

#### ARTICLE

# Supporting an Invisible Workforce: The Case for the Creation of the Home Healthcare Workers Support Act

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#### Abstract

This Article seeks to synthesize academic research on home healthcare workers during the COVID-19 pandemic to understand how their workplace challenges were magnified. Crisis communication researchers note that a crisis provides both opportunities and threats for growth. This Article argues that many of the issues that have impacted home healthcare workers have always been present, but the pandemic allows policy makers the ability to see them clearly because the pandemic brought a spotlight to the issues that home healthcare workers face on a daily basis. Consequently, the author employed a narrative analysis of the literature concerning home healthcare workers during the pandemic to understand how the pandemic exacerbated structural issues that led to an increase in mental health difficulties for this population. By understanding how the pandemic exacerbated mental health issues, policy makers can craft solutions that can withstand the next public health crisis which will undoubtedly impact the most disenfranchised.

Keywords: Home healthcare; home health aides; narrative analysis; COVID-19; workplace health and safety; health policy

#### Introduction

Where have all the home health care workers gone? In the United States, as of 2022, there is a national shortage.¹ In part, the shortage can be attributed to the lure of higher wages and better working conditions.² Before the COVID-19 pandemic, many individuals may not have known that this job existed. The pandemic brought into stark reality the essential nature that all members of the health care system play into supporting American society. For many, it was the first time that they learned about home health aides, trained health care employees who assist with activities of daily living (ADLs) such as bathing for patients in their homes. Despite the essential nature of home health aides and by extension home health care workers, they are not given the same benefits as other members of the health care system. Women of color disproportionally make up the ranks of home health aides and are paid substandard wages for their work.³

<sup>&</sup>lt;sup>1</sup>Natalie Krebs, *A shortage of health aides is forcing out those who wish to get care at home*, NPR (May 5, 2022, 5:00 AM ET), https://www.npr.org/sections/health-shots/2022/05/05/1095050780/a-shortage-of-health-aides-is-forcing-out-those-who-wish-to-get-care-at-home [https://perma.cc/KY3W-MMQ6].

<sup>&</sup>lt;sup>2</sup>Ann Oldenburg, *Nationwide Caregiver Shortage Felt By Older Adults*, AARP (Nov. 10, 2022), https://www.aarp.org/caregiving/basics/info-2022/in-home-caregiver-shortage.html [https://perma.cc/ZB43-KK28].

<sup>&</sup>lt;sup>3</sup>Jocelyn Frye, On the Frontlines at Work and at Home: The Disproportionate Economic Effects of the Coronavirus Pandemic on Women of Color, CTR. FOR AM. PROGRESS (April 23, 2020), https://www.americanprogress.org/article/frontlines-work-home/ [https://perma.cc/V2T8-JTJD].

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Compounding this problem is the reality that home health care workers are balancing being an employee of their organization with being treated as a family member by their patient.<sup>4</sup> The combination of emotional labor and unsatisfactory working conditions leads to home health care workers having poor mental health.<sup>5</sup> As the rate of older Americans deciding to live in their home increases, the demand for home health aides will continue to rise.<sup>6</sup> Consequently, it is important to propose specific mental health legislation that supports this workforce because their unique challenges are unrecognized in comparison to the rest of the health care sector.

One way to start is to employ a silver lining of the pandemic: it rendered problems that already existed in the United States' health care system more visible to researchers and the public alike. Home health care workers have been struggling with subpar pay, lack of supportive management from their staffing agencies, and work-related stress before the arrival of the COVID-19 pandemic. However, fear surrounding the virus and the essential nature of their work made these pre-existing issues worse for home health care workers.

Some crisis communication experts, such as those who employ discourse of renewal, purport that a crisis can provide both threats and opportunities for an organization's goals. Using this ethos, I argue in this Article that the pandemic can be used as a starting point to improve working conditions for home health care workers. Using research conducted on this population during the pandemic allows for researchers and policymakers to understand the challenges home health care workers have faced in the worst of times. By understanding how to devise policies in a manner that helps this population in difficult circumstances, these policies can help to better support this sector of the health care workforce.

