



**CARING FOR PERSONS WITH DEMENTIA AT THE
END OF LIFE: A REVIEW OF THE LITERATURE**

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Executive Summary

As the incidence and prevalence of dementia increases with the aging population, it is critical to address the end of life needs of people with dementia, their families and caregivers. Most people with dementia end their lives in a health care institution where little or no attention is paid to their end of life needs. Where palliative care is provided, it is most often based on models developed for people with cancer, which are not appropriate for people with dementia.

End of life care for people with dementia requires an active, compassionate approach, which treats, comforts and supports individuals. The approach must be sensitive to personal, cultural and spiritual values, beliefs and practices. End of life care must encompass support for families and friends up to and including the period of bereavement.

Studies indicate that people with end stage dementia have a number of symptoms for which they generally do not receive effective palliative care. It is common that analgesia is infrequently used, the dying phase is not recognized and some people are given antibiotics inappropriately in the last days of life.

It is very difficult to assess when a person stops living with dementia and starts dying from it. Services should not use expected length of life as part of their eligibility criteria if they are to meet the needs of people with dementia. We need to develop methods of predicting the approach of death, which would enable better planning of care, particularly in moving from actively treating, to the palliative approach. Checklists of clinical indicators for those who would benefit from a palliative approach need to be developed and these tools need to be used in all care settings.

Communication with people with late stage dementia is a challenge but it is possible. Research and experience demonstrate that it is possible and worthwhile to communicate with people in the later stages of dementia. Communication may be in forms that are not verbal and may be difficult to interpret, but care providers do need to be taught that by building their skills and by taking the time to interpret cues they can deliver high quality care.

Caregivers of people with dementia experience greater strain, distress and higher levels of psychological morbidity than caregivers of other older or infirm people. Early and ongoing discussions concerning end of life care between staff and family are essential. Although uncertainty is a common feature of dying with dementia, caregivers find it extremely difficult

when they are not informed about the fact that the person is not far from death. Good palliative care relies on active listening to everyone involved, including the family and caregivers in decisions about care.

The Alzheimer Society B.C. is committed to improving the end-of-life experiences of families affected by dementia. A logical next step is for the B.C. Provincial Framework for End-of-Life Care, published in 2006, to adopt the end-of-life recommendations found within the B.C. Dementia Service Framework.

Background

According to the Alzheimer Society of British Columbia (2009), an estimated 500,000 Canadians have Alzheimer's disease or a related dementia. These data also suggest that more than 70 000 British Columbian residents are living with dementia. With the "rising tide" of the prevalence and incidence of dementia, it is critical to address the end of life needs for those with dementia, their families and their caregivers.

People with dementia experience a long, downhill illness trajectory (Wilkinson & Lynn, 2005). The person is vulnerable to developing acute illnesses as a complication of dementia, resulting in lower levels of physical and cognitive functioning (Sachs, Shega & Cox-Hayley, 2004). In the last phase of their illness, the person may become immobile, need assistance in most, if not all, activities of daily living, and may be unable to verbally communicate. In addition, the person may also experience reduced ability to participate in meaningful activity and become unable to recognize their loved ones.

Eminent researchers in the field contend that despite the potential of severe dementia lasting several years, "individuals in this state can be considered to be dying" (Blasi, Hurley, Volicer, 2002, p. 57). This statement seems to suggest uncertainty in when someone can be identified as 'dying' from dementia. In addition, persons with dementia also experience other conditions that "degrade function in a number of ways [which results in a] disease trajectory...characterized by low initial function, with repeated episodes of sudden deterioration and recovery until a fatal episode" (Keay, 1999, p. 97). In this respect, Lynn and Adamson (2003) contend that, in the face of multiple chronic illnesses, the concept of dying is not clear; suggesting, there is no distinct transition point in which the person comes to be "dying." Lynn and Adamson (2003) write,

"Many chronically ill elderly people have ambiguous medical prognoses: They may be sick enough to die but could also live for many years...people living with serious illness at the end of life can be identified not from certainty of timing of death, but from "living on thin ice" – suffering long periods of illness or disability, diminished functioning, and potential exacerbation of symptoms, any of which could prove fatal. They could keep "living on thin ice" for some years or die in a week" (pp.6-7).

The BC Provincial Framework for End of Life Care (2006) states, "End of life care begins whenever it becomes clear that a person has a deteriorating illness that will lead to death" (p.6). Yet, in the face of chronic illness and dementia, clarity does not seem like a practical reality. Rhetorically, one could argue then, that end of life care could commence upon the

diagnosis of dementia as it is a deteriorating illness that will eventually lead to death. However, while there is a push to advocate to classify progressive dementia as a terminal illness, this may be viewed as problematic in the eyes of health care providers, who are unlikely to identify dementia as a 'cause' of death (Fisher et al., 2000), as well as families who may believe that their family member died of other causes (Sachs, Shega, Cox-Hayley, 2004). This potential gap is illuminated by Mitchell, Kiely and Hamel (2004). In their sample of those with advanced dementia, at admission, 1.1% was identified as having six months left to live; however, 71% actually died within that period.

People with dementia can be supported within their home environment until late into their illness. However, with onset of higher care needs or a support system that can no longer support the person within their own home, a move into a residential care setting is highly likely. While death occurs within the home or residential care settings, it is possible that the person with dementia will be admitted into an acute care setting, and for some, they will die there. Death for those with dementia is most frequently caused by infections like pneumonia, often related to dementia-related impairment such as functional impairment, immobility, eating difficulties and incontinence (Volicer, Brandeis, & Hurley, 1998). However, while death caused by dementia is more likely to be indicated on the death certificate in nursing homes (Ganquili & Rodriguez, 1999), general reporting of dementia as the immediate or even contributing cause of death is relatively rare (Michel et al., 2002). For example, while the US National Centre for Health Statistics ranked Alzheimer's Disease as the 5th leading cause of death, Alzheimer's disease was underreported on death certificates – not only as the immediate cause of death (less than 37% of death certificates of the study sample), but also as a condition contributing to death (Watcherman, Kiely & Mitchell, 2008).

The failure to recognize dementia as a terminal illness seems to walk hand-in-hand with the difficulties in identifying a person as 'nearing the end of life.' Yet, both issues have tremendous implications in the way care is delivered and quality of life at the end of life (Addington-Hall, Fakhoury, McCarthy, 1998). Traditionally, palliative care assumed a "turning away from conventional care" (Lynn & Adamonson, 2003 p.7). However, for those with chronic illness, this shift in care is routinely blurred and the person may need a blend of both curative and palliative intervention throughout their illness trajectory. Proposing a trajectory model of care, the authors contend that "early in the course of their illness, [elders with chronic illness] need both curative treatment as well as "palliative" care aimed at treating symptoms; and late in life, some treatments may still stall the progression of illness, even while most needs are for relieving symptoms and providing support (ibid, pp.7-8). In this model, care planning and the subsequent preparation for death will help ensure that appropriate care occurs in a timely

manner, rather than being addressed in times of crises and when persons are at a point when they are no longer able to make their preferences known or when they are actively dying (Thompson & Parker-Oliver, 2008).

However, palliative approaches are not routinely used in the care of those with dementia nearing the end of life (Mitchell et al., 2004). And researchers reveal that despite gains in biomedical and psychosocial interventions in the treatment of dementia, end-of-life care remains suboptimal (Shega et al., 2003). The focus of this paper is to review research evidence relevant to the different facets of end of life care for persons with dementia in the effort to recommend 'best practice' related to optimal end of life care for those with dementia.

Methods

The search strategy included examining computerized bibliographic databases including Ageline, PsychInfo, CINAHL, Medline, and Google Scholar for studies published in peer-reviewed journals. In addition, a hand search of accessible journals and the grey literature for key discussion papers, best practice guidelines and federal and provincial health care policy was also conducted. Keywords included a combination of: *severe/advanced/end stage dementia; palliative/end of life care; nursing home/assisted living/community/hospital*. Articles meeting the following criteria were reviewed: 1) the sample included those with severe dementia; 2) quality of life/care at the end of life were a focus of the study; 4) non-empirical discussion papers on the efficacy of palliative care in the dementia context; and 5) the publication date of the study was between 1990 and 2009.

The search revealed a plethora of research related to dementia end of life care and all articles were reviewed for relevance to the current topic. Articles kept for review included randomized controlled trials (RCTs), quasi-experimental observational studies and qualitative ethnographies and in-depth interviews. Only a handful of studies were RCTs and only a few included an evaluation of a clinical intervention. Discussion papers that examined advanced dementia end of life care were also kept to help inform recommendations.

