


“Death Is Part of the Job” in Long-Term Care Homes: Supporting Direct Care Staff With Their Grief and Bereavement

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Abstract

For long-term care (LTC) home staff who work directly with residents, death, dying, and grief are day-to-day experiences in their working life. However, staff are often overlooked for grief and bereavement support. This exploratory research used a qualitative approach to understand LTC staff's grief and bereavement experience and to identify the perceived support needs of nurses and personal support workers who work in two faith-based non-profit care homes in Thunder Bay, Ontario, Canada. Findings indicated that participants' experiences are complex, shaped by the emotional impact of each loss, the cumulative burden of ongoing grief, an organizational culture in LTC where death is hidden, and the lack of organizational attention to staffs' support and education needs. Eight recommendations were developed from the findings. It is hoped that this research will assist in the development of organizational policy and procedures, addressing the health and well-being of direct care workers in LTC homes.

Keywords

long-term care, nurses, personal support workers, grief, workplace wellness

Introduction

For registered nurses (RNs) and personal support workers (PSWs; also known as health care aides or nursing assistants) who work directly with residents in long-term care (LTC) homes, death, dying, and grief are usual experiences in their day-to-day working life (Anderson & Gaugler, 2007; Wowchuck, McClement & Bond 2007). LTC homes increasingly provide end-of-life care, with approximately 20% of residents in Canada dying each year (Canadian Institute for Health Information, 2012; Statistics Canada, 2011; Travis et al., 2002). Similar trends exist in England, United States, and Australia (Froggatt et al., 2013; Parker, 2013).

It is estimated that by 2020, this number will reach up to 39% in Canada (Fisher, Ross, & MacLean, 2000). Thus, it should be anticipated that staff working in LTC settings will increasingly care for dying residents on a daily basis. However, these staff who provide direct care and assistance to residents and their families are often overlooked when it comes to recognizing their own grief and bereavement experiences. At the health system level, LTC homes have only recently been recognized as a major location of death, and therefore an important setting for providing palliative and end-of-life care (Hirdes, Mitchell, Maxwell, & White, 2011).

Palliative/end-of-life care literature identifies that specialized training, skills, and education requirements are needed for the delivery of palliative care (Froggatt, 2001; Hall, Koliakou, Petkova, Froggatt, & Higginson, 2011; Kagan &

Stricker, 2010; Sanders & Swails, 2009; Stolley, 2010). Support for grief, loss, and bereavement is acknowledged to be an important component of holistic palliative care as per Canadian Hospice Palliative Care Association's (2013) Model of Care. Research in specialized palliative care and hospice programs is abundant and clearly demonstrates the need for and benefit of addressing staff's emotional needs to improve the quality of care and staff retention (Vachon, 1995). What is not well understood are the emotional experiences of direct care workers working in LTC homes, especially how the organization can better support staff in managing their experience of grief and loss when a resident dies (Anderson, 2008; Anderson & Ewen, 2011; Rickerson et al., 2005). The presented research begins to address this gap in knowledge.

Background

This study was conducted as a sub-study within a 5-year project *Improving Quality of Life for People Dying in Long-Term Care Homes* (2009-2014), conducted by 27

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researchers and 38 community organizational partners, collectively known as the Quality Palliative Care in Long-Term Care Alliance (QPC-LTC Alliance). The overarching research was a participatory action research project that used a comparative case study design, with four LTC homes located in Ontario, Canada, as study sites (Kelley & McKee, 2013). The overall goal was to improve the quality of life for people who are dying in LTC homes through the development of palliative care programs, using a process of community capacity development (Brazil, Kaasalainen, McAiney, Brink, & Kelley, 2012; Kaasalainen, Brazil, & Kelley, 2012; Ramsbottom & Kelley, 2014; Wickson-Griffiths et al., 2014; see www.palliativealliance.ca for further information).

Results of the organizational assessments, conducted in 2009 in the four LTC home study sites, indicated that direct care workers develop close relationships with residents and experience a tremendous sense of loss and grief when these residents die. However, there is minimal recognition and formal organizational response to support staff's feelings of grief and loss. Based on these assessment results, the research team decided to conduct a more focused and in-depth sub-study to better understand the inevitable grief and loss experience of direct care workers in a LTC home, including their perception of how the organization can support them with these losses. Recommendations emerged from these perceptions.

Organizational Context of LTC

Historically, LTC homes in Ontario have operated on a medical model of care, with an emphasis on managing chronic conditions (Brazil, McAiney, Caron-O'Brien, & Kelley, 2004). LTC has now become an extension of chronic and complex continuing care where residents are frailer, have a number of life-limiting illnesses, and choose to remain in LTC at the end of life (Brazil, Krueger, Bedard, & Kelley, 2006; Wijk & Grimby, 2008). The average age of an Ontario LTC resident on admission is 83, with 85% of residents classified as requiring high levels of care, meaning they need constant supervision and assistance in performing one or more activities of daily living (Sharkey, 2008).

Eighty to ninety percent of direct care in LTC homes is provided by unregistered PSWs (Berta, Laporte, Zarnett, Valdmanis, & Anderson, 2006; Riggs, & Rantz 2001). These workers are responsible for multiple tasks, such as assisting in bathing, eating, and dressing; reporting changes in physical symptoms; and caring for the psychosocial needs of the resident (Anderson & Gaugler, 2007). Their workload is heavy, the resident-to-care worker ratio is high, and there is a great attention focused on the completion of care tasks (Anderson, 2008; Sharkey, 2008). In addition, LTC homes are being required to take on a prominent role in end-of-life care (McClement, Wowchuk, & Klassen, 2009) and thus are assuming many hospice-like functions. These conditions are the context in which LTC staff currently work.

It is within this environment that the grief, loss, and bereavement experience of LTC staff is both framed and managed. Presently in Ontario, there are no policies or established practices that require LTC homes to address grief and bereavement support for their staff. The *Long-Term Care Homes Act*, developed by the Ontario Ministry of Health and Long-Term Care (2007), establishes the need for policy to support all formalized programs, but the actual framework and content of a formalized palliative care program including the psychosocial and training needs of caregivers has not been defined. Therefore, developing and implementing the palliative care program is left up to each home, and as a result, the LTC homes demonstrate inconsistent approaches (Brazil et al., 2004).

The LTC setting provides little formal support for staff in managing their grief and loss when a resident dies. Some homes may have formal memorial services for deceased residents that can promote healthy grieving; however, staff are rarely provided with space, time, and professional assistance to attend these memorials. Likewise, staff does not systematically receive training on grief and bereavement, despite the regular occurrence of death (Anderson, 2008; Anderson & Gaugler, 2007; Burack & Chichin, 2001). As more residents live and die in LTC homes, it is important for staff to have access to support that enhances their ability to continue providing compassionate and quality care (Rickerson et al., 2005).