Part I provides a brief overview of home health care workers in the United States and their working conditions. Part II of this Article lays out the methodology for the narrative analysis of literature surrounding home health care workers' experiences during the pandemic. Part III is a synthesis of the journal articles included in the narrative analysis. Part IV delves into how these findings can be implemented into a way to support home health care workers – an amendment to the Public Health Services Act. However, as I will argue, simply allocating resources will not be enough to support this population. Any policy creation and implementation should be done with home health care workers being present to ensure that the policy reaches those that need it the most.

# Part I: Home Health care Workers in the United States

The home health care workforce in the United States is rapidly growing, and that growth shows no signs of stopping, mainly due to the "silver tsunami" that is approaching as the population ages and more individuals decide to age at home. Home health care has varying definitions depending on the employer and the scope of the work, but in essence, workers in this sector provide help to individuals (oftentimes called "clients" or "patients") in their home. Some of the main duties of home health care workers are

<sup>&</sup>lt;sup>4</sup>EMILY FRANZOSA & EMMA K. TSUI, "FAMILY MEMBERS DO GIVE HARD TIMES": HOME HEALTH AIDES' PERCEPTIONS OF WORKER–FAMILY DYNAMICS IN THE HOME CARE SETTING IN AGING AND THE FAMILY: UNDERSTANDING CHANGES IN STRUCTURAL AND RELATIONSHIP DYNAMICS (2021).

<sup>&</sup>lt;sup>5</sup>Emily Franzosa, et al., "Who's Caring for Us?": Understanding and Addressing the Effects of Emotional Labor on Home Health Aides' Well-being, 59 The Gerontologist 1055 (2018).

<sup>&</sup>lt;sup>6</sup>Alexia Fernández Campbell, *Home health aides care for the elderly. Who will care for them?* Vox (Aug. 21, 2019, 9:50 AM EDT), https://www.vox.com/the-highlight/2019/8/21/20694768/home-health-aides-elder-care [https://perma.cc/SY4F-3ATM].

<sup>&</sup>lt;sup>7</sup>ROBERT R. ULMER, ET AL, EFFECTIVE CRISIS COMMUNICATION: MOVING FROM CRISIS TO OPPORTUNITY (4<sup>TH</sup> ED. 2017). 
<sup>8</sup>Tamara Felice Small et al., *Home Healthcare Workers: A Growing and Diverse Workforce at High Risk for Workplace Violence*, CTRS. FOR DISEASE CONTROL & PREV. (Sept. 2, 2021), https://blogs.cdc.gov/niosh-science-blog/2021/09/02/hhc-violence/ [https://perma.cc/47Y8-4TFF].

assisting clients with bathing, dressing, going to doctor's appointments, and keeping clients connected to their social networks.  $^{10}$ 

Members of this workforce can work as personal care assistants, home health aides, and assistive care providers. <sup>11</sup> While these job titles may seem interchangeable, the differences in these titles come down to job training and certifications. <sup>12</sup> For instance, personal care assistants have widely different standards of training depending on the state where they work because the work they do is not considered medical care which means they are ineligible for Medicare reimbursement. <sup>13</sup> Consequently, personal care assistants are typically covered by certain Medicaid programs such as Medicaid Home and Community-Based Services (HCBS) waiver programs. <sup>14</sup> Meanwhile, home health aides are considered to be performing medical care under their job description, so they are required to receive training if their agency is funded by Medicare or Medicaid. <sup>15</sup> While federally funded programs are held to a set of standards, there is more flexibility in terms of training for home health care workers who work for private agencies. <sup>16</sup> Furthermore, home health care workers who work as independent contractors are not bound by training requirements.

Despite these differences in training across the home health care workforce, there are certain aspects that remain consistent: this work is incredibly taxing; the structural conditions of work make it difficult to prioritize one's health; and the work leads to negative mental health outcomes. <sup>17</sup> In part, the physical demands of the job (i.e., lifting patients) creates these conditions, but also possible abuse by clients and low wages also create unsatisfactory working conditions. <sup>18</sup> The negative aspects of home health care reinforce inequalities for some of the country's most marginalized communities because many home health care workers are people of color, women, or immigrants. <sup>19</sup> Thus, the COVID-19 pandemic did not create the structural conditions that created oppressive working conditions for home health care workers, but rather shined a light on how undervalued this group has remained in the United States.

