Dancing with the Roles: Towards Designing Technology that Supports the Multifaceted Roles of Caregivers for Older Adults

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ABSTRACT

Caregivers of older adults often undertake their caregiving journey driven by filial obligation, facing inherent expectations and multifaceted roles. While Human-Computer Interaction (HCI) research has explored these roles, some invisible work in managing them remains under-examined. To address this gap, we interviewed 19 informal caregivers of older adults to uncover their invisible work and the potential role of technology in supporting these complex responsibilities. Our findings detail the caregivers' lived experiences, highlighting the challenges and strategies they employ in managing multiple roles. We discuss design opportunities that include facilitating the identification and reflection on existing roles, leveraging this understanding for coordination, aiding in role-based scheduling with acknowledgment, and providing support for the dynamic roles transitioning between various responsibilities. These insights could inform future caregiving technology design, enhancing support for caregivers in their multifaceted roles.

CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in HCI**; *Collaborative and social computing*.

KEYWORDS

caregiver, informal caregivers, roles, role dynamics, older adults, filial obligations, invisible work, caregiving ecosystem

1 INTRODUCTION

What is the first image that comes to your mind when you hear "caregiver for an older adult"? Search engine results for "caregiver" often show a smiling individual pushing a smiling older adult in a wheelchair. As such, many Human-Computer Interaction (HCI) studies have identified caregivers in task-oriented roles, such as

planners [4, 10, 41], navigators [4], and decision-makers [4] for the care recipient's medical conditions, diseases, or meal plans [6, 7]. HCI research since has offered various technological solutions for task-oriented roles – providing wheelchair support [30], offering cues in everyday life [32], aiding with distance care through remote monitoring, websites, calls, and video calls [25, 69, 71] – or suggesting gamification persuasive systems to motivate assistance [22, 68]. However, the responsibilities of a caregiver extend beyond the visible act of pushing a wheelchair. Beyond the visible caregiving tasks, caregiving's emotional and psychological aspects are often not immediately apparent. Moreover, caregiving roles are multifaceted, with layers of responsibilities beyond their caregiving duties, and constitute an interconnected ecosystem unique to each caregiver.

The concept of a 'care ecosystem' is not new in the HCI literature. Some studies have focused on scenarios where the care recipient is at the core surrounded by formal and informal caregivers [42, 43] or in dyadic interactions between caregiver and their care recipient [7]. Other research has described and visualized this intricate network through a caregiving ecosystem model, emphasizing the need to consider caregiving technology in the context of the various roles assumed by different caregivers in the family, the social interaction space, and the evolving nature of these roles [24]. Other times, research calls such ecosystem a family network, suggesting Ambient Displays to visualize and make older adults' medication information visible to different family members [57]. However, while much research in this area focuses on the multiple actors within the care ecosystem, there is often an insufficient emphasis on how individual caregivers, with their multifaceted roles, are integral to this ecosystem. This oversight presents an opportunity to discuss the *invisible work* individual caregivers invest in managing the intricate care ecosystem and the potential for technology to support these practices.

Invisible work refers to tasks of significant importance that often remain unnoticed by others [44, 66]. Similar to the hidden context of work beyond the office setting [66], caregiving includes invisible work, sometimes recognized in existing HCI research as invisible roles. These roles are often described as those of a companion [41], a communicator with care recipients [63]. A coordinator with other stakeholders– such as therapists, health professionals in hospitals, community-based healthcare systems [4, 41, 58], or teachers in schools [6]. Technological implications in these scenarios often focus on enhancing face-to-face interactions for companionship [41], emphasizing the importance of efficient communication skills [63], and promoting cooperative technologies that facilitate information sharing among stakeholders [67].

Maintaining a care ecosystem involves significant invisible work, posing challenges to caregivers. This work includes maintaining balance by prioritizing visible tasks, such as caring for the recipient, while navigating additional responsibilities beyond caregiving duties [10, 38]. It also involves managing role transitions and adapting to new identities that emerge from caregiving relationships [16]. The invisible work of managing roles and juggling different responsibilities can be challenging [9], often due to conflicting expectations from these roles [17, 19, 55, 70]. Ineffective role management may lead to role strain, caregiving burden [19], feelings of guilt [22], adversely impacting caregivers' well-being [12, 45], and increasing the risk of depression [11].

Navigating the intricate terrain of caregiving roles may raise questions about the burden and effort involved. The prevalence of informal caregivers is significant, constituting 21% of the US population in 2020 [13] and continuing to grow with the aging and disabled population [13, 46]. One of the reasons why they commit to caring for aging loved ones is the universal, cross-cultural [31] aspect rooted in "filial obligations." These obligations, expressing gratitude and responsibility, require family members (parents, grandparents, or a spouse [15, 53]) to provide assistance and care to their aging relatives, aligning with societal norms and expectations [20, 49, 50]. Striving to embody societal ideals [2, 35, 39], individuals assimilate caregiving roles over time, influenced by observations and modeling from similar positions [17, 51, 59]. Care recipients, in turn, expect affection, respect, independence, and a willingness to take on responsibilities from their children [5]. Understanding these dynamics informs the broader context of caregiving and emphasizes the importance of addressing caregivers' multifaceted challenges.

Motivated by the existing literature on invisible work and multifaceted role management, we aim to delve into how caregivers navigate the intricacies of multifaceted roles, viewing it as a form of invisible work. This perspective offers a unique angle that could contribute to the HCI literature and enhance the well-being of caregivers. We focus on the following research question: *What invisible work do caregivers undertake when managing multiple roles in the caregiving ecosystem?*

To answer these questions, we interviewed 19 caregivers, focusing on their invisible roles and use of technologies. We believe this work contributes to the field of HCI by highlighting the significance of invisible work in maintaining caregiver multifaceted roles, including identifying, reflecting, and coordinating role-based scheduling and finding gratitude during role transitions. The insights from this study can inform future design and development of technologies for caregivers of older adults.

2 BACKGROUND: THE INVISIBLE WORK MANAGING THE CARE ECOSYSTEM

In this section, we discuss the challenges in managing the caregiving roles within the context of the invisible work of a care ecosystem. We also discuss how previous HCI researchers have explored technology to help address the challenges.

