“I Depend on Her for Everything”: A Retrospective Chart Review of Home Care Worker Service Disruptions for Homebound Older Adults During the COVID-19 Pandemic

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Abstract
Home care workers played critical roles in meeting the complex medical and social needs of homebound adults during COVID-19, yet their contributions remain underappreciated. This study characterizes home care workers’ roles during COVID-19 and examines how home care disruptions impacted homebound individuals and caregivers. Using a qualitative analysis of electronic medical records among a randomly sampled subset of homebound patients in a home-based primary care practice, we found that home care workers were essential in meeting existing and new needs of homebound individuals. Insufficient home care worker services, including unstable schedules and inadequate hours of paid care, became particularly disruptive, leading to risks for patients and their caregivers. Given their integral role on care teams, home care workers must be a policy focus to prepare for emergent situations and ensure that homebound individuals have access to high quality, stable home care.

Keywords
COVID-19, caregiving, home care

What this paper adds
- Home care workers played an essential role in meeting the complex medical and social needs of homebound older adults during the COVID-19 pandemic.
- The COVID-19 pandemic worsened existing challenges accessing stable home care worker services that impeded continuity of care and left already vulnerable homebound individuals without adequate support.
- Lack of adequate home care worker services during a time when in-person medical and family caregiving visits were disrupted led to risks for homebound older adults and additional family caregiver strain.

Applications of study findings
- Instability and shortages of the paid caregiving workforce must be addressed, particularly with respect to future emergency planning.
- Formalized integration of home care workers on home-based primary care teams can enhance the multi-disciplinary, team-based approach of home-based care.

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Introduction

The devastating impact of the COVID-19 pandemic on long-term care facilities has highlighted the importance of home-based care for medically complex older adults. In particular, homebound older adults (i.e., those who rarely or never leave their homes) are a medically and socially complex population, experiencing high prevalence of disability and cognitive impairment (Ornstein et al., 2015). Many homebound individuals have multiple chronic conditions and high rates of hospital utilization. Home-based primary care (HBPC) practices provide multi-disciplinary support to homebound individuals to promote independence and reduce hospitalizations (Stall et al., 2014). However, only 11.9% of homebound individuals receive HBPC services (Ornstein et al., 2015).

While some homebound individuals have access to HBPC, many rely on family and other unpaid caregivers (i.e., informal caregivers) (DeCherrie et al., 2012; Wilkins et al., 2009). Due to the intense nature of caregiving, these caregivers often experience emotional, physical, and financial challenges (Wolff et al., 2018). During COVID-19, caregivers experienced heightened anxiety, depression, and financial challenges compared to non-caregivers due to limited visits and access to health care support (Beach et al., 2021).

Home care workers (HCWs) frequently provide additional care in the home, supporting both patients and their family caregivers (Reckrey et al., 2021). HCWs (also known as paid caregivers, personal attendants, and home aides) may be employed by home health agencies or paid privately by families. HCWs assist with activities of daily living, such as eating, bathing and dressing, as well as other non-medical tasks for homebound individuals, many of whom have dementia (Reckrey et al., 2019; Scales et al., 2020).

The COVID-19 pandemic has underscored the essential services provided by HCWs, yet HCWs are often underpaid and undervalued; despite providing direct care to their clients, HCWs are often not considered part of the medical team, and many are not paid a living wage (Sterling et al., 2018). Additionally, many HCWs have provided direct care to individuals with COVID-19, risking self-exposure and transmission to their other clients due to lack of personal protective equipment (PPE), especially during the first year of the pandemic (Shang et al., 2020). HCWs have also reported elevated stress due to inconsistent communication on the COVID-19 pandemic from their agencies (Sterling et al., 2020). These challenges have been compounded by the already low-wage and stressful nature of the position (Jang et al., 2016). These stressors have contributed to high turnover rates and a growing shortage of HCWs, which affects the continuity and quality of care that their clients receive (Sterling et al., 2018).

