BRIEF REPORT

Home Health Care Workers' Interactions with Medical Providers, Home Care Agencies, and Family Members for Patients with Heart Failure

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Background: **Despite providing frequent care to heart failure (HF) patients, home health care workers (HHWs) are generally considered neither part of the health care team nor the family, and their clinical observations are often overlooked. To better understand this workforce's involvement in care, we quantified HHWs' scope of interactions with clinicians, health systems, and family caregivers.**

Methods: **Community-partnered cross-sectional survey of English- and Spanish-speaking HHWs who cared for a HF patient in the last year. The survey included 6 open-ended questions about aspects of care coordination, alongside demographic and employment characteristics. Descriptive statistics were performed.**

Results: **Three hundred ninety-one HHWs employed by 56 unique home care agencies completed the survey. HHWs took HF patients to a median of 3 doctor appointments in the last year with 21.9% of them taking patients to ≥ 7 doctor appointments. Nearly a quarter of HHWs reported that these appointments were in ≥ 3 different health systems. A third of HHWs organized care for their HF patient with ≥ 2 family caregivers.**

Conclusions: **HHWs' scope of health-related interactions is large, indicating that there may be novel opportunities to leverage HHWs' experiences to improve health care delivery and patient care in HF. (J Am Board Fam Med 2023;36:369–375.)**

Keywords: **Caregivers, Chronic Disease, Cross-Sectional Studies, Delivery of Health Care, Heart Failure, Home Health Care, New York, Outcomes Research**

Background

Adults with heart failure (HF) are increasingly using home health care and relying on home health care workers (HHWs) for help at home during the postacute period or for longer periods of time.[1] HHWs, which include home health aides, attendants, and personal care aides[2] employed by licensed and certified home care agencies, are one of the most rapidly growing workforces in the United States. There are currently 3.4 million HHWs, and this number is expected to grow by 34% by 2030.[3] HHWs, who spend hours in the home, assist patients with instrumental activities of daily living and medical care and provide emotional support.[4–7]

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Our prior work in HF has found that HHWs readily contribute to key aspects of HF care including weighing patients, taking vitals, preparing meals, reminding patients to take medications, and accompanying them to doctor appointments. Owing to their role and scope of care, HHWs are often the minute-to-minute observers of patients' health in the home.[8]

Despite this integral role, HHWs are generally considered neither part of the family nor part of the health care team, and their clinical observations are often overlooked.[9,10] Prior qualitative studies of HHWs have found that they are rarely asked to contribute their observations of patients (including their symptoms) during telephone calls with doctors (made by patients or family members) or during office visits.[5] In addition, written or verbal instructions about how patients should manage their care at home are rarely transmitted from the hospital or doctor to the HHW. Within the home care agency, studies have found that HHWs often struggle to reach their supervising nurse when they have clinical questions or need help in the home.[5,10] Beyond this, studies of older adults have found that they often have multiple caregivers, some family members and some paid HHWs, and their interactions vary.[11,12]

To our knowledge, no studies have quantified the extent of HHWs' interaction with clinicians and other caregivers. Characterizing these interactions is important because it could illuminate opportunities to leverage this workforce to improve patient care. Thus, we quantified the scope of HHWs' interactions with clinicians, health systems, and family caregivers while caring for HF patients.

Methods

Setting, Design, and Population

This cross-sectional study examined the experiences of HHWs caring for adults with HF. The study was conducted from June 2020 to July 2021 in partnership with the 1199 Service Employees International Union (1199SEIU) Training and Employment Funds (TEF), a benefit fund of the 1199SEIU United Healthcare Workers East, the largest health care union in the United States. TEF is a nonprofit labor management organization that provides training and services to 55,000 HHWs in New York.

A convenience sample of HHWs who are active members of TEF comprised the study sample. To be eligible, HHWs had to be English- or Spanish-speaking, currently employed by a licensed or certified home care agency in New York, NY, and have cared for a HF patient in the past. TEF staff administered an electronic survey to HHWs on their listservs via an electronic link generated by Research Electronic Data Capture, a web-based, secure data collection and storage system. Eligibility was assessed (in both languages) by self-report on opening the survey link. Participation was voluntary, and all participants provided electronic consent (IRB # 19-07020476). Participants received a $10 gift card for their participation.

