

“We can learn. Why not?”: Designing Technologies to Engender Equity for Home Health Aides

Emily Tseng
Cornell University
New York, NY, USA
et397@cornell.edu

Fabian Okeke
Cornell University
New York, NY, USA
fno2@cornell.edu

Madeline Sterling
Weill Cornell Medicine
New York, NY, USA
mrs9012@med.cornell.edu

Nicola Dell
Jacobs Institute, Cornell Tech
New York, NY, USA
nixdell@cornell.edu

ABSTRACT

HCI researchers have increasingly studied how technology might improve the lives of marginalized workers. We explored this question through a qualitative study with home health aides in New York City, a vulnerable group of frontline caregivers whose work with patients is poorly paid and highly stressful, often involving life-or-death situations. To elicit the perspectives of aides and their supervisors on how technology interventions might contribute to moving aides towards a better future, we created a design provocation that centers aides' needs and suggests more equitable roles for them within the home care ecosystem. Findings from design sessions with 16 aides, nurses, and aide coordinators illuminate the ethical and pragmatic dilemmas inherent in this complex ecosystem, and show that designing technology for equity requires attention to structural problems in addition to workers' stated needs. We analyze our findings through the lens of social justice-oriented interaction design, and discuss how our work extends key strategies within this framework.

Author Keywords

home health aides; home care; community health; design for social justice; design justice; design provocation.

CCS Concepts

•Human-centered computing → Empirical studies in HCI;

INTRODUCTION

In recent years, HCI has increasingly considered the role of technology design in addressing large-scale systemic problems, for example homelessness [58], domestic abuse [7, 21],

and inequitable labor systems [22, 25, 28]. Broadly, this work might be described as *design for social justice*, an effort to articulate how HCI can improve the lives of systemically marginalized communities. Researchers and designers drawn to this type of work have several theoretical orientations to draw upon, including feminist [4], queer [34] and postcolonial [24] approaches to technology design. In this work, we consider one such framework, social justice-oriented interaction design, put forth by Dombrowski et al. [17]. We use this framework to shed light on the complexities of designing to improve equity for a particular group of marginalized frontline workers in the U.S.: home health aides, who are the fastest growing segment of the American workforce [40].

Aides are formal, paid caregivers who work long hours caring for clients (the word used to refer to patients in this context) with serious illnesses like heart disease and dementia. The majority of paid caregivers are women, usually Black and/or Latinx. They provide personal and medically oriented care in clients' homes, and help them navigate the many follow-up encounters with the healthcare system their conditions require [54]. Aides often labor within an agency structure in which they are directly supervised by nurses, who periodically visit clients' homes to triage symptoms and provide medically oriented care, and coordinators, who manage aides' work on a daily basis. Home health aide duties might include helping clients track and take medications, weighing and measuring clients, monitoring fluid intake, and preparing meals for clients who adhere to specific nutrition requirements. The work is difficult and unpredictable, involving a mix of physical and emotional labor in response to clients' shifting needs and often life-or-death situations [54].

Despite the growing importance of their roles within healthcare and clients' increasing reliance on their services, prior work has shown aides are underpaid, undervalued by other stakeholders in the ecosystem (e.g. nurses and doctors), and have not received sufficient training [54, 53]. The equity challenges aides face in their work are especially troubling given their current and near-future roles in the changing landscape of U.S. healthcare. As the population ages, and as the provision

Permission to make digital or hard copies of all or part of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for components of this work owned by others than ACM must be honored. Abstracting with credit is permitted. To copy otherwise, or republish, to post on servers or to redistribute to lists, requires prior specific permission and/or a fee. Request permissions from permissions@acm.org.

CHI '20, April 25–30, 2020, Honolulu, HI, USA.

Copyright is held by the owner/author(s). Publication rights licensed to ACM.

ACM ISBN 978-1-4503-6708-0/20/04 ...\$15.00.

<http://dx.doi.org/10.1145/3313831.3376633>

of care shifts from hospital to home and other post-acute settings, an increasing number of adults in the U.S. will require home health and personal care aides. Yet, we currently don't have a system in place that supports the very workers who will be needed to meet this demand: wages for aides are stagnant, job turnover is high, and opportunities for career advancement are limited [54, 53].

Addressing these structural problems requires ongoing attention, especially in light of new policies under value-based care models that will hold home care agencies accountable for patient outcomes [6]. For example, in heart failure, a condition characterized by high morbidity and mortality and frequent hospitalizations, hospitals and agencies are being penalized when patients have excess trips to the emergency department (ED) [1]. Home health aides, who are the eyes and ears for patients in the home, could potentially avert unnecessary ED visits by observing and reporting changes early [31, 61], but only if they are trained, paid, and working in a system that values them and their input.

Motivated by the challenges aides face, and the need for them to gain recognition and higher status for their vital yet underappreciated roles, our work sought to understand how we might improve the lives of these marginalized workers by designing technologies that enable them to be more integral to healthcare and to take on more clinical responsibilities. Prior work examining aides' technology ecosystems has shown these tools are outdated, hard to use, and largely revolve around monitoring aides' labor rather than supporting their workflows. In this, they reinforce the systematic deprioritization of their needs and perspectives [44]. To study these problems, we constructed a provocation: a non-functional prototype of a tablet application that appeared to center aides' needs by providing them with resources for educational content, improved communication with their supervisors, and improved ability to record their daily tasks. We then used this provocation in a field study with 16 participants (aides, nurses, and aide coordinators) to provoke an exploration of currently existing and possible future design spaces around aides' work.

Our study surfaced key insights into the current and near-future perspectives of aides, nurses, and coordinators. Aides perceived our provocation as a way to gain more control over their own labor, but they clashed with nurse and coordinator participants in their desire for better communication. Participants were similarly mismatched in their opinions on providing aides with educational resources. Across stakeholder groups, participants also perceived the provocation to be a trigger for conflict in clients' homes. Finally, participants expressed contrasting levels of concern about whether and how aides might respond to the added workload and learning curve that the provocation might represent.

We show how our work provides a concrete enactment of Dombrowski et al.'s [17] framework of social justice-oriented interaction design, and discuss extensions of three key strategies within it: 1) the ways in which our provocation explored designing for *transformation* as a way to see how near-future political shifts might change marginalized workers' experiences; 2) the need for designers who seek to *enable* marginal-

ized workers to weigh the heightened expectations created by such projects; and 3) the difficulty of designing for *reciprocity, distribution, and accountability between stakeholders* within complex multi-stakeholder environments such as this.

Taken together, our contributions to the HCI community are as follows: 1) We provide an empirical enactment of a well-known framework for justice-oriented technology design; 2) We uncover the tensions inherent to enacting this framework in a delicate health context; and 3) We give recommendations for designers seeking to similarly enable marginalized workers.

RELATED WORK

HCI has had a longstanding interest in technologies for health-care. Within home management of chronic disease, prior work has investigated approaches like collaborative tools for home care [50], informal caregiving by family members [20, 26, 57, 32, 43], self-care through technology [59, 60, 12, 42], and remote symptom monitoring [30, 38, 35]. Relatedly, the HCI for development (HCI4D) community has examined how technology can provide daily support to community health workers (CHWs) in non-U.S. and often low-resource contexts [11, 49, 41, 10]. Prior work has also advanced HCI's role in addressing the social determinants of health, e.g. transportation access [56, 15]. Notably, this literature has advanced community-level conceptions of care, and investigated how social technologies can address health at scale [47, 46, 48].

We focus on how technology can improve health by better enabling home health aides, who are paid, formal caregivers working with patients in their own homes. To the best of our knowledge, the design of technologies specifically centering aides as users has received little attention in the literature. Beyond this, there is a growing need for research examining how technology design might in fact engender greater systemic equity for aides themselves as a marginalized frontline workforce. We now describe work related to this broader goal.

Justice-oriented design sensibilities

We draw on growing communities within HCI establishing theoretical foundations for how designers can improve the lives of underserved, marginalized, or oppressed communities in the face of large-scale systemic inequities. Much of this work (e.g., [3, 24]) has outlined sets of design sensibilities that stand in contrast to the paradigm of HCI as a practice of engineering technology solutions in response to commercial or user requirements. Expanding the design space beyond individuals' immediate needs to collective social problems requires a corresponding expansion of designers' approaches. We locate our work on this frontier.

We focus on Dombrowski et al.'s [17] framework for how designers might practice a social justice orientation. Such a perspective, the authors posit, helps designers ground their work in a landscape shifting from technological possibility as the prime directive to designing ethically, responsibly, and with accountability. To start, designers make personal commitments to 1) the *conflict* inherent to a polyvocal design process; 2) the *reflexivity* required to acknowledge their own biases and how they might color the work; and 3) taking a personal stance in the *ethics and politics* of creating change.

