

“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

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Background—Home care workers (HCWs) increasingly provide long-term and posthospitalization care for community-dwelling adults with heart failure (HF). They observe, assist, and advise these patients, yet few studies have examined their role in HF. As the foundation for future interventions, we sought to understand the perspectives of HCWs caring for adults with HF.

Methods and Results—We conducted 8 focus groups in partnership with the Home Care Industry Education Fund, a benefit fund of the 1199 Service Employees International Union United Healthcare Workers East, the largest healthcare union in the United States. English- and Spanish-speaking HCWs with HF clients were eligible to participate. Data were analyzed thematically. Forty-six HCWs employed by 21 unique home care agencies participated. General and HF-specific themes emerged. Generally, HCWs (1) feel overworked and undervalued; (2) find communication and care to be fragmented; (3) are dedicated to clients and families but are caught in the middle; and, despite this, (4) love their job. With respect to HF, HCWs (1) find it frightening and unpredictable; (2) are involved in HF self-care without any HF training; and (3) find the care plan problematic.

Conclusions—Although frequently involved in HF self-care, most HCWs have not received HF training. In addition, many felt poorly supported by other healthcare providers and the care plan, especially when their clients’ symptoms worsened. Interventions that provide HF-specific training and aim to improve communication between members of the home health care team may enhance HCWs’ ability to care for adults with HF and potentially lead to better patient outcomes. (*J Am Heart Assoc.* 2018;7:e010134. DOI: 10.1161/JAHA.118.010134.)

Key Words: community-partnered research • heart failure • home care workers • home health care • qualitative research

Home care workers (HCWs), which include home health aides and personal care aides, represent one of the fastest-growing sectors of the US workforce and healthcare industry.^{1,2} According to the Bureau of Labor Statistics, there are currently 2.2 million HCWs in the United States, and HCWs will add more jobs to the economy than any other occupation over the next

10 years.^{1,3–5} Unlike physicians and home care nurses, HCWs are with patients on a daily or near-daily basis,^{6,7} often serving as the eyes and ears in the home.^{8,9} Thus, they have a unique vantage point from which to observe, assist, and advise patients.

HCWs spend a significant amount of time helping their clients manage their chronic diseases and navigate the

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Clinical Perspective

What Is New?

- Although home care workers (HCWs) are increasingly caring for adults with HF, few studies have examined their role in patient care.
- In this qualitative, community-partnered study, we describe the experiences of English- and Spanish-speaking HCWs who care for home-dwelling adults with HF in New York, NY.
- HCWs are involved in key aspects of HF self-care, but many have not received HF training.
- HCWs are frustrated by poor communication and team integration among other home health care providers, especially when HF patients experience worsening symptoms.

What Are the Clinical Implications?

- Increased awareness of HCWs and their role in the care of HF patients among healthcare providers is warranted.
- Interventions that train HCWs in aspects of HF self-care and improve communication among the entire home health care team may improve HCWs' ability to care for HF patients.

healthcare system.^{8,10,11} Among these conditions, they are increasingly providing long-term assistance and posthospitalization care for adults with heart failure (HF).^{12–15} As such, they may be involved in key aspects of HF self-care, including HF maintenance (meal preparation, physical activity, medication compliance, and transportation to appointments) and HF management (symptom perception, monitoring, and decision-making). It is likely that HCWs' involvement in these activities influences their clients' ability to manage their disease, yet few HF studies have focused on HCWs or examined their role in HF patient self-care.¹⁶

To address these gaps, we sought to understand the perspectives of agency-employed HCWs who care for community-dwelling adults with HF. Specifically, we aimed to (1) elicit their perspectives on taking care of adults with HF; (2) assess their training and involvement in their HF clients' self-care; and (3) identify challenges and needs associated with caring for adults with HF.

Methods

Data Availability

The data will not be made freely available to other researchers for purposes of reproducing the results or replicating the procedure because the complete study data set contains potentially identifying data; however, the analytic methods and study materials are available in this article and in the supplemental online material, and the code book can be made

available by the corresponding author to other researchers upon inquiry.