Survey Instrument and Scope of Care

The survey included novel and validated items that collected information on HHWs' sociodemographics, employment history, and experience with HF patients.

We included 6 open-ended questions about care coordination for their most recent HF patient (Table 1). Specifically, we asked HHWs about their scope of interactions with medical providers, health care system(s), clinicians at their home care agencies (nurses) and other HHWs, and the family members of their HF patients.

Statistical Analysis

We calculated descriptive statistics with frequencies and means and medians and interquartile ranges (IQRs) for non-normally distributed data. To facilitate interpretation of the 6 questions that pertained to HHWs' scope of care, we dichotomized variables at the 75th percentile.

We conducted all analyses using Stata version 16 (StataCorp., College Station, TX).

Results

The survey was sent to 4829 HHWs, of which 1379 were eligible and opened it, 648 consented, and 391 HHWs completed it (response rate 60.3% [Appendix]).[13,14] The 391 HHWs, employed by 56 unique home care agencies, had a mean age of 48.5 years (SD 11.5) and a median of 10 years of job experience (IQR: 5, 17); 97.7% were female and 60% were Hispanic (Table 2).

Table 1. Scope of Home Health Care Workers' Interactions with Clinicians, Health Systems, and Family Caregivers of Heart Failure Patients

Survey Questions	Value
About how many different doctors' appointments have you taken your client with heart failure to in the last year?	n = 343
0	72 (21.0%)
1	30 (8.7%)
2	48 (14.0%)
3	41 (12.0%)
4	30 (8.7%)
5	19 (5.5%)
6	28 (8.2%)
≥7	75 (21.9%)
If you accompanied a client with heart failure to doctors' appointments in the last year, about how many different doctors were those appointments with (counting only one doctor per appointment)?*	n*= 259
1	56 (21.6%)
2	72 (27.8%)
3	48 (18.5%)
4	32 (12.4%)
≥5	51 (19.7%)
If you accompanied a client with heart failure to doctors' appointments in the last year, about how many different health systems were those appointments in?*	n*= 254
1	124 (48.8%)
2	71 (28.0%)
≥3	59 (23.2%)
For your client with heart failure, about how many other home health care workers were assigned to the same client over the last year?	n = 352
0	61 (17.3%)
1	64 (18.2%)
2	137 (38.9%)
3	36 (10.2%)
≥4	54 (15.3%)
For your client with heart failure, about how many different nursing supervisors did you work with over the last year?	n = 360
0	43 (11.9%)
1	94 (26.1%)
2	134 (37.2%)
≥3	89 (24.7%)
For your client with heart failure, about how many different family members did you organize care with over the last year?	n = 364
0	80 (22.0%)
1	159 (43.7%)
2	68 (18.7%)
3	34 (9.3%)
≥4	23 (6.3%)

Responses were left as continuous values; values above 75th percentile were categorized together.
Missing for each question includes: # of doctors' appointments (n = 48), # of different doctors (n = 132), # of different health systems (n = 137), # of home health care workers assigned to same client (n = 39), # of different nursing supervisors (n = 31), # of different family members organized care with (n = 27).
*Had to answer 1st question to respond to questions 2 and 3.

Table 2. Characteristics of Study Participants

Characteristics	Value
n	391
Age (in years), mean (SD)	48.5 (11.5)
Gender	
Men	9 (2.3%)
Women	382 (97.7%)
Race/ethnicity	
Non-Hispanic White	30 (7.7%)
Non-Hispanic Black	80 (20.5%)
Hispanic	234 (60.0%)
Asian/Pacific Islander	7 (1.8%)
Other	39 (10.0%)
Were you born in the United States?	
No	343 (87.7%)
Yes	48 (12.3%)
How many years have you lived in the United States? Median (IQR)	19 (9, 30)
How many years have you been a home care worker? Median (IQR)	10 (5, 17)
As a home care worker, about how many clients have you cared for with heart failure	
1 to 5	281 (71.9%)
6 to 10	48 (12.3%)
11 to 15	8 (2.0%)
More than 15	12 (3.1%)
Not sure	42 (10.7%)

Fifty-six unique agencies represented in the analytic sample.
Abbreviations: SD, standard deviation; IQR, interquartile range.

