Barriers to Staff Involvement in End-of-Life Decision-Making for Long-Term Care Residents with Dementia*

Nisha Sutherland, Elaine Wiersma,◉ and Paula Vangel
Lakehead University, Thunder Bay, Ontario

RÉSUMÉ

Bien que le personnel infirmier (autorisé et auxiliaire) et de soutien à la personne des centres de soins de longue durée (CSLD) fournisse des soins directs aux résidents atteints de démence, son implication est rarement considérée dans la prise de décisions en fin de vie. L'objectif de cette étude était d'examiner les obstacles et les facilitateurs à la participation du personnel des CSLD dans la prise de décisions liées à la fin de vie chez les personnes atteintes de démence sévère. Nous présentons les obstacles rencontrés en matière de participation à cette prise de décision pour ces travailleurs. Un design descriptif interprétatif a permis de mettre en évidence quatre principaux obstacles liés à la participation du personnel dans la prise de décisions : a) la prédominance d'un modèle de soins biomédical, b) les divergences dans la compréhension de l'approche palliative, c) la complexité des relations avec les familles, et d) le malaise associé aux discussions concernant le décès. Les résultats suggèrent que le modèle biomédical, qui est important et prédominant dans les CSLD, devrait s'inspirer d'une approche philosophique mettant davantage l'accent sur les relations entre les résidents atteints de démence, leur famille et le personnel.

ABSTRACT

Although providing direct care to residents with dementia, long-term care (LTC) home staff of registered nurses', registered practical nurses', and personal support workers' involvement in end-of-life decision-making is rarely acknowledged. The purpose of this study was to examine barriers and facilitators to LTC home staff involvement in end-of-life decision-making for people with advanced dementia. We report on the barriers to staff involvement in decision-making. Using an interpretive descriptive design, four major barriers to staff involvement in decision-making were identified: (a) the predominance of a biomedical model of care; (b) a varied understanding of a palliative approach; (c) challenging relationships with families; and (d) a discomfort with discussing death. Findings suggest that the predominant biomedical model in LTC homes, while important, must be imbued with a philosophy that emphasizes relationships among residents with dementia, family and staff.

La correspondance et les demandes de tirés-à-part doivent être adressées à : / Correspondence and requests for offprints should be sent to:

 Nisha Sutherland, RN, PhD
 Assistant Professor
 Lakehead University
 955 Oliver Road
 Thunder Bay, ON P7B 5E1
 (nsutherl@lakeheadu.ca)

Introduction

Although long-term care (LTC) homes are the place of death for most residents (Hirdes, Mitchell, Maxwell, & White, 2011), end-of-life care in LTC homes has been reported to be suboptimal, with poor management of pain and symptoms, invasive treatments (e.g., naso-gastric tube feeds), and unnecessary hospitalizations (Mitchell et al., 2009; Small, Froggatt, & Down, 2007; van der Steen et al., 2014). End-of-life experiences are further complicated for LTC home residents with dementia as they face loss of cognitive function and opportunities for choice. This may be why people with dementia are at greater risk for poor quality end-of-life care than people without dementia (Goodman et al., 2010; Thuné-Boyle et al., 2010).

End-of-life decision-making significantly impacts the quality of life and care of residents with dementia. These decisions can be critical to survival, the time and place of death, and the comfort level of residents with dementia (Givens, Selby, Goldfeld, & Mitchell, 2012; Mitchell et al., 2009; Toscani et al., 2015). LTC home staff, including personal support workers (PSWs), registered practical nurses (RPNs), and registered nurses (RNs), spend significant time and are familiar with residents with dementia and their family members; however, little attention has been paid to how every-day relationships and interactions among residents, family members, and staff in the LTC homes shape decision-making processes for people with dementia. The LTC home staff's and families' personal knowledge of the person with dementia has led to better assessments (Chang et al., 2009) and prevented potentially harmful transfers to hospital (Robinson, Bottorff et al., 2012). These informal interactions involving discussions of the resident's preferences, history, changes, and expected outcomes may be critical to informing decision-making. Yet LTC home staff involvement in end-of-life decision-making has been largely unacknowledged. We sought to address this gap by examining staff perceptions of their involvement in end-of-life decision-making. The research question that guided this study was: What are the barriers and facilitators to LTC home staff's involvement in end-of-life decision-making for people with dementia? For this article, we report on the barriers to LTC home staff involvement in decision-making for people with dementia.

End of Life, Palliative Care, and a Palliative Approach for People with Dementia

The time of end of life is inconsistently defined for LTC home residents with dementia. Evidence indicates that people with dementia typically encounter infections and nutritional problems during the last six months of life for which family must make decisions about the administration of antibiotics, hydration, nutrition, or treatment of symptoms related to pain or restlessness (Givens et al., 2012; Mitchell et al., 2009; Toscani et al., 2015). These end-of-life decisions can potentially lead to aggressive treatment, compounded delirium, unnecessary suffering, or death at hospital, and impacts on the quality of life for the person with dementia. Family members have described this time of decision-making as one of uncertainty and ambiguity (Caron, Griffith, & Arcand, 2005b; Lopez, 2007, 2009), and while family decision makers have specified goals towards quality of life (96%), nearly half (41%) of LTC home residents with dementia have received aggressive treatment that is of little benefit in the advanced stages (Mitchell et al., 2009). These findings raise serious questions about the processes and interactions involved in end-of-life decision-making for people with dementia.

A key factor to improving end-of-life for LTC home residents with dementia is decision-making about palliative care early in the illness trajectory (van der Steen et al., 2014). Palliative care is a holistic approach that aims to relieve suffering and focus on comfort and quality of life (World Health Organization, 2011). However, as chronic conditions such as Alzheimer's disease can have long and fluctuating disease trajectories, with progressive loss of functioning, it is difficult for health care providers to accurately predict when death may occur (Mitchell et al., 2009; Sawatzky et al., 2016; van der Steen et al., 2014). A palliative approach has been promoted in which palliative care is provided long before death occurs (Sawatzky et al., 2016). Instead of palliative care specialty services, a palliative approach is integrated into non-specialized care units such as LTC homes with existing generalist staff. A palliative approach in LTC homes blends philosophies of rehabilitation and palliative care throughout the resident's stay (Sawatzky et al., 2016), and focuses on relational care involving early and ongoing discussions among family, members of the health care team (Sawatzky et al., 2016; van der Steen et al., 2014), and all workers who come in contact with the resident (e.g., PSWs or housekeeping staff) (Kaasalainen et al., 2017; Pallium Canada, 2018; Sims-Gould et al., 2010). This study took place following a research project (Kaasalainen et al., 2010; Kelley & McKee, 2012; Sims-Gould et al., 2010) that implemented a palliative approach in two urban LTC homes.

A major component constituting a palliative approach is advance care planning (ACP), defined as formalized discussions of an individual's future preferences, in the case that the individual loses decision-making capacity (Robinson et al., 2012b). However, ACP can be problematic for people with dementia because of issues such as the timing of professionals to introduce ACP and the unwillingness of people with dementia and

family to discuss the future (Lord, Livingston, & Cooper, 2015; Robinson et al., 2012b). Moreover, the principle underlying ACP to maintain the autonomy of the individual overlooks how a person's sense of self and social events such as death or decision-making occur within the context of relationships (Sabat, 2005), and it does not reflect the concept of personhood (Kitwood, 1997), an idea that has been pivotal in bringing attention to the link between the subjective experiences of people with dementia and their relationships with others (O'Connor & Purves, 2009). Advance care planning does not include the contemporary subjective experiences of the person with dementia and the relationships and contextual factors surrounding end-of-life decision-making. However, a palliative approach philosophy that emphasizes ongoing relationships rather than the disease integrates the concept of personhood.

