

# Caring for Caregivers: Designing for Integrality

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## ABSTRACT

Health and wellness have drawn significant attention in the HCI and CSCW communities. Many prior studies have focused on designing technologies that are patient-centric, allowing caregivers to take better care of patients. Less has been done in understanding and minimizing the burden of caregiving in caregivers' own lives. We conducted a qualitative interview study to understand their experiences in caregiving. The findings reveal a great magnitude of challenges in the caregivers' day-to-day lives, ranging from the physical and social, to the personal and emotional. Caregivers have to constantly balance their personal lives with work, family, and their caregiver roles, which can be overwhelmingly stressful. We discuss how caregivers attempt maintaining this balance through two concepts: first, *giving-impact*, and second, *visibility-invisibility*. Our study's findings call for system design that focuses not only on patients but also caregivers, addressing the burdens that often impair their health and wellness.

## Author Keywords

Caregiving; caregiver; health and wellness; integrality; invisibility; healthcare technology.

## ACM Classification Keywords

J.3 Life and Medical Sciences, Health, Medical Information Systems; H.5.2 User Interfaces, User-centered design; H.5.3 Group and Organization Interfaces, Computer Supported Cooperative Work

## INTRODUCTION

With an increasingly aging population and the spread of chronic diseases like diabetes, obesity, and dementia, managing health and wellness has become an urgent topic facing today's society. In particular, the challenges of maintaining health and wellness lie in the extremely long duration and complex nature of the issue. It is well noted that ICT systems can provide great benefits to those trying

to stay well, e.g. mobile phone-based interventions for tracking and managing diabetes [19].

Maintaining health and wellness, especially for patients and older adults, is seldom a solo task; instead, there are many people involved in the caring process. Strauss et.al [30] introduced the concept of *trajectory work* to conceptualize the social organization of managing chronic care, where an illness trajectory refers “*not only to the physiological unfolding of a patient's disease but to the total organization of work done over that course [of illness], plus the impact on those involved with that work and its organization*” [30 p8]. Strauss's work [30] suggests that chronic care is collectively managed by an organization of stakeholders that can range from healthcare professionals who assist patients in clinical settings to caregivers who often provide care to patients in residential environments. Because of its collaborative nature, many previous CSCW studies have explored the caregiving process, and how technologies can be designed to offer improved physical, social, and emotional support for patients, e.g. [3]. Overall, these systems designed to support patients facilitated the coordination of necessary care endeavors and provided convenient means for caregivers to help patients.

In addition to patients, healthcare consumers also include other users, such as caregivers, who are heavily involved with day-to-day patient care activities related to chronic illness management. Caregiving-related activities may also have significant impact on caregivers' lives. Like Strauss states, trajectory work also includes “*the impact on those involved with that work and its organization* [30, p8].” In a sense, the work of caring for others may exert certain effects on those involved in the process. However, the “*impact*” Strauss deems as an essential part of the total organization of care work has seldom been studied in prior CSCW literature. In this article, we focus on the involvement of caregivers in the caregiving process. We aim to understand the impact of caring for patients on caregivers. The goal of this paper is not to examine how caregivers can better devote themselves to patient care, but rather how caregivers can manage their own health and wellness in the process of helping others.

The impact of caregiving has been widely noted in prior medical and nursing literature, with a focus on *caregiver burden* that denotes the overall impact of physical, psychological, social, and financial demands of caregiving

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[9]. Studies found that there is often stress, anxiety, and even high mortality rates among caregivers, especially those for family members [26, 27]. These findings suggest that addressing caregivers' own health and wellness is an unavoidable issue. In the HCI/CSCW field, the lack of attention to caregiver burden in system design may exacerbate this already severe problem, since new chronic care management systems are often designed to facilitate caregivers to do more, and may increase the amount of burden they already have. It is clear that there is an urgent need to not only address disease management for patients, but also the overall well-being of caregivers. This insight calls for an in-depth examination of caregiver behaviors that can inform the design of future consumer health informatics systems that not only support patients' needs, but also caregivers' health and wellness.

In the rest of this paper, we present the findings of our qualitative study on caregivers. Specifically, we describe how caregivers strive to maintain their own health and wellness through four main aspects, which we term *the physical self*, *the emotional self*, *the social self*, and *the reflective self*, respectively. We further discuss these aspects using two lenses of thought: *giving-impact* and *visible-invisible*. We believe this work makes a solid contribution to the field of CSCW by advocating for the often neglected caregiver role. The insights gained in this study can inform the future design of chronic care management systems to attend to patients' needs while alleviating the burden of caregivers.

#### **RELATED WORK**

The impact of caring for caregivers is well -documented in prior medical and nursing research. Studies have suggested that caregiving often demands a variety of efforts from caregivers, ranging from physical and emotional, to financial – all of which can cause extreme stress for family caregivers [26, 27]. In particular, one study examined 392 caregivers and 427 non-caregivers who were living with their spouses and concluded that *“being a caregiver who is experiencing mental or emotional strain is an independent risk factor for mortality among elderly spousal caregivers. Caregivers who report strain associated with caregiving are more likely to die than non-caregiving controls [26].”*

The burden of caregiving is further specified into two categories, objective burdens, and subjective burdens [20]. According to Montgomery et.al. [20], objective burdens include activities associated with the caring process or practical consequences of the physical and behavioral changes in the care receiver, while subjective burdens are the emotional reactions of caregivers. It was found that the negative impact on family members mainly resulted from depression, financial strain, and disruptions in family routine and dynamics [26, 27]. One study found that nearly 80% of caregivers for terminal breast cancer patients had to miss work, an objective burden [12]. Meanwhile, their subjective burdens, such as anxiety and stress level, increased as patients' functional statuses declined [12]. In

the end, it was concluded that *“strategies are needed to help reduce the psychosocial, occupational and economic burden associated with caregiving [12].”*

To that end, the use of technology as a strategy to mitigate the challenges in chronic care management has been a well-established area of study, with a majority of studies focusing on the use of technologies to assist the care of patients. For example, one study presents an innovative monitoring system that can send photos to caregivers via mobile phones. This device is designed to ensure caregivers are aware of patients' activities [7]. Similarly, other studies utilized mobile phones for remote communication among young adults with cognitive disabilities and their parental caregivers [6], in addition to GPS enabled communication tools for caregivers to track and locate Alzheimer patients [18]. As such, technologies are considered lifelines [16] that bring together the ones in need of help with those providing the help.

