Co-creating technological experiences to enhance dementia care partnerships

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
Rehabilitation Sciences Institute
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Abstract

Dementia is on the rise and society faces the challenge of how to manage its impacts. Challenging the biomedical discourse, sociocritical work has underscored relational aspects of caring and promoted ‘partnerships’ between persons with dementia (PwD), informal care partners, and formal care providers (the ‘partners’). Technological research has only begun to explore how innovation may enrich lived experiences with dementia beyond compensating for cognitive deficits or alleviating care ‘burdens’. My central thesis aims were to better understand the nature of care partnerships from the perspectives of PwD and family care partners, and to describe how co-creating technological experiences may impact care partnerships. Data were gathered from three qualitative studies. Study I co-designed with family care partners how they support PwD in activities, and how they envision technology complementing their care. Study II employed focus groups with adult children that constructed an understanding of how adult children sustain caring within their family and formal care contexts. Study III used a multiple case study to describe how four care networks adapted to new technologies, and how doing so impacted care practices. Toward my central thesis aims, these findings together demonstrate that care partnerships are comprised of diverse and interdependent care relationships. Partners exercise different forms of knowledge, expertise, and perspectives in ways that may converge,
complement, or conflict with one another. Partners interact by responding and adapting to care changes, balancing and negotiating with one another, entrusting and diffusing care responsibilities, and learning and growing throughout their care journeys. Whether co-creating technological experiences challenges or enhances care partnerships is influenced by how partners make meaning with technology, learn and foster technological support resources, adapt care practices, and reconfigure their care relationships through technology use. Future work is encouraged to adopt relational approaches to understanding and designing to enrich lives with dementia.
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Chapter 1
Introduction

With a globally aging population, dementia is on the rise, and public and private sectors face the challenge of how best to manage the health care, economic, and social impacts. Dementia, which is most commonly caused by Alzheimer’s Disease, is a progressive condition that is most commonly characterized by cognitive and functional decline [1]. From a biomedical standpoint, dementia care is understood to be highly complex and challenging due to its progressive and degenerative nature [1]. Most persons with dementia (PwD), especially in the early stages, continue to live in the community with support from informal care partners, who are most often family members. In the later stages of cognitive decline, PwD and family care partners may seek additional support from formal care providers, such as public or private home care services, or long-term residential care facilities [2]. From a socio-critical standpoint, which challenges the prevailing biomedical discourse, dementia care is understood as psychosocial and relational, where the multiple actors (‘partners’) – specifically, persons with dementia (PwD), family or informal care partners, and formal care providers – each possess knowledge that should be valued equally, and should actively participate in care decision-making [3]. Based on this perspective, a move away from ‘expert’ or ‘person-centred’ care towards care ‘partnerships’ is currently underway [3]-[5], seeking to empower PwD to fully participate in care decisions, and create synergistic relationships and interactions between the three partners.

At the same time, there has been increasing interest in technologies to support dementia care. However, these have had questionable real-world impact. One stream of research, advanced by the engineering and computing sciences, has taken a ‘systems development’ approach, which has attempted to apply technological innovation (e.g., machine learning, ubiquitous computing) to the dementia ‘problem’. Other research has taken a ‘user-centred’ approach, which attempts to study and gather design requirements from ‘users’ to guide the development and evaluation of new technologies. A smaller body of work has revealed that PwD and/or care partners devise their own technological arrangements using everyday objects, devices, or commercial off-the-shelf technologies ([6]-[9]). This may be attributed to individualized and particularistic care needs [1], the limited awareness or accessibility of publicly subsidized assistive technologies [6],
[10], the ubiquity of mobile information and communication technologies, and the arguably greater accessibility of touch-screen devices by PwD [11]. From the latter stream of research, new design paradigms for dementia have emerged (e.g., ‘experience-centred design’ [12], [13], ‘critical dementia’ [14]). These paradigms have underscored the need to understand the human and social complexities of living with dementia and co-create with actors – particularly PwD and their family care partners – meaningful technological experiences.

In this thesis project, I assume that two key paradigm shifts may help ‘move the needle’ on realizing technologies to better support and enrich the lives of PwD and care partners. First, the view that dementia care encompasses more than the management of functional deficits or behaviours; it involves living partnerships between multiple actors. The focus is placed on actors’ respective and mutual needs, values, and agendas; the relationships between actors; and the interactions through which they ‘partner’ in dementia care (e.g., care decision-making, care practices). The second proposed shift is to broaden the design space from the view of technology as instrumental or ‘assistive’ (i.e., compensates for deficits, alleviates care burden) in caring, to one in which technology transforms and begets enriched care experiences. From this view, technology is expected to shape, and be shaped by, human interaction when situated within care partnerships.

1.1 Dementia care: from ‘caregiving’ to ‘care partnerships’

Dementia care is most often associated with increasing degrees of assistance with activities of daily living (ADLs), with typical transitions from supporting instrumental ADLs (e.g., finances, shopping), to basic ADLs (e.g., bathing, dressing), to constant care and supervision [1]. The term “caregiving” has been used to refer to the skilled care provided by paid formal care providers (e.g., personal support workers, nurses) or the “informal” care provided by family members, friends, or neighbours on an unpaid basis. PwD are mostly cared for ‘informally’ in community and, subsequently, with additional formal care support, either privately, through home care services or in institutional care facilities (where available and accessible). The conceptual distinction between informal care and formal care has been described as blurry, where informal care partners, such as family members, may perform more “skilled” tasks, and formal care may develop emotional, “family-like” relationships with their clients [15]. Another blurred distinction has been noted between the ‘social support’ typically provided within familial or social
relationships and ‘caregiving’ where “the point at which [social support] becomes caregiving is not clear” [15]. Assumptions about the caregiver-care recipient relationships have also been critiqued for suggesting a unidirectional flow of support where care is ‘given’ by a caregiver to a PwD. Such assumptions have reinforced the dominant stress and burden discourses in dementia care, where PwD are assumed to be too incapacitated to participate in their own care, and care partners shoulder the burden of managing their deficits and behaviours, thereby creating their own negative health consequences.

Dementia activism has challenged such notions that PwD are passive recipients of care, and several scholars have advocated for their inclusion, empowerment, and full participation. Despite person-centred care models that have attempted to individualize care for PwD, critics challenge that such care models have rarely included PwD in care decision-making [3], [4], [16]. Another charge is that person-centred care tends to ignore the “fundamentally relational” [17] nature of care relationships, which are based on interdependencies and reciprocities between actors [4], [18]. Such a view has also framed the dominant caregiver stress discourse, which views caring as solely burdensome and stressful for care partners, which has been challenged by evidence demonstrating the positive aspects of caregiving (e.g., [19]), and reinforced by a reappraisal of population-based informal caregiving studies [20]. Instead, some scholars have stressed that dementia care should be viewed as relational or relationship-centred, and have promoted the notion of care ‘partnerships’ between PwD, informal care partners, and formal care providers [3]-[5]. Nolan advanced the Senses Framework [18], believing that care relationships between PwD, informal care partners, and care professionals should be “reciprocal, complementary and symmetrical”, through the promotion of a sense of security, belonging, continuity, purpose, achievement, and significance for all actors. To this, Adams’ and Clarke’s [3] added how partnerships in dementia care may be supported – particularly through valuing all actors’ knowledge perspectives equally, including those of PwD, and focusing on the dynamics of relationships and interactions between actors. Also stressing PwD as “equal partners” who can and should be included in care-decision-making, Dupuis et al. [4] expanded on both of these previous works by providing principles and a process for supporting partnerships in their model of ‘authentic care partnerships’. They propose with their model three principles for authentic care partnerships. First, *a genuine regard for self and others* values individual uniqueness, diverse perspectives, and potentiality for human growth and development. Secondly, *synergistic*
relationships view the collective wisdom gained from sharing different knowledge perspectives as facilitative of richer solutions to support the care context than the knowledge of any one individual. Thirdly, a focus on process allows for creative, non-traditional solutions to result from learning and unlearning (never-ending processes) and flexibility and responsiveness to change. Drawing from these works, my conceptualization of a ‘care partnership’ is comprised of three key aspects. First, it is a relationship between actors in which each actor possesses his or her own experiential knowledge, expertise, and perspectives on dementia care. Secondly, the relationships between actors in a care partnership tend to be interdependent (i.e., actors mutually influence or affect one another) and reciprocal (i.e., actors share mutual feelings). Thirdly, actors in a care partnership interact with one another in care decision-making and care processes, which involve continuous learning and unlearning, generating creative solutions, and the fostering of collective wisdom.

Although the cited works view dementia care partnerships as involving PwD, family care partners, and formal service providers, further investigation into the nature of care partnerships from the perspectives of PwD and family care partners is needed. First, dementia care approaches have historically regarded the views of health care professionals (“experts”) as dominant [3], [4]. Although psychosocial approaches have aimed to recognize the expertise and perspectives of family care partners [3], [4], their relationships with and specific roles vis-à-vis professional providers tend to be ambiguous [3]. Most problematically, however, is that care approaches have long excluded PwD altogether from care decision-making [3], which calls for novel and usable models (e.g., [4]) that demonstrate how PwD can contribute their knowledge perspectives and valuably participate in care decision-making. Secondly, previous work has indicated that dementia begets complex relationship dynamics (e.g., role changes, influence of relationship history, strained communication, working together vs. apart [21]) that PwD and family care partners may experience throughout their care journeys, yet limited insight into how these actors ‘partner’ in navigating these complexities. Thirdly, shifting population demographics (e.g., smaller families, greater female workforce participation, geographically separated families) [1]), together with formal dementia care inadequacies [22], [23] and varying sociocultural norms and expectations related to caring [1], [24], [25] call for a closer examination of the nature of family care partnerships specifically.
1.2 Technological research: from designing for ‘users’ to co-creating experiences with them

Technological research in support of persons and families living with dementia has been approached by different disciplines. Driven by significant advances in computing and artificial intelligence, systems development research has focused on developing novel systems and algorithms for applications to dementia care contexts. Examples include intelligent sensing environments that can monitor activity, detect physiological or environmental changes, aid cognition, or respond to ‘users’ with support for activities of daily living [26], [27]. Technology studies aiming to support PwD and care partners, in general, were previously found to bias caregivers’ needs (e.g., safety, managing activities of daily living) over PwD’s needs (e.g., leisure activities, socializing, accessing outdoors) [28]. Although PwD and care partners have increasingly been involved in the research and design of assistive, everyday, and information and communication technologies, their involvement has typically been pursued from a ‘user-centred’ paradigm of studying user problems or needs, specifying design requirements, and developing technological ‘solutions’ for these ‘users’ (critiqued by [12]). More recently, however, technological advancements spreading from workplaces to home contexts have steered technological research toward understanding persons’ lived experiences, including such aspects as emotions and culture. ‘Experience-Centred Design’ [12], for instance, emphasizes meaning-making as central to persons’ experiences with technology. Fundamentally, this line of work assumes that technological experiences are shaped by human behaviour, and vice versa. Applied to supporting dementia care, this paradigm shift has challenged the ‘assistive’ and ‘solution-oriented’ design paradigms. Methodologically, this has led to involving PwD and care partners in more interpretive ways, and inviting their active participation with researchers and designers in the design process for exchanges of empathy, dialogue, and felt experiences [12], [13]. Moreover, with the ubiquity of technological devices and applications for everyday life, care actors have been found to fashion their own technological arrangements [6], [9], [29], providing fruitful opportunities to investigate these living processes in real-world contexts. Not only may such real-world investigations inform design outputs, but it also enables the design process to produce insights into actors’ behaviours and contexts – that is, producing research through design [30].
Related to technological experiences, this thesis is framed by two key concepts that were used to guide data gathering and focus data interpretations. First, the view of technology as experiential [31] was adopted, where technological experiences were expected to impact actors’ relationships and interactions (i.e., their care partnerships), and vice versa. Secondly, the concept of ‘co-creation’ [32] – defined as any act of collective creativity between two or more people – upholds that all persons are creative. Employing the concept of co-creation in this thesis called for sensitivity to the ways in which PwD and care partners exercised collective creativity in their design involvement and their interactions with technology.

1.3 Positionality

As integral to any qualitative research inquiry, I discuss in this section my positionality as the primary researcher, and its influence on my theoretical perspectives, chosen research methods, data interpretations, and knowledge production.

First, I identify as a heterosexual Chinese-Canadian female, most fluent in English and secondarily Cantonese Chinese (basic conversational only). I do not consider myself disabled physically or mentally. I am a dual Canadian-American citizen, having been born in Denver, Colorado but raised in Toronto, Canada (since 2 months’ of age). I consider myself privileged socially and materially and have always identified myself as ‘middle-class’. I funded myself through approximately 70% of my undergraduate education and 100% of my graduate education, and have been working in either part-time or full-time capacities since the age of 12. Since 2006, I have qualified for financial assistance to support my post-secondary education. I have never experienced unemployment for longer than 3 months or sought social welfare assistance.

My individual and family experiences, together with my ethnocultural values, have undoubtedly shaped my perspectives on individualism versus collectivism. I would describe my upbringing as ‘east meets west’ insofar as being instilled with western values of individual freedom, achievement, and ambition, concurrent with common Chinese cultural values of filial piety and intergenerational family unity. Living and travelling internationally (Canada, Singapore, Sweden) since 2004 indeed fostered my self-awareness of this held ‘hybrid’ identity.

My lived experiences with health, illness, and disability have also shaped my research interests and perspectives. In 1992, my mother suffered from multiple strokes, traumatic brain injuries,
and an auto-immune disorder, which together left her with emotional, mental, and physical impairments (especially speech and communication impairments), and contributed to her loss of vocation as a secondary school teacher. In 2007, both of my maternal grandparents (with whom I was emotionally very close) moved into assisted living and long-term care homes for mental health disorders, physical impairments, and dementia. These circumstances of family illness and disability not only motivated my initial research and professional interests in disability, rehabilitation/occupational science; my grandparents’ care needs and changes would frequently prompt me to reflect on and put them in dialogue with my research findings. In particular, I brought to my research sensitivity to the emotional complexities and ambivalences that family care partners may experience (as I did), and the feelings of vulnerability, stigma, loss, and insignificance that may be expressed by persons living with disability or dementia.

I also consider my technological perspectives influential to my research. Academically, I completed a Bachelor of Computing (Honours), with a focus on cognitive science and human-computer interaction. Throughout this degree, I held various summer positions in technology-related roles within consumer retail sales and financial services. I then worked in the technology/telecommunications industry, managing both enterprise and consumer-targeted services, for 3 years. Here, I worked largely alongside technical personnel (engineers and developers). From there, I worked for 4 years at Toronto Rehab’s Cardiac Rehabilitation Program, implementing both technological processes and clinical services for patient alumni and family members. For my graduate studies, I then situated myself in the Intelligent Assistive Technology and Systems Lab at University of Toronto – again alongside technical students and professionals – during my graduate studies. Together, these shaped my perspectives of technology potentially assistive, experiential, and largely shaped by the ‘users’ who use or engage with them. A key insight fostered from these experiences was that technology can both be a problem and a solution (sometimes simultaneously), depending on how people adopt and adapt to or with them. Moreover, I learned that using any new technology engenders a process of change – for systems, people, and practices – that is often taken for granted by the people encouraging that new technology.
1.4 Thesis aims

1. To better understand the nature of dementia care partnerships from the perspectives of persons with dementia and family care partners.

2. To describe how co-creating new technological experiences may impact dementia care partnerships.

1.5 Research questions

The two thesis aims were pursued through four key research questions, which drove the three empirical studies within this thesis project.

1. How do family care partners envision new technology complementing their care of PwD? (Study 1)

2. How do family care partners sustain caring for PwD within their family and formal care contexts? (Study 2)

3. How do care partnerships between PwD and family care partners appropriate (i.e., adopt and adapt to) new technology? (Study 3)

4. How does appropriation impact the care practices of these care partnerships? (Study 3)

1.6 Project activities, logic, and outcomes

Figure 1 provides a mapping of the three empirical studies that were completed in this thesis project, the guiding logic between the studies, and the outcomes (publications).

Figure 1. Overview of three empirical studies, their research questions (black boxes), emergent topics that were pursued (arrow labels), and outcomes (publication titles in italics).
1.7 Thesis overview

The subsequent chapters of this thesis are organized as follows:

*Chapter Two* presents an article, entitled, ‘*Co-designing ambient assisted living (AAL) environments: unravelling the situated context of informal dementia care*’ [33]. The article begins by reviewing previous work on informal care partners’ perspectives, anticipated needs, and awareness of technology in support or complement of their care activities. Results are then presented from a *Study I*, a four-phase co-design study with six family care partner participants, including insights into their interactions and relationships with PwD when providing activity support. This is followed by a discussion of the highly personalized care needs and unpredictable situations that technology would need to accommodate, and the complexity that care partners may experience when entrusting care to another party. The article concludes that technology should be customizable by actors and play a mediating role in supporting their collaborative ‘craft’ of care practices as their relationships evolve.
Chapter Three presents an article, entitled, ‘Sustaining care for a parent with dementia: an indefinite and intertwined process’ [34]. This chapter further investigates the complex nature of care relationships and care processes that were revealed in Chapter Two. The article includes background on dementia care in the Ontario context, including a critique of formal home care services, and a rationale for examining how adult children, in particular, sustain caring within their family and formal care contexts. Results from Study II, involving two gender-segregated, half-day focus groups with nine adult children participants are presented in the form of three interrelated themes. The article concludes with a discussion of how family values and relationships interplay with mistrust in formal care services to influence care decisions, and how positive and negative aspects of care may influence one another.

Chapter Four presents a submitted manuscript, entitled, ‘Exploring how persons with dementia and their care partners collaboratively appropriate information and communication technologies’ [35]. This chapter explores the updated (i.e., since Chapter Two) technological landscape of ubiquitous and mobile technologies, which has driven commercially-available technologies to support “aging-in-place” and afforded ‘users’ the means to create and adapt their own technological arrangements using mainstream products. Furthermore, it implements a methodological shift based on my fostered theoretical perspectives and empirical insights, from the use of more traditional methods of user-centred design (i.e., in Study I) and qualitative research (i.e., Study II) to methods more suitable to naturalistic settings and co-creative inquiry with partners in care. The article includes a critique of the ‘assistive’ paradigm of technological design, an overview of related work on assistive and everyday technologies to support PwD and their care partners, and a rationale for studying ‘collaborative appropriation’ – how multiple actors adopt and adapt (to) technology – with dementia care networks. The results of Study III, a longitudinal, descriptive, multiple case study of four dementia care networks are presented, and a model of collaborative appropriation is proposed, including two key processes and four driving forces. The importance of technological literacy, technology learning, and meaning-making are emphasized, and the influence of the nature and quality of care relationships on technological appropriation, and vice versa, is discussed. The article concludes with key methodological, research, and design implications.

Chapter Five presents an integration of the key findings from the three empirical studies, which addresses each thesis aim. Following this, the inferred research, practice, and design implications
for technological innovation to support or enhance dementia care partnerships are discussed. This chapter concludes with an overview of research limitations and concluding remarks.
Chapter 2
Co-designing ambient assisted living (AAL) environments: unravelling the situated context of informal dementia care

This chapter was published in BioMed Research International (17 June 2015) in the special issue, entitled “New technologies for the management and rehabilitation of chronic diseases and conditions.” This article reports on Study I of this thesis project.

Article citation:


2.1 Abstract

Ambient assisted living (AAL) aims to help older persons “age-in-place” and manage everyday activities using intelligent and pervasive computing technology. AAL research, however, has yet to explore how AAL might support or collaborate with informal care partners (ICPs), such as relatives and friends, who play important roles in the lives and care of persons with dementia (PwD). In a multi-phase co-design process with six (6) ICPs, we envisioned how AAL could be situated to complement their care. We used our co-designed “caregiver interface” artefacts as triggers to facilitate envisioning of AAL support and unpack the situated, idiosyncratic context within which AAL aims to assist. Our findings suggest that AAL should be designed to support ICPs in fashioning “do-it-yourself” solutions that complement tacitly improvised care strategies, and enable them to trial, observe, and adapt solutions over time. In this way, an ICP could decide which activities to entrust to AAL support, when (i.e., scheduled or spontaneous) and how a system should provide support (i.e., using personalized prompts based on care experience), and when adaptations to system support are needed (i.e., based alerting patterns and queried reports). Future longitudinal work employing participatory, design-oriented methods with care dyads is encouraged.
2.2 Introduction

As the most important contributors to dependence and institutionalization, dementia and cognitive impairment [1] profoundly impact, not only persons living with impairment, but their significant others, relatives, and friends. While public health systems strive to assist persons with dementia (PwD) to live at home [36], Canadian home care resources continue to fall short in meeting real-world needs [22], consequently shifting care responsibilities to informal care partners (ICPs) – most commonly family members [37]. The role of an ICP involves responding to increasing care needs and dependency over time. With or without formal support, an ICP will typically transition from supporting instrumental activities of daily living (ADLs) (e.g., finances, shopping) to assisting with basic ADLs (e.g., bathing, dressing) to providing constant care and supervision [1]. Although the stress and burden associated with caring for a PwD is well documented (e.g., [38]-[42]), ICPs may wish to continue caring for as long as possible for reasons that include fulfilling filial duties [43] or continuing their relationships with PwD [44], [45]. Taken together, there is a need for policies, services, and interventions that can better support and collaborate with ICPs in the care of PwD [22], [46].

Concurrently, the emerging field of ambient assisted living (AAL) has positioned itself to enable older adults, including PwD, to “age-in-place” (i.e., at home and in their communities) through the support of intelligent and pervasive computing (also referred to as “smart home”) technologies. This class of technologies aims to deliver unobtrusive, context-aware assistance by sensing and learning patterns of behaviour and, in turn, tailoring its support to specific users (e.g., [27]). Beyond studies that have aimed to demonstrate technological efficacy to this end, user studies have involved PwD to investigate AAL applications to promote memory, safety, and functional independence in the home [26]. Although many have suggested the importance of also considering ICPs in AAL research and development [26], [47]-[49], the field has yet to address how these technologies might co-exist with ICPs in the care of PwD, as opposed to replacing the care they provide. In a qualitative study with ICPs, which followed on earlier longitudinal work together with PwD [50], Rosenberg et al. [51] found that ICPs showed an overall readiness to use everyday technology to support their caring roles. In another study using home visits and interviews with PwD and their ICPs, Wherton & Monk [52] identified dressing, medications, personal hygiene, food preparation, and social communication as potential areas for prompting and sensing technologies. Another quantitative study with ICPs concluded that these
stakeholders lacked knowledge of the capabilities of intelligent technologies and recommended future user-centred design approaches to address this knowledge gap in the research process [53], [54]. This previous work recognizes ICPs as an important stakeholder group in AAL research whose needs should be considered in the design of holistic AAL solutions to meet the needs of multiple key stakeholders.

To this end, this study extends our earlier discussion of the design considerations for this context [55] to a deeper description of how ICPs envision AAL support alongside their own care of PwD. Guided by the philosophy that AAL supporting PwD should be designed, not to replace, but rather to complement and collaborate with ICPs, our key study objectives were to explore 1) when or with which day-to-day, home-based activities ICPs envisioned AAL could support their care, and 2) how ICPs envision interacting with the technology to specify and obtain the desired support. We pursued these objectives through an inductive co-design process with ICP participants. This participatory approach aimed to scope the needs and perspectives of ICPs in an envisaged future with AAL support; educate these stakeholders on the capabilities and potential of AAL technologies; and, together, creatively explore new possibilities for AAL design.

2.3 Method

2.3.1 Study design

As AAL represents an imagined technological future in which the roles of ICPs have yet to be explored, our study employed a co-design approach [56] that involved ICP participants in group design workshops, followed by paper prototyping sessions with individual participants in their homes. Co-design utilizes the “collective creativity of designers working together with non-designers”, and is well suited for early stages of the design process, where complex challenges and embodiments of imagined future user experiences can be explored [56]. Integral to this process was the use of “creativity triggers” – visual artefacts that explained the concept and capabilities of AAL, guided our questions, and facilitated participants’ envisioning of the design space [57]. The first trigger was an animated video demonstrating an activity-assistance AAL system, “COACH” [58], which acted as a point of departure from which participants could envision, ideate, and design their interactions with similar AAL systems. Subsequent triggers were presented in the forms of user interface designs and paper prototypes to focus participants
on the co-design of a “caregiver interface” – a tool to enable an ICP to set up and specify AAL support. In this way, prototypes helped to “concretize and externalize conceptual ideas” [59] and our co-design process reflected research through design, an approach whereby “artefacts [are] intended to be carefully crafted questions … [that] stimulate discourse around a topic” [30]. In addition to serving as triggers, the co-designed artefacts also constituted data, together with the discussion, reflection, and interpretation they facilitated. Similar to how “technology probes” aim, in part, to collect sociological data about the contextualized use of technology [60], we focused our study on what these artefacts revealed about the needs, perspectives, and particularities of ICPs in their care contexts, rather than issues of user interface aesthetics, usability, and form factor.

2.3.2 Participants and recruitment

Six participants were recruited from a community-based agency supporting PwD and ICPs. Agency staff members facilitated recruitment through word-of-mouth promotion and recruitment flyers, referring all prospective participants to the research team. The first author conducted a telephone screen to qualify each prospective participant based on our study inclusion criteria: provides at least seven hours (i.e., approximately half the average provided to persons with mild dementia [61]) of unpaid care each week for a community-dwelling PwD (i.e., diagnosed or assumed dementia); assists with most or all listed ADLs (i.e., bathing, toileting, handwashing, toothbrushing, dressing, meal preparation, and taking medications); and has been providing care for at least six months. Table 1 summarizes the six ICP participants who participated in Phase 1 and Phase 2, and the asterisks indicate the two participants who participated in Phase 3.
Table 1. Study I – Description of participants. The activities of daily living (ADLs) participants reported assisting with were among bathing, toileting, handwashing, toothbrushing, dressing, meal preparation, and taking medications. The asterisks indicate the two participants selected to participate in Phase 3.

<table>
<thead>
<tr>
<th>Participant (pseudonyms)</th>
<th>Age</th>
<th>Relationship</th>
<th>Living with the PwD?</th>
<th>Severity of dementia (PwD)</th>
<th>Assists with how many ADLs (of 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jacklyn</td>
<td>55</td>
<td>Daughter</td>
<td>No, same apartment building</td>
<td>Mild-moderate</td>
<td>6</td>
</tr>
<tr>
<td>Heather</td>
<td>67</td>
<td>Daughter</td>
<td>No, within a five-minute drive</td>
<td>Moderate</td>
<td>7</td>
</tr>
<tr>
<td>Kristine</td>
<td>74</td>
<td>Spouse</td>
<td>Yes</td>
<td>Mild-moderate</td>
<td>7</td>
</tr>
<tr>
<td>Tabitha</td>
<td>77</td>
<td>Spouse</td>
<td>Yes</td>
<td>Moderate</td>
<td>7</td>
</tr>
<tr>
<td>Melissa*</td>
<td>37</td>
<td>Daughter</td>
<td>No, father was moved to nursing home two months ago</td>
<td>Moderate to severe</td>
<td>7</td>
</tr>
<tr>
<td>Hilda*</td>
<td>62</td>
<td>Daughter</td>
<td>Yes</td>
<td>Severe</td>
<td>7</td>
</tr>
</tbody>
</table>

2.3.3 Our co-design process

Our co-design method was informed by two relevant models. The conventional four-stage user-centred design (UCD) model [62] – studying users, designing for the problem space, building prototypes, and evaluating prototypes – guided our design process, and the Usability, Safety, Attractiveness Participatory (USAP) design model [63] formed the successive phases of this study, as shown in Figure 2. Moreover, our study adopted a participatory approach whereby, over multiple phases, we shared control with participants in design decisions, and exchanged our
respective expertise (i.e., researchers on technological capabilities and participants on informal care practices) that could then be articulated through collaboratively designed artefacts [64].

Figure 2. Study I – Our research/design method adapted from the USAP design model [63]. Phase 0 and Phase 4 indicate our additional/adapted stages from the original USAP model.
Phase 0: Design preparation. This preparatory phase aimed to set the stage for active participant engagement by developing tools to guide them in imagining a future with AAL support. We developed an animated video based on the COACH system, which has demonstrated efficacy in guiding a PwD through an ADL (e.g., handwashing) using context-aware prompts and learning from a specific user’s behaviours to improve prompting over time [58]. This video was to serve as a creativity trigger [57] to familiarize participants with the capabilities of AAL and demonstrate how an AAL system might assist a PwD who requires prompts and cues to complete an activity. As shown in Figure 3, the video depicts an older man (PwD) washing his hands in the bathroom with successive audio, picture, and video prompts from COACH, delivered only as needed, if the man experiences difficulty progressing to the next correct step of handwashing. The man’s daughter is shown in the video to be preparing dinner in the kitchen while he is able to wash his hands independently.

Figure 3. Study I – Our developed video demonstrating to participants how COACH, an AAL environment, could guide a PwD (father) in independently completing an ADL (e.g., handwashing) while his ICP (daughter) performs other tasks.

Phase 1: Concept development. This phase aimed to address the first research objective – to explore when and with which activities ICPs envisioned AAL support. The first 90-minute group design workshop, held in the boardroom of the recruitment agency, involved a professional facilitator, the first and last authors, and the recruited participants. Upon collecting consent, we played the animated video and followed with a discussion of participants’ initial
questions and comments. Participants were then given 20 minutes to complete an individual reflection/design activity: they were asked to describe (i.e., through text or sketches) how they envisioned seeking care assistance from COACH. Following this, each participant presented her idea(s) to the group, stimulating others’ comments and generating new ideas. The facilitator summarized and clarified discussion themes aloud before closing the session. After the workshop, the first author reviewed field notes, participants’ design submissions, audio transcripts, and workshop video. Guided by a general inductive approach [65], data were coded and categorized into activities and situations participants suggested for AAL support. Categories relevant to how participants envisioned interacting with an AAL system (i.e., our second research question) were also generated from data analysis, including aspects of AAL support participants wished to control or customize, and information they wished to receive from an AAL system. To prepare for the second workshop (Phase 2), the first author emailed a summary of findings to all participants to promote additional reflections, and generated preliminary caregiver interface artefacts (“Design v1”) with which to trigger participants in Phase 2.

Phase 2: Concept refinement. This phase aimed to steer discussion and co-design from the activities/situations for which ICPs envisioned AAL support (first research objective) toward how participants envisioned specifying and obtaining this support (second research objective). During this group design workshop, we asked participants to review, critique, annotate, and discuss their design recommendations for Design v1, first in two small groups, each of which were audio recorded, followed by a discussion altogether. After the workshop, audio transcripts, session video, field notes, and annotated copies of Design v1 were analyzed, again using a general inductive approach [65]. This analysis generated five scenarios for specifying and obtaining AAL support: 1) setting up and orientating an AAL system for the first time; 2) modifying how the system assists the PwD with a selected activity (i.e., toothbrushing); 3) creating and customizing how the system assists the PwD with a new activity; 4) generating a report on how the PwD is responding to system assistance; and 5) using the system to “check up” on the PwD while the ICP is away from home. Following this workshop, the first author developed the next iteration of caregiver interface artefacts (“Design v2”), which would serve as triggers to participants in Phase 3.

Phase 3: User trials. To continue exploring how ICPs would specify and obtain AAL support in the generated scenarios, the first author constructed a paper prototype of Design v2 and, in
collaboration with the second author, developed an two-hour prototype evaluation session, guided by [66]. The session was then piloted with three domain experts affording early design recommendations, consistent co-facilitation, session timing, and anticipated responses to participants’ interactions with the prototype. During the evaluation session, each of five scenarios was posed as a task for the participant to complete. For each task, the participant read aloud the task instruction sheet (i.e., scenario description, task goals, and pertinent information needed to complete the task) before attempting to complete the task. As she progressed through the task using a pen to select actions or input information on the paper prototype, the first author flipped the prototype to the next “screen” based on her interaction. Throughout each task, the participant performed a think aloud [67] (i.e., ongoing commentary on her actions and thought processes [68]), critiqued the content and sequence of the prototype, and reflected on the appropriateness of the design to her own situation. If the participant was unsure how to proceed in a task, the lead facilitator (second author) explained the expected actions and paused to discuss the participant’s design recommendations, which were then annotated on the prototype. After all tasks were completed, we discussed the participant’s overall reflections on the tasks, scenarios, prototype, and its applicability to her context. We conducted the sessions with the two selected participants in their respective homes. We selected these participants based on their interest and engagement with the research problem and process, as emphasized by [69] for participatory design in this context, and participants’ availability and diversity of care experiences from mild through to late-stage dementia. After both evaluation sessions, the first and second author debriefed and reviewed all field notes together with the paper prototypes annotated with participants’ feedback. Over multiple discussions, and the review of selected video footage (by the first author), the first and second author organized the key findings into contextual influences to specifying AAL support; AAL design ‘tensions’; and new design concepts for Design v3.

Phase 4: Concept interpretation. This final phase involved a literature review, which aimed to facilitate our interpretation of the conceptual findings manifested in our prototypes [30], and explore new design possibilities (“Design v3”) that reflect the current knowledge base. The first author conducted a focused literature review across several databases (i.e., MedLine, EMBASE, PsycInfo, CINAHL, AgeLine, Scopus, Web of Science, Social Work Abstracts and ASSIA), combining the search terms (carer* OR caregiv*), (burden OR strain OR stress), and (elder* OR senior* OR older adult*). After reviewing titles and abstracts for relevance to ICPs of PwD, we
selected qualitative studies that discussed ICPs’ care experiences, routines, and strategies of ICPs. We then synthesized and linked relevant themes to the key findings from Phase 3 (i.e., contextual influences, AAL design tensions, and new design concepts). Concurrent with the literature review, the first author collaborated with undergraduate engineering design students to produce Design v3 artefacts, which aimed to harmonize Phase 3 findings and themes from the synthesized literature.

The original study protocol and all amendments proposed throughout this multi-phase study were approved by the University of Toronto Research Ethics Board (Protocol ID 26622).

2.4 Results

In the following sections, we describe our key findings across successive research phases. To address our first research objective, we first discuss the activities and situations for which participants envisioned AAL support alongside their own care. We then address our second research objective by describing how participants envisioned specifying and obtaining the desired support – by setting up and orientating the AAL system to persons and the home setting; by specifying and personalizing how the system would assist their relatives (PwD) in activities; by scheduling and spontaneously requesting system support; and by retrieving from the system care-related information and using the system to “check up” on PwD if and when left home unattended. Although our co-designed artefacts may refer to “COACH”, we note that this system name was maintained in discussion with participants for consistency throughout the co-design process. From the perspective of the research team, the animated video of COACH was used as trigger to help participants conceptualize the capabilities of AAL support. We contend that our findings are not limited to the capabilities of the actual COACH system, but are also relevant to the broader class of AAL technologies designed to guide PwD through home-based activities. As such, we hereafter use “the system” to refer to these technologies. In addition, as our participants were all family members of PwD, we use “relatives” to refer to the PwD to whom they provide care.
2.4.1 Envisioned activities and situations for which AAL can complement care

Overall, participants shared varying opinions about when and with which activities they would entrust or desire AAL support in the care of their relatives. They were amenable to the idea of AAL enabling their relatives to complete ADLs and other home-based activities independently, while concurrently relieving them of some care duties. Participants envisioned AAL support for several activities (i.e., handwashing, toothbrushing, toileting, grooming, dressing, preparing and dispensing meals, making telephone calls, watching television, and gardening), but maintained mixed opinions about which they would feel comfortable entrusting to technology. Participants also enthusiastically agreed they would find it valuable to be able to create and specify how AAL could assist with “custom” activities that were particularly meaningful to their relatives. For example, Melissa felt it was important to keep her father “as independence as possible” in his valued activities: “Gardening [was my father’s] passion...so, for my mom, [she couldn’t show him what to do, she could only] repeat herself, like ‘the shovel’s over there, don’t you see it?’ So something [to help him with] tool recognition - like ‘this is what a shovel looks like...it’s by the recycling bin’...[using my mom’s] voice recording, or mine, or somebody familiar... to [help my father stay] a little independent.” This finding was reinforced by our review of literature (Phase 4) emphasizing the need to support PwD in continuing meaningful activities [70] and maintaining as much control as possible over their everyday occupations [71]. In doing so, however, participants shared feelings of stress and frustration in having to constantly repeat information, prompts, and cues, and suggested this AAL could potentially alleviate some of this repetition. Situations demanding these reminders included orientating their relatives to day and time, helping them remember and recognize others, reminding them of the scheduled outings, and double-checking their personal belongings before outings. Ultimately, participants believed that AAL could be valuable if an ICP could select the activities and situations to which they would delegate and specify its support.

2.4.2 Specifying and obtaining the desired AAL support

2.4.2.1 Orientating the AAL environment to persons and spaces in the home

As with familiarizing a new formal care worker to persons, care routines, and the home, participants felt a similar orientation would be needed when specifying ‘personalized’ support
from an AAL environment. We co-designed a “setup wizard” through which an ICP could indicate which locations in the home were ‘augmented’ with the necessary hardware (e.g., sensors, cameras) to enable AAL assistance; specify for the system who else shared in the care of their relatives (including other ICPs and formal care workers) and how they could be contacted (Figure 4); specify the preferred prompt types (e.g., verbal, picture, video) and prompting language most suitable for their relatives; and receive an initial tutorial on how to select activities and define situational reminders for AAL support.

**Figure 4.** Study I – Design v2 showing how ICPs might initially set up and orientate the system to the home setting, including the protocol for sending alerts to a specific care partner.