Results

There are several areas that need to be addressed in order to provide 'good' care to those with dementia at the end of life. These concerns centre on inadequate pain and symptom management (Sachs, et al., 2004) and the burden of aggressive and invasive medical

interventions (Mitchell, Kiely & Hamel, 2004). In addition, lack of advance care planning (Mitchell, Morris, Park & Fries, 2004; Morrison & Sui, 2000), poor communication between family and health care providers (Caron, et al., 2005), staffing issues and unsupportive physical environments (Kayser-Jones et al., 2003; Komaromy, Sidell & Katz, 2000) contribute to compromised care and ultimately detract from supporting well-being at the end of life.

The following discussion is grounded in the perspective that in order to give direction for better end of life care for those with dementia, a broad net must be cast. Thus, over and above reviewing literature related to clinical issues, decision-making and the role of family thereof, it is also imperative to address psychosocial-spiritual support. Moreover, it examines the settings in which care is provided and the education of care providers.

Clinical Issues

Overall, clinical issues emerge regardless of site of care and are extremely complex considering the multiplicity of ethical, cultural, religious experiences shrouding them. The following discussion highlights the main areas of clinical concern most evident in the research: pain management, meeting nutrition and hydration needs, management of intercurrent infections, resuscitation and supporting psychosocial and spiritual needs.

PAIN MANAGEMENT

There is significant concern that persons with advance dementia might be in pain yet pain is often undetected and thus undertreated (Cole, et al., 2006; Ferrell, Ferrell & Rivera, 1995; Forbes-Thompson & Gessert, 2005). Untreated pain can profoundly impact the quality of life of the person with dementia and is linked to sleep disturbances and reduced social interaction (Ferrell, Ferrell & Osterweil, 1990) as well as increased functional impairment (Morrison et al., 2003). However, the prevalence of pain for those with advanced dementia is not fully understood. In a study of 217 nursing home residents with dementia, Ferrell, Ferrell and Rivera (1995) found that 62% of their sample expressed pain complaints. Similarly, Husebo and colleagues (2008) found that persons with dementia experience similar levels of pain intensity as compared to those cognitively intact. However, the authors also found that persons with severe dementia receiving opioid analgesics experienced higher pain intensity than those cognitively intact. Yet, others have found decreasing prevalence of pain related to increasing levels of cognitive impairment (Leong & Nuo, 2007; Proctor & Hirdes, 2001). The Proctor and Hirdes' study compared the prevalence of pain in long-term care facilities in Ontario,

Saskatchewan and Manitoba using the Pain scale embedded in the Minimum Data Set (MDS). The authors found that 31.5% of those with cognitive impairment reported pain as opposed to 61% of those cognitively intact. However, when examining those with pain more closely, the researchers found that clinical characteristics such as hip fractures, falls and unsteady gait, and clinical depression were more strongly associated with pain for those with cognitive impairment than those cognitively intact. These results suggest that the experience of pain is compounded by the burden of other comorbid conditions.

Despite the differing results in the prevalence of pain, it is clear that persons with advance dementia experience pain. Research examining pain management demonstrates that the use of analgesics improves pain symptoms for those with dementia (Kovach et al., 2001) and the Australian Pain Society (2005) suggests that good pharmacological intervention is to use pain medication regularly, not just as required. In general however, research has shown that older adults are less likely to have their pain managed (Ferrell et al., 1990; Won et al., 1999). In a study describing end of life care for those with dementia in the community and care facility setting Morrison and Siu (2000) compared treatment following a hip fracture for those with dementia (n=38) to those who were cognitively intact (n=59). The authors found that those with dementia received a third of the total daily does of morphine equivalents and had fewer standing orders for analgesics than those cognitively intact. Similarly, Husebo and colleagues (2008) found that persons with severe dementia did not receive the same amount of opioids as those cognitively intact (24% versus 37% respectively). The authors offer that the care providers' desire to avoid unwanted side-effects may help explain this result. The development of delirium contributes to this reluctance to prescribe opioid analgesics (Morrison et al., 2003). However, examining the relationship between pain, opioids and the development of delirium following hip fractures Morrison and colleagues found that the opposite occurred. In their sample, those with undertreated pain were more likely to develop delirium than those whose pain was adequately managed. The researchers conclude that avoiding opioids or administering very low doses is associated with an increased risk of delirium for both cognitively intact and cognitively impaired patients.

Barriers to effective pain management is also related to conducting effective pain assessments with persons with advance dementia due to their increased difficulty with reporting the presence and severity of pain (Sachs et al., 2004). While self-report of pain is considered the 'gold standard (Herr, Bjoro & Decker, 2006), in the face of diminished verbal communication, assessment needs to encompass a broader scope. Researchers advocate for ongoing pain assessment that encompasses several assessment strategies such as observations of behaviour and estimates of pain by family or care providers (Herr, Bjoro and Decker, 2006;

Kovach et al., 1999). It also requires careful consideration of the person's history and current experiences (Sachs et al., 2004). Intimate knowledge of the person can help as observable behaviours and changes in normal behaviour patterns are often indications pain and other distress. Signs such as anxiety, agitation, depression, sleep disturbances and resistance to care have been noted as pain responses particularly during the terminal phase (Zieber, Hagen, Armstrong-Esther & Aho, 2005). Other researchers have observed that nonverbal cues exhibited by persons with severe dementia such as vocal outbursts, tense body language, combative behaviour, agitation, sad facial expression, and vocal perseverations were indicative of pain and discomfort (Cipher, Clifford & Roper, 2006; Kovach, Weissman, Griffe, Matson & Muchka, 1999; Proctor & Hirdes, 2001). While these behavioural expressions may also be an indication of other unmet needs (Cipher et al., 2006), it is important to recognize that the need could also be pain and to respond accordingly. Family input on how their relative previously expressed or coped with pain (Mentes, Teer, & Cadogan, 2004) as well as their sense of the current experience of pain (Cohen-Mansfield, 2002) is also an important assessment piece.

However, in residential care facilities, observational assessment practices are hampered by placing unskilled frontline workers to care for those with dementia at the end of life (Parker & Macleod, 2001). While they may be able to recognize the presence of pain, they are less able to determine the intensity of pain (Mentes, Teer, & Cadogan, 2004). Moreover, there is a lack of policy or protocol around ongoing pain assessment (Cohen-Mansfield, 2004). In BC, while pain assessments occur on admission into a care home, routine assessment occurs primarily through the quarterly MDS process. Yet, as Cohen-Mansfield argues, the MDS underreports pain for those with advanced dementia. Thus, researchers advocate for not only increased training and education for frontline workers, but also change in organizational policies such that pain is regularly assessed with tools that are sensitive to the experience of those in end-stage dementia (Allen et al., 2005; Cohen-Mansfield, 2004; Ferrell et al., 1995). Herr and colleagues (2006) offer the following recommendations for the assessment of pain in those with advanced dementia:

- Utilize self-report methods if possible;
- Search for potential causes of pain and discomfort;
- Observe the person's behaviour and use reliable behaviour assessments;
- Engage family perceptions;
- Educate frontline workers to recognize the presence and severity of pain; and
- Attempt an analgesic trial and evaluate for effectiveness

While these recommendations can support pain management strategies, there is little evaluation on whether they are effective or not. However, other quality improvement projects have demonstrated success in improving pain management. For example, Kovach and colleagues (1999) observed improvement in pain management techniques including an increase in the use of scheduled analgesics and the use of non-pharmacological interventions following the implementation of the Assessment of Discomfort in Dementia (ADD) Protocol. Similar results were observed in another quality improvement project. This study saw an increase in pain assessments from 18% to 60% as well as orders for non-pharmacological pain treatments following a quality improvement intervention (Hanson, Reynolds, Henderson & Pickard, 2005). Another study observed the efficacy of multidisciplinary guidelines to manage pain (Lloyd-Williams & Payne, 2002). However, all studies were limited by weak methodology and further testing of the guidelines/protocol is warranted.

To conclude, while it is evident that persons with advanced dementia experience pain, it is also apparent that assessment is difficult and thus, effective pain management an obstacle to best possible quality of life at the end of life. Utilizing the above recommendations to help care providers become more sensitive to the expressions of pain, engaging in quality improvement initiatives and conducting ongoing pain assessment are important directions to address the issue of pain adequately.

MEETING NUTRITION AND HYDRATION NEEDS

Nutritional issues occur along the dementia trajectory to the point where the person with dementia will likely need full assistance with feeding and hydration. Feeding assistance is further complicated by swallowing difficulties, dysphagia and food refusal (Morris & Volicer, 2001). Food refusal and a lack of appetite or interest in food is possibly another sign that the person is dying. However, inadequate nutrition and hydration is linked to an increased risk for malnutrition, pressure sores, aspiration pneumonia and infection (Gessert, Forbes, & Bern-Klug, 2000-2001; Gillick, 2000; Li, 2002). To prevent the development of such risks, providing nutrition through a nasogastric tube or percutaneous endoscopic gastronomy (PEG) tube (collectively known as tube feeds) has been regarded as a viable alternative. However, whether to initiate tube feeds is one of the most difficult dilemmas facing families, clinicians and organizations caring for those with advanced dementia (McMahon, Hurely, Kamath, & Mueller, 2005).