## Part II: Methodology

This Article focuses on the experiences of home health care workers in the United States during the COVID-19 pandemic via narrative review. The guidelines offered by Demiris and colleagues<sup>20</sup> were used: (1) conduct a search, (2) identify key words, (3) review abstracts and articles, and (4) document results. Additionally, to ensure rigor throughout the narrative review process, I used the Scale for the Assessment of Narrative Review Articles (SANRA)<sup>21</sup> as a way to guide my search.

<sup>&</sup>lt;sup>10</sup>Home Health and Personal Care Aides, Bureau of Labor Statistics, U.S. Dept. of Labor, Occupational Outlook Handbook (last visited Mar. 16, 2023), https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.htm [PERMA CC].

<sup>&</sup>lt;sup>11</sup>Home Healthcare, Occupational Safety & Health Administration, U.S. Dept. of Labor, https://www.osha.gov/home-healthcare [https://perma.cc/A6RN-TY5T].

<sup>&</sup>lt;sup>12</sup>Felice Small et al., *supra* note 8.

<sup>&</sup>lt;sup>13</sup>The National Landscape of Personal Care Aide Training Standards, UCSF Health Workforce Rsch. Ctr. on Long-Term Care (Oct. 31, 2014), https://healthworkforce.ucsf.edu/sites/healthworkforce.ucsf.edu/files/Report-The\_National\_Landscape\_of\_Personal\_Care\_Aide\_Training\_Standards.pdf.

<sup>&</sup>lt;sup>14</sup>Id.

<sup>&</sup>lt;sup>15</sup>Manisha Sengupta et al., *Training of Home Health Aides and Nurse Aides: Findings From National Data*, 33 Gerontology & Geriatrics Ed. 383-401 (2012).

<sup>&</sup>lt;sup>16</sup>Id.

<sup>&</sup>lt;sup>17</sup>Madeline R. Sterling et al., Prevalence and Predictors of Home Health Care Workers' General, Physical, and Mental Health: Findings From the 2014–2018 Behavioral Risk Factor Surveillance System, 111 Am. J. of Pub. Health 2239-50 (2021).

<sup>&</sup>lt;sup>18</sup>Sunniva Grønoset Grasmo et al., *Home health aides' experiences of their occupational health: a qualitative meta-synthesis*, 40 Home Health Care Servs. Quarterly, 148–76 (2021).

<sup>&</sup>lt;sup>19</sup>Direct Care Worker Disparities: Key Trends and Challenges, Paraprofessional Healthcare Inst. (Feb. 8, 2022), https://www.phinational.org/resource/direct-care-worker-disparities-key-trends-and-challenges/ [https://perma.cc/X8ZE-4TY5].

<sup>&</sup>lt;sup>20</sup>George Demiris et. al., Chapter 3: Defining and Analyzing the Problem, Behavioral Intervention Research in Hospice and Palliative Care: Building an Evidence Base 27-29 (2019).

<sup>&</sup>lt;sup>21</sup>Christipher Baethge et. al., *SANRA*—a scale for the quality assessment of narrative review articles, 3, 1-7 (2019).

# Search Strategy

I ran the search at several intervals: October 2022, December 2022, and April 2023. This step was an iterative process, as I was defining the scope of who would be counted in terms of the population. As noted in Part I, different states and even agencies have varying definitions about who counts as a home health care worker. Consequently, I decided on an inclusive definition of who would be included in the analysis which is reflected in the April 2023 search strategy.

The databases that were used for the April 2023 search were Web of Science, CINAHL, PubMed, Embase, and Medline. These databases were chosen because they focus on indexing health sciences and behavioral sciences research. The search strategy that was used for each database was as follows: "home health aide" AND "COVID-19 pandemic" AND "United States". While I attempted to use other key words that fall under the home health care workforce, the search results were irrelevant to the search based on the inclusion criteria. However, to ensure that I had a representative account of the literature on home health care workers experience, I also manually searched for articles using Google Scholar.

#### Inclusion and Exclusion Criteria

I did not create restrictive parameters for the inclusion criteria, in order to capture a variety of data sources and methodologies used to explore home health care workers' experiences. To sift through the search results, I employed the following inclusion criteria: (1) published in peer-reviewed journals, (2) written in English, (3) home health care workers who were working in the United States, (4) focused on care provided during the COVID-19 pandemic, and (5) focused on home health care workers.

