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Experiences of Home Health Care Workers in New York City During the Coronavirus Disease 2019 Pandemic
A Qualitative Analysis

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IMPORTANCE Home health care workers care for community-dwelling adults and play an important role in supporting patients with confirmed and suspected coronavirus disease 2019 (COVID-19) who remain at home. These workers are mostly middle-aged women and racial/ethnic minorities who typically earn low wages. Despite being integral to patient care, these workers are often neglected by the medical community and society at large; thus, developing a health care system capable of addressing the COVID-19 crisis and future pandemics requires a better understanding of the experiences of home health care workers.

OBJECTIVE To understand the experiences of home health care workers caring for patients in New York City during the COVID-19 pandemic.

DESIGN, SETTING, AND PARTICIPANTS From March to April 2020, a qualitative study with 1-to-1 semistructured interviews of 33 home health care workers in New York City was conducted in partnership with the 1199SEIU Home Care Industry Education Fund, a benefit fund of the 1199 Service Employees International Union United Healthcare Workers East, the largest health care union in the US. Purposeful sampling was used to identify and recruit home health care workers.

MAIN OUTCOMES AND MEASURES Audio-recorded interviews were professionally transcribed and analyzed using grounded theory. Major themes and subthemes were identified.

RESULTS In total, 33 home health care workers employed by 24 unique home care agencies across the 5 boroughs of New York City participated. Participants had a mean (SD) age of 47.6 (14.0) years, 32 (97%) were women, 21 (64%) were Black participants, and 6 (18%) were Hispanic participants. Five major themes emerged: home health care workers (1) were on the front lines of the COVID-19 pandemic but felt invisible; (2) reported a heightened risk for virus transmission; (3) received varying amounts of information, supplies, and training from their home care agencies; (4) relied on nonagency alternatives for support, including information and supplies; and (5) were forced to make difficult trade-offs in their work and personal lives.

CONCLUSIONS AND RELEVANCE In this qualitative analysis, home health care workers reported providing frontline essential care, often at personal risk, during the COVID-19 pandemic. They experienced challenges that exacerbated the inequities they face as a marginalized workforce. Interventions and policies to better support these frontline health care professionals are urgently needed.

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Supplemental content

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The illness caused by the novel severe acute respiratory syndrome coronavirus 2 infection, coronavirus disease 2019 (COVID-19), was first reported in New York City (NYC) at the beginning of March.[1] Two months later, the US surpassed 1 million diagnosed cases, with NYC reporting one-third of these cases and more than 20 000 deaths.[2] Home health care workers, who are composed of home health and personal care aides and home attendants, care for community-dwelling adults and therefore play an important role in supporting those with confirmed and suspected COVID-19 who remain at home.[3-5] Unlike other health professionals, whose interactions with patients are relatively brief, home health care workers spend hours to days with patients, assisting with activities of daily living (eg, bathing and dressing), instrumental activities of daily living (eg, preparing meals and cleaning), and medically oriented tasks (eg, vital signs and wound care). In addition, these workers frequently provide companionship and emotional support.[6] The COVID-19 pandemic brings many potential challenges to this caregiving role given the risk of virus transmission to both patients and workers in the community.

Despite being integral to patient care, home health care workers—who are mostly middle-age women, people of color, and immigrants—are often an invisible and vulnerable workforce.[5,7] They work long hours, earn minimum wages, and have limited opportunities for career advancement.[8,9] Indeed, 1 of every 6 workers lives below the federal poverty line.[5] These conditions have led to high turnover rates and workforce shortages.[10,11] As the COVID-19 pandemic escalates and as home health care workers continue to care for elderly patients and for medically complex patients in the home, it is likely that this workforce will become increasingly more vulnerable, both physically and financially.

In this context, the present study aimed to understand the experiences of home health care workers caring for patients in NYC during the COVID-19 pandemic because, to date, the majority of studies and lay press articles have focused on the experiences of hospital-based health care professionals and employees. Specifically, we sought to elucidate the challenges home health care workers face regarding disease transmission, preparedness, and well-being, to inform future studies, interventions, and policies.

