The Illusion of Choice in Discussing Cybersecurity Safeguards Between Older Adults with Mild Cognitive Impairment and Their Caregivers

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Although continual online interaction is beneficial for an older adult with mild cognitive impairment, cybersecurity risks can become more pronounced. Prior work has touted the benefit of shared decision-making between care recipients and caregivers who may want to instill cybersecurity safeguards, particularly in the area of online safety and security. In this study we investigated the current online safety and security decision-making practices of care recipients with mild cognitive impairment and their spousal caregivers. We identified a gap between optative and actual decision-making: whereas couples expressed their desire to engage in shared decision-making, the actuality was most caregivers were compelled to take sole action. We further determined that shared-decision making was not feasible as there was a lack of suitable safeguarding options along a spectrum of care for the couple to choose from. We relate these findings to prior work that highlights similar challenges and discuss how there needs to be more offered than simply an illusion of choice.

CCS Concepts: • **Human-centered computing → Empirical studies in collaborative and social computing**; • **Security and privacy** → *Social aspects of security and privacy*.

Additional Key Words and Phrases: mild cognitive impairment, dementia, caregivers, care, cybersecurity, security, safety, safeguards, privacy

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1 INTRODUCTION

Health conditions like memory loss, frequent forgetting, and impaired geographic orientation affect the everyday life of many older adults [24]. Some conditions are considered “normal for the age” [7]; however, when these initial signs become more frequent, they may indicate something more significant, such as mild cognitive impairment (MCI) [24]. MCI is characterized by memory loss, decision-making impairment, and visuo-spatial impairment, that significantly interrupts everyday life. Because of these cognitive challenges, those with MCI are more susceptible to scams and can

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engage in risky or socially inappropriate behavior online. Prior researchers have shown that the approach families take to this problem is to limit a person with MCI's online access [32, 36]. For instance, Piper et al. [36] has shown that caregivers for those with dementia reconfigure social media and email account preferences and settings with more restrictive security options.

However, a diagnosis should not stop an older adult with mild cognitive impairment from engaging in the activities that bring them personal fulfillment, such as keeping up with family and friends on social media [36]. Being able to interact online is essential for older adults' independence, well-being, and social interactions [11]. To find the right balance between online access and security, both Piper et al. [36] and Mentis et al. [32] suggested that a caregiver and care recipient need to engage in shared decision-making: both partners should be made aware of the challenges and options to make modifications accordingly. Unfortunately, Piper et al. [36] and Mentis et al. [32] also showed how caregivers make decisions to instill online safety and security safeguards that often end up limiting online access without consulting the person with MCI.

In considering how we can encourage discussions and shared decision-making between caregivers and people with MCI, we are particularly guided by a person-centered approach [13, 26, 28]. Person-centered care has been globally promoted as a culture change to improve caregiving in long-term care for older adults [26]. This is in direct contrast to the predominant models of design for the aging and cognitively impaired populations where there has been a focus on alleviating the "burdens of caring" [12, 18, 35, 38]. With this perspective, one preserves the right of older adults with mild cognitive impairment to be a part of decision-making processes as opposed to being isolated and "decided for" by their caregivers or other family members [13]. This perspective is also in alignment with recent HCI studies on the collaboration within spousal care recipient-caregiver dyads with multiple chronic conditions [4]. Thus, before making any modifications to their online usage, the older adult with mild cognitive impairment and their caregiver should have a discussion and collaboratively make a decision that preserves not only their safety but also their autonomy.

To this end, in the following study we aim to understand the current online safety and security safeguards decision-making practices to create implications for design that would lead to shared decision-making between a care recipient with mild cognitive impairment and their caregiver. We interviewed 10 older adult couples where one partner has mild cognitive impairment about their online safety and security safeguarding decision-making practices. We uncover the shared decision-making that is and is not occurring, the limited choices that preclude shared decision-making's feasibility, and finally the desperately desired opportunity for shared decision-making to occur. From this investigation, we realize that the misalignment of the couples' desire for shared decision-making and the reality of their actual decision-making practices is due to the lack of choices beyond the two ends of the "spectrum of care" that Mentis et al. [32] identified — i.e., no adaptions on one end and remove all online access on the other end. This leads us to a set of design implications around providing 'choice' in online safety and security safeguards that provide more scope for partner discussions and thus an impetus for shared decision-making to occur.

2 RELATED WORK

2.1 Mild Cognitive Impairment Among Older Adults

By 2030, the second biggest generation, the Baby Boomers, will be older than 65 years [41]. By 2035 the percentage of the population of babies and adults over 65 years will be equal, and further projections show that by 2060 there will be 4% more adults over 65 than babies [41]. The US population is dramatically aging with more people leaving the workforce and joining retirement. The increasing numbers of aging adults who are 65 and older will also increase the need for more specialized medical or personal care.

One of the conditions that may require a caregiver is a decline in cognitive abilities and the development of neurocognitive impairment, the main risk of which is age. Over 5.1 Million Americans age 65 and older may have Alzheimer's, which is the most common cognitive impairment [40]. The projection for 2050 is that the number will be close to 14 million, which is almost triple the current statistic [40]. And this statistic only shows the number of people who have already developed Alzheimer's — it does not account for the ones who are currently developing it or may never develop it, but still experience a cognitive decline in their ability and need special care or assistance.

The initial symptoms of mild cognitive impairment could often be mistaken as typical symptoms of aging and be left undiagnosed [22]. Modest memory loss problems are known to come with age, but there are methods for recognizing whether there is a cognitive decline and how much, if any, other symptoms there are. If misplacing items, re-asking questions, or struggling to find appropriate words started to happen often, then an assumption could be made that those symptoms are something more than just typical aging signs [24]. Significant impairments are easier to identify and do not get confused with symptoms of healthy aging, due to their severity rating which shows a fluctuation of two or more standard deviations of cognitive decline from the appropriate personal norms. Nonetheless, it is common for people not to pay attention to minor signs of mild cognitive deficit and call it typical aging because its severity rating falls within one to two standard deviations [3].

Some behaviors could be categorized as signs of healthy aging as well as mild cognitive decline. These include individuals requiring more time to complete specific tasks like remembering a plot of a TV show or a short grocery list. These behaviors could be due to healthy aging, so careful notetaking of occurrences by a family member or by their caregiver is essential when assessing whether they are experiencing a cognitive decline of ability or not. The earlier this decline of ability gets noticed, the better the outcomes for the care recipient would be.

MCI is described as a transition between healthy aging and dementia. Mild cognitive impairment is a diagnosis given to older individuals who experience a cognitive decline that is not severe enough to be classified as dementia [29]. It is hard to determine specific categories within the progression of MCI due to the condition being strictly individual and heavily dependent on one's lifestyle. As described in the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, 5th edition) [3], someone's "low" current status may not differ much from their baseline, so their cognitive decline could be slim to none. In contrast, for someone who has been a high-functioning individual, their decline of ability might be left unnoticed due to their current situation still falling into "normal aging" regardless of the big cognitive gap between the current condition and their baseline.

