Every Cloud Has a Silver Lining: Exploring Experiential Knowledge and Assets of Family Caregivers

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Family caregivers of patients with chronic conditions often subject themselves to drastic life changes. The quality of life of the caregivers often decreases noticeably at the beginning of the caregiving trajectory, because they typically reorient their lives to focus on the patient's health status. As a result, previous studies viewed caregivers primarily as people who need help and focused on how technologies can support them. However, in our study, we found that caregivers are also capable of developing their own experiential knowledge and strategies, which have been invisible in previous caregiver studies. By conducting in-home interviews with fourteen family caregivers, we present the types of new knowledge and coping strategies family caregivers have developed from their lived experiences during everyday caregiving tasks. These include 1) establishing new mindsets, 2) developing mindful activities, 3) building relationship management strategies, and 4) sharing experiences with people in their own networks. Based on our findings, we call for an asset-based approach that will help researchers notice the capabilities of caregivers. This approach could enable researchers to be more reflexive in the incorporation of caregivers' devalued knowledge within their system designs.

CCS Concepts: • **Human-centered computing → Empirical studies in HCI**.

Additional Key Words and Phrases: Family, caregivers, caregiving, informal caregivers, healthcare, design, asset, resilience, strength

ACM Reference Format:
Ji Youn Shin, Dima Chaar, Catherine Davis, Sung Won Choi, and Hee Rin Lee. 2021. Every Cloud Has a Silver Lining: Exploring Experiential Knowledge and Assets of Family Caregivers. *Proc. ACM Hum.-Comput. Interact.* 5, CSCW2, Article 416 (October 2021), 25 pages. https://doi.org/10.1145/3479560

1 INTRODUCTION

The public healthcare system depends on friends and relatives to provide care for individuals with chronic conditions[1]. When individuals have difficulties functioning independently, family members are often expected to become their caregivers by assisting in everyday self-maintenance activities, accompanying them to healthcare facilities, and providing emotional support. In the United States, 22.3% of individuals, who are 45 years old or older, reported that they had provided care for their friends or family members within the preceding month (Center for Disease Control) [86]. A majority of people provide care for a family member at some point during their lives.

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2573-0142/2021/10-ART416 $15.00
https://doi.org/10.1145/3479560

Becoming a family caregiver for a family member with a chronic health issue, such as cancer or dementia, leads to drastic changes in an individual's life [62]. Caregivers often reorient their lives to focus on the patient's health status across the course of caregiving in response to mobility restriction, essential clinic appointments, and high risk of infection [9]. Regardless of the numerous tasks that caregivers must perform (from the patient's self-care activities in a home setting to emotionally supporting the patient [72]), caregiving resources are limited. Consequently, caregivers' daily routines — including careers, finances, and social lives — are put aside. As a result, they often report a significant decline in their physical, psychological, and social functioning throughout the long-term illness care process [85].

To support these declines in caregivers, CSCW and HCI studies investigated how computing technologies can support caregivers by addressing their limited health literacy [59], emotional burden [40, 63, 98], and social isolation [81]. These caregiver studies let caregivers gain more attention as individuals with their own needs (rather than as non-professional assistants to patients) and suggested helpful technologies that could improve caregivers' own quality of life as well as their caregiving practices. However, despite the benefits of these studies to caregivers, they view caregivers primarily as people who need continuous support from healthcare professionals, health researchers, the public health system, and technologies. The suggested technologies aim to supplement caregivers' limited abilities. By focusing on their deficits, these studies shed less light on the existing capabilities and knowledge of caregivers.

Recent medical literature has found that caregivers acquire knowledge that includes coping strategies and insights while undergoing challenging experiences [43]. Similar to these recent medical studies, a few CSCW and HCI studies mention caregivers' capabilities and coping strategies (e.g., learning how to balance life values and acquiring medical information [6, 73]). Building on these recent studies that acknowledge the capabilities and knowledge of caregivers, we propose a better way incorporate the strengths of caregivers, which were previously not very visible. This study suggests an asset-based approach as an alternative framework that assimilates the knowledge and capabilities of caregivers into technology design. In this paper, we highlight caregivers' existing assets, including their accumulated knowledge, strengths, and lessons learned while patients undergo intensive medical procedures and recovery. We do so using information obtained through fourteen semi-structured, in-home interviews with family caregivers (spouse, sibling, or parent). Our contribution is threefold:

- This paper sheds light on the roles of caregivers as knowledge, rather than people who merely need help to handle their difficulties. Caregivers' capabilities have been less discussed in previous caregiver studies in CSCW and HCI.
- This paper suggests an "asset-based approach" as an alternative frame to incorporate caregivers' existing strengths that have largely benefited caregivers but not been deliberately considered in previous system designs.
- This paper shows how asset-based caregiver studies could provide the potential of an asset-based approach as a frame for HCI and CSCW researchers to practically perform reflexivity.

In the following sections, we present related work, data collection methods, and analysis, followed by main findings and discussion.

2 RELATED WORK

Family caregivers have long been invisible actors in healthcare studies [62] and in broader society [20]. The work of family caregivers in home settings was typically not paid, and their knowledge was not valued as an important part of healthcare practices [14]. As a growing number of studies examine caregivers and their needs, they have gained more visibility in HCI and CSCW studies.

However, their existing capacities have not been discussed as the main theme when designing technologies for them. On the other hand, a stream of studies has investigated an asset-based approach as a way to focus on the capabilities of socially marginalized groups and avoid a needs-focused model for understanding these groups. In this section, we will review how these two lines of studies have been discussed and look for potential to bridge them to position caregivers as active and knowledgeable social actors in healthcare studies.

2.1 Caregivers as people with their own complex needs

Scholars have long viewed caregivers as supporting actors who perform various tasks for patients (e.g., interpretation of lab results, medication management, and care coordination) [19, 22, 75, 76]. In these studies, the caregivers' own needs were invisible. To support caregivers' information work, studies have examined how to better provide information for caregivers, so they can enhance their ability to care for patients [59, 92]. These studies viewed caregivers as information receivers and aimed to facilitate their informational work through online platforms and mobile technologies. The studies can be categorized into three groups: 1) technologies for educating caregivers (e.g.,[78, 93]); 2) technologies that support caregivers' decision-making processes (e.g., [26, 65]); and 3) technologies that facilitate caregivers' care coordination (e.g.,[32, 33, 56, 83, 99]) and communication with clinicians (e.g.,[4, 21, 27]).

These studies commonly view caregivers as non-professional assistants to healthcare professionals who administrate the medical activities and care coordination of patients. Although the studies highlighted that caregivers are critical in the patient's treatment process, caregivers are seen primarily as supporters or assistants rather than as individuals with their own lives. Even when the active roles of caregivers were discussed as more than information receivers in patient empowerment studies (e.g., [60]), caregivers were still considered supporting actors for patients. Thus, caregivers' wellness and health have been overlooked in these studies, despite that many caregivers have experienced a significant decline in physical, psychological, and social functioning due to long-term illness, caregiving processes [64].

The caregiver studies in CSCW and HCI have altered the conception of caregivers from supporting actors for their patients to individuals with their own complex needs that are associated with their value and emotions. They have addressed the importance of caregivers' emotional work and how they should be more visible in system designs [18, 39, 98]. For example, Chen et al. discussed the necessity of acknowledging family caregivers as whole persons engaged in social-emotion work and reflective learning while providing care for patients [18]. In their ethnographic study, Kaziunas et al. discussed how caregivers' emotional work is entangled with informational work (e.g., emotional work involved in the interpretation of medical information about a family member[39]). To ease caregivers' emotional work, these studies suggested providing social contact (e.g., online support groups [2, 88, 89]) and various activities (e.g., exergames [81]) to promote wellness mediated by technologies [10, 28, 55, 71, 81, 89].

In more recent studies, the unique needs of caregivers were discussed within the context of family social dynamics [6, 73]. They focused on caregivers' values, desires, and dilemmas that resulted from the conflicts of obligations as a family member (e.g., as a parent [73], spouse [6]). For example, in a recent interview study by Seo et al., of parental caregivers of pediatric cancer patients [73], researchers identified three unique tensions from caregiver's strategies and practices: ensuring the child's social growth while limiting social contact for health reasons; managing illness-related information that they disclosed to the child; and balancing attention, generosity, and discipline.

2.2 An asset-based approach in HCI and CSCW

Unlike needs-finding and needs-solving perspectives, asset-based approaches help researchers to start the research process by considering how existing knowledge, capacities, and stories of the socially marginalized group can be leveraged and reoriented [45, 100]. Rather than viewing socioeconomically marginalized communities as people who lack capabilities or capital to tackle their issues, asset-based studies focus on how to visualize their existing capacities and mobilize them. In this way, people from underserved communities take a more active role in handling their difficulties, learn how to utilize their existing assets, and develop sustainable solutions for the challenges that they face.

The rich body of HCI and CSCW literature has borrowed asset-based approaches from CRT (Critical Race Theory) and ABCD (Asset-Based Community Development) [45, 57, 100]. These studies have applied asset-based approaches to amplify and support the existing strengths that various communities have developed through their own culture and experiences [46]. Because each community's assets have different characteristics (e.g., tangible, intangible, fragile) [30, 96], researchers strove to look at multiple levels of assets, including individual and relational strengths (e.g., familial, community). Based on identified characteristics that are unique to each research context, researchers suggested ways to leverage technologies to build on the particular strengths of each community [46, 95].

For example, Gautam et al. identified the assets of sex-trafficking survivors, which are their craft skills and their social bond [30]. Based on these assets, the researchers suggested that technologies should prioritize strengthening the survivors' feeling of group solidarity by supporting their expression, presentation, and learning. Using a case study with Latino immigrant parents, another study discussed the potential of assent-based design approaches. This study showed how the trust-focused strategies of Latino parents are crucial to parent-education technologies for the user group [95]. By applying the lens of intersectionality, Karusala et al. emphasized, because of their diverse cultures, the importance of identifying and using assets of community health workers when designing digital payment methods [37]. These studies collectively showed that the situation and contexts of individual assets are critical for more sustainable approaches for technology design.