With these commitments established, designers proceed along one or more of six strategies. Designing for *transformation* aims for large-scale, long-term approaches to systemic change. Designing for *recognition* identifies unjust phenomena as a precursor to addressing them. Designing for *reciprocity* creates conditions in which relationships within an inequitable system can become more equitable. Relatedly, designing for *distribution* seeks a more even sharing of a social system's benefits and burdens among stakeholders, and designing for *accountability* enables those who benefit from others' oppression to be held responsible. Finally, designing for *enablement* aims to foster human capacity and self-determination.

This framework draws on related threads within HCI complicating the paradigm of user-centered design with feminist [4, 3], postcolonial [24], and queer lenses [34]. It also engages with questions of self-determination at play in the HCI subfield of accessibility, notably Ladner's [29] concept of designing for *empowerment*. Projects with this tenor must ensure that a marginalized user group has both the ability to actively participate in or lead the design process and sufficient pre-existing self-determination to carry the resultant technology forward. Outside of accessibility, recent works in HCI critiquing participatory design have similarly called for these processes to better center marginalized users [8, 23, 2, 19].

Our work provides an empirically-grounded study of how these approaches play out in practice. Based on our efforts to conduct justice-oriented technology design to improve equity for home health aides caring for clients with heart failure, we discuss extensions of Dombrowski et al.'s [17] framework.

Enactments of justice-oriented design

In considering aides as a workforce, we were inspired by work examining how the tenets of social justice-oriented design might be applied to improving the lives of marginalized workers – drawing us closer to what Crivellaro et al. [9] define as “fairer workforce futures.” Extensive ethnographic work has built a nuanced picture of worker marginalization within ride-sharing apps in the U.S. [22, 32] and in the Global South [28, 51], pointing out how the technology-mediated gig economy affects workers by creating perceptions of behavior control and expectations of emotional labor [39, 52, 27]. Outside of gig economies, scholars have examined how workers might use technology to address wage theft [16], and how workers react and adapt to technology-mediated forms of workplace surveillance [33]. Researchers have also adopted an activist stance and deployed technology interventions that directly address these inequalities, by providing tools for crowd workers to review their employers [25] or for low-income individuals to find employment or entrepreneurial opportunities [14, 13]. Our work joins this growing body of literature extending applications of design justice to a less-studied site for worker marginalization: frontline healthcare workers in the U.S.

METHODOLOGY

We conducted a qualitative study of how stakeholders in the ecosystem surrounding home care of heart failure patients reacted to a design provocation that suggested a possible future in which aides are afforded greater equity. In this section, we 1)

discuss how we arrived at our design methodology. We then 2) detail specific choices we made in designing the provocation, and 3) describe our field study with 16 stakeholders across aide, nurse, and coordinator groups.

Design Method

Methodologically, we were inspired by ongoing work in interaction design and HCI advancing discursive design methods such as speculative design [18] and design fiction [5, 36, 37]. Our goal was not to “solve problems” for our users, an approach Vallgård et al. [55] characterize as movement towards a defined solution within a known context, but rather to use design to explore the space of potential contexts. We contrast this approach with traditional methods in user research, i.e. interviewing or contextual enquiry, which are more on understanding an existing design space. In short, we did not test a *prototype*, but rather developed an artifact that might serve as a *provocation*, and focus on participants' *interpretations* of it.

We were also inspired by ongoing work examining how designers might create technologies that serve underserved people. As Costanza-Chock has articulated, projects with social justice goals should “center the voices of those directly impacted”, and designers in these contexts should serve as “the facilitator rather than the expert” [8]. Our provocation presented stakeholders with a deliberately incomplete vision of a future in which aides have more “clinical” responsibilities, and are thus more integral to the healthcare team—an outcome increasingly possible under the shifts in U.S. healthcare towards value-based payment schemes. We did not ask aides to imagine a more equitable future from scratch, but rather asked how this upcoming disruption might benefit them more directly. Thus we sought to mitigate what Harrington et al. [23] have described as a potential pitfall of participatory design strategies: their tendency to focus on “blue-sky” ideation, which can perpetuate inequitable systems by leading to “infeasible solutions that ultimately frustrate underserved individuals.”

To seed participants' imaginations with specific cues while refraining from prescriptively stifling them, we structured our provocation as a *medium*-fidelity prototype of a digital application with some level of interaction, but without actual function. By centering this digital technology on the aide as its sole user, we aimed to create a material starting point from which our participants could begin to articulate aides' experiences, as well as their visions of the future.

Designing the Provocation

In prior work mapping aides' roles in caring for heart failure patients [44, 54, 53], researchers synthesized **three key needs** for aides: 1) the ability to record their daily tasks seamlessly and reliably; 2) the ability to communicate with agency nurses and supervisors about their clients' health in real-time, including flagging emergencies; and 3) the ability to access on-device educational content on medical topics, like normal blood pressure ranges, and health topics, such as the components of a low-salt diet.

We used these findings as a starting point for our provocation, which took the form of a tablet application fulfilling these needs and extending them into new design spaces. The tablet

form factor was chosen because it offered a mobile device modality familiar to participants, and could plausibly encapsulate data entry, communication, and multimedia content. We created a series of screens that mimicked the design motifs expected in a modern mobile application. Users could tap on select buttons to move screens; however, we stopped short of actual functionality in order to leave space for future imaginings. For instance, the provocation does not store information or actualize real-time messaging. We now discuss how our provocation engaged with aides' three key areas of need.

The ability to record daily tasks seamlessly and reliably.

In their current technology ecosystems, a home health aide's work revolves around recording the tasks they have completed for their clients via a telephonic punch-code system [44]. Each day, when an aide arrives at her client's home, she uses the client's home telephone to call into an automated phone line. This is how aides "clock in", or register with their employers that they have arrived at the client site. The aide then consults the client's *care plan*, a document written by the client's nurse and signed by the client's doctor that outlines the tasks the aide is to perform for the client each day. Care plans are often left in paper format for the client to display prominently in the home, for example on the refrigerator.

The aide performs the tasks outlined on the care plan for the duration of her shift. At the end of her shift, the aide dials again into the automated telephone system using her client's phone and follows prompts to "clock out". As the system records her time of clock-out, she also completes an important step: task recording via telephonic punch-code. She enters numbers into the system that map to the activities she has performed for the client. This registry of aides' activities forms the basis of agencies' electronic visit verification (EVV) schemes, and is critical to how insurance companies reimburse for home care.

Despite their central role in aides' work, these systems are seen as unreliable and cumbersome, and are often the source of tension between aides and coordinators. When the telephonic punch-code system fails to record an arrival, the coordinator must call the patient to verify that the aide is present. The telephonic punch-code system also offers users no visibility into the numbers already entered, and no way to correct an entry in the event that a user accidentally enters the wrong code. In fact, prior work [44] has shown aides have so little trust in the system that they carry paper timesheets to be safe.

Our provocation engages with the challenges described above by appearing to provide aides with digital tools for the data collection they already conduct. Specifically, we constructed a way for aides to 1) reference clients' paper care plans in digital format and 2) record their daily tasks in an interface that appeared to provide reliability and convenience. In addition to fulfilling these needs, we also extended this capability into newer territory: Since aides are the natural observers of data to which clients' doctors and nurses currently do not have access, what if at the times of clock-in and clock-out, aides also collected and uploaded data on their client's health status? For example, an aide who helped her client keep track of her weight over time could record that she had completed this task, and also record the values themselves and send them directly

to the client's clinical team. We saw this as an avenue for elevating aides' importance within home care.

The recording of patient medical indicators also presented an opportunity to provide aides with "just-in-time" decision support. Particularly in the context of heart failure, a disease for which patients may have a long and difficult post-hospitalization recovery, extensive prior work [54, 53, 44] has shown aides often struggle with whether and when to call for help from emergency services or from a client's doctor. To extend the possibility of aides making more informed decisions in these moments of crisis, we asked: What if aides received immediate feedback from a technology tool itself on whether clients' levels of leg swelling were cause for alarm, and when to call a doctor? Such decision support may be an avenue for aides to provide better and more efficient care.