Key Points

Question What are the experiences of home health care workers caring for older adults and for patients with chronic illnesses during the coronavirus disease 2019 (COVID-19) pandemic?

Findings In this qualitative study of 33 home health care workers employed by 24 unique home care agencies across New York City, participants reported that they were at heightened risk for contracting and transmitting COVID-19. Despite providing integral care to vulnerable patients, home health care workers felt inadequately supported and generally invisible.

Meaning During the COVID-19 pandemic, home health care workers experienced challenges that increased their vulnerability as a workforce.

Methods

Setting and Study Population

This qualitative study was conducted from March 26 to April 30, 2020, in partnership with a benefit fund of the 1199 Service Employees International Union (SEIU) United Healthcare Workers East, the 1199SEIU Home Care Industry Education Fund (hereafter called the Education Fund). The 1199SEIU is the largest health care union in the US, representing more than 400 000 workers in hospitals, nursing homes, clinics, and home care agencies.[12] The Education Fund provides education and training benefits to 75 000 home health care workers employed by 55 home care services agencies in NYC.[13] We used purposeful sampling to achieve a balanced sample of home health care workers with respect to their agency (range of sizes of certified and licensed home care agencies) and borough of employment in NYC.[14] To be eligible, workers had to be currently employed by a home care agency in NYC and speak English. Using a standardized script, Education Fund staff members conducted general outreach via telephone calls among home health care workers who had in-person training courses at the Education Fund headquarters that needed to be rescheduled given the COVID-19 pandemic. During these calls, staff assessed workers for their interest and eligibility. The lead investigator (M.R.S.) then approached these individuals via email or telephone with a standardized script explaining the details of this voluntary study. To ensure even more perspectives, the lead investigator conducted written outreach to a few agencies (affiliated with the Education Fund) that represented additional geographic diversity and whose workers had not yet been included in the sample. This article adheres to the Consolidated Criteria for Reporting Qualitative Research (COREQ) reporting guideline.[15] The study was approved by the Cornell University institutional review board. Participants provided verbal informed consent—because interviews were not conducted in person for safety during the COVID-19 pandemic—including permission to record the interview and to publish deidentified excerpts from the interview. Informed consent was obtained in a manner consistent with the Common Rule requirement. Following the interview, participants received $25.00 gift cards.

Data Collection

Three researchers (M.R.S., E.T., and A.P.) trained in qualitative methods conducted 1-to-1 interviews using a semistructured topic guide and Zoom video conference software.[16] The topic guide was informed by prior research conducted by members of our team,[7,17,18] informal discussions with agency leaders at the beginning of the pandemic, and prior studies on home care workers' preparedness during past epidemics.[19-21] Interview questions broadly focused on (1) what workers knew about COVID-19; (2) how COVID-19 affected their work; and (3) the challenges they experienced during COVID-19 (eAppendix 1 in the Supplement). In addition, self-reported demographic characteristics data, including age, sex, race/ethnicity, educational level, and employment history, were collected.

Table. Demographic Characteristics of 33 Participants[a]

Characteristic	No. (%)
Age, mean (SD), y	47.6 (14.0)
Female sex	32 (97)
Race/ethnicity	
White	3 (9)
Black	21 (64)
Hispanic	6 (18)
Asian	2 (6)
Mixed or other	1 (3)
Educational level	
<High school	3 (9)
Completed high school or GED	8 (24)
Some college	9 (27)
College or more	13 (39)
Mean (SD) No. of years as home health care worker	10.9 (7.0)
No. of (unique) home care agencies	24
Self-reported suspected or confirmed COVID-19	4 (12)

Abbreviations: COVID-9, coronavirus disease 2019; GED, General Educational Development.

[a] Data were self-reported using open-ended questions. Responses for sex, race/ethnicity, and educational level were subsequently categorized (as shown).

Figure. Geographic Map of New York City and the Locations of the Home Care Agencies in Which Participants Were Employed

Each star represents the headquarters of a home care agency from which participants in the study were employed. Some agencies had more than 1 headquarters. JFK indicates John F. Kennedy.