2.4.2.2 Personalizing how the system will assist the PwD with the selected activities

Participants insisted that activity assistance would need to be personalized to the PwD. Over Phase 2 and Phase 3, we gradually interpreted personalization to mean specifying the appropriate prompt type, prompt content, and triggers. Participants envisioned specifying prompt type (e.g., verbal, picture, video) based on their relatives’ intact abilities and their own established prompting and cueing strategies. For example, some participants felt that displaying visual prompts through the mirror was clever and congruent with their own current care practices; others, however, were concerned that this may startle or confuse their relatives. To be effective, prompt content would need to be based on established strategies used by ICPs and be delivered in a supportive, non-patronizing manner: “I see how my husband reacts... if anybody would say ‘great job’, he would be kind of put down... at the early stage, you really have to worry an awful
lot about their pride... and consider their feelings, you can’t take over.” As it seemed the system would need to learn from and adopt ICPs’ established support strategies, we co-designed caregiver interface artefacts reflecting functionality that would enable an ICP to audio-record, take a photo/video, or select a saved media file to define a personalized prompt (Figure 5). In Phase 3, our discussions indicated the need to specify activity steps and triggers as prerequisites to defining the content of a prompt. Triggers referred to their relatives’ specific actions at a particular activity step (e.g., erroneous or inappropriate action, amount of time elapsed since the PwD’s last action, verbal phrase uttered) that would signal to the system that a prompt was needed. The need for such detailed specification raised participants’ concerns about the practicality of AAL, particularly in the context of caring for a relative whose fluctuating and declining abilities may demand frequent system modification. They also described prompting and cueing strategies to be highly idiosyncratic, intuitive, and tacit; explicating and “programming” this information into the system was perceived as onerous. Despite these concerns, however, we observed participants to be enthusiastic about the potential of AAL support. In particular, upon completion of Phase 3 in their respective homes, both participants engagingly recommended more naturalistic interaction methods or heuristics by which they could quickly specify AAL support for their relatives.
Figure 5. Study I – Design v2 showing how an ICP may specify an activity’s steps and create (e.g., audio- or video-record) personalized prompts that they believe would assist the PwD in completing the activity (e.g., making tea).

In Phase 4, we explored a future design concept (Design v3) that aimed to respond to this design recommendation, build on literature in support of technology-mediated peer support between ICPs (e.g., [72]-[77]), and draw inspiration from emerging social media applications (e.g., Pinterest™). The concept proposed a social network that would allow ICP ‘subscribers’ to create, specify, and share with one another (i.e., via upload and download) AAL activity support solutions using a common AAL platform. On the simplest level, sharing may enable the exchange of supportive narratives to inspire new care strategies for other ICPs. On a more sophisticated level, sharing could allow subscribers to create and upload ‘activity templates’ containing an activity’s steps, prompts, and triggers, which other subscribers could then view, download, and personalize for their own use.

2.4.2.3 Scheduling and spontaneously seeking AAL support

Through co-design with participants, we also explored how ICPs could specify the appropriate timing of AAL support. In Phase 2, participants initially expressed a desire to pre-schedule AAL support as far in advance as possible. While completing Phase 3, however, they reflected on the practical limitations of pre-scheduling all system support: “How do you program the unpredictable? How do you program something that’s not routine? How do you program into the technology the specific personality of [the PwD]?” Consistent with our review of literature in Phase 4, improvisation was discussed as both a care strategy [8] and a natural characteristic of
home life [78], which would demand sufficient flexibility for ICPs to spontaneously request, put on hold, or cancel its support as needed. Moreover, our discussion also exposed the multidimensionality of supporting home-based activities for their relatives. On a time dimension, some activities must occur at specific times (e.g., scheduled transportation pick-ups), while other activities must only be appropriately ordered (e.g., medications to be taken immediately after a meal); there are activities that are important but can occur at any time and frequency (e.g., drinking water). On a necessity dimension, there are activities that are necessary but cannot be scheduled (e.g., toileting) and others that are entirely optional (e.g., watching television). On a support dimension, certain activities might only be initiated based on their relatives’ moods or abilities, an ICP’s availability or stress level, or certain logistic factors. The latter led to participants’ enthusiasm for AAL support in mentally or socially stimulating their relatives.

In Phase 4, we translated these findings into a new design concept, reflected in Figure 6: an alternative calendar design that accommodates scheduled, ordered, and suggested (i.e., optional leisure) activities. To support improvisation, we added functionality that would allow an ICP to spontaneously cancel, pause (i.e., delay), or initiate AAL support to their relatives with leisure activities.
Figure 6. Study I – Design v3 screenshot illustrates a working mock-up of an alternative calendar design that organizes scheduled, ordered, and suggested (leisure) activities, in order of decreasing priority. The red and green coloured items indicate support by an ICP and the system, respectively. The check marks indicate if the activity has been completed, where the red check mark indicates that an ICP was called to help the PwD complete the activity after the system’s prompting was not successful. The top-right circular icon in the scheduled “Meeting with Friends” item indicates that the ICP has paused (delayed) this activity. If the scheduled item is not reinitiated after 12:15PM, the system may help initiate “Call Jane” if the PwD is in the living room.

2.4.3 Retrieving relevant care information and “checking up” while away

Participants also perceived receiving care-related information from the system as another means of seeking AAL support in the care of their relatives. They agreed that being alleviated from care duties, even briefly, could be immensely valuable to them. They also shared a common desire for reassurance if and when their relatives were home alone, though mixed opinions were
discussed on which activities they would entrust to the system in their absence. Unpacking these needs and preferences over study phases led to the co-design of multiple options for conveying the desired information from the system to ICPs: “check up” functionality, status updates, alerts, and reports.

While away from their relatives, participants expressed the need to “check up” if they were to entrust the system to look after their relatives in their absence. In Phase 2, we initially co-designed passive video monitoring with optional two-way video communication through the AAL system. This would allow an ICP to review video, at a later time, if activities were completed in their absence (Figure 7a), or check up in real time and communicate if needed. In Phase 4, however, we strived toward a more ‘mediating’ design that could both reassure an ICP of a relative’s safety while reducing “surveillance” that may only exacerbate a PwD’s feeling of restricted freedom [79]. Here, we considered enabling video monitoring and communication only in situations of safety risks (e.g., wandering) (Figure 7b) or replacing live video with less invasive sensor data (e.g., motion, light, temperature), as Vines et al. [80] explored in a recent telecare system field trial.
**Figure 7.** Study I – Illustrates how an ICP might be able to use the system to a) view recorded video to check up to determine if a PwD had completed an activity (e.g., eaten lunch) (Design v2), or b) initiate a video call in response to an alert a potentially unsafe action is detected (e.g., leaving the house without communicating with the ICP) (Design v3).

Our co-design of *status updates* also aimed to address how AAL could potentially mediate the safety vs. freedom conundrum. Initially, we designed passive real-time *status updates* that were displayed on the home screen of the caregiver interface and presented in text format (e.g., “COACH is currently helping Dad brush his teeth.”). In Phase 4 (Design v3), we built on this design by adding more status details (e.g., current activity step, percentage of activity complete), speculating that this additional information may adequately reassure ICPs of their relatives’ safety without the need for surveillance.

*Alerts* were another co-designed function that participants felt could afford them more peace of mind to leave their relatives at home unattended. Unsurprisingly, they wished to be immediately alerted of any potentially dangerous situations (e.g., leaving the stove on). During AAL activity assistance, if the system detected no action from a PwD over a specific time period, participants desired to be alerted for further assistance. Notably, alerts were perceived as a means of enabling a PwD to attempt activities independently while relieving ICPs of worry and constant assistance. In Phase 4, we compiled all co-designed alerting options that an ICP could specify in
advance (Figure 8a) and explored the notion of “smart alerts”, where the system could recommend information to an ICP based on geographic location and learned patterns of information retrieval (Figure 8b).

**Figure 8.** Study I – a) Design v3 screenshot illustrating different alerting options (i.e., SMS, email, “myCOACH” mobile application) that ICPs can specify for a particular activity, and b) sample SMS alert.

Lastly, participants were enthusiastic to receive from the system “on-demand” activity reports that could describe functional patterns or indicate decline. We used Design v2, shown in Figure 9, to probe participants in Phase 3 for more desired reporting parameters. Doing so clarified additional parameters: activity completion (partial or full), number of prompts (total and by type), time to activity completion, identification of problematic steps, identification of incorrect actions, and summary of alerts they received (e.g., for additional support when COACH could not longer assist). Participants anticipated that this information could signal the need for health care consultation and facilitate communication with health care providers: “I’m not saying [there should be] printout on a regular basis, [just] as required...because sometimes my mother has a bad evening [and the] next day she’s fine...but then if that runs several days in a row, you’ve got to know when it’s time to talk to the doctor.”
Figure 9. Study I – Design v2 illustrating how ICPs might a) query and b) retrieve reports that summarize how a PwD is managing in a particular activity with support from the system.

2.6 Discussion

Our findings demonstrate the need for AAL design to consider how technologies can be situated to complement the care of ICPs, and emphasize the important role we expect ICPs will play in AAL customization, adoption, and ongoing use. Toward our first research objective, we learned that ICPs envisioned being able to choose which activities and situations they wished to entrust to system, and indicate when they would desire this support (i.e., via care schedules or
spontaneous requests). Such choices would vary based on dynamic interrelationships between home routines; their relatives’ abilities, moods, and preferences; and their own availability, priorities, and emotional states. Exploring our second research objective, we gained insight into how ICPs envisioned specifying and obtaining AAL support. This specification may involve first-time system set up, activity selection, and detailed activity and prompt specification – processes in which ICPs would be called to translate their care expertise into system instructions. “Personalized” assistance was considered necessary for both effective support (i.e., correct activity completion) and preserving their relatives’ abilities and dignity. ICPs may also desire relevant information from the system related to care. This information could be in the form of real-time monitoring and bimodal communication with their relatives, less invasive status updates on current support, alerts based on pre-defined triggers, and activity reports based on ICPs’ specified parameters. Overall, our co-design method afforded us depth in envisioning the needs, preferences, and imagined interactions from the perspectives of ICPs. We now synthesize our findings and reflect on its strengths, limitations, and implications for future work.

Our findings reinforce that AAL technologies should be designed to be flexible, customizable, and potentially with “do-it-yourself” (DIY) capabilities to complement care routines, relationships, and experiences. From an ICP’s perspective, seeking AAL support means sharing and/or turning over an aspect(s) of care, from a menial task to more complex activity assistance. Whether an ICP enlists the system to provide direct assistance (e.g., activity prompting), retrieve care-related information, coordinate care between AAL and multiple care partners, the decision and process by which ICPs entrust care to another party cannot be taken for granted. For instance, while an ICP may find caring stressful or burdensome, he or she may also ascribe significant meaning to their care roles; they may derive a sense of pride or view caring as a natural continuation of bonds with PwD [43], [45], [81]-[83]. Such mixed feelings may lend themselves to fluctuating preferences for AAL support, depending on moods, stress levels, and current circumstances. Entrusting care to a technology may also require some means of orientating and instructing the system to provide support based on an ICP’s established strategies. The need to explicate such detailed specifications is challenged by the often tacit, improvised nature of care routines and support strategies (e.g., prompting), which previous work confirms [8], [84]. We therefore continue to advocate (i.e., in [85], [86]) that AAL technologies be designed with “do-it-yourself” (DIY) capabilities, to the greatest extent possible, allowing
users to iteratively build and modify custom AAL solutions. First, in early-stage support, DIY capabilities may enable collaborative solution-building between ICPs and PwD, affording both users a sense of control, which related work stresses is a central concern for smart home users [78]. Secondly, it may allow users (i.e., again, where possible, both stakeholders) to flexibly trial, modify, and scale up solutions over time, as care needs, experience, and technological proficiency evolve. As developing DIY solutions may challenge users to develop technological proficiency, doing so could promote positive feelings of mastery and self-efficacy [46], as well as reflective learning and technology adoption at one’s own pace, two central principles of the “Slow Design” philosophy that aims to achieve more meaningful and sustained technology use [87], [88].

We can also extend the concept of DIY to how ICPs specify and obtain system support, problematizing this in relation to AAL technologies. Unlike most AAL approaches that “overemphasize the importance of smart devices” [48], our findings reveal that ICPs wish to maintain control in specifying, personalizing, and customizing support (e.g., activity steps, prompts, triggers, alert preferences). Although co-design afforded us insight into their learned and largely tacit support strategies, we speculate that this assumption led to participants’ concerns about the time and effort such detailed specification would demand. Ongoing work [85], [86] aims to address this by exploring more naturalistic ways in which ICPs can express and specify this information in order to iteratively build DIY AAL solutions. Moreover, to exploit the value of AAL technologies, it is also crucial to determine the appropriate degree of human interaction and control vis-à-vis the autonomy of an intelligent system – a discussion that Sun et al. [48] encourage AAL researchers to consider. Here, we may apply the Scale of Degrees of Automation [89] that places system automation and human interaction on a continuum. Applied to our context, AAL support might range from the system providing no assistance (i.e., the ICP assists the PwD with no AAL support); to offering suggestions to the ICP (i.e., AAL support with ICP’s permission); to providing fully autonomous assistance, where the AAL system assists without any input or confirmation from the ICP. For instance, giving an ICP the option to accept or reject AAL support in the moment may mitigate the stress of post-hoc alerts from an autonomous system that are difficult to spontaneously act upon. Future work is needed to investigate the desired balance between interaction and automation in AAL applications.
Arguably the biggest insight from this study suggests an opportunity for AAL, not only to assist a PwD while alleviating an ICP(s), but also to support both stakeholders as they transition to greater dependency. Our study provided insight into the situated context in which dependency on an ICP(s) involves learning, adapting, and negotiating with PwD. Although our study confirmed ICPs’ concerns for safety and respite [79], our participants continually advocated for the needs, values, personalities, and dignity of their relatives. Most relevant to our context, and supported by studies with PwD, was the enthusiastic emphasis on enabling their relatives to continue meaningful activities, even if adaptive strategies and dependency were needed [70], [71]. These findings suggest ICPs may be seeking solutions that satisfy both the needs of PwD, for whom they advocate, and their own needs. We believe AAL solutions are positioned to play this mediating role, where ICPs and PwD can negotiate support from early stages of dependency, through a shared process of exploring and fashioning technology-enabled support strategies. In this way, this study afforded us a new conceptualization of this research/design problem, where AAL design should be based on an understanding of the contextual and temporal particularities of the “caregiving dyad” [46], and consider the “user” as the PwD together with his or her ICP(s) as an interconnected, interactional unit undergoing constant negotiation and transition.

Our described substantive findings were afforded by a fluid co-design process for which we acknowledge study limitations, strengths, and future research directions. First, our study recruited a small sample, female-only sample from a single community-based support agency, thus, biasing the described findings to ICPs who have accessed some degree of formal care support (e.g., psychosocial, educational, respite care) and who likely share similar cultural, socioeconomic, and environmental characteristics. Secondly, we acknowledge that participants’ feedback may have been influenced or constrained by our creativity triggers, including our animated video of the COACH system, caregiver interface artefacts, and constructed scenarios/tasks. We, however, advocate for our co-design method, as it facilitated focused, productive participant involvement; richly contextualized information about current care strategies and envisioned AAL support; and enthusiastic attitudes toward AAL, as compared to previous attitudinal findings by colleagues [54]. In particular, our meticulous pilot sessions in Phase 3 allowed us to rehearse co-facilitation that would promote participants’ envisioning beyond the actual capabilities of COACH or any other specific AAL system. Lastly, we recognize that this study reflects only the perspectives of these ICPs and their accounts of the
needs and values of PwD in the discussed context of AAL. As emphasized, future work should involve PwD-ICP dyads to investigate how AAL can potentially support different needs and positive relationships as dependency is negotiated over time. Our next study, for example, will involve care dyads to co-design “technology probes” [60] that can then be deployed and longitudinally studied in real-world home settings. We expect this subsequent investigation to produce a ‘toolkit’ of design guidelines, techniques, and methods that can holistically interpret social contexts of care, creatively explore AAL design opportunities [90], and guide empathic co-design collaboration between researchers, designers, and the beneficiary end stakeholders.

2.7 Conclusion

With a better understanding of the role of AAL in everyday dementia management, we advocate that technologies should be designed to complement and collaborate with the care of ICPs to PwD. As the care experience involves a nuanced and evolving relationship between two (or more) people, designing AAL with DIY capabilities may enable ICPs to organically craft context-appropriate solutions to support and balance the needs of PwD with their own needs. As we attempted to reflect in this paper, delivering such capabilities relies on a situated understanding of care contexts and, most centrally, the value-driven needs of the intended technology users. To this end, we plan and encourage others toward future work that investigates PwD together with their ICPs as an interactional user “dyad”, and employs longitudinal designs with participatory, design-oriented methods to promote envisioning of experiences in a technological future.
Chapter 3
Sustaining care for a parent with dementia: an indefinite and intertwined process

This chapter was published in the *International Journal of Qualitative Studies on Health and Well-being* (20 October 2017). This article reports on *Study II* of this thesis project.

**Article citation:**

3.1 Abstract
This study aimed to understand how adult children sustain caring for persons with dementia (PwD) within their family and formal care contexts in Canada. Half-day focus groups were conducted with adult daughters and adult sons in Toronto, Canada. Using constructivist grounded theory, we examined both substantive concepts and group dynamics. Sustaining care was interpreted as an indefinite process with three intertwined themes: *reproducing care demands and dependency*, *enacting and affirming values*, and *‘flying blind’ in how and how long to sustain caring* (i.e., responding to immediate needs with limited foresight). Family values and relationships, mistrust toward the institutional and home care systems, and obscured care foresight influenced care decisions and challenged participants in balancing their parents’ needs with their own. Positive and negative aspects of care were found to influence one another. The implications of these findings for research and policy are discussed.

3.2 Introduction
As our population ages, the problem of how and by whom older adults will be supported is both pressing and complex. Conceptually, aging in place has garnered increasing attention in efforts to align the priorities of older adults, families, care providers, and policymakers [91]. However,
reports that unpaid family members and friends provide 70% to 80% of community-based care in Canada [92], and save the public systems $25 billion in Canada [93] and $470 billion in the United States [94], question how equitably the responsibility of care is currently distributed between the public system and its citizens.

Problematically, the caregiving literature has been dominated by prevailing narratives of caregiver stress, burden, and health hazards [20]. Important social and structural forces known to influence care experiences [15], [95] have been marginalized, along with evidence of the positive aspects of care (e.g., accomplishment, enhanced relationships) [19], despite a recent majority (83%) of family care partners who view care as a positive experience [96]. A more balanced view of caring is therefore needed to provide targeted support to those family care partners who are most vulnerable to stress and strain, and to enhance the positive aspects of care that encourage and support family care partners as valued partners in care [20]. To this end, a richer contextualized understanding of how care of persons with dementia (PwD) is currently sustained is needed.

3.2.1 Sustaining care for persons with dementia at home

For persons living with dementia and cognitive impairment, who comprise the majority of residents in long-term residential care settings [1], sustaining care in the home is particularly complex and challenging, and increasingly depends on formal care services. In Ontario, Canada’s most populated province, care is primarily managed by informal care partners (e.g., family members, friends), who may or may not access subsidized home care services (i.e., personal support and homemaking, nursing, therapy, and social work) by a local Community Care Access Centre [2]. Individuals and families may also hire private care through a community agency or independently. Ontario’s Local Health Integration Networks provides additional programs, including adult day programs, transportation, and meal delivery services [2].

Previous work that examined home care services highlighted fundamental incongruences between the formal care services and actual needs. A critical ethnographic study found that dementia home care services in Canada assumed inexhaustible familial care and diminished as care needs increased over time [22]. Service inaccessibility also derives from a mismatch between formal and informal care priorities. Formal care is provided based on objectivity and
efficiency [97], where lineal time allocations (e.g., two hours of personal care service) are incongruent with “unshiftable” care tasks, such as personal care [98]. Such a structure of formal care services tends to neglect important priorities held by informal care partners, such as the quality of their interactions and relationships with service providers [23]. Moreover, current representations of caregiving have typically assumed a single primary care partner, which is challenged by work that has illustrated complex informal care networks [17] and changes to these networks over time [99]. Thus, it remains unclear how care is sustained within the context of informal-formal care interactions and relationships.

3.2.2 Adult children as care partners

Examining how adult children sustain caring is timely based on population demographics and sociocultural trends. Adult children and adult children-in-law together represent the largest group (48%) of informal care partners in Canada [100] and (49%) in the United States [94]. They are known to experience care differently than spouses, typically balancing numerous roles – such as adult child, parent, and employee [101]; use more informal supports [102]; and tend more toward managing care (e.g., arranging services) than providing hands-on assistance [103]. With the majority of females employed in the labour market, caregiving is increasingly viewed as “work” beyond normative family expectations, which has created greater demands for public services [24]. As the extent of filial obligation remains an open philosophical and policy question [25], care responsibilities tend to be unequal among adult child siblings [104] with inconclusive explanations of how various factors (e.g., employment, geographic proximity, family relationships [105]) influence certain adult children to sustain care responsibilities over others.

3.3 Aim

In an effort to better understand and support adult children in their care experiences, this study aimed to understand the processes through which they sustain caring for persons with dementia (PwD), and how these processes are shaped by their family and formal care interactions.

3.4 Methodological approach and method

This study adopted a constructivist grounded theory (CGT) approach [110] in two, half-day focus groups. The approach is rooted in pragmatism and relativist epistemology and assumes
that data are co-constructed by researchers and participants. We employed this methodology in order to explore the depth and complexity of a phenomenon through group interactions [106].

As related work has commonly used individual interviews with family care partners, focus groups were employed to explore and clarify views and experiences of caring as an adult child; encourage explanations of how and why these views are held; and facilitate critical discussion about structural factors [107] that influence care experiences. The two focus groups were gender-segregated (i.e., one with adult daughters and one with adult sons) based on literature that highlights gender-based differences in how adult children experience caring (e.g., males tend to approach care as tasks to be completed, while females take a more emotional approach) [83].

3.4.1 Setting and participants

With open sampling followed by purposive sampling, we recruited a sample to explore a range of experiences [107], [108]. Initially, we recruited through public advertisements (print, radio, website), word-of-mouth, and a participant database at University of Toronto that included family care partners who had expressed interests in participating in rehabilitation research. Participants were recruited based on the criteria that they lived in the Greater Toronto Area, provided unpaid care for at least six months to a community-dwelling parent (or in-law) with dementia (self-reported), and identified themselves as primarily responsible for their parents’ care and care arrangements. The first author telephoned each prospective participant and collected descriptive data on age, marital status, employment status, parent’s diagnosis, duration of care, and living and care situations (e.g., co-residing, informal and/or formal care arrangements, nature of care work). These data identified important similarities and differences between participants (Table 2), which both guided the recruitment of a varied sample and sensitized us to the variations to expect between participants in focus group discussion. Referred by two recruited participants, we also managed to recruit two full-time, homebound adult children that we believed could add important perspectives. As expected for a hard-to-reach group [109], focus group coordination with the recruited participants proved to be challenging. Scheduling constraints arose between participants who had competing responsibilities (e.g., spousal care, child care), and those who were unemployed and providing homebound care had limited respite care resources that would be required for them to participate. For this reason, we decided to design each focus group as one half-day session and amended our study protocol to
compensate all participants for six hours of respite care, which was accepted by all but one participant who participated without claiming this compensation.

Descriptive data were collected at the time consent was obtained (Table 2). All participants were assigned pseudonyms, which will be used to refer to each participant. As listed in Table 2, all four sons reported that their mothers (-in-law) had been diagnosed with dementia. Two daughters reported that their parents had been diagnosed with dementia, while the other three had assumed dementia. Our participants also reported wide variations in their parents' functional limitations, which are also summarized in Table 2 (see three columns, entitled "Parent's activities"). In the daughters' group, functional limitations ranged from functional independence in basic activities of daily living (Hilary's mother) to full assistance with every basic activity (Denise's mother). The functional range was similarly varied in the sons' group from David's mother-in-law, who still lived independently without any formal caregiver support, to Timothy's mother, who had recently been institutionalized due to her full-time care needs.
Table 2. Study II – Description of participants. For activities, HW = handwashing, DH = dental hygiene, BT = bathing, TL = toileting, DR = dressing, MP = meal preparation, FD = feeding, MD = medications, CM = verbal communication, FN = personal finances, SH = shopping, SC = socializing, HC = household cleaning, TP = transportation, EX = exercise accompaniment (e.g., walks).

<table>
<thead>
<tr>
<th>Participant (pseudonym)</th>
<th>Age</th>
<th>Occupation</th>
<th>Parent receiving care &amp; diagnosis?</th>
<th>Length of care at study</th>
<th>Living arrangement in relation to parent</th>
<th>Parent’s activities – without assistance</th>
<th>Parent’s activities – assisted by participant</th>
<th>Parent’s activities – assisted by formal caregiver</th>
<th>Formal care arrangement (PSW = personal support worker)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eric</td>
<td>67</td>
<td>Retired; photographer &amp; politician (part-time)</td>
<td>Mother, diagnosed dementia</td>
<td>7 years</td>
<td>Separate; mother lives in own house</td>
<td>TL, HW, DR, MD, CM (needs prompting)</td>
<td>TP, SH, FN</td>
<td>BT, MP, MD</td>
<td>24/7 private care: 2 live-in caregivers + 1 day shift</td>
</tr>
<tr>
<td>Timothy</td>
<td>57</td>
<td>Puppeteer (part-time, self-employed)</td>
<td>Mother, diagnosed mixed dementias</td>
<td>10 years</td>
<td>Partial co-residence in adjacent units; mother institutionalized 2 months prior</td>
<td>HW (sanitizing wipes)</td>
<td>TL, DR, MD, CM (translation)</td>
<td>BT, TL, TB, DR, MP, MD</td>
<td>Subsidized PSWs, 2 hours per day</td>
</tr>
<tr>
<td>David</td>
<td>70</td>
<td>Retired health services consultant</td>
<td>Mother-in-law, diagnosed dementia (Note: Wife did not participate in study)</td>
<td>10 years</td>
<td>Separate; mother in her own condominium</td>
<td>TL, DR, MP (simple), MD (with prompts), CM</td>
<td>DR, MP, MD, CL, TP, SH, SC, FN; BT (wife only)</td>
<td>No formal caregiver</td>
<td>No formal care arrangements</td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>Status</td>
<td>Mother’s Condition</td>
<td>Length</td>
<td>Care Details</td>
<td>HCP</td>
<td>BT</td>
<td>PSW Details</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Patrick</td>
<td>55</td>
<td>Semi-retired; part-time paper route &amp; volunteering</td>
<td>Mother, diagnosed dementia</td>
<td>4 years</td>
<td>Co-residing in Patrick’s house (diapers), HW, DH, DR, CM</td>
<td>DH, MP, MD, CM, SC, EX, PF, HC</td>
<td>BT</td>
<td>Subsidized PSW 2 days a week, 1 hour per day</td>
<td></td>
</tr>
<tr>
<td>Florence</td>
<td>47</td>
<td>Senior manager, consulting firm</td>
<td>Father, diagnosed dementia</td>
<td>3 years</td>
<td>Separate; parents in own house</td>
<td>None</td>
<td>HW, DH, DR, MP, MD, CM, FN, SH</td>
<td>HW, DH, DR, MD, BT, TL</td>
<td>24/7 PSW coverage; subsidized &amp; private</td>
</tr>
<tr>
<td>Carla</td>
<td>58</td>
<td>Retired (early)</td>
<td>Mother, assumed dementia</td>
<td>7 years</td>
<td>Co-residing in Carla’s &amp; husband’s house</td>
<td>None</td>
<td>BT, TL, HW, DH, DR, MP, MD, CM, FN, SC</td>
<td>Same as Carla</td>
<td>Subsidized PSW 1 day per week, day program</td>
</tr>
<tr>
<td>Denise</td>
<td>56</td>
<td>Retired (early)</td>
<td>Mother, diagnosed dementia</td>
<td>12 years (with late father)</td>
<td>Co-residing in Denise’s house with Denise’s son &amp; daughter</td>
<td>None</td>
<td>BT, TL, HW, DH, DR, MP, FD, MD</td>
<td>“96%” co-assistance with Denise</td>
<td>3 subsidized PSWs per day, 7 days per week</td>
</tr>
<tr>
<td>Thema</td>
<td>50</td>
<td>Unemployed, on social assistance</td>
<td>Mother, assumed dementia</td>
<td>4 years</td>
<td>Co-residing in Thema’s apartment with Thema’s daughter</td>
<td>HW, DH, TL</td>
<td>DR, MP, MD, CM (translation), EX</td>
<td>BT, DR, MP, MD, EX</td>
<td>4 subsidized PSWs, 12 hours/4 days per week; day program</td>
</tr>
<tr>
<td>Hilary</td>
<td>69</td>
<td>Retired (motor vehicle accident)</td>
<td>Mother, assumed dementia</td>
<td>11 years</td>
<td>Separate; mother in her own apartment (needs prompting)</td>
<td>TL, HW, DR, MD, CM</td>
<td>TB, DR, MP, MD, SH, FN</td>
<td>BT, TB, MP, MD, CL</td>
<td>3 subsidized PSWs, 20 hours per week; private housekeeper, bi-weekly</td>
</tr>
</tbody>
</table>
3.4.2 Data collection

Both focus group sessions extended over an afternoon (i.e., approximately four hours), including lunch and refreshment breaks [107]. This duration afforded a comfortable pace for participants to establish rapport and discuss a set of open-ended themes (Table 3) and facilitation probes (Appendix E and Appendix F). Participants were encouraged to discuss with each other and explore issues they felt most important to them [107]. The daughters’ group was co-facilitated by a hired facilitator and the first author (i.e., who was new to focus group methodology). The sons’ group was facilitated by the first author after debriefing with the hired facilitator and discussing respective field notes, reviewing the audio from the daughters’ group, and generating early analytic memos. A research assistant took observational field notes during the sons’ group and similarly debriefed with the first author immediately after the session, which generated additional analytic memos, including comparisons and contrasts between discussed content and the social dynamics observed between the two groups. In both groups, these research team members were discussion facilitators, where they explored with participants their perspectives and experiences (as per the focus group guide and their own observations noted in their own researchers’ field notes). Our dataset includes descriptive data (Table 2), focus group audio recordings and transcripts, researchers’ observational field notes, and any typed or handwritten notes voluntarily submitted by participants before or after the focus group sessions.

Table 3. Study II – Focus group discussion themes

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Tell us about how it is you came to care for your parent.</td>
</tr>
<tr>
<td>2.</td>
<td>What does being a ‘caregiver’ mean to you?</td>
</tr>
<tr>
<td>3.</td>
<td>What do you want the world to know about what it is to care for your parent?</td>
</tr>
<tr>
<td>4.</td>
<td>What is it like being a [daughter or son] who is a caregiver?</td>
</tr>
</tbody>
</table>
3.4.3 Ethical considerations

The study was conducted with the approval of the Health Sciences Research Ethics Board at University of Toronto (Protocol #29463). All participants provided written consent after obtaining verbal and written information regarding the study, data privacy and security protocols, and how and to which audiences the study results would be disseminated. Participants were offered compensation for transportation and respite care expenses.

3.4.4 Data analysis

Taking a social constructivist perspective, data analysis focused on examining the processes through which our participants sustained caring, and their social and structural conditions. We viewed ‘processes’ in Charmaz’s terms – as “unfolding temporal sequences that may have identifiable markers with clear beginnings and endings and benchmarks in between…and lead to change.” [110]. Moreover, the researchers brought their own theoretical perspectives to their interpretation of the data – in particular, the perspective that care and caring is highly complex and should not be reduced to the narrow parameters of stress and burden. Preliminary analysis of the daughters’ group guided but did not restrict topics to further explore with the sons’ group. These included: ambivalent feelings toward caring; differences in care values and care approaches; the influence of sibling relationships on care arrangements, and vice versa; participants’ attitudes toward and behaviours resulting from their formal care experiences; and shifts in the meaning of caring over protracted care journeys. After each focus group, the first author generated early memos based on the notes that participants voluntarily wrote and submitted; researchers’ field notes; and debriefing discussions (i.e., with the hired facilitator from daughters’ group and the research assistant from sons’ group). The first author then listened to and transcribed both audio recordings, generating analytic memos throughout. Using NVivo 10 software, the first author conducted initial line-by-line coding of the daughters focus group transcript, then grouped the codes into broad topic-oriented categories (e.g., interacting with formal care providers, navigating family dynamics, implementing care strategies). Throughout coding and categorizing, the first author continuously compared data in a back-and-forth fashion, between participants and between group discussion at different points in the session, to look for substantive similarities and differences [110]. After the first author coded, three authors (AH, LR, and LN) met multiple times to discuss substantive categories, where the data from salient codes and categories were shared and scrutinized. When these co-authors had
different interpretations of the data, which were occasionally based on authors’ respective prior perspectives [110], the first author routinely re-checked and compared the data (i.e., transcript and, as needed, audio) again. Subsequently, the three co-authors then reconvened to reach consensus about which interpretation(s) was best substantiated by the data. Group interactions were also analysed in order to examine how participants co-constructed their views within these “social spaces” [111], and highlighted knowledge claims on which “common ground” was established (e.g., avoiding institutionalization) or contested (e.g., strategies for negotiating care with siblings). For group-level analysis, the first author re-coded the transcript based on an analytic template for group interactions [111] and then, through the same collaborative process with the second and last authors, prioritized the codes that were salient across substantive and group-level analysis. These analysis processes were repeated for the sons focus group transcript, and earlier codes and categories were treated as tentative topics [110] while remaining open to generating new codes. Later analytic meetings between the three authors (AH, LR, and LN) refined topic-oriented categories by comparing and contrasting newer categories with those created earlier in the analysis process. Charting and diagramming facilitated the mapping of processes [110] across participants’ varied care durations, family contexts, and formal care access experiences. During this iterative team process, different interpretations between the three co-authors were scrutinized [110], which led to their agreement on important similarities shared between gender-segregated groups (e.g., possessing an intrinsic “need to care”, sibling and formal care tensions, protracted care journeys), which were more salient in the data than the noted gender differences (e.g., the daughters’ group described caring more in terms of scheduling and ‘case management’, while the sons’ group discussed more personal relational aspects of caring). These three authors also agreed that the quantity and quality (i.e., rich rigour [112]) of focus group data were adequate [106]. To achieve credibility [112], working interpretations were presented for critical scholarly discussion at research seminars with dementia and caregiving experts at Karolinska Institutet (Sweden), University of Toronto (Canada), which included other co-authors, and an international dementia conference. All other co-authors contributed to two final iterations of data analysis, which generated the final three analytic themes (see Table 4), their embedded subthemes, and the relationships between themes.
3.5 Findings

Findings from two focus groups with nine participants (described in Table 2) are summarized by the themes and subthemes in Table 4. The three themes are interrelated and together construct the core theme, which interprets sustaining care as an indefinite and intertwined process.

Table 4. Study II – Summary of analytic themes and sub-themes

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reproducing care demands and dependency</td>
<td>Resigning to care responsibilities and family conflict</td>
</tr>
<tr>
<td>Enacting and affirming values</td>
<td>Preserving one’s parent and family relationships</td>
</tr>
<tr>
<td>“Flying blind” in how and how long to sustain caring</td>
<td>Bootstrapping care through one’s own resources</td>
</tr>
<tr>
<td></td>
<td>Focusing on present needs – obscuring consequences</td>
</tr>
</tbody>
</table>

3.5.1 Sustaining care as an indefinite and intertwined process (core theme)

Sustaining care within participants’ family and formal care contexts was understood as an indefinite process characterized by three intertwined themes (summarized in Table 4). Reproducing care demands and dependency captures how participants’ own care negotiations and conflicts when relating to parents and siblings, together with their fostered mistrust in the formal care system, created a dynamic wherein the care demands and dependency placed on them was further sustained. Shouldering these demands, however, led to positive outcomes, which participants invoked to justify and reinforce their care commitments through enacting and affirming values. Guided by these values, as care demands precipitated over uncertain trajectories, participants relied on their intuition and own resources to meet immediate care needs.
that is, ‘flying blind’ as the magnitude of their responsibilities and opportunity costs (i.e., personal, social, and financial opportunities) accumulated over protracted care journeys.

In the forthcoming quotes, the square brackets house terms that are inserted into or altered from the direct quotation to clarify the speaker’s meaning (e.g., “[my mother]” may be inserted to clarify who the participant is referring to when using “her”). When a participant’s pseudonym is indicated in the square brackets (e.g., “[Carla: … ]”, this indicates an interjection by another participant(s) during the speaking participant’s quote.

3.5.2 Reproducing care demands and dependency

For our participants, sustaining care within their family and formal contexts tended to reproduce care demands and care dependency. First, negotiating care arrangements with parents (PwD) and siblings tended to stir relationship conflicts between family members, which resigned our participants to disproportionate care dependency and social isolation in caring. Secondly, mistrust in both institutional and home care services led participants to limit their service utilization and continue shouldering complex care demands.

3.5.2.1 Resigning to care responsibilities and family conflict

Both groups discussed the demands of negotiating care arrangements with their parents (PwD) that they deemed in their parents’ and their own best interests. David and his wife, for instance, had been struggling to convince his mother-in-law to accept a hired caregiver. They hoped this would alleviate some of his wife’s hands-on care tasks, since it was felt to compromise their enjoyable mother-daughter time together. This discussion led the sons’ group to establish common ground on the ‘aging-in-place’ argument that they would invoke when negotiating new care arrangements with their parents. As reasoning and recall capacities varied between participants’ parents, some participants across groups would persist in their attempts to reason with their parents when discussing practical care arrangements, and obtain their parents’ consent to implement arrangements. Other participants, however, asserted the need to circumvent or override their parents’ resistance to such arrangements. Florence aptly describes this tension:

So...we've, we do it I think, it is, it is hard – sometimes it breaks my heart 'cause my mother wants to sleep in, but we have someone showing up at seven o'clock to get her washed, but if she doesn't wash at that time...she won't go out because her hair wasn't washed.... So it's...it's for our sanity as
swell, and … where my mom is at any given time, and um, and then it gives us the flexibility to spend time with my father. …. and I'm always the first point of contact…[so] when somebody isn’t cooperating … I would have to calm the situation down with the caregiver and, or try to get [the parent] on the phone so that I could talk them through it … and if I can't, I would have to jump in my car … and get over there. (Florence)

For some participants, care dependency expanded to social dependency. Denise’s and Patrick’s full-time homebound arrangements meant including their mothers in their limited social visits or outings with friends. As care demands increased, Carla and David also attested to including their mothers (-in-law) in all family holiday gatherings and vacations, which transformed the nature of their social and leisure time because of their continued care efforts. This was juxtaposed with their siblings, whom they reported to maintain clearer nuclear family boundaries, for which several participants shared a feeling of resentment.

Caring with and without sibling support reproduced demands, despite participants’ differing expectations of care involvement from their siblings. Some daughters, for instance, described how they did not expect care involvement from their brothers; their traditional gender and ethnocultural values prescribed caring as a female responsibility. Other participants described battling with siblings over care matters, which strained or estranged their sibling relationships, and ultimately relegated participants to shoulder care responsibilities with reduced social support. In some cases, participants resigned from “fighting” with their siblings and accepted their siblings’ lesser care involvement, in an effort to restore their sibling relationships or manage their own emotional stress. Others, however, severed relationships with siblings due to unresolvable care conflicts. In all instances, without the possibility of sharing care responsibilities, our participants’ personal sacrifices mounted as care demands increased over time, and threatened their pursuits of education, employment, and personal leisure.