Figure 1 shows the screens of our provocation that realize these ideas. Care tasks like personal care and nutrition are tabbed on the left-hand side. Under "HF Monitoring", aides can enter medical indicators with clear relevance to heart failure, such as weight and blood pressure, as well as checkboxes for additional indicators like shortness of breath, chest pain, and leg or ankle swelling. As shown, an aide who selects an indicator that gives reason for alarm is directed to contact a supervising nurse or 911. Of note, in developing the decision support feature of our provocation, we consulted with nurses and medical doctors with experience in home care of heart failure patients for a clear decision-making algorithm.

The ability to communicate with nurses and coordinators

Much of aides' current daily work also revolves around communication with agency nurses and coordinators. Coordinators, full-time office-based employees who work on rotating shifts, are aides' immediate supervisors at home care agencies. They are responsible for assigning aides to clients, directing them to client sites and monitoring aides' clock-in, clock-out, and task recording data for inconsistencies, such as the failure of the punch-code system to record a visit. Clients and their family members also often correspond with coordinators to manage their arrangements with the agency.

Nurses also work for an agency on rotating shifts. When a client is deemed to be home-bound and have skilled need, a nurse is assigned to provide an initial assessment, draft the care plan, and subsequently supervise the aide, who provides day-to-day care. Nurses then visit every few weeks to adjust the care plan as needed.

Currently, aide-nurse and aide-coordinator communication occurs largely via phone call, and coordinators and nurses alike may manage dozens of aides at once. Coordinators are meant to be aides' first points of contact for all issues that arise, but aides have voiced it is often difficult to contact them in a timely manner: prior work has shown aides can spend hours waiting for a call back [44]. Aides have also voiced that coordinators do not have the medical expertise to provide clinical guidance in dire situations—and that nurses are difficult to contact when these situations arise.

We engage with these challenges in our provocation through a chat feature that appears to provide aides with an interface

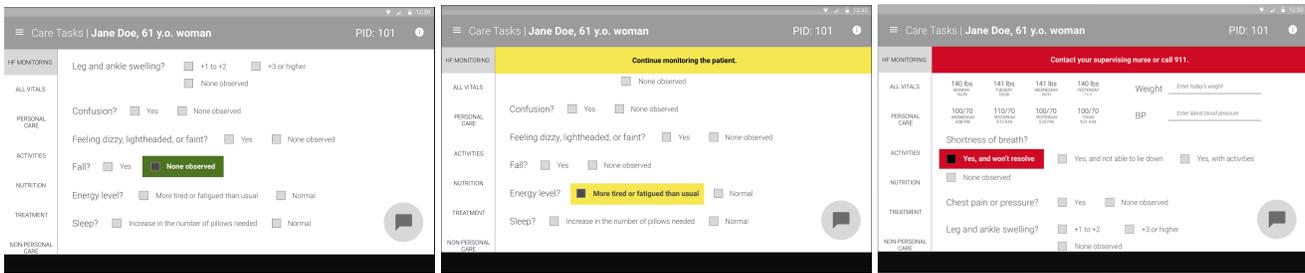


Figure 1. The decision support features of our design provocation. From L to R: Green indicates no cause for concern at this time; Yellow indicates cause for concern, and recommends the aide keep monitoring the client; and Red indicates a possible emergency for which the aide should seek help.

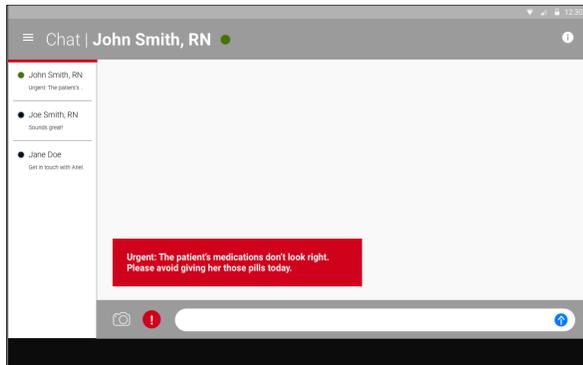


Figure 2. The instant messaging feature of our provocation.

for instant-messaging nurses and/or other agency staff (Figure 2). This alone suggests disruptions to the current workflow, moving communication from phone calls to asynchronous messaging and providing aides with a direct line to clinical staff. This chat interface also appears to be accessible from all other screens in our provocation as a persistent chat icon. On several screens we also created the appearance of new message notifications with a red flag on the chat icon.

To extend the disruptive potential of our provocation, we suggest additional possibilities for this computer-mediated communication channel. A green circle next to the nurse's name hints at whether the nurse is online or offline. A red icon next to the message input box suggests the ability to flag certain messages as urgent. Finally, a camera icon in that same dialog suggests the ability to send photos or videos. In order to maintain focus on future communication possibilities, we did not incorporate explicit cues to signal whether the messages exchanged were compliant with Health Insurance Portability and Accountability Act (HIPAA), a U.S. statute that sets privacy guidelines for patient information.

The ability to review on-device educational content.

Aides working with heart failure patients have expressed that they often feel the need for more health and medical education to properly care for their clients [54, 53]. Agencies currently provide required training programs (known as “in-services”) that might cover relevant baseline information, like the elements of a low-salt diet, but previous work has shown that aides supplement these trainings with information they source on their own, often by searching the Internet [44].

In our provocation, we engaged with the need for educational resources through a button on the “home screen” labeled “*Learn about Heart Failure*”, which led to a screen with six buttons: “*About Heart Failure*”, “*Diet*”, “*Physical Activity*”, “*Symptoms*”, “*Glossary*”, “*Medications*”. These six high-level information categories were developed in consultation with nurses and medical doctors familiar with heart failure care, but the buttons did not provide actual resources. We intentionally kept this section of our provocation vague, to leave room for participants to fill in what it might contain.

Field Study

We conducted an IRB-approved field study in the winter of 2018 and spring of 2019 in New York City, in which we showed our provocation to 16 participants from three stakeholder groups (Table 1). Our research team consisted of three women and one man who all reside in the U.S. All had experience working with underserved populations. Three have extensive research experience designing technologies for marginalized populations in low-resource environments. One researcher, a medical doctor, has clinical expertise caring for heart failure patients at a large academic medical center and established relationships with multiple home care agencies in New York state.

Recruitment

We recruited participants through direct outreach via our partnership with 1199SEIU United Healthcare Workers East, the largest healthcare workers' union in the U.S. Partnering with the aides' union enabled us to hold focus groups at safe spaces, ensuring participants anonymity from their employers. Many participants were hourly employees paid roughly the minimum wage in New York City (\$15/hr), so we compensated them \$25/hr in recognition of their time and expertise. Participants were assured that participating in our research would not affect their employment status or benefits, and that participation would be strictly anonymous. All participants provided written or verbal consent to participate.

Participants

The majority of our participants were women (see Table 1) who worked primarily in English. A notable proportion of our aide participants (4/11) worked at least half the time in Spanish. All agencies in our study follow many of the same industry-standard procedures, including having aides utilize the telephonic punch-code system for clocking in and out, routing aide communications through coordinators, and centering

day-to-day operations around the plans of care created by traveling agency nurses and left with the client. All agencies also operate under the jurisdiction of HIPAA.

Design Sessions

We conducted eight focus groups with 2 to 3 participants and 1 to 2 moderators per session, each lasting 60 to 90 minutes. Focus groups were chosen over one-on-one interviews to encourage group discussion and counter-point. Though aides were the target users of the provocation, we sought participation from nurses and coordinators to better understand all relevant perspectives. All sessions were conducted in English, except one conducted in Spanish via an interpreter familiar with the domain.

We were sensitive to the tensions that occur in research with underserved people, particularly in labor contexts: the design research process itself can reinforce inequity, and can be exclusionary and traumatizing for marginalized participants [19, 23, 2, 8]. Thus we prioritized ethical research practice, e.g. encouraging participants to share full accounts of their experiences over “honest disclosure”, and affirmed throughout that our participants were the experts. In addition, all groups were homogeneous with respect to stakeholder category, meaning aides were grouped only with other aides, nurses with nurses, etc. By not mixing aides and supervisors, we enabled all to speak without the power dynamics inherent to a mixed group.

Each session began with a discussion of participants’ roles in the heart failure ecosystem, including the challenges they experienced in their jobs. All participants were then shown the provocation displayed on a tablet, and encouraged to interact with it, to freely share thoughts about how it might impact their jobs, and to imagine it in different settings. Drawing on design recommendations of prior work [44], we also asked participants about their perspectives on keeping the tablets in client’s homes, versus aides carrying the devices at all times.