Study Design

This qualitative study was conducted in partnership with the Home Care Industry Education Fund (HCIEF), a benefit fund of the 1199 Service Employees International Union United Healthcare Workers East, which is the largest healthcare union in the United States and represents more than 400 000 workers in hospitals, nursing homes, clinics, pharmacies, and home care agencies.¹⁷ The HCIEF is a 501(c)(3) charitable organization that offers HCWs training that helps them gain English language proficiency, prepare for high school equivalency and college entrance examinations, attend college, and learn specific caregiving skills. Each year the organization trains between 15 000 and 20 000 HCWs who work for 55 licensed home care services agencies in New York, NY,¹⁷ most of which serve Medicaid recipients. To conduct this study, we partnered with HCIEF leadership and staff. Neither staff nor leadership of the 1199 Service Employees International Union at large were involved in this study.

Community-partnered approach

A community-partnered approach was used because of the HCIEF's understanding of HCWs and their expertise in home care.^{18–21} HCIEF leadership and staff informed the study design, screened participants for eligibility, provided space to conduct the study, and offered feedback on the results. They were not involved with recruiting participants, obtaining informed consent, or collecting or analyzing data.

Study design and population

Focus groups were conducted to understand HCWs' perspectives. The HCIEF leadership felt that focus groups, rather than one-on-one interviews, were likely to capitalize on group dynamics and shared experiences.²² Focus groups were held in private rooms at the HCIEF headquarters from August to November 2017. This location was chosen because of its familiarity to HCWs and its accessibility by public transportation. HCWs were eligible to participate if they had at least 2 years of experience as a HCW and took care of a HF client within 12 months of the recruitment period. Exclusion criteria included an inability to speak English or Spanish, severe hearing loss, and severe visual impairment. Using a telephone-based transcript developed by Weill Cornell investigators, HCIEF staff members assessed eligibility and interest among HCWs who were registered for afternoon training courses during the study period. If eligible and interested, HCWs were approached by 2 investigators (M.R.S., A.F.S.) in person after their course to explain the details of the study and obtain informed consent.

Purposive sampling was used to achieve a balanced sample with respect to primary language spoken (English and Spanish) and duration of caregiving.²³ In addition to conducting separate language focus groups, we interviewed home health aides and personal care aides separately because of differences in their training, scope of care, and time spent with clients.^{2,7}

All participants provided written informed consent and received a \$25 gift card for their participation. Materials that Spanish-speaking participants received during the study were professionally translated by a certified company, inLingua. The study was approved by the Institutional Review Board of Weill Cornell Medicine and all participants gave written informed consent. This study adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ)²⁴ (Table S1).

Topic guide

The focus group topic guide was informed by the literature, our clinical experience with HF patients who have HCWs, the HCIEF expertise, and a conceptual model developed by Franzosa et al (Figure S1).¹⁰ The Franzosa model was derived from the experiences of agency-employed, English-speaking HCWs, and integrates several domains that we a priori anticipated would be relevant to our study (agency characteristics, work environment, training and supervision, worker–client relationship, worker satisfaction, and quality of care). It is one of the few models that focuses on HCWs but also describes the relationship between the quality of care rendered and client (patient) health outcomes.

Because the model was not disease specific, and our focus was HF, the majority of the questions in our topic guide focused on HCWs' involvement in their clients' HF self-care, the HF training they received, their experience with HF clients' other healthcare providers, and their comfort assisting with HF-related self-care tasks (Table S2). Once developed, the guide was piloted and refined for ease and comprehensibility with 5 HCWs who were not included in the final study.

Focus groups

One investigator (M.R.S.), with training in qualitative research methods, moderated focus groups in English, while another investigator (A.F.S.), who is fluent in Spanish and has been trained in qualitative interviewing, moderated focus groups in Spanish. Both moderators met before and after each focus group to ensure consistency across the groups. Focus groups lasted up to 60 minutes and were comprised 5 to 7 participants. Two investigators (A.L.S., P.B.K.L.) served as focus group assistants. Data saturation, or the point at which no new themes emerged, was achieved by the sixth focus group.²⁵ We conducted 2 additional focus groups, however, because of the number of HCWs who wished to participate and had already rearranged their work schedules to do so.