There have been studies done to monitor the percentage of people who start off having MCI then after watching their development for a few years, they either progress to dementia, their cognitive abilities have "reverted" back, or they show little to no changes within their level of MCI [16]. It takes a couple of years, depending on the individual, to progress from mild to a major impairment such as Alzheimer's or another type of dementia. Interestingly enough, a study done in Minnesota shows that 40% of the participants "reverted" their abilities back to normal. However, in the next six years, 60% of those who have "reverted" went on to progress to dementia [16, 19].

The care recipients with MCI are only one side of the equation with whom this work is concerned. A declination of cognitive ability affects not only the direct individual but also their family members, although, in the initial stage of it, care recipients need little to no additional assistance [24]. Clipp et al. [10] study how the extra physical, emotional, and even financial stresses affect caregivers and their correlation with the level of cognitive decline. The challenges in caregiving increase as the cognitive ability of the care recipient decreases. Although the transition from an independent adult to one who needs assistance may be gradual, the emotional and physical stress that comes with it increases with each additional task. Even though most of the duties are offline, such as helping with daily activities [36], online safety and security incidents that may arise can contribute to an increasing number of tasks for the caregiver.

2.1.1 Cybersecurity and Rising Threats.

The digitalization of services in the modern world presents not only convenient usage of online services, but it also exposes the user to cyber threats. Having the possibility of doing everything through phones or computers could end up endangering some of the most sensitive personally identifiable information, affecting not only the direct user but also their family, finances, and private information. With the continually increasing usage of the Internet, the risk of cyber threats is growing exponentially — 16.7 million Americans have been victimized in 2017, which is the highest number by far, with an 8% increase from last year and a total of $16.8 billion stolen [17].

Being able to recognize and permanently protect people from these threats has become a goal for many researchers. The field of cybersecurity has been rapidly developing, but not fast enough to protect from increasingly frequent attacks. Unfortunately, there is no defense mechanism developed yet which can protect from all types of attacks and malicious activity [21]. Many threats have found their way into beating antivirus systems and are left up to the person to responsibly engage online [44]. Being able to recognize a threat as such requires a level of cognitive ability that is specifically on decline by those with MCI. Huber et al. [27] found that it was hard for older adults without cognitive decline to identify phishing scams based on text or video information, and found it challenging to protect themselves from it [27]. A different approach to the same problem was taken by Garg et al. [15], who designed an online security toolbar as an automated method to protect older adults from phishing and scams; however, they could not prove that the system was effective [15].

Piper et al. [36] identified guiding, stimulating, protecting, and connecting to be the main ways in which caregivers support their care recipients online while balancing protection and independence. The authors found that caregivers would filter information, block websites of inappropriate content, or set limited privacy settings as a way of protecting their loved ones [36]. The study also presents the challenge of deciding when it is right to take tech access away, block content, and remove friends who were there before the condition got worse. The research team suggested that the caregiver makes those decisions with the help of the care recipient and whether there have been incidents threatening personal information exposure [36] – termed 'adverse events'.

Later, Mentis et al. [32] found that, despite a person with MCI's high digital literacy and security knowledge, the couples all had experienced at least one recent minor security incident. In response to these incidents, the authors showed a spectrum of safeguarding approaches taken to ensure safety in the care recipient's online interactions. This spectrum included 'hovering' over the person with MCI when they were online, providing only 'selective access' to online applications, becoming the 'interactor' on behalf of the person with MCI for applications such as email or Facebook, simply 'checking' that the person with MCI used an online system correctly such as booking travel, or finally, no interference at all. However, the authors also showed that there was a lack of discussion, forethought and planning for these inevitable decisions to be made. Most of the couples were simply reacting to incidents as they arose. Mentis et al [32] recommended discussing appropriate support and shared decision-making regarding online safety and security safeguards between caregivers and care recipients to reduce the prevalence of adverse incidents and increase the care recipient's autonomy. This suggestion was informed by a person-centered perspective [28], which aims to create mechanisms for a person with MCI to feel they have a say in the approaches that are put into place. This was the impetus for the following study.

3 METHODS

The goal of this study was to understand the current online safety and security safeguards decision-making practices between a care recipient (CR) with mild cognitive impairment and their caregiver (CG): to better understand how MCI carepartners (CPs) are currently engaging in shared decision making and the barriers in shared decision-making. This is in service of determining how a system could support shared decision-making of safeguarding options against the rising risk of cyber threats.

3.1 Participants

The participants were recruited from the Memory Clinic of Intergrace Center in the greater Baltimore, MD, USA, area as well as Erickson Living's Riderwood continuing care retirement community. We were open to including CRs in this study who were at any length of time since a formal diagnosis of their mild cognitive impairment. This was particularly important due to the progressive and constantly changing nature of the illness among older adults [22]. The condition can be mild over a long period with intermittent moments of more significant impairment before it proceeds into a major cognitive disorder [24]. Being able to look at the cognitive decline along a spectrum of MCI was useful in two ways. First, it helped us understand how the transition from no cognitive issues to major cognitive impairment affects decision-making practices between CG and CR. Second, it shows us that our implications for design have to be able to accommodate people at various levels of decline due to the unpredictability of how fast and far one would progress.

Table 1. Participant Demographics

CP ID	CR gender (age, race)	CG gender (age, race)	MCI Dx	CG current employment	CR previous employment
CP1	Male (74, W)	Female (70, W)	3 mo.	Retired teacher	Procurement
CP2	Male (76, B)	Female (66, B)	24 mo.	Retired teacher	Engineer
CP3	Female (76, W)	Male (77, W)	24 mo.	Video editor	Nurse
CP4	Male (80, W)	Female (73, W)	10 mo.	Retail	Purchasing
CP5	Male (78, B)	Female (76, B)	6 mo.	Retired teacher	Company owner
CP6	Female (70, W)	Male (71, W)	7 mo.	Government	Government
CP7	Male (70, W)	Female (71, W)	12 mo.	Office manager	Physicist
CP8	Male (74, W)	Female (72, W)	18 mo.	Retired	Scientist
CP9	Female (64, W)	Male (65, W)	12 mo.	Technician	Horse rancher
CP10	Female (72, W)	Male (72, W)	16 mo.	Retired scientist	Government

There was a total of 20 participants, 10 CPs of a CG and CR. See Table 1 for the participant demographics. In this study, we specifically attempted to broaden our participant pool reach in order to have some diversity in our participant's experiences and thus perspective. We primarily did this by, for instance, recruiting from two different facilities that tend to serve different patient demographics and through snowball sampling. The resulting age range of our participants was wide – between 64 and 80 years of age – and our participants had some diversity in race, although they are still predominantly white. There was also no diversity in sexual orientation as all were heterosexual couples. However, our participants were almost evenly split between the CR being the husband or wife. All of the CPs were married and had lived together for an extensive amount of time (average was about 25 years) before the cognitive decline was identified.

The CPs also came from different professional backgrounds. Their job occupations indicated to an extent their experience level with technology and online services. However, not all of them needed to be technology experts in their workplaces. Therefore, their experience level with technology varies. Nonetheless, they all reported having multiple online accounts and have been using or still are using online services.

