

“I Go Beyond and Beyond”: Examining the Invisible Work of Home Health Aides

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Home health aides are paid professionals who provide long-term care to an expanding population of adults who need it. However, aides’ work is often unrecognized by the broader caregiving team despite being in demand and crucial to care—an invisibility reinforced by ill-suited technological tools. In order to understand the invisible work aides perform and its relationship to technology design, we interviewed 13 aides employed by home care agencies in New York City. These aides shared examples that demonstrated the intertwined nature of both types of invisible work (i.e., emotions- and systems-based) and expanded the sociological mechanisms of invisibility (i.e., sociocultural, sociolegal, sociospatial) to include the sociotechnical. Through these findings, we investigate the opportunities, tensions, and challenges that could inform the design of tools created for these important, but often overlooked, frontline caregivers.

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

Additional Key Words and Phrases: invisible work, caregiving, frontline health workers, emotional labor, future of work, sociotechnical mechanisms of invisibility

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1 INTRODUCTION

Home health aides are essential but vulnerable workers. The rapidly growing population of adults who require long-term skilled care combined with the reduced availability of family members, friends, and neighbors who can serve as caregivers culminate in an impending “*care gap*” in the United States [65]. Roughly 3.2 million home health aides have been filling this gap by providing

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post-hospitalization or home-based care to help their clients¹ navigate the “*inadequate patchwork of medical and social services*” [65] assisting with both daily living (e.g., light housekeeping, arranging doctor’s visits) and clinical monitoring (e.g., taking temperature, giving medication reminders) [55]. Despite the importance, home care is seen as a “*job of last resort*” that is often left to women of color and immigrants who have no other choices [29]. These workers are “*not valued, compensated, or supported at the level they deserve*” by their clients, their agencies, and other medical professionals [54]. Moreover, 24% of home care workers still live in households below the federal poverty line, a rate higher than U.S. workers in general [56].

Their vulnerability is in part due to the fact that much of the labor that aides perform in their jobs is “*invisible work*”—essential to their job, but not recognized by other stakeholders (i.e., employers, consumers, workers, policy makers) [17]. Like many other health workers (e.g., nurses [4], community health workers [78]), the labor of the home health aides does not stop at the completion of the tasks assigned to them, rather, also includes additional labor to ensure the well-being of their clients and navigate the complexities of a challenging work environment. As this labor is beyond what the aides are expected to do, often done in the background, and not considered productive labor [24], it is not seen by their supervisors or clients as effort that should be valued, compensated, or supported. Moreover, as the current apps aides use are designed only to track the completion of tasks [53], invisible work is also not accounted for in technology design. It is projected that the home care workforce will grow 34% in the next decade [76] and it is inevitable that many new technologies will be created to handle this load. Therefore, in order to develop these technologies in a way that does not further the devaluation of the aides and their work, as seen in other instances where technology reinforces power dynamics that oppress workers [38, 40, 60], it is important we examine the full extent of the labor that the aides perform.

This examination builds upon the tradition in CSCW of investigating invisible work for the development of sociotechnical systems and a deeper understanding of work itself. Prior work has asked questions about what counts as invisible work, why work is invisible, and why we should investigate it in the first place [50, 66, 71]. Additionally, previous literature has explored the manifestations and implications of different types of invisible work in various settings, including work done by hidden workers in the gig economy [30, 35, 60] or hospital and other healthcare settings [39, 40, 49, 69, 78]. We contribute to this discussion of invisible work and technology by examining the following research question: **What invisible work do home health aides do and how could this inform the design of technology?**

To answer our research question, we conducted semi-structured interviews with 13 English-speaking aides employed by home care agencies in New York City and asked about the types of invisible work they do and how technology fits into their work and its visibility. Through these interviews, we found four categories of invisible work. The aides were (1) handling their own and others’ emotions by managing agitated clients with dementia and regulating their own reactions to racist incidents. Moreover, the aides were (2) engaging in additional labor due to emotional connections and filling in for other aides due to their sense of camaraderie even if they were not being paid. When interacting with their clients’ families, the aides were (3) coordinating and negotiating boundaries while soliciting help from the family in caregiving but also having to assert and reassert the scope of their assigned tasks. Finally, the aides were also (4) learning more information to make decisions on-the-fly, using Google or YouTube to fill in gaps of knowledge left by a perceived lack of support from their agencies.

These findings exemplify the different types of invisible work shown in prior work (i.e., emotions-based [33] and systems-based [72]), while additionally demonstrating the inextricable relationship

¹The term “*clients*” is used for patients or beneficiaries of care in the home health context.

Table 1. Sample Plan of Care

Category	Example Tasks
Personal Care	sponge bath, toileting, dressing
Vital Signs	oral temperature, blood pressure, weight
Activities/Exercises	walking, exercises, assist with application of medical device
Nutrition	reinforce diet instruction, feed patient, meal preparation
Treatment	medications assist/remind, catheter care, finger stick for blood monitoring
Environmental/Non-Personal Care	clean, grocery shopping, accompany patient to MD/clinic

between the two. Moreover, they provide specific examples for each of the sociocultural, sociolegal, sociospatial mechanisms of invisibility identified by Hatton [32] and suggest a fourth mechanism: the sociotechnical, which highlights the role of technology in enabling invisible work. Finally, we discuss how this understanding of both formal and informal workflows and the tensions that arise when considering invisible work could inform technology design.

In sum, our study makes the following contributions: a comprehensive understanding of the types of invisible work done by aides and the reasons for it, an exploration of how this understanding of invisible work reveals processes and networks that could lead to design of more appropriate and equitable technologies, and a discussion of how technology is not only affected by invisible work, but can enable more invisible work or make work more visible.

2 BACKGROUND AND RELATED WORK

2.1 Research Context of Home Health Aides

Responsibilities. Home health aides are frontline health workers who give care in their clients' homes, helping them manage a range of chronic diseases and navigate the healthcare system [5]. As paid, professional caregivers, aides help clients with activities of daily living (i.e., bathing, grooming), instrumental activities of daily living (i.e., meal planning around dietary specifications, arranging and attending doctor's visits, doing light housekeeping), and clinical monitoring under supervision by medical practitioners (i.e., taking temperature, recording mental/physical status, giving medications) [55, 56]. Aides are given a *plan of care* or *care plan*, a customized list of tasks to complete created by the client's doctors and nurses (Table 1 is an example from a partner agency). Aides can be employed directly by the client through in-person networks or care platforms [73] as well as through private care agencies or certified health/hospice agencies [55]. Agencies that receive payments from federally-funded programs are subject to state and federal requirements, including minimum "*short-term on-the-job training*" [76] that focuses on the activities of daily living and health-related tasks listed on the care plan, but does not fully prepare the aides for the physical, social, and emotional labor of the job [55].