Factors associated with feeding tube use with those with advanced dementia vary considerably between different settings of care (Mitchell, Kiely & Gillick, 2003) and between countries (Mitchell & Kiely, 2001). In a recent study conducted in the United States, the most common diagnoses associated with feeding tube placement in persons with advanced dementia included: aspiration pneumonia, dysphagia, urinary tract infections, malnutrition and pneumonia (Kuo, Rhodes, Mitchell, Mor & Teno, 2009). In another large US study (n=186,835) describing facility and resident characteristics related to feeding tube use among persons with cognitive impairment residing in US nursing homes, researchers found 34% of residents with advanced cognitive impairment had tube feeds (Mitchell, Teno, Roy, Kabumoto & Mor, 2003). Resident characteristics independently associated with feeding tubes included: younger, male, non-Caucasian, lack of do-not-resuscitate (DNR) orders, no identified power of attorney, no living will, and a recent decline in functional status (Kuo et al., 2009; Mitchell et al., 2003). Facility characteristics included the lack of nurse practitioner on staff, if the facility did not have a dementia care unit, facilities located in urban areas, for-profit facilities, and those that had more than 100 beds (Mitchell et al., 2003). Published BC data in terms of prevalence and factors associated with tube feeds was not found. However, clinicians in residential care in one health authority believe that the use of tube feeds in dementia care is not so common (Powell, personal communication).

Although no prospective randomized controlled trials have been conducted, other evidence suggests that tube feeds do not demonstrably prevent aspiration pneumonia, pressure ulcers, improve functional status or provide comfort (Gillick, 2000; McMahon, 2005). In addition, survival rates are not necessarily improved (Arinzon, Peisakh, & Berner, 2008; Meier et al., 2001; Sanders et al., 2000). In a cohort study of tube feed placement of 361 patients, Sanders and colleagues found increased mortality rates. The mortality rate for those with dementia at one year was 90%. In a more recent study, the overall one-year survival rate was 64.1% with a median survival of 56 days. 20% of those who had a feeding tube inserted, had the feeding tube replaced or repositioned (Kuo et al., 2009).

Moreover, increased use of restraints to prevent the person from pulling out the tube and other adverse effects such as tube leakage, reflux and diarrhoea increase the burden of intubation for people with dementia (Gillick, 2000; Li, 2002; Peck, Cohen & Mulvihill, 1990). As Young (2002) asserts, "no one who has achieved such advanced years should end their days in undignified circumstance where they are restrained, unable to express their resentment at this restraint, and furthermore, no longer able to enjoy the simple pleasures of eating and drinking" (p. 21). Based on clinical findings such as these, Finucane and colleagues (1999) discourage the routine use of tube feeds for those with advanced dementia.

Considering this evidence, it is surprising that physicians believe that tube feeds have considerable benefit in advanced dementia (Shega et al., 2003). In a random sample of over 400 American internal medicine and family medicine physicians, Shega and associates found that the majority believed that PEG feeds were associated with reduced aspiration pneumonia, improved healing of pressure ulcers, improved survival, nutrition and functional status. In addition, a third reported that they would honour family requests for tube feeds even if the patient had earlier expressed refusal of tube feed placement. Further, while many stated that placement of tube feeds was a standard in dementia care, they themselves would not opt for such an intervention. These results point to the need for education for physicians and other care providers. Research has shown that consultation with palliative care teams providing education prior to intubation is related to a reduction in the incidence of tube feeding (Monteleoni & Clark, 2004).

The belief of the efficacy of tube feed placement is not limited to physicians. Family members, in their role as surrogate decision makers, also believe that placement of tube feeds will prevent aspiration and prolong life (Mitchell & Lawson, 1999). In this study, of those surrogate decision makers who opted for tube feed placement only 57% felt that the person would have wanted this intervention. Overall, support and communication from the health care team with respects to decision making was inconsistent and while surrogates felt they understood the benefits of tube feeds, they were less informed about the risks. These issues will be addressed further in a subsequent section.

Another important piece is the ways in which US nursing homes are reimbursed with respects to tube feeding. In a study in one US nursing home, researchers compared the cost of tube feeding versus hand feeding. The results revealed that while daily costs for hand-feeding were higher as compared to residents with tube feeds, reimbursement to the nursing home was greater for those residents with tube feeds (Mitchell, Buchanan, Littlehale, & Hamel, 2003). These data suggest that, as Finucane, Christmas and Leff (2008) argue, incentives within the health care system may influence the use of tube feeds despite the evidence of limited efficacy for those with advanced dementia. While these arguments are limited to the American system, it seems important to take heed of their cautionary messages – particularly in light of the mandated use of the Minimum Data Set in BC residential care facilities and the potential to use this assessment as a funding mechanism.

It is also important to determine if weight loss is related to poor feeding assistance or a lack of consideration of alternatives such as a mechanically altered diet. Within the residential care context, the dining experience is often rushed and task-oriented which detracts from not only ensuring a pleasurable experience but also making certain that residents receiving

adequate nutrition and hydration (Hung, 2008; Kayser-Jones, 1997; Sydner & Fjellstrom, 2005). The issue is more complex in light of understaffing, poor supervision and the use of agency staff who may not know the strategies and nuances of effective assistance with feeding (Kayser-Jones et al, 1999). Research has shown that efforts to improve the mealtime experience including hand-feeding, use of verbal prompts, relaxed pacing, encouragement of self-feeding and social interaction is related to increased intake (Morris & Volicer, 2001; Simmons et al., 2001). Moreover, prevention of choking, thus prevention of aspiration pneumonia, through modifying the consistency of food (i.e. using thicker liquids) is also a viable intervention (Morris & Volicer, 2001). In this light, efforts to improve feeding assistance are an important and necessary direction to explore. As Gillick (2000) stated, “feeding by hand is an act of nurturing that cannot be accomplished by hanging a bag of nutrients on a pole for delivery through a tube” (¶12).

In light of the above discussion, placement of tube feeds is a highly emotionally and ethically charged issue. While overall consensus in the medical community supports palliative approaches in the care of persons with advanced dementia, the use of tube feeds, as noted in the American literature, is still quite commonplace (Gillick & Volandes, 2008). The face value of inserting tube feeds is very strong. While research in the area of cancer tells us that those who are dying do not feel hunger or thirst (AUTHOR) the perception that tube feeds will prevent a long and painful death and that the alternative is akin to letting someone starve to death is very strong (Kunin, 2003; Young, 2002). Moreover, family members may express feelings of guilt for not doing ‘everything possible’ and feelings of sadness that their loved one is declining (Black & Arnold, 2005). Taken together, these affective experiences suggest that the issue is a moral one as opposed to a scientific one. In this context, Gillick and Volandes (2009) suggest that a better approach in the discussion of tube feeds with family members who want them for their loved one, is to acknowledge the symbolic meaning of nutrition and what it means to ‘care’ for someone and together, explore alternative ways to meet the person with dementia’s nutritional needs. Responding empathetically to the lived experiences of the family and the person with dementia helps to reframe emotionally charged issues (Black & Arnold, 2005).

MANAGEMENT OF INTERCURRENT INFECTIONS

The risk of development of urinary tract infections (UTI), respiratory and gastrointestinal infections has been noted as a consequence of advanced dementia. Compromised immune

response, swallowing difficulties, inability to ambulate, functional impairment (Volicer, Brandeis & Hurley, 1998) as well as the decreased likelihood of persons with end-stage dementia reporting feelings of discomfort (Sachs, Shega & Cox-Hayley, 2004) are significant risk factors for the development of intercurrent infections.

Researchers have shown that vaccinations can reduce the risk of the development of intercurrent infections (Brandeis, Berlowitz & Coughlin, 1998). While there is some debate in the use of pneumococcal vaccinations for the very old, Jansen and Krause (2004) suggest that vaccinations do lower the risk of pneumonia. In terms of the influenza vaccine, while it does not completely protect against the development of influenza, it has been shown to be effective in both the community (Voorouw et al., 2003) and the residential care setting (Pregliasco et al., 2001). In addition, good oral health programs have been found to reduce the occurrence of pneumonia (Yoneyama, Yoshida, Ohrui, & Mukaiyama, 2002).