Data Analysis

Where participants permitted, design sessions were audio-recorded and professionally transcribed. We also took detailed notes during all sessions. We analyzed this data thematically [45], beginning with a close reading of the data and allowing codes to emerge. Multiple passes resulted in 58 distinct codes (e.g., *magical technology*, *paper trail*, *aides want to learn*, and *distrust of Internet information*). We clustered related codes into high-level themes (e.g., *record-setting*, *mismatched interests*, *triggers conflict*). After multiple discussions and iterative refinement, we arrived at a final set of themes that comprehensively represented the data.

FINDINGS

Our findings cover five major themes that emerged from our design sessions. We begin by 1) describing how aides perceived the provocation as a way to gain more control over the narrative of their work. We then 2) highlight a clash in how aides and other stakeholders envision the utility of the provocation’s communication functionality. We show that 3) participants across groups worried that the aides’ use of tablets in clients’ homes could trigger conflicts with clients and clients’ families. Next, we 4) discuss how participants’

Ppt ID	Role	Employer	Language	Gender
1	HHA	Other	English	Female
2	HHA	Other	English	Female
3	HHA	Other	English	Female
4	HHA	Other	English	Female
5	Nurse	Other	English	Female
6	HHA	Agency A	English	Female
7	HHA	Agency A	English	Female
8	HHA	Agency A	Spanish	Female
9	HHA	Agency A	Spanish	Female
10	HHA	Agency A	Spanish	Female
11	Nurse	Agency B	English	Female
12	Nurse	Agency B	English	Female
13	HHA	Agency B	English	Female
14	HHA	Agency B	Spanish	Female
15	Coordinator	Agency B	English	Male
16	Coordinator	Agency B	English	Female

Table 1. Participant demographic characteristics. Agency A is a worker-owned home care agency headquartered in the Bronx, NY. Agency B is a community-based nonprofit in Queens, NY. Agencies represented with “Other” are all comparable home care agencies in New York City.

interest in the provocation’s educational resources differed sharply between aides and other stakeholders. Finally, we 5) uncover participants’ perceptions of how the application would increase learning requirements and workload for aides.

Taking control of setting the record

We initially hypothesized that, given the precedent established by the telephonic punch-code system, aides might perceive the task recording feature of our provocation as yet another means through which their employers could monitor their work, and mete out disciplinary measures if they were not performing up to par. Instead, we found that aides viewed the provocation as a way for them to take control and set the narrative around their work—to actively engage in *record-setting*, instead of passively having records kept on them.

This affordance was immediately relevant for many of our aide participants’ ongoing relationships with their employers. Specifically, aides said the records would give them greater power when negotiating with their employers over the number of hours they had worked. Several shared they were already keeping personal notes of their tasks in separate paper notebooks or digital calendars on their personal smartphones for the same purpose. A system like the provocation, one aide said, would provide an additional point of leverage:

“This would protect me, because once [my task] is in, it’s recorded. There’s no ‘you didn’t call’. It would be my backup, my paper trail.” (P6, aide)

These records were seen as especially powerful for cases that could veer into medical emergencies (e.g. when a patient’s feet suddenly become swollen—a common scenario in heart failure patients). Aides described that after these sorts of situations, they often felt pressure from both their agencies and their clients’ broader clinical teams to have taken some “*creative*”

action to help the patient, or at least to have immediately reported the situation to their coordinator.

But to aides, the issue was not so much about placing phone calls to their coordinators or to a nurse to seek recommendations on what to do in dire situations; rather, it was that these phone calls often went unanswered. With a tool like our provocation, aides felt they would have a reliable way to establish and prove that they had done everything they could. One participant shared:

“A bed sore progresses. I’ve made several calls, it’s growing, it gets worse and worse. This would document my persistence.” (P7, aide)

As this quote suggests, aides perceived that our artifact would serve as formal documentation of their actions beyond the personal records they already maintained. To help them record information in more detail, aides also immediately wanted the design to include features beyond those depicted in the provocation, for example photo and video capture.

This finding shows aides responded not only with feedback on the provocation’s design, but also with visions of what it might enable them to do. In Discussion, we detail how precise outcomes like this, surfaced from aides, might be used to measure whether a tool like our provocation succeeds in helping them achieve greater equity.

Clash in the desire for better communication

Our work also showed how aides, nurses, and coordinators perceived the prospect of real-time messaging differently. Aides viewed this feature as a way to improve on current communication practices, and a potentially vital tool for their day-to-day. As discussed previously, aides report their calls to nurses and coordinators often go unanswered. The chat feature of our provocation might address these communication challenges, aides said, most notably by providing “urgency flags” that could alert nurses and coordinators to messages from aides in particularly emergent situations.

Coordinators felt differently. One coordinator (P15) pointed to the red button on the chat interface providing a way to urgent-flag a message, and said, *“If I know these aides, everything would be red.”* Aides already sought to monopolize their time, coordinators explained, and the addition of another way to reach them would only create more work for them.

Another issue was aides’ tendencies to reach out to *specific* coordinators, regardless of whether or not those coordinators were currently assigned to their case. While an agency might have reassigned new coordinators, aides often only wanted to speak to a coordinator they already trusted. This created difficult situations for coordinators, who were often implicitly expected to be available to an aide long after reassignment. One coordinator (P16) explained that after accidentally giving out her personal cellphone number, she experienced an influx of reach-outs from aides who wanted to speak to her only:

“On the weekend, I say I’m not working. They’ll call me on my cellphone, because when you use your phone to call them, they get your number. And I say, ‘I’m not

talking to you, I’m not working. Call the emergency number, because I’m not working today’... If you forget to block your number, it’s free-for-all. They WILL text you on it.” (P16, coordinator)

Nurses viewed the urgency flags as a potentially useful way to triage within what they anticipated as a “fire hose” of messages from aides, but described concerns around expectations of availability similar to coordinators’. One nurse (P5) said that indicating availability on the chat was vital, so that aides would know when nurses might see a critical communication. But simply indicating online or offline status was not enough—a message sent to an offline nurse might contain critical information, for example, that would have warranted an immediate response if the nurse had been available.

Still, coordinators did see some benefit to chat communication; specifically, they felt the permanence of a chat record would allow aides to look back at previous messages to remind them of directions from their coordinators, thus saving all parties time. Centralizing these communications in a digital record would, in our coordinators’ views, improve on current practices:

“One of the first things we tell aides is to buy a little book from the 99-cent store so they have all their addresses in that book. A lot of aides don’t comply with that. When they start working and you tell them something, they just tear off a sheet of paper and write it down, but they don’t save it. So by texting like this it seems a little more permanent, I should say.” (P15, coordinator)

This set of findings shows that in complex ecosystems like ours, making systems more equitable can require redistribution of burden from one group (aides) to another (nurses and coordinators). We unpack this tension in Discussion.

A trigger for conflict in patients’ homes

In our design sessions, we asked participants for their perspectives on aides working with a device like our tablet provocation placed at clients’ homes, versus a device aides carried to and from the site. Across groups, participants agreed that no matter where the device was housed, it would create problems between aides and clients.

Nurses and coordinators said they already spent significant time fielding complaints from clients who felt aides were distracted by their personal devices. In their view, the addition of another device, even if for work purposes, would make the problem worse. One nurse (P5) said she often performed pop-up visits to client sites when the client’s family reported the aide for *“being on their phone all day long.”* Coordinators, who naturally bore the brunt of client complaints, said they knew aides would *“always be texting”* (P16) if given an additional device. One coordinator said the addition of a work tablet would in fact give aides cover for personal messaging:

“The biggest complaint we get from clients is that aides are always on their phones. ‘She don’t do nothing, she just sit on her phone all day, texting texting.’ So I don’t know how I would explain it to the clients. They’d be sneaky, they’d be telling the patients ‘Oh, I’m texting my supervisor...’ ” (P16, coordinator)

Aides raised the issue that placing tablets in clients' homes would cause friction for a different reason: clients would suspect they were for surveillance. As one aide said:

"If this were to get piloted, people would need to be informed, meaning the patients. They can get funky. They can feel like you're spying on them." (P10, aide)

Participants agreed that the agencies would need to clarify that aides were using the tablets for task recording only. However, even in the hypothetical case of agencies successfully reassuring clients, the tablets themselves would still be a source of conflict. Specifically, aides voiced concerns that patients and families might steal the tablets if left in the home.

Similar to the last finding, here we see that the redistribution of burden from aides to other stakeholders (patients and families) can cause tension. We unpack this further in Discussion.

Mismatched interests in educational resources

An important component of our provocation was the provision of educational resources on heart failure for aides to reference at any time. When we showed this to nurses and coordinators, they conveyed little interest in this part of the provocation. They felt it was fine to have, but not critical for aides to do their jobs. In stark contrast, the educational resources elicited hearty responses from aides who perceived them as an opportunity to satisfy a long-awaited need to learn more about how they could improve in their work.