2.3 Bridging caregiver studies and asset-based studies

This recent wave of asset-based approaches provides a useful lens to learn and apply caregiver's strengths in design practices. In the domain of caregiver studies, it was a breakthrough to make caregiving labor visible by redefining caregiving as demanding rather than mundane work. Caregivers finally became individuals with their own complex needs. However, because of the emphasis on caregivers' deficits or difficulties, caregivers are seen primarily as people who needed support rather than those with strength and assets. In addition to a discussion about how technologies compensate caregivers' needs, more recent caregiver studies have begun to briefly mention how, through their caregiving experience, caregivers attain capabilities to become more mature or to learn to focus on what is of the most crucial value to them. Building on these studies, we suggest an asset-based approach as a promising approach to reframe caregivers as active and knowledgeable actors in caregiver studies. In this paper, we report our findings that show the strengths and knowledge of caregivers. These demonstrate the possibility of 1) how an asset-based approach could be useful for caregiver studies, and 2) how asset-based caregiver studies could provide insights for the HCI and CSCW communities.

3 METHODS

3.1 Study context: caregivers of blood and marrow transplantation patients

Our participants were caregivers of patients who had received bone marrow transplantation (BMT) to treat a variety of conditions, including cancer. This is a high-risk treatment, because the patient can undergo a wide variety of life-threatening complications. In addition, the possibility of relapse exists throughout the transplant and recovery phases [15, 40]. Because of these risks, the treatment requires a dedicated primary caregiver, who accompanies the patient during both hospitalization and post-discharge, in-home, recovery phase [40]. The caregiver is required to be available at all times for the first three months after transplantation and to receive training by clinicians in performing medical activities, including catheter line care and medication management. The caregiver must also monitor symptoms of complications and be aware of emergency action plans. The caregiver accompanies the patient during lab tests and interactions with clinicians and must review the results. Because these clinic visits occur at a high-frequency during the first three months post-transplant (e.g., several times a week, depending on the severity of complications), patients and caregivers must reside within ninety minutes of travel distance from the medical center. As a result, patients and caregivers are often asked to relocate for the duration of this phase. This leads the caregiver to reorient his/her life entirely around the patient's care; often, jobs, social activities, and other relationships are temporarily set aside. Because patients are immuno-compromised, caregivers are required to remain at home and minimize contact with outsiders due to risk of infection. These life-altering circumstances have a negative influence on the overall structure of the caregiver's own life and wellness.

This study was originally designed to explore technologies that could help the mental health management of caregivers. As a part of a larger project that aims to enhance the well-being of BMT caregivers [16, 41, 74], our team included HCI design researchers, clinicians, public health researchers, and positive psychologists. Before conducting the in-home interviews that we present in this paper, the team observed our participants for two years in hospital settings.

3.2 Study settings: in-home interviews

To understand how family caregivers internalized useful strategies and developed knowledge to minimize the effects of stressors related to daily caregiving, we performed semi-structured interviews in their permanent or temporary residences (e.g., hotels, apartments). From the Summer of 2017 to the Winter of 2018, two research team members traveled to participants' homes for all of the interviews and conducted approximately 60-80 minutes of semi-structured interviews. With participants' permission, the interviews were audio recorded. We took photographs that are related to caregivers' stories, including get well cards from their friends and family, materials that they used for stress-relieving activities, systems for organizing medication, and their living environments. Photographs of the artifacts and narratives shared during the interview were used for an in-depth understanding of caregivers' experiences. We also took field notes while engaged in the conversations with our participants.

Interviews in clinical settings could frame participants primarily as passive, healthcare service receivers, because their main role in that context is to receive information from healthcare professionals. Because we wanted caregivers to have active roles in the study, we interviewed them in settings in which they could openly share their experiences, emotions, and views. In this sense, the home environment was an appropriate place for the caregivers to feel more at ease to express their views [49]. Therefore, we conducted semi-structured, home interviews with participants in their permanent or temporary residences (e.g., hotels, rental housing). Home interviews allowed us to thoroughly understand within a real environment their daily, caregiving routines and the mental health issues associated with those routines. The main interview themes included general caregiving tasks, daily routines, significant challenges, technology use, and strategies to maintain wellness. The interview themes were developed after 250 hours of observations conducted in both outpatient and inpatient units. They were also based on previous caregiver studies that aimed to improve caregiving practices in chronic illness contexts.

Although we had major themes that we wanted to examine throughout the interviews, we were aware that new themes that we had not considered could emerge as narratives and experiences critical to understanding the caregivers' strengths. Therefore, we were careful to present ourselves as listeners and learners to understand participants' lived experiences rather than interviewers who dominated the conversation [48, 50, 53, 84]. Whenever the caregivers mentioned their strategies and acquirements during the caregiving experiences, we encouraged them to share and exhibit in-depth information about the themes. This methodological approach was essential for us to find assets that are otherwise not readily visible. By actively collaborating with clinicians, nurse practitioners, design researchers, and psychologists, we designed our study to explore technologies to support caregivers' mental health management and improve their wellbeing during the caregiving experience. Audio-recorded interview data were de-identified, professionally transcribed verbatim, and entered into NVivo Pro 11 for analysis.

3.3 Study participants

Study participants were fourteen family caregivers of patients who had received BMT in a major university hospital located in a college town in the mid-western United States. All participants were from the United States and lived within 90 minutes of travel distance from the hospital. Participants were identified through referrals from their clinicians and recruited at outpatient clinic appointments. The clinical team verbally asked caregivers if they were willing to participate in the study, and notified the research team if the caregiver agreed. Eligibility criteria for study participation included being a primary family caregiver who had accompanied a loved one during BMT; being comfortable with speaking English; and able to participate in a face-to-face interview in their home setting.

The median age of the study participants was 59.5 years (range, 39-71 years). The majority were married or in a domestic partnership (13/14 [93%]), white (13/14 [93%]), and female (12/14 [86%]). In addition, 10/14 (71%) had at least a two-year college degree and 5/14 participants (36%) had received at least a four-year college degree. The interviews took place in permanent residences (6/14 [43%]), rental apartments (5/14 [36%]), or local accommodations (3/14 [21%]). Participants were mostly parents (6/14 [43%]) or spouses (6/14 [43%]) of the patient, but some were siblings (1/14 [7%]) or friends (1/14 [7%]). See Table 1 for participants' demographic information.

Patients were present during the interviews and provided their own views on the experience. However, because our primary purpose was to gain caregivers' perspectives, we focused primarily on caregivers' responses when analyzing data. During the analyses, patients' insights were used as supplementary information to understand caregivers' statements regarding their relationships (e.g., conflicts and cooperation) with patients. The Medical Center's Institutional Review Board provided ethical approval for this study. Before we visited their home, participants signed informed consent.

3.4 Data analysis

We used a grounded theory with a constructivist approach for our analysis [17]. This approach helped us analyze our data in a flexible manner without strict research direction. For example, while we gathered data, the research team met weekly to discuss the themes that emerged during the interviews. Interviewers presented interesting themes and new findings to the team without any specific restrictions in terms of themes. As a result of this process, the discussions allowed for

Table 1. Demographic Information of Caregiver Participants (F=Female)

Participant ID	Relationship to patient	Sex	Age	Race	Interview place
1	Mother	F	57	White	Apartment (rental)
2	Mother	F	55	White	Home
3	Wife	F	57	White	Apartment (rental)
4	Wife	F	68	White	Home
5	Mother	F	55	White	Hotel
6	Mother	F	62	African American	Apartment(rental)
7	Husband	M	60	White	Home
8	Sister	F	60	White	Hotel
9	Friend	F	62	White	Home
10	Mother	F	70	White	Apartment (rental)
11	Wife	F	59	White	Apartment (rental)
12	Wife	F	39	White	Home
13	Father	M	71	White	Home
14	Wife	F	58	White	Hotel

iterative calibration of the interview questions to encompass the rich information on caregivers' experiential knowledge, positive aspects of caregiving, and strategies developed during their practices. Considering theoretical saturation [17], data collection ended when additional new information no longer provides fresh perspectives. Because audio-recorded, interview data were transcribed immediately after each interview, the lead author could read and become familiar with the data while the interviews were taking place. The collected field notes and photographs were used to facilitate weekly team discussions and the initial phase of the data analysis when identifying emerging themes. As emerging ideas can be found at any point during the research [17], we shaped and reshaped our data collection and analysis procedures with these iterative steps in a scrutinizing manner. The refined process enabled us to learn caregiver's perspectives through our collected data. The weekly team discussions with transcription, memos, and photographs during the data-collection period allowed us to identify interesting themes and data patterns for further investigation. They were (1) the caregiver's negative and positive experiences throughout caregiving phases; (2) the caregiver's attitude towards a stressful situation; (3) knowledge accumulated through the experience; and (4) technology design ideas for possible future, caregiving, support tools. Using NVivo Pro 11, we performed open coding for fourteen transcripts with these primary focuses. Because we focused on caregivers' experiential knowledge and the useful strategies they developed through the caregiving practices, open coding resulted in codes that represented the caregivers' strengths. We then performed axial coding to find relationships in the data by identifying commonalities and differences.

We established high-level themes that represented the rest of the subthemes. Throughout this analysis process, caregivers' strengths, such as experience-based strategies and knowledge established by family caregivers throughout their caregiving practices emerged as major themes, which we will explain further in the following section.

4 RESULTS

From the interviews, we learned how caregivers underwent intensive illness procedures alongside their loved ones and how they turned their experiences into useful coping strategies. During the interview, the participants frequently reported their difficulties associated with caregiving. Because of the high-risk of infection for patients, caregivers had to subject themselves to unfamiliar and uncomfortable life restrictions. This led to varying types of burden, including alienation, beginning soon after diagnosis. However, our caregiver participants addressed that the most important points of their experiences were not the hardships resulting from desperation, relationship conflicts, or intensity of their tasks, but the strategies and knowledge that they acquired through their experiences as caregivers.

During the interview, they shared four types of coping strategies and knowledge that they developed: 1) establishing new mindsets, 2) developing mindful activities, 3) building relationship management strategies, and 4) sharing experiences with people in their own networks.

