

Access to this work was provided by the University of Maryland, Baltimore County (UMBC) ScholarWorks@UMBC digital repository on the Maryland Shared Open Access (MD-SOAR) platform.

Please provide feedback

Please support the ScholarWorks@UMBC repository by emailing scholarworks-group@umbc.edu and telling us what having access to this work means to you and why it's important to you. Thank you.

Grief and Loss during Care Transitions: Experiences of Direct Care Workers

[Stephanie P. Wladkowski](#)^{ID}, [Nancy Kusmaul](#)^{ID}, [Abigail Latimer](#)

Abstract

Direct Care Workers (DCW) provide both personal care to patients and emotional support to patients and caregivers in hospice and palliative care. DCWs often develop close ties and are then expected to work with new clients immediately following a care transition, with little or no time to grieve. A qualitative pilot study (n=24) was conducted to explore the experience of DCWs during care transitions. Data was collected via focus groups and individual interviews. Thematic analysis was used. Results suggest DCWs managed their experiences (n=19), by anticipating and accepting grief and loss (n=21), employing personal coping strategies (n=19), and saying good-bye (n=15). Relational factors impacted the experience of care transitions (n=22), including building and maintaining the relationship (n=14), and the strength of perceived connections (n=15). Increased organizational support and training to help address grief and loss will better support DCWs and the direct care workforce.

Introduction

There are nearly 2.3 million personal care and home health aides working in the United States, a workforce which doubled between 2008 and 2018 (PHI, 2019). Also classified by the umbrella term Direct Care Workers (DCWs), DCWs, including personal care aides, home health aides, nursing assistants, or aides provide essential care in a wide array of settings such as the home, assisted living, and nursing homes. DCWs' primary responsibility is to care for and assist vulnerable populations such as older adults and individuals with disabilities (Bureau of Labor Statistics, 2019), including personal care and assistance with activities of daily living (i.e., bathing, dressing, mobility). Additionally, DCWs offer emotional support to patients and their caregivers and are integral members of the interdisciplinary care team (Wholihan & Anderson, 2013).

DCW's jobs are physically and emotionally demanding, and limited occupational resources contribute to health concerns and high levels of turnover (Olson et al., 2016). There are no standard training guidelines and certification requirements vary across states, making accurate job analyses challenging (Blau et al., 2015; Newquist et al., 2015). Agencies employ most paid DCWs in the United States (e.g., hospice, home care, long-term care) (Howes, 2014), and their hourly work structure focuses on maximizing the production of work hours. In a study of 180 agency representatives across multiple states "[the] time spent training was variable ranging from none to 1 week" and supervision and work quality assessments were limited (Lindquist et al., 2012, p. 1256). DCWs are typically employed only part-time and in temporary positions with low wages (PHI, 2019). They have insufficient training and support (Dawson, 2016), all of which places additional hardship on the disproportionate number of women of color and immigrants who comprise the DCW workforce (PHI, 2019). Given these realities, it is

unsurprising that the DCW industry experiences high turnover rates, which can negatively impact patient care and continuity (Dawson, 2016).

Turnover and communication gaps with DCWs can be especially detrimental during care transitions which are inherently difficult for patients and families (Mitchell et al., 2018). Care transitions from hospital to home or a facility can be wrought with a lack of adequate communication and disruption in service delivery. Frequent handoffs during care transitions and unfamiliarity with care providers compromise patient care and can leave patients and families feeling insecure and distrusting of providers and the health system (Mitchelle et al., 2018). DCWs in their roles across the care continuum are central to meeting patient and family needs during these times. In hospice and palliative care, DCWs often have more consistent contact with patients and families than other team members (Wholihan & Anderson, 2013); yet, they feel excluded from care planning discussions (Lai et al., 2018). While many care transitions occur while the patient is still living (e.g., hospital or nursing facility discharges), their families and caregivers experience a final care transition from provided services when patients die. The quick termination of services may not adequately validate the longstanding and close relationship established through hours of close and intimate contact with the DCW.