In addition to advanced communication capabilities, other online systems, such as Personal Health Record (PHR) systems, were also introduced with the hope of providing better information-sharing and coordination of caregiving related tasks [1, 28]. These technologies center on facilitating better care coordination among multiple caregivers. Consolvo et al. use the term *Computer Supported Cooperative Care (CSCC)* to describe the area of coordination systems that can help caregivers allocate and assign tasks [3]. Consolvo stresses that the goal of CSCC applications is to keep people healthy, and that system design has to consider issues of emotion, trust, and privacy.

It is notable that although caregiving has been studied extensively in medical and social science literature, current HCI and CSCW studies focus primarily on patients, and often neglect caregivers as potential users of patient care systems. These systems are often designed to help better execute caregiving tasks for patients. Consequently, these systems may lead to increased burden on caregivers who are the ones actually conducting the tasks. There are only a few studies primarily devoted to decreasing the burden of caregivers, e.g. [17]. In terms of objective burden for instance, mobile and ubiquitous computing is indicated as one promising direction for decreasing the amount of burden for caregivers, since *“everyday objects, from hearing aids and watches to alarm clocks and refrigerator doors, can serve as computing surfaces to help these individuals [21].”* Another study introduced a robotic wheelchair to support wheelchair users and reduce caregivers' workloads [15]. In terms of subjective burden, technologies are used to provide social and emotional support for caregivers. One study introduced a telecommunications system for family member caregivers of dementia patients. The system facilitated caregiver communication among family members, especially those who were far distances away. Caregivers found participation in “online discussion” groups to be very valuable also [5]. Likewise, ComputerLink was found to

increase the amount of psychological support provided by nurses to a group of homebound caregivers looking after Alzheimer's patients. It also enabled caregivers to share experiences, and make new friends through a caregiver support network [8].

Despite the dominant concern on caregiver burden, recent research has turned its attention to positive aspects of caregiving, such as a sense of reward, satisfaction, and companionship [2]. Peacock et.al [25] found that caring for dementia patients was often coupled with several positive experiences, including personal growth, a sense of competence, and closer family relationships. In particular, connecting with others was found to be an effective coping strategy in managing the stress and frustration associated with caregiving [25]. These positive experiences provide opportunities for introducing early supportive interventions that can lead to better health outcomes for both patients and caregivers [2, 11, 13], in addition to influencing caregivers' experiences in their long journey [25].

Overall, the challenges and opportunities identified in prior research raise important question on how technologies can be designed to diminish the negative impacts, and meanwhile enhance the potential positive experiences associated with caregiving. Addressing this issue is critical for caregivers' own health and wellness, as well as for the patients they provide care for. We believe this is an important area for HCI/CSCW communities, since neglecting the needs of caregivers while over-emphasizing patient-centric design may lead to increased caregiver burden. To do so requires researchers to truly understand caregivers' needs, behaviors, and preferences in managing their own lives rather than focusing solely on what they do for the patient.

## **METHODOLOGY**

To understand how caregiving tasks are managed and how technologies can help leverage the challenges of being a caregiver, we conducted a qualitative interview study centered exclusively on understanding caregivers' behaviors.<sup>1</sup>

### **Data Collection**

Study participants were recruited from an outpatient clinic, where patients and their caregivers were approached and asked whether they had caregiving experience or were willing to introduce their current caregivers to us. The participants were recruited from the clinic because it was a convenient location to meet caregivers, since many caregivers accompany patients to their medical visits. It is notable that the clinic is only a location for recruitment, and the actual interviews were conducted at caregivers' homes. We studied 15 individuals, including current caregivers and those who had provided care in the past.

Semi-structured interviews were chosen as the main data collection method. Qualitative interviews provided an opportunity to gather insight into the participants' experiences and perspectives on caregiving. As previously mentioned, interviews were conducted at caregivers' homes: the locale where most caregiving activities take place. The comfort and privacy of these settings helped us to gain a better understanding of the physical caregiving environment, as well as provided access to care-related artifacts such as travel bags, notebooks, and calendars. Occasionally during the interviews, patients and other family members, e.g. spouses or children, joined the conversations and provided their insight. Talking with other family members in the household also confirmed some of the challenges perceived by the caregivers with whom we had spoken.

The study participants covered a broad range of situations: from chronic to extremely needy patient cases; and from current to past caregivers. The diversity of illnesses and types of involvements afforded us a way to understand common themes across a variety of caregiving situations, rather than focusing exclusively on a particular illness or it's associated tasks. In doing so, we uncovered common behavioral patterns across many illnesses that helped to generalize our design insights for a broader audience.

