios such as remote usability testing, which allows for modified methods to meet the unique needs of each participant with dementia [82].

More work is needed to create a distinctive group structure that signifies a collaborative dynamic among peers in virtual environments, drawing from *interdependence for assistive technology design* framework to emphasize interpersonal relationships and collective work [7]. Virtual settings bring new challenges and opportunities for building things together as a team or engaging in group activities to promote interaction and a sense of accomplishment. Prior work has mobilized technologies to negotiate barriers and support agency in virtual environments, e.g., expanding dementia-friendly and online community platforms [59]. The benefits of social collaboration can be extended to both virtual and physical spaces, as shown in videogame-based systems for dementia daycare centres [76]. Tangible and multisensory materials found effective in co-located activities can be incorporated into technology-mediated spaces, as shown in our two studies, but require careful integration and alignment among senses and media [57]. Future platforms can draw inspiration from research in related areas, such as compiling collective memories online to connect older and younger users [58], exploring a less linear narrative of personal histories within a timeline [74], and creatively adapting accessible communication to videoconferencing [64].

Active roles in sharing in the moment Supporting agency in virtual environments poses nuanced challenges in terms of losing diversified roles and socializing in the moment. We find that in-person Tales & Travels affords greater flexibility in 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, contributing to meaningful communications [1]. Such dynamic roles can benefit group interactions as previously found in engaging people with dementia as performers or spectators in music sessions [61]. More active sharing invites more participants to become content producers, in line with the studies on improving older adults' self-expression and community-based care [79], as well as self-esteem and sense of usefulness [12]. In-person environments also aid participants in sharing their emerging reflections and personal stories, affirming the 'in-the-momentness' felt by people with dementia and establishing a visible, co-present audience, both found beneficial in prior work [14]. 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 [44]. Recent work on virtual reality explored supporting participants' agency in selecting environments, with the following identified as preferable: animals and pets, art experiences, nature, personalized content and home environment, hobbies and sports, social interaction features, and travel [56].

Another potential approach to affirming agency is to solidify digital media and bridge the virtual and the physical. As byproducts of social sharing experiences, souvenirs can serve as a reminder of the event, as previous work has found it important for people with dementia to have a physical cue [27]. The in-person Tales & Travels participants often took home some printed materials, especially the large print maps and images they liked. Yet, such opportunities for souvenirs are tentatively lost in the virtual format. Recent work on real-time usage of a communication system that integrates digital messages with printed postcards demonstrates a successful example to promote lasting social contact and inclusive social dynamics among participants [75].

Promoting agency in caregivers

Our virtual fieldwork highlights how the pandemic overshadows the caregivers' agency, particularly their reduced respite and social participation. In addition to complicating the families' abilities to remain socially active, the distancing restrictions force the caregivers to join events with their loved ones and play a bigger supporting role, thus losing the respite opportunities offered by in-person community programs. The prominent burden on caregivers to collect materials and set up systems has been evident in previous research to support storytelling and socializing, such as in the progress of creating portraits of people with dementia [80]. However, the shift to virtual interactions brings more profound and nuanced impacts, as uncovered by our findings. Home-bound situations heighten the conflicting attitudes towards outside assistance between caregivers and their loved ones (C1). A robot dog could keep her loved one busy and relieve C1 from time to time, but remote art therapy sessions and residences' virtual visits require considerable energy from C6 and C5 respectively. The caregivers appreciate reciprocal help within their neighbourhoods or the dementia network while pointing out the loss of spontaneity in their leisure activities with more planning burdens on them.

More encouragingly, the caregivers demonstrated their agency through individual resilience and new social engagements, adopting technological tools and joining online activities like courses and fitness programs. Notably, we uncover caregivers' extended collaborator roles in the new virtual contexts of social experiences. Caregivers collaborate more with professionals (e.g., providing technical and logistical support for art therapy sessions) and family members (e.g., during virtual visits with their loved ones in residences). At virtual Tales & Travels, caregivers' collaborative roles become more prominent through the experience of asking or answering questions, showing personal items related to the discussion, and selecting materials through facilitators' screen share.

These nuanced findings reveal the challenge of supporting caregivers' agency in virtual community settings. Prior HCI work has successfully provided support through a dedicated focus. For example, a pervasive social exergame designed for caregivers helped relieve stress and increase physical activity, promoting caregivers' time for themselves and connections with other caregivers [50]. In co-located contexts, design probes such as a musical interface can facilitate collaborative activities, towards equal partnership between caregivers and care recipients, promoting shared expression and reinforcing agency [36]. Tales & Travels has the long-standing benefit of being inclusive of caregivers, but the virtual format reveals the additional challenge of balancing the active participation of both parties. Future community-based work can draw from previous studies in home or residence settings, e.g., exploring embodied technologies to mediate the interactions between caregivers (relieving burdens and increasing confidence) and their loved ones (cultivating agency and a sense of normalcy) to support emotional wellbeing in care tasks [30]. A connected space can be created to set the ambiance across households to form a community by mobilizing commercially available physical components as an "intervention in a box" for optimized integration into daily responsibilities with the potential for expanded content [28]. Caregivers' agency can also be promoted through online communities for sharing care strategies as in the case of using music therapeutically at home [9].

4.5.3 Diversifying HCI support across communities and stakeholders

Our findings illustrate the heightened need for a diversified toolbox for varied social and technological characteristics across communities and stakeholders. In the ever-changing social and healthcare contexts, some communities might be able to retain in-person activities to a certain degree while others could be restricted to virtual ones for prolonged periods. Likewise, the overall technology adoption among participants tends to vary across communities, e.g., some people with dementia might be comfortable with videoconferencing or joining other virtual engagements independently as in [82]. The community in which our studies are situated shows minimal technology use among participants with dementia and some of their caregivers (many of whom are older adults themselves). Remote social programs would have been deemed unsuitable for this community before the pandemic, which has undoubtedly been a catalyst for virtual interactions. As reported by caregivers and observed at virtual Tales & Travels, participants with dementia adapt well to enjoying the new virtual format with the help of caregivers and professionals. However, we find that virtual social programs pose significant demands on the technical skills of caregivers and professionals. The nuanced barriers to community space and agency as discussed above can motivate the expansion of HCI support for all stakeholders.

Collaborative approaches As our findings highlight the interdependence among members of the dementia community, collaborative approaches to supporting various stakeholders can open up design space. The dementia community can be better served with expanded space for individual interests and mutual support, including opportunities for streamlining the technological process to support the spontaneity that the caregivers are missing in their social lives. Virtual programs like Tales & Travels can benefit from more flexible platforms to accommodate personal and group needs and mediate conflicts (e.g., managing several breakout rooms with participants trickling in and accommodating those participants who rely on text communication without audio or video). Similarly, the technological considerations revealed in our findings call for increased system design efforts to help facilitators manage divided attention during complex multitasking, streamline their communication, and handle emerging problems (e.g., external disruptions and facilitation fatigue).

Future work can continue to build upon the previous direct focus on practitioner approaches to meaningful engagement while tracing epistemological understandings of dementia to different configurations of technology [24]. Opportunities for interdisciplinary research arise in collaboration with community-based establishments and related academic fields, e.g., our prior examination of in-person Tales & Travels through the lens of library and information science [16]. The HCI community has developed awareness and advanced collaborative approaches, illuminating potential tensions with community partners such as the relative power and position of researchers and computing environments [13].

Usability, security, and privacy Our findings identify some 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). Future design can enhance such experiences by leveraging helpful features of existing commercially available platforms to construct social experiences for the dementia community. Meanwhile, extra care is needed to balance ease of use and privacy and security concerns (e.g., creating an inviting, barrier-free environment while considering the effects of lowered inhibition in home settings). The usability and security/privacy trade-offs have been echoed in recent work on online conferencing tools for older adults, with extended attention to contextual trust across various scenarios from social events to medical and financial appointments [68].

Prompting systems As dementia care and broader accessibility settings increasingly adopt videoconferencing, future work can better support people with complex communication needs when independently using such platforms, e.g, through specialized prompting systems. Such prompts can aid participants in meeting controls (including but not limited to joining, leaving, muting, and unmuting), drawing from recent dementia work leveraging mixed reality. For example, physical gestural actions and audio prompts in human voice, complemented by visual prompts such as text, have been found effective in directing people with dementia towards physical or virtual worlds [20]. Sound has been recommended to be incorporated in assistive mixed reality technologies, forming an augmentative platform with other modalities (such as visual prompts), to improve the independence of people with dementia [21]. Additionally, recent work on video-mediated collaboration can provide more inspiration such as a "What-You-See-Is-What-I-See" videoconferencing system by blending, repositioning, and resizing mirrors that "denote shared video feeds of people and screens" [29].

4.5.4 Limitations and Future Work

As both studies are set in a populous municipality in Canada, some findings might have inherent social and demographic limitations when applied to other communities. Although the participants with dementia and their caregivers come from various cultural, educational, and professional backgrounds, most of them have higher education and comfortable socioeconomic status, which may have pre-conditioned their active involvement in social events and research. To expand the insights from our case studies, future work can diversify perspectives across various communities and programs. Direct interviewing and observing on participants' end can extend our previous methodological self-reflections on in-person research [18] to surface the voices of people with dementia in remote and hybrid research engagements.

4.6 Conclusion

The changing social and technological landscapes highlight the need for broadening the HCI toolbox to support in-person and remote social scenarios for the dementia community. Building upon our on-site fieldwork focusing on community-based social sharing, our virtual fieldwork delves deeper into the remote interactions, in particular contrasting the in-person and the virtual formats of Tales & Travels. Through thematic analysis on interview transcripts and reflective facilitation notes, we propose to reimagine community social spaces, deepening the understanding of placemaking in physical/virtual and public/private environments. We suggest affirming agency in people with dementia by creating collaborative group dynamics and supporting active in-the-moment sharing, as well as ways to promote agency in caregivers. We further discuss diversifying HCI support across communities and stakeholders by developing collaborative approaches, attending to usability, security, and privacy, and building specialized prompting systems.

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Bibliography

[1] Sarah Alsawy, Sara Tai, Phil McEvoy, and Warren Mansell. 2020. 'It's nice to think somebody's listening to me instead of saying "oh shut up"'. People with dementia reflect on what makes communication good and meaningful. *Journal of psychiatric and mental health nursing* 27, 2 (2020), 151–161. `https://doi.org/10.1111/jpm.12559`

[2] Alzheimer's Association. 2020. 2020 Alzheimer's disease facts and figures. *Alzheimer's & Dementia* 16, 3 (Mar. 2020), 391–460. `https://doi.org/10.1002/alz.12068`

[3] Alzheimer's Association. 2022. 2022 Alzheimer's disease facts and figures. *Alzheimer's & Dementia* 18, 4 (Apr. 2022), 700–789. `https://doi.org/10.1002/alz.12638`

[4] Arlene J Astell, Maggie P Ellis, Lauren Bernardi, Norman Alm, Richard Dye, Gary Gowans, and Jim Campbell. 2010. Using a touch screen computer to support relationships between people with dementia and caregivers. *Interacting with Computers* 22, 4 (2010), 267–275. `https://doi.org/10.1016/j.intcom.2010.03.003`

[5] Jeanette Bell and Tuck Wah Leong. 2019. Collaborative futures: Co-designing research methods for younger people living with dementia. In *Proceedings of the 2019 chi conference on human factors in computing systems*. 1–13. `https://doi.org/10.1145/3290605.3300582`

[6] Erin Beneteau. 2020. Who Are You Asking?: Qualitative Methods for Involving AAC Users as Primary Research Participants. *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*, 1–13. `https://doi.org/10.1145/3313831.3376883`

[7] Cynthia L. Bennett, Erin Brady, and Stacy M. Branham. 2018. Interdependence as a frame for assistive technology research and design. *ASSETS 2018 - 20th International ACM SIGACCESS Conference on Computers and Accessibility*, 161–173. `https://doi.org/10.1145/3234695.3236348`

[8] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3 (1 2006), 77–101. Issue 2. `https://doi.org/10.1191/1478088706qp063oa`

[9] Romina Carrasco, Felicity A. Baker, Anna A. Bukowska, Imogen N. Clark, Libby M. Flynn, Kate McMahon, Helen Odell-Miller, Karette Stensaeth, Jeanette Tamplin, Tanara Vieira Sousa, et al. 2020. Empowering Caregivers of People Living with Dementia to Use Music Therapeutically at Home: Design Opportunities. In *32nd Australian Conference on Human-Computer Interaction*. 198–209. `https://doi.org/10.1145/3441000.3441082`

[10] Janghee Cho, Samuel Beck, and Stephen Voida. 2022. Topophilia, Placemaking, and Boundary Work: Exploring the Psycho-Social Impact of the COVID-19 Work-From-Home Experience. *Proceedings of the ACM on Human-Computer Interaction* 6, GROUP (2022), 1–33. `https://doi.org/10.1145/3492843`

[11] Shaan Chopra, Emma Dixon, Kausalya Ganesh, Alisha Pradhan, Mary L. Radnofsky, and Amanda Lazar. 2021. Designing for and with People with Dementia using a Human Rights-Based Approach. In *Extended Abstracts of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–8. `https://doi.org/10.1145/3411763.3443434`

[12] Sharon Lynn Chu, Brittany Garcia, Taylor Quance, Lisa Geraci, Steven Woltering, and Francis Quek. 2016. Understanding storytelling as a design framework for cognitive support technologies for older adults. In *Proceedings of the International Symposium on Interactive Technology and Ageing Populations*. 24–33. `https://doi.org/10.1145/2996267.2996270`

[13] Ned Cooper, Tiffanie Horne, Gillian R Hayes, Courtney Heldreth, Michal Lahav, Jess Holbrook, and Lauren Wilcox. 2022. A Systematic Review and Thematic Analysis of Community-Collaborative Approaches to Computing Research. In *CHI Conference on Human Factors in Computing Systems*. 1–18. `https://doi.org/10.1145/3491102.3517716`

[14] Raymundo Cornejo, Robin Brewer, Caroline Edasis, and Anne Marie Piper. 2016. Vulnerability, Sharing, and Privacy: Analyzing Art Therapy for Older Adults with Dementia. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*. ACM, 1572–1583. `https://doi.org/10.1145/2818048.2819960`

[15] Masashi Crete-Nishihata, Ronald M. Baecker, Michael Massimi, Deborah Ptak, Rachelle Campigotto, Liam D. Kaufman, Adam M. Brickman, Gary R. Turner, Joshua R. Steinerman, and Sandra E. Black. 2012. Reconstructing the Past: Personal Memory Technologies Are Not Just Personal and Not Just for Memory. *Human–Computer Interaction* 27, 1-2 (Apr. 2012), 92–123. `https://doi.org/10.1080/07370024.2012.656062`

[16] Jiamin Dai, Joan C Bartlett, and Karyn Moffatt. 2023. Library services enriching community engagement for dementia care: The Tales & Travels Program at a Canadian Public Library as a case study. *Journal of Librarianship and Information Science* 55, 1 (2023), 123–136. `https://doi.org/10.1177/09610006211065170`

[17] Jiamin Dai and Karyn Moffatt. 2020. Making space for social sharing: Insights from a community-based social group for people with dementia. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. ACM, 1–13. `https://doi.org/10.1145/3313831.3376133`

[18] Jiamin Dai and Karyn Moffatt. 2021. Surfacing the voices of people with dementia: Strategies for effective inclusion of proxy stakeholders in qualitative research. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. ACM, 1–13. `https://doi.org/10.1145/3411764.3445756`

[19] Jiamin Dai and Karyn Moffatt. 2023. Enriching social sharing for the dementia community: Insights from in-person and online social programs. *ACM Transactions on Accessible Computing* 16, 1 (2023), 1–33. `https://doi.org/10.1145/3582558`

[20] Shital Desai, Alethea Blackler, Deborah Fels, and Arlene Astell. 2020. Supporting people with dementia: Understanding their interactions with Mixed Reality Technologies. *Proceedings of DRS2020 Synergy: Impacts. Vol. 2.* (2020), 615–637. `https://doi.org/10.21606/drs.2020.266`

[21] Shital Desai, Joel Ong, Deborah Fels, and Arlene Astell. 2022. Sound Mixed Reality Prompts for People with Dementia: A Familiar and Meaningful Experience. In *Designing Interactions for Music and Sound*. Focal Press, 151–176. `https://doi.org/10.4324/9781003140535-7`

[22] Timothy J Dickey. 2020. Programming for Dementia and Dementia Caregivers. In *Library Dementia Services*. Emerald Publishing Limited. `https://doi.org/10.1108/978-1-83867-691-920201006`

[23] Emma Dixon, Jesse Anderson, Diana Blackwelder, Mary L. Radnofsky, and Amanda Lazar. 2022. Barriers to Online Dementia Information and Mitigation. In *CHI Conference on Human Factors in Computing Systems*. 1–14. `https://doi.org/10.1145/3491102.3517554`

[24] Emma Dixon and Amanda Lazar. 2020. Approach Matters: Linking Practitioner Approaches to Technology Design for People with Dementia. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. ACM, 1–15. `https://doi.org/10.1145/3313831.3376432`

[25] Emma Dixon and Amanda Lazar. 2020. The Role of sensory changes in everyday technology use by people with mild to moderate dementia. In *The 22nd International ACM SIGACCESS Conference on Computers and Accessibility*. 1–12. `https://doi.org/10.1145/3373625.3417000`

[26] Emma Dixon, Anne Marie Piper, and Amanda Lazar. 2021. “Taking care of myself as long as I can”: How People with Dementia Configure Self-Management Systems. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–14. `https://doi.org/10.1145/3411764.3445225`

[27] Sarah Foley, Daniel Welsh, Nadia Pantidi, Kellie Morrissey, Tom Nappey, and John McCarthy. 2019. Printer Pals: Experience-Centered Design to Support Agency for People with Dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 1–13. `https://doi.org/10.1145/3290605.3300634`

[28] Gabriela Purri R Gomes, Sydney Rubin, Leah I Stein Duker, Donna Benton, Andreas Kratky, Sze Yu A Chen, Maryalice Jordan-Marsh, and Marientina Gotsis. 2020. Healing spaces: feasibility of a multisensory experience for older adults with advanced dementia and their caregivers. In *Proceedings of the 13th ACM International Conference on PErvasive Technologies Related to Assistive Environments*. 1–9. `https://doi.org/10.1145/3389189.3392607`

[29] Jens Emil Grønbæk, Banu Saatçi, Carla F Griggio, and Clemens Nylandsted Klokmose. 2021. MirrorBlender: Supporting Hybrid Meetings with a Malleable Video-Conferencing System. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–13. `https://doi.org/10.1145/3411764.3445698`

[30] Connie Guan, Anya Bouzida, Ramzy M Oncy-Avila, Sanika Moharana, and Laurel D Riek. 2021. Taking an (embodied) cue from community health: Designing dementia caregiver support technology to advance health equity. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–16. `https://doi.org/10.1145/3411764.3445559`

[31] Steve Harrison and Paul Dourish. 1996. Re-place-ing space: the roles of place and space in collaborative systems. In *Proceedings of the 1996 ACM conference on Computer supported cooperative work*. 67–76. `https://doi.org/10.1145/240080.240193`

[32] James Hodge, Madeline Balaam, Sandra Hastings, and Kellie Morrissey. 2018. Exploring the Design of Tailored Virtual Reality Experiences for People with Dementia. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. ACM, 1–13. `https://doi.org/10.1145/3173574.3174088`

[33] James Hodge, Sarah Foley, Rens Brankaert, Gail Kenning, Amanda Lazar, Jennifer Boger, and Kellie Morrissey. 2020. Relational, Flexible, Everyday: Learning from Ethics in Dementia Research. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. ACM, 1–16. `https://doi.org/10.1145/3313831.3376627`

[34] James Hodge, Kyle Montague, Sandra Hastings, and Kellie Morrissey. 2019. Exploring Media Capture of Meaningful Experiences to Support Families Living with Dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 3300653, 1–14. `https://doi.org/10.1145/3290605.3300653`

[35] Maarten Houben, Rens Brankaert, Gail Kenning, Inge Bongers, and Berry Eggen. 2022. Designing for Everyday Sounds at Home with People with Dementia and their Partners. In *CHI Conference on Human Factors in Computing Systems*. 1–15. `https://doi.org/10.1145/3491102.3501993`

[36] Maarten Houben, Benjamin Lehn, Noa van den Brink, Sabeth Diks, Jasmijn Verhoef, and Rens Brankaert. 2020. Turnaround: exploring care relations in dementia through design. In *Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems*. 1–8. `https://doi.org/10.1145/3334480.3382846`

[37] Debbie Kinsey, Iain Lang, Noreen Orr, Rob Anderson, and Daisy Parker. 2021. The impact of including carers in museum programmes for people with dementia: a realist review. *Arts & Health* 13, 1 (2021), 1–19. `https://doi.org/10.1080/17533015.2019.1700536`

[38] Julia Kirkham, Carrie L Shorey, Andrea Iaboni, Hannah Quirt, Alisa Grigorovitch, Arlene Astell, Esther Lin, and Colleen J Maxwell. 2022. Staff perceptions of the consequences of COVID-19 on quality of dementia care for residents in Ontario long-term care homes. *International journal of geriatric psychiatry* (2022). `https://doi.org/10.1002/gps.5725`

[39] Wei Qi Koh, Sally Whelan, Pascale Heins, Dympna Casey, Elaine Toomey, and Rose-Marie Dröes. 2022. The Usability and Impact of a Low-Cost Pet Robot for Older Adults and People With Dementia: Qualitative Content Analysis of User Experiences and Perceptions on Consumer Websites. *JMIR aging* 5, 1 (2022), e29224. `https://doi.org/10.2196/29224`

[40] Celine Latulipe and Amy De Jaeger. 2022. Comparing Student Experiences of Collaborative Learning in Synchronous CS1 Classes in Gather. Town vs. Zoom. In *Proceedings of the 53rd ACM Technical Symposium on Computer Science Education V. 1*. 411–417. `https://doi.org/10.1145/3478431.3499383`