2.1 Deciding when and to what extent to portray specific roles within their caregiving responsibilities

An invisible aspect of caregiving involves the intricate decision-making process of portraying specific roles within the care ecosystem, where caregivers face challenges prioritizing roles when interacting with care recipients. This decision-making involves considering unfamiliar factors, such as healthcare collaboration, where responsibilities may be unclear [58]. Not having a clear definition of roles can lead to "role ambiguity," involving conflicting expectations and an incomplete understanding of caregiving role demands [16, 17, 70]. In situations like parents caring for children undergoing medical treatments, caregivers must navigate between their roles as caregivers in the hospital setting and as parents at home [62]. This challenge becomes more complex when children express needs beyond medical necessities, leading to conflicts with normal disciplinary practices at home [62]. In work-from-home situations, parents juggle being parents, teachers, technology support, providers, and employees [40], determining when to prioritize each role.

In facing role ambiguity, technological designs in caregiving often focus on addressing conflicts within caregiving roles. Some suggest mitigating conflicting roles with technology, as seen in situations addressing parent caregivers during work-from-home scenarios, where the emphasis is on supporting visible task-related roles. Recommendations include child-friendly technology to alleviate specific caregiver tasks [40]. Similarly, in caregiving and parenting, technology suggests combining these roles and establishing flexible standards [62]. Others propose solving role conflict through communication with other stakeholders and advocating for explicit delineation of roles and caregiving activities [23]. Moreover, technology can play a role in identifying the components that influence informal caregiving and the associated roles. For instance, Gutierrez and Ochoa highlighted factors that technology could help with, such as caregiving requirements, family members' willingness, and capabilities, and assumed commitments based on individuals' roles [24]. Another study pointed out how cultural contexts, like those in Chile and Argentina, add additional layers of expectations based on gender and kinship relationships [22, 23]. These technological interventions could assist with roles involving multiple people, but what about roles only one person can fulfill?

More specifically, caregiving for older adults is rooted in filial obligation, the obligation often entails being both a child and a caregiver simultaneously. In these cases, one cannot simply reduce one role or coordinate with other family caregivers. Setting lower standards can be helpful for caregivers to feel better, but it may not contribute to resolving conflicts that arise when managing multiple roles. Thus, there is a need to understand the intricacies of each role and the interactions between these roles.

2.2 Balancing multiple roles

Balancing multiple roles in the care ecosystem represents another facet of invisible work, extensively discussed in previous literature as the challenge of allocating time among diverse responsibilities. Caregivers, in addition to their primary caregiving duties, often hold other roles in their social world, such as a spouse, parent, relative [34, 52], or colleague [18]. Time constraints become a limiting

factor for caregivers, forcing them to invest additional effort in finding the right balance. Juggling these diverse roles requires a constant trade-off due to their interconnected nature. Poorly managed role balancing, where caregivers invest more time and energy than anticipated, can lead to role overload [55]. This poorly management could be due to caregivers' struggle with the perception of not dedicating "enough time" to care recipients due to competing expectations in other areas of life, such as personal time, work, and leisure [7, 14, 28, 33]. These competing expectations may lead to not fulfilling obligations well and, in turn, feelings of guilt. As such, caregivers need to intentionally manage their time to meet expectations and maintain a balance among multiple roles.

Despite the need for emotional support in dealing with expectations through these transitions, most HCI studies focus on strategies to support coordination between caregiving and other obligations, such as setting work calendars and alerting caregivers when they have a heavy task schedule [7]. Additionally, research specifically addressing the challenge of managing caregiving roles has discussed that much of the previous work in design focuses on maintaining relationships and coordinating task-based schedules [61]. Other technological studies on helping caregivers balance self-care time have suggested small steps, such as adopting a mindset of "taking one day at a time" for roles that caregivers feel are lacking. They create short-term plans and goals, incorporating mindful activities, such as engaging in creative work, shopping, playing computer games, or moments of relaxation [63]. However, these suggestions often emphasize the division of tasks, overlooking the emotional aspect, such as guilt, when choosing one role over another. There is a need to consider both aspects and develop strategies to effectively address the multifaceted nature of caregiving roles and the associated invisible work.

2.3 Adapting and transitioning between caregiving roles

Adapting and transitioning between caregiving roles is a nuanced and often unnoticed aspect of caregiving, frequently discussed in the literature from the perspective of role transitions. These transitions can occur at various stages of caring for care recipients. The initial acceptance of a new role involves changing the care ecosystem, requiring caregivers to navigate shifts from family members to full-time caregivers, often without training or being forced to learn [60, 61]. Another transition occurs as care recipients' health deteriorates, making coordination with healthcare professionals more prominent [8]. This phase of transition requires caregivers to make trade-off decisions, as the roles of self-care and seeking social support become crucial [64]. However, the emotional experiences from changing roles during the transition in the care ecosystem can be difficult for caregivers. The emotional experience of new roles and shifts in identity can be confusing and stressful for caregivers, as observed in the study of caregivers for COVID-19 ICU patients [56]. The confusion and stress may worsen when individuals lose their identities and struggle to fully adapt to the new caregiving role [16].

While managing caregivers' emotions is a crucial aspect of invisible work, technological solutions frequently prioritize support focused on the task-oriented aspects of caregiving roles, typically emphasizing care recipient needs, often in parent-child interactions. In the case of children with diabetes, parents are often uncertain about managing their children's health as they undergo hormonal changes and developmental stages [6]. Thus, Cha et al. proposed a system that could help with trial and error with the children's diet, design diet experiments, and provide optimal suggestions based on historical data and various resources [6]. Another similar HCI study focused on the conflict in caregiving and parenting also suggested an integrated system that provides information adjusted to children's changing health, educational, and social needs so that caregivers know how to navigate between caregiving and parenting roles during the illness trajectory [62]. These studies demonstrate how technology could offer informational support when facing role changes when caring for children. However, these studies focusing on caring for children may not fully capture the different role dynamics in caring for older adults. A better understanding of the emotional challenges caregivers face during the continuous changes in their roles when caring for older adults is an important but underexplored design space.

