Critical Issues for the LTSS Workforce

SOUTHERN GERONTOLOGICAL SOCIETY

Journal of Applied Gerontology
2022, Vol. 41(2) 332–340

DOI: 10.1177/0733464821989859
journals.sagepub.com/home/jag
SAGE

Interventions to Reduce the Impact of Client Death on Home Care Aides: Employers' Perspectives

Emma K. Tsui[1], Emily Franzosa[2,3], Jennifer M. Reckrey[3], Marita LaMonica[1], Verena R. Cimarolli[4], and Kathrin Boerner[5]

Abstract

For home care agencies and aides, the death of clients has important, yet often unrecognized, workforce implications. While research demonstrates that client death can cause grief and job insecurity for aides, we currently lack home care agencies' perspectives on this issue and approaches to addressing it. This study uses key informant interviews with leaders from a diverse sample of eight New York City home care agencies to explore facilitators and barriers to agency action. We found that agencies engaged primarily in a range of informal, reactive practices related to client death, and relatively few targeted and proactive efforts to support aides around client death. While leaders generally acknowledged a need for greater aide support, they pointed to a lack of sustainable home care financing and policy resources to fund this. We recommend increased funding to support wages, paid time off, and supportive services, and discuss implications for future research.

Keywords

home care, workforce, end of life, stress, qualitative methods

Introduction

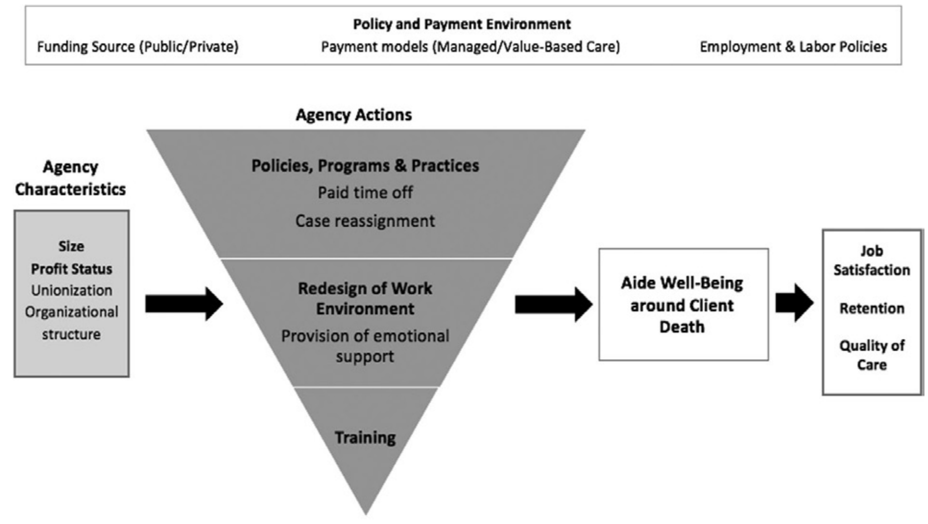
Home care aides, including home health aides, personal care aides, and nursing assistants working in the home, are a critical and rapidly growing workforce. They assist clients with the activities of daily living and provide health care support to older adults and individuals with disabilities in their homes (Bureau of Labor Statistics, 2019). The size of the home care workforce doubled between 2008 and 2018 to almost 2.3 million workers nationally, and continues to grow as a result of the increasing older adult population and ongoing deinstitutionalization of care (PHI, 2019). The increase in individuals preferring home-based care due to COVID-19 is likely to accelerate these trends (Holly, 2020). Women, people of color, and immigrants disproportionately perform this work, which is primarily funded by Medicaid and Medicare (PHI, 2019). Finally, and importantly for this project, the majority of paid home care aides in the United States are employed by agencies (Howes, 2014).

Because home care aides typically work with older and ill clients, the death of clients is an important feature of work, and often a significant stressor. While no study has yet estimated the frequency of client death for aides, this experience is likely to be common, and its significance has been noted in studies of work stress among aides from California to Maine (Butler, 2017; Delp et al., 2010; Zoeckler, 2017). Research suggests that client death can result in two primary, sometimes intersecting, experiences for aides: temporary job loss and emotional strain (Boerner et al., 2015, 2017; Delp et al., 2010; Tsui et al., 2018). For agency employed aides, job loss following client death is likely to be relatively brief. Rapid case reassignment, however, may cause aides to take temporary or part-time cases, leading to reduced hours (and thus pay, and perhaps health

Manuscript received: August 21, 2020; **final revision received:** November 16, 2020; **accepted:** January 2, 2021.