Exclusion criteria were the following: (1) home health care workers who worked in long-term care facilities and assisted living facilities were excluded and (2) data from only agencies without corresponding data from home health care workers was excluded. Long-term care and assisted living facilities are the types of organizations that fall under the Long-Term Care Ombudsman Program, a federal advocacy program created under the Older American Act.<sup>22</sup> Each state is required to have a version of the Ombudsman Program, and while different stakeholders may argue about its effectiveness,<sup>23</sup> it has the potential to help to standardize the working conditions for health care workers in a way that home health care workers may not experience.

#### Search Results

Based on an initial search using the four databases, I received sixty-three results across the five databases, and these numbers reflect duplicate entries: Web of Science (15), CINAHL (15), PubMed (29), Medline (0), and Embase (4). After screening the articles and removing redundant search results, seven database-retrieved articles and one manually pulled article were included in the analysis. Since academic research can have a long timeline to publication, not all research regarding home health care workers' experiences during the pandemic may be represented.

#### Part III: Synthesis

Based on the search strategy, eight articles were included in the final analysis. Seven articles were found via databases and one article<sup>24</sup> was manually pulled. Below is a data abstraction table with the text pulled directly from the articles without paraphrasing:

<sup>&</sup>lt;sup>22</sup>Long Term Care Ombudsman Program, N.Y. STATE OFF. FOR THE AGING (2021), https://aging.ny.gov/long-term-care-ombudsman-program [https://perma.cc/Q4VT-NLV6].

<sup>&</sup>lt;sup>23</sup>Raga Justin, *Over half of NY nursing homes lack proper oversight, advocates say*, TIMES UNION (Feb. 20, 2023), https://www.timesunion.com/state/article/half-ny-nursing-homes-lack-proper-oversight-17793697.php [https://perma.cc/V9X4-HLQN].

<sup>&</sup>lt;sup>24</sup>Julia Bandini et al., *Home care aide safety concerns and job challenges during the COVID-19 pandemic*, 31 NEW SOLUTIONS: A J. of Environmental & Occupational Health Pol'y 20-29 (2021).

Title	Journal	Method	Sample Size	Main Findings
Forgotten Front Line: Understanding the Needs of Unionized Home Health Aides in Downstate New York During the COVID-19 Pandemic <sup>25</sup>	Home Health Care Services Quarterly	Cross-sectional survey	Over a four-month period, a total of 256 HHAs employed by forty-nine agencies participated in the survey (response rate of 22%).	First, workers bore significant risks of COVID-19 exposure and infection, often with limited information and resources to help them navigate these risks. Second, HHAs experienced mental and physical stress that was exacerbated by the pandemic conditions. Third, due to COVID-19, this work force experienced employment disruptions and greater difficulties maintaining financial security.
All alone: A qualitative study of home health aides' experiences during the COVID-19 pandemic in New York <sup>26</sup>	American Journal of Infection Control	Semi-structured qualitative interviews	25 [Home Health Aide] HHAs employed by 4 unique home care agencies participated	Three major themes related to the experience of HHA's working during the COVID-19 pandemic emerged: (1) all alone, (2) limited access to information and resources, and (3) dilemmas related to enhanced COVID-19 precautions.
Home Health Aides' Increased Role in Supporting Older Veterans and Primary Healthcare Teams During COVID-19: a Qualitative Analysis <sup>27</sup>	Journal of General Internal Medicine	Interviews	Eight home health aides, 6 home health agency administrators, and 9 primary care team members (3 RNs, 3 social workers, 3 MDs) serving veterans at a large, urban, Veterans Affairs medical center	Four main themes emerged around aides' roles in the car team during COVID-19: (1) aides as physically present "boots on the ground" durin medical and caregiving disruptions, (2) aides as care coordination support, (3) aides as mental health support, and (4) intensification of aides' work
"We want to hear your problems and fix them": A case study of pandemic support calls for home health aides <sup>28</sup>	Services Quarterly	Qualitative, single case study design involving semi- structured interviews and analysis of one year of thematic notes from the calls	interviews with call staff and agency leaders (n = 9)	Difficult emotions were a dominant theme among the issues that aides raised, including sadness, grief, frustration, and anger. Another core theme of the ca notes was aides' appreciatio for two primary aspects of th calls: agency responsiveness to their requests and the emotional support received.
"It changed everything": The safe Home care qualitative study of the COVID-19 pandemic's impact	BMC Health Services Research	Phone interviews	[Home Care] HC clients (n = 9), aides (n = 16), and agency managers (n = 12).	Fear of infection and transmission among HC clients and aides were strong themes. Infection prevention and control became the top priority guiding day-to-day