Data analysis

Focus groups were audio-recorded, translated into English, and professionally transcribed by Ubiquis. Our analytic team was multidisciplinary, consisting of physicians, a nurse practitioner, a social worker, health services researchers, and qualitative research experts. We performed a thematic analysis of the data, which is an approach that has been widely used in health-related research.²⁶ Since prior models detail the experiences of HCWs and because we sought to understand HCWs perspectives towards specific phenomena in HF, this approach was well suited.²⁷ While we presumed that our data would fall within the Franzosa Model, we also recognized that because our study was disease specific, unique concepts and themes pertaining to HF were likely to emerge. Therefore, we took a flexible analytic approach, using established codes when appropriate, but also open coding when we came across new concepts.^{28,29}

Our analysis had several stages.^{26–28} First, 4 investigators (M.R.S., A.F.S., P.B.K.L., A.L.S.) familiarized themselves with the data. Next, 2 investigators (A.F.S., P.B.K.L.) independently coded the first 2 transcripts. Codes were applied to segments of text, usually defined by 1 or more relevant concepts.^{30,31} One investigator (M.R.S.) reviewed the first 2 transcripts and both code lists before reconciling the discrepancies and consolidating the lists into a final codebook. Next, A.F.S. and P.B.K.L. independently reviewed the transcripts a second time, coding the data using the uniform codebook, which was subsequently applied to the remaining 6 transcripts. All new codes were added to the codebook and subsequently applied to the first 2 transcripts and then the remaining transcripts. The codebook was refined until all transcripts were coded. As is often done, common codes were compared using dimensions and properties and were collapsed into broader categories, which then evolved into even broader themes. A fourth investigator (A.L.S.) reviewed the transcripts and the evolving themes to validate that the data were reflected in the themes. Themes were iterated among the individual coders until consensus was reached. Finally, we compared our findings to those in the Franzosa model to look for congruence and discordance. To ensure that our thematic analysis was rigorous and of high quality, we followed the Braun and Clarke 15-point Checklist for Thematic Analyses (Table S3).

Of note, while we conducted separate focus groups by HCW type (home health aides versus patient care assistants), our data analysis revealed no substantial differences between the groups, and thus the data are presented as 1 population of HCWs.

Results

A total of 46 HCWs participated in 8 focus groups (Figure 1). The characteristics of the study participants are shown in

Table. They had a mean age of 49 years (SD 10), 98% were female, 37% were black, 54% were Hispanic, and 91% had at least a high school education. Participants were HCWs for an average of 16 years and spent an average of 3.5 days per week with HF clients.

Major Themes

Seven major themes emerged from the data, 4 of which pertained to being a HCW in general and 3 of which were specific to HF (Figure 2).

General Themes

While the main goal of the study was to ascertain HCWs' perspectives on caring for adults with HF, 4 themes pertaining to the general experience of being a HCW emerged (Figure 2).

Overworked and undervalued

Participants described their job as physically and emotionally taxing. The majority reported working for multiple clients at a time, traveling long distances to get to each job, and having little free time:

"We work 365 days a year. We really don't get time off—it's ridiculous because their lives are literally in our hands."

Many reported earning low wages and feared losing their job: "We work multiple jobs, get paid minimum wage, and have no sick days. I love my clients, but it's tough. If they turn on you, or if they die, you're canned."

These factors, along with their dedication to clients, led to feelings of burnout and social isolation:

"We're always following a schedule. . .that of an 85-year-old who doesn't want to go outside. So, you're inside, cleaning, cooking, and changing beds. It's lonely."

In addition to feeling overworked, poorly compensated, and burned out, many participants reported not feeling valued by their agencies, other healthcare providers, and sometimes the clients' family members.

"The client is in a healthcare team, but we are treated as the lowest class, like a housekeeper sometimes. It's like they forget that there's the word 'health' in 'home health aide.'"

Not feeling valued was compounded, or in some cases initiated, by a lack of role definition for the HCW. Participants reported that their job description and overall scope of tasks were rarely defined to the clients, their families, and other home health care providers:

"The agency doesn't make clear to anyone who we are or what we do. You know, we're not just the help!"

