

Technology Opportunities to Support Unpaid Caregivers

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ABSTRACT

Unpaid caregivers face significant mental health and emotional challenges as they tend to the health of their loved ones. Unaddressed, these issues can have drastic impacts on the caregivers themselves and on the care recipients. To identify technology design opportunities to support caregivers' mental health, we reviewed six in depth interviews with unpaid caregivers to learn about the specific difficulties they face and how they may currently use technology to address them. Based on themes that came up in the interviews, two focus groups of information workers, who were also unpaid caregivers, were conducted to discuss problems related to caregiving responsibilities and what role technology might play in alleviating them. We found that unpaid caregivers sought technology support for knowledge sharing, while often struggling to manage three distinct areas of their lives: emotional states, social networks, and logistical challenges. Based on these four areas of need, we propose concrete solutions using feasible technology to assist caregivers in their daily lives.

KEYWORDS

caregiver technology; caregiver mental health; assistive technology; unpaid caregiving; caregiving in aging populations

INTRODUCTION

According to the 2020 survey conducted by the National Alliance for Caregiving (NAC and AARP, 2020), an estimated one in six adults in the United States provide unpaid caregiving services (with an average of 25.8 hours a week) to their loved ones aged 50 or older, most often a parent or parent-in-law (57% of caregivers). Care recipients are most often women (63%) and over the age of 75 (53%); they often live near their caregiver (76% within 20 minutes of caregiver) and face long-term physical conditions (66%). The so-called "no choice caregivers" who provide assistance often face tough physical, emotional, financial, and logistical challenges of coordinating care for comorbidities and handling multiple care tasks (e.g., medical, advocacy). Unpaid caregivers pay on average \$7,242 for out-of-pocket expenses (e.g., housing, medical) due to caregiving. These burdens that unpaid caregivers carry also have a significant impact on their own health and wellbeing as they will continue to age themselves (average 50.1 years old): one in five report inability to take care of their own health and worsening of their own health and one in five report high physical strain. Unsurprisingly, caregivers in the United States face significantly higher rates of emotional distress and mental health issues, with nearly 40% reporting high emotional stress (NAC and AARP, 2020) and a prevalence of over 40% for depression and anxiety for caregivers of patients with cancer (Geng et al., 2018). The health and wellbeing of caregivers also directly impacts that of the care recipients (Lwi et al., 2017). Therefore, supporting the mental health and emotional wellbeing of unpaid caregivers is a top priority.

In the same report, more than 60% of unpaid caregivers are employed full time and often need support from their workplace (e.g., paid or unpaid leave, employee assistance programs, flexible work hours) to maintain caregiving as well as their own lives. More than half of the unpaid caregivers also use technology regularly to help with caregiving, and many technology-based interventions for caregivers have been proposed and discussed (Lindeman, 2020; Brown, 2019). In fact, the NAC and AARP report indicates that caregivers are more likely to use technology to aid their caregiving tasks for older care recipients (age 85 or older) and when dealing with particularly challenging situations such as feeling alone in their responsibilities. At the same time, research indicates that older age can correlate with lower technology literacy and usability (Wang et al., 2019). The gap is described as bidirectional: on one hand, aging populations may have less familiarity with how technology functions (i.e., lower tech literacy), but on the other hand technology often limits usability for older users with lower mobility or vision (Wang et al., 2019). In order to capitalize on the opportunity technology has to offer, both gaps can be bridged through thoughtful technology design that engages both caregivers and care recipients for a true win-win.

To understand these technology design opportunities for supporting caregiver mental health and emotional wellbeing, along with higher quality caregiving outcomes, our research targets full-time employees who are

navigating care for a loved one. As a first step, we specifically target those that work in the domain of information technology (IT) to ideate ways that technology can be integrated into their caregiving experiences, including creating a healthier relationship with caregiving and making incremental improvements to alleviate stressors caregivers might face daily. Caregivers in the IT sector are more likely to be familiar with technology, and such familiarity may act as a bridge for aging populations who may not be as familiar with new technology options and integrations.