For one aide participant (P6), the educational features were *"the best part, because [they] would give me information"*. Aides were quick to volunteer ways to extend these features: They requested content ranging from medication guides to personalized diets to embedded videos demonstrating how to do cardiopulmonary resuscitation (CPR). Aides also suggested crowdsourcing its contents. One aide (P2) said that over decades of aide work, she had developed an index *"stored in [her] brain"* of side effects of common medications. She asked whether such resources could be made part of the provocation for others' benefit: *"So this would be like a Wikipedia of information that could help people?"*

Compared to nurses and coordinators, our aide participants were quick to ascribe more *trustworthiness* to the information provided by the provocation than the information they currently utilized. Specifically, aides drew a distinction between what they saw the provocation would provide and their current practice of searching the Internet:

"I don't trust Google. Not everything is accurate. I know this would be designed with accurate information, and help guide me ... Knowledge is power." (P6, aide)

Aides also voiced that such a tool would lend them emotional reassurance as they went about caring for their extremely sick patients. This emotional reassurance, aides said, would be the result of acquiring more knowledge on what they could do for patients with difficult conditions like heart failure:

"You'd have something to anchor you and take away your anxiety – 'oh my god, heart failure, what is it, what do I do'. This gives you a foundation." (P6, aide)

This finding resonates with another core tension we detail in Discussion: stakeholders may disagree on how systems advantage or disadvantage fellow stakeholders.

An additional workload and learning curve

The fundamental elements of the provocation were disruptive enough to raise concerns from all stakeholder groups about how aides might receive its implementation. Participants agreed that, just as they would have to be trained on any new tool, the provocation would require aides to engage in additional learning and practice. But they disagreed on how aides would handle this new learning curve.

Several participants voiced doubts around whether aides would *want* to use the tool. They said they had seen other technologies for aides deployed at their agencies in the past, and were convinced a tool like our provocation would not work in practice because aides would not want learn to use it:

"They don't know how to use the tablet, and they don't want to use it, because most of the time they don't like to use it." (P11, nurse)

At issue was the perceived level of additional work required. In a job where they already felt overburdened, aides might be reluctant to engage with the additional responsibilities and expectations that features like blood pressure monitoring and heart failure education would create. This was voiced by not just nurses and coordinators but also aides:

"Some people want to go, follow the care plan and that's it. Stuff like this would seem like extra work." (P13, aide)

Participants were also concerned about the English literacy required to engage with a tool like our provocation. All text was presented in English, and for the purposes of this study we did not create a Spanish-language version. As one aide who worked in both English and Spanish explained:

"Some [aides] don't even know how to write and read in Spanish. How are they gonna be writing and reading in English?" (P13, aide)

Still, some aides felt they had the ability and desire to expand their capabilities to use a tool like our provocation. Many were already doing additional work outside of agency-mandated courses to learn more about the diseases they worked with each day. As one aide (P14) said: *"We can learn. Why not?"*

This tradeoff between engendering equity through increased capability and overburdening an already stressed workforce is a core finding of our work. We unpack it further in Discussion.

DISCUSSION

Our findings reveal the numerous tensions and trade-offs inherent in designing technologies to improve equity for home health aides as their role in U.S. healthcare changes. We also find compelling connections from this work to discussions within HCI on how to design technology for marginalized workers. Specifically, we contribute lessons from a concrete enactment of Dombrowski et al.'s [17] framework of social justice-oriented interaction design.

First, we note that in engaging with multiple stakeholders, we invited a sense of conflict into our polyvocal design process. All participants found the provocation disruptive in different ways: Coordinators and nurses were quick to point to aides as the source of numerous problems; aides were quick to tell us how difficult it was to get in touch with coordinators and nurses; and all were quick to point out the challenges of dealing with clients and clients' families. Constructing a provocation that principally centered on aides also bolstered the turbulent nature of the feedback we received. Here we see a reflection of the *commitment to conflict* outlined in Dombrowski et al. [17] as a prerequisite for designers engaging in social justice-oriented work, as well as an enactment of their strategy of *recognition*. In provoking these conversations, we invited contestation, and in doing so surfaced larger injustices around how aides are valued by the other stakeholders.

Second, we note that as a research team we pursued a shared vision in this project: a healthcare workforce in which aides, specifically, are able to achieve greater parity. We are aware that in doing so, we centered on a specific stance originating from our perceptions of the world. Taking cues from what Dombrowski et al. [17] articulate as a *commitment to reflexivity*, we acknowledge that our visions for aides may not necessarily map onto those aides may pursue for themselves.

Nevertheless, our study design was *intended* to provoke participants to contemplate the political; at no point was it construed as the apolitical development of technology against an efficiency measure or a static set of user needs. In taking a stance at all, we align our work with what Dombrowski et al. [17] call a *commitment to ethics and politics*. Similarly, we claimed responsibility for our design choices and our provocation's underlying assumptions and biases, and never gave the impression to one stakeholder group that another group had created our provocation. We thus enacted the strategy of *accountability* [17] in the designer-participant relationship.

Our empirical study provides a grounded look at how these concepts can be developed. We now discuss how our work extends three key strategies within Dombrowski et al.'s [17] framework: 1) the use of methods like ours in designing for *transformation*, as a way to explore how near-future political realities might manifest in marginalized workers' experiences; 2) the need for designers who seek to *enable* marginalized workers to weigh the heightened expectations created by such projects; and 3) the difficulty of designing for *reciprocity, distribution, and accountability between stakeholders* within complex multi-stakeholder environments like ours.

Design to concretize transformation

Designing to combat large-scale structural inequities necessitates a shift in focus, from attending to individual needs with user-centered design to attending broadly to oppression-producing contexts. Dombrowski et al. [17] articulate the need for this shift in their strategy of *transformation*, which focuses not only on "*immediate innovation*" for individuals but also on designing for longer-term collective action.

An approach like this may at first seem distant to the practice of HCI, which has retained a focus on creating and experiment-

ing with digital technologies for people to use—something closer to engineering innovation than to political activism. The balance between these two orientations has been the subject of much literature, notably Bardzell's articulation how feminist interaction design should retain the quality of advocacy [3]. But as designers and builders of technologies, *how can we actualize such orientations and qualities in our work?*

We suggest practices like the design provocation used in this paper as a tactical methodology by which designers might bridge the gap between the political and the material. Our provocation was situated in a near-future shift in healthcare payment models, and concretized a broader transformation in which aides occupy a more valued role in home care. Within contexts like this, experimentation is limited and heavily regulated due to the life-or-death nature of the processes at hand. With these pressures, it is tempting to reduce innovation processes to the traditional cycles of building and evaluating tools against rigid and predetermined measures. This is expected, since lives are at stake—yet, doing so emphasizes outcomes based on incremental improvements on a present reality.

As seen in our findings, our method garnered insights on both individual needs and longer-term collective goals. Participants responded to our provocation with feedback proximal to their immediate needs, e.g., by describing how real-time chat would overburden nurses and coordinators, or how placing a tablet in clients' homes would result in conflict. But they also responded with distal feedback highlighting potential broader changes, e.g., how accurate record-keeping could help aides negotiate with their employers, or how aides might crowd-source information on side effects of common medications.

Designing and testing a provocation also gave us a window into the kinds of measures to prioritize in designing a future system aimed at helping aides achieve equity. A tool that gives aides a way to keep task records, for example, might be evaluated against not just its technical stability ("Does it record and store aides' tasks?") or its user experience ("Can aides use this?"), but also whether it engenders specific equity goals ("Have aides used this to negotiate a raise?") Such a study might meaningfully address the individual and collective dimensions of the expected transformation while grounding measures in realities sourced from aides themselves. If we supplement near-term measures with equity measures sourced from studies like ours, we might achieve a process of innovation that bolsters broader social transformation.

Weighing enablement and expectations

We now turn to *enablement*, a principle defined in Dombrowski et al.'s [17] framework as a focus on "*fostering human capacity by creating platforms for participation and self-determination.*" We saw this enacted in aides' reactions to many of the affordances of our provocation. For some, the educational features were seen as a way for aides to fulfill their potential. Aides also saw the task recording and chat features as ways by which they could better control the narrative around their labor.

Despite this, several features in our provocation were seen not as a means for enablement within inequitable labor systems, but rather as a way for additional *expectations* to be levied

upon aides. For example, the addition of instructional videos for CPR may alleviate aides' immediate anxieties around caring for heart failure patients, but, as participants pointed out, aides might feel even more anxious around the newfound expectation to know and one day carry out this skill.