For some participants, strained sibling relations and disproportionate care responsibilities were reproduced by legal and financial arrangements. In particular, participants described how their appointments to, or family negotiations of, power of attorney and legal executorship not only fueled sibling conflict, but also discouraged care involvement from non-appointed or non-beneficiary siblings. For example, Eric described feeling discouraged from requesting more care involvement from his siblings. This derived from his appointment as his mother’s legal decision-maker, which stirred conflict with his siblings, led them to scrutinize and subsequently
withdraw their care involvement, and, in turn, limited their understandings of his day-to-day care challenges and decisions. Eric writes in a typed note he brought to the focus group session:

As the primary caregiver, I have gone through a painful process that has led to me accepting these [responsibility]. I have also seen my siblings struggle with this as they question my acquired control and then see the need for it when they have exposure to the issue. They usually start by accusing me of cruelly grabbing power then come to realize that I had no choice. For me, it is a repetition of the process that I went through making the decision as I have to justify my methods and see their slow acceptance of my methods. (Eric)

Those participants whose siblings were involved in care arrangements reported enacting ‘quarterbacking’ roles – that is, leading, delegating, and sharing care responsibilities – which reproduced a different set of demands. This was most evidenced by Florence, who was adamant in demanding consistent efforts from two siblings, and deeply resented her eldest sister who was reportedly uninvolved in their parents’ care arrangements. While managing complex care arrangements (e.g., family members, formal caregivers, care decisions, schedules), Florence had learned to temper her demands in order to maintain harmonious sibling relationships. She felt, however, that this balancing act had “enabled” her siblings to rely on her fully and precluded her from any real respite.

Like I, I would never put my … guard down … [my siblings] will take advantage of that. They are … all of our mothers and fathers, so I don't, I...it's my struggle and it's something I have, I should actually work harder at (...) and I will get to the point where I have to be careful because I don't want to [Carla: Sever]...ruin my relationships with them, and it's gotten very close with, in some situations because I just don't understand it. (Florence)

3.5.2.2 Mistrusting and limiting utilization of “the system”

The most pronounced reason constructed by both groups for sustaining care was their shared mistrust of the care offered by “the system” – a term that participants in both groups used to refer the formal care services offered in both institutional and home care settings.

With respect to institutionalized care in long-term care homes, discourses of risk and fear were prominent among the daughters who cited security and physical risks, presumed accelerated health decline, social isolation, and limited opportunities for meaningful engagement for their parents.
Carla: {Recalling when her late father lived in nursing home} So we lived in the long-term care with my dad for three years …. those workers are really worked off their feet and they can only do things physical, like uh, change their diapers, move them to the cafeteria, put them in front of the T.V. [Thema: Yeah] …. I think I'm giving [my mother] a life sentence [by putting her in a home].

Thema: I felt the same thing, um... in my, like my mom...she cannot interact with other people [in a home] because of language barrier, and …. when I did my [nursing] practical in a ... long term care facility, I realized sometimes [the staff] want to make things as much easier as possible, so they can put a diaper on somebody who doesn't need [right, right], and they will leave that diaper for a whole day [Florence: Oh my God] ... and eventually the person went in as a healthy person, but within a time the person develop a whole lot of … like you push your loved one in the facility and then it's like you kiss the person bye, you know [Florence: Yeah, I feel, I feel sick to my stomach].

The sons’ group shared similar attitudes, citing media expositions of unethical care practices and criminal incidents to frame their commitments to sustaining care at home, despite its precipitating demands (e.g., medical appointments, transportation, home care services, community and respite programs, family care coordination).

Avoiding institutional care entailed accessing public home care services that most participants also grew to mistrust, which created more care work and influenced some to limit service utilization and rely on their own resources. Participants experienced more work and worry when new or substitute personal support workers (PSWs) arrived to the home without any knowledge of their parents or care routines. This led our participants to “stick around” in order to supervise and give instructions to new or untrusted PSWs. Doing so prevented those with limited alternative resources from fulfilling other personal obligations, such as education, employment, and childcare.

Participants with greater financial resources acquired private care resources for more control and flexibility in nature of care provided (e.g., tasks supported, care schedules). Yet private services also reproduced a different set of demands on our participants. Hilary, Florence, and Eric bore substantial managerial and personal responsibilities to their private care staff, including recruiting and managing trusted private caregivers. This entailed administrative responsibilities (e.g., taxes, immigration); managing caregivers’ workloads to mitigate stress; scheduling
between private and subsidized home care, community care services, and health care appointments; resolving day-to-day care problems; and maintaining positive personal relationships and working environments (e.g., housing for live-in caregivers).

3.5.3 Enacting and affirming values

Sustaining care was also characterized by a spiral process through which our participants continuously enacted and affirmed their values, which, in turn, reinforced their care commitments over time. Enacting values captures how participants embodied certain values through their actions or behaviours, and often came to prioritize caring over their other social roles, employment, and personal leisure. Affirming values captures the complementary process of how participants reconciled such ‘value-conflicts’ (e.g., between filial, family, gender, ethnocultural, personal/moral, vocational, and financial values) by deriving affirmation from positive aspects of care, which, in turn, reinforced their value enactments. This spiral was constructed in both groups and most evident in two ways: how participants’ beliefs that they were preserving their parents (PwD) and their family relationships reinforced their continued care efforts, and how participants cultivated and derived personal meaning through caring.

3.5.3.1 Preserving one’s parent and family relationships

Sustaining care enacted participants’ shared value orientation toward preserving their parents’ health, wellbeing, and social relationships, which they believed not to be possible in institutional care settings. Sustaining home care arrangements, however, competed with other held family values. For example, Carla admitted that her decision to retire early and move her mother into her home had compromised her family financially, competed for quality time with her husband, and socially distanced her from her sisters who now excluded their mother and Carla from social events and vacations. The latter consequence, which resonated with multiple participants, derived from a value-conflict between siblings over whether or not it was time to institutionalize their parents.

One way in which participants reconciled these value conflicts was through a shared belief that their care arrangements were “working” insofar as delaying their parents’ cognitive and functional losses, extending their longevities, or maintaining their happiness and social engagement. While some participants attributed their parents’ continued wellness to the
schedules or “programs” (e.g., Hilary) they had established between their PSWs and community services, Patrick felt that his homebound care arrangement was keeping his mother and their relationship well. This included the shared routines he had established with his mother (e.g., daily walks together, co-attending a weekly seniors program), which were made possible by his decisions to forego other personal opportunities (e.g., full-time employment, romantic relationships) in order to care for her on a full-time basis.

So [my mother is] … she still has some, you know, mental cognitiveness, um ... and ... it's, it's you know, it's working ... and it's just because of the way my life is. You know, I have no kids, I’ve, I’ve…it’s basically, you know I [laughs] – it’s going to sound sad if I said I have nothing but my mom [laughs] … but it’s okay (…) now my priorities are different.” (Patrick)

Caring also afforded frequent opportunities for participants to nurture their own relationships with their parents, such as adapting new and enjoyable communication strategies. Florence, for instance, had created “special games” using specific words, gestures, and eye contact with her father, which her siblings and formal caregivers emulated in their own interactions. The sons also discussed learning to relate to their parents through a “slightly risqué” sense of humour and the shared enjoyment derived by fostering this:

My mother-in-law and I enjoy our laughs … and usually that's when we're alone [mhm]. You know, she'll go into her apartment and I'll say, “Don't pick the guy up outside the door,” and I'll say, “Give you a call when I get home,” and she'll say, “Well, I may not be done then!” [others laugh] [laughs] ... and, and you know, we both laugh about it and … those are the rewards. (David)

Preserving and strengthening other family relationships also constituted both reason for and reinforcement of their care commitments. Some connected these to their previous family experiences, reasoning based on promises made to late family members to care for the living parent, or atoning for regrets about the care of a late parent (e.g., accelerated decline in institutional care, neglected health events). Bonds with spouses were also fostered through sharing the day-to-day joys and challenges of caring. Lastly, intergenerational solidarity also strongly affirmed participants’ value orientations toward sustaining care. They believed that sustaining their care arrangements instilled good family values in their children, made evident by their children’s demonstrated compassion and empathy toward their parents, and by their own confidence that their children would, in turn, care for them in future. Eric also underscored the continued reciprocity that he believed his mother’s home care arrangement preserved.
Other people are involved in [my mother’s] life, still...and well you think, what's best for her? What about them? They need this contact, they need to see her … So, it's more than just, just her quality of life. It's other people's quality of life…which she's part of. (Eric)

3.5.3.2 Deriving and cultivating personal meaning from caring

Sustaining care both enacted participants’ personal values and affirmed these values as they ascribed personal meanings to caring over time. Although most participants described forgone personal opportunities (e.g., education, employment, financial health, personal goals), different forms of validation affirmed these sacrifices. For instance, both groups discussed receiving social validation and praise for their care efforts from friends, acquaintances, and service providers. Some participants also described upholding their ethnocultural values, which reinforced their commitments to sustaining care. Thema, for example, was validated by her ethnocultural, family, and gender values that she enacted through caring, which reinforced her decision to abandon her nursing education and intended financial independence from social assistance.

With my experience with others … in [my West African community] ... they call me and they tell me, “Oh, you are doing a wonderful job, to care for your parents!” …. [but others outside my community] tell you, uh, to put your mom [in a nursing home] because she really qualifies to be in a … long-term [Carla: Home] facility. But, in my culture, if you do that, it's like you, uh, you are very, very mean … like even though, like it's something that I really wanted but ... [I told the doctor], “No, I want to keep her in the house.” (Thema)

Our participants also attested to enacting and cultivating their inherent affinities, aptitudes, and skills through caring. Most felt that caring enacted their intrinsic empathetic nature, which they contrasted with their siblings’ natures. For example, both Carla and Timothy emphasized that their decisions to sustain caring were “in the heart” and owing to their personal natures rather than being forced extrinsically. Florence also recognized her inherent “need to care and take care” of others, which Patrick echoed in his expressed “passion” for helping others, now fulfilled by his full-time caring role. Sustaining care also created opportunities for participants to apply and foster skills and interests, from which they derived mastery or achievement. Some examples included exercising one’s management skills with private PSWs and applying business and technology skills to the development of mobile applications to support PwD.
3.5.4 “Flying blind” in how and how long to sustain caring

“Flying blind” characterizes how, amidst uncertain and indefinite care trajectories, participants responded to immediate care demands through intuitive and adaptive problem-solving, and reliance on their own resources (e.g., learning, knowledge, time, money, new support relationships) – or “bootstrapping”. Doing so, however, demanded a present orientation, which obscured the personal consequences that participants accumulated over protracted care durations.

3.5.4.1 Bootstrapping care through one’s own resources

Participants continuously adapted to the growing demands of caring. Reducing working hours, retiring early, leaving the workforce, forgoing educational opportunities, ‘gaming’ with service providers, and hiring private caregivers evidenced how participants negotiated between time and money to sustain caring through their own resources. Adapting also involved continuous learning, problem-solving, and seeking ad hoc support resources, often outside of one’s strained sibling relations and mistrusted “system” resources, from neighbours, community organizations (e.g., church), casual hired help (e.g., babysitters), and peers. The latter was evidenced by Carla and Denise advising Thema on how to request consistent PSWs from the agency, and in this exchange of home modification ideas between the sons:

Timothy: Uh...your point about the learning...I mean, I would certainly say that ten years ago I had no clue what caregiving was about, and everyday you're learning, learning, learning, learning. And one of the great things about [caregiver] support groups is how if you say something, it {snaps his fingers} ... it happened here [in today’s focus group] too when I said motion-sensitive switches [and it gave Eric the idea] (...) That’s happened to me a couple times [in other groups]: everyone goes, “Yeah! Of course that's what!” And that whole learning process is a big part of it.

Eric: I'm going to install one tomorrow ... in [my mother’s] washroom.

3.5.4.2 Focusing on present needs – obscuring consequences

Bootstrapping, as described, entailed meeting present needs with limited foresight into the durations and trajectories of caring. Florence, recalls her family’s decision to move her father to a transitional care unit when he became aggressive and was thought to place their mother and their formal caregivers at risk. With some regret, she recounts making the decision based on then-present circumstances and the agency’s recommendations, without anticipating that her father could no longer move back home due to unsuccessful interventions to manage his
aggressiveness. For Denise, flying blind encompassed successive “short-term” decisions that enabled her to sustain caring for her late father and mother. According to Carla (Denise’s friend), however, this eventually left Denise’s home “completely transformed” with hospital beds, nursing stations, and assistive equipment, and complex care responsibilities that came to eclipse most aspects of her personal life.

No one expected this is where you’re going to be in five or ten years, but you think short term, and it becomes long term (...) until you're actually hands on, you do not get it (...) the scope of things (...) it's just at the emotional, the physical, it's the day to day, like you've got not just paperwork, you might have [an occupational therapist] coming in, you might have [a physiotherapist] coming in, you may have a case manager coming in, uh, social work – it just goes on and on...and these are added things that come into your life. (Denise)

Such hindsight realizations revealed to our participants how focusing on the present obscured the cumulative magnitude of their care responsibilities and personal opportunity costs. This raised important political discussion in both groups, including such consequences as indefinite suspensions of employment income, health benefits, and pension contributions, and diminishing employment opportunities due to age and time away from the labour force. Timothy and David also grappled with the possibility of being outlived by their mothers (-in-law), which both felt would deprive them of opportunities to fulfill their own later life goals. Where David admitted that he felt “cheated” by the seemingly irreconcilable situation, Timothy explained that these feelings led to his decision to institutionalize his mother in an effort to “restore a life of my own”. For this, he was conflicted between feelings of guilt and justification, having eventually realized he could not singlehandedly sustain his mother’s care indefinitely.

In a perfect world, where everyone is a perfect human being, we don't [put our parents in homes] ... you know? We carry on to the bitter end .... [I] would've been able to stick it out indefinitely and learned enough to be able to cope and...blah-blah-blah. This is fantasy that we're in now … because the reality is where she is now [in the nursing home] … there's a staff of twenty people who interact with her on a daily basis, each with their own specialties … and of course, there's no way I can have that base of knowledge of twenty different people, never mind the stamina of twenty different people, never mind the adaptive technology and the facilities. (Timothy)
3.6 Discussion

Our study contributes a situated understanding of how (i.e., the processes through which) adult children may sustain caring for PwD within their familial and formal care contexts. Two extended-duration focus groups afforded rich debates and establishments of common ground, from which we interpreted sustaining care as an indefinite process with three intertwined themes. These themes illustrate how care demands and dependency are reproduced on ‘primary’ adult children, who rely largely on their own resources to meet immediate care needs, and are affirmed and reinforced in sustaining their care commitments by positive aspects of caring.

Our findings of how family and formal care relations reproduce care demands underscore the important influence of social and structural interactions on an adult child’s care experiences and decisions. Where prevailing notions assume that caregiver stress and burden are the results of providing PwD with functional assistance (critiqued by [20]) and managing PwD’s “behaviours” (critiqued by [113]), our study asserts an alternative explanation that stresses the consequences of limited family support and inadequate home and institutional care supports. Others have similarly charged the dominant construction of burden as imprecisely understanding of the sources of stress [20] and burden [114], and neglecting important structural factors that produce negative consequences for family care partners [22], [23], [95]. While the mismatched logics between informal and formal care systems [23] and diminishing formal care support [22] have been documented, our study adds two novel insights. First, a more fundamental issue of “value-conflicts” can exist not only between systems but also within informal care networks, including family members who might be expected to share the same ethnocultural values. Moreover, conflicting values between “primary” adult children and their siblings (e.g., if and when to institutionalize a parent), and between family care partners and formal care providers (e.g., personal relationships between care providers and parents vs. time- and activity-specified assistance, respectively), may explain why adult children limit seeking support from either stakeholders. Family conflict and ineffective care collaboration that ensues may explain why care responsibilities tend to be disproportionate between adult children [104]. Secondly, our findings not only confirm that dementia care demands increase over time [22], but emphasize that these demands increase unforeseeably and indefinitely. Primary adult children consequently have limited foresight with which to make care decisions and arrangements, and may accumulate direct and opportunity costs when care journeys protract longer than expected without responsive
support from informal or formal care resources. Amidst growing recognition of caregiver needs (e.g., [92]), our study elucidates a temporal dimension of how adult children may become increasingly vulnerable insofar as financial insecurity due to unforeseen care costs and care demands that threaten their employment, and political disenfranchisement when they lack the wherewithal (e.g., time, knowledge, language, social status) to access formal care services or when utilizing services threatens their held values. Mistrust in and limited utilization of public home care and institutional care also adds to previous evidence [22], [23] that has called for systemic reforms that build trust with informal care partners by responding to their values and priorities (e.g., greater social opportunities and connectedness for PwD, family care collaboration, financial security). Future work to drive such change may longitudinally examine care journeys and relationships, and the personal, social, and financial impacts to care partners once they are no longer caring for their parents. Moreover, we advocate for the use of broader contextual frameworks when investigating care and caring. Adopting a citizenship lens [16], [134], [147], for example, would recognize the political nature of dementia care and promote the rights and opportunities of PwD and adult children who experience different forms of vulnerability as care is sustained.

Secondly, our study confirms related work that has conceptualized the positive aspects of caring for PwD, and further theorizes how positive and negative aspects of providing care are interrelated. Carbonneau et al.’s [19] three domains of positive aspects of caring (i.e., caregiver-care recipient relationships, caregivers’ feeling of accomplishment, and meaning of caregiving role) were evident in our findings. The development of skills (e.g., management skills) that adult children foster through sustaining care, for example, demonstrates one way in which complex care management is not solely experienced as stressful or burdensome. Our study also adds that positive relational aspects can extend to the enhancement of multiple family relationships, including spousal and intergenerational relationships. Moreover, our findings suggest that positive aspects of caring not only provide uplifts [19]; they may also be invoked to justify and reinforce an adult child’s care commitments despite negative consequences. In this way, our study conceptualizes positive aspects of caring as a “double-edged sword”; these aspects enhance care experiences but can also obscure an adult child’s need to balance her parents’ needs with her own. From this view, we caution decision-makers from interpreting and translating positive aspects of caring into policies and practices that shortsightedly encourage adult children to
sustain caring irrespective of cumulative costs to their own security and wellbeing. Rather, it is crucial that reforms prioritize and facilitate care foresight and informed decision-making, to promote positive outcomes over the care journey and mitigate the aforementioned vulnerabilities that adult children may experience.

Thirdly, our study advances challenges to the dominant conceptualization of caring as support that is unidirectionally given by a “caregiver” and passively received by a “care recipient” [17]. First, our findings emphasize that care partnering by adult children entails more than assisting parents in everyday tasks per se; it also involves the complex management of time, resources, relationships, and ongoing changes to care circumstances. Secondly, our study adds to previous work [15], [17] that has highlighted the interdependencies – often between several care stakeholders – on which care decisions and arrangements are based, and which are inherently overlooked by the person-centred care paradigm [4], [16], [46]. For example, our findings elucidated how strained sibling relations can resign an adult child to sustaining care with little to no family support, and explain greater needs for informal community-based respite resources (e.g., neighbours, church, friends) when home care support is inadequate or inaccessible (e.g., cost prohibitive). In contrast, cooperative care coordination by multiple family members may reduce home care and institutional care needs, but create greater needs for family education, mediation, and legal and financial planning. Thirdly, our findings demonstrated that personality and value differences shaped these interdependent relationships between care stakeholders, particularly between adult children siblings, and between adult children and their parents (PwD). We therefore encourage future research to examines the nature and quality of care relationships through relationship-centred frameworks that promote equitable, synergistic care relationships that reconcile the needs of all partners in care [4], [18]. Moreover, it is crucial that policy and services aim to be value-sensitive and flexible to accommodate a wide range of personalities, values, and care arrangements, from no adult child involvement to active care collaboration with multiple adult child siblings.

3.7 Limitations

Several limitations and trade-offs of this study were recognized. One limitation common to any focus group study is that group norms and viewpoints may discourage individuals from voicing deviant viewpoints [107]. The advantage offered by group dynamics, however, is that
individuals have the opportunity to concur or challenge others’ views, thus, eliciting depth, range, and complexity of experiences across participants. Given the constitutive role of the researcher in data collection [110], a second limitation was the difference in facilitators between the two focus groups. The presence of the first author at both groups, and analytic debriefs with the hired facilitator (daughters’ group) and research assistant (sons’ group), was intended to mitigate this limitation. Another trade-off was the recruitment of two participant dyads – one within each group – that had pre-existing relationships. Practically, this snowball sampling afforded the recruitment of homebound participants who otherwise would have been difficult to recruit. Moreover, these relationships promoted naturalistic interactions between the two dyads who could relate to and share observations about each other’s experiences [115]. Conducting two single-session, extended-duration focus groups also had both advantages and disadvantages. We note that conducting longer half-day focus groups may have fatigued our participants, however, these extended durations accommodated our participants’ resource constraints, and we observed that longer sessions strongly promoted rapport-building in both groups. Moreover, we recognize this study’s small sample size, and posit that our findings offer insights that may have important conceptual or qualitative generalizability [84] to adult children, care partners, or other persons in comparable contexts or conditions, which we encourage future work to further explore. Lastly, our final interpretations emphasized experiential similarities between our gender-segregated groups. Although we initially attended to both similarities and differences between genders, after multiple iterations of analysis, all authors concurred that the variations not explicitly attributed to gender were most salient in our dataset. While we certainly cannot conclude from this small study that adult sons and daughters sustain caring in similar ways, our findings can inform future work that explores how care experiences compare and contrast between genders.

3.8 Conclusions and recommendations

This focus group study elucidated the processes through which adult children of PwD sustain caring within their familial and formal contexts. Overall, both singlehandedly caring and seeking care support (i.e., from siblings and/or service providers) tended to reproduce care demands and dependency placed on primary adult children. The indefinite and ambiguous trajectories of dementia care precluded longer-term care planning, which exacerbated these consequences insofar as accumulating direct and opportunity costs to adult children. While our
findings confirmed positive aspects of caring, these affirmations can simultaneously reinforce commitments to challenging care arrangements in spite of negative, cumulative personal consequences. Together, our findings necessitate longitudinal, relational, and sociopolitical frameworks through which to conceptualize care and caring. In culturally diverse contexts (e.g., Canada), where the roles and expectations of adult children vis-à-vis parental care are difficult to prescribe, more flexible support schemes are needed to accommodate a wide variety of informal-formal care arrangements. At a minimum, policy should not assume the availability, willingness, and wherewithal of adult children and family networks to provide care for their parents. However, adult children who wish to and have the means to sustain caring should receive adequate and value-sensitive support that enhances positive aspects of caring while mitigating risks to their own health and financial security – both present and future. We recommend streamlined case management resources that are sensitive and responsive to diverse values (e.g., ethnocultural) and care arrangements, which may include different combinations family and formal care resources; hands-on care vs. care management arrangements; and co-residence vs. local care vs. caring from a distance. Resources are also needed to facilitate access to public and private services offered within home, community, and institutional settings, and provide family education and holistic (e.g., health, social, financial, legal) advance care planning. Additional support schemes that may promote financial stability for adult children may include flexible work time, leave policies, and telecommuting technologies; universal tax benefits and continued pension contributions; and direct payments to replace reduced or foregone income. Importantly, schemes should be available to adult children irrespective of their mix of care resources (e.g., other family members, neighbours, friends, community groups or programs, formal home care). It is promising that several of these recommendations to better support informal care partners – including adult children – have been proposed in recent aging and dementia strategies (e.g., [1], [92], [116]). To these proposals, our study stresses the need for such schemes to be accessible over highly unpredictable and indefinite care durations, and irrespective of workforce participation and living arrangements vis-à-vis PwD. Moreover, strategies should incentivize care involvement and collaboration by adult children siblings and other informal care partners (e.g., tax benefits to multiple adult children providing care, rather than only a co-residing care partner). These may promote the distribution of care demands within families who choose to provide care and, in turn, facilitate ongoing social support for adult children as care demands increase over time. Such reforms are expected to improve the equitability and sustainability of
systemic reliance on the continued care efforts by adult children care partners, who experience the benefits and challenges of balancing their parents’ needs with their own.
Chapter 4
Exploring how persons with dementia and care partners collaboratively appropriate information and communication technologies

This chapter was submitted to *ACM Transactions on Computer-Human Interaction* (TOCHI) on April 23, 2019. This article reports on *Study III* of this thesis project.

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### 4.1 Abstract

Persons with dementia (PwD) and their care partners have been found to adapt their own technological arrangements using commercially-available information and communication technologies (ICTs). Yet, little is known about these processes of technology appropriation and how care practices are impacted. Adopting a relational perspective of care, we longitudinally examined how four family care networks appropriated a new commercial ICT service into their existing technological arrangements and care practices. Cross-case analysis interpreted collaborative appropriation to encompass two interrelated processes of creating and adapting technological practices and negotiating and augmenting care relationships. Four driving forces were also proposed: motivating meanings that actors ascribe to the technology and its use; the learnability of the technology and actors’ resourcefulness; the establishment of responsive and cooperative care practices; and the qualities of empathy and shared power in care relationships. The importance of technological literacy, learning, meaning-making, and the nature and quality of care relationships are discussed. Future work is urged to employ longitudinal and naturalistic
approaches, and focus design efforts on promoting synergistic care relationships and care practices.

4.2 Introduction

As aging and dementia garner increasing design research attention, socio-critical HCI scholars have advocated for more humanistic, experience-centred, and participatory approaches to designing for and with persons with dementia (PwD) [13], [14], [117]-[119]. This shift attempts to redress the ‘biomedicalized’ paradigm [119], [120] from which technology attempts to compensate for PwD’s cognitive deficits [13], [14], [117], [118]. Not only does such a view reduce a person to a narrow set of clinical parameters, it overlooks design opportunities that may otherwise enrich PwD’s lived experiences [13], [119]. Research involving PwD has underscored that they can and should be involved in the design process, and suggests that their experiences could be enriched with the continuity of meaningful and enjoyable activities [70], [121]-[123]; a greater sense of control and security in their everyday activities [124], [125]; and greater social inclusion and social connectedness [118], [122], [126]-[128].

Toward enriching experiences for PwD, greater attention to PwD’s relations with family care partners has been recommended [34], [119], [129]. Several technological studies have reported differing needs and values between PwD and their care partners, and some have challenged that technology tends to be biased toward the priorities of care partners (e.g., safety, security) [10], [28], [126], thus, marginalizing the concerns of PwD themselves. Others have emphasized that care partners influence if and how PwD adopt certain technologies [6], [50], [51], [132], and described how technologies may engender different forms of care efforts by family care partners when supporting older persons [80] or persons with cognitive impairment [29], [33]. The extent to which care partners support technology use may be considered a form of “discretionary effort” [157] that may depend on the nature of the care relationship [9], and require reconciliation with competing roles or other care demands [29], [55]. Caring should be recognized as an interpersonal process through which PwD and care partners continuously balance and negotiate their needs [46], [119] – a shift from the traditional dyadic conceptualization of care [17] as
being given by a family member and passively received, for example, by a PwD. Taken together, designing technological experiences should aim to mutually and synergistically enrich the experiences of and relationships between PwD and their care partners.

Within their complex care dynamics, little is known about how PwD and care partners appropriate technologies over time – that is, how they adopt and mutually adapt technologies to their practices, and vice versa [130], [131]. PwD and their care partners have been found to primarily devise “do-it-yourself” solutions (e.g., information and communication technologies (ICTs), adaptations of everyday household products) and, secondarily, privately purchase “off-the-shelf” technologies (e.g., “dementia-friendly” products) [6]. Such trends would appear to be facilitated by the limited public resources available for assistive technology (AT) provisioning [6] and specialized dementia care services [22], [23], [34]; the stigma that PwD and care partners feel is avoided with the use of everyday mainstream (vs. specialized or assistive) products [7], [51]; the greater accessibility of touch-screen devices by PwD [11], [122]; and the need for individualized solutions [7], [9], [126]. While a few longitudinal studies have examined how PwD and care partners adopt assistive technologies (ATs) [50], [132], less is known about the processes by which mainstream or specialized ICTs are adopted and adapted into everyday practices. Studying these processes can provide greater insight into how technologies are woven into complex dementia care dynamics, and better situate design efforts in the current landscape of ubiquitous technology.

Consequently, our study aimed to describe how PwD (living with mild dementia) and their care partners (“care networks”) appropriate commercially-available ICTs, and how their appropriation impacts care practices. Theoretically, we pursued these aims from three points of departure (further elaborated in Section 4.4.1). First, the concept of technology appropriation recognizes that users often adopt and adapt technology in unanticipated ways, and evolve their existing practices around the use of new technologies. Secondly, the concept of bricolage (adapted from [133] by [9]), highlights how consumers have been found to pragmatically “blend” new and legacy technologies to create new technology arrangements. Thirdly, we assumed a relational perspective of care (advanced by [4], [18], [134]), wherein we conceptualize caring between PwD and their care partners as reciprocal enactments of their social relationships in the forms of non-medical, emotional or practical support. From these views, we expected the PwD to be “active partner[s] in the dementia care experience” [134] and, as such, the technology
appropriation processes under study. In this paper, we refer to “care partners” as those individuals with whom the PwD sustain a caring relationship (e.g., familial) and, owing in some part to its nature and quality, PwD have nominated to provide technological support. We use “care network” to refer to a network of relationships between a participating PwD and one or more of his/her care partners. Lastly, we use “care practice” to refer to routine behaviours through which care is enacted, and we focus this study on how care practices are impacted through the appropriation process.

4.3 Technology use and dementia care practices

The HCI literature related to dementia has predominantly focused on the design of bespoke systems in support of PwD and care partners. Some studies outside HCI, however, have examined the use of ATs (i.e., a wide range of low-to-high tech devices [6] designed to compensate for deficits [50]) and everyday technologies (ETs) (i.e., both new and common analog and digital devices that exist in people’s everyday lives [7] e.g., kitchen appliances, telephones) by PwD and their care partners. Fewer studies have investigated the use of commercially-available mainstream ICTs (e.g., smartphones, tablets, computers). To note, these technology classifications should be understood to overlap. As examples, ATs can be used in everyday contexts, or can be provisioned through health services or purchased commercially; mainstream ICTs (e.g., cell phones) can be considered a subset of ETs; and ETs may offer ‘assistive’ applications (e.g., smartphone calendar reminders). In this section, we review empirical work that has examined technology use by PwD and care partners and present their key findings as they relate to care practices.

Previous work has suggested that technology use may promote positive experiences for PwD, care partners, and their care relationships. Over seven-day home trials with 21 care dyads (i.e., persons with early-stage dementia and their care partners) using Apple iPads, Lim et al. [163] demonstrated that iPad use provided PwD with independent leisure time and care partners with temporary respite. Astell et al.’s [126] single case study over 12 months investigated the impact of mainstream technology use on one PwD. The studied PwD was able to relearn to use his desktop computer, a laptop, and a smartphone, for such activities as emailing, travel planning, and creating slideshow presentations. Their study highlighted that, with ongoing and individualized support from both the researcher and the PwD’s wife, the PwD gained a more
positive outlook on life and renewed his self-identity through greater self-confidence, independence, control, pleasure, and a sense of participation in society. Positive relational experiences were also found by Lazar et al.’s [128] six-month case study of one care dyad using a specialized, commercially-available technology containing applications for social interaction, exercise, reminiscence, and cognitive stimulation. They found that using the system allowed the daughter to augment her mother’s usual care by supporting the daughter’s (care partner) discovery her mother’s interests and cognitive limitations; facilitating shared participation and enjoyment of individualized leisure activities (e.g., photo sharing); and cultivating her mother’s positive emotions, which altogether supported the quality of their relationship. In another interview study with spouses of PwD, McHugh et al. [135] found that specialized ICTs supported spouses’ access to information about dementia, services, and informal resources (e.g., friends); alleviated them from being “tied to the house” if mobile devices were incorporated in their daily care routines; facilitated sustaining social networks of both themselves and PwD; and had the potential of supporting better quality relationships with PwD through supported communication.

While such benefits may be possible, other studies have highlighted the nature and extent of efforts that technology use may require of care partners. In their qualitative interview study, Gibson et al. [6] found that care partners of PwD play pivotal roles in identifying, purchasing, installing and managing technology, as well as performing the continual “background work” of reminding and reassuring PwD throughout learning and use. Similar findings were reported by Rosenberg & Nygard’s [136] interview and observational study of PwD’s self-selected everyday technology use (e.g., cell phones, television and DVD players), where “significant others” (i.e., adult children, grandchildren, friends, and neighbours) were found to motivate technology use, provide the technology, and provide support through teaching or solving technology-related problems. In another focus group study involving care partners of persons with cognitive impairment (including some who cared for PwD), Piper et al. [29] emphasized that care partners support online activity (e.g., email, messaging, social media) by constantly monitoring, assessing, and adapting their technological support. They delineated four forms of work that care partners may perform: guiding describes when care partners functionally assist (i.e., work side-by-side, set up or configure), teach (i.e., cooperate with, learn the technology themselves, and devise strategies to simplify concepts), or mentor (i.e., encourage, motivate) persons with
cognitive impairment in their online experiences; **stimulating** describes how care partners stimulate persons with cognitive impairment through informational, social and emotional means; **connecting** describes how care partners facilitate social connectedness for persons with cognitive impairment, by setting up video calls, or reading and posting online updates with or on behalf of them; and **protecting** describes how care partners block harmful or distressing content, vet and filter the person’s online contacts, mediate their information disclosure, and avoid phishing attempts.

Studies have also indicated that care partners not only support PwD’s needs and goals through technology use, but also promote care partners’ own agendas or perspectives. In an interview study with over a six-month period, Lindqvist *et al.* [132] found that those care partners who benefitted from the PwD’s AT use (e.g., reduced worrying, saved time) were the most involved in supporting AT use, while care partners who did not directly benefit were less involved. Other studies found that care partners may persuade [6] or force [136] PwD to use technologies in order to facilitate care efforts or activities. Moreover, care partners may exercise their own technological preferences, such as supporting mainstream devices, instead of specialized ATs, with which care partners are more familiar or experienced [6]. In their case study of three PwD and their “significant others” (e.g., family members), Rosenberg & Nygard’s [50] found that actors held differing viewpoints about the ATs and, ultimately, the party with decision-making power bore the greatest influence on AT selection and use.

Some scholars have articulated how PwD and care partners balance and negotiate between their differing needs when appropriating technology into their care practices. In their interviews with relatives of PwD that aimed to describe their reflections on different ICT devices (e.g., alarms, tracking devices, modified telephones, and memory aids) used in their daily care of PwD, Olsson *et al.* [165] described how relatives shifted their perspectives between prioritizing their own and their relatives (PwD’s) needs for safety and security. Here, they demonstrated the reciprocal and negotiated natures of decision-making about ICT use and non-use between stakeholders. Piper *et al.*’s [29] study also illuminated how online activity is cooperatively negotiated between persons with cognitive impairment and their care partners, often moment-to-moment. Rosenberg ’s [51] grounded theory study found that relatives of PwD constructed a “utility perspective” where they were generally ready to support PwD to use technology and to use technology themselves if they believed the technology would keep PwD active in mind and lifestyle; help PwD maintain their
desired self-image and avoid stigmatizing them; could be integrated into existing habits; and placed minimal demands on PwD and themselves in supporting technology use.

Taken together, previous work underscores both the practical and social complexities of appropriating new technologies into dementia care practices. Questions remain about how the collaboration appropriation process unfolds over time in real-world contexts and within different types of care networks, and how new ICTs are blended with existing products to adapt or create new care practices. The current state of knowledge also suggests investigating these questions in early stages of decline, where PwD retain abilities to learn new technologies and can actively participate in negotiating new care practices with their care partners. Consequently, our study examined multiple cases to describe how different early-stage dementia care networks collaboratively appropriated a commercial ICT product, attempted to situate or adapt it within their existing technological arrangements (i.e., the ETs and ICTs they already use), and how this process impacted their care practices.

4.4 Our multiple case study

4.4.1 Theoretical points of departure

Our theoretical points of departure for this study included the concepts of appropriation [131] and bricolage ([133] as adapted by [9]), and a relational perspective of care. We describe here our perspective, each concept, and how they interact with one another.

Our study adopted the concept of appropriation as the process of “mutual adaptation” where, by adapting and adapting to a new technology, users reshape its features and find their own practices reshaped through use [131]. In this study, we focus on collaborative appropriation, which examines how the studied care networks participated in new technology appropriation and mutually adapted their care practices to their technology use, and vice versa. We were sensitized to three forms of adaptation that can occur during appropriation (summarized by [144]):

- **Semantic** – changes in the meaning ascribed to technology through in-context use;

- **Behavioural** – new usage patterns that emerge through in-context use; and

- **Technological** – modifications or adaptations of the technology itself.
We were also sensitized to the concept of *bricolage* ([133] as adapted by [9]) – the way in which new technologies are combined with existing technologies to devise new technology arrangements. Here the emphasis on the *bricoleur* and the *bricoleur-participant relationship* is consistent with the primary role that care partners have been found to enact in influencing and supporting PwD’s technology use [50], [51], [132], [136], [29], [157], [119]. Relating this to our concept of appropriation, we assumed that appropriating a new technology may change the meanings ascribed to the new or existing technologies (semantic); displace, shift, or change the use of existing technologies (behavioural); or demand modifications or adaptations to both the new technology and existing technologies (technological). Whether a new technology is adopted at all is also assumed to be influenced by existing technology arrangements. Bricolage also relates to our relational perspective of care in its emphasis on the nature of the caring relationship [9]. Moreover, the pragmatic nature of bricolage resonates with the commonsense and self-initiated ways that PwD have been found to address challenges to their everyday activities [71], and the way in which dementia care partners intuitively ‘craft’ tools, strategies, and spaces to support care routines and relationships [8].

Our relational perspective of care viewed caring between PwD and their care partners as enactments of their relationships, which vary in nature and quality – for example, by different expressions of reciprocity and interdependence. Importantly, this contrasts the more traditional dyadic conceptualization of caregiving and care-receiving [17] – for example, unidirectionally from a family member to a PwD. We also deviate from the medicalized use of ‘caring’ as support in the management of health and symptoms; rather, we focus on caring in the forms of non-medical social support [15] (i.e., emotional or practical) in the management of everyday life, activities, and social relationships.