In this workshop, we hope to present our findings from two rounds of user studies with unpaid caregivers: six interviews of technology users and two focus group studies with IT workers. Although we recognize that these participants do not necessarily reflect the broader caregiving community outlined above, we hope to use this data to contribute design recommendations for health-based information technology, additional understanding of caregiver wellness, and new strategies for alleviating negative mental health outcomes for caregivers. Specifically, we will review opportunities for technology to provide a platform for knowledge sharing, help manage emotions, weave a complex social life, and assist with organizational needs. We hope to discuss how supporting caregiver productivity and mental health can have a significant impact on aging individuals who may rely on these unpaid caregivers in their lives.

METHODOLOGY

The first stage of our research involved analyzing already completed interviews of six unpaid caregivers from the broader population (i.e., not necessarily IT workers) to get a sense of the difficulties they face in their daily lives and how they currently and might use technology to assist them. From these interviews, we identified various topic areas that we wanted to explore further in the second user study. Our second stage revolved around two focus group sessions with 18 IT workers employed at a large technology company who were also primary caregivers of aging family members. These sessions were guided by the following questions:

- What advice would you give to your younger self?
- What are existing mental health strategies that you currently use?
- How do you balance productivity and wellbeing?
- How do you integrate or compartmentalize your life and the life of your care recipient?
- How do you plan for wellbeing or when do you need in-the-moment wellbeing support?

For each question, participants were asked to independently write their answers into virtual sticky notes for 5 minutes and react to other responses using thumbs-up or heart stickers. Then, the group discussed their responses for an additional 5-10 minutes. Both studies were conducted virtually. The discussions during the focus group sessions were facilitated with FigJam, an online brainstorming tool.

RESULTS AND DISCUSSION

In this workshop, we plan to discuss four key findings and their related design implications based on our focus groups. Here we provide a high-level description of our results, which we hope to expand upon in more detail if accepted to the workshop.

Caregiver Knowledge Sharing

Advice that caregivers would give their younger selves revolved around tackling problems early in the process and protecting their personal mental health. Specifically, participants resonated with the following:

- *Discuss tough topics early*: participants encouraged taking on sensitive topics such as understanding how care is going to be paid for, writing wills, do-not-resuscitate orders, and power of attorney.
- *Personal care*: at times, participants reflected that they wish they made more time for themselves and tried not to take harsh comments personally.
- *Share wisdom and cherish moments*: participants would cherish moments with their loved ones more thoughtfully and would want to be able to share and receive reminders of wisdom as they move through the caregiving journey.

Based on these findings, we recommend caregiver support technology should remind users to have difficult discussions early in the process and provide accessible resources to help guide difficult conversations. These resources could also be offered through online social interactions with other caregivers who are facing or have faced similar situations. While an online social network could provide the wisdom of the crowd, a small group or one-on-one peer-mentoring could provide personalized attention and sharing of resources. Technology can also provide a clear log of difficult decisions made. Such documentation can help ease tension surrounding difficult times; for instance, a record of wills, hospital bills, and other important documents with individual sharing settings would be useful for keeping everyone in the care team on the same page. However, care needs to be made in

managing permissions among the care team. Technology could allow the primary caregiver to share that decisions have been made without revealing the content unless there is explicit permission.

We also recommend technology to remind caregivers to take time for personal care. Technology could proactively capture personalized messages for themselves during “good” times that can be viewed during “bad” times, and it could elicit supportive reminders from the care recipients as well as the rest of the care team. Technology support for the caregiver could facilitate the curation of cherished moments and words of wisdom with their loved ones to foster a sense of endearment.

Handling Emotions for Caregivers

A major theme throughout our discussions was how to handle emotions that came up which were difficult to manage or process in the moment. Based on this, we found a few key points:

- *Contextual strategies for emotion management:* some participants discussed meditation, prayer, and gratitude as options they used when they felt overwhelming emotions.
- *Watch for strong emotions:* logistical challenges and difficult interpersonal relationships can lead to a “breaking point” – which seemed to be a good indication for some participants that they needed to focus on some self-care.
- *Shed expectations of perfection:* caregivers spoke of having internal and external expectations that may not be realistic, and letting go of those expectations could help manage their emotions. For instance, participants brought up work performance and home cleanliness as metrics that they felt were slipping.