[1]The City University of New York Graduate School of Public Health & Health Policy, New York City, USA
[2]James J. Peters VA Medical Center and Geriatric Research Education and Clinical Center, Bronx, NY, USA
[3]Icahn School of Medicine at Mount Sinai, New York City, NY, USA
[4]LeadingAge LTSS Center @UMass Boston, Washington, DC, USA
[5]University of Massachusetts Boston, Boston, USA

Corresponding Author:
Emma K. Tsui, Department of Community Health & Social Sciences, Graduate School of Public Health & Health Policy, The City University of New York, 55 W. 125th Street, 7th Floor, New York City, NY 10027, USA.
Email: emma.tsui@sph.cuny.edu



Informed by: Franzosa, Tsui, and Baron (2018) and Lee, Hudson, Richards, Chang, Chosewood, and Schill (2016).

Figure 1. How home care agencies influence home care workers' experiences of client death.

benefits) for a period of time. Regarding emotional strain, a study of direct care workers demonstrates that grief experiences related to client death are associated with burnout, particularly depersonalization (i.e., cynicism and detachment from clients), and thus may have implications for both client care and aide retention (Boerner et al., 2017).

Existing studies from aides' perspectives indicate that agencies currently take few, if any, steps to acknowledge the significance of client death in aides' lives (Gleason et al., 2016; Tsui et al., 2018). As a result, aides often speak of feeling ill-prepared to handle client death (Tsui et al., 2018). Aides and researchers have thus recommended several agency-level interventions, including additional training around end-of-life issues, enhanced emotional support, paid time off, and more responsive case reassignment practices (Barooah et al., 2019; Gleason et al., 2016; Tsui et al., 2018). These recommendations can directly affect both retention and aide well-being. High-quality certification training and on-the-job training[1] have been linked with increased job satisfaction and retention (Ejaz et al., 2008; Feldman et al., 2017). In addition, research shows emotional support from agency staff sometimes increases aides' well-being and satisfaction, and aides have noted that paid time off after a client's death could improve their economic and emotional well-being (Gleason et al., 2016; Tsui et al., 2018).

Existing research on the impact of client death for aides has focused primarily on outcomes for aides and aides' perceptions of factors shaping these outcomes. Only one study investigates the impact of agency policy using an objective measure: Boerner et al. (2016) compared the experiences of aides working for an agency that did not allow contact with clients' families following a client's death with an agency that had no formal policy, and found aides subject to the restrictive policy were more likely to be considering other job options. This demonstrates how a single policy can be a powerful determinant of aides' experiences. However, little is known about home care agencies' perceptions of policies and practices relevant to client death. Research with agency staff on how they conceptualize the range of remedies described above, and others that could be useful for supporting aides, is a major gap in the literature and critical for strengthening the home care workforce.

In this study, we use interviews with home care agency leaders in New York City to explore the perspectives of agencies regarding supporting home care aides in navigating client death.

Conceptual Framework

To guide our research, we refined an existing conceptual model of factors affecting aide well-being (Franzosa et al., 2019) (see Figure 1). Rooted in the home care literature (Delp et al., 2010; Feldman et al., 2017; Schulte et al., 2015), this model highlights how home care financing, alongside policies relevant to home care labor, shapes the way aides' jobs are structured and their quality in terms of wages and benefits, the forms of support they receive, and how they are trained, all of which (among other factors) directly influence well-being. Well-being is conceptualized as a multidimensional construct that includes emotional, physical, and economic well-being (Franzosa et al., 2019; Schulte et al., 2015) and serves as a key driver of job satisfaction, retention, and quality of care (Delp et al., 2010; Franzosa et al., 2018). We see both the affective (including emotional demands and intrinsic rewards) and the economic dimensions of well-being as critical to this model.

Our revised model adds agency characteristics, like size and profit status, as potential influences on agencies' actions. We expected these factors would shape the ways in which agencies addressed client death; for instance, for-profit agencies seeking to maximize revenue may not invest in worker supports, while smaller agencies may not have the resources. These specific linkages have not been documented in the literature, although profit status is known to affect care quality (Cabin et al., 2014).

Informed by an occupational health model from the Centers for Disease Control (CDC) (Lee et al., 2016), we also added relative levels of action agencies can take to promote worker well-being. This model conceptualizes these actions as a hierarchy in descending order from greatest to least anticipated effectiveness. It posits that health-promoting changes to policies, programs, and practices that protect all workers (e.g., paid time off after client death) are more effective at mitigating harm than redesign of the work environment (e.g., training agency staff like coordinators/supervisors to provide aides' emotional support) that ultimately relies on individuals to protect themselves and others. We map the agency actions examined in this study onto these levels to illustrate their potential effectiveness.

