

# Invisible Work in Two Frontline Health Contexts

Joy Ming  
jming@infosci.cornell.edu  
Cornell University  
Ithaca, New York, United States

Srujana Kamath  
srujana.kamath@gmail.com  
Independent Researcher  
Mumbai, Maharashtra, India

Elizabeth Kuo  
ek566@cornell.edu  
Cornell Tech  
New York, New York, United States

Madeline Sterling  
mrs9012@med.cornell.edu  
Weill Cornell Medicine  
New York, New York, United States

Nicola Dell  
nixdell@cornell.edu  
Cornell Tech  
New York, New York, United States

Aditya Vashistha  
adityav@cornell.edu  
Cornell University  
Ithaca, New York, United States

## ABSTRACT

Frontline health workers provide essential services for their communities, but much of their work remains invisible—undervalued and underappreciated. Examining this invisible work ensures new technologies do not amplify or reinforce inequitable power structures, especially as governments and organizations push to digitize health work processes. We build on a burgeoning conversation by studying how invisible work manifests and how this invisibility can be challenged in two contexts of frontline health: home health aides in New York City, USA and Accredited Social Health Activists (ASHAs) in Uttar Pradesh, India. We highlight three shared manifestations of invisible work: (1) work done outside of the workers’ boundaries (2) work done to gain and share knowledge and (3) work done to manage relationships. These common categories are experienced differently in the two contexts, raising nuances to consider when designing technology for frontline health workers. We discuss these nuances and other tensions through concrete examples of how workers can escalate feedback and conflicts, quantify implicit expertise about patients, or build more awareness of their situation. Our paper guides the creation of technologies that take into account a more comprehensive understanding of the frontline health workers’ processes and highlight more of their contributions.

## CCS CONCEPTS

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

## KEYWORDS

future of care work, feminist solidarity, community health workers, home health aides

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## 1 INTRODUCTION

Frontline health workers provide essential care services to underserved communities—extending the reach of overstretched public health infrastructures, performing vital data collection, and serving as “eyes and ears” [88] in the community [11, 91]. However, despite the importance of their work, they are often undervalued and underappreciated. They lack status as workers—not officially considered part of the medical team and poorly paid, with most living below the poverty line [36, 88]. Moreover, they are asked to do additional or demeaning tasks outside of their scope of work and face discrimination and violence based their gender or racial identities [72, 76, 84]. The technology that is developed for frontline health workers often reinforces this inequitable dynamic, disregarding the workers’ voices and experiences and focusing instead on compliance and surveillance rather than supporting their needs [59, 68, 98].

As technology continues to be built to handle the increased reliance on the frontline health workers as the backbones of the underlying healthcare systems, we need to better center the perspectives and realities of essential workers in the design process to avoid the proliferation of harmful systems [17]. One lens through which to understand frontline health workers’ overlooked contributions and ensure the design of more equitable technologies is by examining their “invisible work”—labor that is unnoticed, unacknowledged, undervalued, or unregulated [18, 19]. This invisibility factors into the devaluation and backgrounding of key articulation and “glue” work that health workers perform [7, 84]. Learning about frontline health workers’ invisible work will enable the creation of technologies that take into account a more comprehensive understanding of their processes and highlight more of their contributions [14, 66, 85]. Prior work has started to pull back the “screens of invisibility” [77] around the work of frontline health workers [65, 90, 100] to identify how technology can draw from, complicate, or reinforce invisible work. However, this work has generally focused on singular contexts.

As design in information and communication technologies for development (ICTD) has an increasingly global inspiration and cross-cultural relevance, it is important to balance both “human universals” and “cultural differences” [97]. We extend the literature at the nexus of invisibility and frontline health by using the approach of feminist solidarity [63] to juxtapose two contexts. Doing so, we examine both the “general” issues frontline health workers face and the “particular” [48] design relevant to specific contexts [53]. Our qualitative study consists of semi-structured interviews

with two groups of frontline health workers: 13 home health aides in New York City, United States and 15 Accredited Social Health Activists (ASHAs) in Uttar Pradesh, India. We studied the invisible work they perform, the factors that contribute to their invisibility (e.g. their identities as women of color and the feminized nature of care work [30, 44]), and what they are willing or able to do about it.<sup>1</sup>

Our findings revealed three main manifestations of invisible work and their implications across the two settings. These included: (1) work done outside of the health workers' boundaries (e.g., outside of work hours, outside of prescribed job scope); (2) work done to gain and share knowledge (e.g., handling uncertainty in tasks, serving as a point of information for patients and other medical professionals); and (3) work done to manage relationships (e.g., dealing with the emotional burdens placed by challenging patients,<sup>2</sup> adjusting their emotions to present a specific face). While the aides and ASHAs shared categories of invisible work, the way they actually experienced it differed. For example, doing work outside work hours for an aide meant they stayed overtime because their patient did not want to be alone. For ASHAs, it meant that they could be called to report for duty at any hour of the day. The problem of having to account for the extra time and energy the aides and ASHAs expend was a shared problem, but technological design would require accounting for these different nuances.

Given these manifestations and nuances, we discuss how technology could be designed to increase visibility in the form of support, respect, and recognition. We present some examples of technology that could help the aides and ASHAs achieve these goals, such as technology that can escalate feedback and conflicts, quantify implicit expertise about patients, or build more awareness of their situation. However, such technological solutions come with many considerations. For example, while both aides and ASHAs were interested in two-way feedback that is constructive, each conceptualized feedback differently—aides wanted more positive reinforcement and ASHAs wanted more critiques. Moreover, using technology to address these manifestations of invisibility is not necessarily straightforward and we discuss the tension between visibility and surveillance with regards to attitudes towards privacy, potential retaliation, and the specificity of the home setting.

In summary, our paper contributes the following: (1) a comprehensive examination of the manifestations of invisibility in two frontline health contexts; (2) how the commonalities and nuances across the two contexts could be designed into technology to make the workers more visible; and (3) broader considerations of visibility when designing technology for frontline health workers in these and other related contexts.

<sup>1</sup>We use the word "aide" and abbreviation "ASHA" because this is how their patients refer to them. We refer to them collectively as "health workers" rather than "caregivers" to highlight their professional/paraprofessional roles and distinguish them from family caregivers.

<sup>2</sup>The frontline health workers often use different terms to refer to care recipients, including "client" which is most commonly used by aides and "patient" which is most commonly used by ASHAs. For clarity, in this paper we use "patients" to refer to those who receive care from frontline health workers.

