

# 'That just breaks my heart': Moral Concerns of Direct Care Workers Providing Palliative Care in LTC Homes\*

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## RÉSUMÉ

Les publications traitant de l'éthique dans les soins de santé et des préoccupations morales des prestataires de soins sont le plus souvent centrées sur les professionnels de la santé et les dilemmes éthiques associés aux soins aigus et aux soins de santé de première ligne. Peu d'attention a été portée aux environnements de soins de longue durée (SLD) et au personnel non réglementé offrant des soins directs. Afin de combler cette lacune, cette recherche a examiné les préoccupations morales des préposés aux services de soutien à la personne qui apportent des soins directs aux résidents. Les données ont été recueillies dans le cadre d'un projet de recherche-action participative de cinq ans visant à formaliser les programmes de soins palliatifs dans les centres de SLD. Onze groupes de discussion se sont penchés sur les expériences des préposés fournissant des soins palliatifs dans les centres de SLD, leurs défis et leurs besoins de formation (n=45). Une analyse secondaire approfondie des préoccupations morales ressenties par ces préposés a été réalisée. L'identité des préposés a été marquée par la construction de relations étroites avec les résidents, à tel point qu'ils se décrivent souvent comme des membres de leur famille élargie. Les dilemmes moraux des préposés concernent principalement deux aspects : éviter que les résidents ne meurent pas dans la solitude et la prestation de soins adéquats et respectueux des volontés du résident. Les contraintes organisationnelles s'articulaient autour de quatre domaines spécifiques : les politiques, la hiérarchie, le temps et l'équilibre entre les besoins des résidents. Les préposés ont réagi de deux manières à leur détresse morale : par la négociation des contraintes ou par l'acceptation des contraintes. Ces résultats démontrent l'importance d'explorer davantage ces concepts chez le personnel de soins directs dans les centres de SLD.

## ABSTRACT

The literature on ethics in health care that explores the moral concerns of care providers typically focuses on registered health professionals and ethical dilemmas in acute and primary care. Far less attention has been paid to the long-term care (LTC) environment and non-registered, direct care workers. To address this gap, this research examined the moral concerns of personal support workers (PSWs) who provide direct care to residents. Data were collected during a 5-year participatory action research project to formalize palliative care programs in LTC homes. Eleven focus groups explored PSWs' experiences providing palliative care in LTC homes, their challenges and learning needs ( $n = 45$ ). In-depth secondary analysis of these focus groups found that PSWs experienced moral dilemmas. Two main moral dilemmas were ensuring that residents don't die alone; and providing the appropriate care based on residents' wishes. Their organizational constraints coalesced around policies, hierarchy, time, and balancing residents' needs.

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## Background

The literature on the moral and ethical concerns of health care providers typically focuses on various registered health professionals and dilemmas experienced in acute and primary care (Corley, 1995; Corley, Minick, Elswick, & Jacobs, 2005). However, far less attention has been paid to the long-term care (LTC) environment and non-registered staff who provide direct care to LTC residents. Using concepts drawn from existing literature on nursing ethics to frame this work, we have attempted to elucidate the moral concerns for non-registered staff in LTC settings, specifically by examining the moral concerns experienced in LTC environments by the direct care workers who provide day-to-day care for residents, especially care at the end of life. These workers, depending on jurisdiction, may be called health care aides, nurses' aides, or personal support workers. For the purposes of this article, we refer to direct care workers as personal support workers, or PSWs, as they are commonly referred to in Ontario, Canada.

In recent years, much research has focused on the ethical dilemmas that nurses face in their work, particularly within hierarchical acute care organizations (Corley, 1995; Corley et al., 2005). Nurses have multiple and often conflicting responsibilities, including to patients, families, physicians, the work organization, and the nursing profession and other colleagues (Meaney, 2002). However, translating the work on ethical dilemmas outside of the acute care environment has been more problematic, particularly in the LTC environment, where the issues faced by staff and within the organizational context differ significantly.

A brief discussion of the terms used in nursing ethics will provide necessary background and context. Nursing ethics literature has elucidated various concepts of ethics, including moral distress, moral residue, moral resistance, and moral reckoning. Jameton (1984) described moral distress as occurring when a nurse knows what is "right" to do, but is unable to act on that knowledge because of institutional constraints. More recently, moral distress has been described as constraints on nurses' moral identities, responsibilities, and relationships; moral agency is socially connected and occurs within relational contexts (Peter &

Liaschenko, 2013). A study by Edwards, McClement, and Read (2013) found that nurses' stories of moral distress in the LTC environment could be classified into three main categories: (a) treatments or interventions requested by family or by the care team that were contrary to resident wishes and best interests; (b) negative effects on resident care due to a lack of resources; and (c) residents' dignity compromised by care provided to them.

The concept of moral residue describes the consequences of moral distress (Webster & Baylis, 2000). Moral residue can leave the nurse feeling that his or her professional integrity has been compromised (Mitchell, 2001). Moral resistance describes how nurses use various actions, some more covert such as persuasion and policy use, and others overt such as whistle blowing, to ensure they are able to make decisions and actions consistent with their ethical and moral values (Peter, Lunardi, & Macfarlane, 2004).