3.2 Data Collection

The data collection process consisted of semi-structured interviews that were audio-recorded and transcribed verbatim at a later time. Semi-structured interviews are when an interviewer has an 'interview guide' with a list of questions and topics that need to be covered during the conversation, usually in a particular order. The interviewer can follow the guide but is also able to follow topical trajectories in the conversation that may stray from the guide when he or she feels this is appropriate [5]. Each family was very different, and it was important to phrase the questions in a way that made most sense to the participants. For instance, if we learned early on that a CR used email often, we would prompt the CPs on any safety and security decisions for email. Thus, the planned protocol of the questions for the interviews was slightly modified to match each couple's technology experience and usage so they could relate to the questions. The interview guide we used can be found in Appendix A.

Two interviewers, the second and fourth authors of this paper, conducted the interviews together. The second author is a trained qualitative researcher and has used semi-structured interviews before – she uses this interview methods as a mechanism to probe deeper through follow up questions. The fourth author would also provide follow-up questions and would ensure that both the CR and CG were provided the opportunity to weigh in on the discussion.

3.3 Procedure

The interviews were conducted in each couple's home at their convenience. Each interview lasted for about an hour, where the participation by the CR was strongly encouraged not only by the research team but by the CG as well.

The interviews started with an explanation and signing of the consent form by both parties, followed by a brief description and introduction of the team and our project. We wanted to make sure that our participants fully understood what our goal was and what type of information we were looking for – namely, understanding the CPs' online safety and security safeguards decision-making practices. Another reason for the extended introduction was to create a more personal relationship by sharing a little bit about ourselves as it placed our participants at ease. This get-to-know-you session with the individual with MCI and their caregiver would include them telling us stories of how they met, share any family and health history they felt comfortable with, including their experience with the diagnosis of cognitive impairment, and other general interest questions. For instance, if we saw a picture in the home, we would ask who was in the picture. Although not related to our immediate questions, these get-to-know-you conversations allowed the participants to become more comfortable with the interviewers as well as provided backstory for us to better understand the context for our specific interview questions.

Questions were explicitly directed to both CG and CR. The expectation was to understand both perspectives, as well as to make sure that the CR was given the opportunity to speak. The participants were strongly encouraged to share their individual experiences and opinions. We followed this practice set out in Mentis et al. [32] of interviewing CPs as a unit as the sense of identity of the person with cognitive impairment is a product of the dyadic caregiver-care recipient relationship. They refer to Mulvenna et al. [33] and Whitlatch et al. [43] who argue that this approach actually enhances the inclusion of the CR's thoughts and experiences rather than prohibit the CR from interacting. This is also well-aligned with Berry et al. [4] and [34] who highlight the need to treat the caregiver dyad as a unit of analysis.

3.4 Data Analysis

The investigative lens we used to analyze the data were framed by the Person-Centered Care approach and looked for how the CPs makes decisions and what challenges prevented any shared decision-making.

Thematic analysis was chosen to systematically analyze the data [6]. This provided us with the ability to move beyond surface level similarities to more tacit themes. The analysis focused on how the couples described the decisions that were made and how those decisions came to be including discussions between the CR and CG. We quickly achieved saturation after 7 couples, but we included all 10 for completeness and for additional nuances to be found. Subsequent integration of these themes with our interpretation of the literature helped us form the basis for the discussion of design implications. The analysis was primarily conducted by the first author — the first author coded the data and sorted them into themes which she then presented to the second and third author for review and discussion.

After an initial thematic coding of the data, three primary themes arose: examples of discussions that were had, the desire to have shared decision-making, and the work that the CG had to perform in order to continue to provide online safety and security without taking away online access. Further analysis delved into these three themes (see Appendix B for the coding scheme that emerged). The first was a focus on when there was or was not a discussion. We uncovered themes around those that planned ahead, discussions that happened on the spot during the interview, an incident that led to the discussion occurring, the involvement of other people in discussions, and then the prevalence of no discussion occurring. The second focus of coding the transcripts was on their desire to engage in shared decision making that seemed to be at the heart of decisions that were made. This later, in conjunction with the third theme, clarified the lack of options in support of shared decision making. The third part of the coding was the way in which the CG's showed an immense amount of work and savvy to try to provide options that ensured online safety and security in the face of MCI. All quotes are evidence of the existence of these themes but are not the only examples we had in our data.

4 RESULTS

Our study sought to understand how CGs and CRs currently discuss online safety and security safeguarding. In the following, we first present how our CPs had a desire for shared decision-making. However, despite this explicit desire, shared decision-making was not occurring as often as it could. We then uncovered a barrier to shared decision-making that indicated a lack of choices in online safety and security safeguards – a lack of options along a spectrum of care. This barrier had the unintended consequence of reducing the motivation for these conversation to occur and increased the online safety and safeguarding work of the CG in providing another option than simply taking away online access.

4.1 The Desire for Shared Decision-Making

What was most evident with all of our couples is that the CG had no intention of making decisions without their CR's input. In fact, what was most striking is the insistence by all of our CGs that they do not make decisions without consulting their CR for matters of consequence. We have a number of examples, such as the two below, where the CG spoke of how they are considering how their partner feels and wanting to maintain the way they interacted before the cognitive impairment interrupted their lives.

> **CG4:** *But now I gotta make a lot of decisions, but I always go over them with him. But if he's by himself, and rightfully so, he'll think he can make a decision, he does. And sometimes he remembers to tell me and sometimes he doesn't. There's nothing important that he's going to do that I have to worry about. But I do all the rest of the stuff. I always run it by him, don't I hon? Always. You know, we're married, I want him to feel like he's married.*

> **CG3:** *I learned my lesson, how many years ago was that? 1980 and it . . . was almost 40 years, it was about 38 years ago, when I didn't consult [wife's name] on making a major purchase. And I realized, I didn't think about it at the time I was just, heck, it's on sale, I'll get it. But it was coming out of money that was both of ours, that was the-*
> **CR3:** *That was the bad thing.*
> **CG3:** *Which is what I hadn't even considered. And I don't think I've ever done that since.*
> **CR3:** *You haven't. You haven't. You've always asked.*
> **CG3:** *I've always. . . we've always discussed anything that-*
> **CR3:** *That we wanted to. . .*
> **CG3:** *As any kind of a purchase like that.*

What is really interesting here is how their prior relationship really carries over into this new world they must navigate together. Thus, when asked about how they make decisions on safety and security safeguards, our couples made it clear that their intention is to always engage in shared decision-making as that is what is done in a partnership. This on the whole is what we might expect and want, however, as we will see in the following section, when a decision regarding online safety and security was raised, shared decision-making was not engaged.

4.2 Shared Decision-Making on Online Safety/Security Safeguards Not Occurring

What we see above is a strong explicit insistence by the CPs that they always engage in shared decision-making in matters of consequence. And yet, in the following section, we have evidence that they do not engage in shared decision-making in matters of instilling online safety and security safeguards. Our findings reiterate that which Piper et al. [36] and Mentis et al. [32] have both shown — that discussions of online safety and security safeguards is simply not occurring between couples.

We had a predominance of our CGs explain to us the safe and secure online environment that they created for their partner in order to allow them to continue to engage online. These environments were designed and implemented by the CG without a process of shared decision-making with the CR. For instance, CG9 had taken it upon himself to implement technology organization and phone alarms in order to support his wife in her continued semi-independence.

