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Making a Bad Situation Worse: Examining the Challenges Facing Rural Home Care Workers

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Abstract

This study examines the unique challenges facing rural home care workers. Semi-structured interviews were undertaken between July 2021 and February 2022 with 23 participants that have experience in rural home care delivery. The major challenge confronting rural home care workers involved distance and transportation. This challenge emerged due to long distance between clients, unreliable vehicles, inadequate reimbursement, and inclement weather. In turn, this challenge exacerbated three other types of challenges facing rural home care workers: workforce challenges that consisted of a persistent labor shortage and shorter visits that forced workers to rush through tasks, client isolation due to the social and physical seclusion of households, and the poor working conditions of home care work more broadly. Without policy interventions that respond to these particular challenges, the care gap in rural areas can be expected to grow.

Keywords

caregiving, home and community based care and services, home care, rural

What this paper adds

- A research perspective that emphasizes the direct experiences of rural home care workers.
- A more comprehensive understanding of the challenges facing rural home care workers.
- Emerging themes that identify different types of challenges facing rural long-term care delivery.

Applications of study findings

- To confront the growing care gap in rural areas, policy interventions need to acknowledge and respond to the particular challenges facing rural home care workers.
- A range of stakeholders, including the federal and local government, employers, long-term care organizations, and labor organizations, need to collaborate to invest in and expand support for rural home care workers.

Background

As the population in the United States ages, the demand for caregivers continues to grow. Projections suggest that nearly seven million job openings will need to be filled in the direct care workforce by 2028, with most of these jobs in home health care (Campbell et al., 2021). Home care workers (HCWs)—direct caregivers who provide personal, medical, and emotional care to clients with a range of health conditions—are essential to filling the care gap and enabling people to age in place (Cutchin, 2003; Milligan, 2009). Despite the importance of HCWs to the long-term care system, these workers experience low compensation (Campbell et al., 2021), inadequate training (Polacsek et al., 2019; Sterling et al., 2018), high turnover (Butler et al., 2013), and perform emotional labor that often goes unrecognized and uncompensated (Franzosa et al., 2019;

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Hochschild, 1983). The burdens confronting HCWs are magnified by their exclusion from broader healthcare teams, despite performing a wide range of medical tasks such as taking vital signs and preparing healthy meals (Osterman, 2017; Sterling et al., 2022a).

The presence of a higher proportion of older adults (age 65+), worse health outcomes for residents, and fewer formal HCWs suggest that the demand for home care services is especially pronounced in rural areas of the United States. Older adults are expected to account for 28% of the total population in rural communities by 2030, compared to 20% in urban and suburban areas (Campbell et al., 2021). Rural residents generally suffer worse health outcomes and more difficulties accessing health services due to a variety of factors, from inadequate transportation to a lack of physicians and healthcare providers (Arcury et al., 2005; Douthit et al., 2015; Lahr et al., 2021; van Dis, 2002). Fewer direct service workers are available in rural areas (Brown et al., 2011) and rural residents are more likely to rely on informal family caregiving than urban residents (Sterling et al., 2022b). Despite this variation, the impact of geography on HCWs is relatively undertheorized (Goins et al., 2009). Recent research on informal rural caregivers identifies inadequate access to resources, transportation, and increased social isolation as major challenges (Henning-Smith & Lahr, 2018). Roberto et al. (2022) find that the cultural attributes of rural Appalachian communities, such as particular beliefs and family norms, impact access to care and define caregiving duties.

Despite the clear need for home care services in rural areas, researchers have largely ignored the challenges facing rural HCWs who form the backbone of formal care. Most scholars have focused on the impacts of geographic variation in home care delivery on clients (Coburn et al., 2016; Forbes & Janzen, 2004; Kenney, 1993; Siconolfi et al., 2019), agencies and other providers (Ma et al., 2022; Weech-Maldonado et al., 2007), and the long-term care system more broadly (Bolda & Seavey, 2001). While client and agency outcomes are undoubtedly important components of home health delivery, the absence of empirical evidence regarding the experiences of rural HCWs limits the ability to develop a comprehensive understanding of the long-term care system and its impact on workers.