We employed these theoretical perspectives and concepts as tentative starting points [110] for an inductive inquiry, and, as such, remained open to evolving concepts throughout data collection and analysis.

### 4.4.2 Study design

This study employed a descriptive multiple case study design [137], which allowed us to examine and compare appropriation in four different care networks. This design calls for investigation using a variety of methods, and is appropriate for naturalistic settings wherein the
boundaries between phenomenon and context were not clearly delineated [138]. Consistent with case study design, this study sought to achieve a deep understanding of each case and create concepts through cross-case analysis [137].

4.4.3 Study context

This study was conducted in an urban Canadian city in collaboration with a small technology company (CP), and a local neighbourhood organization (NO). One of the NO’s mandates is to provide non-medical services to older adults living in the local neighbourhood. The commencement of the study closely aligned with the NO’s implementation of a one-year pilot program (“NO program”) that aimed to provide volunteer support to persons with mild cognitive impairment or early Alzheimer’s-type dementia who were interested in learning to use the CP’s ICT product (“CP system”). This was the first program at the NO that explicitly aimed to support persons with cognitive impairment. All of our informants were recruited from the pilot program at the NO. Common to ethnographic approaches, the first author (“Amy”) played a dual role of researcher and program volunteer, in order to facilitate access to informants and obtain rich data from informants’ viewpoints [138]. Her specific role varied between cases and is described in Section 4.

4.4.4 Technological context

This study set out to examine the collaborative appropriation of the CP system in combination with other new or existing ICTs (e.g., landline telephones, desktop PCs, laptops, and other mobile and smart devices) used by the participating PwD and their care partners. The CP system was designed to facilitate social connectedness and aging-in-place for older adults. It consists of a simplified tablet computer designed for technologically novice older adults, accompanied by a web-based portal (“web console”) for family care partners to configure and manage the front-end tablet. During the course of the study, the CP also released a mobile application (Android and iOS) that delivered the same functionality as the web console. Communication that is sent from the front-end tablet can be received by care partners via text messaging, email, or through the web console or mobile application. The CP system’s features that were examined in this study were:
• **Call requests**, where the PwD can send a request to a selected contact (care partner) to call him/her on the tablet;

• **Events** that the care partner can program using the web console, which will deliver date/time-based reminder chimes on the tablet to prompt the PwD;

• **Medication alerts** that the care partner can program using the web console, which will deliver successive reminder chimes on the tablet to prompt the PwD to take medications;

• **Messaging**, which exchanges text-based messages between the PwD and their programmed contacts (e.g., care partners); contacts can send and receive messages via SMS, email, or web console, while all messages will be received within one Messaging function on the tablet by the PwD;

• **Photos and Videos**, which populate media galleries for the PwD to browse through when they receive Messages with media attachments, or care partners upload media via the web console;

• **Exercise videos**, which can be browsed through and watched by the PwD on the tablet once the care partner has uploaded the video via the web console;

• **Web links**, which lists on the PwD’s tablet only those websites that the care partner has added via the web console; and

• **Video Calling**, where the PwD can initiate or receive video calls on the tablet from their contacts.

### 4.4.5 Data collection

The NO program’s staff coordinator (‘Coordinator”) supported recruitment, which was facilitated by the co-authors’ previous research collaboration with the NO. Our inclusion criteria for PwD matched the NO’s pilot program criteria: 55 years or older, living in community, and formal diagnoses of mild cognitive impairment or mild dementia. To pursue our research aim, we first recruited those PwD from the NO program who self-reported some degree of family support (e.g., co-residence, frequent assistance). We also recruited into the study those family
members whom PwD ‘nominated’ to participate with them. We considered family members ‘nominated’ if they were already co-participating in the NO program and also agreed to participate in the study together, or if the PwD invited a specific family member(s) to participate with him, when suggested by the first author. In addition, the NO volunteers who were assigned to support the PwD were also recruited into the study. In total, across four cases, we recruited 10 unique informants: 4 PwD, 4 family members, and 3 volunteers. There were two instances of overlap: one informant provided data for two cases, as a former spouse to one PwD and as a volunteer to another PwD; and one volunteer was assigned to two different PwD. Section 4 describes each case and its informants in further detail.

Pilot data were collected from the first two cases (Pete and Daniel). Pilot data were comprised of one interview and one participant-observation (i.e., observing through participation in the case by assuming a functional role [138]). Pilot data analysis guided purposive sampling of the second two cases (i.e., Edwin and Patrick) in which family members co-resided or lived locally, and actively supported PwD’s daily activities and ICT use.

Descriptive, primary and secondary data were collected from all cases. Descriptive data included demographic and living and care arrangement information, which are summarized in the Case Descriptions (Section 4.5). In addition, once during the study, each PwD and care partner informant responded to a relationship questionnaire (self- or verbally administered), in which they compared the nature of their relationship before and after they had used the studied ICTs for some time (sample questions in Table 5). This questionnaire was developed based on ten relational maintenance strategies by [166], and informants were encouraged to qualitatively supplement their Likert responses. These data guided and complemented primary data collection insofar as providing descriptions of the nature and quality of informants’ care relationships and the influence of and on ICT appropriation.
Table 5. Study III – Selected questions from the relationship questionnaire that yielded salient qualitative data to accompany Likert ratings (Strongly Disagree, Disagree, Neutral, Agree, and Strongly Agree).

<table>
<thead>
<tr>
<th>Question inquiring about before ICT use (E.g., “Before you started using the [CP system], how would you rate this statement about you and father?”)</th>
<th>Question inquiring about before ICT use (E.g., “After you started using the [CP system], how would you rate this statement about you and father?”)</th>
</tr>
</thead>
<tbody>
<tr>
<td>We spent time doing activities together.</td>
<td>My everyday technology helps us spend time doing activities together.</td>
</tr>
<tr>
<td>We assured each other that our relationship was important.</td>
<td>My everyday technology helps us assure each other that our relationship is important.</td>
</tr>
<tr>
<td>We stayed in frequent contact when apart from each other.</td>
<td>My everyday technology helps us stay in frequent contact when apart from one another.</td>
</tr>
</tbody>
</table>

Primary data were comprised of semi-structured interviews; participant-observations; and one focus group involving most informants (i.e., except Alison and Amelia). Semi-structured interviews and participant-observations were conducted by the first author and took place at informants’ homes or in the neighbourhood (i.e., café or park), at the NO site, or via telephone. Interviews probed further into informants’ relationship maintenance questionnaire responses (e.g., Which aspect or feature of the ICT brought about your mentioned relationship change?), and inquired about their appropriation as it related to their care relationships and practices (e.g., Tell me about your experience so far learning and using the CP system; How has using it impacted the way that you relate to your [family member]?). Participant-observations attended to how informants were interacting with the ICTs, their physical contexts (e.g., objects, spaces), and each other (e.g., comfortable vs. tense; aligned vs. misaligned interests; power dynamics). The focus group presented photos of fictitious characters using the CP system in different use cases and posed questions related to care practices (e.g., A reminder pops up on Joan’s (PwD) CP system tablet that reads: “Walk on Saturday with Karen.” What does Joan do after she reads
this? How does Joan feel about this reminder that Karen programmed for her?). The focus group was co-facilitated by the first and second authors, and a hired facilitator, and took place at the NO site. The focus group also probed informants to compare their practices using the CP system with practices using existing (e.g., landline telephone) or other new ICTs (e.g., new iPhone), which informants had discussed or demonstrated during previous interviews or participant-observations.

Secondary data included first authors’ field notes from informal communications with informants (in-person, telephone, email, text messaging); field notes from her participant-observations during NO volunteer training workshops; and case information contained in NO program documents (e.g., intake forms, volunteers’ training diaries). Data were collected between October 2015 and July 2016 and based on informants’ availabilities (e.g., health events, adult children’s visits) and the NO’s program implementation timelines (e.g., recruitment support, focus group scheduling, volunteer turnovers).

Table 6 summarizes the total time and duration of data collection by case.

**Table 6. Study III – Summary of time and duration of data collection by case.**

<table>
<thead>
<tr>
<th>Case</th>
<th>Informant</th>
<th>Gender</th>
<th>Age</th>
<th>Relationship</th>
<th>Total N hours by informant</th>
<th>Duration of data collection</th>
<th>Total N hours by case</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Pete</td>
<td>M</td>
<td>79</td>
<td>PwD</td>
<td>10.2</td>
<td>9 months</td>
<td>12.1</td>
</tr>
<tr>
<td></td>
<td>Rebecca</td>
<td>F</td>
<td>52</td>
<td>Adult daughter</td>
<td>1.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Alison*</td>
<td>F</td>
<td>20</td>
<td>Volunteer</td>
<td>0.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Amelia</td>
<td>F</td>
<td>32</td>
<td>Volunteer</td>
<td>2.25</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Daniel</td>
<td>M</td>
<td>77</td>
<td>PwD</td>
<td>5.8</td>
<td>9 months</td>
<td>5.8</td>
</tr>
<tr>
<td></td>
<td>Alison*</td>
<td>F</td>
<td>20</td>
<td>Volunteer</td>
<td>1.75</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Edwin</td>
<td>M</td>
<td>55</td>
<td>PwD</td>
<td>2.5</td>
<td>2 months</td>
<td>6.3</td>
</tr>
<tr>
<td></td>
<td>Anita</td>
<td>F</td>
<td>54</td>
<td>Wife</td>
<td>5.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Wendy**</td>
<td>F</td>
<td>64</td>
<td>Volunteer</td>
<td>2.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Patrick</td>
<td>M</td>
<td>71</td>
<td>PwD</td>
<td>7.8</td>
<td>2 months</td>
<td>11.3</td>
</tr>
<tr>
<td></td>
<td>Wendy**</td>
<td>F</td>
<td>64</td>
<td>Former wife</td>
<td>8.25</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Max</td>
<td>M</td>
<td>37</td>
<td>Adult son</td>
<td>3.25</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note 1:* Informants’ real names have been anonymized using the pseudonyms shown in the Informant column.

*Note 2:* The calculation of total N hours by case (right-most column) counts co-participation by multiple informants in one data collection session once.

*Note 3:* The asterisks indicate the unique informants who provided data across cases.

*Note 4:* See Section 4 for detailed descriptions of all cases and their informants.
4.4.5.1 Researcher’s role

Amy Hwang (first author, 33 years old) is a Chinese-Canadian doctoral student in Rehabilitation Science with experience working with older adults and their family members in outpatient and home-based rehabilitation services. In order to gain access to, establish rapport with, and gather rich data from informants, she enacted the role of a NO program volunteer. To note, between cases, the stage of CP system appropriation, existing ICT arrangements, and technical support provided by care partners vis-à-vis volunteers varied. As such, the way in which the researcher enacted her dual researcher-volunteer roles also varied between cases. This is further described within each case description in Section 4.5.

4.4.6 Data analysis

Pilot data were analyzed with ongoing guidance as part of the first author’s qualitative research methods course. Subsequently, data from all cases were primarily analyzed by the first author (as recommended by [137]) who collected and generated all case data. The first author’s analytic memos and categories were scrutinized and critiqued by co-authors, whereupon the first author performed data checks and refined categories. Within-case analysis strived to achieve a particularistic understanding of each case (i.e., gleaned from conducting and transcribing interviews, and generating all field notes). Cross-case analysis was then conducted as each case was analyzed, where analytic categories were generated and iteratively refined [137]. Final interpretations were critiqued by all co-authors.

*Within-case analysis.* For each case, data were first categorized in NVivo 11 into three forms of adaptation (i.e., semantic, behavioural, and technical) [144]. Each category was then reviewed, and data were further organized into more substantive subcategories. For example, the subcategories, managing multiple devices and trial and error troubleshooting, were created under the “technical adaptation” category, and the subcategories, enhancing family inclusion and relying on others, were created under the “semantic adaptation” category. This process highlighted the most data-populated and salient subcategories, for which the first author generated analytic memos. As several data overlapped between multiple categories, analytic memos also described their interrelationships. For example, in some cases, the process of persevering with technical adaptations became semantically meaningful for family members in
that they enacted care for PwD through supporting their technology use. All analytic memos for each case were then synthesized into detailed case descriptions for each case (Section 4.5).

**Cross-case analysis.** After Case 1 and Case 2 were analyzed, substantive subcategories, analytic memos, and full case descriptions were compared. Preliminary cross-case analytic categories were generated with accompanying memos that described the similarities, differences, and nuances between cases. These categories were revised and refined as each case was analyzed. For example, in the analysis of Case 1 and Case 2, the category, disrupting care practices, was generated to capture how technological support from family members disrupted their emotionally or geographically distant care practices. When analyzing Case 3 and Case 4, this ‘disruption’ was reinterpreted as a nuance of a broader category, diffusing care involvement, which was disruptive in some cases but, in other cases, promoted care collaboration between family members. Subsequent team analysis between all co-authors during manuscript development critiqued first author’s initial cross-case themes and analytically delineated between processes and driving forces of collaborative appropriation. This cross-case analysis generated the model that is described in Section 4.6.

### 4.5 Case descriptions – informants, care practices, and appropriation experiences

Toward our first study aim, for each case, we describe all informants, their care practices, and their ICT appropriation experiences during the study period. We also describe the first author’s specific involvement and role within each case, which yielded different insights between cases.

#### 4.5.1 Case 1: Pete, Rebecca, and Amelia

#### 4.5.1.1 Informants

*Pete* *(PwD, 79 years old)* is Jewish-American who immigrated to Canada after marrying his second wife, Linda. Pete has an easy-going disposition and enjoys socializing, making jokes, and keeping conversations light-hearted. Since retiring from careers in research and entertainment, he has enjoyed keeping busy with travelling and joining writing groups. He was diagnosed with mild cognitive impairment (MCI) 3-4 years ago by a geriatrician and completed a 6-week,
hospital-based patient education program on MCI. Since then, he has continued to participate in a community-based MCI support group, and a social group, which led to his recruitment into the NO program. At the beginning of the study, Pete reported that his doctor had diagnosed him with MCI and expected it would progress to Alzheimer’s Disease. Pete, however, was not convinced of this initial diagnosis that he believed was based on “a terrible test”. Pete report that, the following year, his doctor had “apologized” and told Pete that his condition did not appear to be progressing to Alzheimer’s Disease. Six months later in the study, Pete updated Amy that his diagnosis was a topic of “controversy” between him and his doctor. Following this, with Pete’s process consent (and encouragement) to openly discuss any details of his case with his daughter (Rebecca, below), Amy was told by Rebecca that Pete’s most recent diagnosis was “moving on toward dementia”.

Pete and Linda live in a downtown apartment building. Pete felt that Linda had become very “overprotective” since his diagnosis, and their relationship is now more “separate” than before; he attends his activities alone, and they often travel separately. Pete maintains close relationships with his son (John) and daughter (Rebecca, below) from his first marriage, who both live in the U.S. Pete chats with each on the phone at least once a week to catch up and “make plans”, and they each visit him a few times a year. Pete enjoys bringing them along to his community activities when they are in town. Since his recent hospitalization (during the study period), Pete noticed that John and Rebecca call and visit him more. When Linda is away, she tries to arrange one of them to come and stay with Pete, or at least phone him every day to check in with him.

Rebecca (Pete’s daughter, 52 years old) lives in the U.S. with her husband and two stepsons and is an elementary school teacher. She and Pete have always had a very close and open relationship. She has always been supportive of his interests and activities and has been especially committed to helping him stay active (e.g., through his NO program participation) and in good spirits, given his recent health issues.

Alison (Pete’s initial volunteer, 20 years old) is an East Asian-Canadian university student who had been volunteering at the NO for one month. Before the study, she had visited Pete once at the NO and three times at his apartment. One month after the study start, however, Alison unexpectedly discontinued her volunteer role at the NO.
Amelia (Pete’s current volunteer, 32 years old) is an Irish emigrant and elementary school teacher. She started volunteering with Pete two months after Alison discontinued. She met with Pete weekly, initially at his apartment but, more recently, at a nearby café (Pete’s preference). Over the two months, their meetings grew more social in nature with less time spent on technology training. Recently, Amelia noticed some memory decline in Pete (e.g., taking the wrong bus to their meeting) and became concerned after he shared that he had been hospitalized. Having cared for a family member with dementia herself, Amelia proactively offered to the Coordinator to meet Pete more often or to discuss with Rebecca how Amelia could better support him locally.

4.5.1.2 Researcher’s role

Over five in-person encounters and multiple phone calls, Amy developed friendly rapport with Pete. Amy communicated with Pete initially by email and home phone, and later intermittently on his new iPhone (i.e., phone calls, text messages) in order to arrange their meetings.

4.5.1.3 Existing ICT arrangements

Pete’s ICT use markedly changed over the study period. Initially, Pete was highly independent in his ICT use. He primarily used his home telephone and desktop computer for daily emailing, including photo-sharing, and occasional web browsing and Skype with John and Rebecca. He was enthusiastic about learning the CP system when presented the opportunity through NO. He had always enjoyed new technological gadgets and was excited at the prospect of learning how to use modern-day technology. In addition, Pete felt valued when the NO had invited him to pilot the CP system, as well as sit on the NO program advisory board. He interpreted his role as a “volunteer” who was expected to provide feedback on the CP system.

4.5.1.4 CP system appropriation: non-adoption due to working ICT arrangements and negative meanings

In anticipation of getting started with the CP system and his first volunteer (Alison), Pete shared his enthusiasm with Rebecca. When he had received it, Rebecca and Pete sat together a few times to explore the CP system during her visits, and she sent him a few photos and videos. Alison and Pete, on one occasion, also tried to video-call Rebecca in the U.S. with no luck getting the audio to work. Rebecca reported that, despite Pete’s initial enthusiasm, they both
struggled to “find a purpose for [the CP system]”; Pete was proficient using his desktop PC for daily emails, including photo-sharing. He occasionally used Skype for video-calling with Rebecca, but he was mostly satisfied with their frequent telephone calls. Pete did, however, find the CP system’s medication reminders useful (albeit “insistent”) after Alison programmed them for him. He also ideated a creative use for the Events feature, and asked Alison to program a daily morning reminder to shut off his bed heater – a safety concern expressed by Linda. This morning chime soon became their “alarm clock”. Despite this successful use case, however, Pete mostly resented not having direct control over specifying and modifying the CP system’s functions; requiring everything to be managed by a “caregiver” (in this case, Rebecca or Alison) made Pete feel “like a second-class citizen”. He thought it was impractical to burden others to make changes when he was used to managing his own schedule and routines, albeit imperfectly (e.g., occasionally missed medications, appointment mix-ups). His disappointment was reinforced when Alison discontinued volunteering and Pete lacked the control to deactivate the morning “alarm clock” during the darker winter months. He resorted to unplugging and hiding the CP system away to avoid its disruptions. Ultimately, Pete concluded that the CP system would be useful for people who are “further along” (i.e., in their cognitive decline) and more dependent on other people for daily help.

4.5.1.5 iPhone appropriation: supported adoption, intermittent learning, and divergent meanings

Throughout his experience with the CP system, Pete reported that his son (John) had urged him to consider the iPhone instead. Both John and Rebecca thought that Pete would enjoy learning to use its social features and being able to keep in touch while he was out and about. Pete grew more excited about the iPhone after a few outings with John to the Apple Store during his visits to Canada. After Pete’s decision to discontinue using the CP system, John purchased Pete an iPhone and Rebecca agreed to pay the monthly subscription. Initially, Rebecca reported that they all enjoyed trying out FaceTime (video calling). Rebecca, however, soon realized that the iPhone may be too complicated for Pete to learn, given no previous cell phone experience and no one local to help him practice with it daily. She also noticed that Pete’s abilities were declining, and everyday tasks were taking him longer. She had tried crafting her own iPhone “flashcards” with step-by-step instructions (e.g., How to take a photo using your iPhone) but noticed no progress by Pete. Amelia did occasionally offer to help Pete with his iPhone during their meetings (e.g.,
set up daily alarms for his medications), but she was not an iPhone user herself, and Pete preferred to spend their meetings chatting. Altogether, Pete’s iPhone learning was slow and piecemeal. Unlocking his phone was observed to be slow and laborious (e.g., difficulty keeping track of which digit he had just entered), but he insisted on a 6-digit passcode for his own security against Rebecca’s and John’s advice. Pete had also not saved many numbers in his contact list, which led him to sometimes confuse with whom he was communicating. Text message responses to Amelia and Amy were delayed by days (if sent at all), and he missed multiple voice calls. Rebecca had the impression that Pete rarely used his iPhone. More than the subscription costs, she was concerned that Pete’s slow learning was discouraging and adding to his anxiety about cognitive decline. She agreed that John had the best of intentions with the iPhone purchase, but she lacked confidence that Pete would be able to master it. In contrast, Pete had quite a positive attitude toward his iPhone. He admitted that he was slow to learn but repeated with pride that his kids had bought it for him, and he was appreciative and happy to let them “pull him into the 21st century”.

4.5.1.6 TeamViewer appropriation: crafting a new, mutually meaningful care practice

Toward the end of the study, Rebecca shared her recent concerns about Pete’s waning email use, despite previously being a daily practice that he valued. She had proactively logged into his email account, which immediately confirmed that he was extremely behind on reading and responding to even important messages from family members and his valued writing group. Seeing this “quantified” to Rebecca that Pete’s cognitive abilities had indeed declined, which mobilized her to “take charge more”. She started a new daily practice of logging into his email and deleting some emails, hoping to make it more manageable for Pete to catch up. She reported that Pete had no problems with Rebecca accessing his account, but was concerned about burdening her with this task, plus losing control over which messages were deleted. This led to a daily practice of reviewing his inbox while they were on the phone. This was initially time-consuming, where Rebecca first had to talk Pete through the login process and then verbally describe what she was doing as she navigated through his email interface. This shared practice, however, improved markedly when Rebecca’s cousin recommended TeamViewer, a screen-sharing application that allowed Rebecca to remote-control into Pete’s computer. Using TeamViewer while on the telephone, Pete and Rebecca could review his inbox together, Pete
could instruct Rebecca as to which messages to delete, and Pete could see how Rebecca was doing it. To Rebecca’s delight, Pete eventually learned how to do this independently with minimal remote-access and prompting by Rebecca. Despite the time and effort involved, Rebecca was “happy to do it”, she felt good about supporting Pete and she knew how much he appreciated her efforts and valued being able to manage his email again.

4.5.2 Case 2: Daniel and Alison

4.5.2.1 Informants

Daniel (PwD, 77 years old), Caucasian, is a former bus driver and former volunteer at his late mother’s (with Alzheimer’s disease) care facility while taking care of her. He moved to the city from a small town ten years ago to live with his only son, daughter-in-law, and granddaughter. He lives in their basement suite with his own kitchen, bathroom, and single bedroom, which he also uses as his living area and office. Daniel appears to be in good physical shape and is warm and soft-spoken. From his recollection, he was diagnosed with Alzheimer’s disease about four years ago and struggles to place words and keep up during social conversations.

Daniel is highly independent in his day-to-day life and activities, and he reported that he did not know “anybody who might be interested or available” to participate with him in the study. He describes his relationships with his family members upstairs as distant and tense. He reports that they travel often and perceives them to be too “busy, busy, busy” for quality conversations. Admitting that he mostly “tries to stay out of the way”, he primarily communicates with them about his household tasks (e.g., feeding the dog, garden) and when he housesits during their travels. He describes experiencing intermittent moments of “blank space” and confusion, during which he prefers not to interact with anyone. He feels that this withdrawal and his dementia are misunderstood by his family (e.g., perceived as rudeness), and he wishes for a separate entrance to his suite. In later interviews, Daniel shared that his son had suggested that Daniel may need to find an alternative living arrangement, but Daniel was unsure if and when that would happen; serious family conversations are few and far between. Daniel’s strained family relationships motivated him to “branch out” socially, especially now that he no longer drives and visiting old friends is infrequent. The year before the study, he happened to drop in to the NO one day and got a “good feeling”. He gradually started attending the NO’s meal events and senior’s programs, and also likes to “hang around” in case someone can help him with his iPhone or tablet.
Alison (Daniels’ first volunteer, described in Case 1) is the same volunteer as described in Case 1 above. She met Daniel once at the NO and during one home visit with Amy, before she discontinued her volunteer role at NO.

4.5.2.2 Researcher’s role

Amy (first author) met Daniel on six occasions during recruitment and data collection – once in his home and five times at NO. After the first home visit, he requested to meet at NO due to his tense family environment. Playing a concurrent role as a NO volunteer, Amy fielded a few of Daniel’s iPhone questions. After confiding in her about his family situation, she conveyed Daniel’s housing concerns to NO staff and provided him information for support at the province’s Alzheimer’s Society.

4.5.2.3 Existing ICT arrangements

Daniel owns two tablet computers (Galaxy and iPad), an iPhone, and several peripherals (Bluetooth keyboard, printer, router), but reports that he has been mostly unsuccessful in “getting things to work”. Over time, he accumulated these on the piecemeal advice of tech-savvy friends and store sales staff but feels that no one had the time nor understanding of his needs to teach him how to use anything. He mostly blames “[his] mind” for not being able to learn the “language” of today’s technology. Determined to “get answers” to his many technological questions from empathetic people, and to foster new social relationships, Daniel was keen to participate in the NO’s pilot program by trialing the CP system. Over the course of the study, Daniel developed new relationships with NO program staff from whom he regularly asked for support with his iPhone and tablet computer.

By the study start, Daniel had managed to master a few functions on his iPhone – his newfound “lifesaver” – by piecing together support from acquaintances at the NO, friends, and store staff. He now used it as his one trusted source for verifying the date and time. Learning how to make voice calls and text messaging also meant that he could communicate briefly and directly with his family members, which he preferred to in-person conversations that he felt to be straining within their fast-paced lifestyles. Daniel had also found tremendous meaning in mastering how to take and review photos on his iPhone; using it helped him document and recall his outings, and his photos gave him conversation topics and experiences to share with others. For example, when
scrolling through photos during our home visit, we shared laughter with Daniel as he happily retold stories of his encounters with remarkable ease and detail.

4.5.2.4 CP system appropriation: non-adoption due to complicated technological adaptation and inadequate care partner support

Although the Coordinator had met Daniel’s daughter-in-law during her home visit, Daniel elected to participate in the NO program and study without a care partner. After two meetings between Daniel and Alison at the NO, Alison and Amy visited Daniel at home for his first training session. By then, Daniel admitted that he had entirely forgotten what the CP system was for and his role in the program. As we started reminding him of its features, he proposed that the CP system might be a good way for the NO program to ‘broadcast’ information (e.g., calendar reminders for upcoming events) to its program participants – a use that NO program had not intended but later considered offering. He thought this would resolve his feeling of being “disheveled in my mind” when trying to manage the program’s paper brochures and remembering which program he was to attend on which date and time.

Getting started with the CP system training sessions introduced several technical problems. Initially, there were problems connecting to the home Wi-Fi network, which repeatedly sent Daniel upstairs to seek help from his daughter-in-law, whom we noted he never invited to join us. Once finally connected, Alison reintroduced Daniel to the Messaging feature. He struggled to use the touchscreen keyboard and Alison was unable to connect his Bluetooth keyboard to the CP system. We moved on to trying the Photos feature, as Daniel thought he could transfer photos from his iPhone. This led to difficulties resolving why the CP system could not receive the photos as email attachments from his iPhone. After much trial and error (e.g., emailing test photos from Alison’s smartphone), we realized that Daniel’s email address needed to be added to the CP system as an ‘authorized’ Contact. Alison, who was still training on the CP system herself, had overlooked this requirement. Despite eventually resolving the issue, our protracted troubleshooting process left Daniel feeling all the more confused, excluded from the process, and discouraged about his limited technological knowledge.

After this visit and Alison’s discontinuation of her volunteer role, Daniel decided that the CP system was not suitable for him. He concluded that he did not have family members who were available to help him manage his content, nor was the CP system as portable as his iPhone or
tablet computer. It also seemed unsuited to his goals of typing comfortably and printing out his personal journals. He had found that typing allowed him to get his thoughts down quickly and clearly and printing out his journals might be a better way for him to communicate; not only would sharing his journals create conversation with his family members, they had also previously complimented him on his writing, which made him feel good about himself. Instead, he was determined to persist in learning to use the devices that he had already purchased. Daniel also felt it was not enough for him to learn to use individual devices; he felt he also needed to learn more broadly and cumulatively so that he can be conversant in the ‘language’ of technology that everyone else seems to speak.

4.5.2.5 iPhone voice recorder appropriation: leveraging acquired know-how and available support to create meaningful self-management practices

At the end of a later interview, when Amy had stopped her audio recorder, Daniel expressed an interest in having an audio recorder. Spontaneously, Amy pointed out that Daniel had a native voice recording application on his iPhone and he excitedly asked for her instruction. Amy mapped the application to his iPhone home screen and stepped through the process of how to access the application and then start, stop, and save the audio recording. Daniel practiced the process once by himself, and Amy noted how quickly and comfortably he was able to recall and repeat her actions, navigating through each interface with comfort and ease. She juxtaposed this learning pace with his laboured pace of navigating through the CP system—an entirely unfamiliar interface. At the beginning of their next interview two weeks later, Daniel showed Amy that he had started making a habit of using the voice recorder during meetings and conversations, and proudly placed his iPhone on the table to show that he had started his own audio recording.

4.5.3 Case 3: Edwin, Anita, and Wendy

4.5.3.1 Informants

_Edwin (PwD, 55 years old)_ is a Chinese-Canadian former businessman who emigrated with his family from Hong Kong. He lives in a house with his wife (Anita) and their three kids who all attend university locally. In 2010, Edwin was diagnosed with hydrocephalus and underwent neurosurgery that left him with brain damage, further complicated by a diagnosis of Alzheimer’s
Disease. Edwin, who was the family’s sole income provider, stopped working in 2012 after being admitted to hospital, completing in-patient rehabilitation, and then coming home. As Edwin is susceptible to seizures, Anita provides constant supervision. Edwin attends a day centre twice weekly plus a weekly dementia social group. A personal support worker comes to the home one afternoon each week. He and Anita have grown accustomed to always being together outside these programs. Although they can no longer travel as much as they would like, they go on daily walks, run errands together, attend church, and meet friends at different restaurants.

Anita (Edwin’s wife, 54 years old) is a former professional secretary from Hong Kong. She stopped working after their second child to take care of their home and kids. These days, Anita says with mixed feelings that she and Edwin spend “almost twenty-four hours” together. Practically, she manages the household and all of Edwin’s care and activities, but was observed to regularly check with Edwin about his preferences before making decisions (e.g., study participation, inviting Amy into their home). Due to his risk of seizures, she avoids leaving Edwin alone for more than 15 minutes. She also worries that he will be inactive and unstimulated, which she finds dampens his mood. She therefore tries to keep him busy by suggesting simple chores for him to do (e.g., washing plates), turning on programs for entertainment (e.g., television and Internet radio), and arranging social outings with their friends. She helps Edwin develop and maintain relationships with his family members, friends, and new acquaintances. Lately, Anita feels overwhelmed and wishes her kids would help her more, but she finds them preoccupied with their studies and social lives. She is thankful for Edwin’s personal support worker, with whom they both developed good relationships over the previous three years. Their case manager suggested that Anita consider placing Edwin at a respite centre when she wants a break (e.g., travel with her friends), but Anita does not want to hurt Edwin’s feelings; he will feel confused and abandoned without her, and she would feel terribly guilty.

Wendy (Edwin’s volunteer, Case 4 family care partner) met Edwin and Anita at a social club for persons with dementia and referred them to participate in the NO program, for which Wendy became their volunteer supporting their CP system training. After two sessions, however, Wendy experienced health problems and stopped volunteering. Anita was reluctant to onboard a new volunteer, concerned how well Edwin would get along with someone entirely unfamiliar. They have discussed Wendy resuming her support when she is back to health.
4.5.3.2 Researcher’s role

After meeting twice during recruitment and developing trust and rapport, Edwin and Anita invited Amy (first author) to volunteer with them in their home. Amy spent two visits providing technical support to Anita on the CP system, which led to configuring and troubleshooting it together with several of their existing mobile devices.

4.5.3.3 Existing ICT arrangements

Managing ICTs is integral to how Anita supports Edwin daily; it mediates his enjoyment of constant stimulation with her priority of promoting his mental and physical activity while she manages their household, family, and care routines. As all of their ICTs (i.e., laptop, smartphone, smart TV) are too complicated for Edwin to use independently, Anita must find content that he would enjoy, turn on the device(s), and set up the content to play. Anita also facilitates Edwin’s social communication. He has the same smartphone as Anita but relies on her to use it. They mostly use WhatsApp (text messaging application) to keep in touch with Edwin’s mother and sister in Hong Kong, as well as participate in a group chat with their Hong Kong friends. Anita needs to alert Edwin to new messages and open them for him to read. She admits that neither her nor Edwin have strong technological acumen so, for more complicated setup and configuration tasks (e.g., creating new accounts, passwords, settings), she either asks their kids for help or they hire technicians. With Wendy’s recommendation and initial training support, Anita was interested to participate in learning the CP system. As the television and computer had become “too complicated” for Edwin to use independently, Anita hoped that the CP system could provide Edwin with ongoing stimulation and entertainment that tended to lift his mood and “arouse his spirit”. After discussing with Edwin, they agreed to participate in the NO program to see if the CP system could benefit them. Anita, however, did not expect her and Edwin to benefit from using it as much as Wendy and Patrick, who lived separately.

4.5.3.4 CP system appropriation: selective and unanticipated feature use, complicated technical configuration, and purposing different devices for different needs

For Edwin and Anita, appropriating the CP system came with successes, challenges, and unanticipated uses. Initially, Edwin had difficulty remembering what the device was for but grew fond of it over the study period, especially as Anita grew proficient in adding content to it. By
the end of the study, Edwin had started using it regularly to browse through family photos and videos, which made him “feel loved” and as if he had his own “personal computer”. The reminder features, however, were less amenable to Edwin, despite Anita’s efforts. For example, Anita had hoped Edwin could learn to respond to Event reminders that she programmed. Through trial and error, she learned to create successive reminders leading up to an event (e.g., leaving home for appointment), as Edwin would quickly forget with a single reminder. Edwin, however, admitted that he preferred to “have conversations” rather than responding to a chime. As such, in persisting in her verbal prompts, she unexpectedly discovered the CP system’s Medication reminder valuable to her: the chime alerted her to remind him of his medications, which she would occasionally forget to do on a busy day. Appropriating the Messaging feature also came with a positive albeit unexpected outcome. Initially, Anita felt they would not use this feature because she and Edwin lived together. However, as Edwin started to use the CP system more frequently, Anita tried sending him messages when she was out of the house (e.g., notifying him she was delayed in coming home, suggesting some light chores or activities to keep him busy). She was pleasantly surprised that, after she had shown him the text messaging feature a few times, he had learned to send back simple replies (e.g., “OK”). These replies gave Anita peace of mind to know that he was safe and comfortable on his own and having this connection to Edwin gradually allowed her to feel more comfortable leaving home for slightly longer periods of time. The last feature that Anita and Edwin came to enjoy was the Exercise video (i.e., that the NO program had loaded onto the CP system), which they would often do together. Hoping to add more exercise videos, Anita requested Amy’s help to find and add new video content to their CP system.

In response, Amy attempted to add to their CP system’s Web Links list 1) their preferred Chinese Internet radio website, and 2) additional exercise videos from YouTube. These goals led Amy and Anita to extensive technical configuration and troubleshooting over two visits (in total around 3 hours), in addition to multiple email exchanges between Amy and the CP system’s technical support personnel. The problems that were encountered included:

- Media player incompatibility between those supported by the CP system and the one used by the Chinese Internet radio website;
• Apple ID requirements, where Anita needed to reset her Apple ID in order to download the web console iPad application, but did not know what password her daughter had specified for her account. The password retrieval emails turned out to be sent to Edwin’s email address, not to Anita’s. Additionally, Anita needed to enter a valid credit card information even to download a free iPad app;

• Hidden URLs to the desired YouTube videos when using the YouTube iPad app, which was incompatible with the CP system that required the URL to save a specific website;

• Multiple steps (i.e., 4 clicks) to view YouTube videos in full-screen mode on the CP system; and

• Losing sound on the CP system due to the device battery level dropping below a specific threshold, without a notification indicating that it must be placed back on its charging base for sound to resume.

Ultimately, the goals of accessing the Chinese Internet Radio website and adding exercise videos from YouTube were both partially achieved. Amy and Anita were unable to add the Chinese Internet Radio website to the CP system, but instead saved it as a bookmark on Anita’s iPad Mini, which meant that Edwin would still need Anita’s help to access it. Fortunately, however, Anita and Edwin realized that accessing this content on her iPad Mini would allow Edwin to enjoy this content on a more portable device, which meant that he could stay entertained when they were away from home (e.g., while travelling). Secondly, a YouTube playlist of tai chi videos was added on the CP system but, again, Anita would need to help Edwin click through to play the videos in full-screen. Nevertheless, both Anita and Edwin were pleased with the outcomes, which were beyond their initial expectations of the CP system. Anita, in particular, however, recognized the time, knowledge, and efforts, in collaboration with a third-party, which were needed to configure her devices and applications. While she felt that her kids would not have persisted through the troubleshooting process, she still felt apprehensive about onboarding a new NO volunteer, in case Edwin did not feel comfortable.
4.5.4 Case 4: Patrick, Wendy, and Max

4.5.4.1 Informants

Patrick (PwD, 71 years old) is a German-Canadian former web press editor and former mariner. Four months prior (during study recruitment), he moved from living independently to an assisted living residence in a one-bedroom apartment. He was diagnosed with Alzheimer’s Disease four years ago. He is divorced but remains close and primarily supported by his former wife, Wendy. The two had committed to supporting each other to “age gracefully”, which Patrick does by “keep[ing] an eye on” Wendy and cooperating with her to ease her care workload. He has become more cognizant of this since Wendy experienced a “burnout period” and was hospitalized. Patrick and Wendy have two adult children (Max in a smaller city in the same province, and Melissa in the U.S.) and five grandchildren. Patrick and Wendy used to travel together to visit their children and grandchildren, but now their family members come to visit them. Patrick has a gentle demeanor with a quiet sense of humour and speaks softly and slowly, pausing frequently to find the right words. During group conversations Wendy was observed to frequently provide him cues and clarifications, which he seemed comfortable with and appreciative of.