Another set of HCI studies focuses on the coordination between multiple caregivers when roles change. In this setting, previous literature has suggested technologies that can coordinate roles among caregivers [41, 47, 60] by keeping track of parent caregivers' scope and duties of roles [48], incorporating checklists, utilizing recommendation systems based on machine learning approaches [47], and creating generalizable caregiving coordination journey models that prepare caregivers for the next phase [47]. Specifically, these technologies could be useful when parents adapt to new caregiving roles while their children are in the hospital. They require coordination between roles, such as in-person caregivers and those providing updates [48]. Such technologies could also be beneficial when caregivers start with more active roles during the initial hospital stays, transitioning to assistant or navigator roles and reverting to more active roles as needed [41]. While there has been strong emphasis on the invisible work of coordination among visible task-oriented roles, how individuals strive to adapt to ongoing changes beyond coordination, how they manage the emotional burdens over time, and how they navigate the role adoptions and transitions as caregiving needs change are still underexplored in HCI communities.

In summary, the challenges of managing multifaceted caregiving roles are commonly discussed regarding defining roles, time allocation, and transitions. However, the complexity of the older adult care ecosystem involves additional invisible labor that is often underexplored, including deciding when and to what extent to portray specific roles conflicted with filial obligation, balancing roles while addressing emotional aspects like guilt, and managing emotional experiences during role navigation. Our research aims to understand and unpack such challenges and the unseen effort caregivers invest in addressing these challenges.

3 METHODS

To better understand the invisible work of managing their care ecosystem for informal caregivers, we conducted semi-structured interviews with informal caregivers. We chose interviews because

they provide opportunities for participants to reflect on their experiences [36] and allow researchers to understand their roles in their own words. While other methods, such as shadowing to observe day-to-day interactions [37] could potentially provide different perspectives, we were mindful of the burden these research activities might add to informal caregivers and the safety concerns informal caregivers and older adult care recipients with the ongoing Covid-19 threat at the time we were doing the interviews.

Between 2021 and 2022, we hosted most interviews online, with only one in-person interview because the participant felt less comfortable with online interviews.[1] Each interview lasted for an hour, during which we first went over the study information sheet to get verbal consent for caregiver participation. We then asked the participants about their caregiving roles and challenging aspects of their care tasks and relationships. We recorded and transcribed the interviews for analysis. The study protocol was approved by our university's Institutional Review Board (IRB).

3.1 Participants

We interviewed 19 informal caregivers (ages 20 to 82) living in the Midwest U.S. at Indiana. We stopped interviews after reaching data saturation (i.e., no new information or theme emerged from the interviews) after these 19 interviews [21]. All participants had caregiving experiences with their older adult care recipients (ages 62 to 97). The older adults here are defined as 60 or older, as previous research has investigated, ranging from 55 [1], 61 [68], or 65 [54]. All participants were primary caregivers and family members of their older adult care recipients for twelve months or longer. At the time of the interview, the informal caregivers lived with or had experience living with the older adult care recipients.

We recruited these participants through online advertisement, social media platforms, school websites, local caregiver events, and flyers distributed in the local communities. The recruitment material links to a screening survey, which included questions about potential participant demographics, age of the care recipient, caregiving relationships, and length of time they took care of the care recipient. We invited all potential participants who filled out the screening survey to participate in the interview study. Table 1 shows participant information.

3.2 Data analysis

We analyzed the interviews using a mix of inductive and deductive methods. After the first few interviews, the first author read the transcripts multiple times to familiarize with the themes and to support reflections based on the data and the research question. The first author then wrote down and discussed initial themes with the second author to develop the initial codebook and categories. The first author then coded the transcripts iteratively using the codebook.

The iterative coding process evolved through two main stages. The first iteration focused on caregiving challenges, such as conflicting roles, guilt, technological burdens, strategies to cope with challenges and relationships. However, the two authors realized that the coding was too generalized. The second iteration centered on the multiple roles of caregiving, incorporating expectations from

oneself (e.g., managing self-care and well-being as self-care practitioners), expectations from taking care of care recipients (e.g., embracing relationships with care recipients and caregiving tasks as efficient, satisfied, communication-oriented caregivers), expectations from others related to care (including cooperating with others), and expectations from the world outside care (such as navigating other responsibilities in life as external responsibility managers). Following the paper review process, the authors recognized the need to delve deeper into the multifaceted nature of the process, prompting an extension of the second part of the coding. This led to the inclusion of different expectations under the umbrella of invisible work. The final themes highlighted the invisible work of managing roles, including (1) deciding when and how to perform roles (including the previous communication-oriented caregiver), (2) managing time and responsibility (including the previous efficient caregiver), and (3) adapting and transitioning (including the previous the satisfied caregiver). Throughout the process, the two authors met weekly, ranging from 10 to 30 minutes, to discuss and refine emergent codes and themes.

4 RESULTS

The findings from our study reflected on the motivations and the roles that imply the invisible work of caregiving. Caregivers in our study needed to involve themselves in multifaceted roles both from within and outside caregiving. In this section, we described these experiences by presenting a few case studies summarized from our data to show a broader view of what caregiving was like. Through in-depth analysis and synthesis, we present the themes to demonstrate the filial obligation behind caregiving for older adults and the invisible work of managing the roles.

4.1 Case studies

From our participant stories, we chose three illustrative examples and summarized them here to show the invisible work of managing the care ecosystem is multifaceted, diverse, and complicated.

4.1.1 Case study 1. P11 (female/63) was a widow who decided to provide 24/7 care for her mother when the need arose. P11 embraced the filial obligation because she witnessed her mother being positive when caring for her grandfather when she was young. Her **transition** to the caregiving role went smoothly as she deliberately took this role and cherished every moment spent with her mother and called this caring a "beautiful thing" and "a privilege."

Aside from the transition of her role, P11's case highlighted two types of invisible works around managing multiple roles. First, P11 knew **when and how to perform her roles** by spending extra effort to ensure communication with her mother, maintaining her role as a daughter while simultaneously managing the caregiver role. For instance, P11's mother had diabetes, so her mother was restricted to certain foods. If her mother expressed a desire for apples and strawberries, she would find a way to communicate and negotiate with her mother, such as allowing her mother to take a small bite of the apple to satisfy her craving. She also negotiated with her mother about how she cooked. She knew that her mother loved cooking, but to prevent the dangers of injury in the kitchen while her mother cooked alone, she negotiated with her mother to make sure they always cooked together.

