Technological Caregiving: Supporting Online Activity for Adults with Cognitive Impairments

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ABSTRACT

With much of the population now online, the field of HCI faces new and pressing issues of how to help people sustain online activity throughout their lives, including through periods of disability. The onset of cognitive impairment later in life affects whether and how individuals are able to stay connected online and manage their digital information. While caregivers play a critical role in the offline lives of adults with cognitive impairments, less is known about how they support and enable online interaction. Using a constructivist grounded theory approach, data from focus groups with caregivers of adults with cognitive impairments reveal four forms of cooperative work caregivers perform in the context of supporting online activity. We find that staying active online is a way of empowering and engaging adults with cognitive impairments, yet this introduces new forms of risk, surrogacy, and cooperative technology use to the already demanding work of caregiving.

Author Keywords

Caregiving; social computing; vulnerable populations

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous

INTRODUCTION

Going online is an important aspect of daily life for many people and shapes the way we engage in social interaction, search for information, manage finances, and more. Being active online is important for independence and affects social and emotional wellbeing [13]. With much of the population now online, including many older adults [12,44], it is increasingly important to understand how to help people sustain their online lives through periods of disability. For example, changes in a person's cognitive abilities resulting from Alzheimer's disease, stroke, or a brain injury impact whether and how an individual is able to go about her existing online activities, such as corresponding over email,

interacting on social media, and managing bank accounts [29]. Yet, how people sustain such activities in the context of cognitive impairment is an open question with implications for online safety, privacy, social support, and the work of caregivers [3]. Consider the following experience:

Jane is the primary caregiver for her husband, who *"suffers [from] aphasia, mostly communication challenges… But memory is affected when your brain's working on aphasia. I'm very aware of his, you know, when he comes and goes."* She encourages him to go online to keep in touch and look up information about his hobbies. *"Facebook people…would put comments, and it's very nice, because you feel like there's a very caring community that's interested. They can't much do anything except that they can say, 'We're thinking about you.'"* Some days her husband may stare blankly at the computer, and she steps in to help him. Recently, however, her husband *"had his identity stolen… The only reason we knew about it was because somebody tried to get a mortgage… So then, we talked about [the] Internet..."* Despite this unfortunate event, Jane continues to help her husband go online.

Caregiving is a complex and cooperative social practice in which caregivers and other actors support care recipients in a myriad of contexts [35,45]. Prior work details the role of caregivers in supporting activities of daily living (e.g., dressing, bathing, preparing meals, administering medications) [33]. Caregiving can be overwhelmingly stressful work [9], and caregivers often experience high levels of physical, financial, social, and emotional stress – also known as the *burden* of caregiving [11]. Although much work focuses on "offline" or non-technology related caregiver experiences, few studies have examined the impact of technology from the caregiver's perspective [16,34]. Considering how pervasive technology is today, understanding the experience of caregivers is critical given the effects of caregiving on the caregiver's own health and wellbeing [9] and potential to improve overall care by easing the burden on caregivers. While the HCI and CSCW communities are beginning to understand the effects of new technologies on caregiving work, we know much less about how caregivers and care recipients interact in the context of everyday online tools and what staying active online means for the work of caregiving.

This paper reports results from focus groups with 20 caregivers of adults with cognitive impairments, examining the ways in which care recipients interact online, whether

and how caregivers are involved in this online experience, and the benefits and concerns of online activity. Caregivers do much work to support their care recipients' online activities and view staying active online as positive for their care recipients. As the primary contribution of this study, we describe four forms of work caregivers perform in the context of supporting their care recipient's online activity: *guiding*, *stimulating*, *connecting*, and *protecting*. Across these forms of work, caregivers and care recipients cooperatively negotiate the online experience in ways that emphasize empowerment and independence while protecting care recipients through moments of risk and vulnerability. The cooperative use of online tools by caregivers and care recipients introduces tensions related to surrogacy, sharing, and privacy for vulnerable populations. Our analysis contributes insights into how online systems can better support this complex social practice and the dynamics of the caregiver-care recipient relationship.

RELATED WORK

The Work of Caregiving

The health care and nursing literatures often characterize the daily activities of informal caregivers (e.g., family members or friends) as a form of work [17,39,40]. Informal caregivers are unpaid individuals who provide regular care for their care recipient [33]. Providing care consists of assisting and supporting care recipients with various activities of daily living (e.g., dressing, bathing, feeding, etc.) and instrumental activities of daily living (e.g., housekeeping, transportation, medication, etc.).

The literature conceptualizes the emotional and physical strain of providing care for others as the *burden* of caregiving [11]. As part of this framing, prior work has broken this concept into objective and subjective burdens [32]. The objective burden results from concrete events and activities from caregiving (e.g., less personal time), while the subjective burden involves feelings, attitudes, and emotions about caregiving (e.g., resulting loneliness or depression). Objective and subjective burdens may be related to disruptions to a caregiver's life and impact on her wellbeing. Prior studies indicate the ways in which the burden of caregiving impacts the physical health [25], socialization [30], and emotional wellbeing of caregivers [14]. For example, the Alzheimer's Association reported that nearly 40% of caregivers rated their caregiving experience as stressful [1]. Given this intense burden, some caregivers experience high frustration if they do not perceive that their care recipient is making progress [19].

