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Awareness, Acceptance, Avoidance: Home Care Aides' Approaches to Death and End-of-Life Care

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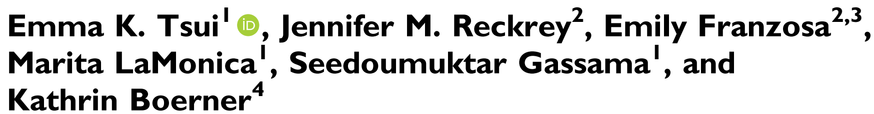

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Abstract

Death and dying are woven throughout the work of home care aides, and yet the care they provide at the end of life (EOL) remains poorly understood. This is due in part to the multiple circumstances under which aides provide EOL care. In this paper, we elucidate the EOL care experiences of aides working in home care agencies in New York City. We conducted in-depth interviews with 29 home care aides, and we analyzed these data using inductive, team-based methods. Our findings show that aides may not be aware of or accept a client's EOL status, and they may avoid EOL care. These conditions shape EOL care, and we detail the committed forms of care aides provide when they are aware and accepting. We recommend improved training, support systems, and policy change to enhance aides' contributions to EOL care, while protecting aides' health and well-being.

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Introduction

In 2016, 71% of Americans reported a preference for dying at home (Hamel et al., 2017), and increasingly they have been able to realize these wishes. Home care and hospice services that allow people to be cared for and die in their homes have grown (Dill & Cagle, 2010) and as a result, the proportion of Americans dying at home has risen steadily (Aldridge & Bradley, 2017). While family members provide the majority of EOL care (Ornstein et al., 2017), home care aides also provide critical support around these deaths. This article centers and explores the work of these aides in providing EOL care, and seeks to identify key dimensions of aides' experiences, as well as the forms of EOL care they provide.

Formally, home care aides help to ensure that older adults and individuals with disabilities and serious illnesses are able to stay in their homes by supporting their activities of daily living, helping to keep home environments safe, and providing some limited health care support (U.S. Bureau of Labor Statistics, 2019). In practice, the role of home care aides is much more encompassing. Research shows that aides engage in complex relational care in the service of clients' emotional, social, and cognitive well-being (Buch, 2013; Franzosa et al., 2018; Stacey, 2011), and that they may also engage in health-related tasks to support client health that go beyond their training (Reckrey et al., 2019). Aide care may improve patient outcomes and is often rewarding to aides, but results in substantial work stress for aides, including both emotional and physical strain (Delp et al., 2010; NIOSH, 2010). Aides' stress also stems from limited wages, benefits, and job security, and the marginalized status of the women, people of color, and immigrants who primarily do this work (PHI, 2019).

In providing home-based EOL care, there are a range of ways that aides may be involved. First and most simply, aides may work for home hospice agencies, providing multifaceted non-curative, team-based care for patients with a life expectancy of six months or less (Institute of Medicine, 2015). Second, and the focus of this paper, are aides who work for home care agencies that provide services including but not limited to hospice. Depending on their structure, such agencies may offer a mix of long-term care (usually funded by Medicaid but sometimes paid privately), shorter term rehabilitative care (usually funded by Medicare), and/or hospice services (most commonly funded by the Medicare hospice benefit).

In long-term care or even shorter term rehabilitative care, aides may work with a client for a period of time that can extend into the EOL, sometimes without clear signals that the EOL is near. Importantly for this paper, in some agency structures, aides may be assigned to both hospice and non-hospice cases. Together, this array of possible EOL care situations potentially introduces confusion for aides around care tasks and relational care practices. What we know of aides' work at the EOL is limited to a small

literature that is concentrated around hospice work in hospice agencies (Ghesquiere & Bagaajav, 2018; Lai et al., 2018), which generally does not acknowledge situations in which aides engage in both hospice and non-hospice care. Additionally, though many training programs do briefly address EOL and hospice aides may receive supplemental training (Tsui et al., 2021), it is worth noting that EOL issues are not a required part of home health aide and personal care aide training curricula, which offer only limited training (Office of the Federal Register, 2011).

The broader picture of paid home-based EOL aide care—that includes but is not limited to hospice—thus, remains important and understudied. In addition, hospice and home care are treated as separate domains, when in reality there can be substantial fluidity in how aides work across these domains since all care could potentially become EOL care. In this paper, our research objective was to describe the EOL care experiences of aides providing a mix of home-based hospice and non-hospice care. The insights from this analysis help to map the consequences of current working conditions for care and for aides, and suggest ways of improving the quality of aide care at the EOL while also supporting aides' health and well-being.