Prior to the start of the interview, participants were given a short questionnaire to gather demographic information (e.g. age, gender, ethnicity), and questions on technology-use and health-management. The interviews lasted approximately 1-2 hours in length, were audio-recorded, and later transcribed for further analysis. The approach yielded a rich set of raconteur-like retellings of the caregiver experience, with individual transcripts averaging 40 pages in length. The semi-structured interviews explored the following three sets of questions:

- *The interviewee's caregiver experience*
- *How caregiving affects the interviewee's own life behaviors*
- *Whether technologies were used in managing both the interviewee's and the patient's health, and if so, how.*

Among the 15 interviewees, 11 were female and 4 male. 9 participants were Caucasian, 3 were Asian, and 3 were Latin American. Participants were aged between 24-76 at the time of the study, with 6 over 60 years of age. 10 of our interviewees were current caregivers, while the remaining 5 were caregivers in the past. Caregivers in our study engaged in caring for individuals with of a variety of health conditions, including severe chronic back pain, glaucoma, diabetes, cancer, stroke, and dementia. With regards to the use of technologies, 13 out 15 participants were using a computer and the Internet at home, and almost everyone claimed that they used technologies on daily basis, either at home, or in work environments.

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<sup>1</sup> Institution Review Board (IRB) approvals were obtained from both the university and the field site prior to the data collection.

### **Data Analysis**

Data analysis for this study was guided by grounded theory [4, 10] that emphasizes the co-evolution of data and theory by conducting data collection and analysis simultaneously. Following the constant comparative method [10], immediately after the first few interviews, initial data analysis sessions were held among the three authors to identify the main issues noted down during each interview. Audio data were transcribed into text as promptly as possible. 5 interview transcripts were randomly selected for the initial round of data analysis. Sample data were analyzed using an open coding method by each researcher to identify salient concepts. The impact of caregiving activities on the caregivers' own life was identified as the main concept from this initial round of analysis. Once this core theme was identified, axial coding was then performed to extract categories of impact in the dataset. The themes produced by each researcher were compared, discussed and revised through a series of discussions until agreements were reached. Results of the sample interviews were used to guide the next stage of coding, during which one author coded the remaining data using the developed coding scheme. This second stage of the analysis generated similar concepts and themes to those identified in the initial coding stage, demonstrating the consistency of the findings. Through these activities, we were able to reveal how caregivers manage their tasks, cope with their emotions, collaborate with others, and deal with the lasting effects of caring in their own lives.

### **FINDINGS**

Our study revealed many caregiver challenges, including a need to maintain and balance caregiving obligations with other parts of their life. For most caregivers, incorporating caregiving into their own lives is by no means an easy task, but caregiving is "an integral part of [their] life [#06]" that they choose to accept.

Caring for a patient, especially the elderly and those with a severe illness, can be highly demanding. Other than the obvious medically-driven tasks, such as attending a patient's doctor appointment and dispersing a patient's medication, being a caregiver also implies many non-medical tasks: from the small chores of cleaning the house, cooking meals, and picking up groceries; to providing financial assistance, emotional comfort, and even IT help. The caregivers we spoke with reported making frequent home/clinic visits, taking phone calls, dealing with various errands, and staying in constant contact with the patient in order to deal with the numerous tasks that are necessary for them. Although most of the participants we studied were healthy, working professionals, the telling of their caregiving experience revealed a sense of burden which, combined with other work and family obligations, resulted in unbearably high workloads and stresses that often were not recognized by their family and friends. Many caregivers experienced frustration and even depression; some even had to consult doctors to maintain their own wellness, thus making the health of caregivers a critical issue to address.

This high demand from all aspects of their lives forces caregivers to constantly *balance* tasks between caring for others and sustaining their own lives. This can have a major impact on the caregiver, resulting in the need for physical, emotional and social support. Meanwhile, the experience of seeing patients struggle with diseases can lead to self-reflection and new life lessons.

In what follows, we elaborate on four aspects of wellness that caregivers strive to maintain in their day-to-day lives. These four themes emerged from the iterative interview analysis process, and are considered the main findings of the study. They are the 'physical self,' the 'emotional self,' the 'social self,' and the 'reflective self'. We use participants' own quotes to illustrate the attitudes, concerns, and experiences they had in maintaining the integrity of their lives while engaging in caregiving responsibilities. To maintain patients' confidentiality, all names used in this paper are pseudonyms.

#### **Physical Self**

The first aspect of wellness is what we called the *physical self* – the needs for managing, coordinating, and handling the physical activities in one's everyday, personal, and caregiver life. We use physical to refer to the actual tangible tasks being performed by caregivers, as opposed to the emotional or social aspects of caregiving. As briefly mentioned earlier, many caregiving tasks are intrinsically medical; nevertheless, the tasks themselves can extend much further into activities that deal not only with disease management, but also with patients' quality of life. As a result of their high variability, tasks can grow in size very quickly. Since each task is important in ensuring some level of patient care, caregivers feel obligated to attend to all care tasks – even if it means sacrificing a portion of their own lives. The following example shows how patient care may conflict with a caregiver's personal obligations. Diane described how difficult it is to manage her own family while caring for her mother who suffers from dementia:

*Diane [#09]: "...it's been challenging. It's affected my marriage. We've had a lot of talks about it, and the time away from my family. It's a balancing act. It's that sandwich generation."*

Many of the caregivers we spoke with are facing the similar dilemma in their daily lives, where they take on the major roles of caring for both older parents and younger children at the same time. Taking on the dual roles means they may be the strongest person in a family in order to coordinate, cope, and manage all forms of physical activities they are responsible for; in the multiple roles they engage in. In the case described earlier, when her mother was diagnosed with dementia, Diane was only a few years into her marriage and had a newborn baby. Caregiving certainly impacted Diane's personal life, and took away quality time with her own family. Allocating time between the patient and one's own personal commitments was a conflict we encountered consistently across all the interviewees. As Diane describes,

the situation always involved a kind of *balancing act* between the caregiving life and the personal life. In her case, it is also a balance between caring for an older parent and younger child. Unfortunately, many of our participants must make two ends of responsibilities meet. This balance may not always be achieved. As a result, caregivers sometimes have to sacrifice one end in dealing with an overwhelming workload. Similarly, another interviewee told us how he had difficult times balancing the two responsibilities of his life.