Despite a growing body of research illustrating the experiences of HCWs and their agencies during COVID-19, less is known about how homebound individuals and providers experienced disruptions in HCW services or how HCWs managed the needs of homebound older adults during this pandemic. Through a qualitative analysis of medical records, we aimed to explore the roles of HCWs caring for homebound older adults during COVID-19 and how disruptions have impacted homebound individuals and their caregivers.

Methods

Setting

Our analysis is a sub-study of a larger project investigating the impact of COVID-19 on homebound older adults in the Mount Sinai Visiting Doctors (MSVD) practice (Franzosa et al., 2022; Reckrey et al., 2022). MSVD is a HBPC practice within the Mount Sinai health system providing comprehensive primary care to approximately 1300 homebound individuals in Manhattan, NY (Ornstein et al., 2011). MSVD primarily cares for frail older adults living with multiple comorbidities, a majority of whom receive care from HCWs.

Data Sources and Sample

We conducted a qualitative analysis of electronic medical records (EMRs) from patients enrolled in MSVD as of December 1, 2019 who received paid HCW services and did not live in congregate housing (i.e., assisted living). We included EMR data from December 1, 2019–December 31, 2020 to establish baseline patient characteristics, including presence, number, and identities of HCWs and family caregivers prior to the COVID-19 pandemic start in March 2020.

We determined whether a patient received HCW services by reviewing their full EMR (including intake and unstructured notes) for the terms “home care worker,” “home health aide,” “home attendant,” “aide,” and their respective abbreviations (e.g., “HHA”). The use of a HCW is generally documented in the MSVD intake form and may also be included in clinician narrative notes. Patients who did not meet these criteria were excluded. We initially sampled the EMRs of individuals with HCW services from the larger study sample, which consisted of individuals who died in the initial spring 2020 COVID-19 surge (March 1–June 30, 2020), since we expected that they would require more intensive HCW care and experience substantial HCW disruptions. Then, to gain a broader understanding of the experiences of homebound individuals over the first year of the pandemic, we randomly sampled additional patients with HCW services who were still living following the first COVID-19 surge (June 30, 2020). Patients were included if their EMR contained 5 or more clinical notes that mentioned HCWs to provide sufficient data for analysis. We continued sampling until reaching data and thematic saturation, when additional analysis did not yield new information or themes (Braun &
Clarke, 2006; Saunders et al., 2018). Our final sample included 53 patients.

Data Collection

For each homebound individual, we obtained sociodemographic data (age, sex, race/ethnicity, primary language, marital status, insurance status, dementia diagnosis, and Elixhauser comorbidity index, which uses 30 comorbidity indicators to predict outcomes including length of stay, hospitalizations, and mortality (Elixhauser et al., 1998)) from Mount Sinai Hospital’s centralized patient database. We used EMRs to confirm dementia diagnosis and abstract additional data from standardized intake forms for the MSVD practice, including household characteristics (living alone/with family/HCW and type of housing), functional status, and HCW characteristics (hours of paid care, payment method). We additionally used an individual’s receipt of Medicaid, the largest payer of home care services, as a proxy for distinguishing if HCWs were paid through Medicaid or another source, as we assumed that individuals receiving Medicaid would receive Medicaid-funded HCW services.

We then abstracted unstructured data from EMR notes. One of two researchers (PK or EX) independently reviewed and abstracted unstructured data from EMR notes. These included records of phone calls, emails, and other electronic communications between the interdisciplinary team, patients, caregivers, and ancillary service providers as well as clinical notes documenting interactions with patients and caregivers, care needs and treatment plans, and communication within the interdisciplinary team. These data were abstracted into a secure, web-based REDCap database (Harvey, 2018) developed by the researchers for the parent study (Franzosa et al., 2022). The database included six a priori domains of COVID-19-related disruptions (family caregiving, paid caregiving/HCW care, medical services and supplies, hospital services, symptom management, and hospice) developed and refined by the parent study team through a pilot abstraction of four individual EMRs.