Van der Steen and colleagues (2002) report that after an episode of pneumonia, because of weight loss and aspiration, mortality is increased for those with more severe dementia. Similarly, Morrison and Siu (2000) found that persons with advanced dementia, following hospitalization due to pneumonia, have a very poor prognosis; reporting a six-month mortality rate of 53% for those with dementia and pneumonia as compared to 13% for those cognitively intact with pneumonia. Antibiotic therapy is effective after a single episode; however, it is less effective with the recurrent nature of these infections. In an early study comparing the use of antibiotics to comfort measures only for maintenance and symptom control during an infection episode for those with advanced dementia, Fabiszewski, Volicer and Volicer (1990) found that antibiotics offered no improvement in survival or comfort. Moreover, intravenous therapy for persons with dementia may necessitate the use of restraints (Hurley, Volicer & Volicer, 1996) causing significant distress and discomfort to the person. If antibiotics are used, they must be used judiciously and with full understanding of significant clinical adverse effects and impact on quality of life (Hanrahan, et al., 1999; Luchins et al., 1997; Volicer et al., 1998).

CARDIOPULMONARY RESUSCITATION

Cardiopulmonary resuscitation (CPR) also is a contentious issue yet research has noted that survival rates following resuscitation are extremely low. For example, Dull, Graves, Larsen & Cummins (1994) examined survival after a cardiac arrest in the pre-hospital setting and found

that in the nursing home sample, only 3% of residents survived to hospital discharge. Others have observed the discharge rate from hospital after cardiac arrest from 0% (Benkendorf et al., 1997) to 3.4% (Finucane & Harper, 1999). Moreover, if CPR is initially survived and the person is taken to an intensive care unit (ICU), research has shown that most die within 24 hours (Zweig, 1997). Kaufman (2005) asserts that because ICU itself is an environment that causes additional confusion, delirium and shifts in care focus, it is not a place for dying with dignity. As such, considering the balance between benefits and burden, Zwieg (1997) suggests that within the residential care setting CPR should not be considered the default position and do not resuscitate orders should be explicitly stated. Decision-making around this issue will be further discussed in a following section.

PSYCHOSOCIAL AND SPIRITUAL SUPPORT

There is a perception that progressive dementia equates with the progressive loss of self (Kitwood, 1997; Post, 1995). This view has serious consequences in shaping our response to persons with advanced dementia including dehumanization, debasement and lack of acknowledgement of the PERSON who is living with dementia (Kitwood, 1997). Chenoweth and colleagues (2009) write that “personhood is a product of relationship with others and can be nurtured or diminished depending on whether the person is valued or depersonalized in care” (p. 302). Jennings (2004) argues that “Alzheimer’s does not...close off the possibility of meaning-making activity by a person supported by the right types of interpersonal relationships and caring systems” (p.275). This section examines spiritual and psychosocial needs of those with advanced dementia.

Enhancing a person’s quality of life and minimizing his or her suffering is tremendously important at the end of life and is central to providing good care. Thus, it is essential to focus clinical practice on the treatment of human suffering with respect to the full constellation of suffering, rather than just one aspect, such as physical suffering (Black & Rubinstein, 2004). In this light, older adults have voiced end of life concerns outside the domain of physical needs. These include: fears of isolation, marginalization, loss of relationship and control; of being vulnerable; and loss of opportunity to find meaning and personal growth (Fisher et al., 2000). These experiences may lead to undue suffering and distress. Yet, as Forbes-Thompson and Gessert (2006) contend, suffering is difficult to define, particularly for an older population who have experienced multiple losses. However, the authors do offer the following definition:

“suffering is a personal state of anguish in response to a perceived or real loss or threat to one’s personhood...It has physical, social, psychological, and existential dimensions and will influence one’s perception of her or his quality of life” (p. 235).

These fears are also salient for those with dementia and the notion of unrelieved suffering becomes particularly germane as the persons’ ability to articulate their concerns diminishes.

While a considerable body of research explores the dimensions of supporting the psychosocial and spiritual needs of people with dementia, it is surprising that little research specifically addresses these needs at the end of life. In residential care, Forbes-Thompson and Gessert (2006) suggest that this paucity is related to the fact that many care facilities operate within a “medical model that...does little to address the psychosocial needs of most residents” (247). Additionally, care homes may be ill-equipped to provide spiritual care, relegating the service to religious social gatherings rather than addressing deeper existential issues (Orchard, 2001). Teno and colleagues’ (2004) examined family perceptions of end of life care in care facilities or the home environment. Over half of family members reported that their relative did not receive enough emotional support. These results point for a greater understanding of the nature of psychosocial and spiritual support.

A British study illuminates the psycho-social experience of those with advanced dementia (Perrin, 1997). Using dementia care mapping (DCM), 109 individuals from nine different dementia care settings were observed over 63 hours. The author found that residents spent little to no time interacting with staff or other residents. Specifically, over 50% of the time was spent in passive behaviours and most of the DCM ratings for “ill-being” (as opposed to well-being) were related to extended periods of daytime sleeping. Only eight percent of the observation time was related to social interaction; however, most of this was related to the briefest of exchanges. Perrin writes, “...it would be true to say that less than half of this figure represents sustained interaction of any real depth and quality” (938). Further, observations recorded reluctance on the part of staff to engage for any length of time with a resident in anything other than a task-related activity. Perrin, like Ersek and colleagues (1999), deduced that care staff were uncomfortable interacting with those with advanced dementia and felt ineffectual in engaging meaningfully with them. Similarly, in a study addressing activity and interaction levels, Nolan, Grant and Nolan (1995) found that those totally dependent in activities of daily living (ADLs), who were disoriented and had difficulty holding conversation, spent 87% of their day in solitude. The authors observed that interaction outside expected routines of care were rare, and seldom did carers spontaneously talk with persons with advanced dementia.

Froggatt (2001), drawing on fieldwork undertaken in four English nursing homes, noted similar occurrences. However, she also observed that residents “who were perceived to have experienced a loss of personhood or demonstrated signs of unbounded bodies” (p. 328), were sequestered from other residents. This occurred spatially through the use of public and private spaces and also through the activities that occurred in the public spaces, with those unable to engage in any activity being separate from those who were able. While persons at the end of life may not want to join or be in proximity to social activities, the practice of physical segregation or separation, as observed in this study, excludes those with advanced dementia to continue to engage, however they are able, in social relationships and activity.

Conversely, other research has shown that relationship and sensitive activity can promote psychosocial wellbeing. Sensory stimulation, interpersonal touch, hugs and even gentle massage have been shown to have a calming and comforting effect on persons with end-stage dementia (Calkins, 2005; Witucki & Twibell, 1997). The physical presence of another person has also been shown to provide comfort for those with dementia at the end of life (Department of Health and Ageing, 2004). In an intervention study to improve relationships between nurses and residents with advanced dementia, Hansebo and Kihlgren (2002) found that clinical supervision significantly changed the relationship from primarily task-oriented care to one that balanced task and “relation-centring” care. Staff members were more likely to promote resident involvement in ADL activity, use humour, empathy and touch to communicate and show respect for individual preference. Others have found that individualizing care and valuing the persons’ preferences for activity, food, morning and evening routines are vital interventions to reduce or alleviate suffering and enhance the elders’ quality of life (Forbes-Thompson & Gessert, 2006).

In terms of spiritual needs, only one study was found that specifically explored persons with dementia’s concerns about existential matters such as meaning, suffering and isolation. Albinsson and Strang (2002) found that approximately half of those interviewed (n=31) had experienced residents talking about existential issues in a direct manner – some residents expressed a longing for death and to be released from their suffering. The caregivers were also asked how they dealt with these concerns, and while all the staff expressed the difficulty in handling them, three patterns of responses emerged: the respondent minimized the concern, deferred it to a higher power, and the more common response was the respondent showing affection and emitting that the resident was loved and cared for. The authors concluded that relationship between carer and resident was an important facilitator of the creation of meaning and assuaging the feelings of existential isolation.

However, researchers have observed that many health care providers are uncomfortable talking about dying with residents and addressing residents' fear about death (Ersek, Kraybill & Hansberry, 1999; Wadensten, Conden, Wahlund & Murray, 2007). Consequently, many avoid engaging in quality interactions with residents contributing to the lack of meaningful staff-resident activity (Kayser-Jones et al., 2002; Wadensten et al., 2007). Thus, addressing the persons' emotional state, providing social and spiritual support, is often a struggle for health care providers including physicians (Chibnall, Bennett, Videen, Duckro & Miller, 2004); Milligan, 2004) and care aides (Whittaker et al., 2007). In Chibnall and colleagues study, physicians expressed that providing psychosocial and spiritual care was not valued in their work environment. And in Whittaker and colleagues study, care aides lacked an awareness of cultural or spiritual needs of the residents or families. The authors conclude that education is key in creating a care environment that is skilled in supporting these needs.