## 2 BACKGROUND AND RELATED WORK

### 2.1 The Two Contexts

**2.1.1 Home Health Aides.** Home health aides (aides hereafter) are paid professional caregivers who provide home-based care for people with chronic conditions, who need long-term assistance, and/or who want to age in place [9, 35, 88]. They help patients navigate the healthcare system and manage a wide range of chronic diseases by assisting with activities of daily living (e.g., bathing, grooming, grocery shopping, going to the doctor's office) and performing clinical monitoring (e.g., taking temperatures, recording mental/physical status) [69, 70]. They are often independent contractors or employed by agencies and funded by the government through public assistance programs like Medicare or Medicaid [88]. But due to their low (usually minimum) hourly wage and inconsistent hours, many themselves are on welfare and living below the federal poverty level [71]. Aides are a marginalized group of frontline workers: predominantly women, people of color, and immigrants [84, 88] and the COVID-19 pandemic highlighted their essential but precarious role [89]—they were on the frontlines but felt invisible, unsupported, overworked, and undervalued [84, 88, 91]. Advocacy for aides occurs through unions and other organizations, which have made some strides in legal protections [31, 72], such as only recently being protected from harassment by the human rights law [1], but much work is still needed.

**2.1.2 Accredited Social Health Activists.** Community health workers are trained to provide care for communities in hard-to-reach areas in the Global South [68, 101]. One type of community health worker is the Accredited Social Health Activists (ASHAs) of India. These workers are women recruited to serve their own communities as "remunerated volunteers" or "honorary workers" [11, 58]. They have three main responsibilities: providing community-based care (e.g., home visits to provide essential medicines or treatment for minor ailments), liaising between the community and the health system (e.g., accompanying women and their babies to the hospital), and mobilizing the community for collective action [29]. While there has been increased transparency and a readiness to discuss gaps in service conditions in the ASHA program [11], ASHAs are still the victims of high levels of economic, emotional, sexual, and physical violence due to their low positioning on the healthcare hierarchy, lack of respect from community members, and limited autonomy at home [36, 76]. Some challenges ASHAs may face are due to interpersonal dynamics (i.e., mistrust or conflict within the community due to experience, class, caste, or gender), low compensation (i.e., inadequate payment and misaligned incentives), and job-related concerns (i.e., poor transport, overburdening of work) [6, 36, 62, 81].

### 2.2 The Shared History of Care and Invisible Work

**2.2.1 Historic Context of Invisibility.** As frontline health workers, aides and ASHAs both perform the invisible work associated with giving care. In Marxist-feminist scholarship, invisibilization of giving care can be traced back to the devaluation of reproductive labor and other labor done in the home as "women's work" [8, 19]. "Women themselves became the commons" [30] when their labor

was seen as an asset that was not only unskilled and taken for granted, but also unproductive and justifiably unpaid or underpaid [28]. As women sought employment outside of their own homes, the “public and private worlds [were] mixed together with paid work” [19] and their labor continued to be both culturally and financially devalued [27]. This reinforced a power structure that disadvantaged women and other marginalized identities, leading to underwaged or racialized labor, which meant that they were facing overlapping inequalities not only in their work identities but in the personal identities as well [23, 24, 95]. The introduction of women’s labor to the market when women were paid to give care in other peoples’ homes also led to the commodification of emotional and affective labor. This in turn resulted in increased burdens for the workers to manage and project a certain emotional state as a requirement of their job [44]. The professionalization of medicine reinforced the value of the work in medicine that required elite training and was often performed by men over the supposedly unskilled work of women and health reform advocates [54]. These different facets of invisibility together contribute to giving care being seen as “natural” and less valuable when done by women [33].

The framework of invisible work is especially helpful in understanding how giving care is situated and how that position can be challenged. Invisibility can lead to frontline health workers not realizing their contributions and rights; the beneficiaries of the service disrespecting the physical, emotional, and mental burden of their health workers; employers being able to hide their exploitation of their workers; and policymakers overlooking the importance of protections and measures for these health workers [18, 23]. However, challenging this invisibility raises tensions. One tension is between presenting the work that health workers do as more professional and clinical to achieve short-term material gains versus taking the longer-term argument of advocating for the legitimacy of care itself as work [84]. Moreover, making the work that health workers do more visible can lead to legitimacy and recognition for their work, but also can lead to surveillance of that work and a loss of autonomy [85, 92].

**2.2.2 Technology and Invisibility.** Much of the discussion around how the structures of oppression invisible work are reinforced in the technology sector has been centered around data labor. Gray and Suri [38] present an overview of “ghost workers” whose work to create the data that underlies algorithms and machine-learning models and is often invisible and uncredited to maintain a “vener of automation.” As many of these workers are in precarious labor conditions and older women of color, “today’s hierarchy of data labor echoes older, gendered, classed, and raced technology hierarchies” [46]. D’Ignazio and Klein [23] join this call for transparency, for giving credit where credit is due, to reduce the economic oppression that cuts across the matrix of domination as a whole.

Invisible labor has also been investigated in the context of technological design for healthcare settings. Prior literature has demonstrated that identifying work that is otherwise not visible can help develop more appropriate and equitable technology that can better account for informal processes or networks [14, 26, 65]. Stisen et al. [90] demonstrate this by describing how understanding the cooperative, invisible, non-clinical work of hospital orderlies can help

design better coordination tools to support their work practices. Verdezoto et al. [100] extend the exploration to include community health workers low-and-middle income countries.

Although there is a growing body of research on the types of invisible work, even for frontline health workers, few analyze how this changes across contexts, and there is little discussion around how technology itself could be part of the visibilization process in caregiving specifically. Irani and Silberman [47] demonstrate the power of technology to render visible the work of Amazon Mechanical Turkers. Nafus [65] uses tracking to illustrate to family caregivers the value of their own contributions, but does not explore the tensions that visibility raises. Moreover, there is little work that juxtaposes different settings of invisible caregiving, especially across the Global North and Global South, despite the demonstrated difference in these contexts in terms of their labor movements and sociocultural contexts [99].

### 2.3 The Comparison of Contexts

Comparative research has been used in many different fields (e.g., comparative sociology, comparative literature) to draw insights across different settings that would not otherwise be possible, gaining a deeper understanding of critical issues, opening new and useful directions, sharpening the focus of analysis, or identifying gaps in knowledge [37, 75]. Specifically for theory development, comparisons can be used to test hypotheses, demonstrate parallel instances of a theory, or contrast how processes of change play out in different contexts [16]. For example, Laslett and Brenner [54] point out the importance of taking abstract and generalized theories and tested and refining them in light of the specificity other contexts.

The concept of comparative research in HCI and related fields is still fairly nascent, despite its many potential positive impacts. Much of the notion of comparison is related to experiments like A/B testing where different forms of the technology itself is being tested. More recently, Gharawi et al. [37] shared guidance for cross-national research and Kumar et al. [53] brought in the framework of feminist solidarity as means of contrasting contexts rather than technology. Feminist solidarity, a concept proposed by Mohanty [63] examines “commonalities across differences” [63], where connections are drawn across borders with “situated comparisons” [22] and “situated knowledges” [39] to understand transferability over generalizability. Moreover, the framework highlights the importance of solidarity, of drawing connections between global and local forms of resistance to oppression [25, 63]. This type of contextual comparison is especially relevant to work that is done in low-resource settings because of the multi-national and multi-context nature of these settings, and has the opportunity to contribute to understanding of both the global and the local [53, 97].

