

Managing Finances for Persons Living with Dementia: Current Practices and Challenges for Care Partners

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ABSTRACT

Dementia is a global public health concern. There are more than 55 million persons living with dementia (PLWDs) globally with 10 million new cases annually. Dementia is characterized by declining cognitive and functional abilities over time. This can lead to serious challenges in financial decision-making and stability for PLWDs. Care partners are often required to undertake financial management responsibilities on behalf of PLWDs. In this preliminary work, we explore the needs and challenges for care partners in managing the finances of PLWDs. We interviewed (N=7) care partners for individuals with mild to severe dementia. We describe our initial findings on the emotional challenges for care partners, the transition of their financial responsibilities over time, and the need for preemptive planning and different collaborative financial management support throughout the course of the illness. These findings can inform accessible and supportive financial technology design for PLWDs and their care partners.

CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in collaborative and social computing**; **Empirical studies in HCI**.

KEYWORDS

Dementia, Aging, Financial technologies

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1 INTRODUCTION

Dementia is a global public health concern. There are currently more than 55 million persons living with dementia (PLWDs) globally [48]. Furthermore, there are nearly 10 million new cases each year [48]. The annual global cost associated with dementia is projected to be US\$ 2.8 trillion by 2030 [2]. Dementia is characterized by a

gradual decline in cognitive performance, which can negatively impact the ability to perform complex activities [39].

Specifically, dementia is strongly associated with the deteriorating ability to manage personal finances [32, 35, 45]. Impairment in financial management is an early predictor for dementia [32, 35]. Pérès et al. [35] reported reduced financial capabilities up to ten years before dementia diagnosis. As a result, PLWDs might be unable to perform routine financial tasks (e.g., paying bills), may make poor decisions, and be susceptible to financial fraud and scams [32, 45].

Care partners are often forced to undertake financial management tasks for PLWDs in addition to other care responsibilities. In 2019, over 16 million care partners in the US provided support for individuals with dementia [1]. Informal care responsibilities are mostly shared by women — approximately two-thirds of informal care partners are women [2]. Maintaining financial stability is critical for longterm wellbeing of PLWDs and care partners. However, it can be particularly challenging for care partners as they might not have the necessary training and skills for financial management and decision-making. Furthermore, collaborative financial management can be difficult leading to confrontations and fraught relationships [25].

While previous research has explored dementia informal care partner responsibilities [13], there hasn't been much work to understand their needs and challenges for supporting financial tasks of PLWDs. We think it is a serious knowledge gap that can impact the wellbeing of both PLWDs and their care partners. To address the knowledge gap, this paper focuses on the following research questions:

- RQ1: What are the current practices and challenges faced by care partners in managing finances of PLWDs?
- RQ2: Given the increased digitization of finances [37, 40, 42, 47], what are the priorities for future design of financial technologies to support PLWDs and care partners?

To gather an in-depth understanding of financial collaboration, we chose to first explore the lived experiences of care partners, actively in a financial management role for a PLWD. We interviewed seven individuals about their current tasks, strategies, and existing challenges for managing the finances of a family member. We also asked about the types of resources and technological tools that could help support them in the process of taking on new financial responsibilities.

Based on our initial analysis, we found that care partners have unique needs for transitioning into financial management roles for PLWDs. The majority of participants stressed the importance of pre-planning in making this transition successful. There are also challenges to financial collaboration that stem from existing

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family dynamics and conflicts, such as differing opinions on how and what decisions should be made on behalf of their relatives with dementia. Care partners also experience a significant amount of stress when taking on this new role in their daily lives. This stress can be experienced emotionally, through feelings of being overburdened and having to balance this new role with existing responsibilities in their own lives. Care partners can also experience added financial stressors, such as cutting back paid work hours to accommodate their care duties or covering additional costs of care for PLWDs. These challenges are largely driven by a lack of access to resources and information. For some, this is related to the costs of care and available support programs—a larger systemic issue.

Following the preliminary findings, we have outlined the priorities and research goals to support the full spectrum of care partner needs in this context. Specifically, our findings indicate that future financial management technologies should incorporate the needs of multiple stakeholders within family care settings, aim to balance agency and needs of PLWDs throughout different stages of illness, and provide additional support to mitigate care partner burden and related stress. Additionally, we highlight the need for systemic changes that are crucial to maintain financial stability for PLWDs, including access to resources and financial tools that can better support collaborative interactions and longterm planning. We hope that our preliminary findings will lead to a novel research focus within the HCI community toward designing supportive financial technologies for PLWDs and their care partners. This paper is an initial step to identify and address a critical need of this marginalized community.