To conclude, research examining the psychosocial and spiritual needs of those with advanced dementia, demonstrate a disconcerting picture of what the experience at the end of life may be. The literature that addresses this issue, similar to physical concerns, demonstrates that these needs are not adequately met within the care facility setting and likely not within the acute setting either.

Decision-making at the end of life

Ethical principles guiding decisions to withhold or withdraw various life prolonging interventions have been thoroughly explored throughout the literature. The principle of autonomy or the right to self-determination suggests that adults have the right to control his or her own body from unwanted intervention based on assessing the pros and cons of the intervention. In addition, the principles of beneficence and nonmaleficence require that clinicians' actions must benefit the person and, when possible, avoid harm (Brudney, 2009). However, when a person is no longer able to consent to treatment and the persons' preferences are unknown; these ethical principles are difficult to adhere to. This section looks at decision making with respects to end of life care for those with advanced dementia as well as the role and support of family in decision-making.

Planning future care through the collaboration of clinicians, family and persons with dementia themselves, can help prevent disagreement and lack of direction concerning contentious issues such as cardio-pulmonary resuscitation (CPR) and artificial nutrition and hydration at the end of life. Thus, guidance in end of life decision-making is an important facet to quality end of life care. For those with advanced dementia, in the absence of verbal

communication, decisions related to their care at the end of life are often made without their active participation in the process. Decisions are made in accordance with the persons' known wishes (written in the form of a living will/advanced directive) or are based on their previous wishes (as verbalized prior to incapacity) as identified by a surrogate decision maker and in BC, surrogates are given authority to make health care decisions under the Representation Agreement. In the BC residential care environment, conversations about treatment directives are held soon after the person moves into a facility and are reviewed on a yearly basis or when a significant change in health status occurs. These conversations are documented by way of 'levels of intervention' and are meant to guide treatment decisions.

End of life care preferences are often documented in the form of advanced directives which identifies limits on life-sustaining treatment, such as tube feeds, resuscitation and medication use to treat acute illness. These types of directives have generally been regarded as a broad acceptance of comfort as the focus of care (Mitchell, Kiely & Hamel, 2004). However, research has indicated that while residents in nursing homes are more likely to have an advanced directive than those living in community (Mitchell et al., 2005); generally, documented directives are not that common. In a US study comparing the last year of life of those with advanced dementia to those with terminal cancer, Mitchell, Kiely and Hamel (2004) found that those with advanced dementia were significantly less likely to have directives limiting aggressive care such as tube feeds and resuscitation as compared to those with cancer. In both groups, do not hospitalize orders were unlikely. Morrison and Siu (2000) found that only seven percent of those with advanced dementia had documented decisions to forgo life-sustaining treatment other than do not resuscitate (DNR) orders. Conversely, in a study of five long-term care facilities in Ontario, Hall and colleagues (2002) found that while resuscitation status was clearly indicated on the majority of the resident medical charts, other advance directives were not indicated in 67% of the charts reviewed.

Socio-cultural diversity and health literacy are a significant factor in shaping treatment/intervention decisions at the end of life (Kwak & Haley, 2005; Volandes et al., 2008). As noted in the discussion about nutrition and hydration, non-Caucasian men were more likely to have feeding tubes placed than Caucasians (Kuo et al., 2009). Another US study found that Caucasian nursing home residents were more likely to have a living will, an identified surrogate and DNR orders than other racial categories (Kiely, Mitchell, Marlow, Murphy & Morris, 2001). Volandes and colleagues (2008) also found that race was related to care preferences. 144 subjects were asked what level of medical intervention they would prefer in the event of developing advanced dementia. Results demonstrated that African-Americans were more likely to choose more aggressive care than the Caucasian subjects. In addition to examining the

impact of ethnicity, the researchers also found that health literacy influenced preferences for care. That is, those with lower levels of health literacy were significantly more likely to choose aggressive care than those with adequate health literacy. However, after showing subjects a short video about characteristics of advanced dementia, the majority of subjects across both race and health literacy categories chose comfort care.

These data seem to suggest two significant foci in the understanding of preferences for end of life care. The first centres on cultural competence and the second on health literacy.

While there is a growing understanding of racial and cultural values related to end of life care needs, preferences and perceptions of advance directives, a gap still persists in shaping policy and care practice that supports ethnic and racial diversity. This is an ethical concern as health care provider's lack of cultural competence relates to a lack of "knowing" the person which leads to unmet needs, social isolation and frustration (Chan & Kayser-Jones, 2005). While it is beyond the scope of this paper to delve into the issue of cultural competency further, it is important to appreciate the depth of such a concept. Cultural competence has been defined as a multi-dimensional construct that includes: cultural sensitivity, cultural knowledge, cultural empathy, flexible and culturally relevant relationships and interactions and cultural guidance (Tseng & Streltzer, 2004). Building competency within the health care system will help support the decision making processes for both the person with dementia and their families (Hicks & Lam, 1999).

Volandes and colleagues (2008) findings on health literacy lend strength to the need for public education on the natural course of dementia and health intervention options thereof. Moreover, the moderating effects of the informative video suggest that individuals learn in different ways. Presenting health information in a variety of ways may lead to more effectively communicating the necessary information to enable decisions that are more informed.

However, some of the difficulties noted in identifying health care preferences also centres on the complexity of imagining oneself within the context of a hard to conceive event; that is, the dying process. Consequently, people are ill-at-ease with making absolute decisions about their future care (Moorman, Hauser & Carr, 2009). Moreover, care providers' lack of time and resources to engage in dialogue (Zimmerman et al., 2003) and the lack of agreement and subsequent implementation of a course of care (Travis et al., 2002) are cited *systems* barriers to ensuring advance care planning and directives are in place.

While the lack of advanced directives based on the known preferences of the person with dementia is a pressing issue, researchers call for dialogue and process around care planning versus a directive per se (Small, Froggatt & Downs, 2007). Advance care planning

follows the journey of the person with dementia and thus is more flexible and responsive to emerging care needs as opposed to a directive that may not corroborate with the persons' current situation. Moreover, decisions are not limited to "life or death" interventions, but also include those related to everyday routines; including, ADL care, activity and food preferences (Powers, 2000). The dialogue commences early on in the illness and is ongoing throughout the dementia journey – discussing the natural progression of the disease, what to expect, planning for the future and the identification of a surrogate decision maker (Shega et al., 2003).

The need for advance care planning processes is highlighted by family perceptions that end of life care is poorly coordinated and that there is a lack of a seamless transition from curative to palliative care (Goodridge, Bond, Cameron & McKean, 2005). This is illuminated by a study that examined residents' charts 365 days prior to death looking at the end of life experience and the interventions used to support the experience (Powers & Watson, 2008). The authors found that in terms of pain and symptom management, there was no clear direction over the course of the year as to intervention goals; that is, comfort or curative care. It was not until the last month of life that 40% of the sample were designated hospice care and two-thirds comfort care. While palliative and restorative care can be used concurrently (Lynn & Adamson, 2003; Thompson & Parker-Oliver, 2008), what this study poignantly revealed is the need for planning and process around a comprehensive approach to care.

In sum, ensuring that health care decisions are guided by the ethical principles of supporting autonomy and self-determination as well as beneficence and nonmaleficence can be challenging in dementia end of life care. There appears to be a lack of advanced directives over and above DNR orders and in their absence, health care providers and surrogates are called upon to act in the best interest of the person with dementia. This requires intimate knowledge of the persons' values and life experiences and being competent in respect to their cultural beliefs and mores. Planning for care throughout the dementia journey seems to be an important direction to take to better ensure that decisions are made in accordance to the persons' preference.

SUPPORTING FAMILY ROLES IN DECISION-MAKING

In a recent panel discussion highlighting the activity of the Alzheimer's Association of BC, Margaret, a spouse of an individual living with dementia, talked about how it was not only her husband that was living with dementia, but she was as well. What her statement poignantly suggests is that the dementia journey deeply affects the family system and caregivers are faced with distinct challenges as they walk this journey together. While the previous section touched

on the role of surrogate decision makers, this section looks at their experiences in more detail. First, it looks at the disparities between surrogate treatment choices and their spouses'. Next, it looks at family involvement in care decision processes. Finally, it addresses the need to support family members through the dementia journey.

In a study investigating 84 cognitively well older adults' opinions of life-sustaining procedures in the face of dementia, fewer than 5% thought that they would want CPR, tube feeds or ventilator support with the most severe forms of dementia. One fourth of the sample wanted these procedures in the face of milder forms of dementia and fewer than 40% would not want antibiotics or hospitalization if they were no longer able to recognize a loved one (Gjerdingen, Neff, Wang & Chaloner, 1999). While this study is limited by its small sample it brings to question whether these preferences are articulated or documented in some manner; and if not, what is the likelihood that surrogates will adhere to the person's expressed preferences?