4.1 Establishing new mindsets: new attitude toward life and short-term perspectives

Once patients were diagnosed, the lives of primary caregivers changed drastically, with the introduction of multiple new daily tasks, including administering medication and assisting in self-care (e.g., magnesium infusions, central line maintenance) and in daily activities. As caregivers reoriented their lives to focus on the patients, they had to adopt wholly new mindsets. Caregiver 1 described her current status as “learning to balance just everything, home life, family, bills, priorities.” Caregivers learned to assist in patient self-care activities and stayed with the patients around the clock to monitor side effects (e.g., swelling, rashes); as a consequence, they were no longer able to work full-time. Among a significant majority of the caregivers in our study, these life changes and the associated challenges enabled them to establish new mindsets that facilitated positive thoughts. Over time, they adapted to their life situations, having changed from what they had previously wanted. These attitudes enabled caregivers to avoid excessive focus on factors they could not control (e.g., lab results, slow recovery, or side effects of treatment) and instead, concentrate on giving care. We identified two primary strategies that helped caregivers overcome negative aspects of the experience of tending someone with a long-term illness: *establishing new attitudes toward life and focusing on the short term, “taking one-day at a time.”*

4.1.1 Establishing new attitude toward life. Caregivers shared how the caregiving experience influenced them to find new perspectives, including the ways that both caregivers and patients perceived their own lives, treated others, and became more willing to accept help. During the interviews, participants shared how their drastic life changes helped them to realize the value of seemingly trivial things. Caregiver 3 learned the fact that life-threatening experience can happen to whoever and whenever, without any forewarning. As a result, she was able to learn ways to appreciate what she had already:

> *"What I am saying is just be happy every day for what you have. He [the patient] was fine, he was healthy as could be. We had no medical [issues]. He never even had a headache in his life. Never, nothing. Then one day, we’re going along fine and the next day he’s down here, a bone marrow transplant. I think it’s helped a lot of people that we know realize, too, that you just have to be happy every day with what you have."*

She learned from the caregiving experience that it is essential to be satisfied with her ordinary days, and this helped her to be happy; she subsequently helped people around her to realize this also. Similarly, Caregiver 8 and her patient were relieved that the patient’s circumstances were not as bad as they could have been. Caregiver 10 developed a mindset of calm, so that she could focus on what was actually possible for her to do, rather than being influenced by less important details:

> *"Just be patient. Do what you have to do when you have to do it. That about all I could tell anybody. That’s all there is to it. Know what you got to do, and just do it. Don’t get angry with someone. Or get frustrated with them. Just got to keep calm and do it as you can."*

It is a lens for reexamining not only their own life, but their interactions with other people. Throughout the caregiving experience, many caregivers were able to treat others the way they wanted to be treated themselves. As they went through the difficulties, the caregivers learned generosity and tolerance that they did not consider before. Caregiver 3 mentioned that going through the caregiving journey alongside her husband was an opportunity to develop empathy for others:

> *"I've even said to other people, if somebody's having a bad day, you see somebody and they're crabby, don't be mean back to them because you don't know what they're going through. They might be crabby because somebody's sick and dying that they know. You don't know what they're going through. Even if they're mean to you and crabby, just ignore it. Be nicer to them because you don't know what they're going through."*

Similar to Caregiver 3, Caregiver 12 pointed out how her experiences had given her increased empathy and kindness, so that she could appreciate other people's difficulties and listen to their stories:

> *"I think it's changed me a lot but it's also every day is different. I'm a lot more… It's an interesting position to be in because you see the world a lot differently. I appreciate other people's problems even more, which is weird because people think like, "Oh you're going through this horrible thing. I can't tell you my problems." But it's actually opened me up more to like, "Hey, life, whatever it throws at you, it's tough. You need support and love to deal with it."*

Caregivers 3 and 12 were able to turn their challenging experiences into learning opportunities that gave them increased compassion for other people's situations even without knowing all the details of their life stories.

As another example of the attitude change, some caregivers mentioned developing a greater sense of community. Even though they had not previously been the types of people who would ask for help, the caregiving experience gave them new perspectives on living with other people — both families and neighbors. Caregiver 7 had to relocate to a new area for his wife's treatment and could not maintain their permanent residence or tend their livestock; they needed help from other people. He mentioned how important it had been for him to learn to ask for help from his neighbors:

> *"Some special and amazing things have happened because of it that we wouldn't have experienced had this not happened. The generosity. People probably say you find out who your real friends are and we did. A lot of people were requesting to step up and I'm the person that doesn't ask for help very often. I had to learn to ask for it because I couldn't take care of her and all the property and all the animals without some help."*

Although Caregiver 7 had an independent personality which made him reluctant to ask for help, his situation left him no choice; this gave him the chance to recognize the generosity of his close friends and learn a sense of belonging. He specifically mentioned that, without the caregiving experience, he never would have had such an opportunity to feel gratitude.

4.1.2 Establishing short-term plans. Another way of establishing a new mindset was to look at short-term plans and goals. Caregivers controlled their negative thoughts associated with difficulties by focusing on the current situation: organizing a list of daily requirements and establishing practical goals. During the interview, caregivers highlighted the difficulties associated with the post-transplant recovery phase, which typically lasted at least five years and was sometimes lifelong. Many treatment milestones took longer than caregivers had initially anticipated, and return to a 'normal' life was often significantly delayed; this led caregivers to find new resources of patience. Caregivers expressed that they just wanted to get through the difficult time; this was easier if they focused on shorter intervals with specific sets of tasks. One caregiver referred to this practice as “making it day by day.” Caregiver 9 explained how her method of short-term planning — making a daily list of what needed to be done — helped her stay positive and emphasize her sense of accomplishment:

> *"I think that’s important for part of goals and accomplishments and you need to know that when you’re feeling worthless, or sick, or not right. You need to know that you’ve had times pass you’ve done these things, the accomplishments and all the things that you do, it’s going to change who you are tomorrow. I think they’re all important. I think they’re all good things. Do I make notes the things I need to? That’s in my list writing every day. I got a list in the other room right there, two of the things I should’ve done this morning, which I’m going to have to get to this afternoon. They’re going to be difference, then things I’ve done in the past or mundane things."*

As shown, even small achievements provided her with some satisfaction; her strategy for mental management involved accumulating these into a sense of greater progress.

Other caregivers have similarly mentioned that they try to establish short-term goals in order to be motivated. Simply reminding each other about family events and activities positively influenced their patience during the prolonged recovery period. Caregivers 3 and 9 mentioned that having a shared goal as a family, such as playing golf in the coming Spring or going on a vacation, helped keep their spirits up and focus on enduring the long-term treatment procedures. For example, Caregiver 3 and her husband (the patient) considered their current situation as “just a bump in the road.” They kept reminding each other that, "in a year", they would go on vacation again like they used to.

This subsection shows how caregivers help themselves overcome negative aspects of the long-term illness experience by developing a new attitude toward life and focusing on short-term perspectives. These mindsets helped caregivers focus on factors that they can control, and made it easier for them to cope with their negative situations.

4.2 Developing mindful activities: quick and easy routine behaviors and envisioning activities for positive mindset

One common change in caregivers’ lives was temporary relocation so as to be closer to the healthcare institution. During the first three months of the post-transplant phase, patients had to be within 90 minutes of travel from the medical center, to enable multiple clinic visits every week. Forced into new and unfamiliar environments where they had limited resources, caregivers experienced significant isolation and perceived that their competence in daily activities had declined. Furthermore, because of patients’ suppressed immune systems, both they and their caregivers are typically asked to avoid public places, to minimize pathogen exposure. One caregiver described their current status as “taking a three-month block of [their] life” and “locked into a very limited environment.” However, despite the social isolation and physical limitations, caregivers gradually *developed stress-relieving activities* to refresh their minds and maintain wellness. Although the hospital provided a list of peer support opportunities and group-based therapy classes for caregivers suggested by healthcare professionals, caregivers found that the suggestions did not align with their situations well; rather, caregivers devised their own activities. Also, caregivers *envisioned small activities* to improve wellness.

4.2.1 Selecting low-intensity, low-effort activities that could be easily set aside. The most frequently mentioned activities were those which were easy to both start and stop: creative work, shopping, small computer games, or just general relaxation. Caregiver 14 said she often leaves her patient (her husband) for a few hours, to visit the bookstore or art supplies shop and just browse. This was enough to refresh her. Other caregivers described recontextualizing their daily routine into leisure activities. For instance, Caregiver 3 stated that the highlight of her day was strolling around the shopping mall and the neighborhood, particularly on her way to the mailbox for get-well cards from her friends:

> *"Shopping. I've always liked shopping and I'm doing that more now. I always try to make sure, it's just down the corner, down the road to [a store], but it's my highlight of the day. To go to the mailbox, we've even joked about that. I walk down the hill here, that's the highlight of my day, going to the mailbox. We might get a card today. Before, at home, I didn't care if I ever got the mail. Now it's like, I haven't gotten a card from somebody."*

Caregivers 14 and 9 described how engaging in arts and crafts helped them stay positive. Caregiver 14 said that focusing on her own work helped her feel alive so she could provide care for her husband. Caregiver 9 also stated that craftwork enabled her to express her creativity, and reduced her concerns about the intensive caregiving schedule:

> *"These things [cards] here are all things that I make and I sell at the markets. I have a creative outlet. For me, that's better than sitting down and telling somebody, "Oh, I'm going through this, poor me. I need somebody to lift me up." I don't really need that. Neither of us are that way. Just sit down and do your craft. If you're doing your craft and you're happy and you like where you live and you like your life, then there's no problem."*

As shown, Caregiver 9 considered handcrafting cards to be more than a simple manual task; instead, it was a way to express herself, delineate emotions, become optimistic, and feel alive during a difficult time.

