

Broadening End-of-Life Comfort to Improve Palliative Care Practices in Long Term Care

Tamara Sussman,¹ Sharon Kaasalainen,² Susan Mintzberg,¹ Shane Sinclair,³ Laurel Young,⁴ Jenny Ploeg,² Valérie Bourgeois-Guérin,⁵ Genevieve Thompson,⁶ Lorraine Venturato,³ Marie Earl,⁷ Patricia Strachan,² John J. You,⁸ Robin Bonifas,⁹ and Margaret McKee¹⁰

RÉSUMÉ

Cette étude qualitative canadienne rapporte les résultats de 19 groupes de discussion comprenant 117 participants, incluant des bénéficiaires, des familles et des membres du personnel. Elle avait pour objectifs : 1) d'explorer les soins palliatifs offerts en soins de longue durée (SLD) en vue de faire face aux tensions associées à la prestation de soins aux personnes qui sont encore bien vivantes et celles en fin de vie dans une même communauté de soins et 2) d'identifier des améliorations qui pourraient être apportées aux pratiques en soins palliatifs afin de mieux répondre aux besoins de tous les bénéficiaires en vie ou mourants dans les établissements de SLD, ainsi que celles des familles et du personnel qui leur apportent du soutien. Notre étude a montré que les perspectives liées au confort en fin de vie du personnel en SLD, celles des bénéficiaires et de leurs familles étaient appliquées à ceux qui se trouvaient en fin de vie ou aux familles qui les soutenaient. Cette compréhension du confort limitait l'intégration des principes de soins palliatifs lors des derniers jours de vie des bénéficiaires. Les résultats de notre étude ont aussi suggéré que le fait de recueillir les perceptions des bénéficiaires liées au confort en fin de vie, de partager l'information à propos de la mort d'un bénéficiaire d'une manière plus personnelle, et de s'assurer que les bénéficiaires, leurs familles et le personnel aient des occasions de participer dans les soins de confort pour les bénéficiaires mourants pouvaient accroître le confort en fin de vie et soutenir une plus grande intégration des principes de soins palliatifs en SLD.

ABSTRACT

This study aimed to (1) explore how palliative care in long-term care (LTC) addresses the tensions associated with caring for the living and dying within one care community, and (2) to inform how palliative care practices may be improved to better address the needs of all residents living and dying in LTC as well as those of the families and support staff. This article reports findings from 19 focus groups and 117 participants. Study findings reveal that LTC home staff, resident, and family perspectives of end-of-life comfort applied to those who were actively dying and to their families. Our findings further suggest that eliciting residents' perceptions of end-of-life comfort, sharing information about a fellow resident's death more personally, and ensuring that residents, families, and staff can constructively participate in providing comfort care to dying residents could extend the purview of end-of-life comfort and support expanded integration of palliative principles within LTC.

¹ School of Social Work, McGill University

² School of Nursing, McMaster University

³ Faculty of Nursing, University of Calgary

⁴ Department of Creative Arts Therapies, Concordia University

⁵ Department of Psychology, Université du Québec à Montréal

⁶ College of Nursing, University of Manitoba

⁷ School of Physiotherapy, Dalhousie University

⁸ Departments of Medicine, Health Research Methods, Evidence and Impact, McMaster University

⁹ School of Social Work, Arizona State University

¹⁰ School of Social Work, Lakehead University

Manuscript received: / manuscrit reçu : 20/07/16

Manuscript accepted: / manuscrit accepté : 20/12/16

Mots clés : vieillissement, fin de vie, soins de longue durée, soins palliatifs

Keywords: aging, end of life, long-term care, palliative care

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

Tamara Sussman, MSW, Ph.D.
Associate Professor
School of Social Work
McGill University
3506 University, Room 305
Montreal QC H3A 2A7
<tamara.sussman@mcgill.ca>

Seventy per cent of residents living in long term care (LTC) die after months or years of residency (Menec, Nowicki, Blandford, & Veselyuk, 2009; McGregor, Tate, Ronald, & McGrail, 2007; Morin, Johnell, & Aubry, 2015). Yet the majority of residents do not enter LTC homes with the primary goal of receiving end-of-life care, and most would prefer to live elsewhere as a result of long-standing stigmas associating LTC with neglect, deterioration of health, and death (Goodman, Amador, Elmore, Machen, & Mathie, 2013). Families likewise choose LTC for reasons other than palliative care and often experience guilt when electing to relocate their relative to what is considered a less desirable option than community care (Sussman & Dupuis, 2012). These realities present LTC home residents, their families, and staff with the challenge of trying to focus on quality living while also preparing for and supporting quality dying (Caouette, 2005; Kinley, Froggatt, & Bennett, 2013; Leggett, Davies, Hiskey, & Erskin, 2011).

Given the unique context of LTC, an international literature is emerging documenting the obstacles and opportunities associated with the provision of palliative (end-of-life) care alongside restorative (rehabilitative) care in LTC (see, for example, Bollig, Gjengedal, & Rosland, 2016 [Norway]; Pleschberger, 2007 [Norway]; Glass, 2016 [U.S.]; Goodman et al., 2013 [U.K.]; Mathie et al., 2011 [U.K.]). Challenges noted include complexities related to unpredictable dying trajectories, lack of palliative care knowledge or skills among staff, workload demands, and apprehensiveness in talking about dying (Brazil et al., 2004; Johnson & Bott, 2016; Parker Oliver, Porock, & Oliver, 2006; Seymour, Kumar, & Froggatt, 2011; Sims-Gould et al., 2010). Yet much of the empirical work and subsequent practice recommendations to date have been based on staff perceptions and experiences (Brazil, et al., 2004; Cartwright, Miller, & Volpin 2009; Reynolds, Henderson, Schulman, & Hanson, 2002; Johnson & Bott, 2016; Kaasalainen, Brazil, Ploeg, & Martin, 2007; Parker Oliver et al., 2006; Seymour et al., 2011; Sims-Gould et al., 2010; Waldrop & Kirkendall, 2009) with far fewer studies exploring the perspectives of families (Glass, 2016; De Roo et al., 2015; van Soest-Poortvliet et al., 2015; Waldrop & Kusmaul, 2011) and residents (Mathie et al., 2011; Ng,

Cheong, Raj, Teo, & Leong, 2016; Goodman et al., 2013; Bollig et al., 2016). This gap is most notable in Canada where only one study could be located that captures residents' and families' views – alongside those of staff in LTC – on death, dying, and end-of-life care (Cable-Williams & Wilson, 2014). Consequently, we know relatively little about how the recommendations purported to improve practice complement the needs and experiences of residents living and dying in LTC and the families that support them.