Studies on care transitions have demonstrated a need to further explore the complex and nuanced experiences for everyone involved. One study of caregivers of adults with Alzheimer's disease or related dementias (ADRD) (n=24) following a live discharge from hospice, found that the hospice patient and caregiver experienced a loss of the relationship with the DCW (Author, 2017). Another study by Zmora and colleagues (2021) with caregivers of individuals with ADRD (n=85) within residential long-term care facilities found that caregivers value

communication, perceptions of care, and relationships with staff following care transitions from home to facility.

While we have gleaned some perspective of how care transitions can impact patients and families, there is less insight into how these transitions impact DCWs. As DCWs are often overlooked in agencies (Staley et al., 2015) and as team members (Lai et al., 2018), insight into supporting DCWs during these transitions, individually and professionally, is needed. Existing literature suggests DCWs have a similar grief reaction to family caregivers (Boerner et al., 2015). More concerning is how common their grief is disenfranchised where they have neither the institutional or personal support to name and validate their loss (Ghesquiere & Bagaajav, 2018; Tsui et al., 2019). The lack of supportive supervisors, processes, and policies likely hinders grief processing (Gleason et al., 2016; Staley et al., 2015).

Compounding the emotional grief of losing a client is often a loss of financial support. Once a client dies or is no longer enrolled with the agency, the hours allotted to spend with the client are gone. DCWs may choose to begin work with a new client to prevent lost wages leaving no time to grieve (Tsui et al., 2021). A study of DCWs demonstrates that grief experiences related to client death can be associated with burnout and detachment from clients, impacting both patient care and aide retention (Boerner et al., 2017). Since DCWs are integral to caring for the patient and caregiver, supporting the emotional well-being of DCWs to ensure the quality of patient care is essential (Ayalon & Roziner, 2016; Boerner et al., 2015).

Emotional support, education, and training is thought to benefit DCWs' death preparedness and general well-being (Gleason et al., 2016; Risenbeck et al., 2015; Tsui et al., 2019). Yet existing studies from DCW's perspectives indicate that agencies currently take few, if any, steps to support the experience of client loss (Gleason et al., 2016; Tsui et al., 2018),

resulting in DCWs feeling ill-prepared to handle client death (Risenbeck et al., 2015; Tsui et al., 2018). DCWs often learn of client deaths or are discharged in ways that do not support an opportunity for grief, such as with a schedule change or during a staff meeting, if at all (Authors, in press; Staley et al., 2015). Additionally, agencies do not have clear policies for DCWs regarding post-transition contact (Staley et al, 2015), which may impact the overall experience of loss.

Creating agency policy that considers DCWs' needs, such as allowing for grief processing could both improve job satisfaction and reduce turnover (Olson, 2016). Expanding our understanding of how DCWs, who provide frequent and intimate care, navigate and experience care termination is needed to promote necessary policy and administrative changes (Tsui et al., 2019). In addition, agencies who employ DCWs can further support families of older adults who wish to remain in their homes and seek end-of-life care and their families (Spillman, 2016). This study explored DCWs experiences of care transitions in hospice and palliative care, whether for a termination of services (i.e. transfer or relocation of care), live discharge from hospice, or death.

Methods

All participants in the study were working as a DCW (HHA, CNA, HA), had a minimum of 3 months experience in end-of-life care, and were employed by an agency that directly employs DCWs (hospice, palliative care, home health, skilled nursing facility). Over the course of 6 months, purposeful, convenience sampling occurred in a Midwestern state in the United States through hospice and home health care agencies, and personal and professional contacts. All participants were given a \$25 gift card to a local grocery store. Institutional Review Board (IRB) approval was obtained from [blinded for review].

Semi-structured, audio-recorded interviews were conducted by the first author. Questions included inviting examples of how DCWs deal with planned and unexpected client care transitions, including a change in schedule, a termination of services (i.e. client relocation or transfer of services), live discharge from hospice, and death. Additionally, questions of available supports, suggestions for support, and preparation for care transitions were included.

Four focus groups were conducted (n=19) as part of a professional development day at one home health agency with an average length of 49 minutes. Participation was voluntary and individuals could choose to arrive early or stay later than their scheduled training session. Five additional individual in-person interviews (average length of 28 minutes) were completed separately from the focus groups and at a location of the participant's choice. Privacy and confidentiality in public spaces were discussed prior to consent.