Nathaniel (2006) suggested that moral distress is a narrow concept that fails to explain the long-term ongoing process that nurses experience, and presented a new concept called *moral reckoning*, which better explained a process of moral dilemmas using a stage- or process-based theory. Nathaniel defined moral distress as "pain affecting the mind, the body, or the relationships that result from a patient care situation in which the nurse is aware of a moral problem, acknowledges moral responsibility, and makes a moral judgment about the correct action, yet, as a result of real or perceived constraints, participates, either by act or omission, in a manner he or she perceives to be morally wrong" (2006; p. 421). Nathaniel's (2006) theory of moral reckoning has three stages: the stage of ease, the stage of resolution, and the stage of reflection. The stage of ease occurs when the nurse becomes comfortable with professional and institutional social norms and participates in the work of nursing. A situational bind interrupts the state of ease and places the nurse in conflict with his or her core beliefs and other claims. The stage of resolution is an attempt on the part of the nurse to set things right either by making a stand or by giving up. The stage of reflection occurs as nurses reflect on their actions, and question their judgements, actions, and sense of self.

Although there are more concepts related to ethics in nursing, our literature review focussed on the four concepts most frequently discussed in the literature – moral distress, moral residue, moral resistance, and moral reckoning. These concepts are extensions of each other, and as such, are linked conceptually. Moral distress is the main concept, and as nurses attempt to resolve moral dilemmas and distress, this can lead to moral resistance and/or moral residue. Nathaniel's theory of moral reckoning (2006) brings moral distress, ethical decision-making, moral residue, and moral resistance together under one theory of moral reckoning to explain the long-term, ongoing process that nurses experience.

Studies focusing on moral dilemmas for nurses have typically been conducted in acute care settings (McCarthy & Deady, 2008; Pijl-Zieber et al., 2008). Less research, however, has been conducted in LTC settings; consequently, we know little about the moral distress or dilemmas of staff working in LTC homes. The LTC environment may put nurses at risk of developing moral distress due to a number of factors (Pijl-Zieber et al., 2008). First, human resource constraints are particularly relevant as the chronic understaffing of LTC homes may cause staff to work in an unsafe manner (Wiersma & Dupuis, 2007). The competing value systems within the health care environment, particularly between cost and care and time and task (Henderson, 1995), can also play a role in moral distress. Staff may also have competing demands from residents, families, and management. The lack of managerial and administrative support (Lopez, 2006; Wiersma & Dupuis, 2007) may also be a factor in the moral distress of staff working in LTC homes. Although Pijl-Zieber et al. (2008) suggested that moral distress may be a problem for nurses working in LTC environments, it may be an issue for many other staff working in LTC homes who face these same issues of human resource constraints, competing value systems, competing demands, and the lack of managerial and administrative support. Indeed, these factors may particularly impact the PSWs who deliver the majority of care for residents in LTC homes.

Much research has examined the ethical concerns of registered nurses including moral distress, moral reckoning, moral resistance, and moral identity, as well as a host of other concepts, yet little research has examined the issues around moral concerns in LTC homes. In particular, little or no attention has been given to the moral and ethical concerns of PSWs who provide palliative care in LTC homes.

### *Structure of Long-Term Care Homes*

The LTC environment has often been described as different from typical health care environments.

Most health care environments focus on acute care and cure, whereas LTC homes tend to focus on comfort and care in a home-like environment. The focus of care is broad in long-term care, making it a unique health care environment. Long-term care is an environment wherein residents live and die; therefore, staff are meeting residents' restorative care needs along with palliative care needs. Many residents entering LTC homes are now advanced in age, typically over 85 years of age, and live with co-morbidities such as heart disease, dementia, arthritis, or diabetes (Hirdes, Mitchell, Maxwell, & White, 2011; Canadian Institute for Health Information, 2012). Given the advanced age and frailty of residents, it is not surprising that LTC homes provide care until the end of their lives. Death in LTC homes is not uncommon. Recent statistics from the Canadian Institute for Health Information (2012) show that in Ontario in the years 2011 and 2012, 44.4 per cent of all discharges were related to death. Providing palliative care or a palliative approach to care has become a prominent need within LTC homes today. Palliative care is a philosophy and a specialized set of care processes that encompasses the physical, emotional, social, psychological, spiritual, and financial needs of individuals and their families. Palliative care aims to relieve suffering and enhance the quality of living and dying of any individual who is living with a life-limiting or terminal illness. (Canadian Hospice Palliative Care Association, 2013).

LTC homes have a different organizational structure than do acute care institutions. Although the hierarchical structure is still present (Diamond, 1992; Foner, 1995), registered nurses, who often have supervisory roles, are not the most common front-line staff in LTC homes. Direct care workers such as PSWs provide most of the direct care to residents, including bathing and assisting individuals to perform activities of daily living such as dressing or eating. They often develop strong personal attachments to the residents in their care that they describe as "family like bonds" (Sims-Gould et al., 2010).

The competencies of PSWs providing quality palliative care in LTC homes have been outlined by Kelley and McKee (2013; Quality Palliative Care–Long Term Care, 2012). These competencies focus on care of the resident and family, communication, time management skills, teamwork, professional development, ethical and legal issues, and advocacy, to name a few. These competencies demonstrate the vital role that PSWs play in caring for the residents. PSWs have the most nursing minutes spent with the resident or on behalf of the resident compared to that of all other team members (Hirdes et al., 2011), not least because as Harris-Kojetin, Lipson, Fielding, Kiefer, and Stone (2004) explained, direct care

workers “serve as the eyes and the ears of the formal LTC system ...” (p. 1).