Our study contributes to this space by examining frontline health workers from otherwise disparate groups. Despite differences in their sociocultural contexts, both aides and ASHAs are vulnerable frontline health workers whose experiences are influenced by their positionality as women of color and immigrants [6, 83] and their job as intermediaries between their patients and the health system, while not having status as a member of the clinical team themselves [76, 91]. Following Mohanty [63]’s proposal, it is focusing on these

**Table 1: Participant Demographics**

| ID    | Age | Gender | Education        | Years |
|-------|-----|--------|------------------|-------|
| HHA1  | 56  | Female | Some college     | 7     |
| HHA2  | 22  | Female | High school      | 2     |
| HHA3  | 50  | Female | High school      | 8     |
| HHA4  | 32  | Female | High school      | 11    |
| HHA5  | 35  | Female | High school      | <1    |
| HHA6  | 58  | Female | Primary school   | 29    |
| HHA7  | 57  | Female | High school      | 25    |
| HHA8  | 56  | Female | High school      | 25    |
| HHA9  | 39  | Female | GED              | 4     |
| HHA10 | 37  | Female | High school      | 10    |
| HHA11 | 62  | Female | Middle school    | 16    |
| HHA12 | 43  | Female | Some high school | 13    |
| HHA13 | 54  | Female | Some college     | 24    |

| ID     | Age | Gender | Education        | Years |
|--------|-----|--------|------------------|-------|
| ASHA1  | 42  | Female | Middle school    | 16    |
| ASHA2  | 38  | Female | High school      | 16    |
| ASHA3  | 58  | Female | Some high school | 16    |
| ASHA4  | 35  | Female | Bachelors        | 13    |
| ASHA5  | 36  | Female | Middle school    | 16    |
| ASHA6  | 48  | Female | Primary school   | 15    |
| ASHA7  | 52  | Female | Middle school    | 16    |
| ASHA8  | 41  | Female | Some high school | 16    |
| ASHA9  | 38  | Female | Some high school | 16    |
| ASHA10 | 46  | Female | Primary school   | 16    |
| ASHA11 | 57  | Female | Some high school | 16    |
| ASHA12 | 59  | Female | Middle school    | 16    |
| ASHA13 | 42  | Female | High school      | 16    |
| ASHA14 | 31  | Female | High school      | 3     |
| ASHA15 | 47  | Female | Some high school | 16    |

different kinds of feminisms, pulling from the strengths of each of the contexts, that allows us to have a more comprehensive understanding of both of the contexts and the underlying concepts that are shaped by them.

### 3 METHODS

We conducted an IRB-approved qualitative study consisting of semi-structured interviews with frontline health workers in New York City, USA and Uttar Pradesh, India. Since we engaged with health workers in two different sites, our team consisted of a diverse group of researchers with different backgrounds, including designing technologies for marginalized populations, medicine, and labor relations. All team members have experience working with under-served populations—three each have 10+ years of experience studying frontline health workers in South Asia, Africa, and the United States. Members of the team have spent several years working with our specific partner organizations in New York and Uttar Pradesh. Our interdisciplinary team is conscious of our positionality as academics and worked closely with local community organizations to follow principles of design justice [17] and center the frontline health workers.

#### 3.1 Recruitment and Participants

**3.1.1 Home Health Aides.** We conducted interviews with 13 aides in New York City from April to August 2021. We recruited participants through direct outreach and partnerships with two home healthcare agencies. Agency staff independently identified aides willing to participate and shared their contact details. Participants

were given USD \$25 gift cards for the time they gave to the study, as suggested by our agency partners. All aides spoke English and identified as women of color, with between 2 months and 29 years of experience working as aides (see Table 2).

**3.1.2 Accredited Social Health Activists.** We interviewed 15 ASHAs from September to November 2021. We recruited participants through a partnership with Nehru Yuva Sangthan-Tisi [4], a grassroots organization that runs multiple programs to strengthen community health systems in western Uttar Pradesh, India. To recruit participants, an organization staff member contacted ASHAs, explained the purpose of our study to them, and then gave us the contact information of those who expressed interest. Participants were not monetarily compensated at the request of our partner organization, rather, were provided with a small gift to thank them for their time. The interviews were conducted in Hindi. The majority of participants we interviewed had around 15 years of experience working as ASHAs (see Table 2).

#### 3.2 Procedure

We conducted semi-structured interviews with our 28 frontline health worker participants. Each interview lasted approximately one hour. Due to the ongoing COVID-19 pandemic, the audio-only interviews were conducted remotely and participants were called on the phone or via Zoom. All participants consented verbally before participating. For the aide interviews, one researcher led the interview and another took notes and asked clarifying questions. For the ASHA interviews, one researcher who spoke Hindi led the interview and the other researchers were debriefed. Participants were asked questions about: (1) the types of invisible work health workers might perform and how technology impacts/is impacted by it (e.g., *What are examples of 3 tasks you do that are not in your job description?*); (2) how different sociocultural dynamics impact their visibility, including interpersonal dynamics and their identity/positionality (*Have you ever faced any challenges due to your gender?*); (3) the health workers’ perceptions of their visibility, specifically how they may resist or advocate for themselves (e.g., *How do you handle the challenges/stresses of your job?*).

We followed the considerations outlined by Gharawi et al. [37] to enable comparisons across contexts and carefully translated both the language and concepts in our questions (i.e., having native language speakers involved in question writing and interviewing), maintaining relatively consistent timing across the two sites (i.e., making sure to interview both after their separate peaks of the COVID pandemic), and developing comparable research instruments (i.e., semi-structuring the questions around similar points and principles).

#### 3.3 Data Analysis

The interview data was audio recorded, translated into English (if necessary), and professionally transcribed. We then conducted thematic analysis [12], a constructivist approach inspired by grounded theory [34] that uses in-vivo coding with gerunds [15]. Each of the interviews was coded by at least two authors. We first iteratively conducted and coded the interviews with aides, starting with an initial codebook of 70 codes based on the first three interviews, adding codes needed for a final codebook of 110 codes. These 110 codes

were then used as the initial codebook for coding the interviews with ASHAs, with new codes added as necessary. Most (80) of the original aide codes also applied to the ASHA interviews, while an additional 28 new codes were added, for a complete codebook of 138 codes. Then, the final set of codes was clustered into 36 themes that represented the data (e.g., *feeling like family*, *ways to build trust*), which were then organized into the 3 main categories presented in the findings. In line with the approach of feminist solidarity in HCI [53], these categories were based on similarities drawn across the two contexts, though the codes and specific quotes themselves demonstrated differences included in the analysis.

### 3.4 Limitations

Our study focuses on two settings to highlight differences and similarities across the contexts. We do not claim to comprehensively represent all of the rich experiences of each group, nor do we assume we can generalize our findings across frontline health workers. We recruited aides through their agencies and ASHAs through a local training organization. This may have resulted in a sample that has a strong relationship with their employers. Further research is needed to explore a wider diversity of voices, including health workers from other settings (i.e., rural America or urban India) or methods with wider reach (i.e., surveys). Moving forward, it would also be important to assess the perspectives of the employers around visibility of their health workers and organizers on their efforts in advocacy and resistance.