To center the experience of HCWs, we make use of Zarska et al. (2021) conceptual framework outlining the relationship between working conditions, worker outcomes, and patient outcomes. They argue that worker outcomes are determined by working conditions, organizational practices, worker characteristics, and patient care characteristics. In turn, both working conditions and worker outcomes impact patient outcomes, emphasizing the importance of developing policy solutions to improve the working conditions of frontline HCWs. We explore whether this framework holds in rural settings by examining the working conditions of rural HCWs.

In this study, we aim to understand the perspectives of HCWs and other key stakeholders in home care on the unique challenges of providing formal care in rural areas. A perspective emphasizing the direct experiences of HCWs is especially important considering the existing and growing care gap, particularly in rural areas. *What are the unique challenges facing rural HCWs*? Answering this question contributes to an improved understanding of geographic variation in the challenges facing HCWs and serves to inform specific policies and strategies needed to confront the increasing care gap.

Methods

Setting and Study Design

To examine the unique challenges facing rural HCWs in the United States, we undertook a qualitative interview study with HCWs from across upstate New York between July 2021 and February 2022. Eligibility criteria included: being currently employed as a home care worker in a rural area, which the research team defined as areas outside of cities and their immediate suburbs. We used convenience and snowball sampling to recruit participants. We started with outreach to multiple types of home health-related organizations, beginning with the upstate New York division of SEIU 1199, a labor union of HCWs and other healthcare workers across the United States, and the Tompkins County Long Term Care Committee, a local group in Tompkins County, New York, that advocates for and supports clients who require long-term care services. After meeting with representatives from both organizations, we obtained the contact information for a range of HCWs and home care providers—including representatives of both agencies and private employment registries—across rural areas of upstate New York. We also relied on snowball sampling to identify participants independent of these organizations. This study received IRB approval at the authors' university [#1810008331].

Data Collection

One researcher (JK), trained in qualitative research methods, conducted all semi-structured interviews and was joined by a research assistant to improve notetaking. Interviews lasted between 40 min and one hour and took place virtually over Zoom. The interviews were a mix of audio-only and video conference as a result of the ongoing COVID-19 pandemic. All participants provided informed verbal consent prior to the interview over Zoom. Interview questions focused on the types of care HCWs provide, the unique challenges facing HCWs in more rural areas, and any potential comparisons between caring for clients in rural versus urban areas if the participant had experience in both settings. Each participant received a US $25 gift card to compensate them for their time.

Data Analysis

All interviews were professionally transcribed and analyzed according to a general inductive approach and grounded

theory (Foley & Timonen, 2015; Thomas, 2006). We used grounded theory in our analysis because limited prior research has examined the challenges facing rural home care workers in the United States. In phase one of analysis, the first author (JK) read through the transcripts of interviews completed up to that point and took note of unique and important findings. In phase two, through discussion with the last author (AA), these initial findings were used to shape and inform subsequent interviews. The remaining phases occurred after the completion of all interviews. In phase three, we implemented in-vivo coding of all interviews. Two co-authors (EM; EK) coded all 23 transcripts and the first author (JK) resolved lingering questions and discrepancies in the coding process. In phase four, the first author (JK) and last author (AA) identified emergent themes that served as the basis for the findings section. Major issues, such as the content and grouping of major themes, were resolved through consensus. This article adheres to the Consolidated Criteria for Reporting Qualitative Research (COREQ) reporting guideline.

Findings

A total of 23 participants were interviewed for this study. Nineteen of the participants work as HCWs, while the other four are agency or registry representatives (two) or long-term care advocates (two) who provided additional context on the challenges facing rural HCWs. Nearly all (22) of the 23 participants identified as women and a large majority (19) identified as white. All HCWs had experience providing home care in rural areas of upstate New York. More information about interviewees can be found in Table 1.

The major *unique* challenge facing rural HCWs emerging from our interviews involved distance and transportation. Rural HCWs require reliable transportation to service clients over long distances and through inclement weather. This major challenge, in turn, exacerbated three other types of challenges—workforce and workflow issues, client isolation and noncompliance, and poor working conditions common to the broader home care industry—identified in our study. In the rest of this section, we discuss the major unique challenge of distance and transportation and how it exacerbated the other three types of challenges. We conclude by situating our findings in the literature and discussing potential policy implications and prescriptions.