> **CG9:** *But the program thing is on there and she could go find it, but it doesn't interest her. Whatever she wants to use is right there on the bottom, so if you look at the bottom, what's there? Internet Explorer, solitaire. . . Oh, the alerts. I have her alarm set for a quarter till nine and when it beeps she looks at it and says, "What's this." It's like it doesn't mean anything to her. It's an alarm. It goes off every single day and every morning when it goes off, she asks me what this is.*

This quote illustrates the online safety and security decisions that the CG has made for his partner. He organized her computer desktop to only display those programs he observed her showing interest in and hid away all others and he has taken the initiative to set alarms that he has deemed her needing. CG9 obviously cares for his wife, but he later explained that his immediate reaction is to step in and take care of the problem for her:

> **CG9:** *I have a tendency…If something really makes her miserable and, to me, crying is miserable. When she starts crying over trying to do something then I don't think she needs to do it. She doesn't have to do it. I'll help her. That may not be the perfect solution, but I don't want to see her suffering any more than necessary, so I go pitch in.*

CG9 recognizes that stepping in and taking over is not "the perfect solution", but his desire to take away her pain means that some action must be taken. Like many of our one-sided CG decisions, this need for immediate action came about in reference to an incident that occurred. In other words, when there is no pre-planning or time for a focused discussion with the CR, the decision is that of the CG alone. And even when an incident happens that sparks a conversation around online safety and security needs, the reaction of our CGs was usually one of one-sided decision making. In the following example, there was an attempt to engage the CR in problem solving, but then the CG decided to move ahead and figure out a solution.

> **CG3:** *The very first time it happened [accidental purchase on a Kindle], I asked her because I thought…she used to buy an awful lot of books. I mean, she's an avid reader.*
>
> **CR3:** *Yeah. Not now.*
>
> **CG3:** *But I think I asked her if she bought a book, this particular book. And she said no. And I said, okay, I said, you must have hit something by mistake. And she says, "No I didn't." I said, "Well, it's there." I said, "Maybe you didn't notice it but let me call. I'll go and call Amazon and make sure they take it off."*

We had not one online safety and security safeguard decision that came from a place of mutual decision-making. These were decisions made by the CG for the CR – completely from a place of care, but, still, all the same, not from a place where they were decided upon and thus meaningful to the CR.

4.3 Lack of Online Safety and Security Safeguarding Options

The lack of shared decision-making around online safety and security safeguards was hard to comprehend until our analysis showed that the shared decision-making the participants said they wanted could not be supported by the options they had to choose from.

As Piper et al. [36] and Mentis et al. [32] previously showed, incidents are what forces a discussion regarding the need for online safety and security safeguards to occur, if at all. The 'adverse event', as coined by Piper et al. [36], might not be a significant breach of security, but in comparison to what was normal behavior for the CR, it indicates that there needs to be a solution put into place. When the cognitive impairment has progressed to the point where an online safety or security intervention must occur, there were not a lot of options that provided sufficient online safety and security while also maintaining any semblance of continued access. In essence, the decision as to what has to happen now was made for them both. In the following explanation from CP7, there was a point where a car accident and other incidents came together to make it clear that the CG needed to take over a number of functions in the home including managing all of the home finances that are done online.

> **I:** *We have already talked about [husband's name] you don't do the finances any more that's on [wife's name], but how did you make that decision? How did that conversation…*
>
> **CR7:** *Oh, that was easy*
>
> **I:** *That was easy? There was no pushback or anything?*
>
> **CR7:** *Yeah, yeah, I mean the handwriting is on…*

CG7: *I should have realized before I did, [husband's name] used to handle all the bills, and it was taking all weekend to do the bills, and I should have realized that, but I didn't…*

CR7: *Yeah!… Well, that was a surprise and the best I can do is either it was aging or infect… I had been in an auto accident. And there was more than one actually. And ah I think that there have been some damage that wasn't recognized that finally started playing out that was doing things that was very unexpected. You know, and so…*

CG7: *And he realized it*

CR7: *And soo … Yeah we were both grownup enough … yeah so … ok. I am happy to be seventy years old and was able to answer questions*

I: *Yeah, and [wife's name] how did you approach [husband's name] with that conversation you know was it out of the blue or did you guys have mini conversations leading up to the conversation?*

CR7: *Yeah, I think we both knew that they were*

CG7: *It was pretty much like you take care of this now, so I did*

CR7: *And thankfully it was easy enough. And also, it's been what a year or two or whatever,*

CG7: *Longer than that*

CR7: *Or a little longer than that and it seems to be you know holding*

CG7: *Yeah finally I do all the taxes*

Thus, we are first showing that if discussions occurred at all, it was primarily after an incident occurred that forced the need for a decision to be made. At that point, often the couples found themselves with not a lot of options to choose from. In the case of CP7, the impairment had gotten to the point where multiple incidents forced their hand to make a choice with regards to online finances and that choice was to have the CG completely take over the work. And yet, as we can see in this example, usually the CRs shared that they understood that this is just what needed to happen. Because of this reaction, we may determine that the couples may not need shared decision-making as there is not much of a decision to be made. With regards to online safety and security safeguards, the options were limited to 'wait and see if it happens again' or 'you cannot do that online activity anymore'. This is what Mentis et al. [32] would refer to as the two ends of the spectrum of safeguarding approaches – on one end the option of complete removal of access and on the other end, the option of no intervention at all. The challenge is to ensure that there are choices that can be made along the spectrum between these two points and then we can further support the shared decision-making around those choices.

And in most cases, our CPs showed that they would do most anything to have another option than simply taking away access. In the first example below, CG5, whose husband was demonstrating fairly significant cognitive impairment during our interview, made it very clear that she does not just want to take away access without first trying other options. And both CG5 and CG4 talked about doing everything they can to ensure their partner's continued online access despite safety and security challenges.

CG5: *You would do everything in your power [to maintain access]. But if it becomes a safety factor, then you have to look at it from a different standpoint. So safety and security and help is one aspect, but you have to do it, but you try to do some modifications. … I'm saying you try to continue and let an individual have as much participation as possible. You do modifications, but you look at it from a safety factor also. You know, I mean that, that's the one thing that I really do.*

CG4: *I wouldn't take it away from him. I'd get it fixed, whatever the problem is that made me take it away, I'd fix. Whatever it took. Because I know how much that means to him. [referring to watching a game on the tablet]*

And in the following example, the interviewer asked if CG3 ever thought about limiting CR3's access to the Kindle and both CPs were emphatic in their response.

CG3: *No.*
CR3: *No.*
CG3: *No, I work on the other ideas, how do I make it accessible without purchasable. What do I call Amazon about? I said, "Solve this problem for me. I want her to use it, she enjoys using it because she uses it for jigsaw puzzles."*

It is important to note that the 'No' responses of both the CG and CR above were immediate and in succession. It was similarly clear with all of our CPs that their desire was to find 'another way' to safeguard their technology and some CGs went to great lengths to do it.

Thus, before any form of shared decision-making can occur, online safety and security safeguard options need to be present that can accommodate any level of intervention need. In addition, it seems that options that can provide very lightweight intervention needs may be beneficial for instilling safeguards at an earlier point in the cognitive impairment so that incidents can be mitigated as early as possible.