End-of-Life Decision-Making for People with Dementia

Both formal and informal discussions among family members and staff have been found to be critical to relationships and positive decision-making experiences in LTC homes (Black et al., 2009; Caron, Griffith, & Arcand, 2005a). However, findings from a systematic review indicate that family members have not been consistently supported in decision-making and have been dissatisfied with the process (Petriwskyj et al., 2014). Many have complained about the lack of communication with care providers (Caron et al., 2005b; Davies et al., 2014; Hennings, Froggatt, & Keady, 2010); when there has been communication, it has often been during times of crisis (Hennings et al., 2010). Not wanting sole responsibility, family members have relied on LTC home staff to proactively discuss changes to their relatives' conditions (Forbes, Bern-Klug, & Gessert, 2000; Goodman et al., 2010). Moreover, family are grieving at the same time as they are making decisions (Hennings et al., 2010), thus needing continual explanations from staff throughout the resident's stay (Bern-Klug, 2008). How and when these interactions are enacted in decision-making processes needs further analysis.

Research examining staff perspectives of their involvement in end-of-life decision-making has indicated that LTC home staff tends to be excluded, and exclude themselves, from decision-making. Studies have found that nurses perceive a lack of power and knowledge and are ambiguous regarding their role related to end-of-life conversations (Laging, Ford, Bauer, & Nay, 2015; Lopez, 2007, 2009; Reimer-Kirkham, Sawatzky, Roberts, Cochrane, & Stajduhar, 2016; Sawatzky et al., 2017). Nurses have characterized their role as playing the middle person between family members and physicians (Bryon, Gastmans, & de Casterle, 2008; Lopez, 2007, 2009). Structural issues such as a lack of formal

policies (Ramsbottom & Kelley, 2014) of staff and family roles in decision-making have been identified. However, other studies examining palliative care in LTC homes have found that nurses (Dreyer, Ford, & Nortvedt, 2011; Kaasalainen, Brazil, Ploeg, & Martin, 2007) and PSWs (Bauer, 2007; Munn et al., 2008; Waskiewich, Funk, & Stajduhar, 2012) listen to, inform, and prepare families for end of life. Because of a perceived lack of power, staff may be more comfortable to discuss end of life after formal decisions are made for goals towards comfort. Other studies have found that end-of-life decision-making tools (e.g., Liverpool Care Pathways) have helped to empower nurses and PSWs to be involved in decision-making (Watts, 2011).

The literature suggests that positive relationships and discussions among family and staff are needed to lead to palliative care goals (Caron et al., 2005b; Hennings et al., 2010). To enhance quality of life for people with dementia in LTC homes, there needs to be a nuanced understanding of what hinders these important staff, resident, and family relationships and decision-making interactions. For a comprehensive understanding, however, end-of-life decision-making for residents with dementia needs to be contextualized within the culture of LTC homes.

End-of-Life Decision-Making in the Context of Long-Term Care Homes

Much of the research conducted in LTC homes has pointed to the hierarchical culture. Direct care workers, including PSWs, RPNs, and RNs, tend to work separately and make known their status through distinctions, such as how they are named, and the type of work expected of them (Banerjee, Armstrong, Daly, Armstrong, & Braedley, 2015; Baumbusch, 2008; Diamond, 1992; Kontos, Miller, & Mitchell, 2010). These stratifications have been classified according to the level of education, placing unregulated PSWs with the least education to the bottom of the hierarchy. PSW bodily work has been considered low on the ladder, and physicians and RNs with clinical, objective knowledge have achieved higher status (Banerjee et al., 2015).

Additionally, LTC homes have been structured predominately by a biomedical paradigm (Baumbusch, 2008; Gubrium, 1975), making the focus of care on maintaining life (Banerjee & Rewegan, 2016; Diamond, 1992; Foner, 1995). This medicalization of LTC homes has also led to a focus on body parts and measurable outcomes. Long-term care routines are thus organized around body work of toileting, cleaning, and meal and medication times (Wiersma & Dupuis, 2010). As a result, staff's work is often understood in terms of "tasks" to be done (Banerjee & Rewegan, 2016; Henderson, 1995; Wiersma & Dupuis, 2010), with little priority given for

staff to develop relationships and engage in end-of-life discussions with families and residents.

The LTC home literature often describes relationships between staff and family members as uneasy (Austin et al., 2009; Bauer, Fetherstonhaugh, Tarzia, & Chenco, 2014; Baumbusch & Phinney, 2014; Haesler, Bauer, & Nay, 2007; Ward-Griffin, Bol, Hay, & Dashnay, 2003), in part because family and staff have misunderstood and under-valued each other's roles (Bauer et al., 2014; Ward-Griffin et al., 2003). Although staff appreciate that family members assume tasks such as feeding, staff have viewed family as outsiders and have limited family involvement in care (Bauer, 2007; Baumbusch & Phinney, 2014). Family members also have actively controlled situations by being assertive or limiting engagement with staff (Gladstone, Dupuis, & Wexler, 2007), suggesting that both staff and family hold power to shape relationships and practices in LTC homes.

Additionally, death has largely been hidden within LTC homes. Dying residents have often been secluded and deaths have been unrecognized, without ceremony (Diamond, 1992; Munn et al., 2008). Alongside heavy workloads and hierarchical work environments, other barriers have been identified such as lack of LTC home leadership and staff's lack of knowledge and discomfort with death (Brazil, Brink, Kaasalainen, Kelley, & McAiney, 2012; Kaasalainen et al., 2010; Kelley & McKee, 2012; Sims-Gould et al., 2010). Given the complexities of LTC homes, a contextual analysis is needed to gain in-depth understanding of the barriers to LTC home staff members' involvement in end-of-life decision-making for people with dementia.

Methods

We used an interpretive descriptive design (Thorne, 2008) to move beyond description and gain theoretical understanding of barriers to staff involvement in decision-making. The purpose of this design is to locate subjective experiences within common understandings and broader contexts. This methodology is appropriate to examine barriers to a staff member's decision-making involvement, a practice process that is constructed through both subjective and collective understandings.

Recruitment and Sample

After obtaining approval from two Research Ethics Boards, we recruited participants from two urban not-for-profit facilities, one owned by a charitable organization (112 beds) and one by the municipality (150 beds). We obtained permission from LTC home managers and placed recruitment notices on units describing the purpose and process of the study. We also arranged short presentations on the units to explain to staff the

study and what could be involved in participating. Interested participants approached or called the researcher to arrange an appointment. Inclusion criteria for the study were (a) to be employed in the facility as a PSW, RPN, or RN; (b) to work on the unit for at least one year; and (c) to speak English well enough to participate in a conversation about their experiences.