Design and Methods

Our study used inductive approaches to analyze semi-structured in-depth interviews with 29 English-speaking home health aides in New York City who had experienced a client death in the previous year. This analysis is part of a larger study of both home care aides' EOL labor and the support they use in managing this care and client death.

Recruitment. Aides were recruited primarily from two large home care agencies in New York City that provide long term, short term rehabilitative, and hospice care. We purposively sampled aides who had worked in the field for at least one year and had experienced at least one client death in order to ensure that aides had sufficient experience with this topic. Although we were unable to include non-English speaking aides due to limited resources, we focused on including those with diverse nationalities as well as aides who were Black and Latinx to gather data from aides with a range of cultural experiences. We conducted recruitment principally in-person during required annual in-service training sessions (n= 27), and then continued via aide referrals with a particular focus on purposive sampling of additional Latinx aides (n = 2).

Sample Description. Overall, participating aides were female, majority Black (n = 19), with mixed race, White, and Asian individuals making up the remainder of the sample (see Table 1). Six aides identified as Latina. Almost all aides identified as religious (n = 27), and a majority of these identified as Christian. Finally, aides had a wide range of experience in home care in general (1–27 years, median = 8) and hospice care in particular (no experience to 14 years). In order to facilitate comparisons in our analysis, we categorized aides' levels of hospice experience as follows: We defined aides with "substantial" hospice experience as those who worked at least 1 year of hospice cases

Table 1. Sample Description (n = 29).

Age		
	Median	53
	Range	30–67
Gender		
	Female	29 (100%)
Race		
	Black	19 (65%)
	Mixed	4 (14%)
	White	4 (14%)
	Asian	2 (7%)
Ethnicity		
	Hispanic	6 (20%)
Country of birth		
	Foreign-born	17 (59%)
Home care experience (years)		
	Median	8
	Range	1–27
Hospice experience		
	None	6 (21%)
	Minimal	10 (34%)
	Substantial	13 (45%)
Religious affiliation		
	Christian	18 (62%)
	Muslim	2 (7%)
	Religious/spiritual, affiliation not clear	7 (24%)
	Non-religious	2 (7%)

and who had worked at least 25% of the time in hospice (n = 13). Of these, three reported working exclusively hospice cases. Aides with "minimal" hospice experience were those who had some hospice experience but had not reached those thresholds (n = 10). Aides with no hospice experience were categorized as "none" (n = 6). We used aides' work experiences rather than training levels to determine these categories since EOL training for aides is both limited and varied, as we will describe.

Data Collection. All but two interviews were conducted in-person (by ET and ML) at the two agencies between October 2019 and February 2020 (immediately prior to the beginning of the COVID-19 pandemic in New York City). The initial interview guide focused primarily on aides' experiences with client death and how they participated in and viewed the EOL care they provide. Taking an iterative approach to data collection, after reviewing early interviews, we updated the guide to include emerging topics, like

aides' perspectives on death and dying, and questions related to religious and spiritual beliefs, as context for aides' EOL care. The final two interviews were conducted via phone after the pandemic began. Interviews were 40 minutes to over one hour in length.

Analysis. All interviews were recorded, professionally transcribed, and quality checked. Based on the transcripts and fieldnotes taken in conjunction with the interviews, two authors (ET and ML) developed a two-level preliminary coding scheme. Once the coding scheme was refined through discussion, transcripts were coded in Dedoose (Dedoose, 2015) through a consultative and iterative process between three coders (ET, ML, and SG), which further refined the coding scheme. Code families that became most central for this analysis were: hospice experience, death and dying training, description of EOL care, EOL care perspectives, and death and dying perspectives. Additionally, for the analysis presented in this article, we used the Framework Method (Gale et al., 2013) to help make systematic comparisons between and across aides. In this process, we gave particular attention to participants with different levels of home care experience and hospice experience, given that aides develop many of their skills on the job. Finally, we used a range of strategies to help ensure the credibility of the analysis, including practices of reflexivity (on the part of participating coders), triangulation (of analysts), and peer debriefing with authors outside of the coding team (JR, EF, and KB) (Lincoln & Guba, 1985).