The Medical System

HHWs reported taking their HF patient to a median of 3 (IQR: 1, 6) doctor appointments in the last year (range 0 to 50), with 21.9% of HHWs taking patients to ≥ 7 doctor appointments (Table 1, Figure 1). HHWs reported taking their HF patient to a median of 2 different doctors (IQR: 2, 4) in the last year, with 19.7% of HHWs taking them to ≥ 5 different doctors. Nearly a quarter of HHWs reported that these appointments were in ≥ 3 different health systems.

Home-Based Care

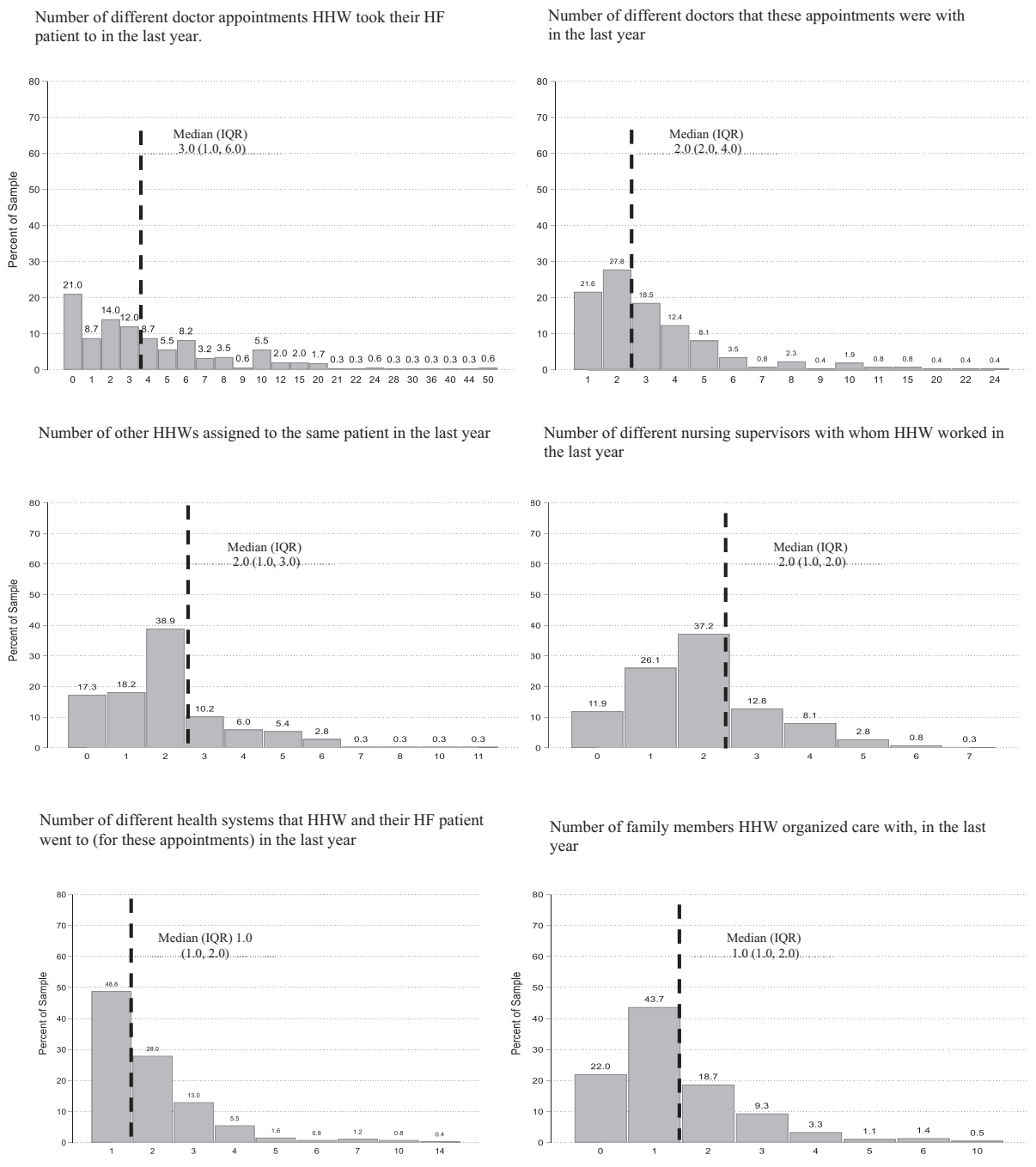
HHWs reported being supervised by a median of 2 (IQR: 1, 2) different nurses and working alongside a median of 2 (IQR: 1, 3) different HHWs while caring for a HF patient in the last year (Figure 1). HHWs reported organizing care with a median of 1 (IQR: 1, 2) family caregiver(s) (range 0 to 10), with a third of HHWs organizing HF care with ≥ 2 family caregivers in the last year (Table 1).