One of the characteristics of the LTC culture is the focus on time and task (Henderson, 1995). Because of the time constraints and number of tasks to be completed, most staff have little time to attend to residents’ psychosocial issues (Paterniti, 2000). The culture of LTC facilities demonstrates the dichotomy between comfort and care delivered within the LTC structure that regulates and routinizes (Gubrium, 1975; Henderson, 1995; Paterniti, 2000; Wiersma & Dupuis, 2010). Residents are often reduced to “bed-and-body work” (Gubrium, 1975); that is, care focused on the residents’ physical bodies, often at the exclusion of psychosocial care (Diamond, 1992; Henderson, 1995; Paterniti, 2000; 2003; Wiersma & Dupuis, 2010). The implication is that residents’ emotional and psychosocial needs can be ignored as the staff work is reduced to a series of tasks to be ticked off at the end of the shift (Diamond, 1992).

Wiersma and Dupuis (2010) found that as residents became socialized into the LTC home, they became “institutional bodies”. Institutional bodies referred to their primary identity as a physical body or object in interactions with the staff and others in the institution. Within this context, staff often struggled with the necessity of accomplishing tasks focused on the body while being emotionally present for the residents. Thus, staff were often caught between the moral demands of “being there” for residents and the pressures to get the job done (Diamond, 1992; Henderson, 1995).

The context of LTC has many unique challenges, such as inadequate staff-to-resident ratios, the chronic nature of residents’ illnesses, and non-professional and unregulated staff who provide the majority of care. The ethical or moral dilemmas may have a scope (Kane & Caplan, 1990; Powers, 2003) that differs from that of acute care for the following reasons: (1) PSWs deliver most of the care to residents and often take on direct-care roles in LTC homes that registered nursing staff typically have in acute care settings; and (2) their scope of practice does not include tasks that registered staff perform. Specifically, dilemmas leading to moral distress arise day to day at the interface between personal relationships of residents and staff, the care of residents, and the culture and environment that prioritizes “time and task” (Powers, 2003).

This article is a sub-study of a 5-year (2009–2014) program of participatory research called “Improving Quality of Life for People Dying in Long Term Care” (QPC-LTC) involving four Ontario LTC homes as study sites. This research was a Community University Research Alliance (CURA) grant funded by the Social Sciences

and Humanities Research Council (SSHRC) (2009–2014) with knowledge translation support from the Canadian Institutes for Health Research (CIHR) (2011–2012). The goal of the overall QPC-LTC research was to generate knowledge to guide the development of palliative care programs specific to the context of LTC homes. Research outcomes included a framework for formalizing palliative care programs in LTC homes and over 40 research-informed resources for enhancing resident care, communication, education, and community partnerships. (For more information regarding the overall research and to view related publications, please visit [www.palliativealliance.ca](http://www.palliativealliance.ca).)

We were members of the QPC-LTC research team. As part of the team, we conducted comprehensive organizational assessments in each of the LTC homes that included collecting the data used in this sub-study. For this secondary analysis, we used these data to provide an in-depth analysis of PSWs’ perspectives on their moral concerns regarding palliative care provision to LTC residents.

## Methodology

Four LTC homes participated in this study. Two LTC homes were situated in northern Ontario and two in southern Ontario. All four homes were not-for-profit; however, two homes were private faith-based organizations and two were municipally run. Each home had between 96 to 200 residents. PSWs and other staff and family members from the four homes throughout the study period (2009–2014) participated in this study. The data discussed in this article were collected in 2013 as part of the QPC-LTC research.

Forty-five unregulated providers, or PSWs, from the four study sites participated in 11 focus groups that explored their perceptions about palliative care provision in LTC homes, their challenges, and learning needs. All participants were given an information letter and consent form describing the research. Research staff conducted the 11 focus groups in the LTC homes with each focus group consisting of between two to eight participants. Each focus group was approximately one hour in length. All focus groups were audio recorded and transcribed verbatim. This research was reviewed and approved by three institutional Research Ethics Boards.

The QPC-LTC co-investigator team created a 16-question focus group guide to collect data. Each question was open ended, and allowed the participants to respond accordingly, enabling the research team to understand the current status of palliative care delivery within each home. Participants were asked about their understanding of palliative care and quality of life, the role that they played in providing palliative care, the role of

the family in providing palliative care, how the organizational structure facilitated or hindered their abilities in providing palliative care, and what they would change regarding palliative care delivery in their home if they could.

### Data Analysis

Initially, the project manager and knowledge broker coded 10 transcriptions utilizing content thematic analysis (Saldana, 2009). A coding framework was developed through this initial coding and discussions with the research team. The project manager and knowledge broker then developed definitions for each of the codes within the coding framework. These definitions and coding framework were given to three graduate student research assistants who coded the rest of the data. Once complete, the focus group data were given back to the project manager and knowledge broker for verification prior to entering the data into NVivo. All discrepancies were discussed with the project manager and/or knowledge broker and decisions were recorded within a decision log.

Themes related to ethics and moral concerns emerged from the initial analysis. After further discussions, we therefore decided to conduct a secondary, in-depth analysis of the data using the moral constructs described in the literature review as sensitizing concepts. Although these constructs sensitized us to the emerging findings, we analysed data inductively – specifically exploring what staff said, and coding this into broader themes. All data and previous coding were read through exploring ethical concerns or dilemmas described by LTC staff. As such, the ethical concepts described in the literature review were not used deductively, but iteratively as we explored the data, reviewed the concepts, and discussed as a team what the data meant.