<sup>&</sup>lt;sup>25</sup>Sanjay Pinto et al., Forgotten Front Line: Understanding the Needs of Unionized Home Health Aides in Downstate New York During the COVID-19 Pandemic, 41 Home Health Care Servs. Quarterly 124. (2022).

<sup>&</sup>lt;sup>26</sup>Zainab Toteh Osakwe et al., *All alone: A qualitative study of home health aides' experiences during the COVID-19 pandemic in New York.* 49 Am. J. of Infection Control 1362. (2021).

<sup>&</sup>lt;sup>27</sup>Emily Franzosa, et al., Home Health Aides' Increased Role in Supporting Older Veterans and Primary Healthcare Teams During COVID-19: a Qualitative Analysis, 37 J. of General Internal Med. 1830 (2022).

<sup>&</sup>lt;sup>28</sup>Emma K. Tsui et al., "We want to hear your problems and fix them": A case study of pandemic support calls for home health aides, 41 Home Health Care Servs. Quarterly 124 (2022).

#### (Continued)

Title	Journal	Method	Sample Size	Main Findings
on home care aides, clients, and managers <sup>29</sup>				business operations at agencies; sourcing adequate personal protective equipment for staff was the most urgent task. HC aides expressed concerns for their clients who showed signs of depression, due to increased isolation during the pandemic. The disappearance of comforting touch – resulting from physical distancing practices – altered the expression of compassion in the HC aide-client care relationship.
Experiences of Home Health Care Workers in New York City During the Coronavirus Disease 2019 Pandemic: A Qualitative Analysis <sup>30</sup>	JAMA Internal Medicine	1-to-1 semi structured interviews	33 home health care workers in New York City	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.
Essential but Excluded: Building Disaster Preparedness Capacity for Home Health Care Workers and Home Care Agencies <sup>31</sup>	JAMDA	Summary of existing empirical research	N/A	Fear of contracting and transmitting COVID-19     Limited resources, including PPE, testing, and information     Physical, emotional, and financial impact on [home health care workers] HHCWs and agencies
Home Care Aide Safety Concernsand Job Challenges During the COVID-19 Pandemic <sup>32</sup>	NEW SOLUTIONS: A Journal of Environmental and Occupational Health Policy	Journaling approach with aides as well as in-depth interviews with aides and leadership representatives	For a period of six weeks, thirty-seven aides in [Western New York] WNY and [Southeast Michigan] SEMI submitted journal entries at least weekly; interviews with fifteen aides and leadership representatives from nine home health agencies in New York and Michigan.	Workers described a range of concerns around workplace safety including uncertainty around whether a client had COVID-19, inadequate access to personal protective equipment and safe transportation, as well as fundamental changes to interactions with clients.

<sup>&</sup>lt;sup>29</sup>Pia Markkanen et al., "It changed everything": The Safe Home Care qualitative study of the COVID-19 pandemic's impact on home care aides, clients, and managers, 21 BMC HEALTH SERVS. RSCH. 1-14 (2021).

<sup>&</sup>lt;sup>30</sup>Madeline R. Sterling et al, Experiences of home health care workers in New York City during the coronavirus disease 2019 pandemic: a qualitative analysis, 180 JAMA INTERNAL MED. 1453-59 (2020).

<sup>&</sup>lt;sup>31</sup>Emily Franzosa et al., Essential but excluded: building disaster preparedness capacity for home health care workers and home care agencies, 23 J. of the Am. Med. Directors Ass'n. 1990-96 (2022).

<sup>&</sup>lt;sup>32</sup>Julia Bandini et al., *Home care aide safety concerns and job challenges during the COVID-19 pandemic*, 31 NEW SOLUTIONS: A J. of Environmental and Occupational Health Pol'y, 20-29 (2021).

