Technology, Home Health Care, and Heart Failure: A Qualitative Analysis with Multiple Stakeholders

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ABSTRACT

Home health aides (HHAs) increasingly being used by adults with heart failure for long-term assistance and post-hospitalization care. Despite being heavily involved in numerous aspects of heart failure management, most HHAs have not received heart failure training. They also struggle to get in touch with supervising nurses or other members of the care team when they have clinical questions, which may result in unnecessary visits to the emergency room. In addition, despite serving as a backbone in the health system for patients, HHAs, who are mostly women and minorities, are a marginalized and vulnerable group of frontline caregivers, enduring erratic employment, low wages, discrimination, and high levels of burnout. Although digital technologies could help to address many of the challenges HHAs face, little is known about the current impact of technology on HHAs work practices. To this end, we conducted a multi-stakeholder qualitative study with 38 participants in New York City using semi-structured interviews and focus groups. We uncover the ways in which technology is used, the complex socio-technical factors that underpin heart failure care, and stakeholder suggestions for how technology could improve HHAs work. Building on these insights, we synthesize design opportunities for researchers and designers interested in developing tools that support the delivery of home health care for patients suffering from life-threatening diseases like heart failure.

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1 INTRODUCTION

Home health aides (HHAs) are an important group of frontline health workers and one of the fastest-growing sectors of the US workforce and healthcare industry [49, 56]. There are currently two million HHAs in the U.S. [7] and, between 2014 and 2024, HHAs will add more jobs to the US economy than any other occupation [7, 23]. Largely employed by agencies receiving public funding (Medicare and Medicaid), HHAs care for 48 million Americans and account for 74 billion dollars of healthcare spending per year [49]. Prior work shows that HHAs work in patients' homes, helping them to manage a wide range of chronic diseases and navigate the healthcare system [3, 11, 18]. In particular, many HHAs provide long-term assistance and post-hospitalization care for adults with heart failure [27, 28, 40].

Caring for patients with heart failure is a pressing concern. In 2013, heart failure became the leading cause of hospitalization in the US and Europe [1]. In the US, there are one million heart failure-related hospitalizations per year and 25% of patients are readmitted within 30 days [9, 26, 33]. Frequent re-hospitalization contributes to patient morbidity and mortality, and also financially impacts hospitals since, beyond the cost of the hospital visits themselves, under value-based healthcare reform in the US, hospitals now incur additional financial penalties for 30-day patient readmissions [19].

HHAs may represent an important but untapped opportunity to improve patient outcomes, such as reducing re-hospitalizations in heart failure. Unlike physicians or visiting nurses, HHAs are with patients and in their homes on a near-daily basis, up to 24 hours a day, which gives them a unique vantage point from which to observe, assist, and advise. They are often central in the lives of their patients, assisting with meal preparation, medication compliance, physical activity, symptom management, attending medical appointments, and more [3, 22, 57].

Yet, to date, they have not been the focus of research in heart failure or interventions to improve patient outcomes [55]. They do not receive educational resources to help them learn about heart failure [50, 54], and struggle to reach their supervising nurses and patients' doctors when patients are symptomatic and they need clinical help [54]. Beyond the difficulties they face in providing care to heart failure patients, HHAs are themselves a vulnerable

and marginalized workforce. Although one of the fastest growing sectors of the healthcare industry, HHAs, who are often women and minorities, endure erratic employment, low wages, discrimination on the job, and high levels of burnout [5, 27, 28]. Indeed, prior work has characterized the home care workforce as "*invisible*", "*ubiquitous*", and "*continually undervalued*" [57].

We hypothesize that digital technologies have the potential to address some of the educational, communication, and equity challenges that HHAs face, thereby improving healthcare delivery for heart failure patients as well as the sustainability of the US healthcare system more broadly. However, little is currently known about if or how technology currently impacts HHAs' work practices as they care for heart failure patients in the home. To this end, we contribute a multi-stakeholder qualitative analysis with 38 participants that examines the role of technology in HHAs' care of heart failure patients in New York City (NYC). Through 17 semi-structured interviews and seven focus groups, we sought to understand how technology is used, why it is used in the way it is, particularly in the context of existing organizational rules and infrastructures, and how stakeholders feel technology could better serve them. Although HHAs were our target users, we gathered the views of multiple groups of stakeholders to provide a rich and balanced perspective of how technology is integrated into day-to-day activities.

Our findings show that when a HHA begins working with a heart failure patient, they become part of a complex set of socio-technical systems, digital and non-digital, that enable them to deliver care. The HHA begins by working with a nurse to derive a set of tasks that should be performed for the patient and that are recorded on a paper-based care plan that remains in the patient's home. Any tasks that HHAs accomplish while working with a patient are then reported at the end of their shift by calling into a telephonic punch-code task reporting system using the patient's in-home telephone. These paper care plans and telephonic punch code systems constitute the entirety of the tools purpose-built to support HHAs' work. However, to fill in the gaps between these tools and the complex needs of modern home care, HHAs in our study reported using their personal mobile devices for a range of activities (despite patient privacy concerns) including incident reporting, calling emergency services, searching the Internet for information, and recording and storing patient information necessary for care.

We discuss the ways in which these existing socio-technical systems challenge or disadvantage HHAs in their work by systemically deprioritizing their needs and perspectives. For example, we show existing information systems focus primarily on monitoring HHAs rather than providing tools to support their work. Compounding this is a lack of integration between home care and medical teams, as well as a lack of investment in sustainable information architectures. In light of these challenges, our participants shared their ideas for how technology could be used to better serve HHAs' needs, such as revising the task recording system to become more flexible and dynamic, enabling better communication between care teams, and enhancing agency management systems. We conclude by synthesizing a set of concrete design opportunities for HCI researchers, system designers, and medical researchers interested in developing technologies that support the delivery of home health care for patients suffering from life-threatening diseases like heart failure.