Through the secondary data analysis process, we explored areas where staff described challenges in their work, and where they described their emotional responses to these challenges. Informed by the previous literature on ethics for nurses and issues in LTC homes, we explored organizational constraints – how those impacted staff's emotional responses, everyday decision-making, and the repercussions of these decisions on PSWs' sense of the "right action". Although the different concepts in the literature provided us with an awareness of what we might find in the data, we did not go into our analysis with these concepts being imposed on the data. Rather, as key themes emerged, we compared them to some of the key concepts in the literature and quickly found that some of the concepts in the literature in fact described what was emerging from the data.

## Findings

PSWs experienced moral concerns in their work, which can be characterized as everyday moral dilemmas, in providing palliative care to residents in LTC homes. Accordingly, the moral concerns surfaced around issues relating to everyday quality of care and were influenced by PSWs' relationships with residents. Staff, in discussing how they were the most familiar with the residents' desires and wishes, constructed their identities through their relationships with the residents. Additionally, PSW staff saw themselves fulfilling a role beyond that of carers and more as extended family to the residents. The moral concerns experienced created moral distress within PSWs, because PSWs identified the "right action" to take, but were often constrained from doing so. The moral dilemmas that PSWs experienced typically focused on two areas in providing palliative care – ensuring that residents don't die alone; and providing the appropriate care based on residents' wishes. The organizational constraints coalesced around four specific areas: policies, hierarchy, time, and balancing residents' needs. PSWs had two responses to these situations of moral distress: negotiating constraints and accepting constraints.

### *Context of Moral Distress: Staff Relationships with Residents*

PSWs described their identities clearly in terms of their relationships and work with the residents. They described themselves as the staff who "knew" the residents and their wishes and desires because they interacted with them more frequently than other staff. They also described themselves as extended family to the residents. Because of their interactions and relationships, residents' deaths were particularly emotional for them. These aspects of their identities clearly laid out their expectations and perceptions of the "right action" or the best course of action for the resident.

Because of the extended amount of time PSWs spent with residents, PSWs felt that they knew the residents' wishes and desires best. One PSW commented, "we are the ones 24 hours with the resident." Another PSW stated, "we're front-line staff, right? Because us PSWs [are] with the resident more than the registered staff, right? We're there 24/7." A number of focus group participants made similar, related comments about their closeness with the residents. One PSW commented, "we sometimes get really close, you know ..." while another PSW said, "we get pretty frigging attached to some of them, don't we?"

PSWs also referred to themselves as family to the residents. The following conversation between PSWs

during a focus group illustrated their knowledge of residents because of caring for them:

PSW1: But I think too, like with our residents because you've looked after them for a while and kind of becomes like a family.

PSW2: Yeah, you know what they want.

PSW1: So, so you're there for them like family will be.

The deaths of residents can be particularly emotionally difficult for staff because of their close attachment to the residents. Many of the participants spoke about the close relationships that they developed with the residents and their sadness when residents died. One PSW commented,

Well, they know that we loved them, that we cared about them. At the end of the day, every resident in this home, like I am an emotional person ... They are my family. I love each and every one of them. When they pass or when they get ill I feel it. I suffer, just like, maybe not so intensely as a family does, but I feel it because as you grow very attached to these people and I want them to know that we at [name of facility] care about them, we love them and we want to do something to help them to make them feel more comfortable. We get really attached.

Another PSW observed how relationships were formed because of the nature of care for the residents and the extended amount of time that they spent together. In this way, residents' deaths became very difficult for staff.

Oh, I've shed tears quite a bit. God, I went home and was kind of messed up, and you know you get emotionally attached to them, and you can't tell me that nobody does and if you don't, then, you know, maybe it's not a line of work for you ... Yeah, we're very passionate aren't we? ... I think I get attached; it's not a process where I'm used to this. It's not that attitude at all. ... Especially when you see this person every day for five years or four years and you always go into that resident's room and do care on them.

The close, familial type of attachment to residents provided the context of how PSWs experienced palliative care and the associated everyday moral concerns, and contributed to the challenges they experienced in their work.

### *Moral Distress: Knowing the Right Action*

A component of moral distress is that a person is aware of what the right action is, but is constrained from doing so. The experiential and relational context of the PSWs informed their perceptions of what the right action was in providing quality palliative care. PSWs' perceptions of right actions focused on two areas: that of

providing appropriate care based on residents' wishes, and ensuring that residents did not die alone.

One PSW commented on the type of care that she felt should be provided during palliative care:

I think they get more attention, more frequent checks, like being checked on a little more often. To somebody that's palliative, you're going to walk in, you're going to be quiet, you're going to be a little more softer ... I think the tone changes to a gentler, kinder, more compassionate ... for me it does, and I would hope for everybody else that you're not walking in there talking loudly and flicking on lights. You know, you're going to go in there and be just that extra ... gentle ... kind ..., compassionate and empathetic for this person that's laying there that knows that they're going.

