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Giving a Voice to Home Care Workers

An Empowering Data Collection Method and Source of Caregiving Support During the COVID-19 Pandemic

In 2019, there were more than 4.6 million direct care workers in the United States—2.4 million of these workers represent the home care workforce, composed primarily of home health aides and personal care aides. These workers provide home care to older adults or individuals who are disabled (PHI, 2020). Home care workers are one of the country's largest and fastest-growing occupations (U.S. Bureau of Labor Statistics, 2020), with demand for services driven by the aging population, reduced nursing home care utilization, and increased demand for home- and community-based services, all of which have been directly affected by the coronavirus disease 2019 (COVID-19) pandemic (PHI, 2020). In this Perspective, we provide a brief background on (1) the important role that home care workers play in the United States, particularly during the COVID-19 pandemic, (2) how we gathered these workers' perspectives through the use of journaling, and

(3) how journaling served as a valuable source of support and a flexible data collection method during a stressful time.

Home care workers help their clients with the daily activities necessary for independent living, including personal hygiene, dressing, meal preparation and eating, mobility and transportation, shopping, medication management, and providing general companionship and support (Yoon, Probst, and DiStefano, 2015). Home health aides specifically also provide other clinical support tasks, such as wound care or range-of-motion exercise. Therefore, to fulfill their duties, home care workers must be in close proximity to their vulnerable clients, risking COVID-19 transmission or exposure to provide needed care. Many aides are faced with a decision to put themselves at risk or take unpaid leave, which might not be a viable option for those already struggling to make ends meet. Although reliable data are not yet available, there might be additional demand for home care services for mild or moderate symptoms of COVID-19, for post-discharge care after a hospitalization for severe illness, or for management of long-term health problems from post-COVID-19 syndrome. Furthermore, some individuals might opt for home care instead of nursing home care because of the pandemic's surge in that setting (Reddy, Stall, and Rochon, 2020).

Even before the pandemic, maintaining a sufficient supply of home care workers was challenging because of relatively low pay and high emotional demands. Turnover estimates vary greatly because of data quality issues, but estimates prior to the pandemic in 2019 were as high as 82 percent (Holly, 2020). With an average median income of approximately \$17,200 and a median hourly wage of \$12.12 (PHI, 2020), home care workers are poorly compensated. Many are financially vulnerable—more than half rely on some form of public assistance—and the field faces issues with racial and gender disparities. Almost 9 in 10 home care workers are women, 3 in 5 are people of color, and 1 in 4 are immigrants to the United States (PHI, 2020). Despite the fact that the services of home care workers are essential to the independence and well-being of their clients, those services are often not appropriately valued. Home care workers report being viewed by their supervisors as second-class citizens, interchangeable, and not essential members of the care team (Franzosa, Tsui, and Baron, 2018).

The long-standing marginalization of home care workers in the workforce continues to worsen during the COVID-19 pandemic, and these workers' opinions and needs—or more broadly, their voices—have not been prioritized (Kinder, 2020). Giving voice to the experiences of

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marginalized groups—such as home care workers—could benefit the individuals in those groups by allowing them to express their feelings and experiences. It also might aid decisionmakers by providing insight into what supports could help these groups during the pandemic and beyond. The Ralph C. Wilson Jr. Foundation, a philanthropic organization, regularly invests in efforts to support caregivers' ongoing success by directing attention to their voices to influence public thinking about their role as valued, essential workers in our economy. In April 2020, the Foundation provided funding for the RAND Corporation to conduct an exploratory study on the experiences of home care workers in western New York and southeastern Michigan. The study focused on capturing concerns and challenges introduced by the COVID-19 pandemic for home care workers and potential solutions to mitigate them.

Approach

RAND collected qualitative data to examine concerns of home care workers during the COVID-19 pandemic and develop potential solutions and supports. The team engaged with regional partners (i.e., Healthcare Workers Rising and the Detroit Area Agency on Aging) to connect with home care workers who were interested in journaling about their experiences.

Journaling offered a way to obtain home care workers' reflections on their work experiences during the pandemic while minimizing constraints on when data would be collected by the study team and eliminating physical contact, in compliance with COVID-19 public health measures. The study used established methods from other journaling or diary-based studies (Herron et al., 2019). Participants were enrolled on a rolling basis and asked to keep a journal for a period of six weeks. The study team provided weekly questions for consideration focused on the impact of COVID-19 on their job, such as “What are the biggest changes you

have experienced as an aide from before the coronavirus to now?” However, participants were encouraged to express thoughts and experiences in other areas on a weekly basis or more frequently. Participants shared written (e.g., a picture of a paper entry, email) or verbal (e.g., audio recording) entries at least once a week and received a monetary incentive for their participation. The study team reviewed all entries no less than once a week and provided feedback to participants to ensure they felt heard, to build rapport, and to encourage continued participation. The feedback provided by the RAND team was generally one to two sentences and offered words of encouragement or reinforcement of major themes in the aide’s original entry:

It sounds like it has been a stressful week with getting constant calls to pick up hours, challenges with transportation, and running out of PPE [personal protective equipment]. We hope you are able to get some assistance with your grandchild soon. (RAND team member sample feedback)

Thank you for yet another thoughtful entry this week, especially given the incredibly long hours you continue to work. We are happy to hear you

took some time off to rest and take care of yourself. (RAND team member sample feedback)

The journaling component was supplemented by contemporaneous phone-based interviews with a subset of workers and representatives from home health agency leadership, which provided additional context and insights. Journal entries were coded by major themes in Dedoose, a qualitative software that facilitates systematic coding. The team analyzed patterns in these themes to better understand pressing concerns introduced by the pandemic, ways to alleviate them, and overall job-related effects of the pandemic on home care workers.

Impact of COVID-19 on a Sample of Home Care Workers

Our sample of home care workers was consisted of 37 individuals from western New York and southeastern Michigan who self-identified as personal care aides and/or home health aides. Participants were mostly women (86 percent) and identified as Black or African American (81 percent). More than 90 percent had a household income of \$40,000

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or less, and 45 percent reported a household income of \$20,000 or less.

Through their weekly journal entries, these home care workers shared their perceived anxieties and stressors related to their work and personal lives. They also consistently expressed appreciation for being asked to relate their thoughts and experiences during a challenging time. Unsurprisingly, they experienced elevated levels of fear because of the COVID-19 pandemic; aides specifically expressed uncertainty about going to work because of the possibility of coming in contact with COVID-19:

When my job put me back on the schedule [I was] actually scared to go, because it's so scary going to work. And outside, you don't know what you will touch or who you will come in contact with. (Excerpt from aide's journal entry)

Aides described additional anxieties about not knowing whether their clients had been in contact with someone who had the virus or whether the client and their families were taking appropriate precautions, such as hand washing. Although many aides were provided with PPE, consistent access to the needed quality or quantity of PPE was a concern (Bandini et al., 2021).

Beyond job-specific concerns, aides also reported several other factors adding to their stress. One major factor was their increased personal caregiving responsibilities because of COVID-19 (e.g., caring for children who were no longer spending the day in school) on top of their professional caregiving responsibilities. Home care workers felt that their work was potentially exposing their families to COVID-19, those same family members they needed to work to support. In addition, many aides were not provided with additional compensation or benefits during this trying time; only 34 percent of our sample reported receiving hazard pay. The following are representative examples:

I work so much I barely have time for my son. [I] feel like he's growing up without me but in order to make enough to make sure my bills are paid and my house has food and my kids have clothes and shoes, I have no choice but to continue to work like a slave. I'm on 4 doubles in a row this week . . . The hardest part about all of this is I'm making \$11.80/hour busting my ass and people on unemployment are making about as much as me. (Excerpt from aide's journal entry)

This is very stressful working every day and not knowing whether or not the people around you have

the virus; also scared to be around your kids because you work in the health care field. It's overwhelming at times. Just having someone to talk to or understand your pain would be great. (Excerpt from aide's journal entry)

Although the perspectives of aides tended to focus heavily on challenges and concerns, they also touched on potential solutions to improve the worker experience. These included simple, personal actions (e.g., asking aides how they are doing and stressing appreciation for their work), local or regional changes (e.g., establishing more-meaningful connections between home care workers and their community), and state and federal options (e.g., increases to compensation during the pandemic):

My employer could help by taking the time to ask their employees [and] clients how they feel and what's going on and by showing sympathy [and] compassion. (Excerpt from aide's journal entry)

My church has posted that they are giving masks and hand sanitizer and tissues and stuff, and I spread that around on Facebook. They always have something going on. (Excerpt from aide interview)

We're still getting paid minimum wage for stuff we should at least get a raise for or a couple more dollars

because we're the ones putting our lives on the line to go into people's homes and work with these people. (Excerpt from aide interview)

Journaling: A Promising Source of Support

One major takeaway from our exploratory study was the apparent impact of journaling and how it can be more than just a tool for data collection. Giving voice to experiences helps the person sharing them make sense of complex life events without judgment (Dimitroff et al., 2017). Journaling might be a promising intervention to help home care workers and other caregiving professionals exercise self-care and cope with the various stressors they are facing in their professional and personal lives, particularly in very demanding periods, such as during a pandemic. When used by other health care workers, such as nurses, journaling has been found to improve an individual's ability to handle stress and compassion fatigue—a type of burnout often associated with individuals in the helping profession (Dimitroff et al., 2017).