Finally, there are pressing organizational reasons to support staff grief and bereavement. Acknowledging grief reactions and examining staff's experience with death and grief are known to be crucial for providing compassionate care as the person's grieving history provides the foundation upon which one builds skills for helping others with their losses (Churchill, 1999). However, a lack of organizational focus on staff well-being and the lack of support from management can lead front line workers to experience complex grief reactions (Anderson & Ewen, 2011). Other research suggests problematic outcomes where health care providers who deal with death in an ineffective manner run the risk of not properly caring for their clients (Brunelli, 2005; Durall, 2011).

High rates of turnover among nursing home staff are well documented, especially among PSWs (Riggs & Rantz, 2001). Rosen, Stiehl, Mittal, and Leanna (2011) studied factors associated with nursing assistants in nursing homes leaving their job and identified low job satisfaction and emotional well-being as the most prevalent reasons. Staff turnover, in turn, negatively affects the nursing homes ability to provide high-quality care. Recruitment and orientation of new staff is time-consuming for managers and costly to the organization. In the palliative care field, lack of support for staff grief and bereavement has been shown to contribute to compassion fatigue, burnout, and poor retention (Showalter, 2010; Slatten, Carson, & Carson, 2011; Vachon, 1995). One strategy to improve staff satisfaction and potentially improve staff retention in LTC homes is to provide a more supportive

workplace that includes effective organizational strategies to help staff manage their grief and loss.

Direct Care Workers' Relationship With LTC Residents and the Impact of Their Grief

The relationships that are formed between LTC staff and residents are significant. Direct care workers perform duties that have a high level of social and physical contact with residents; subsequently, the relationships they form with residents are deeper than those formed by other health care professionals (Anderson & Gaugler, 2007; Black & Rubinstein, 2005). The close bonds that are formed allow direct care workers to learn about the life experiences of the resident, gauge residents' emotional responses, and detect early changes in their physical condition. This information is critical in providing holistic care for residents and their family (McClement et al., 2009).

Given the level of care provided and the relationships that develop between residents, their families, and direct care workers, it may not be surprising that staff often view these relationships with residents as familial. A metaphor of "family like" or that residents are "extended family" has often been used by staff (Black & Rubinstein, 2005; Moss, Moss, Rubinstein, & Black, 2003; Rickerson et al., 2005; Sims Gould et al., 2010). When residents are considered like family, the emotional attachment may provide staff with a feeling of being appreciated and cared for by the residents (Burack & Chichin, 2001), and for many residents, these formal caregivers become surrogate families (Rickerson et al., 2005).

Research has identified that the closer the staff-resident relationship, the more intense the grief experience (Anderson & Gaugler, 2007; Durall, 2011). Individuals who deal with death as part of their work, such as in LTC, need to find a way to make sense of death and dying. There is also evidence in the literature that how staff manage their strong grief reactions has an impact on resident care. Moss et al. (2003) state that emphasizing self-control over the expression of feelings can result in staff detaching from residents, especially when there is an expectation for staff to emotionally distance themselves to carry out their work duties efficiently. Van-Hein Wallace (2009) states that nurses may hesitate asking for emotional support for fear of being considered unprofessional or unable to work in a highly emotional workplace. This perceived expectation of emotional distance reinforces an organizational culture of denial and silence around death and dying in LTC homes.

Given the lack of support, time, training, and opportunity to manage grief in the workplace, it may not be surprising that direct care workers believe that they are expected to just "deal with it" when it comes to managing grief (Brunelli, 2005; Burack & Chichin, 2001). This belief may lead care staff to maintain a culture where death of a resident is structured to have a minimum impact on the work at hand (Moss

et al., 2003). Literature shows that LTC workers do not feel supported in sharing their grief at work due to the lack of time and heavy workload, and thus they bring their grief home (Kaasalainen, Brazil, Ploeg, & Martin, 2007).

To maintain their overall well-being, staff need to work through the grieving process to arrive at a healthy resolution with the client's death (Brunelli, 2005). Anderson, Ewen, and Miles (2010) found that health care aides who perceived their feelings of loss were validated experienced greater growth from the loss. LTC organizations may therefore want to consider the impact that unresolved grief can have on their employees, and recognize the benefit of providing grief and loss support to their staff. In examining how grief can be managed, Durall (2011) suggests the "the culture of silence" that surrounds the grief and loss needs to be broken. Creating a work environment where staff are able to express their grief, work within a supportive clinical team, and create a meaningful context in which to place death are all identified ways in managing grief (Burack & Chichin, 2001; Durall, 2011).

In summary, the LTC environment provides the context in which the grief and loss of staff are experienced and need to be managed. As more residents remain in LTC during the end of life, the direct care staff face the challenge of coping with these deaths. The relationships that are formed between staff and residents are close bonds, and thus the loss and bereavement needs recognition and support. Close emotional relationships form the foundation of compassionate, well-informed quality care, specifically the kind of care that is necessary in providing good palliative care. Therefore, it is important for LTC homes to provide grief and bereavement support for their staff, and ensure that staff's health and well-being are considered equally as important as the care of the older adults for whom the LTC environment is designed. Supporting staff's grief may also contribute to improving retention of staff by enhancing their feelings of satisfaction and emotional well-being.

Method

The overall purpose of this study in LTC homes was to understand direct care workers' experiences of grief and loss related to the death of residents, their support needs, and their perception of the role the organization should play in supporting staff with these losses. The following research question was used to guide the study:

Research Question: What supports do LTC staff want and need in the workplace to help them manage their grief and loss when residents die, and how are these best offered?

This research addresses an identified gap in the literature as previous research has not concentrated on the impact of grief on direct care workers in LTC settings. These findings

can provide the organization valuable directions to create strategies and policies to promote workplace wellness, which include supporting staff grief. The outcomes of this research have been incorporated into the QPC-LTC Alliance's framework and toolkit that are available to guide developing palliative care in LTC homes (see www.palliativealliance.ca).

This exploratory research used a qualitative approach to understand the experiences and perspectives of nurses and PSWs who work in two faith-based non-profit care homes in Thunder Bay, Ontario. The first home, built in 1979, provides specialized nursing care to 110 residents, and it offers a palliative care room for residents' and families' privacy. The second home opened in 2004 and accommodates 96 residents. A unique feature of this home is in its construction and design, providing each room with a view of an outdoor space.

Ethics approval was obtained from Lakehead University and St. Joseph's Care Group.

Participants

A purposive sampling technique was used to recruit nine staff members who represented all three categories of LTC direct care workers: RNs, registered practical nurses (RPNs), and PSWs. Participants were recruited by two PSWs who worked in the study site homes, each working in one of the LTC homes. They selected and invited staff who they perceived to be knowledgeable informants for the study purpose to participate in the research. These two PSWs were well respected and well known by all of the LTC staff. Nine participants volunteered for the study who had extensive experience caring for dying residents and spent the majority of their working time providing direct care to residents.