Another way of providing appropriate care was communicating with the resident normally while providing appropriate physical care. As one PSW observed, "Well, we try and keep them as comfortable as we can ... and make sure we turn them to prevent open areas ... [we] still talk to them normally." Other PSWs felt that residents should not be out of bed if near the end of life:

For me personally is that once they are palliative, this is my own opinion, is for them to stay in bed because sometimes when you get them up or whatever they will die in the chair or and so forth because that happened to me already, yeah ... (PSW 1)

Yeah, it's better to be in bed and be comfortable. (PSW 2)

Keeping residents comfortable was a key part of providing good palliative care: "keep them comfortable, you know?" Compassion was also mentioned numerous times: "Well, I think we would probably be more compassionate than normal".

Another key perception of the right action to take when providing palliative care was ensuring that residents did not die alone. Most of the PSWs who participated in this study consistently stated that residents should never die alone because death is "scary". One PSW commented, "it must be scary to know that you're going to die ...". Another PSW stated,

And I've seen people here like they don't have families come in until ... And that's the worst ... it's so horrible, you know when somebody ... tells me that so-and-so passed, the first thing I say is was somebody with them? ... I don't even care who it is, was somebody with them? We come in this world with people. We should go out of this world with somebody.

Another PSW stated that ensuring that residents did not die alone related to the need for a human presence to calm residents' fears.

Well ... you have the human touch ... human presence like maybe they might be frightened... we'd make a lot more effort to be in the room so that they're never really ... alone maybe.

In one focus group, two PSWs recounted experiences when residents had no family and were often alone during their last days.

Because I have this resident ... when she was passing she would say, "Don't leave me, don't leave me, don't leave me." (PSW1)

Because they're scared. (PSW2)

Which we have to leave, so it's tough. (PSW1)

You know that there's nothing more that frightens people than the thought of death and ... that just elevates it a million times. (PSW2)

PSWs were particularly distressed when residents had no family to visit them at the end of life.

They have nobody and then we need somebody to sit with them you know ...

There's some people ... that their children never come and see them right? And you know, they don't live very far and there's no reason, ... you wonder, what's in their heart when they die? They probably have something to resolve in their life, right?

PSWs related these experiences to what they would want for themselves or their own relatives.

Especially some people who don't have very much family, there isn't really anybody to come in and see them just to have that hand or to have that – I don't know, connection with somebody. I wouldn't want to be by myself.

Providing appropriate palliative care and ensuring that residents did not die alone were perceived to be the two key actions to caring for residents in the context of developing close familial relationships with residents. These two aspects of care were the basis for the moral distress experienced by PSWs.

### *Organizational Constraints Impacting Moral Distress*

PSWs described numerous constraints that impacted abilities to provide quality palliative care. The inability to provide this quality of care was not related to staff being calloused towards death or uncaring towards the residents, but because of organizational constraints – organizational hierarchy, policies, and time – that prevented them from providing the desired care.

### *Hierarchy*

The hierarchy of LTC homes was clearly evident in PSWs' descriptions of their experiences providing palliative care, and affected their abilities to make decisions

they felt were in the best interests of the residents. Their relational and experiential knowledge of the residents were often undervalued in decisions that were made about the residents' care. Decisions were sometimes made by registered staff that were contradictory to what PSWs felt were the best decisions for the resident. PSWs believed that their perspectives could be overruled by registered staff members. As one PSW put it:

It's like, it's okay what we think as long as they [registered staff] agree with it. If they don't agree with it, that's it. Whatever we say or think doesn't matter. You know ... it's like our judgement doesn't count.

PSWs indicated they felt a tremendous amount of pressure from registered nursing staff to carry out care that was in line with the registered nurses' perspectives:

You would get a lot of pressure from your team to – (PSW1)

– Not [from] the team, the registered staff. (PSW2)

The hierarchy was also demonstrated in how shift reports were valued. PSWs indicated that their verbal reports to co-workers and registered staff were not valued in the same way. Different LTC homes have diverse requirements for PSWs' electronic documentation. Some PSWs stated they were unable to document their perspectives in the residents' electronic medical record, stating that was something that was beyond their scope of practice. One PSW noted:

We know from the report that, that how she had been the night before, right, and is she declining anymore, definitely we go and tell our nurses about that, but we are not charting it yet. It's out of our scope ...

Although PSWs did not discuss the frequency with which these situations occurred, they were important enough that the PSWs shared these issues with the research team and focus group.

### *Policies*

In addition to the staff hierarchy, PSWs were often troubled by organizational policies that they felt were not in the best interests of the residents or families, particularly as they related to confidentiality and the turnover of beds after a resident died. One of those policies related to confidentiality with families and the challenge PSWs encountered in discussing resident information with the appropriate family member. This was demonstrated when one PSW explained,

The POA [power of attorney] can be the daughter that's from South Africa that hasn't visited in 6 years but the other daughter comes in every single day. ... you have that relationship with the daughter that comes in every day, but you're still not supposed to ... give her the information because she's not the POA ...

PSWs also discussed their inability to talk to families, which was related not only to confidentiality, but also to the staff hierarchy. Although PSWs did not indicate how these practices were enforced or communicated, they clearly perceived that they were unable to discuss care issues with family and that this should be handled by registered nursing staff instead. One PSW observed:

Confidentiality is important, and what we are allowed to say – we shouldn't say anything. It has to come from the registered staff. It has to come from them. Anything you're unsure of, you can't just fill in and say what you feel. It's got to be factual and come from registered staff, I believe.