Data Analysis

Interviews were audio recorded and professionally transcribed. Data were analyzed using grounded theory.[22,23] To ensure rigor of the method, a constant comparative approach was used at each stage. First, 3 investigators (E.T., A.P., and J.C.) independently reviewed and open coded 3 transcripts. Data were analyzed in Excel spreadsheets, and codes were analyzed using a custom-built and Python-based visualization tool.[24] The preliminary coding schema totaled 91 codes. Two lead investigators (M.R.S. and N.D.) reviewed the first 3 transcripts and consolidated the preliminary codes into a final codebook of 66 unique codes (eAppendix 2 in the Supplement). The 3 investigators then recoded these 3 transcripts using the uniform codebook and subsequently applied it to remaining transcripts. The 3 coders met to revise the codebook every 2 transcripts, and the 2 lead investigators reviewed each version of the codebook. Saturation, that is, the point at which no new codes were added, was achieved at the 25th interview. We conducted 8 additional interviews beyond saturation because these participants were already scheduled and had rearranged their work schedules to participate.

Once coding of all interviews was completed, the 5-person team (M.R.S., E.T., A.P., J.C., and N.D.) consolidated the codes into 19 categories by consensus.[25] The team then iteratively consolidated these categories into unifying themes, reconciling discrepancies by discussion.[26] Themes were further refined by team members (A.C.A., L.M.K., and C.K.A.) who had not conducted or coded interviews but who had content expertise.

Results

In total, 33 home health care workers employed by 24 unique home care agencies across 5 boroughs of NYC participated (**Table**). Participant mean (SD) age was 47.6 (14.0) years, 32 (97%) were women, 21 (64%) were Black participants, 6 (18%) were Hispanic participants, and 22 (67%) completed some college or more education. Overall, participants had a mean (SD) of 10.9 (7.0) years of experience as home health care workers. Of 33 participants, 4 (12%) reported that they had become ill with suspected or confirmed COVID-19 during the study period and that they had stopped working once they experienced symptoms. The **Figure** shows the geographic distribution of the 24 agencies that employed the participants. Interview duration ranged from 25 to 40 minutes. The analysis resulted in 5 major themes with subthemes (**Box**). We present them alongside representative quotations.

Theme 1: On the Front Lines of COVID-19 Medical Management, but Invisible

Participants reported that they were considered essential workers in NYC. As such, they continued to work and care for their patients despite social distancing policies that would otherwise require keeping people 6 feet apart. Participants reported that the majority of their patients had several chronic conditions, which rendered patients high risk for COVID-19. In addition to their normal caregiving tasks, the participants also monitored patients for COVID-19 symptoms. This process presented new challenges because symptoms, such as cough and shortness of breath, often mimicked patients' usual symptoms. When concern for the potential of COVID-19 arose, participants acted; some participants called their agency, whereas others called the patients' physicians and some called 911.

Box. Major Themes and Subthemes Summarizing Home Health Care Workers' Experiences When Caring for Patients During the Coronavirus Disease 2019 (COVID-19) Pandemic

Theme 1: On the Front Lines of COVID-19 Medical Management, but Invisible
Subthemes
- Providing day-to-day care for patients with chronic conditions
- Monitoring patients for COVID-19 symptoms
- Taking precautions to prevent COVID-19 in the home
- Feeling invisible

Theme 2: Heightened Risk for COVID-19 Transmission to Patients and Themselves
Subthemes
- Risk of transmitting COVID-19 to patients
- Risk of contracting COVID-19 themselves
- Reliance on public transportation, which increases exposure risk
- Numerous home care workers per patient, increases risk of spread

Theme 3: Varying Levels of Support From Agencies, Including Information and Personal Protective Equipment
Subthemes
- Differing amounts of COVID-19 information
- Limited personal protective equipment
- Lacking COVID-19–specific training

Theme 4: Reliance on Alternative Sources for Support
Subthemes
- Information sources included news media, social media, and others
- Nonagency sources of personal protective equipment
- Peer support

Theme 5: Forced to Make Tough Trade-offs Between Their Own Health and Finances
Subthemes
- Working vs risk of exposure
- Working vs risk of losing wages and benefits
- Risk of transmission vs duty to provide care

"I will ask them how long they had the cough. . . . I know even with a cough, you can't go to an ER [emergency room]. . . . So I will call the doctor, who will give us information. Then I will try to do that for the patient and myself."