Participants included one RN, one RPN, and seven PSWs. All participants were female, ages ranging from 20 to 54, and all with more than 3 years of experience working in LTC. The majority of the LTC staff in the study sites were female, and no males volunteered for the study. However, the absence of male staff in the sample was a limitation of the study.

Data Collection

Individual semi-structured interviews were used to collect data. All interviewers were trained graduate students in the Master of Social Work (MSW) program at Lakehead University, Thunder Bay, with each student conducting one interview, using an interview guide. The location of the interview was selected by the participant, and the interviews lasted from 30 min to 1 hr. The meetings all occurred in locations that allowed confidential conversation, such as at the workplace in a meeting room, in the public library meeting room, or in the participant's or interviewer's private home. Interviews were conducted in a conversational style. Open-ended questions guided the interview yet allowed flexibility to adapt to the narratives emerging and areas of interest raised by the participants.

The interviews began by asking the participants to generally describe the extent to which grief is an issue for staff working directly with residents. Participants were then asked how the death of a resident affects them emotionally. The interviewer explored more specific interpersonal factors such as the coping strategies used by each participant and how the workplace environment supports them through the grieving process. Participants were also asked to comment on how the workplace can better assist and improve support services.

Data Analysis

The interviews were audio taped and transcribed verbatim by the research assistants (RAs). All transcripts were then made available to all RAs to review. A three-level process of analytic induction (Huberman & Miles, 1994) was used to reduce the data into four overarching categories that together portrayed a complex picture of the staff's experience and support needs related to grief, loss, and bereavement. To ensure rigor, a process of peer review occurred among eight researchers at each level of analysis. Consensus was reached on the evolving analysis.

RAs initially independently coded the transcripts manually to identify all participants' ideas. Sitting as a group with the senior researcher, the ideas were systematically compared and discussed, and the themes were agreed upon. Discussion continued at four weekly 3-hr meetings until agreement was reached that the analysis fully and accurately represented the participants' narratives.

During the analysis meetings, initial ideas were grouped into 38 (Level 1) themes according to their common features and meanings. These themes were then grouped into 12 (Level 2) explanatory themes and finally into four overarching (Level 3) categories. The categories were created inductively to explain the Level 2 themes and informed by the purpose of the research. At each level of coding, the emerging themes and categories were displayed on the wall using concept maps. These concept maps are included in the description of the findings.

Results

The grief and bereavement experience and support needs of LTC direct care workers can be understood through four overarching categories: (a) organizational context influences staff's experience of grief and loss, (b) the burden of grief, (c) the emotional impact of grief, and (d) grief support needs of direct care staff. Each category has a number of themes and sub-themes that are supported by direct quotes from participants that are taken from the data.

Organizational Context Influences Staffs' Experience of Grief and Loss

The organizational context is the first overarching theme that emerged from the data in understanding the grief process of

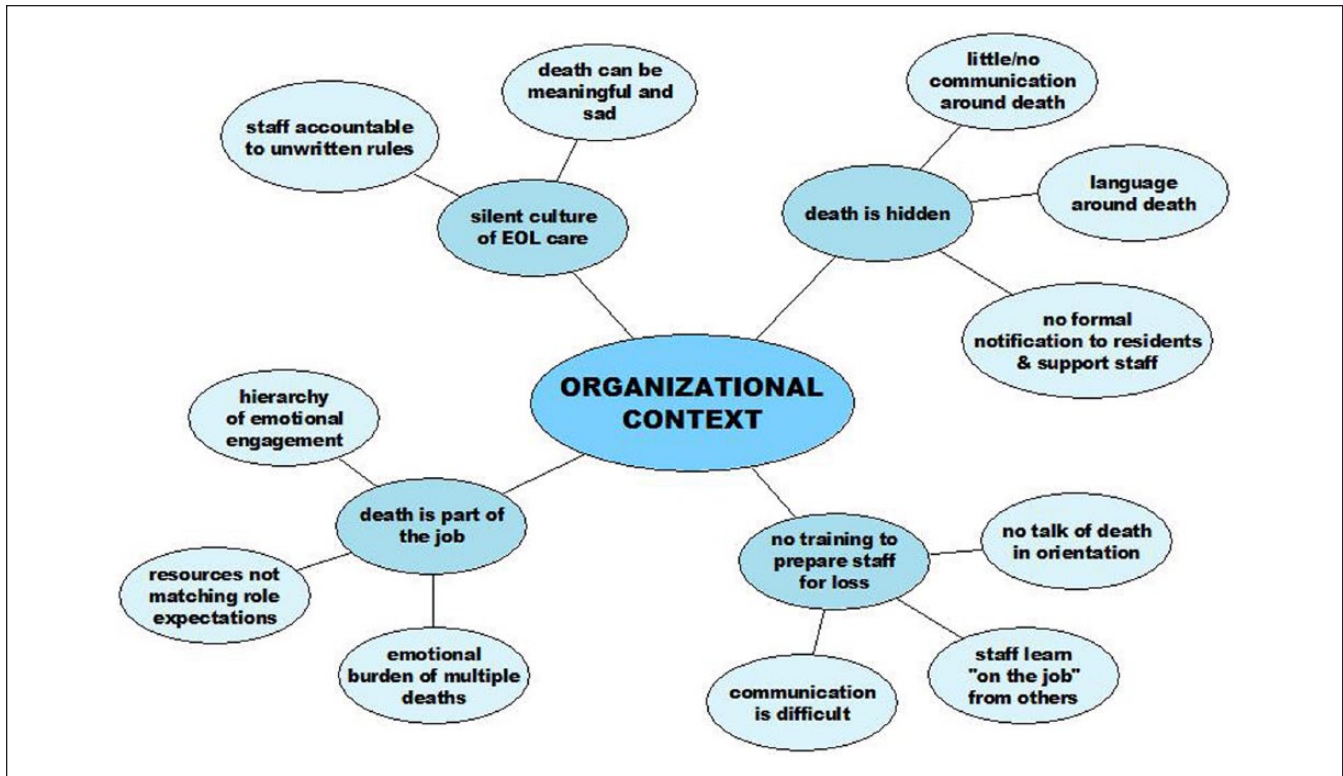


Figure 1. Organizational context of LTC influences grief and loss for direct care staff.

Note. LTC = long-term care. EOL = end-of-life.

direct care workers. The participants spoke about the work environment and how this environment affects their grief experience. Several themes were identified: death is hidden, there is no training to prepare staff for loss, death is part of the job, and there is a silent culture that exists around dying. A thematic diagram, depicting the category, theme, and sub-themes, is included in Figure 1.