They indicated that if family members asked them questions regarding a resident or their care, they must refer the family member to a registered staff member. One PSW reported that "the nurse talks about [the resident's] actual care ... if they have questions we just refer them to the nurse." Another PSW said:

We don't [we don't] tell them this thing [no]. We can't, we don't. See, we are not supposed to talk to families. We are not even asked if you go, become professional then family comes and say, "How is my mom?" "Well, you've got to talk to my nurse." ... that's the basic question we hear. We have seen some difficult families here. [Families ask] "How is your mom?" [We have to say] "Please go to the nursing station. Our nurse's name is Tiffany," whatever, and that's it, no information.

PSWs indicated that when they saw a decline in the resident or that a resident's care needs had changed, they needed to discuss this information with their co-workers and with registered staff because they were not able to talk to the resident or family directly. A participant indicated:

Because we are not to deal [talk or provide information] with the family. See, we are not going to tell the family, "Okay, maybe your mom is going to die on my shift." We deal with our nurse and our co-workers. That's how we deal, with our co-workers and our nurse.

Another policy that PSWs were particularly concerned about related to the quick turnover of a room after the resident died. Families were asked to remove the belongings from the residents' rooms within 48 hours of the resident's dying. PSWs were very concerned that this was insensitive to the family's grieving process.

When you see the transition that they have only have a short period of time for that family to get their room out, well, that person was a part of this home, and all of a sudden you got two days or whatever it is to get your stuff out. That's hard to digest. It's like wow they're in and now they're out. ... It was like they weren't important enough and yes they are important. ... That bothers me a lot.

That really, really irritates me. 'Cause the family need to be grieving ... They got to make arrangements. They got to do funeral arrangements, contact families, and they have a day to get their stuff out or two days ...

Both the PSWs' perceived inability to speak to families as well as the turnover after a resident died were challenging, particularly to providing appropriate care and ensuring that residents did not die alone.

#### *Time*

Time was a significant theme that emerged from the data, and was also viewed as a constraint to moral action. Participants indicated consistently that there was not enough time to complete the tasks that were required of them. One PSW indicated that "There's never enough time [laughter] ... never enough time, but we try our best." PSWs indicated that they perceived a decrease in their staffing levels over the years, and were thus faced with providing care to more residents with no extra time, causing PSWs to be unable to meet all resident needs.

I mean there back in the day there used to be more nurses for less, less residents, and you can sit there. And if someone isn't feeling well, you can cheer'em up, and having a conversation or ... go down memory lane or play a game or give them a foot massage or whatever random thing that might make them feel better. But now it's like you've got something to say, you say it quick but I gotta go.

PSWs spoke to the inability to talk to residents to explain why they were not able to respond to their needs quicker.

"Well why didn't you come to me right away?", well I can't tell them ... so-and-so is passing or I'm doing palliative care on a person so ... So that is a challenge in that respect.

Another PSW indicated that PSWs were only able to do assigned care tasks and that they did not have time to provide additional care, particularly emotional support.

But the one thing that I know I find, and a lot of staff have said, is that we don't get enough time to spend with them. Like I mean we go in, we do what we have to do, and then it's like okay, we have to go ... we have other stuff to do. ... it's very short ... you can't go in, spend time with them ... hold their hand. ... we are the ones that they have seen most over the years.

The PSWs also indicated how having a limited amount of time to provide the care required for each resident hindered their ability to provide quality palliative care. One PSW spoke to the fact that they were required to rush and that even when trying their best, there was



still insufficient time to spend with residents who were dying.

We have this resident who — this one is passing, but this one also needs us. So you know, it's like busy, busy in, out, so we try but I would say there's enough time to spend with the person who is palliative. Like we can't get that one-to-one with them but we will try our best.

PSWs also reported their emotional difficulties when no one was able to spend time with the resident such as a volunteer or family member.

I think the hardest part is when there isn't a volunteer there or a family to sit with them and talk to them that we get so busy that sometimes we can't find the time to sit there with them.

A consistent message was that PSWs felt that it is important for residents who were dying to be assigned a dedicated PSW to meet their needs and to ensure residents did not die alone.

I think it would be a good idea, and you know some people can handle it very well depending on their floors, but I think it would be nice if ... each floor, or each shift have one or two people that are palliative attendants maybe. Not that everybody wouldn't want to share on it, but everybody'd be assigned so that if there is that case [palliative] that person is assigned to that person. I thought we used to do that here, though; what happened to it? But I think that's very important.

#### *Moral Resistance and Moral Residue: Responding to Moral Distress*

Moral distress needs a response, and PSWs responded in two main ways while providing palliative care to residents. First, they found ways to negotiate the constraints in various, often quite creative ways, illustrating moral resistance. Second, they accepted the constraints, recognizing they could not change them, which resulted in emotional distress, or moral residue.

PSWs were creative in negotiating the constraints. Negotiating the constraints referred to working around the constraints, and finding ways to minimize the impact or negative consequences on the residents. Although PSWs perceived that they did not have the time to spend with a dying resident, they nonetheless found ways to be with the resident while dying. They felt that ensuring that residents did not die alone was fundamental to good and humane care. A few PSWs described taking their "books", or their charting, into the residents' rooms as a way to find more time to be with the residents.

I've seen it in the unit I used to work in since I come here. When there's somebody palliative, we have

our books to do and they will choose to do the time that they take to do the books and I am going to do my book in my room.