With this information, we considered the following technical opportunities for caregivers. First, a way to track and annotate emotions would allow caregivers to keep a tab on their emotional state and identify particularly triggering discussions or activities, which may help them navigate challenging emotions in a productive way. Additionally, the possibility to celebrate “wins” during the day can help motivate caregivers who may feel that they are constantly struggling to finish tasks or complete long checklists; tracking “lows” could also provide more insight into what did not work as well in a particular set of tasks. Sharing caregiver emotions with others in the care team could elicit support and affirmation. However, sharing such sensitive information needs to take into account a level of trust in their relationship. Finally, a suite of tools, such as prompted meditation or breathing exercises, could help manage emotions in the moment, especially if the technology can detect moments of need based on past trends or calendar content.

Social Implications of Caregiving

Maintaining a strong social network and utilizing this network effectively came up multiple times in our focus groups. Participants tended to focus on three distinct aspects of their social lives:

- *Friends and family can be a support network:* participants want to be able to lean on the other people in their lives while they are taking on the new challenge of caregiving. This might look like others stepping in to help or reminding the caregivers to take time for themselves.
- *Ideation of new solutions and accountability:* friends and family can help come up with new ways of doing things, relate about difficult challenges, or even help keep a caregiver accountable when tackling personal goals.
- *Manage complex social webs:* with the extremely complicated nature of caregiving, there is a new challenge of managing social dynamics. Different groups of people in the care network need different information, and sometimes caregivers just want their own space to vent about their experiences.

Given these findings, we believe the following technologies could aid with managing social interaction. Caregivers should have a place to vent about their frustrations, either with other caregivers or with trusted friends or family. In a similar vein, primary caregivers should have communication channels that they can fully control in terms of access and distribution. Finally, caregivers should have a way to share their needs with others in their care network, such as time off or help with specific tasks. One participant described this as “rings” of access control, where caregivers would have complete control over what is shared publicly (e.g. inspiration quote), with the entire care team (e.g. doctor visit schedule), or privately with a select few close relatives (e.g. venting channels). This would also allow certain information to be kept private for need-to-know members of the care team and would help caregivers prioritize reading and responding to specific channels (e.g., if there is only time to read through a single channel, the caregiver can quickly choose based on the channel content).

We recognize that this area of improvement requires significantly more research into privacy, social technology, and the inner dynamics of a care team when converted to a digital platform. There is certainly potential for increased conflict over administrator privileges and other socio-technical challenges.

Time Management and Organization

A major component of what makes caregiving so challenging is the amount of time and scheduling that comes with it. Participants reflected on the following specific challenges:

- *Schedule flexibility*: some caregivers spoke of the need to quickly update their schedules and maintain flexible lives in order to make sure they can incorporate care whenever possible
- *Time for themselves*: it seemed that if self-care was not specifically incorporated into a day, it would not happen. Carving out self care time in advance was essential for some participants.
- *Bundling tasks*: Some caregivers mentioned that they bundle their own needs with caregiving tasks - for instance, taking their vitamins at the same time that they give their family member medications.

Using this feedback, we formulated some solutions for technology assisted time management and scheduling. Most importantly, participants wanted to make sure they didn't miss anything critical when their schedule was shifted, so reminders of critical tasks that rollover would be useful. Self-care prompts can be included in a day overview to remind caregivers to take time for themselves. Technology can also recommend different groupings for tasks so that they can be completed efficiently. In this way, caregivers and care recipients can tackle objectives as a unit, collaborating and reinforcing each other to achieve mutually beneficial goals: reminders to take medication at the same time, suggestions to exercise together, and other healthy behavior prompts become a way that technology can encourage spending time together and truly working as a team.

CONCLUSION

By and large, caregivers have a huge and often overwhelming task at hand: on top of everything else in their lives, they must also take on a new role of caring for someone who may be in a state of physical and emotional dependence. Oftentimes this is not a planned or predictable journey, and it has the possibility of throwing life into chaos for the caregiver. Given the way technology can help organize other aspects of life, we believe there are ample opportunities to address some of the biggest pain points we found for caregivers. Focusing on emotion management, social life management, and scheduling management, there seems to be some significant opportunities for alleviating some of the external forces that make caregiving so difficult. Many of the best ways to support caregivers already exist in a basic form in the technology landscape but are dispersed across many platforms and without some of the key elements that caregivers need. With technology-facilitated support of unpaid caregivers in the areas identified in our study, we hope that caregivers could spend more time on more fulfilling activities and spending quality time with those they love.

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