Broader Conditions. Despite being a core contributor to their clients' quality of life, home health aides are overworked and undervalued, as seen in their poor treatment, minimum-wage compensation, and lack of legal protections [70]. Home health aides are mostly funded by Medicare or Medicaid with a median hourly pay of USD 13.02, resulting in over half relying on public assistance themselves [56, 76]. As the aides' work is dependent on client needs, two-thirds of home care workers work part-time or for part of the year, with a median annual income of \$13,300 [56]. The aides themselves are further disadvantaged by their identity—9 out of 10 are women, more than half are people of color, and over one-quarter are born outside of the U.S. [56]. While some aides are part of unions (half a million belonging to the largest, the Service Employees International

Union [45]) or workforce cooperatives (such as the Cooperative Home Care Associates [57]), aides continue to advocate for better pay and more protections [25].

Tools and Technology. Recent work investigated aides' sociotechnical ecosystems—their workflows, processes, and technology use [53, 67]. One of their main uses of technology is reporting the completion of tasks on the care plan by using a paper checklist, telephonic punch-codes, or smartphone applications. This technology is mainly focused on compliance for the agencies and largely inadequate for supporting the aides' workflows [75]. In addition to information and communications technology, some aides may participate in the operation of medical equipment, such as ventilators, with special training [76]. Outside of day-to-day technology use, some aides also use asynchronous e-learning technologies to participate in training [55].

2.2 Conversations About Invisible Work

What Counts As Invisible Work. *Invisible work* has been framed as labor that goes “*unnoticed, unacknowledged, unvalued, or unregulated*” [36]. According to Crain et al. [17], invisible labor has two main components: it is essential to doing their job well (“*crucial for workers to generate income, to obtain and retain their jobs, and to further their careers*”) and unrecognized by other stakeholders (“*often overlooked, ignored, and/or devalued by employers, consumers, workers, and...the legal system*”). Invisible work can also be considered “*surplus work*” [65] because the employer benefits from the additional value the worker provides, as they are alienated from their work and from other workers and stakeholders [18, 24]. It can also be framed as “*shadow work*” [34] or “*immaterial work*” [60] that is difficult to identify or pinpoint.

The discussions in prior work can be split into covering two main types of invisible work: emotions-based and system-based. Emotions-based invisible work includes both *emotional labor* (i.e., worker management of emotion) and *emotional burden* (i.e., impacts on the workers' emotions) [33]. Prior explorations of the emotional labor performed by home health aides highlighted handling client emotional health, navigating interpersonal relations, and maintaining personal mental health—culminating in the potential burnout from such emotional regulation [27]. In HCI and CSCW literature specifically, there have been proposals for technology that can help caregivers handle emotions-based work, including Chen et al. [14]'s proposal for an app that tries to minimize the burden of caregiving in their lives or Poon et al. [58]'s creation of spaces to share strategies for handling this emotions-based work.

System-based invisible work is when workers are positioned as a point of contact between different parts of the system. It includes *relational labor* (i.e., building and maintaining of connections) [6], *organizing work* (i.e., taken-for-granted “glue work” that keeps the system running) [4], and *maintenance and articulation work* (i.e., bringing together of different parts of the system) [72]. Previous research explored organizing work in hospital settings, including nurses' nonclinical contributions that influenced service quality [4] and orderlies' invisible role in maintaining local and global coordination [69]. Outside of the hospital, invisible work has been studied by Verdezoto et al. [78] in the unrecognized but crucial maintenance and articulation work done by community health workers in India and by Nafus and Mehta [49] in the unpaid work of family caregivers that they themselves did not acknowledge.

Home health aides blend the navigation of the broader healthcare system as seen in a hospital with developing one-on-one intimate relationships in their community-based caregiving. Our study builds upon these explorations of invisible work of caregivers in technology design and engages the home health aides' specific context. We highlight examples of both emotions-based and system-based types of invisible work. Furthermore, we expand on this framework to demonstrate

the intertwined nature of how the different types of invisible work influence each other and could be accounted for in sociotechnical systems.

Why Work is Invisible. Prior literature has proposed different mechanisms by which work has often been rendered invisible. This includes the proposition that certain types of work, like most systems-based invisible work, are simply harder to pinpoint, or, have immaterial outcomes [60]. However, care work, and the work done by home health aides specifically, is devalued beyond the fact that the work itself is unseen. This is due to Hatton [32]’s three intersecting mechanisms of invisibility: sociocultural (e.g., who a worker is), sociolegal (e.g., what counts as employment), and sociospatial (e.g., where work is done).

Caregiving work is considered “*multiply invisible*” [32] across these different mechanisms. It is impacted by sociocultural devaluation of the work. Feminist political economy chronicles how reproductive labor (i.e., labor traditionally done in the home and by women) is often not considered productive work, meaning it remains unpaid (or paid meagerly) and not covered by laws that protect workers sociolegally [24]. Moreover, it is sociospatially devalued since the work is done in the home—hidden from public view and in a nontraditional workplace. Domestic workers are often seen as “*nonpersons*” in the background, a designation further compounded by the sociocultural devaluation of the workers’ identities as predominantly women of color and immigrants [65].

Technology that has been developed for work done in the domestic space has been impacted by sociocultural and sociospatial mechanisms, bringing into question the definition of work [64] and creating more invisible work for women [62, 63], hinting at a potential sociotechnical mechanism that influences invisibility. Our study presents examples from the aides’ day-to-day experiences that reflect these sociocultural, sociolegal, and sociospatial mechanisms and explores this fourth mechanism, the sociotechnical influence of technology on the aides’ visibility.

Why We Should Examine Invisible Work. Prior literature has shown it is important to investigate invisible work because when work is invisible from the worker, consumer, and policymaker, exploitation by the employer can be hidden as well. Crain et al. [17] point out that investigating invisible work can give workers “*full consciousness of benefits and losses*” and help other stakeholders realize the importance of the workers and their contributions [8].