Recorded interviews were transcribed verbatim and two raters (Authors 1 and 2), independently coded 3 individual interviews in Microsoft Word to create a codebook (Creswell & Poth, 2018). Using thematic analysis (Braun & Clark, 2006), the authors continued to search and review themes while defining and naming themes. After initial coding, each transcript and its codes were reviewed against the initial framework. Throughout each stage of searching for and reviewing themes, the authors met and modified or adjusted the codebook as needed.

Findings

Study participants identified as female (96%), Caucasian/white (67%), Black/African American or Multicultural (33%), with a mean age of 36 years old. Most identified their professional title as Home Health Aide (83%), and they worked with clients who live in private residences (98%); assisted living facilities (67%); independent living facilities (54%). A quarter

of participants (25%) identified as working full-time at over 32 hours a week, 29% as part-time or between 20-32 hours per week, and 29% reported they work less than 20 hours per week.

Both personal and professional ways of managing the experience of loss through a care transition were identified. Two main themes emerged: how DCWs managed their experience of loss (n=19), and how the perceived connection and relationship influenced the experience of care transitions (n=22).

Managing Experience of Loss

DCWs described three main ways they manage their experience of loss: anticipating and accepting grief and loss (n=21), employing personal coping strategies such as mantras or spirituality (n=19), and having a specific process of saying good-bye (n=15).

Anticipation and acceptance of loss. Eight-eight percent of participants (n=21) reported grief and loss as an expected part of their profession. Participants described loss as a reality of their job, such as this DCW who said, "... you sort of accept it and going into each job having this idea that this is probably temporary." This sentiment was expanded by another DCW, "I don't want to seem hardcore but, it's a job ... I'm going to miss you but I cannot ... deepen myself in sympathy and worry, because then I won't be able to take care of myself."

Another participant shared they are prepared for a loss:

... whenever it's time for them to pass over or for them to go in the nursing home, I'm ready for it. [laughter] It's not that I don't like them anymore ... I'm excited for the next person ... it's just like a box of chocolate for me. [laughter] It really is. I'm sad, I do get connected with them, but that's life. I've accepted that ...

One participant reported a mindset of the specialness of their professional role in assisting the experience of loss:

... some people say, 'Oh it's so sad, like it must be so hard,' but I think I can't do anything to prepare, but like a mindset you can have ... I always think it is such an honor to take care of someone like at this point in their lives and ... even when it's hard and you are struggling with what they're going through, you're the one that's there for them.

Employing personal coping strategies. Eighty percent of DCWs (n=19) expressed how they accepted loss and found meaning in their work was through spirituality or personal mantras. One participant simply said, "Say a prayer for 'em at night and keep on going, that's all you can do." Another expanded on this thought:

I think the spiritual part of me helps with that [moving on], having a connection with, I say, the Lord, some people say a Higher Power, whatever your connection is spiritually that keeps you going in that strength that you know. That's the time when you connect with it so you can pull yourself up by the bootstraps.

Participants described still experiencing grief, but anticipating and knowing loss is inevitable and part of their job, provide assistance in their coping and ability to continue their work.

Finding a process of saying good-bye. Sixty-three percent of DCWs (n=15) shared that saying good-bye was a personal process and they found their own way to say good-bye. For some, saying good-bye is emotional as this participant said, "I cry. Every client I lose ... It hurts and it takes a little piece of you every time. I would go home and cry. And I would talk to anybody who would listen ... Sometimes it was my dog." Another expressed, "When they pass, it will be peaceful and I do get emotional, I get a lot emotional" Another participant stated, "I never say goodbye. I never say goodbye, I think it would kind of hurt." For others, the process of saying good-bye included evaluating their role in being present for the unique stage of a person's life. One participant shared:

I've been with and lost a number of clients myself, and ... you create a relationship with that client and ... when you do [click], it's kind of like a, it's a special thing, you have a unique relationship with that person. ... if and when they pass away, you sort of feel like you were able to help them through a transition ... and it feels like you are able to give them a gift in a way and allow them to die with, not just dignity, but some peace.

Additionally, the structure of their work schedule and responsibilities did impact their process of saying good-bye. Several DCWs described the need to rely on themselves and move on quickly.