Design and Method

Sampling and Recruitment

In this exploratory qualitative study, we conducted 14 key informant interviews with leaders from a sample of eight New York City home care agencies. We used a purposive recruitment approach focused on recruiting agencies of different sizes and profit status (see Table 1). We identified agencies through a variety of avenues, including boards of the Home Care Association of New York, the 1199SEIU Home Care Industry Education Fund, and previous participants in a local New York State Medicaid Redesign network. We also used a referral method in which experts recommended possible participants. In total, 14 agencies were approached. Leaders from eight of these agencies (14 key informants) were interviewed in person or by phone.

Data Collection

The first author conducted interviews ranging from 30 min to over 1 hr, using a semi-structured guide covering policies and practices pertaining to client death, end-of-life training, ideal approaches, and barriers (see Supplemental Appendix A.) At five of the eight agencies, we conducted individual interviews with one agency leader. At the remaining agencies, we interviewed more than one leader (see Table 2). All participants provided written informed consent.

Table 1. Agency Sample.

Characteristic	Number of agencies ($n = 8$)
Size[a]	
Small ($\leq$1,100 aides)	3
Medium (1,101–2,000 aides)	3
Large ($>$2,000 aides)	2
Non-profit	5 (4 within multiservice organizations)
For-profit	3
Unionized	8

[a] We trichotomized agencies by size to facilitate comparison.

Table 2. Participating Agencies' Characteristics and Number of Interviewees.

Agency	Characteristics	Interviews
Agency 1	Large, non-profit	5 interviewees (group interview)
Agency 2	Large, for-profit	2 interviewees
Agency 3	Small, for-profit	1 interviewee
Agency 4	Medium, non-profit within multiservice organization	1 interviewee
Agency 5	Small, non-profit within multiservice organization	1 interviewee
Agency 6	Medium, for-profit	1 interviewee
Agency 7	Medium, non-profit within multiservice organization	2 interviewees (group interview)
Agency 8	Small, non-profit within multiservice organization	1 interviewee

Analysis

In analyzing these qualitative data, we emphasized deductive techniques, though we also sought to identify emergent ideas. This directed content analysis approach (Hsieh & Shannon, 2005) was possible because of our team's existing understanding of these issues from the perspective of aides (Boerner et al., 2015; Tsui et al., 2018). Through iterative readings of the data, the first author created a codebook incorporating both a priori and emergent codes, applied codes, and documented analytical steps. To make comparisons systematically, we also utilized the framework method (Gale et al., 2013). This method involved charting coded data into a matrix, which facilitated comparison within and across sites. The second author was in discussion with the first author throughout data collection and analysis, and provided input on the framework matrices of coded data.

We took several steps to help ensure trustworthiness of the data (Lincoln & Guba, 1985). First, this study is the product of our team's prolonged engagement with this topic (especially E.K.T., E.F., and K.B.). Second, we used triangulation within agencies where possible, via multiple interviews at some sites. Third, we conducted member-checking by sending preliminary results to agency leaders for their feedback. Although we only heard back from two agencies, both were in agreement with our findings and made only minor suggestions, which we incorporated. All activities were approved by the CUNY School of Public Health IRB.

Sample

Leaders represented three types of agencies: independent non-profit agencies, non-profit agencies embedded in community-based multiservice organizations, and for-profit agencies (see Tables 1 and 2). They also represented agencies of a wide range of sizes, employing 600 to several thousand aides, with a median of 1,600 employed aides. All agencies were unionized, although their aides were represented by three different unions. Finally, leaders were a mix of senior management and division leads. We interviewed each agency's president, vice president, or director. When multiple leaders were interviewed, we also included directors of training, human resources, and/or managers of aides. All had extensive experience working in the home care industry, with a minimum of 9 years and a maximum of 36 years (median = 24.5 years).

Results

None of the agency leaders in our sample reported any formal client death-related workforce policies. In the following sections, we describe how agency leaders conceptualized their motivations for supporting aides around client death, detail agencies' approaches to actions around it (including paid time off, case reassignment, emotional support, and training, as detailed in the conceptual model), and delineate their views on ideal approaches and barriers to improving support.

Agency Leaders' Motivations

Leaders varied in their interest in client death as a workforce and care quality issue. Those who expressed interest described three primary motivations: a sense of responsibility to aides, concerns about aide retention, and a desire to improve end-of-life care quality.

A few leaders demonstrated strong, existing interest. As one leader of a medium-sized, non-profit agency said, this issue is "incredibly important" and noted that "We have all the interest!" (Agency 4). This leader, and others from a large for-profit (Agency 2), seemed to feel supporting aides around client death was the right thing to do.

For others, the interest was less fervent, but still notable. One leader from a small non-profit described being well aware of the issue; they had occasionally provided responsive support groups for aides, but provided limited ongoing support (Agency 5). Another leader from a medium-sized, non-profit agency said that, upon hearing about the topic, "My flags went off" because "we need a standard way of dealing with this" (Agency 7), and then spoke extensively about the importance of retention. Others referenced a focus on retention because aides are core to the business (Agency 8, small non-profit) and because of growing demand (Agency 4, medium non-profit). On a different note, one leader said that attending to client death was part of "creating an overall experience for [clients and their families]" (Agency 6, medium for-profit), offering a rationale more focused on quality of care. Finally, a leader at a large non-profit indicated that they had given the topic relatively little attention prior to our contact, but had since begun conversations within the agency, leading to enthusiastic participation in the study (Agency 1).