4.4 Working to Create Online Safety/Security Safeguard Options

To have any option other than one of the two ends of the spectrum, some of our participants had to put significant work into creating 'another way'. This embodies a significant amount of the CGs resources, such as time, for them to identify what modification or intervention is available to them. A significant upfront investment of time by the CG and CR was to slowly transfer knowledge, access, and/or responsibility to the CGs. We had a few CPs that were planning ahead for the inevitable situation when the CR is unable to continue engaging online as they have.

I: *Okay. So when it started how did you… did you just all of a sudden take control over the online… all the technical online activity or was he trying to teach you?*
CG2: *Oh yeah, he's been, over the years, trying to teach me things. Lot of things, you know as much as he can. It wasn't all of a sudden because for me it's a little bit challenging for me because I don't see myself as a real tech person.*

CR10: *Because as I said, we're really doing that now, we got into this stage…*
I: *Where you're planning?*
CR10: *Yeah. Want to make sure that he knows where everything is, because he's going to be the one who has to do everything.*

CR8: *So, I've tried to get her more involved with all these technologies over time. She's done fairly well in doing that. So, I'm relying, that on the fact as my dementia problems increase, is that she would be there to do that for me.*

As one may see from these three examples, the practice of planning ahead was a shared decision and has really been motivated by the need to slowly transition the online work from the tech-savvy CR to the less technologically adept CG. This has been encouraging to see as coming up with options that work for continued access and engagement in the face of online safety and security concerns can be difficult to identify all on one's own.

But we also had CGs who engaged in a significant amount of work alone to create a safe and secure online experience in order to ensure that their partner could continue to use the technology they loved most. This is still an example of one-sided decision-making by the CG — and we are not saying it is ideal. Rather, it is indicative of the need for options to choose from in order to fulfill their safety and security needs beyond removing online access.

In the following example, over the course of about six months, CG3 was on the phone with Amazon regarding his wife's Kindle to try to address the safety flaw it had that led to numerous unintended purchases by his wife. The following story by CG3 is long, but the detail of the challenges and his efforts to address them are demonstrative of the invisible work that CGs do to create choices.

> **CG3:** *I had to work on finding how… all of a sudden I'm seeing these little purchases, even some books being bought, so I called Amazon immediately … [and] I explain … the situation to them that my wife has dementia. I said she uses the Kindle because it's a form of enjoyment doing crossword puzzles, jigsaw puzzles. But I said, by mistake she hit this, she didn't realize it, and I said it was just too easy for her to hit. … I said, "Help me make this Kindle safe for her." … I thought I had put a parental protection on the Kindle so she couldn't buy anything but they said that …, one of the things on the Kindle I couldn't turn on, it had to be turned on by them. [T]hey said, "Alright, we will remove… " they said, "Usually we charge $25 for this, but we'll remove the ads from her computer." And so they finally after we saw some more purchases being made, which they refunded, they went ahead and said, "Okay, we're turning it [off] now." [But then] that presents a little bit of an issue because many times there's a free puzzle of the day and you can get it, and sometimes though you have to get it through Amazon, or some certain things that are free, they still treat it as a purchase, even though it's zero dollars. And if you block the purchasing, you block those. And I had to tell them, I said, "Look, my wife will occasionally get a free puzzle, she wants to get it. I want to know that she can get that without a problem." Well, I think the way around it was I had to do it. I had to actually type in the password and clear it for her.*

Multiple calls and incidents led to a co-created solution between the Amazon customer support center and CG3 to create a technology that provided enjoyment and cognitive stimulation for CR3. Although in our sample, CG3 was certainly an anomaly in terms of the time invested in getting to a suitable option for his wife to continue to engage with her beloved Kindle, he is certainly not an anomaly in terms of the motivation behind this persistence.

Finding a way to solve a problem was the work that all of our caregivers spoke about, but most interesting was when they chose not to simply take away access or do something all themselves. They might have invested significant upfront time to create a more suitable option such as CG3 above, or else they devised an option that created more work for themselves on a continual basis. For instance, most of our CPs spoke of 'doing it together'. In essence, being online together or only when in the same room. For instance, CG4 spoke of checking email with her husband after he had progressed over the past 6 months.

> **CG4:** *But we like do it [checking email] together now, if they need him it all goes to the same [email address] now. Because he has trouble knowing what the buttons to push. I mean you know tech, if you don't know what's going on, you push the wrong button, you're lost.*

In order to ensure they could now check email together, CG4 first changed the contact email for everyone to a shared email account – including, for instance, any doctors they were seeing. Then she took the time to sit down with her husband and review the emails together and help him use the technology so he could continue this form of online communication. We again see the care in doing upfront work to setup a choice as well as the ongoing work of supporting that choice that caregivers are already doing.

Through this analysis, we have uncovered that there would be more of a motivation for shared decision-making with regards to online safety and security safeguarding solutions if there were options available to even choose from. The explicit need of our CPs is that they do not want to have their hands tied by only one viable option – i.e., take away access – but rather are desperately looking for and investing time to work towards modifications or work arounds.

5 DISCUSSION

Through this study, we have uncovered the current practices of online safety and security safeguards decision-making between spousal caregivers and care recipients with mild cognitive impairment. At the start, we showed that CPs really wanted to engage in shared decision-making, but were not. Most often the CPs were compelled to take action because an incident has raised their mutual awareness of the severity of the impairment. Although this set of findings echoed that of Piper et al. [36] and Mentis et al. [32], who have both shown that discussions around online safety and security safeguards is not occurring between couples and if those discussions happen it is usually due to an incident or 'adverse event', we are also showing that these couples want to have these discussions and mutually agreed upon decisions. The caregiver does not want to make a rash decision with no input from their partner. Time and time again we heard how much our caregivers want to support the autonomy and input of their partner and that their intentions are always to gain their input.

This is a discrepancy between intention and behavior. We show that when the cognitive impairment has progressed to the point where an intervention must occur, the lack of choices that lie on a spectrum precluded any discussions as to what do to and thus limited the opportunity for shared decision-making. This lack of options is vitally important as caregivers were motivated to create choices and engaged in a lot of hard work to do that. This reiterates that the four ways for supporting care recipients with cognitive impairment to continue with their online activity – guiding, connecting, stimulating and protecting [36] – all entail significant work that the caregivers perform to provide a suitable choice to their loved one. It is significantly easier to engage in passive mitigation strategies, where one limits the use of technology or avoid it altogether – the two ends of the "spectrum of care" – instead of the work necessary to engage in active mitigation strategies that might include configuring privacy and authentication settings or using protective software and services [14]. But, even though the caregivers expressed strong desires to preserve their spouse's input into the decision-making process and both partners in the interviewed couples spoke of trusting one another, lack of options limited how much shared decision-making they could actually engage in.

This is troubling as the concept of person-centered care in aging aims to preserve the person's choice, particularly in their most vulnerable state [13, 26, 28]. Choice is one of the most critical elements of person-centered care and it allows for those caring for the individual to see them as a person and not a patient – making choices about one's own life, being listened to and heard are basic human desires as we age. This is particularly important to honor and provide space for the individual to maintain their identity and participate in the decision-making process, despite the various challenges both parties face. This "continuity to adaption" is an important component of person-centered care as it shows that an older person's choices persist (continuity), however are modified in response to life's realities and resources available (adaption).