## 4 FINDINGS

The aides and ASHAs discussed different ways invisibility manifested: in the extra work they did that was above and beyond their assignments, in the crucial knowledge they held was overlooked by experts in their respective healthcare systems, and in the struggles for respect they faced due to their disadvantaged identities as workers and as people. We present these themes that are commonalities across the two contexts and raise some key nuances.

### 4.1 Working Above and Beyond

The boundaries of the aides' and ASHAs' jobs were often porous. In some cases, the loosely defined boundaries were due to their scope of work being unclear to themselves or their patients. In other cases, the porousness was because their emotional connection with patients and coworkers led them to knowingly work outside their assigned hours or do tasks that were not part of their assignment. In all of these cases, the aides and ASHAs did additional work to define and uphold these partially clear boundaries and suffered the consequences of a lack of recognition of their investments.

**4.1.1 Being Motivated to Do More.** Many of the aides and ASHAs chose this line of work because they desired to care for others and frequently used this motivation to justify working additional hours. HHA3 elaborated on how she liked helping vulnerable people and was proud of her ability to enable something that would otherwise not be able to happen:

*“Well, I like helping people, so I look forward to going to work every day... At least I'm influencing, helping*

*somebody to do something that they cannot do for themselves. I'm there to help and do it.”* (HHA3).

HHA12 talked about how she helped an asthmatic patient do extra dusting, saying “*you just do a little extra because...they can't do it themselves... and they don't have no family or anybody.*” HHA3 gave an example where she did extra work for a patient that was unpaid. Even though her patient knew her shift ended at 5:00pm, the patient would not decide to go grocery shopping until 4:30pm. She felt she could not simply abandon her patient at the supermarket, and, as a result, ended up putting in the extra time and extra work that was not compensated by her agency.

Participants also spoke about how their care extended to doing extra work to help their coworkers. Their feelings of camaraderie with other aides and ASHAs encouraged them to “*work together, for each other*” (ASHA1) and “*work as a team*” (HHA6), sharing responsibilities even if they were seen and compensated as individual workers. HHA6 gave an example of helping the previous aide complete tasks:

*“If I come to work and the other aide in the morning is not finished with bathing the patient or cleaning up after her and it's her time to clock out, I'll tell her 'It's okay, you can clock out. I will continue.' That's what we do. We continue for each other.”* (HHA6)

The ASHAs expressed similar levels of solidarity with their coworkers. ASHA1 said that even if she took over for another ASHA, she would “*enter that ASHA's name only, because [the other ASHA] has done the hard work*”—she believed that simply filling in for another ASHA once or twice did not compare to the work the other ASHA did to build the relationship with patients. She described it as mutually beneficial as others would help her out when she needed it. ASHA4 expanded on the idea of “*equal give and take*,” saying that if she needed any financial assistance, she would feel comfortable asking the ASHA for whom she substituted to lend her money. Although these communal feelings among aides and ASHAs gave them comfort knowing they had each others' support, the solidarity required investment of additional time and money.

Another motivation was being asked by their supervisors or patients to do more, sometimes because it was unclear what counted as “*additional*” in the first place. The ASHAs gave contradicting reports of what they thought their job responsibilities included, but all agreed that their job did not have traditional boundaries (e.g., fixed working hours). This meant that they relied on their supervisors to set the boundaries of their work. While ASHAs like ASHA1 believed that supervisors would not assign them anything extraneous, allowing supervisors to define the boundaries of their work meant that ASHAs felt they had a “*24-hour duty*” (ASHA9). ASHA12 elaborated on this, saying that she had to be willing to drop everything to do her work:

*“We get called at any time, whether it be any kind of weather or anything else. If duty calls, we go despite the fact [of whether] we get paid or not.”* (ASHA12)

On the other hand, although aides had clearly defined job scopes from their supervisors via patient care plans, patients and their families would often ask them to do things “*outside my scope of practice*” (HHA13) like deep cleaning beyond the required light cleaning or “*against my license and certificate*” (HHA4) like giving patients their

medications. These examples show how work boundaries were ill-defined—constantly changing and challenging to enforce.

**4.1.2 Facing Hidden Costs of Ill-Defined Boundaries.** When asked to do things outside the boundaries of their work, aides and ASHAs were placed in difficult situations. Frequently, they had to do even more work to stand up for themselves and enforce their limits. When aides tried to refuse tasks that were not part of their job, patients often responded, “*But, the other aide did it!*” (HHA7)—even if, upon verification, the other aide had no idea what the patient was talking about. HHA10 gave another example of how her patients were confused about aides’ responsibilities and would complain about aides who were using their phones, even if it was necessary for them to clock-in. ASHAs also faced frustrations explaining to their patients about their scope of work. For example, ASHA13 had to explain to patients that, as an ASHA, she was not responsible for paying patients’ hospital fees. The constant need to establish and enforce the boundaries of their job led to emotional burdens when aides like HHA5 found it was difficult to argue and was disheartened that “*I cannot convince my ‘No’ to them*” (HHA5).

The extra work, including the work to uphold boundaries, was not factored into their compensation, which resulted in financial costs. Some aides and ASHAs pointed to personal satisfaction of their impact on patients as sufficient compensation, that “*there’s a comfort in knowing that we’re doing a social work and it’s okay how much we’re getting paid*” (ASHA11). Others believed the extra care they did was insufficiently compensated, as HHA11 shared:

*“They don’t know how hard our job is . . . You go to the [patient’s] house, you do laundry, you take your patients to the doctor, you clean the [patient’s] house, you go to get groceries—you do a lot. And [for] only \$15 an hour and then . . . we don’t even have enough hours”* (HHA11)

Their low compensation meant that many aides had to take on multiple jobs, either with another agency or for off-the-books private patients. Some mentioned this was because their supervisors were not fully aware of what they were doing and the struggles they went through. ASHA2 echoed this sentiment, that “*nobody understands ASHAs’ pains . . . that we work so hard.*”

Beyond not receiving compensation for extra work, the aides and ASHAs were sometimes forced to implicitly take on the costs associated with the extra work—costs that remained unreimbursed. For example, during the COVID-19 pandemic, there was a lot of uncertainty around aides’ and ASHAs’ job descriptions, and both had to acquire personal protective equipment and on their own dime and their own time. Moreover, both aides and ASHAs had to commute long distances to reach their patients, which had financial and safety costs:

*“We don’t have a lot of resources so when we are called to far off places on emergency basis, it becomes a trouble to travel back.”* (ASHA11)

This cost was not acknowledged or defrayed by their supervisors, nor were the costs of traveling to required meetings, having to bribe officials to get patients to the hospital or, at times, even paying for patients’ expenses. As ASHA2 put it, “*they eat so much of ASHAs’ money.*” The aides also discussed the unseen costs of fearing for their personal safety due to long commutes. HHA12 spoke about

how sometimes she would make the long commute to her patient’s home, only to have to wait for them outside in the cold or in a dangerous neighborhood. In these cases, aides and ASHAs felt the hidden costs of having to extend themselves to handle emergency situations or travel far distances and were dissatisfied that the extra efforts they made were unseen and unpaid.