Only one small for-profit agency expressed less interest in this issue. This leader noted that the impact of client death on aides was "not a focus" for their agency because they "never really had anything that needed real intervention" in this area (Agency 3), suggesting that this is an issue to be addressed reactively, rather than proactively.

Agency Actions

Paid time off. Participating agencies did not have organizational paid time off policies related to client death. A leader from a small, for-profit agency reported giving paid time off to coordinators to attend client funerals if invited, but not to aides (Agency 3). In part, the lack of agency-based paid time off after client death may be due to the fact that all aides in New York City who have worked for more than a year have access to up to 5 days of paid leave through city and state laws (New York City Department of Consumer Affairs, 2018). However, several leaders noted that aides prefer to save this time for "their own purposes" (Agency 2, large for-profit), rather than using it for a work-related stressor.

Agency leaders expressed that allowing an aide time off unpaid between cases was possible, but typically not a standard option. A critical agency staff member in these interactions is the person who assigns and manages cases, often called a "coordinator." This staff member conducts the majority of agency contact with aides, usually by phone. A coordinator might hear that an aide is having a strong emotional response to a client's death and suggest taking time off. However, leaders perceived taking unpaid time off as difficult and rare since many aides "are living hand to mouth" so "they need to work" (Agency 7, medium non-profit).

Case reassignment. When asked about case reassignment practices following client death, most leaders spoke of aides' universal desire to be placed swiftly on a new case, often for financial reasons. However, others acknowledged possible variation in aides' preferences. For instance, a leader at a medium-sized, non-profit agency said "there is some tactfulness around" reassignment on the part of coordinators, who will ask aides, "Are you ready to go back to work?" (Agency

4). Only one leader, from a small non-profit agency, emphasized the financial impact of client death. This leader said that coordinators try to find aides "an equivalent job, not reduce the income, but you can't just pull somebody off a case [to ensure that an equivalent job is open]. It depends on availability and it's difficult" (Agency 5).

Emotional support. Agency leaders described emotional support around client death as largely informal and reactive, although some modest, proactive efforts were noted. Most often, aides themselves had to request support. As one leader from a medium-sized, non-profit agency said, "If you need help, you need to reach out" (Agency 7). Asking aides to voice their distress to receive help is complicated by agencies' treatment of aide–client relationships. Agencies typically discourage close aide–client relationships, a point shared by some agency leaders. Aides are thus strongly disincentivized to admit emotional distress rooted in a personal relationship with a client who has died.

The primary point of contact for assessing need, and potentially providing informal support, was again the coordinator. A minority of agencies noted that coordinators might be more focused on "staffing" (i.e., ensuring that cases are covered) than ensuring that aides feel supported. While coordinators were mentioned frequently as key sources of communication with aides around client death, some agency leaders noted that other staff (e.g., nurse supervisors, human resources staff, on-staff social workers) might also provide support.

Leaders noted union-based "member assistance programs" (mentioned by representatives of four agencies), or in one case, a similar employee assistance program offered through a medium-sized, non-profit agency, as the most prominent form of formal support. These programs provide counseling by phone or in person, and offer referrals. Leaders said that an agency staff member (usually a coordinator) might refer an aide to this kind of program, but more often the program was referenced as a resource that aides themselves might know about. More proactively, a few agency leaders from non-profits mentioned sporadically running support groups for aides that sometimes focused on bereavement. In one case, these were a collaborative effort with union staff who had counseling expertise (Agency 5, small non-profit within a multiservice organization).

Training. We learned that some agencies touch briefly on end-of-life topics during certification training with offerings that exceed the mandated 75 hr. More commonly though, agencies address the end of life through required in-service training and elective trainings associated with hospice contracts. All but one agency (Agency 5, small non-profit) offered one of these forms of training. In-services related to end of life (usually 1–3 hr in length) were offered at least every few years, and usually developed in-house. Leaders repeatedly noted that the number of state-mandated training topics (like value-based payment and disease-specific training) was the primary barrier to offering more end-of-life in-service training. Separately, agencies provided longer end-of-life training of 6 to 8 hr to qualify aides to work under hospice contracts. Topics included the following: "death and dying," "hospice," and "stages of death/grief." Content generally focused on patients and caregivers. One leader from a medium-sized, non-profit agency said that most end-of-life training for aides is "based on what to expect, not how aides will feel" (Agency 7). If training did address aides' emotional experiences, leaders indicated that it was likely through informal discussion. Only one 7-hr hospice contract training at a large non-profit appeared to explicitly address aides' emotional experiences (discussing "their own feelings and coping," Agency 1).