One way HCI and CSCW literature has framed the importance and contributions of workers is through understanding the assets that they bring to the table in the form of different types of “*capital*,” as Kumar et al. [43] put it. This includes “*ad-hoc processes or networks*”—invisible work in the form of tacit knowledge, informal social networks, or expertise built through experience and long-term teamwork [50]. Without careful consideration of invisible work, technological systems could end up being inappropriate or inequitable—circumventing or complicating undocumented but important processes [11], displacing the burden of invisible work to other workers, or risking the continued oppression of vulnerable workers through extreme oversight or violation of their autonomy [66]. Many sociotechnical systems do not account for this invisible work and Kaziunas et al. [40] find that in healthcare specifically, the more informal the practices or locations in which care is sought out, the less they are supported by organizational processes or technological systems.

While the literature has many examples of invisible work [4, 43, 60, 78], Raval [59] points out the paucity of literature that acts upon these examples. We hope to move towards this action by discussing how to account for invisible work in sociotechnical system design. However, taking invisible work into account requires careful consideration of how it is being done—as Bowker and Star [9] give an example of how a classification system for nursing work codified some of the previously invisible activities nurses performed but also opened the possibilities for these activities to be curtailed or controlled. This difficulty is similarly illustrated by Karusala et al. [39]’s discussion

Table 2. Participant Demographics

ID	Age	Gender	Race/Ethnicity	Education	Years	Mode
P1	56	Female	Black or African American	Some college	7	Part-time
P2	22	Female	Black or African American	High school	2	Part-time
P3	50	Female	Black or African American	High school	8	Full-time
P4	32	Female	Black or African American	High school	11	Full-time
P5	35	Female	Asian	High school	<1	Full-time
P6	58	Female	Black or African American	Primary school	29	Full-time
P7	57	Female	Black or African American	High school	25	Full-time
P8	56	Female	Black or African American	High school	25	Full-time
P9	39	Female	Asian	GED	4	Full-time
P10	37	Female	Asian	High school	10	Full-time
P11	62	Female	Black or African American	Middle school	16	Part-time
P12	43	Female	Black or African American	Some high school	13	Part-time
P13	54	Female	Black or African American	Some college	24	Full-time

of how an organizationally sanctioned chat system could make some of the offline, invisible work nurses do more visible and recognized but also more monitorable and controllable.

Our study builds upon the literature that underlines the importance of understanding invisible work and contributes to the discussion of the potential tensions that arise. As Star and Strauss [66] discusses in their seminal work on invisibility, one key question is “*what exactly is work, and to whom it might (or should) be visible or invisible.*” We use this question as an underlying motivation and engage with it by exploring what counts as work for aides and the role technology could have in accounting for or influencing the visibility of the work.

3 METHODS

We conducted an IRB-approved, remote interview study from April to August 2021 with 13 home health aides based in New York City. Our team consisted of six women and two men, all of whom have experience working with underserved populations. Five have extensive experience in technology design for marginalized populations, two in medicine, and one in labor relations. This study benefits from the team’s interdisciplinary expertise and consideration of principles like social justice orientation [22] and design justice [16].

Recruitment. We recruited participants through direct outreach and partnerships with two home healthcare agencies through the local union. Staff at the agencies independently identified aides willing to participate and shared their contact details and were not notified of which aides ended up participating. Since our interview topics related to the relationship the aides have with their employers, participants were assured that participating would not affect their employment status or benefits and that their participation would be strictly anonymous. We retained this anonymity and did not report back to their employers which aides participated in our research. All participants gave consent to participate and, since it was a remote interview, this consent was given verbally. Participants were compensated with USD 25 gift cards.

Participants. All participants spoke fluent English. All identified as women of color with a range of ages (20–65 years) and education levels (primary school to two years of college). Participants also had a range of experience in the home health aide profession, from 2 months to 29 years. Most worked full time (9 out of 13). Table 2 has additional participant information that includes age, gender, self-reported race/ethnicity, level of education, years of experience as a home health aide, and mode of employment with their agency.

Procedure. We conducted 13 semi-structured, audio-only interviews. Each interview lasted approximately one hour. Due to the ongoing COVID-19 pandemic, interviews were conducted remotely and participants were called on the phone through Zoom online conferencing software. One researcher led the interview and, in most of the interviews (9 out of 13), there was at least one other researcher taking notes and asking clarifying questions. Participants were asked questions about:

- What activities they did outside of the main job responsibilities listed on the clients' care plans, probing specifically into topics like how they managed clients' emotions, interacted with clients' families, handled emergency situations, or used technology.
- Which activities they felt were the most frustrating or emotionally exhausting.
- How they perceived other stakeholders recognized or appreciated their work (i.e., clients, clients' families, other aides, medical professionals, the agency).

Data analysis. Interviews were recorded with participants' consent and professionally transcribed. We then conducted thematic analysis [10], a constructivist approach inspired by grounded theory [26], and used in-vivo coding with gerunds [13]. The first author did open coding of three interviews to generate a list of 217 codes and then used affinity mapping to consolidate them into an initial codebook of 70 codes (e.g., "*Justifying doing things outside of care plan*," "*Trying not to force/anger the patient*," "*Feeling like the agency only pays attention when they want something*"). This codebook was then shared with two other coders and each of the interviews was double-coded, where the first author reconciled codes with at least one of the other coders, adding or removing codes as necessary. Codes were then clustered into 13 subthemes that represented the data (e.g., "*surveillance/observation*," "*getting/giving information*," "*handling patients' emotions*"). These were then consolidated into the four main categories presented in the findings.

Limitations. We conducted a small-scale study to get rich insights from a set of aides' experiences. While these insights provide a deeper understanding of the aide experience and lift voices of participants who are generally underrepresented in HCI research, the goal of this qualitative research study was not to present a representative or quantitatively generalizable sample. There are several unique characteristics of the aides we interviewed. We interviewed only aides that are employed by agencies, which would not include approximately quarter of aides who are independent contractors and have even less protections [42, 51]. As mentioned before, regulations around what types of medical tasks aides can do is state-dependent (i.e., aides can dispense medications in some states and not in others). Aides in New York State, and New York City more specifically, are also more likely to be unionized and have union-negotiated benefits and protections [2]. Moreover, since they are based in a large city, the aides provided responses that often reflected unique urban situations (i.e., commuting a long distance on the subway between different boroughs).