Death is hidden within the LTC culture. The organization attempts to create a home-like setting for residents, and death is not explicitly incorporated into the culture. The participants identified the theme that *death is hidden* from the residents and from direct care staff, including those not providing direct care such as dietary staff. Staff elaborated that there is *little communication about death* although there are informal and unofficial pathways of communication within the homes. Staff may learn of a resident's death informally through coworkers or outside community sources. The responsibility to obtain information rests with the staff member as illustrated in the following quote:

I was off for three days and I walked off the elevator and never noticed that her name was on the board, but she'd passed . . . and in the middle of report I was . . . "you know this bed's empty" . . . it's like hold it, what happened here? (PSW)

The participants indicated that explicit *language around death* does not exist. When staff refer to death, the terms

letting go and *passing* are used in place of dying or died. This idea is indicative of the lack of comfort within the organization to explicitly name the events that are taking place when it comes to the dying process. Participants often stated, "So when she left, like when she passed away . . ." or "If I am having trouble with somebody just passing . . ." These statements all make reference to death, without actually using the word.

Participants identified that *no formal notification to residents and support staff* about a resident's death exists in the home. Residents will ask staff about other residents who have died; however, this information is not provided due to the misperception of many staff that confirming that a resident has died is a breach of confidentiality. There is no immediate formal service or ceremony within the homes that would inform residents of a death, although there are memorial services held twice a year. Death is also hidden from other support staff such as dietary or housekeeping as there is no formal process of notification in place. The following quotes provide evidence of how death is hidden:

When they die, their tag from outside their room goes on the "in memoriam" board. So that's how they officially know that the person is dead . . . that's it, they don't have a little announcement or a moment at breakfast . . . (RPN)

You know it really affects them [residents]. Like you can have four people at a table every day for dinner, breakfast, lunch, and

then that person's not there . . . so all of a sudden there's a new face at the table. (PSW)

No training to prepare staff for loss. Participants identified that there is no training to prepare staff for loss of a resident, nor is there any information given with regard to available supports and resources when experiencing grief. They stated that during the orientation process *there is no discussion around the prevalence of death*. The purpose of orientation was to prepare staff for their role within the organization and to give them an opportunity to ask questions. However, the focus of management in training initiatives centers on direct care practice, and not on grief and loss. The lack of discussion identifying the prevalence of death does not give staff a chance to inquire about death or provide staff an opportunity to ask about the resources available to them. The following gives evidence:

There's nothing that I'm aware of that's in place . . . it is bad because I think even with orientation as a new employee you should be told what you can do, and there's nothing that I'm aware of that's even in place. (RPN)

Participants stated that they *learn how to manage grief "on the job,"* primarily by observing others and monitoring reactions from them. In particular, when new staff are trying to integrate into the existing culture, they learn from more experienced workers. The informal relationships among staff, in trying to help one another cope with the demands of the workplace, are integral to the culture in LTC. There are no written procedures to cope with grief; rather, it is the relationships developed among staff that guide others through the process. This idea was spoken of several times:

. . . there's a lot of knowledge, like even approaching family and dealing with families and as new people come into the home . . . they get watched lots by the older staff . . . that's how I learn too . . . my older staff and how they deal with people . . . (PSW)

Our senior staff . . . they've been around a long time . . . they're the ones that are teaching us how to deal with everything. (PSW)

Participants indicated that *communication with residents and their families is difficult*; however, it is an important part of their role, and these skills require education. They are frequently asked questions about death and dying by family and residents. Participants stated that they are often uncomfortable and feel unprepared to respond to difficult questions. Staff were aware of bereavement pamphlets for family but identified that sending family off to talk to someone else felt impersonal.

Death is part of the job. Participants have an implicit understanding that managing residents' death is part of what they do. This understanding does not come from open discussion or instruction; it comes from the experience of working in an

environment where death is a common occurrence. Participants identified that there is an *established hierarchy* of emotional engagement between staff and the residents, depending on their professional role. This hierarchy begins with the PSWs at the bottom, and works up through the RPNs to the RNs, and then to managers. The participants' perception is that the emotional burden of grief decreases the higher the staff member is on the professional hierarchy. Evidence of this perception is demonstrated with the following quotes:

. . . there's support . . . not from the managers so much . . . I don't think that it's intentional . . . they have their own things that they worry about . . . I think because they don't have as much interaction with the clients as we do . . . that's not one of their priorities. (PSW)

. . . we've always approached each other, "how are you doing?" or "are you doing ok?" . . . I've never seen an RPN, RN, or management come up to a worker and say "are you ok?" and "are you going to be attending the funeral?" . . . I have never seen anything like that. (PSW)

There are many expectations placed on staff to provide emotional and informational support to the resident, as well as their family. However, *resources do not match role expectations*. Participants identified that there is nothing in their training to prepare them for the supportive role, and the resources available within the home such as pamphlets and guidelines do not support the staff with this expectation. Furthermore, the lack of time, the demand to complete tasks, and the lack of emotional support offer little comfort to staff with their own grief experience. This idea is illustrated with the following quote:

So it's always the staff, the staff helping the staff which isn't bad, but if you don't have the training you know how do you help someone through that [grief] (RPN).

Participants indicated that they have close relationships with residents and their families, and they are accustomed to seeing families regularly. However, once a resident dies and the room is cleared of the body and possessions, this relationship with the family abruptly ends. Participants identified an emotional loss of both resident and family; there is no opportunity to express their grief over the loss of these relationships, just expectation to carry on with the job. These multiple losses result in an *emotional burden for the care providers*. The following quotes demonstrate staffs' multiple losses and the emotional burden:

They're all very important to me . . . I've pronounced many, I've seen a lot in my life . . . we've just lost six in the last few months . . . it was pretty hard, we hadn't grieved yet . . . I lost track now. (RN)

Because what happens is they become our family, like you get close, you see them every day and all of a sudden it just stops. (RPN)

Silent culture exists around dying. PSWs identified that there are many unwritten rules and implicit expectations around the delivery of care that guide practice and help staff in coping with the demands of work. This silent culture assists them to meet the expectations placed on them by management. There is an understanding among staff that death is part of the nursing culture. The significance of this understanding emerges as staff strongly believe that during the dying process the residents are not to be left alone in their rooms. There should always be someone present, especially if there is no family around. *Staff hold one another accountable* to provide comfort to the dying client. The following quotes support this idea:

We are here for a reason and the reason is for the end of life. (PSW)

She died [with no family], she was a ward of the state and she was by herself, and that's what killed us the most . . . these people that have no family, they need someone to represent them. And she died alone, but she was in her home, right? (PSW)

Staff develop close relationships with residents and subsequently do not like to see residents suffer in any way. When death is imminent, staff view it as a welcome end to the pain and suffering that the resident may be experiencing. At the same time, however, there is a sad emotional reaction to the loss of the relationship. In welcoming an end to the pain and suffering, staff acknowledged that giving the resident permission to let go is a form of support for the resident and a form of closure for the staff. They view *death of a resident as meaningful and sad*. A participant shared her experience, stating:

I hate the part of watching them suffer. So once they go, you know it's kind of a relief to some extent . . . I would never want somebody to stay alive and in pain. (PSW)

The Burden of Grief

Grief is undeniably present in the LTC homes. It is also inevitable that staff develop relationships with residents as they are providing not only physical care but also a continued presence in a resident's everyday life. Each staff member's experience of grief is individualistic, with a complex set of personal and organizational circumstances affecting the grief burden. Two themes are identified: no relief from grief and loss, and staff's coping strategies to manage grief. A thematic diagram depicting the burden of grief is included in Figure 2.