2 RELATED WORK

Technology and Heart Failure Management

Prior work explores the use of technology for heart failure management, including tools for monitoring physiological symptoms [35, 41, 51]. In the medical literature, researchers have explored how technology broadly supports home care support. Cipriano et al. [10] described recommendations for designing technologies that support collecting, analyzing and sharing information with providers, patients and caregivers. Matthew-Maich et al. [42] performed a scoping review of mobile technologies for managing chronic conditions, including heart failure, and pointed out the limited use of technologies in homes. Morey et al. [45] looked at the challenges of common mHealth apps designed to manage congestive heart failure and highlighted design issues that limit usability.

However, this prior research on heart failure management has focused on tools that facilitate interactions with doctors, nurses, and patients – not paid HHAs. A systematic review found only six out of 7,032 studies focused on HHAs, revealing that this workforce has largely been neglected in research and interventions around heart failure [55]. This work also showed that HHAs feel overworked and undervalued, experience a myriad of challenges caring for heart failure patients, and find heart failure management to be frightening and unpredictable because it involves life-and-death situations [55].

Informal Caregiving for Chronic Diseases

Beyond heart failure, a substantial amount of HCI research has examined the management of chronic diseases such as diabetes [14, 16, 47], dementia [37, 61], cancer [17, 25], and more. Interest in chronic disease management has grown with increasing attentiveness to post-hospitalization and long-term assistance provided through informal caregiving (i.e., caregiving by patients' family members). For example, Kaziunas et al. [31] studied the interconnections between information and emotion work performed by parents as caregivers. Schorch et al. [52] gathered data from observations, interviews and cultural probes to gain a better understanding of the practices of relatives as caregivers. In their qualitative research on family caregivers and patients with multiple chronic diseases, Lim et al. [38] combined interviews, photo elicitation, and home tours to explore the design of socio-technical tools that improve patient-provider communication. More recently, HCI researchers have begun to explore how technologies could play a role in these efforts. Yamashita et al. [62, 63] explored the use of tracking technologies to assist family caregivers caring for depressed patients. Nunes et al. [46] performed a systematic review to understand how patients and carers use self-care technologies.

However, most HCI research on caregiving has focused only on informal caregiving by family members, with little attention on formal, paid caregiving. Our paper expands this body of work on caregiving by providing an in-depth analysis of how formal, paid HHAs use technology to care for adults with heart failure.

Health Services by Frontline Workers

The global impact of frontline workers delivering health services to hard-to-reach communities has been well studied across diverse contexts and communities [4, 8, 12, 48]. Many health programs focused on improving the health of underserved populations

Category	Count	Gender	Age Range	Responsibilities
All participants	38	M(4), W(32), UR(2)	30-90	—
Agency leaders	10	M(2), W(8)	40-60	Oversee and work to improve care at the agency level
Care coordinators	1	M(1)	40-50	Supervise and manage HHAs' work on a daily basis
Family caregivers	2	UR (2)	UR	Support HHAs in caring for their loved ones
Home health aide (HHA)	12	W(12)	UR	Provide home care to patients
Patients	4	W(4)	70-90	Adults with heart failure provided with an HHA
Physicians	2	M(1), W(1)	30-50	Care for patients prior to discharging them to home care
Nurses	6	W(6)	40-60	Occasionally visit patients' homes to perform hands-on care
Social workers	1	W(1)	30-40	Work to ensure patients have a smooth home care experience

Table 1: Participant demographic characteristics and responsibilities (M: man, W: woman, UR: unreported).

increasingly rely on frontline workers, particularly in low- and middle-income countries, because these paraprofessionals can positively cause behavior change and reduce neonatal mortality rates [4, 34]. As such, a number of tools have been designed to support frontline workers in community health programs to achieve their health objectives. For example, researchers have designed automated SMS systems to boost engagement in community health programs [13, 48]. DeRenzi et al. [12] created a personalized feedback system for frontline workers in India that led to more than 20% increase in the average number of client visits performed by each worker. In addition, researchers have explored diverse techniques for collecting useful feedback from users when exploring the design space of tools for frontline workers and community health programs. These techniques include adopting dramatic story lines [8], role playing with skits [44], and exposing people to their neighbors' critical feedback to persuade them to act similarly [59].

However, this prior work has primarily focused on community health programs in low- and middle-income countries, with little HCI research examining community health programs in so-called "developed" or resource-rich regions (such as HHAs in New York City). Outside of HCI, a growing number of studies in the medical literature have showed that interventions by frontline health workers in resource-rich locations (e.g. the United States) can improve the health outcomes of underserved populations [24, 30, 39, 60].

Our paper extends prior research with an empirical study of how paid, formal caregivers (HHAs), who are themselves a marginalized and vulnerable workforce, use technology in their day-to-day work caring for adults with heart failure. Our study yields rich insights and design recommendations for researchers and system designers interested in creating technical tools to aid the management of heart failure and potentially other chronic diseases.

3 METHODOLOGY

Our research took place in New York City (NYC) over a six-month period in 2018. We worked with 38 participants from 8 stakeholder groups (see Table 1). Before beginning our research, we received IRB approval for all study procedures.

Recruitment and Participants

We recruited participants through snowball sampling and direct outreach to home care organizations. Patients and family caregivers were recruited from internal medicine and geriatric practices in NYC. Participants were interviewed either in person or by telephone. All participants provided verbal or written consent to record the interview with the assurance of strict anonymity. HHAs, patients, and nurses received compensation in the form of a $25 gift card. As Table 1 shows, participants ranged from 30 to 90 years old.

Qualitative Methods

We conducted seven focus groups with 21 participants in groups of two to eight people including groups of nurses, HHAs, and agency leaders. We also conducted 17 semi-structured interviews with a nurse, a social worker, a care coordinator, several physicians, patients, agency leaders, and family caregivers. All focus groups and interviews were conducted in English and lasted for 30-60 minutes. The focus groups and interviews were structured around a set of high-level topics and tailored to each participant group. We asked participants about the routines of HHAs during home visits, how patient data was collected, how a patient's health status was shared with health practitioners, and the challenges participants encountered around technology. In total, our dataset consisted of about five hours of focus groups and 11 hours of interviews.