As a subset of a larger Canadian study aimed at strengthening a palliative approach to care in LTC, this article reports findings from a series of focus groups with staff, families, and residents intended to (1) explore how palliative care in LTC is currently being realized to address the tensions associated with caring for the living and dying within one care community, and (2) explain how palliative care practices may be improved to better address the needs of all residents living and dying in LTC as well as those of the families and staff that support them.

Background

According to the World Health Organization (2011), palliative care is a philosophy of care that (1) affirms life and regards death as a normal process; (2) intends neither to hasten nor postpone death; and (3) should begin to guide practice from the time of diagnosis of any life-limiting illness for which there is no cure. The Canadian Hospice Palliative Care Association (2002) has further suggested that palliative care is whole-person care that aims to relieve physical, social, psychological, and spiritual suffering for dying individuals and the families that support them, from the time of diagnosis and into bereavement care.

A number of national and international organisations advocate that palliative care should be integrated into practice in LTC home settings because most residents are living with multiple co-morbidities for which there is no cure, and death is a common event in LTC (National Health and Medical Research Council, Australian Palliative Residential Aged Care [APRAC] Project Team, 2006; Canadian Hospice Palliative Care Association,

2002; World Health Organization, 2011; National Gold Standards Framework, 2012). Yet most LTC home administrators and staff continue to struggle with how and when to use palliative principles to guide practice including when to initiate open communication about end-of-life wishes and preferences, how to identify transitions from living to dying, when to shift goals of care from restorative to palliative, and how to appropriately record and share information about death with other residents, families, and staff (Bollig et al., 2016; Cable-Williams, & Wilson, 2014; Froggatt, Hockley, Parker, & Brazil, 2011; Johnson & Bott, 2016; Mathie et al., 2011).

The few studies focused on residents' and families' perceptions of death and dying within LTC further illuminate the challenges staff face when implementing palliative care principles from the time a resident relocates to LTC. More specifically, findings suggest that residents and families are hesitant to speak of end-of-life care issues, tending instead to be more focused on living in the present (Bollig et al., 2016; Goodman et al., 2013; Mathie et al., 2011). Hesitations include divergent cultural beliefs, personal preferences, and a propensity to protect one another from difficult conversations. This poses barriers to treating death as a normative process and to initiating discussions with residents and families around end-of-life wishes and care preferences.

Perhaps as a consequence, activation of palliative care principles in LTC appear to be delayed to the final days of life, deferring the initiation of comfort measures that may (a) help to maximize each person's potential for quality of life throughout the full duration of their dying process (Cable-Williams & Wilson, 2014); (b) support a peaceful death (De Roo et al., 2015); and (c) contribute to family satisfaction with end-of-life care (Thompson, McClement, Menec, & Chochinov, 2012; van Soest-Poortvliet et al., 2015). As the population ages, particularly among those aged 80 years and older, the prevalence of relocation to LTC is expected to increase dramatically (Summerfield & Babb, 2004; Banerjee, 2009). Within this context, LTC homes will likely become a primary location of death for older adults in an advanced age (World Health Organization, 2010). Examining how palliative care principles can best be integrated in this unique care environment is, therefore, a pressing issue for most Western industrialized countries facing these significant demographic shifts. It is particularly pressing in the context of Canada where national palliative care guidelines have not been developed, hospice services are rarely if ever available within LTC, and the perspectives of residents and families have exerted a limited influence on the literature which have instead focused heavily on challenges identified by staff (Brazil et al., 2004; Froggatt et al., 2011; Sims-Gould et al., 2010).

Study Aim and Questions

The aim of this qualitative study was to inform how palliative care principles can be used to enhance end-of-life practices in LTC and ultimately improve the care experience for all residents living and dying in LTC and the families and staff that support them. To this end, the current study sought to answer the following research questions: (1) how do staff, residents, and families currently understand and experience palliative care in LTC? and, (2) how might current understandings and experiences of palliative care be adapted to address the needs of all residents living and dying in LTC, and those of the families and staff that support them?

Methods

We selected focus groups for data collection for both methodological and practical reasons. Methodologically, focus groups are ideal when a study aims to uncover the perceptions, ideas, and experiences of participants, particularly when addressing sensitive topics, since participants can help one another open up, elaborate, and reflect. Through group interaction, focus groups tap into various forms of communication (dialogue, laughter, body language, empathy, etc.) and allow outgoing participants to break the ice for those who might normally be more shy or unresponsive (Krueger & Casey, 2000; Kitzinger, 1995). Pragmatically, focus groups allow for the collection of data, from large numbers of participants, in a timely manner in comparison to one-on-one interviews.

A qualitative methodology informed by the analytic principles of grounded theory was employed to meet the study's aims. Qualitative methods are ideal when seeking to uncover what lies behind complex phenomena such as personal experiences of palliative care (Patton, 2002). The analytic principles of grounded theory are founded in the constant comparative method. This approach to analysis encourages comparisons both within the data and with other related empirical and theoretical work so that conceptualizations can be developed, expanded, or modified (Corbin & Strauss, 2008; Glaser & Strauss, 1967; Strauss & Corbin, 1998). As already mentioned, some conceptualizations of palliative care exist, but challenges have been noted in putting these principles into practice within an LTC home setting (Brazil et al., 2004; Froggatt et al., 2011; Sims-Gould et al., 2010). Engaging in an analysis of current practices, in light of these conceptualizations (e.g., the importance of early and ongoing intervention that is adapted as the dying process unfolds, viewing death as a normative process, addressing bereavement) could help to optimize and identify targeted time points for practices to be implemented, thereby improving

the quality of living and dying for residents as well as the end-of life experience and bereavement of families. Such an analysis would also better equip the staff that support the dying and their families.

Site Selection and Recruitment

We recruited participants from four LTC homes in southern Ontario, Canada, purposefully selected to represent the mix of contexts found in LTC homes across Canada (Berta, Laporte, Zarnett, Valdmanis, & Anderson, 2006). More specifically, the homes represented a mix of for-profit (three) and not-for-profit (one) facilities; ranged in size from large (two; 169 and 206 beds), medium (one; 120 beds), and small (one; 60 beds); included contexts with high staff turnover (two), and low staff turnover (two); and comprising religious-based (one) and secular (three) facilities.