5.1 The Illusion of Choice in Cybersecurity

Even in an ideal, healthy relationship, cybersecurity choices are often challenging. For most of the last decade, legal scholars have noted the increasing failure of traditional "notice and choice" approaches to supporting consumer decisions regarding privacy and security [9]. McDonald and Cranor [31] noted that an active Internet user may need to spend over 300 hours reading privacy policies just to be informed in this system. The result of current practice is a virtual absence of consumer concerns about privacy and security in the design process for most consumer products [42]. Companies often take advantage of the "privacy paradox" by asking users to trade long term privacy for short term benefits [1]. Many otherwise healthy users find this sort of tradeoff difficult to navigate [39].

Given this environment, many of the discussions we observed between caregivers and care recipients are impressive. We observed CPs attempting to plan ahead and taking cybersecurity seriously, which fits the theory behind the "notice and choice" regulatory approach to privacy and security. Similarly, we observed couples taking action after an incident occurred, which is not dissimilar from typical, individual users [39]. Caregivers and care recipients may actually be making healthier decisions than otherwise healthy individuals if only because they are willing to admit that forgoing some online activities may be the only safe approach. Negative experiences online can actually reinforce or encourage continued online activity in a destructive cycle [25], but caregivers and care recipients may avoid this cycle simply by being more open about these experiences.

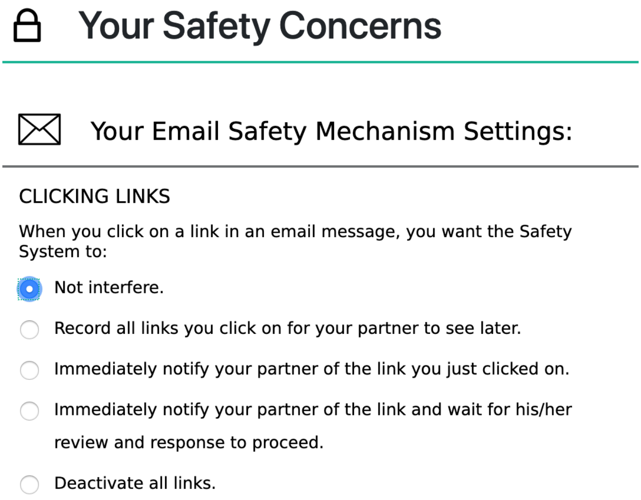
Discussions from our study lead us to believe, however, that more subtle manipulations found in behavioral advertising [30] or dark patterns [20] are particularly difficult to navigate for these CPs. Gauging the scope of this problem is an important area for future work. The CPs in the study clearly sought to continue using technologies and websites they enjoyed, but creating and safeguarding these experiences required significant work from caregivers. However, the academic research community does not fully understand the effectiveness of behavioral advertising or dark user experience patterns on the typical, healthy population as a point of comparison.

The CPs' desire to seek autonomy, respect, and shared decision-making highlights a critical challenge within cybersecurity: trust. Although trust has been central to both technical and legal approaches to cybersecurity [2, 23, 37] actual examples of users discussing and making trust-based decisions regarding technology use are rare. Perhaps the only technology designed to support trust-based relationships between users are parental controls designed to help limit or monitor technology use in parent-child relationships [8]. Such solutions could be used in a CP situation, but we posit not without discussion within the context of a shared decision. But this is the opportunity that presents itself for this population of users. By providing further options and having those options based in a sense of mutual trust between caregiver and care recipient, we may be able to stimulate the shared decision-making that is most beneficial for a MCI population.

5.2 Providing an Environment of Choice for Shared Decision-Making

In translating these findings to action, we suggest two solutions that could be combined to spur on carepartners' shared decision-making on online safety and security safeguards. The first solution is presenting a complete list of options a CP can then choose from. This list would provide safeguard features the partners can select together, agreeing together where they ultimately situate themselves along the continuum. By providing a combined list of offerings, it reduces the work necessary for the care partners to do in identifying what the options are at one's disposal. It also can be used as a discussion space that can occur before or after an incident occurs – before is to familiarize themselves with the safety and security issues they may need to be aware of and after an incident is to reevaluate the safety and security safeguards they have in place. The second solution is to provide a spectrum of choices in how to handle potential issues - one that presents various tradeoffs between safety/security and privacy/autonomy. When presented with the spectrum, they can see this tradeoff more clearly. Thus, the first solution is to clearly present the options available while the second solution is to expand the options that are offered.

Along these lines, it is clear that more options need to be provided. For situations in which they typically use technology, including email, Facebook, online banking or money transfer, online shopping, password management, and online browsing, couples could select settings for each separately. And each application/situation may have multiple actions one may taken that could expose them to risk. For instance, in email, risky actions maybe be when the person with MCI clicks on a link in an email message or when they attempt to open an email attachment. For each action, then, there can be a spectrum of choice provided including: “not interfere,” “record for partner to see later,” “notify partner,” “partner review before continuing,” and “deactivate/not allow.” This is a much more nuanced level of intervention that gets beyond simply tracking everything a care recipient may do or completely removing access from all online applications.



Your Safety Concerns

Your Email Safety Mechanism Settings:

CLICKING LINKS

When you click on a link in an email message, you want the Safety System to:

● Not interfere.
○ Record all links you click on for your partner to see later.
○ Immediately notify your partner of the link you just clicked on.
○ Immediately notify your partner of the link and wait for his/her review and response to proceed.
○ Deactivate all links.

Fig. 1. Options display for the email action of clicking on a link.

Figure 1 shows an example of such a set of options for clicking on a link in an email. The spectrum of care ranges from no interference – i.e., the system does not interfere when the person with cognitive challenges performed the action – to what we deem ‘full interference’ – i.e., the system ensures that the action cannot be completed. What is important to note is that between these two ends of the spectrum were three to four additional ‘levels’ to choose from. As the choices moved from no interference to full interference, the choices generally added more security, with a corresponding reduction in autonomy or privacy.

As we think through other types of online actions that may open one up to a safety or security violation, such as online shopping or social media interactions, the same range of options can be used. We took the approach of having a range of options that included the caregiver as a collaborative partner. There could also be an argument to have a range of options that provide only system support such as automated assessment of the link’s safety based on keywords and URL indicators. An open area for exploration is to determine how nuanced of options care partners may want. Here we have five choices, but perhaps there are more or less that are desired. In addition, it may be that there is a desire to have many choices at the lower end of the spectrum, for when the cognitive impairment is still fairly mild, but then not as many choices are necessary or needed at the higher end of spectrum, for when the impairment has become fairly severe. An evaluation of such a set of settings could provide answers to these questions as well as provide further guidance on how options can be presented to support shared decision-making.

6 CONCLUSION

The mismatch between desired shared decision-making and actual decision-making practices shows that the participants have identified a problem. Being able to create a smaller gap between their desired decision-making style and the one-sided practices they are currently using would increase the comfort level in the relationship as well as the continuous usage of online services would preserve the well-being and social life of the care recipients long after their diagnosis [11]. Lastly, allowing a safer and more extensive input into the decision-making process by the care recipients follows the idea of creating a more person-centered care environment by the caregivers where the approach is more humanistic and cares more about the actual person as opposed to the caregiving tasks as such [13, 26, 28].