Data Analysis

We audio-recorded and transcribed our interviews and focus groups. We analyzed the data thematically [58], beginning with a close reading of the transcripts and allowing codes to emerge from the data. Multiple passes through the data resulted in 37 distinct codes (e.g., *frequency of communication*, *desired feature*, and *challenges with data*). We clustered related codes into high-level themes (e.g., *desired usage*, *privacy*, and *lack of team integration*) and organized them in a codebook. After multiple discussions and iteratively refining the codes and themes, the research team arrived at a final set of themes that comprehensively represented the data.

4 FINDINGS

We begin by describing how technology is currently used in HHAs' care of adults with heart failure. We then highlight specific mechanisms through which the current ecosystem systematically deprioritizes HHAs' needs and perspectives. Finally, we detail participants' suggestions for how their ecosystems could be improved.

4.1 The Technology Ecosystem in Home Care

Our research shows that from the moment a HHA begins working with a patient, they are tied into an ecosystem of technologies, digital and non-digital, that enable them to deliver care. Complex and uncoordinated, this ecosystem centers around four core tools: 1) the paper care plan; 2) the telephonic punch-code task reporting system; 3) the HHA's personal mobile device; and 4) the call chain for incident reporting. While our participants described all of these tools as central and commonplace in HHAs' work, our analysis shows that when the first two tools fail to meet HHAs' needs, HHAs turn to the last two tools.

Paper care plans for understanding tasks

Our analysis revealed that HHAs begin their work by referring to a patient's care plan, a guide for how the HHA should assist with the patient's personal and medical care. Written by a visiting nurse early in a patient's episode of home care, the care plan contains such details as emergency phone numbers and a list of tasks the HHA should perform for the patient each shift. While care plans can be updated upon a follow-up visit from a nurse, they can also remain the same for long periods of time.

We heard how this critical document is typically provided on paper, and displayed prominently in the patient's home (i.e. on the refrigerator) so that multiple aides can have access to it. Because they intentionally omit information pertaining to a patient's diagnosis and medical history (due to privacy laws we discuss in a later section), care plans were cited by many stakeholders in our study as a significant source of HHAs' frustration and confusion. Both nurse and HHA participants said care plans were not individualized or specific enough to help aides understand when a given task was disease-related. One nurse participant was also frustrated by the convention of fitting care plans onto one page: *"You can't even read the print because it's so small"* (P1, Female, Nurse).

Telephonic punch-codes for recording tasks

Our participants shared that once a HHA has referred to a patient's care plan, they settle into a daily rhythm of arriving at the patient's home, performing the outlined tasks, and leaving at the end of the shift. Throughout this routine, the HHA's work is tracked and mediated through the mandatory use of a commercially available telephonic punch-code system.

We learned that, at the start of each shift, agencies require HHAs to use their patient's home phone to call into a provided telephone number and follow a series of automated voice prompts to "*clock in*". In the event that a HHA calls in from their own personal phone, agency coordinators are to follow up with a call to the patient's phone to confirm whether the HHA is on-site. These procedures, participants explained, are to verify that the HHA is in fact with the patient at the time of clock-in.

Participants explained that at the end of each shift, HHAs are required to call into the system again to *"clock out"*, again using their patient's phone. During these calls, HHAs are to report all the activities they performed during their shift by entering a series of numeric codes corresponding to specific actions. A mapping of actions to codes is provided on the patient's care plan. For example, if a HHA prepared a meal for a patient, this task is looked up on the care plan, and the corresponding number, *58*, is punched in response to an automated prompt. Agencies use these records to confirm which tasks HHAs performed during their shift, to understand patients' conditions, and to bill a patient's payer accordingly.

Personal mobile devices for filling in the gaps

The combination of paper care plans and telephonic punch codes constitutes the entirety of the tools purpose-built to support HHAs' care work. However, we discovered how, to fill in the gaps between these tools and the complex needs of modern home care, HHAs in our study use their personal mobile devices for a range of activities. These activities fall into four buckets: (1) reporting incidents and general communication with agency coordinators; (2) calling emergency services; (3) searching the Internet for more information; and (4) recording and storing patient information necessary for care.

First and foremost, participants described HHAs using their personal devices to communicate with their agency coordinators via phone call, photo or video message, or text. It is especially important for HHAs to immediately contact coordinators to **report incidents** like patient falls, sudden weight gain, and more. Upon receipt of an incident report, coordinators are to assess the situation, advise the HHA, and reach out to additional resources if necessary.

Phone cameras in particular were described as a valuable tool for communicating around tasks that were difficult to describe in words like open wound care and cleaning. These tools were especially useful in such contexts:

> *"We had another client that actually got stuck in her bed and they kept trying... The aide kept trying to explain to us how she was stuck in the bed and I was like I don't get it. This lady, how did she get stuck? So they sent over a picture with the name of the bed. We got her another replacement and she did not go to the ER. So it was pretty powerful."* (P1, Female, Nurse)

In cases that might constitute emergencies rather than incidents, HHAs also use their personal phones to **directly call 911**. This impulse is especially strong for heart failure patients, participants described, because the unpredictable nature of the disease means HHAs are sometimes afraid they will be held responsible if a patient is to quickly deteriorate. One participant explained,

> *"The party line was always call 911. I think that call 911 came out of a place of fear that if we don't call 911, what is the impact of doing that?"* (P1, Female, Nurse)

Outside of communication, participants also described HHAs using their smartphones and other personal mobile devices to **conduct general Internet searches** for information relevant to their day-to-day. One nurse called Google search *"my best friend"*, and said she used it to look up more information on health conditions, map directions to patients' homes, and more.