4 FINDINGS

4.1 Managing Emotions of Self and Others

4.1.1 Handling Challenging Clients. The aides encountered stressful situations with clients. Technology was a point of contention that spurred additional emotional labor as the aides were chastised for using their smartphones, even for work-related purposes (e.g., calling nurses for updates or recording daily tasks). P10 did not use her phone because she would "*hear [clients] complaining of other aides ... talking on their phone all day*." COVID also created a difficult work environment because "*some clients ... treat[ed] us as if we would bring COVID in their homes*" (P2) and the aides themselves feared getting COVID. This increased their stress for their personal safety in their

sociospatial environment, compounding concerns of working in a dangerous neighborhood, commuting through difficult weather, or encountering an unacceptable living situation. Some even were threatened—a client with dementia shouted “*I’m going to kill you, get out of my house.*” (P9)

The aides also needed to build experience identifying and reacting to the client’s mood. Sometimes, the aides used strategies like P9, playing the music her patients liked on her iPhone to calm them down. However, the aides had to develop many different strategies because “*you don’t know what state [the client] will be in for the day*” (P3). P10 described the difficulty and additional work aides face because “*we just go into their home and we have to adapt ... and everybody’s different. Everybody have their own way of doing stuff.*” As an on-call aide who did not have a regular client day-to-day, P13 had to approach an unknown situation every night where clients might refuse to let her do her job—some would not let her shower them because they saw her as a stranger they did not trust.

None of this work was recognized or rewarded by their agencies nor was there a way to communicate these challenges. The aides themselves saw the empathy required for their job as natural because “*we are all human beings*” (P10), an example of the sociocultural devaluation of care skills. Since care skills were seen as something the aides innately had, the aides were rarely trained and their resulting efforts were unrecognized.

4.1.2 Coping with Emotional Burdens. Their agencies did not recognize emotional burden, and actually increased that burden. During training, their agencies instructed the aides not “*push*” or “*force*” (P5) clients. P10 said this was difficult because “*if I do [what the patient is insisting] and something go wrong with them, I’m the one that gets blamed*” since “*the agency wouldn’t stand behind me.*” This conflict between the agencies’ prescribed rules and the aides’ own ethics of care gave the aides both the emotional burden of managing clients’ emotions as well as the emotional labor of handling their emotions in response.

The aides talked about how they had to adjust their attitudes give quality care. When one of P12’s patients called her racist names, she tried not to let it affect her personally. She held the attitude that “*you can’t control how people are,*” asserting she was “*not going to let that one person make me feel [badly] because they no good.*” Some aides regulated their emotions so much that they themselves were no longer conscious they were doing it, attributing success not to their attitude adjustments but to their personality, saying things like “*I’m just relaxed*” (P4) or “*friendly*” (P9).

Other aides tried to separate their emotions from their work life, saying that “*work is work*” (P4), feeling like “*all work is frustrating but I am not making it a frustrating job*” (P11), or leaving emotions outside to “*be [a] different person with the patient*” (P9). This coping required substantial work which developed with experience:

“First, when I started doing the job ... certain things would bother me. But now, I work with so many different people and I know what to expect, what not to expect. I don’t make it bother me. I just do what I have to do and that is about it ... You go to people’s homes, you don’t know what to expect when you go there, whatever it is, you just got to deal with the situation as best as you could.” (P10)

Some of the aides turned to practices and rituals to manage their attitudes and expectations. P9 explained how “*running is my peace of mind*” that helps her emotionally reset between patients. P8 turned to religion, saying she “*give[s] God the credit and the thanks.*” And P13 would “*say a prayer, knock the door, and hope it’s a good night*” because as an on-call aide, “*you don’t know what you’re going to meet behind those doors.*” She considered her flexibility a necessary component of her ability to provide good care, even if the agency did not recognize it.

4.2 Accumulating Labor from Emotional Connections

4.2.1 Going Beyond and Beyond for Clients. The aides explored not only the importance and inevitability of being emotionally close with their clients, but also its costs. Many found it difficult to maintain the emotional distance they reported their agencies requested of them and tensions around these restrictions created more invisible work. P1 elaborated:

“Of course I do ... more than what the plan of care tells me to do. I go beyond and beyond ... The company is saying you’re not supposed to get attached to the client. Regardless, if you [are] working for this client for a while, you will get attached. ... Now, my client is blind, [and] I’m not supposed to be taking her blood pressure, her vital signs or nothing. She can’t see it and the doctor needs it. So what do I do? Do I get in trouble for my job for ... doing this? Or do I take care of my client?” (P1)

As P1 expressed, the attachment aides had with clients encouraged them to go “*beyond and beyond*,” taking on responsibilities or tasks beyond their assignment and, sometimes, against their agency’s wishes. P1 would often stay overtime, unpaid, to keep the client company. Additionally, P7 said that she and the other aides who worked would “*treat [her client] like our mother*” and helped her client do tasks outside of her job scope like billing and correspondence because her client “*never had nobody in New York*”. The emotions-based invisible work the aides performed (i.e., treating their client like their mother) in turn resulted in additional systems-based work (i.e., overtime, billing and correspondence).

P8 mentioned that she had such a strong bond with the client that she was put as her client’s emergency contact and was contacted by hospitals and the client outside of work, adding additional hours of work that were not visible or compensated. She also did extra work when she called and visited multiple pharmacies on a holiday weekend to pick up her client’s medication or handled layers of bureaucracy to get her client a vaccination appointment. However, P8 did not feel the extra work was an imposition because she “*choose to do that job [(care work)] because I like doing that kind of job*” (P8). P9 agreed and even said it went beyond a job for her, that “*you do what you do, and not because it’s a job, [but] because it’s empathy*.”