Beyond monitoring their patients' physical symptoms, participants also tried to assist with their patients' emotional health. Many reported that this endeavor was worsened by patients watching the news.

"It's become a very stressful environment. She watches the news constantly. . . . As soon as I set foot in the door—'did you see this, did you see that, about coronavirus?'"

In addition, participants went to great lengths to take COVID-19 precautions while in patients' homes. They described engaging in elaborate cleaning routines whenever possible during their shifts.

"I clean like there's no tomorrow. I wipe down every surface—the table—the chair. I walk with the little bleach wipes."

However, despite these efforts to keep their patients healthy and safe, many described feeling invisible to the health care community and society.

"We're definitely a forgotten field. . . . You hear people clapping, thanking doctors and nurses, even the hospital cleaning staff. . . . I'm not doing this because I want praise; I love what I do. But it would be nice for people to show us gratitude."

Theme 2: Heightened Risk for COVID-19 Transmission to Patients and Themselves

Participants explained that providing care to patients placed them in a unique position with respect to COVID-19 transmission. They worried about their patients becoming ill in general and about transmitting the virus to them.

"I feel guilty because since they're not going outside, I know if they catch it, it's because of me. That's my fear going to work."

To protect patients, participants went to the grocery store and pharmacy on their behalf, which increased their own risk for contracting COVID-19. Although sometimes they volunteered, other times they were asked.

"He needs to stay inside the house, so he tells me, 'I need you to go there, go here.' I really don't want to, but I can't say no. I'm the aide; I'm supposed to do this."

Participants also worried about their own risk of contracting COVID-19, and nearly all felt that their dependence on public transportation increased this risk. Many participants reported using public transportation to get to their patients' homes, to run errands for them, and to travel to their agency for supplies.

"I take 3 buses to get to work: the 9, the 19, and the 5. . . . That's a lot of traveling and different people around."

Finally, many participants cared for a patient alongside other workers who entered and left the home each day. This added to their fear of transmitting COVID-19 to their patients and to one another.

"There are 5 of us that work with her. . . . What happens if we all get sick?"

Owing to this concern, some participants tried to coordinate hygiene and handoff practices with the other aides caring for common patients.

Theme 3: Varying Levels of Support From Agencies, Including Information and Personal Protective Equipment

Participants described receiving varying levels of support from their agencies, specifically regarding receiving information about COVID-19, the availability of personal protective equipment (PPE), and receiving COVID-19 training. Although some agencies adapted quickly to the pandemic by providing workers with COVID-19–related information on a weekly or daily basis, others reportedly barely communicated about the pandemic.

"Nobody ever told us, 'you gotta take precautions' and blah blah; nobody tell us anything."

Many home health care workers also reported that they lacked adequate PPE from their agencies, including masks and gloves, which they felt was essential for care.

"I'm worried about getting infected because I don't have the right equipment. The agency has not really been providing for their workers, at all."

Participants reported that they had not received COVID-19–specific training from their agencies but had hoped that it would be offered in the future. Some agencies asked participants to perform daily "self-assessments." Self-assessments, which were usually automated by phone, were intended to screen home health care workers for COVID-19 symptoms. Depending on how they answered, workers would be encouraged to go to work or to call their doctor.

"They text a 4-question screener every day. They want to know if something changes in your body. Do you have a fever? Do you have a cough?"

Theme 4: Reliance on Alternative Sources for Support

Owing to varying levels of institutional support, participants often relied on others for information and help. For example, if their agency did not provide information on COVID-19, participants turned to the news media, social media, government briefings, and their worker union.

"I watch the television, the news. I listen. I read on my phone, like on Facebook. I try to read about it everywhere."