Ten percent of cases were reviewed and validated by a second team member [EX] to limit bias in individual abstractor interpretations and maintain rigor. Throughout the data extraction, researchers flagged clinical questions, such as determining COVID status or medical diagnoses and clarifying medical terminology. These cases (n = 9, 17% of sample) were reviewed and confirmed by MSVD clinicians on our study team (MZ and JR) (Graneheim & Lundman, 2004).

Data Analysis

We examined the frequency and distribution of clinical and demographic characteristics of our sample (Table 1). We used a hybrid inductive and deductive qualitative thematic approach to analyzing the abstracted medical record notes (Fereday & Muir-Cochrane, 2006). We analyzed qualitative data iteratively throughout the data collection process to identify and explore emerging categories and themes. To examine HCW roles and impact of HCW care, medical student and lead author EX reviewed all abstracted notes to develop an initial codebook with a priori codes from our REDCap tool (e.g., HCW disruptions, caregiver disruptions) and identify emergent codes and subcodes. The codebook was reviewed and refined with a senior qualitative researcher (EF) on our study team. The lead author coded the EMR excerpts and analyzed coded passages across cases specifically related to 1) HCW disruptions (HCW changes, HCW stress, HCW support, HCW disruptions and adaptations), and 2) the impact of these disruptions on caregivers (caregiver support, caregiver disruptions, and caregiver stress) and homebound individuals (symptom management, hospitalization, COVID). Emerging ideas were reviewed in regular meetings with the full study team to identify major themes (Braun & Clarke, 2006; Fereday & Muir-Cochrane, 2006). Researchers kept detailed notes of the analytic decision-making process as an audit trail (Lincoln & Guba, 1986).

The study received an exempt determination from the Icahn School of Medicine at Mount Sinai Program for the Protection of Human Subjects (IRB-20-03,724) (Tong et al., 2007).

Results

Sample of Homebound Individuals with HCW Services during COVID-19

Our sample consisted of 53 homebound individuals who received care from a HCW during the COVID-19 pandemic. The sample was generally reflective of the demographic characteristics of the entire MSVD patient population, which is composed of homebound older adults who are majority female (69.2%), unmarried (65.9%), and close to half of whom have been diagnosed with dementia (45.2%). 38.4% of the MSVD patient population is non-Hispanic white.

One-third (34%) of our patient sample has 24-hour HCW services prior to the start of the pandemic. Individuals in this sample are primarily female (79.2%), unmarried (66%), and about half of the sample have dementia (50.9%). 41.5% of the sample are non-Hispanic white. 34% of the sample lived alone, and over 40% lived in publicly funded housing. The mean Elixhauser Comorbidity Index was 4 (SD = 2.43). Nearly half (41.5%) of sample had HCWs that were paid for through Medicaid. 18 of the homebound individuals in the sample died over the study period (3/1/2020–12/31/2020). (Table 1).

Impact of COVID-19 on HCW Services, Homebound Individuals and Caregivers

Thematic analysis identified 4 major themes related to the impact of COVID-19 on HCW services: 1) Shift to remote medical care and changing individual needs led to task
shifting and new tasks for HCWs, 2) Caring for homebound individuals during COVID-19 increased the intensity and risks of HCWs’ work, 3) Pandemic-related staffing challenges disrupted care and put homebound individuals at risk, and 4) Lack of adequate and quality HCW services increased caregiver strain. Our analysis showed that while disruptions were more frequent in the first 3 months of the COVID-19 pandemic, they persisted throughout the study period. (Table 2).