Even though the aides were motivated in part by an emotional connection, some raised questions around this burden and its lack of compensation. P13 talked about how her clients would “*get so attached to me*” they refused to work with other aides when she was on vacation. P1 felt this burden and believed aides like her were not being properly compensated for all of the additional tasks they took on for their clients:

“You need a big heart. You need to be able to be a psychiatrist, their secretary, their grocery store. That’s what you got to be. You got to be more than a home health aide. So that’s what I’m saying. That we need more money. We need more incentive. We need more.” (P1)

4.2.2 Filling in for Other Aides. The aides also did additional work when coordinating with other aides. P6 discussed how the four aides who worked with the same patient would share details at points of transition, like whether the patient has taken their medication or what mood that patient was in. Beyond simply checking in with the aides who were working before them, P5 elaborated on a sticky note system on the fridge where she left relevant updates for the other aides, including on the contents of the fridge itself. These coordination efforts, as crucial as they were, were not part of the list of recorded care plan tasks and not seen or recognized by the agency.

The relationships and solidarity between the aides could also influence them to do more work than they were assigned or expected to do. Some aides would complete the task to allow another aide to clock out on time. Others stayed a bit longer, unpaid, to finish their task before the other aide began. Although this extra labor and time were not recognized by their agency, P6 talked about

how aides, “*work as a team*”, saying “*that’s what we do, we continue for each other.*” This camaraderie also led to emotions-based work, including when P6 called and checked-in when the other aides were not there for a day or two.

While it was mostly positive connections that led to more work, sometimes it was because they were played against each other. P7 was asked by her client’s husband to give her client a massage and when she tried to say no, the client’s husband pushed back that “*the other aide did it.*” P6 said that even though most of the time that is not true, “*there are some aides that do what they’re not supposed to do and they make it difficult for some of us.*” P2 talked about how those aides might “*spoil*” the clients and create more work for them.

4.3 Coordinating and (Re)asserting Boundaries

4.3.1 Negotiating Expectations of Family Members. The aides often performed the invisible coordination labor of interacting with family members as part of the caregiving team—soliciting help when the patient was in a poor mood or giving updates on abnormal situations. However, some of their clients’ family members allocated tasks that were outside of the aides’ scope of work, like climbing a dangerously tall structure to do cleaning. Being asked to do extra cleaning or chores went beyond the aides’ role as a healthcare worker, as P2 elaborated:

“Some people see us as a maid . . . They don’t acknowledge the fact that we are home health aide[s], [that] there are certain stuff we can do, something like medical supplies . . . and so forth. We’re not just here to clean your house . . . Maid are different from an aide.” (P2)

The clients’ family members’ mistaken expectations meant the aides had to do either the extra work being requested or the work of asserting their boundaries. P2 was asked by a family member to clean the bathroom, even though the client was bedridden and could not even use the bathroom. When refusing this task, she expressed her hesitation and said “*I am not sure if I’m right for that or if I am wrong*” because “*when you stand up for yourself, [the family members] make it look like you’re the bad one*” (P2). This need to stand up for themselves added more pressure and emotional labor to the aides’ already heavy load, making aides feel “*invisible*” (P5) and furthering the sociocultural devaluation of both the aides and their labor.

Moreover, the aides had to handle not just the task-based expectations of the family members but also the emotional toll of the caregiving process. P13 would lend an ear to family members of her hospice client who were distressed, helping them come to terms with how the client was feeling. This type of work impacted her emotionally, but she said that she learned to handle it over time, despite not being trained by her agency to handle such cases. She was extending her caregiving to the clients’ family, which was outside of her scope of practice and invisible to the agency. Further, as this was also relational labor, it was often overlooked.

4.3.2 Navigating Unequal Attention From Their Agency. The aides’ complicated relationship with their agencies served as a source of additional labor. Most complained about how they had to do extra systems-based logistical work to reach their agencies. One aide, P6, gave an example of how it took her two weeks to get a job letter from the agency, calling multiple times and then finally making the trek to the physical office. Others reported also calling multiple times or trying different extensions until they were able to contact the right person.

The aides also felt like the poor communication meant agencies did not listen to their feedback or support them. P2 asserted that “*we need strong supervisors who don’t just listen to one side of the story*” and that situations with patients meant that “*it’s their [(the client’s)] word against our words.*” Some felt their agency was keeping crucial information about the clients from them—since the client P5 was working with had been served by her agency for 7 or 10 years, her agency must know

if the client had issues with other aides. Even though scheduling had a large impact on the aides' experience, many expressed that they felt that they had no control or say into that process.

The communication difficulties further engendered an impression that the agency did not care about them and that their efforts were invisible to the agency. They felt their supervisors did not know what they were doing—one of the trainers at the agency admitted as much and said *"I know you guys work hard, but I don't really know what you guys do"* (P8). P10 postulated that this lack of understanding led the agency to not respect their calls or call back and *"if they know what we are doing, they would appreciate us more and ... answer you when you call."* P7 felt this lack of attention was unfair, saying *"when they want you they know how to get you but when you call them, if you have any questions or something you want to discuss with them, they never answer the phone."*

This perception that their agencies were not *"aware of what we really do"* (P8) confounded the aides because their agencies were collecting information about the tasks they did day-to-day. The aides were frustrated that they had little insight into how the information collected was being used. P5 talked about how the record she sent to the agency through the task-tracking application says she *"did ... this task and that task and all my list of tasks, but I'm not sure if they're paying attention or not."* The only feedback P13 got was indirect and from the clients and family members rather than the agency—if she was not doing a good job, she would get complaints.

4.4 Learning and Making Decisions On-the-Fly

4.4.1 Performing Clinical Tasks with Uncertainty. The aides also worked to monitor and record the clients' health to help medical professionals, which was part of the aides' scope of work. However, they did not always receive sufficient training, without which, the aides lacked confidence in their ability. P5 mentioned that when she was checking her client's vital signs she was confused, thinking *"Is this accurate?"* or *"Did I take it right or not?"*

In addition to having to handle their doubt, the aides had to engage in more work to learn the procedures on their own and fill in their gaps of knowledge. P2 talked about how she *"would just rush to Google and research what I don't understand"* to clarify communications she had with the nurse or in place of getting timely feedback from the agency. The aides had to learn on their own how to work with patients with Alzheimer's and dementia, looking up YouTube videos (P9) or taking a weekend course (P7). Even with all of this additional learning and organizing work, the aides were recognized only inasmuch as they were able to complete their tasks, rather than how proficient they were or the knowledge that they gained.