The burden of caregiving often extends beyond simple frustration. Caregivers may struggle to balance the work of caregiving with the emotional burden it entails and ultimately end up neglecting their own needs. For instance, Liu et al. [30] found that caregivers of high-risk infants struggle to reach out for social support and face challenges re-connecting with their social networks. Moreover, caregivers may want to connect with others who are in similar caregiving situations [30]. Chen et al. [9] studied how caregivers balance their personal lives with the work of caregiving for people with a variety of illnesses (e.g. cancer, stroke, diabetes, dementia). Their work describes tensions between providing support and its impact on the caregiver's life. Caregivers' efforts and time invested in providing support for their care recipients goes mostly unnoticed by their relatives and friends. The "invisibility" of caregiving work – or that the burden may only be salient to the person immersed in providing care – limits opportunities for others to step in, collaborate with, and help the primary caregiver. This prior research highlights the importance of understanding and designing to support the work of caregivers, and not simply for care recipients.

Technology to Support Caregiving

The vast majority of technology-related research on caregiving for individuals with cognitive impairments focuses on new tools for supporting remote caregiving and aging in place [16,23,34,42,47]. Prior work [26,41] introduces robotic wheelchairs to support movement among elderly patients, which reduce the caregiver's physical workload. While valuable, this work does not consider caregivers' expectations or needs in other regards, such as coordinating care and social support. To date, few studies have focused on technology to support the needs and practices of caregivers in particular. Some of these efforts aim to alleviate a specific activity performed by the caregiver (e.g. [16,34]). For example, the AwarePad [34] is a mobile application designed to help caregivers manage repetitive questions from care recipients diagnosed with Alzheimer's disease. Chiu and Massimi [10] proposed a digital tool to speed up appointment decisions but also support the caregiver by simplifying communication activities and improving access to community resources. Similarly, the Estrellita system [30] is a collaborative prototype to support caregivers of high-risk infants and their healthcare professionals. Other systems that disseminate health information within a social network (e.g., [43]) stand to help coordinate and catalyze social support for patients and caregivers. New technologies that address caregivers' needs and practices can decrease the burden on caregivers and, in turn, allow caregivers to provide better care for their care recipients.

Supporting Online Activity through Life Transitions

The present study contributes to the literature on how others support online activity for individuals through life transitions. Work by Ammari et al. [2] introduces the notion of parental disclosure management, in which parents decide how and what to share online about their children from birth through adolescence. Hence, children's early online identities are created by their parents and affected by their parents' decisions about what is appropriate to be shared.

In contrast to online identity in childhood, recent studies also investigate cooperative online activity at the end of life (e.g., in hospice [18]) and after an individual passes away [5,6,31].

While family and friends use technology to share information about an individual in hospice, this can lead to privacy violations and conflicts about what should be shared [18]. Our work extends this literature by detailing the cooperative work caregivers perform in the context of their care recipient's online activity, calling attention to issues of vulnerability and surrogacy through life transitions.

METHOD

Participants

We conducted four focus groups with a total of 20 participants (age 27 to 56; *M*=41; *SD*=8; 10 female). All focus group participants were *informal, un-paid caregivers* of an adult with a cognitive impairment, whom we refer to as the *care recipient*. We recruited individuals who indicated that they were a primary caregiver of an individual with cognitive impairment (e.g., memory or speech-language impairment). All caregivers were family related to their care recipient (e.g., provide care for their mother, father, uncle, spouse, or grandparent). Caregivers reported that their care recipients had varying levels of cognitive impairment as a result of conditions such as Alzheimer's disease, stroke, or brain injury from an accident, and all experienced cognitive impairment in middle or older adulthood (i.e., not in early childhood from a developmental disability). Care recipients were between age 51 and 89 (8 female) and were at varying stages of their life (including one who passed away prior to the focus group). All care recipients had been involved in online activity, although with varying levels of independence. All caregivers had some experience going online themselves and supporting care recipients' online activities, and as a result, the average age in our sample of caregivers is somewhat younger than comparable studies that focus broadly on caregiving experiences (e.g. [32]). We aimed to organize groups of caregivers who care for adults with similar conditions (e.g., severe memory loss, speech-language impairment and memory loss), as this cohesion can foster a comfortable environment for participants and help elicit in-depth conversation among participants [27]. Focus groups were conducted in a university conference room.

Procedure

One researcher moderated the focus groups and two other researchers observed and took notes. The moderator guide focused on the ways in which caregivers and care recipients engage online, including using e-mail, social media (e.g., Facebook, Twitter), video chat, banking tools, etc.; benefits and concerns regarding online activity; and any changes in online activity with respect to the care recipient's abilities over time. We allowed the conversation to evolve among participants depending on each group's dynamics, and at times caregivers asked each other questions about their experiences, exchanged strategies, and provided encouragement and empathy to one another. This interaction provides important data about caregivers' shared or conflicting practices, assumptions, concerns, and benefits of online interaction. All focus groups were video recorded and transcribed for analysis. Pseudonyms are used in place of actual names of caregivers and care recipients.

Data Analysis

Data analysis followed a constructivist grounded theory approach [7,8]. Our process of data analysis emerged through interactions with our informants, with our data, and between members of our research team. All researchers read the transcripts, performed initial open coding of data, and discussed the emerging themes. Based on this, we began to view our informants' role in online technology use with respect to their care recipient as a form of "work". This analytic frame is influenced by informant language (e.g., talk of exhaustion from caregiving work, need for support, and constant duties as a caregiver) as well as by prior research in the field that predominantly characterizes caregiving as a form of work [19,20,46]. With this analytic frame in mind, we conducted a second phase of coding to identify the forms of work described by caregivers, how caregivers accomplish this work, and the ways in which various goals in this work support or compete with each other. We iteratively coded data and related these codes to one another through a process of memoing and theorizing. Analysis focused on constant comparison of data, seeking to further refine our understanding of this practice.