Wendy (Patrick’s former wife, 64 years old), also German-Canadian, is a retired nurse and now Patrick’s primary “care partner” (her preferred term). She is highly organized, resourceful, and technologically competent. Admitting that she sometimes finds herself overcommitted, she keeps busy with her involvement in various Alzheimer’s and community organizations. Just before Patrick moved to his assisted living residence, “running two households” led to her being hospitalized. Thanks to the care services (e.g., medications, meals, bathing) at his new residence, she has been better able to manage and is now extremely mindful about prioritizing her own health. In the past year, she has become more communicative with Max and Melissa in requesting their help, and stresses that the CP system has been integral to facilitating their care involvement (e.g., event management, photos and videos for social connectedness).

Max (Patrick’s son, 37 years old), Patrick’s son, lives in a smaller city within the same province, with his wife and three children. He is a camp director and working on his Master’s degree. Over the past year, in support of Patrick and Wendy, he started using the CP system to communicate more frequently with Patrick and relieve Wendy of managing Patrick’s schedule when she is out
of town. Max is particularly attuned to – even admittedly protective of – Patrick’s feelings of anxiety and vulnerability, which he believes are, in part, due to Patrick’s constant concern for Wendy’s wellbeing. He strives to be a source of positive support for Patrick and assuage his anxieties about his cognitive decline.

4.5.4.2 Researcher’s role

Amy (first author) maintained a researcher-only role and did not perform any NO volunteer duties for Case 4.

4.5.4.3 Existing ICT arrangements

Due to his cognitive problems, Patrick can no longer independently use his computer, which he previously enjoyed for Internet browsing. He also previously used his cell phone frequently, but now has trouble remembering he has it, what it is used for, and differentiating it from his cordless landline telephone. Patrick does, however, try to remember to take his cell phone when going on outings alone (e.g., taking transit to his social club), which he and Wendy agree is important.

4.5.4.4 CP system appropriation: negotiating and cooperating through new practices, improving family communication, and restoring the social nature of care relationships

Before using the CP system, Wendy had been actively looking around for a “solution” to her overwhelming care workload; she previously considered herself Patrick’s “information highway”, receiving sometimes ten telephone calls a day when he became disoriented or unsure of upcoming events. From Patrick’s perspective, learning the CP system was his way of supporting Wendy by helping to reduce her workload. For both Patrick and Wendy, participating in the NO program and this study was also a way to fulfill their shared commitment to supporting Alzheimer’s Disease research. Due to their positive experience with and advocacy of the CP system, they have established direct relationship with CP’s founder, who provides them ongoing technical support as needed.

Particularly since adjusting to his day-to-day life at his new residence, Patrick feels anxious when he is disoriented to the day, time, and scheduled events. Although Wendy and Max regularly remind Patrick that he can “trust” the information provided by the CP system, Patrick
admitted that he would not always “obey”; rather, he preferred to triangulate based on multiple “clues” – his wall clock, wall calendar, care routine cues (e.g., arrival of “pill lady”, shower time), as well as information and alerts from his CP system. To Patrick, being able to make sense of information from multiple sources and successfully orientate himself meant that he could still trust his mind. Appropriating the CP system together helped Wendy and Max empathize with Patrick’s anxiety about his memory difficulties. With patient and persistent use, cooperation between Patrick and Wendy, and increasingly more involvement from Max and Melissa, the CP system has become a regular tool through which Patrick’s family supports him in day-to-day life.

Wendy regularly uses the Events feature to add upcoming outings (e.g., appointments) and events, and has established different communication practices with Patrick for different event types. She has learned to add multiple, successive reminders for when Patrick needs to get ready and then leave on time. For these, she will usually phone Patrick to discuss the event first and confirm that he would like to go. To ease Patrick’s anxiety about forgetting the future event, Wendy will remind him that she will add the discussed event to his Events calendar in the CP system, which will trigger timely reminders. In contrast, for daily scheduled events (e.g., meals, optional leisure activities, scheduled TV programs), she will input them into his CP system without a prior conversation with Patrick. On a regular basis, Wendy is the “boss” and first to respond to any CP system alerts (e.g., missed medications), but Max and Melissa have also learned how to help with managing Patrick’s scheduled activities this way when Wendy is out of town. The family also uses the Messaging and Photo features fairly regularly, which have allowed Patrick to be more “tied in” with his family (and a few of his friends) despite the distance between them. Max and Wendy have also been encouraging Patrick to use the Call Request feature, which he initially interpreted as a call button in case of emergencies.

Each family member has come to feel “grateful” for the CP system for different reasons. For Patrick, when he forgets how many grandchildren he has or how old they are, he can go into his Photos to “get the answers”. Adding Google to Patrick’s Web Links list has also restored his ability to surf the Internet – an activity he could no longer manage after using the computer became too complicated for him. Today, Patrick is proud to be able to do this on his own, and his family members are happy that he can resume some entertainment independently. For Max, he can involve Patrick in his young family’s life more frequently and draw on this content to have enjoyable conversations with Patrick. He also likes that Patrick can initiate a chat (i.e., via Call
Request) and avoid the complexity (i.e., remembering or retrieving Max’s telephone number, dialing, etc.) of using the telephone to call him. For Wendy, she no longer needs to be the “go-between” between Patrick and their children and solely responsible for maintaining his social relationships. She is, however, able to manage the people who communicate with Patrick through the CP system, which she does in order to prevent Patrick from feeling confused or overwhelmed if contacted by someone he does not remember, or someone who may not understand his cognitive limitations. Moreover, with Patrick more independent in his day-to-day life, both Patrick and Wendy agree that the CP system has alleviated the “business” and tensions of day-to-day care and restored more quality time and conversations together.

4.6 Collaborative appropriation: processes and driving forces

Our cross-case analysis generated a model of collaborative appropriation shown in Figure 10. We interpreted collaborative appropriation as comprised of two related processes: creating and adapting technological practices and negotiating and augmenting care relationships. We delineated four driving forces that facilitate these two main processes: motivating individual and relational meanings that actors ascribe to the ICTs themselves or the appropriation process; the learnability of the ICT and related resourcefulness of the actors appropriating it; responsive and cooperative care practices that are adaptations of existing practices or newly developed through appropriation; and empathy and shared power in the care relationships between the actors involved in appropriation. Diagrammatically, adjacent driving forces relate to one another, and diagonally placed driving forces relate to one another through the mutually adjacent force. For example, ‘motivating individual and relational meanings’ relate to ‘responsive and cooperative care practices’ by influencing ‘learnability and resourcefulness’, and by influencing the ‘empathy and shared power in care relationships’. Each process is situated atop the two driving forces that most influence that process. In this section, we describe each process (and sub-process) and driving forces, and how they are related to one another.
4.6.1 Processes of collaborative appropriation

Our cross-case analysis generated two main processes and four sub-processes of collaborative appropriation, which are summarized in Table 7. *Creating and adapting technological practices* involves the sub-processes ‘back-end’ support involves care partners (or other nominated actors, e.g., volunteers) independently learning, configuring, and troubleshooting ICTs, while ‘front-end’ support involves care partners teaching and supporting PwD in their learning and negotiating new or adapted technological support practices. *Negotiating and augmenting care relationships* involves diffusing and nominating care involvement from PwD to care partners and other actors (e.g., service providers), and reconfiguring and developing care relationships. As depicted in our model (Figure 10), the two main processes inform, produce, and reproduce one another; that is, adapting technological practices leads actors to negotiate their care relationships and, in turn, their relationship changes influence the development of their technological practices.
Table 7. Study III – Processes and sub-processes of collaborative appropriation

<table>
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<td>‘Back-end’ support: independent learning, configuring, and troubleshooting ICTs for use</td>
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4.6.1.1 Creating and adapting technological practices

4.6.1.1.1 ‘Back-end support’: independent learning, configuring, and troubleshooting ICTs for use

Supporting ICT appropriation required dedicated time and persistent efforts by those care partners and/or volunteers who were supporting PwD in appropriation. One part of these efforts included care partners or volunteers to, first, independently learn the unfamiliar ICTs and then configure them for meaningful use by PwD. Most descriptively illustrated in Daniel’s and Edwin’s CP system appropriation, back-end support entailed a host of technical tasks and challenges, including: managing Internet connectivity; managing multiple devices and different user accounts and applications for each; adding and finding Internet content; troubleshooting and obtaining third-party technical support; and configuring ICT features that they believed PwD would be motivated and able to learn. These complex efforts involved care partners and/or volunteers exploring, practicing and learning how to configure different features, and ‘programming’ the specific functions (e.g., event reminder) that they would subsequently trial with the PwD. Substantial time and efforts were involved troubleshooting unexpected problems with setup and configuration, which care partners and/or volunteers attempted to resolve independently or with external support from peripheral care network members (e.g., other family
members) or service providers. Through their back-end support, care partners and volunteers developed knowledge and know-how about the ICT, which guided subsequent front-end support efforts with PwD.

4.6.1.1.2 ‘Front-end support’: teaching ICT use and negotiating support

Care partners and volunteers alternated between providing back-end support and ‘front-end’ support to PwD through teaching, configuring, and adapting ICTs. Front-end support was an iterative and negotiated process whereby specific functions were trialed, teaching strategies were devised (e.g., verbal instructions, instructional “flashcards”), and meanings were ascribed to ICT appropriation by each involved actor. Front-end support tended to make visible PwD’s motivations, preferences, abilities, and vulnerabilities (cognitive and emotional), both to themselves and their care partners and/or volunteers. For example, Rebecca acquired insight into Pete’s weakened cognitive abilities when she observed his waning email use. In collaborating with Pete, they established his desire to maintain decision-making control over his email inbox while re-learning how to manage his email independently. This led to Rebecca’s back-end efforts of seeking advice from her cousin and eventually appropriating the TeamViewer application that would facilitate their real-time virtual practice of re-learning email. This exemplifies how care partners and/or volunteers continuously learned and adapted ways of providing support within their own knowledge, resources, and constraints, and how front-end and back-end efforts relate to one another.

4.6.1.2 Negotiating and augmenting care relationships

4.6.1.2.1 Diffusing and nominating care involvement

Learning new technology and obtaining technological support tended to diffuse care involvement from PwD (i.e., with their own self-support strategies) outward to immediate care partners. From whom to seek support, or nominate, was found to be selective and was influenced by the nature and quality of the care relationship. For Edwin and Patrick, obtaining technological support from Anita and Wendy, respectively, seemed to be a natural continuation of their care relationships, whose natures already involved practical, day-to-day support. For Daniel and Pete, who were more independent in their day-to-day activities, appropriation triggered a new set of needs that they had difficulty managing independently. Seeking technological support, however, was found to confront or disrupt the established nature of their care relationships. Daniel, who described his
relationships with co-residing family members as tense and preferred to “stay out of [their] way”, reluctantly asked for technological help from his family members and friends. Moreover, his very reason for not adopting the CP system was that he did not feel he had the support he needed from family members, for which the system was designed. This led him to pursue new relationships at the NO program and seek support with learning his existing ICTs. Pete also found that the CP system disrupted the more social and emotional nature of his relationship with Rebecca, placing an impractical burden on her for tasks that he was accustomed to manage himself (e.g., his weekly schedule). Further, the technological support that the CP system demanded, especially in the initial stages of exploration and configuration that required responsive, continuous, and knowledgeable support. This turned out to be greater than the support that an NO volunteer could provide within a weekly time commitment.

Appropriation was also found to diffuse care involvement from primary to peripheral care partners or other nominated actors, which was also selective. Care partners also sometimes ‘nominated’ with whom and how PwD kept in social contact. For this reason, Wendy and Anita found useful the CP system’s feature that only allowed invited contacts to send messages to the CP system. In Patrick’s case, the CP system enabled Wendy to add Max and Melissa to Patrick’s contact list. Care partners were also found to nominate others to participate in care tasks or routines through technological support. Over time, Wendy delegated and distributed some of her care responsibilities to Max and Melissa, who were previously less involved in her’s and Patrick’s care routines. Similarly, Anita’s and Edwin’s children were periodically involved in supporting them technologically (e.g., setting up accounts, password reminders). Although Anita desired more support, she also felt that they needed to be selective about anyone invited into their home and whether Eric would feel comfortable. Lastly, especially to support their back-end efforts, care partners may also seek help from service providers, evidenced by both Wendy and Amy who sought technical and troubleshooting support from CP’s founder.

4.6.1.2.2 Reconfiguring and developing care relationships

The studied cases demonstrated the different ways in which appropriation confronted care relationships, leading actors to reconfigure their existing care relationships or develop new relationships. Learning to use text messaging on his iPhone allowed Daniel to communicate more clearly and directly with his family members, and sharing his written thoughts allowed him
to express himself and feel recognized by them. As the nature and quality of Daniel’s existing relationships did not lend themselves to practical and technological support, he proactively sought to develop new relationships at the NO program – thus, augmenting his existing support network. Learning to audio-record on his iPhone also facilitated Daniel’s new relationship building by reminding him of previous conversations. Similarly, for Edwin and Anita, appropriation led to building new supportive relationships with Wendy and Amy, which fulfilled their unmet needs for technological support that their existing relationships (e.g., with children). By developing technological support practices, Pete’s and Rebecca’s relationship shifted toward more practical and frequent forms of support. In Patrick’s family, the diffusion of care involvement led to reconfigured relationships. Max was able to develop a more direct relationship with Patrick (i.e., independent from Wendy, their previous “go-between”), and provide practical support to Wendy in her care demands. Moreover, Max positioned his relationship with Patrick as complementary to Wendy’s practical support role, in that Max prioritized emotionally supporting Patrick’s anxieties about Wendy’s health and wellbeing.

Lastly, in different ways between our studied cases, appropriation led to restored or enhanced care relationships. For Wendy, being relieved of Patrick’s repetitive phone calls, mediating his social relationships, and scaffolding all of his leisure activities (e.g., Google) allowed her to support him “from a place of love and compassion” and restore the quality time they had previously enjoyed. Patrick, in turn, became attuned to Wendy’s “more considerate” demeanor and was able to simply enjoy her company without feeling like a burden. Similarly, the independence that Edwin gained from appropriating the iPad Mini and the CP system into his day-to-day routines improved his mood and reduced Anita’s worries and guilt when she was occupied or away from home. To the benefit of both Edwin and Anita, having access to entertainment on a portable iPad Mini also allowed them more freedom to go on outings and family travel because Edwin could almost or mostly access his media content independently, which allowed Anita her own leisure time. Common across all cases, the sharing of photos and videos was found to enhance the social natures of the studied care relationships. Retrieving saved media created opportunities for PwD to recall and reminisce about enjoyable events, memorable moments, and relationships of significance. This was particularly valuable in the case of geographically distant relationships, where these media bridged quality time spent together during visits (e.g., Patrick being more “tied in” and socially included in Max’s family life thanks
Moreover, sharing photos and videos during social interactions made for enjoyable topics of conversation, which was observed to facilitate rapport building in new relationships, such as between PwD and their volunteers.

In summary, creating and adapting technological practices led actors to renegotiate their care relationships. In turn, changes to their relationships sustained and produced their new or adapted technological practices.

4.6.2 Driving forces of collaborative appropriation

We generated four driving forces that facilitated the two described processes of collaborative appropriation: a) motivating individual and relational meanings; b) learnability and resourcefulness; c) responsive and cooperative care practices; and d) empathy and shared power in care relationships. We describe how these forces drove collaborative appropriation forward and how, if lacking or absent, appropriation was impeded or thwarted.

4.6.2.1 Motivating individual and relational meanings

All four cases demonstrated how positive meanings that actors associated with learning or using ICTs motivated and drove their appropriation. In contrast, negative meanings, or lack of meaning, impeded or thwarted appropriation. Often, actors ascribed initial meanings to the technology or its use. These meanings, however, sometimes transformed through ICT learning, appropriation, or ongoing use, and the negotiation of care relationships.

Individual meanings derived from actors’ personalities (e.g., sociable); interests, preferences, or values (e.g., maintaining autonomy); or the self-image that they wished to promote (e.g., independent). Relational meanings were often layered together with individual meanings, and concerned enhancing empathy or shared power in the care relationships between actors, and supporting their desired ways of relating to one another (e.g., offering help and assistance to enact one’s value of family connectedness). First, meanings may be ascribed to simply owning or possessing a certain technology. Pete, for example, found his iPhone meaningful irrespective of his learning difficulties and intermittent use; just owning an iPhone meant that he could pursue his interest in technological gadgets, attempt to “catch up with [modern society]”, and symbolized his adult children’s care for him. Secondly, the technology learning process itself may be meaningful. Pete, for instance, loved learning new things and, for Rebecca, teaching and
supporting Pete offered a way for her to “take charge more” in supporting for him. For Daniel, the learning process afforded him opportunities to build new supportive relationships at the NO program. Thirdly, successfully learning and appropriating technology may also produce meanings that sustain actors’ use. It may mean restoring independent leisure time (e.g., through website browsing, news, photos, videos) that had been lost due to cognitive barriers to accessing previous ICTs; discovering new practices that support everyday activities (e.g., Daniel’s audio-recording practice) or care practices (e.g., Anita’s use of medication reminders); adapting better ways of communicating and connecting with others; or restoring the social and reciprocal aspects of care relationships through alleviated care demands. Fourthly, successfully appropriating technology may confer a sense of mastery or achievement to actors, which can be affirming both individually and relationally. Lastly, the informants in our study were additionally motivated by meanings of being valued, feeling empowered, or serving an altruistic purpose through their NO program and study participation; they felt that they were contributing to dementia research and programs to support persons and families living with dementia. Thus, the ways in which actors construct and layer different positive meanings to technology use was found to strongly shape their appropriation decisions and trajectories.

This was also the case for negative meanings or a lack of meaning that actors ascribed to learning or using technology, which discouraged or impeded appropriation. Pete resisted the CP system because he felt it labeled him as dependent on others. Rebecca, despite trying to support Pete, could not find a meaningful use for the technology vis-à-vis her and Pete’s established ICT practices (e.g., telephone, email). The learning process may also be hampered if it evokes a PwD’s frustration, anxiety, or sense of vulnerability. A PwD may also resist a new technology, or some of its features, that undermines his preferences or established strategies. Both Edwin and Patrick, as examples, resisted “obeying” prompts by the CP system due to preferred or established practices. Therefore, negative meanings or a lack of meaning, may lead to non-adoption when actors feel immediately alienated or disempowered by a technology’s design intentions; disappropriation, where actors try it but cannot establish positive meaningful practices; or selective appropriation, where actors empathetically negotiate the use of specific features vis-à-vis their personal preferences or established practices.
4.6.2.2 Learnability and resourcefulness

Together, the learnability of the ICT and actors’ resourcefulness were found to drive appropriation. Learnability was related to the ‘resources’ that actors brought to the learning process – that is, their ‘technological literacy’ and know-how: their understanding the ICT’s functions and applications, how to interact with it (e.g., buttons, icons, gestures), its different applications, if and how it could interoperate with other hardware or software, and their understanding of its technological infrastructure (e.g., Internet connectivity, software and system compatibilities, account management, hardware requirements). For PwD, cognitive resources contributed to their learnability: the ability to remember the purpose of the technology, the sequence of actions needed to initiate specific functions, and how to respond to feedback from the technology. Despite cognitive challenges, however, PwD all demonstrated resources of creativity in exploring, making sense of, creating meaningful uses for, and situating ICTs within their practices. This resource allowed them to explore and contribute meaningfully to the adaptation of a technology, which facilitated collaborative appropriation. Other ‘resources’ included the *money/means* to purchase the technologies, services, or supports; the *time* to invest into learning the technology, exploring potential uses for it, integrating it into existing technological arrangements and practices, and problem-solving technical issues; and the appropriate *people* to provide technological support – those with time, knowledge, know-how, and supportive teaching skills.

When learnability and resourcefulness were limited for PwD, appropriation relied more on the establishment of responsive and cooperative care practices with care partners or volunteers, where available. Creativity was especially important to care partners in crafting teaching strategies, exploring purposes for the technology, and situating the technology in order to derive benefits from it vis-à-vis existing arrangements. This was aptly evident in the way Rebecca and Pete appropriated TeamViewer to facilitate his re-learning of email use.

Learnability and resourcefulness were also closely related to motivating meanings. First, meanings provided a reason or reinforcement for learning technology and exercising resourcefulness in finding and obtaining the needed support resources. Care partners, for example, may be more willing to be a support resource for those ICTs that promised some meaningful benefit to themselves (e.g., Wendy expected reduced care workload from the CP
Due to limited family support to learn technology, Daniel chose to persevere with the iPhone instead of the CP system, as he had already mastered a few functions on the iPhone, and found it easier to seek help from acquaintances with a mainstream device. Anita and Edwin were motivated to persevere with the CP system owing to Wendy’s and Patrick’s positive experiences, Wendy’s knowledge and initial technical support, and Amy’s subsequent technical support. Similarly, Wendy had established CP’s founder as a reliable support resource, which facilitated her and Patrick’s learning of the CP system. Moreover, she had additional support from Max and Melissa who committed time to learning the CP system, which carried a meaning of family cooperation for all of them.

4.6.2.3 Responsive and cooperative care practices

Appropriation was driven by the development of responsive and cooperative care practices between actors, which were either newly established practices or adapted from existing care practices. Effective care practices mobilized people as a resource for learning and appropriation. Responsive care practices provided support that was timely (e.g., as frequent and consistent as needed) and appropriate (e.g., effective, empathetic, context-sensitive). For example, learning and problem-solving with a new ICT may require consistent teaching or timely troubleshooting. Alison’s support of the CP system, for example, was not adequately responsive to support Pete’s CP system appropriation, nor was Rebecca’s remote support for his iPhone learning. PwD may respond to their own needs by establishing self-support practices (e.g., Daniel’s audio-recording practice), or developing support practices within new relationships (e.g., Daniel bringing his technical questions to NO program staff). Alternatively, appropriation may transform existing care practices, such as Anita herself using CP system’s medication reminder, or messaging Edwin to check-in when she was away from home.

Appropriation was also facilitated when cooperative care practices were established, wherein actors mediated differences in their respective needs, goals, and constraints, and pursued their own motivating meanings. Patrick and Wendy, for example, developed cooperative care practices through the appropriation of the CP system. Doing so promoted Patrick’s independence while reducing care demands on Wendy, as well as peace of mind for both actors. Moreover, cooperating to learn and appropriate the CP system enacted their mutual commitment to supporting one another to “age gracefully”, and eventually Max’s and Melissa’s care for both
parents. Care practices were cooperative to the extent that actors were willing to respond and adapt to one another’s needs, and establish practices that were mutually supportive. Importantly, cooperation and responsiveness were found to rely on a certain nature and quality of the care relationship.

4.6.2.4 Empathy and shared power in care relationships

Care relationships that were characterized by empathy and shared decision-making power were found to facilitate collaborative appropriation. Both characteristics supported learning and appropriating technology when emotional and cognitive vulnerabilities in PwD were encountered, or the dynamics of care relationships were disrupted. As their care relationships evolved and they appropriated the CP system together, Wendy and Max, for example, came to empathize with Patrick’s anxieties about feeling disorientated, and understand why it was important for him to be able to continuing exercising his established orientation strategies instead of solely “obey[ing]” the CP system’s alerts. Reciprocally, Patrick empathized with Wendy’s care demands and cooperated with in appropriating the CP system, while persevering with the social communication features as his way of keeping in touch more with Max. Anita and Edwin also demonstrated empathy and shared decision-making in their relationship, which facilitated their appropriation. Anita repeatedly considered Edwin’s feelings when making care decisions and involved him in all decision-making about their participation in the NO program and study. Reciprocally, Edwin persevered in his practice with the CP system and also came to enjoy and benefit from using it. Both examples demonstrate how relational meanings may motivate or reinforce collaborative appropriation by promoting reciprocity between actors; nurturing their relationships; alleviating care tensions; or providing alternative practices that benefit the care relationship. In contrast, the care relationships that were reportedly characterized by misunderstandings (e.g., between Pete and Linda, and between Daniel and his family members) were not selected for program participation or technological support, even when they were co-residing. Instead, PwD may choose to foster new relationships (e.g., with volunteers) in which they feel understood and empowered.

To note, collaborative appropriation was best facilitated in relationships of empathy and shared power that were also able to establish responsive and cooperative care practices. That is, not all of the studied empathetic care relationships were selected for technological practices, due to such
influencing factors as time, distance, availability, and the nature of the relationship. For example, Pete’s and Amelia’s relationship developed to be more social in nature. Although Edwin felt “loved” by his children, Anita reported that, due to time and other priorities, they were minimally involved in providing practical assistance to Edwin and Anita in their day-to-day care routines. In this way, the influence of care practices and care relationships on the processes of appropriation are interrelated.

4.7 Discussion

In this study, we longitudinally examined four cases of ICT appropriation by PwD and their nominated care partners and/or volunteers. Using multiple case study methodology, we yielded rich descriptions of how these actors collaboratively appropriated new ICTs, and how care practices were transformed or created in the appropriation process. In sum, we found that collaborative appropriation encompassed two interrelated processes, which inform, produce, and reproduce one another: creating and adapting technological practices and negotiating and augmenting care relationships. Driving these processes were motivating meanings that actors ascribed to the technology and its use; the learnability of the technology and actors’ resourcefulness; the establishment of responsive and cooperative care practices; and the qualities of empathy and shared power in their care relationships. Based on these, we highlight in this section three key takeaways for future design and implementation of ICTs for PwD and their care partners. First, we accentuate the often taken-for-granted knowledge, resources, and social support needed for ICT appropriation. Secondly, we stress that collaborative appropriation entails a meaning-making process through which actors negotiate personal and relational meanings as they explore, learn, adapt, and adapt to technology use. Thirdly, we articulate the potential of collaborative appropriation – in both its processes and outcomes – to promote positive care relationships and care practices.

Our findings underscore that the knowledge, resources, and social support (i.e., emotional and practical) needed to appropriate new ICTs by, for, or with PwD warrant greater consideration. While mainstream devices, such as touchscreen devices, may indeed deliver greater usability and accessibility for PwD [11], we found that the learning and appropriation of ICTs may still demand prerequisite understandings of and know-how to navigate several ‘layers’ of technological complexity (i.e., Internet connectivity, hardware and/or interoperability, account
and password management, etc.). Care partners, or other nominated actors (e.g., volunteers), when available and willing to support these layers, may find themselves straddling multiple roles, including technology purchaser, systems administrator, technical support, and teacher, which others have also highlighted [29], [126], [136].

Our findings delineate between two intertwined streams of effort that these nominated actors may undertake: “back-end” efforts demand technological literacy and know-how, resourcefulness (e.g., seeking external support), persistence, and personal motivation; “front-end” efforts in directly supporting PwD require responsiveness, cooperation, and empathy with PwD’s unique and changing needs, abilities, and challenges. Importantly, we found that learning and using technology may evoke feelings of vulnerability by PwD, where PwD may be confronted by their cognitive or learning challenges, and feel frustrated, overwhelmed, or discouraged. In response, a care partner may face the challenge of filtering or masking technological complexities from PwD, while attempting to include PwD in the process of decision-making, creative adaptations, and pursuing their learning goals. This tension resonates with how Piper et al. [29] describe care partners’ “conflicting goals of protecting versus empowering”.

A further support complexity we found was that technological support needs may vary over the appropriation process. Our cases indicated substantial back-end support efforts by care partners or volunteers early in appropriation, when technology features were being explored, learned, and configured. This was consistent with the “take-off” run, described by [139], which marks a period of difficulty demanding substantial social and technological support that may need to be endured before the benefits of technology use can be realized. We found that the lack of appropriate and responsive support during this period may easily lead to non-adoption or disappropriation when the potential benefit of the technology is obfuscated by technical complexities beyond what a PwD is motivated or able to learn, or a care partner is willing or able to support.

This also raises the temporal consideration of when technology may be most supportively appropriated by PwD and their care partners. Previous work has typically framed this question in terms of which stage of cognitive decline would be most useful for technology to support PwD and care partners. Tensions between introducing technology too late or too early have been
discussed – that is, arguing before the point that a PwD has lost the ability to learn new technologies [50] and giving both PwD and care partners time to learn and familiarize themselves with it [6], but not so early that it forces PwD to confront their deficits [6] or overcompensates for intact abilities that can continue to be exercised [50].

Piper et al. [29] highlight that care partners adapt their technological support over time to the changing cognitive, physical, and emotional states of persons with cognitive impairment. Our model adds to this support consideration by underscoring that cognitive challenges are one among several factors to consider when timing technology for use by multiple involved actors. Our findings would pose additional questions, including: what individual and relational meanings are currently motivating the PwD and care partner(s) (e.g., Independence? Autonomy? A better relationship?) to adopt this technology? How learnable is the technology for each involved actor given his or her respective technological literacy and know-how, the technical complexity of the technology itself, and the available learning and support resources at present? Are there existing care practices within which appropriating this technology would provide benefit to all involved actors? Does the care relationship between actors suggest that technological support will be empathetic and collaborative, and will this technology promote the development of the relationship? Considering these driving forces together, and the way in which practices influence relationships, and vice versa, may better indicate whether all involved actors are, at any given time, are positioned to appropriate and mutually benefit from the technology in question.

Secondly, our study demonstrates that collaborative appropriation is indeed a meaning-making process, which involves negotiating personal and relational meanings between actors. Such meanings that actors ascribe to ICT use may substantially influence which technologies they select, if and how they adapt their practices (or not), and whether or not usage is sustained. Meaning-making has been emphasized as central to understanding the technological experiences of PwD and their care partners [7], [13], [14], [119], [140], [141]. Our study illustrated how different actors initially ascribed, negotiated, and sometimes came to make new meanings related to the technology and their appropriation of it over time.

With respect to Muller’s [144] concept of semantic adaptation (i.e., changes to actors’ meanings of technology), we found this to be related to their other forms of adaptation – behavioural (i.e.,
usage patterns) and technological (i.e., technical modifications) adaptation. For example, initially ascribing a positive meaning (e.g., social inclusion) to a technology (e.g., iPhone vs. CP system) may motivate an actor to endure a steep technological learning curve and trial new usage patterns using it. However, initial positive meanings ascribed to the technology may transform into negative meanings if, through use, actors learn that the technology disrupts their existing practices, relationships, or self-images. Moreover, the complex and onerous process of technical modifications may make an actor feel vulnerable, and, in turn, discourage them from developing usage patterns. Notably, while one actor may ascribe positive meanings – such as restored independence, reassurance, competency, or social connectedness – to their use of a particular technology, another actor may ascribe the very same technology negative meanings of vulnerability, dependence, social stigma, or social exclusion.

These differences have previously been attributed to the type of technology; specifically, where actors associate mainstream and aesthetically ‘fashionable’ products with positive self-images (e.g., independence, competence), and reject of ‘assistive’ technologies that they associate with negative stereotypes (e.g., dependence) [142]. Rosenberg & Nygard’s [140], who investigated PwD’s lived experiences of learning technology, found that how PwD position themselves in the technological landscape seemed decisive for their learning. For instance, a PwD who positions himself as an “updater” may ascribe learning new technology the symbolic meaning of “being like everybody else” despite being diagnosed with dementia.

While our findings indeed recognize the importance of a PwD’s view of himself as technology user, we also demonstrate how meanings are negotiated between actors may bear additional influence on appropriation decisions and trajectories. For instance, where some care partners may be supportive of the emotional value of a technology over its practical usefulness, others may steer PwD toward ‘assistive’ systems that seem to deliver benefits to both actors within a more manageable “take-off run” [139]. A care partner may worry that the PwD may feel frustrated or distressed with the complexity of a mainstream ICT’s technical complexity, or the ICT may not be feasible or desirable for the care partner to support due lack of knowledge or know-how, time, geographical distance, and/or competing care demands. In negotiation, PwD may choose to accept technologies that care partners prefer as a way of cooperating and enacting empathy for care partners’ needs, assert their own technological preferences and seek alternative
supports, or negotiate a compromise (e.g., Patrick selectively “obeying” the CP system; Edwin rejecting its medication alerts but accepting social functions).

The two important findings here are, first, that PwD – like any other persons – may have their own ideas about using or not using certain technological features, which would require care partners to pivot with their own care practices and expectations of appropriation. Secondly, the ways in which care relationships and practices are negotiated between actors may result in unexpected ways of using (or resisting to use) the designed features of a technology. Together, these insights contribute a social relational dimension that offers an alternative explanation as to why some technologies remain in a “liminal zone” [9], [143] of being unused after being purchased, or altogether ‘disappropriated’ (i.e., abandoned or rejected based on some evaluation through use [131]). These findings suggest that appropriation engenders important meaning-making processes that steer how interdependent actors complete design in or through use [131], [144] as they adapt to technology and each other in the process.

Thirdly, from our view, the most promising insights from our study describe how both the process and outcomes of appropriation may promote positive care relationships and care practices. Since Kitwood’s seminal work that emphasized the importance of PwD’s psychosocial contexts [145], several scholars have advocated for promoting positive dementia care relations and relationships [4], [18], [33], [34], [119], [129], [141]. Empirical studies have shown how technology use may support these relationships by augmenting usual care practices [128]; sustaining social networks [135]; or supporting enjoyable shared activities between PwD and care partners [128], [129].

Our study describes the processes and key driving forces through which these relational benefits can be realized. For a PwD who does not have supportive care relationships, technology learning and appropriation goals motivate or create opportunities to seek and build new relationships through which supportive practices can be developed. When PwD are supported by care partners in technology appropriation, there may be opportunities to enhance their care relationship through mutual empathy-building, learning, and cooperation. This may support care partners in sustaining their roles, as learning, skill development, and nourishing relationships may be highly meaningful and personally affirming to care partners [19], [34]. Reciprocally, PwD may feel better understood and supported by care partners, and develop a greater sense of inclusion,
connectedness, and belonging – the meanings that PwD have been found to pursue through their activity engagement [70].

Our findings on the processes and driving forces of collaborative appropriation also relate to how PwD and care partners have been found to negotiate the impact of dementia on their relationships, according to a thematic synthesis by [21]. Specifically, we have shown how the appropriation process and ongoing technology use may help actors experience more opportunities to communicate openly about the difficulties they are experiencing, develop mutual respect and appreciation for one another, negotiate new ways of managing and coping together, and discover new ways to maintain togetherness (e.g., through enjoyable shared activities through technology use or the alleviation of care demands it allows) and time apart (e.g., independent leisure for PwD, respite for care partners who may maintain greater responsibilities). In sum, the process of appropriation is not only influenced by the strength of actors’ care relationships [9], but may create opportunities, in turn, to transform, nurture, and enhance those care relationships.

4.8 Study limitations and considerations

We recognize certain limitations of our study, including our sample of only male PwD and an opportunistic recruitment strategy from one community-based program. The ‘nomination’ process of care partners by PwD may have been influenced by power dynamics in care relationships, and produced data that was more reflective of one informant’s experiences. Informants’ NO program participation and the first author’s dual role as researcher and program volunteer, which differed between cases, may also have influenced informants’ motivations for and commitments to learning the CP system. In particular, the extensive (i.e., hands-on, persistent, in-home) technological support offered by the first author playing her volunteer role may have introduced problems, experiences, or attitudes that informants may not otherwise have encountered. On the other hand, the insights gleaned from the first author’s dual role enriched understandings of the relational complexities and barriers to successful collaborative ICT appropriation, and enabled her access to the felt experience of providing technological support. While our complementary observational and interviewing methods aimed to address this, we are cognizant that a PwD receiving technological support may respond differently to a family care partner than a volunteer, or another party with whom their relationship is new or developing.
Data collection and analysis were also limited to the sensitivity and interpretations of the first author, which team data analysis attempted to mitigate.

4.9 Implications

Our study adds empirical support to two important notions that HCI scholars in dementia are currently advancing: that technology should be viewed as part of people’s lived experiences [12], [31], not simply tools that are used, and that HCI research and design for PwD should aim to enrich lived experiences, not only compensate for PwD’s cognitive deficits [13], [14], [117]-[119]. Methodologically, both imply that traditional techniques of gathering design requirements and attempting to ‘parachute’ into the real-world ‘solutions’ to defined problems cannot fully capture how actors (e.g., their meanings, relationships, practices) shape, and are shaped by and through their experiences with technology. Moreover, application design on mainstream platforms should also be sensitive to the ‘layers’ of technological complexity that may hamper accessibility by the intended actors. Our study stresses the need to longitudinally and naturally study appropriation as part of the design process in order to understand the organic ways that people make meaning with and creatively adopt and adapt to technology.

Adopting a “technology-in-use” perspective [146] that employs complementary methods of interviewing, observing in-context, and participating in real-time processes is strongly recommended. Here, researchers and designers may reflexively consider how they co-construct experiences, and recognize their roles as “thinking, feeling tool[s] in the design process” [13], as different insights can be gained through different methods of accessing people and experiences. We argue that this is especially important in sensitive or vulnerable contexts, such as those of PwD and care partners who may be managing the impact of dementia on their self-identities, relationships, and everyday practices. This should be balanced with a researcher view that, despite vulnerability, PwD and care partners may still exercise their power and creativity through the ways that they self-initiate strategies, and ascribe positive meanings to the learning process.

A promising future direction would be to examine care networks (described further by [146]) as units of analysis which should be expected to vary widely by actor composition, actors’ motivations, and the nature and quality of care relationships, which tend to be undergoing change when living with dementia.
We also recommend greater focus on the technology learning process and facilitating PwD and care partners in learning mainstream technologies. First, our study and others have indicated a sense of social inclusion that may be promoted through participation in modern technological society. Applications that are built on mainstream platforms with familiar user experiences not only promote learnability; they may also promote PwD’s ‘inclusion’ in family members’ (and society’s) everyday technological experiences. Still, the process of learning technology for PwD, owing to its complexity, should not be underestimated. It also cannot be assumed that PwD will automatically nominate family members for technological support, or that care partners are willing or able to provide it. PwD may value the learning process, sense of accomplishment, or improved independence afforded by technology mastery. Learning may also bring about opportunities for building new and meaningful relationships. As the prevalence of dementia will only increase with the aging population, the need to promote technological acumen for PwD and their care partners is also expected to grow. Technological support services that support or complement care partners’ efforts may promote mutually enjoyable and beneficial care arrangements further into the dementia care trajectory. Services that provide extra support to both PwD and care partners during “take-off runs” or enable them to collaborate efficiently and remotely may be particularly fruitful.