Other caregivers did not specify any particular activities, but rather emphasized their preference for just pausing in their daily routine to enjoy being alive - sitting on the patio, or tending to the garden. For Caregiver 9, relaxing for a short time became a habitual activity to organize herself during her busy routine:

> *"I think that's [savoring the moments] just always been a part of my daily thing. Whether it's having your coffee, I do what I need to do in the morning, then I need to stop before the day gets started. Whether it's a phone call, or whether it's a coffee, or whether it's playing with the dog on the porch or laying in the sun with him… Getting a call from somebody is important."*

In this quote, Caregiver 9 noted that she had always tried to ensure that her morning routine included pauses between her personal tasks and her work. These small activities, such as having a coffee or calling a friend, were old habits that she maintained even while caregiving; during the interview, she specifically mentioned that they enhanced her caregiving performance.

4.2.2 Envisioning types of activities to promote positive mindset in the midst of difficulties. During our interview, many caregivers expressed their desire to engage in small activities to improve their wellness. Caregiver 2 shared her feelings of emptiness when the patient concentrated on her own interests: because her focus had shifted outside herself, she had nothing to do when the patient did not need help:

> *"When she [the patient] went away or she does her own stuff, I feel like I don't have anything to do. (Laughter.) I feel empty, like I should be doing something."*

Caregivers also showed willingness to perform different activities, including sports, or exploring their temporary new neighborhoods. Many caregivers particularly mentioned gardening and harvesting as their stress relief, and expressed a desire to continue gardening after their current situation is resolved. Caregiver 6 stayed at her temporary residence during the patient's recovery phase, but planned to resume gardening as soon as she got back home. Tending plants relieved her stress:

> *"If I were home, I would be outside in the garden later this afternoon planting, taking out weeds. That's helped me with stress a lot."*

Other caregivers mentioned that they had stopped socializing due to the severity of the patient's condition, but hoped for an eventual "caregiver's night out." Caregiver 8 noted that it would be nice to explore the region with their patient, because they had never been in that area before. Similarly, Caregiver 14 mentioned many places near their temporary residence that she and her husband were interested in visiting; because they would be there for months, she expected that she would enjoy a tour:

> *"Fun things for someone to do or interesting places. There's an amazing art gallery downtown that's part of the university that's free. Never knew that. Maybe having something that shows people things they can do that are inexpensive or free or easy enough to do. Wouldn't it be nice if someone came to make you go on that walk with them? That's something that I would love to be involved in."*

As these examples show, what caregivers desired for stress relief was simple everyday activities that can be integrated into their daily routine. While the caregivers were excited to share their plans and describe their own activities, they emphasized that activities must not be burdensome, as their daily lives are dedicated to caregiving, and are already busy and exhausting. In particular, some participants were displeased with the notion — suggested by a psychologist who was a part of our research team — of writing 'gratitude journals' to list all the things they were thankful for. Some expressed that this might cause schedule conflicts with their daily caregiving tasks. Caregiver 3 noted that even the idea of such an activity was difficult, due to the burdens of the situation. Similarly, Caregiver 7 was hesitant to take up any new regular activity that was not part of caregiving:

> *"Quite frankly, I wouldn't do it. There was just so much here and now stuff that I have to do that there isn't anything left over for that."*

As this quote shows, he was overwhelmed by his required tasks, and did not want to add anything else that was not directly part of caregiving, even if it would have helped relieve his burden.

In summary, our results show that caregivers independently developed activities to maintain a stable mindset, rather than relying on pre-existing external resources that were suggested by their healthcare institutions or clinicians. It is essential that any stress-relief activities suggested to caregivers not require learning or acquiring new skills; rather, they should be simple, quick, and familiar.

4.3 Learning relationship managing strategies: efficient communication and having separate time

Caregivers needed their patients to comply with health requirements at all times; this is frequently a cause of tension, as pre-diagnosis relationships (most often parental or spousal) changed dramatically in nature. Many caregivers noted that caregiving is like "having a toddler in the home" as they have to pay constant attention to their patient: remind them to take medications, wear a mask, wash their hands, and eat properly. When patients were hospitalized, they had a professional team filling these clinical roles; caregivers were able to revert to being supportive and comforting family members. However, after patients were no longer in hospital, all tasks — including the medical ones (e.g., central line care), — became the responsibility of the caregiver. They often struggled with patients who were reluctant to fully comply with medical requirements, which caused significant frustration to both. To handle these issues, caregivers gradually *developed the skills of having efficient communication and spending time apart from each other.* As a result, they eventually realized the value of their family relationships.

4.3.1 Having efficient communication with patients. We identified how caregivers handle the difficulties coming from the relationship changes. The most commonly mentioned ways to alleviate tension involved use of communication strategies. Examples include having open conversations to alleviate potential misunderstandings, and strategies to persuade the patient to comply with medical requirements. Caregiver 14 shared her method for reducing unnecessary tensions. Although asking the patient to comply with strict requirements (on, e.g., fluid intake) had some negative influences on their relationship, her ways of being open and sharing emotions with her husband worked well for them:

> *"There is that dynamic. . . Being a caregiver, I was worried about it because he can be kind of stubborn if he would listen to me. Sometimes I have to be not very nice and say you have to do this. It doesn't matter what you want. I know you don't like it. And that's not fun, but he understands. And if there is that then a few hours later it's like I'm sorry I had to nag you about that and he goes, "I know I needed to do it.". . . We've been dealing with a son with chronic pain for almost nine years."*

As the quote shows, Caregiver 14's way of expressing her feeling made her husband step back, understand the caregiver's real intention, and know his requirements as a patient. They mentioned that relationship conflicts could be pervasive in the caregiving context; however, her previous experience as a caregiver for her son had taught her how to navigate these difficulties with open communication strategies. Similarly, Caregiver 10 pointed out the importance of direct and candid communication about what they disliked. Because they were able to have open conversations, their relationship was not affected by the challenging experience:

> *"We both tell each other how it is. We don't get mad at each other. We just say tell each other. He does something I don't like. I just tell him. He's the same way with me. It works out fine. We've always had a good relationship."*

Some caregivers had to resort more to persuasion than to open communication. Caregiver 8 noted that her brother persistently disobeyed the clinicians' instructions, despite her best efforts — a major source of stress. Although he had been repeatedly told of the importance of precautions that he needed to follow (e.g., minimized exposure to the public), he ate in public restaurants, exercised in a public gym, and did not wear a mask. Finally, she used a metaphor which one of the home nurses had suggested:

> *"I'm trying incredibly [hard] to come up with analogies, similes, and examples and all the stuff for the last three weeks to get him to understand that things that are not prepared and he cannot eat them. So the one home visit nurse gave us this analogy, he told her about the exercise machine. And she said, "Oh my goodness, you can't do that. You don't want to get on an exercise machine where people are all sweaty. It would be as if you went in and sat down on the floor of a public restroom to sit on that machine." So I have now used that analogy on eating food and it's starting to click."*

To minimize struggle while helping patients follow the necessary steps to recover, caregivers had to learn from their experiences how to effectively communicate with their loved ones.

4.3.2 Spending time apart from each other. Other caregivers noted that spending time apart from their patients allowed them to vent their feelings and maintain stable relationships. Time apart was acquired by involving other people, and by allocating activities of daily life to the patient once they are physically able; this enabled the caregiver and patient to rebalance their relationship. Caregivers pointed out the importance of respite care: having family and friends take turns with the patient. Caregiver 10 mentioned that sometimes the patient's girlfriend would stay with him, and sometimes his daughter would; in this way, the caregiver got time off. Similarly, Caregiver 12 received regular assistance with her husband, from her parents.

Dividing self-care tasks with the patient was another way to minimize conflict: as patients recovered, they became more able to handle tasks like medication intake and daily life activities like cooking and cleaning. For example, Caregiver 5 focused on cleaning the room, and left Patient 5 in charge of medication management and organizing her personal belongings. Similarly, as Patient 11's condition improved, he began to manage some aspects of his routine, including medication refills.

Having their own time was important not just for the caregiver, but also for the patient. Patient 7 mentioned that she has friends who would take turns caring for her, so that her husband (Caregiver 7) could have his own time: she wanted him to not be exhausted during the long-term care process:

> *"I have one friend that has self-volunteered to come over Wednesdays because that works for her, and I love it when she comes over. We just do something or nothing depending on how I feel. I love that. Someone else that tends to come over on Saturday. Again, we do whatever I can do. It's important to take care of the caregiver so you don't burn them out. Now that I'm doing better and I can stay home alone a little bit. He's just a phone call away and that works."*

As Patient 7's health status improved over time, she was able to stay at home alone a little longer. As such, Caregiver 7 and her husband could then spend more time apart like they used to. Similarly, Patient 5 also enjoyed her time with her brother, which alleviated the tension with Caregiver 5 (her mother). The major reason for this was that she had different relationships with different family members; interacting with her brother helped her to vent her feelings about her mother so that she could be around her for longer periods:

> *"With my brother, it helps because he knows our family dynamic. Usually, it's like, "Oh, man, I'm like a baby. I'm being swaddled." Or me complaining about, "I can't drive anymore." This stuff. With my parents, they're like, "You need to focus on your health. You need to focus on your health." Sometimes we've had a little bit of misunderstandings because I'm like I lost a lot of other stuff, too, because I had to move and quit my job right abruptly. Just a whole bunch of change I was just not ready for with the diagnosis. It was all like, "We have to take action now, or you're going to die.""*

As this quote shows, patients were able to ease their feelings by talking to people who already understood the relationship dynamics between patient and caregiver. Just sharing her feelings with her brother was enough to ease Patient 5's mind, so that she could properly feel cared for and understood.

During the interview, all caregivers noted how they felt connected to their patients, and with their friends and relatives who provided unconditional, generous support to overcome difficulties during their caregiving journey. Our findings show that, by going through life-threatening experiences with the people who were close to them, they were able to learn coping strategies and properly appreciate the value of their interpersonal relationship.