As with all LTC homes in Ontario, the facilities selected were all publicly regulated under the Ontario Long-Term Care Homes Act (2007) which recognizes palliative care as an important component of service delivery in LTC (Wahl, 2011). All homes in the study also had access to a palliative pain and symptom management consultation service, enacted by the Ontario Ministry of Health and Long-Term Care in 2007 to offer service providers consultation and education from a nurse practitioner with expertise in palliative care (Ontario Ministry of Health and Long-Term Care, 2007).

All partnering LTC homes were asked to recruit participants for five distinct focus groups: (1) residents with the cognitive ability to participate in a group discussion, (2) family members of current residents, (3) personal support workers (i.e., care aides or nursing aides), (4) support staff (e.g., kitchen staff, cleaning staff, activation aides), and (5) regulated health professionals (e.g., nurses, physiotherapists, dieticians, social workers). We opted to separate staff into three distinct groups to acknowledge the differential roles they play in LTC, and to optimize comfort in sharing perceptions and experiences (Hanson, Henderson, & Menon, 2002).

All staff, current families, and residents with capacity to take part in a 60-to-90-minute focus group discussion were eligible to participate. Recruitment strategies included sending emails to families and staff; posting flyers within the care homes; making announcements at staff and programming meetings; and placing sign-up boards in a visible part of the homes so that individuals could directly sign up for a group. For resident groups, staff encouraged residents with known capacity to participate. Administrative staff endorsed the project and permitted staff focus groups to be scheduled during paid working hours.

Data Collection

The focus groups were held for approximately 60–90 minutes at study sites and were each co-facilitated by two members of the research team. Focus groups were conducted in the spring of 2015. A semi-structured interview guide was developed to guide focus group discussions. Building on the literature, the guide was designed to elicit participants' views on palliative care in general (what it is and should be), and experiences with palliative care within the facilities. The interview guide was circulated to all members of the research team to ensure that the questions were clear and relevant to the stated objectives. Minor alterations were made based on team members' recommendations.

Written consent was obtained for all participants prior to conducting each focus group. For residents, all facilitators devoted 20 minutes to a detailed discussion about the purpose of the focus groups, the voluntary nature of participation, and the areas that would be explored during focus group discussions. This provided facilitators (who were all trained health practitioners) with additional reassurance that all residents present understood the meaning of their participation. Willingness and physical/cognitive capacity to participate were also monitored during the focus group discussions by ensuring that residents were following and contributing to discussions (Brown Wilson, 2011).

We conducted the research in accordance with the standards of the *Tri-Council Policy Statement for Ethical Conduct for Research Involving Humans* 1998 (with 2000, 2002, and 2005 amendments). Procedures were approved by the Office of Research Ethics Board at McGill University and McMaster University.

Data Analysis

Consistent with grounded theory, we used the constant comparative method of analysis to interpret the data in four stages (Corbin & Strauss, 2008; Strauss & Corbin, 1998). In the first stage of open coding, each focus group transcript was examined by a team of two researchers (TS and SM) for ideas and observations that were treated independently from one another and noted in the margins of the text. The researchers also began memo writing and exchanging observations to discuss initial possibilities for linking ideas together. For example, it was noted at this first stage that resident participants across groups consistently appeared to express surprise when asked to discuss their perceptions of good end-of-life care. The researchers noted this observation and wondered what it said about communication and end-of-life care in LTC from the perspective of all stakeholder groups.

In the second stage of axial coding, all initial ideas and observations were re-examined by the two researchers who attempted to determine their meaning based on other evidence included within and across transcripts. Memo writing and discussions continued to guide analysis. At this stage, initial observations were turned into preliminary descriptive and interpretive categories such as (1) conceptualizations of palliative care across groups, (2) communication about death and dying, and (3) the unique features of LTC.

In the third stage of selective coding, and through continued exchange and discussion by the two researchers, the core category end-of-life comfort emerged as it seemed to underlie how palliative care was understood and experienced by multiple stakeholders and to connect ideas expressed within and between preliminary categories (Hallberg, 2006). At this stage, for example, it was noted that conceptualizations of palliative care were consistently understood to be about the provision of comfort at end-of-life (a pattern between transcripts) and appeared to shape when and how communication about death and dying was initiated (a connection between preliminary categories). Following the emergence of this core idea, coding focused on (1) properties that stakeholders ascribed to end-of-life comfort; (2) factors that supported or hindered end-of-life comfort; (3) the relationship between end-of-life comfort and other ideas expressed by participants; and (4) how end-of-life comfort connected to the phases of palliative care described in the literature.

In the fourth and final stage of the analytic process, the full research team reviewed categories, emerging themes, and verbatim excerpts. Members of the team confirmed the “fitness” (applicability), “generality” (applicability in multiple situations and LTC settings), and “understanding” or “workability” (accessibility) between the themes evolving from the study, evidence in the transcripts, and their own knowledge of palliative care practice in an LTC environment (Glaser & Strauss, 1967; Cutcliffe, 2005).

Participants

A total of 117 individuals in 19 focus groups across four study sites participated in this study: 20 residents, 16 family members, and 81 staff. Resident participants were predominantly aged 75 years and older (15/20; 75%), resided in LTC for at least one year (15/20; 75%), and had known at least one other resident who had died within the past year (13/20; 65%). Family participants were predominantly aged 55 and older (12/16; 75%), were primarily either adult children (8/16; 50%) or spouses (4/16; 25%), and had supported a relative in LTC for an average of 6 years (ranging from 4 months to 12 years). Half (8/16; 50%) of the family participants

had known someone who had died in LTC. Staff participants included nursing aides (32/81; 40%), registered nurses (22/81; 27%), support workers (19/81; 23%), and other regulated health professionals (8/81; 10%), with an average of 10 years' work experience (ranging from 6 months to 32 years) in LTC across professions.

Findings

End-of-Life Comfort: Central Feature of Current Palliative Care Practice

Participants in all focus groups spoke of palliative care as a practice centred on providing comfort to dying residents and their families. One participant who was asked to define their understanding of palliative care stated “it is comfort care towards the end of your life” (Support Staff, Site 3). Another participant affirming these views stated that palliative care is “end-of-life care focused on comfort and support” (Nurse, Site 4). Families echoed this view: “... palliative to me is very close to hospice, you know – death. What we're doing for comfort measures, just as they are dying” (Family Member, Site 4).