This is an important ethical question. In the absence of advanced directives or other documented wishes, families are often called upon to make significant decisions regarding medical interventions for their relative (Teno et al., 1997). This often occurs in times of crisis, requiring family to make immediate decisions related to hospital transfers, nutrition and hydration and the use of antibiotic therapies. However, families often do not realize that they are the primary decision-makers and have not discussed end-stage planning with their relative (Luchins & Hanrahan, 1993). Thus, decisions made are often rushed, without adequate information and with insufficient support from care providers. While it is assumed that family surrogates would make a decision based on the persons' values and life experiences, this is not always the case. For example, in a study of healthy older adults and spousal agreement with respect to end of life treatment, Moorman and colleagues (2009) found that surrogates chose interventions based on their own preferences as opposed to their spouses. In this context then, it is no surprise that family decision-makers often choose more aggressive interventions than what the person with dementia may have chosen. In a telephone survey of surrogates for persons residing in residential care facilities, only 57% of those who opted for tube feeding were confident that the person would have wanted the procedure and only a minority who agreed to tube feeds, felt they would want the procedure for themselves (Mitchell & Lawson, 1999)

Similarly, spouses of those with cognitive impairment were more likely to choose CPR over those healthy adults (Volicer, 2005). Mezey and colleagues (1996) found that while half of spouses of those with moderate-severe Alzheimer's disease would opt for life-sustaining treatment such as CPR, tube feeds and a respirator, only 10% would forgo antibiotics. Spouses

who consented to treatment were much more comfortable with their decision than those who decided to forgo treatment. Conversely, in a study examining appropriate care for those with advanced dementia from the perspectives of physicians, gerontologists and family members of persons with dementia, Luchins and Hanrahan (1993) found that the majority of physicians, gerontology professionals and family members favoured the least aggressive level of care for those in end-stage dementia. This type of care was conceptualized as comfort and pain management excluding tube feeds, resuscitation and medication for an acute illness, with a goal to maximize the quality of life.

These results suggest that families are unprepared to make decisions on behalf of their relative. Families feel that they do not have sufficient knowledge about the course of the illness and potential medical complications to make an informed decision about their relatives' care (Caron Griffith & Arcand, 2005; Gessert, Forbes & Bern Klug, 2000-2001; Thompson, Menec, Chochinov & McClement, 2008). In a Canadian study, only half of surrogates felt that they received the needed support to make decisions around tube feeding. While the majority felt they understood the benefits of a tube feed, less than half indicated they understood the risks. (Mitchell & Lawson, 1999; Mitchell, Berkowitz, Lawson & Lipsitz, 2000). Moreover, families who need to 'search out' information from care providers are less likely to be satisfied with end of life care provided to their relative (Thompson, et al., 2008).

This lack of preparedness is directly related to the communication patterns between health care providers and family. Thus, communication is a factor directly related to family satisfaction with end of life care (Engle et al., 2006; Sloane et al., 2008; Thompson et al., 2008; Travis et al., 2002). What is more, communication between care providers; that is, the sharing of information and care planning goals, is also associated with family satisfaction with end of life care (Thompson et al., 2008). Family satisfaction research also suggests that the general frequency of contact between family and care providers – especially contact with a physician, is related to family's perception that their relative received better care at the end of life (Travis et al., 2002). However, researchers have found that length of time spent in discussion regarding significant decisions is negligible (Engle et al., 2006). In fact, Mitchell & Lawson (1999) observed that 37% of surrogate decision makers spent 15 minutes or less in discussion about tube feeding with a physician while 28% had no discussion whatsoever.

Lack of contact with care providers directly leads to poor communication processes and thus, insufficient information to make an informed decision about treatment interventions (Caron et al., 2005). This can result in emotional burden and confusion of making important decisions (Gessert, Forbes, & Bern-Klug 2000-2001; Forbes, Bern-Klug & Gessert, 2000). Moreover, families who are unsatisfied with the care provided bear a tremendous burden of

frustration, stress, anger and guilt - guilt for not ensuring that their relative did not have a 'good death' as well as guilt over feeling ambivalent about the anticipated death of their relative (Forbes, et al., 2000; Ory, et al., 1999; Thompson, et al., 2008). Burden and strain experienced by caregivers is related to higher levels of depression following the death of their relative as compared to non-caregivers (Schulz et al., 2003). As Teno and colleagues (1997) aptly stated, without adequate psychosocial supports "a family members' memory of their loved one's death may be marred by a constant battle of advocating for their loved one and ensuring that appropriate palliative care occurs" (p. 28).

Approaching end of life care as a collaborative, interdisciplinary process shows to the family a concerted effort to effectively honour the resident's journey (Aupperle, MacPhee, Strozski, Finn, & Heath, 2004). Involving family in advanced care planning and providing them with appropriate information ensures the ongoing communication, identifies the surrogate decision maker and helps prepare the family for the eventual death of their relative. For example, Mitchell and colleagues (2001) found that family members who were given an audio booklet that reviewed the options and outcomes for nutritional problems in their relative with dementia reported more accurate knowledge and less conflicted in decision making. In the care facility environment, forming family partnerships in care has been related to improved relations between family and care staff, better communication as well as improved resident outcomes (Gaugler, Anderson, Zarit & Pearlin, 2004; Maas et al., 2004; Robison et al., 2007).

Efforts to ensure good communication and forming partnerships in care helps foster relationships built on trust and the resulting support is considered essential to quality care (Caron et al., 2005; Thompson et al., 2008). And this support is vital as families have observed the progressive deterioration of their relative, they've experienced multiple losses and it is likely that their grieving process is complicated (Wilkinson & Lynn, 2003). Moreover, their openness to end of life care is shaped by their own beliefs, cultural mores and personal relationship with the resident. While anticipatory grief may be the experience for some, denial of death could be the experience for others (Doka, 2004). Further, families who have decided to forgo treatment require tremendous support (Mezey et al., 1996). As such, ensuring positive relationships within the care setting and opening the lines of communication around end of life care is an important way to facilitate a supportive environment. Furthermore, the care planning process presumes revisiting the goals and interventions on an ongoing basis and is inclusive of formal and informal approaches to the current and future plan of care. Finally, supporting the family through bereavement helps them achieve closure on their relative's dying experience and is another important aspect to end of life care.

In sum, family members are often called upon to make decisions on behalf of their relative. However, research has shown that often surrogates' decisions do not necessarily agree with that of their spouses. In the absence of expressed preferences, making decisions on behalf of another is a stressful process and researchers have noted that surrogates often lack the necessary information to make these decisions. Communication between care providers and family has also been a notable issue. Supporting family members is an important part of end of life care. Providing them with relevant information, forming partnerships in care within the care facility setting and engaging them in advance care planning are ways to support family through the dementia journey.

End of life care in differing settings

Mezey and associates (2002) assert that "Setting has a palpable, direct and immediate impact on the quality of life that an older adult experiences at the end of life...In turn, setting at time of death exerts an influence on the quality of death" (p.54). This assertion suggests that while dementia as an illness considerably affects the dying experience, so to does the place of care. Underlying concerns in meeting persons with dementia's needs at the end of life relates to care providers' knowledge of dementia and end of life care; organizational capacity to support care providers to meet the unique needs of those with dementia; resources within the setting and the 'culture' of the organization. While dying in acute care settings has been associated with the experience of burdensome treatment (Volicer et al., 1998), dying at home or in residential care is not necessarily optimally supported either (Mitchell et al., 2005). Moreover, transitions between these settings are difficult on the person with dementia and do not necessarily equate with better care provided (Mezey et al., 2002). As such, there appears to be tremendous variability in the settings' responsiveness to progressive functional impairments and psychosocial and spiritual well-being.

ACUTE CARE SETTINGS

A primary reason for persons with end-stage dementia to enter into the acute care setting is related to infections such as pneumonia and shortness of breath (Mitchell et al., 2004; Morrison & Sui, 2000; Volicer et al., 2003). However, research reveals that care in acute settings is not necessarily related to more positive outcomes and that there are differences in care provided for those with dementia compared to those who are cognitively intact (Morrison &

Sui, 2000). In comparing end of life care for those with dementia and those with cancer, Aronheim and colleagues (1996) found that while both groups were equally likely to receive non-palliative treatment, those with dementia were more likely to receive tube feeds than those with cancer. Morrison and Siu (2000) also observed differences in care provided to persons with dementia and those cognitively intact following pneumonia or hip fractures. Moreover, the authors found that the mortality rate were significantly higher for those with dementia than those who were cognitively intact. Others have found that those with dementia receive significantly fewer referrals to specialist palliative care and less palliative medication (Sampson et al., 2006)

Mitchell and colleagues (2004) found that hospital admissions just prior to death are frequent occurrence. In their sample, 43.7% of the residential care facility cohort versus 31.5% of the community dwelling cohort was hospitalized within 90 days prior to their death. Bottrell and colleagues (2001) identified that it is not uncommon for care facilities to send residents to the hospital once they have been identified as dying. Do not hospitalize (DNH) directives can help prevent transfers to hospital settings (Mitchell et al., 2007); however, the prevalence of such orders in BC care facilities is unknown.