In this, we see a core tension: *How do technology designers balance the goals of enablement with the realities of increasing expectations of marginalized workers?* The answer is not as simple as giving an enabling technology to an employer and encouraging them to make its use optional. It is possible that in deploying a disruptive technology, a subset of marginalized workers might refuse to train themselves to new capacities and be fired as a result. As job loss is not a desired outcome of social justice-oriented technology design, we would define this as a failure of the project.

If we assume that creating the enabling technology is to raise expectations for marginalized workers, then the possible positive outcomes of enablement would need to be worthwhile for workers who did choose to upskill. Yet, our findings show this is not guaranteed. As the reactions to our provocation illuminated, aides may perceive a new technology as “*extra work*,” which would be unwanted if they simply seek stability and predictability in their jobs: “*to go, follow the plan of care, and that's it*,” as one aide described. For these aides, upskilling on new technologies might in fact impose especially impactful burdens on the more marginalized in the labor force. As *improving* the lives of these workers is a core motivation of our work, we would define this, too, as a failure of the project.

Thus we arrive at a final reality: technology enablement projects may only achieve their goals for the subset of users who take and leverage the opportunities they create. To design tools for marginalized workers is to decide what level of upskilling to mandate, to appropriately weigh the promises of enablement with the opposing realities of creating additional expectations. Frameworks for how designers can make these decisions is a compelling area for future work.

Negotiating reciprocity and distribution

Designing for equity within multi-stakeholder ecosystems like ours requires foregrounding what Dombrowski et al. [17] call *reciprocity*: a focus on “*relationships and the ways they maybe need to change to become more equitable for all stakeholders*.” Closely related to this concept is the strategy of *distribution*, in which designers focus on equitable rebalancing of “*the benefits and burdens of social systems*.” We also find close ties to Dombrowski et al.'s [17] strategy of *accountability*, which emphasizes that “*those who foster or unduly benefit from the oppression of others*” should be held responsible.

Here, we find a tension core to the work: *How do technology designers enable the most marginalized while reassuring all stakeholders of mutual benefit, so that conflicts over the realities of redistribution do not prevent progress?* Our work shows that the realities of managing multi-stakeholder projects mean that technology designers must often make trade-offs between emphasizing enablement for marginalized workers and systemic equity for all. Our participants' reactions to the chat feature of our provocation, for instance, seem to demand

that we “pick a side”: our findings are replete with comments from nurses and coordinators on how aides' behaviors would cause problems for all stakeholders if they were given a tool like our provocation. Coordinators feel better communication would lead to aides sending a deluge of urgent-flagged messages, and nurses point out they already regularly make house calls to assuage clients who feel aides are constantly texting.

One way to handle these trade-offs is to create a platform through which stakeholders might themselves engage with the messiness of enacting reciprocity through distribution. However, just as designers of enablement projects must reckon with how their design choices impose implicit expectations upon users, designers of technologies for reciprocity and distribution must reckon with the idea that designers do not control how these platforms might be used, or whether the eventual outcome is one in which equity has been achieved. For example, it is possible that the chat feature of our provocation could provide a vector through which employers (e.g., agencies) enact greater surveillance and control over their employees. Another compelling area of future work is developing technology design frameworks that ensure that when stakeholders begin to use a tool, the resulting process of redistribution for reciprocity achieves an equitable result. The goal would be to ensure accountability, while leaving room for shifts in who in the ecosystem are allies, oppressors and oppressed.

CONCLUSION

In this work, we explore the design space of how technology might improve equity for home health aides by analyzing how aides, nurses, and coordinators reacted to a design provocation of what appeared to be a tablet-based application that provided aides with a set of potentially disruptive affordances. Findings from design sessions with 16 participants reveal a broad set of ethical and pragmatic dilemmas that suggest improving equity for aides requires more than simply responding to their immediate needs. We make sense of our findings through Dombrowski et al.'s [17] lens of social justice-oriented design and discuss how our work pushes this framework to better account for multi-stakeholder ecosystems.

We acknowledge that our study has several limitations. Our sample size of 16 is small, and consists of aides, nurses, and coordinators, with sparse representation from the latter two groups (3 and 2, respectively, compared to 11 aides). We did not directly engage with patients or their family members as part of this study, and acknowledge that these are significant stakeholders in the home care ecosystem. An examination of patients' reactions to a provocation centering aides is another tantalizing area of future work.

ACKNOWLEDGEMENTS

This work was funded in part by grant #76487 from the Robert Wood Johnson Foundation. Dr. Sterling is additionally funded by the National Heart, Lung, and Blood Institute (K23HL150160). We sincerely thank all of our participants for lending their time and expertise. We additionally thank Andrea Gallardo, Harveen Kaur and Jacklyn Cho for their comments and assistance with our study.

REFERENCES

- [1] Coby Annema, Marie Louise Luttik, and Tiny Jaarsma. 2009. Reasons for readmission in heart failure: Perspectives of patients, caregivers, cardiologists, and heart failure nurses. *Heart and Lung: Journal of Acute and Critical Care* 38, 5 (2009), 427–434. DOI: <http://dx.doi.org/10.1016/j.hrtlng.2008.12.002>
- [2] Mariam Asad. 2019. Prefigurative design as a method for research justice. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW (11 2019). DOI: <http://dx.doi.org/10.1145/3359302>
- [3] Shaowen Bardzell. 2010. *Feminist HCI: Taking stock and outlining an agenda for design*. Technical Report. 1301–1310 pages. DOI: <http://dx.doi.org/10.1145/1753326.1753521>
- [4] Shaowen Bardzell and Jeffrey Bardzell. 2011. Towards a feminist HCI methodology: Social science, feminism, and HCI. In *Conference on Human Factors in Computing Systems - Proceedings*. ACM, 675–684. DOI: <http://dx.doi.org/10.1145/1978942.1979041>
- [5] Julian Bleecker. 2009. Design Fiction: A Short Essay on Design, Science, Fact and Fiction. *Near Future Laboratory March* (2009), 49. <http://www.nearfuturelaboratory.com/2009/03/17/design-fiction-a-short-essay-on-design-science-fact-and-fiction/>
- [6] Sylvia M. Burwell. 2015. Setting value-based payment goals - HHS efforts to improve U.S. health care. *New England Journal of Medicine* 372, 10 (3 2015), 897–899. DOI: <http://dx.doi.org/10.1056/NEJMp1500445>
- [7] Rachel Clarke, Peter Wright, Madeline Balaam, and John McCarthy. 2013. Digital portraits: Photo-sharing after domestic violence. In *Conference on Human Factors in Computing Systems - Proceedings*. ACM, 2517–2526. DOI: <http://dx.doi.org/10.1145/2470654.2481348>
- [8] Sasha Costanza-Chock. 2018. Design Justice: towards an intersectional feminist framework for design theory and practice. *DRS2018: Catalyst 2* (2018). DOI: <http://dx.doi.org/10.21606/drs.2018.679>
- [9] Clara Crivellaro, Lizzie Coles-Kemp, Alan Dix, and Ann Light. 2019. Not-equal: Democratizing research in digital innovation for social justice. *Interactions* 26, 2 (2019), 70–73. DOI: <http://dx.doi.org/10.1145/3301655>
- [10] Brian DeRenzi, Leah Findlater, Jonathan Payne, Benjamin Birnbaum, Joachim Mangilima, Tapan Parikh, Gaetano Borriello, and Neal Lesh. 2012. Improving community health worker performance through automated SMS. In *ACM International Conference Proceeding Series*. ACM, 25–34. DOI: <http://dx.doi.org/10.1145/2160673.2160677>
- [11] Brian Derenzi, Jeremy Wacksman, Nicola Dell, Neal Lesh, Scott Lee, Gaetano Borriello, and Andrew Ellner. 2016. Closing the feedback loop: A 12-month evaluation of ASTA, a self-tracking application for ASHAs. In *ACM International Conference Proceeding Series*, Vol. 03-06-June. ACM, 22. DOI: <http://dx.doi.org/10.1145/2909609.2909652>
- [12] Pooja M. Desai, Matthew E. Levine, David J. Albers, and Lena Mamykina. 2018. Pictures worth a thousand words: Reflections on visualizing personal blood glucose forecasts for individuals with Type 2 Diabetes. In *Conference on Human Factors in Computing Systems - Proceedings (CHI '18)*, Vol. 2018-April. ACM, New York, NY, USA, 538:1–538:13. DOI: <http://dx.doi.org/10.1145/3173574.3174112>
- [13] Tawanna R. Dillahunt, Vaishnav Kameswaran, Desiree McLain, Minnie Lester, Delores Orr, and Kentaro Toyama. 2018. Entrepreneurship and the socio-technical chasm in a lean economy. In *Conference on Human Factors in Computing Systems - Proceedings*, Vol. 2018-April. ACM, 240. DOI: <http://dx.doi.org/10.1145/3173574.3173814>
- [14] Tawanna R. Dillahunt and Alex Lu. 2019. Dreamgigs: Designing a Tool to Empower Low-resource Job Seekers. In *Conference on Human Factors in Computing Systems - Proceedings*. ACM, 578. DOI: <http://dx.doi.org/10.1145/3290605.3300808>
- [15] Tawanna R. Dillahunt and Tiffany C. Veinot. 2018. Getting there: Barriers and facilitators to transportation access in underserved communities. *ACM Transactions on Computer-Human Interaction* 25, 5 (2018), 29. DOI: <http://dx.doi.org/10.1145/3233985>
- [16] Lynn Dombrowski, Adriana Alvarado Garcia, and Jessica Despard. 2017. Low-wage precarious workers' sociotechnical practices working towards addressing wage theft. In *Conference on Human Factors in Computing Systems - Proceedings*, Vol. 2017-May. 4585–4598. DOI: <http://dx.doi.org/10.1145/3025453.3025633>
- [17] Lynn Dombrowski, Ellie Harmon, and Sarah Fox. 2016. Social justice-oriented interaction design: Outlining key design strategies and commitments. In *DIS 2016 - Proceedings of the 2016 ACM Conference on Designing Interactive Systems: Fuse*. ACM, 656–671. DOI: <http://dx.doi.org/10.1145/2901790.2901861>
- [18] Anthony Dunne and Fiona Raby. 2013. *Speculative Everything Chapter Five*. https://mycourses.aalto.fi/pluginfile.php/40001/course/section/15792/Dunne_Raby_Methodological_Physical.pdf
- [19] Sheena Erete, Aarti Israni, and Tawanna Dillahunt. 2018. An intersectional approach to designing in the margins. *Interactions* 25, 3 (5 2018), 66–69. DOI: <http://dx.doi.org/10.1145/3194349>
- [20] Jordan Eschler and Wanda Pratt. 2017. "I'm so glad i met you": Designing dynamic collaborative support for young adult cancer survivors. In *Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW (CSCW '17)*. ACM, New York, NY, USA, 1763–1774. DOI: <http://dx.doi.org/10.1145/2998181.2998326>