Comfort was viewed by most participants as a multi-faceted concept and included attention to physical, social/emotional, spiritual, and environmental factors such as pain and symptom management, frequent check-ins, and creating a calm and peaceful environment. One resident emphasizing the importance of end-of-life physical care commended staff for providing good palliative care to her roommate. She stated, “They were just looking after her, making her comfortable. ... they gave her morphine ...” (Resident, Site 2). A nurse emphasizing the importance of personal presence and attention said,

When somebody is on palliative [care] we always, always try to give more attention to this resident, because sometimes we just pass by the room and you see them, the resident's alone, and I think when someone's on palliative, somebody should be there to comfort them. (Nurse, Site 2)

When families were present, staff viewed their role as providing comfort to them by offering access to food and drink so that they did not need to leave the premises; flexibility in visiting hours; a private room (if available) to allow families to sleep onsite, if desired; and care and support so that they could be present for their dying relative. Families who had witnessed this type of support also emphasized how meaningful these actions taken by staff were. As one family member stated,

Now what I have noticed is that when someone does pass or is very, very ill, there are a lot of kind

things that are done. There's a trolley that's brought in with coffee and tea for the family member ... you know, they have comfortable chairs and things. So you can be by the bedside, so I think some of that is nice. And they are very respectful." (Family Member, Group 4)

In sum, participants in all focus groups considered comfort to be a central component of a palliative approach. The idea of comfort encompassed physical, emotional, spiritual, and environmental features. Comfort became the focus of care during the final days of a resident's life, and was seen as relevant for both residents who were dying and the families that were supporting them.

Conversing about End-of-Life Comfort: Missed Opportunities

Although end-of-life comfort was described as a central feature of palliative care in LTC, honest discussions about residents' perceptions of end-of-life comfort did not appear to be part of routine clinical practice. Although most resident-focus-group participants had witnessed, or been present for, the death of a fellow resident, they seemed perplexed, uncertain, and even surprised at being asked about their preferences for end-of-life care. Comments such as "I never thought about that", "I just don't really know what happens or anything" (Resident, Group 1), and "Oh. I haven't thought of dying" (Resident, Group 2) prevailed, suggesting that these types of discussions were rare and, for many, occurring for the first time while in these focus groups.

Staff comments affirmed that direct discussions about end-of-life care with residents were unusual. When making decisions about the type of end-of-life care that would be most comforting to residents, staff tended to rely on their professional instincts, their familiarity with residents, and/or the families' preferences. Describing how they determine what is comforting to each dying resident, staff shared different observations:

I just use my common sense, and if they were in pain or uncomfortable with what I was doing, you know, I would stop. (Nurse, Site 2)

We carry out the things that we know that they would wish, or that the family wishes. (Nursing Aide, Group 1)

Okay, I know they like this [kind of music] and they like that kind of activity, so using that knowledge, [I ask], what can I do now to make them comfortable?" (Support Staff, Site 3)

Interestingly, when residents began to discuss personal views of comfort in the context of focus group

deliberations, divergent perceptions emerged. One resident, for example, highlighted that frequent visitation may not be perceived as comforting by all residents. Describing his feelings about the end-of-life care that his roommate received, he stated, "I wouldn't want that kind of crap, knocking on doors, wondering if someone is dead, I would just want to be left alone without people running in and out" (Resident, Site 4). Another resident questioning whether she would want morphine at the end-of-life stated,

A month ago ... somebody died on my floor. And she had a hard time to die. And they gave her morphine. To die peacefully. I don't know if this is good or bad. I don't know. But I don't want that. (Resident, Site 2)

Hence, while providing comfort to dying residents and families was seen as the ultimate goal of palliative programs in LTC, residents were rarely offered opportunities to discuss what they may find comforting at end-of-life. It is noteworthy that most resident participants were able to articulate their personalized views of comfort when asked, and that their perceptions of comfort sometimes differed from those typically provided by staff. In discussing these perceptions, residents often referred to times when they had witnessed the end-of-life care of other residents. Seemingly, these experiences provided residents with the opportunity to reflect upon their own mortality and wishes for end-of-life care.

Questioning LTC Capacity to Provide End-of-Life Comfort

In the absence of opportunities to express personal wishes, and in the context of witnessing some deaths perceived as non-comforting, some residents worried about staff capacity or willingness to provide comfort at end-of-life. As one resident stated, "You haven't got any control over whether you suffer or not. The [staff] have the control over that. And when your time comes, you go ... If they want you to suffer, you suffer" (Resident, Site 2). Although this resident may eventually experience a comforting death, her remarks suggest that she is concerned about whether her end-of-life experience in LTC will be comforting, and whether she will have any capacity to exercise control over her own end-of-life care.

Another resident described her fear of her deceased body being left unattended should she die in LTC. Having seen this occur with the death of a fellow resident, she concluded that a hospital setting would provide a more dignified death. She explained, "When my husband died [in the hospital] they took him away right away in less than an hour. But over here [LTC] you could be lying around for twenty-four hours;

that's no good" (Resident, Group 3). Other resident participants in the group, who had witnessed these practices, affirmed that it was undignified to leave a dead body in a room unattended, and expressed fears that this could happen to them.

Although resident participants had little direct communication with staff about preferences or views on end-of-life comfort, many had witnessed care practices that either worried or reassured them. In the case of perceived non-comforting practices and in the absence of opportunities to communicate their fears, some resident participants questioned whether their dying process would be one of comfort.

