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]

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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 the reasons underpinning what may prove to be excessive transmission rates across this population.

The article by Sterling et al[8] is of far more importance than might be expected in a study of modest size. It functions as the critical first step in understanding a larger health care crisis, using a powerful and relevant qualitative approach. As a Veterans Affairs home-based primary care physician and former medical director (T.A.A.), a nurse and program evaluator (A.O.), and a former home hospice administrator (K.L.H.), we find that the stories of unionized home care workers resonate with our experiences as researchers in home-based care for seriously ill older adults. We have heard the similar themes of invisibility, inconsistent levels of support, and difficult tradeoffs between personal health and finances from nonunionized home care workers and family caregivers. Frustrations over the lack of reliable information and PPE supplies extend far beyond this group of organized home care workers in New York City. The fears of COVID-19 transmission to and from the people they care for are the same fears that we have heard from families each weekend when following-up on the COVID-19 symptoms for patients under our care. More than 7 million older Americans are estimated to need care in their homes due to functional, cognitive, or social limitations.[7] Per the findings of Sterling et al,[8] home care workers need to be recognized and treated as essential members of our health care teams that enable older adults to remain at home and indirectly protect our emergency departments and hospitals from becoming overwhelmed during a pandemic.

The work of Sterling et al[8] serves as an important call to action. With continued increases in COVID-19 transmission rates and a vaccine still months to years away, it is time to address the needs of a population for whom it is not possible to practice physical distancing at work. The demand for home care workers will only increase as people hospitalized

with COVID-19 return home weak and debilitated and as older adults attempt to remain at home after contracting COVID-19.

First, to reduce transmission of COVID-19 in the home setting, home health agencies need to provide PPE, funding, education, and research. Home care workers have to navigate infection control issues similar to those in hospitals or nursing homes. Yet they do so in less supported and more complicated settings that include pets, other family members, and limited space.

Second, coordinated efforts between public health departments and home care agencies could collect accurate data (through surveillance testing and contact tracing) assessing the magnitude of COVID-19 infection rates in home health workers. The infection rate in this study is triple that of the most affected areas in New York City.[9] Accurate data will enable us to understand whether the infection rate is unique to this group of New York City home care workers, reflective of larger trends comparable to nursing facility staff, or reflective of infection rates in communities of color.

Third, states can respond by legislating supports and protections for home care workers. The challenges affecting home care workers are exacerbated by scant legislative and regulatory protections, inadequate pay, and for 19%, no health insurance.[5] Home care workers can be excluded from taking paid sick leave under the Families First Coronavirus Response Act. It will take legislation to protect home care workers, such as the proposed US House and Senate's Coronavirus Relief for Seniors and People with Disabilities Act that provides Medicaid grants to states to provide wage increases, overtime pay, and paid sick, medical, and family leave to home care workers.[10]

Ultimately, we need to recognize that home health worker disparities are the result of structural racism and that this problem can be addressed through structural reforms. Just as COVID-19 has accelerated other aspects of medical and social progress, it is time to use the pandemic as an opportunity to engage in social justice for home care workers, recognizing the value of their work by investing in their health and financial security.

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