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[1]We followed COVID-19 precautions in this one in-person interview.

Table 1: Informal Caregiver Participant Demographics

ID	Age	Gender	Care Recipient Relationship (Age)	Caregiving Exp. (Years)	Other Roles
1	58	F	Mother (88)	1-2	Daughter, wife
2	36	F	Mother (64)	2-5	Daughter, mother, wife
3	65	F	Mother (97)	1-2	Daughter, mother, wife
4	29	M	Mother (65), Father (68)	1-2	Son
5	58	F	Mother (89)	>5	Daughter, sibling
6	20	F	Mother (62), Father (74)	>5	Daughter
7	67	M	Mother (95)	1-2	Son, father, grandfather
8	82	F	Husband (81)	2-5	Wife, mother, grandmother
9	64	F	Husband (62)	2-5	Wife
10	26	F	Grandma (82)	1-2	Granddaughter, friend
11	63	F	Mother (85)	2-5	Daughter, colleague
12	50	F	Mother (78)	1-2	Daughter, wife, sibling
13	78	F	Husband (81)	1-2	Wife
14	30	N/A*	Grandma (89)	1-2	Grandchildren, children, niece/nephew
15	27	M	Grandma (90)	2-5	Grandson, son
16	63	F	Mother (88), Father (90)	1-2	Daughter, sibling, wife
17	65	F	Husband (68)	1-2	Wife, mother
18	74	F	Husband (74)	>5	Wife, mother
19	65	F	Mother (87)	2-5	Daughter

*Prefer not to disclose

P11 also had to do the invisible work of **balancing roles outside care**, especially her professional job that took some time and energy away from taking care of her mother. During the pandemic, she could work from home and teach online courses. Having her mother at the same place allowed her to quickly transition between her roles of educator and caregiver for her mother in case of emergency. After the pandemic, P11 struggled between being at school for teaching and staying at home when her mother needed to.

In short, P11 kept a positive mindset to fulfill her filial obligation and respect her mother's agency by thoughtfully communicating and negotiating with her mother. Returning to her work at school after the pandemic emphasizes the challenge she faced in balancing her caregiving responsibilities with her job.

4.1.2 Case study 2. P3 (female/65) recently retired from a bustling city and began caring for her mother when her mother experienced serious falls and hallucinations with dementia at the age of 95. P3 and her mother had expected P3 to become the primary caregiver as part of filial obligation where they "*recognized that something had to be done.*"

P3 constantly had to balance and transition between multiple roles within and outside of caregiving, demonstrating examples of additional indivisible labor on top of visible caregiving tasks. First, P3 needed to **determine when and how to fulfill the caregiver role**, specifically struggling to remind herself of her daughter's responsibilities to respect her mother's agency. Next, P3 worked on **balancing multiple caregiving tasks** by creating routines for caregiving tasks that she knew she could handle, hiring a housekeeper, and assisting her mother with daily tasks and grocery shopping. In addition, having P3's own life - a happy retired life - was very important to her and served as a break from P3's caregiving responsibilities. Secondly, she also tried to make time for her role as a wife, especially considering that swimming with her husband

at their pool was something she had longed for in her retired life. Squeezing in this time allowed her to spend quality moments with her husband.

P3's most significant challenge was navigating the **transition of her caregiving role**, primarily because she was uncertain about her mother's evolving personality as she mentioned how she used to be "*pretty close*" with her mother, as she would assume of a "friend" role taking her mother. Over time, her mother had become critical, frugal, and unhappy, forcing her to adjust her friend role to become the problem solver she was struggling to be. P3 attempted to improve her mother's happiness by offering to buy her lunch to encourage her to socialize with a friend and by seeking out a therapist. However, her mother did not accept these gestures due to financial concerns, which left P3 emotionally drained with the ongoing task of adjusting to multiple caregiving responsibilities, as well as communicating and collaborating with various individuals involved in her mother's care.

As much as she desired to fulfill her mother's needs and manage her roles as a wife efficiently, she discovered herself struggling to find suitable ways and was emotionally challenged when transitioning into the role of a caregiver, especially given her mother's changing personality.

4.1.3 Case study 3. P13 (female/78) found herself in an unexpected role of caring for her husband when he was diagnosed with dementia. P13 was adept at accepting the role change with her husband's health decline, with a **smooth transition**: "*Oh, my husband has dementia. And I'm his wife. So basically, lives we live at home together. So that's all there is to it.*" She was successful in managing other invisible tasks as well. As a professional caregiver before, P13 knew how to **balance multiple roles** by putting details of the schedules down so that her husband would do what she had asked. She also worked on reminding herself on **how to perform each role** by

reminding herself that she was a wife and made an effort not to let her speech sound angry when talking to her husband. Moreover, being a caregiver was not the only role for P13 – she purposefully reserved her time to be a self-care practitioner and an art enthusiast. She assiduously worked on arranging schedules with her daughter to seek what she finds important in her life. She would find time for her husband to be with her daughter so she could spend some personal time walking in the galleries. P13's story provides another example of invisible labor needed to manage the multifaceted nature of caregiving relationships effectively and skillfully balance and coordinate multiple roles.

These three case studies are some examples of how the multifaceted roles and stakeholders within and outside caregiving often require invisible labor to manage and engage with intentionally. Case Study 1 highlighted the struggle to balance these roles, Case Study 2 showed the difficulties in role transitions, and Case Study 3 demonstrated deliberate role management and coordination.

4.2 Invisible work of managing the roles

The invisible work includes the management of diverse responsibilities, including understanding when and how to perform different roles, efficiently allocating time, and transitioning between roles as time proceeds.

4.2.1 Deciding when and how to perform potentially conflicting roles. Sometimes, the caregiving roles require additional actions and decisions that potentially conflict with their existing roles. Caregivers had to evaluate conflicting expectations and obligations when performing caregiving tasks constantly. To address these challenges, caregivers often had to learn and engage with various strategies to negotiate with care recipients and coordinate with other caregivers carefully. Such invisible labor was built on already burdensome caregiving tasks and emotional struggles but was essential to support caregivers in managing the coexisting multiple roles.