Discussion

In this cross-sectional survey of agency-employed HHWs caring for HF patients, we found that HHWs have frequent contact with multiple doctors and across different health care systems. Moreover, HHWs interact with a variety of other home-based clinicians (nurses) and fellow HHWs, and organize care with family caregivers.

To date, HHWs' interactions with other providers in HF have only been examined qualitatively, with studies finding that despite their involvement in the home, they are infrequently included in conversations surrounding patient care. Our data's quantification of their scope of interactions suggests that HHWs frequently accompany their patients to a wide array of doctor appointments. This workforce has the potential to serve as both a source of information for physicians who might want to understand how patients are doing at home and a partner in ensuring that patients carry out aspects of self-care at home (ie, adherence to medication, dietary and physical activity recommendations, etc.). Notably, a recent study of US households found that older adults with chronic conditions often use HHWs, and when they do, they frequently do so alongside family caregivers, a concept known as "shared

Figure 1. Scope of home health care workers' interactions with clinicians, health systems, and family caregivers, visually displayed with medians and interquartile ranges (IQRs). Abbreviations: HF, heart failure patients, HHWs, home health care workers.



care."[7] Our study adds to this by quantifying how many HHWs and family caregivers can be involved in HF care—notably, that there are multiples of each.

Although we were able to document the breadth of interactions and scope of care, future studies are needed to better elucidate what transpires when HHWs are at doctors' appointments and physician and family caregiver attitudes' toward integrating their insights. Intervention-based studies that leverage HHWs' observations may be warranted. For example, designing and testing communication-

based systems (mHealth applications) for HHWs or providing them with after-visit summaries from doctors (with patient permission) may integrate the HHW workforce more effectively into the care team and have the potential to improve patient care and outcomes. We note a few limitations. First, although a large, diverse, and representative sample, participants were all employed by licensed and certified home care agencies in New York, NY, thus their experiences may not be wholly generalizable to HHWs employed by other models or in nonurban or northeast areas. Second, we lack data on HHWs who did not open or complete the survey, which may introduce bias. Third, although we asked participants to report on their most recent experiences caring for a HF patient, we lack specific data on the temporality of the relationship, including for how long they provided care and which types of doctors they interacted with (ie, specialty vs primary care) and the nature of those interactions. We also lack data on the patient for whom they were answering the survey about, including their severity of illness. Future studies would benefit from including these additional data.

Conclusion

HHWs' scope of health-related interactions is large, indicating that there may be novel opportunities to leverage HHWs' experiences. In particular, improving communication with other clinicians and sharing information across health care systems could help to reduce unplanned health care use for HF patients.

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To see this article online, please go to: http://jabfm.org/content/36/2/369.full.

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Appendix.

Exclusion Cascade. Abbreviation: HHWs, home health care workers.