Of the eight articles, six were qualitative studies, one was a quantitative study, and one was a summary of prior literature. The studies covered topics such as challenges caring for patients,<sup>33</sup> needs of unionized home health aides,<sup>34</sup> experiences of home health aides caring for veterans,<sup>35</sup> support calls offered by a home health agency,<sup>36</sup> and learning from the pandemic in terms of creating disaster preparedness infrastructure.<sup>37</sup> Apart from two articles, the empirical data for these articles were collected with samples from New York. One common theme across all the articles was mental strain from the COVID-19 pandemic which was either made through direct claims by home health care workers or through complaints about symptoms (i.e., harder to get out of bed in the morning).<sup>38</sup> The other themes emerging from the synthesis were primarily workplace tensions.

# Theme #1: Tensions with Agency

This theme manifested in two ways. One way was the lack of support for home health aides such as financial support, emotional support, or even enough PPE (personal protective equipment) to safely do their job. For instance, in terms of emotional support:

People who work in nursing homes and hospitals are better. They have more support. We go through worse, there is no support. Because sometimes you need someone to talk to, because sometimes you are so burdened...now nurses don't visit patients often anymore...<sup>39</sup>

Being a home health aide during this time period was incredibly isolating—based on my personal interactions with home health aides, home health aides can build community with one another and those within their patient's care team. To be deprived of those connections can help contribute to anger toward one's agency. However, one article<sup>40</sup> did note that the agency did try to recognize some of these tensions by giving aides a place to talk – while it was not perfect, aides did note that it helped them feel to be seen in a more holistic light by their agency.

The second way this theme manifested was disagreements about how to best proceed with patient care during the pandemic. As previously mentioned, in many instances, home health aides were the only other health care professional in a patient's home. In terms of veterans' care for instance, home health aides ended up having more responsibilities due to the circumstances, but agencies were worried about this shift due to potential liabilities.<sup>41</sup>

In conjunction with the other tensions, disagreements about patient care can appear be short-sighted in the eyes of home health care workers. As previously noted, while some efforts were made to support home health care workers' mental health during this time, <sup>42</sup> it was the exception rather than the rule. The

<sup>&</sup>lt;sup>33</sup>Zainab Toteh Osakwe et al., *All alone: A qualitative study of home health aides' experiences during the COVID-19 pandemic in New York*, 49 Am. J. of Infection Control 1362 (2021); Madeline R. Sterling et al., *Experiences of home health care workers in New York City during the coronavirus disease 2019 pandemic: a qualitative analysis*, 180 JAMA Internal Med. 1453-59 (2020); Markkanen et al., *supra* note 29, at 1-14; Julia Bandini et al., *Home care aide safety concerns and job challenges during the COVID-19 pandemic*. 31 NEW SOLUTIONS: A J. of Environmental and Occupational Health Pol'y, 20-29 (2021).

<sup>&</sup>lt;sup>34</sup>Pinto et al., *supra* note 25, at 124.

<sup>&</sup>lt;sup>35</sup>Emily Franzosa et al., Home Health Aides' Increased Role in Supporting Older Veterans and Primary Healthcare Teams During COVID-19: a Qualitative Analysis, 37 J. of General Internal Med. 1830 (2022).

<sup>&</sup>lt;sup>36</sup>Emma K. Tsui et al., "We want to hear your problems and fix them": A case study of pandemic support calls for home health aides, 41 Home Health Care Servs. Quarterly 124 (2022).

<sup>&</sup>lt;sup>37</sup>Emily Franzosa et al., Essential but excluded: building disaster preparedness capacity for home health care workers and home care agencies, 23 J. of the Am. Medical Directors Ass'n. 1990-96 (2022).

<sup>&</sup>lt;sup>38</sup>Pinto et al., supra note 25, at 124.

Franzosa et al., supra note 38, at 1830.

<sup>&</sup>lt;sup>39</sup>Osakwe et al., *supra* note 33, at 1362.

<sup>&</sup>lt;sup>40</sup>Tsui et al., *supra* note 39, at 124.

<sup>&</sup>lt;sup>41</sup>Franzosa et al., *supra* note 38, at 1830.

<sup>&</sup>lt;sup>42</sup>Tsui et al., supra note 39, at 124.

majority of the articles implicitly indicated that agencies only care about aides insofar that they are profiting from them, but not necessarily when it comes to doing what is best for patients.

