

Assisting care recipients with dementia in accessing and using their online financial accounts: Practices of caregivers

Sarah Ryan

Computer and Information Sciences, University of Strathclyde, sarah.ryan@strath.ac.uk

Wendy Moncur

Computer and Information Sciences, University of Strathclyde, wendy.moncur@strath.ac.uk

Ian Ruthven

Computer and Information Sciences, University of Strathclyde, ian.ruthven@strath.ac.uk

1 ABSTRACT

Online accounts such as e-commerce accounts, social media, and email and are not designed for use by people who are experiencing dementia. As the disease progresses, they will begin to require assistance from their caregiver to continue accessing and using their online accounts. This puts caregivers in the difficult position of having to balance their care recipient's safety and autonomy. This scoping review details five key themes which emerged linked to caregivers assisting their care recipient in using their online accounts: the adverse event; the transition; collaborative financial actions between caregiver and care recipient; balancing autonomy, safety and privacy; and the risks of existing practices. We find that caregivers implement a wide range of online safety strategies when assisting online, but that these strategies often have negative implications for the care recipient's independence and privacy. We also identify the shortcomings of online accounts when it comes to providing appropriate access levels for people with dementia.

CCS CONCEPTS • Human-centered computing.

Additional Keywords and Phrases: Dementia, aging, financial technologies.

2 INTRODUCTION

In the UK life expectancy is increasing and this pattern is set to continue¹. This means that our chances of having dementia, or looking after someone who does, are increasing too. Dementia describes a range of conditions, such as Alzheimer's Disease and vascular dementia, that cause symptoms affecting the sufferer's memory and cognition². Alzheimer's Research UK estimates that by 2040, more than 1.4 million people in the UK will be living with dementia³.

People experiencing dementia will need support from a carer at some point as the condition progresses. A carer is defined as someone who provides help and care to a family member, partner or friend who needs assistance due to illness or disability⁴. Increasingly, part of a caregiver's duties is to assist with accessing online accounts and carrying out online activities and financial transactions. While those in the later stages of the disease are unlikely to be able to go online at all,

¹<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/articles/mortalityinenglandandwales/pastandprojectedtrendsinaveragelifespan>

² <https://www.dementiauk.org/information-and-support/about-dementia/what-is-dementia/>

³ <https://dementiastatistics.org/about-dementia>

⁴<https://www.england.nhs.uk/commissioning/comm-carers/carers/#:~:text=A%20carer%20is%20anyone%2C%20including,care%20they%20give%20is%20unpaid>

people experiencing the earlier stages of dementia are still able to carry out some tasks online. For this population, technology use can be a risky endeavour: They are at an increased risk of falling for online scams or phishing attempts [1] and are more likely to engage in poor password practices such as sharing their passwords or re-using the same password for multiple accounts [8]. They may also make online payments that are unintended or out of character [1]. To keep their care recipients safe online, many caregivers engage in collaborative online practices to reduce the inherent risk posed by going online. However, these strategies can infringe upon the care recipient's privacy and strip them of their agency. This presents a problem; How can we design payment systems for online accounts that support the safety of people with dementia while preserving their privacy and autonomy?

People experiencing dementia will often enact a Power of Attorney (POA) to enable a nominated individual to make decisions on their behalf. Access to online financial accounts can be granted under Power of Attorney in the UK as part of gaining access to the person's finances, but there is no legal mechanism by which a caregiver can be given access to other types of online account. This is important because these other types of account may still have stored card details and be financially relevant for the account holder's caregiver to access.

There has been significant prior research towards supporting shared online access during a life transition. Prior work [10] has explored shared accounts which allow parents to collaborate with their children on privacy settings and content management for social networking sites. Moncur et al (2012) examined what happens to our online accounts and assets when we die, and how someone can be granted stewardship of them [9]. Less focus has been placed on online account sharing practices as someone transitions through dementia.

In this paper, we report on the findings of a scoping review undertaken as part of a PhD, which asked: *"How does a caregiver for someone with cognitive impairments assist their care recipient in accessing and using their online financial accounts?"*. Below we detail our search strategy and then discuss our key themes in more detail. Key findings are that while care givers and care recipients strive to work collaboratively to ensure safe access to online accounts, in practice there is a difficult balance between ensuring the care recipient's safety, privacy and autonomy. More could be done by online service providers to support care givers and care recipients to achieve this balance.

3 SCOPING REVIEW

Our scoping review involved a search of the ACM Digital Library. The strategy is detailed in Appendix A. The review returned 1369 papers for potential inclusion in the review. After abstract screening, 40 papers were read to assess suitability for inclusion. This resulted in 10 papers being included. Five key themes emerged: the adverse event, the transition, collaborative financial actions between caregiver and care recipient, balancing autonomy, safety and privacy, and the risks of existing practices. We discuss each of these in turn below.