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REFERENCES

[1] Alessandro Acquisti and Jens Grossklags. 2005. Privacy and rationality in individual decision making. *IEEE Security and Privacy Magazine* 3, 1 (jan 2005), 26–33. https://doi.org/10.1109/MSP.2005.22

[2] Alessandro Acquisti, Ionnis Krontiris, Marc Langheinrich, and Martina Angela Sasse. 2013. 'My Life, Shared'-Trust and Privacy in the Age of Ubiquitous Experience Sharing (Dagstuhl Seminar 13312). *Dagstuhl Reports* 3, 7 (2013), 74–107.

[3] APA. 2013. *Diagnostic and Statistical Manual of Mental Diorders* (5th ed.). American Psychiatric Publishing, Arlington, VA.

[4] Andrew B.L. Berry, Catherine Lim, Andrea L. Hartzler, Tad Hirsch, Edward H. Wagner, Evette Ludman, and James D. Ralston. 2017. How values shape collaboration between patients with multiple chronic conditions and spousal caregivers. In *Conference on Human Factors in Computing Systems - Proceedings*, Vol. 2017-May. Association for Computing Machinery, New York, NY, USA, 5257–5270. https://doi.org/10.1145/3025453.3025923

[5] Ann E. Blandford. 2013. Semi-structured qualitative studies. In *The Encyclopedia of Human-Computer Interaction.*, M. Soegaard and R. Dam (Eds.). Interaction Design Foundation, Denmark. https://discovery.ucl.ac.uk/id/eprint/1436174/

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

[7] John C S Breitner. 2014. Mild cognitive impairment and progression to dementia: new findings. *Neurology* 82, 4 (jan 2014), e34–5. https://doi.org/10.1212/WNL.0000000000000158

[8] Serkan Çankaya and Hatice Ferhan Odabaşı. 2009. Parental controls on children's computer and Internet use. *Procedia - Social and Behavioral Sciences* 1, 1 (jan 2009), 1105–1109. https://doi.org/10.1016/J.SBSPRO.2009.01.199

[9] Fred H. Cate. 2010. The Limits of Notice and Choice. *IEEE Security & Privacy Magazine* 8, 2 (mar 2010), 59–62. https://doi.org/10.1109/MSP.2010.84

[10] Elizabeth C. Clipp, Michael J. Moore, and Linda K. George. 1996. The content and properties of the Caregiver Activities Time Survey (CATS): An outcome measure for use in clinical trial research on Alzheimer's disease. *American Journal of Alzheimer's Disease* 11, 6 (nov 1996), 3–9. https://doi.org/10.1177/153331759601100602

[11] Shelia R. Cotten, George Ford, Sherry Ford, and Timothy M. Hale. 2012. Internet use and depression among older adults. *Computers in Human Behavior* 28, 2 (mar 2012), 496–499. https://doi.org/10.1016/J.CHB.2011.10.021

[12] Sara J. Czaja and Mark P. Rubert. 2002. Telecommunications technology as an aid to family caregivers of persons with dementia. *Psychosomatic Medicine* 64, 3 (2002), 469–476. https://doi.org/10.1097/00006842-200205000-00011

[13] Patrick J. Doyle and Robert L. Rubinstein. 2014. Person-Centered Dementia Care and the Cultural Matrix of Othering. *The Gerontologist* 54, 6 (dec 2014), 952–963. https://doi.org/10.1093/geront/gnt081

[14] Alisa Frik, Florian Schaub, Leysan Nurgalieva, Julia Bernd, Joyce S Lee, and Serge Egelman. 2019. Privacy and Security Threat Models and Mitigation Strategies of Older Adults. In *Fifteenth Symposium on Usable Privacy and Security (SOUPS)*. USENIX Association, Santa Clara, CA. https://blues.cs.berkeley.edu/

[15] Vaibhav Garg, L. Jean Camp, Katherine Connelly, and Lesa Lorenzen-Huber. 2012. Risk Communication Design: Video vs. Text. In *Proceedings of the 12th international conference on Privacy Enhancing Technologies*. Springer-Verlag, 279–298. https://doi.org/10.1007/978-3-642-31680-7_15

[16] Serge Gauthier, Barry Reisberg, Michael Zaudig, Ronald C Petersen, Karen Ritchie, Karl Broich, Sylvie Belleville, Henry Brodaty, David Bennett, Howard Chertkow, Jeffrey L Cummings, Mony de Leon, Howard Feldman, Mary

Ganguli, Harald Hampel, Philip Scheltens, Mary C Tierney, Peter Whitehouse, and Bengt Winblad. 2006. Mild cognitive impairment. *The Lancet* 367, 9518 (2006), 1262–1270. https://doi.org/10.1016/S0140-6736(06)68542-5

[17] William E. Gibson. 2018. Identity Theft Soared to a Record High in 2017. https://www.aarp.org/money/scams-fraud/info-2018/id-theft-fraud-fd.html

[18] Laura N. Gitlin, Louis D. Burgio, Diane Mahoney, Robert Burns, Song Zhang, Richard Schulz, Steven H. Belle, Sara J. Czaja, Dolores Gallagher-Thompson, Walter W. Hauck, and Marcia G. Ory. 2003. Effect of multicomponent interventions on caregiver burden and depression: The REACH multisite initiative at 6-month follow-up. *Psychology and Aging* 18, 3 (sep 2003), 361–374. https://doi.org/10.1037/0882-7974.18.3.361

[19] Janice E Graham, Kenneth Rockwood, B Lynn Beattie, Robin Eastwood, Serge Gauthier, Holly Tuokko, and Ian McDowell. 1997. Prevalence and severity of cognitive impairment with and without dementia in an elderly population. *The Lancet* 349, 9068 (1997), 1793–1796. https://doi.org/10.1016/S0140-6736(97)01007-6

[20] Colin M. Gray, Yubo Kou, Bryan Battles, Joseph Hoggatt, and Austin L. Toombs. 2018. The Dark (Patterns) Side of UX Design. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems - CHI '18*. ACM Press, New York, New York, USA, 1–14. https://doi.org/10.1145/3173574.3174108

[21] Hassan Halawa, Konstantin Beznosov, Yazan Boshmaf, Baris Coskun, Matei Ripeanu, and Elizeu Santos-Neto. 2016. Harvesting the low-hanging fruits. In *Proceedings of the 2016 New Security Paradigms Workshop on - NSPW*. ACM Press, New York, New York, USA, 11–22. https://doi.org/10.1145/3011883.3011885

[22] Zaffar Haider Janjua, Daniele Riboni, and Claudio Bettini. 2016. Towards automatic induction of abnormal behavioral patterns for recognizing mild cognitive impairment. In *Proceedings of the 31st Annual ACM Symposium on Applied Computing - SAC '16*. ACM Press, New York, New York, USA, 143–148. https://doi.org/10.1145/2851613.2851687

[23] Carlos Jensen, Colin Potts, and Christian Jensen. 2005. Privacy practices of Internet users: Self-reports versus observed behavior. *International Journal of Human-Computer Studies* 63, 1-2 (jul 2005), 203–227. https://doi.org/10.1016/J.IJHCS.2005.04.019

[24] David S. Knopman and Ronald C. Petersen. 2014. Mild Cognitive Impairment and Mild Dementia: A Clinical Perspective. *Mayo Clinic Proceedings* 89, 10 (oct 2014), 1452–1459. https://doi.org/10.1016/J.MAYOCP.2014.06.019