Although some agencies did provide PPE, many participants felt that the amount supplied was insufficient to meet their daily patient care needs. In response, some participants purchased their own supplies or turned to family members and friends.

"I don't think we should have to go out and buy masks. I spent $20.00 to get a box of masks. . . . I walk all over just to buy a small can of Lysol for $7.00."

Some participants also relied on other home health care workers for advice and support or turned to religion.

"We talk to each other. We need to protect ourselves for the clients, if you want to keep working."

Theme 5: Forced to Make Tough Trade-offs Between Their Own Health and Finances

Owing to these challenges, participants described constantly navigating hard choices. For example, when patients contracted COVID-19, workers had to decide whether to continue caring for them, which meant potentially exposing themselves. Sometimes, however, patients fearful of contracting COVID-19 declined home care services, leaving workers to decide whether they should accept a new patient who they did not know. Workers also weighed whether they should remove themselves from cases they perceived to be risky. Taken together, they tried balancing the risks of work with their own health and financial well-being.

"You have to contribute certain hours to get benefits. . . . I have to go out there because I have bills to pay."

"It's just not a job where you can work from home."

In addition, many spoke about balancing the risks of caring for patients during the COVID-19 pandemic with the duty or "calling" they felt to help patients.

"I see a fire. Am I going to walk right into that fire? . . . If I have the backup, the proper gear, yes, I'm going to be there on the front lines to help that person."

Discussion

To our knowledge, this is the first study to describe home health care workers' experiences caring for older adults and for persons with chronic health conditions in the home during the COVID-19 pandemic. Our findings suggest that, although these study participants acted as essential health care professionals, they often felt poorly supported and generally invisible. Not only were they caring for a vulnerable patient population, but, owing to shortages in PPE and a heavy reliance on public transportation, they were at high risk for contracting COVID-19 and for transmitting it to their patients, other workers, and their own families. However, many could not afford to stop working, and others continued working out of a sense of duty. Taken together, caring for patients during the COVID-19 pandemic exacerbated this workforce's existing vulnerabilities and professional challenges.

Another key finding was that, across all 5 themes, home health care workers expressed feelings of anxiousness stemming from numerous stressors. As health care professionals, they feared what the virus could do to their patients and to themselves. As marginalized workers, however, they also feared the economic toll the virus might have on their ability to maintain their pay and benefits. Prior studies have found that, even before the COVID-19 pandemic, home health care workers endured high levels of stress and job insecurity.[27,28] The additional strain placed on workers by the pandemic, coupled with their already tenuous standing as minimum wage workers, exacerbated this stress. Our findings suggest that additional efforts to support workers' mental and physical well-being during the pandemic are needed. Encouragingly, the 1199SEIU is now offering well-being and resiliency training for this workforce.[29]

Some of the trade-offs that home health care workers have navigated during the COVID-19 pandemic are similar to those faced by other health care professionals, but other challenges are unique and warrant separate attention from government officials and policy makers. First, although hospitals initially experienced PPE shortages,[30,31] supplies in many regions of the United States have generally improved. Agencies, on the other hand, remain understocked. Indeed, a survey conducted by the Home Care Association of New York found that 67% of home care and hospice agencies in NY do not have sufficient PPE.[32] Given that the number of cases is expected to rise, legislation that makes PPE available to home care agencies is critical. Second, the financial hardships that workers have endured point to the need for them to be considered "essential workers" across the US, a designation that they already have in NY. Without such designation, workers cannot receive benefits, such as paid sick leave and childcare, during the pandemic.[33] Third, whereas hospitals have communicated COVID-19 information to clinicians and staff regularly, such information provided to home health workers has varied by agency, which may reflect uncertainty with respect to guidelines in the long-term care sector. To address this situation, unions

and some agencies have recently added COVID-19 information to websites and (virtual) town halls.[13] Our findings suggest that an approach integrating this information alongside COVID-19–specific training needs to be systematically implemented. Fourth, policies at the agency level that geographically organize cases to minimize public transportation use are important to protect home health workers and patients from community spread.