2 RELATED WORK

2.1 Dementia and Its Financial Burden

Dementia leads to a progressive deterioration in cognitive and functional skills, significantly affecting the wellbeing and life quality of PLWDs and their caregivers. There is currently no cure to this disease and current treatment focuses on delaying the progression of the symptoms [38]. This chronic disease often results in significant financial burdens for families and society at large [15]. Early cognitive impairment symptoms can adversely affect job performance and personal relationships, potentially leading to decreased work hours or unemployment, which in turn causes economic hardship [11]. Recent studies show that as the severity of dementia increases, the associated care costs rise correspondingly [33, 41].

In addition, individuals' financial capacity can be significantly compromised even in the early stages of dementia leading to financial errors [14] and exploitation risks [44]. Several studies have focused on the loss of financial skills as indicators of functional decline [43, 44]. As a result, care partners frequently encounter a dual burden, grappling with increased financial pressures while simultaneously overseeing the financial management and decision-making for PLWDs [8, 23]. The burden of lifelong financial management for care partners — especially, in terms of balancing the risks and autonomy of PLWDs over extended periods — presents a significant challenge. Consequently, there's a pressing need to develop specialized financial technology (fintech) that support PLWDs and their care partners towards greater financial stability and resilience. Despite the pressing need, there's a noticeable lack of comprehensive

research focusing on supporting PLWDs and their care partners in sustained and collaborative financial management and decision-making. Our study strives to bridge this gap by examining these challenges.

2.2 Dementia in HCI

In HCI research, there is growing recognition of the need to understand dementia experiences in their social and cultural contexts and to involve PLWDs in design processes [27, 29, 30]. Extending upon McCarthy and Wright's [31] work with experience-centered design, Foley et al. [20] have presented a receipt-based print media device that facilitates PLWDs social engagement and autonomy in care home settings. Lazar et al. [28] created a design that enhances agency among PLWDs, enabling them to engage in art therapy for creative self-expression and to share their artworks with family and friends. Dixon et al.'s [19] study revealed that even those with mild to moderate dementia possess the capacity for inventive creation and the ability to manage their own self-care systems. In light of these findings, we intend to explore new opportunities to design supportive technologies that can facilitate PLWDs involvement in collaborative financial decision-making with their care partners.

2.3 Fintech for Marginalized Users

The HCI community is witnessing an increase in research focused on financial management across various communities and contexts. Perry and Ferreira [36] delved into the social and interactional aspects of monetary transactions, proposing a transaction framework to understand the processes surrounding payments, and discussed its implications for digital systems design. Prior studies have also focused on the financial practices and fintech accessibility among diverse underrepresented or marginalized groups [3, 5, 10, 22, 24, 46]. For example, Tang and Chandra's [46] investigation focused on how social and cultural factors influence the financial practices of older Hong Kong immigrants, highlighting the importance of contextualizing fintech design within existing communities and cultural practices. Latulipe et al. [26] have broadened the scope of research by identifying design strategies that facilitate collaborative financial practices among older adults and their close others while ensuring their privacy and agency and safeguarding them against financial abuse. Our research distinguishes itself by looking into a different and complex situation where individuals progressively rely on care partner assistance for financial management, as a result of ongoing cognitive decline.

3 METHODS

In this study, we conducted seven semi-structured interviews with individuals residing in the U.S. and Canada, who self-identified as unpaid family care partners of PLWDs. The decision to exclusively recruit care partners was informed by prior research, which suggests that care partners predominantly undertake the responsibility of financial management tasks in these circumstances [8, 23]. The participants varied in their familial roles and were responsible for care recipients with a range of cognitive impairments and diverse living conditions. Detailed demographic information about the participants and their care recipients is presented in Table 1.

We conducted these interviews remotely via Zoom. The interview topics included the complexities of managing financial activities for PLwDs, collaborative dynamics among different parties, and the overall management of financial resources. We also explored their expectations of future financial technology. The primary aim of these interviews was twofold: first, to understand the habits and challenges associated with current financial management practices among care partners; and second, to identify design opportunities for financial technologies that tailor to their varied needs.

For recruitment, we distributed our study flyers on social media (e.g., TikTok and Reddit) and reached out to online and local dementia support groups via the Alzheimer's Association. Our inclusion criteria included family care partners of PLwDs who are also responsible for managing the finances for PLwDs.