Caregivers often struggled with the roles of *being the care recipient's children/grandchildren/spouse and also being a caregiver*. For example, P3 (female/65) from Case study 2 with a 97-year-old mother described how she sometimes felt that caring for her mother was similar to caring for a child. She emphasized the need to continually remind herself of her role as a daughter to respect her mother's agency: *"I have to remember that she's not a child,… just making sure that her opinions are, you know, taken care of."*

P1 (female/58) had a similar experience. Although her 88-year-old mother was capable of doing many things on her own, P1 had to make sure that she ate properly and took her medication on time. She thought these parenting moments were difficult for both her mother and her:

> *"Very difficult. Because if she was my kid, you can just be like, 'Well, I'm the mom so you just have to do it. But she's not; she's my mom. So she kind of feels like she can tell me what to do. Because she's my mom. And it makes it a difficult dynamic because you're trying to be respectful of your mom and not tell her what to do. But at the same time, it's like, no, you need to do these things. Just the way it's got to be. So yeah, it's when you flip it and you're suddenly kind of parroting your*

> *mother. It's just very difficult. Because there's that line of, you know, she's still your mom. And she knows she's still your mom. So you can't parent her too much."*

Spousal informal caregivers also expressed the conflicts between being a spouse and a caregiver, similar to a parent role. For example, P18 (female/74) had been taking care of her husband, who had Parkinson's disease, for more than five years. She struggled to know when it was appropriate to act as taking care of a child rather than being together with a husband: *"I feel like more of a child that I have to take care of. And it's hard to be a loving wife. We're having to take care of a person."*

At times, caregivers struggled with *negotiating roles with other caregivers* and determining the extent to which they should assume the caregiving role. For instance, P16 (female/63) talked about her effort to communicate with her brothers regarding her father's care; however, her brothers did not appreciate her effort. Although she tried to get her brothers involved in the care, such communication experience was frustrating:

> *"My brothers did not help at all … My husband and I had to do it all. So we've given up a lot … I care about my brothers. I've tried to get them to be involved in some activities together, and they're not interested in doing anything with anybody…I'm not doing very good job as far as my brothers are concerned."*

Learning how to thoughtfully negotiate and communicate with care recipients. Often, caregivers had to learn to communicate in a way that could perform caregiving tasks while still being a child/grandchild/spouse), through appropriate conversations and negotiations with care recipients.

Just as P11 in Case study 1 (female/63) shared how she handled a potential conflict between her mother's desire to eat more fruits and her role in managing her mother's diabetes diet restrictions, P2 (female/36) also intentionally focused on better ways to communicate with her mother. She highlighted how she worked to converse with her mother in a respectful and daughterly tone:

> *"It's more when I'm not being respectful with like, when I tell someone to do something like I would my children, 'I'd say pick this up', I don't ever want to be that way with my mom, it's I have to remind myself, did you ask in a respectful way, whatever this thing was? "*

Intentionally involving and collaborating with other caregivers. Oftentimes, caregivers intentionally assume the role of communicator to establish clear responsibilities regarding their caregiving tasks with other caregivers, including family members. Effective communication plays a crucial role in ensuring the well-being of care recipients and fulfilling their financial obligations. P18 (female/74), who was caring for her husband, showed how she involved her children and delegated caregiving tasks as necessary:

> *"My son lives next door… helps me get to him in bed…sometimes my daughter came, if she's here, then we don't use the machine to get him out of a chair and into the wheelchair. Two people can do it. But I cannot do it any longer by myself… we just cry on each other's shoulders and move on."*

In a similar vein, P1 (female/58) collaborated with her sister to delegate her caregiver role while she was shopping. She mentioned how she would find her sister for help when her mother "*need to go sit down.*":

> "*The store that we went to [was where] my sister works at, she worked over in the bistro. And over by the bistro area, there was a recliner with a TV. So whenever my mom got tired, I would take her and put her in the recliner by the TV. And I knew that my sister was right nearby, so she could kind of keep an eye on or you know, make sure she wasn't wandering off.*"

Later, P1 mentioned how "*it was kind of nice. Yeah, I could just leave her there alone.*"

In summary, although some caregivers faced uncertainties in deciding when and how they should assume specific roles, they worked to navigate these decisions, often through communication, coordination, and delegation. Additionally, they engaged in clear communication and expectation, delivering the role and tasks to other caregivers.

4.2.2 Managing time and responsibilities among multiple roles. Faced with multiple roles with having only 24 hours in a day, whether directly linked to the care recipients or not, caregiver participants need to understand how to balance these roles to ensure efficiency and strive to balance these diverse responsibilities.

Sometimes, finding the right balance wasn't easy. P5 (female/58), who took care of her mother because of her decision to "*put herself on hold*" and fulfill her mother's "*desire to live at home,*" also described how challenging it was to deal with the general fatigue of caring for her mother 24/7 and how it took away her own life. She described:

> "*[My routine] is centered around her routine and what makes her happy and comfortable. During certain times of the day, it's definitely geared toward her happiness and her lifestyle rather than my own lifestyle.*"

These examples describe how roles can take too much time, leading to stress and difficulties for the caregivers, resulting in a lack of balance in terms of personal time for the caregiver, hindering their ability to find themselves and manage self-care.

Other times, it could be challenging to acknowledge that the roles can't be balanced when things happen at a specific moment and/or place. P1 (female/58) was taking care of her 88-year-old mother with her husband because she believed that "*living with your family when you're older, is better than living in a nursing home.*" However, when taking care of her mother, both she and her husband struggled to fulfill the roles of a wife or husband. Here, she described how she went to a party when her nephew asked her where her 'husband' was, as he expected husband and wife to come together to a party:

> "*When I went to the birthday party, my nephew was there. And he asked me where my husband was. And I'm like, 'Well, he's at home taking care of mother. If I'm here, he's got to be at home.'...no one around us. She can't use the phone. She can answer the phone [but] can't make phone calls. So if we left her, if anything*

> *happened, while we were gone, she would have no way to call someone.*"

Here, she expressed her concern about her inability to meet the expectations of being a wife of her husband to her nephew, primarily because of the responsibilities of caring for her mother.