*Jeff [CG05]: At some point I definitely ignored my own family, ignored my wife and my kids because I took care of him...My dad would sometimes get upset if I was paying attention to my son, my son would get upset that I was paying more attention to my dad.*

Family was not the only personal obligation that was affected by caregiving activities. Taking time away from work also created additional strain for our caregivers, since it could affect work performance. Many interviewees also talked about the needs to coordinate work responsibilities with patient needs, such as making sure patients' medical appointments are scheduled on days they can take off from work. In such cases, communication among the patient, clinic, and employer turns into another task that caregivers must take on. This often resulted in the need to compensate missed work time by working on the weekends, further invading an already-impacted family life. Another participant, Jeremy, commented on the challenges of integrating caregiving in all aspects of his life, and wished that his sister would help with more tasks.

*Jeremy [CG06] "So last year was me trying to get, not only worrying about my mom's health and condition and well-being, but trying to get my sister to step up... She has no children. She has no husband. She has no boyfriend. She just works... I work, too. I have a wife. I have two kids. I coach soccer. I do this. I do that..."*

Jeremy's quote not only indicates the multi-faceted roles he simultaneously engaged in, and the unbearable responsibilities weighing on his shoulders, but also reflects how other family members were unaware of how much work and time he sacrificed in taking on the main caregiver role for his mother. Indeed, the numerous tasks involved with caregiving can be as small as making phone calls to clinics and picking up medication on the way back home; however, these tasks can quickly accumulate and become overwhelming while still remaining unnoticed by others.

To address conflicts in balancing their lives, the caregivers we studied utilized various tools and technologies to coordinate their tasks, such as daily planners, 12-month calendars, and online calendars. Nevertheless, the use of these tools was not a remedy to the challenges involved with caregiving, and success varied among participants. Most interviewees emphasized that the technologies only served as tools, and were not complete remedies when handling all their tasks.

The difficulties we described in maintaining the 'physical self' clearly indicates a need to introduce new applications to help caregivers balance personal and care related tasks. However as previously noted, most current health and wellness applications are patient-centric in design, with the goal of "helping" caregivers to better serve their patient. How to incorporate the caregivers' lives in system design is a less studied topic. There is a need to design a platform to integrate the innumerable tasks caregivers manage on a daily basis. The lack of systems that support the busy and often challenging tasks of caregiving can lead to breakdowns when addressing tasks and even emotional difficulties among caregivers.

### **Emotional Self**

Not only are caregivers physically invested in the care process, but their lives are also emotionally affected. Consistently across all the interviews, there was an indication that the caregivers felt "stress," "frustration," and "difficulty." The accumulated tasks related to care in conjunction with personal obligations can certainly take its toll on caregivers and lead to stress in handling these tasks, especially when caregivers have difficulty balancing the various facets of their life. Melissa mentioned the guilt she felt regarding her inability to take on more caregiving tasks.

*Melissa [CG04]... always that conflict like "I can do more. I should be doing more."*

Indeed, much frustration stems from the inability to handle all the tasks involved, not to mention the helplessness a caregiver feels in watching their loved one suffer from pain or seeing their patient's health slowly decline. Many participants commented not only the challenges in managing a patient's chronic illness, but also their own emotional wellbeing – an important aspect of wellness that we term the *emotional self*. When caring for others, there are undoubtedly negative emotions involved such as stress and frustration that also affect the caregivers' own wellbeing. Not surprisingly, the inability to maintain the 'physical self' resulted in overwhelming stress for Jeremy:

*Jeremy [CG06]: "I have a teenager now and a pre-teen here pretty quick. And he was starting to go through puberty at the same time that I had to start working with [my] mom. So actually I...[whispering to prevent his family from hearing]...I went to therapy for about eight months because of it and I was on some meds for a while because I wasn't handling it well. It was a lot of change. It was a lot of stress, and I didn't know what to do."*

In this case, Jeremy's 'emotional self' had to be maintained by consulting a professional therapist and taking medication. This shows the extreme emotional impact that caring for others may have on the caregiver. Notably during the interview, Jeremy whispered the fact that he had been in therapy to prevent his wife from knowing. As we quoted earlier in Diane's case, many caregivers have to take on dual roles in caring for both older adults and younger

children simultaneously. Meanwhile, they are often left alone to cope with the resulting stress and negative emotions involved, since it is difficult for them to vent their emotional concerns to those who are even more vulnerable than they are. In Jeremy's case, his emotions were hidden from his wife, and there was no way that she could help care for him during these difficult times without knowing how he suffered.

Finding ways to manage the 'emotional self' is necessary among caregivers. Other than consulting healthcare professionals, caregivers in our study deployed other strategies to cope with their emotions. Darlene mentioned that the most effective way to cope was to share her feelings and experiences with her two sisters. In addition, she also wrote in her blog as a means of sorting out and dealing with her emotions.

*Darlene [CG13]: "I did start writing a blog. And no one really knows about it. No one reads it except for me {laughs} actually. But I just started one so that I could just get down information and feelings and thoughts that I have...writing that blog I think helps me deal with all of the emotional stuff that comes along with [caregiving]."*

Darlene's experience gives interesting insight into how technology can be used to assuage the emotions that are accumulated during the caregiving process. The blog Darlene kept was not shared with others; however, writing it serves the same comforting role as talking with her siblings or consulting a therapist. In some cases, venting emotions – either with people or simply writing thoughts down – can have a calming effect. Since expressing emotional concerns with patients or family members may not always be an option for caregivers, and not everyone has the courage to consult mental health professionals, technologies can provide an alternative channel for caregivers to vent their emotions.