As the first author and primary investigator, I (NS) obtained written, informed consent from 21 participants (RNs [$n = 4$], RPNs [$n = 8$], and PSWs [$n = 9$]) prior to data collection, which occurred from April to December 2016. Participants included four males and 17 females, of which 16 were full-time and five were part-time employees (see Table 1). Fifteen participants had LTC home work experience greater than 10 years, and all received additional palliative and/or dementia care education through in-services or other formal education.

Data Collection

We conducted semi-structured face-to-face interviews for which participants received an honorary gift card of $10. Apart from one interview conducted at a coffee shop, all others were conducted in private rooms made available at the LTC homes. I asked open-ended questions such as "What is a palliative approach?"; "How are you involved in end-of-life discussions?"; "What helps or hinders your involvement?" A research assistant and I also conducted a focus group to acquire detailed explanations and share and confirm common experiences (Lambert & Loiselle, 2008). For the focus group, there were three participants – a PSW, an RPN, and an RN – all of whom had participated in individual interviews. All interviews were digitally recorded and transcribed verbatim for analysis. Consistent with qualitative research, we conducted data collection and data analysis concurrently.

Data Analysis

We conducted data analysis through thematic analysis (Lofland, Snow, Anderson, & Lofland, 2006). Initially, the first and third authors conducted line-by-line analysis, labelling phenomena and patterns. In this process, we developed general categories. We continually compared categories to existing and new data until patterns emerged. This was the start of a focused coding that involved development of conceptual themes and constant comparison of themes with data. The team discussed the emerging themes, and although there were no disagreements, there were lengthy discussions of the relevancy of the themes to the findings, thus adding rigour to the study. Trustworthiness was also attained by maintaining an audit trail of codes and memos and returning to participants. We used NVivo

Table 1: Profile characteristics of study participants

n (%)	Age	Sex n (%)	Employment Status n (%)	Years of Experience in LTC Homes n (%)	Highest Level of Education[a] n (%)	Dementia Care Education[a] n (%)	Palliative Care Education[a] n (%)
PSW 9 (43)	Range 38–65	F 7 (78) M 2 (22)	FT 7 (78) PT 2 (22)	< 10 yrs. 2 (22) > 10 yrs. 7 (78)	Vocational 4 (45) College 4 (45) University[b] 1 (11)	In-services 9 (100) Courses 2 (23)	In-services 9 (100) Courses 2 (22)
RPN 8 (38)	Range 29–62	F 8 (100) M 0 (0)	FT 7 (88) PT 1 (12)	< 10 yrs. 1 (13) > 10 yrs. 7 (87)	Vocational 2 (25) College 6 (75)	In-services 6 (75) Courses 2 (25)	In-services 2 (25) Courses 4 (50)
RN 4 (19)	Range 27–52	F 2 (50) M 2 (50)	FT 1 (25) PT 3 (75)	< 10 yrs. 3 (75) > 10 yrs. 1 (25)	College 1 (25) University 3 (75)	In-services 2 (50) Courses 1 (25)	In-services 0 (0) Courses 3 (75)
TOTAL n = 21	Range: 27–65 Average Age: 46	F 17 (81) M 4 (19)	FT 15 (75) PT 6 (25)	< 10 yrs. 6 (29) > 10 yrs. 15 (71)	Vocational 6 (29) College 11 (52) University 4 (19)	In-services 17 (81) Courses 5 (24)	In-Services 11 (52) Courses 9 (43)

Note. FT = full-time; PT = part-time; PSW = personal support worker; RPN = registered practical nurse; RN = registered nurse
[a] **Columns may not total 100% as more than one category, or no category, could be selected**
[b] **Degree outside of health care**
In-Services: Education provided by LTC homes (e.g., PIECES, dementiability, gentle persuasive approach)
Courses: Certificate, college or university

software to enter transcripts and manage data coding and retrieving.

Findings

Using interpretive descriptive design, we identified four barriers to staff involvement in decision-making for people with advanced dementia: (a) the predominance of a biomedical model of care; (b) a varied understanding of a palliative approach; (c) challenging relationships with families; and (d) a discomfort with discussing death. These themes are interconnected. For instance, the privileging of a biomedical model of care contributed to staff's discomfort in discussing death with family members. Further explication is provided as themes are discussed.

Predominance of a Biomedical Model of Care

Regulated documentation in LTC homes required staff to routinely assess residents' biomedical signs of health and wellness. Consequently, staff members tended to focus on residents' patterns of elimination, nutrition, or movements. Thus, care and interactions related to care were framed around bodily functions, as one nurse suggested:

A lot of times when you're looking through the documentation, there is going to be different things … whether it's their vitals are changing or … different subtle hints. Whatever is going on in the body … the in and output. Anything that I'm seeing changing, like any wounds, shortness of breath (RPN5).

Decision-making was also focused on bodily functions and treatments to resolve issues:

We'll see the trend when we do documentation every three months … and that's generally when we get involved is when eating and drinking tends to slow down, because now it's becoming a medical discussion with the families … "Okay this is what we are seeing. What are we doing? Do you want us to try to rehydrate them? Do you want us to try some antibiotics?" (RN4)

The RN first offered the family choices for medical treatment, rather than discussing the history, values, and preferences of the person with dementia. The privileging of the biomedical model of care in LTC homes constructed knowledge of values and emotions as trivial and less important knowledge, potentially precluding staff members from discussing personal knowledge of the person with dementia. One PSW

described self-expectations to be able to provide biomedical knowledge and aid in decision-making:

> I have tried [to talk to family,] and if I still can't [get] through to them, then I do direct them to the RN. They know a lot more medical terms, more pain meds … I think the RN can explain it a little bit better than I can. … But I do know … a lot of the meds and what goes on and I can explain that, but sometimes they need … more authority. I guess because a lot of times the family just looks at us that we're just the bum wipers. (PSW3)

The PSW sensed that the caring of bodies was viewed to be of lower status compared to clinical knowledge related to physiological functioning and medical treatments. One PSW described how computer documentation left little time for the emotional work done in LTC homes:

> The PSWs are charting. It used to take 5 minutes and now we can be on the computer for 45 minutes. … and that's not even getting on the computer to chart about the little lady who is saying, "Please don't let me die." Like that is so important too … but that's not being captured. If it's not written, it's not said or done … and there's so much (PSW7).

Regulated documentation tended to frame care and discussions around bodily functions and thus constrain staff responses and shape their everyday attitudes and practices. The predominance of the biomedical model in LTC homes tended to exclude and silence not only staff care work and their personal knowledge of the residents' emotions or preferences, but what may be also highly meaningful interactions among staff, residents, and families about decision-making towards quality of life for the person with dementia. This singular focus also shaped staff's understanding of palliative care and a palliative approach.

A Varied Understanding of a Palliative Approach

Most participants perceived palliative care to be within a traditional medical model of care in which palliative care is provided only when curative treatment is exhausted. Although a few staff members articulated an understanding of early and ongoing discussions as key to a palliative approach, most referred to palliative care as a transition to end of life: "Well, when they are palliative – when we decide for end of life, nothing more to do for them – there is nothing more" (PSW1). The terms end of life, palliative care, and care directives often were used interchangeably in discussions. This conflation of terms was a source of confusion which led many staff to reduce the concept of palliative care to acquiring care directives. As one participant stated:

> [There is] contact with the family to discuss the treatment direction, really based on the resuscitation, whether it's primary or … Often those discussions haven't necessarily taken place thoroughly or consistently so, [we may say], "This is what we're seeing and this is what the treatment directive indicates at this time, and just to confirm with you, what the treatment direction would be – would you want [your relative] sent to hospital or kept here?" (RN3)

In this context, staff may discuss goals and directives only when end of life was near or during times of crisis. Additionally, palliative care was viewed as a type of care provided, as described by one staff member:

> But [with] palliative [care], residents are in bed most of the time … we change them after two hours if they are in bed, [and] turn [reposition them], so they don't have any bed sores or any infection there. And palliative means … we do everything for them (PSW6).