In one focus group, two DCWs reflected amongst themselves the need for independent grief:

a: I have me. I got me. I'm just strong. You just gotta be strong.

b: I don't know. I feel like it, maybe it just doesn't bother you, does it? You gotta keep going

a: I'm not gonna say it doesn't bother me ... It hurts, it hurts, I have feelings, But ... I'm just going to ... get it out ...

b: And then you're over it ... we do that a lot ... even this morning where it's just like 'So-and-so passed away, you now have this time block open do you want this shift?' You just "boop" [sound] right on over it and we don't really do like grief counseling. We don't really sit and talk about it.

a: ... I have my own grief ... I'm going to grieve myself ... I ain't got time to go to grief counseling [laughing]

This need for self-sufficiency in managing grief was apparent. As one DCW said, "I think it's part of the nature of this job that we kind of do our own support or else we wouldn't be in this kind of field."

Impact of Relationship on Grief Experience (n=22)

Participants expressed how their relationship with the patient and/or the patient's extended network impacted their grief experience. Specifically, how building and maintaining relationship (n=14) and the perceived connections (n=15) impact the experience of losing the patient.

Building and maintaining relationships. Sixty percent of DCWs (n=14) discussed the role of their care relationships with clients, such as how and why they build connections and maintain them. DCW's highlighted how building rapport was part of their role in working with clients. Many felt that part of their professional role is to see each patient as more than just a patient:

... I treat them as if my grandparents, because I treat my grandparents very well and I do a lot for them. ... this is the last place they are going to be before they pass so you want to make it as comfortable at home as possible. ... it takes a compassionate person to do this job, everybody cannot do this job. When you walk in there, you have to pull all your issues and problems that you have to the side, your focus is on them, so it's not about you, it's about them.

For others, the amount of time contributed to the experience of the relationship, such as with both the patients and the patient's extended network contributed to the experience of loss:

I think it has a lot to do with how *long* you've been with the client ... if it's just a couple of months deal and they pass ... I don't continue on with the family or anything. ... if I do have a real *deep* relationship with them, I usually do continue on seeing them ...

They're part of my life, you know?

Other DCWs shared how any change can contribute to feeling of a relationship loss, such as when "...you're pulled off a client because your schedule doesn't fit into the times they need.

... I'm kind of upset ... like, 'Oh, I don't get to see them anymore,' you fall in love with your clients." Another described how the expectations of relationship building is part of their job responsibility:

... you try to have a good fit ... we want the client and the caregiver to have a relationship ... if you have different people going in and out of there, they don't know what his normal day is. ... you do build like a relationship because a lot of our clients they, their families are either out of state or ... they don't have that companion care from their families.

Participants reported various ways their relationships with patients, and their particular role in caring for the patient, contribute to the experience of loss.

Perceived connections and impact of loss. Sixty-three percent of DCWs (n=15) expressed the level of connection with their patient added to their experience of loss. For example, "I would say that I think that the closer you get to someone I think it's gonna be more difficult." Another DCW expanded this sentiment, saying, "You kind of learn yourself, closures. And it's easier if you're not too attached to them, it's a lot easier to do." DCWs also illustrated the connection with clients and their extended care network contributes to the anticipatory grief:

when you get attachment ... And you've been with 'em for a while and it's a good fit, you get concerned about 'em, kind of pulls on your heart because you have developed a relationship with 'em, ... They may remind you of a, a parent or something, or a relative or somebody that you know that you've known ...

The perceived connection also contributed to how a DCW may experience a non-death loss, such as, "I had a client ... that went to a nursing home and I had a hard time with that ...

she had to go ... but in the back of my head, I'm like, *man*, 'cause she was my friend." Another shared:

... they had to move her into a [dementia] facility ... and that was hard. I didn't really *lose* her, she didn't die or anything, but I lost her. I thought she was my friend. And she thought of me as a friend, she sent people home because they weren't me.

Both the amount of time working together and the connection and impact of the relationship were detailed in the experience of loss. One DCW said:

I worked with her [client] for 4 years ... and she passed. ... It messed me up bad. Because you almost feel like they're a grandparent to you ... I used to joke around at everybody, "You can't wipe somebody's butt and not love them" [laughter] it takes a special person to do what we do ...