Another PSW negotiated the hierarchy by capitalizing on her personal relationship with the doctor to get medical attention for one of her residents.

When a doctor comes we don't go and jump in his room and say, "Dr. Jones, Cindy's doing this ..." No, that's not my job; that's my nurse's job to talk. Okay, she's got all these things, 16, 32 people. We give her all the information and then she passes it on to the doctor. And then sometimes, ... I know him for last 15 years ... so if nurse is not there and we see him coming in, I'll say, "Doc, if you're on the floor, can you have a look at her today? I feel she's changed a little bit," this and that, and he, out of respect, he'll say, "Sure I will. Let's go now ..."

Part of negotiating constraints was to ensure that quality palliative care was provided insofar as possible to residents. When staff didn't have time to be with the resident who was dying, they would nonetheless take turns to ensure that at least one person was with that individual: "Because even if you can't go stay there for your 8 hours' work, we make sure we go back and forth, back and forth to the room to make sure that someone is there." Even when staff were unable to change some of the constraints, one PSW stated, "But you can still be compassionate, you can still be caring, still be positive. You know they need your support. And [you can] listen." As another staffer put it: "Do the best you can do with the things that you can control."

#### *Moral Residue*

Although PSWs found many creative ways to negotiate the constraints, they were still often in positions where they had to accept the constraints that limited them from providing what they believed to be quality palliative care. As an example, PSWs described a situation regarding a resident who needed palliative care (i.e., the resident wanted to stay in bed and the PSW wanted to respect that resident's choice). The PSWs were not listened to by the nurse. Although they had to do what the nurse asked them to on that occasion, in the focus group they articulated their opinions and focused considerable discussion on the situation. The following quote illustrates the distress resulting from the PSW's inability to change the registered nurse's instruction:

And sometimes when we say, "You know what, I think we should leave her in bed today." And the nurse will feel, "No, no, you've got to bring her here." At that time, I understand she's a nurse but she doesn't know the palliative care very much. When I'm telling you that this person should stay in bed, I mean it, because I've been dealing with her for so many years. I know how she looks in the

morning, how she talks, right? And if she said, "Please leave me. I'm begging you, leave me in the bed," will I do that same thing to my mother? If she was my mother, right? No, so sometimes you feel helpless, you can't do anything, but then it becomes your job. "Okay, I'll bring her. I'll bring her."

Another staff member, in responding to questions from the interviewer about the resident's preferences that differed from what registered nursing staff required of the PSWs, stated bluntly, "There's nothing you can do about it."

The lack of time given to PSWs to perform their assigned tasks and care for residents meant they had to prioritize who and what was more important. This posed great difficulty, causing them to make decisions that they did not agree with simply because there was no other choice. PSWs talked about having to leave residents in distress because of many other residents who also required care. One PSW said:

Yeah, we have somebody who is palliative right now and I would love nothing more to sit with her and just hold her hand and talk to her and, ... reassure her as best as you can. And then when I get up to leave after a few minutes, she says "oh don't go, please don't go." You know, if you go, can you come back really soon? And it's heartbreaking because there's 23, 24 other residents. And you walk out in the hall and it's like, can I get this and can you come here and I can have, can you help me with this?

PSWs spoke about how deciding on who or what takes priority had consequences for other residents that they cared for, and these decisions were difficult. One PSW indicated the challenge of wanting to take more time with a resident's needs and stating the consequence of the time delay:

I am really sorry. I feel bad but I can't [take time for one particular person] 'cause if I don't do all these other people they're not going to get done, lunch isn't gonna happen, breakfast isn't gonna happen, and it will be on my head and I am gone, so I think that's a sad thing about here. They say client resident care but to a certain point. ... there's residents that are not getting the same amount of care needs [taken care of].

In describing another situation where care was unevenly balanced between two residents where one resident might receive two hours of morning care and another resident may only get 15 minutes, one PSW stated "it's terrible, terrible, terrible." Finally, a PSW stated,

There was some good things, but there are some bad things and every bad thing, and it's gonna keep back coming to that same thing — time. If we had more time to devote to people and if we had put the human back into everything. Like when we

try it, they are trying to humanize dying, but at the same time now, what ... do you know what I mean? Does that make any sense?

Not only did their choices have consequences for residents, but PSWs also reported that their choices had consequences for their co-workers. PSWs reported feeling guilty when they performed extra tasks as it put an increased burden on their co-workers as demonstrated by the following quotes.

You could not just say, "oh I am going to go sit with Mary for half an hour because there was nobody there", because we can't. It's like me leaving today. It sounds awful, but like my partner would come back and have nobody. And we did 7 people while the other people were gone.

It's not like I can say to this team, okay, you guys finish working with your other 25 people. I want to go sit with them ...

One staffer described how residents dying alone broke her heart.

They [the residents] might not be able to say anything to me but being able just to be there and hold their hand, and when they're instantly leaving them there alone, because that just breaks my heart ... I don't care if they ... know I am there or not: they know. But what you're saying — that's not always possible ... There's not enough of us, there's not enough time.

In summary, PSWs' moral concerns revolved around the quality of palliative care that they thought residents should have, and these dilemmas were contextualized by the staff's relationships and identities within those relationships with the residents. PSWs described knowing the right action to take for the resident but being unable to because of constraints involving organizational hierarchy, policies, and time.