Recommendations and General Approaches to Support

Only two agency leaders offered no strong recommendations for how they might improve support for client death. In one case, this was because the small, non-profit agency already conducted proactive outreach to aides (described further below) and used a faith leader on staff within the larger multiservice organization to support those struggling (Agency 8). In the other, a small for-profit agency leader said that resources were too limited to take action (Agency 3). Leaders from the remaining six agencies said that ideally they would provide (a) more and better quality end-of-life training for aides and coordinators, (b) better access to emotional support services (e.g., dedicated counselor, support groups), and (c) a more standardized protocol for what happens after a client dies, although leaders did not clearly articulate what this might look like. Of these recommendations, training coordinators had particular traction among leaders.

Notably, a few agencies described employee support programs and practices aimed at workforce retention and aide well-being in general, and suggested they might also help address client death. For example, two agencies (one medium and one small non-profit, both embedded in multiservice organizations) mentioned agency staff who are tasked with supporting aides (Agencies 7 and 8). In both cases, they helped aides access benefits and other services, and at the medium-sized agency, this position also addressed work challenges and emotional support. Another initiative at a medium-sized, non-profit agency (Agency 7) involved a private Facebook group allowing aides to connect with each other and agency staff. Creating a method for aides to raise topics important to them allowed this agency to respond with tailored training and support.

Barriers to Addressing the Impact of Client Death on Aides

Agency leaders mentioned multiple barriers to improving support. Most importantly, all leaders noted insufficient funding was a stumbling block. With a system based on reimbursement for client services, funding ceases when a client dies. Describing how payers operate, one leader from a medium-sized, non-profit agency, mimicking a payer, said, “Listen, that person dies at that minute, and do not bill me a second past that minute. And for [the agency], how do we respond to that?” (Agency 4). Leaders articulated a need for higher reimbursement rates to meaningfully address client death. Similarly, a leader from a small, for-profit agency said with their “tiny” profit margin they are “so stretched.” In this environment, a desire to be more sensitive to aides’ needs too often “goes by the wayside” (Agency 3). Relatedly, some agency leaders were concerned about coordinators’ limited capacity for participating in these efforts, while others were concerned about their “buy-in” (Agency 1, large non-profit). Unrelated to funding and resources, a few leaders mentioned the broader avoidance of discussions of death in American culture was a barrier to addressing client death directly. A leader from a medium-sized, for-profit agency articulated this by saying, “Death is hard and not something the agency is comfortable talking about” (Agency 6).

Discussion

Research with home care aides demonstrates that they often experience client death as an important emotional and financial stressor (Boerner et al., 2016; Franzosa et al., 2019; Tsui et al., 2018). Home care agency leaders’ perspectives, however, suggest client death receives little attention in how agencies structure home care employment. This is despite the fact that leaders typically demonstrated awareness of the impact of these events on aides. In asking leaders about several levels of action recommended by aides and researchers, we found relatively little targeted or formal activity. Specifically, agencies described an absence of paid time off after client death; a heavy reliance on coordinators to navigate aides’ needs regarding time off, lack of responsive case reassignment and emotional support; little end-of-life training, and almost no training addressing aides’ emotional experiences of client death.

Based on our conceptual model, we expected that specific agency characteristics—most significantly, size and profit status—would shape the efforts that agencies made around client death, but we did not consistently see these relationships, particularly along non-profit/for-profit lines. We hypothesize that agency size and profit status are not strong determinants of client death support for aides in this sample for two reasons. First, the cost-constrained Medicaid and Medicare environment affects all agencies accepting public funds, regardless of type, and indeed, the vast majority of agencies cited funding as a serious barrier. Home care agencies have also struggled to balance the financial demands of both employment policy and health care policy as a result of new minimum wage and wage parity laws, aides’ inclusion in the Fair Labor Standards Act starting in 2015, and the transition to mandatory managed long-term care in New York (Nisbet & Morgan, 2019). Second, in a context of extremely limited support for aides’ well-being and retention generally, client death support may be too narrow an issue to have registered strongly on leaders’ radar. The fact that some leaders drew linkages between client death support and more general aide support and retention efforts may be evidence of this. It is worth noting, however, that only one small, for-profit agency was not motivated to address this issue.

Other characteristics represented in our sample may play a greater role in shaping agency actions. Two of the few formal mechanisms that agency leaders cited for addressing aides’ experiences of client death—paid time off (in the form of annual leave) and emotional support (in the form of member assistance programs)—were provided by unions. Although neither of these benefits seemed to meet aides’ needs (previous studies suggest that aides typically have little awareness of this kind of support mechanism (Franzosa et al., 2019)), unions may be able to both push and help agencies to better address the powerful economic and structural aspects of job stress from client death (Boris & Klein, 2015).[2] Finally, we found that agencies embedded in multiservice organizations may be an important organizational structure to explore further, given their access to a greater variety of resources, such as linkages to services and staff trained in counseling.