Another shared:

And it's been very traumatic. I've had one lady, one day a week and we went shopping, and to lunch and to the beauty parlor appointment and all this, and we were really buddies, plus I knew some of her other family members and she died. And she didn't seem that sick but she was and she was a little younger than I, so I really miss her.

Finally, DCWs shared that in evaluating their relationship with the patient and their professional responsibilities, the grief they experience, even when felt as personal, is to remain professional:

When they pass, it will be peaceful and I do get emotional, I get a lot emotional, But I bond with their family members. ... in the beginning ... I was upset 'cause families wouldn't come see them a lot, but I had to put myself in their shoes to say, "Hey, sometimes family can't deal with this situation, they can't handle it." ... it takes a

compassionate person to do this job, everybody cannot do this job. When you walk in there, you have to pull all your issues and problems that you have to the side, your focus is on them. So it's not about you, it's about them.

Participants highlight the different ways their perceived connection with the patient informs their experience and demonstration of the loss. For some, the loss feels personal, while for others, their professional status helped them both prepare for and cope with the inevitable loss.

Discussion

This study explored the perspectives of direct care workers whose views are highly underrepresented in research and in practice. Results demonstrate that DCWs *are* grieving. They use both personal and professional ways to manage the anticipation of and the experience of loss through a care transition in the absence of structured support. The participants identified a variety of ways their relationships with their patients and the specific functions of their job informed their experience of loss. Consistent with previous research of home health workers (Ghesquiere & Bagaajav, 2018; Tsui, et al., 2019), DCWs incorporate their personal understandings of both caring for others and how to grieve, including though personal mantras and spirituality. Both personal coping strategies and their understanding of loss contributed to how they managed anticipatory grief and the impact of losing a patient through death or relocation. Previous experiences with personal and professional loss and grief also informed their coping, such as the expectation of loss as part of the job, to never show grief publicly, or if possibly, to grieve alone.

The range of grief experiences provide opportunities for hospice and home health agencies to consider the organizational supports available to their team and whether these

supports are extended to DCWs. A study investigating home health agency policies and practices, found that none of the agencies that employed a median of 1,600 employees, reported any formal client death-related workforce policies (Tsui et al., 2021). Agencies should recognize the challenges in working with individuals who are seriously ill or have a terminal prognosis and provide ongoing support coupled with education and training for the anticipation of loss. As one participant shared, “I don’t think there really is any real preparation that you do, to just actually get yourself ready,” which suggests agencies should make support for the expected losses explicit. In considering implementing formal policies, agencies and organizations can explore the role spirituality and personal mantras play in coping and where within their professional roles can this be expressed.

Care transitions, and the varied complexities within healthcare systems, must be further explored. As older adults continue to need to transition across care settings, the role of the DCW will become even more important to support within organizations. For example, it is well documented that empowering DCWs within nursing homes and other residential care is associated with higher service quality (Shield et al., 2013), including patient care and safety (Hamann, 2013), and customer satisfaction (Scotti et al., 2009). However, DCWs work across different settings and must receive support appropriate for the level of care and the corresponding psychosocial needs. Further research to address care transitions within the community and home care settings is needed.

Our results support previous findings that education and training may help DCWs feel better prepared for the death of their clients, in addition to feeling supported by their agency (Gleason et al., 2016; Risenbeck et al., 2015; Tsui et al., 2019). Hospice and home health agencies can provide training opportunities related to care transitions and losing patients as

DCWs begin with an agency. Examples include strategies to make meaning of their experience, honoring the loss, and preparing for the inevitable changes to their work schedules for both death and non-death losses, including financial compensation when hours are unavailable.

In addition, ongoing psychosocial support at an organizational level and from team members will also be beneficial (Authors, In Press; Tsui et al., 2019). Results show the perceived connection and relationship influence the experience of care transition and agencies have an opportunity to develop space for DCWs to grieve their losses. Currently, DCWs do not have adequate time between losing one patient and caring for another (Ghesquiere & Bagaajav, 2018; Tsui et al., 2019). To better support DCWs, agencies could provide an outlet such as an answering service (Authors, in press), or group opportunities (Ghesquiere & Bagaajav, 2018) to provide an opportunity to share their grief during their paid work hours.