Outcomes are not necessarily better following an acute admission. For example, Mylotte and associates (1998) found that while immediate survival rates following pneumonia are similar comparing nursing homes and hospital settings, long-term outcomes are better when the resident was treated in the nursing home. Moreover, hospitalizations for pneumonia results in more frequent deaths and functional decline (Fried, Gillick & Liptsitz, 1997). In consideration of the 'appropriateness' of the transfer from the residential care facility to the hospital, Saliba and associates (2000) revealed that 40% of admissions were inappropriate for medical reasons and increased to 45% in context of advanced directives. These results suggest that the person with dementia could have been cared for safely within the care facility. However, the authors propose that some transfers may have been associated with poor quality of care within the care facility itself and this issue will be further explored in a subsequent section.

Kaufman's (2005) discussion about end of life care within acute care settings raises ethical and moral issues around dying, death and dignity and the role these environments have in shaping the dying experience for both the person with dementia and their family. While, hospital care may be a route of action considered by family based on needs and cultural/religious morays, it is an important area of concern as any one of the clinical issues discussed above could lead to care in an acute setting. However, like Kaufman, Johnson (2005) contends that hospital care is not optimal end of life care for those with dementia. Care

providers do not fully understanding the context (both biographical and physical) of the individual and family. Consequently, they cannot build the depth of relationship needed to deliver person-centred care at the end of life. Moreover, if the person was transferred from a residential care facility, the shift from one health team, from one environment to another, can result in increased confusion, falls, incontinence, anorexia and considerable functional decline often managed by aggressive medical intervention (Ahronheim, et al., 1996).

As hospitalizations are not necessarily equated with better health care (Travis, Loving, McClanahan & Bernard, 2001) and are more likely to be associated with burdensome treatment (Morrison & Siu, 2000), it is likely that directives that do not address this, have potential to thwart quality of life at the end of life. While, researchers are observing declines in hospitalization rates (Mor et al., 1997), what is promising is the growing understanding of the management of persons with dementia in an acute and ICU setting. For example, in describing a proactive approach to end of life care, Campbell and Guzman (2004) found that by offering early assistance to ICU staff about optimal care for those with dementia decreased hospital and ICU stays. More importantly, this approach decreased the time between identifying prognosis and the establishment of DNR goals, reducing the burden and increasing the comfort for those with end-stage dementia.

THE CARE FACILITY ENVIRONMENT

The prevalence of dementia amongst persons residing in Canadian care facilities is estimated to be over 50%. Of the remaining 50%, an additional 30% of care facility residents have some degree of cognitive impairments that do not meet the criteria for a dementia diagnosis (Graham et al., 1997). Research also suggests that there is an increasing expectation that terminally ill residents residing in care facilities will die there (Fisher, Ross, & MacLean, 2000). Indeed, a report from Manitoba suggests that 83% of older adults residing in care facilities have in fact died there (Menec et al., 2004). Reports emerging from the United States reveal that 70% of those with dementia die in a care facility (Mitchell, Teno, Miller & Mor, 2005) and while similar Canadian statistics were not found, these data suggest that death is an inevitable outcome for a large proportion of those with dementia residing in care facilities.

In a review of the literature examining end of life care in US nursing homes, evidence suggests that care is suboptimal. (Parker-Oliver, Porock & Zweig, 2004). Apart from poor pain control, the authors found the following factors related to poor end of life care: inadequate care planning, poor communication between family and care staff, insufficient knowledge and

skill of staff, frequent and often unnecessary hospitalizations and a total lack of spiritual and social support to residents, family and staff. The authors conclude that “[End of life] care in nursing homes is inadequate and despite its frequent occurrence, dying goes unrecognized. There is no empiric evidence that indicates a positive, pain-free dying experience in the [long-term care] environment” (p. 154). .

Other researchers have found unsuitable physical environments (Kayser-Jones et al., 2003; Komaromy et al, 2000; Sloane et al., 2003), lack of physician presence and family dissatisfaction with care (Caron, Griffith & Arcand, 2005; Engel, Kiely & Mitchell, 2006; Teno et al., 2004) as indicators of poor end of life care. Moreover, others have observed inadequate pain and symptom management (Hall et al., 2002), unmanaged dyspnea (Hall et al., 2002; Teno et al., 2004), inappropriate use of physical restraints (Allen et al., 2005; Sloane et al., 2008), inadequate nutrition and hydration (Kayser-Jones et al., 1999); preventable contractures and pressure ulcers (Kayser-Jones et al., 2003); little recognition of cultural and spiritual needs (Chan & Kayser-Jones, 2005; Komaromy et al., 2000) and the use of aggressive medical intervention (Mitchell, Kiely & Hamel, 2004). Part of the challenge in providing optimal care is that those with advanced dementia often cannot make their wishes known and are unable to report pain and uncomfortable symptoms (Mezey et al., 2002) and it is difficult to determine precisely when someone has entered the final phase of life (Mitchell et al., 2004).

In the US, the use of hospice within in the nursing home setting has been linked to the provision of better end of life care including pain and symptom management. In a recent study, Sloane and colleagues (2008) observed that the provision of hospice in the US has risen remarkably. In Canada, specialist palliative care teams are available to some residential care facilities. However, there is no consistent access to these teams across Canada or within BC and in general, palliative care remains a patchwork of services across the country (Carstairs & Beaudoin, 2000). Similarly, others have observed that hospice or specialist palliative care services remain an elusive service for many persons with dementia. In fact, a palliative specialist once said that “as a rule, patients suffering from dementia and wanting to be managed by a palliative care unit ought to remember to develop some form of cancer” (as cited in Small, Froggatt & Downs, 2007, p.85).

Mezey and associates (2002) contend that care facilities often do not perceive themselves as a place of care for the dying. Rather, the customary goal of care has been to maximize the independence and functionality of residents to the highest level of attainment. In addition, the regulatory environment emphasizes facility performance as opposed to quality of life for the residents (Kane, 2003). As Johnson (2005) writes, “...once dying is recognized as an

undeniable part of living – including living in a nursing home – it is clear that the ideal of health promotion will have to embrace care for the dying” (p.541).

Dying with dementia in assisted living facilities has received far less attention than the care facility context. Sloane and colleagues (2003) compared general end of life care in assisted living to care facility environments and found no remarkable difference between the settings. More research is needed to examine the assisted living environment and the relationship to dementia end of life care. In particular, it would be useful to explore to what extent assisted living environments enable ageing in place for those with dementia.

HOME SETTINGS

While the majority of persons with dementia receive end of life care in residential care settings, home deaths are possible (Mitchell et al., 2004; Schulz et al., 2003; Volicer et al., 2003). However, care at home can be particularly difficult for informal caregivers and a breakdown in the informal caregiver system often necessitates a shift towards institutional care (Schulz et al., 2003).

Although those with end-stage dementia may transition to acute settings or residential care (Mitchell et al, 2003; Volicer et al., 200) from the home setting, there is little understanding of the experience of dying at home for those with dementia. Research into the end of life experience for those with dementia living at home demonstrates mixed results. For example, while Volicer and colleagues (2003) report that the provision of end-of-life home care has been related to fewer symptoms and discomfort than those with dementia dying in acute or care facility settings, Mitchell and associates found that pain and untreated shortness of breath were more likely observed in their home care cohort. Schulz and colleagues (2003) also report high levels of pain experienced by those dying at home. Both Mitchell et al., and Volicer et al., found that someone with dementia can be successfully supported at home with involvement of hospice programs, effective pain management and the provision of psychiatric care (Mitchell et al., 2004; Volicer et al., 2003). However, Schulz and colleagues found that of their sample of family caregivers, hospice was not utilized and the primary care physician was the only formal service used.

Education and support for formal care providers

Scholars have stressed the importance of care providers’ knowledge of end of life care and dementia care. However, there is a deficit in skills and knowledge with respects to

dementia and end of life care (McCloskey, 2004). As physicians and nurses are the most likely professionals to guide end of life discussions, it is urgent that they have the requisite knowledge and interpersonal skills to effectively engage in these conversations. However, end of life and dementia care in both medical and nursing curricula is not clearly understood (Ferrell, Virani & Grant, 1999; Sachs et al., 2004). In a survey of 16 Canadian family medicine teaching programmes, Oneschuk and Bruera (1998) sought to determine the extent to which family medicine residents received palliative care education. The researchers found that while the majority of the universities offered lectures and reading material in palliative care, only 56% have a designated faculty position for palliative medicine.