Finally, our data shows HHAs use their personal devices to **record and store patient information**, often in violation of agency policy. HHAs report storing lists of patient medications on their phones for easy access at the pharmacy or at a patient's doctors appointment. One participant mentioned a prior incident in which she had suspected domestic violence at a client site and used her personal device to capture photographic evidence of bruises on her patient's face, in case they became relevant later on. In all cases,

participants acknowledged privacy was a concern, but did not report using additional security measures on their personal devices to account for the sensitivity of the information.

Call chain for escalating reports

As discussed above, reporting incidents to agency coordinators is a common practice for HHAs in the field. Our data shows the initial call placed from a HHAs' mobile phone kickstarts a long and complicated call chain process intended to escalate incidents to the appropriate clinical authorities.

We learned that HHAs were to share incident reports by immediately calling their agency coordinators. Then, if needed, the agency was to reach out to an on-call agency nurse. If the on-call nurse needed another opinion, he or she would reach out to the agency nurse who had put together the patient's initial care plan, or attempt to reach either the patient's primary medical doctor or the physician who had overseen their discharge. Ultimately, someone from the patient's clinical team would follow up with either a phone call or a visit to the patient's home to triage. We note that this entire process could take anywhere from hours to days.

4.2 Barriers in the Workflow of Patient Care

Having established a clear picture of the tools HHAs use in their day-to-day, we move to understanding the ways in which these technology ecosystems challenge or disadvantage aides in their work. Our analysis shows these ecosystems are currently systemically deprioritizing HHAs' needs and perspectives.

From participants' frustrations, we synthesize three key themes that explain the ways in which HHAs are disadvantaged by their tools: 1) agencies' commitments to information systems that serve as means for monitoring HHAs rather than tools to support their work; 2) the lack of integration between home care and clinical care teams; and 3) a lack of investment in sustainable information architectures. We describe each of these in turn.

Tools for monitoring, not support

Our participants described numerous undue burdens placed on HHAs by their current tools, principally the telephonic punch-code system used throughout the industry to record tasks. These frustrations, participants asserted, stemmed from the fact that the systems were built to monitor HHAs while on the job, not to support them in patient care.

Participants reported frustrations around the *utility* of the telephonic punch-code system, and its *suitability for managing complex cases*, like patients with heart failure. We were surprised to learn the system did not allow task records to be updated if entered incorrectly. As participants explained, since a patient's care plan was not liable to change very much over time, after a few days with a new patient a HHA would begin to enter the same series of numeric codes day in and day out. As the task of recording tasks itself became a matter of rote, the HHA would enter codes rapidly and sometimes make mistakes – but in such scenarios, they would continue on to the next task to be reported, because the only way to edit an erroneous entry would be to end the call, redial, and start the process all over again.

Even when they were able to correctly enter tasks, our HHAs explained they could not be certain whether their reports were successfully sent, since the system did not provide confirmation of receipt. In fact, our HHAs explained they did not trust the punch-code system, because it *"could be bugging"* and fail to deliver their daily reports to their agency.

In these scenarios, protocol dictated that HHAs' agency coordinators were to request that they submit paper timesheets, a process that would require HHAs to travel to agency offices to submit hard copies or fax them within two days of the unreported shift. HHAs who were not able to complete these submissions within the provided timeframe were not paid for their work.

We note the paper submission process is clearly onerous and places the burden of effort solely on the HHA. Nevertheless, participants described the punch-code system to be so unreliable that they carried paper timesheets around with them just in case. One reported submitting timesheets at least once a week:

> *"The system was made so long ago, it doesn't work that good. I know at least once a week I'm going to have to put in one or two [timesheets]. Sometimes I get a good week and I don't have to put in any. Last week I had to put in two."* (P34, female, HHA)

In addition to describing the punch-code system as unreliable and barely usable, HHAs also reported it was not flexible enough to capture vital information, including details relevant to heart failure care. For example, a HHA preparing a meal for a heart failure patient might want to indicate whether the meal had adhered to the low-salt diet often prescribed for heart failure recovery — but such a task could only be captured by a general *"meal preparation"* record under the predefined terms of the task recording scheme.

Lack of care team integration

Participants also described ways in which HHAs' information systems encoded a sharp divide between a patient's clinical and home care teams. We bucket these into two themes: 1) divisions due to privacy laws and 2) divisions due to the culture of medicine.

First, our analysis found that the laws and procedures governing patients' privacy played a central role in the asymmetry of HHAs' technology ecosystem. Specifically, we found that agencies' interpretations of the U.S. Health Insurance Portability and Accountability Act of 1996 (HIPAA) effectively prevented HHAs from knowing vital information about their patients. This manifested in HHAs' technology ecosystem as a systemic lack of clarity around what exactly their patients were recovering from, relegating HHAs to executing tasks without higher-level rationale.

Under HIPAA, a patient's healthcare professionals (HCPs) were permitted to receive their protected health information (PHI) from other HCPs. However, our analysis showed most agencies did not consider HHAs to be HCPs, and therefore did not always provide HHAs with vital information like a patient's diagnosis or list of medications. As one participant shared:

> *"Home health aides are invisible ... the nurse has the care plan, but because of the HIPAA Law, they [HHAs] can't be informed of certain things ... I think the home care aide is not considered as a professional. So is there any way ... can the HIPAA Law include that change right*

here, that [HHAs] are entitled to have that information?" (P4, Female, HHA)

Our multi-stakeholder analysis showed the problem began at the discharge level, when physicians and social workers handed patients off to agencies. One participant shared,

> *"The information we get on the aide side is very skimpy. The initial discharge from the hospital is like 'so and so is going home tomorrow and the pick-up time is at such and such a time.' There's very little information as to what diagnosis the patient has or what medications they are on. Really then the aides are stuck with what to do."* (P31, Female, Nurse)

The effective ban on HHAs receiving PHI had clear ramifications for the quality of care HHAs were able to provide: For instance, a HHA who knew she was caring for a patient with heart failure might emphasize hydration and low-sodium meals more than a HHA who did not. Indeed, participants agreed that the effective ban presented significant obstacles to positive patient outcomes. Social worker participants corroborated HHAs' impressions that initial discharge instructions were left intentionally vague due to HIPAA, and added that this had consequences for patient care:

> *"We work to make the safest plan possible... but because of HIPAA, it's unlikely the person who is with the patient all day ever sees this information. And then the patient comes back, gets readmitted, and the whole process starts all over again... A lot of the time they are in the ER when they don't need to be. I think if we were communicating with the person in the home, providing the care, we would be in a lot better shape in terms of improving outcomes."* (P26, Female, Social Worker)

Working with their patients in their homes day in and day out, HHAs who wanted to know what to expect from their patients' health were relegated to two workarounds: 1) hoping their patients and their families would volunteer the information or 2) inferring disease status from the care plan. Both avenues are far from foolproof, offering ample opportunity for patients and families to misinform HHAs, or for HHAs to themselves erroneously assume what patients are suffering from. We note that several of the more experienced HHAs in our study described they had over time picked up homegrown knowledge on the signs and symptoms of heart failure, and could infer with reasonable certainty when a patient was suffering from it.

We note the centrality of the paper-based care plan was particularly problematic. Participants made reference to state and local health board laws that held patients must be provided with a hard copy of their care plans. While agencies may have intended for these paper-only documents to serve as the definitive record of the tasks HHAs were to perform, our HHAs agreed that many patients hid, obscured, or altered their care plans instead, to the detriment of HHAs' ability to give proper care.

Indeed, stakeholders in our data agreed that the problem was *"deep-rooted"*, affecting agency nurses' ability to provide meaningful instructions on their care plans as well. Nurse participants shared,

> *"We walk in blind. There's a primary diagnosis that is the most recent diagnosis that the plan or the peer source is sending us. There's one ICD-10 code that's written on that authorization. And so you walk in, and maybe you thought it was all arthritis, but [you're actually] ten diagnoses later – which oftentimes you are figuring out from the medications, because the patient may not be an accurate historian. And then you have to validate that with the physician. And that doesn't happen necessarily at the point [where] you've developed the first plan of care with that first aide."* (P3, Female, Nurse)

HIPAA also impacted HHAs' technology ecosystem as an effective ban on the use of personal devices in their work for messaging, taking pictures, or otherwise handling patients' information on unsecured machines. When asked whether HHAs engaged in informal communication via consumer chat tools like WhatsApp, HHAs agreed this did not happen *"because of HIPAA"*; agency leaders also agreed blanket bans on the use of personal devices in patient care were the industry norm. As previously noted, however, HHAs in our data admitted the use of personal phones was commonplace in practice, to store patient medication lists or compile photographic evidence of patients' conditions.

Interestingly, our analysis showed that while HIPAA stipulations gave explicit legal definition to some parts of the misalignment, for example by stipulating who could have access to a patient's diagnosis, much of the entrenched asymmetry manifested in the information system was simply cultural. A coordinator said:

> *"It's not necessarily HIPAA. I think most people just feel like a lot of the medical stuff is above the home health aide, so the perception affects what they are then told."* (P29, Female, Coordinator)

Across stakeholder groups, our participants agreed that home care was undervalued by physicians, but vital to patients' compliance and eventual recovery. Indeed, our HHAs felt that even though they served as the *"eyes and ears"* of the clinical team because they spent the most time with patients, their voices were not taken into account when making clinical decisions. We heard of several cases in which doctors and nurses were unaware outright of the activities that HHAs performed during home visits. One participant shared,

> *"We've been doing this work for a long, long time and I've always believed that 'Without a good aide, you don't have a good chance'. You can quote me on that! Unfortunately, because of the way the system is set up – different nurses, seeing different doctors, aides sit outside in the doctors' office – patients are non-compliant. Physicians are just not very involved in home care at all. They don't want to be bothered. The system is fragmented and broken. It's a mess."* (P31, Female, HHA and Coordinator)

The lack of integration manifested in HHAs' technology ecosystem most clearly through the complicated call chain required for HHAs to report incidents to clinicians. Our analysis also showed it led to an overall dissatisfaction among HHAs with the demands of their data collection and reporting tasks. Specifically, participants felt a sense of disconnection in this work, as it was unclear who saw the collected data, and how or in what part the collected data was used by other stakeholders. One participant described,

> *"I think that one thing that was not clear was how [the] data was being managed. There was still a barrier with, is it going directly to the nurse, or what was ... How is it being reviewed? It's all on how the home care aide is instructed on collecting the data... Those kinds of things should be clear on how the aide is documented and the frequency of the documentation, because those things can leave room for what's not important and what is important."* (P2, Female, Nurse)

Sustaining Technology in the Home Care Environment

Our analysis also showed how many of the issues faced by HHAs in their day-to-day interactions with technology could be explained by a lagging level of investment in creating technological solutions that would be sustainable over the long term.

First, our participants were quick to point out that the telephonic punch-code system had been developed and initially deployed decades ago, in an analog technology environment. This legacy system remains in place despite advances in digital technologies in large part because the system relies on HHAs' use of patients' in-home technology infrastructure that, especially in light of the advanced age of many patients, is not guaranteed to be any more updated than analog (i.e., landline) phones.

In addition, although Internet and cellular networking has improved since, many home care contexts lack guaranteed persistent connectivity, even in New York City. One way to resolve this problem would be to set up reliable connectivity that works even in poor cellphone reception. However, agencies had attempted this approach and found the process challenging to implement. One participant explained,

> *"We're exploring external modems with data, without data. It's really cumbersome. It's an interesting thing, because if you would have gone back 10 years ago and said, oh, everybody's gonna get a tablet and be able to connect, it would be a miracle. But it's very cumbersome, and very glitchy."* (P17, Female, Agency Leader)

In addition to the technical challenge of low connectivity, our analysis found agencies also struggled with the general challenges of sustaining long-term interventions in community health. Our participants explained that the integration of new tools into existing care workflows often incurred compounding costs. For instance, uptake of a new tool in an agency required not just investing in the tools themselves, but also retraining existing HHAs to use these tools, revamping onboarding processes for new HHAs to include the tool, and establishing new protocols for continuing certification.