# Theme #2: Tensions Arising from Increased Responsibilities

Many home health care workers become the connection between their patients and other health care professionals, a role that expanded during the pandemic. <sup>43</sup> During this time, many health care professionals moved to telehealth options for their patients, but home health aides did not have that opportunity because they are deemed essential workers. This title comes from the fact that aides help their patients with ADLs – without these aides, patients could not safely live in their homes. Consequently, home health aides were doing more work in the patient's home, but they were not appropriately compensated, leading to strain on their mental health.

Second, the stay-at-home orders meant that many patients could not interact with their loved ones due to the limited ability to travel. Essentially, these home health care workers were the main source of in-person contact for many patients. Home health care workers provided that due to their clients' inability to go outside, those clients became increasingly depressed, which ultimately strained these workers' mental health as well.<sup>44</sup>

# Part IV: Community Driven Solutions for a Healthier Home Healthcare Workforce Rationale for the Creation of the Home Healthcare Workers Support Act

The COVID-19 pandemic made the lives of home health aides far more difficult than they previously were. Consequently, as signs of stability amidst the virus emerged (i.e., access to vaccinations and growth in jobs across different industries), home health care workers took the opportunity to leave their current positions. However, to retain qualified home health care workers and attract new individuals to the role, better policies need to be implemented to help deal with this issue. The lack of home health aides is already an emergency as older individuals are going without care in their homes, leaving them with few options for managing their health.

Given the growing nature of this emergency, I propose an amendment to the Public Health Service Act. One purpose of this Act is to "to stimulate and assist states and communities with the development of local health resources, and to further development of education for the health profession," which in essence means it allows resources to be allocated for health education efforts within the health care workforce. Throughout the years, different amendments have been passed or attempted to be passed. Specifically, an amendment could be proposed in Congress called the Home Healthcare Workers Support Act with authorizes grants for training and support services for home health care. The amendment could be fashioned in similar manner to the Alzheimer's Caregiver Support Act, <sup>46</sup> a bill that was introduced in 2021.

The focus of the Support Act is solely on mental health for several reasons. First, many of the individuals who are home health care workers come from backgrounds where mental health is not discussed. For this Support Act to be effective, it will take resources and willingness from the community to agree to discuss defining the problem of mental health and implementing solutions. If other aspects of health are including in the Support Act (i.e., physical health), then the risk is stretching agencies or groups working to improve home health care workers' health (i.e., advisory boards) too thin and no actionable solutions will be achieved. Second, by addressing mental health through structural solutions that are created in cooperation with home health care workers, it increases the possibility that home

<sup>&</sup>lt;sup>43</sup>Franzosa et al., *supra* note 38, at 1830.

<sup>&</sup>lt;sup>44</sup>Markkanen et al., *supra* note 29, at 1-14

<sup>&</sup>lt;sup>45</sup>H.W. Schultz, Food Law Handbook (1981).

<sup>&</sup>lt;sup>46</sup>S. Res. 56 117th Congress (2021).

health care workers can move forward to taking care of other aspects of their health (i.e., physical) because they start to have the mental tools or structural changes within their agencies to do so.

## Culture-Centered Approach and Effective Implementation

The amendment and its implementation should be grounded in a culture-centered approach (CCA). CCA emphasizes listening to disenfranchised populations when crafting legislation in order to be sensitive to the needs of this population rather than being another blanket policy statement that perpetuates mental health inequalities.<sup>47</sup> It stands in contrast to other approaches (i.e., community based participatory research) because the goal of CCA is to build spaces where dialogue within a community can occur in order for community members to create inclusive and participatory communication based on particular cultural nuances.<sup>48</sup> CCA is composed of three tenets: culture, structure, and agency.<sup>49</sup> As Dutta notes about these components:

Culture reflects the shared values, practices, and meanings that are negotiated in communities, grounded in the notion that communities are heterogeneous sites of contestation and meaning making. In this sense, culture is both static and dynamic; it passes on values within a community, and at the same time co-creates opportunities for transforming these values over time. Structure refers to the systems of organizing that enable or constrain access to resources. In the realm of communication, structures constitute the communicative resources, rules, logics, and assumptions in a community. These rules, logics, resources, and assumptions are constituted within social, political, and economic structures, tied to the flows of power within social systems. Agency depicts the enactment of everyday choices and decisions by community members amid structural constraints that reflect the daily negotiations of structures.<sup>50</sup>