Findings

Our findings begin with the background necessary for understanding the EOL care that aides provide: their views of and preparation for doing EOL work. We then describe the forms of care they provided to clients, and also highlight several aspects of EOL care that were troubling for aides.

Aides' Views of and Preparation for EOL Work

Moving into and out of EOL work. As noted, most aides in our study had worked a mix of hospice cases that were exclusively EOL and non-hospice cases that were typically not initially EOL but could become so. Movement across these types of care depended on both what kinds of cases aides were assigned by their coordinators (aides typically had limited influence over this), and by their level of desire or tolerance for working hospice cases. Some aides spoke directly about avoiding hospice cases. After a client died early in one aide's career, she said, "I didn't wanna do hospice ever again in life because it was a feeling [that] I never ever wanna feel again" (Participant 206, 20 years of work experience, minimal hospice). In spite of this, some aides, like this one, continued to work a mix of hospice and non-hospice cases over the course of their career because they were continually offered those cases and needed the hours. When taking these cases, many aides hoped not to be present when a client died ("Make it happen that day that I'm not at work" (Participant 201, 10 years of work experience,

minimal hospice)). However, others seemed actively drawn to the particular work of EOL care, as our description of the forms of care provided will help to illustrate.

Understanding of whether care was EOL care. Preferences aside, for aides, awareness of whether one was providing EOL care could be fuzzy for multiple reasons. Indeed, as has been well documented, for all people involved in care—from physicians and nurses to aides and family members—understanding and deciding when the EOL period has begun is challenging (Gawande, 2015). For non-hospice cases, sometimes no one knew that the EOL was near. At other times, aides lacked this knowledge while others (e.g., their coordinators or other members of the care team) perhaps did know and did not share due to perceived privacy concerns. As one less experienced aide said, "It [the client's death] was just like abrupt news to me because I never knew that she was on hospice. I didn't know that she was on oxygen and sometimes that she would have pains and things like that. I didn't really know the full history of what her medical condition was" (Participant 101, one year of work experience, minimal hospice).

In other cases, aides did know that a client was at the EOL and yet resisted this understanding. Aides with more hospice experience sometimes acknowledged the EOL but still sought to prolong life and restore health. As one aide who had worked a mix of hospice and non-hospice cases said, "What I want to do is see people in hospice improve. That's what I wish for them" (Participant 211, 4 years work experience, substantial hospice). Another aide working a mix of cases spoke of telling hospice patients to "think positive" and encouraging them to eat (Participant 208, 3 years of work experience, substantial hospice). Though aides with substantial hospice experience did sometimes fail to fully acknowledge the EOL status of the patient (the aides above were both borderline "substantial" as they reported only a little over 25% of their work as being hospice), this was particularly the case for aides with less or no hospice experience. These aides described hearing from a clinician that a client was dying or noticing signs that a client may be moving toward death and still hoping or assuming that that was not the case. As one aide said, "I was pretty much in denial and all, like, I saw the signs. I heard things. I just didn't want to listen to it" (Participant 218, 16 years of work experience, minimal hospice).

Training and preparation for EOL care. Experiences with training on topics of death and dying varied among aides. With one exception, the aides who had worked hospice cases reported receiving some training in death and dying. Some described these efforts as basic and focused on what to do when caring for a hospice client. As a less experienced aide who had trained more recently said, "They just gave us information about [...] what a hospice patient is. Pretty much what it entails and how to move forward if the patient passes away, what to do" (Participant 101, one year of work experience, minimal hospice). Some described their hospice training experience as more "sensitive" and noted that training included material on "how to cope with death" (Participant 204, 10 years of work experience, substantial hospice; Participant 102, 8.5 years of work experience, minimal hospice). Others who did not work hospice cases described their death and dying training as brief and sometimes problematic: "The topic is quick. [...] And the training is, they said the patient is not family. That's it. We can't

give [our] heart [to] the patient. Even we can't give a personal [phone] number, but we do it" (Participant 003, 2 years of work experience, no hospice). One aide who had not worked hospice cases noted that she wishes for training on how to cope with client death but has never received it (Participant 207, 2.5 years of work experience, no hospice).