All of the interviews were video recorded and transcribed by the first author. A bottom-up thematic analysis was performed on interview transcripts by two authors, using a Grounded Theory approach [9]. The process consisted of two phases. In the first phase, each author reviewed transcripts individually and identified themes within participant responses. In the second phase, the authors worked together to integrate common themes and identify consistent sub-themes within various categories until an agreement was established.

4 FINDINGS

In the following subsections, we document the common steps care partners take to transition into a financial management role, the importance of preplanning and social support, the types of financial collaboration involved, and the emotional stress care partners encounter throughout this process.

4.1 Transitioning into New Financial Roles

Financial management in the context of dementia is a transitional process taken on by care partners to eventually become responsible for all money-related tasks for PLwDs. The majority of our study participants were care partners of individuals in more severe stages of dementia. As such, these care partners were in the later stages of this transition and managing financial decisions with very little to no input from the individual with dementia. For many participants, this transition was triggered by a specific event or financial problem indicating that the individual was losing their capacity to keep up with their finances on their own. For example, P2 noted: *“it was a lot of impulse buying and a lot of debt that my mom had even before I helped out. She almost lost the condo.”* Participants also noted recurring missed payments as a common challenge, as P3 commented: *“when I kind of knew that she was having issues when she was missing payments. [...] I've been married 48 years, and for 45 years we didn't even have a late charge.”* For some participants, it was the risk of financial exploitation that pushed care partners to get involved. As P7 recalled: *“she must have had about 5 or 6 different children through different organizations that she was sponsoring. She was really vulnerable to these sort of pleas, and she wanted to donate for everything, and she wasn't able to monitor her own spending.”*

A common first step in this process was for care partners to try to gain access to PLwDs' financial information. For many, this involved the arduous task of locating many different accounts,

such as online banking, utilities, or credit cards, and all of their associated passwords. For care partners of spouses with dementia, some aspects of this transition were easier as these were often joint accounts. Adult children of PLwDs faced additional obstacles to accessing financial information if their parents had not given them prior access to their accounts. Additionally, adult children of PLwDs were often less aware of their parents' financial situations. For example, P2 noted: *“I was shocked to see she still had a mortgage. I don't know how that happened. This house should have been paid off a long time ago.”* Those who were able to start this process at earlier stages of dementia experienced a smoother transition, as noted by P7: *“when she first got diagnosed, she was still well enough that she transferred or added me to all of her accounts. We also did an enduring power of attorney, which gives me the capacity to act on her behalf. She was well enough to understand this was important.”*

Once care partners gained access to all these accounts, they often trimmed down any unnecessary payments in anticipation of future healthcare costs and to ensure that they would have enough funds (*“My mom had a travel credit card. [It] was costing us more than we're benefiting from it, so I canceled it”* – P7). For others, this helped reduce the number of accounts to manage if they were no longer needed. For example, P4 noted: *“I discovered that he had a lot of warranty stuff that he really didn't need, or he certainly wasn't going to need from that point on. So I had to call each of those companies to cancel.”*

Following this, many compiled a record of all existing financial obligations—most often in an Excel spreadsheet or on paper—and set any recurring payments to autopay. This simplification meant that care partners could instead focus on whether enough money would be available each month. While this helped simplify things, managing unexpected costs was still challenging, as P7 noted: *“the utilities were easier because I know she has a phone. She has TV. She has the Internet. She has electricity. But a lot of the house repairs were more challenging and less predictable.”*

4.2 The Importance of Pre-planning and Social Support Systems

The rapid change in cognitive functionality that can occur in PLwDs can make financial planning a challenge for care partners. Because of this, participants stressed the importance of planning out this transition well in advance of when it would be needed. Our participants ranged in their feelings of preparedness—from those who had prior financial management experience and existing knowledge, to those who believed they started making arrangements far too late and felt very unprepared. Income differences and access to insurance or healthcare made pre-planning even more important to make ends meet. As P1 noted: *“he's now in a skilled nursing home. It's \$12,500. So the money goes quickly. So if you don't have a lot saved, it's terrifying. We've got like a couple more months left of money for him. But after that, difficult choices need to be made.”*

Some care partners, such as P3, characterized their planning as being in the right place at the right time to access key resources. *“I'm fortunate that I happened to go to a session where somebody basically said: you need to listen to this [...] My wife and I both did healthcare proxies. We both did power of attorney. We did all of these things ahead of time in anticipation of something happening.”* Much

Table 1: Characteristics of Participants and Their Care Recipients (PLwDs)