## 4.2 Serving as Overlooked Experts

One of the aides’ and ASHAs’ main roles was to help patients navigate complex medical systems and advocate for them. As a result, the aides and ASHAs were often unique sources of patient information. Both aides and ASHAs were tasked with collecting information about their work and patients, which required a lot of effort. They then facilitated transfer of this information to supervisors and organizations. However, aides and ASHAs felt unsupported in these efforts, despite their key positions, the value of the information, and the lengths they went to procure it.

**4.2.1 Sharing But Not Receiving Information.** The aides and ASHAs kept different types of records about their tasks and patients. The aides tracked which tasks they completed on the patient’s care plan using paper checklists or smartphone applications. The ASHAs focused mainly on recording information about patients (e.g., births, deaths, illnesses, vaccinations) in paper registers. Some kept their own records in addition to these required ones. HHA9 started keeping notes in her own notebook and on the computer after she got a call inquiring about the status of a patient she worked with months ago. Similarly, ASHA1 kept notes in a register that she purchased on her own (another hidden cost) so that she could freely make mistakes before copying the information neatly over to official records.

The aides and ASHAs also discussed how they often served as experts about their patients to other medical professionals, especially during emergencies. ASHAs described how they compiled reports with patients’ information for supervisors, sometimes having to respond quickly to requests for information and “*give lists [reports] right on the spot*” (ASHA10). The aides also had crucial information about their patient that was valuable on-demand. HHA1 chronicled an incident where she noticed her patient’s vitals were really low compared to the past month and notified the doctor just in time for them to catch a requisite change in the patient’s prescription:

*“Now my [patient] is blind, so I’m not supposed to be taking her blood pressure, her vital signs or nothing. . . . So what do I do? Do I get in trouble . . . Or do I take care of my [patient]? . . . Whoever comes out here to assess the [patient] is not doing a great job. . . . [But] the doctor needs . . . a vital taken every day. Now, 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.”* (HHA1)

This incident demonstrated that HHA1 knew her patient well enough to catch subtle changes and that she was willing to do the extra work of checking her patient’s vitals—even though she said she was not supposed to.

Despite being important in information exchange, the aides and HHAs felt that they were not being kept in the loop. In addition to feeling taken by surprise by constantly changing demands from

their supervisors, they did not know how the information they were collecting would be used. HHA5 expressed uncertainty, saying that even though she was giving information to her supervisors, she was “*not sure if they're paying attention or not.*” HHA8 was confused about why she had to record so much information and resisted downloading the clock-in app on her phone, asking “*Why should I put that tracking device on my phone to track me down?*” HHA9 wanted her supervisors to not know as much because “*it's better nobody knows what you do, because then they're expecting more from you.*” This lack of insight or input into how the information was being used also resulted in the aides and ASHAs feeling less responsibility over the information. ASHA7 and ASHA15 expressed that they were not concerned if anyone had access to the ledgers full of patient information — it's not like anyone else would be able to understand or use the information anyways.

Additionally, the aides and ASHAs were not being given the key information they needed to provide high quality care. HHA5 spoke about her frustration with her supervisors because they did not warn her about a difficult patient. HHA5 felt that because the patient had been with the agency for 7-10 years, the “*agency [and] coordinator know that this client is having these issues,*” yet did not let her know. This lack of information meant the aides and ASHAs would not be prepared for a situation because, as ASHA8 lamented, “*you never know what kind of patients you'll get.*” The aides and ASHAs also spoke about how a lack of information meant they felt unsure about what they were doing, especially when they first started their jobs. ASHA5 said she at first felt “*hesitant*” when she returned from training and had to attend her first delivery as an ASHA. HHA5 resonated with this feeling of uncertainty, saying that even though she felt comfortable communicating reports of vital signs, she felt unsure when she was taking it, wondering “*Is this accurate' or 'Did I take it right or not?*” ASHA1 frames this lack of information as impacting her performance, she “*definitely want[s] that we are informed better ... then only would we be able to do a great job*” (ASHA1).

**4.2.2 Challenges Getting Support.** One challenge involved in collecting and transferring information was that the collection process itself required a lot of work on the part of the aides and ASHAs. ASHAs found the process cumbersome, with some saying that older ASHAs “*can't read the small letters in the reports*” (ASHA9), and that it was burdensome to keep draft copies of the registers and produce copies of their records on demand. Aides had to manage a diverse ecosystem of paper, phone, and smartphone options for tracking their tasks and faced issues learning how to use and troubleshoot the technology. When the technology “*goes haywire*” (HHA1), the aides would have to do extra work to fix not only the issues with the technology, but also the incomplete or incorrect information that resulted from the issues. For example, HHA8 described a time when she did not get paid for a few days and had to call numerous agency representatives to resolve the issue that stemmed from the GPS on her smartphone application not recognizing she was with the patient when she was asked to go buy a newspaper or take her patient to the doctor. HHA7 had to ask her daughter to help her email her timesheets when her phone clock-in did not work. ASHA10 also had to ask her husband and children for help with half of her work because there was too much information for her

to keep track of. These frustrations indicated that these paper and digital tools furthered participants' invisibility by not accounting for their workflows and requiring them to do even more invisible work to troubleshoot resulting problems.

The aides and ASHAs attributed their lack of support to a lack of appreciation on part of their supervisors. For example, ASHA7 spoke about how her supervisors only “*look at whether work is being done—they don't really support [me] in any way.*” They felt they were not regarded as a priority for their supervisors. The aides expressed frustration and felt their superiors “*should at least pick up the phone*” (HHA10) when they were calling to be more supportive, because otherwise, they felt that their agency, “*they don't care—they just send you over there and that's about it*” (HHA10). They felt that if their supervisors did care, they would express it through positive and constructive feedback. HHA1 elaborated how the feedback they received during the pandemic was lackluster and indicative of a lack of care:

*“They needed us, but they didn't give us anything ... not even thank you. What we are looking for is just for somebody to say I'm thinking about you, I'm caring about you, job well done, you did good today.”* (HHA1)

When the aides and ASHAs lacked information and could not turn to their supervisors for support, they had to be creative about how they got the information and had to make decisions on-the-fly. This meant that the aides and ASHAs were not able to count on their supervisors for information in a time of need. ASHA5 felt frustrated, saying, “*there's no point in calling up supervisors ... the supervisor would just end up in a dilemma and nothing would be solved.*” Even if they wanted to contact their supervisors in a time of need, the lack of response meant they ultimately had to make calls on their own. For example, HHA2 had learned that during an emergency, she was on her own:

*“I simply rush to Google and try to do some research, because if I'm supposed to call a supervisor, I would not get anybody to assist me.”* (HHA2)

HHA1 found that by the time she was able to reach her supervisor, she had already handled her patient's emergency and “*there was nothing they had to tell me—I told them*”. In cases such as these, the aides and ASHAs were exasperated that their supervisors did not see or respond to them, they had to do extra work to fill that gap of knowledge, and were not given recognition when they did something above and beyond and essential to patients' well-being.