Similarly, P18 (female/74) was a caregiver for her husband and grandchildren, especially when her son's family came over:

> "*When they're [son and daughter-in-law] over here, not only am I watching my taking care of my husband, sometimes watching the three kids because my son and daughter-in-law are tired. They may both take a nap or one or the other. Sometimes it's a little much.*"

She later described how she hoped she could be better at her grandmother role: "*Sometimes it's stressful because I would like to be a more involved grandmother. But I can't because I have another responsibility.*" This example showed how the caregiver role for her husband was affecting her role as a grandmother.

As seen from the experiences above, caregivers struggled to balance their other roles when caregiving became the priority.

Intentially scheduling time for multiple roles. One way to cope with these challenges was to intentionally separate and dedicate time to each of these roles. To do so, all caregivers in the three case studies spent mental effort managing caregiving tasks through careful scheduling. For example, P11 (female/63) in Case study 1 managed a calendar that included both caregiving tasks and other responsibilities: "*I have to set the schedule. For the day, I have to make sure that she has her time in my schedule...there are two people with two different schedules. So, we need to have compromises.*"

P19 (female/65), whose 87-year-old mother needed constant attention, also mentioned adjusting tasks related to her housekeeping roles around her mother's sleeping schedule: "*The stores opened at six or seven o'clock. And you do get in and get out and I can get home before she's even up.*" Matching her mother's sleeping schedule ensured that P19 could complete the grocery tasks while avoiding situations when she could not attend to her mother's needs while away.

P2 (female/36), who was also a mother and a wife, used various strategies of time management to fulfill each of her roles, sometimes by performing two roles at the same time and other times by purposefully separating two roles:

> "*I try to double up as much as possible. So if I'm spending time with my mom, I try to bring a kid to spend time with them. So in my head, I always have a scale going like: 'Okay, I did this with you. I want to make sure that I do this with you within a certain timeframe.' Sometimes I might try to do things with my husband during the day like we might do a lunch date because then it's not taking time away from the kids or from my mom.*"

These examples show the invisible effort caregivers put into navigating roles within and outside of caregiving. They had to plan their days carefully, balance time commitment among multiple roles, and adjust each task to fulfill various responsibilities and expectations that come with these roles.

4.2.3 Adapting and transitioning between caregiving roles. As family members age and their condition progresses, caregivers often

adjust their emotions along with the role change. Caregivers in our study thought that they not only had an obligation to take on the caregiving role, but they also encountered emotional challenges to follow through with the transitions of these roles.

Transitioning into the caregiving role of a child, grandchild, or spouse role was just the beginning of an emotional journey. P9 (female/64) has known her husband for 40 years. She described that she used to be the care recipient, where "*he used to be very active, I would be the one to go to work, and he would take care of everything else, for the last 20 years.*" However, as her husband's dementia symptoms gradually worsened, she began to feel that caring for him was like losing the husband she once knew for a long time, describing it as "*a grief, it's like a death. It's like mourning a death.*"

Other times, caregiving roles changed with care recipients' personalities and health status, and caregivers needed to adjust these roles and associated responsibilities.

P17 (female/65), married to her husband for 35 years, found it increasingly difficult to witness his declining health: "*that general decline is hard; it is terrible to see in the person you love.*" In addition to the transition of caretaking tasks and the associated emotional challenges, she also had to learn to manage increased communication with his care team and insurance companies:

> "*When things started, where I was maybe a little more involved in his care. But then he was diagnosed with sleep apnea... it's been kind of like a gradual adding on of health issues and me taking a bigger role in his healthcare and medication management, and insurance issues.*"

As care recipients age and approach the end of life, caregivers also need to adjust their roles and gradually accept the end of these roles. P14 (prefer not to disclose [we used "they" as their pronoun]/30), who was taking care of their grandmother with their mother, shared, "*A big motivating thing for her was taking care of her kids and then taking care of her grandkids. And when she got to a point where she couldn't really do either one of those, I think she just kind of started shutting down. And for her to say, 'I'm ready to pass away' was very unlike her, that was very uncharacteristic of her.*" P14 also described the emotional challenges they experienced when their grandmother was no longer able to live with them, "*I think it kind of went through the grieving process when I was living with her towards the end... that was very difficult emotionally.*"

Transitions in caregiving are practically and emotionally difficult, adding on more invisible labor that caregivers must perform to manage their roles.

Embracing the change transition and change in roles To cope with the changing roles, some caregivers learned to adapt their mindset by practicing gratitude, even with the difficult changes. P5 (female/58), who took care of her 89-year-old mother, kept a grateful mindset towards her mother's attitude about aging and caregiving: "*She's been very good-natured about this entire aging process. And sometimes she knows how much I do for her or expresses.*"

Other caregivers saw the caregiving relationship as reciprocal and appreciated its benefits. For example, P2 (female/36) expressed that she was grateful that her mother helped them take care of the young kids:

> "*When my mom moved in, we only had one child. We talked about because she lived with us, we could have a second child because there'd be someone there to watch the baby. So we wouldn't have had a second child if my mom didn't live with us because we wouldn't have been able to afford childcare... I feel very fortunate that she's with us.*"

Moreover, seeing how the care relationship evolved also made participants appreciate the opportunity to provide care for their family members. For example, P16 (female/63) was grateful that she had the opportunity to take care of her father and felt that her father, who had "*never been a social person*" began to open up with her:

> "*He's not fighting it anymore. ... relaxing and watching TV with him just seems to be something we haven't done since I was a kid. And he's more relaxed. And he talks to me about what's bothering him. And his struggles. I've enjoyed that.*"

P14 (prefer not to disclose/30) learned to embrace the inevitability of death and acknowledged their caregiving efforts when their grandmother passed away: "*We (P14 and their mother) drove back to [town name, away from the hospital], and she passed away. So I wasn't there when she passed away, and neither was my mom... we were both kind of relieved because we felt like we had done everything as far as our responsibility. We set her up; the last thing I said to my grandma was I love you.*"

Although the changing nature of caregiving can be difficult and emotionally taxing, caregivers worked to adopt a positive mindset to navigate the constant transitions in caregiving.