Constructivist grounded theory requires reflexivity about how we construct our actions and our position as researchers. Three key factors influence our position as researchers, which both strengthen and limit our analysis. First, our data captures the perspectives of caregivers, which calls attention to their needs in this cooperative social practice. While some care recipients would be able to voice their own opinions, and additional studies should examine this (e.g. [22]), the purpose of the present study is to understand the lived experience of caregivers in the context of their care recipient's online activity. Understanding the perspective of caregivers is important but understudied in HCI [10,30], and our analysis contributes to this literature. Second, our view of this social practice as a form of work risks focusing on functional caregiving activities and the "burden" of caregiving rather than the ways in which caregivers may enable and empower care recipients. We remain cognizant of this in our analysis and return to this point in the discussion. Third, our analysis positions care recipients as a vulnerable population. We note that the positioning as vulnerable is socially constructed and framed by normative ideology, in which the non-disabled person is considered "normal" by society. However, our analysis unpacks the social practices of caregivers of individuals with cognitive impairments as a way of calling attention to how systems could better support transitions in vulnerability and the cooperative nature of online activity for vulnerable populations.

FINDINGS

Caregiving is demanding work, and caring for an adult with cognitive impairments presents unique challenges in the context of helping care recipients engage in and maintain

online activity. Before detailing these challenges and the work caregivers perform, we briefly describe our informants' caregiving experiences to contextualize our results. Caregivers in our study provide full-time, unpaid care for an adult with a cognitive impairment. The interaction among focus group participants was both empathetic and supportive. Participants described periods of extreme stress and loneliness from the work of caregiving, to which other participants offered encouragement and advice. Participants had a wide range of experience using the Internet. Caregivers with less experience going online took notes as others shared strategies related to a wide variety of caregiving concerns (e.g., remote activity monitoring, medication reminders, online safety). While the focus group discussion drew out caregiving work related to online activity, this work was in the context of many other responsibilities caregivers assumed – managing medications; scheduling and attending doctor visits; overseeing finances; cooking; cleaning; assisting with bathing and toileting; and providing social and emotional support. Additionally, many caregivers work outside the home and have other family responsibilities.

"Some days, I'm just sitting there, and I just sit and cry, because…this is somebody that used to take care of me, and now the roles are reversed, and [I] need some help, dammit, and I'm not getting it… I work two jobs and take care of my father, along with trying to have a social life, and I have two children of my own. So I'm overwhelmed." (Nancy)

Although care recipients all had a form of cognitive impairment, caregivers detailed care recipients' idiosyncratic memory, speech, language, and/or motor abilities; how this affected their work as a caregiver; and the changes they observed over their care recipients' lives. Caregivers characterized the years between a diagnosis, accident, or other life-changing event, as constant fluctuation – ups and downs – in terms of their care recipient's state.

"Well, for him, it's kind of like a roller coaster. It's up and down… It's a vicious cycle, and it's not just going down and stay down, he'll go down then come back up a little… It's more like a zig-zag than one direction." (Edward)

"Yeah. It's not even day-to-day, it's like hour-to-hour. You can't even say 'This is a good day; this is a bad day.' You've got to just break it down into smaller increments than that." (Constance)

This constant fluctuation requires caregivers to be vigilant of their care recipient's current cognitive, emotional, and physical state, and to constantly assess and monitor their needs. Caregivers learn to recognize when a care recipient is more lucid and cognizant as well as periods of disorientation and declines in memory or communication, and then adjust their own behavior and support accordingly.

"It was really, really hard to gauge just how much I would have to do or not do for him. Because at first you think, 'I have to do all this work for him,' and…he might not have all

his faculties, and then the next day he might be…up earlier than I am, doing whatever he wants to do…" (John)

The ongoing changes in a care recipient's cognitive state have significant implications for the ways in which care recipients use technology to go online as well as the work caregivers perform to help care recipients interact online.

"When he's doing really badly, like-- if I walk in on him and he doesn't know what's going on at all… For that moment, I try and…figure out what's going on to see how badly his memory is suffering, or what exactly he's trying to do. And in some cases, he's on the computer when he's doing this. So, he'll be in the middle of writing a Facebook post or something, and he'll just completely blank." (John)

Many caregivers described similar situations, which led them to establish practices around how to facilitate, take part in, and at times prevent online activity for their care recipients. Caregivers described these practices based on their personal experiences, as current educational resources (e.g. caregiver's handbook [37]) do not provide guidance on online activity. The following sections describe these practices as four forms of work, which caregivers perform in the context of their care recipient's online activity. These four forms of work – *guiding*, *stimulating*, *connecting*, and *protecting* – emerged through our qualitative analysis and are the core contribution of this study.

Guiding

A primary way in which caregivers engage in cooperative online activity with their care recipients is through what we call *guiding*. The behavior of guiding includes providing functional assistance, teaching, and mentoring care recipients in online activity.