### 4.3 Struggling to be Respected

The aides and ASHAs also shared how they constantly needed to fight to be respected by patients, supervisors, and broader care teams. Both groups of shared ways in which they struggled to be better acknowledged and supported, as well as their struggles developing trust with patients due to their identities as women and as home-based care workers.

**4.3.1 Dealing With How They Are Treated.** Both aides and ASHAs described how patients would treat them with disrespect because of their gender identities. They shared examples of times when they feared for their safety, including HHA1 who talked about a patient

who raised a butcher knife to her and ASHA9 who heard community members threaten to beat the ASHAs. They also each shared instances of being treated like they were “housemaids” (HHA2, HHA5, HHA6, HHA7) or “servants” (ASHA2, ASHA12). Although the perception of both the aides and ASHAs as housekeepers may draw from the gendered views of domestic work [18, 30, 42], the discrimination had different flavors to it. ASHAs described facing resistance as women with jobs, with others mocking them and saying “Look! She’s someone’s daughter-in-law and yet going door-to-door” (ASHA3). ASHA13 discussed how she had to convince her husband to be allowed to take the job, saying:

*“Of course, as a woman, I had to face a lot of problems. The men at home didn’t understand the work and the men in the field thought I wasn’t competent enough to do the work.”* (ASHA13)

The ASHAs found that some patients would rather turn to “quacks” (P5), unqualified people posing as doctors and spreading misinformation, rather than listen to them. HHA2 further felt that patients questioned her expertise “because I’m young, they also think I’m dumb” and tried to take advantage of her by asking her to do additional tasks.

The aides and ASHAs also faced challenging experiences based on other intersectional identities, including race and caste. While aides did not face as overt gender-based resistance, they did face judgement due to their race. HHA10 talked about a patient who refused to be touched by someone of HHA10’s race and HHA12 talked about a patient who called aides a race-related pejorative term. For ASHAs, race was not as salient, but they navigated caste-based challenges. ASHA13 surmised that if she had been of a lower caste, “people would not have let me in the premises of their homes” and felt lucky she did not face those problems. Even though the ASHAs themselves faced discrimination, they had to extend grace to others. ASHA15 shared that she had to go home and purify after working with someone of a lower caste. ASHA5 made sure to ask for a glass of water from her patients, even just to have a few sips, to demonstrate that “I am not there to act superior.”

The work that aides and ASHAs put into developing trust with patients was evident. Both groups spoke about the familial relationship they had with patients: HHA7 said that she treated her patient like her mother. ASHA4 described how the familial and friendly feeling enabled her to give advice on taboo topics like menstruation or intimacy:

*“They treat me as a friend and they trust that I can solve their issues ... I feel proud to be doing ASHA work because people think we’re worthy enough for them to share things.”* (ASHA4)

The ASHAs worked hard to build this trust, giving more information to the community, and, as ASHA11 said, “[because] people [are] getting more educated and informed, there are no problems now.” The aides focused on developing trust in their one-on-one relationships with patients, enacting strategies that handled this individual conflict. HHA2 said “once you stand up to [a patient] ... they will see you as a different person.”

**4.3.2 Overcoming Judgements To Be Acknowledged.** Adjusting their attitudes in order to do their jobs led to more emotional burdens on

aides and ASHAs. Participants discussed how their supervisors instructed them how to act. For example, HHA5 and HHA6 described how they were told that “we cannot push [patients]” and ASHA5 said “the very first thing we were taught was to have the power to listen and endure.” The advice to act in ways that do not force or anger patients is an example of emotional labor, where the workers were given instructions on how to act in ways that contradicted how they felt [44]. This made them feel pressured to perform the ‘proper’ emotions as a requirement of their jobs, as “an ASHA should present herself well” (ASHA2). This resulted in aides and ASHAs having to take on the emotional burden to “shrug it off” (ASHA3) or “leave the job on the job” (HHA6). HHA13 even described how she chose to be an on-call aide, opting for one-off interactions with patients, despite the unpredictability, so that she would not have the emotional burden of longer-term attachment and feel guilty for leaving her patient when she went on vacation. Overall, both aides and ASHAs had to do substantial emotional labor to build peaceful relationships with patients.

When things went awry, aides and ASHAs often turned to their supervisors or other authority figures for help with interpersonal conflicts. ASHA7 explained how her supervisor came to help her convince villagers to get vaccinated against polio, while ASHA12 discussed how her supervisor stood up for her when the villagers were treating her poorly:

*“If somebody puts up a fake complaint against me, she [my supervisor] always defends me ... She tells them that I’m not their personal servant and that they should be nicer to me and that I’m a hard worker.”* (ASHA12)

However, sometimes participants did not feel supported by their supervisors when they needed them. They felt that, when conflicts with patients got back to their supervisors, “it’s [the patient’s] word against our words” (HHA2) and that “of course [supervisors] will believe the villagers” (ASHA9). Therefore, some participants escalated their issues to other authorities for support. ASHA5 said she would “straightaway call the police”—that even threatening to call the police would result in more respect.

In light of all these concerns, aides and ASHAs felt they were not able to change their situation, made worse by the fact that they were not respected. ASHA2 said “there is nobody to listen to ASHAs” and elaborated:

*“ASHAs are not even considered, when all the work is getting done by ASHAs. We manage our homes as well as our jobs. We ASHAs work so hard. You think about it, if there’s anyone in the country who is working the hardest right now, it is ASHAs. But nobody is listening to us ... Nothing.”* (ASHA2)

She even suggested that there should be a specific officer who simply listens to ASHAs’ pains and issues, similar to a suggestion that HHA10 gave for their agency to have meetings with aides and listen to their problems. This neglect of their voices was also reflected in the ASHAs’ protests and strikes that happened in light of the COVID-19 pandemic [60, 82]. Even though the ASHAs said they coordinated on WhatsApp large groups of workers to attend, they were frustrated that “nothing comes of it” (ASHA15). Some still had some hope and believed their collective voice would be harder to ignore:



**Table 2: Summary of Findings**

| Working Above and Beyond (§4.1)  | Serving as Overlooked Experts (§4.2)   | Specific considerations that address the types of technology that would be used to adapt to the workflows and technological literacy of the workers. Below we discuss potential design ideas for technologies that may begin to make frontline health workers more visible, along with tensions that must be considered on the way. |
|--|--|---|
| <b>Manifestations</b> <ul style="list-style-type: none"> <li>• Wanting to give 100% care</li> <li>• Solidarity/filling-in for others</li> <li>• Confusing/changing requirements</li> <li>• Asked to work outside of job scope</li> </ul> | <b>Manifestations</b> <ul style="list-style-type: none"> <li>• Providing patient info on</li> <li>• Anticipating emergencies</li> <li>• No insight/input into how info is used</li> <li>• Missing key information</li> </ul> | <b>Manifestations</b> <ul style="list-style-type: none"> <li>• Careful treatment of race and caste</li> <li>• Developing trust over time</li> <li>• Community of practice</li> </ul>  |
| <b>Implications</b> <ul style="list-style-type: none"> <li>• Burden of (re)asserting boundaries</li> <li>• Not paid/recognized for extra work</li> <li>• Unreimbursed financial/safety costs</li> </ul>                                  | <b>Implications</b> <ul style="list-style-type: none"> <li>• Having to fix issues with tech/info</li> <li>• Feeling unsure/unappreciated</li> <li>• Forced to learn/act on the fly</li> </ul>                                | <b>Implications</b> <ul style="list-style-type: none"> <li>• Emotional labor of presenting well</li> <li>• Turning to authority in conflicts</li> </ul>   |

*“Whatever happens, we will face it together. We should have unity, because it’s everyone’s fight for their rights. The results will be the same for all of us. The same for both who are sleeping and those that are fighting. Everyone should support each other in such times.” (ASHA5)*

These struggles for participants to be recognized for their important work reflected not only the disregard of aides and ASHAs, but also their feelings of solidarity and ideas of what a better future might look like.

## 5 DISCUSSION

Our findings illustrate how invisibility is manifested for aides and ASHAs: (1) through the invisible work they do above and beyond their duties, (2) in their overlooked position in key knowledge transfer, and (3) via their treatment due to their devalued identities as women and care workers. In response to these manifestations of invisibility, the aides and ASHAs called for more support in the form of actionable feedback, on-the-job knowledge, and clearer boundaries; more respect as people and workers; and more recognition in the form of thanks and compensation. Drawing on these findings, we discuss potential technological approaches that specifically address their concerns around visibility along with design considerations for technologists working for and with frontline health workers.

### 5.1 Technology for Visibility

Many of the tensions and challenges that ASHAs and aides discussed may result from intractable, systemic problems: How might we change society’s treatment of women, racial minorities, or domestic workers? How might we ensure respect and recognition for marginalized workers efforts? Such problems are sometimes referred to as “wicked” problems [79]—difficult or impossible to solve due to incomplete, contradictory, and changing requirements that are often hard to recognize. Research in ICTD has long acknowledged that technology is unlikely to be able to solve these wicked problems once-and-for-all. Indeed, prior work suggests that, in some cases, technology may instead exacerbate or amplify problems if not designed carefully in ways that take into account existing power dynamics [96]. Nevertheless, participants in our study wanted to improve their situations—to receive support, respect, and recognition for their essential role providing care to vulnerable communities—and our findings provide some constructive ideas

for how we might begin to make progress. These ideas draw from common concerns the frontline workers expressed, but differ in the specific considerations they address and the types of technology that would be used to adapt to the workflows and technological literacy of the workers. Below we discuss potential design ideas for technologies that may begin to make frontline health workers more visible, along with tensions that must be considered on the way.

### 5.1.1 Feedback Systems and Incident Reporting

The aides and ASHAs reported trying to make visible some of the challenges they encountered to their supervisors, a process that could be enhanced through a feedback and reporting system. Currently, the aides and ASHAs have to call their supervisors when they face a difficult or abusive patient, which is not a reliable way of getting support. A formalized system could help them log issues or complaints which could then be sent to their supervisors or other relevant stakeholders to act upon. Prior literature has presented similar ideas, including digital worker feedback reporting tools (e.g., mobile-based audits of working conditions) [10, 41, 78] as well as incident reporting software for sexual harassment (e.g., the applications Callisto and Lighthouse that have been used in university settings) [49, 55, 93].

The prior research in similar fields indicates that the design of such a system presents rich opportunities for future research and customization to fit the specific needs of aides and ASHAs. Some open questions include: how to collect verifiable feedback, how to ensure reports are monitored and action gets taken, how to do so in a way that protects workers from retaliation, and how to ensure that the burden of invisible work is not simply shifted onto supervisors. The veracity of the reports is one that especially applies to frontline health workers, as aides and ASHAs expressed concerns that their perspectives or experiences may be questioned, that their supervisors would not believe them, or would take the side of their patient. These concerns are a result of unequal power dynamics, both having to deal with their voices being minimized due to their disadvantaged gender or racial identities, and the aides specifically facing the difficulty of speaking up against the people who were funding their services. Technological considerations would need to take into account this compounding relative lack of power. One way to address this would be to aggregate complaints across workers, which could help reinforce claims, identify problematic patterns or individuals, and raise larger systemic issues. However, aides and ASHAs also shared suspicions that their supervisors and broader organizations may already have information about difficult patients, but did not have the time or incentive to share this information with them or were barred by privacy considerations (in the case of the aides).

These challenges in verifiability and actionability of the workers’ feedback point towards a system that turns to peer groups rather than the supervisors. Literature in HCI and ICTD has explored how groups of peers might enable workers to communicate among themselves and identify problematic actors, harnessing the power of multiple workers’ perspectives to help warn each other about potential difficulties. An especially salient example is Turkopticon [47], a tool that enabled workers on Amazon’s Mechanical Turk

to report and raise awareness about problematic employers. Additionally, prior work has suggested that peer support could be a powerful mechanism specifically for isolated, distributed frontline health workers to have a safe space to discuss their problems, receive emotional support, learn tips for enforcing boundaries, get advice for handling challenging patients, and more [74]. An example of such an initiative is a Facebook support group for Walmart Workers to share their concerns with other workers who hold similar positions all over the world [5]. For the frontline health workers, this could involve building in elements explicitly related to emotional and strategic support in existing WhatsApp groups for ASHAs and training sessions for aides.

**5.1.2 Sharing Clinically-Relevant Data.** Although aides and ASHAs are the “eyes and ears” [88] for the healthcare system in patients’ homes, ours and others’ findings [86–88, 98] suggest that their knowledge and insights are frequently not recognized or incorporated into clinical data pipelines. Prior ICTD work investigating digital tools for other community health workers (e.g., CommCare [32, 94], Open Data Kit [13, 40], Medic Mobile [61], MoTeCH [57]) have demonstrated that these workers have the capability to collect and report important patient data. Building on this work, our findings highlight important avenues for improvement: how to enable frontline workers to capture salient changes in patient wellbeing beyond mundane surveillance data collection and how to provide recognition and respect for workers who contribute this data, rendering their essential work more visible. Of course, key challenges would be to ensure that such tools do not simply add to workers already burdensome workloads, requiring careful consideration to ensure it fits in their workflow and there are resources to train the frontline health workers and help them troubleshoot any issues that may arise.