In addition to not feeling valued by their agencies, participants spoke about being ignored in most healthcare settings. This was not the case, however, in the emergency department, where clients were often too sick to answer

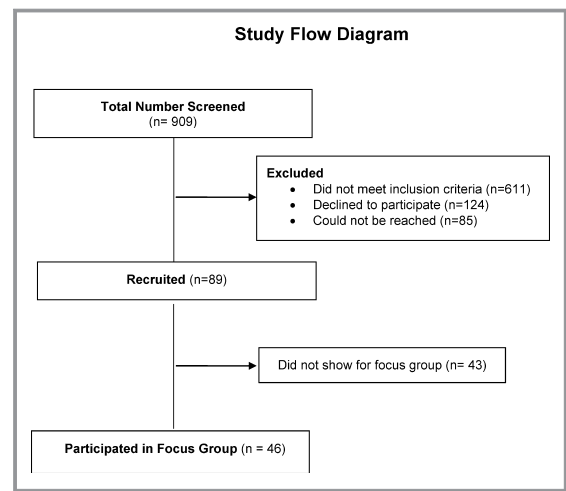


Figure 1. Flow diagram of study participant recruitment.

medical questions. In this setting, physicians often asked HCWs to give an account of the events leading to the 911 call: "The emergency room doctor is the only one that wants to talk to us. They ask us what happened because they know that we're there [with the client] 90% of the time."

Communication and care are fragmented

HCWs described communication with other healthcare providers as highly fragmented and frustrating. HCWs reported that despite being with clients on a near-daily basis, they were not included in conversations surrounding clients' care:

Table. Participant Characteristics

Characteristics	N=46
Age, mean (SD)	49 (10)
Female sex, N (%)	45 (98)
Race/ethnicity, N (%)	
Black	17 (37)
Hispanic	25 (54)
Asian/Pacific Islander/other	4 (8)
Educational degree, N (%)	
Some high school (HS)	4 (9)
GED or HS completed	13 (28)
Some college	19 (41)
4-y college or graduate degree	10 (22)
Primary language spoken, N (%)	
English	25 (54)
Spanish	21 (46)
Duration of caregiving, mean y (SD)	16 (8.4)
Time/wk spent with HF client, mean d (SD)	3.5 (1.8)

GED indicates general equivalency diploma; HF, heart failure.

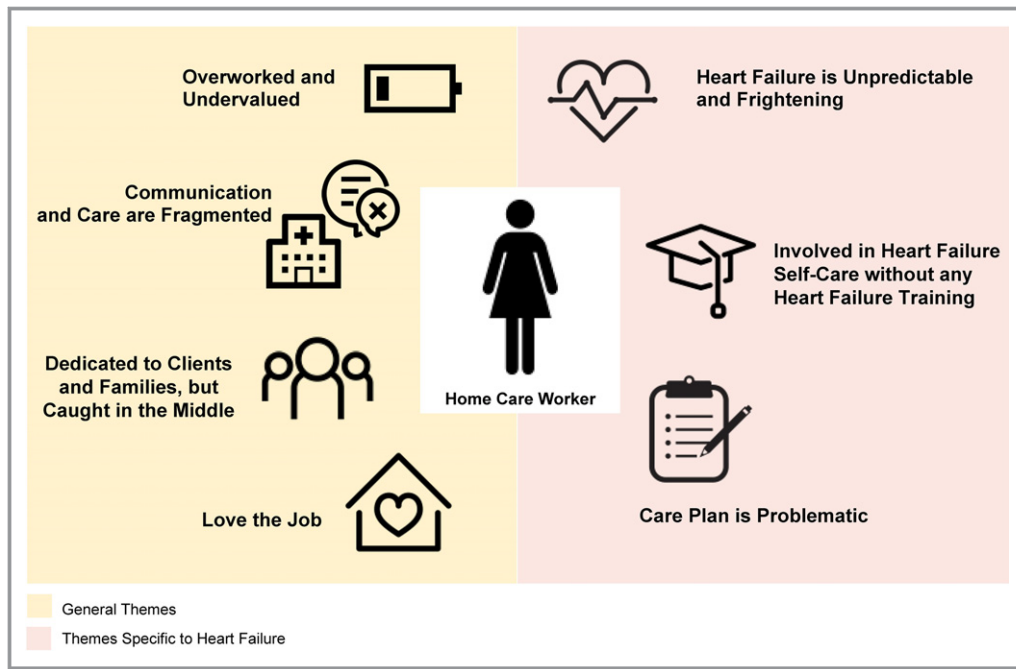


Figure 2. Major themes that emerged from focus groups with home care workers who care for adults with heart failure (HF). The 7 major themes that emerged are depicted by representative icons. Those in orange are general themes, and those in pink are HF-specific themes.