Expanding End-of-Life Comfort: Support for Those Who Care for the Actively Dying

Being in a position to provide comfort to residents who were actively dying gave a sense of comfort to other residents, families, and staff. Conversely, conditions that hindered this capacity left residents, families, and staff with lingering thoughts and feelings about their inability to comfort the dying. For residents, conditions that increased their capacity to provide comfort to other dying residents included being able to visit good friends in the last days of life, and being given the opportunity to provide a roommate and their family with privacy. One resident, who was able to visit a good friend during his last days of life in LTC, stated,

I found that – we have recently lost a friend. And we first met him when we came here some time ago. We talked every night at dinner time and so forth. But I found it very comforting, and I think his wife did, too, that I was able to drop in almost every day and have a visit. And I would talk even though he was not aware. ... That helped me. (Resident, Site 4)

Another resident concurred with the importance of participating in a friend's end-of-life care. She stated:

When someone is dying here, it means that we can visit. If he was in the hospital, there's no way I was gonna go to the hospital to visit. So I think there's a lot of pluses in that way. (Resident, Site 2)

Having opportunities to offer privacy to dying residents and their families was also comforting to other residents, particularly those who were in a shared room. A resident who was offered the opportunity to leave her room during the very end stages of her roommate's life stated, "When the family came down I just got out of the room and let them be. I think [the staff] handled it very well" (Resident, Site 1). Another resident who was not offered the same opportunity expressed, "They never asked me to move out; it's very uncomfortable. They should have taken me out. It was terrible" (Resident, Site 3).

Staff experienced comfort when they were able to be physically and emotionally present for a dying resident, and could control the resident's pain or discomfort. One personal support worker who spoke of how good she felt providing emotional presence to a dying resident explained:

And one day I took her outside and wheeled her around in the sunshine. She was so happy. And two days – I went off and the following day I came back, she died. Yeah, so, that felt good to have done that for her. (Personal support worker, Site 1)

Conversely, staff experienced discomfort when they were not able to provide comfort to dying residents. As one nurse stated, "So, the same person who takes care of the thirty-two takes care of the palliative care. So, [sighs] any time when we have a palliative care [patient], our heart unfortunately is, um, aching" (Nurse, Site 1).

Common barriers to providing comfort included complex medical issues, heavy workloads, and family requests for interventions that staff perceived as being non-comforting to dying residents. Conditions to provide comfort included protocols that allowed staff to offer one-on-one comfort in the last days of life, and having palliative care experts readily available for complex medical needs. One nurse who did not have access to a palliative expert when needed said,

Like with [XXX] during her end-of-life care, she was very hungry. It would be nice if we had someone to turn to that could answer that question so she wasn't suffering so much near the end. She was always complaining of hunger, and we didn't know what to do. (Nurse, Site 3)

Creating conditions that allow staff and other residents to provide comfort to a dying resident was not only a helpful process for that resident, but also a comforting process for other residents, families, and staff. Conversely, an inability to comfort the dying could leave others feeling distressed which often had an enduring impact. Most had not had the opportunity to discuss their experiences and instead had to cope with their lingering thoughts and feelings on their own.

Honouring Death: A Form of Comfort

All LTC homes had some form of ritual to acknowledge the death of a resident such as posting obituaries, creating candle vigils in a central area of the home, and organizing monthly or quarterly memorials honouring all residents who had died. Although these rituals were formalized and regularly implemented, no protocols or guidelines were established to describe how to inform residents, staff, and families about the death of a resident after it had occurred. More typically, the

news of a death came to the attention of other residents, families, and even staff through indirect means such as via a bulletin board announcement, a new admission, seeing a body bag, or the sudden absence of a table mate at mealtime. When the news of a death came indirectly, the significance of the loss seemed diminished or unacknowledged. Conversely, when the news of a death and the circumstances surrounding it were personally and directly communicated, it had a positive impact.

One resident who described the importance of being informed about the death of a fellow resident stated,

I think they do pretty good. They know if you know the person they'll come and tell you. Exactly what time and how they were doing prior to that and if they were having a hard time, or if they were okay, you know. It's better than just thinking about them, you know? (Resident, Site 2)

Conversely, another resident expressed surprise when a roommate died and nobody came in to ask her what had happened. She stated, "I mean, nobody came and asked what, whether she died or why she died or anything else. They didn't come to the room. 'Cause I was in the room with her. It was as if nobody cared" (Resident, Site 1). It appeared that residents appreciated being told when a fellow resident died, not only because it acknowledged the loss of the person, but it also allowed them to vicariously feel assured that when they died, they, too, would be remembered.

Although staff sometimes described situations where a colleague called them on their days off if a resident they were close to had died, more often than not, they learned of deaths indirectly or were informed in passing, allowing little time to reflect, process, and mourn. One staff person described receiving this news indirectly as follows,

Yeah, it does come as a shock when you come to work and there's a little bulletin board that they put their names [on]. ... to honour the person who passed away. So once you get off the elevator you see and you're like, oh my goodness. (Support Staff, Site 3)

A compounding factor was that staff were expected to resume their duties, caring for other residents with little or no time to reflect on the loss of a resident with whom they may have had a close connection. As one staff person stated,

It's hard sometimes when somebody passes away. You have a day maybe to process it, and then there's somebody new in their bed. And then you have to start focusing on the new person, but depending on your relationship with the person that passed away, sometimes that can sit heavy with you, and it would be nice to be able to sit with

other people that cared for them and be like, "okay, let's talk about this." (Support Staff, Site 2)

Most staff suggested that an opportunity to re-group and acknowledge a death together could be very helpful and comforting in moving forward with the work and their grief. As one nurse stated,

The only part that I think somehow we could be lacking, for me anyways, is that soon after someone passes away we never actually regroup, and – you know. Because some people ... do get very close to the residents, and you'll see that they're really grieving. We don't seem to come together and regroup or give [ourselves] time to maybe talk about the resident. (Nurse, Site 3)

In sum, although most LTC homes acknowledged the death of a resident through a ritual, obituary, or ceremony, it was rare for staff, family, and residents to converse and reflect on the circumstances and meaning of a resident's death. In not providing such opportunities, participants felt that this could inadvertently minimize the significance of relationships formed, and diminish the impact of the death. Brief one-on-one or group debriefing aimed at sharing particularities about a resident's death, may help both staff and residents process and make meaning of the loss. For residents, openly acknowledging the death of a fellow resident could also serve as reassurance that they, too, will be valued and remembered following their own death.

Discussion: Broadening the Purview of Comfort to Improve Palliative Care Practices in LTC

Our study findings illuminate that LTC home staff, residents, and families viewed end-of-life comfort as a central feature of palliative care in LTC but considered comfort as a focus only when residents were actively dying. This understanding of comfort limited the integration of palliative care principles to the final days of residents' lives. Our study findings further suggest that eliciting residents' perceptions of end-of-life comfort, sharing information about a fellow resident's death in more personal ways, and ensuring that residents, families, and staff have opportunities to constructively participate in the provision of comfort care for dying residents, could extend the purview of end-of-life comfort, and support an expanded integration of palliative principles within LTC. The discussion that follows details how recognizing and supporting the comfort associated with *talking about* and *participating in* the provision of end-of-life care could enhance the care and caring experiences of all residents living and dying in LTC, and the families and staff that support them.