The challenge in communicating with the agency not only created more work for the aides, but also forced them to make difficult decisions on their own when the agency did not pick up. P2 expressed her lack of trust in her agency, saying this she did use Google or YouTube searches *"because if I'm supposed to call a supervisor, I would not get anybody to assist me as quick as possible."* Similarly, P1 described an incident when her patient fell and hit her face on the ground, she was unable to get support from her agency:

"By the time the agency got through, I walked my supervisor [and] the nurse through it. I told them what was going on. And what they was telling me, I already had did what they was telling me. Already have put the cold compress. I already did this, already did that. So there was nothing they had to tell me. I told them." (P1)

P3 also corroborated this disenchantment, saying she had to use *"initiative"* and *"the right judgement"* when she could not reach her supervisor. This was important glue work that allowed the system to run smoothly but that the aides' supervisors did not know about.

Through the tacit knowledge that they built over time, aides were more aware of their clients' states and more perceptive to changes. P1 talked about an incident where her clients's vitals dropped

drastically and how “*if I didn’t catch that, I could have come in there the next morning, she could have been gone. She needed her medicine changed. I caught it.*” This was a crucial piece of knowledge P1 had to maintain the functioning of the larger system. Some of the aides took the initiative to create and update their own systems of documentation of the patients’ states on their own notebooks or computers beyond the checklist-based reporting required by their agencies. P9 said this system she created outside of her work requirements already came in handy, as she was asked by both doctors and her supervisor to report some of the information she tracked.

4.4.2 Uncovering the Black Box of Technology. The aides described two smartphone applications: Sandata [3] for clocking-in and out and recording completed tasks and CareConnect [1] to select cases or get details about shifts. Since these processes were originally paper and phone-based, the majority of aides were still transitioning between writing or dialing in their daily clock-ins and inputting them on the new smartphone application. P13 had to piece together different sources of information from old and new technology—she still got direct calls from her supervisor about her case assignments but used the scheduling app to figure out details, like the address. As for clocking-in, she simply did not use the new processes, saying “*they have an app but I don’t know how to use the app—I’ve never used it*” (P13).

The aides talked about their difficulties in learning technology. P9 elicited help from her daughter but posited that other aides did not have such support and would “*rather work for ... small agencies, which [do] everything by the phone or in-person.*” The lack of familiarity with technology made the logic behind the technology seem opaque—P2 felt she had to be “*lucky*” to be able to do what she needed to with the app. When she selected the cases she wanted on the scheduling application, she kept getting the message that the case was no longer available. She found it was easier to just call to ask for case availability instead. The aides had to do more work to learn or get help using the smartphone applications, work that was necessary but not rewarded or recognized.

In addition to learning how to use the applications, the aides had to put in extra effort to handle technical issues. P1 said the clocking-in application often “*goes haywire.*” When she had an issue, it took her three to four days to get back on, which led her to not trust the application. This trust was further violated because when the app malfunctioned, the aides felt its material impacts. P8 shared an incident where she “*didn’t get paid for a couple of days*” because the GPS system could not clock her in when she was outside of the home at the doctor’s office with her client. To resolve the issue, she had to explain herself and her situation to multiple people.

The aides were concerned about how the smartphone applications could result in too much visibility and surveillance of their activities by their agencies. P8 felt that the agency “*trick[ed] us*” into downloading a tracking application for her to clock-in and clock-out, saying “*I’m sorry, this is my personal phone. Why should I put that tracking device on my phone to track me down?*” Similarly, P9 preferred that the agency had less insight into what she did on a daily basis, saying:

“I always say it’s better nobody knows what you do, because then they’re expecting more from you. So I just do my stuff, and that’s it. I don’t expect nothing, the agency knows what I do. Just my job, and can put food on the table for my kids.” (P9)

5 DISCUSSION

Our findings give a better understanding of the invisible work home health aides do, which could help develop new technology that does not continue to reinforce the existing, oppressive power dynamic. We delineate how the aides perform the emotions-based and systems-based invisible work that other health workers perform, but also further demonstrate the intertwined nature of these two types. Moreover, we explore how specific characteristics of home health aides reflect the sociocultural, sociolegal, and sociospatial mechanisms of invisibility and expand this framework by

Table 3. Summary of Findings

Stakeholder / Category	Managing Emotions of Self and Others	Accumulating Labor from Emotional Connections	Coordinating and (Re)asserting Bounds	Learning and Making Decisions On-the-Fly
Clients	Handling clients' moods* Coping with stress	Helping b/c they care*		
Clients' Family	Emotional support Feeling background	Tasks outside care plan	Soliciting help* (Re)asserting bounds	
Other Aides	Played against others	Filling-in for others	Transitions*	
Doctors/nurses	Lacking clinical status		Reporting status*	Clinical tasks Close monitoring*
Agency	Unequal attention		Difficulty contacting*	Deciding on-the-fly* New technology* Technical issues*

* involves tech

demonstrating sociotechnical mechanisms. Finally, we discuss considerations required to design technology that accompanies systemic changes to reduce the aides' vulnerability.

5.1 Types of Invisible Work

Emotions-Based and Systems-Based. A lot of the aides' invisible work is emotions-based. They adjusted their own attitudes in order to handle the emotional burden of stressful situations and continue the emotional labor of providing care. Prior literature on emotional labor points out the potential for burnout from emotional regulation work [33], especially around "*deep acting*" (i.e., changing internal feelings) [80]. This is seen in the aides when they adjusted their emotions so much that they felt like it was part of their personality, making the emotional regulation and recovery labor less visible to the aides themselves and even less acknowledged by their agency.

Additionally, the aides also performed key system-based invisible work to fill in gaps and connect different parts of the system together. The aides filled training gaps by taking the initiative to learn how to complete medical tasks and filled information gaps by reporting the client's vitals to medical professionals or day-to-day status to family members. They also coordinated care among the stakeholders, soliciting help from family members or the community and managing hand-off with other aides. This echoes the framing of community health workers, similarly home-based caregivers, as "*system-builders*" [78] that perform crucial maintenance and articulation work that is immaterial and thus, invisible [60].