[41] Celine Latulipe and Deborah Turnbull Tillman. 2022. Curating Interactive Art for Online Conferences: Artist, Curator and Technologist Experiences in Gather. Town. In *Proceedings of Creativity and Cognition (CC '22)*. 380–391. `https://doi.org/10.1145/3527927.3532811`

[42] Amanda Lazar, Robin N Brewer, Hernisa Kacorri, Jonggi Hong, Mary Nicole Dugay Punzalan, Maisarah Mahathir, Olivia Vander Hyde, and Warren Ross III. 2021. How Content Authored by People with Dementia Affects Attitudes towards Dementia. *Proceedings of the ACM on Human-computer Interaction* 5, CSCW2 (2021), 1–32. `https://doi.org/10.1145/3479542`

[43] Amanda Lazar, Raymundo Cornejo, Caroline Edasis, and Anne Marie Piper. 2016. Designing for the third hand: Empowering older adults with cognitive impairment through creating and sharing. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems*. 1047–1058. `https://doi.org/10.1145/2901790.2901854`

[44] Amanda Lazar and Emma E. Dixon. 2019. Safe Enough to Share: Setting the Dementia Agenda Online. *Proc. ACM Hum.-Comput. Interact.* 3, CSCW (Nov. 2019), 1–23. `https://doi.org/10.1145/3359187`

[45] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. A Critical Lens on Dementia and Design in HCI. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM, 2175–2188. `https://doi.org/10.1145/3025453.3025522`

[46] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. Supporting People with Dementia in Digital Social Sharing. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (Denver, Colorado, USA) *(CHI '17)*. Association for Computing Machinery, New York, NY, USA, 2149–2162. `https://doi.org/10.1145/3025453.3025586`

[47] Amanda Lazar, Jessica L. Feuston, Caroline Edasis, and Anne Marie Piper. 2018. Making as Expression: Informing Design with People with Complex Communication Needs through Art Therapy. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. ACM, 1–16. `https://doi.org/10.1145/3173574.3173925`

[48] Amanda Lazar, Hilaire J. Thompson, and George Demiris. 2016. Design Recommendations for Recreational Systems Involving Older Adults Living With Dementia. *Journal of Applied Gerontology* (Apr. 2016), 1–25. `https://doi.org/10.1177/0733464816643880`

[49] Barbara Leporini, Marina Buzzi, and Marion Hersh. 2021. Distance meetings during the COVID-19 pandemic: are video conferencing tools accessible for blind people?. In *Proceedings of the 18th International Web for All Conference*. 1–10. `https://doi.org/10.1145/3430263.3452433`

[50] Xin Yao Lin, Herman Saksono, Elizabeth Stowell, Margie E Lachman, Carmen Castaneda-Sceppa, and Andrea G Parker. 2020. Go&Grow: an evaluation of a pervasive social exergame for caregivers of loved ones with dementia. *Proceedings of the ACM on human-computer interaction* 4, CSCW2 (2020), 1–28. `https://doi.org/10.1145/3415222`

[51] Stephen Lindsay, Katie Brittain, Daniel Jackson, Cassim Ladha, Karim Ladha, and Patrick Olivier. 2012. Empathy, participatory design and people with dementia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 521–530. `https://doi.org/10.1145/2207676.2207749`

[52] Szu-Yu Liu, Brian A Smith, Rajan Vaish, and Andrés Monroy-Hernández. 2022. Understanding the Role of Context in Creating Enjoyable Co-Located Interactions. *Proceedings of the ACM on Human-Computer Interaction* 6, CSCW1 (2022), 1–26. `https://doi.org/10.1145/3512978`

[53] Hanuma Teja Maddali, Emma Dixon, Alisha Pradhan, and Amanda Lazar. 2022. Investigating the Potential of Artificial Intelligence Powered Interfaces to Support Different Types of Memory for People with Dementia. In *CHI Conference on Human Factors in Computing Systems Extended Abstracts*. 1–7. `https://doi.org/10.1145/3491101.3519858`

[54] Galina Madjaroff and Helena Mentis. 2017. Narratives of Older Adults with Mild Cognitive Impairment and Their Caregivers. In *Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility*. ACM, 140–149. `https://doi.org/10.1145/3132525.3132554`

[55] Emanuela Marchetti, Sophie Grimme, Eva Hornecker, Avgi Kollakidou, and Philipp Graf. 2022. Pet-Robot or Appliance? Care Home Residents with Dementia Respond to a Zoomorphic Floor Washing Robot. In *CHI Conference on Human Factors in Computing Systems*. 1–21. `https://doi.org/10.1145/3491102.3517463`

[56] Maria Matsangidou, Fotos Frangoudes, Theodoros Solomou, Ersi Papayianni, and Constantinos Pattichis. 2022. Free of Walls: Participatory Design of an Out-World Experience via Virtual Reality for Dementia In-patients. In *Adjunct Proceedings of the 30th ACM Conference on User Modeling, Adaptation and Personalization*. 326–334. `https://doi.org/10.1145/3511047.3537651`

[57] Fabian Mertl, Nadine Meißler, Lena Wiek, Alina Fröhlich, and Alina Huldtgren. 2019. "Traumreise"-Exploring the use of multisensory digital media in dementia groups. In *Proceedings of the 13th EAI International Conference on Pervasive Computing Technologies for Healthcare*. 189–197. `https://doi.org/10.1145/3329189.3329199`

[58] Luca Morganti, Giuseppe Riva, Silvio Bonfiglio, and Andrea Gaggioli. 2013. Building collective memories on the web: the Nostalgia Bits project. *International Journal of Web Based Communities* 9, 1 (2013), 83–104. `https://doi.org/10.1504/IJWBC.2013.051373`

[59] Kellie Morrissey, Andrew Garbett, Peter Wright, Patrick Olivier, Edward Ian Jenkins, and Katie Brittain. 2017. Care and Connect: exploring dementia-friendliness through an online community commissioning platform. In *Proceedings of the 2017 CHI conference on human factors in computing systems*. 2163–2174. `https://doi.org/10.1145/3025453.3025732`

[60] Kellie Morrissey, John McCarthy, and Nadia Pantidi. 2017. The value of experience-centred design approaches in dementia research contexts. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. 1326–1338. `https://doi.org/10.1145/3025453.3025527`

[61] Kellie Morrissey, Gavin Wood, David Green, Nadia Pantidi, and John McCarthy. 2016. 'I'm a rambler, I'm a gambler, I'm a long way from home' The Place of Props, Music, and Design in Dementia Care. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems*. 1008–1020. `https://doi.org/10.1145/2901790.2901798`

[62] Diego Muñoz, Stu Favilla, Sonja Pedell, Andrew Murphy, Jeanie Beh, and Tanya Petrovich. 2021. Evaluating an App to Promote a Better Visit Through Shared Activities for People Living with Dementia and their Families. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–13. `https://doi.org/10.1145/3411764.3445764`

[63] John Muñoz, Samira Mehrabi, Yirou Li, Aysha Basharat, Laura E Middleton, Shi Cao, Michael Barnett-Cowan, Jennifer Boger, et al. 2022. Immersive Virtual Reality Exergames for Persons Living With Dementia: User-Centered Design Study as a Multistakeholder Team During the COVID-19 Pandemic. *JMIR Serious Games* 10, 1 (2022), e29987. `https://doi.org/10.2196/29987`

[64] Timothy Neate, Vasiliki Kladouchou, Stephanie Wilson, and Shehzmani Shams. 2022. "Just Not Together": The Experience of Videoconferencing for People with Aphasia during the Covid-19 Pandemic. In *CHI Conference on Human Factors in Computing Systems*. 1–16. `https://doi.org/10.1145/3491102.3502017`

[65] Elly Park, Hollis Owens, David Kaufman, and Lili Liu. 2017. Digital storytelling and dementia. In *International conference on human aspects of IT for the aged population*. Springer, 443–451. `https://doi.org/10.1007/978-3-319-58536-9_35`

[66] S Tejaswi Peesapati, Victoria Schwanda, Johnathon Schultz, Matt Lepage, So-yae Jeong, and Dan Cosley. 2010. Pensieve: supporting everyday reminiscence. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 2027–2036. `https://doi.org/10.1145/1753326.1753635`

[67] Barbara A Purves, Alison Phinney, Wendy Hulko, Gloria Puurveen, and Arlene J Astell. 2015. Developing CIRCA-BC and exploring the role of the computer as a third participant in conversation. *American Journal of Alzheimer's Disease & Other Dementias®* 30, 1 (2015), 101–107. `https://doi.org/10.1177/1533317514539031`

[68] Hirak Ray, Ravi Kuber, and Adam J Aviv. 2022. Investigating older adults' adoption and usage of online conferencing tools during COVID-19. In *Proceedings of the 19th International Web for All Conference*. 1–11. `https://doi.org/10.1145/3493612.3520447`

[69] Mary Beth Riedner, Karen Maki, and Miriam Lytle. 2018. Becoming a dementia-friendly library. In *The Relevant Library: Essays on Adapting to Changing Needs*, Carol Smallwood Vera Gubnitskaia (Ed.). McFarland, Jefferson, NC, 187–194.

[70] Matthew Seita, Sarah Andrew, and Matt Huenerfauth. 2021. Deaf and hard-of-hearing users' preferences for hearing speakers' behavior during technology-mediated in-person and remote conversations. In *Proceedings of the 18th International Web for All Conference*. 1–12. `https://doi.org/10.1145/3430263.3452430`

[71] Panote Siriaraya and Chee Siang Ang. 2014. Recreating living experiences from past memories through virtual worlds for people with dementia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 3977–3986. `https://doi.org/10.1145/2556288.2557035`

[72] Ponnusamy Subramaniam and Bob Woods. 2016. Digital life storybooks for people with dementia living in care homes: an evaluation. *Clinical interventions in aging* 11 (2016), 1263. `https://doi.org/10.2147/CIA.S111097`

[73] Kong Saoane Thach, Reeva Lederman, and Jenny Waycott. 2021. Adoption of Videoconferencing for Social Connectedness among Older Adults: A Systematic Review. In *ACIS 2021 Proceedings, 15.* `https://doi.org/acis2021/15`

[74] Elizabeth Thiry, Siân Lindley, Richard Banks, and Tim Regan. 2013. Authoring personal histories: Exploring the timeline as a framework for meaning making. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 1619–1628. `https://doi.org/10.1145/2470654.2466215`

[75] Myrte Thoolen, Francesca Toso, Sebastiaan TM Peek, Yuan Lu, and Rens Brankaert. 2022. LivingMoments: Bespoke Social Communication for People living with Dementia and their Relatives. In *CHI Conference on Human Factors in Computing Systems*. 1–18. `https://doi.org/10.1145/3491102.3517430`

[76] David Unbehaun, Konstantin Aal, Daryoush Daniel Vaziri, Rainer Wieching, Peter Tolmie, and Volker Wulf. 2018. Facilitating collaboration and social experiences with videogames in dementia: results and implications from a participatory design study. *Proceedings of the ACM on Human-Computer Interaction* 2, CSCW (2018), 1–23. `https://doi.org/10.1145/3274444`

[77] Jayne Wallace, Peter C. Wright, John McCarthy, David Philip Green, James Thomas, and Patrick Olivier. 2013. A design-led inquiry into personhood in dementia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 2617–2626. `https://doi.org/10.1145/2470654.2481363`

[78] Jenny Waycott, Ryan M Kelly, Steven Baker, Barbara Barbosa Neves, Kong Saoane Thach, and Reeva Lederman. 2022. The Role of Staff in Facilitating Immersive Virtual Reality for Enrichment in Aged Care: An Ethic of Care Perspective. In *CHI Conference on Human Factors in Computing Systems*. 1–17. `https://doi.org/10.1145/3491102.3501956`

[79] Jenny Waycott, Frank Vetere, Sonja Pedell, Lars Kulik, Elizabeth Ozanne, Alan Gruner, and John Downs. 2013. Older adults as digital content producers. In *Proceedings of the SIGCHI conference on Human Factors in Computing Systems*. 39–48. `https://doi.org/10.1145/2470654.2470662`

[80] Gemma Webster and Deborah Fels. 2013. Portraits of people with dementia: three case studies of creating portraits. *American Journal of Alzheimer's Disease & Other Dementias®* 28, 4 (2013), 371–376. `https://doi.org/10.1177/1533317513488908`

[81] Daniel Welsh, Kellie Morrissey, Sarah Foley, Roisin McNaney, Christos Salis, John McCarthy, and John Vines. 2018. Ticket to talk: Supporting conversation between young people and people with dementia through digital media. In *proceedings of the 2018 CHI conference on human factors in computing systems*. 1–14. `https://doi.org/10.1145/3173574.3173949`

[82] Rachel Wood, Emma Dixon, Salma Elsayed-Ali, Ekta Shokeen, Amanda Lazar, and Jonathan Lazar. 2021. Investigating Best Practices for Remote Summative Usability Testing with People with Mild to Moderate Dementia. *ACM Transactions on Accessible Computing (TACCESS)* 14, 3 (2021), 1–26. `https://doi.org/10.1145/3460942`

Chapter 5

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

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Preface

This chapter advances HCI methodologies through critical self-reflections on our on-site fieldwork presented in Chapter 3. This chapter was inspired by a CHI 2020 Workshop, "*Rethinking Notions of 'Giving Voice' in Design*" [65], to which we contributed a position paper [15]. Even though the workshop itself was unfortunately canceled along with the CHI 2020 conference due to the COVID-19 pandemic, we continued to reflect on our practice through an iterative content analysis approach and successfully published a full paper at CHI 2021.

The chapter solidifies our prolonged community-based research experiences and consolidates practical lessons throughout preliminary work, study design, data collection, and data analysis. It further fills in the gap of community-oriented HCI work for dementia care through a methodological lens. It stems from our first-hand experiences and reflections in the process of ensuring inclusive research practice, navigating interpersonal communication complicated by dementia, and engaging a range of stakeholders from different work and education backgrounds.

This chapter adds methodological contributions to the thesis and offers insights into improving empirical HCI work in sensitive settings. It examines the dataset and the field experiences gathered from in-person contexts, but its findings can have extended implications for remote access in dementia-related research. For example, the pandemic has prompted more family members, especially younger caregivers, to actively engage in virtual visits to their loved ones living with dementia. Future research might reach a wider range of proxies, and the practice and nuanced reflections in this chapter can provide immediate benefit to HCI researchers and practitioners working with vulnerable populations.

Abstract

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.

5.1 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 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.

5.2 Related Work

5.2.1 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].

5.2.2 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].

5.2.3 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.

5.3 Methods

5.3.1 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 5.1 and Table 5.2. 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 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).

5.3.2 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

Table 5.1 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 5.2 Facilitators' professional backgrounds

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

[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.

5.4 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.

5.4.1 Prioritizing Participants' Voices in Collaboration with Proxies

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.

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.

5.4.2 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.

5.4.3 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.

5.4.4 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.

5.5 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.

5.5.1 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 rapports 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]).

5.5.2 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].

5.5.3 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].

5.5.4 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.

5.6 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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Bibliography

[1] Meghan Allen, Rock Leung, Joanna McGrenere, and Barbara Purves. 2008. Involving domain experts in assistive technology research. *Universal Access in the Information Society* 7, 3 (Jan. 2008), 145–154. `https://doi.org/10.1007/s10209-008-0112-5`

[2] Alzheimer's Association. 2020. 2020 Alzheimer's disease facts and figures. *Alzheimer's & Dementia* 16, 3 (Mar. 2020), 391–460. `https://doi.org/10.1002/alz.12068`

[3] Ernesto Arias, Hal Eden, Gerhard Fischer, Andrew Gorman, and Eric Scharff. 2000. Transcending the individual human mind—creating shared understanding through collaborative design. *ACM Transactions on Computer-Human Interaction (TOCHI)* 7, 1 (Mar. 2000), 84–113. `https://doi.org/10.1145/344949.345015`

[4] Arlene Astell, Norman Alm, Gary Gowans, Maggie Ellis, Richard Dye, and Phillip Vaughan. 2009. Involving older people with dementia and their carers in designing computer based support systems: some methodological considerations. *Universal Access in the Information Society* 8, 1 (May 2009), 49–58. `https://doi.org/10.1007/s10209-008-0129-9`

[5] Ruth Bartlett. 2012. Modifying the Diary Interview Method to Research the Lives of People With Dementia. *Qualitative Health Research* 22, 12 (2012), 1717–1726. `https://doi.org/10.1177/1049732312462240`

[6] Alan Borning and Michael Muller. 2012. Next steps for value sensitive design. In *Proceedings of the SIGCHI conference on human factors in computing systems*. ACM, 1125–1134. `https://doi.org/10.1145/2207676.2208560`

[7] Tula Brannelly and Ruth Bartlett. 2020. Using Walking Interviews to Enhance Research Relations with People with Dementia: Methodological Insights From an Empirical Study Conducted in England. *Ethics and Social Welfare* 14, 4 (2020), 432–442. `https://doi.org/10.1080/17496535.2020.1839115`

[8] Tone Bratteteig and Ina Wagner. 2012. Disentangling power and decision-making in participatory design. In *Proceedings of the 12th Participatory Design Conference:*

Research Papers - Volume 1. ACM, 41–50.
`https://doi.org/10.1145/2347635.2347642`

[9] Margot Brereton, Laurianne Sitbon, Muhammad Haziq Lim Abdullah, Mark Vanderberg, and Stewart Koplick. 2015. Design after design to bridge between people living with cognitive or sensory impairments, their friends and proxies. *CoDesign* 11, 1 (Mar. 2015), 4–20. `https://doi.org/10.1080/15710882.2015.1009471`

[10] Yunan Chen, Victor Ngo, and Sun Young Park. 2013. Caring for caregivers: designing for integrality. In *Proceedings of the 2013 conference on Computer supported cooperative work*. ACM, 91–102. `https://doi.org/10.1145/2441776.2441789`

[11] Raymundo Cornejo, Robin Brewer, Caroline Edasis, and Anne Marie Piper. 2016. Vulnerability, Sharing, and Privacy: Analyzing Art Therapy for Older Adults with Dementia. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*. ACM, 1572–1583.
`https://doi.org/10.1145/2818048.2819960`

[12] John W. Creswell and Dana L. Miller. 2000. Determining Validity in Qualitative Inquiry. *Theory Into Practice* 39, 3 (2000), 124–130.
`https://doi.org/10.1207/s15430421tip3903_2`

[13] Masashi Crete-Nishihata, Ronald M. Baecker, Michael Massimi, Deborah Ptak, Rachelle Campigotto, Liam D. Kaufman, Adam M. Brickman, Gary R. Turner, Joshua R. Steinerman, and Sandra E. Black. 2012. Reconstructing the Past: Personal Memory Technologies Are Not Just Personal and Not Just for Memory. *Human–Computer Interaction* 27, 1-2 (Apr. 2012), 92–123.
`https://doi.org/10.1080/07370024.2012.656062`

[14] Jiamin Dai and Karyn Moffatt. 2020. Making space for social sharing: Insights from a community-based social group for people with dementia. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. ACM, 1–13.
`https://doi.org/10.1145/3313831.3376133`

[15] Jiamin Dai and Karyn Moffatt. 2020. Using proxies in supporting the voice of people with dementia in HCI research. In *CHI'20 Workshop, Rethinking Notions of 'Giving Voice' in Design*. 1–4.