Rather than adopting a philosophy of caring, palliative care was considered a set of physical tasks to be completed. Such an approach places attention on the physical aspects of care rather than focusing on residents' and family members' emotions, history, preferences, and quality of life throughout the stay in the LTC home. With a focus on daily tasks, staff members fail to think about future events, possibilities, discussions, or psychosocial needs of the resident and family, thus having an overall effect of impeding end-of-life discussions.

Participants in our study also had a varied understanding of end-of-life decision-making. A few participants described decision-making as offering residents choices in everyday living in LTC homes. Most assumed that end-of-life decision-making was a rational decision to be made in a formal meeting:

> [Doctors] like to have a family meeting so that [family] are formally in front of them, explaining … if their treatment directive is in comfort care or it's send to hospital (PSW7).

> It's a very emotional time and … I feel I'm in the best position to help direct that interaction, because I'm the least emotionally involved in that relationship. (RN1)

By viewing decision-making as occurring at one time, staff may not be proactive in engaging in everyday discussions with family about the resident's deterioration. Also, staff would be inclined to put off discussions that they assumed would be better accomplished in formal, private interactions and with "higher level" providers. Staff members thus may not have discussions to avoid often difficult conversations with family members who may be experiencing grief and loss.

Challenging Relationships with Family

Another barrier to engaging in end-of-life discussions was staff's perceptions of dealing with family members, whom staff recognized as experiencing guilt and denial. Because of family emotions, staff anticipated that some interactions with family members may be uneasy. A nurse described family members' experiences of emotions and sense of denial:

> I find in my experience that [family] don't want to say bye yet, because they have a feeling of guilt of not being there … when they bring that person in to the LTC home. They wanted to care for them … at home, but they couldn't anymore, the safety wasn't there. … I try and see it through their eyes. (RN2)

Most staff members commented that a predominant complaint by family members was when the resident with dementia refused to eat. Family members frequently attributed the relative's reluctance to eat to staff's lack of attention and time to care. As stated by two staff members:

> I've seen families who are in denial: "[Dad] eats when I'm here, you know," [Family members] are able to encourage a little bit more … and the relative might eat for them. But if we go and try, [the resident is] not going to eat for us. Sometimes the family is in denial, they don't want to see it. They say, "[Dad] does that for me, so I don't know what you're talking about." (PSW3)

> The family member is saying, it must be the staff approach. The resident is becoming more aggressive [and family say]: "They are not aggressive with me. They are not resistive with me." (RPN 2)

The family member's reluctance to believe staff may have led to nurse and PSW perceptions that their knowledge and expertise were not appreciated. These struggles could potentially lead to tense relationships and an avoidance of discussions. One nurse described the delicate approach used to interact with family members who were not accepting of the resident's possible death:

> I would just reinforce [to family] that [the resident] was not eating, [that] the body needs nutrition and if they're not getting the adequate nutrition and hydration, sometimes the body shuts down. I would possibly say the same things repetitively, without being argumentative (RPN5).

Although empathetic, staff members at times were anxious about possible confrontations with family. Most staff members referred families to the "higher-level" health care worker (e.g., RN or physician), if family members were not accepting of the resident's decline. Thus, the thought of confrontations with family could preclude staff from engaging in spontaneous

discussions about the disease trajectory and expected outcomes. Also, staff may have believed it pointless to have discussions with family members who did not believe them and who denied the possibility of death for the relative with dementia. From this perspective, staff-family interactions may be imbued with power struggles, rather than grounded in a collaborative, partnership approach. Also, staff members were uncomfortable about discussions related to death.

Discomfort with Discussing Death

Participants expressed a general discomfort with discussing the possibility of death. Most assumed that speaking to family about future possibilities entailed discussing death when it was near. One PSW stated:

> Palliative care, it's just hard in general. Talking to somebody about their mother dying or their father dying never gets easier. Even teaching them earlier … it may be … nothing will ever prepare you for losing a family member … it's never easy (PSW1).

Because staff members were uncomfortable discussing the possibility of death, staff tended to converse about end of life indirectly. Some used subtle language or employed the use of metaphors and euphuisms. One nurse stated:

> We try to do it subtly. So, that, you don't go up to somebody and say [in] a cold, callous way, "Hey, your parent is dying." You try to do it as gently. For instance, if a person is not eating, you say, "You know what, they're not eating, it's the way that the body is … the natural course … Or maybe Dad's having a hard time swallowing because he's having a hard time getting his breath" (RPN5).

Staff sending subtle messages to family members about deterioration and possible death of a relative would not provide the candid information that family members may need. Leaving out essential end-of-life conversations could also lead to mistrust and a breakdown in staff-family relationships. One staff member described how truthful discussions, though difficult, may lead to more positive relationships:

> [Family] will ask, "Is my Mom ever going to get better?" I've heard staff say … "Well … that's possible, that could happen" – just because they don't know how to let them down … [Some say] "I don't want to burst anyone's bubble." But … people need to know where they stand and so my response … might sound a little bit harsh, [I say]: "No, I don't think so, I think that we are just going to continue to see these things happen." I say … "I will help you, I will let you know what I think is coming. I can't tell you anything for sure, but I can tell you what I've seen in the past and how this develops …" I have a person in my mind that I had a similar conversation with, and the look on his face was

somewhat hurt at the time, but the next day that person came back and said, "thank-you so much" (PSW8).

Staff members reluctant to "burst anyone's bubble" expressed the importance of maintaining an environment in which residents could be happy:

> We just tell [family], "Oh my God, today your Mom … she was so happy, she was painting and drew a nice picture … she was enjoying, smiling, laughing, so we tell them that … just like the good things and less … if she's not feeling good. And [if] they ask, "Why is she in bed?" I have to tell them that this … happened … [then], I report it … I won't say any negative to them (PSW6).

> I have so many clients – I just try to be that friendly face that's encouraging, give them their pills, listen to their needs. It's not like I'm talking about death every day with them unless someone said, you know, "I'm depressed, I want to die" … and then you have to inquire more (RPN8).

These statements suggest that there is a delineation between living and dying, rather than a philosophy of living well while ill and dying. Staff members perceived that they had a responsibility to ensure that residents were "happy". Additionally, family members may consider residents' appearances and deportment as reflective of staff's work. Staff also perceived that keeping residents happy was counter to discussing deterioration, probable expectations, and possible death. However, although conversations about the resident's good days may be important for family members to hear, family members want and need knowledge about what may be expected to better prepare for end of life and decision-making towards quality of life.