- [21] Diana Freed, Jackeline Palmer, Diana Minchala, Karen Levy, Thomas Ristenpart, and Nicola Dell. 2018. "A stalker's paradise": How intimate partner abusers exploit technology. In *Conference on Human Factors in Computing Systems - Proceedings*, Vol. 2018-April. ACM, 667. DOI: <http://dx.doi.org/10.1145/3173574.3174241>
- [22] Mareike Glöss, Moira McGregor, and Barry Brown. 2016. Designing for labour: Uber and the on-demand mobile workforce. In *Conference on Human Factors in Computing Systems - Proceedings*. 1632–1643. DOI: <http://dx.doi.org/10.1145/2858036.2858476>
- [23] Christina N. Harrington, Sheena Erete, and Anne Marie Piper. 2019. Deconstructing community-based collaborative design: Towards more equitable participatory design engagements. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW (11 2019). DOI: <http://dx.doi.org/10.1145/3359318>
- [24] Lilly Irani, Janet Vertesi, Paul Dourish, Kavita Philip, and Rebecca E. Grinter. 2010. Postcolonial computing: A lens on design and development. In *Conference on Human Factors in Computing Systems - Proceedings*, Vol. 2. ACM Press, New York, New York, USA, 1311–1320. DOI: <http://dx.doi.org/10.1145/1753326.1753522>
- [25] Lilly C. Irani and M. Six Silberman. 2013. Turkopticon: Interrupting worker invisibility in Amazon Mechanical Turk. In *Conference on Human Factors in Computing Systems - Proceedings*. 611–620. DOI: <http://dx.doi.org/10.1145/2470654.2470742>
- [26] Maia Jacobs, James Clawson, and Elizabeth D. Mynatt. 2014. Cancer navigation: Opportunities and challenges for facilitating the breast cancer journey. In *Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW (CSCW '14)*. ACM, New York, NY, USA, 1467–1478. DOI: <http://dx.doi.org/10.1145/2531602.2531645>
- [27] Vaishnav Kameswaran, Lindsey Cameron, and Tawanna R. Dillahunt. 2018. Support for social and cultural capital development in real-time ridesharing services. In *Conference on Human Factors in Computing Systems - Proceedings*, Vol. 2018-April. ACM, 342. DOI: <http://dx.doi.org/10.1145/3173574.3173916>
- [28] Neha Kumar, Nassim Jafarainaimi, and Mehrab Bin Morshed. 2018. Uber in Bangladesh: The tangled web of mobility and justice. *Proceedings of the ACM on Human-Computer Interaction* 2, CSCW (11 2018), 1–21. DOI: <http://dx.doi.org/10.1145/3274367>
- [29] Richard E. Ladner. 2015. Design for user empowerment. *Interactions* 22, 2 (3 2015), 24–29. DOI: <http://dx.doi.org/10.1145/2723869>
- [30] Mars Lan, Lauren Samy, Nabil Alshurafa, Myung Kyung Suh, Hassan Ghasemzadeh, Aurelia MacAbasco-O'Connell, and Majid Sarrafzadeh. 2012. WANDA: An end-to-end remote health monitoring and analytics system for heart failure patients. In *Proceedings - Wireless Health 2012, WH 2012 (WH '12)*. ACM, New York, NY, USA, 9:1–9:8. DOI: <http://dx.doi.org/10.1145/2448096.2448105>
- [31] Adrienne Lapidos, Jeremy Lapedis, and Michele Heisler. 2019. Realizing the value of community health workers - New opportunities for sustainable financing. (5 2019). DOI: <http://dx.doi.org/10.1056/NEJMp1815382>
- [32] Hung Chi Lee, Ya Fang Cheng, Szu Yang Cho, Hsien Hui Tang, Jane Yung Jen Hsu, and Chien Hsiung Chen. 2014. Picgo: Designing reminiscence and storytelling for the elderly with photo annotation. In *Proceedings of the Conference on Designing Interactive Systems: Processes, Practices, Methods, and Techniques, DIS (DIS Companion '14)*. ACM, New York, NY, USA, 9–12. DOI: <http://dx.doi.org/10.1145/2598784.2602769>
- [33] Karen E C Levy. 2015. The contexts of control: Information, power, and truck-driving work. *The Information Society* 31, 2 (2015), 160–174.
- [34] Ann Light. 2011. HCI as heterodoxy: Technologies of identity and the queering of interaction with computers. *Interacting with Computers* 23, 5 (9 2011), 430–438. DOI: <http://dx.doi.org/10.1016/j.intcom.2011.02.002>
- [35] Birgitta Lindberg, Carina Nilsson, Daniel Zotterman, Siv Söderberg, and Lisa Skär. 2013. Using information and communication technology in home care for communication between patients, family members, and healthcare professionals: A systematic review. In *International Journal of Telemedicine and Applications*, Vol. 2013. ACM Press, New York, New York, USA, 1–7. DOI: <http://dx.doi.org/10.1155/2013/461829>
- [36] Joseph Lindley and Paul Coulton. 2015. Back to the future: 10 years of design fiction. *ACM International Conference Proceeding Series* (2015), 210–211. DOI: <http://dx.doi.org/10.1145/2783446.2783592>
- [37] Joseph Lindley and Paul Coulton. 2016. Pushing the limits of design fiction: The case for fictional research papers. *Conference on Human Factors in Computing Systems - Proceedings* (2016), 4032–4043. DOI: <http://dx.doi.org/10.1145/2858036.2858446>
- [38] Ahmad S. Manshad, Muhanad S. Manshad, and Sara S. Manshad. 2017. Real-time activity-sensitive wearable ankle edema monitoring system for elderly and visually impaired heart failure patients. In *ASSETS 2017 - Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '17)*. ACM, New York, NY, USA, 391–392. DOI: <http://dx.doi.org/10.1145/3132525.3134792>
- [39] Elizabeth B. Marquis, Sangmi Kim, Rasha Alahmad, Casey S. Pierce, and Lionel P. Robert. 2018. Impacts of perceived behavior control and emotional labor on gig workers. In *Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW*. Association for Computing Machinery, 241–244. DOI: <http://dx.doi.org/10.1145/3272973.3274065>