Participants explained the compounding costs problem was exacerbated by the transient nature of many HHAs' roles. *"Aide turnovers"* disincentivized agencies from supporting expensive workforce retraining programs, but also made HHAs themselves less likely to participate. Even those HHAs who were open to technological innovation would be reluctant, participants described, to train on a new tool for a job they planned to soon leave.

Finally, one agency leader explained that agencies struggled to deploy new technologies because they required strong partnerships with not just clinical groups but also software companies. Some technological pilots had failed in the past, agency leadership participants explained, due in part to poor collaboration between home care agencies and the software organizations involved. Participants described these partnerships as tough to build because they *"take time and trust"*.

4.3 Stakeholders' Suggestions for Technologies

Our study participants were eager to share ideas on how technology could be used to better serve HHAs' needs. From their suggestions our analysis derived three key themes: 1) revising the task recording system to become more flexible and dynamic; 2) enabling communication with clinical teams; and 3) enhancing agency management systems. We detail these in turn.

Revising the task recording system

Across roles, stakeholders in our dataset had numerous suggestions for improving the current task recording paradigm through technology. Acknowledging that a system centered on a static paper-based care plan was ill-suited for home care of heart failure in particular, participants felt the system could be revised to emphasize *flexibility* beyond the care plan schema. HHAs voiced that they often wanted to record more finely grained data on a patient's mood throughout a shift, whether there had been any changes in appetite, and other pertinent information that existing care plan-to-punch code mappings did not account for. Participants also agreed that adding richer media to task records would improve their experiences, in particular photos and videos taken with a mobile device.

In addition to expanding the schema and data types used in task records, participants saw a need to revise the entire task recording framework from a *post facto* "clock-out" procedure built for billing purposes to a dynamic "just-in-time" system built to supply HHAs with decision support at the point of need. Such a system could, for example, send a HHA tips for low-sodium cooking as he or she was preparing a meal for a patient with heart failure. This was viewed as one way to honor the clinical significance of the care plan while enabling dynamism in HHAs' experiences through technology.

Enabling communication with clinical teams

Our analysis also found that improving communication along both the HHA-agency nurse and HHA-doctor axes would be a way for technology to improve HHAs' experiences. As described previously, stakeholders agreed that HHAs needed on-call access to a verifiable clinical opinion. One participant said:

> *" 'Here's these three things, and there's gonna be a nurse on call who can answer your questions if any of these three things happen today.' The experience for the aide, and the outcome for the patient, would be changed dramatically if that could be universal."* (P5, Female, Agency leadership)

Despite widespread agreement that providing HHAs with access to clinical opinions would improve both system inefficiencies and patient care, participants across roles also agreed that a direct-access system could result in *"a fire hose of random messages"* that might overwhelm clinicians' already-stretched time. For perspective, one nurse in our research was in charge of 66 HHAs. To mitigate potential communication overload, our participants recommended a level of filtering for "urgent vs. non-urgent" issues. Clinicians

also suggested a role for technology in ensuring they were only contacted if patient metrics exceeded set thresholds. One shared:

> *"You know, if I was getting loads of info from home health aides, regularly, that would be annoying. But if it was a once in a while alert of a change, now that would be potentially quite useful. It would depend on how it was done."* (P28, Female, Physician)

Participants also agreed that direct communication tools could be difficult to implement given the previously discussed restrictions on HHA access to PHI under HIPAA. However, our analysis found stakeholders across roles appeared flexible with respect to allowing HHAs more access to patient information that would help them provide high-quality care.

In addition, HHAs had developed their own mental models for which care tasks might correspond to which conditions—for instance, mapping low-sodium diets to heart failure—and desired clear clinical education to supplement what they had learned through experience. Most tellingly, patient participants in our study described wanting HHAs to have access to their PHI in electronic form, in order to improve their quality of care. One patient participant shared:

> *"Well, give [my aide] access to my chart, and let them know what maybe thoughts are with blood work and stuff, so they have an idea what's going on with me. I want them to have access to all of that. I wouldn't want to keep it private because they're helping me to get as better as I'm going to get."* (P21, Female, Patient)

Enhancing agency management systems

Finally, our analysis showed key opportunities for technological innovation in the data management systems used at the agency level. Our agency leader participants were frustrated by the user experience of existing agency management software systems because these systems did not provide the necessary affordances for robust interaction with reported data. For example, agencies relied on a software tool that involved multiple labor-intensive steps that could have been automated. One participant explained,

> *"We're all sort of brought onto a software package, which is a piece of dreck. You know what dreck is? Dreck is garbage, that's all it is. Nothing worse than that... To give you an idea, I'm currently compiling and managing a list of all of our patients who receive Medicaid home care services. I have to update that every week by asking. There's no place for me to look."* (P17, Female, Agency Leader)

Although one could manage by hand a data system for a small set of users, this approach would not be feasible for agencies in our research context that consisted of nurses, coordinators, and hundreds of HHAs. As a result, participants desired a system that went beyond *"basic"* functionalities to provide more relevant features, for example the ability to re-organize documents for easy retrieval instead of simply uploading them. More importantly, they wanted these features available without becoming *"very glitchy, very labor-intensive."*

In addition, our participants yearned for a system that simplified the experience of assigning HHAs to patients. Recall we previously described that HHAs could work for more than one agency and that multiple HHAs could be assigned to care for a single patient. As such, it is paramount for agencies to understand the schedules and availability of patients and HHAs to successfully pair them. However, existing technological systems were lacking in this regard as they only provided a view of patients' schedules but not that of HHAs. One participant described,

> *"It's fundamentally flawed. A HHA is supposed to come in for in-service, supposed to go to get their physicals done. You can't schedule the aide when they've got that work being done, but you will never see it. It's a very clunky system, and then the work in the field is just awful... If I'm a HHA who works for two agencies … the software package doesn't differentiate between one and the other... They haven't figured it out yet."* (P16, Male, Agency Leader)

This lack of cross-agency scheduling integration for both HHAs and patients is problematic because it leads to schedule conflicts: HHAs who appear available to one agency may not be truly available because they have been assigned by other agencies to care for other patients. Unless agencies have the opportunity to *"to look at schedules in two ways"* i.e. for both HHAs and patients, the experience of assigning HHAs to patients may become increasingly unproductive with time spent rescheduling conflicts.