Reflecting further on the hierarchy of agency actions, the reliance on coordinators to decide on and provide the primary support that aides receive at multiple levels of the model is concerning. Several studies describe coordinators’ general emphasis on staffing cases over supporting aides’ needs and the difficulty that aides have in contacting coordinators (Buch, 2018; Franzosa et al., 2019; Stacey, 2011). Although research documents situations in which coordinators have provided emotional support to aides in the wake of client death (Gleason et al., 2016; Tsui et al., 2018), the lack of training to do so and potential burden on coordinators are worthy of exploration. Coordinators may be experiencing increasing caseloads already as a result of changes in the policy and payment environment (Nisbet & Morgan, 2019). Effectively offering formal resources to aides through this avenue is impossible without significant additional support for coordinators. We also note that further training for aides, coordinators, and even administrators regarding end of life, emotional support, and supportive agency culture might substantially improve outcomes for aides (Brannon et al., 2010; Tsui et al., 2019).

Notably, agency action was particularly limited at the level of policy (e.g., paid time off for client death), the most powerful level in CDC’s model for promoting well-being. Agency leaders also made clear that changes to federal and state policies and payment systems that can enable agencies to do this work are critical. Advocating for such changes is our first and most important recommendation. Potential policy solutions range from strategically increasing Medicaid funding to broader efforts like Caring Across Generation’s universal family care proposal (Veghte et al., 2019) that would improve the safety net for all low-wage workers through stronger paid sick leave, paid family and medical leave, and affordable child care and long-term care policies (Espinoza, 2020). From a research perspective, we should continue to explore how unionization, as well as the model of home care embedded within multiservice organizations, affect aide support, well-being, and retention. In line with this recommendation, an important step for researchers is to assess how well more general support strategies address the effects of client death. Examining leaders' personal characteristics, like demographics and direct experience with client death, and experimenting with off-site interviews may also be illuminating.

Our study has several limitations. Most importantly, this is a purposive sample that prioritizes active, engaged, and unionized home care agencies, with sufficient interest in participation. These agencies are not representative of home care in New York City or nationally, where for-profit and smaller home care companies predominate (Campbell, 2020). Given our sampled agencies' levels of engagement in home care policy and workforce issues, we anticipate a broader sample would have shown relatively few additional activities related to client death. Second, the study's trustworthiness may have been strengthened by the use of multiple interviewees at every agency site rather than allowing the agency itself to determine their preferred number of interviews. The degree to which these findings are transferable to other geographic regions is best assessed by readers (Lincoln & Guba, 1985). We expect some barriers to be common and others unique. For instance, the constraints on long-term care financing are present everywhere, although the interweaving of specific managed care approaches and localized labor policies vary by location.

Given its impact on home care concurrent with this study, the COVID-19 pandemic deserves special mention. There are some preliminary signs that agencies' largely informal and reactive approaches to supporting aides may become more proactive and robust as more aides are exposed regularly to client death and intense work stress. The chaotic early months of the pandemic in the United States indicate that home care agencies are currently dealing with a wide range of concerns (Bryant, 2020b), but emerging evidence suggests that some are taking preliminary steps toward providing more general support, including hazard pay (Bryant, 2020a). The pandemic powerfully underscores the importance of retaining home care aides and perhaps may drive some forms of positive change in long-term care. Whether greater changes at the levels of home care financing and policy will also emerge remains to be seen.

Conclusion

Many home care agencies recognize client death as a workforce issue potentially affecting aide retention and well-being. However, agencies in this sample engaged only in a limited range of informal, reactive practices related to client death, and relatively few targeted and proactive efforts. While leaders generally acknowledged a need for greater support for aides, they also highlighted a lack of sustainable home care financing and policy resources to fund these efforts. Despite barriers, some agencies undertook broader efforts to support aides, which they saw as potentially addressing stress from client death. Policy changes allowing for paid time off following client death and dedicated emotional support would strengthen the well-being and retention of this critical workforce.

Authors' Notes

The contents do not represent the views of the U.S. Department of Veterans Affairs or the U.S. Government.

Acknowledgments

We extend our sincere thanks to the home care workers who brought this issue to our attention and to the agency staff who took time to participate in this project.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The research was supported in part by a PSC-CUNY Award, jointly funded by The Professional Staff Congress and The City University of New York. Dr. Tsui was supported by a K01 grant from NIOSH (K01OHO11645) at the time this article was written.

IRB Approval

This research was approved by the CUNY School of Public Health IRB (protocol number: 2016-1353).