- [40] Dalton Mayfield, Aida Garcia, Patricia Smith, Stephen O. Joseph, Maria Castaneda, William Kee, and Isaac Nortey. 2017. 1199SEIU 2017 Annual Report. (2017). http://www.1199federalcu.org/PDFs/2018_06_AnnualReport_2017.pdf
- [41] Maletsabisa Molapo, Melissa Densmore, and Limpho Morie. 2016. Apps and skits: Enabling new forms of village-to-clinic feedback for rural health education. In *Proceedings of the 7th Annual Symposium on Computing for Development, ACM DEV-7 2016 (ACM DEV '16)*. ACM, New York, NY, USA, 10:1–10:10. DOI: <http://dx.doi.org/10.1145/3001913.3001922>
- [42] Stephanie A. Morey, Laura H. Barg-Walkow, and Wendy A. Rogers. 2017. Managing heart failure on the Go: Usability issues with mHealth apps for older adults. In *Proceedings of the Human Factors and Ergonomics Society*, Vol. 2017-Octob. SAGE Publications Sage CA: Los Angeles, CA, 1–5. DOI: <http://dx.doi.org/10.1177/1541931213601496>
- [43] Aisling Ann O’Kane, Yvonne Rogers, and Ann E. Blandford. 2015. Concealing or revealing mobile medical devices? Designing for onstage and offstage presentation. In *Conference on Human Factors in Computing Systems - Proceedings (CHI '15)*, Vol. 2015-April. ACM, New York, NY, USA, 1689–1698. DOI: <http://dx.doi.org/10.1145/2702123.2702453>
- [44] Fabian Okeke, Emily Tseng, Benedetta Piantella, Mikaela Brown, Harveen Kaur, Madeline R. Sterling, and Nicola Dell. 2019. Technology, home health care, and heart failure: A qualitative analysis with multiple stakeholders. In *COMPASS 2019 - Proceedings of the 2019 Conference on Computing and Sustainable Societies*. ACM Press, New York, New York, USA, 122–133. DOI: <http://dx.doi.org/10.1145/3314344.3332487>
- [45] Julie L. Ozanne, Anselm Strauss, and Juliet Corbin. 1992. *Basics of Qualitative Research*. Vol. 29. Sage publications. 382 pages. DOI: <http://dx.doi.org/10.2307/3172751>
- [46] Andrea Grimes Parker. 2013. Designing for health activism. *Interactions* 20, 2 (2013), 22–25. DOI: <http://dx.doi.org/10.1145/2427076.2427082>
- [47] Andrea G. Parker, Vasudhara Kantroo, Hee Rin Lee, Miguel Osornio, Mansi Sharma, and Rebecca E. Grinter. 2012. Health promotion as activism: Building community capacity to effect social change. In *Conference on Human Factors in Computing Systems - Proceedings*. ACM, 99–108. DOI: <http://dx.doi.org/10.1145/2207676.2207692>
- [48] Andrea G. Parker, Herman Saksono, Jessica A. Hoffman, and Carmen Castaneda-Sceppa. 2018. A Community Health Orientation for Wellness Technology Design & Delivery. In *Designing Healthcare That Works: A Sociotechnical Approach*. Elsevier, 59–76. DOI: <http://dx.doi.org/10.1016/B978-0-12-812583-0.00004-3>
- [49] Trevor Perrier, Nicola Dell, Brian Derenzi, Richard Anderson, John Kinuthia, Jennifer Unger, and Grace John-Stewart. 2015. Engaging pregnant women in Kenya with a hybrid computer-human SMS communication system. In *Conference on Human Factors in Computing Systems - Proceedings (CHI '15)*, Vol. 2015-April. ACM, New York, NY, USA, 1429–1438. DOI: <http://dx.doi.org/10.1145/2702123.2702124>
- [50] David Pinelle and Carl Gutwin. 2001. *Collaboration Requirements for Home Care*. Technical Report HCI-01-01. Department of Computer Science, University of Saskatchewan. 1–16 pages.
- [51] Shantanu Prabhat, Sneha Nanavati, and Nimmi Rangaswamy. 2019. India’s "uberwallah": Profiling Uber drivers in the gig economy. In *ACM International Conference Proceeding Series*. Association for Computing Machinery. DOI: <http://dx.doi.org/10.1145/3287098.3287139>
- [52] Noopur Raval and Paul Dourish. 2016. Standing out from the crowd: Emotional labor, body labor, and temporal labor in ridesharing. In *Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW*, Vol. 27. 97–107. DOI: <http://dx.doi.org/10.1145/2818048.2820026>
- [53] Madeline R. Sterling, Amy L. Shaw, Peggy B.K. Leung, Monika M. Safford, Christine D. Jones, Emma K. Tsui, and Diana Delgado. 2018a. Home care workers in heart failure: A systematic review. (2018). DOI: <http://dx.doi.org/10.2147/JMDH.S175512>
- [54] Madeline R. Sterling, Ariel F. Silva, Peggy B.K. Leung, Amy L. Shaw, Emma K. Tsui, Christine D. Jones, Laura Robbins, Yanira Escamilla, Ann Lee, Faith Wiggins, Frances Sadler, Martin F. Shapiro, Mary E. Charlson, Lisa M. Kern, and Monika M. Safford. 2018b. “It’s like they forget that the word ‘Health’ is in ‘Home health aide’”: Understanding the perspectives of home care workers who care for adults with heart failure. *Journal of the American Heart Association* 7, 23 (2018), e010134. DOI: <http://dx.doi.org/10.1161/JAHA.118.010134>
- [55] Anna Vallgård, Erik Grönvall, and Jonas Fritsch. 2017. Experimental engineering: Articulating and valuing design experimentation. In *DIS 2017 Companion - Proceedings of the 2017 ACM Conference on Designing Interactive Systems*. Association for Computing Machinery, Inc, 197–201. DOI: <http://dx.doi.org/10.1145/3064857.3079145>
- [56] Tiffany C. Veinot, Jessica S. Ancker, Heather Cole-Lewis, Elizabeth D. Mynatt, Andrea G. Parker, Katie A. Siek, and Lena Mamykina. 2019. Leveling Up: On the Potential of Upstream Health Informatics Interventions to Enhance Health Equity. *Medical Care* 57 (2019), S108–S114. DOI: <http://dx.doi.org/10.1097/MLR.0000000000001032>

- [57] Kevin Winoto, Piao Chen, Yongfu Wang, and Pinata Winoto. 2018. MeTAP - A personalized spatial memory training for improving functional autonomy of adults with mild cognitive impairments in China. In *DIS 2018 - Companion Publication of the 2018 Designing Interactive Systems Conference (DIS '18 Companion)*. ACM, New York, NY, USA, 249–252. DOI: <http://dx.doi.org/10.1145/3197391.3205444>
- [58] Jill Palzkill Woelfer, Amy Iverson, David G. Hendry, Batya Friedman, and Brian T. Gill. 2011. Improving the safety of homeless young people with mobile phones: Values, form and function. In *Conference on Human Factors in Computing Systems - Proceedings*. ACM, 1707–1716. DOI: <http://dx.doi.org/10.1145/1978942.1979191>
- [59] Naomi Yamashita, Hideaki Kuzuoka, Keiji Hirata, Takashi Kudo, Eiji Aramaki, and Kazuki Hattori. 2017. Changing moods: How manual tracking by family caregivers improves caring and family communication. In *Conference on Human Factors in Computing Systems - Proceedings (CHI '17)*, Vol. 2017-May. ACM, New York, NY, USA, 158–169. DOI: <http://dx.doi.org/10.1145/3025453.3025843>
- [60] Naomi Yamashita, Hideaki Kuzuoka, Takashi Kudo, Keiji Hirata, Eiji Aramaki, and Kazuki Hattori. 2018. How information sharing about care recipients by family caregivers impacts family communication. In *Conference on Human Factors in Computing Systems - Proceedings (CHI '18)*, Vol. 2018-April. ACM, New York, NY, USA, 222:1–222:13. DOI: <http://dx.doi.org/10.1145/3173574.3173796>
- [61] Rachael B. Zuckerman, Karen E. Joynt Maddox, Steven H. Sheingold, Lena M. Chen, and Arnold M. Epstein. 2017. Effect of a hospital-wide measure on the readmissions reduction program. *New England Journal of Medicine* 377, 16 (10 2017), 1551–1558. DOI: <http://dx.doi.org/10.1056/NEJMs1701791>