Caregivers play an important role in supporting functional use of technology due to care recipients' physical impairments that co-occur with their cognitive condition, such as limited motor ability resulting from a stroke or advanced Alzheimer's disease. Functional support often involves working side-by-side with a care recipient to search online for specific information (e.g. typing words in search engines), set up or configure the technology, or operate the computer mouse. Caregivers provide varying levels of guidance depending on their care recipient's needs and abilities – sometimes getting them started with a task and other times completing the entire task for them. Guiding behavior also varies depending on the care recipient's prior technology experience and comfort level. Our sample included older adult care recipients, some of whom had more limited experience going online prior to their impairment. For example, one older care recipient went online minimally before his stroke, but now, being largely confined to his home, works with his caregiver to go online more regularly.

Guiding also involves caregivers' efforts to teach (or re-teach) their care recipient how to use technology. That is, even care recipients who were previously tech-savvy may need to re-learn how to use a specific technology. Teaching

care recipients to use technology is a cooperative process in which caregivers use the technology in conjunction with care recipients. Caregivers may work alongside care recipients to demonstrate and teach them how to perform a particular action with a device or application.

"I'm trying to teach my husband to text… Because it--it matters with our kids" (Jane)

Guiding behavior is about teaching a care recipient how to use technology as well as conveying the benefits of this way of interacting, such as Jane's goal of teaching her husband to text message as a way of communicating with their children. In this respect, caregivers encourage and motivate the use of new technology as part of guiding them through initial use, and teaching care recipients in this way can be rewarding.

"I feel good about [helping her online]. I can take care of her. She's been taking care of me forever. That's the least that I can do. Just to make sure you're comfortable and all right. It's like a badge of honor for me to do it." (Derek)

However, teaching care recipients to use technology also may introduce an additional subjective burden for caregivers. That is, caregivers must understand the technology (including its terminology and benefits), keep up with technology updates, and simplify unfamiliar concepts and procedures in ways that their care recipients can understand.

"One example, the first time I said spam to my mom, she goes, 'Spam? What do you mean spam? Like the food, spam?' I go, 'No.' So, she's trying to think. 'Junk mail mom.' Trying to show her over the years, you know, the claims, 'Get a free Walmart card. Gift Card.' Stuff like that. It's like, 'Mom, don't click on those.'" (Joan)

Caregivers guide care recipients through successful technology use by devising strategies to facilitate their care recipient's independent use of technology and avoid routine challenges. Caregivers shared strategies for helping care recipients independently look up login credentials (e.g., usernames/passwords written on whiteboards or notepads), printing information to serve as a reference or for readability, and creating shortcuts on the desktop or tablet for the most used applications.

"I leave my dad logged in because he's not going to remember the password, and even though you got that paper right there [with all of the passwords], he's not going to remember what all them letters and numbers are for. But I leave him logged in so that during the day. I'm at work during the day and so he gets on there himself. And I like the fact that he's into social media because I know he's at least socializing… I know he is using his mind, not watching the same program." (Amy)

As Amy notes, guiding behavior involves configuring the physical and digital environment in ways that afford independence for the care recipient and ease of mind for the caregiver. However, the work of guiding a care recipient through successful technology use is affected by fluctuations in a care recipient's cognitive state and abilities. Caregivers constantly assess and determine the level of support care recipients need when implementing these strategies, and caregivers may need to adjust their strategies on a daily or even hourly basis. The level of support is continually negotiated between caregivers and care recipients. While caregivers work hard to implement strategies that afford independent technology use by care recipients, care recipients may push back and want the caregiver to do more of the work of using technology. At times, providing this guidance can be more difficult for caregivers than having the caregiver "take over" and perform the actions themselves. Furthermore, caregivers monitor their care recipient's aggravation and stress levels when using technology and decide to step in and provide greater assistance in times of high anxiety. Hence, technology use for care recipients is rarely a fully independent activity; caregivers are constantly monitoring, stepping in, and providing guidance when needed. This change in independence has a significant impact on the work of caregivers and the role they now assume.

"Back then, they were really independent, and speaking, probably for everybody here when I say, before anything like this, everybody had their own judgment. They weren't impaired. They could make their own decisions, and they didn't need somebody looking over their shoulder to make sure what they were doing was in their best interest." (John)

As John describes, caregivers now take on a new role and new work associated with ensuring successful online activity for their care recipients, including deciding whether a care recipient's online activity is "in their best interest", which we describe further in the sections below. Prior to experiencing cognitive impairment, care recipients were independent, and actively used e-mail, social media, electronic banking, and other online services. In fact, a few caregivers described that their care recipient was previously the one teaching others how to use new technologies and perform online activities. The onset of cognitive impairment created a role reversal in which caregivers shifted from the ones learning from their care recipients to now filling the role of a guide, teacher, and mentor. In cases in which care recipients were previously quite independent online, it can be frustrating or upsetting for caregivers to shift into this new role.

While supporting online activity for care recipients introduces new work and concerns for caregivers, this interaction has several positive consequences, such as stimulating and connecting care recipients.

Stimulating
The second form of work caregivers perform in the context of care recipients' online activity is what we call *stimulating*. Caregivers and care recipients cooperatively use technology and go online to stimulate care recipients through informational, social, and emotional means. Some caregivers help their care recipients play "brain games" online as a form of cognitive exercise. In this case, caregivers described

helping their care recipient access and setup these games and encouraging this type of activity as a form of stimulation. Caregivers also described the cooperative use of Google search, Yahoo News, YouTube, and Facebook as a way of stimulating their care recipient.