[16] Janet Davis and Lisa P. Nathan. 2013. Value Sensitive Design: Applications, Adaptations, and Critiques. In *Handbook of Ethics, Values, and Technological Design: Sources, Theory, Values and Application Domains*, Jeroen van den Hoven, Pieter E. Vermaas, and Ibo van de Poel (Eds.). Springer Netherlands, Dordrecht, 1–26.
`https://doi.org/10.1007/978-94-007-6994-6_3-1`

[17] Melissa Densmore, Casey Fiesler, Cosmin Munteanu, Michael Muller, Janet C. Read, Katie Shilton, and Özge Subaşı. 2020. Research Ethics Roundtable. In *Conference Companion Publication of the 2020 on Computer Supported Cooperative Work and Social Computing*. ACM, 195–198. `https://doi.org/10.1145/3406865.3419015`

[18] Audrey Desjardins and Aubree Ball. 2018. Revealing Tensions in Autobiographical Design in HCI. In *Proceedings of the 2018 Designing Interactive Systems Conference*. ACM, 753–764. `https://doi.org/10.1145/3196709.3196781`

[19] Emma Dixon and Amanda Lazar. 2020. Approach Matters: Linking Practitioner Approaches to Technology Design for People with Dementia. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. ACM, 1–15. `https://doi.org/10.1145/3313831.3376432`

[20] Emma Dixon and Amanda Lazar. 2020. The Role of sensory changes in everyday technology use by people with mild to moderate dementia. In *The 22nd International ACM SIGACCESS Conference on Computers and Accessibility*. 1–12. `https://doi.org/10.1145/3373625.3417000`

[21] Paul Dourish. 2006. Implications for design. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 541–550. `https://doi.org/10.1145/1124772.1124855`

[22] Robert Ferguson, Emily Crist, and Karyn Moffatt. 2016. A Framework for Negotiating Ethics in Sensitive Settings: Hospice as a Case Study. *Interacting with Computers* 29, 1 (2016), 10–26. `https://doi.org/10.1093/iwc/iww018`

[23] Sarah Foley, Nadia Pantidi, and John McCarthy. 2019. Care and Design: An Ethnography of Mutual Recognition in the Context of Advanced Dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 1–15. `https://doi.org/10.1145/3290605.3300840`

[24] Sarah Foley, Daniel Welsh, Nadia Pantidi, Kellie Morrissey, Tom Nappey, and John McCarthy. 2019. Printer Pals: Experience-Centered Design to Support Agency for People with Dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 1–13. `https://doi.org/10.1145/3290605.3300634`

[25] Julia Galliers, Stephanie Wilson, Abi Roper, Naomi Cocks, Jane Marshall, Sam Muscroft, and Tim Pring. 2012. Words are not enough: empowering people with aphasia in the design process. In *Proceedings of the 12th Participatory Design Conference: Research Papers - Volume 1*. ACM, 51–60. `https://doi.org/10.1145/2347635.2347643`

[26] Foad Hamidi, Melanie Baljko, and Isabel Gómez. 2017. Using Participatory Design with Proxies with Children with Limited Communication. In *Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility*. ACM, 250–259. `https://doi.org/10.1145/3132525.3132527`

[27] James Hodge, Madeline Balaam, Sandra Hastings, and Kellie Morrissey. 2018. Exploring the Design of Tailored Virtual Reality Experiences for People with Dementia. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. ACM, 1–13. `https://doi.org/10.1145/3173574.3174088`

[28] James Hodge, Sarah Foley, Rens Brankaert, Gail Kenning, Amanda Lazar, Jennifer Boger, and Kellie Morrissey. 2020. Relational, Flexible, Everyday: Learning from Ethics in Dementia Research. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. ACM, 1–16. `https://doi.org/10.1145/3313831.3376627`

[29] James Hodge, Kyle Montague, Sandra Hastings, and Kellie Morrissey. 2019. Exploring Media Capture of Meaningful Experiences to Support Families Living with Dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 3300653, 1–14. `https://doi.org/10.1145/3290605.3300653`

[30] Megan Hofmann, Devva Kasnitz, Jennifer Mankoff, and Cynthia L. Bennett. 2020. Living Disability Theory: Reflections on Access, Research, and Design. *ASSETS 2020 - 22nd International ACM SIGACCESS Conference on Computers and Accessibility*, 1–13. `https://doi.org/10.1145/3373625.3416996`

[31] Maarten Houben, Rens Brankaert, Saskia Bakker, Gail Kenning, Inge Bongers, and Berry Eggen. 2020. The Role of Everyday Sounds in Advanced Dementia Care. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. ACM, 1–14. `https://doi.org/10.1145/3313831.3376577`

[32] Maarten Houben, Rens Brankaert, and Eveline Wouters. 2020. Stakeholder Perspectives on Design Interventions in Dementia Care. In *Companion Publication of the 2020 ACM Designing Interactive Systems Conference*. ACM, 43–47. `https://doi.org/10.1145/3393914.3395868`

[33] Dorothy Howard and Lilly Irani. 2019. Ways of Knowing When Research Subjects Care. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 1–16. `https://doi.org/10.1145/3290605.3300327`

[34] Hsiu-Fang Hsieh and Sarah E. Shannon. 2005. Three Approaches to Qualitative Content Analysis. *Qualitative Health Research* 15, 9 (Nov. 2005), 1277–1288. `https://doi.org/10.1177/1049732305276687`

[35] Dhruv Jain, Audrey Desjardins, Leah Findlater, and Jon E. Froehlich. 2019. Autoethnography of a Hard of Hearing Traveler. In *The 21st International ACM SIGACCESS Conference on Computers and Accessibility*. ACM, 236–248. `https://doi.org/10.1145/3308561.3353800`

[36] Dhruv Jain, Venkatesh Potluri, and Ather Sharif. 2020. Navigating Graduate School with a Disability. In *The 22nd International ACM SIGACCESS Conference on Computers and Accessibility*. ACM, Article 8. `https://doi.org/10.1145/3373625.3416986`

[37] Jazette Johnson, Rebecca W. Black, and Gillian R. Hayes. 2020. Roles in the Discussion: An Analysis of Social Support in an Online Forum for People with Dementia. *Proc. ACM Hum.-Comput. Interact.* 4, CSCW2 (2020), Article 127. `https://doi.org/10.1145/3415198`

[38] Rose Johnson, Yvonne Rogers, Janet van der Linden, and Nadia Bianchi-Berthouze. 2012. Being in the thick of in-the-wild studies: the challenges and insights of researcher participation. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 1135–1144. `https://doi.org/10.1145/2207676.2208561`

[39] Pia Kontos and Wendy Martin. 2013. Embodiment and dementia: Exploring critical narratives of selfhood, surveillance, and dementia care. *Dementia* 12, 3 (2013), 288–302. `https://doi.org/10.1177/1471301213479787`

[40] Amanda Lazar, George Demiris, and Hilaire J. Thompson. 2016. Evaluation of a multifunctional technology system in a memory care unit: Opportunities for innovation in dementia care. *Informatics for Health and Social Care* 41, 4 (Jan. 2016), 373–386. `https://doi.org/10.3109/17538157.2015.1064428`

[41] Amanda Lazar and Emma E. Dixon. 2019. Safe Enough to Share: Setting the Dementia Agenda Online. *Proc. ACM Hum.-Comput. Interact.* 3, CSCW (Nov. 2019), 1–23. `https://doi.org/10.1145/3359187`

[42] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. A Critical Lens on Dementia and Design in HCI. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM, 2175–2188. `https://doi.org/10.1145/3025453.3025522`

[43] Amanda Lazar, Jessica L. Feuston, Caroline Edasis, and Anne Marie Piper. 2018. Making as Expression: Informing Design with People with Complex Communication Needs through Art Therapy. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. ACM, 1–16. `https://doi.org/10.1145/3173574.3173925`

[44] Amanda Lazar, Hilaire J. Thompson, and George Demiris. 2016. Design Recommendations for Recreational Systems Involving Older Adults Living With Dementia. *Journal of Applied Gerontology* (Apr. 2016), 1–25. `https://doi.org/10.1177/0733464816643880`

[45] Jonathan Lazar, Jinjuan Heidi Feng, and Harry Hochheiser. 2017. *Research methods in human-computer interaction* (2nd ed.). Morgan Kaufmann Publishers, an imprint of Elsevier, Cambridge, MA.

[46] Stephen Lindsay, Katie Brittain, Daniel Jackson, Cassim Ladha, Karim Ladha, and Patrick Olivier. 2012. Empathy, participatory design and people with dementia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems.* ACM, 521–530. `https://doi.org/10.1145/2207676.2207749`

[47] Galina Madjaroff and Helena Mentis. 2017. Narratives of Older Adults with Mild Cognitive Impairment and Their Caregivers. In *Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility.* ACM, 140–149. `https://doi.org/10.1145/3132525.3132554`

[48] Deborah J. Mayhew and Todd J. Follansbee. 2012. User Experience Requirements Analysis within the Usability Engineering Lifecycle. In *Human Computer Interaction Handbook: Fundamentals, Evolving Technologies, and Emerging Applications* (3rd ed.), Julie A. Jacko (Ed.). CRC Press, Boca Raton, 945–954.

[49] Nora McDonald, Sarita Schoenebeck, and Andrea Forte. 2019. Reliability and Inter-rater Reliability in Qualitative Research: Norms and Guidelines for CSCW and HCI Practice. *Proc. ACM Hum.-Comput. Interact.* 3, CSCW (2019), Article 72. `https://doi.org/10.1145/3359174`

[50] Helena M. Mentis, Galina Madjaroff, and Aaron K. Massey. 2019. Upside and Downside Risk in Online Security for Older Adults with Mild Cognitive Impairment. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems.* ACM, 1–13. `https://doi.org/10.1145/3290605.3300573`

[51] David L. Morgan, Jutta Ataie, Paula Carder, and Kim Hoffman. 2013. Introducing Dyadic Interviews as a Method for Collecting Qualitative Data. *Qualitative Health Research* 23, 9 (Aug. 2013), 1276–1284. `https://doi.org/10.1177/1049732313501889`

[52] Cosmin Munteanu, Amy Bruckman, Michael Muller, Christopher Frauenberger, Casey Fiesler, Robert E. Kraut, Katie Shilton, and Jenny Waycott. 2019. SIGCHI Research Ethics Town Hall. In *Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems.* ACM, Paper panel05. `https://doi.org/10.1145/3290607.3311742`

[53] Cosmin Munteanu, Heather Molyneaux, Wendy Moncur, Mario Romero, Susan O'Donnell, and John Vines. 2015. Situational Ethics: Re-thinking Approaches to Formal Ethics Requirements for Human-Computer Interaction. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*. ACM, 105–114. `https://doi.org/10.1145/2702123.2702481`

[54] Timothy Neate, Aikaterini Bourazeri, Abi Roper, Simone Stumpf, and Stephanie Wilson. 2019. Co-Created Personas: Engaging and Empowering Users with Diverse Needs Within the Design Process. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 1–12. `https://doi.org/10.1145/3290605.3300880`

[55] Mary Beth Riedner, Karen Maki, and Miriam Lytle. 2018. Becoming a dementia-friendly library. In *The Relevant Library: Essays on Adapting to Changing Needs*, Carol Smallwood Vera Gubnitskaia (Ed.). McFarland, Jefferson, NC, 187–194.

[56] Jennifer A. Rode. 2011. Reflexivity in digital anthropology. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 123–132. `https://doi.org/10.1145/1978942.1978961`

[57] Marén Schorch, Lin Wan, David William Randall, and Volker Wulf. 2016. Designing for Those who are Overlooked: Insider Perspectives on Care Practices and Cooperative Work of Elderly Informal Caregivers. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*. ACM, 787–799. `https://doi.org/10.1145/2818048.2819999`

[58] Kate Stephens, Matthew Butler, Leona M Holloway, Cagatay Goncu, and Kim Marriott. 2020. Smooth Sailing? Autoethnography of Recreational Travel by a Blind Person. In *The 22nd International ACM SIGACCESS Conference on Computers and Accessibility*. ACM, Article 26. `https://doi.org/10.1145/3373625.3417011`

[59] Suziah Sulaiman, Siti Nur Syazana Mat Saei, Foong Oi Mean, and Halabi Hasbullah. 2010. Understanding domain expert's perspectives and expectations in assistive technology. In *2010 International Symposium on Information Technology*, Vol. 3. 1164–1167. `https://doi.org/10.1109/ITSIM.2010.5561491`

[60] John C. Thomas and John T. Richards. 2012. Achieving Psychological Simplicity: Measures and Methods to Reduce Cognitive Complexity. In *Human Computer Interaction Handbook: Fundamentals, Evolving Technologies, and Emerging Applications* (3rd ed.), Julie A. Jacko (Ed.). CRC Press, Boca Raton, 491–514.

[61] David Unbehaun, Konstantin Aal, Daryoush Daniel Vaziri, Peter David Tolmie, Rainer Wieching, David Randall, and Volker Wulf. 2020. Social Technology

Appropriation in Dementia: Investigating the Role of Caregivers in Engaging People with Dementia with a Videogame-based Training System. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. ACM, 1–15. `https://doi.org/10.1145/3313831.3376648`

[62] John Vines, Peter C. Wright, David Silver, Maggie Winchcombe, and Patrick Olivier. 2015. Authenticity, Relatability and Collaborative Approaches to Sharing Knowledge about Assistive Living Technology. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing*. ACM, 82–94. `https://doi.org/10.1145/2675133.2675222`

[63] Jayne Wallace, Anja Thieme, Gavin Wood, Guy Schofield, and Patrick Olivier. 2012. Enabling self, intimacy and a sense of home in dementia: an enquiry into design in a hospital setting. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 2629–2638. `https://doi.org/10.1145/2207676.2208654`

[64] Jayne Wallace, Peter C. Wright, John McCarthy, David Philip Green, James Thomas, and Patrick Olivier. 2013. A design-led inquiry into personhood in dementia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 2617–2626. `https://doi.org/10.1145/2470654.2481363`

[65] Cara Wilson, Roisin McNaney, Abi Roper, Tara Capel, Laura Scheepmaker, Margot Brereton, Stephanie Wilson, David Philip Green, and Jayne Wallace. 2020. Rethinking Notions of 'Giving Voice' in Design. In *Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems*. ACM, 1–8. `https://doi.org/10.1145/3334480.3375171`

Chapter 6

Discussion

This chapter consolidates key threads across all three studies, presenting a deepened understanding of social spaces in the dementia community and revisiting the conceptual frameworks. Then, we discuss future work through two avenues: situating design work and guidelines in communities and extending academic and professional partnerships. We conclude with further reflections on the limitations of our work and researcher wellbeing in conducting emotionally demanding research.

6.1 Reframing Social Spaces in the Dementia Community

Our work delves deep into the nuances of social sharing in the dementia community and contributes new perspectives of technological design in this space. Inter-related and cross-referenced, our three studies collectively reveal opportunities for broadening social experiences and enhancing the agency of people with dementia and their caregivers.

6.1.1 Weaving common threads across studies

Building upon the individual discussions of each results chapter, here we selectively pull out key themes from across the manuscripts. Delving deep into community programs as an increasingly integral part of the social lives of families living with dementia, our on-site fieldwork (Chapter 3) underscores key positive factors such as mature and intellectual activities, positive and inclusive topics, and person-centered, multisensory materials. As these elements translate well into virtual programs, our virtual fieldwork (Chapter 4) demonstrates the challenges of maintaining other effective factors from in-person formats, including normalized environments and peer collaboration. The virtual fieldwork also extends implications on promoting the agency of both people with dementia and their caregivers, building upon our self-reflection (Chapter 5) on prioritizing the voices of people with dementia in collaboration with proxies.

Artefacts constitute another example of common threads across our three studies, highlighting the evolving need for developing effective prompts at multiple levels and finding the ones working best for different participants in various scenarios. Our on-site fieldwork finds tangible materials (e.g., large print images, maps, objects, clothing, and food) beneficial in engaging participants in storytelling and socializing. Our self-reflection furthers the attention to personal cues as home interviews enabled caregivers to take advantage of props at hand (e.g., paintings created by the participant in art therapy) to motivate more engaging responses from their loved ones. Our virtual fieldwork shows the advantage of remote social programs in affording easy and spontaneous sharing of objects, i.e., the ability to pull in personal artefacts was better supported as attendees were at home and could share personal possessions as the need arose.

Weaving these threads together, we can explore additional technological opportunities for promoting social sharing and supporting both people with dementia and their caregivers in the process. Our on-site fieldwork proposes more open-ended experiences, more diversified and dynamic participant roles, and more flexible platforms while our virtual fieldwork brings forward the increasingly blurred boundaries of private/public and physical/virtual settings. Our discussion on active sharing in the moment is echoed in recent HCI research that highlighted how older adults valued technological aid in identifying their roles in families and community and preserving social values and traditions [11]. New initiatives on supporting social connectedness for older adults in marginalized communities during the pandemic also resonate with our work on peer mentoring and flexible roles within community programs [12].

Adding the common thread of artefacts, we envision that hybrid social programs can extend beyond physical and virtual forms of attendance towards a structure in which virtual interactions work in tandem with tangible materials to create new social experiences. For example, a recent study in the UK highlights local artists leveraging weekly deliveries of Home Art Boxes during the COVID-19 lockdown to facilitate remote art workshops for people with dementia and their caregivers. With pictures of themed artefacts, art-making materials (e.g., paint, brushes, and paper), and instructions for that week's activity, these deliveries added tangible elements to virtual activities and could adjust to participants' declining conditions through timely feedback [1]. These artefacts in remote sessions can help strengthen virtual community environments, echoing our proposal on developing digital toolkits for both private/public and physical/virtual settings based on the current Tales & Travels suitcase kits on loan from the library.

6.1.2 Revisiting the conceptual frameworks

Our work echoes and deepens the notions proposed by the three conceptual frameworks reviewed in Chapter 2, collectively advancing the applications of these framework with the most recent HCI work in dementia.

1) As highlighted by *critical dementia* [17], positioning people with dementia as competent, engaged, and capable of meaningful expressions has been the cornerstone of successful social programs such as Tales & Travels. Our on-site fieldwork findings reveal mature and intellectual activities as an effective agency for social interaction, and our self-reflection center around collaborating with proxies to help people with dementia get their voices heard. Such empowering and collaborative approaches have continued being adopted in more recent HCI research. For example, researchers promoted user autonomy and long-term engagement by designing medication management support through conversational assistants for older adults with mild cognitive impairment [23].

2) As emphasized by *technology narrative* [22], enjoying life with the help of technology

has been a common thread reported by our participants. Our virtual fieldwork particularly showcases the transition to much-needed online activities through videoconferencing and social media to connect members of the dementia community during the pandemic. Recent work has taken a first step towards understanding the use of mobile phones among people with mild to moderate dementia to create more cognitively accessible technological environments [13].

3) As stressed by *interdependence for assistive technology design* [2], interpersonal relationships and collective work have been increasingly helpful in constructing in-person and online social spaces in dementia care. Both our on-site and virtual fieldwork signifies a distinctive group structure that enables people with dementia, caregivers, and professionals to contribute to social activities with a collaborative dynamic. More recent work has continue to examine interdependcies in dementia-friendly social programs, expanding to online and hybrid settings [6].

6.2 Future Work

6.2.1 Situating design work and guidelines in communities

As the world tackles aging and dementia care challenges, the notions of community-dwelling (e.g., [29]) and aging-in-place (e.g., [21]) have been increasingly recognized as effective strategies for promoting the wellbeing of people living with dementia. The most recent World Alzheimer Report 2022 underscores integrated treatment, care, and support, showcasing a range of non-pharmacological interventions for both people with dementia and their caregiving families and friends [15]. Aligning with these emerging global initiatives of care and support, our work demonstrates opportunities for better situating design work and guidelines in person-centered and community-centered approaches to public social programs. Public spaces open new opportunities for building upon the assets and strengths of people with dementia in social computing. Our work reveals effective strategies for promoting the agency of people with dementia such as peer collaboration and active in-the-moment sharing. Other recent studies have drawn from the Asset-Based Community Development framework to surface the strength and capacity of people with dementia in navigating public space and engaging in social inclusion and encounters, calling for dementia-informed community development and public space design [30]. All these avenues echo the development of an assets/strengths-based conceptual framework of wellbeing in dementia, potentially contributing to the call for newer technology-based in-the-moment measurement of psychosocial intervention outcomes [4]. Our paper reporting on the on-site fieldwork, published at ACM CHI 2020, has inspired ongoing HCI research focused on dementia-inclusive community spaces [5].

While exploring new design spaces, future work can continue to build upon existing design recommendations for people with dementia. For example, the hardware needs to be reliable and robust systems requiring minimal maintenance (e.g., waterproof, fall-proof, and easy to clean), as well as accommodating seated people and easy to reach [3, 18]. The user scenarios and requirements of the device need to be taken into consideration as home environments would be different from care facilities. Care needs to be taken in finding the most suitable devices for the target activities. For example, touchscreens provide more intuitive control interfaces for people with dementia, as less coordinated actions are required, and pressing seems a lot easier than other forms of interaction such as toggle switches [26, 18]. In general, participants' technology use data has been collected at small scales in different studies, only providing background or baseline information, thus leaving a gap for up-to-date reporting and systematic analysis. With the rising opportunities and need for hybrid activities, more efforts are needed in developing hybrid design recommendations for the dementia community.

In terms of methodological self-reflection, our findings are coming from reviewing one specific study, limited to the scope of our on-site fieldwork (e.g., participant and proxy backgrounds and community characteristics). To expand the insights from our investigations, future work can provide additional perspectives and broader reflections across more projects, diversifying perspectives across various communities and programs. Direct interviewing and observing on the participants' end can extend our previous methodological self-reflection on in-person research to surface the voices of people with dementia in remote and hybrid research engagements. This self-reflexive paper, published at ACM CHI 2021, has been cited by diverse HCI researchers and designers spanning dementia and other accessibility contexts in the UK, Netherlands, and Australia, strengthening their research design, inclusivity, and adaptivity (e.g., [31]). We hope that our work can continue to spur broader interdisciplinary discussion in advancing inclusive and accessible research and design.

6.2.2 Extending academic and professional partnerships

Our long-term engagement with the local dementia community has shed light on further academic collaborations across disciplines and professional partnerships in different avenues of dementia care. Similar to the increasing HCI work in dementia, the library and information science (LIS) field has seen dementia-friendly programs emerging in information organizations. For example, libraries have adapted spaces to facilitate sensory stimulation through the creative use of tactile objects [10]; museums have mobilized art collections to offer specialized guided tours and art-making workshops in an aesthetically pleasing environment [24].

As a cornerstone of community activity, information services are optimally positioned to enhance dementia care and social programming as part of the information service infrastructure. LIS researchers have examined professional communication for dementia and uncovered an ethic of care [8], and more recent work studies public libraries as social infrastructure through online programming for older patrons during the pandemic [9]. As community social programs provide notable opportunities for promoting engagement and inclusivity, future work can advance interdisciplinary collaborations through in-depth assessments and analyses to guide further research and practice. Such work can achieve deeper social impact by directly informing community partners, e.g., increasing their readiness to leverage caregiver support in the much-needed transition to more technology-mediated virtual activities.

Examining the on-site fieldwork data from LIS perspectives, our additional publication in the Journal of Librarianship and Information Science offers insights immediately applicable in practice and advances librarianship research on library services for dementia care [7]. This work echoes recent interdisciplinary studies on the impact of including caregivers in museum programs for people with dementia by researchers from Medical Studies backgrounds [16] and pedagogical practice in a dementia daycare centre for an undergraduate ”Social Design” course [19]. We hope that these efforts will collectively inspire future initiatives in which HCI researchers and practitioners can work with other professionals to help improve the wellbeing of vulnerable populations.

6.3 Further Reflections

6.3.1 Limitations

Our in-person and virtual fieldwork (presented in Chapters 3 and 4) is situated in greater Montreal, a populous municipality in Canada. Thus, some findings might have inherent social and demographic limitations when applied to other communities. Although our participants with dementia and their caregivers come from various cultural, educational, and professional backgrounds, most of them have higher education and comfortable socioeconomic status, which may have pre-conditioned their active involvement in social events and research. These limitations echo the growing discussions on the predominant

Western, educated, industrialized, rich, and democratic (WEIRD) populations in research across disciplines. HCI researchers have recently examined this WEIRD problem through the 2016–2020 ACM CHI proceedings, revealing 73% of the studies are based on Western participant samples, which represent less than 12% of the world's population [20]. Another recent survey study has examined dementia research participation via an online platform, exploring volunteer motivation, identity, and meaning-making to better support future research participants [25]. Echoing these renewed efforts, we hope that the above-mentioned extension of research partnerships across communities and professions can aid in more diverse and inclusive future recruitment.