To deal with their feelings, the caregivers we spoke with engage in various strategies to maintain their emotional wellbeing, such as confiding in health professionals, family, and friends. Interestingly, we found that technologies like blogs were also effective. This brings new perspective into how emotions can be alleviated through technology use when other coordination strategies are not available, and what technologies can help caregivers cope with their emotions. What we found in our exploration of the caregivers' 'emotional self' suggests that compared with the obvious emotional needs patients have, the caregivers' emotional wellbeing is a more invisible and less studied area of research.

### **Social Self**

In addition to their emotional wellbeing and their skills for everyday life management, the 'social life' of caregivers has also been impacted by the demanding role of caregiving. In many cases, the burden of caregiving both emotionally and physically diminishes opportunities to

socialize with others. Maintaining social wellness can be reflected in both decreased social activities within the family and less opportunities to interact with friends. In our study, Melissa mentioned how it felt when her mother moved in her home after the stroke.

*Melissa [CG04]: She [her mom] had that stroke in January, then she was in rehab for a while...and then she stayed with us for a while until we could figure out something else for her to do...it's very isolated here. We don't have any socialization. It's just us...everyone kind of doing their own things; the kids are in school and we all have our things to do. And so, it's not like a social – we didn't provide the same kind of social activities.*

For Melissa, staying together was not equal to "being together"; the busy caregiving-work-family schedule left almost no space for family members to catch up or to partake in social activities with each other. In such cases, being in the same household even created more of a sense of isolation since family members were busy engaging in their own activities separately.

Furthermore, the needs in accommodating to care related activities can also dramatically change the day-to-day life of caregivers. Darlene mentioned how she left her 11-year job and life in New York to become the primary caregiver for her mother in California.

*Darlene [CG13]: Well I mean it's totally changed...I have no social life, really. I mean I have some friends, and for a long time that was never a big deal to me - being alone. But now all of a sudden it is... So, I mean, in essence my whole life has changed."*

In Darlene's case, caregiving is a "24 hour a day, 7 days a week" job (from here on referred to as 24/7). Darlene's situation is especially challenging since her life now completely revolves around care for her mother. As the interview quote indicates, not only did Darlene give up her own personal life, she also disconnected herself from her social life back in New York. Being a caregiver occupies her both physically and emotionally, and in such a situation, social connections become even more important. As Darlene said, alone was never an issue in the past, but it turned into an issue when she became a caregiver.

In both these scenarios, socializing is an important aspect of life that has been deeply disrupted by the work of caregiving. Patient care tasks may conflict with a caregiver's social life; in extreme cases, where a particularly debilitating disease is involved, 24/7 care is required that entails caregiving efforts without breaks. There can be a dramatic disruption in one's 'social self' if the caregiver does not have the resources and time to socialize, or even if the mood and time to socialize diminishes when family members are co-located in the same household. No doubt socializing is desired among caregivers, since it can eliminate their sense of isolation and

offer breaks in their already stressful lives. What needs to be considered is how to connect caregivers with their social circles when they have very little time or when their other obligations overlap with social events. Also of important consideration is how to mobilize and inspire relaxing social moments to eliminate the isolation among families and individuals living in a caregiving situation, and how technologies can help facilitate this process.

### **Reflective Self**

Even though the undesirable effects of caregiving may cause unpredicted stress and frustrations to caregivers, the care process also provides opportunities to reflect and rethink personal values. As one study participant [#01] told us “*I have a deeper appreciation for life.*” We found many participants engaged in self-reflection throughout the caregiving process. These reflections often centered on health issues, but also extended beyond to other aspects of their lives. We use the term ‘reflective self’ to represent the process of self-reflection and the management of new life perspectives that may change current beliefs and behaviors.

First, being a caregiver entails reliability for the patient. Caregivers need to be constantly prepared to handle unpredictable care situations and obligations. To do so, they have to be healthy themselves and attend to their own personal health issues.

*Sean [CG 03]: I never wanted to call out sick because I knew she needed me and also because it was so hard to find somebody else that knew how she liked things because I knew that – I knew how to do what she liked and we were so compatible together.*

As this case shows, caregiving motivates Sean to stay healthy and not miss workdays. This shows a process of self-reflection that reconsiders caregiving aligned with work responsibilities so he can make himself available for the patient.

In addition, more than affecting day-to-day personal life, caregiving may have deeper impact on the way caregivers perceive and approach their lives. Caregiving is an opportunity to peer into life with a chronic disease without being the patient. Managing a patient’s disease can involve learning about the illness, in turn prompting the caregiver to take preventative measures in the present to avert the onset of the disease later in their life.

*Jeff [CG05]: but certainly one of the things that, having seen my dad being so excessively obese...is something that we’re concerned...So that’s what we watch our weight certainly... It’s not going to change in two days or three days, but there’s just that thing mentally. We watch our weight, certainly. We watch what we eat.*

As Jeff’s case indicates, caregiving for his obese father and watching the difficulties he faced warns Jeff and his family to avoid obesity in their own lives. They started to proactively monitor their own weight and be cautious about

food intake. Similarly, Wendy, another participant, mentioned that she recommends not eating sugary foods to her diabetic grandfather, and at the same time, avoids them herself on a day-to-day basis. Additionally, she and her husband have cut alcohol out of their lifestyle, since they recognize it as a risk factor for many diseases. The recognition of risk factors related to a patients’ disease was consistent across all the interviews. Although some interviewees were not as proactive as Wendy or Jeff in changing their lifestyles, they at least acknowledged a need to change the undesirable and less healthy practices in their lives. Typical lifestyle changes included eating healthier, consuming less sugar, and exercising more frequently.

The influence of caregiving in relation to the ‘reflective self’ is much more profound than reading educational materials, since caring for a patient is a reminder of the everyday importance of being healthy. Thus, caregiving entails the process of reflecting on current life practices with lessons learned from the caregiving endeavor. Consequently, the caregivers’ self-reflection on these life lessons may affect the way they perceive their lives.