Participant	Relationship to PLwDs	Cognitive Status	Years since Diagnosis	Living Place	Location
1	Daughter	Severe	6	Memory care	U.S.
2	Daughter	Mild	0.5	Home	U.S.
3	Husband	Severe	6	Nursing home	U.S.
4	Daughter	Severe	N/A	Nursing home (before deceased)	U.S.
5	Husband	Moderate to Severe	6	Home	U.S.
6	Husband	Moderate to Severe	2	Home	U.S.
7	Daughter	Severe	13	Memory care	Canada

of the challenge stems from how time-sensitive this process can be. Not only do care partners have to anticipate the potential decline in financial capacity of PLwDs and increasing healthcare costs, but some assistance programs have specific windows of time in which they can be accessed by care partners. As P3 described, *“I have what’s called the Testamentary Trust. Essentially all of our assets are in the trust in my name to support me and her. [...] So when she goes to a nursing home, Medicaid (a government health program in the US) will step in because she doesn’t have assets.”* However, this assistance comes with time constraints, as P3 went on to explain, *“from the time you initiate this, you can’t use it for 5 years.”* If care partners miss these windows of opportunity or are unaware of them altogether, there can be significant consequences to getting the necessary financial support and healthcare coverage to ensure stable care for PLwDs. For others, it felt as if any amount of pre-planning still might not be enough, given the unpredictable nature of dementia and the possible healthcare costs involved. This sentiment was exemplified by P1: *“it’s a pretty pathetic situation for people who purposefully saved. They weren’t irresponsible. They saved money. You can’t possibly save for a catastrophic illness where your health insurance then doesn’t cover it.”*

Unfortunately, many care partners do not have experience with these complicated systems or background knowledge of how to support PLwDs. Therefore, they end up taking a learn-as-you-go or learn-from-others approach to their new financial care partner roles: *“it’s like you get this horrible diagnosis and then the family is just sort of on its own. We’ve done it all ourselves and every step of the way you’re learning a new thing that you wish you would have known 6 months earlier”* (P1). Our participants, who were involved in dementia care support groups, spoke openly about how important these spaces were for learning new information or strategies from other people’s lived experiences. *“I’m blessed in that I have that male caregivers group, because with Alzheimer’s no one can really predict the progression. [...] So, having that large number of male caregivers who also have spouses that are going through this process—some of their wives are ahead of where my wife is. So I know I can plan. I know [what is] coming down the pike because I learned from and through their experiences”* (P6). P4 had a similar experience: *“it would be nice if this kind of thing came with an instruction manual. There’s just no way to know. Fortunately I found a support group, and from their experiences. I learned a lot.”*

4.3 Financial Collaboration Among Different Parties

Rising healthcare costs, coupled with the reduced financial capabilities of PLwDs, require more intricate financial management. Consequently, financial collaboration could encompass PLwDs, their care partners, other family members, and external agencies. Although our participants had taken on financial management responsibilities, several PLwDs maintained an interest in their financial matters. For instance, P2 mentioned having disagreements over financial decisions with her mother who had previously been characterized as a highly independent person. P7 recalled that during visits, her mother, who resides in a nursing home, often inquires about the living costs at the facility. Furthermore, primary care partners also engage in cooperative efforts with other family members to effectively manage finances. P1 stepped in to assist her mother with paying for dementia care, despite her mother previously being the exclusive manager of the family’s finances. P4 shared financial management responsibilities with another family member, her brother. While P4 handles all the administrative aspects, her brother takes care of the payments and reimburses P4 by check. Many care partners, unfamiliar with managing healthcare finances, find it challenging due to the complexity and unpredictability of dementia care costs, and often turn to professional financial and legal advisors for help. P3 hired a financial specialist so that *“if Medicaid comes up with a change somewhere, they get it immediately [and] incorporate it into their decision making and their advice.”*

Collaborating with different individuals, especially other care partners, is not always smooth. P1 described conflicts with her mom in collaboratively managing finances of the PLwD: *“my mom and I scream at each other 10 times each week. It’s related to the financial management [because] different people have different ways of managing their money.”* Financial conflicts can also stem from the need to prevent exploitation by other family members. P2, observing her mother’s cognitive decline, took on a power of attorney role to ensure that *“[her sister] doesn’t fly in, and try to—I’m just making sure that my mother’s not flimflammed by anyone.”* P4 highlights the challenges in allocating financial responsibilities within families, noting that reimbursements from her brother are often delayed because this financial task *“never made it to the top of his priority list.”* While in some cases this additional family support can be helpful, some aspects can add to the growing number of tasks care partners must undertake.