Eliciting Residents' Perceptions of End-of-Life Comfort

Providing end-of-life comfort to dying residents and their families was described as a central feature of palliative care in LTC. End-of-life comfort was portrayed as multidimensional and included managing residents' pain and symptoms; providing food, drink, and attention to families; ensuring an ongoing and frequent presence for dying residents; and creating a quiet and calming atmosphere for dying residents and the families that support them. These features of comfort are similar to those described elsewhere, and emphasize comfort as a concept that guides practice for both dying residents and the families that support them (Bern-Klug, 2009; Cable-Williams & Wilson, 2014; Waldrop & Kirkendall, 2009).

Because the framework of comfort in our study was confined to the final days of care, residents who were not actively dying were rarely, if ever, invited to share their personalized view of what they might consider to be comforting at end-of-life. This is particularly noteworthy considering that each of the resident participants not only found these discussions tolerable, but in many instances, therapeutic. The absence of such discussions left staff and families to rely on their own knowledge of residents' end-of-life care preferences rather than making an informed decision based on the resident's expressed wishes (Cartwright et al., 2009; Hanson et al., 2002). Although this approach seemingly allowed staff and families to protect residents from the ambivalence and uncertainty they may have felt discussing their own death, it also led to unexpressed views and wishes about end-of-life comfort (Bollig et al., 2016; Goodman et al., 2013) and left families with the burden of making inferences and decisions about what their relatives may find comforting (Bollig et al., 2016; De Roo et al., 2015; van Soest-Poortvliet et al., 2015).

Although end-of-life preferences were rarely discussed with residents who were not identified as actively dying, resident participants were able to express preferences for end-of-life comfort, particularly when they had observed fellow residents' end-of-life care. In some cases, these experiences led to concerns about non-comforting practices while, in other cases, these preferences diverged from those commonly considered by staff to be comforting for residents. For example, although staff considered their ongoing presence to be comforting to dying residents, some resident participants suggested they would not want this type of attention from staff in their final days of life. We therefore propose that staff encourage residents to talk about their observations of other residents' end-of-life care as a mechanism for learning about their views on their own end-of-life comfort. Talking indirectly with

residents about their personal views of death and dying by eliciting their observations of others' end-of-life care could address some of the key barriers noted in the literature around engaging in pro-active end-of-life discussions with residents. First, this fits with the normative tendencies described in the literature which suggest that some older adults in advanced age talk about death in an indirect rather than direct manner (Nicholson, Meyer, Flatley, Holman, & Lowton, 2012). Second, it empowers staff to talk openly about end-of-life care without the ambiguity of judging that a resident is approaching death and, therefore, must engage in such a discussion (Bern-Klug, 2006; Cable-Williams & Wilson, 2014).

Conditions that Comfort the Dying Also Appear to Comfort the Living

Findings from the focus groups indicated that providing comfort to dying residents was also comforting to other residents, families, and staff. Thus, conditions that fostered a capacity to provide comfort to the dying were extremely important to all. For example, residents who were given the opportunity to offer privacy to dying residents (by leaving a shared room for a few days), or to sit with them for their final days of life, described how these experiences provided them with the comfort of knowing they had supported a dignified death. Building on the work of others, these findings suggest that unnecessary hospitalizations at end-of-life and lack of access to private spaces may not only compromise quality care for the dying but also negatively impact those living among them in LTC (Brazil et al., 2004). These findings also suggest that processes and practices which engage willing residents in comforting someone dying in their care community could ensure the human presence considered so paramount to end-of-life comfort, and provide a sense of comfort to the residents attending to the dying individual. For example, creating a roster of resident volunteers interested in supporting dying residents without families (and who are interested in this form of support) through their presence may be one way of involving more residents to comfort the dying while prospectively assisting them to prepare for their own death. This is in stark contrast to current practice which seems to protect residents from witnessing dying by placing it "back stage", away from their view (Parker Oliver, Porock, & Oliver, 2006).

For staff, accessing palliative care expertise in complex situations and spending additional time with dying residents were seen as pivotal in supporting a comfortable death. In many cases these conditions were not readily available to staff, resulting in lingering feelings and regrets that were rarely, if ever, expressed or processed. Others have likewise suggested that systemic

resources (i.e., reducing staff workloads when a resident is dying on their floor) which provide staff with additional time to comfort dying residents are important to support a comprehensive palliative care program in LTC (Brazil et al., 2004; Sims-Gould et al., 2010). Our findings extend this view by noting that such time serves not only to improve workloads but also supports the relational aspects of care that acknowledge the benefits staff themselves may garner by actively participating in the provision of end-of-life comfort through personal presence (Cartwright et al., 2009; Parker Oliver et al., 2006, Sinclair, 2011).

Sharing Information about a Resident's Death

Acknowledging and openly discussing the death of a resident also served as a form of comfort to residents, families, and staff. The death of a resident felt acknowledged when information was shared about the death experience, or when people were informed directly that a resident had died. This form of personalized communication served to validate the significance of the relationships between staff and residents and to communicate to fellow residents that they were valued and would be honoured following their own death. This was in contrast to learning of a death indirectly through a bulletin board announcement or obituaries posted within the LTC home. Others have noted that systemic pressures, such as admitting new residents quickly after a death, hinder the process of recognizing death as a significant life event for all parties involved (Brazil et al., 2004) and dismiss the significant attachments staff can develop with residents (Pélissier et al., 2015). Our findings suggest that despite these organizational pressures, staff and residents found comfort and validation in speaking openly with one another about a resident's death.

Our findings further suggest that when end-of-life comfort was perceived to have been delivered, most staff and residents required little more than exchanging information and thoughts about the dying process. However, in cases of non-comforting endings, further debriefing and support would have been beneficial to all who were involved. This adds to a small but growing literature advocating for the implementation of bereavement supports for staff and residents following a death in LTC by suggesting when and under what circumstances more post-mortem support may be indicated (Temkin-Greener et al., 2015).