“We’re with the clients all day, more than anyone else. So why aren’t we included in the conversation?”

Participants remarked on an inability to speak with their supervisors in a timely fashion, particularly when the clients’ symptoms were escalating:

“You’re calling and calling. You’re by yourself and no one picks up at the agency. You’re stranded with the client and you don’t know what to do and you need help. It’s a huge problem.”

Because of this, many described taking their clients to the hospital even when they felt the problem could have been resolved without an emergency department trip. Notably, many participants were dissatisfied with this outcome, because it meant spending hours or days in the emergency department, which often resulted in worsening of their clients’ cognitive functioning and mood.

Interestingly, none of the HCWs in our study called their clients’ doctors. When asked about this, 2 remarked:

“That’s just not an option for us.”

“Nope. Never. I’m not even sure which doctor we would call.”

In light of these issues, many participants voiced a desire for improved communication among various members of the client’s healthcare team.

Dedicated to clients and families, but caught in the middle

Despite the aforementioned issues, many participants spoke positively about their clients and the joy that comes with building close relationships:

“You have clients that really look at you like a family member and they want you there. And I want to be there for them too.”

They revealed that it was also satisfying when family members appreciated the care they provided:

“She kept sayin’ it’s shoulder pains. But I took her to the ER and turns out she was having a heart attack. Her family gave me a hug and they said, ‘We keeping you.’ That meant a lot to me.”

Of note, this desire and ability to form strong ties with clients was expressed most heavily among Spanish-speaking HCWs.

Although strong relationships with clients led to job satisfaction, participants noted that in some cases, it also led to them feeling caught in the middle of family arguments and discussions with doctors:

“I’m with the client all day. She’s complaining of having chest pain all the time. The doctor will ask her, ‘How are you feeling?’ She will say, ‘Oh, I’m fine, doctor.’ And she does the same thing when her daughter asks, too. It’s maddening!”

Because of a fear of being fired, many participants revealed that they do not interject their observations or opinions, afraid that this could negatively impact client loyalty.

“We have a policy at my agency: don’t get involved with family things. Don’t ever say, ‘This is the truth.’ Call your supervisor and tell them the situation, let them deal with it.”

Love the job

Many participants reported that despite the challenges associated with being a HCW, they loved their job:

“I went into this field because I care about people. Plain and simple. I love helping my clients.”

Participants conveyed that many aspects of their work brought them satisfaction, eg, the ability to be creative and problem-solve with their clients:

“When she pulls out one of those canned soups, I say, ‘Why don’t you eat this or that?’ I try to make her see how much salt the soup has, and then see if we can find a solution.”

HF-Specific Themes

In addition to the general themes, 3 distinct themes related to caring for adults with HF emerged (Figure 2).

HF is unpredictable and frightening

While they care for clients with a variety of chronic diseases, participants remarked that HF was particularly frightening. The disease course felt unpredictable to them, and they noted that their clients’ symptoms escalated quickly and often without warning:

“You need to be alert. Even though you see the person [looks] healthy, anything can happen. The whole night, you can’t close your eyes because if anything happens—a fall or shortness of breath. . .”

Some of this unpredictability started at the beginning of a home care assignment. Participants explained that because of agency policies, they are not always told what disease their assigned client has, and often they rely on prior experiences with HF to guide them:

“When you start a job, you don’t know they have heart failure. The agency doesn’t tell us because of HIPAA. We find out when we get there. You know it’s heart failure pretty quickly. The shortness of breath and the fat swollen legs. The ones who get sick quickly.”

In addition to these issues, HCWs reported feeling nervous about the death of their HF clients. Not only was it frightening to see the illness progress, but it also meant they would lose their job:

“When my client with heart failure died, it was hard. I went to the ICU every day. I wanted to go to his funeral, but I was assigned to someone else the next day.”