4.4 Care Partner Stress

The burdens of financial management, including uncertainties about financial means and decision-making can also result in emotional stress for care partners. P1 expressed the frustration: *“his brain could shut down next month. His brain could shut down next year. That’s the difference of \$150,000. It’s a heartbreaking feeling to be sort of betting on your parents’ death and I feel like that’s what we’ve been doing for months now.”* P7 mentioned that she had to sacrifice her career in order to care for her mother and feeling frustrated: *“my employer demoted me 3 pay grades. [...] I think it’s against the human rights code, but I have to pick my battles. I don’t have energy for everything.”* The complexity inherent in managing the financial aspects of healthcare systems not only adds to the operational challenges, but also contributes additional emotional stress for care partners. P1 observed that establishing an online social security account requires a complex mix of online and offline procedures: *“we tried to set up an online account with [social security website], We set it up and then they’re gonna send you a letter in the mail. And when you get the letter in the mail, it’s gonna include a code. [...] It’s like every single step of the way there’s like more confusion and I can’t figure out some days.”* Overall, experiencing this financial stress while also trying to emotionally cope with the declining health of a loved-one left some care partners feeling burnt-out and overwhelmed. As P7 commented: *“I don’t regret caring for her, but I regret the balance and how much energy I put into her. It’s sort of like a frog in boiling water. You don’t realize how much of yourself you’re giving until one day you do.”*

5 DISCUSSION

5.1 Designing to Support Care Partners and PLwDs Across the Stages of Illness

Participants put a strong emphasis on the varying needs of dementia over time and the importance of pre-planning. Therefore, future financial management systems should be designed to assist individuals and their families from pre-diagnosis to the advanced stages of dementia, adapting to their changing needs throughout. These financial management systems should also accommodate multiple stakeholders with different support roles and varying degrees of financial responsibility for PLwDs, echoing Dai et al.’s suggestion on collaborative digital payments [16]. For instance, a PLwD may have a spouse as their primary care partner who takes care of daily financial needs and adult children who occasionally assist with specific tasks.

However, designers must also ensure that these systems protect PLwDs [27]. For instance, we must prioritize maintaining the agency of PLwDs in relation to their decision-making capacity across the illness course [18, 20]. By leveraging similar approaches noted in fintech research with other vulnerable populations, we can help preserve their independence for as long as possible and protect against potential exploitation [3, 4, 6, 7]. Role-based access within financial systems can leverage existing legal agreements and reinforce them through system infrastructure. Having these systems in place to dictate and restrict which pre-approved parties can act on a PLwD’s behalf could help mitigate the intra-family conflicts described by some of our participants. Additionally, systems with

role-based permissions could help facilitate these important but often difficult discussions within families.

New technology can also provide opportunities to simplify the day-to-day tasks managed by care partners. Participants stressed the need to reduce the number of financial responsibilities they oversee and consolidate them into one easily accessible centralized system. Rather than using ad-hoc methods of spreadsheets and reminder notifications, a system dashboard could allow care partners to view the most important information and prompt upcoming payments or deadlines in one location. With the proper security considerations, a centralized system could help reduce the coordination work involved with managing multiple accounts and passwords [21]. These systems could also serve as a knowledge hub to help care partners organize and find necessary information or records that are pulled from disparate online government or medical sources, echoing prior work [17]. This could provide care partners with suggested timelines and prompt new steps to add to their financial care plans. Considering how important social ties and support groups were to our participants, future systems could also provide new opportunities for care partners to connect with each other to share information, resources, and emotional support.

5.2 The Need for Systemic Support and Increased Resources

Lastly, it is important to note that there are also societal-level changes that could further help care partners. Access to health-care and governmental systems, as well as information related to dementia care and financial support opportunities are all open challenges that care partners regularly navigate [34]. Additionally, the often stigmatizing way we view dementia, late-life care, and financial challenges makes it more difficult to develop care plans well before they are needed [12, 19]. By providing more information about this complicated but crucial process and normalizing financial planning conversations within families, care partners could feel more prepared to take on new financial roles.

5.3 Future Work

To expand on this preliminary work, we aim to involve PLwDs at mild, earlier stages of dementia and their care partners to advance our understanding of the needs and challenges for financial management. Future fintech development could benefit from a participatory design approach involving individuals with mild dementia or those who are at higher risk of developing dementia, along with their families. Through this body of work, we hope to design systems that can help PLwDs and their care partners plan for their future needs and maintain financial stability and overall wellbeing.