Table 1. Demographic Characteristics.

Characteristic	No. (%)
Age, mean, y	53. 9
Female sex	22 (96)
Race/ethnicity	
White	19 (83)
Black	3 (13)
Latino/a	1 (4)
Educational level	
High school	9 (39)
Some college	7 (30)
College or more	7 (30)
HCW	19 (83)
Mean no. of years as HCW	16. 25*
Full-time HCW	10 (53)*
Part-time HCW	9 (47)*

*Generated from sample of 19 HCWs.

Major Theme: Distance and Transportation

The major challenge confronting rural HCWs involved commuting to and from clients. HCWs reported traveling very long distances from their own homes to get to work and between client residences throughout the day. For example, the average travel time between clients in the Adirondack region of upstate New York, a particularly remote area, is approximately 30 min, meaning HCWs spend a large portion of their work time traveling (P07). P20, who worked in this region, reported driving as many as 800 miles each week traveling to and from clients (P20). It is important to note that agencies, for the most part, do not provide transportation and rural HCWs need access to a reliable vehicle to service clients due to inadequate public transportation. Travel time can also serve as a source of contention between agencies and HCWs. P18 explained:

> "They've [the agency] learned to give me half an hour in between, because they never know what's going to happen…it gives you a little wiggle room and you're not in such a panic mode trying to get from one patient to the other. You know that, okay, I have time to breathe. I have time to stop and go to the bathroom if I have to. I can catch my breath before I get to the next one" (P18).

Inclement winter weather in upstate New York makes transportation between clients difficult and, sometimes, impossible. HCWs need a reliable car not only to deal with the physical distance between clients, but also dangerous road conditions. This requires HCWs to invest in snow tires to travel more safely between clients. As P08 mentioned, extremely hazardous road conditions may mean clients go without care for the day:

> "I mean travel-wise, winters can be pretty drastic… around here. So, I make sure I have snow tires now. There's been times I haven't been able to get to clients because they're so far out in the country and snow blows over the roads. So that can be a challenge…they would go without care for that day" (P08).

Other HCWs determine that even after investing in reliable transportation, they would not take the risk of caring for clients who need total care because of the dangers involved with inclement weather:

> "Well, I have my own vehicle. And I make sure it's in good running order. I have missed work a couple of times due to severe weather. I always plan that out the night before. I don't work with anybody that has to have somebody there, no matter what. I don't do that anymore." (P14).

These transportation obstacles also exacerbate other challenges as well. HCWs discussed how the combination of navigating difficult weather conditions and the realities of a labor shortage leads to a perfect storm. If a HCW feels unsafe traveling through inclement weather but knows that no one will take care of their client if they call out, it creates a nearly impossible situation and places additional stress on the caregiver. P06 remarked:

> "But that probably is one of the biggest challenges is when there's weather situations or any situation where you might not be able to make it in, there's nobody to fill your spot" (P06).

Sub-Theme I: Workforce and Workflow Challenges

Labor shortages serve as another persistent challenge facing both rural providers and HCWs (P07; P08; P09; P20; P23). A lack of reliable transportation and low compensation both contribute to the widening care gap in rural areas. The shortage of caregivers places an additional burden on home care workers who incur transportation costs to care for clients in remote areas. For example, P20 noted that:

> "I would say… just lack of help. We don't have home health aides, especially that travel in that area. If I'm not here, if I don't go, they really don't have coverage" (P20).

In the Adirondack region, the labor shortage has become increasingly worse over time as younger residents leave in search of better economic opportunities while older residents continue to require healthcare services. The distance between clients also impacts compensation, as providers need to pay HCWs for travel time but are not reimbursed to the same extent by payers like Medicaid (P07; P09). With HCWs having multiple cases per day and the average driving time between clients approximately 30 min, the current reimbursement scheme creates structural barriers for higher compensation. One agency representative noted:

> "We can't pay them appropriately, because we don't have the money to do it with. So, until the healthcare system recognizes the value of that hands-on care person in the home, and is willing to pay for it, our whole system is going to be a mess. Because we are not going to be able to get to keeping people out of hospitals and [the] emergency room without that level of care" (P07).