"Sometimes I go on Yahoo News, and we'll sit there and go through the new celebrity gossip. That keeps his mind kind of flowing; that's just something he likes to do." (Beth)

Caregivers stressed the importance of finding ways to keep care recipients' minds active and stimulated, and many described viewing online photos of family members, friends, and even famous people as a way of achieving this.

"I also use my e-mail, because my dad is from Memphis. All his family's out there, but my cousins and my aunts, they're able to scan pictures and send them to my e-mail, and I'm able to pull them up there. But they're old pictures… Sometimes…he'll tell a story about that picture, but then sometimes, he'll look at it and be like, 'Who are these? Where did these come from?' So, you know, some days are good, and some days are bad." (Sidney)

As Sidney mentions, jointly viewing family photos is an effective way of stimulating care recipients. Similarly, Beth enthusiastically described the value of social media as a form of social entertainment and stimulation for her care recipient.

"I think Facebook and social media might be a tool to keep dementia patients and people with memory loss motivated… It's more of a social entertainment, but it might actually be helpful to people… When they get likes—any likes, and they're happy… They're like, '100 likes, that's a lot.' They feel appreciated. So it might be a good tool for them, to keep them interactive, to keep the brain going." (Beth)

The stimulation that caregivers aim to provide by using social media with care recipients is related to the work of *connecting*, which we describe below. Jointly viewing online content, such as family photos or familiar movies, also serves as a positive bonding experience between caregivers and care recipients, providing further stimulation.

"I remember we used to watch Blazing Saddles together a couple of times, and [laughing] it's now one of my favorite movies but, kind of on a whim one day…I turned that video on [the computer]… Towards the end…noises come out because it's just a bean scene-- and, then the guy says something like, 'We need more beans,' and the guy's like, 'I think you've had enough,' and all of a sudden, I hear this noise from behind me, and I'm like, 'Dad, I haven't heard you laugh in like two years.'… He's laughing so hard he's crying. [It was] the happiest moment of my year… Such a great moment to be able to experience that with him… " (Constance)

Stimulating a care recipient by helping them engage online introduces new forms of work for caregivers, such as searching for content, identifying meaningful photos or videos, and bringing it into discussion. This interaction,

however, also helps alleviate some of the burden on caregivers by providing a mutual source of enjoyment and occupying care recipients. At times, viewing online content can provides a positive outlet for the care recipient without requiring caregivers to be the sole source of entertainment.

"I don't know what I would do without the Internet in this situation. As far as caregiving goes and keeping Adam occupied with social media and current events and things, it's a godsend, seriously. Because he just feels…so abreast about everything that's going on in the world. He can watch newsreels, he can watch friends' videos… If I didn't have that, we-- I think he would go absolutely bonkers." (Jared)

"If we didn't have the Internet in this day and age, our lives as a caregiver would be [taken] up much more... Because of things like the Internet…we have a bit more freedom as a caregiver...because they don't have to be completely occupied by us… They can entertain themselves. They can remind themselves of things. They can be more independent, while having us as more of backline support." (John)

In this way, caregivers depend on the Internet as a way of keeping care recipients busy – as important stimulation, entertainment, and a way of knowing what is going on in the world – and through their online activity caregivers achieve some much needed freedom and separation from their care recipients. Yet, as John mentions, caregivers are still the "backline support" when their care recipient needs help interacting online, echoing the way in which care recipients fade in and out of online independence.

Connecting
Many care recipients interact through e-mail, video chat, and social media websites, and caregivers play a critical role in supporting care recipients' online social activity through the work of *connecting*. This work involves setting up video calls, reading and posting on behalf of care recipients, and mediating their care recipient's online interaction. Video chat, for example, can be a useful way of helping care recipients stay socially connected but presents challenges in remembering who various family members are and understanding the virtual experience (i.e., understanding that video chat enables communication between two parties who are not physically co-located).

"It helps because they actually see the person they're talking to, but just trying to get them to remember is kind of hard." (Trish)

"We would do Skype conversations with people that were on the west coast… We would find her wandering around the house, and we'd say, 'What are you doing?' and she'd say, 'Well, I'm looking for Michael.' And we'd say, 'Well, Michael's not here,' and she says, 'Well he is here, because I was talking with him earlier.'" (Bobby)

Caregivers described that some care recipients do better with text-based communication (e.g., e-mails, comments on social media), which they read with a caregiver and revisit

periodically. Caregivers view interacting via social media as a positive experience for their care recipients and help care recipients stay connected through various websites.

"He wanted his own Facebook page. So, we set him up with a Facebook page… and so I have it set up so he doesn't have to keep logging in. He's constantly logged in… He just goes to Facebook…so he can keep in contact… It keeps him occupied… but then again, there's some days that he'll just stare blankly at the screen… 'Who's that?' You know, he doesn't remember people. I think it's good that he is on Facebook, that these images are coming up daily, so maybe it will help him to remember. It will keep his memory hanging by a thread…" (Amy)

Caregivers described Facebook as a particularly important site for care recipients to receive social support and highlighted the importance of social feedback via online mechanisms (e.g., Facebook Likes, comments).

"We use Facebook. He has a thousand people that want to wish him well..." (John)

"I'll post something and I'll get a couple likes. Whenever Adam posts something, it's like, you know, 200 likes, and everybody's commenting… Whenever we're out, I'm like, 'You post this on your page, because I don't get any, as many likes as you get.'" [all laughing] (Jared)

Many caregivers described posting on behalf of their care recipients as a way of helping them stay connected and informing others of their care recipient's condition or needs. Caregivers mentioned posting weekly updates on Facebook, Instagram, Blogger.com, and Caregiver.com.