No relief from grief and loss. The grief and loss are part of the nature of work that is done in LTC home, and the direct care workers learn to manage emotional detachment from residents after their death. There is no control over death, and staff learn individually to cope with the loss of residents. Participants explained that grief is a continual emotion that is *embedded in the nature of the work* that is done. Although

death is part of the LTC environment, they expressed difficulty with experiencing death on a regular basis. Evidence supporting this notion is given with the following quote:

They're [deaths] all hard to deal with . . . even though you do a lot of it, you still have a hard time . . . doesn't matter how many you've looked after or dealt with. (PSW)

Participants spoke about *managing emotional attachment and detachment*. They have dual responsibility to effectively attach to residents in an effort to provide what they describe as quality care, while they must be able to detach when the resident dies to carry on with their routines. This idea is described with the following evidence:

I guess we're just expected to be strong and we just have to . . . accept that it's gonna happen . . . we're always getting new people in afterwards right? So we just have to keep going. (RPN)

Sometimes we have a resident that dies and two days later there's someone in that bed . . . and you're learning all about somebody new and you haven't actually grieved the loss of the last person. (RPN)

As a result of feeling a *lack of control over death*, staff seek ways to regain control through their work and relationships. They recognize that everything they did for the residents and their families had an impact. Through their proactive and positive actions, staff members are able to recover some of their lost control. The following quote supports this idea: I'm the one who takes control, everybody else gets to cry. I don't. I cry on my own, but with helping them I've helped myself. (RPN)

Staff use coping strategies to manage grief. Some of the participants reported that they do not feel sufficiently prepared to deal with the grief process in LTC. As a result, participants rely on their own personal coping strategies, which vary from person to person. A number of sub-themes emerged when staff spoke of these strategies.

The importance of *letting go* of the resident is an experience shared by many participants. They clearly expressed the importance of being present at the time of death to offer comfort to the resident and also to give themselves a comfort knowing the resident was not alone. By drawing on personal experience, expressing love for the resident, and mentally preparing themselves for loss, staff members feel that they are better able to cope with the resident's death, as expressed through the following quotes:

I spend time with them . . . if I want to sit and hold their hand . . . or talk to them . . . just doing care on them. Being there, letting them know that I'm here . . . it all helps. (RPN)

If you go in knowing you're there to make them comfortable just until they pass away, then you mentally prepare yourself for it. It'll still hurt, but you're mentally knowing that person's dying. I'm just here to make them comfortable till they're gone. (RPN)

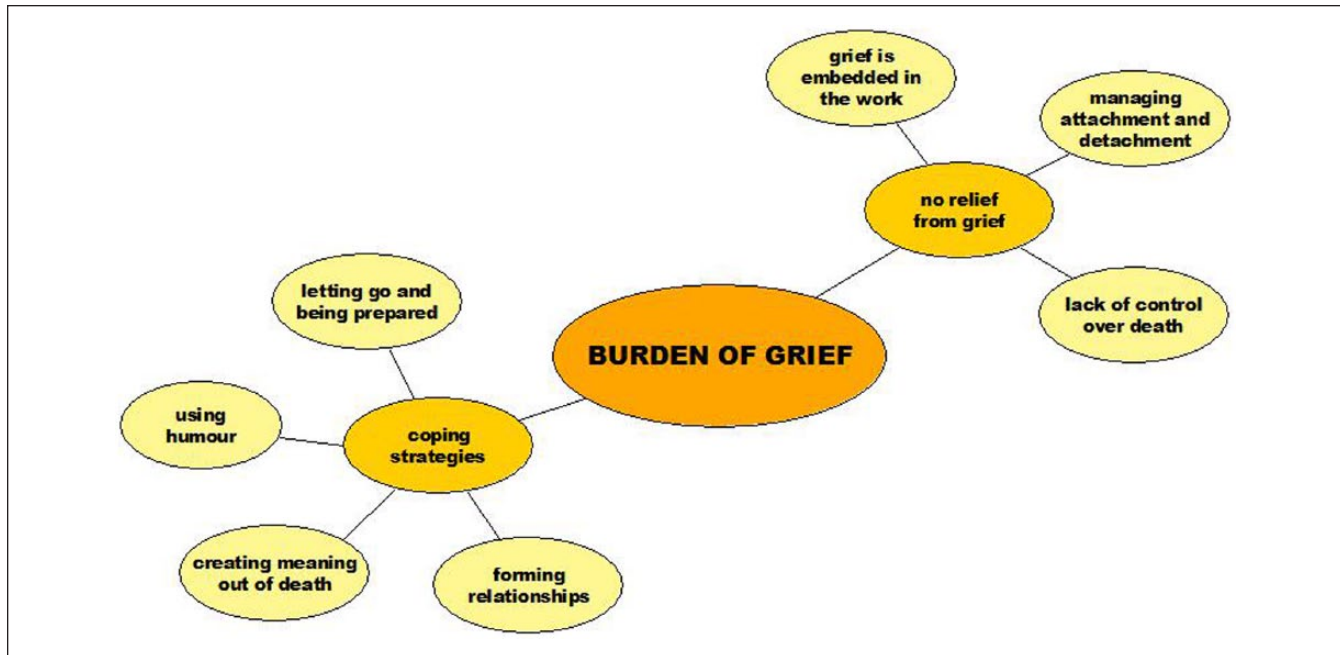


Figure 2. The burden of grief for direct care staff working in LTC.
Note. LTC = long-term care.