Short visits—2 h or less—are common in rural areas and create greater burdens due to large distances between clients. If HCWs work with multiple clients per day, they are spending more travel time between clients and incurring more transportation-related costs. For example, P11 reported working with as many as 300 clients in her career as a HCW and never working with a client for more than 2 h at a time (P11). P20 reported working with anywhere from two to five clients per day (P20). Many HCWs see the same client for no more than 2 h per day multiple times each week, commuting long distances between several clients daily (P12).

Short visits also impact the type of care that clients receive. HCWs focus primarily on personal care tasks and completing all items on a care plan during shorter visits. While companionship and emotional support are regarded as important and invisible components of home care work, the relationship and bond between HCWs and clients are influenced by case lengths. As P12 noted, you may spend half of an entire shift picking up items at the grocery store, leaving little time for other care duties:

> "[Going to the grocery store is] in the one to two hours that I'm with them. Yes. I've gotten pretty quick with things so like a lot of my clients, they'll pile on a bunch. I need you to do all this stuff in like an hour…[I've] been in the store, I know where everything is now because I've been there a couple of times" (Interview 12).

Challenges related to client resources also affected HCWs workflow in rural areas. For example, water issues impact the cleaning and bathing responsibilities of caregivers. P20 discussed a client who lacked running water in the kitchen, forcing her to clean dishes in the bathroom (Interview 20). The same client's hot water tank is no longer functioning properly, meaning more disruptions of daily care:

> "With the person that I have with the water issue, and now their hot water tank is going, so we have to turn the hot water tank off and then turn the water on, every time we're going to use it. So, that definitely affects him and how often he wants to bathe and stuff like that, because he just doesn't have the proper facilities" (P20).

A higher proportion of clients rely on well water in rural areas, meaning that problems may arise as a product of inconsistent water quality and availability (P18). These challenges related to basic necessities affect many of the personal care tasks HCWs need to perform on a daily basis, such as providing nutritious meals and clean water to clients. They also require HCWs to problem solve and confront unpredictable challenges unique to rural households.

Sub-Theme II: Social Isolation and Defiance

Clients may be particularly vulnerable to social isolation—physical separation, lack of social support, and inadequate access to medical care—in rural communities. Some

interviewees remarked that clients in both urban and rural areas experienced isolation (P16), while others believed that the physical separation and inadequate resources in rural communities exacerbated this issue. P07 stated that:

> "In our rural region, people that get very debilitated or very ill have traditionally, often, had to be placed in nursing homes because they don't have the family structure or the healthcare resources around" (P07).

Unsurprisingly, the physical distance experienced in rural communities often leads to loneliness (P12). For example, P20 discussed a client who lived in a particularly remote area:

> "I have somebody that's actually on a private dirt road. Sometimes we could just walk to the end of his driveway, but that's the extent of the fun there for him. So, yes, I do have a couple of clients, both gentlemen, where they basically are in recliners unless they get up to get onto a commode or something. But 24 hours a day, they're just looking at the same walls" (P20).

Social isolation and loneliness impact the day-to-day responsibilities of HCWs. This may suggest that companionship and emotional support becomes an even more important role for rural HCWs if clients lack social resources (P07). However, the short visits observed in rural areas may hinder companionship and other forms of emotional support that often go unrecognized. Home care delivery in remote areas also has broader health implications. With services like grocery stores or the nearest hospital miles away, rural HCWs need to be particularly vigilant in observing changes in a client's health. P22 remarked:

> "So being in a very rural area adds another layer of difficulty and concern…because they just can't get to the services they need and can't easily get what they need to stay healthy and safe at home" (Interview 22).

HCWs explained that clients in rural areas may also exhibit a lack of compliance towards care protocols and requirements, which also influences how HCWs navigate daily responsibilities. This lack of compliance usually begins when trying to convince older adults to accept care in the first place. While a resistance to seeking care is obviously experienced across geographic boundaries, the independence and isolation inherent to rural life may explain why clients are more likely to resist care in rural areas. An agency representative noted:

> "It's just the difference in the sensibilities or the difference of the culture, I think, up here. Sometimes you have to literally convince people that they need care" (P07).