Self-reflection touches all aspects of the caregivers’ lives – some caregivers are more appreciative of what they have and what is important in life; others proactively prepare for their own future by educating their children on the procedures and costs in caring for the elderly. Here we see that caregiving has changed people’s perceptions in life, creating opportunities to be more affectionate and understanding with one’s own relationships and experiences, and to be even more prepared for future care of themselves and others – all positive impact on caregivers’ lives. However, the benefits of these lessons serve no purpose if the caregivers do not take action. Many of the interviewees were not as proactive as Jeff or Wendy in changing their behaviors to live healthier, suggesting that there is a need to help caregivers more aggressively turn these reflective thoughts into action.

### **DISCUSSION**

Our study on caregivers reveals a multitude of challenges they face in their daily lives. In this section, we discuss how caregivers strive to manage the integrality of their lives through two lenses of thought that both emphasize the collaborative nature of caregiving. The first is *giving and impact*, the second – *visibility and invisibility*.

#### **Managing Integrality**

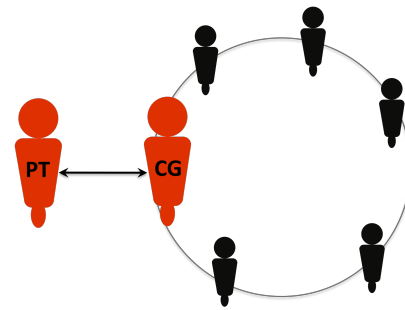
The findings of this study show that caregivers have to constantly balance numerous tasks involved in caring for others, while maintaining their own physical, emotional, and social needs. The process of caregiving is by no means a small part of the caregivers’ lives, but affects all aspects of their daily activities. In this sense, managing the caregiving role cannot be separated from the other parts of life. Here we use the term *integrality* to refer to the need to understand the complete spectrum of a caregiver’s life, instead of separating caregiving from other life facets.

Prior studies in health management have advocated that the management of disease should be embedded in the rest of life behaviors, e.g. [14, 24]. Nevertheless, the foci of these studies are often on how patients integrate and struggle with their multi-faceted lives; the experiences of caregivers in helping patients remain a relatively underexplored area. The integrality concept can be more challenging since it involves multiple layers of impact. Here we discuss maintaining the integrality of the caregivers' lives in the following two ways. *First*, we argue that managing integrality is a multi-faceted activity that involves not only negotiating the 'physical self', but also the 'emotional', 'social', and 'reflective' self. In this sense, integrality covers multiple layers that need to be coordinated, instead of only one aspect. As we have seen in the study, the caregivers' struggles can result from the incapacity of managing physical tasks, but more profoundly, they are deeply rooted in the challenges of managing social and emotional wellbeing. While physical tasks can be reallocated easily, the emotional side of integrality is more difficult to maintain, and deserves more attention in future work. *Second*, in managing integrality, caregivers have to coordinate all aspects of their lives with individuals who are tied to other life activities, such as their spouse, children, friends, co-workers and managers. Hence, maintaining integrality is a collaborative activity that involves many people. Negotiating activities with these parties may not be easy, since the needs of a caregiver may not always be appropriately perceived, compared to the patients' cases. Design for life integrality needs to consider not only the physical involvement of the caregiver and their emotional involvement, but also the broader spectrum of people who each connect to various aspects of a caregiver's life.

### **Caregiving as a Collaborative Endeavor**

Although the focus of the study was set on understanding what caregiving entails to caregivers' real lives, the task of caregiving is intrinsically collaborative in nature. First, caregiving is a process of devoting time, energy, and emotion to helping others better manage illness. It cannot be termed *giving* without at least two people's involvement. Second, as we mentioned in the section above, in the process of maintaining integrality, caregivers negotiate their relationships and activities with family members, co-workers, and even other caregivers. In this sense, caregiving work can be viewed as a collaborative endeavor that emanates between a patient and a caregiver, and onwards to collaboration among caregivers and others who are involved in the caregiver's multi-faceted life [Figure 1].

In the following, we elaborate on two factors we deem critical to the collaborative caregiving endeavor. Specifically, we use the idea of '*giving and impact*' to frame the impact of caring for patients on caregivers' own lives, and '*visibility and invisibility*' to explain the need for better coordination among the role of caregiver and the other roles a person undertakes simultaneously [Figure 2].



**Figure 1: Collaborative Caregiving.** Left side represents patient-caregiver interaction, and the right shows how a caregiver connects to others in real life.

### **Giving-Impact**

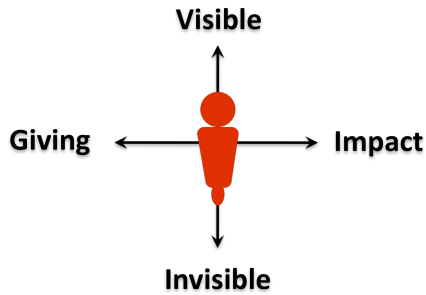
To better understand the collaborative nature of caregiving work, we revisit the illness trajectory concept introduced at the beginning of the paper. Strauss describes an illness trajectory involving, "*not only the physiological unfolding of a patient's disease but the total organization of work done over that course [of illness], plus the impact on those involved with that work and its organization*" [30, p8]. In this definition, clearly the work involved in patient care is necessary; however, it also states that the "impact of those involved" is essential in maintaining the illness trajectory. Here we use giving and impact to categorize the process of caregiving to caregivers' own lives.