[25] Jaron Lanier. 2018. *Ten arguments for deleting your social media accounts right now.* Bodley Head. 146 pages. https://go.gale.com/ps/anonymous?id=GALE{%}7CA595353624{&}sid=googleScholar{&}v=2.1{&}it=r{&}linkaccess=abs{&}issn=08922675{&}p=AONE{&}sw=w

[26] Junxin Li and Davina Porock. 2014. Resident outcomes of person-centered care in long-term care: A narrative review of interventional research. *International Journal of Nursing Studies* 51, 10 (oct 2014), 1395–1415. https://doi.org/10.1016/j.ijnurstu.2014.04.003

[27] Lesa Lorenzen-Huber, Mary Boutain, L. Jean Camp, Kalpana Shankar, and Kay H. Connelly. 2011. Privacy, Technology, and Aging: A Proposed Framework. *Ageing International* 36, 2 (jun 2011), 232–252. https://doi.org/10.1007/s12126-010-9083-y

[28] Galina Madjaroff and Helena M. Mentis. 2017. Narratives of older adults with mild cognitive impairment and their caregivers. In *ASSETS 2017 - Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility*. https://doi.org/10.1145/3132525.3132554

[29] Diane F. Mahoney, Ruth B. Purtilo, Frank M. Webbe, Majd Alwan, Ashok J. Bharucha, Tim D. Adlam, Holly B. Jimison, Beverly Turner, and S. Ann Becker. 2007. In-home monitoring of persons with dementia: Ethical guidelines for technology research and development. *Alzheimer's & Dementia* 3, 3 (jul 2007), 217–226. https://doi.org/10.1016/J.JALZ.2007.04.388

[30] Aaron K. Massey and Annie I. Anton. 2011. Behavioral Advertising Ethics. In *Information Assurance and Security Ethics in Complex Systems: Interdisciplinary Perspectives*. Information Science Reference, Hershey, PA, 162–182.

[31] Aleecia M. McDonald and Lorrie Faith Cranor. 2008. The Cost of Reading Privacy Policies. *I/S: A Journal of Law and Policy for the Information Society* 4 (2008). https://heinonline.org/HOL/Page?handle=hein.journals/isjlpsoc4{&}id=563{&}div={&}collection=

[32] 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 Press, New York, New York, USA, 1–13. https://doi.org/10.1145/3290605.3300573

[33] Maurice Mulvenna, Suzanne Martin, Stefan Sävenstedt, Johan Bengtsson, Franka Meiland, Rose Marie Dröes, Marike Hettinga, Ferial Moelaert, and David Craig. 2010. Designing & evaluating a cognitive prosthetic for people with mild dementia. In *Proceedings of the 28th Annual European Conference on Cognitive Ergonomics - ECCE '10*. ACM Press, New York, New York, USA, 11. https://doi.org/10.1145/1962300.1962306

[34] Francisco Nunes and Geraldine Fitzpatrick. 2015. Self-Care Technologies and Collaboration. *International Journal of Human-Computer Interaction* 31, 12 (dec 2015), 869–881. https://doi.org/10.1080/10447318.2015.1067498

[35] Debbie Parker Oliver, Sonal Patil, Jacquelyn J. Benson, Ashley Gage, Karla Washington, Robin L. Kruse, and George Demiris. 2017. The Effect of Internet Group Support for Caregivers on Social Support, Self-Efficacy, and Caregiver

Burden: A Meta-Analysis. *Telemedicine and e-Health* 23, 8 (aug 2017), 621–629. https://doi.org/10.1089/tmj.2016.0183

[36] Anne Marie Piper, Raymundo Cornejo, Lisa Hurwitz, and Caitlin Unumb. 2016. Technological Caregiving. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems - CHI '16*. ACM Press, New York, New York, USA, 5311–5323. https://doi.org/10.1145/2858036.2858260

[37] Neil Richards and Woodrow Hartzog. 2015. Taking Trust Seriously in Privacy Law. *Stanford Technology Law Review* 19 (2015). https://heinonline.org/HOL/Page?handle=hein.journals/stantlr19{&}id=447{&}div={&}collection=

[38] Birgitte Schoenmakers, Frank Buntinx, and Jan DeLepeleire. 2010. Supporting the dementia family caregiver: The effect of home care intervention on general well-being. *Aging & Mental Health* 14, 1 (jan 2010), 44–56. https://doi.org/10.1080/13607860902845533

[39] Manya Sleeper, Alessandro Acquisti, Lorrie Faith Cranor, Patrick Gage Kelley, Sean A. Munson, and Norman Sadeh. 2015. I Would Like To..., I Shouldn't..., I Wish I.... In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing - CSCW '15*. ACM Press, New York, New York, USA, 1058–1069. https://doi.org/10.1145/2675133.2675193

[40] Betzaida Tejada-Vera. March 2013. Mortality from Alzheimer's disease in the United States; data for 2000 and 2010. https://stacks.cdc.gov/view/cdc/13601 Journal Issue.

[41] US Census Bureau. 2018. US Census bureau projections show a slower growing, older, more diverse nation a half century from now. https://www.census.gov/newsroom/releases/archives/population/cb12-243.html

[42] Ari Ezra Waldman. 2017. Designing Without Privacy. https://papers.ssrn.com/sol3/papers.cfm?abstract{_}id=2944185

[43] Carol J. Whitlatch, Katherine Judge, Steven H. Zarit, and Elia Femia. 2006. Dyadic Intervention for Family Caregivers and Care Receivers in Early-Stage Dementia. *The Gerontologist* 46, 5 (oct 2006), 688–694. https://doi.org/10.1093/geront/46.5.688

[44] Wira Zanoramy A. Zakaria, Mohd Faizal Abdollah, Othman Mohd, and Aswami Fadillah Mohd Ariffin. 2017. The Rise of Ransomware. In *Proceedings of the 2017 International Conference on Software and e-Business - ICSEB 2017*. ACM Press, New York, New York, USA, 66–70. https://doi.org/10.1145/3178212.3178224

A SEMI-STRUCTURED INTERVIEW GUIDE

(1) How do you make decisions with regards to cyberaccess?
(2) Did this change before and after the diagnosis?
(3) Have CR's online access been limited cyberaccess? What did that conversation look like, when did it take place?
(4) Is there anything that you think you would like to mediate such a conversation?
(5) If you haven't had this conversation, how could you imagine having it, what would this be like?

B THEMATIC CODING CATEGORIES

(1) Discussions about making changes in their lives due to the MCI.
    (a) About online safety and security safeguards
    (b) Not about online safety and security safeguards
    (c) If example of discussions had:
        (i) Planned ahead
        (ii) Happened on the spot during the interview
        (iii) Incident that led to the discussion occurring
        (iv) Involvement of other people in discussions
        (v) Decision occurring with no discussion.
(2) Articulated desire for shared decision-making.
    (a) Because that is just what they do
    (b) In order to preserve autonomy of CR
    (c) In order to preserve relationship
(3) Work that the CG had to perform in order to continue to provide safety and security while maintaining access.
    (a) About online safety and security safeguards.

(b) Not about online safety and security safeguards.

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