6 CONCLUSION

In this study, we interviewed seven care partners to understand their practices and challenges to manage finances for PLwDs. Our findings highlight four key areas: the transition in financial management following a diagnosis, the importance of financial planning and social support, collaborative efforts among various stakeholders, and the emotional challenges faced during financial management. These findings indicate that there is an unmet need to support

collaborative financial management involving different stakeholders while preserving the agency of PLWDs. Furthermore, there is also a lack of systematic support and resources for this community. Given the increasing prevalence of dementia [48] and digitization of personal finances, there is an urgent need to improve access to resources and create supportive technologies to help with collaborative financial management.

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REFERENCES

- [1] Alzheimer's Association. 2020. 2020 Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia* 16, 3 (2020), 391–460. <https://doi.org/10.1002/alz.12068>
- [2] Alzheimer's Disease International (ADI). 2023. Dementia Fact Sheet. (June 2023).
- [3] Belén Barros Barros Pena, Bailey Kursar, Rachel E Clarke, Katie Alpin, Merlyn Holkar, and John Vines. 2021. Financial technologies in the cycle of poor mental health and financial hardship: Towards financial citizenship. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–16.
- [4] Rosanna Bellini. 2023. Paying the Price: When Intimate Partners Use Technology for Financial Harm. In *Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems*. ACM, Hamburg Germany, 1–17. <https://doi.org/10.1145/3544548.3581101>
- [5] Johnna Blair, Jeff Brozena, Mark Matthews, Thomas Richardson, and Saeed Abdullah. 2022. Financial technologies (FinTech) for mental health: The potential of objective financial data to better understand the relationships between financial behavior and mental health. *Frontiers in psychiatry* 13 (2022), 810057.
- [6] Johnna Blair, Dahlia Mukherjee, Erika FH Saunders, and Saeed Abdullah. 2020. Opportunities for Collaborative Clinical Work: Predicting Relapse Onset in Bipolar Disorder from Online Behavior. In *Proceedings of the 14th EAI International Conference on Pervasive Computing Technologies for Healthcare*. 234–238.
- [7] Johnna Blair, Dahlia Mukherjee, Erika FH Saunders, and Saeed Abdullah. 2023. Knowing How Long a Storm Might Last Makes it Easier to Weather: Exploring Needs and Attitudes Toward a Data-driven and Preemptive Intervention System for Bipolar Disorder. In *Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems*. 1–12.
- [8] Geraldine Boyle. 2013. 'She's usually quicker than the calculator': financial management and decision-making in couples living with dementia. *Health & Social Care in the Community* 21, 5 (2013), 554–562.
- [9] Virginia Braun and Victoria Clarke. 2012. *Thematic analysis*. American Psychological Association.
- [10] Jeff Brozena, Johnna Blair, Thomas Richardson, Mark Matthews, Dahlia Mukherjee, Erika FH Saunders, and Saeed Abdullah. 2024. Supportive Fintech for Individuals with Bipolar Disorder: Financial Data Sharing Preferences to Support Longitudinal Care Management. In *Proceedings of the 2024 CHI Conference on Human Factors in Computing Systems*. 1–15. <https://doi.org/10.1145/3613904.3642645>
- [11] Laila Mohrsen Busted, Dorte S Nielsen, and Regner Birkelund. 2020. "Sometimes it feels like thinking in syrup"—the experience of losing sense of self in those with young onset dementia. *International journal of qualitative studies on health and well-being* 15, 1 (2020), 1734277.
- [12] Clara Caldeira, Novia Nurain, and Kay Connelly. 2022. "I hope I never need one": Unpacking Stigma in Aging in Place Technology. In *Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems*. 1–12.
- [13] C.-Y. Chiao, H.-S. Wu, and C.-Y. Hsiao. 2015. Caregiver Burden for Informal Caregivers of Patients with Dementia: A Systematic Review. *International Nursing Review* 62, 3 (2015), 340–350. <https://doi.org/10.1111/inr.12194>
- [14] Winston Chiong, Ming Hsu, Danny Wudka, Bruce L Miller, and Howard J Rosen. 2014. Financial errors in dementia: testing a neuroeconomic conceptual framework. *Neurocase* 20, 4 (2014), 389–396.
- [15] Norma B Coe, Cynthia M Boyd, and Joshua Chodosh. 2021. Chronic care, dementia care management, and financial considerations. *Journal of the American Medical Directors Association* 22, 7 (2021), 1371–1376.
- [16] Jiamin Dai, John Miedema, Sebastian Hernandez, Alexandra Sutton-Lalani, and Karyn Moffatt. 2023. Cognitive accessibility of digital payments: A literature review. In *Proceedings of the 20th International Web for All Conference*. 116–121.
- [17] Emma Dixon, Jesse Anderson, Diana C Blackwelder, Mary L Radnofsky, and Amanda Lazar. 2022. Barriers to online dementia information and mitigation. In *Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems*. 1–14.