4.4 Reducing uncertainty by sharing experience with people in their own networks: benefiting from other people's experiences and using group-based communication channels

After patients were discharged from their hospitals, healthcare professionals provided in-home caregiving education; this was also done via home nurse visits and outpatient clinic appointments. This education informed the caregivers what medical milestones to expect, and what in-home activities to perform (e.g., central line care, magnesium infusion, medication administrations). However, these objective, technical instructions provide no guidance on how caregivers can deal with the post-transplant emotional uncertainty. To manage the uncertainty and associated emotional burdens, many caregivers *seek advice from people in their own networks,* to supplement the medical information from healthcare professionals. Caregivers also enjoyed helping others (e.g., their family members, friends) handle the uncertainty about their patients' conditions by *using group-based communication channels.*

4.4.1 Benefiting from people in their own networks who have experience and knowledge of upcoming treatment phases. To get background information, and to understand what would happen based on what rationale, caregivers often relied on friends or relatives who had previously undergone similar experiences (e.g., cancer treatment and caregiving). To ease her mind, Caregiver 2 reached out to her acquaintances who had gone through a similar experience:

> *"I have friends, a friend of my son, she actually went to, took him to his prom with her. He ended up [the chronic condition], so I talk to his mom. Somebody who's been through it. She's got two friends that have been through cancer. I talk with them occasionally, or one of the mom's… It helped at first. The first few months, a lot of crying, a lot of screaming and yelling when you're by yourself."*

As the quote shows, many caregivers found that the first several months of the caregiving trajectory were the most extreme. In this difficult time, what helped her was communicating with friends who had gone through similar experiences.

Caregivers also felt relieved when they talked to other people - both patients and other caregivers - at the outpatient clinic of inpatient facilities. Although they did not know each other, this allowed them to be more aware of the upcoming situation. Caregiver 11 shared her experience of talking to a man who went through the same process as her husband during their hospitalization:

> *"There was a gentleman that came into the hospital, probably the second week after the transplant, and he was nine years out from having the exact same thing. He was awesome. He talked for a half hour, maybe. He stood there and talked to us and told us what he went through, "Not that you're going to go through the same thing." I would love to see more people do that. The one thing I said to him the next day is, I wish I had asked if his wife ever comes with him. His wife, from what he said, was a huge supporter and really good and everything. I would have liked to have a woman or a support person in there to give more information about that. She was great."*

Even though Caregiver 11 acknowledged that each person's experience is unique, just listening to other people tell her about having gone through the same treatment processes was valuable: it gave her guidance on how to be a better caregiver. Her experiences in the clinic left a positive impression, and she wanted to know more people who had similar illness-and-caregiving experiences. She found existing support groups inadequate, because they only connected still-active caregivers; what relieved her anxiety was talking with people who had finished caregiving. Like Caregiver 11, Caregiver 3 connected to a previous patient who had gone through a similar experience:

> *"There was a [guy] that came to the hospital that had the transplant done a number of years ago, that just came to the hospital and just came in and talked to people. I thought that was great, to let them know what his journey was all about. He was very encouraging. I certainly would like to be able to do something like that somewhere down the road. If you're capable of doing something you try to give something back. I've attempted to do that through things like this."*

As the quote shows, she felt encouragement from the person who visited the clinic and shared his illness experiences with others. She hopes to, in the future, give back to others who undergo the same difficulties.

4.4.2 Using group-based communication channels to update their close family and friends. In addition to alleviating their own uncertainties by acquiring knowledge from their networks, they also provided their own information to others involved in the caregiving process, via group-based communication channels: in particular, our results show that — like the caregivers and their patients — their friends and relatives. Because friends and relatives were aware that the patient was undergoing a life-threatening event, they were anxious about the patient's condition. To ease their concerns and keep them informed, caregivers established private communication channels, such as group chats, email lists or social network service (SNS). Caregivers found those group-based communications were helpful as they could comfort people who they care about. For example, Caregiver 3 and her husband (patient) shared how their daughter used the SNS channel to keep friends and family informed. They initially exchanged status updates via text messages and phone calls, but were soon overwhelmed by the amount of work involved; an SNS group made it easier to post necessary details such as care transition events or new physical addresses. Caregiver 7 shared similar strategies for updating people:

> *"We have a list of family and friends, a picked-out list of who we want to share the information with. My daughter writes email updates that go to those people. Initially, it was a bit of a problem because everybody that you talk to, you've got this life-changing event. You see your friend Joe at the bar or you're having dinner and it's like, "What's going on? How's it going?" The usual answer is it's fine, everything is good. You've got to go through this long thing. I found that therapeutic to be able to say it over and over again, to internalize it. It gets old and you don't have to share it with every single person."*

As the quote shows, the caregiver's family created a list of people who wanted updates on the patient's status. It also helped the caregiver accept the situation, by giving him a platform to vent his feelings. Although delivering information and revealing the life-threatening experience was not easy, sharing their harrowing story inadvertently became a therapeutic activity that allowed them to accept the illness experience as a part of their lives, by discussing it openly and repeatedly. Rather than setting up her own channel, Caregiver 11 created an account on a pre-existing website, run by a non-profit organization and dedicated to allowing patients, caregivers, and family and friends to communicate. They can invite people and exchange comments about the patient's progress. She found this website to be helpful to keep everyone informed and updated. Like Caregivers 3 and 7, she found that it took too much time and effort to tell all her friends and relatives about the patient's status separately, and so she created an account on the support website:

> *"It's a website that you go into, and you can invite people in to look at it. Then I just go in and put a journal entry in. Then when I do, everybody gets something that says there's been something edited, and they can go in and look at it. They have to be invited. Then they go in and just sign up, make their own password. I was planning to do it the whole time before he went in, but then when he had that heart issue it was like spur the moment,*

> *so I was texting a thousand people. Finally, it's like, I can't do this anymore, so we use that. It's so much better. I just do a few now, the family members and the rest on there."*

As shown by these examples, caregivers gradually developed effective group-based communication channels, to inform people, allowing them to provide updates and information and thereby ease people's concerns about the patient.

In summary, our results show that caregivers acquired useful information and resources from the existing healthcare system, such as clinicians, social workers, and their healthcare institution. However, the system is procedure-centric, and does not provide guidance on ways to alleviate emotional difficulties or ease their loved ones by updating them regularly. This led caregivers to rely on themselves or the experiences of people in their network.

5 DISCUSSION

5.1 From needs-driven to asset-based approaches for viewing caregivers

Before conducting in-home interviews, we spent two years observing BMT patients and their caregivers in hospital settings. We observed caregivers and patients while they were hospitalized for transplantation or visiting physicians in outpatient clinic rooms. When caregivers were in the hospital context, they were always busy receiving, memorizing, and understanding instructions from healthcare professionals. Typically, the information flow was in one direction only. However, during the in-home interviews, we were surprised by how much knowledge caregivers had acquired and how many strategies they had developed independently. These strategies were often more practical than the ones suggested by healthcare professionals. For example, clinicians suggested that caregivers could relieve their stress by using a hospital's designated, social support services (e.g., support group, group-based therapy classes). However, caregivers perceived these suggestions as extra work and in conflict with their busy, caregiving schedules. Rather, they found emotional comfort, encouragement, and reduced anxiety in small craft activities and brief, daily pauses. Our participants developed coping strategies by focusing on everyday caregiving tasks. Healthcare providers have not recognized these strategies as valuable assets, regardless of how useful they are.

In previous patient-centered studies [59, 61], caregivers were invisible actors or secondary actors whose main role was to support patients as medical information trackers or decision makers for patients' medical procedures. When caregivers' knowledge was discussed in these studies, it was for supporting patients rather than for themselves. After caregivers became a primary actor in healthcare studies, caregivers' problems (e.g., their emotional burdens) were mainly investigated and technologies were envisioned to help them handle these challenges. Previous studies briefly mentioned the coping strategies of caregivers, but the capacities of caregivers were rarely at the center of the discussion. For example, Kaziunas et al. discussed communicating with fellow caregivers, following clinicians' health management protocols, or creating information artifacts with rich meanings as useful coping strategies for caregivers [40]. However, those coping strategies are just one small portion of the study's finding. The study viewed caregivers primarily as individuals who were experiencing difficulties with a large amount of emotional and informational work. Thus, the main goal of this body of research [6, 18, 40, 73] was to fulfill the needs and deficits of caregivers with technologies. Building on these previous studies that highlighted the complex social needs of caregivers, our main focus was to examine the strengths and capacities that the caregivers already possessed.

In our study, participants showed that a challenging experience offered them strengths and experiential knowledge of how to navigate the situation. Like the knowledge-making process of any researcher, the long-term, hands-on experience of a topic can offer nuanced understanding of the issues as well as practical solutions. In that sense, caregivers are the domain experts of caregiving who have invaluable experiences that healthcare professionals or other researchers do not have. By placing the focus on the caregivers' accumulated strategies and strengths, we suggest an asset-based approach as a way to incorporate caregivers' devalued knowledge into technology design. An asset-based approach will enable design researchers to 1) pay more attention to caregivers' knowledge and strategies, 2) leverage the knowledge developed by caregivers, and 3) incorporate them into their research processes and design. We are not arguing that caregivers do not need support from healthcare practitioners, social workers, or technologies. Instead, we suggest that those assistants should support caregivers to find and develop their existing strengths and assets rather than merely to provide prescribed solutions. In this way, the support from others could be more sustainable solutions for caregivers [96].

A rich body of recent CSCW/HCI work has highlighted the importance of strength, assets, and resilience [36–38, 46, 56, 82, 82, 91, 95, 97]. The integration of caregivers' assets into technology designs can change the social dynamics between caregivers and healthcare professionals, so that caregivers can no longer be considered to have inherently less knowledge. With this alternate system, the knowledge flow between the healthcare professional and the caregiver becomes reciprocal. When caregivers share their experiential knowledge and strategies with clinicians, they can provide constructive feedback and contribute to idea development. Caregivers' experiential knowledge can be stored and circulated as part of organizational resources (e.g., pre-transplant education videos, discharge education, or booklets for caregivers) within the existing infrastructure.

5.2 Supporting the strength of caregivers through asset-based design

As an asset-based approach has been used in various disciplines, each discipline utilizes this framework in heterogenous ways. For example, Yosso focused on the capacities of students of color, such as the ability to speak two languages [100]. Previously, such an ability was considered a problem that hindered their capacity to learn English. On the other hand, Mathie and Cunningham maintained that existing infrastructure (e.g., libraries, community centers) of the community should be considered for their ABCD research [57]. However, there are two aspects that asset-based studies commonly incorporate and that also align well with the findings of our caregiver study. One is to focus on the existing capacities of participants to avoid researchers' presumptions (e.g., caregivers as people with difficulties). Another is the importance of existing social relationships, which participants have built within their family or community.