Intersecting Dynamics. While prior work focuses on a single type of invisible work, our findings revealed that these types of invisible work are in conversation with each other because one activity could necessitate work of both types. For example, learning on their own and on-the-fly is nominally an example of *organizing work* because it is required to fill in gaps in the system. However, it is also an example of an *emotional burden* because the aides often had to do this in pressurized, high-stakes situations and, in turn, required *emotional labor* to cope with this stress and present a positive face to their clients and agency. There can also be a causal relationship between the different types of work. Learning on the fly could also lead to additional *relational labor* required to navigate how they request more support or adapt to gaps in their relationship with their agency.

While (1) handling one's own and others' emotions (e.g., managing a challenging client's mood, coping with emotions that resulted from the encounter) is most clearly emotions-based work, it could also be considered important for the smooth running of the system without emotional

hiccups. The finding that (2) engaging in additional labor due to an emotional connection is a prime example of the causal relationship where the emotions-based work of managing relationships with their clients or other aides can lead to additional systems-based work to stay overtime to assuage their client or to fill in for other aides. Furthermore, (3) coordinating and (re)asserting boundaries with the client's family or the agency can be seen as maintaining the boundaries of the system, but, as relational labor, also engages in emotions-based work of handling these interpersonal dynamics. The final category, (4) learning more information to make decisions on-the-fly (e.g., Googling information during an emergency) is described above as involving both systems and emotions-based work and can lead to additional work that reflects both as well.

Designing for Both. Prior work has focused primarily on one type of invisible work and this is reflected in the technology design as well. Discussions about health workers' roles in systems-based invisible work has brought up ideas of workflow management tools that can help manage tasks or communicate information [69] and focus on emotions-based invisible work has suggested various tools to help workers manage their emotions [14, 58]. While tools that separately account for the "*tacit knowledge*" and "*informal social networks*" [50] in workflows or give aides actionable emotional advice could be valuable, another approach could be to design solutions that account for both systems-based and emotions-based invisible work. Combining designs for both types of invisible work might lead to workflow management tools that also manage emotions, giving space for aides to handle their own emotions (i.e., tracking emotions [46], integrating stresses from personal life [14]) and navigate emotional interactions (i.e., share strategies [58]).

Our findings emphasize the importance of understanding invisible work holistically when designing technology. It is not enough to focus on digitizing task-based inefficiencies or invisibilities of the workers, but needs to also consider the emotional impact or labor that may emerge from these processes. Any system that gets built could potentially exacerbate emotional burden or become less effective due to emotional labor. For example, aides reported being chastised by clients or their family for using their phone during work hours, even if the app being used is part of their job. The aide then has to work to calm down a client who reacts strongly to their phone use as well as manage their own frustration or anxiety about the client complaining to the agency, all of which likely makes the app less effective. Future approaches might want to allow for more transparency or feedback to the client and client's family regarding the apps in use and reasons aides need to use their phones as part of providing care, building upon discussions of stakeholder-specific disclosure in design [52].

5.2 Mechanisms of Invisibility

Sociocultural, Sociolegal, and Sociospacial. On the sociocultural front, the aides' experiences reflect the hegemonic ideals that devalue both the aides' labor and identities. We saw this in the findings since both the aides and their supervisors overlooked the aides' skills in caregiving as natural and not needing to be compensated fully. Since the aides pointed mostly to how the job was personally fulfilling even if it was not financially fulfilling, they also demonstrate the "*prisoner of love*" effect [23]. Additionally, the aides we interviewed were all women of color and noted how their identity related to the invisible work that they had to engage in. The aides' invisibility was reinforced because their marginalized identities meant that they were overlooked culturally as a "*non-person*" [66]—navigating disrespect in the form of offensive and racist comments made by clients, questioning of their authority by clients' families, and their agencies' lack of attention. These power dynamics are important to keep in mind when designing technology, potentially by examining and challenging them through frameworks like data feminism [20] or design justice [16].

Our findings also reflect the impacts of the sociolegal mechanisms of invisibility unique to home health aides. We see the precarity of the aides' situation in the aides' concerns around benefits and pay and how it factors into their decisions to do their job well and how much compensation they felt they deserved. The legal status of the aides sometimes prohibited them from doing some medical tasks (i.e., giving the clients their pills), but allowed them to do others (i.e., remind clients to take the pills) [37], which impacted whether they are considered part of the clinical team or have the requisite training. Their lack of clinical status and training meant more invisible work to look up information to make decisions on-the-fly.

Finally, our findings demonstrate sociospatial invisibility in intimate, geographically distributed domestic spaces. It is especially heightened for the aides because they are often employed in multiple different homes, described in previous literature as a key contributor to the physical strain of their commute or emotional isolation as the main caregivers in the clients' homes [65]. In our findings, we see how sociospatial mechanisms influenced the aides' invisible work because the tight bond the aides felt with their clients was a source of invisible work both systems-based and emotions-based. Moreover, the disparate distribution made it difficult for the aides' agencies to see their work and created the tendency for the agencies to want to keep track of what the aides are doing each day, contributing to the aides' concerns around observation and surveillance, as discussed further in Section 5.3.

Sociotechnical. The aides' experiences extended the existing work and demonstrated that sociotechnical mechanisms also influenced their invisibility. Using apps and tools required by their agencies created more invisible work associated with the technology itself, as they needed to learn how to use the technology or handle issues that arose from applications malfunctioning. Moreover, they needed to do extra work to balance a mix of different generations of technologies (i.e., paper reports, phone calls, text messages, and smartphone apps). This reflects what the prior literature has shown, that aides may be resistant to learning new technology [75] and require more training [68]—so systems designed for aides will need to consider how to minimize the potential added burden on aides. However, careful consideration is required, as training could in turn cause additional emotional burden of being perceived technologically illiterate or undue dependence on the intermediary [48].

Outside of uses of technology prescribed by their agencies, aides also used their own devices to contact people (e.g., texting updates to clients' family members), look things up (e.g., playing music to soothe a client), or write things down (e.g., recording clients vital signs). This may create conflict between the aides and their clients who may not understand why the aides are using technology, increasing the invisible work required from the aides to handle the situation. Additionally, through these uses, technology also facilitated more invisible work by extending the availability of the aides. Some aides shared instances when they were called by clients outside of work hours and continued to give care off-the-clock. This supports prior literature in other care work domains that has discussed how the invisible work that arises due to being constantly available through cell phones can increase the stress workers feel (e.g., teachers [77], nurses [39]). But, on the other hand, can be vital for emergency situations [79]. Future systems should be careful to balance this tension.