**Theme 1: Shift to Remote Medical Care and Changing Patient Needs Led to Task Shifting and New Tasks for HCWs.** As the COVID-19 pandemic began, MSVD, like many practices, discontinued in-person medical team visits from providers to limit exposure. While MSVD providers continued to care for homebound individuals through virtual avenues, some in-person medical tasks had to be shifted to HCWs to maintain care. For example, some HCWs were asked to administer morphine and perform wound care, two tasks usually

| Table 1. Characteristics of Sample of MSVD Homebound Patients Receiving Care from a Home Care Worker. |
|-------------------------------------------------|------------------|
| Patient Characteristics | N   | %     |
| Total               | 53  | 100   |
| Age, mean (SD)      | 84.0 (12.5)   |
| Sex                 |      |       |
| Female              | 42  | 79.2  |
| Race/Ethnicity      |      |       |
| Black or African-American | 2 | 3.8   |
| Hispanic or LatinX  | 10  | 18.9  |
| White               | 22  | 41.5  |
| Asian American or Pacific Islander | 1 | 1.9   |
| Unknown/Other       | 18  | 34.0  |
| Primary language    |      |       |
| English             | 43  | 81.1  |
| Spanish             | 6   | 11.3  |
| Unknown/Other       | 4   | 7.5   |
| Marital status      |      |       |
| Single              | 35  | 66.0  |
| Married             | 25  | 47.2  |
| Unknown/Other       | 6   | 11.3  |
| Housing type        |      |       |
| Private home        | 30  | 56.6  |
| Public housing      | 10  | 18.9  |
| Clinical characteristics |    |       |
| Dementia diagnosis  | 27  | 50.9  |
| Elixhauser comorbidity index (SD) | 4.0 (2.4) |
| Patient status      |      |       |
| Patients living as of 12/31/2020 | 35 | 66.0  |
| Died during study period (3/1/2020–12/31/2020) | 18 | 34.0  |
| Household characteristics |    |       |
| Lives alone         | 18  | 34.0  |
| Lives with paid caregiver only | 11 | 20.8  |
| Lives with family/friends | 24 | 45.3  |
| Functional status   |      |       |
| Dependent in all ADLs | 11 | 20.8  |
| Dependent in all IADLs | 11 | 20.8  |
| Home care worker services as of 12/1/2019 |    |       |
| Medicaid            | 22  | 41.5  |
| Full-time (24 hours/7 days) care | 18 | 34.0  |

*a*Includes patients who are single, divorced, widowed, and legally separated.

*b*ADL/IADL criteria/scoring differed depending on which test they used. Max scores for ADL is either: 7 or 22; Max score for IADL is either: 9 or 22. Counts are of those who have max scores.

*c*Medicaid status was used as a proxy to determine if HCWs were paid through Medicaid or another source.
performed by family members, nurses, or other providers. Although agency-employed HCWs do not typically perform these tasks (and they are outside Medicaid-paid HCWs’ scope of practice in New York State), it sometimes became necessary because they were the only ones in the home providing care.

HCWs’ responsibilities sometimes changed as the pandemic affected the amount and type of care that homebound individuals needed. For example, one MSVD provider wrote that their patient who was experiencing food insecurity relied on his HCW to pick up free meals at a local school because he was “trying to stay home and avoid going out and risking getting sick” [MD note, ID 79, 5/18/2020].

**Theme 2: Caring for Homebound Individuals during COVID-19 Increased the Intensity and Risks of HCWs’ Work.** In addition to new tasks, HCWs’ existing work also became more intense during the pandemic and exposed them to new risks. Some HCWs were tasked with caring for individuals who developed COVID-19 or who exhibited COVID-19 symptoms. HCWs often risked COVID-19 exposure to stay and care for their homebound clients with COVID-19, despite stay-at-home orders, lack of personal protective equipment (PPE), and a growing understanding of the high transmissibility of COVID-19. For one HCW, this was an intense responsibility with an emotional burden. The doctor reported that the HCW was “shaken up” when her patient started showing signs that suggested a COVID-19 diagnosis [MD note, ID 965, 11/26/2020]. Some HCWs quit or stopped reporting to work for fear of exposure. One caregiver told the doctor that their HCW quit because she was “afraid to ride the subways” [MD note, ID 940, 4/10/2020]. Some tasks that HCWs traditionally performed took on a new level of intensity, particularly for patients with dementia who experienced heightened agitation during the pandemic. While some of these behaviors were not new, they added to the difficulty of providing care. For instance, one MSVD provider noted that a patient “spit at an aide, scratched an aide, and threw coffee the other day” [MD note, ID 538, 3/31/2020] and a family caregiver of a different homebound individual who was having “more angry yelling spells” reported that the individual’s HCW was “frightened by the intensity of them” [Caregiver note, ID 424, 11/20/2020].