Our self-reflective work (presented in Chapter 5) is limited by our 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 my 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 [28]. 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. Qualitative researchers across disciplines have long been rethinking reflexivity as a methodological tool, advocating for ongoing self-critiques of research attempts in complex contexts [27]. We hope that our efforts can spur further methodological considerations among HCI researchers in deconstructing and reinterpreting design problems.

6.3.2 Researcher wellbeing

Our extended fieldwork in the dementia community carries the weight of emotionally demanding research. Our interviews with families living with dementia inevitably touched upon sensitive personal experiences of coping with hardship and loss. Collecting and iteratively analyzing the fieldwork data exposed us researchers to some disturbing facts about the disease and healthcare/social supports. During the extended period of our preliminary work and fieldwork (2018–2021), we witnessed the deterioration of people with dementia, as well as all the ever more strenuous caregiving situations, worsened by the disruption of physical and social activities due to the pandemic. As we followed up with our participants during the pandemic, one of the most difficult pieces of news we received was the passing of one participant with dementia whom we knew well.

Looking back on our research process, we deeply appreciate the mutual support among researchers in confronting emotional stress. During data collection and analysis, the timely debriefs among us co-authors not only deepened our interpretation of the data and research contexts but also offered emotional support. Especially for the methodological self-reflection (presented in Chapter 5), this trusted relationship mitigated the potential authority issue and extra layers of stress among us as co-authors. The power dynamics between a PhD student and their supervisor could have hindered candid revealing of the setbacks during data collection and analysis. Fortunately, we have known each other for over seven years and built a supportive, collaborative working relationship. The mutual trust and communicative rhythms helped us overcome the difficulties in exposing researcher vulnerability, conducting iterative self-examination, and maintaining researcher wellbeing. We also appreciate the support from our extended network such as colleagues in the lab and academic writing groups outside our field.

Academics have recognized such researcher distress, often referred to as secondary trauma, brought on by sensitive topics or prolonged immersion in qualitative data. Recent work has reflected on triggers to secondary trauma, cumulative impacts, competing demands, coping strategies, and rewarding experiences [32]. HCI researchers have started to discuss self-care principles and strategies related to mental, physical, and emotional wellbeing for conducting emotionally demanding work, such as the ACM CHI 2022 workshop "Researcher Wellbeing and Best Practices in Emotionally Demanding Research" [14]. We joined this workshop with HCI researchers working in a wide range of sensitive settings to discuss our experiences and envision practical supports at the individual, collaborator/team, and institutional levels. Hopefully, such emerging discussions will contribute to best practices, guidelines, and resources that can benefit future research practice and researcher wellbeing.

Bibliography

[1] Christina Armstrong, Anji Archer, Valerie Critten, and Sarah Critten. 2022. Art box deliveries: The experiences of people with dementia and their carers during the Covid 19 lockdown. *Dementia* (2022), 14713012221124863. `https://doi.org/10.1177/14713012221124863`

[2] Cynthia L. Bennett, Erin Brady, and Stacy M. Branham. 2018. Interdependence as a frame for assistive technology research and design. *ASSETS 2018 - 20th International ACM SIGACCESS Conference on Computers and Accessibility*, 161–173. `https://doi.org/10.1145/3234695.3236348`

[3] Inga-Lill Boman, Ann-Christine Persson, and Aniko Bartfai. 2016. First steps in designing an all-in-one ICT-based device for persons with cognitive impairment: evaluation of the first mock-up. *BMC geriatrics* 16, 1 (2016), 1–11. `https://doi.org/10.1186/s12877-016-0238-x`

[4] Chris Clarke, Bob Woods, Esme Moniz-Cook, Gail Mountain, Laila Øksnebjerg, Rabih Chattat, Ana Diaz, Dianne Gove, Myrra Vernooij-Dassen, and Emma Wolverson. 2020. Measuring the well-being of people with dementia: a conceptual scoping review. *Health and quality of life outcomes* 18, 1 (2020), 1–14. `https://doi.org/10.1186/s12955-020-01440-x`

[5] Elaine Czech. 2022. Applying Technology in a Hybrid-Fashion to Create Dementia-Inclusive Community Spaces. In *The 24th International ACM SIGACCESS Conference on Computers and Accessibility*. 1–6. `https://doi.org/10.1145/3517428.3550412`

[6] Elaine Czech, Paul Marshall, and Oussama Metatla. 2022. “Just like meeting in person”-Examination of interdependencies in dementia-friendly virtual activities.. In *The 24th International ACM SIGACCESS Conference on Computers and Accessibility*. 1–15. `https://doi.org/10.1145/3517428.3544815`

[7] Jiamin Dai, Joan C Bartlett, and Karyn Moffatt. 2023. Library services enriching community engagement for dementia care: The Tales & Travels Program at a

Canadian Public Library as a case study. *Journal of Librarianship and Information Science* 55, 1 (2023), 123–136. `https://doi.org/10.1177/09610006211065170`

[8] Nicole K Dalmer and D Grant Campbell. 2020. Communicating with library patrons and people with dementia: Tracing an ethic of care in professional communication guidelines. *Dementia* 19, 3 (2020), 899–914.

[9] Nicole K Dalmer and Bria L Mitrovica. 2022. The public library as social infrastructure for older patrons: Exploring the implications of online library programming for older adults during COVID-19. *Library & Information Science Research* 44, 3 (2022), 101177.

[10] M Damron. 2019. A sensory wonderland: A programming space for the special needs community. *American Libraries* 50, 6 (2019), 24–25.

[11] Shital Desai, Colleen McGrath, Heather McNeil, Heidi Sveistrup, Josephine McMurray, and Arlene Astell. 2022. Experiential value of technologies: A qualitative study with older adults. *International Journal of Environmental Research and Public Health* 19, 4 (2022), 2235.

[12] Shital Desai, Pablo Vivanco, and Deborah Fels. 2022. Connecting seniors in marginalized communities during covid-19. *Interactions* 29, 5 (2022), 63–67.

[13] Emma Dixon, Rain Michaels, Xiang Xiao, Yu Zhong, Patrick Clary, Ajit Narayanan, Robin N Brewer, and Amanda Lazar. 2022. Mobile Phone Use by People with Mild to Moderate Dementia: Uncovering Challenges and Identifying Opportunities: Mobile Phone Use by People with Mild to Moderate Dementia. In *The 24th International ACM SIGACCESS Conference on Computers and Accessibility*. 1–16. `https://doi.org/10.1145/3517428.3544809`

[14] Jessica L Feuston, Arpita Bhattacharya, Nazanin Andalibi, Elizabeth A Ankrah, Sheena Erete, Mark Handel, Wendy Moncur, Sarah Vieweg, and Jed R Brubaker. 2022. Researcher wellbeing and best practices in emotionally demanding research. In *CHI Conference on Human Factors in Computing Systems Extended Abstracts*. 1–6. `https://doi.org/10.1145/3491101.3503742`

[15] Serge Gauthier, Claire Webster, Stijn Servaes, José A Morais, and Pedro Rosa-Neto. 2022. World Alzheimer Report 2022-Life after diagnosis:Navigating treatment, care and support. (2022). `https://www.alzint.org/u/World-Alzheimer-Report-2022.pdf`

[16] Debbie Kinsey, Noreen Orr, Rob Anderson, and Iain Lang. 2022. A conceptual model of the impact of including carers in museum programmes for people with dementia. *Dementia* (2022), 14713012221126803. `https://doi.org/10.1177/14713012221126803`

[17] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. A Critical Lens on Dementia and Design in HCI. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM, 2175–2188. `https://doi.org/10.1145/3025453.3025522`

[18] Amanda Lazar, Hilaire J. Thompson, and George Demiris. 2016. Design Recommendations for Recreational Systems Involving Older Adults Living With Dementia. *Journal of Applied Gerontology* (Apr. 2016), 1–25. `https://doi.org/10.1177/0733464816643880`

[19] Cláudia Lima. 2023. Designing for people with Dementia in academic contexts. *Perspectives on Design and Digital Communication III* (2023), 181–193. `https://doi.org/10.1007/978-3-031-06809-6_12`

[20] Sebastian Linxen, Christian Sturm, Florian Brühlmann, Vincent Cassau, Klaus Opwis, and Katharina Reinecke. 2021. How weird is CHI?. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–14. `https://doi.org/10.1145/3411764.3445488`

[21] Lisa Lole, Jessica Conway, Anthea Oorloff, and Cameron Duffy. 2022. The role of day-respite centers in supporting people with dementia to age in place: An interpretive phenomenological study. *Health Promotion Journal of Australia* (2022). `https://doi.org/10.1002/hpja.652`

[22] Galina Madjaroff and Helena Mentis. 2017. Narratives of Older Adults with Mild Cognitive Impairment and Their Caregivers. In *Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility*. ACM, 140–149. `https://doi.org/10.1145/3132525.3132554`

[23] Niharika Mathur, Kunal Dhodapkar, Tamara Zubatiy, Jiachen Li, Brian Jones, and Elizabeth Mynatt. 2022. A Collaborative Approach to Support Medication Management in Older Adults with Mild Cognitive Impairment Using Conversational Assistants (CAs). In *The 24th International ACM SIGACCESS Conference on Computers and Accessibility*. 1–14. `https://doi.org/10.1145/3517428.3544830`

[24] Montreal Museum of Fine Arts. 2018. Art Links: Periods of respite at the MMFA for over 800 persons with Alzheimer's and their caregivers [Press release]. (2018). `https://www.mbam.qc.ca/wp-content/uploads/2018/09/MMFA-Press-release-Alzheimer_Final.pdf`

[25] Khushnood Z Naqshbandi, Yun-Hee Jeon, and Naseem Ahmadpour. 2022. Exploring Volunteer Motivation, Identity and Meaning-Making in Digital Science-Based Research Volunteering. *International Journal of Human–Computer Interaction* (2022), 1–22. `https://doi.org/10.1080/10447318.2022.2109246`

[26] Roger Orpwood, James Chadd, Deborah Howcroft, Andrew Sixsmith, Judith Torrington, Grant Gibson, and Garuth Chalfont. 2010. Designing technology to improve quality of life for people with dementia: user-led approaches. *Universal Access in the Information Society* 9, 3 (2010), 249–259. `https://doi.org/10.1007/s10209-009-0172-1`

[27] Wanda Pillow. 2003. Confession, catharsis, or cure? Rethinking the uses of reflexivity as methodological power in qualitative research. *International journal of qualitative studies in education* 16, 2 (2003), 175–196. `https://doi.org/10.1080/0951839032000060635`

[28] Jennifer A. Rode. 2011. Reflexivity in digital anthropology. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 123–132. `https://doi.org/10.1145/1978942.1978961`

[29] Theresa L Scott, Ying-Ling Jao, Kristen Tulloch, Eloise Yates, Oliver Kenward, and Nancy A Pachana. 2022. Well-Being Benefits of Horticulture-Based Activities for Community Dwelling People with Dementia: A Systematic Review. *International Journal of Environmental Research and Public Health* 19, 17 (2022), 10523. `https://doi.org/10.3390/ijerph191710523`

[30] Jodi Sturge, Mirjam Klaassens, C Allyson Jones, France Légaré, Marie Elf, Gerd Weitkamp, and Louise Meijering. 2021. Exploring assets of people with memory problems and dementia in public space: A qualitative study. *Wellbeing, Space and Society* 2 (2021), 9. `https://doi.org/10.1016/j.wss.2021.100063`

[31] Sandra Suijkerbuijk, Myrte Thoolen, Henk Herman Nap, Mirella Minkman, Wijnand IJsselsteijn, Rens Brankaert, and Yvonne de Kort. 2023. Adaptivity in Research Practice with People Living with Dementia: A Designer's Reflection. In *Dementia Lab Conference*. Springer, 13–25. `https://doi.org/10.1007/978-3-031-14466-0_2`

[32] Emma Williamson, Alison Gregory, Hilary Abrahams, Nadia Aghtaie, Sarah-Jane Walker, and Marianne Hester. 2020. Secondary trauma: Emotional safety in sensitive research. *Journal of Academic Ethics* 18, 1 (2020), 55–70. `https://doi.org/10.1007/s10805-019-09348-y`

Chapter 7

Conclusion

Families living with dementia face major challenges in their social lives, and community-based activities are well-positioned to engage people with dementia socially and relieve some caregiving burden. As growing HCI research explores technological opportunities for social activities at home and care facilities, comparatively less work has focused on community settings. This thesis helps fill this critical gap in HCI research on supporting community-based social sharing, both in-person and virtual, inclusive of people with dementia and their caregivers.

7.1 Thesis Contributions

Through on-site fieldwork, virtual fieldwork, and methodological self-reflection, this thesis fulfills the three goals set in Chapter 1 by making contributions in the following three categories.

7.1.1 Technological opportunities for people with dementia in community-based social sharing in in-person settings

Situating our on-site fieldwork in Tales & Travels, a storytelling and socializing program in the Montreal dementia community, we interviewed 5 dyads of people living with early-middle stage dementia and their primary family caregivers, 3 individual caregivers, and 4 Tales & Travels facilitators. Concurrently, we observed 8 Tales & Travels sessions. Through thematic analysis on the interview transcripts and observational fieldnotes, we make empirical contributions to dementia-related HCI research in in-person settings by identifying four factors that aid in achieving positive outcomes and four design avenues for diversifying the range of social spaces.

Factors that aid in achieving positive outcomes in community-based social programs for people with dementia:

1. Building mature, positive, and person-centered social settings through effective agencies such as
    - Mature and intellectual activities,
    - Positive and inclusive topics,
    - Person-centered stimuli,

    - Multisensory materials;

2. Creating normalized and friendly environments to bring a sense of normality, spark spontaneous expressions, and offer social opportunities;
3. Leveraging group settings through peer collaboration and teamwork;
4. Mediating social cues and communication barriers to manage group dynamics and avoid conflicts.

Avenues for designing new social technologies to diversify the range of social spaces in community settings:

1. Expand peer collaboration and leverage physical and virtual spaces;
2. Create dynamic experiences through richer content (e.g., sharing personal stories, thoughts and opinions, skills and expertise, and mutual learning) and more open-ended structures (e.g., exploring the social experience itself as the end goal);
3. Advocate for synchronized creating and sharing processes (e.g, the "in-the-moment" and "here and now" approaches) and more diversified participant roles (e.g., storytellers/listeners, contributors/audiences, and collaborators);
4. Develop more flexible social platforms to offer person-centered yet inclusive activities.

7.1.2 Technological opportunities for people with dementia in community-based social sharing in virtual settings

Building upon our on-site fieldwork, our virtual fieldwork investigates remote social activities explored by the Montreal dementia community in response to the impacts of the pandemic. We conducted follow-up interviews with 3 caregivers and 2 facilitators who participated in our previous study. Then, we reflected on our volunteering and facilitation experience in 35 virtual Tales & Travels sessions. Through thematic analysis on the interview transcripts and reflexive facilitation notes, we make empirical contributions to dementia-related HCI research in virtual settings by deepening the understanding of virtual social sharing and proposing four new design avenues.

A deepened understanding of virtual social sharing for the dementia community:

1. Complexities in virtual social engagements in terms of more challenging social lives with more complicated caregiving situations, as well as individual resilience and collective support in the dementia community;

2. The positive and negative roles of technology in the much-needed online activities while highlighting the corresponding additional demands on caregiver support;

3. Efforts for re-building social experiences as a virtual community by leveraging physical objects and environments, enhancing open and flexible experiences,

expanding collaborative space, and making technological accommodations.

Avenues for designing new social technologies through holistic approaches:

1. Reimagine community social spaces and deepen the understanding of placemaking in physical/virtual and public/private environments;
2. Affirm agency in people with dementia by creating collaborative group dynamics and supporting active in-the-moment sharing;
3. Promote agency in caregivers through their extended collaborator roles in the new virtual contexts of social experiences;
4. Diversify HCI support across communities and stakeholders by developing collaborative approaches, attending to usability, security, and privacy, and building specialized prompting systems.

7.1.3 Methodological guidance for qualitative work in dementia settings

Critically reflecting on our on-site fieldwork, we re-analyzed our interview transcripts and observation notes, as well as the process of study design, data collection, and data analysis. By deconstructing our experience, we examined how we succeeded and failed to capture the perspective of people with dementia while involving proxies (i.e., caregivers and facilitators) in the process. Through qualitative content analysis, we make methodological contributions to HCI research in dementia and broader accessibility settings by identifying four key strategies and developing 12 guidelines.

Strategies for effective inclusion of proxy stakeholders in qualitative HCI work in sensitive settings such as dementia care:

1. Prioritizing participants' voices in collaboration with proxies by ensuring that proxies amplify rather than suppress participants' voices and carefully managing disputes and power dynamics;
2. Triangulating findings across multiple sources;
3. Learning from proxies and cross-referencing multiple cues;
4. Extending engagement with the community.

We illustrate these strategies through concrete excerpts from diverse data sources our on-site fieldwork (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. We further propose a set of guidelines for better engaging participants by effectively involving proxies.

Guidelines for preliminary work and research design:

1. Engage with the community extensively to establish trust and rapport with participants and proxies, as well as allowing for deeper understanding of the context;

2. Involve relevant proxies and choose appropriate approaches for the research context and the spectrum of dementia;
3. Explore multiple information sources and facets of research design;
4. Assess the power dynamics among participants and proxies and develop concrete redirection plans;
5. Prepare multisensory probes and personalized prompts in collaboration with proxies.

Guidelines for data collection:

6. Create an open and flexible research setting to provide private and comfortable space for participants and proxies;
7. Enable proxies to facilitate communication and prepare to intervene if necessary (even when proxies are trying to be supportive);
8. Empathize with both participants and proxies to avoid potential disputes among them;
9. 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;
10. 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.

Guidelines for data analysis:

11. Conduct an additional round of data analysis to explicitly focus on power dynamics and risks of participants' voices being overshadowed;

12. Triangulate findings across different sources and delve deeper to interpret both alignments and contradictions in the data.

These guidelines can benefit researchers and practitioners working with vulnerable populations, leading to further discussion and critique to strengthen and improve research practices in the domain of dementia care.

7.2 Further Recommendations

Through the above empirical and methodological contributions, we establish the integral role of community social programs in improving the quality of life for families living with dementia. We call for reframing social spaces in the dementia community through HCI work in two directions:

1. Better situate design work in person-centered and community-centered approaches to public social programs. Future work can leverage public spaces in

assets/strengths-based activities to promote the agency of people with dementia and their caregivers;

2. Advance design guidelines in community spaces. The ever-changing technological landscape and user needs necessitate continuous examination of hardware and software considerations, including meeting the emerging hybrid activities and users across the spectrum of technology adoption.

For future HCI work in dementia and broader contexts, we further recommend the following avenues:

1. Expand methodological reflections across various dementia communities and social programs;
2. Extend research collaborations with related disciplines and practical partnerships with dementia professionals;
3. Exchange thoughts on self-care strategies and external supports for researcher wellbeing in emotionally demanding work to develop best practices and guidelines at the individual, team, and institutional levels.