Participants noted that *using humor* is often necessary to manage work-related grief. Staff indicated that the work environment would be depressing if they could not find some humor in their work. This idea is supported with the following quotes:

Some of us are very good to each other . . . we are all laughing and goofing the vast majority of the time . . . it could be a really depressing place if you let it be, but I figure . . . I'm going to work for like eight hours a day every day of my life . . . I want to be happy while I'm there. (PSW)

He hadn't conversed with anybody or said anything . . . and we thought there's no way this guy's going to sing. Oh we started singing "Happy Birthday" and he sang along with us . . . it was hilarious. Oh it was funny . . . humor and bad singing. (PSW)

Participants indicated the significance of *creating meaning around a resident's death*. This meaning is constructed by focusing on the value of the lived life of the resident, bringing attention to what the resident brought into the LTC facility, and the contribution the resident made to the lives of staff who cared for him or her. The importance of creating meaning is illustrated below:

If it's an 80 or 90 year old and you think about all the things they've accomplished in their life, I just find it so much easier to get over it. It doesn't bother me as much. (RPN)

Participants pointed out that the *relationships that are formed* in LTC among staff, residents, and family are essential to managing their grief experience. The relationships were often described as being family-like bonds that provide

a source of support and aid in staff's coping with the loss when a resident dies. The idea of forming relationships is evidenced through the following quote:

It's a family . . . you become part of the family when you work there . . . nobody's really excluded. (PSW)

The Emotional Impact of Grief

Participants were able to describe the emotional impact that grief has on them. Two themes emerged from the data: there are no formal organizational processes to handle their grief, and participants' coping strategies to manage the grief. A thematic map, illustrating the emotional impact of grief, is shown in Figure 3.

No formal organizational process to handle grief. Participants clearly indicated that there is no organizational process available to address their grief experience. When a resident dies, there is *no formal opportunity for closure*. The participants are expected to carry on with their tasks, without any formal acknowledgment that the residents' death may have an impact on them. The following quotes illustrate this:

I went home crying [after a resident died]. You know, there was no one to talk to, no one to vent nothing. It was just "oh my gosh, this woman just died today and we didn't say nothing and there was nothing for us." (PSW)

She passed away last week . . . she's got no funeral, no nothing and it's really, really hard. How can we have closure for that

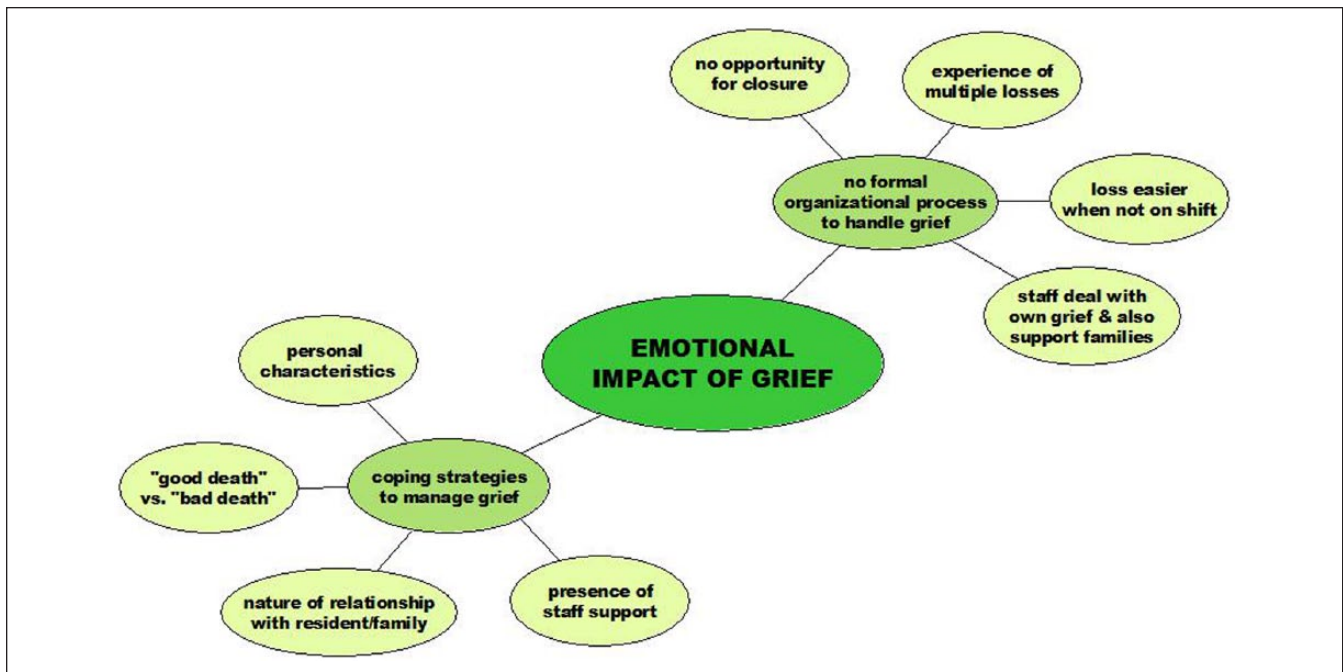


Figure 3. The emotional impact of grief on direct care staff in LTC.
 Note. LTC = long-term care.

lady? It's sad . . . we don't have a funeral for her, we don't have anything in place at work other than us talking about her and talking about the little funny stories. (PSW)

The meaningful relationships that exist with residents also exist with the resident's family. When residents die, staff members lose not only the resident but also the relationships formed with family members. This *multiple loss experience* was mentioned on several occasion and evidenced by the following quote:

The full time staff that are there 5 days a week . . . really get to know the residents well . . . and the families as well. So when someone passes, it affects them quite a bit. (RPN)

It was explained that given the relationships formed with residents, it is sometimes *easier to deal with the death of a resident when staff is not working at the time*. Being present at the time of death can be difficult, and reading about it in the paper at a later date is sometimes easier. This was evidenced when a participant stated,

I feel that when you're away from the facility, you don't have that much of an emotional connections with them as when you're right there beside them and you're watching them. (RPN)

Despite their own emotional struggle over the loss of a resident, participants identified the *importance of offering support to family* who are grieving the loss of their loved one. There is also an awareness the colleagues may be

experiencing grief at the same time. Each participant spoke of witnessing other coworkers struggling emotionally following the death of a resident, and this often has the effect of staff pushing aside their own grief to support their fellow coworker. Evidence of this idea is given with the following quotes:

You can see that they're in pain and the suffering from the . . . partner, you can kind of see it in their eyes . . . so we support her. (RPN)

I graduated two years ago . . . they [school] deal with death and dying . . . the breathing slows down, the organs shut down, they deal with the book, they don't deal with the life. They don't say okay . . . you're going to see families be hysterical . . . you have to let them grieve their way and you have to be there to try and support them if you can. (PSW)

Coping strategies to manage grief. Participants identified a number of factors that have an influence on how grief is experienced in the LTC setting. This theme has a number of supporting sub-themes that emerged from the ideas in the data.