In the current study, participants described how this journaling exercise helped them to deal with the strain

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of being a home care worker during the pandemic. They pointed to the therapeutic nature of journaling to help them cope with added stressors:

Journaling has helped me tremendously to better deal with my anxiety, depression, stress, and work-related issues that may come up due to COVID-19 . . . I feel like I'm able to express myself in writing to decrease my symptoms of depression which at times is difficult for me to do so verbally . . . Since I've been writing I feel like a huge weight has been lifted off my shoulders. (Excerpt from aide's journaling entry)

It has proved to be therapeutic . . . Things aren't really going well, and you see it. And you're like, "I'm doing this and this and that . . ." Being able to sit down and think about it and write some feelings down, and what's been going on. It reminds me of when I was a child and I had my diary. You just write stuff down even though it's more focused, specific things. It's really been a help. (Excerpt from aide's interview)

Participants also described how writing helped them reflect on better ways to carry out job tasks:

The journaling process has helped me to recognize my strengths and weaknesses while working . . . the second week of journaling I spoke about how it was a bit difficult for [me to help a patient] get up from her chair to get my patient dressed because it was hurting my back[,] so that helped me to figure out ways to make it easier and safer for the both of us. (Excerpt from aide's journaling entry)

Furthermore, journaling provided participants with an opportunity to reflect, express themselves without judgment, and advocate for themselves and their profession at a time when home care received little attention as an essential service during the pandemic. Several home care workers expressed their gratitude for the opportunity to participate in the journaling process, and many appreciated the chance to have their voices heard, given the objectives of the study.

I like the journaling process because it gives the caregivers a voice to other people who are not on the

front lines and don't know what is really going on.
(Excerpt from aide's interview)

I feel as if someone does care about what I have to say, I feel as if I have a voice and that my voice does matter. Although I haven't fully overcome my anxiety, stress, and depression by writing, I feel as though I can cope better with day to day obstacles and challenges. (Excerpt from aide's journaling entry)

I hope this helped with letting everyone know us aides go through a lot and sacrifice a lot as well. We're essential but we're also human. (Excerpt from aide's journaling entry)

In addition to some of the potential benefits of providing support to participants at a stressful time, journaling might also be a promising method for data collection, especially when circumstances are changing rapidly, as during a public health crisis. By collecting data from journal entries weekly over the course of several weeks, we were able to

examine experiences of and concerns raised by home care workers as they responded to changing circumstances and as the COVID-19 pandemic continued to unfold. The journaling process was also a useful tool for collecting data when in-person contact was limited.

Future research should explore journaling and similar interventions—such as the use of a diary—to expand the knowledge base around support for home care workers, other caregivers, and other health care professionals, given the reported therapeutic benefits of journaling practices (Furness and Garrud, 2010; Jayalath, Ashaye, and Kvavilashvili, 2016; Välimäki, Vehviläinen-Julkunen, and Pietilä, 2007). For example, it would be valuable to investigate relationships between journaling and home care worker outcomes—such as burnout, stress, mental health, and aide retention—both during high-stress situations, such as the COVID-19 pandemic, and beyond (Sorensen et al., 2016). In addition, it will be important to examine which aspects of journaling are most beneficial. This study incorporated a feedback mechanism in which someone

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from the study team reacted to each entry; this might have been a critical step that contributed to reported benefits for participants.

In the interim, journaling approaches show promise as one way to help home care workers process their feelings and experiences. This is vital given that they work in what is often considered a socially isolated profession that is at heightened risk during stressful times, and that they serve as a source of comfort for their clients. Journaling can be implemented as a form of self-care, initiated by home care workers and done independently, or it can be implemented with more structure and feedback, adding of the benefit of feeling heard for those who feel comfortable sharing their perspectives with others. The latter could be organized through formal or informal networks of home care workers to share common experiences and lift each other up. This type of infrastructure could even be supported by employers, if implemented in a nonjudgmental way, as an avenue for them to truly listen and help employees reflect on their experiences.

Journaling offers a promising option for giving home care workers a voice and serving as a means of social support in an isolating profession. However, to truly improve the caregiving landscape and the safety and well-being of a vulnerable worker population, comprehensive and

integrative approaches are needed at multiple levels, particularly as demand for caregiver services continues to grow. Although journaling might be able to reduce stress and anxiety, policy-level changes are needed to address the structural issues of low wages and minimal benefits. Employers need to ensure that home care workers feel recognized, appreciated, and adequately compensated for their work. More broadly, the general public needs to better understand the contributions of this vital workforce and the essential services they provide.

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About This Perspective

The authors of this Perspective share different ways that journaling served as a flexible and empowering data collection tool to highlight the consequences of the coronavirus disease 2019 (COVID-19) pandemic on home care workers, and as a source of support for workers' whose job responsibilities were particularly affected by COVID-19.

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