Master Bibliography

Bibliography

[1] Meghan Allen, Rock Leung, Joanna McGrenere, and Barbara Purves. 2008. Involving domain experts in assistive technology research. *Universal Access in the Information Society* 7, 3 (Jan. 2008), 145–154. `https://doi.org/10.1007/s10209-008-0112-5`

[2] Sarah Alsawy, Sara Tai, Phil McEvoy, and Warren Mansell. 2020. 'It's nice to think somebody's listening to me instead of saying "oh shut up"'. People with dementia reflect on what makes communication good and meaningful. *Journal of psychiatric and mental health nursing* 27, 2 (2020), 151–161. `https://doi.org/10.1111/jpm.12559`

[3] Alzheimer Society of Canada. 2022. Navigating the Path Forward for Dementia in Canada: The Landmark Study Report 1. (2022). `https://alzheimer.ca/sites/default/files/documents/Landmark-Study-Report-1-Path_Alzheimer-Society-Canada_0.pdf`

[4] Alzheimer's Association. 2019. 2019 Alzheimer's disease facts and figures. *Alzheimer's & Dementia* 15, 3 (2019), 321–387. `https://doi.org/10.1016/j.jalz.2019.01.010`

[5] Alzheimer's Association. 2020. 2020 Alzheimer's disease facts and figures. *Alzheimer's & Dementia* 16, 3 (Mar. 2020), 391–460. `https://doi.org/10.1002/alz.12068`

[6] Alzheimer's Association. 2022. 2022 Alzheimer's disease facts and figures. *Alzheimer's & Dementia* 18, 4 (Apr. 2022), 700–789. `https://doi.org/10.1002/alz.12638`

[7] Ernesto Arias, Hal Eden, Gerhard Fischer, Andrew Gorman, and Eric Scharff. 2000. Transcending the individual human mind—creating shared understanding through collaborative design. *ACM Transactions on Computer-Human Interaction (TOCHI)* 7, 1 (Mar. 2000), 84–113. `https://doi.org/10.1145/344949.345015`

[8] Christina Armstrong, Anji Archer, Valerie Critten, and Sarah Critten. 2022. Art box deliveries: The experiences of people with dementia and their carers during the Covid 19 lockdown. *Dementia* (2022), 14713012221124863. `https://doi.org/10.1177/14713012221124863`

[9] Arlene Astell, Norman Alm, Gary Gowans, Maggie Ellis, Richard Dye, and Phillip Vaughan. 2009. Involving older people with dementia and their carers in designing computer based support systems: some methodological considerations. *Universal Access in the Information Society* 8, 1 (May 2009), 49–58. `https://doi.org/10.1007/s10209-008-0129-9`

[10] Arlene J Astell, Maggie P Ellis, Lauren Bernardi, Norman Alm, Richard Dye, Gary Gowans, and Jim Campbell. 2010. Using a touch screen computer to support relationships between people with dementia and caregivers. *Interacting with Computers* 22, 4 (2010), 267–275. `https://doi.org/10.1016/j.intcom.2010.03.003`

[11] Ruth Bartlett. 2012. Modifying the Diary Interview Method to Research the Lives of People With Dementia. *Qualitative Health Research* 22, 12 (2012), 1717–1726. `https://doi.org/10.1177/1049732312462240`

[12] Jeanette Bell and Tuck Wah Leong. 2019. Collaborative futures: Co-designing research methods for younger people living with dementia. In *Proceedings of the 2019 chi conference on human factors in computing systems.* 1–13. `https://doi.org/10.1145/3290605.3300582`

[13] Erin Beneteau. 2020. Who Are You Asking?: Qualitative Methods for Involving AAC Users as Primary Research Participants. *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*, 1–13. `https://doi.org/10.1145/3313831.3376883`

[14] Cynthia L. Bennett, Erin Brady, and Stacy M. Branham. 2018. Interdependence as a frame for assistive technology research and design. *ASSETS 2018 - 20th International ACM SIGACCESS Conference on Computers and Accessibility*, 161–173. `https://doi.org/10.1145/3234695.3236348`

[15] Susanne Bødker. 2015. Third-wave HCI, 10 years later—participation and sharing. *interactions* 22, 5 (2015), 24–31. `https://doi.org/10.1145/2804405`

[16] Inga-Lill Boman, Ann-Christine Persson, and Aniko Bartfai. 2016. First steps in designing an all-in-one ICT-based device for persons with cognitive impairment: evaluation of the first mock-up. *BMC geriatrics* 16, 1 (2016), 1–11. `https://doi.org/10.1186/s12877-016-0238-x`

[17] Alan Borning and Michael Muller. 2012. Next steps for value sensitive design. In *Proceedings of the SIGCHI conference on human factors in computing systems.* ACM, 1125–1134. `https://doi.org/10.1145/2207676.2208560`

[18] Tula Brannelly and Ruth Bartlett. 2020. Using Walking Interviews to Enhance Research Relations with People with Dementia: Methodological Insights From an Empirical Study Conducted in England. *Ethics and Social Welfare* 14, 4 (2020), 432–442. `https://doi.org/10.1080/17496535.2020.1839115`

[19] Tone Bratteteig and Ina Wagner. 2012. Disentangling power and decision-making in participatory design. In *Proceedings of the 12th Participatory Design Conference: Research Papers - Volume 1*. ACM, 41–50. `https://doi.org/10.1145/2347635.2347642`

[20] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3 (1 2006), 77–101. Issue 2. `https://doi.org/10.1191/1478088706qp063oa`

[21] Margot Brereton, Laurianne Sitbon, Muhammad Haziq Lim Abdullah, Mark Vanderberg, and Stewart Koplick. 2015. Design after design to bridge between people living with cognitive or sensory impairments, their friends and proxies. *CoDesign* 11, 1 (Mar. 2015), 4–20. `https://doi.org/10.1080/15710882.2015.1009471`

[22] Robin Brewer and Anne Marie Piper. 2016. "Tell It Like It Really Is": A Case of Online Content Creation and Sharing Among Older Adult Bloggers. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*. 5529–5542. `https://doi.org/10.1145/2858036.2858379`

[23] Lisa S Caddell and Linda Clare. 2010. The impact of dementia on self and identity: A systematic review. *Clinical psychology review* 30, 1 (2010), 113–126. `https://doi.org/10.1016/j.cpr.2009.10.003`

[24] Romina Carrasco, Felicity A. Baker, Anna A. Bukowska, Imogen N. Clark, Libby M. Flynn, Kate McMahon, Helen Odell-Miller, Karette Stensaeth, Jeanette Tamplin, Tanara Vieira Sousa, et al. 2020. Empowering Caregivers of People Living with Dementia to Use Music Therapeutically at Home: Design Opportunities. In *32nd Australian Conference on Human-Computer Interaction*. 198–209. `https://doi.org/10.1145/3441000.3441082`

[25] Alan Chamberlain, Andy Crabtree, and Mark Davies. 2013. Community engagement for research: contextual design in rural CSCW system development. In *Proceedings of the 6th International Conference on Communities and Technologies*. 131–139. `https://doi.org/10.1145/2482991.2483001`

[26] Yunan Chen, Victor Ngo, and Sun Young Park. 2013. Caring for caregivers: designing for integrality. In *Proceedings of the 2013 conference on Computer supported cooperative work*. ACM, 91–102. `https://doi.org/10.1145/2441776.2441789`

[27] Janghee Cho, Samuel Beck, and Stephen Voida. 2022. Topophilia, Placemaking, and Boundary Work: Exploring the Psycho-Social Impact of the COVID-19 Work-From-Home Experience. *Proceedings of the ACM on Human-Computer Interaction* 6, GROUP (2022), 1–33. `https://doi.org/10.1145/3492843`

[28] Shaan Chopra, Emma Dixon, Kausalya Ganesh, Alisha Pradhan, Mary L. Radnofsky, and Amanda Lazar. 2021. Designing for and with People with Dementia using a Human Rights-Based Approach. In *Extended Abstracts of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–8. `https://doi.org/10.1145/3411763.3443434`

[29] Sharon Lynn Chu, Brittany Garcia, Taylor Quance, Lisa Geraci, Steven Woltering, and Francis Quek. 2016. Understanding storytelling as a design framework for cognitive support technologies for older adults. In *Proceedings of the International Symposium on Interactive Technology and Ageing Populations*. 24–33. `https://doi.org/10.1145/2996267.2996270`

[30] Chris Clarke, Bob Woods, Esme Moniz-Cook, Gail Mountain, Laila Øksnebjerg, Rabih Chattat, Ana Diaz, Dianne Gove, Myrra Vernooij-Dassen, and Emma Wolverson. 2020. Measuring the well-being of people with dementia: a conceptual scoping review. *Health and quality of life outcomes* 18, 1 (2020), 1–14. `https://doi.org/10.1186/s12955-020-01440-x`

[31] Rachel Clarke, Jo Briggs, Ann Light, and Pete Wright. 2016. Situated encounters with socially engaged art in community-based design. In *Proceedings of the 2016 ACM conference on designing interactive systems*. 521–532. `https://doi.org/10.1145/2901790.2901882`

[32] Simon Coghlan, Jenny Waycott, Amanda Lazar, and Barbara Barbosa Neves. 2021. Dignity, autonomy, and style of company: dimensions older adults consider for robot companions. *Proceedings of the ACM on human-computer interaction* 5, CSCW1 (2021), 1–25. `https://doi.org/10.1145/3449178`

[33] Tira Cohene, RM Baecker, Elsa Marziali, and Simona Mindy. 2007. Memories of a life: a design case study for Alzheimer's disease. *Universal Usability: Designing Computer Interfaces for Diverse User Populations* (2007), 357–387. `http://ron.taglab.ca/papers/B14.pdf`

[34] Ned Cooper, Tiffanie Horne, Gillian R Hayes, Courtney Heldreth, Michal Lahav, Jess Holbrook, and Lauren Wilcox. 2022. A Systematic Review and Thematic Analysis of Community-Collaborative Approaches to Computing Research. In *CHI Conference on Human Factors in Computing Systems*. 1–18. `https://doi.org/10.1145/3491102.3517716`

[35] Raymundo Cornejo, Robin Brewer, Caroline Edasis, and Anne Marie Piper. 2016. Vulnerability, Sharing, and Privacy: Analyzing Art Therapy for Older Adults with Dementia. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*. ACM, 1572–1583. `https://doi.org/10.1145/2818048.2819960`

[36] John W. Creswell and Dana L. Miller. 2000. Determining Validity in Qualitative Inquiry. *Theory Into Practice* 39, 3 (2000), 124–130. `https://doi.org/10.1207/s15430421tip3903_2`

[37] Masashi Crete-Nishihata, Ronald M. Baecker, Michael Massimi, Deborah Ptak, Rachelle Campigotto, Liam D. Kaufman, Adam M. Brickman, Gary R. Turner, Joshua R. Steinerman, and Sandra E. Black. 2012. Reconstructing the Past: Personal Memory Technologies Are Not Just Personal and Not Just for Memory. *Human–Computer Interaction* 27, 1-2 (Apr. 2012), 92–123. `https://doi.org/10.1080/07370024.2012.656062`

[38] Elaine Czech. 2022. Applying Technology in a Hybrid-Fashion to Create Dementia-Inclusive Community Spaces. In *The 24th International ACM SIGACCESS Conference on Computers and Accessibility*. 1–6. `https://doi.org/10.1145/3517428.3550412`

[39] Elaine Czech, Paul Marshall, and Oussama Metatla. 2022. "Just like meeting in person"-Examination of interdependencies in dementia-friendly virtual activities.. In *The 24th International ACM SIGACCESS Conference on Computers and Accessibility*. 1–15. `https://doi.org/10.1145/3517428.3544815`

[40] Jiamin Dai, Joan C Bartlett, and Karyn Moffatt. 2023. Library services enriching community engagement for dementia care: The Tales & Travels Program at a Canadian Public Library as a case study. *Journal of Librarianship and Information Science* 55, 1 (2023), 123–136. `https://doi.org/10.1177/09610006211065170`

[41] Jiamin Dai and Karyn Moffatt. 2020. Making space for social sharing: Insights from a community-based social group for people with dementia. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. ACM, 1–13. `https://doi.org/10.1145/3313831.3376133`

[42] Jiamin Dai and Karyn Moffatt. 2020. Using proxies in supporting the voice of people with dementia in HCI research. In *CHI'20 Workshop, Rethinking Notions of 'Giving Voice' in Design*. 1–4.

[43] Jiamin Dai and Karyn Moffatt. 2021. Surfacing the voices of people with dementia: Strategies for effective inclusion of proxy stakeholders in qualitative research. In

Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems. ACM, 1–13. `https://doi.org/10.1145/3411764.3445756`

[44] Jiamin Dai and Karyn Moffatt. 2023. Enriching social sharing for the dementia community: Insights from in-person and online social programs. *ACM Transactions on Accessible Computing* 16, 1 (2023), 1–33. `https://doi.org/10.1145/3582558`

[45] Nicole K Dalmer and D Grant Campbell. 2020. Communicating with library patrons and people with dementia: Tracing an ethic of care in professional communication guidelines. *Dementia* 19, 3 (2020), 899–914.

[46] Nicole K Dalmer and Bria L Mitrovica. 2022. The public library as social infrastructure for older patrons: Exploring the implications of online library programming for older adults during COVID-19. *Library & Information Science Research* 44, 3 (2022), 101177.

[47] M Damron. 2019. A sensory wonderland: A programming space for the special needs community. *American Libraries* 50, 6 (2019), 24–25.

[48] Janet Davis and Lisa P. Nathan. 2013. Value Sensitive Design: Applications, Adaptations, and Critiques. In *Handbook of Ethics, Values, and Technological Design: Sources, Theory, Values and Application Domains*, Jeroen van den Hoven, Pieter E. Vermaas, and Ibo van de Poel (Eds.). Springer Netherlands, Dordrecht, 1–26. `https://doi.org/10.1007/978-94-007-6994-6_3-1`

[49] Melissa Densmore, Casey Fiesler, Cosmin Munteanu, Michael Muller, Janet C. Read, Katie Shilton, and Özge Subaşı. 2020. Research Ethics Roundtable. In *Conference Companion Publication of the 2020 on Computer Supported Cooperative Work and Social Computing*. ACM, 195–198. `https://doi.org/10.1145/3406865.3419015`

[50] Shital Desai, Alethea Blackler, Deborah Fels, and Arlene Astell. 2020. Supporting people with dementia: Understanding their interactions with Mixed Reality Technologies. *Proceedings of DRS2020 Synergy: Impacts. Vol. 2.* (2020), 615–637. `https://doi.org/10.21606/drs.2020.266`

[51] Shital Desai, Colleen McGrath, Heather McNeil, Heidi Sveistrup, Josephine McMurray, and Arlene Astell. 2022. Experiential value of technologies: A qualitative study with older adults. *International Journal of Environmental Research and Public Health* 19, 4 (2022), 2235.

[52] Shital Desai, Joel Ong, Deborah Fels, and Arlene Astell. 2022. Sound Mixed Reality Prompts for People with Dementia: A Familiar and Meaningful Experience. In *Designing Interactions for Music and Sound*. Focal Press, 151–176. `https://doi.org/10.4324/9781003140535-7`

[53] Shital Desai, Pablo Vivanco, and Deborah Fels. 2022. Connecting seniors in marginalized communities during covid-19. *Interactions* 29, 5 (2022), 63–67.

[54] Audrey Desjardins and Aubree Ball. 2018. Revealing Tensions in Autobiographical Design in HCI. In *Proceedings of the 2018 Designing Interactive Systems Conference*. ACM, 753–764. `https://doi.org/10.1145/3196709.3196781`

[55] Timothy J Dickey. 2020. Programming for Dementia and Dementia Caregivers. In *Library Dementia Services*. Emerald Publishing Limited. `https://doi.org/10.1108/978-1-83867-691-920201006`

[56] Tawanna R Dillahunt, Alex Jiahong Lu, Aarti Israni, Ruchita Lodha, Savana Brewer, Tiera S Robinson, Angela Brown Wilson, and Earnest Wheeler. 2022. The Village: Infrastructuring Community-based Mentoring to Support Adults Experiencing Poverty. In *CHI Conference on Human Factors in Computing Systems*. 1–17. `https://doi.org/10.1145/3491102.3501949`

[57] Emma Dixon, Jesse Anderson, Diana Blackwelder, Mary L. Radnofsky, and Amanda Lazar. 2022. Barriers to Online Dementia Information and Mitigation. In *CHI Conference on Human Factors in Computing Systems*. 1–14. `https://doi.org/10.1145/3491102.3517554`

[58] Emma Dixon and Amanda Lazar. 2020. Approach Matters: Linking Practitioner Approaches to Technology Design for People with Dementia. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. ACM, 1–15. `https://doi.org/10.1145/3313831.3376432`

[59] Emma Dixon and Amanda Lazar. 2020. The Role of sensory changes in everyday technology use by people with mild to moderate dementia. In *The 22nd International ACM SIGACCESS Conference on Computers and Accessibility*. 1–12. `https://doi.org/10.1145/3373625.3417000`

[60] Emma Dixon, Rain Michaels, Xiang Xiao, Yu Zhong, Patrick Clary, Ajit Narayanan, Robin N Brewer, and Amanda Lazar. 2022. Mobile Phone Use by People with Mild to Moderate Dementia: Uncovering Challenges and Identifying Opportunities: Mobile Phone Use by People with Mild to Moderate Dementia. In *The 24th International ACM SIGACCESS Conference on Computers and Accessibility*. 1–16. `https://doi.org/10.1145/3517428.3544809`

[61] Emma Dixon, Anne Marie Piper, and Amanda Lazar. 2021. “Taking care of myself as long as I can”: How People with Dementia Configure Self-Management Systems. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–14. `https://doi.org/10.1145/3411764.3445225`

[62] Paul Dourish. 2006. Implications for design. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 541–550. `https://doi.org/10.1145/1124772.1124855`

[63] Deborah I Fels and Arlene J Astell. 2011. Storytelling as a model of conversation for people with dementia and caregivers. *American Journal of Alzheimer's Disease & Other Dementias®* 26, 7 (2011), 535–541. `https://doi.org/10.1177/1533317511429324`

[64] Robert Ferguson, Emily Crist, and Karyn Moffatt. 2016. A Framework for Negotiating Ethics in Sensitive Settings: Hospice as a Case Study. *Interacting with Computers* 29, 1 (2016), 10–26. `https://doi.org/10.1093/iwc/iww018`

[65] Jessica L Feuston, Arpita Bhattacharya, Nazanin Andalibi, Elizabeth A Ankrah, Sheena Erete, Mark Handel, Wendy Moncur, Sarah Vieweg, and Jed R Brubaker. 2022. Researcher wellbeing and best practices in emotionally demanding research. In *CHI Conference on Human Factors in Computing Systems Extended Abstracts*. 1–6. `https://doi.org/10.1145/3491101.3503742`

[66] Sarah Foley, Nadia Pantidi, and John McCarthy. 2019. Care and Design: An Ethnography of Mutual Recognition in the Context of Advanced Dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 1–15. `https://doi.org/10.1145/3290605.3300840`

[67] Sarah Foley, Daniel Welsh, Nadia Pantidi, Kellie Morrissey, Tom Nappey, and John McCarthy. 2019. Printer Pals: Experience-Centered Design to Support Agency for People with Dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 1–13. `https://doi.org/10.1145/3290605.3300634`

[68] Julia Galliers, Stephanie Wilson, Abi Roper, Naomi Cocks, Jane Marshall, Sam Muscroft, and Tim Pring. 2012. Words are not enough: empowering people with aphasia in the design process. In *Proceedings of the 12th Participatory Design Conference: Research Papers - Volume 1*. ACM, 51–60. `https://doi.org/10.1145/2347635.2347643`

[69] Serge Gauthier, Claire Webster, Stijn Servaes, José A Morais, and Pedro Rosa-Neto. 2022. World Alzheimer Report 2022-Life after diagnosis:Navigating treatment, care and support. (2022). `https://www.alzint.org/u/World-Alzheimer-Report-2022.pdf`

[70] Aideen Gibson, Claire McCauley, Maurice Mulvenna, Assumpta Ryan, Liz Laird, Kevin Curran, Brendan Bunting, Finola Ferry, and Raymond Bond. 2016. Assessing usability testing for people living with dementia. In *Proceedings of the 4th Workshop*

on ICTs for improving Patients Rehabilitation Research Techniques. 25–31. `https://doi.org/10.1145/3051488.3051492`

[71] Gabriela Purri R Gomes, Sydney Rubin, Leah I Stein Duker, Donna Benton, Andreas Kratky, Sze Yu A Chen, Maryalice Jordan-Marsh, and Marientina Gotsis. 2020. Healing spaces: feasibility of a multisensory experience for older adults with advanced dementia and their caregivers. In *Proceedings of the 13th ACM International Conference on PErvasive Technologies Related to Assistive Environments*. 1–9. `https://doi.org/10.1145/3389189.3392607`

[72] Jens Emil Grønbæk, Banu Saatçi, Carla F Griggio, and Clemens Nylandsted Klokmose. 2021. MirrorBlender: Supporting Hybrid Meetings with a Malleable Video-Conferencing System. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–13. `https://doi.org/10.1145/3411764.3445698`

[73] Connie Guan, Anya Bouzida, Ramzy M Oncy-Avila, Sanika Moharana, and Laurel D Riek. 2021. Taking an (embodied) cue from community health: Designing dementia caregiver support technology to advance health equity. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–16. `https://doi.org/10.1145/3411764.3445559`

[74] Foad Hamidi, Melanie Baljko, and Isabel Gómez. 2017. Using Participatory Design with Proxies with Children with Limited Communication. In *Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility*. ACM, 250–259. `https://doi.org/10.1145/3132525.3132527`

[75] Steve Harrison and Paul Dourish. 1996. Re-place-ing space: the roles of place and space in collaborative systems. In *Proceedings of the 1996 ACM conference on Computer supported cooperative work*. 67–76. `https://doi.org/10.1145/240080.240193`

[76] Steve Harrison, Deborah Tatar, and Phoebe Sengers. 2007. The three paradigms of HCI. In *Alt. Chi. Session at the SIGCHI Conference on human factors in computing systems San Jose, California, USA*. 1–18.