Involved in HF self-care without any HF training

Participants reported being involved in several aspects of their clients’ HF self-care, including weighing clients, grocery shopping and preparing low-sodium meals, fluid monitoring, taking vital signs, reminding clients to take their medications, and transporting clients to medical facilities:

“His ankles usually get swollen, so I elevate his legs during the day. I also try to keep his sodium low. I weigh him every other day, just to see if he’s retaining fluids.”

Despite this level of involvement, few participants received training on HF maintenance or management. Instead, they tried to pick up information about HF when they could:

“I’ve never received any training on heart failure. I get information from the pamphlets in the hospital.”

Of note, the majority of participants reported that they would like to learn more about HF:

“My new client has heart failure. . .It’s challenging, but also a great experience. I look forward to learning more because we don’t really get any training on it.”

In particular, many wanted HF training geared to a higher level than what some of them currently receive. Specifically, many requested that HF training explain the disease, the tasks involved in disease maintenance, symptom recognition, and what to do in emergencies:

“I’ve gotten some training, but they teach it to us at a kindergarten level. So, if they say she needs a low-sodium diet, they’ll say oh, ‘low sodium.’ It’s like, okay. . . but what does that mean? How do I do that?”

Participants remarked that their agencies do provide disease-specific training, but the courses most commonly focus on diabetes mellitus and dementia, not HF.

Care plan is problematic

The care plan, a document that is intended to help HCWs and visiting nurses care for adults in the home, was felt to be inadequate by many participants. The issues they identified were (1) a lack of detailed instructions on HF maintenance and management and (2) few opportunities for communication about the care plan with the visiting nurse(s) at the beginning of the job assignment or when client symptoms escalated:

“We’re supposed to follow the care plan. . . but it is very basic and often not that helpful.”

“No one orients us to the plan of care and if we have a question, forget about it. Can’t get through on the phone.”

Participants also voiced frustration with clients who did not want to follow its terms. Among the most problematic were dietary guidelines:

“And a lot of times, they don’t want to adhere to what’s on the care plan or the diet that the doctor gives us. They say, ‘Give me my fried chicken, pork chops,’ and ‘I want my salt on that, please!’”

Not wanting to adhere to the care plan could be detrimental to their clients’ health but also had implications for HCWs. Although required to enforce the care plan, participants explained that they could be fired for going against clients’ wishes. This was compounded by the fact that the nurse was not always physically present or reachable by phone to reinforce the care plan.

Conceptual Model

The themes that emerged were similar to those in the Franzosa Model but differed in 3 main ways. First, we found

that the experience of HCWs—as well as the quality of care they delivered to clients—was influenced by several stakeholders (eg, nurses and other healthcare providers) as well as their own personal attributes and those of their clients. These multi-layered dynamics were not described in the Franzosa Model. Second, HCWs of HF patients were in frequent contact with the health system, often dialing 911, and bringing clients to the hospital, and transporting clients to and from medical appointments. Healthcare providers and the healthcare system were not included in the Franzosa Model. Third, we found that relationships existed between the HCWs, the quality of care they delivered, and their clients' health outcomes, whereas in the Franzosa model they appeared unidirectional.

Because of these key differences, we modified the Franzosa Model to create our own conceptual model (Figure 3), which we believe more fully explains the perspectives of HCWs caring for adults with HF. This approach of adapting and refining conceptual models is common in health services research.³² Because of the interrelatedness of the various people and entities with whom HCWs work and interact, our results aligned closely with the Social Ecological Model, a model known for the interrelatedness of individual, interpersonal, organization, community, and policy domains.³³ While it retains elements of the Franzosa Model, we have adapted the model to more accurately convey our findings.

Discussion

This qualitative study is the first to investigate the perspectives of agency-employed HCWs who care for community-dwelling

adults with HF. We found that many HCWs find HF to be a complex and challenging disease, made even more frightening by their clients' frequent and unpredictable symptom exacerbations. Although HCWs are highly involved in their clients' HF self-care, including aspects of HF maintenance and management, the majority have not received any education or training on HF. Finally, we identified several challenges that HCWs experience while caring for adults with HF: The care plan is not sufficiently detailed for HF, HCWs have trouble getting in touch with their supervisors (often nurses) when they need help, and HCWs do not feel like they are a part of the healthcare team.