Strengths and Limitations

The findings from this study should be interpreted in light of five important limitations. First, although all cognitively able residents, families, and staff were invited to participate, the views reflected by those who

elected to participate may not have been shared by non-participants which could, in turn, affect the transferability of the results. To overcome this limitation, analysis of the data included constant comparisons between emergent themes and the existing literature on end-of-life care in LTC (Corbin & Strauss, 2008; Strauss & Corbin, 1998). Second, focus groups at each of the study sites were co-facilitated by two different members of the research team, resulting in a total of eight moderators. Given the variability in interviewing style, and facilitation experience among the moderators, the reliability (equivalence) of the data may have been affected (Kidd & Parshall, 2000). To address this threat to internal consistency, two researchers (TS and SM) oversaw the analysis of all transcribed data and field notes.

A third limitation is that all residents included in this study had the cognitive capacity to express their thoughts and ideas during focus group deliberations. This limits the transferability of findings to residents lacking this cognitive capacity. The results of this study may, therefore, be particularly pertinent for residents dying of illnesses other than dementia and the families that support them. Comforting residents with dementia at the end-of-life has been described as particularly challenging (Kaasalainen et al., 2007), and thus future work should examine how to best support staff, other residents, and families in providing comfort to residents with dementia. Fourth, the LTC homes wherein the research was conducted were all located in southern Ontario. Because health is legislated provincially in Canada, regional variations may exist. Future research would benefit from comparing the results emanating from this study with other localities across Canada. Finally, although the staff focus groups included strong representation from key stakeholders implicated in the provision of palliative care in LTC, no groups included the perceptions and experiences of physicians. Future research would also benefit from including physician perspectives whose views may differ from those expressed by other staff.

Conclusion

There is a growing recognition that palliative care principles should be integrated into LTC environments given the prevalence of death in these settings. Yet openly acknowledging death and dying has proven to be a difficult balance in many LTC settings. This research suggests that recognizing and supporting the comfort associated with talking about and participating in the provision of end-of-life care could extend the purview of comfort care beyond those individuals who are actively dying and benefit all those who care for, support, and co-exist with them.

References

- National Health and Medical Research Council, Australian Palliative Residential Aged Care (APRAC) Project Team. (2006). *The national palliative care program. Guidelines for a palliative approach in residential aged care*. (Enhanced version). Canberra, AUS: Australian Government Department of Health and Ageing, Commonwealth of Australia.
- Banerjee, A. (2009). *Long-term care in Canada. An overview*. In P. Armstrong, M. Boscoe, B. Clow, K. Grant, M. Haworth-Brockman, B. Jackson, A. Pederson, M. Seeley, & J. Springer (Eds.), *A place to call home: Long-term care in Canada* (Chapter 2, pp. 29–57). Halifax, NS: Fernwood.
- Bern-Klug, M. (2006). Calling the question of “possible dying” among nursing home residents: Triggers, barriers, and facilitators. *Journal of Social Work in End-of-Life & Palliative Care*, 2, 61–85.
- Bern-Klug, M. (2009). A framework for categorizing social interactions related to end-of-life care in nursing homes. *The Gerontologist*, 49(4), 295–507.
- Berta, W., Laporte, A., Zarnett, D., Valdmanis, V., & Anderson, G. (2006). A pan-Canadian perspective on institutional long-term care. *Health Policy*, 79(2–3), 175–194.
- Bollig, G., Gjengedal, E., & Rosland, J. H. (2016). They know!—Do they? A qualitative study of residents and relatives views on advance care planning, end-of-life care, and decision-making in nursing homes. *Palliative Medicine*, 30(5), 456–470.
- Brazil, K., McAiney, C., Caron-O’Brien, M., Kelley, M. L., O’Kafka, P., & Sturdy-Smith, C. (2004). Quality end-of-life care in long-term care facilities: Service providers’ perspective. *Journal of Palliative Care*, 20(2), 85–92.
- Brown Wilson, C. (2011). The value of reflexivity in resolving ethical dilemmas in care homes. *Journal of Advanced Nursing*, 67(9), 2068–2077.
- Cable-Williams, B., & Wilson, D. (2014). Awareness of impending death for residents of long-term care facilities. *International Journal of Older People Nursing*, 9(2), 169–179.
- Canadian Hospice Palliative Care Association (2002). *A model to guide hospice palliative care: Based on national principles and norms of practice*. Ottawa, ON: Author.
- Caouette, E. (2005). The image of nursing homes and its impact on the meaning of home for elders. In G. D. Rowles & H. Chaudhury (Eds.), *Home and identity in later life: International perspectives* (Chapter 12, pp. 251–275). New York, NY: Springer.
- Cartwright, J. C., Miller, L., & Volpin, M. (2009). Hospice in assisted living: Promoting good quality care at end of life. *The Gerontologist*, 49(4), 508–516.
- Corbin, J. M., & Strauss, A. (2008). *The basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Thousand Oaks, CA: Sage.
- Cutcliffe, J. (2005). Adapt or adopt: Developing and transgressing the methodological boundaries of grounded theory. *Journal of Advanced Nursing*, 51(4), 421–428.
- De Roo, M. L., Albers, G., Deliens, L., de Vet, H. C. W., Francke, A. L., Van Den Noortgate, N., & Van den Block, L. (2015). Physical and psychological distress are related to dying peacefully in residents with dementia in long-term care facilities. *Journal of Pain and Symptom Management*, 50(1), 1–8.
- Froggatt, K., Hockley, J., Parker, D., & Brazil, K. (2011). A system lifeworld perspective on dying in long term care settings for older people: Contested states in contested places. *Health & Place*, 17(1), 263–268.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine.
- Glass, A. P. (2016). Family caregiving and the site of care: Four narratives about end-of-life care for individuals with dementia. *Journal of Social Work in End-of-Life & Palliative Care*, 12(1–2), 23–46.
- Goodman, C., Amador, S., Elmore, N., Machen, I., & Mathie, E. (2013). Preferences and priorities for ongoing and end-of-life care: A qualitative study of older people with dementia resident in care homes. *International Journal of Nursing Studies*, 50(12), 1639–1647.
- Hallberg, L. R. M. (2006). The “core category” of grounded theory: Making constant comparisons. *International Journal of Qualitative Studies on Health and Well-Being*, 1(3), 141–148.
- Hanson, L. C., Henderson, M., & Menon, M. (2002). As individual as death itself: A focus group study of terminal care in nursing homes. *Journal of Palliative Medicine*, 5(1), 117–125.
- Johnson, S., & Bott, M. J. (2016). Communication with residents and families in nursing homes at the end of life. *Journal of Hospice & Palliative Nursing*, 18(2), 124–130.
- 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), 173–180.
- Kidd, P. S., & Parshall, M. B. (2000). Getting the focus and the group: Enhancing analytical rigor in focus group research. *Qualitative Health Research*, 10(3), 293–308.
- Kinley, J., Froggatt, K., & Bennett, M. I. (2013). The effect of policy on end-of-life care practice within nursing care homes: A systematic review. *Palliative Medicine*, 27(3), 209–220.
- Kitzinger, J. (1995). Qualitative research: Introducing focus groups. *British Medical Journal*, 311, 299–302.
- Krueger, R. A., & Casey, M. A. (2000). *Focus groups: A practical guide for applied researchers* (3rd ed.). Thousand Oaks, CA: Sage.
- Leggett, S., Davies, S., Hiskey, S., & Erskin, J. A. K. (2011). The psychological effects of considering a move into residential