Another barrier to end-of-life discussions was staff's fears of giving misinformation. One staff member expressed her discontent that she was unable to predict a resident's disease trajectory:

> One of our nurses left me a note saying call this family member … So I phoned him … asked him to come in and … We had a great conversation about [his mother's] likes, her dislikes, what he expected. I explained to him about our different initiatives … also, I talked to him about our pain and symptom management consultant … and he was really happy … Unfortunately, right now I'm seeing … her deteriorate and it's not what I told him. That really upsets me, that really upsets me. (PSW7)

Although there is considerable uncertainty in predicting time of death for people with chronic conditions, staff members tended to blame themselves for stating imprecise information on how the end stages would unfold. Staff members' fears of discussing end-of-life issues were largely driven by their perceived lack of biomedical knowledge.

Discussion

Using an interpretive descriptive design, this study sheds light on the barriers to staff involvement in decision-making for people with dementia in LTC homes. This study contributes to findings in the literature that suggest LTC home policies and practices have not yet been tailored to a relational approach to palliative dementia care (Banerjee & Rewegan, 2016), thus hindering staff's involvement in end-of-life discussions and decision-making. Our study suggests that the privileging of the biomedical model in the LTC home, while important, tends to exclude other sources of knowledge such as information that arises from personally knowing people with dementia, their biographical history, or preferences. Along with this hierarchy of knowledge, the stratification of labour in LTC homes tends to hamper authentic collaborative teamwork. Additionally, our study reflects findings in the literature of participants' varied understanding and uptake of a palliative approach as a model of care rather than a philosophy woven into everyday care (Forbes et al., 2000; Sawatzky et al., 2016). Overall, findings from this study suggest that, as relationships between and among residents, family, and staff are crucial to end-of-life discussions and decision-making for people with dementia, more attention needs to be paid to the relational, social, and emotional aspects of LTC home dementia care.

Study findings suggest that the privileging of biomedical knowledge in LTC homes tends to exclude other types of knowledge relevant to care. Scholars (Benner & Tanner, 1987; Chinn & Kramer, 2011; Kontos & Naglie, 2009) have emphasized experiential, "practical" or intuitive knowledge, in addition to biomedical knowledge in the provision of care. Kontos and Naglie (2009) found that PSWs use knowledge of the resident's personal history, sociocultural background, nuances, and preferences to help with dressing, eating, and decision-making. However, this tacit knowledge has been marginalized because primacy is given to scientific and economic-based concerns (Banerjee & Rewegan, 2016; Barken & Lowndes, 2018). As found in our study and others (Lopez, 2007, 2009), a biomedical focus has led staff to perceive that decision-making involves an objective knowledge and that personal and subjective knowledge is less important. This privileging of physical needs over psychosocial needs (Banerjee & Rewegan, 2016; Barken & Lowndes, 2018; Ryan, Nolan, Reid, & Enderby, 2008) may have prevented staff in our study from actively engaging in relational care and end-of-life discussions. Although we are not suggesting that objective knowledge is unimportant, we contend that knowledge beyond the biomedical paradigm should also be valued and considered in decision-making, particularly to promote a humane, relational approach to dementia care.

Study findings also suggest that although there was a team approach, the hierarchy in LTC homes may have prevented genuine interprofessional collaborative practice. Nurses and PSWs in our study referred "challenging" situations to "higher level" providers, indicating a regimented order of communication and labour. Family meetings were considered formal gatherings arranged primarily for physicians and did not include PSWs. These findings suggest that PSWs worked remotely from physicians and within their relegated confines. Similar to our study, research has indicated that family and LTC home workers at times undervalue and exclude PSW knowledge (Banerjee et al., 2015; Kontos et al., 2010). Nurses also have been dominated by other professionals and administrators (Halcomb, Shepherd, & Griffiths, 2009; Ho, Jameson, & Pavlish, 2016) and often lack confidence and understanding of their role in end-of-life discussions and decision-making (Lopez, 2007, 2009; Reimer-Kirkham et al., 2016). The focus on biomedical knowledge and lack of support from other disciplines may contribute to staff role ambiguity (Laging et al., 2015). Taking on roles such as facilitating end-of-life decision-making discussions requires not only subjective perceptions of the role, but a collective understanding of team roles and functioning. Further research is needed to examine how direct care staff function within the power dynamics of the LTC home interdisciplinary team.

Additionally, our study revealed that participants had a varied understanding of palliative care and a palliative approach. Similarly, Sawatzky et al. (2017) found that incorporating a palliative approach to acute and LTC home units rested on how it was understood in practice contexts. Some staff viewed palliative care as a specialty model of care. In our study, participants' understandings were a result of their attachment to traditional models in which palliative care is initiated only when curative treatment is exhausted. This understanding dichotomizes care that is imbued with cure and hope from care that involves acceptance and decline of death. This dichotomy tends to place the focus of care on the physical death and risks viewing death as a technical procedure (Banerjee & Rewegan, 2016) and palliative care as relevant only to those actively dying (Thompson & Roger, 2014; Small et al., 2007). Ontario LTC homes have been mandated under the LTC Home Act (Ministry of Health and Long-Term Care, 2007) to incorporate a restorative model of care that maintains physical functioning. Although important, a singular focus on physical and mental functioning without consideration of relationships is in opposition to caring for people with dementia and people who are dying (Banerjee & Rewegan, 2016; Small et al., 2007). Moreover, separating palliative care from treatment-oriented care can unintentionally create a liminal space between living and not dying, a space of ambiguity in which dying residents with dementia may be marginalized as "non-persons" (Small et al., 2007; Syme, 2011).

Although the health care system tends to divide care as acute or palliative (Petriwskyj et al., 2014), research has shown that patients with life-limiting conditions and their family members transition over time (Barnard, Towers, Boston, & Lambrinidou, 2000; Black et al., 2009; Caron et al., 2005b; Hansen, Archbold, Stewart, Westfall & Granzini, 2005). In examining patients and families in palliative care, Barnard et al. (2000) found that the transition to palliative was rarely unidirectional and was instead oscillating from acceptance to denial. Thus, there must be a focus on quality of life that integrates both restorative and palliative care over time (Thompson & Roger, 2014). This is consistent with a palliative approach that emphasizes early integration and ongoing discussions to ensure quality of life.

Another factor that has contributed to a varied understanding is that participants in our study understood a palliative approach as a model of care, rather than a philosophy to be integrated into daily practice. Similarly, studies have found that a palliative approach must be viewed as a philosophy of care to be embedded in daily workings of care units, rather than a set of practices (Forbes et al., 2000; Sawatzky et al., 2017). End-of-life frameworks incorporating a palliative approach, while found to empower nurses and aides (PSWs) in being involved in end-of-life decision-making, have been found to be reduced to checklists (Watts, 2011). Additionally, instituting change in highly regulated facilities such as LTC homes add to difficulties because of competing program priorities such as least restraint policies (Ministry of Health and Long-Term Care, 2007). In introducing a palliative approach to rural nurses, Pesut, McLeod, Hole, and Dalhuisen (2012) questioned the appropriateness to expect nurses to incorporate more philosophies in their everyday demanding workload. Participants in our study consistently discussed demands on their time to provide care. Other researchers implementing a palliative approach have noted the importance of facility management to support staff (Brazil et al., 2012; Sawatzky et al., 2017; Sims-Gould et al., 2010). Indeed, staff alone cannot be responsible to incorporate a philosophy that may require a cultural shift and support from all team members (Sawatzky et al., 2017).