Implications

Results inform implications for the design and delivery of high-quality and compassionate end-of-life care and help to identify ways to better support a marginalized working population. As a start, the structural inequalities of low wage workers and lack of support must be addressed (Authors, In press). Results also highlight the lack of employer support following a disruption in client care, either through death or a loss from other care transitions. DCWs must be afforded the same paid opportunities as their team members for training, support, and to grieve (Tsui et al., 2021), which would also expand the role of the DCW within the interprofessional team model.

Potential barriers that keep hospice and home care agencies from providing this type of education and training for staff, including DCWs is critical to investigate. Team members with expertise in psychosocial well being, such as social workers, psychologists, and chaplains can

advise agency policies on best practices to better support the structure of the DCW role in end-of-life care, including formal grief and bereavement support opportunities for staff to say goodbye or manage care transitions. Efforts can contribute to the stabilization of a the DCW workforce with decreased turnover, and for individual agencies to better support their DCWs.

Limitations

This study has several limitations. Though efforts were made to expand recruitment efforts to reflect multiple forms of diversity within this workforce and to reflect national representation, some perspectives were not included in this sample. The fact that all focus groups were held at one home health agency is a limitation, yet most participants had worked for several other agencies and provided varied examples of their experiences. Also, the agency administration was present in the building during the focus groups, and though there was separation, there could have been bias in responses with concern their employer would hear them. A more comprehensive study might seek to obtain a range of racial/ethnic/language groups, as well separating different home care specialties (i.e. solely hospice), which may further illuminate the more specific needs in coping with client death.

Conclusion

This study contributes an in-depth exploration of the perspectives of direct care workers who experience loss through death and non-death care transitions. DCWs care deeply for their patients and demonstrate emotional resilience with very little professional guidance. Their personal strategies and their professional experience help them to cope with these care transitions. While the participants in our study used these strategies successfully, they do not reflect the views of hospice and home care workers who chose to leave the field, possibly

because of an inability to cope effectively. Supporting direct care workers will strengthen the underlying backbone of an essential workforce.

References

Authors (In Press).

Authors (2017).

Ayalon, L., & Roziner, I. (2016). Satisfaction with the relationship from the perspectives of family caregivers, older adults and their home care workers. *Aging & Mental Health, 20* (1), 56-64. DOI: 10.1080/13607863.2015.1020412

Blau, G., Chapman, S. A., & Neri, M. (2015) Testing the relationship between personal/home care aide trainees' career goals and their commitment to home care. *Home Health Care Management & Practice, 28* (3),150-154.

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*, 214–222. doi:10.1016/j.jpainsymman.2014.05.023

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

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101.

Byrne, K., Orange, J. B. & Ward-Griffin, C. (2011). Care transition experiences of spousal caregivers: From a geriatric rehabilitation unit to home. *Qualitative Health Research, 21*(10), 1371-1387. DOI: 10.1177/1049732311407078

Callahan, C. M., Arling, G., Tu, W., Rosenman, M. B., Counsell, S. R., Stump, T. E., & Hendrie, H. C. (2012). Transitions in care for older adults with and without dementia. *Journal of the American Geriatrics Society, 60*(5), 813-820. doi:10.1111/j.1532-

5415.2012.03905.x.

Creswell, J. & Poth, C. (2018). *Qualitative inquiry and research design: Choosing among five approaches*. Sage: Thousand Oaks, CA.

Dawson, S. L. (2016). The direct care workforce-raising the floor of job quality. *Generations*, 40(1). 38-46.

Ghesquiere, A. & Bagaajav, A. (2018). “We take care of people; What happens to us afterwards?” Home health aides and bereavement care in hospice. *Omega – Journal of Death and Dying*, 80(4), 615-628. Doi: 10.1177/0030222818754668

Ghesquiere, A., McAfee, C., Villanueva, C. (2016). Bereavement experiences and coping among hospice home health aides. *Gerontologist*, 56 (Suppl_3), 491.

DOI:10.1093/geront/gnw162.1977

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, 278–283.

doi:10.1016/j.gerinurse.2016.04.001

Hamann, D. J. (2013). Does empowering resident families or nursing home employees in decision making improve service quality? *Journal of Applied Psychology*, 33, 603-623.