"Usually it's at the end of the week, how his week's gone, if he was able to put his socks on by himself, with the one hand… That's an accomplishment for him…" (Amy)

"If I happen to bribe him and he goes outside, I put it on Facebook, but if we don't, then I usually use phone calls… I communicate a lot through Facebook without him. But his pictures are included in it… 'Daddy went outside today, or…Daddy was able to dress himself.'" (Nancy)

These online updates provide an important source of encouragement for care recipients, and caregivers relay this social information and support back to care recipients by reading or showing them posts.

"He wants to know the response… He wants to hear what people say. It's entertaining to him…" (Beth)

"People can write comments. That was a really good inspiration for Adam because, you know, I would read to him what I had written and then all the… well wishes that all of his friends were giving back…" (Jared)

This discussion brought up issues of whether and how caregivers involve care recipients in decisions to share information about care recipients online. Some caregivers were mindful about informing care recipients of posting online, although the care recipient may not remember or understand. Others post without their care recipient's consent. For example, Beth's father does not want to be involved with Facebook, but she still posts about him.

"I post[ed] when he was diagnosed with the dementia. When he's having bad days, I post it. I don't tell him... I don't know how he might feel about that that." (Beth)

The ways in which caregivers post online introduces tensions around surrogacy, privacy, and information sharing for vulnerable populations, and we elaborate these concerns in the discussion section. However, posting content about caregiving also provides caregivers with social support for themselves and allows them to voice their own challenges.

"I actually used it for my own cause…to share my story too… Like a tender moment, 'Hey, here we are celebrating his 85th birthday,' but at the same time, 'Hey, here's a man dying from Alzheimer's…. You guys need to know what it's like.' I want to share a part of my story… 'I just spent the last two hours shopping for diapers and Ensure,'… Kind of promoting my cause a little bit too." (Constance).

Caregivers may post about their care recipient to their own profile or even login to their care recipient's account to make posts on their care recipient's behalf. In this way, caregivers and care recipients are establishing a shared online presence that centers on the caregiving experience, which may support both the caregiver and care recipient's online social life. Further, caregivers help mediate and support their care recipients in staying socially connected online. This may include tagging a care recipient in online posts to make them feel included or copying multiple people on emails to make sure a care recipient receives social support.

"[I] tag him in things that he's not tagged in so he feels…part of the group… It's good to feel connected and to be a part of it, and...If he doesn't already have it on his wall, I'll send it his way. It's really important that he feels connected in our little world." (John)

"Our extended family got in the habit of making sure that all of us were included on emails as well... There was this weird place where she had an account, she was maybe accessing it sometimes or forgetting if something had been sent to her and she was kind of reaching out for support..." (Katherine)

Caregivers also help others in their social network understand their care recipient's online behavior, which may go against social norms in information sharing. For example, Amy's father often re-posts photos several times a week, but she explained to her friends online that she "can't stop him" and does not want to stop him "if he's recognizing." Caregivers view online interaction as a way of helping their care recipient stay socially connected, receive valuable social support, and participate more fully in society. Yet, this introduces new work around ensuring safe, meaningful, and inclusive online social experiences.

Protecting

Going online is a useful way of stimulating care recipients and helping them stay connected with others. However, this online activity introduces new challenges for caregivers around *protecting* care recipients by helping them avoid phishing attempts, blocking harmful websites or friend requests, and mediating information disclosure.

Prior work notes that caregivers co-manage and help care recipients take care of finances [32], and we found that caregivers often setup online banking for their care recipients and regularly check the status of care recipients' online bank accounts. Further, caregivers are vigilant of online financial threats to which their care recipients may be vulnerable, such as phishing attempts via email and overspending on unwanted or repeat items online. As Amanda explained, her mother received online offers over email that led to unnecessary purchases.

"… as far as e-mail, I think we all were just too uncertain of what could happen, um, making purchases. I think there may have been a couple times where purchases were made, and we quickly realized that the credit cards needed to be taken away, and this needs to stop, and it all kind of changed at that point." (Amanda)

The challenge is deciding when and under what circumstances a care recipient should not have access to credit card information required for online purchases. Sometimes it is not until an adverse event (e.g., identity theft, extreme over spending) that a caregiver is aware of the need to protect care recipients online. However, caregivers perceived that their care recipients were particularly susceptible to phishing attempts associated with their diagnosis or medical condition, noting care recipients' desperation to find a cure along with not knowing how to protect themselves online.

"When you present someone who has a medical condition, a severe medical condition, with information saying you have a drug like a cancer drug or whatever that's going to cure you, they get excited and want to, you know, purchase it… I've had to control and really train him…not to give out his credit card number online." (Edward)

As part of protecting care recipients online, caregivers learn to use spam filters, set restrictive privacy settings, and block inappropriate content (e.g., adult websites). Although caregivers can block specifics websites, they also work to filter online information that may be particularly distressing to care recipients, such as violent news stories or notices about the passing of loved ones. In fact, many caregivers described instances in which care recipients came across distressing news stories online that greatly affected their emotional and physical state (e.g., shaking from distress). And, some care recipients with memory loss would experience the same distressing content over and over, not remembering that they had already viewed this information.

Filtering online information is a complex task that involves determining which information may harm the care recipient and then blocking or deleting it, and caregivers often lack the controls or options to achieve this.