[77] James Hodge, Madeline Balaam, Sandra Hastings, and Kellie Morrissey. 2018. Exploring the Design of Tailored Virtual Reality Experiences for People with Dementia. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. ACM, 1–13. `https://doi.org/10.1145/3173574.3174088`

[78] James Hodge, Sarah Foley, Rens Brankaert, Gail Kenning, Amanda Lazar, Jennifer Boger, and Kellie Morrissey. 2020. Relational, Flexible, Everyday: Learning from Ethics in Dementia Research. In *Proceedings of the 2020 CHI Conference on Human*

Factors in Computing Systems. ACM, 1–16. `https://doi.org/10.1145/3313831.3376627`

[79] James Hodge, Kyle Montague, Sandra Hastings, and Kellie Morrissey. 2019. Exploring Media Capture of Meaningful Experiences to Support Families Living with Dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 3300653, 1–14. `https://doi.org/10.1145/3290605.3300653`

[80] Jesse Hoey, Pascal Poupart, Axel von Bertoldi, Tammy Craig, Craig Boutilier, and Alex Mihailidis. 2010. Automated handwashing assistance for persons with dementia using video and a partially observable Markov decision process. *Computer Vision and Image Understanding* 114, 5 (2010), 503–519. `https://doi.org/10.1016/j.cviu.2009.06.008`

[81] Jesse Hoey, Krists Zutis, Valerie Leuty, and Alex Mihailidis. 2010. A tool to promote prolonged engagement in art therapy: design and development from arts therapist requirements. In *Proceedings of the 12th international ACM SIGACCESS conference on Computers and accessibility*. 211–218. `https://doi.org/10.1145/1878803.1878841`

[82] Megan Hofmann, Devva Kasnitz, Jennifer Mankoff, and Cynthia L. Bennett. 2020. Living Disability Theory: Reflections on Access, Research, and Design. *ASSETS 2020 - 22nd International ACM SIGACCESS Conference on Computers and Accessibility*, 1–13. `https://doi.org/10.1145/3373625.3416996`

[83] Maarten Houben, Rens Brankaert, Saskia Bakker, Gail Kenning, Inge Bongers, and Berry Eggen. 2020. The Role of Everyday Sounds in Advanced Dementia Care. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. ACM, 1–14. `https://doi.org/10.1145/3313831.3376577`

[84] Maarten Houben, Rens Brankaert, Gail Kenning, Inge Bongers, and Berry Eggen. 2022. Designing for Everyday Sounds at Home with People with Dementia and their Partners. In *CHI Conference on Human Factors in Computing Systems*. 1–15. `https://doi.org/10.1145/3491102.3501993`

[85] Maarten Houben, Rens Brankaert, and Eveline Wouters. 2020. Stakeholder Perspectives on Design Interventions in Dementia Care. In *Companion Publication of the 2020 ACM Designing Interactive Systems Conference*. ACM, 43–47. `https://doi.org/10.1145/3393914.3395868`

[86] Maarten Houben, Benjamin Lehn, Noa van den Brink, Sabeth Diks, Jasmijn Verhoef, and Rens Brankaert. 2020. Turnaround: exploring care relations in dementia through

design. In *Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems*. 1–8. `https://doi.org/10.1145/3334480.3382846`

[87] Dorothy Howard and Lilly Irani. 2019. Ways of Knowing When Research Subjects Care. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 1–16. `https://doi.org/10.1145/3290605.3300327`

[88] Hsiu-Fang Hsieh and Sarah E. Shannon. 2005. Three Approaches to Qualitative Content Analysis. *Qualitative Health Research* 15, 9 (Nov. 2005), 1277–1288. `https://doi.org/10.1177/1049732305276687`

[89] Stephan Huber, Jan Preßler, Nam Ly Tung, and Jörn Hurtienne. 2017. Evaluating interaction-triggered emotions in people with dementia. In *Proceedings of the 2017 CHI Conference Extended Abstracts on Human Factors in Computing Systems*. 2659–2667. `https://doi.org/10.1145/3027063.3053251`

[90] Dhruv Jain, Audrey Desjardins, Leah Findlater, and Jon E. Froehlich. 2019. Autoethnography of a Hard of Hearing Traveler. In *The 21st International ACM SIGACCESS Conference on Computers and Accessibility*. ACM, 236–248. `https://doi.org/10.1145/3308561.3353800`

[91] Dhruv Jain, Venkatesh Potluri, and Ather Sharif. 2020. Navigating Graduate School with a Disability. In *The 22nd International ACM SIGACCESS Conference on Computers and Accessibility*. ACM, Article 8. `https://doi.org/10.1145/3373625.3416986`

[92] Jazette Johnson, Rebecca W. Black, and Gillian R. Hayes. 2020. Roles in the Discussion: An Analysis of Social Support in an Online Forum for People with Dementia. *Proc. ACM Hum.-Comput. Interact.* 4, CSCW2 (2020), Article 127. `https://doi.org/10.1145/3415198`

[93] Rose Johnson, Yvonne Rogers, Janet van der Linden, and Nadia Bianchi-Berthouze. 2012. Being in the thick of in-the-wild studies: the challenges and insights of researcher participation. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 1135–1144. `https://doi.org/10.1145/2207676.2208561`

[94] Sukran Karaosmanoglu, Sebastian Rings, Lucie Kruse, Christian Stein, and Frank Steinicke. 2021. Lessons learned from a human-centered design of an immersive exergame for people with dementia. *Proceedings of the ACM on Human-Computer Interaction* 5, CHI PLAY (2021), 1–27. `https://doi.org/10.1145/3474679`

[95] Chantal Kerssens, Renu Kumar, Anne E Adams, Camilla C Knott, Laura Matalenas, Jon A Sanford, and Wendy A Rogers. 2015. Personalized technology to support older

adults with and without cognitive impairment living at home. *American Journal of Alzheimer's Disease & Other Dementias®* 30, 1 (2015), 85–97. `https://doi.org/10.1177/1533317514568338`

[96] Basel Kikhia, Josef Hallberg, Johan Bengtsson, Stefan Sävenstedt, and Kåre Synnes. 2010. Building digital life stories for memory support. *International journal of Computers in Healthcare* 1, 2 (2010), 161–176. `https://doi.org/10.1504/ijcih.2010.03746`

[97] Debbie Kinsey, Iain Lang, Noreen Orr, Rob Anderson, and Daisy Parker. 2021. The impact of including carers in museum programmes for people with dementia: a realist review. *Arts & Health* 13, 1 (2021), 1–19. `https://doi.org/10.1080/17533015.2019.1700536`

[98] Debbie Kinsey, Noreen Orr, Rob Anderson, and Iain Lang. 2022. A conceptual model of the impact of including carers in museum programmes for people with dementia. *Dementia* (2022), 14713012221126803. `https://doi.org/10.1177/14713012221126803`

[99] Julia Kirkham, Carrie L Shorey, Andrea Iaboni, Hannah Quirt, Alisa Grigorovitch, Arlene Astell, Esther Lin, and Colleen J Maxwell. 2022. Staff perceptions of the consequences of COVID-19 on quality of dementia care for residents in Ontario long-term care homes. *International journal of geriatric psychiatry* (2022). `https://doi.org/10.1002/gps.5725`

[100] Wei Qi Koh, Sally Whelan, Pascale Heins, Dympna Casey, Elaine Toomey, and Rose-Marie Dröes. 2022. The Usability and Impact of a Low-Cost Pet Robot for Older Adults and People With Dementia: Qualitative Content Analysis of User Experiences and Perceptions on Consumer Websites. *JMIR aging* 5, 1 (2022), e29224. `https://doi.org/10.2196/29224`

[101] Pia Kontos and Wendy Martin. 2013. Embodiment and dementia: Exploring critical narratives of selfhood, surveillance, and dementia care. *Dementia* 12, 3 (2013), 288–302. `https://doi.org/10.1177/1471301213479787`

[102] Pia C Kontos. 2005. Embodied selfhood in Alzheimer's disease: Rethinking person-centred care. *Dementia* 4, 4 (2005), 553–570. `https://doi.org/10.1177/1471301205058311`

[103] Thomas Kosch, Thomas Grote, Albrecht Schmidt, and Paweł W Woźniak. [n.d.]. Engagement, not Dependence: Ethically Designing Assistive Systems for Users with Cognitive Impairments. In *Proceedings of Nordic Human-Computer Interaction Conference (NordiCHI '22)*. 1–13.

[104] Celine Latulipe and Amy De Jaeger. 2022. Comparing Student Experiences of Collaborative Learning in Synchronous CS1 Classes in Gather. Town vs. Zoom. In *Proceedings of the 53rd ACM Technical Symposium on Computer Science Education V. 1*. 411–417. `https://doi.org/10.1145/3478431.3499383`

[105] Celine Latulipe and Deborah Turnbull Tillman. 2022. Curating Interactive Art for Online Conferences: Artist, Curator and Technologist Experiences in Gather. Town. In *Proceedings of Creativity and Cognition (CC '22)*. 380–391. `https://doi.org/10.1145/3527927.3532811`

[106] Amanda Lazar, Robin N Brewer, Hernisa Kacorri, Jonggi Hong, Mary Nicole Dugay Punzalan, Maisarah Mahathir, Olivia Vander Hyde, and Warren Ross III. 2021. How Content Authored by People with Dementia Affects Attitudes towards Dementia. *Proceedings of the ACM on Human-computer Interaction* 5, CSCW2 (2021), 1–32. `https://doi.org/10.1145/3479542`

[107] Amanda Lazar, Raymundo Cornejo, Caroline Edasis, and Anne Marie Piper. 2016. Designing for the third hand: Empowering older adults with cognitive impairment through creating and sharing. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems*. 1047–1058. `https://doi.org/10.1145/2901790.2901854`

[108] Amanda Lazar, George Demiris, and Hilaire J. Thompson. 2016. Evaluation of a multifunctional technology system in a memory care unit: Opportunities for innovation in dementia care. *Informatics for Health and Social Care* 41, 4 (Jan. 2016), 373–386. `https://doi.org/10.3109/17538157.2015.1064428`

[109] Amanda Lazar and Emma E. Dixon. 2019. Safe Enough to Share: Setting the Dementia Agenda Online. *Proc. ACM Hum.-Comput. Interact.* 3, CSCW (Nov. 2019), 1–23. `https://doi.org/10.1145/3359187`

[110] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. A Critical Lens on Dementia and Design in HCI. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM, 2175–2188. `https://doi.org/10.1145/3025453.3025522`

[111] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. Supporting People with Dementia in Digital Social Sharing. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (Denver, Colorado, USA) *(CHI '17)*. Association for Computing Machinery, New York, NY, USA, 2149–2162. `https://doi.org/10.1145/3025453.3025586`

[112] Amanda Lazar, Jessica L. Feuston, Caroline Edasis, and Anne Marie Piper. 2018. Making as Expression: Informing Design with People with Complex Communication

Needs through Art Therapy. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. ACM, 1–16. `https://doi.org/10.1145/3173574.3173925`

[113] Amanda Lazar, Hilaire J. Thompson, and George Demiris. 2016. Design Recommendations for Recreational Systems Involving Older Adults Living With Dementia. *Journal of Applied Gerontology* (Apr. 2016), 1–25. `https://doi.org/10.1177/0733464816643880`

[114] Jonathan Lazar, Jinjuan Heidi Feng, and Harry Hochheiser. 2017. *Research methods in human-computer interaction* (2nd ed.). Morgan Kaufmann Publishers, an imprint of Elsevier, Cambridge, MA.

[115] Christopher A Le Dantec and Sarah Fox. 2015. Strangers at the gate: Gaining access, building rapport, and co-constructing community-based research. In *Proceedings of the 18th ACM conference on computer supported cooperative work & social computing*. 1348–1358. `https://doi.org/10.1145/2675133.2675147`

[116] Fong Yoke Leng, Donald Yeo, Stacey George, and Christopher Barr. 2014. Comparison of iPad applications with traditional activities using person-centred care approach: impact on well-being for persons with dementia. *Dementia* 13, 2 (2014), 265–273. `https://doi.org/10.1177/1471301213494514`

[117] Barbara Leporini, Marina Buzzi, and Marion Hersh. 2021. Distance meetings during the COVID-19 pandemic: are video conferencing tools accessible for blind people?. In *Proceedings of the 18th International Web for All Conference*. 1–10. `https://doi.org/10.1145/3430263.3452433`

[118] Fabian S Lim, Tim Wallace, Mary A Luszcz, and Karen J Reynolds. 2013. Usability of tablet computers by people with early-stage dementia. *Gerontology* 59, 2 (2013), 174–182. `https://doi.org/10.1159/000343986`

[119] Cláudia Lima. 2023. Designing for people with Dementia in academic contexts. *Perspectives on Design and Digital Communication III* (2023), 181–193. `https://doi.org/10.1007/978-3-031-06809-6_12`

[120] Xin Yao Lin, Herman Saksono, Elizabeth Stowell, Margie E Lachman, Carmen Castaneda-Sceppa, and Andrea G Parker. 2020. Go&Grow: an evaluation of a pervasive social exergame for caregivers of loved ones with dementia. *Proceedings of the ACM on human-computer interaction* 4, CSCW2 (2020), 1–28. `https://doi.org/10.1145/3415222`

[121] Stephen Lindsay, Katie Brittain, Daniel Jackson, Cassim Ladha, Karim Ladha, and Patrick Olivier. 2012. Empathy, participatory design and people with dementia. In

Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. ACM, 521–530. `https://doi.org/10.1145/2207676.2207749`

[122] Sebastian Linxen, Christian Sturm, Florian Brühlmann, Vincent Cassau, Klaus Opwis, and Katharina Reinecke. 2021. How weird is CHI?. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–14. `https://doi.org/10.1145/3411764.3445488`

[123] Szu-Yu Liu, Brian A Smith, Rajan Vaish, and Andrés Monroy-Hernández. 2022. Understanding the Role of Context in Creating Enjoyable Co-Located Interactions. *Proceedings of the ACM on Human-Computer Interaction* 6, CSCW1 (2022), 1–26. `https://doi.org/10.1145/3512978`

[124] Rebecca G Logsdon, Laura E Gibbons, Susan M McCurry, and Linda Teri. 2002. Assessing quality of life in older adults with cognitive impairment. *Psychosomatic medicine* 64, 3 (2002), 510–519. `https://doi.org/10.1097/00006842-200205000-00016`

[125] Lisa Lole, Jessica Conway, Anthea Oorloff, and Cameron Duffy. 2022. The role of day-respite centers in supporting people with dementia to age in place: An interpretive phenomenological study. *Health Promotion Journal of Australia* (2022). `https://doi.org/10.1002/hpja.652`

[126] Hanuma Teja Maddali, Emma Dixon, Alisha Pradhan, and Amanda Lazar. 2022. Investigating the Potential of Artificial Intelligence Powered Interfaces to Support Different Types of Memory for People with Dementia. In *CHI Conference on Human Factors in Computing Systems Extended Abstracts*. 1–7. `https://doi.org/10.1145/3491101.3519858`

[127] Galina Madjaroff and Helena Mentis. 2017. Narratives of Older Adults with Mild Cognitive Impairment and Their Caregivers. In *Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility*. ACM, 140–149. `https://doi.org/10.1145/3132525.3132554`

[128] Emanuela Marchetti, Sophie Grimme, Eva Hornecker, Avgi Kollakidou, and Philipp Graf. 2022. Pet-Robot or Appliance? Care Home Residents with Dementia Respond to a Zoomorphic Floor Washing Robot. In *CHI Conference on Human Factors in Computing Systems*. 1–21. `https://doi.org/10.1145/3491102.3517463`

[129] Michael Massimi, Emma Berry, Georgina Browne, Gavin Smyth, Peter Watson, and Ronald M Baecker. 2008. An exploratory case study of the impact of ambient biographical displays on identity in a patient with Alzheimer's disease. *Neuropsychological rehabilitation* 18, 5-6 (2008), 742–765. `https://doi.org/10.1080/09602010802130924`

[130] Niharika Mathur, Kunal Dhodapkar, Tamara Zubatiy, Jiachen Li, Brian Jones, and Elizabeth Mynatt. 2022. A Collaborative Approach to Support Medication Management in Older Adults with Mild Cognitive Impairment Using Conversational Assistants (CAs). In *The 24th International ACM SIGACCESS Conference on Computers and Accessibility.* 1–14. `https://doi.org/10.1145/3517428.3544830`

[131] Maria Matsangidou, Fotos Frangoudes, Theodoros Solomou, Ersi Papayianni, and Constantinos Pattichis. 2022. Free of Walls: Participatory Design of an Out-World Experience via Virtual Reality for Dementia In-patients. In *Adjunct Proceedings of the 30th ACM Conference on User Modeling, Adaptation and Personalization.* 326–334. `https://doi.org/10.1145/3511047.3537651`

[132] Deborah J. Mayhew and Todd J. Follansbee. 2012. User Experience Requirements Analysis within the Usability Engineering Lifecycle. In *Human Computer Interaction Handbook: Fundamentals, Evolving Technologies, and Emerging Applications* (3rd ed.), Julie A. Jacko (Ed.). CRC Press, Boca Raton, 945–954.

[133] Nora McDonald, Sarita Schoenebeck, and Andrea Forte. 2019. Reliability and Inter-rater Reliability in Qualitative Research: Norms and Guidelines for CSCW and HCI Practice. *Proc. ACM Hum.-Comput. Interact.* 3, CSCW (2019), Article 72. `https://doi.org/10.1145/3359174`

[134] Helena M. Mentis, Galina Madjaroff, and Aaron K. Massey. 2019. Upside and Downside Risk in Online Security for Older Adults with Mild Cognitive Impairment. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems.* ACM, 1–13. `https://doi.org/10.1145/3290605.3300573`

[135] Fabian Mertl, Nadine Meißler, Lena Wiek, Alina Fröhlich, and Alina Huldtgren. 2019. ”Traumreise”-Exploring the use of multisensory digital media in dementia groups. In *Proceedings of the 13th EAI International Conference on Pervasive Computing Technologies for Healthcare.* 189–197. `https://doi.org/10.1145/3329189.3329199`

[136] Sanika Moharana, Alejandro E Panduro, Hee Rin Lee, and Laurel D Riek. 2019. Robots for joy, robots for sorrow: community based robot design for dementia caregivers. In *2019 14th ACM/IEEE International Conference on Human-Robot Interaction (HRI).* IEEE, 458–467. `https://doi.org/10.1109/HRI.2019.8673206`

[137] Montreal Museum of Fine Arts. 2018. Art Links: Periods of respite at the MMFA for over 800 persons with Alzheimer’s and their caregivers [Press release]. (2018). `https://www.mbam.qc.ca/wp-content/uploads/2018/09/MMFA-Press-release-Alzheimer_Final.pdf`

[138] David L. Morgan, Jutta Ataie, Paula Carder, and Kim Hoffman. 2013. Introducing Dyadic Interviews as a Method for Collecting Qualitative Data. *Qualitative Health*

Research 23, 9 (Aug. 2013), 1276–1284.
`https://doi.org/10.1177/1049732313501889`

[139] Luca Morganti, Giuseppe Riva, Silvio Bonfiglio, and Andrea Gaggioli. 2013. Building collective memories on the web: the Nostalgia Bits project. *International Journal of Web Based Communities* 9, 1 (2013), 83–104.
`https://doi.org/10.1504/IJWBC.2013.051373`

[140] Kellie Morrissey, Andrew Garbett, Peter Wright, Patrick Olivier, Edward Ian Jenkins, and Katie Brittain. 2017. Care and Connect: exploring dementia-friendliness through an online community commissioning platform. In *Proceedings of the 2017 CHI conference on human factors in computing systems*. 2163–2174.
`https://doi.org/10.1145/3025453.3025732`

[141] Kellie Morrissey, John McCarthy, and Nadia Pantidi. 2017. The value of experience-centred design approaches in dementia research contexts. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. 1326–1338.
`https://doi.org/10.1145/3025453.3025527`

[142] Kellie Morrissey, Gavin Wood, David Green, Nadia Pantidi, and John McCarthy. 2016. 'I'm a rambler, I'm a gambler, I'm a long way from home' The Place of Props, Music, and Design in Dementia Care. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems*. 1008–1020.
`https://doi.org/10.1145/2901790.2901798`

[143] Diego Muñoz, Stu Favilla, Sonja Pedell, Andrew Murphy, Jeanie Beh, and Tanya Petrovich. 2021. Evaluating an App to Promote a Better Visit Through Shared Activities for People Living with Dementia and their Families. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–13.
`https://doi.org/10.1145/3411764.3445764`

[144] John Muñoz, Samira Mehrabi, Yirou Li, Aysha Basharat, Laura E Middleton, Shi Cao, Michael Barnett-Cowan, Jennifer Boger, et al. 2022. Immersive Virtual Reality Exergames for Persons Living With Dementia: User-Centered Design Study as a Multistakeholder Team During the COVID-19 Pandemic. *JMIR Serious Games* 10, 1 (2022), e29987. `https://doi.org/10.2196/29987`

[145] Cosmin Munteanu, Amy Bruckman, Michael Muller, Christopher Frauenberger, Casey Fiesler, Robert E. Kraut, Katie Shilton, and Jenny Waycott. 2019. SIGCHI Research Ethics Town Hall. In *Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, Paper panel05.
`https://doi.org/10.1145/3290607.3311742`

[146] Cosmin Munteanu, Heather Molyneaux, Wendy Moncur, Mario Romero, Susan O'Donnell, and John Vines. 2015. Situational Ethics: Re-thinking Approaches to Formal Ethics Requirements for Human-Computer Interaction. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*. ACM, 105–114. `https://doi.org/10.1145/2702123.2702481`

[147] David G Myers. 2003. Close relationships and quality of life. *Well-being: Foundations of hedonic psychology* (2003), 374–391.

[148] Khushnood Z Naqshbandi, Yun-Hee Jeon, and Naseem Ahmadpour. 2022. Exploring Volunteer Motivation, Identity and Meaning-Making in Digital Science-Based Research Volunteering. *International Journal of Human–Computer Interaction* (2022), 1–22. `https://doi.org/10.1080/10447318.2022.2109246`

[149] Timothy Neate, Aikaterini Bourazeri, Abi Roper, Simone Stumpf, and Stephanie Wilson. 2019. Co-Created Personas: Engaging and Empowering Users with Diverse Needs Within the Design Process. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 1–12. `https://doi.org/10.1145/3290605.3300880`

[150] Timothy Neate, Vasiliki Kladouchou, Stephanie Wilson, and Shehzmani Shams. 2022. "Just Not Together": The Experience of Videoconferencing for People with Aphasia during the Covid-19 Pandemic. In *CHI Conference on Human Factors in Computing Systems*. 1–16. `https://doi.org/10.1145/3491102.3502017`

[151] Noelannah Neubauer, Christa Spenrath, Serrina Philip, Christine Daum, Lili Liu, and Antonio Miguel-Cruz. 2022. Identifying adoption and usability factors of locator devices for persons living with dementia. *Dementia* 21, 3 (2022), 862–881. `https://doi.org/10.1177/14713012211065381`

[152] Emma Nichols, Jaimie D Steinmetz, Stein Emil Vollset, Kai Fukutaki, Julian Chalek, Foad Abd-Allah, Amir Abdoli, Ahmed Abualhasan, Eman Abu-Gharbieh, Tayyaba Tayyaba Akram, et al. 2022. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. *The Lancet Public Health* 7, 2 (2022), e105–e125. `https://doi.org/ttps://doi.org/10.1016/`

[153] Roger Orpwood, James Chadd, Deborah Howcroft, Andrew Sixsmith, Judith Torrington, Grant Gibson, and Garuth Chalfont. 2010. Designing technology to improve quality of life for people with dementia: user-led approaches. *Universal Access in the Information Society* 9, 3 (2010), 249–259. `https://doi.org/10.1007/s10209-009-0172-1`

[154] Elly Park, Hollis Owens, David Kaufman, and Lili Liu. 2017. Digital storytelling and dementia. In *International conference on human aspects of IT for the aged population*. Springer, 443–451. `https://doi.org/10.1007/978-3-319-58536-9_35`

[155] S Tejaswi Peesapati, Victoria Schwanda, Johnathon Schultz, Matt Lepage, So-yae Jeong, and Dan Cosley. 2010. Pensieve: supporting everyday reminiscence. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 2027–2036. `https://doi.org/10.1145/1753326.1753635`

[156] Carrie Beth Peterson, Neeli R Prasad, and Ramjee Prasad. 2012. Assessing assistive technology's quality of life outcomes with dementia. *Gerontechnology* 11, 2 (2012), 195. `https://doi.org/10.4017/gt.2012.11.02.414.00`

[157] Alison Phinney, Habib Chaudhury, and Deborah L O'connor. 2007. Doing as much as I can do: The meaning of activity for people with dementia. *Aging and Mental Health* 11, 4 (2007), 384–393. `https://doi.org/10.1080/13607860601086470`

[158] Wanda Pillow. 2003. Confession, catharsis, or cure? Rethinking the uses of reflexivity as methodological power in qualitative research. *International journal of qualitative studies in education* 16, 2 (2003), 175–196. `https://doi.org/10.1080/0951839032000060635`

[159] Public Health Agency of Canada. 2021. A Dementia Strategy for Canada: Together We Achieve - 2021 Annual Report.