While recent data suggest that 25% of adults hospitalized for HF are discharged home with home care,¹² most studies that aim to improve the hospital-to-home transition have not focused on HCWs.¹⁶ Rather, the goal has been to harness the expertise of other healthcare professionals (nurses, physicians, pharmacists, social workers, and physical therapists) to improve patient outcomes.^{15,34–36} In fact, over the last 20 years, only 3 studies have examined the effect of having a HCW on the risk of rehospitalization,^{37–39} and only 1 study has incorporated HCWs into an intervention aimed at improving HF patient self-care and quality of life.⁴⁰ Unfortunately, most of these studies have had small sample sizes, methodological limitations, and mixed results. The shortcomings of the existing literature, taken with the findings of this qualitative study, suggest that further research on HCWs in HF is needed, especially in larger, more representative populations.

Our results also suggest that HF-specific training for HCWs may be warranted. Such interventions could be informed by our findings and new conceptual model, as well as The

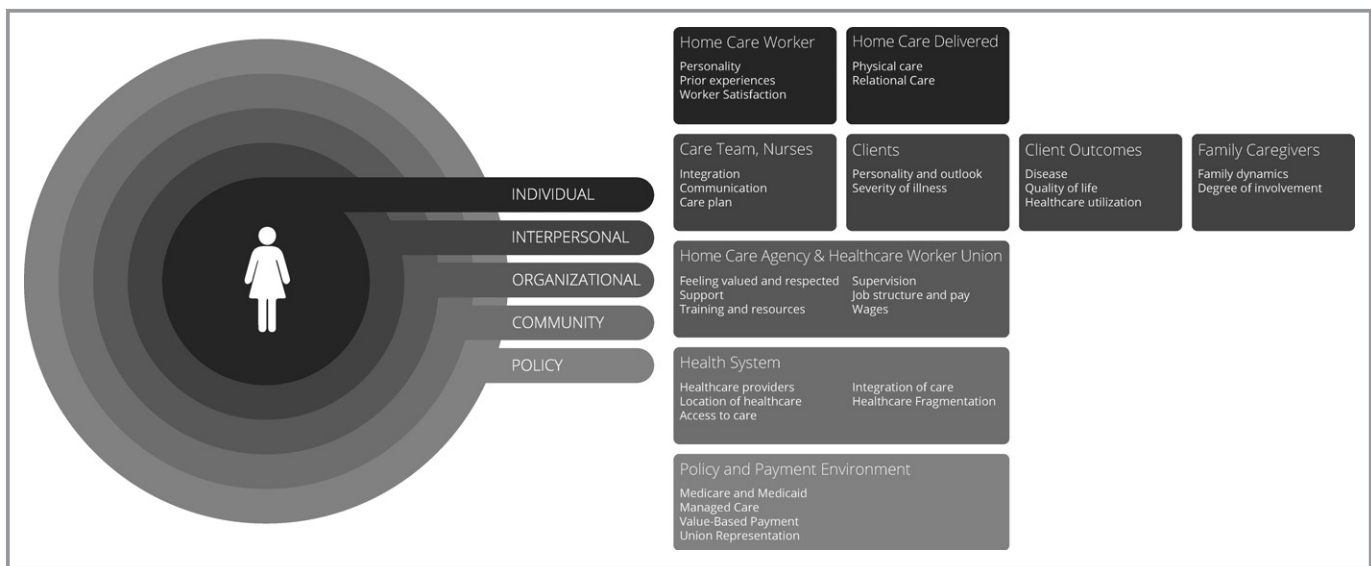


Figure 3. Conceptual model of factors influencing the delivery of care by home care workers (HCWs) to adults with heart failure HF. The themes that emerged from this study fit nicely within the existing Social Ecological Model, since we found that the experience and ability of HCWs to care for adults with HF was influenced by and has effects on individual, interpersonal, organizational, community, and policy-level factors. Important entities are outlined within each level.