ORCID iDs

Emma K. Tsui https://orcid.org/0000-0001-8944-6129
Jennifer M. Reckrey https://orcid.org/0000-0001-8904-8200
Kathrin Boerner https://orcid.org/0000-0002-6591-9371

Supplemental Material

Supplemental material for this article is available online.

Notes

1. Home health aides undergo certification training with a state-mandated curriculum of at least 75 hr, which sometimes takes place at the agency where they are employed. They then are required to participate in at least 12 hr of in-service training each year. In-service training is often provided by agencies, which have some control over what topics are covered.
2. A 2010 report estimated that a majority of aides in NYC are unionized (approximately half of home health aides and all personal care aides; PHI, 2010), in contrast to the rest of the United States where approximately 30% of aides are unionized (Cancino, 2014).

References

Barooah, A., Boerner, K., Gleason, H. P., & van Riesenbeck, I. (2019). Immediate aftermath of a client's death: The experience of home health aides. *Home Health Care Services Quarterly*, *38*(1), 14–28. https://doi.org/10.1080/01621424.2018.1561586

Boerner, K., Burack, O. R., Jopp, D. S., & Mock, S. E. (2015). Grief after patient death: Direct care staff in nursing homes and homecare. *Journal of Pain and Symptom Management*, *49*(2), 214–222. https://doi.org/10.1016/j.jpainsymman.2014.05.023

Boerner, K., Gleason, H., & Barooah, A. (2016). Home health aides' experience with client death: The role of employer policy. *Home Healthcare Now*, *34*(4), 189–195. https://doi.org/10.1097/NHH.0000000000000360

Boerner, K., Gleason, H., & Jopp, D. S. (2017). Burnout after patient death: Challenges for direct care workers. *Journal of Pain and Symptom Management*, *54*(3), 317–325. https://doi.org/10.1016/j.jpainsymman.2017.06.006

Boris, E., & Klein, J. (2015). *Caring for America: Home health workers in the shadow of the welfare state*. Oxford University Press.

Brannon, S. D., Kemper, P., Heier-Leitzell, B., & Stott, A. (2010). Reinventing management practices in long-term care: How cultural evolution can affect workforce recruitment and retention. *Generations*, *34*(4), 68–74.

Bryant, B. (2020a, April 9). Appreciation pay, gifts and more: How providers are keeping caregivers amid COVID-19. *Home Health Care News*. https://homehealthcarenews.com/2020/04/appreciation-pay-gifts-and-more-how-providers-are-keeping-caregivers-amid-covid-19/

Bryant, B. (2020b, April 16). Calm before the storm: In-home care providers brace for COVID-19 surge. *Home Health Care News*. https://homehealthcarenews.com/2020/04/calm-before-the-storm-in-home-care-providers-brace-for-covid-19-surge/

Buch, E. D. (2018). *Inequalities of aging*. New York University Press. https://nyupress.org/9781479807178/inequalities-of-aging

Bureau of Labor Statistics. (2019). *Occupational outlook handbook, home health aides and personal care aides*. U.S. Department of Labor. https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.htm

Butler, S. S. (2017). Exploring relationships among occupational safety, job turnover, and age among home care aides in Maine. *NEW SOLUTIONS: A Journal of Environmental and Occupational Health Policy*, *27*(4), 501–523. https://doi.org/10.1177/1048291117739418

Cabin, W., Himmelstein, D. U., Siman, M. L., & Woolhandler, S. (2014). For-profit Medicare home health agencies' costs appear higher and quality appears lower compared to nonprofit agencies. *Health Affairs*, *33*(8), 1460–1465. https://doi.org/10.1377/hlthaff.2014.0307

Campbell, S. (2020). *We can do better: How our broken long-term care system undermines care*. PHI. https://phinational.org/resource/we-can-do-better-how-our-broken-long-term-care-system-undermines-care/

Cancino, A. (2014, August 14). SEIU stops collecting fees from non-member home health workers. *Chicago Tribune*. https://www.chicagotribune.com/business/chi-seiu-fees-from-non-member-workers-20140812-story.html

Delp, L., Wallace, S. P., Geiger-Brown, J., & Muntaner, C. (2010). Job stress and job satisfaction: Home care workers in a consumer-directed model of care. *Health Services Research*, *45*(4), 922–940. https://doi.org/10.1111/j.1475-6773.2010.01112.x

Ejaz, F. K., Noelker, L. S., Menne, H. L., & Bagaka's, J. G. (2008). The impact of stress and support on direct care workers' job satisfaction. *The Gerontologist*, *481*, 60–70. https://doi.org/10.1093/geront/48.supplement_1.60