This study also found that staff used a passive approach when discussing residents' conditions with family. Participants in our study understood family members' experiences of grief and loss. Staff, however, was reluctant to engage with emotional family members and potentially provoke conflict. Studies have found that family members have experienced enduring guilt after

admitting their relatives to LTC homes (Bern-Klug, 2008; Thompson & Roger, 2014) and grief at witnessing their relative's decline (Austin et al., 2009; Bern-Klug, 2008; Caron et al., 2005a). Family members' emotions have been found to infiltrate into everyday family-staff interactions (Austin et al., 2009). Also, as found in our study, staff have perceived questioning by families as a lack of trust (Austin et al., 2009). Amid these power-laden interactions, there may be missed opportunities to have discussions. Thus, staff and LTC home policy makers need an understanding that discussions require repetition (Bern-Klug, 2008) and that relationships between staff and family members are crucial to decision-making. As family members are mainly concerned with preserving the identity of their relatives (Gladstone et al., 2007), a staff focus on resident and family relationships is important and consistent with the concept of person-hood in which the person with dementia's sense of self (through relationships) is kept at the forefront of care. Further research is needed to examine how social relations of status, gender or ethnicity shape decision-making experiences among residents, family, and staff.

Study Limitations

Data gained from 21 LTC home staff members were sufficient to fully develop themes (Morse, 2015). However, a sample consisting of more RNs, male nurses, or staff of varying ethnicities may have provided different results. Another limitation is that participants who volunteered for the study may have had an interest in palliative dementia care and may not include staff who have contrary attitudes. Finally, findings may be applicable only to the LTC homes in which the study was conducted. However, these study findings provide a nuanced understanding of barriers to staff involvement in decision-making and may be transferrable to LTC home residents with or without dementia.

Conclusion

The study findings revealed barriers to LTC home staff involvement in end-of-life discussions for people with dementia. Study findings suggest that LTC home policies and practices need to be adapted to a relational approach to palliative dementia care. The predominant biomedical model in LTC homes, although important, should also include and value a philosophy that emphasizes relationships among residents, family, and staff to include and better meet the needs of people with dementia and their family members.

References

Austin, W., Goble, E., Strand, V., Mitchell, A., Thompson, E., Lantz, … Vass, K. (2009). Supporting relationships between family and staff in continuing care settings. *Journal of Family Nursing*, 15(3), 360–383. doi: 10.1177/1074840709339781

Banerjee, A., Armstrong, P., Daly, T., Armstrong, H., & Braedley, S. (2015). "Careworkers don't have a voice:" Epistemological violence in residential care for older people. *Journal of Aging Studies*, 33, 28–36. doi: https://doi.org/10.1016/j.jaging.2015.02.005

Banerjee, A., & Rewegan, A. (2016). Intensifying relational care: The challenge of dying in long-term residential care. *Journal of Canadian Studies*, 50(2), 396–421. Retrieved from https://www.utpjournals.press/doi/abs/10.3138/jcs.50.2.396?journalCode=jcs

Barken, R., & Lowndes, R. (2018). Supporting family involvement in long-term residential care: Promising practices for relational care. *Qualitative Health Research*, 28(1), 60–72. doi: 10.1177/1049732317730568

Barnard, D., Towers, A., Boston, P., & Lambrinidou, Y. (2000). *Crossing over: Narratives of palliative care*. New York, NY: Oxford University Press.

Bauer, M. (2007). Staff–family relationships in nursing home care: A typology of challenging behaviours. *International Journal of Older People Nursing*, 2(3): 213–218. doi: 10.1111/j.1748-3743.2007.00075.x

Bauer, M., Fetherstonhaugh, D., Tarzia, L., & Chenco, C. (2014). Staff–family relationships in residential aged care facilities: The views of residents' family members and care staff. *Journal of Applied Gerontology*, 33(5), 564–585. doi: 10.1177/0733464812468503

Baumbusch, J. L. (2008). *Decommissioning citizenship: The organization of long-term residential care* [Doctoral dissertation]. University of British Columbia, Vancouver. Retrieved from https://open.library.ubc.ca/cIRcle/collections/ubctheses/24/items/1.0066610

Baumbusch, J., & Phinney, A. (2014). Invisible hands: The role of highly involved families in long-term residential care. *Journal of Family Nursing*, 20(1), 73–97. doi: 10.1177/1074840713507777

Benner, P., & Tanner, C. (1987). Clinical judgment: How expert nurses use intuition. *The American Journal of Nursing*, 87(1), 23–31. doi: 10.2307/3470396

Bern-Klug, M. (2008). The emotional context facing nursing home residents' families: A call for role reinforcement strategies from nursing homes and the community. *Journal of the American Medical Directors Association*, 9(1), 36–44. doi: 10.1016/j.jamda.2007.08.010

Black, B. S., Fogarty, L. A., Phillips, H., Finucane, T., Loreck, D. J., Baker, A., … Rabins, P. V. (2009). Surrogate decision makers' understanding of dementia patients' prior wishes for end-of-life care. *Journal of Aging and Health*, 21(4), 627–650. doi: 10.1177/0898264309333316

Brazil, K., Brink, P., Kaasalainen, S., Kelley, M., & McAiney, C. (2012). Knowledge and perceived competence among nurses caring for the dying in long-term care homes.

International Journal of Palliative Nursing, *18*(2), 77–83. doi: 10.12968/ijpn.2012.18.2.77

Bryon, E., Gastmans, C., & de Casterlé, B. D. (2008). Decision-making about artificial feeding in end-of-life care: Literature review. *Journal of Advanced Nursing*, *63*(1), 2–14. doi: 10.1111/j.1365-2648.2008.04646.x

Caron, C. D., Griffith, J., & Arcand, M. (2005a). Decision making at the end-of-life in dementia: How family caregivers perceive their interactions with health care providers in long-term care settings. *The Journal of Applied Gerontology*, *24*(3), 231–247. https://doi.org/10.1177/0733464805275766

Caron, C. D., Griffith, J., & Arcand, M. (2005b). End-of-life decision making in dementia: The perspective of family caregivers. *Dementia*, *4*(1), 113–136. doi: 10.1177/1471301205049193

Chang, E., Daly, J., Johnson, A., Harrison, K., Easterbrook, S., Bidewell, J., … Hancock, K. (2009). Challenges for professional care of advanced dementia. *International Journal of Nursing Practice*, *15*(1), 41–47. doi: 10.1111/j.1440-172X.2008.01723.x

Chinn, P., & Kramer, M (2011). *Integrated theory & knowledge development in nursing*. St. Louis, MO: Elsevier.

Davies, N., Maio, L., Vedavanam, K., Manthorpe, J., Vernooij-Dassen, M., & Illife, S. (2014). Barriers to the provision of high-quality palliative care for people with dementia in England: A qualitative study of professionals' experiences. *Health and Social Care in the Community*, *22*(4), 386–394. doi: 10.1111/hsc.12094

Diamond, T. (1992). *Making gray gold: Narratives of nursing home care*. Chicago, IL: University of Chicago Press.

Dreyer, A., Ford, R., & Nortvedt, P. (2011). Ethical decision-making in nursing homes: Influence of organizational factors. *Nursing Ethics*, *18*(4), 1–23. doi: 10.1177/0969733011403553

Foner, N. (1995). *The caregiving dilemma: Work in an American nursing home*. Lincoln, NE: University of Nebraska Press.