In caring for a patient, a caregiver often devotes large amounts of time, energy, financial assistance, and emotional support to the patient. While much of the previous literature is centered on understanding what patients' need from caregivers, less attention has been spent on the consequences of these activities on caregivers. We argue that the process of caregiving inevitably results in impact on caregivers, regardless if it is negative or positive. The more involved and helpful a caregiver is, the more impact s/he may experience from the act of giving. The counter-effect exerted on caregivers can be felt physically, emotionally, socially, and in other ways. This is because when a caregiver devotes more time and energy to a patient, less time and energy remains for his/her other life activities; when a caregiver is more emotionally involved in a patient's care, the more difficulty there is in maintaining emotional wellness.

The association of 'giving and impact' in this section suggests that caregiving is a balance act, where the amount of work invested in the giving effort is related to the amount of impact one may receive. As such, focusing only on the needs of patients and neglecting the potentially strong impact that caring may have on caregivers can be problematic or even dangerous. In the cases mentioned in this paper, the wellbeing of patients may be coupled with the impaired wellbeing of a caregiver. When designing technologies to facilitate better caregiving for patients, the advanced technologies may in turn increase levels of impairment exerted on caregivers unintentionally. What we



have found in the study suggests that it is critical for system design to consider both the obvious beneficiaries, e.g. patients, and those who may receive the counter impact in the process of helping others.



**Figure 2: Factors affecting the collaborative caregiving process.**

**Visible-Invisible**

As our study shows, the impact on caregivers largely results from the tension between the busy, multi-faceted lifestyle of caregivers, and the new tasks created by the caregiving role. Managing day-to-day wellness is actually a process of negotiating all the different social connections in a caregiver’s own life – a collaboratively driven activity in nature. Nevertheless, the negotiating process may not always be successful, and sometimes may not even occur. On many occasions, even the closest of family members were not fully aware of the struggles involved in the caregiving process. For example, the accumulated task and mental stress remained only visible to Jeremy, and was invisible to those who were connected to him through only one aspect of his life. Many of our study participants took dual roles of both caring for patients and their children. The huge responsibilities imposed on them made it difficult to vent their stresses and frustrations to friends, family and co-workers. Consequently, outside individuals were unaware of the needs of these caregivers during difficult times.

The visible and invisible nature of tasks presented here is similar to what Lucy Suchman pictured in workspace collaborations [31], where certain behind-the-scenes work cannot be appreciated by collaborators and may lead to a misrepresentation of workload in system design. As we described earlier, when the amount of care and concerns stay invisible to family members and co-workers, these “collaborators” may not have a chance to offer help, especially when caregivers themselves are reluctant to reveal the challenges they have to others. In such situations, we suggest that technological design for caregivers take advantage of the *articulation work* that is deemed essential in collaborative work. By definition, articulation work is a type of “*work that gets things back ‘on track’ in the face of the unexpected, and modifies action to accommodate unanticipated contingencies* [29].” In caregivers’ cases, articulation work can be managed at both the behavioral and system levels: caregivers can be encouraged to articulate the concerns, problems, and issues they face in

maintaining their own wellbeing; systems could map out the entire workload a caregiver routinely undertakes for other people, and open opportunities for them to offer help whether physically or emotionally.

**DESIGN IMPLICATIONS**

This section details specific design suggestions based on the study’s findings. As indicated, the design of health systems should not merely address what caregivers can do for patients, but should include how to improve the health and wellness of caregivers while attending to their patients.

**Support Coordination among Care and Personal Tasks**

As we have shown in the study, balancing caregiving with personal life can be challenging. Caregivers have to constantly deal with rearranging their personal tasks to accommodate caregiving obligations, and vice versa. It is not surprising that having a multitude of medical, non-medical, and personal tasks can lead to challenges in remembering and organizing tasks efficiently. Oftentimes, caregivers have to deploy various artifacts, tools, and routines to integrate and coordinate tasks from different parts of their lives. As such, it is essential that future systems help caregivers via an integrated platform that provides various mechanisms to facilitate the task coordination process. Such a design could support caregivers in balancing and navigating their caregiving responsibilities with their personal lives.

More importantly, this technology should integrate all tasks caregivers have into a single, centralized system that supports the articulation of objective burdens to the caregivers’ other social connections.

We argue that such a system should be an integrated technology. This argument is based on the concept of “giving-impact” we discussed earlier, since balancing multiple parts of one’s life needs to be consistently maintained in the caregiving process. A caregiver only has limited time and energy to deal with the multiple roles s/he is responsible for. Thus, it is necessary to coordinate caregivers’ time and tasks in a visible way so that they can more efficiently synchronize and communicate with co-workers, friends, and family members. The enhanced awareness and improved communication afforded by this system could ease the stress and physical workload of caregivers and make their jobs easier.

For instance, the integrated care system may allow a caregiver to set up his/her comfort task zone for a day, e.g. 12 hours of work. It could link with calendars from work, life and caregiving activities, and automatically calculate the daily workload of a caregiver. When the calculation exceeds the threshold set by the caregiver, the system could send warning signals to remind the caregiver that there are more tasks than s/he can do on a particular day, and also send messages asking for help to the caregiver’s friends, family members, and other non-primary caregivers. Although there is uncertainty in estimating one’s workload, many tasks are scheduled in advance. Take Jeremy’s case

as an example. He knows his kids' school schedule in advance and the time needed for his job, as well as the planned medical visits for his mother. Entering these key events into the system could provide Jeremy a sense of order in properly execute different tasks, and how best to avoid task-conflicts. More importantly, this integrated tool can share the task load of a caregiver without verbal communication. Caregivers could choose to show their actual activities or just a warning signal that their workload has become too high. When co-workers, family members and other caregivers receive the warning message, they are able to intervene and offer help. The system can even automatically assign tasks to other caregivers based on their availability or expertise. In such cases, the work of a caregiver is no longer invisible; instead, it is shared with others in comfortable and non-intrusive ways.