Strengths and Limitations

The strengths of our study include our community-partnered approach to recruit a diverse sample of participants employed by 24 unique home care agencies across NYC. In addition, we analyzed the data using a rigorous, grounded theory approach. We also note limitations. Because this is a qualitative study, the findings are not generalizable but rather convey experiences of participants that may not be captured in quantitative investigations. In addition, owing to our sample's composition, our findings may not reflect the experiences of nonunionized or privately hired workers, non-English speakers, and those in suburban or rural areas. Finally, this study does not include the perspectives of the home care agency leadership or other stakeholders in home care; future research should elicit these perspectives.

Conclusions

Home health care workers have been on the front lines, working to ensure the health of older adults and those with chronic conditions or disabilities during the COVID-19 pandemic. In doing so, these workers are at considerable risk for contracting COVID-19 themselves. The risk of contracting COVID-19 has been exacerbated by inconsistent delivery of information on what home care workers should do to protect themselves and their clients, inadequate PPE, and a heavy reliance on public transportation. Already a vulnerable workforce, home health care workers face additional risks to their physical, mental, and financial well-being during the COVID-19 pandemic. Interventions and policies are urgently needed to protect this workforce and the vital role that they play.

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Invited Commentary

Extreme Vulnerability of Home Care Workers During the COVID-19 Pandemic—A Call to Action

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Coronavirus disease 2019 (COVID-19) has been identified in more than 14 000 US nursing homes and other long-term care settings.[1] More than 316 000 residents and staff members have contracted COVID-19, and they account for 57 000 of more than 140 000 deaths in the US.[1,2] Despite our recognition of the higher mortality rates among older adults and higher overall rates of disease among nursing home staff,[3] we still know little about the risks and experiences of workers who provide help and care to older adults who live at home. Home health aides, personal care aides, and home attendants (hereafter referred to as home care workers[4]) are members of a vulnerable population within health care delivery. Underpaid and overwhelmingly women of color, they shoulder the responsibility for hands-on assistance with bathing, toileting, dressing, and housekeeping for vulnerable older adults in the home.[5] Home care workers are essential to the health of more than 7 million older adults who require care in the home.[6,7]

Author Audio Interview

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In this issue of *JAMA Internal Medicine*, Sterling and colleagues[8] present the findings from in-depth interviews with 33 unionized home care workers (64% Black/African American participants, 18% Latinx/Hispanic participants, and 97% women) across the 5 boroughs of New York City. Thanks to the quick leveraging of relationships between a medical school and a union chapter, the highly efficient use of a skilled qualitative research team, and meticulous inductive qualitative analysis, the authors have provided a window into the vulnerability of home care workers during the COVID-19 pandemic. This is a necessary step toward a robust evidence base on the clinical, educational, and support needs of these health care workers. These findings are prerequisite to improving the health and well-being of home care workers during future pandemics and outbreaks.

The findings are alarming but not surprising to those who are familiar with the work of home care workers. Sterling et al[8] identify the perils of working on the front lines of the New York City epidemic while remaining publicly and privately invisible, including an absence of public recognition and a lack of resources for reducing COVID-19 transmission. The authors provide a glimpse into the concerns of home care workers, showing how daily, face-to-face, hands-on work with care recipients increases the risk of transmission for both home care workers and care recipients during each home visit. Some home care workers had more support from their agencies, while others had little training on the epidemic; inconsistencies in levels of support led to a dangerous lack of knowledge. In particular, home care workers faced shortages in the personal protective equipment (PPE) needed to prevent COVID-19 transmission in home-based health care. Although lack of sufficient PPE has been widespread throughout the first few months of the pandemic in the United States, inadequate PPE in the home increases transmission risks for not only the home health worker and care recipient but also other household members and visitors. As creative professionals, home care workers reported seeking alternative sources of information and equipment. They discussed navigating difficult decisions about risks to their own health (by working) and finances (by not working) and their concerns about the effects of those decisions on care recipients. With 12% of this small sample self-reporting suspected or confirmed COVID-19 in themselves, they also made transparent the magnitude of their vulnerability to transmission of severe acute respiratory syndrome coronavirus 2 during the COVID-19 pandemic. Their stories provide some of