Adverse event: The term 'adverse event' [2,6,1] is widely used to describe an incident which makes the caregiver realise they need to implement more stringent safety measures for the online activities of their care recipient. If the care recipient had been going online without assistance previously, the adverse event is often the trigger for the caregiver to start taking a more active role in overseeing their online activities. If the caregiver has already been assisting the care recipient in going online, this may be when the caregiver starts to limit access to certain sites or watches over the person as they go online [2].

Adverse events include a range of online financial transactions made by people with dementia that are either accidental or out of character. These include buying a scam product online [1], overspending on online offers advertised via email [2] and taking out multiple charity sponsorships [3]. Such transactions can occur seamlessly in an online ecosystem where our financial payment methods are integrated with our online accounts. While FinTech applications strive to create a payment

system that is as frictionless as possible for the end user, they inadvertently fail to meet the requirements of users with dementia, who find benefit in a system where their caregiver can have some level of oversight of their online activities [5].

Transition: Following the adverse event, caregiver and care recipient enter a transition phase. Many caregivers begin the process of managing the care recipient's accounts by doing an audit of all of their bank accounts, online accounts, utility accounts, and credit cards [3]. If care giver and recipient have jointly held accounts, this part of the process is easier, as the caregiver has their own set of login details. Where the caregiver was an adult child, they faced additional difficulty in trying to access their parent's online accounts, as they were unlikely to have a shared account with their parent [3]. After locating the accounts, caregivers would then often cancel any recurring payments or credit cards that were deemed unnecessary, to simplify financial administration and to help the care recipient to save money. Following this, caregivers may compile a record of financial obligations and set up automatic payments for any regular bills [3]. Further work is required to identify whether caregivers undertake a similar process for other types of online accounts, such as online retail and utilities.

Caregiver and Care Recipient - Collaborative Financial Actions: In the absence of a Power of Attorney system that provides caregivers access to their care recipient's online non-banking accounts, caregivers devise workarounds to access these accounts instead. They endeavour to enable safe access to the care recipient's online accounts. Some workarounds are collaborative, others less so. Actions include (i) carrying out all online activities together; and the caregiver (ii) setting up a restricted environment by blocking certain websites or apps; (iii) carrying out online activities on behalf of the care recipient; and (iv) checking online transactions before submission [1][2].

These collaborative actions are forced into existence by a lack of any other suitable options offered by online service providers [6]. The central problem is that online accounts do not currently have a way of providing the caregiver with appropriate access to services. In the absence of other options, caregivers instead engage in workarounds to bridge the gap. These require a lot of effort from the caregiver, both in devising and setting them up, then in continually supporting them [6]. Caregivers have demonstrated a keen determination to involve their care recipient in a shared decision-making process [6][4], however in some cases care recipients are left out of these conversations by their caregivers [6].

Balancing autonomy, safety and privacy: The collaborative actions in which caregivers engage may come at the cost of the care recipient's privacy and autonomy. Methods such as the caregiver sitting beside the care recipient while they go online means that the care recipient has no semblance of privacy [1]. It may be the case that the care recipient has private information online which they do not wish to share with their caregiver, just as any one of us may not feel comfortable disclosing our full online activities to others. However, by sitting beside their care recipient, the caregiver can act as a safety net and mitigate many of the threats the care recipient may face online.

Risks of existing practices: While collaborative financial actions are vital in helping people with dementia to access online services, the mechanism by which these operate can leave both the caregiver and the care recipient open to various risks. When older adults are assisted in using online banking by their caregivers, this usually involves 'credential sharing', whereby the caregiver uses the care recipient's username and password to access an online service on their behalf [7]. This leaves the care recipient at risk of financial abuse. Usually, logging into a financial institution's website allows you to view and access all of the accounts you hold with them. This can include savings accounts and retirement accounts. This is a risk as credential sharing does not allow for you to grant someone access to a specific account: rather it allows them free access to all the accounts you hold within that financial institution [7]. This means that the person who has been given the credentials would be in a position to act in a financially abusive manner. Even if the caregiver does not have malicious intentions, having full access to view these kinds of accounts may be uncomfortable for them, and is a breach of privacy for the care recipient. Credential sharing is also against the terms and conditions for most online accounts, especially those

for bank and financial institutions. This means banks may not be liable for any financial loss that happens as a result of credential sharing [7]. Sharing credentials also means that actions taken by the valid account holder cannot be distinguished from ones that were taken by the caregiver, as there is no log to assign ownership to actions.