Agency leadership participants also voiced a need for better integration of their backend data. It was challenging, agency leadership reported, to retrieve and combine patient data recorded during home visits and hospital discharge because these data were stored in siloed storage systems. One agency found this problem so challenging that it felt data integration could not be achieved; the agency consulted a third-party company to assist but the company also struggled to accomplish this task:

> *"We have five software packages that lead to 10 disparate databases, and those databases are clunky... We actually engaged a third-party software company to come in and pull all the data out of those systems, normalize it, pull it into a data warehouse... And we had a company, a national company that said they wanted to do that and work with us and partner with us, and at the end of the day, we just heard, this past week, they just can't do it. The work effort is just too heavy a lift, they can't do it."* (P16, Male, Agency Leader)

However, data integration is complicated because it involves several non-trivial steps that individually require a lot of time and effort to accomplish. These steps include but are not limited to: tracking down all the data reporting systems used by different health institutions, gaining authorizations to access the data in these systems, understanding the format of data stored, normalizing the data to a uniform format that allows for integration, and eventually integrating the data in a digestible format for agencies to access.

In addition, participants believed that resolving the challenge of data integration could provide rich opportunities to combine data from multiple sources and gain deep insights on how to improve the quality of care provided to patients. One participant shared,

> *"The more information we gather through assessment and clinical and non-clinical documentation, we can pull into this system and then identify people that are*

> *truly at risk . . . Like if a social worker does an environmental scan on the home, and realizes something's not right, and is documenting it on a record somewhere, it would send an alert to our population health unit and say there's a potential risk of fall. And then they could be in communication and do coordination internally on behalf of the patient."* (P16, Male, Agency Leader)

As envisioned in this quote, fusing diverse types of data from multiple sources on the backend could work in tandem with a *"smart"* notification system on the frontend that informs the actions of all providers caring for patients.

Finally, agency leadership participants noted that as of January 2019, U.S. federal law required home care visits to be electronically verified per the 21st Century Cures Act. This legal mandate, participants noted, laid the groundwork for successful partnerships between software companies and home care agencies that might make sweeping changes possible, and even essential.

5 DISCUSSION

Having developed a nuanced understanding of how technology influences the way HHAs care for adults with heart failure, we now synthesize our findings into design opportunities for HCI researchers, system designers, and medical researchers interested in developing technologies that support formal caregiving for heart failure patients. In addition, our paper answers an important call for additional research on the role of HHAs in heart failure self-care [53] and we provide concrete suggestions for future directions.

Knowledge Gaps in Decision Making

Our analysis highlighted that many HHAs do not always have a clear understanding of what to do when patients' conditions change, resulting in unwarranted emergency calls to 911 as knee-jerk reflexes. Moreover, HHAs are attempting to fill their knowledge gaps by Googling for relevant information. Prior research revealed that HHAs find heart failure highly unpredictable and frightening [54, 55], which could in part explain the high rate of 911 calls from HHAs covering their bases. Our work builds on these previous findings and suggests the need for an improved system that supports HHAs in making informed decisions.

A key design opportunity that could reduce knee-jerk reactions and bridge HHAs' knowledge gaps might be an effort to educate HHAs on heart failure symptoms and specific scenarios that require emergency calls. This educational content could be provided to HHAs as static digital information that is accessible in offline mode on a digital device (e.g. a tablet). Our finding that stakeholders saw a need for *"just-in-time"* supplementary information on heart failure also suggests a role for real-time instruction from a technology akin to a personal assistant. For example, if a HHA indicates on the tool that a patient has fluid retained in their body, then the tool could recommend *"lift the patient's legs for 30 minutes"*; if it is reported that the patient's weight suddenly increased by two pounds in the last 24 hours and the patient has short breaths, then the tool could show a red alert recommending *"call the nurse now"*, and provide the functionality to do so.

Similar to prior work in the infographic and design communities that adopt pictographic representations to communicate complex information [20, 21], these educational and decision-support tools could break down complex heart failure symptoms and next-step actions into digestible formats.

Adopting these techniques could reduce the level of uncertainty that HHAs face, and potentially decrease the amount of unwarranted emergency calls that occur. Without addressing this challenge, more financial and medical resources could be wasted on false emergency calls. We note that in the U.S., patient readmission within 30 days incurs financial penalties for hospitals due to Medicare programs around value-based purchasing and hospital readmission reduction [19]. On a global scale, reducing unnecessary emergency calls could also contribute to a more sustainable healthcare approach.

Privacy Concerns in Health Technologies

The extent to which U.S. medical information privacy laws were enforced in home care played a big role in our research context. Concerns around privacy surfaced on two fronts: first, in communications between members of a patient's clinical team and the HHA; and second, in the use of HHAs' personal devices to record and transmit information about their patients. Stakeholders across roles voiced that patient privacy was important, and should be respected and encoded throughout the information systems enabling home care work. However, participants also agreed HIPAA's effective exclusion of HHAs from receiving vital patient information was significantly limiting the quality of home care. This finding adds to the growing amount of research on the tension between government regulations and the implementation of health care systems [2, 32]. We note this is especially pressing in our research context because it involves heart failure, a life-and-death disease.