Finally, we urge design researchers and designers to thoughtfully consider care relationships and relations when designing for PwD and their care partners. Living with dementia cannot be fully understood through the biomedical perspective of experiencing cognitive and functional decline, and increasing care dependency. In particular, design should recognize the creative capacities and self-management strategies that persons with mild cognitive deficits (i.e., mild cognitive impairment, mild dementia) continue to exercise, as well as the social stigma they may experience in their relations with care partners, acquaintances, and broader society. In addition, the meanings and values that both PwD’s and care partners ascribe to technology, as well as how they navigate relationship changes, should be expected to influence technology attitudes, decisions, and behaviours. Designers and service providers should anticipate such changes with time, technology use, and social negotiations, and leverage opportunities to capture this information in order to guide and tailor services that benefit both actors.

It may be also be useful for designers to more precisely match their envisaged services to users and care networks of a specific composition (e.g., multiple family members involved in care
practices), nature (e.g., co-located), and quality (e.g., cooperative, empathetic) of relationship. Reinforcing Piper et al.’s [29] recommendation for “gradations of support”, we would also recommend that user control between PwD and care partners be designated flexibly, in order for actors to organically adapt practices to the ways they choose to relate to each other. Sharing the same functionality, such as through screen mirroring or remote-control access, may scaffold PwD to learn or relearn functions. The ability to assign and re-assign functions between a PwD and care partner(s) may allow functions to be scaled back if they become too complex or frustrating for the PwD, or beyond what a care partner can support. Functionality that promotes collaboration between actors may beget relational benefits that, in turn, sustain new technological practices. Concretely, we recommend greater design focus on creating opportunities for PwD to foster new social relationships that augment their support networks; provide alternative communication methods for PwD to express themselves effectively and creatively; distribute care responsibilities to multiple care partners, where willing and available; enable care partners to provide technological support to PwD, both locally and remotely; alleviate care tensions through empathy-building and shared decision-making; and promote shared enjoyment and social conversations in care relationships.

4.10 Conclusions

In conclusion, collaborative ICT appropriation by PwD and care partners encompasses the development of technological practices and reconfiguration of care relationships – two processes that inform, produce, and reproduce one another. Driving these processes are the meanings that actors ascribe to the technologies and their use; the learnability of the technologies and actors’ resourcefulness; the extent to which responsive and cooperative care practices are already established or can be established between actors; and qualities of empathy and shared power between actors in their care relationships. Technological literacy and know-how on modern mainstream ICTs requires substantial consideration when designing research, products, and services for PwD and care partners. The motives, meanings, and preferences of individual actors are influential to appropriation trajectories, as are the nature and quality of their care relationships and extent to which appropriation promotes actors’ relational dynamics. These technological and social complexities imply that actors may adopt and adapt (to) ICTs in creative and unexpected ways. As such, we advocate that future work employ approaches that examine care relationships and networks; learn from real-world, longitudinal cases of appropriation; and
co-construct enriched, synergistic technological experiences with PwD and care partners. Moreover, the goals of designing ‘solutions’ for PwD and care partners may be better framed as intentions to promote positive care relationships and cooperative care practices through enriched experiences.
Chapter 5
Integration, Implications, and Conclusion

In this chapter, I relate my key empirical findings from Chapter 2, Chapter 3, and Chapter 4 to my two thesis aims: 1) to better understand the nature of care partnerships from the perspectives of PwD and care partners, and 2) to describe how co-creating new technological experiences may impact care partnerships. In Chapter 1, I drew from previous work to conceptualize a ‘care partnership’ as a relationship between actors (hereafter referred to as “partners”) – that is, PwD, family care partners, and formal care providers – that encompasses three aspects: a) wherein each partner possesses his or her own experiential knowledge, expertise, and perspectives on dementia care, b) wherein the relationships between partners tend to be interdependent (i.e., actors mutually influence or affect one another, through their behaviours, decisions, and circumstances) and reciprocal (i.e., actors share and enact mutual feelings), and c) wherein partners interact with one another in care decision-making and care processes, which involve continuous learning and unlearning, generating creative solutions, and the fostering of collective wisdom. My integration in this chapter is therefore organized to address each thesis aim as it relates to each of the above three aspects of care partnerships. Following this, I discuss the implications (i.e., methodological, theoretical, practice, and design), the strengths and limitations of this thesis project, and close with some final concluding remarks.

5.1 Understanding the nature of dementia care partnerships

5.1.1 The knowledge, expertise, and perspectives of PwD

All three empirical studies reinforced that PwD, like any other persons, possess the deepest knowledge about themselves – that is, their personal histories and identities, their everyday practices and routines, the activities that they find meaningful, their home environments, and their values, interests, and personal preferences, especially related to such matters as control, autonomy, safety, and security. Their experiential knowledge also includes the nature and quality of their relationships – particularly their preferences about the nature of support they wish to seek (or not) from those relationships, as well as what they may be seeking from new relationships.
Based on this experiential knowledge and expertise, PwD possess and may exercise their own perspectives related to care decisions and arrangements. Continuing their usual arrangements or habitual routines, supported by contextual cues, may not only be important for preserving a sense of self and continuity; as [71] points out, this continuity may carry implicit meanings of maintaining control, or mitigating the risk of losing control in their everyday doings. Moreover, remaining in their familiar home contexts may allow them to continue their everyday activities, which PwD have been found to ascribe meanings of purpose, enjoyment, belonging, and maintaining a sense of identity [70]. Together, these perspectives held by PwD may lead them to resist the ways that others seek to support them, such as changing their familiar living arrangement, everyday practices or routines, or introducing new care actors (e.g., formal care providers) with whom they have not established trust or rapport. Despite the reasoning argued by care partners or formal care providers, in the terms of Nolan et al.’s Senses Framework [18], feeling coerced into new care arrangements or relationships may threaten a PwD senses of security and continuity, their sense of purpose through which they exercise discretionary choice, their sense of belonging to their familiar community (e.g., neighbourhood), and their sense of significance, where they feel their personal needs are recognized and respected.

Study II and Study III revealed how cognitive or functional impairments challenged PwD in expressing their knowledge and expertise, and sometimes led them to be excluded in care decision-making. Systematic findings have shown that PwD are frequently excluded from care decisions – that is, either not informed about care decisions before implementation, or informed but overridden even when they object [148]. These forms of exclusion were confirmed in Study II and reasoned by care partners as a way to sustainably balance the needs of PwD (e.g., an independent living arrangement) with their own (e.g., manageable care schedules). Study III added that problems with planning, forgetfulness, disorientation, or social communication may also hamper the abilities of PwD to assert and effectively communicate their needs and wishes to others. These problems may not only create emotional turmoil for PwD – such as, frustration, insecurity, and anxiety – but may lead them to socially withdraw, exacerbating misunderstandings, stigma, or exclusion by others who assume that PwD are no longer fit to participate in their own care decision-making. These findings stress that PwD are not only vulnerable in terms of safety and security, which tends to be the focus of the ‘biomedicalized’ discourse, but also emotionally and socially. These forms of vulnerability relate to some of
Kitwood’s delineated aspects of “malignant social psychology” (e.g., disempowerment, infantalization, intimidation, labelling, stigmatization, outpacing, invalidation) [149]. Emphasized in this thesis is that PwD’s justified responses to such ‘malignancy’ (e.g., social withdrawal, resistance) may lead to dilemmas in genuine partnerships when care perspectives conflict, and care partners may (attempt to) exercise most or all of the decision-making power from their own standpoints.

5.1.2 The knowledge, expertise, and perspectives of family care partners

Depending on the nature and quality of their relationships with PwD, family care partners may possess or develop much of the same knowledge about PwD in terms of their personal biographies, identities, values, and perspectives. Family care partners may also be knowledgeable about PwD’s social networks and relationships, which may be shared and integrated with the PwD. *Study I* (Chapter 2) found that family care partners may also accumulate knowledge about the PwD’s health history and condition (e.g., observable cognitive and functional changes), which position them to inform health care providers. Additionally, over their relationship histories and the care journey, care partners may develop experiential knowledge and expertise about how to relate (or not) to the PwD, socially and in care interactions. *Study I* (Chapter 2) elucidated the particularistic knowledge and expertise that family care partners may acquire over time about PwD’s everyday activities, routines, and practices, including ways of providing or exchanging support. *Study III* (Chapter 4) illuminated relational processes through which this occurs, wherein the nature of their care relationships shift in response to health changes, living and arrangements, and new care practices.

Like PwD, family care partners possess their own knowledge and relationship experiences with the PwD, as well as their own care perspectives. On one hand, care partners may strive to advocate for and provide support to PwD that respects the PwD’s wishes, maintains their sense of self, their continuity of activities and relationships, and supports their emotional and social vulnerabilities. Moreover, they may be knowledgeable about the most supportive care strategies and arrangements to support PwD’s cognition, functioning, and overall health. At the same time, however, care partners may be caring under the pressure of limited resources and quality care demanding more time than they have available. Kitwood refers to these as conditions for malignancy experienced by PwD [149]. All empirical studies highlighted care partners’
'balancing acts’ in managing their own personal resources, needs, values, responsibilities and relationships, with their care roles and responsibilities. As described in Study II (Chapter 3), these dilemmas may create specific forms of vulnerability experienced by family care partners. In terms of the Senses Framework [18], they may lack a sense of security in their knowledge and ability to provide care without adequate information or training, or when care demands threaten their vocational or financial stability. Their sense of continuity may be threatened when care demands eclipse the social or familial time they previously enjoyed with PwD. They may also experience a loss of belonging when the demands of caring displace or estrange other valued social relationships (e.g., sibling relationships, friendships), or experience of loss of significance when their care efforts or values are misunderstood or unappreciated by other actors. Disagreements or social conflict with family members (including PwD) over care decisions and care arrangements, and mistrust and alienation toward the public formal care system (also found by [22], [23]) may reproduce these vulnerabilities. That is, unresolved conflicts may resign them to sustain and shoulder the majority of care demands by their own resources for indefinite periods of time.

Simultaneously, however, care partners may maintain positive perspectives on caring, due to aspects or outcomes of caring, that have been increasingly emphasized in the care literature (e.g., [19], [150], [151]). Study II (Chapter 3) and Study III (Chapter 4) found that, through caring, family care partners’ positive perspectives were gained through fostering one’s skills or personal affinities through caring, enhancing relationships with PwD or other family members, sometimes intergenerationally, or developing greater personal meaning through the senses of purpose, achievement, or significance. However, the novel paradox, described in Study II (Chapter 3), is that such positive outcomes may reproduce negative outcomes; that is, positive outcomes may affirm and reinforce a care partner’s commitments to sustaining care for as long as possible, while negative consequences to them accumulate indefinitely. Such outcomes may render care partners all the more politically, economically, and socially vulnerable, which may threaten their sense of partnership in caring.

5.1.3 Care relationships: diversity, reciprocity, and interdependency

All three empirical studies highlighted the diversity of care relationships and Study III (Chapter 4), in particular, drew attention to the influence of the nature and quality of care relationships on
care perspectives and interactions. Compositionally, the studied participants included or reported care networks comprised of the PwD, PwD’s spouses or former spouses, PwD’s children and children-in-law, and PwD’s siblings and grandchildren. Geographically, care relationships ranged from co-residing to local, national, and international. One interesting finding was that PwD did not always seek or accept support (i.e., emotional, practical) from those family members who lived in closest geographic proximity. Moreover, some family care partners reported family members who lived closer to the PwD but were less involved, or uninvolved, in care arrangements. Rather, the nature (e.g., frequency of interaction, extent and form of practical assistance) and quality (e.g., emotional closeness, mutual empathy) of relationships was found to bear a stronger influence on family members’ care involvement than geographic proximity. This corroborates LaFontaine & Oyebode [21] who found consistency across multiple qualitative studies of family relationships and dementia: positive care and coping strategies tended to be established between PwD and care partners who they shared previous (i.e., before dementia) relationships of mutual trust, strong emotional bonds, open communication, and positive past conflict resolution. Additionally, the authors characterize these relationships as being able to maintain such qualities when managing the consequences of dementia, by viewing it as a “problem shared” and enacting commitments to “working together”.

As described, *reciprocity* – where partners tend to share and enact mutual feelings – was found to be a key feature of positive care relationships. PwD and family care partners may strive toward maintaining such relationships, although challenged by changes in respective needs when managing the health and social consequences dementia. To this, my empirical findings from *Study III* (Chapter 4) highlighted relationships in which actors openly expressed their vulnerabilities and, demonstrating Dupuis *et al.*’s concept of ‘relational caring’ [152], used vulnerability as an opportunity to grow together through exchanges of compassion and collaboration. Here, the qualities of empathy and shared power in care relationships influenced responsive and cooperative care practices and, in turn, further nurtured care relationships. When a care partner enacts compassion and understanding of PwD’s needs and perspectives, PwD may reciprocate through their attitudes of openness in care decision-making, or cooperation with arrangements as a way of supporting the needs of the care partner. This evidences how positively reciprocal family relationships respond to “shifting sands”, wherein PwD and care partners cooperatively negotiate changing roles, responsibilities, and new forms of support [21].
Although Ward-Griffin et al.’s typology of care relationships [153] was developed based on a study of mother-daughter caregiving relationships, it does resonate with the reciprocity I identified in some of the care relationships in my study. Her described cooperative relationship type expresses itself as working together as a team, focusing on the strengths of the PwD, and cooperating in care tasks (e.g., In Study III (Chapter 4), demonstrated Patrick and Wendy, and Edwin and Anita). Although not mutually exclusive with the cooperative type, if the nature of the relationship is emotion-based rather than task-based, her described cohesive relationship type enacts mutual problem-solving wherein the care partner promotes the PwD’s decision-making for as long as possible (e.g., In Study III (Chapter 4), demonstrated by Patrick and Max, and Pete and Rebecca). In both types, if caring challenges previous forms of reciprocity in a relationship (e.g., social conversations), partners may actively reconfigure to discover new forms of reciprocity, such as through enjoyable shared activities, collaborative problem-solving, and making care decisions that aim to mediate both partners’ needs.

Reported by care partners in Study II (Chapter 3), and observed in care relationships in Study III (Chapter 4), positive forms of reciprocity may extend to care relationships between family care partners, and between families and formal care providers. Within families, those participants who reported overall positive relationships with their family members and prioritized maintaining their familial relationships beyond care activities reported more support seeking from, collaboration with, and understanding of those family members’ perspectives. Intermittent disagreements and conflicts were reported as difficult, but eventually resolved or accepted through a collective learning process whereby these relationships were sometimes improved. Moreover, some of the studied care partners described growing to appreciate the ‘complementarity’ between family care partners, where individual care relationships were recognized as different in nature (e.g., some more emotionally supportive, others more instrumentally supportive) but, together, created an enhanced care network for the PwD and themselves. Positive reciprocal relationships were also reported between families and formal care providers. Positive care arrangements with personal support workers involved PwD and family care partners treating them “like family” through supportively managing their workload, providing secure housing and employment, and sometimes supporting their immigration. Reciprocally, family care partners experienced feelings of trust and comfort, and PwD experienced nurturing care relationships that they found to complement their family
relationships. Together, these examples demonstrate the possibility of “synergistic relationships” in dementia care that “[build] on the diversity of the group and [incorporate] the gifts each partner brings to the group to generate new ideas and better ways of doing things.” [4]

Negative forms of reciprocity, however, were also found to manifest in some care relationships – sometimes in those relationships that were historically distant or strained. Study II (Chapter 3) highlighted the influence of ‘value conflicts’ over care decisions and arrangements that arose between partners. Study III (Chapter 4) then demonstrated that when PwD feel misunderstood, overpowered, or undermined by a family care partner(s), they may reciprocate by withdrawing and resisting to seek support from that care partner(s). This exemplifies ‘working apart’ [154], [155] in which actors distance or disconnect from one another when dementia impacts their relationship. According to Ward-Griffin et al.’s typology of care relationships [153], these may be characterized as combative relationships that are emotionally charged (and often have been in the past), wherein a family care partner attempts to exert power over the PwD. In her typology, combative relationships may develop from custodial relationships, which are historically emotionally detached and defined by a sense of “duty”, and may lead to the objectification of the PwD based on his or her deficiencies. Therefore, negative forms of reciprocity may derive from previously poor quality relationships, which are further impacted by living with dementia, or develop when actors emotionally, socially, and/or practically disconnect from one another through their care negotiations.

Again, negative reciprocity may also apply to relationships between family care partners and formal care providers, as indicated by care partners’ accounts in Study II (Chapter 3). For example, adult children may disconnect – or even estrange – from one another over unresolved care conflicts. This may result in withdrawal not only from care involvement but altogether from family connectedness. To note, previous relationships that were reported as emotionally close and mutually supportive relationships tended to facilitate positive negotiation outcomes (e.g., working together). This finding was consistent with a previous adult child sibling study that suggested that “a threshold level of emotional closeness may be necessary for informal support within families to be approached as a mutual commitment” [104]. Over the care journey, however, negotiating care between adult child siblings may challenge or strain their relationships. If conflicts cannot be resolved, siblings may distance, disconnect, or estrange from one another, leaving one or a few siblings to shoulder care responsibilities with limited or no
support from other siblings. In relationships between family care partners and formal care providers, family care partners may ‘game’ with, resist, or limit seeking formal care support due to mistrust or alienation. As with positive reciprocity promoting synergistic care relationships, the impact of negative forms of reciprocity within individual care relationships may also influence other relationships due to the interdependent nature of care relationships.

My findings from Study II (Chapter 3) and Study III (Chapter 4) also offer novel insights into the nature of interdependency in care relationships, where partners and relationships mutually influence and affect one another. Adams & Clarke [3] describe interdependency as this: “What happens to a PwD will affect the family, and what happens to the family will have consequences upon the PwD.” These studies illustrate how interdependency exists both within and between care relationships. First, over the care journey, PwD may seek increasing or different forms of emotional support from family care partners, which support them in continuing meaningful activities, living and practical arrangements, or social connectedness to their broader family and social networks. Family care partners, in turn, may rely on PwD’s trust, agreement (e.g., verbal or legal), and cooperation in order to implement care decisions and arrangements.

Secondly, interdependencies may exist between the relationships among multiple family members (e.g., spouses and adult children, adult child siblings, adult children-in-law, grandchildren). For instance, the nature of support that adult children provide PwD may be influenced by the presence or absence of the PwD’s spouse, or the nature and quality of the PwD’s spousal relationship. That is, even if spouses co-reside, a combative, disconnected, or strained spousal relationship may lead a PwD to seek more support from an adult child than his or her spouse. Moreover, interdependencies in care relationships between multiple adult children caring for a PwD (parent) were also revealed. Whether one adult child(ren) is informally or legally nominated by a PwD to provide primary care may influence the nature of care efforts by other adult child siblings, as well as the nature and quality of the sibling relationships. Particularly in cases of ‘value-conflicts’, for example, adult children who do not agree with a primary adult child’s care decisions may withdraw care involvement. This may reduce social connectedness and support between siblings and also extend to the PwD. These examples add explanations to family care literature that shows disproportionate care responsibilities among adult children siblings [104]. They also illustrate a mechanism through which an adult child experiences reduced social support, which has important implications for their wellbeing [101].
In contrast, close and cooperative sibling relationships may beget more collaboration in care decision-making and care arrangements for their parent (PwD) and, in turn, nurture the PwD’s relationship with multiple adult children. Unavailable or limited care involvement from other family members may also explain how and why adult children-in-law and grandchildren become actively involved in care arrangements.

Thirdly, care arrangements that are negotiated between PwD and their family members may influence the nature and degree of formal care service sought, and vice versa. The qualities of caring relationships were found to shape these interdependencies. If care arrangements between the PwD and a family care partner is felt to strain the quality of relationships in the family – for example, shifting the relationship from an emotional, familial relationship to a transactional, assistive relationship – formal care may be sought, in part, to restore the familial nature of and social quality of the relationship. Then, if mutually trusting relationships can be fostered between PwD, family care partners, and formal care providers, all relationships may benefit. For example, all three actors may establish positive ‘family-like relationships’ that involve mutual social and practical support. Family care partners may be alleviated from providing instrumental care to PwD, which may restore or improve the quality of their relationships. However, if PwD and/or family care partners are not able to establish trust with a formal care provider(s), they may limit formal service utilization and assume or continue instrumental care practices and home care arrangements (e.g., co-residing). In turn, this may impact the nature and quality of their own relationship dynamic with PwD. These examples reinforce that structural influences – in particular, relationships with formal care providers or “the system”, in general – are influential to care decisions and arrangements, which scholars have highlighted [16], [134]. Thus, over the care journey, care relationships within families, and between families and formal care partnerships, are highly interdependent.

5.1.4 Care interactions between partners

My empirical studies produced insights into some specific and dynamic interactions related to care decision-making and care processes (e.g., day-to-day practices, arrangements) undertaken by partners in care, from the perspectives of studied PwD and family care partners. Based on my three empirical studies, four interrelated types of care interactions were synthesized: responding and adapting, balancing and negotiating, entrusting and diffusing, and learning and growing.
5.1.4.1 Responding and adapting to care needs and changes

Care needs were found to change continuously and often unexpectedly throughout the care journey, not only due to cognitive or functional problems, but also as care relationships and arrangements were negotiated and reconfigured between partners. Responding to these changes may involve one partner requesting support from another partner, one partner self-initiating support for another partner, or both partners working together and negotiating a shared response. Responding may involve addressing an immediate or urgent change in care needs through the modification of the living arrangement (e.g., relocation, home modifications, fashioning tools or technologies) or care arrangement (e.g., delegating or coordinating care activities between family members, seeking formal care support). This tends to call upon partners to reconfigure their resources of time, effort, and money. Responding also involves ‘personalizing’ new care strategies, wherein partners establish and seek to meet their respective needs and preferences through care practices or routines, while situating them in the fluid nature of everyday life. *Study I* (Chapter 2) revealed the specificities of supporting activities for PwD, in which ‘personalization’ entailed selecting which activities to support for PwD, how and who would support PwD in continuing those activities, when support would be provided (e.g., schedules, steps, triggers) and how support would be coordinated and offered (e.g., prompt type and content, alerts). These particularities add missing insight into the “specificities” of care practices and its “its relation to place and other features of daily living” [156], and underscores the heterogeneity of care needs, preferences, and arrangements. Moreover, related to other care interactions (described shortly), responding may involve deciding on who is involved in care arrangements and devising ways of communicating and negotiating these arrangements (e.g., through open and direct communication, collective problem-solving, using ruses, using coercion or threats).

Responding also entails adapting new ways of doing and relating between partners. *Study I* (Chapter 2) unpacked the nuances and particularities of adapting ways of assisting PwD in everyday activities (e.g., activity steps, triggers, alerts). *Study III* (Chapter 4) further revealed how partners collaborated to creatively adapt technologies to care practices, and vice versa, including complex ‘back-end’ and ‘front-end’ work that this required. These processes of adapting resonate with the ‘Craft of Care’, constructed by [8], in which family care partners act “like artisans” in intuitively and creatively fashioning ruses to negotiate with PwD, languages to
overcome cognitive and language impairments, *spaces* (e.g., home accommodations) and *building tools* (e.g., adaptations to home and personal objects, akin to technological adaptations). Although de la Cuesta’s study was conducted with care partners of persons with advanced dementia and in the Colombian context, the described notion of ‘craft’ resonated strongly with my empirical findings. My studies, however, highlighted some differences, which may be attributed especially to managing early to moderate dementia: the manipulation and management of time (e.g., schedules) and resources (e.g., time, money, care actors), the sharing and coordination of care activities by multiple actors, and the adaptation and reconfiguration of care relationships. Most saliently, responding and adapting involved active participation by PwD, which evidences previous work that PwD self-initiate their own management strategies [71] and do their best to continue their valued activities [70]. The ways in which PwD are involved in caring relates to the hereafter described interactions of balancing and negotiating, entrusting and diffusing, and learning.

5.1.4.2 Balancing and negotiating within and between partners

Partners were found to balance their values, needs, and perspectives, both within themselves and through negotiation with other partners. PwD were found to balance their desire to continue meaningful activities and relationships that support their identities, with seeking or negotiating support from other partners – emotional, social, technological, or practical. Accepting support from others may mean sharing or relinquishing full control over a particular task or activity, being open to how help-seeking changes their previous relationship (e.g., accepting more instrumental assistance), or confronting feelings of burdening others in seeking new forms of support. As such, they may resist seeking support in certain relationships, and seek out new relationships (e.g., with service providers) for support. These findings challenge the conceptualization of PwD as passive recipients of care by illustrating how they may actively participate in negotiating care decisions, relationships, and arrangements with other partners.

Previous work has revealed ways family care partners balance and negotiate. Constructing a central theme of ‘balancing needs’, Quinn *et al.* [45] described balancing in efforts to preserve their relationships with PwD, ensure PwD’s safety, support PwD’s sense of empowerment and self-esteem, manage their care workload, enact their other social roles and responsibilities, pursue personal goals, and the meanings they derived from caring. My empirical findings
illuminated how values and ‘value-conflicts’ may create intra- and inter-relational ‘balancing acts’ for care partners. They may experience conflicting values within themselves due to simultaneously positive and negative outcomes of caring, such as deriving meaning from caring for a parent while recognizing compromises to their other social roles, or vocational and financial opportunities. Secondly, care partners balance and negotiate PwD’s present care needs with their own present needs, as well as their own future needs. In doing so, the described ‘double-edged sword’ may result, through which the positive outcomes (e.g., personal meaning) of caring may reinforce care commitments while reproducing cumulative negative consequences to care partners (e.g., forgone employment and financial resources). Thirdly, my findings revealed how care partners may balance their care relationships with PwD with other family relationships (e.g., sibling). This may include considering care decisions or arrangements that preserve or foster multiple relationships within an extended (sometimes intergenerational) family, or avoid conflict with other family members.

In striving toward balance, PwD and family care partners may exercise different ways of negotiating their respective and mutual needs. Topics of negotiation included changes to roles and responsibilities in the family and care relationships, and how care partners may support PwD in specific activities, living and care arrangements (e.g., family versus formal care), and activity and care schedules. Negotiations between PwD and care partners included communicating openly and directly, withdrawing or withholding, using ruses to circumvent PwD’s input, or one partner exerting power over the other (e.g., care partners circumventing PwD, care partners threatening institutionalization, PwD resisting agreement to care arrangements).

Negotiations between family care partners also varied. Some family care partners successfully cooperated with one another to delegate care roles and create arrangements that aimed to mediate the interests of all family members. On the other hand, family care partners may battle over care values, alienate, distance, or even estrange from one another, wherein negotiations cease and conflict resolution is no longer pursued. Such intermittent negative negotiations were reported even in family care relationships that were able to eventually resolve conflict. Moreover, family negotiations over care matters may be supported or impeded by legal arrangements (e.g., power of attorney). If shared between multiple adult child siblings, negotiations may be necessary to implement care decisions. This may stir conflict but also promote open communication. If decision-making responsibility is assigned to one adult child, however, other siblings may feel
resentful, alienated, or apathetic about care matters, possibly leading them to withdraw from negotiating and, in turn, care responsibilities. Lastly, PwD and family care partners may negotiate if and how support is sought from formal care providers – be it through institutional care, public home care services, or privately hired care workers. Considering the decision as to whether or not to institutionalize a PwD was often accompanied with inter- and intrapersonal conflict, as several others have found (e.g., [158], [159]). Some care partners employed institutionalization as a threat to obtain cooperation from PwD for home care arrangements, while others felt immense guilt for mentioning it to PwD. Study II highlighted that the decision to institutionalize created a fundamental ‘value-conflict’ between adult children, and resulted in disagreements, resentment, and sometimes altogether estrangement in their sibling relationships.

Negotiating with formal care providers was also a key interaction, revealed in Study II (Chapter 3). With home care, especially among those with greater financial means (e.g., those who could afford complementary private care), families tended to be selective and scrutinizing of any home care workers. Study II (Chapter 3) illuminated how families may ‘game’ with public home care services to obtain or demand better services, which not only confirms the inadequacy of public dementia services [22], [23], but adds important insight into how families may respond. In particular, gaming seemed to distinguish between care partners who exercised power from those who resigned themselves to whatever support was provided to them. Ward-Griffin reasoned that those families with fewer resources may not voice their complaints for fear that they may not receive any public assistance [22]. Lastly, negotiations with private care workers may involve demanding flexible, reliable, and personable support in exchange for good working conditions (e.g., mitigating burnout) and providing support for workers’ personal wellbeing (e.g., housing, immigration support).

5.1.4.3 Entrusting and diffusing care responsibilities

When care needs change, partners may selectively entrust care responsibilities to family members, other informal care partners, or formal care providers (e.g., public and/or private personal support workers). My studies found this process of entrusting to crucially rely on trust and rapport being established with whomever is being invited to partner in care – thus, relating this interaction to the nature and quality of the care relationship. All three studies indicated that PwD and care partners may be selective about who they request support from, and the forms and
extent of support they were willing to accept. PwD were found to welcome support from persons with whom they shared a close emotional bond, respected and empathized with their values and needs, and promoted their continuity and self-image. From new relationships, they may be looking for qualities that complement their existing relationships. For example, they may request support for specific activities (e.g., technology use) that they wish to pursue but for which they lack or resist assistance from existing care partners. They may also seek social relationships in order to feel understood, valued, significant, or able to reciprocate vis-à-vis their other relationships. PwD may ‘nominate’ a specific family member(s) – for example, one particular adult child – over others to support them. Additionally, one particular adult child may naturally assume more care responsibilities than his or her siblings, owing to geographic proximity, relationship quality with the PwD, a personal value-orientation or affinity toward caring, or the knowledge, skills, or competencies that support caring or care management. Schaber [160] also found that family roles are changed and redefined based on “geographic proximity, task competence, gender, other family responsibilities, past relationships within the family, and assigned roles from the primary caregiver or [PwD].” For such reasons, at least initially, care may not diffuse evenly (or at all) across a family network. This may explain why care responsibilities tend to be disproportionate among adult child siblings [104].

One novel insight that Study II (Chapter 3) revealed was when a care partner (or provider) is entrusted to care, he or she gains knowledge, expertise, and experience over time. This cumulative learning may sustain this partner in that caring role. Over time, a primary care partner(s) accrues immense practical knowledge (e.g. disease information, available formal care services) and expertise (e.g., intuitive care and communication strategies, resourcefulness, management skills). This may not only deem them integral to the care partnership, but may also shape their value orientations toward and commitments to sustaining care. This may lead to value-conflicts with or misunderstandings with family members or other care partners with only intermittent care involvement. Consequently, PwD or primary care partners may limit or avoid entrusting and diffusing care responsibilities to those actors.

This study, however, also demonstrated the diffusion of care responsibilities in response to evolving care needs, circumstances, and relationships. For example, in the absence of cooperation with adult child siblings, some care responsibilities were fulfilled by their spouses or children. Family relationships that were reported as close and cooperative in nature also reported
different forms of complementarity in their respective care roles and relationships. For example, although a local care partner (or provider) who provides more frequent practical assistance may develop more intimacy with a PwD, consistent with findings [160] that more distant family care partners may, over time, configure ways of supporting care arrangements, emotionally and/or practically. Reported examples included more frequent visits that may alleviate or augment a local primary care partner, finding alternative modes of communication through which to socialize more frequently, assuming care responsibilities that are possible to fulfill remotely (e.g., through or supporting technology), or prioritizing emotional support. These examples articulate different ways in which geographically distant family members may “resurface with a need to reconnect” [160]. Thus, while geographic proximity may initially predict primary care involvement, the composition of and care activities within a care network may organically evolve toward complementary care relationships that overcome distance between family members. Importantly, complementarity may produce “synergistic relationships”, as promoted by [4], wherein the collective wisdom and unique contributions of multiple partners serves to enrich the care experiences of all partners.

5.1.4.4 Learning and growing through caring

Underpinning and shaping the described three care interactions is a fourth care interaction: ongoing learning and growing that takes place within care partnerships. While several studies (e.g., [19], [151]) have highlighted learning as a positive aspect of care that family care partners may experience, Study III (Chapter 4), in particular, emphasized the ways in which PwD may also learn and contribute to learning for other partners in care. First, care interactions may beget learning about one’s own needs and values and those held by another partner (i.e., PwD, family care partners, formal care providers). This informed learning how to relate to other partners in care decision-making and arrangements, or unlearning (i.e., learning from mistakes) unconstructive ways of relating. These may include advising, confronting, arguing, compromising, advocating, resigning, withdrawing, delegating, and collaborating. Indeed, it was possible that relationships strained or grew apart, however, the my participants also shared their personal lessons of communicating differently, letting go, accepting, or making light of things, with which they moved forward. Secondly, learning with one another to develop the collective care knowledge, skills, or resources was evident. PwD intuitively learned new strategies for managing everyday life (e.g., voice recording, environmental cues), and developed new practices
or activities – sometimes adaptations of previous enjoyable activities (e.g., Internet surfing) and, sometimes, new activities (e.g., scrolling through photos). Partners fostered knowledge about the dementia diagnosis and trajectory, formal care services, and financial and legal arrangements. Partners also learned the importance of trial and error and ‘unlearned’ when approaches or strategies were ineffective and needed to be abandoned. For some care partners, this may be learning that they could no longer sustain care arrangements through their own resources and how and from whom to seek support. Through caring about, for, and with one another, partners discovered and fostered mutual understanding. This reinforces McIntyre’s [161] assertion that dementia offers opportunities for both PwD and care partners to reciprocally grow through social relationships. Also exemplified here is a key principle of relational caring – that “through relationships human beings learn and grow” and that “learning and change flows both ways” [152]. Learning engenders growth in care relationships, collective wisdom by all partners, and new and creative ways of caring.

5.2 Describing how co-creating new technological experiences may impact care partnerships

Explored in Study I (Chapter 2) and longitudinally investigated in Study III (Chapter 4), my findings illustrated different ways in which care partnerships were impacted – positively and negatively – when PwD and care partners adopted, adapted, and co-created new experiences with technology. These ‘technological experiences’ included considering and exploring new technologies (e.g., learning about their functionality, comparing them to existing or other technologies or non-technological practices), configuring new technological products or services (e.g., personalizing or customizing it to persons, practices, and contexts), learning to use the technology (e.g., functions, interactions), troubleshooting and adapting the technology, and adapting practices through technology use (e.g., replacing or incorporating new technology into existing practices).

5.2.1 Impacting the knowledge, expertise, and perspectives of PwD and care partners

Consistent with studies investigating PwD using technologies [136], [139], [162], Study III confirmed their challenges to using previously learned technologies and learning new technologies, but also underscored some potential to re-learn or learn with meaningful
motivations and appropriate support resources. Study III emphasized that any individual’s ability to proficiently use mobile and smart information and communication technology relies on cumulative ‘layers’ of knowledge and experience (e.g., WIFI and data service, Bluetooth, passwords and account management, mobile-e-commerce, standard icons/buttons, configuration of printers, keyboards, or other peripherals). Such complexities appear to be taken for granted in the current technological literature that aims to support older adults and PwD, perhaps best evidenced by increasing interest in developing mobile applications and services that seem to minimize or overlook these layers to access. As such, maintaining activities involving technology use or learning to use new technologies may elicit frustration, anxiety, and a feeling of vulnerability for a PwD. One important insight from this project, however, is that PwD – through their experiential knowledge and expertise – may still creatively and valuably contribute to co-creating technological experiences despite their limitations. As illustrated in my proposed model of collaborative appropriation (Study III, Figure 10), the barriers to their learning and appropriation were not solely attributed to cognitive, functional, or technological factors (i.e., learnability and resourcefulness), but rather the interplay between these and the influencing social relational forces – that is, 1) the motivating meanings that PwD or care partners ascribe, 2) the care practices that may be displaced, created, or transformed, and 3) the care relationships that are renegotiated or reconfigured through technology appropriation. As an example, even if a technology is designed to be ‘intuitive’, if it circumvents a PwD’s control, this may threaten their sense of continuity (e.g., in independent technology use) and exacerbate felt anxiety and stigma. Moreover, it may lead him to resist ‘burdening’ a care partner with new responsibilities, which may change the social nature of their existing relationship. In contrast, a PwD may pursue and persevere an aesthetically ‘fashionable’ technology that delivers, not only seemingly useful functions, but also symbolizes inclusion and competence in modern society. This reinforces findings that aesthetically-pleasing technologies may preserve and promote self-image in PwD [142]. Moreover, technology may be “given a new meaning in life after a dementia diagnosis; it could be used as evidence of normality and, thereby, the persons [with dementia] could position themselves as ‘updaters’ because this meant being like everybody else.” [140]. Thus, while technology use may challenge PwD’s knowledge, abilities, and resources, learning (or attempting to learn) may create opportunities for worthwhile and meaningful engagement.
For care partners, teaching and supporting PwD in their technology use was found to call upon their knowledge, expertise, or resources (time, effort, money) – sometimes more than they have available or are willing to commit depending on their own needs, values, and perspectives. Viewed from a utilitarian perspective, some care partners may view supporting technology use for PwD as infeasible or impractical, especially when the learning process illuminates cognitive deficits that may require more intensive support than is available. Care partners may also steer PwD away from using technologies that they believe are too cognitively complex, for fear that it may create more frustration or anxiety for the PwD. Just as care partners may exercise their perspectives on caring, these perspectives may strongly influence the technological support they provide (or not) to PwD. This confirms previous work that care partners tend to support technology use from their own viewpoints [51], and may be more involved in supporting PwD’s technology use when care partners stand to benefit from use themselves (e.g., time saved, reduced worry) [132]. In particular, Study III found that potential benefits to their family relationships may motivate their use of technology with PwD and the technological support they offer to PwD.

5.2.2 Impacting care relationships

Co-creating technological experiences may impact the nature and quality of diverse care relationships. For example, by the nature of their relationship, when a care partner is not involved in a PwD’s everyday activities or routines, appropriating a technology designed for ‘caregiving’ may impose changes to the fundamental nature of that relationship. Through a technology’s learnability, its design, or the meanings that partners ascribe to it, appropriation may confront the existing care relationship, and transform or disrupt its nature. When partners engage in ‘back-end’ or ‘front-end’ support through appropriation, their relationships may be reconfigured. For example, new care practices that arise from technology use may change established practices (e.g., a reminder alarm that replaces social conversations between PwD and care partners). Co-creating technological experiences may also shift common social exchanges of reciprocity (e.g., mutually enjoyable conversations) in a relationship, to a help-seeking nature wherein a PwD may feel like a burden or a care partner may feel overwhelmed. This relates to how new technological experiences may inadvertently create ‘work’ for care partners [80]. Particularly during the discussed “take-off runs” [139], providing technological support may involve care partners in novel time- and effort-intensive tasks, such as schedule/calendar
management, tech administration and troubleshooting, teaching, and service management. PwD may make decisions about what control, autonomy, and privacy to maintain vis-à-vis care partners, what to share, and what to relinquish. Technological complexity that diffuses support needs outward to previously uninvolved actors (e.g., peripheral family members) may beget new expectations of support from them. Technology, therefore, may change the boundaries and dynamics of care relationships, which partners may resist.