In general, aides felt that their personal characteristics or experiences prepared them for EOL work more than training did, as training was typically limited and not deeply engaged with aides' experiences on the job. In light of this, several aides mentioned feeling that nothing can prepare a person for client death. As one aide said, "I don't think there is a class you can take that'd prepare you for that [client death]. It comes with the punches. […] You just got to do what you got to do in hospice" (Participant 211, 4 years of work experience, substantial hospice). In describing what guided their EOL care, without our asking, aides often spoke of their own personal experiences with death, which we will describe further in the next section. Aides' religious beliefs appeared to play a less significant role in shaping care, though we also note that aides may have been hesitant to discuss this given that several of them mentioned agency prohibitions against sharing religious beliefs with clients.

Forms of EOL Care

Next, we describe the forms of care that aides reported providing. Specifically, we begin with a description of aides' perceptions of the elevated importance of the EOL period, and then describe the physical care, emotional care, and family work that stemmed from this understanding. We note that, though we assessed patterns of care by aides' levels of home care and hospice experience, clear connections were difficult to draw between levels of experience and particular forms of EOL care in our sample.

Elevated Importance of the EOL Period. When aides did know that the EOL was near, one dynamic that appeared to animate much of their labor was an understanding of the heightened importance of this period for clients and those involved in their care. In some cases, this sense of the importance came directly from clients, as in the case when a hospice client's family cooked a meal toward the end of the aide's shift and invited her to join them. The client said to her, "'I just want you to stay even five minutes, 10 more minutes because you don't know if tomorrow, you're gonna see me. So, please. I'm asking you'" (Participant 201, 10 years of work experience, minimal hospice). In other cases, aides—especially those with more hospice experience—brought a deep sense of responsibility to their EOL work. One aide described her extensive efforts to understand EOL clients' needs saying, "I just think you have to be open minded to do whatever [needs to be done], because look, you're not going to get a chance to hit the reset button on that. You can't say, 'Can I get another chance?' [...] So how do you try and get it right for that person at that very moment?" (Participant 215, 3 years of work experience, substantial hospice). For several aides, providing this kind of care was motivated by past experiences of death in their personal lives. As an example, one aide

described regret about not being able to take care of her mother at the end of her life, noting the opportunity that home-based EOL care provides to rectify this in a sense. "How I look at it is the people I take care of now remind me of my mom. [...] So, I have the chance to do it over 1001 times" (Participant 211, 4 years of work experience, substantial hospice).

This sense of importance and its roots in personal experience also amplified, for many aides, the need to honor and respect the client's personhood during the EOL period. The client's status as a still living individual, with their own lived experience and needs that should be met, was a driving force in the way that aides described much of the care they provided, across aides with both more and less hospice experience. For instance, several aides described how clients often become angry, aggressive, and particularly difficult near the EOL. In response, they tried to bring to these situations empathic acknowledgment of the clients' humanity and circumstances. As one aide said, "I try to understand them and be in their situation, and say—even though they scream at me, I'm not gonna scream back. I'm gonna be patient with them because I know it's not easy staying in that bed for a long time, can't move, can't do any[thing]. You were so independent" (Participant 212, 8 years of work experience, substantial hospice).

Physical Care. Physical care is one of the most central aspects of aides' assigned tasks under any circumstances. In the EOL period, aides continued the work they do to support activities of daily living to the extent possible, though they also brought new levels of attention to these tasks. One aide illustrated this vividly, saying she asks herself, "Am I quiet enough and still enough to know how to do the right thing for that individual?" (Participant 215, 3 years of work experience, substantial hospice). Because aides generally held a strong value that people should not be in pain at the EOL, physical EOL care sometimes had a particular focus on pain management. With limited tools to address physical pain at their disposal, aides occasionally reported turning to massage, despite agency prohibitions against this. As one aide described helping a patient in acute pain, "I was trying to massage. I'm not supposed to, whatever, but for some reason he felt better when I would just touch his legs" (Participant 203, 3 years of work experience, substantial hospice). In other cases, aides drew a stronger line around the plan of care. As one aide said when providing EOL care on a year-long non-hospice case, "And sometimes, when she's there in pain, he [the client's husband] wants you to do what I tell him I can't. Because I'm not a doctor so I cannot do certain things" (Participant 201, 10 years of work experience, minimal hospice). We find it notable that the aide with substantial hospice experience (and less work experience) felt more comfortable bending the rules for a dying patient than the aide who was more accustomed to working non-hospice cases and had worked longer.