The first aspect of an asset-based approach is about appreciating the existing capacities of participants. Permitting participants to focus on their capacities will help them mobilize those existing assets to change their behaviors or better handle issues that they might face [57, 100]. For example, Mathie and Cunningham pointed out that reminding participants of their successful, past experience lets them find energy to change their behavior [57]. Yosso maintained that acknowledging students' efforts to navigate difficulties and continue pursuing their dream in education processes provides opportunities for them to see themselves as people who have abilities to handle their difficulties [100]. All caregivers in our study shared their challenging experiences. However, more importantly, they came up with their own strategies to work on the difficulties. Through the process, they learned how to change their mind set (e.g., by focusing more on short-term than long-term plans) and develop simple activities to maintain a positive mind set. An asset-based design can be a promising approach in caregiver studies, when one considers the significance to themselves of caregivers' own knowledge and the benefits of incorporating the existing capacities of individuals in previous studies. Using an asset-based design, future work could explore more specific design features to amplify these caregivers' assets with technologies [57].

An additional core aspect of an asset-based approach is about social relationships that develop from formal and informal networks [57, 100]. This refers to familial, and social capital that encompass a sense of family care and bond as well as community resources [100]. Because these types of goodwill and obligation assets originate from individual relationships with others [57], individual behaviors are understood within the relationships. Our findings echoed that caregivers' strategies include seeking advice from fellow caregivers and relationship management strategies with patients as well as information and emotional support from their network. Caregivers learned effective coping strategies in relationships with patients, family members, and fellow caregivers. Caregivers also expressed their desire to disseminate acquired knowledge and experiences through their social contacts and thereby to contribute to larger caregiver community resources. The knowledge implemented in the network and broader institutions would help new caregivers prepare for the challenges they may encounter in caregiving practices. As discussed in previous asset-based studies and in our work, the importance of this social capital indicates that further caregiver studies could actively incorporate the benefits of the existing social relationships of caregivers, so that they can utilize one of their most important assets.

5.3 Exploring practical reflexivity through asset-based design for broader marginalized groups

An asset-based approach has been discussed as a way to criticize existing epistemology and help researchers avoid a stereotyped view of members of marginalized communities. For example, Yosso suggests how students of color possess their own *community cultural wealth* in contrast to the previously dominant beliefs about these students[100]. According to the renowned theory of Bourdieu [11], only the knowledge of the upper and middle classes is considered valuable capital, which lets these classes continue to increase potential social mobility and maintain a hierarchical society. This conventional definition of valuable knowledge permitted education researchers to focus on the *lack* of social and cultural capital of students of color, which has been used to explain the lower academic and social performance of these groups when compared to whites. Yasso found that this deficit-focused approach deprives these people of the opportunity to express their own capital or learn how to utilize their existing capacities.

In a similar way, CSCW and HCI communities have continually discussed how researchers have reflected their unexamined biases towards marginalized groups and explored how to avoid them within technology-design processes [3, 5, 5, 8, 23, 25, 29, 34, 35, 48, 52, 54, 69, 70, 94]. For example, researchers discussed how the knowledge of people in developing countries has been marginalized in system design because of historically developed power dynamics between the global north and south (e.g., colonialism) [25, 35, 46, 58]. Ageism is also an example of an unexamined bias of researchers that reflects a stereotyped view of older adults primarily as people with problems [24, 44, 47, 48, 90]. In addition to these studies, participatory design has been actively utilized to incorporate the contextual knowledge of underserved groups [12, 13, 31, 42, 50, 67, 68, 77, 79]. In line with this series of studies, an asset-based approach could provide an additional conceptual lens for researchers to be reflexive in a practical way.

Experimenting with an asset-based approach within caregiving contexts provides a chance to explore a practical reflexivity with broader, socially marginalized communities. Caregiving has long been invisible and devalued [18, 20, 55, 59, 71]. Recently, caregivers gained more attention and have been included in system design processes; however, the gained visibility does not guarantee that the knowledge or capacities of caregivers can actively be incorporated within design. When compared to the groups for which CSCW and HCI scholars have used an asset-based approach (e.g., human sex-trafficking survivors [30], low-income Hispanic parents [95]), caregivers might be considered a group that is less socio-economically marginalized. However, the knowledge of caregivers that has been devalued in healthcare and broader society. Due to these conventional views towards caregivers' knowledge, researchers might not have been realized the importance of caregivers' assets. Thus, asset-based caregiver studies might convince researchers that an asset-based approach could be useful in that they might look into their unexamined biases about caregivers' knowledge. Such an approach could enhance researchers' reflexivity when they consider the epistemic culture and power dynamics between researchers and participants in boarder contexts. Despite the long discussion of reflexivity in design, the negotiation process between researchers and participants is still not easy [7, 31, 51, 66, 80, 87]. The inclusion of participants in system design processes does guarantee that researchers can avoid their unexamined biases towards participants. An asset-based approach could be a useful framework to help researchers focus on the existing strengths and capacities of participants, which they would not ascertain without additional efforts. Caregiver studies could show the possibilities.

6 CONCLUSION

The position of caregivers in healthcare literature has changed. In earlier studies, caregivers were *invisible actors* who were less important, compared to patients and healthcare professionals. In recent studies, caregivers have received more attention as important actors. However, even after gaining more visibility, caregivers are primarily considered people who need more help because of the challenges and difficulties they face. Like the previous studies, we were originally interested in how to improve the mental health of caregivers in the midst of intensive caregiving for their BMT patients. As we conducted interviews with caregivers, however, the most common themes that emerged were the types of their knowledge rather than the types of their challenges. Based on these findings, we highlight the importance of caregivers' strengths and assets, which they acquired while dealing with the challenges they encountered in their everyday experiences. To focus more on the knowledge and assets of caregivers in a system design, we suggest asset-based approaches as promising perspectives in caregiver studies. The knowledge of caregivers has long been devalued and invisible in healthcare studies as well as in a broader society. We hope this study brings more attention to the role of caregivers as knowledge makers.

ACKNOWLEDGMENTS

This work was funded in part by NIH/NHLBI grant (1R01HL146354) and an American Society of Hematology Bridge Grant. We would like to thank the caregivers and patients who shared valuable assets with us. We would also like to thank the anonymous reviewers, who substantially improved this paper.

REFERENCES

[1] Family Caregiver Alliance. 2009. Caregiving. https://www.caregiver.org/caregiving

[2] Tawfiq Ammari and Sarita Schoenebeck. 2015. Networked empowerment on Facebook groups for parents of children with special needs. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems.* 2805–2814.

[3] Seyram Avle and Silvia Lindtner. 2016. Design (ing)'Here'and'There' Tech Entrepreneurs, Global Markets, and Reflexivity in Design Processes. In *Proceedings of the 2016 CHI conference on human factors in computing systems.* 2233–2245.

[4] Hoda Badr, Cindy L. Carmack, and Michael A. Diefenbach. 2015. Psychosocial interventions for patients and caregivers in the age of new communication technologies: Opportunities and challenges in cancer care. *Journal of Health Communication* 20, 3 (2015), 328–342.

[5] Shaowen Bardzell. 2010. Feminist HCI: taking stock and outlining an agenda for design. In *Proceedings of the SIGCHI conference on human factors in computing systems.* 1301–1310.

[6] Andrew B L Berry, Catherine Lim, Andrea L Hartzler, Tad Hirsch, Edward H Wagner, Evette Ludman, and James D Ralston. 2017. How Values Shape Collaboration Between Patients with Multiple Chronic Conditions and Spousal

Caregivers. (2017).

[7] Jeanette Blomberg and Helena Karasti. 2012. Positioning ethnography within participatory design. *Routledge international handbook of participatory design* (2012), 86–116.

[8] Jeanette Blomberg and Helena Karasti. 2013. *Reflections on 25 years of ethnography in CSCW.* Vol. 22. 373–423 pages.

[9] Kay Blum and Deborah W. Sherman. 2010. Understanding the Experience of Caregivers: A Focus on Transitions. *Seminars in Oncology Nursing* 26, 4 (2010), 243–258.

[10] Lilian Bernadina Josefina Bosch and Marije Kanis. 2016. Design opportunities for supporting informal caregivers. In *Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems.* 2790–2797.

[11] Pierre Bourdieu, Jean-Claude Passeron, Jaume Melendres, and Marina Subirats. 1977. *La reproducción: elementos para una teoría del sistema de enseñanza.* Laia Barcelona.

[12] Tone Bratteteig, Keld Bødker, Yvonne Dittrich, Preben Holst Mogensen, and Jesper Simonsen. 2013. Organising principles and general guidelines for Participatory Design Projects. *Routledge international handbook of participatory design* (2013), 117–144.

[13] Tone Bratteteig and Ina Wagner. 2012. Disentangling power and decision-making in participatory design. In *Proceedings of the 12th Participatory Design Conference: Research Papers-Volume 1.* 41–50.

[14] Joseph V Burger. 1994. Keys to Survival: Highlights in Resilience Research. *Journal of Emotional and Behavioral Problems* 3, 2 (1994), 6–10.

[15] Ayşe G Büyüktür and Mark S Ackerman. 2015. Issues and opportunities in transitions from speciality care: A field study of bone marrow transplant. *Behaviour and Information Technology* 34, 6 (2015), 566–584.

[16] Dima Chaar, Ji Youn Shin, Amanda Mazzoli, Rebecca Vue, Jacob Kedroske, Grant Chappell, David A Hanauer, Debra Barton, Afton L Hassett, and Sung Won Choi. 2019. A Mobile Health App (Roadmap 2.0) for Patients Undergoing Hematopoietic Stem Cell Transplant: Qualitative Study on Family Caregivers' Perspectives and Design Considerations. *JMIR mHealth and uHealth* 7, 10 (2019), e15775.