Numerous HCWs also reported difficulty in convincing clients to complete a required task on the care plan because of social norms in rural communities. For example, clients sometimes refuse to shower or bathe, leading HCWs to ask multiple times or devise creative ways to convince them to do something (P10; P11). P11 discussed a sort of farming mentality that leads certain clients in rural areas to act more defiant:

> "It's more farming, more farm towns. They're used to living or doing things with less. I've had people that never took a bath before or they only, they wouldn't shower. They'd only bathe" (P11).

Sub-Theme III: Low Compensation and Emotional Labor

Distance and transportation challenges also exacerbated the low compensation and undervalued emotional labor that rural HCWs experience. Most agency HCWs reported making less than $15/hour (P05; P08; P16; P21). Those who provide private care outside of an agency generally earn more income than agency workers but receive no benefits and need to find clients through a local registry or on their own time (P02; P13; P14; P19). P06 summarized how low compensation impacts high turnover, and, therefore, the ongoing labor shortage in rural areas:

> "…the turnover in this profession is outrageous. It's ridiculous. And a lot of that is because the wage is absurd like, hello, you're starting people out at $13/h? I've been there for nine years and my base pay is under $15/h. That's absurd" (P06).

Low compensation and transportation challenges negatively impact each other. Rural HCWs not only need access to their own car, but require a vehicle to operate in inclement weather through roads that are not always well maintained (P09; P20). Because agencies rarely provide transportation for caregivers, rural HCWs need to invest resources into reliable transportation and commuting to and from clients in remote areas while experiencing very low compensation. P10 discussed how inadequate access to reliable transportation negatively impacted their pay and benefits:

> "We all get paid $0.45 to the mile, but we're all driving our cars into the ground. If something breaks down, we're calling in, and then that's docked against us…we have to use eight hours of our vacation time to cover that day if our vehicle doesn't work, which has happened to me on several occasions" (P10).

Another challenge that rural HCWs face involves emotional labor and other work outside of the care plan. Several HCWs mentioned providing companionship as an essential part of their work, especially when clients felt particularly isolated or had no reliable family to check in on them (P12; P13; P14). The emotional connection fostered between HCWs and their clients sometimes led to caregivers

performing unpaid labor. Transportation challenges further exacerbated these issues. In one instance, P14 reported staying overnight, without pay, at a client's house before her shift the next morning because of incoming inclement weather:

> "I went and spent the night with her a couple of times when I knew we were going to have a severe storm the next day, because there was nobody to get to her house. So, I did go spend the night with her. I slept on the couch and we had a slumber party…I did that on my own. I didn't get paid for those times, but I get to know my peeps and I love them" (P14).

P14 formed such a strong bond with her client that she spent multiple nights, working as many as 12 unpaid hours, to make sure the client would have care in the morning. Transportation challenges force HCWs to make difficult decisions about whether clients will receive care.

Discussion

Findings from our qualitative study demonstrate that rural HCWs experience both unique challenges due to geographic differences and universal challenges that confront HCWs more broadly. The major, unique challenge confronting rural HCWs in this study involves distance and transportation issues. This challenge, in turn, exacerbated other unique place-based challenges, such as increased social isolation experienced by clients due to the geographic realities of rural life, and universal issues confronting HCWs, like low pay and unrecognized emotional labor (Campbell et al., 2021; Franzosa et al., 2019). These universal challenges also exacerbate the unique challenges confronting rural HCWs, as issues like low compensation impact whether HCWs have access to reliable transportation necessary to travel between clients in remote areas.

This study makes an important contribution to the literature on HCWs and rural healthcare delivery given that academic research has largely ignored the direct experiences of formal rural HCWs, especially in the United States. Our study expands upon prior research on informal rural caregivers, which has also found that issues like transportation and isolation are common challenges (Henning-Smith & Lahr, 2018). Most research on formal rural home care delivery has focused on the perspective of clients and agencies, rather than HCWs (Forbes & Janzen, 2004; Kenney, 1993; Ma et al., 2022; Siconolfi et al., 2019; Weech-Maldonado et al., 2007). Past studies on rural HCWs in the United States have generally examined a specific employment characteristic that leads to turnover, such as travel cost reimbursement (Morris, 2009), instead of generating a comprehensive understanding of the challenges facing rural HCWs. International scholars have taken a similar approach. For example, results from a study in Canada suggest that rural HCWs tend to deal with more substantial client behavioral problems that require tailored training programs and more formal support (Bedard et al., 2004). Researchers in Japan argue that the integration of rural HCWs into the care team is especially difficult due to paternalistic norms that prioritize physicians over other health care workers (Ohta et al., 2018). Our study takes a broader approach to understanding the challenges facing rural HCWs by organizing them into distinct themes.