Use of technology outside of the aides' assigned responsibilities also enabled aides to do more invisible work of filling in gaps in the system, specifically learning on their own how to use technology or perform clinical tasks on-the-fly. These "*ad-hoc processes*" [11] expanded the aides' invisible work because the work to learn itself is additional and its urgency increases emotional burden. Moreover, the aides' ability to fill these gaps of knowledge by doing invisible work on their own gives their agency an excuse to not have as extensive training or support systems. This reinforces the invisible work that the aides need to continue to do and calls into question the quality

of care that is provided if the aides are distracted or unprepared. Furthermore, since technology can reinforce the power dynamics between aides and the other stakeholders by increasing invisible work, future systems need to be vigilant of the relationship between technology and the broader dynamics of the home care ecosystem so aides do not need to suffer doubly from their deprioritization in both the hierarchy and technological system. In the future, analysis of invisible work and its ramifications could take on a similar approach as power mapping [31] and such analyses.

5.3 Technology for Visibility?

Technology and data could be used to improve the aides' broader condition, but requires careful consideration. Aides described how they are not receiving sufficient feedback on their performance, doubting that the agency is even aware of what they do. Using technology to enumerate extra work that is done could help aides get credit for it or demonstrate their impact to advocate for better recognition or compensation. However, it is not as straightforward as adding additional checkboxes to the existing task-tracking systems to account for the invisible aspects of the aides' work. As prior work indicates that technology can only "*amplify*" [74] existing human forces, it is necessary to ensure these forces are in place before design and deployment—that the aides are willing and able to use technology, the power dynamics between the aides and their supervisors have been carefully interrogated, and the potential impact of this additional information has been carefully assessed. However, in those circumstances, technology could potentially have an indelible impact on the invisibility of the aides' work and the aides' vulnerability.

As prior work suggests, even implementing any technological system runs the risk of increasing additional emotions-based invisible work for navigating relationships or learning how to use the application. This further demonstrates the "*wicked*" [61] nature of the problem—so entrenched that efforts to change it unravels even more problems. The lens of invisible work could predict, to some extent, some of these potential externalities so they can be addressed. As discussed above, future technology design could anticipate the potential work for navigating relationships by incorporating more stakeholders earlier in the process or having more transparency around the potential interventions to supervisors, clients, or clients' families. More attentive training and support can help mitigate the additional burden of learning a new technology.

Simply recording more without careful consideration of power dynamics could result in the agencies having even more control over aides. Star and Strauss [66] point out the dichotomy of "*legitimacy*" and "*surveillance*"—if the superiors were seeing exactly what workers were doing, they might not necessarily increase their acknowledgement of the workers, rather, might increase responsibilities or scrutiny of the workers' actions. This is echoed by the aides' sentiments that "*it's better nobody knows what you do,*" (P9) wishing that they could have more autonomy to do their job in the way that makes sense for them. These sentiments build upon literature in worker tracking and surveillance [12, 19], especially in settings of low wage work that are considered nontechnical but frequently regulated and shaped by technology [21]. In the home care space specifically, Mateescu [47] has documented how such tracking affects not only the workers, but also their vulnerable clients. In order to break these patterns of power, Suchman [71] advocates for meaningful input in the data process and ownership of data outputs by those whose work is being made visible, further discussed as workers' data and technology rights by scholars like Colclough [15] and Bernhardt et al. [7]. Therefore, it is important to give aides more control over what data is collected—to better understand what parts of their day aides want to show to their supervisors and potentially allow aides to have more discernment over their specific privacy preferences.

Figuring out what work to make more visible also points to a need to understand the agencies' perspectives, a line of questioning we hope to pursue in further studies. Potential impact can be largely determined by whether an agency would even care or be able to do anything about an aide

who works overtime to help a client feel less alone or complete a task the previous aide was not able to do. To do this, we would need to build on prior work on using data for advocacy (i.e., organizing strategies [25], technology in organizing [28, 41], storytelling [20, 44]). Additionally, engaging with the agency could result in what scholars call a shift in “*the relation between our own social location and our view of others*” [71] and help modify boundaries of visibility. Understanding their supervisors’ perspective could be helpful for aides since it is the lack of insight into what their agency cares about that contributes to the aides’ paradoxical feeling of being tracked with regards to their compliance to the care plan but underappreciated for any of the work they do outside of it. Increased transparency could address the aides’ concerns around how decisions are made and help them to see how their opinions and feedback could improve their agencies’ decisions.

Another question is what the goal of visibility is and could viably be—balancing short-term compensation with long-term redefinition of work. The aides we spoke to raised concerns around immediate, material needs—wanting to be compensated for the many roles they were taking on or wanting to receive incentives or hazard pay at crucial moments like the COVID-19 pandemic. However, since much of the aides’ work is invisible, it is hard to increase compensation for it without redefining what they are being compensated for. Stacey [65] talks about the historic tension between the organizing strategies and how reframing the aides’ work as clinical work might have implications sooner but is potentially not as long-lasting as reimagining the traditionally unpaid companionship aides do itself as valuable work. Therefore, any visibilizing of aides’ work with technology and data needs to both ensure they receive pay that is stable and sufficient but also provide broader alternatives to valuing or validating work. As Raval [59] puts it, it is important that these efforts go beyond “*simply exposing working conditions*” and rather move towards “*transforming the material realities*” of workers. With careful consideration, technology could help this happen.

6 CONCLUSION

Invisible work has long been used in HCI and CSCW research to understand all of the work, visible and invisible, in a given context. Our study applies this lens to understand how to design appropriate and equitable technology for home health aides. Through interviews with aides, we learned about the types of invisible work they engaged in and note that technology design needs to be expanded to account for the intertwined nature of systems-based and emotions-based invisible work. Moreover, we discuss how, beyond the sociocultural, sociospatial, and sociolegal mechanisms of invisibility, the aides are also impacted by technology that enables more invisible work, meaning future designs need to take into account sociotechnical factors. Finally, we discuss how technology could potentially be designed to not only account for the invisible work of home health aides, but also to help visibilize the work itself—though this raises caveats that need to be considered around privacy and transparency. These learnings provide insights into how invisible work could be relevant to the design of technology for and advocacy of workers involved in care, emotional labor, or other forms of unacknowledged or unrewarded labor.

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