We note that adjustments will be needed before implementing such tools so that they also do not simply use the information provided by aides and ASHAs to monitor compliance, but also to address their fundamental concerns around visibility. One way of doing this is by building mechanisms into these tools that encourage supervisors to provide feedback to workers, building on previous work examining performance-related feedback from patients [67] or insights gleaned from self-tracking metrics [21]. We see opportunities for additional feedback mechanisms that include options for differing types of feedback, including the positive recognition that the aides requested and the critiques that the ASHAs wanted. Additionally, as demonstrated by a successful voice-based feedback system for health knowledge gaps [64], the frontline health workers can serve as a channel to elevate concerns expressed by their patients. This would require their supervisors to understand and acknowledge the value that these workers are providing via their insights that goes beyond simple surveillance and monitoring. This would require overcoming any biases held against these workers, including those about their levels of education or the capabilities of their gender (as in the case of ASHAs). However, it may also require workers to do more work to translate their observations into legible and actionable clinical data. Nevertheless, these efforts could lead to increased respect and recognition for frontline health workers as on-the-ground experts, shifting their main prerogative to be analyzing versus just collecting information.

**5.1.3 Advocating for Awareness.** Technology could also be used to foster solidarity—coordinating across large groups of workers, aggregating information, and spreading awareness and gaining support for different causes [23, 56]. One basic example of this is the use of technology for coordination. This could build upon the WhatsApp groups the ASHAs already used to coordinate for strikes or the technological tools the unions (like the one the aides in our study belonged to) also used to organize information about their members and recruit new ones [51]. While designing tools that enable health workers to show solidarity has promise, care must be taken to ensure that these tools are also accessible to health workers who have limited or no digital literacy, as was evident in our findings that some participants were not always comfortable and/or required assistance to use technology.

Another level of technology use would be to aggregate information to help advocate for the frontline health workers with supervisors, agencies, and other stakeholders. However, even if equipped with more information, supervisors may be limited in their capacity to change the status quo, despite expressing interest in doing so—public health programs themselves are often underfunded, which limits how much they can pay frontline health workers. Technology that is using data to advocate for frontline health workers would need to draw on existing strategies employed by organizers, such as the prominent Justice for Janitors campaign that found putting pressure one level up on those that pay the agencies rather than the agencies themselves, to create more leeway in how much they can be paid [20, 45]. In the case of like aides, this could mean petitioning the state governments that fund their employers, the agencies. For ASHAs, this would mean approaching the county-level or state governments who are both their employers and payers.

These larger structural changes require shifts in public opinions around the importance of frontline health work, which technology could also help facilitate. Currently, technology has been used to raise awareness of the plight of frontline health workers to the broader public, including through social media campaigns on the aides’ side (#BuildBackBetter [2], #CareCantWait [3]) as well as the media coverage of the aides’ Fair Pay for Home Care campaign [52, 73] as well as the ASHA strikes during the COVID-19 pandemic [60, 82]. Future initiatives could cross-pollinate across the successes of these media campaigns. However, there is still a long way to go to overcome the prejudices the aides and ASHAs face due to their gender and racial identities and the attitude the public has about care and home-based work. Technology can help amplify some of these efforts and the slow but steady changes that are being made.

## 5.2 Visibility or Surveillance?

Discussing how technology might make workers more visible brings up tensions around what aspects of their work the aides and ASHAs *wanted* to be visible, *to whom* they want those to be visible, and *how* it is actualized. Rendering certain aspects of their work more visible may lead to privacy concerns for frontline health workers. Our findings suggest that both ASHAs and aides were making choices, finding compromises, and developing workarounds that they may not want their supervisors to see, such as having other workers or even family members help them finish their tasks. This raises tensions around balancing privacy with visibility, stated desires with

observed reality to ensure that any resulting technology design does not impose the values of the designers onto the health workers [68, 93]. The workers in different contexts also expressed differing notions of privacy for themselves and their patients—with the aides expressing concerns around the tracking apps they had to install on their phones to the ASHAs feeling comfortable keeping their patient data in a ledger. This could be further extended to other stakeholders who might have their own, different conceptions of privacy, including supervisors, agencies or organizations, patients and their families, and the broader public.

Future work needs to carefully account for the tension between privacy, visibility, and surveillance, since sometimes they are at odds with each other. As Star and Strauss [85] delineated, visibility could bring “legitimacy, rescue from obscurity or other aspects of exploitation” as well as “reification of work, opportunities for surveillance, or come to increase group communication and process burdens.” While the aides and ASHAs might have wanted more recognition for some of their extra tasks or unpaid hours, if their supervisors found out that they were using others to complete their duties, they might end up with retaliation or more restrictions. Supervisors could see these choices as examples of having too much assigned work and too little pay (legitimacy) or as violations of their contract (surveillance). Following Star and Strauss [85]’s postulation, this could mean that their supervisors might want to put in more reporting to make sure the assigned workers are the ones doing the work, which would potentially mean more work for the workers to do the tracking, as well as more resources on the administrative side to do the checking. Therefore, any attempts to make visible the work of frontline health workers requires careful consideration of what parts of their work they want visible and the potential responses and consequences that may result.

The concerns around privacy and surveillance are especially important for frontline health workers because their work is often located in patients’ homes. That means that on one hand, the distributed nature of the workplaces means there might be an increased desire for surveillance, and on the other, the intimate nature of the home means that additional caution should be taken when proposing visibility. For one, technology in the domestic space has the potential to lead to “Big Mother” [80]—having the guise of maternal care but instead managing, monitoring, and marketizing domestic spaces. Moreover, it could lead to “refractive surveillance” [59] because tracking the health worker might lead to also tracking the patient. While these ideas have been discussed at length in the conversation about the GPS tracking aspect of electronic visit verification in the United States [59], this has not yet been extended to settings in the Global South — a gap that our findings bridges. Tracking an ASHA, for example, could lead to surveilling a whole community’s status, which may be helpful in some cases (e.g., when used by the government to identify weaknesses in public health delivery) but may also lead to a violation of privacy of particularly vulnerable and marginalized populations. This tension is exemplified through the mixed benefits and costs of the identity-tracking system for welfare, Aadhaar, by the Indian government [43, 50]. The specific setting of the home, in conjunction with the community’s understanding of privacy, are important to take into consideration when designing technology for these high-stakes contexts.

## 6 CONCLUSION

This paper examined the invisible work performed by home health aides in New York City and the ASHAs in Uttar Pradesh—both important groups frontline health workers whose work is undervalued and underappreciated. Both groups experience invisibility across common categories—in their work done above and beyond their requirements, as overlooked bridges of knowledge between different parts of the care system, and as women performing the feminized labor of care work. Moreover, they have similar desires for support, recognition, and respect which generated ideas for technology that can help them give feedback or report incidents, share clinically-relevant data, or advocate for awareness. However, a more careful examination of these different manifestations of invisibility in the two different contexts raises the importance of considering their different perspectives on visibility and technology. Our findings contribute to the discussion on the balance between visibility and surveillance, legitimacy and retaliation, and privacy and the home. These contributions will guide future creators of technology for frontline health workers in diverse Global contexts.

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