On the other hand, partners may welcome technology that they find enhances their care relationships. This adds insight and debate to findings by Lindqvist et al. [124] that technology was least involved in the area of concern, “Socializing with family friends.” In contrast, my work revealed ‘indirect’ ways in which co-creating technological experiences and using the technology itself benefited relationships between partners in care. Study III (Chapter 4) found that the collaborative learning and appropriation processes may build mutual empathy by providing partners opportunities to learn about each other’s challenges, vulnerabilities, and efforts, and work together toward mutually beneficial ends – be them learning, connecting through, or mastering technology. In these ways, technology may augment the organic process through which partners negotiate and adapt care through opportunities to communicate and collaborate – in turn, supporting positive reciprocity. Technology may help alleviate repetition of support requests, which may also help PwD to feel less burdensome, and alleviate the practical and emotional demands placed on care partners. It may also streamline communication with care partners who regularly use technologies to communicate. In turn, the care relationship may be improved when previously enjoyed social interactions restore the reciprocity and enjoyment of the relationship that care concerns may have come to overshadow. Evidenced in both participant-observations and interviews, access to content through technology may also bring about shared enjoyment that helps to nurture social bonds, and create or prompt enjoyable conversations topics. When PwD (re)learn to use ICTs, they can be more connected and included (“tied in”) in their family networks, keeping up with culture through media, such as online audio and video content. Increased frequency of communication may also improve the quality of their relationships between geographically separated partners. Technology may support transference and repeatability of successful care practices that can be shared within and between care partnerships. It may also enable willing but remote care partners to participate in care arrangements, and promote more meaningful and reciprocal positive relationships without the
primary care partner a “go-between” [Wendy, *Study III* (Chapter 4)]. Other family care partners, through technology use, may gain deeper understandings of care responsibilities and assume some sharing of care responsibilities, helping multiple care partners communicate and delegate care responsibilities more effectively. Fostering greater empathy in care relationships may mitigate family conflict, promote understanding, and facilitate effective care collaboration within their interdependent relationships. Asynchronous forms of communication, such as text-based messaging, may also support better quality communication with care partners for PwD who struggle to keep pace in verbal social conversations. Including PwD in mainstream social technology may also facilitate stronger intergenerational relationships and promote conversation building, which has been identified as an opportunity for supporting care relationships [129]. Thus, social inclusion through technological experiences extends beyond instrumentally supporting the PwD to enhancing different types of care relationships. In sum, co-creating with partners in care may evoke, mediate, and bridge their differing needs, and promote reciprocal relationships that are mutually enriching and foster a sense of belonging, promoted by [4], [18], [152], for all involved partners.

**5.2.3 Impacting care interactions between partners**

Co-creating technological experiences, as explored in *Study I* (Chapter 2) and further investigated in *Study III* (Chapter 4), were found to impact the described care interactions in various ways. First, introducing a new technology may change the existing ways that partners *respond and adapt* to changing care needs. For a PwD, appropriating a technology may involve adapting one’s established self-management practices. This could mean displacing habitual ways of doing things, or adapting to using a new technology alongside previous practices. For care partners, the early stages of appropriating a new technology (the “take-off run” [139]) may call for more frequent or intensive responses through ‘back-end’ and ‘front-end’ support efforts. This may lead to positive or negative experiences. Persevering through the “take-off run” may lead to a successfully learned and appropriated technology from which both partners benefit. Once ‘taken off’, the frequency of technological support may be minimal and challenging or time-consuming care practices may be streamlined. Through the appropriation process, responding and adapting may be facilitated by organically explicating each partners’ needs, values, and preferences, create opportunities for them to build mutual empathy, and work toward cooperative care practices. On the other hand, technology appropriation may challenge responding and
adapting to care needs, when technological configurations or adaptations hamper or compete with other immediate care priorities (e.g., relocation, unexpected health events, interrelational care conflicts). As such, timing technological appropriation for when partners may best leverage its support in responding and adapting should be considered. Previous work has suggested that technologies may be supportive as early as possible in cognitive decline [6], [50] while others have stressed that fluctuating cognitive abilities influence technological caregiving [29]. Moreover, this project adds the dynamic nature of care relationships and arrangements that influence technological learning and appropriation outcomes. In order to time and position new technology that facilitates responding and adapting to care changes, an alternative guideline is proposed. Caron & Bower [44] delineate between two categories of caregiving purposes – interrelational (e.g., “protecting and/or maintaining the caregivers’ view of the care recipient’s sense of self”) and pragmatic (e.g., “providing physical comfort and hands-on care, making sure that other caregivers are providing adequate and appropriate care, and minimizing the cost of caregiving”). They contend that, although both purposes are often pursued simultaneously, one purpose may be more salient at a given time and under particular conditions. To this, they suggest that the “transition points” at which partners shift between categories may be times at which they are “more receptive to accepting help from others”. Thus, technological appropriation may be better timed during periods when partners’ care priorities are shifting from pragmatic to interrelational purposes, and they are focused on maintaining PwD’s identities and their relationships.

Co-creating technological experiences may also impact care interactions of balancing and negotiating. First, technological support needs may alter the social dynamics of the relationship in ways that partners resist. For instance, a technology that requires a PwD to rely on ongoing support from, or transfer control or ‘work’ to a care partner may not be adopted. Moreover, care partners may not be available, knowledgeable, or willing to provide this support, owing to their own resources, needs, or care perspectives. On the other hand, a technological experience may facilitate balancing and negotiating if it mediates the needs and values of respective partners, such as providing valued autonomy or continuity in meaningful activity for a PwD, streamlining or reducing care demands, mitigating relational care conflicts, or providing opportunities for meaningful interactions (e.g., shared activities, conversations, bonding) between partners. The collaborative appropriation process may also create fruitful opportunities to compromise,
cooperate, and collaborate – possibly initiating and facilitating PwD and care partners positive negotiations of care decisions and arrangements.

Co-creating technological experiences may also impede or facilitate entrusting and diffusing. If appropriating a technology demands time-consuming and complex processes of specifying often tacit information (e.g., activities, care routines, alerts, etc.), PwD and care partners may decide that the effort is not worth the expected benefit. Moreover, a technology may not be accepted if using it undermines a valued care strategy (e.g., open communication, self-management routine), threatens a role or responsibility that a partner finds meaningful (e.g., having verbal conversations related to care routines), or reduces valued social contact between partners. The appropriation process may also discourage entrusting and diffusing if it demands more support time or effort than care partners are willing or able to provide. On the other hand, a technological experience may facilitate entrusting and diffusing if it reduces care workload or allows care responsibilities to be meaningfully distributed to other care partners (e.g., family members, formal care partners), thereby alleviating the care demands placed on one primary care partner and facilitating communication, collaboration, and cooperation in a care network. For this reason, partners may perceive the benefits of appropriating a technology to outweigh the resources invested in procuring, adapting, configuring, and managing it. The involvement of formal care providers may also influence whether or not technologies make sense in care arrangements. In private home care arrangements, which were reportedly more time- and task-flexible, it may be possible for formal care providers to contribute to technological experiences with PwD and care partners. In contrast, publicly funded home care providers, who may have more rigid time and task allocations, may not be in a position to participate in technology-enabled support.

Lastly, co-creating technological experiences also impacts care interactions of learning and growing. Steep technological learning curves and limited support resources may impede or discourage learning by PwD or care partners. Disempowering assumptions conveyed by the design of the technology may alienate a PwD, thereby removing his or her motivation to learn to use it. On the other hand, technology may create or augment meaningful shared learning and unlearning opportunities. First, technology may provide a temporary ‘scaffold’ to PwD re-learning skills in order to resume a valued activity. In this way, technology that is woven into and out of care practices may still be valuable even if not continued over the long term.
Moreover, technology may open opportunities for PwD and care partners to exercise creativity, develop valued skills, and broaden their technological literacy. Learning itself may be perceived as a valuable activity in offering a PwD something purposeful to do [70], create opportunities to connect or build relationships, or provide access to a desirable learning context – a place where they can feel they belong like others who share the same challenges [140]. This was indeed evidenced by the PwD in Study III who all expressed and demonstrated motivations that stemmed from a sense of purpose, significance, and belonging afforded by their community program and study participation. Although the learning process may provoke a PwD’s cognitive, emotional, and social vulnerabilities, it may still be meaningful for them to persevere with it. This resonates with the concept of relational caring, which views “vulnerability as a place for potential growth” [152]. Thus, co-creating technological experiences may promote individual and collective growth through meaningful learning experiences.

5.3 Implications

5.3.1 Methodological implications

This project yielded multiple methodological implications that may inform future work. First, employing interpretive and design research paradigms elicited rich qualitative insights about the nature of dementia care partnerships and, in particular, relational care interactions and processes that partners experience with and without technology use. The use of interpretation supported my pursuit of ‘how’ questions and helped me formulate understandings beyond description, thus producing “more generative understandings of experience in its multiplicity, complexity and particularity” [119].

Leveraging group-based data generation methods in all of my three empirical studies, allowed for participants and researchers to co-construct understandings from a range of experiences. Unlike individual interviews, group interactions invited multiple viewpoints, consensus and dissensus, analyzed group interactions, and facilitated discussion of social norms and structural factors. Moreover, combining group-based data with individual data generation in Study I (i.e., home-based paper prototyping sessions) and Study III (i.e., interviews and participant observations) complemented and informed one another, allowing for both breadth and depth of experiences. Longitudinal multiple case study methodology employed multiple methods that allowed me to triangulate between what participants think, say, and do. Future work is
encouraged to employ similar methods for including and empowering different partners in care in the design process. When access to these stakeholders, however, is limited or not feasible, alternative methods for understanding actors and their lived experiences may also be worthwhile. Personas and scenarios, for example, are not only tools for representing actors, activities, and contexts; the development of such tools may be informed by different types of research (e.g., qualitative, quantitative) and offer opportunities for researchers and designers to critically reflect on the underlying assumptions that are driving design specifications [164], which is crucial to understanding and designing for persons and their experiences.

*Study I* (Chapter 2) and *Study III* (Chapter 4) also demonstrated the value of conducting *research through design* (as conceptualized by [30]), wherein design research techniques, methods, and processes may be used to generate research insights. In research through design, design artefacts (e.g., creativity triggers, visual probes, user interface prototypes, technology devices or products) not only facilitate co-envisioning or co-creating imagined futures with participants, but also facilitate insights into their attitudes, behaviours, and practices. *Study III* revealed how “users [complete] design through use” [144] by adapting (to) technologies in the real-world.

Lastly, my role as researcher produced a number of methodological insights. I was open with participants about my positionality as a family care partner of relatives with stroke and dementia, and regularly drew on my previous professional and volunteer experiences working with vulnerable populations (i.e., persons with mental illness, older adults with chronic disease or disability, family care partners), and my cumulative lessons learned (e.g., language, communication style) about relating to family care partners and PwD in different study contexts (e.g., when invited into participants’ homes). I found my disclosure to be a useful resource in building trust and rapport with my participants, some of whom expressed viewing me as a ‘peer’ with relatable lived experiences. In all cases, I found that disclosing these personal details facilitated trust-building, as multiple participants expressed feeling that I could relate to their experiences. In *Study III*, my dual role as researcher and volunteer, wherein the latter I provided hands-on technological support, afforded me access to participants in their home contexts that may otherwise not have been possible. Moreover, I gained access to the ‘felt experience’ – an integral aspect of Experience Centred Design in dementia research contexts [13] – of providing support, which added immensely to my understanding of the roles and responsibilities that care
partners or service providers may play when supporting PwD in their technology learning and use.

5.3.2 Theoretical implications

This thesis project proposes key theoretical implications, which have been synthesized from those described in Chapters 2, 3, and 4.

First, technological design should aim to complement and collaborate with partners in care insofar as supporting or augmenting their care relationships, practices, and arrangements. Given the diversity of care needs and networks, this may entail streamlining or displacing stressful care activities with more sustainable ones, enriching positive aspects or outcomes of caring (e.g., quality of relationships), or creating opportunities for more cohesive, collaborative care arrangements within and between family care partners and formal care providers. To achieve these ends, the design process should respond to how care relationships and arrangements evolve and provide people tools, resources, and opportunities to creatively trial, implement, and appropriate technology into their lives and activities.

Secondly, this work stresses the need to further understand care relations, care relationships, and care experiences in order to better support partners in care through any intervention. My empirical findings vividly illustrated that caring is indeed relational, not transactional. Moreover, my findings contribute to a more balanced view of care and caring as encompassing both positive and negative experiences, which relate to one another through the sustenance of care commitments over indefinite care journeys. Particularly in the ethno- and socio-culturally diverse context of Canada, a better understanding the diversity, reciprocity, and interdependency of care partnerships is expected to inform more targeted social, economic, and political change as the number of citizens living with and impacted by dementia increase.

Thirdly, this work demonstrated the importance of viewing technology adoption and use as a living, relational experience wherein people shape technology use, and vice versa. Certainly, as shown, technologies may introduces new and unforeseen challenges or problems, owing to technological complexity, meanings associated with technology, and they ways in which introducing technology may shift or disrupt care practices and relationships. However, technology, from this view, no longer limits its potential to delivering a tool or solution, but
rather creates opportunities for new forms of engagement or new experiences that are co-created with partners in care, and co-evolve with care partnerships. Furthermore, these theoretical perspectives imply that future imaginaries that promote care partnerships may be achieved through partner-driven or technology-driven approaches – in turn, expanding the ‘design map’ of technology-based interventions.

5.3.3 Practice implications

Over the care journey, the relational complexities of dementia care that PwD and care partners may experience imply both challenges and opportunities to understanding and supporting these stakeholders. First, this project challenges assumptions and stigma toward PwD and advocates for the inclusion of PwD in care decision-making and care processes. Greater attention to the ways in which PwD become vulnerable, stigmatized, and excluded by care partners, formal care providers, and broader society may offer a starting point. As relationships tend to be reciprocal (i.e., both positively and negatively) PwD who feel misunderstood, insignificant, and powerless vis-à-vis other partners in care may withdraw from relationships or resist cooperating or collaborating in care arrangements. As such, adopting a ‘relational caring’ approach, advanced by Dupuis et al. [152], by recognizing “that the person is ‘still there’”, and leveraging their recommended communication strategies, such as simplifying language, listening and repeating, or using body language, may create more mutual understanding with PwD who have and wish to communicate their knowledge, needs, and perspectives. Importantly, promoting relational caring does not only serve PwD’s needs. Given the interdependency between PwD and care partners, and between care relationships more generally, enacting relational caring may reduce the vulnerabilities of care partners through more cooperative care arrangements – when PwD reciprocate attentiveness to care partners’ needs – and more positive outcomes of caring (e.g., improved relationships).

Promoting stronger partnerships between PwD and care partners also calls for greater attention to how structural forces shape the interdependency between family care and formal care relationships. This project highlighted that inadequate and incongruent formal care services – that is, restrictive, time-bound, instrumental care services that are mismatched to time-intensive, relational care needs – may create more stress than support for family care partnerships. Consequently, families who limit their utilization of publicly funded formal care services mean a
two-tiered formal care system is reproduced, driving social and economic disparity. Moreover, family care partners may experience cumulatively social, economic, and political vulnerabilities, which have far-reaching implications for the public system if future projections mean more citizens who have lesser means to afford their future care. With smaller and increasingly more geographically separated families, and changing sociocultural norms (e.g., view of caring as ‘work’ not within the scope of family relationships [24]), it is imperative that scarce public funding is appropriated to support actual care needs. This may include more flexible formal care arrangements within publicly supported schemes, such as family care planning, mediation and counselling (legal, financial, vocational), care reimbursements for family members or privately hired providers, and financial subsidies for adaptive home and care arrangements (e.g., technologies, home modification equipment or services) are recommended. Employer benefits for family care partners, such as flexible working hours, telecommuting arrangements, and extended health and social care benefits may also mitigate vulnerabilities experienced by family care partners who wish to sustain caring for relatives with dementia. Theoretically, relational caring and partnership approaches (e.g., [4], [5], [152]) capture the knowledge, relationships, and dynamics shared and experienced by real-world partners in dementia care. Critical research paradigms combined with citizenship lenses (e.g., [16], [134]) are encouraged to investigate and redress the challenges of promoting the rights and full participation by all partners in care. It is clear that a narrow ‘biomedicalized’ view of living with dementia is inadequate, and that health and social care agencies must better collaborate and coordinate to broaden the supports offered.

This project also recognizes key technological research implications, followed by a discussion of implications for design practice (next section). First, the notions of technology as a tool or a ‘solution’ to a specific problem should be reconsidered; rather, a view of technology as a negotiated experience with the persons appropriating it who are experts in their own domains is needed. This extends the traditional design stage to include investigating real-world appropriation by and with partners in care. From this view, pursuing technology ‘use’ and avoiding technology ‘abandonment’ become less central, and the process of learning, adapting, and making meaning with technology vis-à-vis partners’ personal and social experiences are brought to the fore. Investigating these may produce additional insights into real-world people and experiences with technology. In the context of dementia care partnerships, when technology is viewed as an experience that is co-created by partners, the possibilities for enhancing care
partnerships come in focus. That is, both the outcomes and processes of collaborative technological appropriation offer opportunities to facilitate relational caring [152] through knowledge exchange, synergistic care relationships, and positive care interactions. In recent years, the emerging approaches of Experience Centred Design [12], [13] and Critical Dementia [14] have challenged the ‘biomedicalized’ paradigm and promoted inclusion and empowerment of PwD, designing for new forms of engagement, and enriching life with dementia. To these important works, this project advances the notion of designing for lives with dementia – that is the lived and relational experiences of the multiple partners who are involved in caring, and the complex and dynamic relationships and interactions between them.

5.3.4 Design implications

The design implications that this thesis project proposes may further advance technological research that has focused on redressing the ‘biomedicalization’ of dementia (and aging, more broadly) and, consequently, the ‘assistive’ and ‘solution’ oriented paradigms for designing for PwD and their care partners [13], [14], [117].

Co-create experiences with partners in care – especially PwDs – as care journeys unfold.

This thesis project encourages future work to include all partners in care in research and design efforts. Each partner possesses unique and valuable knowledge, expertise, experience, and perspective worthy of thoughtful consideration. PwD, who have especially been excluded from research and design, possess experiential knowledge and creative capacity, despite ways of communicating that may require learning and adaptation from researchers and designers. Unequivocally, no person should be defined or understood in terms of his or her health deficits alone. Moreover, it is crucial that ‘proxy’ accounts (e.g., from family care partners) are not assumed to represent the voices of PwD themselves, as each partner maintains his or her own purposes and perspectives on care. Considering partners means considering where these perspectives converge and diverge, and focusing design on mediating conflicts and discovering synergies.

This project also advances the notion that technology in itself should not be viewed as a ‘solution’ (i.e., to alleviate, assist, compensate), but rather as an experience that is co-created with the persons using it, adapting it, and adapting to or with it. Metaphorically, technology weaves its way into an already ‘moving motion picture’ of experience. This is all the more true
for dementia care partnerships that already tend to be undergoing continuous change, learning, and adaptation. This fundamentally questions whether ambient technologies that require minimal input from PwD and care partners may provide appropriate and acceptable support to highly complex, dynamic and relational dementia care partnerships. For example, circumventing the organic processes of relationship negotiation, technological appropriation, and collective learning may stifle positive aspects of caring from which partners derive meaning and significance. In contrast, co-creating technological experiences with partners in care leverages their creative capacities, knowledge, and expertise, which may not only lead to embraced technological experiences, but promotes inclusion and empowerment of, and learning by, partners throughout the design process.

This is not to suggest that successful technological innovation can only come from ‘user-driven’ efforts; there is immense value in technology-driven efforts based on cutting-edge advancements. Conceptually, this is where Experience Centred Design [12], [13] may distinguish itself more clearly from ‘user-centred design’. User-centred design has traditionally aimed to represent, analyze, and address problems with existing ways of doing things [12]. Taken for granted by this approach, however, are the ways in which new technology may introduce unexpected problems, unanticipated behaviours, or novel design opportunities through use. Instead, by viewing technology as a relational experience itself (as [31] advocate) and paying attention to how people adopt and adapt to and with (i.e., appropriate) technology, the potential for synergistic user- and technology-driven innovation is created.

**Expect diverse and changing needs, circumstances, and relationships.** This project revealed that the ‘motion picture’ in which dementia care partnerships operate involve changing needs, circumstances, and relationships. As dementia care trajectories tend to be uncertain in nature and duration, design may also seek to support opportunities for advance care planning, family care mediation, and service access. Through the described care interactions, care arrangements and relationships undergo reconfiguration. Importantly, not all care relationshpis or circumstances are conducive to learning and appropriating technology in collaborative ways. Services or interventions may stir negotiations between partners, and may disrupt or shift relational dynamics and interdependencies. Design should be flexible and customizable to facilitate partners in sharing and delegating roles and control, from self-management by PwD to coordinated family care management. The latter, in particular, would enable care involvement by
geographically-distant partners, as they negotiate care arrangements or new ways of contributing to care.

**Seek opportunities for learning and growth.** While dementia is often characterized by progressive cognitive decline, technological and learning abilities in PwD were found to also be influenced by its perceived meanings, and the nature and quality of care relationships and care practices. In the early stages of dementia, PwD may still be able to learn to use new technologies and re-learn technologies with appropriate support. There may also be much to gain from researchers and designers learning from PwD’s intuitive and self-initiated strategies for managing their everyday life, activities, and relationships. Moreover, family care partners may be challenged with balancing PwD’s needs with their own, such as finding ways to engage and empower them while managing their own concerns and resources. While technology may not be ‘the solution’ to such dilemmas, this project revealed opportunities for mutual learning and growth that may produce better quality care relationships and interactions. In other words, enriching partners’ care experiences – especially for those partnerships that are committed to sustaining care – may be more fruitful than a narrow focus on alleviating burdensome aspects of care. Specific design areas for focus may be 1) supporting technological learning and literacy by PwD and care partners, 2) promoting quality social time and social conversations, 3) scaffolding partners as they negotiate complementary care roles and responsibilities across their care networks, 4) enabling social sharing of care support and strategies between partnership networks, and 5) reinforcing partners’ achievements of collaboration, learning, and technological acumen.

### 5.4 Limitations and trade-offs

In addition to the limitations described for each empirical study in Chapters 2, 3, and 4, additional limitations and trade-offs are recognized. To first note, modest sample sizes and participant heterogeneity (e.g., dementia diagnosis, stage of dementia, care settings, and living arrangements) strived for conceptual or qualitative generalizability – that is, to persons in comparable contexts or conditions [166] – rather than statistical generalizability. In terms of limitations, first, the specific technological artefacts (i.e., paper prototypes in *Study I* (Chapter 2), commercial product in *Study III* (Chapter 4)) and my affiliation with a technological research group may have influenced participants to express more positive perspectives on technology or their technological experiences. Secondly, recruitment for all three studies was challenging for
all three studies. Such factors included the limited availability of family care partner participants (e.g., respite care needs in order to participate), and changing health conditions experienced by PwD and family care partners that precluded or affected their participation (e.g., scheduling delays). As such, it was only possible to recruit and schedule participants whose care arrangements were fairly ‘stable’ during the study periods. Thirdly, across all three studies, only three participants were racial minorities, which limited my exploration of culturally diverse care perspectives and experiences. Also, recruitment of only four male PwD with early-stage dementia may limit the transferability of my findings to female PwD. In addition, recruiting only four PwD compared to nineteen family care partners across the three studies challenged me to carefully discern the perspectives of PwD from those of family care partners during both data collection and analysis. For example, although arranging data collection sessions through and involving care partners facilitated study logistics, their presence may have influenced the information or opinions that PwD were willing to disclose. Fourthly, data collection was subject to flaws, as I collected most initial data for Study III (Chapter 4) independently yet had limited experience verbally communicating with PwD, and novice research skills. Lastly, participants in Study I (Chapter 2) and Study III (Chapter 4) involved family care partners and PwD who were accessing community-based services. As such, it is possible that the perspectives and experiences presented reflect those who are already receiving support from formal services. Those who are not may have emphasized different care needs, perspectives, and experiences (e.g., how they manage everyday life without formal support). Moreover, participants in Study III (Chapter 4) may have selectively shared or withheld certain information – for example, emphasizing more positive aspects of their experiences given my dual role in serving them as a volunteer whilst gathering research data.

5.5 Conclusion

While dementia is commonly associated with health and cognitive decline, living with dementia encompasses complex social relational problems and opportunities. This thesis project first aimed to better understand the nature of dementia care partnerships from the perspectives of PwD and family care partners. These partners in care possess and exercise different knowledge, expertise, and perspectives on caring, which may converge, complement, or conflict between partners. Importantly, PwD and care partners experience different forms of vulnerability – physical, emotional, social, economic, and political. The relationships between partners in care
are complex; they are diverse, reciprocal in both positive and negative ways, and interdependent, where individual partners’ decisions, behaviours, and circumstances influence one another, and the care relationships between different partners influence other care relationships. Partners’ care interactions that were synthesized across the three empirical studies demonstrated their dynamic and interrelated nature. These interactions included responding and adapting to care changes, balancing and negotiating within and between partners, entrusting and diffusing care roles and responsibilities, and learning and growing through caring. Importantly, interdependent care relationships are continuously confronted and reconfigured throughout these interactions, which shapes the nature of care partnerships.

The second aim of this thesis project was to describe how co-creating technological experiences with PwD and family care partners impacted their care partnerships. Exploring, learning, adapting, and using technology beget new and transformed care experiences, which may challenge or enhance dementia care partnerships. These outcomes are influenced by how partners ascribe and make meaning with technology, how they learn and foster resources to support technology appropriation, how they establish new, transform, or displace existing care practices, and how they reconfigure the nature and quality of care relationships as they adopt and adapt with technology. While technology may challenge partners’ knowledge, literacy, and resourcefulness, technology may also offer collaborative and creative learning and growth opportunities, both for individual partners as well as their evolving care relationships.

Understanding and supporting dementia care partnerships calls for relational (vs. biomedical) views on caring, as well as critical perspectives that examine the interplay of micro- and macro-level forces, which recognize dementia care as an issue of human rights and citizenship. Partner participation in research and design should be encouraged at different stages of innovation in order to promote mutual learning, empathy, and the exchange of knowledge and creativity. As demonstrated in this thesis project, the value of interpretive research and design paradigms, as well as naturalistic, longitudinal, and reflexive methods is that they afford insight into the ‘co-evolution’ of technological and relational care experiences. Technological research is encouraged to expand its purpose from designing ‘solutions’ to health deficits or care ‘burdens’, to co-creating experiences with partners in dementia care that leverage individual and collective capacities, promote creativity and learning, build stronger care relationships, and, in turn, enrich lives with dementia. Designing for these ‘lives’ means embracing diversity and change in needs,
relationships, and circumstances, and working with partners to weave technology into their broader relational caring experiences. To the greatest extent possible, technologists should refocus from investing in large-scale system or service development, to earlier and more frequent ‘in-the-wild’ studies through which partners in care can organically contribute their experiential knowledge and creative adaptations to the design process, as their care journeys unfold.

References


151


2002.


[165] A. Olsson, M. Engström, K. Skovdahl, and C. Lampic, "My, your and our needs for

## Appendices

### A. Study I - Telephone screening tool for recruitment

#### Telephone Screening Tool for Study Recruitment: Phase 0

<table>
<thead>
<tr>
<th><strong>Telephone introduction</strong></th>
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</thead>
<tbody>
<tr>
<td><strong>Date/time of first call</strong></td>
</tr>
<tr>
<td>Hello, this is Amy Hwang from the assistive technology lab at the University of Toronto, following up on your interest in my research study. I would like to give you more details and ask you a few questions to see if you are available and eligible to participate. Do you have 10 minutes now or is there a more convenient time for me to phone you back?</td>
</tr>
</tbody>
</table>

| **Date/time of rescheduled call** |
| **Demographic information** |
| Participant’s full name |

| **Date of birth** |
| **Gender** |
| Male | Female |
| **Occupation** |
| Studying/working F/T | Studying/working P/T | Not working | Retired |

| **Inclusion criteria** |
| **Relationship to older adult being cared for** |
| **Degree of dementia of older adult being cared for** |
| Mild | Moderate | Severe |

| **Do you provide care on an informal, UNPAID basis?** |
| Yes | No, I receive payment for providing care |

| **What self-care activities do you assist with?** |
| Bathing/showering | Toileting | Hand-washing | Tooth-brushing | Dressing | Meal preparation | Taking medications | Communicating or engaging in conversation with others | Other: |

| **On average, approximately how many hours of caregiving do you provide each week?** |
| < 7 hours per week | 7+ hours per week |

| **How long have you been an informal caregiver?** |
| < 6 months | 6+ months |

| **Do you live with the person you care for?** |
| Yes | No |
### Study overview and informed consent

I will now go over the details of the study and the study consent form which will be emailed or mailed to you if you decide to participate. Please note that we will be allocating participants randomly to different phases of the study; that is, you may not participate in every stage or activity that I describe.

**Review Appendix 2A and 2B**

<table>
<thead>
<tr>
<th>Based on the described study and the rights, responsibilities and expectations of participants, would you feel comfortable participating in the study and signing the consent form?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Yes. I would like to participate. Please send me the study package and consent form.</td>
</tr>
<tr>
<td>□ Maybe – I need more time to think about it. Please send me the study package and consent form.</td>
</tr>
</tbody>
</table>
| If “Yes” or “Maybe”:
  | □ Email: ____________________________ |
  | □ Mail: ____________________________ |
| □ No. I do not want to participate. |

**Do you have any questions or concerns related to participating in this study?**

*(Take note of response)*

**What is your general availability to participate in a 90-minute study session?**

<table>
<thead>
<tr>
<th>Monday:</th>
<th>Morning</th>
<th>Afternoon</th>
<th>Evening</th>
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<td>Tuesday:</td>
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</tr>
<tr>
<td>Sunday:</td>
<td>Morning</td>
<td>Afternoon</td>
<td>Evening</td>
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</tbody>
</table>

**Communication preference**

<table>
<thead>
<tr>
<th>How do you prefer for me to contact you going forward?</th>
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<tbody>
<tr>
<td>□ By telephone</td>
</tr>
<tr>
<td>□ By email</td>
</tr>
</tbody>
</table>
B. Study I – Study guides for two group participatory design sessions

Participatory Design Session #1 Guide

The primary purposes of this participatory design session are as listed below, in order of priority:

1. Demonstrate the functionality of the C.O.A.C.H. system to caregivers by presenting an animated video.
2. Draft a list of proposed requirements for a caregiver user interface (UI) through discussion and feedback on C.O.A.C.H. and creative brainstorming.
3. Generate multiple conceptual designs, scenarios and/or UI mock-ups by encouraging and assisting participants in a hands-on design activity.
4. Discuss the various proposed design concepts as a group, invite feedback and comments and summarize the different design alternatives.

Below is a general guide to help moderators lead the first participatory design session, but flexibility will be exercised to facilitate discussion, creative brainstorming and design. Moderators will begin the session by briefly reviewing the purpose of the session and time estimates for each part of the session.

Before the focus group begins, participants should provide informed consent be reminded that their participation will be recorded using a video recording device.

Target Interview Length: 90 min

INTRODUCTION & INFORMED CONSENT (5 minutes)

• Welcome participants and introduce research team’s roles (Rika, Amy and Alex)
• Emphasize participants’ roles and some session guidelines
  o Only one person talks at a time
  o Confidentiality - what’s shared in the room stays in the room
  o Listen respectfully to everyone’s ideas – no judgment or criticism! No dumb questions/ideas; no right or wrong answers
  o Be open and respectful of both positive and negative experiences
  o All participants encouraged to participate equally – be respectful and considerate
• Briefly explain:
  o Purpose of the study and its overall importance/significance
  o The focus of both participatory design sessions (Aug 16 and Sept 15)
  o Explain the expectations for participants
  o Time commitment (for both sessions)
  o Compensation
• Answer any questions from or address participant’s concerns related to the study
• Ensure all participants have submitted signed consent forms to Amy

PART 1: Presentation of the C.O.A.C.H. system (~10 minutes)

1. Show participants the animated video of how the C.O.A.C.H. system would work in the home.
2. Ask participants if they have any questions about how C.O.A.C.H. works to clarify its functionality.

*Some possible probing questions to segue into Part 2:*

  a. What activities do you think COACH could help with in the home?
  b. Which of these activities would you feel comfortable leaving your loved one to do independently with COACH’s assistance?
  c. What would you need to know from the system to feel comfortable separating yourself from the activity?
  d. How much time would that activity take?
  e. What would this time afford you to do? Where would you be (locational) while they do it?

**PART 2: Discussing requirements for a caregiver UI prototype (~20 min)**

*Gather feedback and generate group discussion and brainstorming around the below questions. The research assistant will take notes throughout this part on the whiteboard or chart paper:*

1. **What aspects or features of C.O.A.C.H. would you want to control? How important is this feature and why? When would you want to control them?**

   *Possible examples for probing:*
   - Turn COACH on/off
   - Customize the types of prompts COACH provides (e.g., verbal only, picture, video)
   - Customize when COACH provides these prompts
   - Add an activity of daily living to the COACH system (e.g., tooth-brushing, toileting, bathing, dressing,
   - Customize when you want the system to alert you (the caregiver)

2. **What information would you want to receive from C.O.A.C.H.? How important is this information and why? When would you want to receive it?**

   *Possible examples for probing:*
   - Alerts from COACH when your assistance is needed
   - View trends/reports on how well your loved one has been able to complete activities successfully using COACH

   **Focused example to help discussion:** Suppose you wanted to add an activity of daily living (e.g., tooth-brushing, dressing) that COACH could support your loved one with. Some parameters you might want to customize could include:

   - The individual steps that your loved one usually takes to complete the task
   - The sequence of the steps
   - What type of prompts your loved one would respond best to (e.g. audio, picture, video)
   - The actual prompt instructions (i.e. what the audio prompt says, what the picture/video looks like)

3. **What modalities, or through what media, would you prefer to use to interact with C.O.A.C.H.?** (E.g., desktop computer, laptop, email, telephone, text message, etc.) What “user interfaces” would you prefer to use to interact with C.O.A.C.H.? (Pass around smart phones and iPad)
PART 3: Conceptual design sketches and/or UI mock-ups (~30 minutes)

1. Read out the generated list for the group as a summary or review.
2. Show on projector different examples of storyboards, sketches, crude UI mock-ups and written text scenarios (place paper copies of examples on table as well).
3. Ask participants to think about the “requirements” generated by the group and write, sketch or create a conceptual design, storyboard and/or UI mock-up. Provide them with ample creative arts supplies (e.g. paper, index cards, coloured writing tools, glue, tape, etc.).
4. The student researcher (moderator) and research assistant will circulate the room to discuss participants’ ideas and assist.

<table>
<thead>
<tr>
<th>What participants should try to include in their designs:</th>
</tr>
</thead>
<tbody>
<tr>
<td>- What problem is your design solving?</td>
</tr>
<tr>
<td>- Locations – loved one, caregiver, device(s)</td>
</tr>
<tr>
<td>- Form factor of device(s), i.e. size/shape/weight, portability, wearability</td>
</tr>
</tbody>
</table>

PART 4: Presentation of sketches and mock-ups and discussion of alternatives (~20 minutes)

Note: The research assistant will take notes during this part of the session either on chart paper/whiteboard, or in his/her field notes, as appropriate.

1. Ask each participant to present his/her ideas to the group if they feel comfortable doing so.
2. The student researcher will then initiate questions about the design and invite other participants to ask questions and comment on each design.
3. After all participants (who feel comfortable doing so) have presented, the student researcher will try to summarize the various design concepts generated during the session.
4. The student researcher will advise participants to expect to receive a summary by email and a reminder to think of additional ideas or concepts to bring forward at the second participatory design session.

SESSION CLOSING (~5 minutes)

- Thank participants for their time and efforts
- Advise participants that they will receive an email with a summary of the design alternatives and encourage them to think of additional ideas or concepts for the second participatory design session
- Briefly overview the purpose and logistical details of the next participatory design session
- Issue compensation where necessary
Participatory Design Session #2 Guide

The primary purposes of this participatory design session are as listed below:

1. Discuss paper prototypes generated based on the conceptual design sketches and mock-ups from the first participatory design session.
2. Have participants criticize, mark-up and build upon the paper prototypes.
3. As a group, discuss all participants’ proposed revisions and improvements to the paper prototypes.
4. As a group, merge all prototype improvements into one final paper prototype design on which the student researcher will develop a functional software prototype.

Below is a general guide to help moderators lead the second participatory design session which will be scheduled approximately one month after the first session. Flexibility from this guide will be exercised to facilitate discussion, creative brainstorming and design. Moderators will begin the session by briefly reviewing the purpose of the session and time estimates for each part of the session.

Target Interview Length: 90 min

WELCOME BACK, CONSENT REMINDER, SESSION GOALS (~5 min, Rika)
- Thank participants for returning to participate in the second session
- Remind them that they have provided consent to have the session video-recorded
- Acknowledge that wonderful ideas came out of the first session and during Amy’s subsequent telephone conversations with participants. However, the purpose of this session is to channel all ideas into the user interface (UI) for caregivers. Additional ideas related specifically to improving the broader COACH system can be discussed or submitted after the session.