Forbes, S., Bern-Klug, M., & Gessert, C. (2000). End-of-life decision making for nursing home residents with dementia. *Journal of Nursing Scholarship*, *32*(3), 251–258. Retrieved from http://onlinelibrary.wiley.com/doi/10.1111/j.1547-5069.2000.00251.x/abstract;jsessionid=6F2F2DADA44E3C820445FE7C12F5864A.f03t04

Givens, J. L., Selby, K., Goldfeld, K. S., & Mitchell, S. L. (2012). Hospital transfers of nursing home residents with advanced dementia. *Journal of the American Geriatrics Society*, *60*(5), 905–909. doi: 10.1111/j.1532-5415.2012.03919.x

Gladstone, J. W., Dupuis, S. L., & Wexler, E. (2007). Ways that families engage with staff in long-term care facilities. *Canadian Journal on Aging*, *26*(4), 391–402. doi: 10.3138/cja.26.4.391

Goodman, C., Evans, C., Wilcock, J., Froggatt, K., Drennan, V., Sampson, E., … Iliffe, S. (2010). End of life care for community dwelling older people with dementia: An integrated review. *International Journal of Geriatric Psychiatry*, *25*(4), 329–337. doi: 10.1002/gps.2343

Gubrium, J. (1975). *Living and dying in Murray Manor*. New York, NY: St. Martin's Press.

Haesler, E., Bauer, M., & Nay, R. (2007). Factors associated with constructive staff–family relationships in the care of older adults in the institutional setting. *International Journal of Evidence-Based Healthcare*, *4*(4), 288–336. doi: 10.1111/j.1479-6988.2006.00053.x

Halcomb, E. J., Griffiths, R., & Sheperd, B. M. (2009). Perceptions of multidisciplinary case conferencing in residential aged care facilities. *Australian Health Review*, *33*(4), 566–571. Retrieved from http://www.publish.csiro.au/AH/AH090566

Hansen, L., Archbold, P., Stewart, B., Westfall, U. B., & Ganzini, L. (2005). Family caregivers making life-sustaining treatment decisions: Factors associated with role strain and ease. *Journal of Gerontological Nursing*, *31*(11), 28–35. Retrieved from https://www.healio.com/nursing/journals/jgn/2005-11-31-11/%7B30cf42fd-055e-41da-bec2-497260382734%7D/family-caregivers-making-life-sustaining-treatment-decisions-factors-associated-with-role-strain-and-ease

Henderson, J. (1995). The culture of care in a nursing home: Effects of a medicalized model of long term care. In M. Vesperi & J. Henderson (Eds.), *The culture of long term care: Nursing home ethnography* (pp. 37–54). Westport, CT: Bergin & Garvey.

Hennings, J., Froggatt, K., & Keady, J. (2010). Approaching the end of life and dying with dementia in care homes: The accounts of family carers. *Reviews in Clinical Gerontology*, *20*(2), 114–127. doi: 10.1017/S0959259810000092

Hirdes, J. P., Mitchell, L., Maxwell, C. J., & White, N. (2011). Beyond the 'iron lungs of gerontology': Using evidence to shape the future of nursing homes in Canada. *Canadian Journal on Aging*, *30*(3), 371–390. doi: 10.1017/S0714980811000304

Ho, A., Jameson, K., & Pavlish, C. (2016). An exploratory study of interprofessional collaboration in end-of-life decision-making beyond palliative care settings. *Journal of Interprofessional Care*, *30*(6), 795–803. doi: 10.1080/13561820.2016.1203765

Kaasalainen, S., Brazil, K., Ploeg, J., & Martin, L. S. (2007). Nurses' perceptions around providing palliative care for long-term care residents with dementia. *Journal of Palliative Care*, *23*(3), 173–183. Retrieved from http://search.proquest.com/openview/c2b6d7ac4427cc6e09d587ec8544f5b6/1?pq-origsite=gscholar

Kaasalainen, S., Sussman, T., Bui, M., Akhtar-Danesh, N., Laporte, R. D., McCleary, L., … SPA/LTCH Team. (2017). What are the differences among occupational groups related to their palliative care-specific educational needs and intensity of interprofessional collaboration in long-term care homes? *BMC Palliative Care*, *16*(1), 33–38. doi: 10.1186/s12904-017-0207-y

Kaasalainen, S., Williams, J., Hadistavropoulos, T., Thorpe, L., Whiting, S., Neville, S., & Tremeer, J. (2010). Creating bridges between researchers and long-term care homes to promote quality of life for residents. *Qualitative Health Research*, *20*(12), 1689–1704.

Kitwood, T. (1997). *Dementia reconsidered*. London, ENG: Jessica Kingsley.

Kelley, M., & McKee, M. (2012). Capacity development in participatory action research. In J. Hockley, K. Froggatt, & R. Heimell (Eds.), *Participatory action research in palliative care*. Oxford, ENG: Oxford University Press.

Kontos, P. C., Miller, K.-L., & Mitchell, G. J. (2010). Neglecting the importance of the decision making and care regimes of personal support workers: A critique of standardization of care planning through the RAI/MDS. *The Gerontologist*, *50*(3), 352–62. doi: 10.1093/geront/gnp165

Kontos, P. C., & Naglie, G. (2009). Tacit knowledge of caring and embodied selfhood. *Sociology of Health & Illness*, *31*(5), 688–704. doi: 10.1111/j.1467-9566.2009.01158.x

Laging, B., Ford, R., Bauer, M., & Nay, R. (2015). A meta-synthesis of factors influencing nursing home staff decisions to transfer residents to hospital. *Journal of Advanced Nursing*, *71*(10), 2224–2236. doi: 10.1111/jan.12652

Lambert, S. D., & Loiselle, C. G. (2008). Combining individual interviews and focus groups to enhance data richness. *Journal of Advanced Nursing*, *62*(2), 228–237. doi: 10.1111/j.1365-2648.2007.04559.x

Lofland, J., Snow, D., Anderson, L., & Lofland, L. (2006). *Analyzing social settings: A guide to qualitative observation and analysis* (4th ed.). Toronto, ON: Thomson, Wadsworth.

Lopez, R. (2007). Suffering and dying nursing home residents: Nurses' perceptions of the role of family members. *Journal of Hospice and Palliative Care*, *9*(3), 141–149. doi: 10.1097/01.NJH.0000269994.21249.f6

Lopez, R. P. (2009). Decision-making for acutely ill nursing home residents: Nurses in the middle. *Journal of Advanced Nursing*, *65*(5), 1001–1009. doi: 10.1111/j.1365-2648.2008.04958.x

Lord, K., Livingston, G., & Cooper, C. (2015). A systematic review of barriers and facilitators to and interventions for proxy decision-making by family carers of people with dementia. *International Psychogeriatrics*, *27*(8), 1301–1312. doi: 10.1017/S1041610215000411

Ministry of Health and Long-Term Care. (2007). A guide to the long-term care homes act, 2007 and regulation 79/10. Retrieved from http://www.health.gov.on.ca/en/public/programs/ltc/docs/ltcha_guide_phase1.pdf

Mitchell, S. L., Teno, J. M., Kiely, D. K., Shaffer, M. L., Jones, R. N., Prigerson, H. G., … Hamel, M. B. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine*, *361*(16), 1529–1538. doi: http://dx.doi.org/10.1056/NEJMoa0902234

Morse, J. M. (2015). "Data were saturated …" [Editorial]. *Qualitative Health Research*, *25*, 587–588. doi: 10.1177/1049732315576699

Munn, J. C., Dobbs, D., Meier, A., Williams, C. S., Biloa, H., & Zimmerman, S. (2008). The end-of-life experience in long-term care: Five themes identified from focus groups with residents, family members and staff. *The Gerontologist*, *48*(4), 485–494. https://academic.oup.com/gerontologist/article/48/4/485/618627

O'Connor, D., & Purves, B. (2009). Decision-making, personhood and dementia: Mapping the terrain. In D. O'Connor & B. Purves (Eds.), *Decision-making, personhood and dementia: Exploring the interface* (pp. 11–22). London, ENG: Jessica Kingsley.