[160] Barbara A Purves, Alison Phinney, Wendy Hulko, Gloria Puurveen, and Arlene J Astell. 2015. Developing CIRCA-BC and exploring the role of the computer as a third participant in conversation. *American Journal of Alzheimer's Disease & Other Dementias®* 30, 1 (2015), 101–107. `https://doi.org/10.1177/1533317514539031`

[161] Kirsten Rassmus-Gröhn and Charlotte Magnusson. 2014. Finding the way home: supporting wayfinding for older users with memory problems. In *Proceedings of the 8th Nordic Conference on Human-Computer Interaction: Fun, Fast, Foundational*. 247–255. `https://doi.org/10.1145/2639189.2639233`

[162] Hirak Ray, Ravi Kuber, and Adam J Aviv. 2022. Investigating older adults' adoption and usage of online conferencing tools during COVID-19. In *Proceedings of the 19th International Web for All Conference*. 1–11. `https://doi.org/10.1145/3493612.3520447`

[163] Mary Beth Riedner, Karen Maki, and Miriam Lytle. 2018. Becoming a dementia-friendly library. In *The Relevant Library: Essays on Adapting to Changing Needs*, Carol Smallwood Vera Gubnitskaia (Ed.). McFarland, Jefferson, NC, 187–194.

[164] Adriana Maria Rios Rincon, Antonio Miguel Cruz, Christine Daum, Noelannah Neubauer, Aidan Comeau, and Lili Liu. 2022. Digital storytelling in older adults with typical aging, and with mild cognitive impairment or dementia: A systematic literature review. *Journal of Applied Gerontology* 41, 3 (2022), 867–880. `https://doi.org/10.1177/07334648211015456`

[165] Jennifer A. Rode. 2011. Reflexivity in digital anthropology. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 123–132. `https://doi.org/10.1145/1978942.1978961`

[166] Andreia Sias Rodrigues, AS Rodrigues, Marcelo Bender Machado, Ana Margarida Pisco Almeida, Jorge Ferraz de Abreu, and Tatiana Aires Tavares. 2019. Evaluation methodologies of assistive technology interaction devices: a participatory mapping in Portugal based on community-based research. In *Proceedings of the 18th Brazilian Symposium on Human Factors in Computing Systems*. 1–9. `https://doi.org/10.1145/3357155.3358458`

[167] Lena Rosenberg, Anders Kottorp, and Louise Nygård. 2012. Readiness for technology use with people with dementia: the perspectives of significant others. *Journal of applied gerontology* 31, 4 (2012), 510–530. `https://doi.org/10.1177/0733464810396873`

[168] Marén Schorch, Lin Wan, David William Randall, and Volker Wulf. 2016. Designing for Those who are Overlooked: Insider Perspectives on Care Practices and Cooperative Work of Elderly Informal Caregivers. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*. ACM, 787–799. `https://doi.org/10.1145/2818048.2819999`

[169] Theresa L Scott, Ying-Ling Jao, Kristen Tulloch, Eloise Yates, Oliver Kenward, and Nancy A Pachana. 2022. Well-Being Benefits of Horticulture-Based Activities for Community Dwelling People with Dementia: A Systematic Review. *International Journal of Environmental Research and Public Health* 19, 17 (2022), 10523. `https://doi.org/10.3390/ijerph191710523`

[170] Matthew Seita, Sarah Andrew, and Matt Huenerfauth. 2021. Deaf and hard-of-hearing users' preferences for hearing speakers' behavior during technology-mediated in-person and remote conversations. In *Proceedings of the 18th International Web for All Conference*. 1–12. `https://doi.org/10.1145/3430263.3452430`

[171] Panote Siriaraya and Chee Siang Ang. 2014. Recreating living experiences from past memories through virtual worlds for people with dementia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 3977–3986. `https://doi.org/10.1145/2556288.2557035`

[172] Sarah C Smith, Joanna Murray, Sube Banerjee, Beth Foley, Joanna C Cook, Donna L Lamping, Martin Prince, Rowan H Harwood, Enid Levin, and Anthony Mann. 2005. What constitutes health-related quality of life in dementia? Development of a conceptual framework for people with dementia and their carers. *International Journal of Geriatric Psychiatry: A journal of the psychiatry of late life and allied sciences* 20, 9 (2005), 889–895. `https://doi.org/10.1002/gps.1374`

[173] Fiona Ssozi-Mugarura, Edwin Blake, and Ulrike Rivett. 2016. Supporting community needs for rural water management through community-based co-design. In *Proceedings of the 14th Participatory Design Conference: Full papers-Volume 1*. 91–100. `https://doi.org/10.1145/2940299.2940311`

[174] Kate Stephens, Matthew Butler, Leona M Holloway, Cagatay Goncu, and Kim Marriott. 2020. Smooth Sailing? Autoethnography of Recreational Travel by a Blind Person. In *The 22nd International ACM SIGACCESS Conference on Computers and Accessibility*. ACM, Article 26. `https://doi.org/10.1145/3373625.3417011`

[175] Jodi Sturge, Mirjam Klaassens, C Allyson Jones, France Légaré, Marie Elf, Gerd Weitkamp, and Louise Meijering. 2021. Exploring assets of people with memory problems and dementia in public space: A qualitative study. *Wellbeing, Space and Society* 2 (2021), 9. `https://doi.org/10.1016/j.wss.2021.100063`

[176] Ponnusamy Subramaniam and Bob Woods. 2016. Digital life storybooks for people with dementia living in care homes: an evaluation. *Clinical interventions in aging* 11 (2016), 1263. `https://doi.org/10.2147/CIA.S111097`

[177] Sandra Suijkerbuijk, Myrte Thoolen, Henk Herman Nap, Mirella Minkman, Wijnand IJsselsteijn, Rens Brankaert, and Yvonne de Kort. 2023. Adaptivity in Research Practice with People Living with Dementia: A Designer's Reflection. In *Dementia Lab Conference*. Springer, 13–25. `https://doi.org/10.1007/978-3-031-14466-0_2`

[178] Suziah Sulaiman, Siti Nur Syazana Mat Saei, Foong Oi Mean, and Halabi Hasbullah. 2010. Understanding domain expert's perspectives and expectations in assistive technology. In *2010 International Symposium on Information Technology*, Vol. 3. 1164–1167. `https://doi.org/10.1109/ITSIM.2010.5561491`

[179] Sunghee H Tak, Hongmei Zhang, and Song Hee Hong. 2015. Preferred computer activities among individuals with dementia: a pilot study. *Journal of Gerontological Nursing* 41, 3 (2015), 50–57. `https://doi.org/10.3928/00989134-20141029-01`

[180] Sunghee H Tak, Hongmei Zhang, Hetal Patel, and Song Hee Hong. 2015. Computer activities for persons with dementia. *The Gerontologist* 55, Suppl_1 (2015), S40–S49. `https://doi.org/10.1093/geront/gnv003`

[181] Barsa Tandukar, Pooja Vazirani, and Aqueasha Martin-Hammond. 2021. Advocacy Through Design: Partnering to Improve Online Communications and Connections in a Life Plan Community. In *Designing Interactive Systems Conference 2021*. 1695–1709. `https://doi.org/10.1145/3461778.3462009`

[182] Kong Saoane Thach, Reeva Lederman, and Jenny Waycott. 2021. Adoption of Videoconferencing for Social Connectedness among Older Adults: A Systematic Review. In *ACIS 2021 Proceedings, 15*. `https://doi.org/acis2021/15`

[183] Elizabeth Thiry, Siân Lindley, Richard Banks, and Tim Regan. 2013. Authoring personal histories: Exploring the timeline as a framework for meaning making. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 1619–1628. `https://doi.org/10.1145/2470654.2466215`

[184] John C. Thomas and John T. Richards. 2012. Achieving Psychological Simplicity: Measures and Methods to Reduce Cognitive Complexity. In *Human Computer Interaction Handbook: Fundamentals, Evolving Technologies, and Emerging Applications* (3rd ed.), Julie A. Jacko (Ed.). CRC Press, Boca Raton, 491–514.

[185] Myrte Thoolen, Francesca Toso, Sebastiaan TM Peek, Yuan Lu, and Rens Brankaert. 2022. LivingMoments: Bespoke Social Communication for People living with Dementia and their Relatives. In *CHI Conference on Human Factors in Computing Systems*. 1–18. `https://doi.org/10.1145/3491102.3517430`

[186] David Unbehaun, Konstantin Aal, Daryoush Daniel Vaziri, Peter David Tolmie, Rainer Wieching, David Randall, and Volker Wulf. 2020. Social Technology Appropriation in Dementia: Investigating the Role of Caregivers in Engaging People with Dementia with a Videogame-based Training System. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. ACM, 1–15. `https://doi.org/10.1145/3313831.3376648`

[187] David Unbehaun, Konstantin Aal, Daryoush Daniel Vaziri, Rainer Wieching, Peter Tolmie, and Volker Wulf. 2018. Facilitating collaboration and social experiences with videogames in dementia: results and implications from a participatory design study. *Proceedings of the ACM on Human-Computer Interaction* 2, CSCW (2018), 1–23. `https://doi.org/10.1145/3274444`

[188] John Vines, Peter C. Wright, David Silver, Maggie Winchcombe, and Patrick Olivier. 2015. Authenticity, Relatability and Collaborative Approaches to Sharing Knowledge about Assistive Living Technology. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing*. ACM, 82–94. `https://doi.org/10.1145/2675133.2675222`

[189] Jayne Wallace, Anja Thieme, Gavin Wood, Guy Schofield, and Patrick Olivier. 2012. Enabling self, intimacy and a sense of home in dementia: an enquiry into design in a hospital setting. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 2629–2638. `https://doi.org/10.1145/2207676.2208654`

[190] Jayne Wallace, Peter C. Wright, John McCarthy, David Philip Green, James Thomas, and Patrick Olivier. 2013. A design-led inquiry into personhood in dementia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 2617–2626. `https://doi.org/10.1145/2470654.2481363`

[191] Jenny Waycott, Ryan M Kelly, Steven Baker, Barbara Barbosa Neves, Kong Saoane Thach, and Reeva Lederman. 2022. The Role of Staff in Facilitating Immersive Virtual Reality for Enrichment in Aged Care: An Ethic of Care Perspective. In *CHI Conference on Human Factors in Computing Systems*. 1–17. `https://doi.org/10.1145/3491102.3501956`

[192] Jenny Waycott, Frank Vetere, Sonja Pedell, Lars Kulik, Elizabeth Ozanne, Alan Gruner, and John Downs. 2013. Older adults as digital content producers. In *Proceedings of the SIGCHI conference on Human Factors in Computing Systems*. 39–48. `https://doi.org/10.1145/2470654.2470662`

[193] Gemma Webster and Deborah Fels. 2013. Portraits of people with dementia: three case studies of creating portraits. *American Journal of Alzheimer's Disease & Other Dementias®* 28, 4 (2013), 371–376. `https://doi.org/10.1177/1533317513488908`

[194] Daniel Welsh, Kellie Morrissey, Sarah Foley, Roisin McNaney, Christos Salis, John McCarthy, and John Vines. 2018. Ticket to talk: Supporting conversation between young people and people with dementia through digital media. In *proceedings of the 2018 CHI conference on human factors in computing systems*. 1–14. `https://doi.org/10.1145/3173574.3173949`

[195] Emma Williamson, Alison Gregory, Hilary Abrahams, Nadia Aghtaie, Sarah-Jane Walker, and Marianne Hester. 2020. Secondary trauma: Emotional safety in sensitive research. *Journal of Academic Ethics* 18, 1 (2020), 55–70. `https://doi.org/10.1007/s10805-019-09348-y`

[196] Cara Wilson, Roisin McNaney, Abi Roper, Tara Capel, Laura Scheepmaker, Margot Brereton, Stephanie Wilson, David Philip Green, and Jayne Wallace. 2020. Rethinking Notions of 'Giving Voice' in Design. In *Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems*. ACM, 1–8. `https://doi.org/10.1145/3334480.3375171`

[197] Rachel Wood, Emma Dixon, Salma Elsayed-Ali, Ekta Shokeen, Amanda Lazar, and Jonathan Lazar. 2021. Investigating Best Practices for Remote Summative Usability Testing with People with Mild to Moderate Dementia. *ACM Transactions on Accessible Computing (TACCESS)* 14, 3 (2021), 1–26. `https://doi.org/10.1145/3460942`

[198] World Health Organization and others. 2017. Global action plan on the public health response to dementia 2017–2025. (2017). `https://www.who.int/publications/i/item/global-action-plan-on-the-public-health-response-to-dementia-2017---2025`

[199] Aaron Yurkewich, Anita Stern, Rushmita Alam, and Ron Baecker. 2022. A field study of older adults with cognitive impairment using tablets for communication at home: Closing technology adoption gaps using InTouch. In *Research Anthology on Supporting Healthy Aging in a Digital Society*. IGI Global, 904–939. `https://doi.org/10.4018/978-1-6684-5295-0.ch050`

[200] Kos Zachos, Neil Maiden, Kristine Pitts, Sara Jones, Ian Turner, Malcolm Rose, Kevin Pudney, and Julie MacManus. 2013. A software app to support creativity in dementia care. In *Proceedings of the 9th ACM Conference on Creativity & Cognition*. 124–133. `https://doi.org/10.1145/2466627.2466637`

Appendix A

List of Publications

Conference proceedings

- **Dai, J.** and Moffatt, K. (2021). Surfacing the voices of people with dementia: Strategies for effective inclusion of proxy stakeholders in qualitative research. *Proceedings of the ACM SIGCHI Conference on Human Factors in Computing Systems* (CHI'21), 1-13. https://doi.org/10.1145/3411764.3445756 (Acceptance rate = 749/2844 = 26.3%)

- **Dai, J.** and Moffatt, K. (2020). Making space for social sharing: Insights from a community-based social group for people with dementia. *Proceedings of the ACM SIGCHI Conference on Human Factors in Computing Systems* (CHI'20), 1-13. https://doi.org/10.1145/3313831.3376133 (Acceptance rate = 647/3126 = 20.7%)

Journal articles

- **Dai, J.** and Moffatt, K. (2023). Enriching social sharing for the dementia community: Insights from in-person and online social programs. *ACM Transactions on Accessible Computing*, 16, 1 (2023), 1–33. https://doi.org/10.1145/3582558

- **Dai, J.**, Bartlett, J. C., and Moffatt, K. (2023). Library services enriching community engagement for dementia care: The Tales & Travels Program at a Canadian public library as a case study. *Journal of Librarianship & Information Science*, 55, 1 (2023), 123–136. https://doi.org/10.1177/09610006211065170

- **Dai, J.** (2020). Empowering people with dementia to share and socialize. *ACM SIGACCESS Accessibility and Computing* (126), Article 3. https://doi.org/10.1145/3386280.3386283

Workshop papers

- **Dai, J.** and Moffatt, K. (2020). Using proxies in supporting the voice of people with dementia in HCI research. *ACM SIGCHI Conference on Human Factors in Computing Systems*, CHI'20 Workshop, Rethinking Notions of Giving Voice in Design
- **Dai, J.** and Moffatt, K. (2018). Beyond communication and social interaction: A review on designing for people with dementia. *ACM SIGCHI Conference on Human Factors in Computing Systems*, CHI'18 Workshop, HCIxDementia

Poster abstracts

- **Dai, J.** and Moffatt, K. (2022). Enriching social sharing for the dementia community: Identifying opportunities for technology design. *Graphics Interface*, GI'22 Poster
- **Dai, J.** and Moffatt, K. (2019). Empowering people with dementia to share and socialize: The Tales & Travels Program as a case study, *1st Annual CS-Can Student Symposium*, Lightning pitch & poster
- **Dai, J.** and Moffatt, K. (2018). Beyond communication and social interaction: A review on designing for people with dementia, *47th Annual Scientific and Educational Meeting of the Canadian Association on Gerontology*, CAG'18 Poster
- **Dai, J.** and Moffatt, K. (2018). Designing for people with dementia to create and share Personal stories, *AGE-WELL Annual Conference*, AGE-WELL 2018 Poster

Appendix B

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Reuse Authors can reuse any portion of their own work in a new work of their own (and no fee is expected) as long as a citation and DOI pointer to the Version of Record in the ACM Digital Library are included.

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Appendix C

Ethics Approvals

McGill

Research Ethics Board Office
James Administration Bldg.
845 Sherbrooke Street West. Rm 325
Montreal, QC H3A 0G4

Tel: (514) 398-6831

Website: www.mcgill.ca/research/researcher/compliance/human/

Research Ethics Board III
Certificate of Ethical Acceptability of Research Involving Humans

REB File #: 312-1218

Project Title: Understanding how people with dementia share and socialize: the tales and travels program as a case study

Principal Investigator: Jiamin Dai **Department:** School of Information Studies

Status: Ph.D. Student **Supervisor:** Professor Karyn Moffatt

Funding: Tri-council/NCE-Promoting social connectedness through collaborating on digital storytelling and knowledge creation and sharing (PI-K. Moffatt); NSERC-Interactive technologies for diverse experiences of later life

Approval Period: January 15, 2019 – January 14, 2020

The REB-III reviewed and approved this project by delegated review in accordance with the requirements of the McGill University Policy on the Ethical Conduct of Research Involving Human Participants and the Tri-Council Policy Statement: Ethical Conduct For Research Involving Humans.

Lynda McNeil
Associate Director, Research Ethics

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* Approval is granted only for the research and purposes described.
* Modifications to the approved research must be reviewed and approved by the REB before they can be implemented.
* A Request for Renewal form must be submitted before the above expiry date. Research cannot be conducted without a current ethics approval. Submit 2-3 weeks ahead of the expiry date.
* When a project has been completed or terminated, a Study Closure form must be submitted.
* Unanticipated issues that may increase the risk level to participants or that may have other ethical implications must be promptly reported to the REB. Serious adverse events experienced by a participant in conjunction with the research must be reported to the REB without delay.
* The REB must be promptly notified of any new information that may affect the welfare or consent of participants.
* The REB must be notified of any suspension or cancellation imposed by a funding agency or regulatory body that is related to this study.
* The REB must be notified of any findings that may have ethical implications or may affect the decision of the REB.

McGill University

ETHICS REVIEW
AMENDMENT REQUEST FORM

This form can be used to submit any changes/updates to be made to a currently approved research project. Changes must be reviewed and approved by the REB before they can be implemented.

Significant or numerous changes to study methods, participant populations, location of research or the research question or where the amendment will change the overall purpose or objective of the originally approved study will require the submission of a complete new application.

REB File #: 312-1218
Project Title: Understanding how people with dementia share and socialize: the tales and travels program as a case study
Principal Investigator: Jiamin Dai
Email: jiamin.dai@mail.mcgill.ca
Faculty Supervisor (for student PI): Professor Karyn Moffatt

In this amendment, we add a new co-investigator and a remote follow-up with existing participants.

New co-investigator:

Name: Dr Joan Bartlett
Status: Associate Professor
Affiliation: School of Information Studies, McGill University
Roles: Co-analyzing the de-identified data and co-authoring a paper based on this study
Access: Full access to the de-identified data collected in this study

Remote follow-up with existing participants:

1. Purpose of the follow-up

In light of the current physical distancing situations, we will remotely follow up with our existing participants to better understand:

- How does physical distancing change the social lives of people with dementia?
- How can technologies and community services help people with dementia maintain socially active and navigate emerging challenges during physical distancing?

2. Recruitment of Participants/Location of the Follow-up

Our invitations will be sent via email or text to the caregivers and the facilitators. We will not approach participants with dementia directly, only through the caregivers but encouraging them to relay comments from participants with dementia. Our follow-up questions will be about daily life and work, with minimal privacy concerns. It will be very low risk for our participants. Please see Appendix A for the invitation script and sample questions.

If participants are interested, they can choose to follow up via email, telephone, or Zoom.

- We will advise participants not to include sensitive or identifiable information in emails.
- Should they choose telephone or Zoom, the follow-up will be audio-recorded only.
- If using Zoom, we will make sure to send meeting links directly to a participant; create a waiting room; have a password to gain entry; lock the meeting once started; inform participants that they can log in with only their first name/pseudonym for further confidentiality and that their video may be turned off. We will turn off the cloud recording feature and record audio directly to our own device.

We will offer $30 honorarium for each follow-up.

- The $30 honorarium for each follow-up will be paid through e-transfer or gift card.
- For gift cards, participants will be able to choose an e-gift card or a mailed gift card from Amazon, Best Buy, or Walmart.
- Receipts will be collected in the form of email or text confirmation of receiving the e-transfer or gift card.

3. Informed Consent Process

We will provide an informed consent form (Appendix B) via email (or other remote means preferred by the participant) after the participants express their interest in the follow-up. Due to the remote research situation, we will ask participants to confirm that they read over the form and consent to participate via email/text or verbally before we present our questions.

Principal Investigator Signature: ________________________ Date: September 29, 2020

Faculty Supervisor Signature: ________________________ Date: September 29, 2020
(for student PI)

For Administrative Use: REB#312-1218(1020)

This amendment request has been approved.