Participants described that there are *different grief reactions among staff*, and these reactions vary according to their work and personal experience. Self-reflections by staff about the value of their role also appear to play a critical role in how a resident's death is experienced. Some participants self-reflect, stating that their work role of caring for those who are dying helped make the life of the residents well lived

and as comfortable as possible. This view provides comfort to the staff as evidenced through the following quotes:

If I can make a difference, that's what life's about. If you make a difference in somebody else's life, then that is what I'm here for. I'm here for that, for sure. (RPN)

Being comforting to the other person, that was my strategy, that was my coping strategy, knowing that I could be comforting for somebody else. (PSW)

However, participants described that the lack of personal experience with death influences how staff would process the event. Many staff beginning employment in LTC have not witnessed a death or experienced a loss through death. The following quote provides evidence to this sub-theme:

Some people don't know how to grieve. Some people are working in long term care and maybe they haven't really lost somebody close to them so they really don't know . . . how to grieve or how their emotions are going. (PSW)

Participants identified that the *circumstance surrounding the death* of a resident is a significant factor contributing to their grief reaction. If the death was described as a "good death," where the resident was not alone, pain was managed, and the resident was comfortable, then staff were better able to come to terms with the resident's death. If the death was described as a "bad death," whereby the resident appeared to be suffering, pain was not managed, and the resident died alone, then staff experience moral angst associated with that death. Participants were strong in voicing the importance of providing the resident with comfort, support, and presence at the end of life as this influences their perception of the resident's experience, as well as their own grief experience. The following quotes provide evidence for this sub-theme:

We were all with him, they finally got the daughter on the phone and we were able to put the phone to his ear and that was the last thing he heard was I love you daddy and then he took his last breath. And it was just, we were all there and it was really humble. It was just incredible to be there at that moment. (PSW)

I felt it was a blessing in a way sometimes it's a blessing that they do go . . . if they lay there and suffer . . . she was suffering through cancer, the top of her head was cancerous and draining . . . you sometimes think it's a good thing. (RN)

Some deaths are not so beautiful. (PSW)

Participants identified that the issue of grief is deeply influenced by the *nature of the relationship* staff have with each of the residents and their families. They stated that although the care they provide may be uniform from resident to resident, the interpersonal relationships they develop with individuals are unique and variable. It is the differences

within these relationships that influence the experience of grief. This is supported with the following quotes:

There are some hard ones. There are some hard deaths . . . not to say you have your favorites, but you do have favorites. So you have people that you really get to love in a way. (PSW)

The staff are very sensitive to their care because we have had most of the residents that pass away or on their way out, have been with us for many years. Sometimes it's almost like their part of them, family wise . . . if they see them any which way in distress while at the end of life, they get very upset and they come to us right away. (RN)

The *support staff offer to one another* appears to be integral to the strength and resiliency displayed among participants in managing their grief experiences. Participants described the importance of camaraderie when death occurs; they turn to one another to find support for their grief. If the support is not there, they take their grief home and seek out support from family and friends.

Grief Support Needs of Direct Care Staff

Participants were asked to suggest how their LTC workplace can better assist and improve grief support. They were very clear in stating that "something" needs to be put in place to support staff with their grief and loss. The 4 themes and 12 sub-themes that emerged from participant data appear to be manageable to implement in an organization and do not appear to require much in added resources or money: education, peer support during grief experience, formal supports, and established protocols after resident's death. Much of the change relates to creating an organizational culture that acknowledges that LTC is a major site of death and that it has consequences for staff who work there. A thematic map, demonstrating the overarching category, themes, and sub-themes, is found in Figure 4.

Education needs. Participants identified that education is needed to support them not only in the palliative care work done in LTC but also with how to manage their own grief and loss. They acknowledged that new workers are often unprepared for managing the emotional experience of a resident dying. It was indicated that if *grief was talked about openly at orientation*, it would prepare new staff for what to expect and also provide them with information on who to contact if further support is needed.

Participants stated that it would be helpful to have *grief and bereavement information* visibly posted on the floors. The workers are currently unaware of what resources are available for them, and where to refer families for grief and bereavement support. It was suggested that cards or pamphlets posted on bulletin boards would be helpful to those seeking assistance.



Figure 4. Grief support needs of direct care staff in LTC.
Note. LTC = long-term care.

Peer support. Participants were very clear that the most beneficial forms of support come from their own peers. Ideally, it should be *peers guiding them through the grief process* as the relationships they have established with their coworkers are comforting. Participants also talked about the importance of mentoring younger staff on what to expect when a resident dies, and how to say goodbye to a resident. The knowledge of experienced staff is a credible source of support and comfort when dealing with the emotional challenges of working in a LTC environment. The following quote illustrates the idea of peers guiding peers:

Having fellow staff members to guide you through something like that, I think that's probably the best way to go through it. (PSW)

Participants stated that *talking about the resident after his or her death* is an important way of memorializing that person. Reminiscing about the resident enables staff to come to terms with the loss of the resident. It also brings meaning to the care staff provided as it is important for workers to feel the care given was appreciated and meaningful. The following quote expresses this idea:

Well sometimes at the nurses' station . . . we will talk about it when it's in private . . . we'll talk about the individual and sharing, you know, good things about the person, and people laughing a little bit, and if somebody wants to cry, they can cry. (PSW)

Formal support for grief and loss. Participants identified several key areas in which the organization can take the lead in

supporting staff with their grief and loss. They frequently mentioned the importance of having some form of *staff debriefing* right after or shortly after a resident had died. The description of the preferred debriefing is to be short in length as it was recognized that staff do not have time to leave the floor. It should be peer-led and provide staff a general opportunity to discuss what had happened. The following quotes give evidence for this idea:

Even a monthly meeting or debriefing where we can all go and say what we want to say about the person or . . . somewhere we can go talk about the people that have passed . . . or just acknowledge that they were there, that they are gone and that they meant something to us, so that formally we can all meet and whoever wants to go can go. (PSW)

A debrief, depending on the circumstance of the death, or the passing of the resident, because some of them are, well some of them are beautiful and some of them are not so beautiful. (PSW)

Participants identified that there is one *spiritual care advisor* who is shared between the two LTC homes involved in the study, and it would be beneficial for both homes to receive equal time. However, they recognize that this is difficult to accomplish and the demands in both facilities need attention. Ideally, having a social worker on premises to assist with family concerns outside the scope of health care staff practice would be helpful. The two LTC homes in this study did not have social workers and this was a perceived need by the participants.

Participants stated that they have rarely experienced *management acknowledgment* of the impact that a resident's death has on staff. They find managers generally caring, and they recognize the demands of the management role. However, participants stated that "it would be nice" if a manager would proactively and explicitly acknowledge staffs' feelings after a resident had died and ask whether there is anything that a staff member may need.

Currently, there is an informal process used among staff to communicate when a resident dies. Participants contact one another via cell phone or text to notify one another of a resident's death. This system works well for some staff, but as this is an informal and non-systematic process; some people may be left out of the notification. Participants identified that it is helpful *to be aware of a death*, instead of learning about it on shift report or from the announcement that a new resident has moved into that room. Knowledge of a death helps them emotionally prepare for the loss and avoids unexpectedly receiving the news, as illustrated in the quote below:

If it's report when we walk in and . . . so and so passed away . . . if you're off for a couple of days, you know it's like What? . . . There isn't anything specifically in place for it. (PSW)

Protocol after resident death. Participants identified a need for acknowledging each resident's death within the home. Specific ideas that would support staff's grief process have emerged from the data. A *memory tree* with residents' names on it and an annual Christmas tree decorated in memory of past residents are suggestions that staff feel would memorialize residents with greater meaning.