Pallium Canada. (2018). *LEAP core course for health professionals*. Retrieved from https://pallium.ca

Pesut, B., McLeod, B., Hole, R., & Dalhuisen, M. (2012). Rural nursing and quality end-of-life care: Palliative care … palliative approach … or somewhere in-between? *Advances in Nursing Science*, *35*(4), 288–304. doi: 10.1097/ANS.0b013e31826b8687

Petriwskyj, A., Gibson, A., Parker, D., Banks, S., Andrews, S., & Robinson, A. (2014). Family involvement in decision making for people with dementia in residential aged care: A systematic review of quantitative literature. *International Journal of Evidence-Based Healthcare*, *12*(2), 64–86. doi: 10.1097/XEB.0000000000000003

Ramsbottom, K., & Kelley, M. (2014). Developing strategies to improve advance care planning in long term care homes: Giving voice to residents and their family members. *International Journal of Palliative Care, 2014*, Article 358457. doi: http://dx.doi.org/10.1155/2014/358457

Reimer-Kirkham, S., Sawatzky, R., Roberts, D., Cochrane, M., & Stajduhar, K. (2016). 'Close to' a palliative approach: Nurses' and care aides' descriptions of caring for people with advancing chronic life-limiting conditions. *Journal of Clinical Nursing*, *25*(15–16), 2189–2199. doi: 10.1111/jocn.13256

Robinson, C., Bottorff, J., Lilly, M., Reid, C., Abel, S., Lo, M., & Cummings, G. (2012). Stakeholder perspectives on transitions of nursing home residents to hospital emergency departments and back in two Canadian provinces. *Journal of Aging Studies*, *26*(4), 419–427. doi: 10.1016/j.jaging.2012.06.001

Robinson, L., Dickinson, C., Rousseau, N., Beyer, F., Clark, A., Hughes, J., … Exley, C. (2012). A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. *Age and Ageing*, *41*, 263–269. doi: 10.1093/ageing/afr148

Ryan, T., Nolan, M., Reid, D., & Enderby, P. (2008). Using the senses framework to achieve relationship-centred dementia care services: A case example. *Dementia*, *7*(1), 71+. Retrieved from https://doi.org/10.1177/1471301207085368

Sabat, S. R. (2005). Capacity for decision-making in Alzheimer's disease: Selfhood, positioning and semiotic people. *Australian and New Zealand Journal of Psychiatry*, *39*(11–12), 1030–1035. doi: 10.1080/j.1440-1614.2005.01722.x

Sawatzky, R., Porterfield, P., Lee, J., Dixon, D., Lounsbury, K., Pesut, B., … Stajduhar, K. (2016). Conceptual foundations of a palliative approach. *BMC Palliative Care*, *15*(5). doi: 10.1186/s12904-016-0076-9

Sawatzky, R., Porterfield, P., Roberts, D., Lee, J., Liang, L., Reimer-Kirkham, S., … Thorne, S. (2017). Embedding a palliative approach in nursing care delivery: An integrated knowledge synthesis. *Advances in Nursing Science*, *40*(3), 263–279. doi: 10.1097/ANS.0000000000000163

Small, N., Froggatt, K., & Downs, M. (2007). *Living and dying with dementia: Dialogues about palliative care*. Oxford, ENG: Oxford University Press.

Sims-Gould, J., Wiersma, E., Arseneau, L., Kelley, M. L., Kozak, J., Habjan, S., & MacLean, M. (2010). Care provider perspectives on end-of-life care in long-term-care homes: Implications for whole-person and palliative care. *Journal of Palliative Care*, *26*(2), 122–129. Retrieved from http://www.palliativealliance.ca/assets/files/Presentations/Article-4-Sims-Gould-Wiersma-et-al-Whole-Person-Care-1.pdfh

Syme, C. (2011). *Organizing transitions in palliative care: Outside/inside cancer systems* [Doctoral dissertation]. University of Victoria, British Columbia. Retrieved from http://dspace.library.uvic.ca:8080/bitstream/handle/1828/3398/Dissertation%20Syme%20V00124834%20Final.pdf?sequence=1&isAllowed=y

Thompson, G., & Roger, K. (2014). Understanding the needs of family caregivers of older adults dying with dementia. *Palliative and Supportive Care*, *12*(3), 223–231. doi: 10.1017/S1478951513000461

Thorne, S. (2008). *Interpretive descriptive*. Walnut Creek, CA: Left Coast Press Inc.

Thuné-Boyle, I., Sampson, E., Jones, L., King, M., Lee, D., & Blanchard, M. (2010). Challenges to improving end of life care of people with advanced dementia in the UK. *Dementia*, *9*(2), 259–284. doi: 10.1177/1471301209354026

Toscani, F., van der Steen, J., Finetti, S., Giunco, F., Pettenati, F., Villani, D., ... Di Giulio, P. (2015). Critical decisions for older people with advanced dementia: A prospective study in long-term institutions and district home care. *Journal of the American Medical Directors Association*, *16*(6), 535–e13. doi: 10.1016/j.jamda.2015.02.012. Epub 2015 Apr 2.

van der Steen, J., Radbruch, L., Hertogh, C., de Boer, M. Huges, J., Larkin, P., … Volicer, L. (2014). White paper defining optimal palliative care in older people with dementia: A delphi study and recommendations from the European Association for Palliative Care. *Palliative Medicine*, *28*(3), 197–209. doi: 1177/0269216313493685

Ward-Griffin, C., Bol, N., Hay, K., & Dashnay, I. (2003). Relationships between families and registered nurses in long-term-care facilities: A critical analysis. *Canadian Journal of Nursing Research*, *35*(4), 150–174. Retrieved from http://cjnr.archive.mcgill.ca/article/viewFile/1863/1857

Waskiewich, S., Funk, L., & Stajduhar, K. (2012). End of life in residential care from the perspective of care aides. *Canadian Journal on Aging*, *31*(4), 411–421. doi: 10.1017/S0714980812000360

Watts, T. (2011). Initiating end-of-life care pathways: A discussion paper. *Journal of Advanced Nursing*, *68*(10), 2359–2370. doi: 10.1111/j.1365-2648.2011.05924.x

Wiersma, E., & Dupuis, S. L. (2010). Becoming institutional bodies: Socialization into a long-term care home. *Journal of Aging Studies*, *24*(4), 278–291. doi: 10.1016/j.jaging.2010.08.003

World Health Organization. (2011). WHO definition of palliative care. Retrieved from http://www.who.int/cancer/palliative/definition/en/