Distance and transportation emerged as the most frequent challenge from our interviews. The inclement weather of upstate New York, and many rural regions across the United States, exacerbate these transportation concerns. While we distinguish between different types of challenges, obvious connections exist between the unique obstacles facing rural HCWs and the issues that continue to negatively impact the long-term care system. The demand for home care services is expected to increase considerably in rural areas as a result of older adults comprising an increasingly larger percentage of the overall population and the closure or merger of more than 400 rural nursing homes over the past decade (Campbell et al., 2021; Healy, 2019). Addressing the concerns of rural HCWs should be a priority in and of itself.

Our findings have clear implications for policy and practice. Efforts to address quality of care concerns for rural patients must take into account the unique challenges associated with the delivery of home care. First, our findings document a broken reimbursement system when it comes to rural home care. Home care agencies receive insufficient reimbursements for travel, making it difficult to adequately compensate HCWs for schedules that include multiple care visits with significant travel between clients. Policymakers and public payers such as Medicare and Medicaid should reevaluate reimbursement models for rural home care, recognizing the real costs of providing care in such areas. In doing so, they can help to address the persistent challenge of low wages, which makes it difficult to attract and retain skilled and committed HCWs.

Second, this study's findings have clear implication for key healthcare industry stakeholders. For example, unions representing HCWs in rural areas should consider issues related to transportation and infrastructure when advocating for their members. It is important to note that some unions have already taken a proactive approach in this regard. Healthcare Workers Rising, an organization of caregivers in Western NY affiliated with SEIU 1199, developed a pilot program to subsidize transportation for HCWs in 2020 (Pinto et al., 2021). Home care agencies, for their part, must also recognize and acknowledge the exacerbated pressures that HCWs in rural areas face and adapt accordingly. While the reimbursement challenges discussed above constrain the resources available to agencies, much more needs to be done to partner with other stakeholders in an effort to confront the unsustainable pressures placed on HCWs. Our findings document unique challenges in caring for rural patients, such as social isolation and lack of compliance. HCWs should receive training designed to both increase awareness to these challenges and provide evidence-based tools to address them.

In the absence of other support systems, providing HCWs with additional training on how best to care for patients that are experiencing social isolation and resisting care is one of the key ways to enhance quality of care. Put simply, the home care system for rural patients is in crisis. Addressing this crisis requires action on the part of policymakers, employers, and unions.

This study is not without limitations. Future research may employ mixed methods or quantitative analysis to test whether the types of challenges facing rural HCWs outlined in this paper extend to other rural regions in the United States. For example, further research could test whether rural HCWs disproportionately work cases that require shorter visits. Additional research may also examine the integration of rural HCWs into the broader care team. This study did not attempt to compare the challenges facing rural HCWs with those facing urban HCWs. The high representation of white HCWs—likely due to our focus on rural home care work—in this study stands in stark contrast to the demographics of this workforce, which is comprised largely of women of color (Campbell et al., 2021). Future studies may compare the experiences facing white HCWs and HCWs of color while sampling HCWs who have experience in both urban and rural settings.

Conclusion

Findings from our qualitative interviews document the types of challenges facing rural HCWs. The major, unique challenge confronting rural HCWs includes distance and transportation. This challenge, in turn, exacerbated workforce and workflow concerns, client isolation and defiance, and the poor working conditions prevalent in the home care industry—specifically low compensation and unacknowledged emotional labor. We believe that improving the working conditions and standards of home care work necessitates specific policy interventions that account for the challenges facing rural HCWs.

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Supplemental Material

Supplemental material for this article is available online.

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