### **Support Management of Social-Emotion Work**

Caregiving is a long, intensive endeavor where the management of a caregiver's emotional wellbeing is as important as the patient's. In dealing with the stress and frustration of completing tasks, different caregivers utilize different strategies to cope with the subjective burden of their workloads. Many look to medical professionals for help, while others confide in siblings and friends to share their feelings and discuss stressful situations. A surprising discovery in our study revealed that blogs serve as a therapeutic tool in helping caregivers manage their emotions. This finding echoed prior work that the writing process can help individuals express "*deeply felt emotions*" [23] even without a reader. In this case, the use of technology affords new opportunities for caregivers to better manage their emotions. In the visible-invisible discussion, we mentioned that the impact to caregiving – especially those that are emotional – is invisible to the caregiver's social connections. In such cases, people who are available to help might not be aware of a caregiver's potential emotional needs. To this end, technologies can be designed to indicate the stress level of caregivers, which can later be shared with social connections.

One possible way to alleviate the caregiving burden is to offer ways to assess and support the caregiver's emotional wellbeing. For instance, in the integrated system, encouraging or rewarding messages can be sent to a caregiver automatically when the system indicates their workload is too high, or when the patient being cared for is in a difficult condition. In addition to these reminders, brief surveys can frequently be sent to caregivers to help determine their emotional states, as a previous study has suggested [17]. Depending on the levels of stress and frustration a caregiver experiences, the system could provide ways to ease their emotions through jokes, family pictures, or suggestions that the caregiver should share with family members.

In terms of making emotions visible to family members, our findings suggest that caregivers are often unwilling to explicitly reveal their emotional concerns with family

members and friends, indicating more implicit and subtle emotional identifiers may be needed. For example, stress, frustration, or anxiety can be marked using different colors. A system could use red to represent different anxiety levels, and the deeper the color, the more anxiety the caregiver feels. Doing so would allow family members and friends to acknowledge a caregiver's emotional state without the caregiver revealing any details.

Technologies can also provide the social support that caregivers need, especially when it is unavailable in their physical surroundings. Just like patients can form online support groups to help and encourage each other remotely, information and communication technologies can be applied to support caregivers virtually, as the ComputerLink study offered to caregivers [8]. This type of social-emotional support is especially useful for those whose lives are deeply involved in and impacted by the caregiving process. Systems such as online groups, or broadcasted micro-blogs in a caregiver group, connect caregivers with similar experiences – especially those who care for patients at a distance. Social support is also critical for caregivers in maintaining their emotional wellbeing, since encouragement from their caregiver peers might be more effective than others' words. It's notable that many caregivers have to remain stationed around their patients and have no time to socialize with others who have similar experiences. However, it is likely that these caregivers have enough time to briefly talk with each other using the social components embedded in our proposed system, such as online chat-rooms, electronic bulletin boards, instant messaging, and text/visual micro-blogging. These social components can easily be managed during the waiting time of a patient's medical visit, or the monitoring time at home.

### **Encourage Reflection and Learning**

Similar to the sense of competence and personal growth gained from learning and living with patients [25], we also found that constant exposure to their patients' illnesses provided caregivers the opportunity to reflect on their own lives, reminding them that they can take preventative measures to stop the onset of disease for themselves. This process, however, requires caregivers to reflect and take action in living a healthier lifestyle that can additionally influence others who are connected to the caregiver. Therefore, we suggest that the system help caregivers engage in the reflection, learning, and eventual preventative measures that can help stop the onset of disease. One way to succeed in this endeavor is to facilitate the sharing of caregiving experiences through blogs and caregiver groups, as we had proposed in the social support section previously. Expressing and summarizing insights in health and wellness through blogs was considered useful in self-reflection [23]. In addition, the insights authored by caregivers can optionally be shared with other family members, friends, or even other caregivers in a social network. The process of reflection can be encouraged through an extra 'rewarding' message, or by obtaining higher levels of status/reputation

in the caregivers' communities. These features can encourage increased awareness of health risks and applicable preventative measure. Other considerations to encourage caregivers' reflection and learning include providing personalized health information for caregivers to read, and to provide them with opportunities to help each other with personal issues – health related or otherwise.

In this section, we advocate for the design of a health system that considers the critical role and potential impact of caregiving on caregivers, instead of solely focusing on patients' needs. With the tight integration of a caregiver's familial, professional, and caregiving lives, and the physical, emotional, social and reflective aspects of self-management, it is necessary to provide an integrated system that better connects the various aspects of life as a whole. The best way to know what caregivers need to do for their patients is through knowing the patients' needs. The total workload of an individual cannot be obtained if work, or family responsibilities are not included with the caregiving duties. Similarly, we view these four aspects of caregiving as overlapping and interconnected. System features that promote the wellness of one aspect will likely positively enhance the other three, such as the case of writing and sharing blogs that can pacify the negative tensions in the emotional self while also positively influencing the social and reflective selves simultaneously. Thus, an integrated platform that addresses all aspects of caregiving is likely to be a successful application.

#### **CONCLUSION**

In studying health and wellness, not only should we address the physical, social, and emotional requirements of patients, but also those of caregivers. Consideration of caregiver needs is especially important, since the burden of care may negatively impact the health and wellness of caregivers, leading to anxiety, stress or even an increased mortality rate. Nevertheless, unlike patients' needs that are clearly perceived, the counter-impact on caregivers often stay invisible, even to their closest friends and family members. In our study of caregivers' lives, we use the metaphor of giving-impact to emphasize the amount of influence caring for others may have on caregivers' lives. Surprisingly, much of the caregiving work remains invisible to other caregivers' social connections. We examined various caregiver activities, wherein we uncovered that caregivers struggle in their multi-faceted lives maintaining their physical, emotional, social and reflective selves. We argue that the future health and wellbeing systems should consider the impact of on caregivers as an integral part of the design.

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