5 DISCUSSION

Overall, our research aims to identify what caregivers undertake while managing their multifaceted ecosystem of roles through the lens of invisible work. To do so, we interviewed 19 caregivers of older adults and analyzed the data in the context of our research question. In the following sections, we identify three categories of invisible work involved in managing caregiving roles and provide specific design recommendations. We also discuss the limitations of our study and propose future research opportunities to address these limitations.

5.1 Identify, reflect, and coordinate to navigate potential conflicts in individual roles

An invisible facet of sustaining the care ecosystem involves navigating and balancing conflicting roles. Our study revealed two dimensions of challenges within the care ecosystem: one where caregivers negotiate among their roles themselves, and the other where they negotiate with other stakeholders.

Similar to previous literature on parent caregivers of children [62], caregivers of older adults face challenges in managing conflicting roles, such as being a caregiving decision-maker and an obedient child. In Case Study 2 and P1's examples, caregivers struggled with the dual responsibility of making decisions for their mothers while acknowledging their role as obedient children. Balancing these roles is crucial for fulfilling filial obligations and is relevant across

various caregiving stages. This type of role conflict, involving filial obligation, may not be easily addressed by technology focusing on alleviating caregiver tasks [40], combining roles, establishing flexible standards [62], or communicating with other stakeholders to distribute roles [23].

Despite these conflicts, some caregivers excelled in managing multiple roles, as seen in Case Study 1, where P11 effectively navigated between her role as a daughter and the caregiving role of managing her mother's diet. Similarly, P2 emphasized respectful communication with her mother, distinct from her interactions with her children. Here, P11 and P2 demonstrated clarity about their roles, understanding their position in caregiving and what tasks they can or cannot undertake. Building upon literature that views caregiver actions as assets [61], we suggest focusing on identifying and establishing roles' clarity. It can aid caregivers in **reflecting and identifying their roles**, considering how each role is performed, and finding a middle ground when conflicts arise, such as communicating in a manner that aligns with both decision-maker and obedient child roles. Similar to visualizing an ecosystem for caregivers and their stakeholders [24], design can support caregivers to understand better their multiple roles within the broader care and relationship contexts. These understandings can then provide clarity of caregiver roles and insights into the interconnected nature of their responsibilities, enabling caregivers to navigate their multifaceted roles effectively.

Another challenge related to navigating roles was stakeholder communication, observed in cases like P16, who struggled with knowing when and how to negotiate her caregiving role with her brother. This challenge aligns with previous literature discussing communication with other stakeholders and the delineation of roles among them [23, 24]. However, not all caregivers have challenges negotiating with other stakeholders. P18 demonstrated success in cooperating with other caregivers and effectively delegating tasks, such as when she asked her children to assist with physical tasks. The key to P18's success was the mutual understanding of these roles between her children and her, which greatly aligns with designs that emphasize collaboration with others in decision-making about portrayed roles [62], clarifying contributions and roles [23], and negotiating responsibilities with children [47]. **Clear understanding of distinctive roles among individuals and stakeholders enables technology to facilitate communication, negotiation, and discussions about caregiver role expectations**. Thus, a clear understanding could enable effective task mitigation and foster a clearer understanding of caregiving responsibilities. Technology can aid caregivers in accurately identifying roles within the caregiving ecosystem by considering factors such as gender, kinship, affection, physical distance, cultural context, caring capability [23, 24], as well as caregiving needs and health and well-being of the care recipient [24, 62]. Through identifying and prompting dialogues around roles, caregivers can delineate their responsibilities, collaborate effectively, and efficiently assign roles [47]. Therefore, to address the coordination challenge in P16's case, technology could build upon the concept of collaboration [23, 47, 62], focusing on identifying the ecosystem of roles and allowing caregivers like P16 to use this as a discussion point with other family members to assess whether they are fulfilling their roles appropriately and avoiding emotional tension.

5.2 Role-based scheduling with acknowledgment to maintain balance while alleviating guilt

In our research and previous studies on caregivers not feeling like doing "enough" [7, 14, 28, 33], addressing the emotional challenges associated with time and responsibility needs emerges as an unseen task for caregivers managing multifaceted roles. Participants in our study commonly reported feelings of guilt when they could not accomplish other roles due to caregiving. For example, P5 struggled with the challenge of putting her life on hold, illustrating the complexities of managing self-care time and energy [61, 63], accompanied by feelings of guilt for oneself. P1 expressed concern about not fulfilling the spousal role when her husband was at home taking care of her mother, and P18 faced challenges in accomplishing their grandparent role when she was taking care of her husband, highlighting the guilt and emotional difficulties associated with balancing familial roles, similar to what was reported in previous literature [34, 52]. These dilemmas become significantly pronounced when caregiving is a filial obligation, raising the question of how caregivers can effectively deal with their emotions while navigating the trade-offs in scheduling and meeting societal and self-expectations, all while attending to other crucial roles in their lives.

To address these challenges, prior studies have outlined various strategies focused on enhancing the management of time and balance through effective scheduling [7, 61, 63]. In this study, we observed caregivers employed such strategies to support the balance of multiple roles. For example, P11 created a structured timetable for caregiving roles or aligning schedules with the care recipient's needs. Additionally, P2 effectively managed time by consciously dedicating separate periods for spending time with their children apart from caregiving activities for her mother. This scheduling technique was evident in the HCI literature, where scheduling can be coordinated with other non-primary caregivers [7] and can serve as a means to improve well-being while incorporating self-management and mindfulness activities [61, 63]. While coordination could be helpful for multiple tasks, what previous literature has not mentioned is P11 and P2's skill in identifying the value of their invisible work and acknowledging their deliberate scheduling across their multiple roles. Thus, it may be beneficial to promote **scheduling based on specific roles** as an alternative to activity-based scheduling from past studies [7, 61], which can be more effective for caregivers. This approach allows for a deeper reflection on their diverse responsibilities. Additionally, incorporating an **encouragement or acknowledgment mechanism within the scheduling process** can help caregivers recognize and emphasize the value of their invisible work. Such a system highlights their comprehensive efforts and elevates awareness of their significant but invisible contributions. Scheduling could include setting short-term goals for each role, an established caregiver technique[63], determining appropriate moments to enact each role, and establishing boundaries to preserve the balance among the roles. Moreover, designs could support scheduling as a deliberate and mindful practice, reminding caregivers to reflect on their objectives and recognize the efficacy of scheduling.