One design opportunity to address this tension could be to *"build a long lasting relationship based on mutual trust and respect"* by adopting the principles of privacy by design [36] in the implementation of technological systems for heart failure management. An agency could, for example, provide tablets with task recording tools and calling features directly to patients as part of their services. These tablets would be secured at patients' homes for rotating HHAs to use for 'clock in and out'. The use of dedicated devices that remain at patient sites would enable these systems to comply with the requirements of HIPAA, including password protection, data encryption, access control and logging [29]. Becoming HIPAA compliant would also enable agencies to provide HHAs with patient information vital to their work, for example patient diagnoses. Adopting these processes could assist stakeholders in reducing ongoing tension between agencies, HHAs and heart failure patients.

Partial Reporting of Patient Conditions

A key finding in our research is that restrictions in reporting tools may prevent HHAs from communicating when patients are in life-threatening conditions. After an episode of home care, HHAs are required to use their patients' phones to call an automated punch-code system to report all the activities they performed. During the call, the HHA has to scan through a long list of tasks on a coded sheet to find all the activities they performed, and for each activity punch the corresponding numerical value using the phone keypad. For example, *cooking a meal* could have *99* as its assigned value, so the HHA types *99* during the call. If a phone call cannot be

placed due to poor cellular network in the patient's home, the HHA records all activities performed on a paper task sheet. HHAs who do not follow these procedures risk losing their jobs.

However, our work highlights several challenges with this reporting process, especially in heart failure. As a disease characterized by an unpredictable and uncertain symptom course, heart failure often requires that all important activities performed for and with patients be captured. For example, HHAs need to monitor patients' salt intake as this could lead to a serious condition of fluid retention and swelling of the body; but list of codes baked into the current industry-standard system does not allow the reporting of *"salt intake"*, and instead broadly captures *"meal preparation"*.

In addition, if HHAs erroneously *"punch"* in the wrong code during reporting, they cannot undo their actions. HHAs do not have the opportunity to review their entries or receive confirmation after submissions have been made. In cases where paper reports are used, HHAs need to fax or submit reports in-person on time or they will not be paid. These drawbacks suggest that HHAs need a more effective process that accommodates the reporting of heart failure activities, allows updates of incorrect entries, and remains fully functional during poor network connectivity.

One design avenue for an effective reporting process could be to create an offline-first tool for HHAs to collect and report data in a modular and granular fashion. The tool could remain fully functional when there is poor network connectivity and then sync back to the cloud when a reliable internet connection is established. This offline-based approach has been well studied and successfully implemented in tools (e.g., Medic Mobile [43], ODK [6], and CommCare [15]) for frontline health workers across the globe.

In addition, the reporting tool could be designed in form of a mobile or web application where HHAs can indicate the specific care activity they performed by quickly clicking through a form that contains both general activities (e.g. laundry) and heart-failure specific tasks (e.g. prepared a low-salt diet). To reduce errors in reporting, the tool could provide an opportunity to review all entries before submission and update activities erroneously logged. Adopting a more streamlined approach of seamlessly capturing care activities during home visits could improve the quality of care provided to heart failure patients.

Promoting HHAs' Value and Integration

Stakeholders across roles expressed a need for greater integration of HHAs into patients' broader clinical teams. Downstream from the finding that stakeholders would like for HHAs to have access to patient diagnoses, we see opportunities for systems to better integrate HHAs' perspectives and the data they collect. This was critical for HHAs in our study, who felt marginalized — they labored to collect data but lacked visibility into its context and use, and were not respected by the system at large. Agencies similarly felt that the data collected by HHAs were spread across several isolated systems in ways that made it complicated to retrieve and perform integrated analyses that might improve patient care. Health practitioners worried that they were missing vital information into patients' everyday conditions – information to which HHAs had access – and simultaneously worried that tools that kept them updated in real time may become overwhelming.

The need for thoughtful integration of HHA perspectives into the broader team presents an opportunity for the design of an end-to-end information system supplying stakeholders with detailed information on configurable notification cycles. On a data level, the ability to see trends in the data they had collected over time might alleviate HHAs' yearning for context. Doctors and nurses might also have their needs addressed through a system allowing them to set notification thresholds and cycles for key patient metrics, for example enabling them to stipulate they only wanted alerts-of-change emailed on a weekly basis. A robust system centered on the collection of patient datapoints relevant to home care could provide agency leadership with the insights they need to optimize outcomes, and scheduling functionalities, strictly enforced, could help agencies achieve operational efficiencies.

On a communication level, stakeholders' desires for better communication might be addressed through a system enabling HHAs to triage whether a patient's condition merited an emergency services call, a call to an on-call nurse, or simply an asynchronous message notifying a patient's doctor of a change. Blending ideas from clinical decision support and call center escalation protocols, such a system might also provide HHAs, coordinators, nurses, and other members of the call chain with *visibility* into the the status of their inquiries (e.g. "Forwarded to primary medical doctor" vs. "Forwarded to agency coordinator").

These improvements would directly address the immediate needs of stakeholders laboring in this asymmetric information environment. While achieving parity for HHAs would require systemic cultural shifts, for which the structure of the underlying technologies can only do so much, we see design opportunities for information systems to encode new social paradigms. For example, we envision compelling future work exploring whether and how algorithmic decision support and triage might change perceptions of what patient states require emergency or medical attention — among not just HHAs, but also doctors, nurses, and patients.

6 CONCLUSION

This paper describes the role of technology in the work practices of HHAs who care for adults with heart failure—a disease characterized by high morbidity, mortality, and utilization in the healthcare system. Our qualitative study with 38 participants in New York shows how technology is used, the complex socio-technical factors that underpin heart failure management (such as patient privacy, knowledge gaps, and poor internet connectivity) and the suggestions of stakeholders on how technology could improve heart failure management. Our work provides concrete takeaways and design recommendations for researchers and system designers interested in integrating technology with formal caregiving for heart failure patients. Building on these insights, we offer ideas that encourage researchers and system designers to adopt technology in a way that takes HHAs' perspectives into account, observes privacy laws, and concurrently improves the quality of care for heart failure patients.

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