These three aspects are interconnected within the communication field, and they help both scholars as well as policymakers to understand how structural forces help to reproduce and maintain inequalities.<sup>51</sup>

Using CCA in policy creation can look different depending on the community seeking to employ the approach. Dutta advocates for using CCA as a way to listen to the narratives that are typically erased and are at the margins of a community in order to reduce health inequalities. However, to implement CCA in order to design interventions (i.e., new legislation), DeTora and Robinson notes one way to keep the spirt of a CCA approach to communication in order to reduce health inequalities is to allow for an openended narrative approach that is informed by race, gender and culture. Ultimately, DeTora and Robinson argue that all members of a community are heard, but special attention is paid to its most marginalized. S4

For the Home Healthcare Workers Support Act, I suggest that to have effective policy implementation, both Dutta's seminal work as well as DeTora and Robinson's additions to CCA should inform the rollout of the Support Act. The home health care workforce is made up of a variety of occupations including home health aides, personal care assistants, and assistive care providers. Furthermore, some home care workers have aspects of their identity that have nothing to do with their work such as their

<sup>&</sup>lt;sup>47</sup>Mohan J. Dutta, Communicating Health: A Culture-centered Approach (2008).

<sup>&</sup>lt;sup>48</sup>Mohan J. Dutta, *Culture-centered Approach in Addressing Health Disparities: Communication Infrastructures for Subaltern Voices*, 12 Comm. Methods & Measures 239-59 (2018).

<sup>&</sup>lt;sup>49</sup>Id.

<sup>&</sup>lt;sup>50</sup>Id.

<sup>&</sup>lt;sup>51</sup>Dutta, *supra* note 47.

<sup>&</sup>lt;sup>52</sup>Mohan J. Dutta, A Culture-Centered Approach to Listening: Voices of Social Change, 28 Int'l J. of Listening 67-81. 2014; Dutta. supra note 47, at 239-59.

<sup>&</sup>lt;sup>53</sup>DeTora et al., Culture-Centered Approaches to Rhetorical Research: Considering Domestic Violence as a Site for Intersectional Interventions in Strategic Interventions in Mental Health Rhetoric (2022).

gender, ethnicity, and socio-economic levels. All of these identity markers and roles need to be taken into account when crafting legislation that is culturally centered. Dutta highlights several touchpoints for employing CCA including having the community members participate to define the problem and working with community members through partnerships.<sup>55</sup>

In practice, a CCA approach to developing mental health resources and support for home care workers can mean writing into the Support Act that home health agencies must work with home health aides to receive funding. If home health agencies or policymakers who have not spent time as a home health care worker try to define what mental health problems are for this workforce, then the eventual programming that results will not be attuned to the workers' needs. For instance, personal care assistants and home health aides can potentially have different workplace issues, but agencies may not realize this point if they do not engage with these sub-groups separately.

However, as previously noted, CCA does not stop at defining a problem. Community members are essential to developing effective solutions. In terms of programming, a CCA approach could mean involving home health aides in the decision-making process of what possible resources are created from the federal funding. By asking home health care workers about their perceptions at every step of the Support Act's implementation, the likelihood increases that these solutions will be taken up by home health care workers and improve their mental health.

#### Conclusion

Oftentimes, when a crisis impacts a community, it disproportionately impacts the community's most vulnerable and marginalized members. The COVID-19 pandemic disproportionately impacted home health care workers, already an underpaid and underappreciated population. The COVID-19 pandemic caused these essential workers increased strain on their mental health as they attempted to care for the patients that they care about while trying to navigate agency bureaucracy, lack of information regarding the coronavirus, and financial costs to keep themselves healthy. The root tensions identified in this Article, an unequal balance between agency and worker along with a lack of support for care work, have always been present for the home health care workforce. However, the research conducted during this national crisis can be used as an opportunity to help strengthen the home health care workforce in order to better prepare for the next public health crisis and better support some of our most marginalized.

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<sup>&</sup>lt;sup>55</sup>Dutta. *supra* note 52, at 239-59.