- [18] Emma Dixon, Jesse Anderson, Diana C Blackwelder, Mary L Radnofsky, and Amanda Lazar. 2022. The Human Need for Equilibrium: Qualitative Study on the Ingenuity, Technical Competency, and Changing Strategies of People With Dementia Seeking Health Information. *Journal of Medical Internet Research* 24, 8 (2022), e35072.
- [19] Emma Dixon, Anne Marie Piper, and Amanda Lazar. 2021. "Taking care of myself as long as I can": How people with dementia configure self-management systems. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–14.
- [20] Sarah Foley, Daniel Welsh, Nadia Pantidi, Kellie Morrissey, Tom Nappey, and John McCarthy. 2019. Printer Pals: Experience-centered design to support agency for people with dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. 1–13.
- [21] Reza Ghaiumy Anaraky, Kaileigh Angela Byrne, Pamela J Wisniewski, Xinru Page, and Bart Knijnenburg. 2021. To disclose or not to disclose: examining the privacy decision-making processes of older vs. younger adults. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–14.
- [22] Changyang He, Lu He, Zhicong Lu, and Bo Li. 2023. "I Have to Use My Son's QR Code to Run the Business": Unpacking Senior Street Vendors' Challenges in Mobile Money Collection in China. *Proceedings of the ACM on Human-Computer Interaction* 7, CSCW1 (2023), 1–28.
- [23] Joanne W Hsu and Robert Willis. 2013. Dementia risk and financial decision making by older households: The impact of information. *Journal of Human Capital* 7, 4 (2013), 340–377.
- [24] Vaishnav Kameswaran and Srihari Hulikal Muralidhar. 2019. Cash, Digital Payments and Accessibility: A Case Study from Metropolitan India. *Proceedings of the ACM on human-computer interaction* 3, CSCW (2019), 1–23.
- [25] Travis Labrum and Phyllis L. Solomon. 2016. Factors Associated with Family Violence by Persons with Psychiatric Disorders. *Psychiatry Research* 244 (Oct. 2016), 171–178. <https://doi.org/10.1016/j.psychres.2016.07.026>
- [26] Celine Latulipe, Ronnie Dsouza, and Murray Cumbers. 2022. Unofficial Proxies: How Close Others Help Older Adults with Banking. In *Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems*. 1–13.
- [27] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. A critical lens on dementia and design in HCI. In *Chi*. 2175–2188.
- [28] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. Supporting people with dementia in digital social sharing. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. 2149–2162.
- [29] Stephen Lindsay, Katie Brittain, Daniel Jackson, Cassim Ladha, Karim Ladha, and Patrick Olivier. 2012. Empathy, participatory design and people with dementia. In *Proceedings of the SIGCHI conference on Human factors in computing systems*. 521–530.
- [30] Ittay Mannheim, Eveline JM Wouters, Hanna Köttl, Leonieke C van Boekel, Rens Brankaert, and Yvonne van Zaaen. 2023. Ageism in the discourse and practice of designing digital technology for older persons: A scoping review. *The Gerontologist* 63, 7 (2023), 1188–1200.
- [31] John McCarthy and Peter Wright. 2015. *Taking [a] part: the politics and aesthetics of participation in experience-centered design*. MIT Press.
- [32] Lauren Hersch Nicholas, Kenneth M. Langa, Julie P. W. Bynum, and Joanne W. Hsu. 2021. Financial Presentation of Alzheimer Disease and Related Dementias. *JAMA Internal Medicine* 181, 2 (Feb. 2021), 220–227. <https://doi.org/10.1001/jamainternmed.2020.6432>
- [33] Hikaru Oba, Yoshihiko Kadoya, Haruka Okamoto, Teruyuki Matsuoka, Yoshinari Abe, Keisuke Shibata, and Jin Narumoto. 2021. The economic burden of dementia: evidence from a survey of households of people with dementia and their caregivers. *International journal of environmental research and public health* 18, 5 (2021), 2717.
- [34] Melissa Oney, Lindsay White, and Norma B Coe. 2022. Out-of-pocket costs attributable to dementia: A longitudinal analysis. *Journal of the American Geriatrics Society* 70, 5 (2022), 1538–1545.
- [35] Karine Pères, Catherine Helmer, Hélène Amieva, Jean-Marc Orgogozo, Isabelle Rouch, Jean-François Dartigues, and Pascale Barberger-Gateau. 2008. Natural History of Decline in Instrumental Activities of Daily Living Performance over the 10 Years Preceding the Clinical Diagnosis of Dementia: A Prospective Population-Based Study. *Journal of the American Geriatrics Society* 56, 1 (2008), 37–44. <https://doi.org/10.1111/j.1532-5415.2007.01499.x>
- [36] Mark Perry and Jennifer Ferreira. 2018. Moneywork: Practices of use and social interaction around digital and analog money. *ACM Transactions on Computer-Human Interaction (TOCHI)* 24, 6 (2018), 1–32.
- [37] Plaid Inc. 2021. The Fintech Effect: Fintech's Mass Adoption Moment. <https://plaid.com/the-fintech-effect-2021-mass-adoption/>.
- [38] Elena Profyri, Phuong Leung, Jonathan Huntley, and Vasiliki Orgeta. 2022. Effectiveness of treatments for people living with severe dementia: A systematic review and meta-analysis of randomised controlled clinical trials. *Ageing Research Reviews* (2022), 101758.
- [39] Susanne Roehr, Steffi G. Riedel-Heller, Hanna Kaduszkiewicz, Michael Wagner, Angela Fuchs, Carolin van der Leeden, Birgitt Wiese, Jochen Werle, Horst Bickel, Hans-Helmut König, Steffen Wolfsgruber, Michael Pentzek, Dagmar Weeg, Silke