[17] Kathy Charmaz. 2014. *Constructing grounded theory.* Sage.

[18] Yunan Chen, Victor Ngo, and Sun Young Park. 2013. Caring for caregivers: designing for integrality. In *Proceedings of the 2013 conference on Computer supported cooperative work.* 91–102.

[19] Nai-Ching Chi and George Demiris. 2015. A systematic review of telehealth tools and interventions to support family caregivers. *Journal of telemedicine and telecare* 21, 1 (2015), 37–44.

[20] Ruth Schwartz Cowan. 1983. *More work for mother.* basic books.

[21] George Demiris. 2020. Caregiver-Centered Communication: A New Tool for Assessment of the Quality of Communication With Family Caregivers. *Innovation in Aging* 4, Suppl 1 (2020), 571.

[22] George Demiris, Karla Washington, Connie M Ulrich, Mihail Popescu, and Debra Parker Oliver. 2019. Innovative tools to support family caregivers of persons with cancer: the role of information technology. In *Seminars in oncology nursing.* Elsevier.

[23] Audrey Desjardins and Aubree Ball. 2018. Revealing tensions in autobiographical design in HCI. In *proceedings of the 2018 designing interactive systems conference.* 753–764.

[24] Mark Díaz, Isaac Johnson, Amanda Lazar, Anne Marie Piper, and Darren Gergle. 2018. Addressing age-related bias in sentiment analysis. In *Proceedings of the 2018 chi conference on human factors in computing systems.* 1–14.

[25] Paul Dourish and Scott D Mainwaring. 2012. Ubicomp's colonial impulse. In *Proceedings of the 2012 ACM conference on ubiquitous computing.* 133–142.

[26] Lori L. Dubenske, David H. Gustafson, Bret R. Shaw, and James F. Cleary. 2010. Web-Based cancer communication and decision making systems: Connecting patients, caregivers, and clinicians for improved health outcomes. *Medical Decision Making* 30, 6 (2010), 732–744.

[27] Pin Sym Foong, Charis Anne Lim, Joshua Wong, Chang Siang Lim, Simon Tangi Perrault, and Gerald C H Koh. 2020. " You Cannot Offer Such a Suggestion" Designing for Family Caregiver Input in Home Care Systems. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems.* 1–13.

[28] Carolina Fuentes, Valeria Herskovic, Jurgen Heysen, and Monica Tentori. 2013. Towards a technology for caregivers' emotional expression and self-reflection. In *Ubiquitous Computing and Ambient Intelligence. Context-Awareness and Context-Driven Interaction.* Springer, 143–150.

[29] Patricia Garcia and Marika Cifor. 2019. Expanding our reflexive toolbox: Collaborative possibilities for examining socio-technical systems using duoethnography. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW (2019), 1–23.

[30] Aakash Gautam, Deborah Tatar, and Steve Harrison. 2020. Crafting, Communality, and Computing: Building on Existing Strengths To Support a Vulnerable Population. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems.* 1–14.

[31] Christina N. Harrington, Sheena Erete, and Anne Marie Piper. 2019. Deconstructing community-based collaborative design: Towards more equitable participatory design engagements. *Proceedings of the ACM on Human-Computer*

Interaction 3, CSCW (2019).

[32] Matthew K Hong, Clayton Feustel, Meeshu Agnihotri, Max Silverman, Stephen F Simoneaux, and Lauren Wilcox. 2017. Supporting Families in Reviewing and Communicating about Radiology Imaging Studies. (2017), 5245–5256.

[33] Matthew K Hong, Udaya Lakshmi, Kimberly Do, Sampath Prahalad, Thomas Olson, Rosa I Arriaga, and Lauren Wilcox. 2020. Using Diaries to Probe the Illness Experiences of Adolescent Patients and Parental Caregivers. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. 1–16.

[34] Dorothy Howard and Lilly Irani. 2019. Ways of Knowing When Research Subjects Care. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. 1–16.

[35] Lilly Irani, Janet Vertesi, Paul Dourish, Kavita Philip, and Rebecca E Grinter. 2010. Postcolonial computing: a lens on design and development. In *Proceedings of the SIGCHI conference on human factors in computing systems*. 1311–1320.

[36] Azra Ismail and Neha Kumar. 2019. Empowerment on the margins: The online experiences of community health workers. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. 1–15.

[37] Naveena Karusala, Isaac Holeman, and Richard Anderson. 2019. Engaging Identity, Assets, and Constraints in Designing for Resilience. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW (2019), 213.

[38] Naveena Karusala, Aditya Vishwanath, Arkadeep Kumar, Aman Mangal, and Neha Kumar. 2017. Care as a resource in underserved learning environments. *Proceedings of the ACM on Human-Computer Interaction* 1, CSCW (2017), 1–22.

[39] Elizabeth Kaziunas, Ayse G. Buyuktur, Jasmine Jones, Sung W. Choi, David A. Hanauer, and Mark S. Ackerman. 2015. Transition and Reflection in the Use of Health Information. *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing - CSCW '15* (2015), 1763–1774.

[40] Elizabeth Kaziunas, Ayse G Buyuktur, Jasmine Jones, Sung W Choi, David A Hanauer, and Mark S Ackerman. 2015. Transition and reflection in the use of health information: the case of pediatric bone marrow transplant caregivers. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing*. ACM, 1763–1774.

[41] Jacob Kedroske, Sarah Koblick, Dima Chaar, Amanda Mazzoli, Maureen O'Brien, Lilian Yahng, Rebecca Vue, Grant Chappell, Ji Youn Shin, and David A Hanauer. 2020. Development of a national caregiver health survey for hematopoietic stem cell transplant: qualitative study of cognitive interviews and verbal probing. *JMIR formative research* 4, 1 (2020), e17077.

[42] Finn Kensing and Jeanette Blomberg. 1998. Participatory design: Issues and concerns. *Computer supported cooperative work (CSCW)* 7, 3-4 (1998), 167–185.

[43] Youngmee Kim, Richard Schulz, and Charles S Carver. 2007. Benefit finding in the cancer caregiving experience. *Psychosomatic medicine* 69, 3 (2007), 283–291.

[44] Bran Knowles, Yvonne Rogers, Jenny Waycott, Vicki L. Hanson, Anne Marie Piper, and Nigel Davies. 2019. HCI and aging: Beyond accessibility. *Conference on Human Factors in Computing Systems - Proceedings* (2019), 1–8.

[45] John Kretzmann and John P McKnight. 1996. Assets-based community development. *National civic review* 85, 4 (1996), 23–29.

[46] Neha Kumar, Azra Ismail, Samyukta Sherugar, and Rajesh Chandwani. 2019. Restoration Work: Responding to Everyday Challenges of HIV Outreach. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW (2019), 1–26.

[47] Amanda Lazar, Mark Diaz, Robin Brewer, Chelsea Kim, and Anne Marie Piper. 2017. Going gray, failure to hire, and the ick factor: Analyzing how older bloggers talk about ageism. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing*. 655–668.

[48] Hee Rin Lee and Laurel D Riek. 2018. Reframing assistive robots to promote successful aging. *ACM Transactions on Human-Robot Interaction (THRI)* 7, 1 (2018), 1–23.

[49] Hee Rin Lee and Selma Šabanović. 2013. Weiser's dream in the Korean home: collaborative study of domestic roles, relationships, and ideal technologies. In *Proceedings of the 2013 ACM international joint conference on Pervasive and ubiquitous computing*. 637–646.

[50] Hee Rin Lee, Selma Šabanović, Wan-Ling Chang, Shinichi Nagata, Jennifer Piatt, Casey Bennett, and David Hakken. 2017. Steps toward participatory design of social robots: mutual learning with older adults with depression. In *Proceedings of the 2017 ACM/IEEE international conference on human-robot interaction*. 244–253.

[51] Hee Rin Lee, Selma Šabanović, and Sonya S Kwak. 2017. Collaborative map making: a reflexive method for understanding matters of concern in design research. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. 5678–5689.

[52] Hee Rin Lee, Selma Šabanovic, and Erik Stolterman. 2014. Stay on the boundary: artifact analysis exploring researcher and user framing of robot design. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 1471–1474.

[53] Hee Rin Lee, Haodan Tan, and Selma Šabanović. 2016. That robot is not for me: Addressing stereotypes of aging in assistive robot design. In *2016 25th IEEE International Symposium on Robot and Human Interactive Communication*

(RO-MAN). IEEE, 312–317.

[54] Silvia Lindtner, Shaowen Bardzell, and Jeffrey Bardzell. 2016. Reconstituting the utopian vision of making: HCI after technosolutionism. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*. 1390–1402.

[55] Kiel Long, Lyndsey L Bakewell, Roisin C McNaney, Konstantina Vasileiou, Mark Atkinson, Manuela Barreto, Julie Barnett, Michael Wilson, Shaun Lawson, and John Vines. 2017. Connecting those that care: Designing for transitioning, talking, belonging and escaping. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. 1339–1351.

[56] Gloria Mark and Bryan Semaan. 2008. Resilience in collaboration: Technology as a resource for new patterns of action. In *Proceedings of the 2008 ACM conference on Computer supported cooperative work*. 137–146.

[57] Alison Mathie and Gord Cunningham. 2003. From clients to citizens: Asset-based community development as a strategy for community-driven development. *Development in practice* 13, 5 (2003), 474–486.

[58] Samantha Merritt and Shaowen Bardzell. 2011. Postcolonial language and culture theory for HCI4D. In *CHI'11 Extended Abstracts on Human Factors in Computing Systems*. 1675–1680.

[59] Andrew D Miller, Sonali R Mishra, Logan Kendall, Shefali Haldar, Ari H Pollack, and Wanda Pratt. 2016. Partners in Care: Design Considerations for Caregivers and Patients During a Hospital Stay. *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing - CSCW '16* (2016), 754–767.

[60] Sonali R Mishra, Shefali Haldar, Ari H Pollack, Logan Kendall, Andrew D Miller, Maher Khelifi, and Wanda Pratt. 2016. " Not Just a Receiver" Understanding Patient Behavior in the Hospital Environment. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*. 3103–3114.