Situation-Specific Theory of HF Self-Care.^{41,42} The theory posits that HF self-care comprises related concepts: (1) self-care maintenance, defined by activities that are done to control the disease; (2) self-care management, a process that includes symptom monitoring, perception, and decision-making in order to limit symptom exacerbations; and (3) self-care confidence, which moderates and sometimes mediates the effect of self-care on various outcomes.⁴³ Since we found that HCWs are heavily involved with self-care maintenance (reminding clients to take medications, weighing them daily, preparing meals low in salt), interventions that train HCWs on these activities, while accounting for agency policies and patient and family preferences, may prove valuable. In addition, since the document that guides these activities—the care plan—often lacked sufficient detail to guide HF-related activities, interventions that seek to improve the quality of the care plan may be worth considering.

Although HCWs are not involved with some of the higher-level decision-making processes that comprise HF management, they reported being involved in symptom monitoring and perception.⁴² In fact, agencies require HCWs to document clients' physical changes (eg, ankle swelling, weight gain, and shortness of breath). The majority of study participants expressed frustration with current processes surrounding this documentation, particularly that communication channels failed them when trying to convey these changes. As a result, many HCWs called 911. While HCWs recognized that some visits to the emergency department and hospital are medically necessary, they also noted that many of these trips could have been avoided through improved communication with nurses and supervisors. Thus, interventions that aim to improve team communication may also be of value in the context of HF.

Another important finding was that despite spending so much time with HF clients, HCWs described being largely ignored by other healthcare providers. While this has been previously reported in the home care literature,^{8,10,44,45} HF may amplify this sentiment. One reason may be that HF patients are frequently hospitalized, causing home health care to be discontinued and reinstated. The HCW and the nurse are required to review the care plan at the beginning of every home health care job, but because of the high degree of turnover, this may not occur in a timely fashion. When it does occur, our findings suggest that the role of the HCW is often not clearly defined to clients, nurses, and family members. As such, their scope of tasks and responsibilities may be unclear to many with whom they interact, which can lead to marginalization. Additionally, despite having some of the most nuanced knowledge about the HF patient in the home environment, HCWs revealed that few providers asked for their input or included them in office visits and hospital encounters. Given that cognitive impairment among adults

with HF is highly prevalent,^{46,47} involving HCWs (when patients or their proxies agree) may be beneficial to patient care and lead to increased visibility and utilization of HCWs.

Strengths and Limitations

This study has several strengths. We used a community-partnered approach to recruit 46 HCWs from 21 unique licensed home care agencies across New York, NY, which enabled us to capture variation in HCWs' perspectives at the agency level. A multidisciplinary team of investigators analyzed the data using a rigorous, thematic approach. Our findings extend an established conceptual model, and our new model can be used to guide future studies on HCWs in HF. Finally, we conducted focus groups in both English and in Spanish, which adds to the generalizability of our findings.

We also note a few limitations. First, while we partnered with the HCIEF in order to gain access to a large population of HCWs, the HCIEF is a benefit fund within the 1199 Service Employees International Union Home Healthcare Workers East. As such, all of the HCWs in our study were employed by licensed home care agencies and were part of the union, which limits our ability to generalize our findings to HCWs who are privately employed or nonunionized. Second, this study was conducted in New York City, and the findings may not apply to areas with different home health care practices, agency policies, and union presence. Finally, like many studies, ours was subject to selection bias, as the perspectives of the HCWs who participated may be systematically different from those of the HCWs who did not.

Conclusion

This is the first study to examine the perspectives of HCWs who care for adults with HF, a patient population increasingly relying on paid caregivers for help at home. Our findings suggest that despite heavy involvement in HF self-care, HCWs have not received HF training. In addition, the majority feel frustrated by poor communication and team integration, especially when their HF clients experience worsening symptoms.

Since qualitative research is meant to generate hypotheses, our findings need to be tested and quantified in larger, more representative populations of HCWs. Such research has the potential to not only illuminate this understudied area, but also to provide evidence to inform policies governing HCW training and certification, reimbursement and payment models of home health care, and healthcare delivery for HF patients. Finally, interventions that train HCWs in aspects of HF self-care, as well as those that improve communication among members of HF patients' home health care team, may be warranted. Such interventions could improve HCWs' ability to provide high-

quality care for adults with HF in the home, and may ultimately improving outcomes for patients with HF.

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Disclosures

None.

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