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>

Lindquist, L., Cameron, K., Messerges-Bernstein, J., Friesema, E., Zickuhr, L., Baker, D.

W. and Wolf, M. (2012), Hiring and screening practices of agencies supplying paid caregivers to older adults. *Journal of American Geriatric Society*, 60,

1253–1259. doi:10.1111/j.1532-5415.2012.04047.x

Lai, D., Cloyes, K. G., Clayton, M. F., Doyon, K., Reblin, M., Beck, A. C., & Ellington, L. (2018). We're the eyes and the ears, but we don't have a voice: Perspectives of hospice aides. *Journal of Hospice and Palliative Nursing*, *20*(1), 47–54.

<https://doi.org/10.1097/NJH.0000000000000407>

Mitchell, S. E., Laurens, V., Weigel, G. M., Hirschman, K. B., Scott, A. M., Nguyen, H. Q., Howard, J. M., Laird, L., Levine, C., Davis, T. C., Gass, B., Shaid, E., Li, J., Williams, M. V., & Jack, B. W. (2018). Care transitions from patient and caregiver perspectives. *Annals of Family Medicine*, *16*(3), 225-231. <https://doi.org/10.1370/afm.2222>

Newquist, D., DeLiema, M., & Wilber, K. (2015). Beware of data gaps in home care research. *Medical Care Research and Review*, *72* (5), 622 - 640.

DOI: 10.1177/1077558715588437

Olson, R., Thompson, S., Elliot, D., Hess, J., Rhoten, Parker, K., Wright, R., Wipfli, B., Bettencourt, K., Buckmaster, A., & Marino, M. (2016). Safety and health support for home care workers: The COMPASS randomized controlled trial. *American Journal of Public Health* *106*(10), 1823-1832.

PHI. (2019). U.S. home care workers: Key facts (2019). Retrieved from:

<https://phinational.org/resource/u-s-home-care-workers-key-facts-2019/>

Rolf, David. (2106). Life on the homecare front: Integrating a workforce and a field of care into the modern healthcare system—and the modern economy. *Generations*, *40*(1), 82-87.

Scotti, D., Harmon, J., Behson, S. (2007). Links among high-performance work environment, service quality, and customer satisfaction. *Journal of Healthcare Management*, *522*, 109-124.

- Shield, R., Looze, J., Tyler, D., Lepore, M., Miller, S. (2013). Why and how do nursing homes implement culture change practices? *Journal of Applied Gerontology*, 33(6), 737-763.
- Staley, M., Gleason, H., Boerner, K. (2015). Home Health aides' experience with client death: The role of agency policy. *Gerontologist*, 55 (Suppl_2), 215.
- 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.
- Tsui, E.K., Franzosa, E., Cribbs, K.A., & Baron, S. (2019). Home care workers' experiences of client death and disenfranchised grief. *Qualitative Health Research*, 29(3), 382-392. Doi: 10.1177/1049732318800461
- Tsui, E. K., Franzosa, E., Reckrey, J. M., LaMonica, M., Cimarolli, V. R., & Boerner, K. (2021). Interventions to Reduce the Impact of Client Death on Home Care Aides: Employers' Perspectives. *Journal of Applied Gerontology*, 0733464821989859.
- United States Department of Labor, Bureau of Labor Statistics. (2019). *Occupational outlook handbook. Home health aides and personal care aides*. Retrieved from <https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.htm>
- van Riesenbeck, I., Boerner, K., Barooah, A., & Burack, O. R. (2015). Coping with client death: How prepared are home health aides and what characterizes preparedness? *Home Health Care Services Quarterly*, 34, 204–219. doi:10.1080/01621424.2015.1108890
- Wholihan, D., & Anderson, R. (2013). Empowering nursing assistants to improve end-of-life care. *Journal of Hospice & Palliative Nursing*, 15(1), 24-32.
- Zmora, R., Statz, T. L., Birkeland, R. W., McCarron, H. R., Finlay, J. M., Rosebush, C. E., & Gaugler, J. E. (2020). Transitioning to long-term care: Family caregiver experiences

of dementia, communities, and counseling. *Journal of Aging and Health*, 33(1-2), 133-146. Doi: 10.1177/0898264320963588.