This increased intensity also manifested as work schedules increased, where some HCWs changed their shift schedules and/or took fewer breaks to provide continuous care during the pandemic and reduce their own and their client’s exposure. One doctor reported that since COVID-19, one individual’s two HCWs were “working 24 hour[s] alternating 3 and 4 days to avoid travel,” a change from their previous schedule of 12 hour split shifts [MD note, ID 624, 9/2/2020]. As one nurse noted, a family caregiver had said that a

**Table 2. Themes Identified Through Medical Records.**

| Theme                                                                 | Representative Quote                                                                 |
|----------------------------------------------------------------------|---------------------------------------------------------------------------------------|
| Shift to remote medical care and changing patient needs led to task shifting and new tasks for HCWs | \[HCW\] is supposed to change her hours [Pt] has been coughing with clear phlegm for 2 weeks ... \[Pt\] has 2 live in aides, none of them are coughing or with any COVID symptoms. They wear masks at work. Give dementia and cough with clear phlegm, we discussed the possible etiologies ... viral infection not excluding COVID-19. Nurse Practitioner note (4/16/2020) |
| Caring for homebound individuals during COVID-19 increased the intensity and risks of HCWs’ work | Patient desperately needs more home care hours ... she [family caregiver] understands that delays given COVID but we will try to get this moving ASAP. Physician note (4/17/2020) |
| Pandemic-related staffing challenges disrupted care and put homebound individuals at risk | Patient is unsafe at home alone and is without HHA at this time ... we cannot open case if pt is unsafe at home. I suggest pt being admitted to hospital or long-term facility until there is someone taking care of pt 24/7. Registered Nurse note (4/20/2020) |
| Lack of adequate and quality HCW services increased caregiver strain | Pt had irritated area on the skin on his backside. - aide was leaving him wet on the commode after a shower. - now she [caregiver] is giving him a bath, scrubbing him down, putting anti-fungal powder (nystatin). Physician note (5/19/2020) |
patient’s 24/7 HCW was “entitled to a break” but was “unsure where he [the caregiver] can find an[other] agency to provide HHA services” [RN note, ID 1197, 11/2/2020].

Theme 3: Pandemic-Related Staffing Challenges Disrupted Care and put Homebound Individuals at Risk. As with many services during the COVID-19 pandemic, continuity of HCW services was difficult to maintain, which made it difficult for homebound older adults to remain safely at home. When HCWs did not report to work, understaffed agencies experienced delays in sending substitute HCWs. For example, one family caregiver had a HCW service request rejected by three different home care agencies. She told the MSVD social worker that the “pandemic is having a serious effect on these agencies” [Social Worker note, ID 275, 5/21/2020].

There were also barriers in acquiring adequate HCW services due to infection prevention policies. HCWs were sometimes exposed to COVID-19, and agency policies on testing for HCWs and their clients often left homebound individuals without any or inadequate home care services. For instance, one doctor wrote that when one HCW tested positive for COVID-19, the home health agency removed the individual without any or inadequate home care services. For instance, one doctor wrote that when one HCW tested positive for COVID-19, the home health agency removed the HCW and told the family caregiver that they “will not put another HHA in for 14 days unless the patient is tested” [MD note, ID 583, 6/8/2020]. This individual required 24/7 care and could not wait for a COVID-19 test, which was not widely available at the time. She ultimately had to move in with a nearby family member to remain safely at home.