4 DISCUSSION AND FUTURE WORK

The results of this scoping review show there is a sizable opportunity to change how we design online accounts and payment systems to make them more supportive of the needs of people experiencing dementia. Moving away from the notion of an individual account where the account holder is responsible for all actions on the account, and towards one that allows for multiple users with clearly defined roles and responsibilities, would better reflect the needs of people experiencing dementia and their caregivers. For example, this could include a mechanism by which caregivers could approve or decline payments before they are finalised. It is vital that such mechanisms are customisable by the users for them to be useful. This would mean presenting a full range of options to the users on setup which would let them decide which payments need approval. This could be based on the payment amount, payment method or the vendor that the payment is being made to.

The rest of this PhD will explore the concept of a “Digital Power of Attorney” (DPOA), where people can nominate a trusted person to be granted guardianship of their online accounts and assets if they experience a cognitive impairment in the future. The standard UK POA system allows for access to be granted to online bank accounts but does not extend to other kinds of online accounts or assets. The feasibility of DPOA, and how it might be implemented, warrants investigation.

ACKNOWLEDGMENTS. This research is funded by The University of Strathclyde.

REFERENCES

- [1] Helena M. Mentis, Galina Madjaroff, and Aaron K. Massey. 2019. Upside and Downside Risk in Online Security for Older Adults with Mild Cognitive Impairment. In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems (CHI '19). ACM, Paper 343, 1–13. <https://doi.org/10.1145/3290605.3300573>
- [2] Anne Marie Piper, Raymundo Cornejo, Lisa Hurwitz, and Caitlin Unumb. 2016. Technological Caregiving: Supporting Online Activity for Adults with Cognitive Impairments. In Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16). ACM, 5311–5323. <https://doi.org/10.1145/2858036.2858260>
- [3] Ling Qiu, Johnna Blair, and Saeed Abdullah. 2024. Managing Finances for Persons Living with Dementia: Current Practices and Challenges for Care Partners. In Extended Abstracts of the CHI Conference on Human Factors in Computing Systems (CHI EA '24). ACM, Article 236, 1–7. <https://doi.org/10.1145/3613905.3650809>
- [4] Nora McDonald and Helena M. Mentis. 2021. “Citizens Too”: Safety Setting Collaboration Among Older Adults with Memory Concerns. ACM Trans. Comput.-Hum. Interact. 28, 5, Article 31 (October 2021), 32 pages. <https://doi.org/10.1145/3465217>
- [5] Nora McDonald and Helena M. Mentis. 2021. Building for ‘We’: Safety Settings for Couples with Memory Concerns. In Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems (CHI '21). ACM, Article 554, 1–11. <https://doi.org/10.1145/3411764.3445071>
- [6] Helena M. Mentis, Galina Madjaroff, Aaron Massey, and Zoya Trendafilova. 2020. The Illusion of Choice in Discussing Cybersecurity Safeguards Between Older Adults with Mild Cognitive Impairment and Their Caregivers. Proc. ACM Hum.-Comput. Interact. 4, CSCW2, Article 164 (October 2020), 19 pages. <https://doi.org/10.1145/3415235>
- [7] 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 (CHI '22). ACM, Article 601, 1–13. <https://doi.org/10.1145/3491102.3501845>
- [8] Galen A. Grimes, Michelle G. Hough, Elizabeth Mazur, and Margaret L. Signorella. 2010. Older Adults’ Knowledge of Internet Hazards. 36, 3 (2010), 173–192. <https://doi.org/10.1080/03601270903183065>
- [9] Wendy Moncur, Jan Bikker, Elaine Kasket, and John Troyer. 2012. From death to final disposition: roles of technology in the post-mortem interval. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '12). ACM, 531–540. <https://doi.org/10.1145/2207676.2207750>
- [10] Tawfiq Ammari, Priya Kumar, Cliff Lampe, and Sarita Schoenebeck. 2015. Managing Children's Online Identities: How Parents Decide what to Disclose about their Children Online. In Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems (CHI '15). ACM, 1895–1904. <https://doi.org/10.1145/2702123.2702325>

A APPENDIX: SCOPING REVIEW STRATEGY SEARCH TERMS

*“dementia” OR “mild cognitive impairment” OR “MCI” OR “Alzheimer’s” OR “memory loss” OR “brain injury”
OR “TBI” or “cognitive decline” OR “incapacity”*

AND

*“social media” OR “financial account” OR “cybersecurity” OR “authenticate” OR “password” OR “accessibility”
OR “digital privacy” OR “proxy access” OR “attorney” OR “digital asset” OR “power of attorney” OR “online account”
OR “online service” OR “online access” OR “online banking”*