Emotional Care. The emotional care that aides provided at the EOL echoes what the literature shows is provided in non-EOL care (Franzosa et al., 2018) but can be laced with hefty forms of emotional labor—that is, managing their own emotions or

performing emotions as part of the work (Hochschild, 2003). Some of this emotional care was conveyed subtly through active presence. This presence may give clients a venue for expressing their emotions, including fear and anger about their nearness to death. For example, one aide described a client as follows: “Sometimes he was angry. […] He told me. ‘I was looking forward to getting retired and I had so many plans in my mind to accomplish. Look at me, where I am. I tell you, don’t put on hold something you’re eager to do […] don’t wait [for] tomorrow’” (Participant 203, 3 years of work experience, substantial hospice). Though aides may not be able to allay fears or regrets directly, here an aide’s presence created the opportunity for a client to turn regrets into life lessons.

Aides also engaged in emotional care that was much more proactive. Several aides described working to ensure that clients felt loved in the critical moments at the EOL. As one aide said, “I probably shouldn’t be saying, Hey, I love you. I think you’re amazing. But if that’s the last thing that they’re going to hear, then I say, why not? Why not?” (Participant 215, 3 years of work experience, substantial hospice). This aide noted that some might tell her, “You crushed your boundaries” in response to these situations. To these imagined critics she answered, “I’m willing. It’s okay for me.” This reflection gestures at two important points. First, the kinds of emotional boundaries that home care agencies train aides to uphold (referenced in the description of training) sometimes did not serve aides’ ability to provide the EOL care they felt clients needed. Second, with the phrase “it’s okay *for me,*” this aide lightly implies that this kind of emotional labor may not be “okay” for all aides.

Family Work. Beyond this intimate work with clients, aides also reported doing sometimes extensive work with families in the EOL period, both before and after a client’s death. In some cases, they sought to ease a client’s transition into death by encouraging family members to speak with the dying client. One aide shared detailed instructions for family members, which included saying to them: “You have to give them that guarantee that they [the client] can go because you are happy” (Participant 220, 5 years of work experience, substantial hospice). Another aide described working with a client’s family on her first hospice case. She said, “I had to tell them [the client’s dying children], ‘Listen, she could still hear. […] So if you need or want to say anything to her, now would be the time to do it.’ He [the client’s son] said, ‘But, I’m not good with words.’ I said, ‘Well, whatever comes out. Just let it flow’” (Participant 206, 20 years of work experience, minimal hospice). After the patient’s death, this aide also supported the client’s family with obituary writing and funeral preparation. When asked about how she knew how to guide this family, she noted that the nurse on the case had taught her about EOL signs, but that otherwise she was simply trying to provide “moral support and comfort.”

In the wake of death, aides also advocated for client’s wishes with their families, as in the aide who said of a long term client, “...I told her [the client’s granddaughter], ‘Your grandfather’s wish was please bury him in Antigua. Don’t bury him [here]!’” (Participant 209, 9.5 years of work experience, no hospice). Other aides supported

families in the context of funerals themselves. One aide described attending a client's funeral as a way of sharing that the client was kinder than her family may have thought: "She [the client] was a nice lady. I just wanted to go for her kids, because she was an orphan. […] She didn't know how to love. […] I just want[ed] to show her kids that their mother was a nice lady afterward. They never really [had] known a mother like that" (Participant 204, 10 years of work experience, substantial hospice). This final example expresses the deep commitment to caring beyond the end of a case that some aides brought with them into this work. Aides' after-death work is particularly notable in light of literature showing that agencies often prohibit contact between aides and client families after death, including funeral attendance (Boerner et al., 2016; Tsui et al., 2021).

Troubling Aspects of EOL Care

The sections above paint a picture of aides' commitment to and assurance in navigating EOL situations when they were aware of a client's EOL status, which aides did often convey. However, these situations could place intense demands on aides, felt particularly keenly by those with less hospice experience and/or working longer-term cases. The vigilance they describe had costs. As one aide said, "I don't blink my eye because every minute I went in there to check on her to see if she [was] going. I just couldn't eat, couldn't sleep. It just worried me a lot. My headache hurt" (Participant 201, 10 years of work experience, minimal hospice). Others said explicitly that patients may need support beyond "the rules" (Participant 003, 2 years of work experience, no hospice), raising the question of what problems these situations might create for aides themselves and in their relationships with employers who enforce these rules. These situations also sometimes raised difficult moral questions for aides. One aide described a situation in which a patient was given 30 days to live, but lived beyond this. The aide said the client "was wondering like, 'Oh, why am I still here?' I can't really tell her why she was still here." She then overhead the client asking the nurse how she could accelerate the dying process. The nurse replied that if the patient stopped eating, eventually her body would shut down. The aide said, "I understand she's the nurse, but is she allowed to tell the lady how to make her death come quicker? This was my question. I don't know, you know" (Participant 206, 20 years of work experience, minimal hospice).