Disruptions in the continuity of long-time aides also affected care quality for homebound individuals. One individual with a long-time HCW expressed that “I depend on her [long-time HCW] for everything.” (SW note, ID 1092, 3/13/2020). When the HCW was unable to care for the patient due to COVID-related scheduling complications, the patient reported the replacement HCW would not help her in the bathroom and “told her she had to do it and closed the door and left the room” (SW note, ID 1092, 5/5/2020). The individual’s SW wrote that the individual “was beside herself and felt like this was abuse.”

Prolonged delays in accessing adequate hours of HCW care during the pandemic put some homebound individuals at risk of medical and social complications. For instance, one individual did not have adequate HCW hours during the night, resulting in no diaper changes and the worsening of existing pressure sores. The day-time HCW reported to the doctor that “the patient has been sitting in this [urine and feces] all night … given this, sores just won’t heal” [MD note, ID 940, 4/17/2020].

Workforce shortages sometimes resulted in delays in receiving other services, risking hospitalization and nursing home placement. For instance, one homebound individual was “left alone for 17 hours a day” [RN note, ID 940, 4/22/2020] due to inadequate HCW hours, but urgently needed visiting nurse services for wound care. However, the visiting nurse service refused to open the case, reporting that “patient’s wound will not heal because there is no one to change patient’s diaper when it is wet and no one to turn and reposition patient. Patient is unsafe” [RN note, ID 940, 4/22/2020]. These safety concerns sometimes led to recommendations that homebound individuals be hospitalized or admitted to a nursing home. Additionally, some individuals who were hospitalized experienced longer hospital stays because they could not safely return home without home care services in place. One doctor wrote that for one homebound individual, both a social worker and the visiting nurse team deemed the individual was “not safe for discharge” [MD note, ID 493, 7/8/2020] due to lacking full-time home care.

Theme 4: Lack of Adequate, Quality HCW Services Increased Caregiver Strain. The disruptions in HCW services shifted the role of family and unpaid caregivers and worsened caregiver strain. As described earlier, HCWs sometimes did not report for work, quit, or became sick or were exposed to COVID-19, and caregivers had to provide care while looking for replacements. One doctor noted that a family caregiver searching for a substitute HCW was told that the agency was “having a hard time finding someone” and requested that the family caregiver provide care in the meantime [MD note, ID 940, 4/10/2020].

Moreover, some families proactively discontinued home care to limit COVID-19 exposure. One family reported to the doctor that they paused their four-hour, 5-day a week homecare because they “did not want the risk of someone coming in and out” [MD note, ID 957, 2/3/2020] and another family reported to the doctor that they discontinued HCW services because the homebound individual was at “serious risk of complications” if he caught COVID-19 [MD note, ID 1083, 3/26/2020]. When HCW services were disrupted in these ways, the family caregivers had to provide care directly or struggle to find and train another HCW.

Providing additional direct care often contributed to caregiver strain. One doctor wrote that a family communicating having a “hard time managing her [the patient’s] care” [MD note, ID 940, 11/18/2020] while another family caregiver noted that they were “desperate for an aide” because “frankly, we need the break” [Caregiver note, ID 66, 5/6/2020]. This burden was compounded by the pandemic, as some caregivers were long distance and/or had their own medical concerns. One caregiver, who had multiple medical conditions and lived in a different borough of New York City, told the MSVD nurse that “she cannot continue to do this,” in reference to having to commute and provide care when no HCW showed up [RN note, ID 940, 4/20/2020].