Espinoza, R. (2020). *Would you stay? Rethinking direct care job quality* (No. 4, Caring for the Future: The Power and Potential of America's Direct Care Workforce). PHI. https://phinational.org/resource/would-you-stay-rethinking-direct-care-job-quality/

Feldman, P. H., Ryvicker, M., Evans, L. M., & Barrón, Y. (2017). The homecare aide workforce initiative: Implementation and outcomes. *Journal of Applied Gerontology: The Official Journal of the Southern Gerontological Society*, *38*(2), 253–276. https://doi.org/10.1177/0733464817707298

Franzosa, E., Tsui, E. K., & Baron, S. (2018). Home health aides' perceptions of quality care: Goals, challenges, and implications for a rapidly changing industry. *NEW SOLUTIONS: A Journal of Environmental and Occupational Health Policy*, *27*(4), 629–647. https://doi.org/10.1177/1048291117740818

Franzosa, E., Tsui, E. K., & Baron, S. (2019). "Who's caring for us?": Understanding and addressing the effects of emotional labor on home health aides' well-being. *The Gerontologist*, *59*(6), 1055–1064. https://doi.org/10.1093/geront/gny099

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, *13*(1), Article 117. https://doi.org/10.1186/1471-2288-13-117

Gleason, H. P., Boerner, K., & Barooah, A. (2016). Supporting home health aides through a client's death: The role of supervisors and coworkers. *Geriatric Nursing*, *37*(4), 278–283. https://doi.org/10.1016/j.gerinurse.2016.04.001

Holly, R. (2020, June 10). Predicting COVID-19's long-term impact on the home health care market. *Home Health Care News*. https://homehealthcarenews.com/2020/06/predicting-covid-19s-long-term-impact-on-the-home-health-care-market/

Howes, C. (2014). Raising wages for home care workers: Paths and impediments. In *A paper series commemorating the 75th anniversary of the fair labor standards act* (pp. 241–279). U.S. Department of Labor. https://www.dol.gov/asp/evaluation/reports/FLSAPaperSeries.pdf

Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*(9), 1277–1288. https://doi.org/10.1177/1049732305276687

Lee, M. P., Hudson, H., Richards, R., Chang, C.-C., Chosewood, L. C., & Schill, A. L. (2016). *Fundamentals of total worker health approaches: Essential elements for advancing worker safety, health, and well-being* (CDC no. 43275). https://stacks.cdc.gov/view/cdc/43275

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. SAGE.

Nisbet, E., & Morgan, J. C. (2019). Where policy meets practice: Employer perspectives on scheduling and hours for home care aides. *Journal of Applied Gerontology*, *38*(11), 1615–1634. https://doi.org/10.1177/0733464817739153

New York City Department of Consumer Affairs. (2018). *Lifting up paid care work: Year one of New York City's paid care division*. https://www1.nyc.gov/assets/dca/downloads/pdf/workers/Lifting-up-Paid-Care-Work.pdf

PHI. (2010). *State facts: New York City's home care workforce*. https://phinational.org/wp-content/uploads/legacy/clearinghouse/PHI-StateFacts-NYC.pdf

PHI. (2019). *U.S. home care workers: Key facts (2019)*. https://phinational.org/resource/u-s-home-care-workers-key-facts-2019/

Schulte, P. A., Guerin, R. J., Schill, A. L., Bhattacharya, A., Cunningham, T. R., Pandalai, S. P., Eggerth, D., & Stephenson, C. M. (2015). Considerations for Incorporating "well-being" in public policy for workers and workplaces. *American Journal of Public Health*, *105*(8), e31–e44. https://doi.org/10.2105/AJPH.2015.302616

Stacey, C. L. (2011). *The caring self: The work experiences of home care aides*. Cornell University Press.

Tsui, E. K., Franzosa, E., Cribbs, K. A., & Baron, S. (2018). Home care workers' experiences of client death and disenfranchised grief. *Qualitative Health Research*, *29*(3), 382–392. https://doi.org/10.1177/1049732318800461

Tsui, E. K., Wang, W.-Q., Franzosa, E., Gonzalez, T., Reckrey, J. M., Sterling, M. R., & Baron, S. (2019). Training to reduce home care aides' work stress associated with patient death: A scoping review. *Journal of Palliative Medicine*, *23*(9), 1243–1249. https://doi.org/10.1089/jpm.2019.0441

Veghte, B. W., Bradley, A. L., Cohen, M., & Hartmann, H. (2019). *Designing universal family care: State-based social insurance programs for early child care and education, paid family and medical leave, and long-term services and supports*. National Academy of Social Insurance. https://universalfamilycare.org/report/

Zoeckler, J. M. (2017). Occupational stress among home healthcare workers: Integrating worker and agency-level factors. *NEW SOLUTIONS: A Journal of Environmental and Occupational Health Policy*, *27*(4), 524–542. https://doi.org/10.1177/1048291117742678