[61] Sonali R. Mishra, Shefali Haldar, Ari H. Pollack, Logan Kendall, Andrew D. Miller, Maher Khelifi, and Wanda Pratt. 2016. "Not just a receiver": Understanding patient behavior in the hospital environment. *Conference on Human Factors in Computing Systems - Proceedings* (2016), 3103–3114.

[62] Sheryl Mitnick, Cathy Leffler, Virginia L Hood, Professionalism American College of Physicians Ethics, and Human Rights Committee. 2010. Family caregivers, patients and physicians: ethical guidance to optimize relationships. *Journal of general internal medicine* 25, 3 (2010), 255–260.

[63] Sanika Moharana, Alejandro E Panduro, Hee Rin Lee, and Laurel D Riek. 2019. Robots for joy, robots for sorrow: community based robot design for dementia caregivers. In *2019 14th ACM/IEEE International Conference on Human-Robot Interaction (HRI)*. IEEE, 458–467.

[64] Laurel L. Northouse, Maria C. Katapodi, Lixin Song, Lingling Zhang, and Darlene W. Mood. 2010. Interventions with Family Caregivers of Cancer Patients: Meta-Analysis of Randomized Trials. *CA: A Cancer Journal for Clinicians* (8 2010), n/a–n/a.

[65] Debra Parker Oliver, David L Albright, Robin L Kruse, Elaine Wittenberg-Lyles, Karla Washington, and George Demiris. 2014. Caregiver Evaluation of the ACTIVE Intervention: "It was Like We Were Sitting at the Table With Everyone". *American Journal of Hospice and Palliative Medicine®* 31, 4 (2014), 444–453.

[66] Suvi Pihkala and Helena Karasti. 2016. Reflexive engagement: enacting reflexivity in design and for'participation in plural'. In *Proceedings of the 14th Participatory Design Conference: Full papers-Volume 1*. 21–30.

[67] Toni Robertson, Tuck W Leong, Jeannette Durick, and Treffyn Koreshoff. 2014. Mutual learning as a resource for research design. In *Proceedings of the 13th Participatory Design Conference: Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts-Volume 2*. 25–28.

[68] Toni Robertson and Jesper Simonsen. 2012. Challenges and opportunities in contemporary participatory design. *Design Issues* 28, 3 (2012), 3–9.

[69] Jennifer A Rode. 2011. Reflexivity in digital anthropology. In *Proceedings of the SIGCHI conference on human factors in computing systems*. 123–132.

[70] Ari Schlesinger, W. Keith Edwards, and Rebecca E. Grinter. 2017. Intersectional HCI: Engaging Identity through Gender, Race, and Class. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI '17* (2017), 5412–5427.

[71] Marén Schorch, Lin Wan, David Randall, and Volker Wulf. 2016. Designing for T hose who are O verlooked – Inside r Perspectives on Care Practices and Cooperative Work of Elderly Informal Caregivers. (2016), 787–799.

[72] Richard Schulz, Jill Eden, National Academies of Sciences, and Engineering Medicine. 2016. Family caregiving roles and impacts. In *Families caring for an aging America*. National Academies Press (US).

[73] Woosuk Seo, Andrew B L Berry, Prachi Bhagane, Sung Won Choi, Ayse G Buyuktur, and Sun Young Park. 2019. Balancing Tensions between Caregiving and Parenting Responsibilities in Pediatric Patient Care. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW (2019), 1–24.

[74] Ji Youn Shin, Dima Chaar, Jacob Kedroske, Rebecca Vue, Grant Chappell, Amanda Mazzoli, Afton L Hassett, David A Hanauer, Sun Young Park, and Barton Debra. 2020. Harnessing mobile health technology to support long-term chronic illness management: exploring family caregiver support needs in the outpatient setting. *JAMIA open* 3, 4 (2020), 593–601.

[75] Ji Youn Shin and Sung Won Choi. 2020. Online interventions geared toward increasing resilience and reducing distress in family caregivers. *Current Opinion in Supportive and Palliative Care* 14, 1 (2020), 60–66.

[76] Ji Youn Shin, Tammy I Kang, Robert B Noll, and Sung Won Choi. 2018. Supporting caregivers of patients with cancer: a summary of technology-mediated interventions and future directions. *American Society of Clinical Oncology Educational Book* 38 (2018), 838–849.

[77] Jesper Simonsen and Toni Robertson. 2012. *Routledge international handbook of participatory design*. Routledge.

[78] Penelope J. Slater, Philippa E. Fielden, and Natalie K. Bradford. 2018. The Oncology Family App: Providing Information and Support for Families Caring for Their Child With Cancer. *Journal of Pediatric Oncology Nursing* 35, 2 (2018), 94–102.

[79] Karin Slegers, Andrea Wilkinson, and Niels Hendriks. 2013. Active collaboration in healthcare design: participatory design to develop a dementia care app. In *CHI'13 Extended Abstracts on Human Factors in Computing Systems*. 475–480.

[80] Marc Steen. 2013. Virtues in participatory design: Cooperation, curiosity, creativity, empowerment and reflexivity. *Science and engineering ethics* 19, 3 (2013), 945–962.

[81] Elizabeth Stowell, Yixuan Zhang, Carmen Castaneda-Sceppa, Margie Lachman, and Andrea G Parker. 2019. Caring for Alzheimer's Disease Caregivers: A Qualitative Study Investigating Opportunities for Exergame Innovation. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW (2019), 1–27.

[82] Franziska Tachtler, Toni Michel, Petr Slovák, and Geraldine Fitzpatrick. 2020. Supporting the Supporters of Unaccompanied Migrant Youth: Designing for Social-ecological Resilience. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. 1–14.

[83] Charlotte Tang, Yunan Chen, Karen Cheng, Victor Ngo, and John E Mattison. 2018. Awareness and handoffs in home care: coordination among informal caregivers. *Behaviour & Information Technology* 37, 1 (2018), 66–86.

[84] Angelique Taylor, Hee Rin Lee, Alyssa Kubota, and Laurel D Riek. 2019. Coordinating clinical teams: Using robots to empower nurses to stop the line. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW (2019), 1–30.

[85] Bonnie Teschendorf, Carolyn Schwartz, Carol Estwing Ferrans, Ann O'Mara, Paul Novotny, and Jeff Sloan. 2007. Caregiver role stress: When families become providers. *Cancer Control* 14, 2 (2007), 183–189.

[86] The Centers for Disease Control and Prevention (CDC). 2015. Caregiving for Family and Friends — A Public Health Issue. https://www.cdc.gov/aging/caregiving/caregiver-brief.html

[87] Mamello Thinyane, Karthik Bhat, Lauri Goldkind, and Vikram Kamath Cannanure. 2018. Critical participatory design: reflections on engagement and empowerment in a case of a community based organization. In *Proceedings of the 15th Participatory Design Conference: Full Papers-Volume 1*. 1–10.

[88] Matthieu Tixier, Gérald Gaglio, and Myriam Lewkowicz. 2009. Translating social support practices into online services for family caregivers. In *Proceedings of the ACM 2009 international conference on Supporting group work*. 71–80.

[89] Matthieu Tixier and Myriam Lewkowicz. 2016. " Counting on the Group" Reconciling Online and Offline Social Support among Older Informal Caregivers. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*. 3545–3558.

[90] John Vines, Gary Pritchard, Peter Wright, Patrick Olivier, and Katie Brittain. 2015. An age-old problem: Examining the discourses of ageing in HCI and strategies for future research. *ACM Transactions on Computer-Human Interaction* 22, 1 (2015), 2.

[91] Dhaval Vyas and Tawanna Dillahunt. 2017. Everyday resilience: Supporting resilient strategies among low socioeconomic status communities. *Proceedings of the ACM on Human-Computer Interaction* 1, CSCW (2017), 1–21.

[92] Sarah B Wackerbarth and Mitzi M S Johnson. 2002. Essential information and support needs of family caregivers. *Patient education and counseling* 47, 2 (2002), 95–100.

[93] By Kathleen E Walsh, Colleen Biggins, Deb Blasko, Steven M Christiansen, and Kathleen M Mazor. 2018. Focus on Quality Quality in Action Home Medication Support for Childhood Cancer : Family-Centered Design and Testing. (2018).

[94] Amanda M Williams and Lilly Irani. 2010. There's methodology in the madness: toward critical HCI ethnography. In *CHI'10 Extended Abstracts on Human Factors in Computing Systems*. 2725–2734.

[95] Marisol Wong-Villacres, Carl DiSalvo, Neha Kumar, and Betsy DiSalvo. 2020. Culture in Action: Unpacking Capacities to Inform Assets-Based Design. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. 1–14.

[96] Marisol Wong-Villacres, Aakash Gautam, Wendy Roldan, Lucy Pei, Jessa Dickinson, Azra Ismail, Betsy DiSalvo, Neha Kumar, Tammy Clegg, and Sheena Erete. 2020. From Needs to Strengths: Operationalizing an Assets-Based Design of Technology. In *Conference Companion Publication of the 2020 on Computer Supported Cooperative Work and Social Computing*. 527–535.

[97] Marisol Wong-Villacres, Arkadeep Kumar, Aditya Vishwanath, Naveena Karusala, Betsy DiSalvo, and Neha Kumar. 2018. Designing for intersections. In *Proceedings of the 2018 Designing Interactive Systems Conference*. 45–58.

[98] Naomi Yamashita, Hideaki Kuzuoka, Keiji Hirata, and Takashi Kudo. 2013. Understanding the conflicting demands of family caregivers caring for depressed family members. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 2637–2646.

[99] Naomi Yamashita, Hideaki Kuzuoka, Keiji Hirata, Takashi Kudo, Eiji Aramaki, and Kazuki Hattori. 2017. Changing Moods: How Manual Tracking by Family Caregivers Improves Caring and Family Communication. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '17)* (2017), 158–169.

[100] Tara J Yosso. 2005. Whose culture has capital? A critical race theory discussion of community cultural wealth. *Race ethnicity and education* 8, 1 (2005), 69–91.

Received January 2021; revised April 2021; accepted July 2021