- Mamone, Siegfried Weyerer, Christian Brettschneider, Wolfgang Maier, Martin Scherer, Frank Jessen, and Tobias Luck. 2019. Is Function in Instrumental Activities of Daily Living a Useful Feature in Predicting Alzheimer's Disease Dementia in Subjective Cognitive Decline? *International Journal of Geriatric Psychiatry* 34, 1 (2019), 193–203. <https://doi.org/10.1002/gps.5010>
- [40] Orkun Saka, Barry Eichengreen, and Cevat Giray Aksoy. 2021. *Epidemic Exposure, Fintech Adoption, and the Digital Divide*. Technical Report w29006. National Bureau of Economic Research. <https://doi.org/10.3386/w29006>
- [41] Jonathan Scrutton and Cesira Urzi Brancati. 2016. *Dementia and comorbidities: Ensuring parity of care*. ILC.
- [42] Omar Shaikh, Cassandra Ung, Diyi Yang, and Felipe A. Chacon. 2022. Six Feet Apart: Online Payments During the COVID-19 Pandemic. *Proceedings of the ACM on Human-Computer Interaction* 6, CSCW2 (Nov. 2022), 327:1–327:33. <https://doi.org/10.1145/3555218>
- [43] Megan G Sherod, H Randall Griffith, Jacquelynn Copeland, Katherine Belue, Sara Krzywanski, Edward Y Zamrini, Lindy E Harrell, David G Clark, John C Brockington, Richard E Powers, et al. 2009. Neurocognitive predictors of financial capacity across the dementia spectrum: Normal aging, mild cognitive impairment, and Alzheimer's disease. *Journal of the international neuropsychological society* 15, 2 (2009), 258–267.
- [44] R Nathan Spreng, Jason Karlawish, and Daniel C Marson. 2016. Cognitive, social, and neural determinants of diminished decision-making and financial exploitation risk in aging and dementia: A review and new model. *Journal of elder abuse & neglect* 28, 4-5 (2016), 320–344.
- [45] Felipe Kenji Sudo and Jerson Laks. 2017. Financial Capacity in Dementia: A Systematic Review. *Aging & Mental Health* 21, 7 (July 2017), 677–683. <https://doi.org/10.1080/13607863.2016.1226761>
- [46] Nicole Tang and Priyank Chandra. 2022. Community, Culture, and Capital: Exploring the Financial Practices of Older Hong Kong Immigrants. In *CHI Conference on Human Factors in Computing Systems Extended Abstracts*. 1–6.
- [47] John Vines, Mark Blythe, Paul Dunphy, Vasillis Vlachokyriakos, Isaac Teece, Andrew Monk, and Patrick Olivier. 2012. Cheque mates: participatory design of digital payments with eighty somethings. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 1189–1198.
- [48] World Health Organization (WHO). 2023. WHO Fact Sheet on Dementia. <https://www.who.int/news-room/fact-sheets/detail/dementia>.