Moreover, finding and training HCWs to meet the unique needs of homebound individuals during COVID-19 created additional work for caregivers. For one individual, being away from family caregivers meant that there was a gap in psychosocial care. One of the family caregivers told the doctor that while their HCW was “very competent,” the HCW “just couldn’t provide adequate connection with patient to...
provide the psychosocial support patients desperately need, especially during the pandemic when the family couldn’t really visit” [MD note, ID 689, 9/21/2020]. The family caregiver had to find another HCW to fill this gap in psychosocial care.

Discussion

HCWs played an essential role in caring for homebound older adults throughout the COVID-19 pandemic, and disruptions had far-reaching impacts on homebound individuals and their caregivers. Homebound older adults are a highly vulnerable population who often rely on home care to meet their needs; many homebound individuals receive 24-hour HCW services and have multiple risk factors, suggesting a high level of medical, functional, and social need and a reliance on HCWs (Ornstein et al., 2015). While HCW disruptions in our sample were greatest during the initial spring 2020 COVID-19 surge, we found that these disruptions persisted for most individuals over the course of our year-long study period despite changes in COVID-19 risks and restrictions. Our findings build on existing knowledge by suggesting that the pandemic created a need for HCWs to take on new and more complex tasks due to stay-at-home orders keeping medical teams and family caregivers out of the home. These shifting responsibilities, as well as changing patient needs during the pandemic, created challenges for HCWs. Moreover, while existing research has shown how disruptions in HCW services negatively impact their clients (Scales et al., 2020), we found that disruptions in HCW services due to and in the context of the pandemic exacerbated existing workforce issues and particularly impeded continuity of care, sometimes leaving homebound individuals without adequate hours of care. This created additional tasks and emotional burden for family caregivers, who were already under considerable strain during the pandemic (Beach et al., 2021).

While HCWs are hired to provide functional support in the home (Scales et al., 2020), HCWs often perform additional critical tasks such as communicating changes in symptoms to the medical team and providing emotional support to their clients (Reckrey et al., 2019). We found that during COVID-19-related disruptions in care, HCWs took on new and more expansive roles. This sometimes left HCWs performing tasks beyond their usual scope of practice, including administering morphine and providing wound care because they were the only person available.

The increased responsibilities of HCWs during the pandemic, particularly in performing higher level tasks for medically and socially complex homebound older adults, may signal an opportunity to expand their role on HBPC teams. For example, homebound individuals often experience multiple comorbidities as well as social risks such as food and housing instability, and issues accessing insurance coverage and other supports (Ornstein et al., 2015). To meet these needs, HBPC is composed of a multi-disciplinary team, including social workers, administrative staff, nurses, and physicians (Reckrey et al., 2014). Since HCWs play key roles in the care of homebound individuals, formalized integration of these paid caregivers on HBPC teams, such as including HCWs in team meetings, bridging communication between HCWs and social workers, and directly hiring HCWs could enhance the already multi-disciplinary, team-based approach to home-based care. While some examples exist of integration of HCWs into team-based programs such as the Program of All-Inclusive Care for the Elderly (PACE), where HCWs are included in multi-disciplinary care teams, and the Care Team Integration of the Home-Based Workforce program, where HCWs were specifically trained on how to communicate with care teams, this is not standard practice (Stone & Bryant, 2019). One study of paid caregivers for homebound individuals showed that HCWs conveyed important medical information between their clients and their families, but their communication with the HBPC medical team was limited (Reckrey et al., 2020). A formal integration of HCWs into home-based care teams could begin with involving HCWs in coordination of care and standardizing reporting by including HCWs in interdisciplinary team meetings or family discussions. In addition, while [practice] records whether a patient has an HCW at intake, this is not standard in all practices and HCWs are often not identified or documented in a patient’s medical record despite their integral role in their clients’ care. We also relied on our analysis of unstructured notes to understand the specifics of the HCWs’ roles and relationships with the patients. Capturing this information systematically in the medical record could help ensure home-based medical teams are aware of their clients’ support systems and can more effectively communicate and share information between HCWs and family caregivers. While some of these changes may require changes in HCW credentialing and scope of practice, it also allows teams to better leverage HCW expertise. These efforts must be accompanied by policy changes that address instability and shortages in the paid caregiving workforce. While many HCWs continued providing essential care for their clients during the pandemic, instability of HCW hours and scheduling created disruptions in care with dangerous consequences. Confirmed COVID-19 exposure, fear of exposure, and increased need to test and quarantine HCWs exacerbated existing HCW workforce shortages (Rowe et al., 2020), resulting in unexpected gaps in care that needed to be filled. These gaps were sometimes filled by caregivers or other HCWs, but HCW shortages and difficulties for caregivers due to distance or safety concerns meant that homebound individuals were sometimes unsafely left alone. Such situations also negatively impacted family caregivers, who experienced additional strain managing disruptions in HCW services during the pandemic. For example, a study of older family caregivers highlighted that shifting roles for caregivers during COVID-19 created employment disruptions and contributed to elevated symptoms of depression, anxiety, and loneliness.
(Truskinovsky et al., 2022). Other studies have suggested the importance of interactions between family caregivers and HCWs, emphasizing difficulties with setting up and maintaining home care and the importance of continued coordination of care even prior to the pandemic (Sims-Gould and Martin-Matthews, 2007; Shaw et al., 2021).