Role-based scheduling can be particularly beneficial for individuals facing emotional challenges due to role conflicts. For instance, P5, who struggled with finding time for self-care, might benefit from intentionally reflecting on how to balance her time between self-care and her caregiving role, potentially alleviating feelings of guilt associated with necessary trade-offs between these roles. Similarly, P18, who faced challenges in her dual roles as a grandparent and spousal caregiver, might find role-based scheduling more effective than activity-based scheduling. This approach would allow P18 to set clear goals for when to assume each role, helping her prioritize and allocate her time effectively when both her grandchildren and husband require attention. Proactive scheduling also offers a way to prevent feeling overwhelmed; knowing that dedicated time is set aside for each role, P18 can manage her responsibilities without the pressure of fulfilling both roles simultaneously.

5.3 Finding gratitude and positivity during role transitions

The emotional effort and understanding involved in transitioning between roles emerge as invisible work that presents challenges for caregivers of older adults [8, 16, 56]. This phenomenon aligns with findings in previous studies, where caregivers often find themselves needing to switch from one role to another throughout the caregiving journey, from the beginning to the end [16, 56]. A common example frequently mentioned by participants in our study was the transition that occurs when a loved one becomes ill or is diagnosed with a disease, such as when P17 transitioned from the role of a wife to a caregiver. During such transitions, caregivers often find it challenging to fulfill their filial obligations while maintaining their previous relationships [16, 56]. This sudden change can leave caregivers confused and unsure of how to navigate and adjust to the new role, causing stress [56]. The confusion and stress intensify when an individual loses their own identity but has not fully adapted to the new role [16]. As the care recipient's health deteriorates, the role of coordinating with healthcare professionals [8] also becomes more prominent, alongside the need to seek self-care and social support roles [64]. For example, P3 from Case Study 2 struggled adapting to her mother's personality changes. Additionally, P14 had to face the emotions that came with the end of his caregiving role. This is similar to the transition where one's role becomes more prominent as they communicate more with healthcare professionals [8] or the changing dynamics of children's roles in the hospital [47]. These transitions and dynamics contribute to the overall complexity of caregiving roles, emphasizing the need for caregivers to continually adapt and navigate through the evolving challenges of the caregiving journey.

While there is a recognized need for emotional support during transitions in caregiving roles, previous HCI literature has primarily focused on the physical or "visible aspect" of caregiving. This emphasis includes topics such as optimal suggestion tools [6], coordination systems [47], and information sharing during role transitions [60]. There has been limited attention devoted to the emotional dimensions of role transitions. In contrast, caregivers in our study have found success by recognizing the positive aspects of the aging process. For instance, P5 expressed appreciation for her mother's graceful aging, P2 identified the benefits of having her

mother live with her, P16 observed positive changes in her father, and P14 acknowledged the caregiving efforts towards the end of the caregiving journey. Therefore, we propose the development of technology designed to assist caregivers in the transition process through **reflecting on and acknowledging the positive aspects of role changes** within the caregiving ecosystem over time. This approach aligns with the theme of gratitude over time, as presented in a prior study [26]. For example, systems could provide support to P17, who struggled with witnessing her husband's declining health, by encouraging reflection on positive moments during her caregiving journey, exploring how she can provide care to her loved one, and recognizing aspects that remain unchanged. Similarly, for P3 from Case Study 2, who struggled with her mother's personality changes that limited social activities, systems could prompt her to cherish the moments they shared at home. By emphasizing the positive aspects of the evolving roles and expectations within the caregiving ecosystem, future systems can offer prompts that aid caregivers in reflecting on these changes, increase awareness, and alleviate stress [29] while fulfilling the obligation and expectations in a caregiver role.

5.4 Limitation and future work

A few limitations in this study provide opportunities for future studies. First, our study primarily relied on qualitative data from caregivers' perspectives. Future research could incorporate perspectives from care recipients and other stakeholders to provide a more holistic understanding of role identification, negotiation, and management. Future studies could also adopt other methods, such as quantitative analysis of the relationship strength and roles, to examine the dynamics within these relationships. Next, we recruited caregivers with various caregiving relationships to understand diverse roles and challenges. Future studies can focus on care recipients with specific types of illness or informal caregivers with specific familial relationships [65], such as older adults living with dementia, Parkinson's, or diabetes, and spouses, grandparents, or parents to probe into specific roles and related strategies caregivers perform and manage. Moreover, our participants are mainly women and white because women are more likely to be informal caregivers [10], and older adult care recipients in the geographic area we recruited were predominantly white [27]. As a result, our findings may not represent caregiver experiences from other regions and populations. We did not ask about the socio-professional information or employment status, which could influence their caregiving roles. Future research is needed to examine caregiving relationships in different demographics [3], socio-professional backgrounds, caregiving stages, and aging stages of older adult care recipients.

6 CONCLUSION

Caregivers of older adults often struggle with multifaceted challenges compounded by the weight of filial obligation. As they balance multiple roles within the caregiving ecosystem, these caregivers engage in invisible work integral to their caregiving responsibilities. Our interviews with 19 caregivers of older adults underscore the necessity for technology that goes beyond addressing caregiving tasks to support managing the complexities of multiple roles

within and outside caregiving relationships. We propose HCI design approaches sensitive to the nuanced nature of caregivers' responsibilities. Our design opportunities include facilitating identification and reflection on existing roles, using this insight for coordination, aiding in role-based scheduling with acknowledgment, and supporting the multifaceted roles involved in transitioning between various responsibilities. Therefore, as HCI researchers and designers, we have a responsibility to rethink our approaches to caregiver design, aiming to provide more comprehensive support for caregivers as they are *dancing with their roles*.

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