Participants noted that the home holds celebration services on an annual basis; however, it was felt that with the large number of residents dying each year, an annual service is not enough. The *celebration services* need to be held sooner in recognition of residents' death. In addition, implementing an *established ritual* immediately after the resident has died would also support staff in their grief process. The following quotes support staffs' desire for a ritual:

I just think it would be nice if there was something that even in your own private time we could even go in there for two minutes and think about that resident that they took care of. You know I think that would be nice. (RPN)

There's got to be something out there and I think just the chance to express yourself . . . what is a funeral, it's somebody talking about this person that they love . . . or respected . . . or was close to and it just gives people a chance to say good-bye. And we don't do that . . . it's a horrible feeling when you don't get that chance to say good-bye. (PSW)

Participants acknowledged the importance of recognizing the impact a resident's death has on other residents and family members. They indicated that not having time to sit with other residents, or inform them that a death had occurred, is emotionally difficult and "not fair." Participants recognized

the need for a protocol to *support residents and family members* when death occurs. The following quotes demonstrate this:

Because you're not going to push off someone who is crying and grieving, and just be like, "no I'm sorry I have to go" . . . they need someone that would listen to their concerns. (RPN)

Once this individual passed, I really expressed my feelings towards the caregiver . . . how much we, how much I enjoyed them, him, the person . . . and if there's anything I can do. (PSW)

Discussion and Implications

The results of this study demonstrate the complexity of direct care workers' experience with grief and loss in LTC. These staff are faced with the presence of grief on a daily basis, with a number of factors influencing how their grief is managed. Although a limitation to the study was a small number of participants working in two LTC homes, the data are rich, and the findings are supported by other literature. This research expands knowledge on the impact that a death of a resident has on the LTC staff, and identifies clear strategies that can assist in developing organizational policies and practice to support the health and well-being of their staff.

The organizational context of LTC clearly influences the experience of grief and how it is managed. The lack of a formal policy and support strategies can be seen as an implicit policy not to recognize death and its impact on the organization. The silence surrounding the death and dying in LTC and lack of acknowledgment that staff are affected by the loss of residents they care for deny staff the opportunity to process and move through their grief.

The findings of this study are supported by other similar research that validates this work. In Durall's (2011) study, the key variables that affect the grief experience of health care professionals are identified, arguing that the silent culture around death needs to be broken to encourage the healthy expression of grief in the work environment. The study by Burack and Chichin (2001) explored nursing assistants' feelings, experiences, and needs when providing care for the dying, and found that even though nursing assistants were taught the mechanical components of the job, staff were not informed about the emotional involvement and responses to the dying. The same findings were obtained in the study presented here as participants indicated that they had no training to prepare them for the losses they inevitably encounter. Thus, care workers rely on one another and learn "on the job" when it came to managing their grief and loss. Even without training, participants acknowledged that death is part of the job; they are faced with the emotional burden of multiple losses, of both residents and residents' families with whom they have formed relationships.

Study participants noted that there is a burden with grief, and grief and loss are embedded in the nature of the work done in LTC. They learn how to emotionally detach from

residents when a death occurs; however, they must learn to reconnect to new residents being admitted to LTC and remain emotionally attached to other residents they are providing care to. Similar findings have been identified in Burack and Chichin's (2011) research, where nursing assistants expressed difficulty adjusting to the fact that the bed is filled immediately after a resident's death, with no time for staff to mourn, and the difficulty in beginning a new relationship so soon after the loss, knowing that the painful process will be repeated. A finding, not previously identified in the literature but presented here, is the existence of many unwritten and implicit rules that guide staff in the delivery of care for dying residents and their families. For example, participants spoke of a strong belief that residents should not die alone. Thus, in the absence of explicit organizational policy to guide them, staff learn through mentoring, use personal life experience, and experience on the job.

Previous research has recommended innovation in looking at ways to improve palliative care provided by LTC (Brazil et al., 2004). In this study, participants offered not only innovative but also practical strategies on how direct care workers can be better supported. Thus, the findings of this study have implications for the development of policy and procedures in LTC homes. The following recommendations for managers in LTC homes emerged from the study findings:

1. Implement a regular program of palliative care education for staff, including strategies for managing their grief and loss. Education needs to occur at orientation of new staff and routinely for all staff thereafter.
2. Make information visible and accessible to staff for both their own use and to offer as support for bereaved families, for example, pamphlets about grief and where to access counseling resources.
3. Recognize the benefits of informal peer support in LTC and the value of experienced staff mentoring inexperienced staff, especially where staff have no previous experience of death and dying. Acknowledge and value the staff mentors.
4. Encourage staff to reminisce about residents after they have died and let staff know that the end-of-life care they provided to the resident is valued and meaningful.
5. Implement organizational procedures to support staff dealing with grief and loss, for example, holding peer-led post-death debriefings after every death, frequent memorial services, and always acknowledging staff's feelings of loss when a resident dies.
6. Implement effective organizational communication systems to share knowledge of a resident's death in a timely way with all staff. Such methods could include issuing an email to all staff or creating bulletin boards.
7. Implement organizational strategies and rituals to acknowledge all residents who die in the LTC home. Examples include creating a memory tree, having a regular memorial service or ceremony, or conducting a room blessing.
8. Support staff with the time and resources to reach out to residents and staff after the death of a resident to acknowledge their grief and loss. This not only supports others but also promotes a sense of completion for staff, aiding in the resolution of grief.

Many of these strategies are examples of innovation from within the home, requiring little in the way of cost or external resources. Involving direct care staff in the development and implementation of these strategies is an effective way to address their support needs related to grief, loss, and bereavement.

Conclusion

The direct care workers' experience of grief and loss is complex. LTC staff are continually faced with the presence of death, with a number of factors influencing how their experience with grief is managed. Currently, there are no formal organizational processes in place to assist staff with handling their grief; this situation compels them to rely on one another for support. Direct care workers are in the best position to identify the support and resources they need to manage their grief and loss. A formal process for supporting grief and loss in the work environment is needed as a component of a holistic and inclusive palliative care program in LTC settings. This may also contribute to staff satisfaction and ultimately retention.

It is hoped that this research will assist in the development and implementation of organizational policy and procedures, addressing the health and well-being of direct care workers in LTC homes. As LTC homes increasingly provide palliative care as a core part of their services, death becomes part of the job of direct care workers. Staff need education and support to manage their grief and loss to provide quality palliative care. The culture of LTC must evolve to explicitly acknowledge that resident care is provided until the end of life. Eight strategies were provided to assist in this evolution.

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