"Uh, it's rough to do. I have-- there's no filtering device to do that on, because we get the RSS feeds from different websites... There's nothing in place like, to monitor key words... Nothing that sophisticated." (Edward)

Social media provides benefits of stimulating and connecting care recipients but at the same time can be a source of negative information. Caregivers may even avoid sharing or posting such stories on social media to reduce the chance of their care recipients seeing the content.

"We do not post about disasters. Because he gets very agitated... The train accident yesterday. The day before yesterday—the Amtrak. He saw it on the news, and when I came home from work, he was on Facebook reading the Yahoo stories about it." (Amy)

However, caregivers noted a tradeoff inherent in restricting content: protecting care recipients from distressing information may prevent discussion of important topics or reminiscence that can be valuable for stimulation.

"I welcome those things because they open up a conversation. It gets you talking through it… There's a lot of bad news out there, but if it triggers a conversation, then something that can be educational, and it keeps his mind active because he'll want to know how the story turned out. Pique his interest." (Dan)

"Yeah, there is some stuff [in family emails] that's a little too invasive, that I found hard to read and didn't really want to let my mom read. But then we decided as a family that she should…" (Mitch)

Caregivers, sometimes with family member involvement, make decisions about what to share with care recipients and how to best protect them online based on the risks they perceive. Yet, this is also negotiated between caregivers and care recipients over time depending on how a care recipient reacts to certain information and their level of independence in discerning potential online threats. Caregivers also work with care recipients to protect them from negative online experiences by "vetting" their care recipient's friend requests and deciding to block certain online contacts.

"Yeah, either delete or defriend… We figure out ways to cleanse his list of people that are doing inappropriate things… It could be anything. It could be violence, it could be pornographic..." (Edward)

"I don't want to block it from him because it's technically his friends, his friend he had before, and when I put in the security measures…I made it so that anybody new, you know, had to go through the filter, but anybody who was there before, whatever they post is there, so...it's kind of just…I have to deal with it." (John)

As John explains, there is a tension between removing friends his care recipient had before his accident versus allowing him to keep these friendships and dealing with potentially negative situations. Hence, caregivers use both proactive and reactive strategies for protecting their care recipients online, weighing the tradeoffs between potential harm and the benefits of staying socially connected online.

Caregivers also protect care recipients by correcting the spread of misinformation online about their care recipient and guarding against social contacts sharing overly personal information, which can cause family tensions [18].

"When she was getting real bad… She broke her leg at one point, she had some seizures, um, bed wetting issues. It was real personal stuff. He was writing like, you know, hourly details, like how her care was and everything. Just like a little too much." (Mitch)

Similarly, caregivers help their care recipients understand which types of information they should not share online with respect to online privacy risks. This includes posting location-based information (e.g., checking in at the bank or hospital) and other personal details.

"Yeah on Twitter…sometimes he does too many personal details about what we're doing… Like, we're going to the bank, or this or that. He puts some sensitive information that I got to kind of delete. So, you know, we don't want all that exposed… So it's kind of rough." (Edward)

As part of protecting, caregivers must remain vigilant of their care recipient's online activity, monitoring information sharing, and at times moderate, block, filter, or delete certain information. Nevertheless, caregivers perform these actions with the aim of creating a safe and inclusive online environment for their care recipient.

DISCUSSION
While prior research characterizes the "offline" work of caregivers, our analysis identifies caregiving work engendered by everyday online technologies, which has yet to be accounted for by existing nursing, health care, or HCI/CSCW literatures. Although online activity introduces additional work and occasional stress for caregivers, they largely view online activity as a way of empowering their care recipients. Further, transitions in a care recipient's abilities affect online activity and the role caregivers play, through which online activity is cooperatively negotiated from moment-to-moment and over time between the caregiver and care recipient. We describe these themes below and suggest several considerations for design.

Narrative of Empowerment through Online Activity
Caregiving work is often viewed as a burden and characterized by the physical, financial, social, and emotional stress of providing ongoing care. Throughout our analysis we learned that caregivers went to great lengths to enable and support online activity for their care recipients, sometimes at the cost of taking time to learn new

technologies, reconfigure settings and accounts for care recipients, instruct care recipients on how to use these tools on a regular basis, and remain vigilant against online threats.

Despite the risks and added work introduced by being online, caregivers view online activity as a positive experience and way of empowering care recipients. Caregivers shared many stories that espoused the benefits of staying up-to-date, stimulated, and connected online, particularly for individuals who are largely confined to their homes. Caregivers configure both physical and digital spaces to promote a sense of independence for their care recipient, even if they are waiting and watching as "backline support". Caregivers act strategically online to ensure their care recipient is included in online interactions and help relay and contextualize these interactions. A care recipient's online profile or blog maintained by a caregiver is a place for family members and friends to provide social support, and caregivers play a role in sharing and interpreting this online support. Receiving hundreds of "Likes" on a Facebook photo of a care recipient accomplishing daily activities such as getting dressed or going outside provides a source of encouragement. These narratives focus on promoting independence and empowering care recipients to live a full life by being active online, which in turn is rewarding for caregivers.

While staying active online is intended to empower care recipients, this also introduces new tensions and challenges for caregivers. Caregivers noted the risks of interacting online and configured accounts to block certain users, filter information, and approve friend requests. Caregivers struggle to balance the conflicting goals of protecting versus empowering: *"I don't like the idea that I'm limiting him… but, unfortunately, I can't let him do that, for his own good," (John)*. Many reflected on their own internal conflicts over making decisions aimed at protecting care recipients, as they realize this often leads to disempowerment.