PART 1: Introduction to caregiver-COACH interactions (~15 min, Amy)
1. Using a PowerPoint presentation:
   o Revisit what the COACH system is, the stakeholders involved (i.e., COACH, older adult user with dementia, his/her caregiver) and the interactions that exist, clarifying that the session will focus on the caregiver-COACH interaction.
   o Discuss the four sections of the caregiver-COACH UI:
     ▪ COACH setup (“wizard”)  
     ▪ Home screen features  
     ▪ Show/change your current activities in COACH  
     ▪ Add a new custom activity  
   o Explain the following terms that the UI prototype using examples:
     ▪ Caregiver/user profiles  
     ▪ Devices  
     ▪ Status updates on home screen (text, “Watch”, “Communicate”)  
     ▪ ON/OFF schedules  
     ▪ Activity steps  
     ▪ Prompts  
     ▪ Triggers  
     ▪ Alerts  
     ▪ Reports  
     ▪ Pre-programmed activities  
     ▪ Reminder calendar, event reminders
PART 2: Improve assigned sections of the UI prototype in groups. (~35 minutes, Steve/Amy/Rika)

1. Participants will be divided into groups of three. Group assignment will be written on chart paper and place cards will be at each seat. Digital/video recorders will be given to each group for later transcription and analysis.
   a. Group 1 (facilitators: Amy and Rika): Helena, Helen, Thecla
      • COACH setup (“wizard”)
      • Home screen features
   b. Group 2 (facilitator: Steve): Mary, Joyce, Kathlene
      • Show/change current activities in COACH
      • Add a new custom activity

Note: Rika may also be asked to join Group 2 to help facilitate as and where needed.

2. Facilitators will begin by asking open-ended questions based on the Part 1 presentation. For example:
   a. What did you think?
   b. What are your initial thoughts/ideas on how you would want to interact with COACH?

3. Facilitators will then lead the discussion into examining Amy’s UI prototypes and ask more specific questions, including:
   a. Are there any features/buttons you would add to the UI?
   b. Are there any features/buttons you would delete from the UI?
   c. Would you change any of the words/expressions (buttons, labels, menu options)?
   d. Would you rearrange the layout of the objects on the screen?
   e. Would you change any of the colors used (buttons, labels, menus)?
   f. Are there icons you would want added, removed or changed?

Participants will again be provided with ample creative arts supplies (e.g., writing tools, tape, paper, glue, etc.) for this activity.

Note: The UI prototype has been designed for a desktop, laptop or touch-screen tablet computer. Two tablet computers will be available for participants to see device form factor

PART 3: Presentation of improved prototypes and discussion (~20 minutes, Rika)

Note: Members of the research team may take notes during this part of the session either on chart paper/whiteboard, or in his/her field notes, as appropriate.

1. A representative from each group will present their improved prototypes to the large group if they feel comfortable doing so.
2. The research team and other participants will be invited to ask questions about design choices and provide additional comments and suggestions.
3. A member of the research team will try to capture the key improvements and changes to the prototype on chart paper to facilitate idea generation, discussion, and summary.

PART 4: Discussion of mobile needs (~15 min, Rika)

In the larger group, towards gathering requirements for a mobile version of the UI, participants will be asked where else (other than in the home) they would want to be able to communicate with COACH. They will be asked to brainstorm and/or select information and features from the tablet-based UI that they would want to have in a mobile/smart phone version. If they feel comfortable doing so, participants will be invited to sketch out their ideas in the form of a mobile UI.
C. Study I - Participant instruction sheets for paper prototyping sessions

**TASK 1:**
Set up the COACH system for the first time

**PART 1**
*Please read the entire task aloud before proceeding.*

The COACH system has just been installed in your home and you are about to power it up for the first time. After hitting the ON button, the computer-based tool ask you a series of questions about you, the person you care for, the activities you want help with and how you can communicate with the system.

**Information you will need to complete the task:**

1. Name your four COACH setups:
   a. Setup #1: Bedroom
   b. Setup #2: Bathroom
   c. Setup #3: Kitchen
   d. Setup #4: Living room

2. Caregivers:
   a. You are the primary caregiver. You can use your first name only.
   b. Pretend you have an additional caregiver named “Josephine”.

3. Activities that you want COACH to help your mother with (please add these only):
   - Tooth-brushing (in the bathroom)
   - Dressing (in the bedroom)
   - Making phone calls (in the living room)

4. Prompts: choose the type that your mother would respond best to.

5. Language: choose English.

6. Alerts: choose how and when you want to receive alerts.
**TASK 1:**

Set up the COACH system for the first time

**PART 2**

*Please read the entire task aloud before proceeding.*

Since tooth-brushing and dressing are both twice daily activities, you want COACH to remind your mother to do these every morning and every night. You also have the impression that your mother has been feeling lonely recently so you want COACH to remind and guide her through calling her granddaughter, Jessica, every Sunday at 8:00PM now that Jessica is away for university. You also want COACH to remind your mother that Jessica will be coming back for a visit at the end of the month.

**Information you will need to complete the task:**

1. Divide your mother’s daily schedule into morning, afternoon and evening time periods.

2. **DAILY activities:**
   a. Your mother needs to brush her teeth and then get dressed every morning, in that order.
   b. Your mother does not need have daily afternoon activities that she needs COACH to help with at the moment.
   c. Your mother needs to change into her pajamas and then brush her teeth every evening, in that order.

3. **RECURRING activities:**
   a. Schedule COACH to help your mother make a weekly phone call to Jessica on Dec 3rd, 10th and 17th from 8:00PM-8:30PM.

4. **Special events/appointments:**
   a. Schedule “Jessica’s visit” into COACH’s calendar to remind your mother.
   b. She will be visiting on Sunday, December 24th, 5:00-9:00PM
   c. Create a picture reminder by taking a picture of a photo of Jessica.
   d. Set two reminders for your mother. The first reminder should play one day before; the second reminder should play 2 hours before.

5. When you are finished your setup, go to your COACH home screen.
**TASK 2:**  
**Modify how COACH helps with toothbrushing**

*Please read the entire task aloud before proceeding.*

Last week at your mother’s dental check-up, the dentist gave her a special cavity-prevention toothpaste and advised you to make sure she brushes her left bottom molars carefully because the x-ray shows a cavity forming. Since COACH usually guides your mother through brushing her teeth, you want to modify its prompts accordingly.

**Information you will need to complete the task:**
1. Modify the evening activity “brush teeth”.

2. Modify the “add toothpaste” step:  
   a. Replace the verbal prompt with a new one that says: “Put on the toothpaste from the blue tube.”  
   b. Replace the picture prompt with a photo of the new, blue toothpaste tube.

**TASK 3:**  
**Obtain a report on your mother’s evening toothbrushing for the past two weeks.**

*Please read the entire task aloud before proceeding.*

One month after modifying how COACH helps your mother brush her teeth, you want to make sure she has been doing this successfully in the evenings.

**Information you will need to complete the task:**
1. The report should show:
   a. Your mother’s evening toothbrushing activity  
   b. The November 13th to November 27th time period  
   c. When your mother completed the activity of tooth-brushing successfully

2. View the report first. Then, email the report to yourself.
TASK 4:

Add a new custom activity so COACH can help with making a cup of tea

Please read the entire task aloud before proceeding.

Your mother loves her 3PM tea time every day but, because of a new construction zone on the way home from work, you are finding it impossible to make it home in time to help her make it. Your personal support worker, Josephine, also only comes to help during the mornings. You decide to purchase an automatic, temperature-regulated coffee/tea machine that seems safe for your mother to use independently with some help from COACH.

Information you will need to complete the task:

1. Name the new activity: Make tea.

2. Add the activity to your mother’s afternoon activities.

3. Create the following steps:
   a. Open machine lid
   b. Pour water to the line
   c. Insert new tea pod
   d. Close machine lid
   e. Press “Brew”

4. Record your own verbal prompts for each of the above steps.

5. Schedule “Make tea” for weekdays between 3:00PM and 4:00PM.

6. Tell COACH the activity “Make tea” should be done before the activity “Make a phone call” in the afternoon.

7. Create the following alerts to yourself:
   a. When COACH has tried all prompts and your mother has not responded, record a mobile phone call alert that tells you: “COACH was not able to help Mom make tea today.”
   b. When your mother has made tea successfully, create a text message alert that reads: “COACH just helped Mom make her afternoon tea.”
**TASK 5:**

Check in using COACH while you are out at an appointment

*Please read the entire task aloud before proceeding.*

Josephine has called in sick and will not be available to help your mother today. You have an important appointment downtown with your accountant and need to leave your mother at home on her own for a few hours. You figure you can use COACH to check in on her periodically.

**Information you will need to complete the task:**

A. Check if your mother ate her lunch at 1:00PM using COACH’s video feature.

B. You see from the status line that COACH is helping your mother make tea.
   a. Watch to see if everything is going smoothly.
   b. Intercom with your mother to let her know you will be home in an hour.
## Telephone Screening Tool for Study Recruitment

### Introduction

**Date/time of first call**

Hello, this is Amy Hwang from the University of Toronto's research department. I am calling to follow up regarding your interest in participating in my research study. I would like to give you more details and ask you a few questions to see if you are available and eligible to participate. Do you have about 10 minutes now or is there a more convenient time for me to phone you back?

### Date/time of rescheduled call

**How did you hear about our study?**

- Care organization
- Public (bulletin board)
- Word-of-mouth
- Other: _______________________________________

### Demographic information

#### Prospective participant ID

(Name stored in secure database)

**Date of birth**

- Year ________
- Month ________
- Day ________

**Gender**

- Male
- Female

**Occupation**

- Employed/studying F/T
- Employed/studying P/T
- Unemployed
- Retired

### Inclusion criteria

**Relationship to older adult receiving care**

- Daughter
- Daughter-in-law
- Son
- Son-in-law
- Other: _______________________________________

**Degree of dementia of older adult receiving care**

- Mild (diagnosed)
- Mild (assumed/estimated)
- Moderate (diagnosed)
- Moderate (assumed/estimated)
- Severe (diagnosed)
- Severe (assumed/estimated)
- Other/comments: _______________________________________

**Do you provide care on an informal, UNPAID basis?**

- Yes
- No, I receive payment from: ________________________________

### Which activities can your parent complete independently?

- Bathing/showering
- Toileting
- Hand-washing
- Tooth-brushing
- Dressing
- Meal preparation
- Medications
- Communication with others
- Other: _______________________________________

### Which activities do you assist with?

**Circle one and/or write comments:**

‘D’ = hands-on assistance  
‘I’ = indirectly (e.g., PSW support)

- Bathing/showering [D / I] ______________
- Toileting [D / I] ______________
- Hand-washing [D / I] ______________
- Tooth-brushing [D / I] ______________
- Dressing [D / I] ______________
- Meal preparation [D / I] ______________
- Medications [D / I] ______________
- Communication with others [D / I] ______________
- Other: [D / I] ______________
- Other: [D / I] ______________
- Other: [D / I] ______________

---

*Study Title: The experience of caring for a parent with dementia at home*
### Study Title: The experience of caring for a parent with dementia at home

**How long have you been an informal caregiver?**
- [ ] < 6 months
- [ ] 6 to 12 months
- [ ] 1+ to 3 years
- [ ] 3+ to 5 years
- [ ] 5+ years

**Comments:** ____________________________________________________________

**Do you live with the person you care for?**
- [ ] Yes, in my parent’s home
- [ ] Yes, in my home
- [ ] No

**Other/comments:** ______________________________________________________

**Study overview and informed consent**

I will now go over the purpose and details of the study, as well as the participant consent form which you may already have, or will be emailed/mailed to you if you choose to participate. **Proceed to review Appendix A.**

**Do you have any questions or concerns related to participating in this study?**

If 'Yes' or 'Maybe', preference/permission to contact and send information to:
- [ ] Telephone: (_____) ____________
- [ ] Email: __________________@_____________________________
- [ ] Mail: __________________@_____________________________

**Study logistics (if ‘Yes’ or ‘Maybe’ to the above question)**

**What is your general availability to participate in a half-day (3.5-4 hr) workshop?**

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**Do you require compensation to travel to the study location?**
- [ ] Yes, I will be travelling by public transit.
- [ ] Yes, I will be travelling by taxi.
- [ ] Yes, I will be travelling by car (i.e., parking and mileage).
- [ ] No, I do not require travel compensation.

**Do you have any food restrictions or allergies?**
- [ ] No
- [ ] Yes, I am a vegetarian
- [ ] Yes, I am allergic to: ________________________________
- [ ] Yes, other: _______________________________________

**Thank you & word-of-mouth referral**

Thank you very much for your time! (Review scheduling and next steps...) Also, if you know of anyone else who would be eligible for and interested in participating, I would appreciate if you could pass on my contact information.
E. Study II – Adult daughters focus group guide

APPENDIX E: Workshop Guide
Adult daughter participants

Participants: 6 adult daughter caregivers to older adults with dementia living at home
Research team: Moderator (leads discussion), co-moderator (Ph.D. candidate, helps steer discussion to meet research goals), assistant (takes notes, records audio & video)
Workshop duration: 4 hours (half-day)

A. WELCOME & ICEBREAKING (35 minutes)
Opportunity for participants and research team to informally introduce one another, build rapport, and mingle over coffee and light refreshments. Student investigator to review study consent form one-to-one with each participant and collected completed and signed forms.

B. INTRODUCTION & INFORMED CONSENT (10 minutes)
1. Welcome participants and introduce the research team (i.e., moderator, Ph.D. student, research assistant).
2. Review the purpose of the study and its overall importance/significance.
3. Review expectations of participants and guidelines:
   - Only one person talks at a time
   - All participants will be encouraged to participate equally
   - Listen respectfully – no judgment/ criticism of others
   - Be open and respectful of both positive and negative experiences
   - Respect your own and others’ comfort zones
   - Confidentiality - what’s shared in the room stays in the room
   - Feel free to excuse yourself to use the restroom (directions)
4. Review time commitment:
   - 3.5-hour workshop with a 30-minute meal break
   - All participants will be invited to come back to participate in Phase 2, which will take place in 6-8 months’ time
5. Provide instructions to participants re: compensation
   a. See Amy Hwang at the end of the session to submit receipts and collect reimbursement for transportation (if applicable)
6. Remind participants of video & audio recording throughout the workshop and its uses outlined in the study consent form...

Invite participants to make their own notes on blank paper provided, if desired, and advise them not to write their names on the
7. Field any questions from participants before proceeding.

C. WORKSHOP PART 1 – FOCUS GROUP DISCUSSION (60 minutes)
Goal: To gain a preliminary understanding of the negative and positive aspects of the caregiving experience, from the perspectives of daughters (or daughters-in-law) who provide care to a parent with dementia.

1. Tell us about how it is that you came to assume the role of a caregiver (i.e. you take care of your parent or parent-in-law).
   - Who is it that you take care of?
   - Who or what led you to take on this role?
   - How did you feel about taking it on? How do you feel about it now?

2. What does being a “caregiver” mean to you?
   - How do you think your meaning/definition relates to how others understand what it is to be a caregiver? Say, for people who don’t have experience caring for a parent with dementia?
     ▪ How do you think others understand it?
     ▪ How might the role/your experience be different from how they understand it, or how it is represented (e.g., media)?

3. What do you want the world to know about what it is to be a caregiver?
   - How do you want others to see you and others who are caring for a parent with dementia?
   - Is there anything you want the world to know about you that might challenge misunderstandings about what it is to care for a parent with dementia?

4. What is it like being a daughter who is a caregiver?
   - Do you think your caregiving is different because you are a woman?
   - How different do you think the caregiving would be if your brother (or if you had a brother) was the caregiver?

5. Here is a statement from a daughter who cares for her mother with dementia [hand out photocopies and read aloud]:

I usually take care of what needs to be done . . . it's just to make sure she's eating and getting her medicine... I don't want to do it. It's not that I don't want any contact with her, I'm just tired of being the babysitter . . . . It feels like a chore sometimes and I feel bad about that because it shouldn't, but I just figured it's my mom, and so someone's got to look after her.

How does this account fit with your own experience caring for your parent?
- Tell me some of the (other) burdensome or stressful aspects of caring for your parent.
- [To defer detailed descriptions of scenarios/examples until Part 2] This part of the discussion will try to touch on some of the key areas that are difficult or stressful. In the second part of our discussion, we will ask you to provide examples and we will go into more depth.

6. Here is a statement from another daughter who cares for her mother with dementia [hand out photocopies and read aloud]:

“I would say [I am] stronger – stronger mentally, emotionally, you know. And also, strong in everything... because of this kind of hardship, I call it hardship, you learn a lot of things to be a better person. You know, to overcome obstacles, you know, things like that, one after another, that's how I feel.”

How does this account fit with your own experience caring for your parent?
- Tell me some of the (other) positive or rewarding aspects of caring for your parent.
- [To defer detailed descriptions of scenarios/examples until Part 2] This part of the discussion will try to touch on some of the key areas that are positive or rewarding. In the second part of our discussion, we will ask you to provide examples and we will go into more depth.

7. This was a great discussion and exactly the kind of discussion we were hoping for today. To recap what we discussed... [moderator to recap].

8. We are going to take a 30 minute lunch break now. While you are eating or after you eat, we will ask each of you to think about some specific situations caring for your parents at home. We would like each of you to come up with one example of a difficult/stressful situation and one example of a positive/rewarding situation. Based on what we've discussed so far, maybe the difficult/stressful examples are related to [draw on negative topics discussed]. Maybe the positive/rewarding examples are related to [draw on positive topics discussed]. In this part of the workshop, we are looking for as much detail as possible. To get you thinking, we have a list of questions related to the level of detail we are interested in. Feel free to help yourself to some paper and pens and jot down notes if that would help you describe your example. After lunch, we will go around the room and ask each of you to tell us about one of your two examples.

On chart paper:
- When did this situation occur?
- What led to or prompted this situation?
- What did you do?
- Describe the different things you tried.
- Describe how your parent responded or didn’t respond to each approach that you took.
- Describe the approach that was effective.
- How long did it take you to resolve the problem or reach your goal.
- In what ways did this situation affect you?
- How do you feel about how you handled this situation?
Were there any particular people who influenced your actions? Tell us how [person identified] influenced you.
  • If things DID go as well as you would have liked, how did this person make it easier?
  • If things DID NOT go as well as you would have liked, in what ways did this person make it difficult?

Were there any particular things that influenced your actions? Tell us how [thing identified] influenced you.
  • If things DID go as well as you would have liked, how did this thing make it easier?
  • If things DID NOT go as well as you would have liked, in what ways did this thing make it difficult?

D. LUNCH BREAK (30 min)

E. WORKSHOP PART 2 – CAREGIVING SCENARIO DESCRIPTIONS (90 minutes)
Goal: To gain a detailed understanding (i.e., problems/goals, time/place context, motivating values, influencing people/factors, actions/responses, feelings) of both burdensome and rewarding caregiving scenarios in the home through personal accounts from adult child caregivers.

1. We hope everyone had a good lunch break and had a chance to think about some examples from their own experiences. As mentioned, in this last part of the workshop, we will be looking for detailed examples of providing care at home. We asked you to each to think about one positive and one stressful/difficult example because we are looking to understand both kinds of experiences. What we’ll do is ask each of you to pick one for now – either positive or negative – and we will work towards hearing about both kinds of experiences by the end of the first round. Would anyone like to start?

2. Go around to each participant and aim to discuss a mix of negative and positive examples. For example, if the first 2-3 examples are negative, ask the next participant to talk about a positive example. Again, use the above questions (on chart paper) as probes to gather as much detail about the situation as possible. Remember to reassure each participant that detail is encouraged, listen actively and paraphrase to affirm her account, and thank her before moving on to the next participant.

F. SESSION CLOSING (15 minutes)

1. Thank participants for their time and efforts.
2. Advise participants that they will be contacted in the next 6 months and invited to participate in Phase 2.
3. Collect any written notes from participants who wish to submit, labelling each document with their anonymous participant codes.
4. Issue compensation where necessary.
F. Study II – Adult sons focus group guide

APPENDIX F: Workshop Guide

Adult son participants

Participants: 6 adult son caregivers to older adults with dementia living at home
Research team: Moderator (leads discussion), co-moderator (Ph.D. candidate, helps steer
discussion to meet research goals), assistant (takes notes, records audio & video)
Workshop duration: 4 hours (half-day)

A. WELCOME & ICEBREAKING (35 minutes)
Opportunity for participants and research team to informally introduce one another, build
rapport, and mingle over coffee and light refreshments. Student investigator to review study
consent form one-to-one with each participant and collected completed and signed forms.

B. INTRODUCTION & INFORMED CONSENT (10 minutes)

1. Welcome participants and introduce the research team (i.e., moderator, Ph.D. student,
research assistant).

2. Review the purpose of the study and its overall importance/significance.

3. Review expectations of participants and guidelines:
   - Only one person talks at a time
   - All participants will be encouraged to participate equally
   - Listen respectfully – no judgment/ criticism of others
   - Be open and respectful of both positive and negative experiences
   - Respect your own and others’ comfort zones
   - Confidentiality - what’s shared in the room stays in the room
   - Feel free to excuse yourself to use the restroom (directions)

4. Review time commitment:
   - 3.5-hour workshop with a 30-minute meal break
   - All participants will be invited to come back to participate in Phase 2, which
     will take place in 6-8 months’ time

5. Provide instructions to participants re: compensation
   a. See Amy Hwang at the end of the session to submit receipts and collect
      reimbursement for transportation (if applicable)

6. Remind participants of video & audio recording throughout the workshop and its uses
   outlined in the study consent form. Invite participants to make their own notes on
   blank paper provided, if desired, and advise them not to write their names on the
paper. They will have the option to submit these notes to the research team at the end of the workshop.

7. Field any questions from participants before proceeding.

C. WORKSHOP PART 1 – FOCUS GROUP DISCUSSION (60 minutes)
Goal: To gain a preliminary understanding of the negative and positive aspects of the caregiving experience, from the perspectives of sons (or sons-in-law) who provide care to a parent with dementia.

2. Tell us about how it is that you came to assume the role of a caregiver (i.e. you take care of your parent or parent-in-law).
   - Who is it that you take care of?
   - Who or what led you to take on this role?
   - How did you feel about taking it on? How do you feel about it now?

3. What does being a “caregiver” mean to you?
   - How do you think your meaning/definition relates to how others understand what it is to be a caregiver? Say, for people who don’t have experience caring for a parent with dementia?
     - How do you think others understand it?
     - How might the role/your experience be different from how they understand it, or how it is represented (e.g., media)?

4. What do you want the world to know about what it is to be a caregiver?
   - How do you want others to see you and others who are caring for a parent with dementia?
   - Is there anything you want the world to know about you that might challenge misunderstandings about what it is to care for a parent with dementia?

5. What is it like being a son who is a caregiver?
   - Do you think your caregiving is different because you are a man?
   - How different do you think the caregiving would be if your sister (or if you had a sister) was the caregiver?

6. Here is a statement from a son who cares for their mothers with dementia [hand out photocopies and read aloud]:
   “When you spend most of your time taking care, your social life and your work have to stop…even relationships. There is fallout from looking after her…my family feel the stress as well as me…you are giving to one and taking from the care.”

   How does this accounts fit with your own experience caring for your parent?
   - Tell me some of the (other) burdensome or stressful aspects of caring for your parent.
- [To defer detailed descriptions of scenarios/examples until Part 2] This part of the discussion will try to touch on some of the key areas that are difficult or stressful. In the second part of our discussion, we will ask you to provide examples and we will go into more depth.

7. Here is a statement from another son who cares for his mother with dementia (hand out photocopies and read aloud):

“In my mother's case, I've gone beyond a mother-son relationship... I always believe that you take care of your mother because of obligation as a son, as most people would do. But I feel, no! It's not; that's only gratitude. I've gone above that. She's another person, a being. I've learnt that it's so hard to meet in this life, so we should cherish whatever time we have left. So I've gone beyond mother and son, my duty to take care of her but I try to lift it above that level of mother and son, to another person... in that sense I grow, you see... it's an enriching experience... initially it was gratitude, a sense of duty – you bring me up, I look after you... It's my chance to do a good deed for her, for another person. So we as humans, we should be kind to each other. It's more noble that way, to give. So I find I have adopted this attitude and I would say in that sense I've grown spiritually.”

How does this account fit with your own experience caring for your parent?

- Tell me some of the (other) positive or rewarding aspects of caring for your parent.

8. This was a great discussion and exactly the kind of discussion we were hoping for today. To recap what we discussed... [moderator to recap].

9. We are going to take a 30 minute lunch break now. While you are eating or after you eat, we will ask each of you to think about some specific situations caring for your parents at home. We would like each of you to come up with one example of a difficult/stressful situation and one example of a positive/rewarding situation. Based on what we've discussed so far, maybe the difficult/stressful examples are related to [draw on negative topics discussed]. Maybe the positive/rewarding examples are related to [draw on positive topics discussed]. In this part of the workshop, we are looking for as much detail as possible. To get you thinking, we have a list of questions related to the level of detail we are interested in. Feel free to help yourself to some paper and pens and jot down notes if that would help you describe your example. After lunch, we will go around the room and ask each of you to tell us about one of your two examples.

On chart paper:
- When did this situation occur?
- What led to or prompted this situation?
- What did you do?
- Describe the different things you tried.
- Describe how your parent responded or didn’t respond to each approach that you took.
- Describe the approach that was effective.
- How long did it take you to resolve the problem or reach your goal.
- In what ways did this situation affect you?
- How do you feel about how you handled this situation?
- Were there any particular people who influenced your actions? Tell us how [person identified] influenced you.
  - If things DID go as well as you would have liked, how did this person make it easier?
  - If things DID NOT go as well as you would have liked, in what ways did this person make it difficult?
- Were there any particular things that influenced your actions? Tell us how [thing identified] influenced you.
  - If things DID go as well as you would have liked, how did this thing make it easier?
  - If things DID NOT go as well as you would have liked, in what ways did this thing make it difficult?

D. LUNCH BREAK (30 min)

E. WORKSHOP PART 2 – CAREGIVING SCENARIO DESCRIPTIONS (90 minutes)
Goal: To gain a detailed understanding (i.e., problems/goals, time/place context, motivating values, influencing people/factors, actions/responses, feelings) of both burdensome and rewarding caregiving scenarios in the home through personal accounts from adult child caregivers.

1. We hope everyone had a good lunch break and had a chance to think about some examples from their own experiences. As mentioned, in this last part of the workshop, we will be looking for detailed examples of providing care at home. We asked you to each to think about one positive and one stressful/difficult example because we are looking to understand both kinds of experiences. What we’ll do is ask each of you to pick one for now – either positive or negative – and we will work towards hearing about both kinds of experiences by the end of the first round. Would anyone like to start?

2. Go around to each participant and aim to discuss a mix of negative and positive examples. For example, if the first 2-3 examples are negative, ask the next participant to talk about a positive example. Again, use the above questions (on chart paper) as probes to gather as much detail about the situation as possible. Remember to reassure each participant that detail is encouraged, listen actively and paraphrase to affirm her account, and thank her before moving on to the next participant.

F. SESSION CLOSING (15 minutes)

1. Thank participants for their time and efforts
2. Advise participants that they will be contacted in the next 6 months and invited to participate in Phase 2
3. Invite participants to make their own notes on blank paper provided, if desired, and advise them not to write their names on the paper. They will have the option to submit these notes to the research team at the end of the workshop.
APPENDIX D1: Relationship Questionnaire – Member Participant

This questionnaire asks you to respond to a series of statements based on ONE significant social relationship. You may complete multiple questionnaires to provide responses for multiple relationships. Part A asks you to indicate the type of relationship; Part B asks you to describe your relationship with this person BEFORE diagnosis; Part C asks you to describe your relationship with this person TODAY; and Part D asks you to describe how your relationship with this person has been influenced by technology use.

Part A – Your relationship type

1. Please indicate how this person is related to you?
   - ☐ Spouse
   - ☐ Former spouse
   - ☐ Son/daughter
   - ☐ Son-in-law/daughter-in-law
   - ☐ Niece/nephew
   - ☐ Grandchild
   - ☐ Friend
   - ☐ Other: ________________________________________________________________

2. Do we have your permission to invite this person to participate in our research study? He/she will be asked to complete a similar survey and participate in an interview (in-person, telephone, Skype).
   - ☐ Yes
   - ☐ No. My reason is (optional): ________________________________________________
APPENDIX D1: Relationship Questionnaire – Member Participant

Part B – Your relationship before diagnosis

3. Please respond to the following statements about your relationship BEFORE you were diagnosed with Mild Cognitive Impairment or Alzheimer’s Disease.

a) We tried to interact cheerfully and pleasantly with each other.
Examples: Acting upbeat and positive; doing favours for each other; acting excited to spend time together; showing affection (e.g., hugs)
☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

b) We listened to each other and had direct, honest conversations.
Examples: Discussing intimate/sensitive topics, problems/feelings, our relationship; giving and receiving advice; addressing conflict with one another; listening without judgment
☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

c) We assured each other that our relationship was important.
Examples: Relying on each other for support; comforting each other emotionally during hard times; at times, putting the other first; expressing love verbally
☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

d) We relied on support from other family members/friends to maintain our relationship.
Examples: Asking someone else to help us resolve our disagreements.
☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

e) We shared tasks, chores, and/or errands.
Examples: Cooking, cleaning, grocery shopping
☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

f) We spent time doing activities together.
Examples: Sharing social conversations, home visits, coffee/meals, outings, activities/hobbies, vacations/getaways
☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

g) We stayed in frequent contact when apart from each other.
Examples: Exchanging cards, letters, emails, telephone calls, text messages, web/mobile calls (e.g., Skype, FaceTime)
☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

h) We avoided each other and/or sensitive issues.
Examples: Giving each other space, avoid discussing about sensitive topics, maintain separate activities or social networks
☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

i) We acted unapproachably toward each other.
Examples: Acting moody around each other, behaving rudely toward each other
☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

j) We used jokes and/or sarcasm in our interactions.
Examples: Telling jokes/stories to make each other laugh, teasing each other
☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

k) Are there any other ways you used to interact with this person?

________________________________________________________________________________________

________________________________________________________________________________________

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APPENDIX D1: Relationship Questionnaire – Member Participant

Part C – Your relationship today

4. Please respond to similar statements based on your relationship TODAY.

a) We try to interact cheerfully and pleasantly with each other.
   Examples: Acting upbeat and positive; doing favours for each other; acting excited to spend time together; showing affection (e.g., hugs)
   ☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

b) We listen to each other and have direct, honest conversations.
   Examples: Discussing intimate/sensitive topics, problems/feelings, our relationship; giving and receiving advice; addressing conflict with one another; listening without judgment
   ☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

c) We assure each other that our relationship is important.
   Examples: Relying on each other for support; comforting each other emotionally during hard times; at times, putting the other first; expressing love verbally
   ☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

d) We rely on support from other family members/friends to maintain our relationship.
   Examples: Asking someone else to help us resolve our disagreements.
   ☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

e) We share tasks, chores, and/or errands.
   Examples: Cooking, cleaning, grocery shopping
   ☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

f) We spend time doing activities together.
   Examples: Sharing social conversations, home visits, coffee/meals, outings, activities/hobbies, vacations/getaways
   ☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

g) We stay in frequent contact when apart from each other.
   Examples: Exchanging cards, letters, emails, telephone calls, text messages, web/mobile calls (e.g., Skype, FaceTime)
   ☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

h) We avoid each other and/or sensitive issues.
   Examples: Giving each other space, avoid discussing about sensitive topics, maintain separate activities or social networks
   ☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

i) We act unapproachably toward each other.
   Examples: Acting moody around each other, behaving rudely toward each other
   ☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

j) We use jokes and/or sarcasm in our interactions.
   Examples: Telling jokes/stories to make each other laugh, teasing each other
   ☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

k) Are there any other ways that you interact with this person today?

________________________________________________________________________________________

________________________________________________________________________________________

Protocol 31850, v22Feb2016
APPENDIX D1: Relationship Questionnaire – Member Participant

Part D – Your relationship and everyday technology use

5. Please respond to the following statements about your relationship and your everyday technology use TODAY. “Everyday technology” may include your home telephone, mobile phone/smartphone, desktop/laptop computer, tablet computer (e.g., iPad), or Claris Companion.

a) My everyday technology helps our attempts to have cheerful and pleasant interactions with each other.
   Examples: Acting upbeat and positive; doing favours for each other; acting excited to spend time together; showing affection (e.g., hugs)
   □ Strongly disagree □ Disagree □ Neutral □ Agree □ Strongly agree

b) My everyday technology helps us have direct, honest conversations with each other.
   Examples: Discussing intimate/sensitive topics, problems/feelings, our relationship; giving and receiving advice; addressing conflict with one another; listening without judgment.
   □ Strongly disagree □ Disagree □ Neutral □ Agree □ Strongly agree

c) My everyday technology helps us assure each other that our relationship is important.
   Examples: Relying on each other for support; comforting each other emotionally during hard times; at times, putting the other first; expressing love verbally
   □ Strongly disagree □ Disagree □ Neutral □ Agree □ Strongly agree

d) My everyday technology helps us rely on other family members/friends to maintain our relationship with each other.
   Examples: Asking someone else to help us resolve our disagreements.
   □ Strongly disagree □ Disagree □ Neutral □ Agree □ Strongly agree

e) My everyday technology helps us share tasks, chores, and/or errands.
   Examples: Cooking, cleaning, grocery shopping
   □ Strongly disagree □ Disagree □ Neutral □ Agree □ Strongly agree

f) My everyday technology helps us spend time doing activities together.
   Examples: Sharing social conversations, home visits, coffee/meals, outings, activities/hobbies, vacations/getaways
   □ Strongly disagree □ Disagree □ Neutral □ Agree □ Strongly agree

g) My everyday technology helps us stay in frequent contact when apart from each other.
   Examples: Exchanging cards, letters, emails, telephone calls, text messages, web/mobile calls (e.g., Skype, FaceTime)
   □ Strongly disagree □ Disagree □ Neutral □ Agree □ Strongly agree

h) My everyday technology helps us avoid each other or sensitive issues.
   Examples: Giving each other space, avoid discussing about sensitive topics, maintain separate activities or social networks
   □ Strongly disagree □ Disagree □ Neutral □ Agree □ Strongly agree

i) My everyday technology helps us behave unapproachably toward each other.
   Examples: Acting moody around each other, behaving rudely toward each other
   □ Strongly disagree □ Disagree □ Neutral □ Agree □ Strongly agree

j) My everyday technology helps us exchange jokes and/or sarcasm in our interactions.
   Examples: Telling jokes/stories to make each other laugh, teasing each other
   □ Strongly disagree □ Disagree □ Neutral □ Agree □ Strongly agree

k) Are there any other ways that your everyday technology helps/harms your interaction with this person?
   _________________________________________________
   _________________________________________________

Protocol 31850, v22Feb2016
H. Study III – Semi-structured interview guide

Semi-Structured Interview Questions

Introduction

• Thank participant(s) for agreeing to participate and, if applicable, hosting me in-home.
• Remind participant(s) of the overall research aim and topic(s) I hope to explore today.
• Remind participants of the data being collected and their specific consents. Verify process consent verbally.
  o Descriptive data
  o Relational Maintenance Questionnaire data
  o Interview, observation, workshop & unstructured correspondence data
  o Pilot data (if applicable, optional)
  o Learning/training diary data (optional)
  o Audio recording data (optional)
  o Photographic data (optional)
• Remind/ask participants to share/discuss what they are comfortable sharing about themselves and others, and that they may withdraw from the study at any time.

Relationship maintenance questions (members & care partners)

• On your relational maintenance questionnaire, you indicated that [your/member’s] you used to relate to one another by [indicated strategy, e.g., showing affection], but that has changed since you/he/she was diagnosed. Can you tell me more about that?
  o Why do you think that changed?
  o How did that change?
    ▪ Influencing/involved people
    ▪ Circumstances (e.g., health, family/social, living arrangements)
    ▪ Key concerns / priorities
    ▪ Time period
  o How has that change been for you?
    ▪ How did you feel about it?
    ▪ How do you feel about it now?
  o How do you think that change has been for [the other person]?
    ▪ How might he/she have felt about it in the beginning?
    ▪ How might he/she feel about it now?

• On your questionnaire, you indicated that everyday technology helps/hinders [indicated aspect of relational maintenance]. Can you tell me more about that?
  o Which everyday technology? (e.g., Claris, mobile phone)
  o Which aspect/feature of the technology? (example scenario)
  o Has this changed your attitudes/feelings using technology, and how?
Why do you think this has affected [the other person’s] attitudes/feelings using technology, and how?

Would you use/avoid using the Claris for these reasons? How/why?

Claris-specific questions *(members, care partners (if applicable), volunteers)*

- Can you tell me your experience learning/teaching the Claris so far? We can walk through your diary entries together if that helps.
  - How are you (and the member) finding the Claris?
    - Mastered Claris features?
    - Questions or problems?
    - Comparisons to other everyday technologies?
- How has the Claris influenced or affected your/member’s relationship and how you/he/she relates to family/friends?
  - Day-to-day routines
  - Specific activities or tasks
  - Ways of relating (drawing from strategies from RM questionnaire)

Wrap-up

- Thank participants again and ask if they have any questions.
- Ask him/her/them if there was anything you discussed that he/she/they prefer not to share with others (i.e., care partner, volunteer, Claudine – Program Coordinator).
I. Study III – Participant observation guide

Participant Observation Guide

Introduction (if conducted separately from interview)
• Thank participants for participating and, if applicable, hosting me in-home.
• Remind participants of the overall research aim and topic(s) I hope to explore today.
• Remind participants that they had consented to observations and, if applicable, photography.
  Note that I will be:
  o Observing how they interact with each other, the technology, and other spaces/objects in the home;
  o Asking questions about what I observe throughout the session.
• Remind/ask participants to share/discuss what they are comfortable sharing about themselves and others, and that they may withdraw from the study at any time;
• Ask if they have any questions before beginning.

Observation probes
• What is happening in the setting?
  o What are the participants doing and why?
  o How are they interacting with information, objects (e.g., technologies, furniture), and spaces?
  o What is the ‘tone’ of their interaction based on their facial expressions, body language, and comments? (E.g., familiar, strained)

• How are participants interacting with each other?
  o Member-care partner, member-volunteer, volunteer-care partner
  o What is the ‘tone’ of these social interactions (e.g., comfortable/amicable, tense/strained, cooperative/resistant)?
  o Do participants’ interests seem aligned? In conflict?
  o How do these observed interactions relate to members’/care partners responses on their relational maintenance strategies questionnaires?
  o Do there seem to be power dynamics/hierarchies between participants?

• Is there anything that strikes you as most noteworthy, telling, interesting, or unexpected?

• If photos are permitted, how are the participants leading, influencing, or reacting to what is being photographed?

Wrap-up
• Thank participants again and ask if they have any questions about what you observed
• If applicable, ask him/her/them if there is anything you observed or discussed today that they prefer not to be shared with his/her volunteer and/or Claudine.
• If applicable, offer to show them the photos that were taken.