- care: An age-related study. *Journal of Housing for the Elderly*, 25, 31–49.
- Mathie, E., Goodman, C., Crang, C., Froggatt, K., Iliffe, S., Manthorpe, J., & Barclay, S. (2011). An uncertain future: the unchanging views of care home residents about living and dying. *Palliative Medicine*, 26(5), 734–743.
- McGregor, M. J., Tate, R. B., Ronald, L. A., McGrail, K. M. (2007). Variation in site of death among nursing home residents in British Columbia, Canada. *Journal of Palliative Medicine*, 10, 1128–1136.
- Menec, V. H., Nowicki, S., Blandford, A., & Veselyuk, D. (2009). Hospitalizations at the end of life among long-term care residents. *Journals of Gerontology Series A. Biological Sciences and Medical Sciences*, 64(3), 395–402.
- Morin, L., Johnell, K., & Aubry, R. (2015). Variation in the place of death among nursing home residents in France. *Age and Ageing*, 44(3), 415–421.
- National Gold Standards Framework. (2012). *Gold standards framework in care homes*. Shrewsbury, ENG: The National Gold Standards Framework Centre.
- Ng, C. W. L., Cheong, S. K., Raj, A. G., Teo, W. S. K., & Leong, I. Y. O. (2016). End-of-life care preferences of nursing home residents: Results of a cross-sectional study. *Palliative Medicine*, 30(9), 843–853.
- Nicholson, C., Meyer, J., Flatley, M., Holman, C., & Lowton, K. (2012). Living on the margin: Understanding the experience of living and dying with frailty in old age. *Social Science & Medicine*, 75(8), 1426–1432.
- Ontario Long-Term Care Homes Act. (2007). Toronto, ON: Ontario Ministry of Health and Long-Term Care. Available at <http://www.health.gov.on.ca/en/common/legislation/ltcha>
- Ontario Ministry of Health and Long-Term Care. (2007). *Community care access centres client services policy manual*. Toronto, ON: Queens Printer for Ontario.
- Parker Oliver, D., Porock, D., & Oliver, D. B. (2006). Managing secrets of dying backstage: The voices of nursing home staff. *Omega Journal of Death and Dying*, 53(3), 193–207.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods*. Thousand Oaks, CA: Sage.
- Pélessier, C., Vohito, M., Fort, E., Sellier, B., Agard, J. P., Fontana, L., & Charbotel, B. (2015). Risk factors for work-related stress and subjective hardship in health-care staff in nursing homes for the elderly: A cross-sectional study. *Journal of Occupational Health*, 57(3), 285–296.
- Pleschberger, S. (2007). Dignity and the challenge of dying in nursing homes: The residents' view. *Age and Ageing*, 36(2), 197–202.
- Reynolds, K., Henderson, M., Schulman, A., & Hanson, L. C. (2002). Needs of the dying in nursing homes. *Journal of Palliative Medicine*, 5(6), 895–901.
- Seymour, J. E., Kumar, A., & Froggatt, K. (2011). Do nursing homes for older people have the support they need to provide end-of-life care? A mixed methods enquiry in England. *Palliative Medicine*, 25(2), 125–138.
- 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.
- Sinclair, S. (2011). Impact of death and dying on the personal lives and practices of palliative and hospice care professionals. *Canadian Medical Association Journal*, 183(2), 180–187.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Grounded theory procedures and techniques* (2nd ed.). Thousand Oaks, CA: Sage.
- Summerfield, C., & Babb, P. (2004). *Social trends*. London, ENG: Office for National Statistics, The Stationery Office.
- Sussman, T., & Dupuis, S. (2012). Supporting a relative's move into a long-term care home: The role of starting point in shaping family members' transition experiences. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 31(4), 395–410.
- Temkin-Greener, H., Ladwig, S., Caprio, T., Norton, S., Quill, T., Olsan, T., ... Mukamel, D. B. (2015). Developing palliative care practice guidelines and standards for nursing home-based palliative care teams: A Delphi study. *Journal of the American Medical Directors Association*, 16(1), 86.e1–86.e7.
- Thompson, G. N., McClement, S. E., Menec, V. H., & Chochinov, H. M. (2012). Understanding bereaved family members' dissatisfaction with end-of-life care in nursing homes. *Journal of Gerontological Nursing*, 38(10), 49–60.
- van Soest-Poortvliet, M. C., van der Steen, J. T., de Vet, H. C., Hertogh, C. M., Deliens, L., & Onwuteaka-Philipsen, B. D. (2015). Comfort goal of care and end-of-life outcomes in dementia: A prospective study. *Palliative Medicine*, 29(6), 538–546.
- Waldrop, D. P., & Kirkendall, A. M. (2009). Comfort measures: A qualitative study of nursing home-based end-of-life care. *Journal of Palliative Medicine*, 12(8), 719–725.
- Waldrop, D. P., & Kusmaul, N. (2011). The living–dying interval in nursing home-based end-of-life care: Family caregivers' experiences. *Journal of Gerontological Social Work*, 54(8), 768–787.
- Wahl, J. (2011). *Long term care homes act 2007: Implications for palliative care*. Toronto, ON: Advocacy Centre for the Elderly.
- World Health Organization. (2010). *Ageing and life course: Our ageing world*. Geneva, CHE: Author.
- World Health Organization. (2011). *Palliative care for older people: Better practices*. Copenhagen, DNK: Regional Health Office for Europe.