## Discussion

This research illustrates that PSWs experience the same ethical concerns that have typically been attributed to nursing, such as moral distress, moral residue, and moral resistance. As evidenced by our research, PSWs experienced moral distress when acting in ways that they knew were not in line with residents' wishes or when they could not provide the quality of palliative care that they felt they should. PSWs experienced moral distress not only because of the organizational context or environment in which they worked, but also because of their conflicting loyalties to residents, balancing residents' needs, their loyalties to other staff, and the expectations that they would perform their tasks in a timely manner. Similarly, Meaney (2002) described the same conflicting loyalties that nurses had towards their patients, their colleagues, and their employers.

PSWs also described moral resistance as they described working “around” some of the obstacles that prevented them from providing quality palliative care to residents. Not surprisingly, PSWs may not have demonstrated the level of resistance as described by nurses (Peter, Lunardi, & Macfarlane, 2004) because they are not protected by a professional body. However, PSWs did demonstrate more covert ways of resisting the obstacles that prevented them from providing the quality of care they felt residents deserved. In addition, parts of Nathaniel’s (2006) theory of moral reckoning applied to our participants as well, as they were faced with situations where they were required to act in conflict with their beliefs about what constituted quality palliative care. The stage of resolution was illustrated by PSWs as they tried to negotiate around the constraints or accepted the constraints and their actions as beyond their control. Although the stage of reflection wasn’t explicitly described by PSWs, the act of reflection was evidenced as they talked about their experiences in the focus groups, often in ways that illustrated their emotional distress.

The nature of relationships between staff and residents in LTC homes differs from that in acute care environments. The extended relationships as residents live and die in LTC homes, and the “family-like bonds” (Sims-Gould et al., 2010) that develop, enhanced the moral distress PSWs experienced because the challenges of care were situated within the context of relationships with residents. The literature highlights that the structural features of the LTC environment mitigates against kind, considerate, and sympathetic treatment of residents and that non-registered direct care staff such as PSWs experience a wide variety of complex issues (Foner, 1995). PSWs experience moral distress because of the relationships developed with the residents in LTC homes, in addition to the organizational constraints.

PSWs described the moral residue they experienced as resulting from not being always able to provide the quality palliative care they felt residents should have. Similarly, registered nurses in the LTC environment described the moral distress they felt with compromised care of residents (Edwards et al., 2013). PSWs thereby experienced the same type of moral residue previously attributed to nurses (Webster & Baylis, 2000). In light of previous research documenting the organizational challenges in LTC homes, it is not surprising that our findings suggest that these organizational challenges contribute not only to staff stress, but also to moral dilemmas that PSWs face in LTC homes. Time or a lack thereof, as found in other studies (Gubrium, 1975; Henderson, 1995; Wiersma & Dupuis, 2010; Wiersma, 2012), was directly related to moral concerns and moral distress that PSWs felt as they cared for dying residents.

Although significant research has explored the concepts of moral distress, moral residue, moral resistance, and moral reckoning for nurses, more research is needed to understand the application of these concepts and theories to other care professions. This is particularly urgent with direct care staff (i.e., PSWs) who are not registered as members of a professional college in most jurisdictions, including Ontario. Mandatory registration with a professional college requires members to follow a code of ethics and maintain certain competencies through continuing education. Registration entitles them to practice and gives them respect and credibility in the health care environment. Although there is a voluntary association in Ontario for PSWs that has a code of ethics for members, PSWs are not required to be members in order to practice.

Other findings of the QPC-LTC research indicated that PSWs in some of the homes rated themselves as low on supervisory support, personal empowerment in the workplace (self-determination and impact) and personal influence in the organization (Quality Palliative Care in Long Term Care, 2010). This suggests that PSWs can be particularly vulnerable to having their moral standards of quality of care compromised because they lack autonomy or support in decision-making. Consequently, rethinking the ways in which PSWs are heard and valued within LTC organizations is important, and valuing PSWs’ knowledge of and relationships with residents is one step to supporting greater autonomy for moral decision-making.

Because the LTC environment is intended to provide both physical and psychosocial care over extended periods of time to vulnerable seniors, the context affecting moral actions is different. Understanding how extended relationships between residents and staff impact moral decision-making, and consequently the emotional distress staff may experience when moral dilemmas occur, is important. Not only do these relationships with residents form the foundation of moral decision-making, it forms the basis of the PSWs’ identities as well. PSWs have little choice but to make decisions based on personal ethics as they lack a professional code of ethics, and their personal ethics is tied to their relationships with residents. Examining how moral distress impacts PSWs’ moral identity should be studied further.

Because this study was part of a larger study in which ethical concerns were not the key foci, further research should explore the ethical lens by which direct care workers approach their work. Understanding personal ethics, organizational and work context, and relationships within the LTC home between staff, management, residents, and families, is also important to illuminate the broader context of ethical concerns and decision-making within the LTC environment for direct care staff.

In conclusion, this research begins to fill a gap in the literature by analyzing the moral concerns of non-registered, direct care workers (PSWs) in LTC homes. Findings indicate that PSWs experience similar moral concerns as registered nurses and that the concepts of moral distress, moral residue, moral resistance, and moral reckoning are useful to understand their experience. At the same time, the unique context of LTC and the low status of direct care staff in relation to registered nurses influence how they can manage moral concerns. The strong relationships that form between PSWs and residents, and the emotional issues surrounding end-of-life care in LTC, provide further complexity that merits exploration.

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