Discussion

Our research shows that aides providing EOL care can be deeply attentive to the existential stakes of the EOL period when they are aware that death is near, regardless of whether they are working on a hospice or long-term care case. However, each permutation of the conditions under which aides work—especially their awareness and acceptance of the EOL status of a case or their avoidance of EOL work—has potential consequences for the quality of care delivered and aide health and well-being. Based on

our findings, we describe the relationships between these conditions, care provided, and consequences for aides in this section.

Conditions reducing awareness of EOL status

Our research suggests that when being assigned to hospice cases, aides were typically more aware that they were dealing with a client's EOL due to information from their coordinators about the case. However, during long-term cases and some hospice cases, our data show that aides may receive little information from coordinators or others about whether a client is at the EOL or not. Confusion around what aides are allowed to know from a patient privacy perspective is also a barrier to their receipt of health status information that can shape their work at the EOL (Franzosa et al., 2021). Interestingly, potential sources of support and information, like nurse supervisors or other care team members, were only very rarely mentioned, in spite of the fact that the majority of aides in our study had at least some hospice experience where the concept of team-based care is central (National Hospice and Palliative Care Organization, 2020). This is notable but not surprising in the context of the literature, which indicates that whether in non-hospice or in hospice work, aides are typically left to operate outside of team communication channels (Franzosa et al., 2019; Lai et al., 2018).

Consequences for Care

When aides know and accept that it is the client's EOL, they appear to provide extraordinarily committed and thoughtful care, highlighting the importance of their awareness of the EOL when possible. When aides do not know or accept a client's EOL status, or are more accustomed to non-hospice work, they may provide more typical independence-oriented care, encouraging patients to eat and "think positive." Importantly, this is care that might be at odds with the EOL client's health trajectory or wishes. In these situations, aides may also find themselves more challenged by navigating agency rules and guidance regarding client care and boundaries, as we saw in examples presented above.

One particularly thought-provoking aspect of aides' EOL care is the work they do with family members prior to, during, and especially following the death of a client. Models of non-EOL aide care and hospice care diverge on this point. Work with family members is at the heart of hospice care, and one of the core services provided by the hospice care team is "assist[ing] the patient and family members with the emotional, psychosocial, and spiritual aspects of dying" (National Hospice and Palliative Care Organization, 2020). However, the status of aides as members of this team or outside of it remains murky—formally they do not function as part of the team, though they are increasingly recognized as central providers of hospice care (Lai et al., 2018; National Hospice and Palliative Care Organization, 2020) with implications for family caregiver outcomes (Reckrey et al., 2021). None of the aides in our sample mentioned receiving training in working with family members specifically, and even aides employed by

hospice agencies have reported receiving no training on how to work with family members (Ghesquiere & Bagaajav, 2018). For aides generally, the question of how best to work with clients' family members is also largely unsettled, with aides reporting immense stress in navigating these relationships with limited support from home care agencies (Franzosa & Tsui, 2021; Tsui et al., 2021). Given that aides do interact and work with families extensively, the actual outcomes of their EOL labor in the lives of clients and their families is worthy of study.

Consequences for Aides

The types of EOL care that aides provide in turn shape the impact of this care on their health and well-being. Labor that recognizes the elevated importance of the EOL period may generate both intrinsic rewards and unique strains. Research on aides' experiences of client death show a range of emotional distress as a result of these experiences, as well as some negative effects on physical health, social life, and financial security, alongside a sense of meaning and purpose (Tsui, Franzosa et al., 2019). Client death is also linked with grief symptoms among aides that echo those of family members (Boerner et al., 2015) and that may contribute to burnout (Boerner et al., 2017). However, existing research has not adequately distinguished between the conditions under which aides may engage in EOL care described in this article (awareness, acceptance, and avoidance of EOL, etc.) and how these factors might shape outcomes. Aides who express an aversion to EOL or hospice work may be particularly impacted by providing this labor in spite of their preferences. Alternatively, aides who are in denial or not aware of a case's EOL status may experience less strain during the life of the client but could experience more grief afterward due to reduced preparedness for death and a sense that they did not do enough (Boerner et al., 2015; Tsui, Franzosa et al., 2019).