Addressing instability in the paid caregiving workforce must include addressing challenges for family caregivers in accessing and maintaining adequate aide hours for homebound individuals.

Integration of HCWs into HBPC teams and other forms of home-based care may be challenging due to the inadequacy of existing payment structures. Formalized integration would require payment reforms at the policy level, with incentives like higher reimbursement rates for long-term services and support (LTSS) under Medicaid and other public plans to incorporate HCWs more closely and comprehensively into care (Scales, 2022). Moreover, shifts towards universal, value-based models could better ensure comprehensive and equitable access to adequate home care for homebound individuals as well as stabilize the HCW workforce (Russell et al., 2022; Scales, 2022; Fong et al., 2022). Studies of one of New York State’s Workforce Investment Organizations, which aimed to recruit, train, and retain long-term care workers, found that value-based payment models encouraged collaboration to support high-risk patients (Fong et al., 2022; Russell et al., 2022). In some cases, this included clinical rounds where HCWs shared their clients’ medical status and any unreported medical changes (Russell et al., 2022). These findings suggest that payment models that incentivize collaboration and care coordination can promote integration of HCWs in home care teams.

To our knowledge, this is the first study to use electronic medical records specifically to understand the roles of HCWs caring for homebound older adults during the COVID-19 pandemic. With our qualitative analysis of unstructured notes and communications, we were able to grasp the details of each case and draw connections between the experiences of homebound individuals, their caregivers, and the MSVD medical team. Because we did not capture information from outside the medical record, our analysis may be biased towards information that the HBPC team considered clinically relevant enough to be documented in the medical chart. Approximately 10% of our sample HCWs did not have a major presence in the medical records, which may suggest that HCW played a limited role with certain clients or may instead indicate that interactions with the HCW were not discussed with the care team or not deemed important to record. However, among cases demonstrating HCW involvement, we were able to document rich and complex themes illustrating the importance of HCWs in caring for medically and socially complex individuals.

During COVID-19, HCWs were essential to keeping homebound older adults safely at home. The roles of HCWs became more demanding and riskier, and inadequate HCW services from unstable schedules and inadequate hours of paid care became particularly disruptive, sometimes leading to risk of hospitalization and prolonged length of stay as well as contributing to caregiver strain. While the pandemic has evolved since the initial surge captured in this study, home care workforce shortages continue (Lenski, 2021). Given the importance of a strong home care workforce for the health of homebound older adults, maintaining the home care workforce must be a priority for the future of health care in the home. Our analysis highlights the need to address workforce shortages and retention as well as more formalized integration of HCWs on medical teams and within payment models to create a strong home-based care system to benefit HCWs, homebound individuals, and caregivers.

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