Signature of REB Chair/ delegate: lynda.mcneil@mcgill.ca Digitally signed by lynda.mcneil@mcgill.ca DN: cn=lynda.mcneil@mcgill.ca Date: 2020.10.05 13:58:59 -04'00' Date: ____________________

Project Approval Expires: January -14-2021

Appendix D

Consent Forms

On-site fieldwork consent forms (for dyads)

On-site fieldwork consent form (for individual caregivers)

On-site fieldwork consent form (for facilitators)

Virtual fieldwork consent form (for caregivers and facilitators)

McGill

School of Information Studies

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PARTICIPANT CONSENT FORM

Understanding How People with Dementia Share and Socialize:
The Tales & Travels Program as a Case Study

PRINCIPAL INVESTIGATOR:
Jiamin Dai, PhD candidate, School of Information Studies, McGill University, Phone: 514-756-4580

FACULTY SUPERVISOR:
Prof. Karyn Moffatt, School of Information Studies, McGill University, Phone: 514-398-3366

Introduction

Thank you for your interest in participating in this study. This project, funded by the Natural Science and Engineering Research Council of Canada (NSERC), the AGE-WELL Network of Centers of Excellence (AGEWELL NCE), and the Fonds de recherche du Québec – Nature et technologies (FRQNT), seeks to understand how people with dementia share stories and socialize. The results of this research will also be included in the principal investigator’s doctoral dissertation.

Before you agree to take part in the study, it is important that you read and understand the information below. If you have any questions about the study or the consent process, please ask.

Purpose and Procedures

This study is investigating the challenges people with dementia encounter when sharing stories and socializing within a small group. Specifically, we are interested in social events such as the Tales & Travels program organized by the Alzheimer Society of Montreal and the Westmount Public Library.

During this joint interview, we are asking for your input to help us understand (1) people with dementia’s preferences and challenges when sharing stories and socializing with others and (2) the effectiveness of materials and prompts for telling stories and social interaction.

Eligibility

You are eligible to participate if you:

- Have early-middle stage dementia
- Are able to communicate in English

As these are joint interviews, both the person with dementia and their primary family caregiver must participate in the interview together.

Risks and Benefits

Some topics in the interview might be a bit personal, and you are free to take breaks, skip the questions, or end the interview if the discussion becomes too emotional or makes you uncomfortable. There is no direct benefit from participation in this research. However, your participation may benefit others by leading to the development of better ways to support people with dementia in participating in social activities.

Remuneration and Compensation

Each pair of participants will receive $30 compensation and a gift from the McGill Bookstore for their time and contribution.

Withdrawal
Participation is voluntary; you may decide to withdraw from the study at any time and for any reason, without penalty. Withdrawing from the study will not impact your relationship with the research team in any way.

If you choose to withdraw, inclusion of the data collected prior to your withdrawal may be appropriate in some of our analyses. It is up to you whether or not your data is included in any analyses. If you decide to withdraw and do not wish to have your data included, please inform the research team at that time.

Confidentiality
Data collected may be used in research journals, conferences, or other scholarly activities. All information collected will be kept secure and confidential, and only the principal investigator, Jiamin Dai, and the faculty supervisor, Prof. Karyn Moffatt, will have access to your data files. The data collected will be destroyed 7 years after completion of the study.

Audio will be recorded during the interviews. These recordings are likely to contain directly and indirectly identifying information through your voice and responses. The audio recordings will be used for transcription purposes only. During transcription, identifying information will be removed and replaced with a code. This code will be kept separate from all other information. You will not be identified by name, nor will any other identifying information be recorded or included in the published paper. In no case, will your name or contact information be released (e.g., in presentations and publications your name will be replaced with an identifier such as Participant 1).

Questions or Concerns
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If you have any questions or concerns regarding your rights or welfare as a participant in this research, please contact the McGill Ethics Officer at 514-398-6831 or lynda.mcneil@mcgill.ca.

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Participant's Printed Name ______________________________

Participant's Signature ______________________________ Date _______________

If applicable:

Legal Guardian's Printed Name ______________________________

Legal Guardian's Signature ______________________________ Date _______________

Participant Number _______
Researcher's Initials _______

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During this joint interview, we are asking for your input to help us understand (1) people with dementia's preferences and challenges when sharing stories and socializing with others and (2) the effectiveness of materials and prompts for telling stories and social interaction.

Eligibility

You are eligible to participate if you are:
- The primary family caregiver of someone who has early-middle stage dementia
- Able to communicate in English

As these are joint interviews, both the person with dementia and their primary family caregiver must participate in the interview together.

Risks and Benefits

Some topics in the interview might be a bit personal, and you are free to take breaks, skip the questions, or end the interview if the discussion becomes too emotional or makes you uncomfortable. There is no direct benefit from participation in this research. However, your participation may benefit others by leading to the development of better ways to support people with dementia in participating in social activities.

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Participant's Signature _____________________________ Date _______________

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Researcher's Initials _______

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During this joint interview, we are asking for your input to help us understand (1) people with dementia's preferences and challenges when sharing stories and socializing with others and (2) the effectiveness of materials and prompts for telling stories and social interaction.

Eligibility

You are eligible to participate if you:
- Have current or past experience of taking care of a family member living with dementia
- Are able to communicate in English

Risks and Benefits

Some topics in the interview might be a bit personal, and you are free to take breaks, skip the questions, or end the interview if the discussion becomes too emotional or makes you uncomfortable. There is no direct benefit from participation in this research. However, your participation may benefit others by leading to the development of better ways to support people with dementia in participating in social activities.

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Participation is voluntary; you may decide to withdraw from the study at any time and for any reason, without penalty. Withdrawing from the study will not impact your relationship with the research team in any way.

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Participant's Signature _____________________________ Date _______________

Participant Number _______
Researcher's Initials _______

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Before you agree to take part in the study, it is important that you read and understand the information below. If you have any questions about the study or the consent process, please ask.

Purpose and Procedures

This study is investigating the challenges people with dementia encounter when sharing stories and socializing within a small group. Specifically, we are interested in the Tales & Travels program organized by the Alzheimer Society of Montreal and the Westmount Public Library.

During this interview, we are asking for your input to help us understand (1) people with dementia's preferences and challenges when sharing stories and socializing with others and (2) the effectiveness of materials and prompts for their storytelling and social interaction.

Eligibility

You are eligible to participate if you:
- Have facilitated at least one Tales & Travels session
- Are able to communicate in English

Risks and Benefits

There is no direct benefit from participation in this research. However, your participation may benefit others by leading to the development of better ways to support people with dementia in participating in social activities.

Remuneration and Compensation

You will receive $30 compensation for your time and contribution.

Withdrawal

Participation is voluntary; you may decide to withdraw from the study at any time and for any reason, without penalty. You are also free to skip any questions. Withdrawing from the study will not impact your relationship with the research team in any way.

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Confidentiality

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Participant’s Signature _____________________________ Date _______________

Participant Number _______

Researcher’s Initials _______

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PARTICIPANT CONSENT FORM

Understanding How People with Dementia Share and Socialize: The Tales & Travels Program as a Case Study

Follow-up Study

PRINCIPAL INVESTIGATOR:
Jiamin Dai, PhD candidate, School of Information Studies, McGill University, Phone: 514-756-4580

FACULTY SUPERVISOR:
Prof. Karyn Moffatt, School of Information Studies, McGill University, Phone: 514-398-1878

Introduction

Thank you for your interest in participating in this follow-up study. This project, funded by the Natural Science and Engineering Research Council of Canada (NSERC) and the AGE-WELL Network of Centers of Excellence (AGE-WELL NCE), seeks to understand how people with dementia share stories and socialize. The results of this research will also be included in the principal investigator's doctoral dissertation.

Before you agree to take part in the study, it is important that you read and understand the information below. If you have any questions about the study or the consent process, please ask.

Purpose and Procedures

This follow-up study is investigating the challenges people with dementia and their caregivers encounter in their social lives during the period of physical distancing. Specifically, we are interested how technologies and community activities (such as the Tales & Travels program) could be adapted to help with those challenges.

During this brief follow-up interview, we are asking for your input to help us understand (1) how physical distancing changes the social lives of people with dementia and (2) how technologies and community services could help people with dementia maintain socially active and navigate emerging challenges during physical distancing. Participating in this follow up interview should take no more than 30 minutes.

You can choose to follow up via email, telephone, or Zoom. Please do not include sensitive or identifiable information in emails; should you choose telephone or Zoom, the interview will be audio recorded; if using Zoom, you can log in with only your first name or a pseudonym and turn off the video. While all precautions are taken, with all electronic communications, such as email and web conferencing platforms, there is the possibility of third-party interception.

Eligibility

You are eligible to participate if you:

- Have participated in the original study as a caregiver or a Tales & Travels facilitator

Risks and Benefits

There is no direct benefit from participation in this research. However, your participation may benefit others by leading to the development of better ways to support people with dementia in participating in social activities.

Remuneration and Compensation

You will receive $30 compensation (e-transfer or gift card) for your time and contribution.

Withdrawal

Participation is voluntary; you may decide to withdraw from the study at any time and for any reason, without penalty. You are also free to skip any questions. Withdrawing from the study will not impact your relationship with the research team in any way.

If you choose to withdraw, inclusion of the data collected prior to your withdrawal may be appropriate in some of our analyses. It is up to you whether or not your data is included in any analyses. If you decide to withdraw, your data will be destroyed unless you indicate that it may be kept. Once the data has been combined for publication, it may not be possible to remove the data in its entirety. It can only be removed from further analysis and publication. Once data has been de-identified, it can't be withdrawn. Data will be de-identified, i.e. the code key destroyed, 7 years after the results are published.

Confidentiality

Data collected may be used in research journals, conferences, or other scholarly activities. All information collected will be kept secure and confidential, and only the principal investigator, Jiamin Dai, and the faculty supervisor, Prof. Karyn Moffatt, will have access to your data files. The data collected will be destroyed 7 years after completion of the study.

Audio will be recorded during the interviews. These recordings are likely to contain directly and indirectly identifying information through your voice and responses. The audio recordings will be used for transcription purposes only. During transcription, identifying information will be removed and replaced with a code. This code will be kept separate from all other information. You will not be identified by name, nor will any other identifying information be recorded or included in the published paper. In no case, will your name or contact information be released (e.g., in presentations and publications your name will be replaced with an identifier such as Participant 1).

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Participant’s Printed Name _____________________________

Participant’s Signature _____________________________ Date _______________

Participant Number _______
Researcher’s Initials _______

Appendix E

Interview Guides

On-site fieldwork: Dyadic interview guide

Hello! My name is Carrie. I'm a PhD candidate at the School of Information Studies at McGill University. We are trying to learn about the social experiences of couples like you. We would love to hear stories and thoughts from both of you. There are no right or wrong answers. You can skip any questions that you don't want to answer. You can stop or take a break whenever you want. Participation is confidential, and your name will be replaced by a number. Thank you for helping us and sharing your stories. [Get informed consent]

Today, I'd like to ask you a few questions about your social lives.

1. To start, I'd like to know a little bit about you. How did you two meet / know each other? How did you like to spend time together back then? May I ask how long have you been retired? How did you like to spend time together when you just retired? What did you like to talk about with each other then? How about now? Often in a relationship, one person does more talking and another does more listening. If you don't mind me asking, which one of you talks more, which listens more? Has this always been the case?

2. I'd like to know a little bit about your daily life. Could you walk me through your last week? We could start with Monday July 15. How was this week different from other weeks? What was a typical week of yours like? From Monday to Sunday.

3. Do you often go to social occasions now? o For example, family gatherings? o Meeting with friends? How does that compare to family gatherings? o Public events? Something related to your hobbies? Entertainments? Who do you meet more often? Who are you in frequent contact with? Do you go to these social activities together?

4. How about a few years ago / when you just retired? Did you go to a lot of socials back then? Did anything change in your social lives over the recent years?

5. Could you tell me about a time when you really enjoyed a social event? What did you think about this event? Which part of the event did you like the best? Did you get a chance to talk to a lot of people there? Did you talk to anybody that you never knew before? If not, what made it difficult?

6. What do you like to discuss with other people at social events? Topics. Do you prefer to have a conversation with one person or several people together? One-on-one or group discussion?

7. Could you tell me about a time when a social event was unpleasant or awkward? Something that made you uncomfortable or made a conversation difficult? It could be the little things, or just an unpleasant moment. What bothered you? How did you deal with it?

8. The Westmount Public Library organizes the Tales & Travels event, exploring a country every week, with the help of images, maps, books, food, and videos. How long have you been attending this event? What do you think of this event? What do you like the most? What's the best part for you? Do you consider yourself to be a storyteller or a listener at T&T? What types of material do you like, images, maps, fun facts, books, food, music, or videos? Could you think of any other materials or objects that have helped you share stories with others? In your opinion, what makes T&T unique / different from other events?

9. Have you attended any similar event? Could you tell me about it? Could you give me a concrete instance of talking about yourself / sharing your stories with others? For example, some people carry pictures of their grandchildren and share with others. What brought you to tell the story to this person?

10. We've talked about sharing stories. Is there anything else that you like to share with other people? Your hobbies, skills, expertise? Books, music, movies you like? News, sports, or food?

11. Are there any activities you'd like to add to your current daily routine? Attending some events more regularly? Visiting some people/places more often?

12. Let's say you are organizing a party and you could have all the money and help you need. Unlimited resources. Whatever you want. What would you do to make it successful? What activities would you like to plan? What equipment or service would you like to have? What would the ideal space look like? How many people would you like to invite? All of your family or friends, or just the closest ones?

13. Is there anything you would like to add about your social lives? Have we missed anything you think is important?

Confirm with the caregiver:

- When was dementia diagnosed?
- What kind of dementia?
- At which stage now?

[Fill the questionnaires]

[Sign money receipt]

Thank the participants for their time.

On-site fieldwork: Caregiver interview guide

Hello! My name is Carrie. I'm a PhD candidate at the School of Information Studies at McGill University. We are trying to learn about the social experiences of people with dementia and their caregivers. We would love to hear your stories and thoughts. There are no right or wrong answers. You can skip any questions that you don't want to answer. You can stop or take a break whenever you want. Participation is confidential, and your name will be replaced by a number. Thank you for helping us and sharing your stories. [Get informed consent]

Today, I'd like to ask you a few questions about your caregiving and social lives.

1. To start, I'd like to know a little bit about you and your caregiving experience. How long have you been a caregiver? Who are you taking care of? How did you like to spend time together a few years ago? What did you like to talk about with each other then? How about now? Has this always been the case?

2. I'd like to know a little bit about you and your father's daily life. Could you walk me through your last week? We could start with last Monday July 8. How was this week different from other weeks? What was a typical week of yours like? From Monday to Sunday. How about a typical week when your father lived with you?

3. Did you and your father often go to social occasions in recent years? Who do you meet more often? Who are you in frequent contact with? o For example, family gatherings? o Meeting with friends? How does that compare to family gatherings? o Public events? Something related to your hobbies? Entertainments? 4. How about a few years ago? Did both of you go to a lot of socials back then? Did anything change in your social lives over the recent years?

5. Could you tell me about a time when both of you really enjoyed a social event? What did you think about this event? Which part of the event did you like the best? Did your father get a chance to talk to a lot of people there? Talked to anybody that he never knew before? If not, what made it difficult?

6. What does your father like to discuss with other people at social events? Does he prefer to have a conversation with one person or several people together?

7. Could you tell me about a time when a social event was unpleasant or awkward? Something that made your father uncomfortable or made a conversation difficult? It could be the little things, or just an unpleasant moment. What bothered him? How did you deal with it?

8. The Westmount Library organizes the Tales & Travels event, exploring a country every week, with the help of images, maps, fun facts, books, food, music, or videos. Have you attended this event? What do you think of this event? What do you like the most? What's the best part for you? Do you consider yourself to be a storyteller or a listener at T&T? What types of material do you like, images, maps, facts, books, food, music, or videos? Could you think of any other materials or objects that have helped participants share stories with others? In your opinion, what makes T&T unique / different from other

events?

9. Have you attended any similar event? Could you tell me about it? Could you give me a concrete instance of talking about himself, sharing his stories with others? For example, some people carry pictures of their grandchildren and share with other people. What brought him to tell the story to this person?

10. We've talked about sharing stories. Is there anything else that your father likes to share with other people? o Hobbies, skills, expertise? o Books, music, movies? o News, sports, food?

11. Are there any activities you'd like to add to your father's current daily routine? Attending some events more regularly? Visiting some people/places more often?

12. Let's say you are organizing a party and you could have all the money and help you need. Unlimited resources. Whatever you want. What would you do to make it successful? What activities would you like to plan? What equipment or service would you like to have? What would the ideal space look like? How many people would you like to invite? All of your family or friends, or just the closest ones? 13. Is there anything you would like to add about your social lives? Have we missed anything you think is important?

- When was dementia diagnosed?
- What kind of dementia?
- At which stage now?

[Fill the questionnaires]

[Sign money receipt]

Thank the participant for his/her time.

On-site fieldwork: Facilitator interview guide

Hello! My name is Carrie. I'm a PhD candidate at the School of Information Studies at McGill University. We are investigating how to better support people with dementia sharing stories and socializing, especially at events such as Tales & Travels. Thank you for helping us. [Get informed consent]

Today, I'd like to ask you a few questions about your experience in facilitating the Tales & Travels sessions.

1. To start, how long have you worked with individuals with dementia? For professionals: What kind of training have you had about dementia? For librarians: Have you had any training about dementia? What kind?

2. When did you start to facilitate the Tales & Travels program? How many sessions have you facilitated?

3. Could you walk me through your preparation process for the last session of Tales & Travels that you facilitated? Why did you choose this type of material (images/facts/books/food/music/video)?

4. Could you walk me through the last session of Tales & Travels that you facilitated?

How many people sat at your table during the story session? Why did you choose to arrange it this way?

5. What changes did you make to the materials or procedures along the way? Why did you make this change?

6. How did you encourage participants to tell their stories? How did they respond to these prompts?

7. Could you recall the feedback/comments you got from the participants after a session? Any comments from their caregivers?

8. Could you tell me about a time when something went really well during the session? Do you remember any interesting discussions among the participants or with you?

9. Could you think of any difficulties you had during the sessions? Anything didn't go well as expected?

10. What challenges have you observed when participants tell stories?

11. What challenges have you observed when participants socialize with each other?

12. Did you notice any difference in the conversation when the caregiver sat at the same table?

13. We've talked about telling stories. Did you recall if there was anything else that the participants like to share with others? Books, music, or movies they like? News and sports? Food?

14. Did you notice any other activities that participants engaged when they came to the library, before or after the Tales & Travels sessions?

15. Do you recall dementia being mentioned during the sessions? What was the occasion?

16. Looking back now, do you have any thoughts about what would make a successful session?

17. What positive outcomes did you observe from your facilitating experience?

18. Have you facilitated or participated in other activities for people with dementia? Anything unique you only observed in the Tales & Travels?

19. Let's say you have unlimited resources, what activities would you add to the current sessions? What equipment or support would you like to have?

20. Is there anything you would like to add? Have we missed anything you think is important?

[Fill in questionnaire]

[Sign money receipt]

Thank the participant for his/her time.

Virtual fieldwork: Caregiver interview guide

o Lock meeting o Turn on recording o E-transfer / e-gift card o To start, I would like to hear about your current life and the changes brought by physical distancing. Could you describe a typical week of yours since last March? What has changed in your social lives since then? How's your mom adjusting? What are her comments during this period? Any difficulties with the masks, worry about the virus, or anything else?

o Could you describe one good change, a new social activity that you've enjoyed, during this period?

o Could you describe one unpleasant scenario, a new social challenge that emerged, during this period?

o What do you think of the changes to Alzheimer Society's activities, like remote yoga, art therapy, or Tales & Travels?

o What have you heard from other caregivers or people you know?

o Could you think of one new activity or support that would help with your social life during this period?

o What devices and platforms have you started to use or used more frequently?

o What are the challenges in using technology to adapt to physical distancing?

o Is there anything you would like to add?

Virtual fieldwork: Facilitator interview guide

o Lock meeting o Turn on recording o E-transfer / e-gift card

For Alzheimer Society coordinators:

o Could you describe the changes to your work with physical distancing measures in place since mid-March?

o How are your clients adjusting based on your observation? Any feedback from them?

o What devices and platforms have you started to use or used more frequently for work during physical distancing?

o Are you / Is the Alzheimer Society continuing the collaboration with libraries and community centres? Could you tell us about how you are adapting your work for these venues?

o How would you envision community programs like Tales & Travels in the future if certain physical distancing measures are in place for a longer period (e.g., 1–2 years)?

o What are the challenges in using technology to adapt your work for people with dementia and their caregivers during physical distancing?

o Is there anything you would like to add?

For librarians:

o Could you describe the changes to your work with physical distancing measures in place since mid-March?

o What are your thoughts and concerns when adapting Tales & Travels?

o What devices and platforms have you started to use or used more frequently for work during physical distancing?

o What are the challenges in using technology to adapt your work for people with dementia and their caregivers during physical distancing?

o Could you tell us about how you are adapting your collaboration with the Alzheimer Society?

o Is there anything you would like to add?

Appendix F

Observation Guides

Note: This is an example set of the observation guides used in our on-site fieldwork. It served as a reminder of what to pay attention to.

Date:
Theme:
Number of facilitators:
Number of caregivers:
Number of participants with dementia:
Number of participants observed:

Story session

Start time: End time: Points of facilitators changing tables:

Verbal cues & description:
Greetings & Small talks
Reading materials out loud
Commenting on maps/pictures/books/facts
Telling stories about travel
Talk about other topics
Asking questions
Asking for personal stories
Responding to questions
Joking

Nonverbal cues & description:
Smiling
Laughing

Nodding
Shaking head
Frowning
Singing
Humming
Whistling
Browsing materials
Touching/Holding materials
Pointing to materials
Gesturing
Eye contact with others
Touching others
Hugs & shaking hands
Listening to others
Wondering
Not engaging
Tone of voice
Gaze direction
Position to others

Coffee break

Start time: End time: Snacks: Related to the theme? Yes/No

Comments on the taste:
Comments on the smell:
Chatting with others:
Other notables:

Video session

Start time: End time: Clips:

Nonverbal cues & description:
Smiling
Laughing
Frowning
Singing
Humming
Whistling

Whistling
Clapping
Moving with music
Pointing
Gesturing
Looking around
Talking to others
Gaze direction
Position to screen
Leaning towards others