Surrogacy and Transitions in Online Activity
For our population of study, caregivers described significant challenges around assessing, understanding, and supporting the changing abilities of their care recipients – both daily (or even hourly) and over the long term. This constant fluctuation requires caregivers to be vigilant of their care recipient's needs when interacting online and to make decisions about when and how to intervene. Notions of surrogacy in caregiving (e.g., a health care proxy) provide a legal framework for understanding how caregivers make decisions on behalf of care recipients [10,21,38]. This framing, however, focuses on end-of-life decisions and neglects the nuance in how caregivers and care recipients cooperatively negotiate decisions through periods of vulnerability, which may last years or decades.

Our sample includes caregivers who provide care for adults with varying cognitive abilities and at varying stages of life, including one who passed away just before the start of this study. This diversity allows visibility into the transitions that are inherent in caregiving work. For example, caregivers

may transition from teaching a care recipient to interact on a social website (e.g., functionally as well as what not to post) to stricter blocking and removal of content when they perceive the care recipient as less able to independently make decisions online. Yet, caregivers constantly assess what constitutes "safe" online behavior in the context of the threats they perceive, which may be financial (e.g., phishing, identity theft) or social/emotional (e.g., hurtful misinformation, distressing news stories).

The cooperative use of accounts between caregivers and care recipients provides additional insights into shifts in online independence and surrogacy. Similar to the account sharing practices within families [15], caregivers and care recipients share accounts explicitly (e.g., financial, medical) and implicitly (e.g., posting photos on behalf of a care recipient). Caregivers and care recipients may assume a shared online presence, which emerges through posting information about the joint experience of caregiving. Tensions may arise around deciding what to share online and how to involve care recipients [18]. Caregivers varied in whether and how they sought approval for performing online actions on behalf of their care recipient, and posting updates and photos of a care recipient without seeking their consent highlights the limited voice some care recipients have in their online presence. Further, privacy research suggests that when an individual is responsible for another person's information disclosure, errors in judgment and even deception may occur [36]. Our analysis highlights many complexities within caregiving work that are introduced by online activity, requiring caregivers and care recipients to continually negotiate online information disclosure [2,28] in the context of vulnerability, risk, and the benefits of interacting online.

Considerations for Design
Our analysis suggests several considerations for designing online systems that better support the dynamics of the caregiver-care recipient relationship as well as the work caregivers perform to empower their care recipients online.

Beyond Individualized Accounts
Our analysis calls attention to yet another context in which the model of an individualized account competes with people's goals and intentions. The notion of "family accounts" was suggested as a way of supporting home computer use among family members [15]. Recent work on how parents manage their children's identities online also suggests shared online accounts to allow cooperative content management and adjustment of privacy settings [2]. Similar features may work well for caregivers and care recipients but should consider how to truly make this a cooperative experience that empowers care recipients, who were at one time autonomous and now need fluctuating levels and types of support. Furthermore, such joint accounts may present ethical and legal challenges [3].

Support Transitions in Vulnerability
Prior work focuses on designing to protect children online before they come of age [2], support the end of life (e.g.,

hospice care) [18], and manage online information post-mortem [4]. Extending this literature, our data suggest the importance of designing for transitions in vulnerability, in which systems can accommodate the convergence and divergence of online identities (or even accounts) and moments of surrogacy versus independence over the course of one's life. The caregivers we study weave in and out of the online lives of their care recipients, highlighting that vulnerability is not a discrete state or permanent way of being. Rather, vulnerability is socially constructed through perceived risk, abilities, and independence and fluctuates moment-to-moment. Designers should consider periods of life in which vulnerability might be transitory (e.g., gradual recovery after a stroke) or progressive (e.g., from early to late stage dementia) that allows for gradations of support as needed. Opportunities for caregivers to discuss and learn about how to facilitate online activity may also help ease the burden of supporting changes in vulnerability.

Awareness of Online Activity and Perceived Risks
While caregivers strive to empower care recipients by helping them stay active online, they weigh this against their goal of protecting care recipients from various risks inherent in online interaction. The challenge in this balance is staying aware of a care recipient's online activity, particularly when not co-located with the care recipient, and being vigilant of potential risks associated with this activity. This adds to the work of already overburdened caregivers who also monitor medication, food intake, and social and emotional needs. Mechanisms that allow caregivers to cue in on risk-related online situations could help alleviate this burden. For example, a system could detect disclosure of sensitive information (e.g., passwords, credit cards) and hold the transaction for review by or feedback from the primary caregiver. Alternatively, future systems could incorporate responsive interfaces based on how a care recipient is interacting (e.g., linguistic markers [24]).

CONCLUSION
Caregiving is demanding and stressful work. Supporting a care recipient's online activity introduces new responsibilities and concerns but also provides benefits of stimulation and social connectivity. As a first study on this topic, we focus on care recipients with a broad range of cognitive impairments, and future work should examine other groups of care recipients (e.g., young adults with traumatic brain injury) and caregivers (e.g., older non-Internet users caring for a partner). Similarly, our analysis focuses on informal caregivers who are related to their care recipients, and it is likely that the work of supporting online activity and the dynamics of the caregiver-care recipient relationship will be different for paid, non-familial caregivers. Nonetheless, caregivers are grappling with how to support online interaction in ways that empower care recipients while minimizing risk, underscoring the importance of understanding and designing for the experience of caregiving throughout the lifespan.

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