Implications

Given these circumstances, how do we help ensure that aides are providing high quality EOL care? And how do we ensure that aides are adequately supported to do this work? Our findings highlight the need for greater training in death and dying for all aides as an important starting point for improving their ability to recognize, accept, and communicate about the EOL. Though federal requirements do not explicitly require training in death and dying for aides (Office of the Federal Register, 2011), effective, evidence-based training for health care professionals on EOL topics does exist. However, these kinds of training have never been tailored to address the full range of aides' unique challenges and needs (Tsui, Wang et al., 2019), and would benefit from engaging deeply with aides' EOL experiences both within and outside of work. Such training could equip aides with best practices for EOL care and family work, help aides identify when EOL care may be appropriate (Meeker & Waldrop, 2019), and give them more equal footing for communicating about EOL with other members of the care team. This

training should be based on an understanding of the potential relational complexity of the work without prohibiting the inevitable relationships between aides, clients, and family members. Training should also assiduously address aides' emotional experiences of client death, which aides and agencies suggest is only addressed by some hospice training currently (Tsui et al., 2021). This kind of preparation may reduce aides' denial of the EOL status of a case and provided added support when they become aware of it.

Additionally, improved communication and support systems for aides are needed. Aides should be oriented regularly to the idea that agencies may staff multiple types of cases, noting that death is a potential outcome for all clients but that the forms of care offered can differ. Coordinators who assign aides to cases ideally would communicate clearly and supportively with aides about types of cases. Aides' ability to provide high quality EOL care would also be improved by greater inclusion and participation in existing care teams, whether this is a hospice team or a typical care team (Lai et al., 2018; Reckrey et al., 2019). Improvement in these communication channels may offer crucial gains in quality of care, as well as also potentially increasing awareness and acceptance of the EOL status of a case. For instance, aides working in a "home health and hospice agency" sometimes advocated for hospice services when they felt that home health patients needed them (Lai et al., 2018). Such a function that makes use of aides' "eyes and ears" (Lai et al., 2018) in the home and could be an important benefit to having aides work across hospice and home care.

Finally, we cannot ignore the racialized labor insecurity experienced by home care aides as context for their work (Cranford, 2020; Glenn, 1992). As long as a disproportionate share of aides are women of color and immigrants working without sufficient wages, benefits, and job security, their choices about whether and how they engage in EOL care will continue to be severely constrained, and aides who prefer not to work EOL cases in many cases will. The implications of these conditions for EOL care have yet to be systematically studied and yet are likely to undermine both quality of care and aide health and well-being. Funding long term care and aides' roles at levels that improve their wages and help to guarantee their job security will enhance aides' ability to work on cases that best fit their training, experience, and preferences. This is particularly urgent in the context of workforce shortage that has been exacerbated by the COVID-19 pandemic (Tyler et al., 2021), as such supports would assist recruitment and retention efforts.

This study has some important limitations. First, we only sampled English-speaking aides, which limits the degree to which our findings can speak to the experiences of the immense diversity of aides. Second, data are drawn from only a small number of agencies in New York City where aides are uniquely diverse demographically. Additionally, in other places, agency structures and hospice contracting that lead to the kinds of fluidity we saw across hospice and non-hospice EOL aide care may be substantially less common. Third, we included categories of time spent working hospice cases as a lens for thinking about these data. However, because aides' understandings of which cases were hospice were sometimes thwarted by the systems in

which they work, their estimates of how much time they have devoted to hospice are likely to be imprecise.

Conclusion

This article details the forms of EOL care that home care aides provide in the context of their awareness and acceptance of the EOL status of cases or their avoidance of EOL cases. In doing so, our findings destabilize the implied binary present in the current literature that divides home care aides from hospice aides, and suggests ways that fluidity across types of cases—where present—may influence the quality of EOL care received by clients, as well as aides' health and well-being. Our recommendations focus on how agencies and training systems might function differently to allay the problems created by the current system—namely, aides' work stress and lack of research on the effectiveness of aide EOL care. However, we also recognize that federal, state, and local policies on labor, employment, long term care, and health care financing play a critical role in shaping the conditions of aide-provided EOL care. If these policies, systems, and employer agencies are able to better prepare aides for EOL care situations and support them in this work, we predict that quality of home-based EOL care would improve alongside aide health and well-being.

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