Ersek, Kraybill and Hansberry (1999) examined end of life educational needs of licensed nursing staff and care aides in US nursing homes. The authors found gaps in skill and knowledge in regards to symptom management, communication difficulties, and conflict with family and physicians. In a British study of care aides' knowledge of palliative care, similar results were found (Whittaker et al., 2007). Of particular significance was the lack of awareness as to what palliative care was and when palliative measures would be of benefit. Further, while care aides expressed confidence in providing care related to activities of daily living tasks they were less so in supporting residents' psychosocial, spiritual and cultural needs.

Research has shown that continuing education significantly improves knowledge attitude and confidence in providing end of life care (Ersek, Kraybill & Hansen, 2005; Mockus-Parks et al., 2005; Monteleoni & Clark, 2004) and has been related to increased family satisfaction (Arcand, et al., 2009). Education specifically geared towards nursing home physicians is related to improved pain control, relief of dyspnea, improved advanced care planning and total comfort (Keay et al., 2003). Education and collaboration provided by palliative or hospice care teams have also been shown to effectively reduce the use of tube feeding (Monteleoni & Clark, 2004) and significantly decreases discomfort amongst persons with dementia (Kovach, Wilson, & Noonan, 1996). Further, providing education on and adopting multidisciplinary guidelines is related to more effective pain management as well as significantly decrease the use of antibiotics (Llyod-Williams & Payne, 2002). Research in the United States indicates that residents in care facilities that utilize hospice services are less likely to be hospitalized at the end of life (Bottrell et al., 2001) and typically, hospice consultations offer an educative component (Sachs et al., 2004).

However, education alone is not necessarily sufficient to change practice or widely affect outcomes for persons with dementia (Ersek, Grant & Kraybill, 2005). Strong leadership and an organizational willingness to implement quality improvement initiatives are also key

(Ersek et al., 2005; Thompson et al., 2008; Sachs et al., 2004). For example, when recruiting facilities to participate in an end of life education initiative, Ersek and colleagues observed 30% non-responses from facility leadership, despite the education being free of charge. The researchers also found that willingness to engage in the initiative was most successful where there was an identified “champion” within the facility. Similarly, when implementing multidisciplinary guidelines to improve care at the end of life, Lloyd-Williams and Payne (2002) found that nursing staff were empowered as “change agents” to help reinforce the case to utilize palliative approaches. Taken together, ensuring that education programs are well-supported by facility management is an important aspect to the continued success of these projects.

Discussion and Recommendations

Kayser-Jones and colleagues (2003) conclude, “To ensure that people who die in nursing homes receive adequate care, changes must be made” (p. 83) and it seems that the end of life experience for persons with dementia is compromised regardless of setting. Yet, significant improvements have been made and were observed in the following areas:

- Pain management: Implementation of multidisciplinary guidelines (Lloyd-Williams & Payne, 2002) and pain assessment tools (Kovach et al., 1999) to improve pain;
- Feeding tube placement: Education and palliative care team consultation reduces feeding tube placements (Monteleoni & Clark, 2004); educating family members in terms of nutrition and hydration promotes more accurate knowledge and reduces the burden of decision-making (Mitchell et al., 2001);
- Managing pneumonia: Use of vaccinations (Brandeis et al., 1998) and good oral health programs (Yoneyama et al., 2002) to reduce the occurrence of pneumonia;
- Improving care staff-resident relationships: Providing a relationship-enhancing intervention improves care staff – resident relationships and increases resident quality of life (Hansebo & Khilgren, 2001);
- Forming partnerships with family: Engaging families in partnership in care (Robinson et al., 2007) improves family satisfaction and enhances resident quality of life;
- Educating frontline workers: Educating ICU staff in optimal dementia end of life care reduces hospital stays (Campbell & Guzman, 2004); continuing education in the care

facility improves knowledge, skill and attitude in providing end of life care (Ersek et al., 2005; Mockus-Parks et al., 2005)

However, these initiatives are not wide-spread, significant gaps are still evident and the need to continually improve still persists. As Downs, Small and Froggatt (2006) state, “a significant change in practice requires a change not just in what we do but also in how we think about what we do” (p. 209).

Yet, pioneering work in recent decades has shown that a ‘good death’ for those with dementia is achievable (Shega et al., 2003). However, despite the trajectory model of palliative care proposed by Lynn and Adamson in 2003, this model does not seem to fully shape the health systems’ response in caring for those with dementia (Thompson & Parker-Oliver, 2008). Small and colleagues (2007) write, “By avoiding thinking about death makes it more difficult to plan for deterioration in functioning and, of course, it makes planning for death impossible” (p. 194). In this current dualistic approach to care (i.e., curative or palliative), persons with dementia are excluded from actively participating in planning for their future care. What makes it difficult lies in the slow, downhill trajectory of a dementia illness making comprehensive and coordinated care hard to sustain (Wilkinson & Lynn, 2005). Thus, rather than addressing end of life early on the illness journey, active participation in planning happens much later, and for some, it happens when they can no longer participate in the process. In this light, there are a growing number of scholars who advocate for a palliative approach to care in the *ongoing* primary care of persons with dementia over years rather than months prior to death (Shega et al., 2003).

In light of the above initiatives and the literature reviewed, the following are recommended:

1. To implement palliative care as a framework of care for persons with dementia

An example of such a program in the community setting is the Palliative Excellence in Alzheimer Care Efforts (PEACE) Project (Shega et al., 2003). The goal of the PEACE project is to bring support to those with dementia much earlier in their illness through to death; with an emphasis on end of life care. Palliative care consultation is integrated into primary care of the person with dementia focusing on the following components:

- Person-centred care
- Advanced care planning
- Family support
- Education on disease processes

- Improved coordination of care

Within residential care, the culture change movement is gaining momentum shifting from medical-based models of care to those considered 'person-centred'. Key components of person-centred care include:

- Acknowledgment and affirmation of person with dementia as a unique individual
- Validation of person's emotional reality
- Support the person's experience or sense of the world (Kitwood, 1997)

In addition, educating care providers, supporting family and being responsive to the resident's needs along their journey are key components to person-centred models of care. What is appealing to both the PEACE model as well as person-centred models is the movement from institutional care to communities of care that can actually help sustain comprehensive and coordinated care (Wilkinson & Lynn, 2005). An integrated 'system' that journeys alongside someone with dementia through the course of their illness helps maintain and preserve essential meanings of personhood; that is, "respect and acknowledgement of the individual as a member of the human moral community" (Jennings, 2004, p. 275).

However, for any 'shift' to take place there is integral need for strong and committed leadership; for leadership to model best practice and to support those who are providing frontline care to those with dementia. These ideas can be extrapolated to the macro-organizational culture as well. The federal and provincial governments can show this type of leadership and innovation by adopting and implementing a palliative care strategy to improve the end of life experience for all Canadians.

2. To engage the voice of persons with dementia

Engaging the voices of persons with dementia is integral to any end of life strategy and quality improvement initiative. Inclusion in planning and decision-making about health services and programs is a necessary direction such that needs and services are effectively aligned.

3. To initiate advance care planning early on in the dementia journey

Dialogue about end of life care preferences need to occur before the person becomes incapable of making them known. Discussions along the dementia journey can be more responsive to the emerging needs of the person with dementia. Goal setting for care and

dialogue about the risk and benefits of various interventions are important pieces in conversation. Coming to consensus prior to a crisis helps alleviate the stress for the resident, family and formal care providers (Travis et al., 2001). Individuals and families should be provided with education that is comprehensive, culturally appropriate and sensitive to health literacy. Moreover, education should be delivered through a variety of methods (printed material, on-line learning, videos etc) that explain the natural course of dementia, the various treatments as well as what to expect when death is imminent. This will help prepare individuals and families for the ongoing dementia journey and give confidence in end of life decision-making. Utilizing a team approach to end of life care planning ensures that information regarding the persons' health status is shared in a timely fashion and that the person and their family will be supported. In all aspects of care planning, key questions to answer centre on 'how beneficial is the intervention for the person with dementia; is the intervention consistent with the person's preferences; and, what intervention would best promote the comfort of the person (Abbey, 2006).

4. To enhance cultural competence of formal care providers

There is a considerable lack of understanding and appropriate response to the socio-cultural needs of people with dementia at the end of life. This gap directly affects supporting the spiritual and psychosocial well being of not only the person with dementia, but also their families. It also affects care providers' understandings of medical and care choices made by family and the person with dementia. Thus, efforts must be made to create a pool of culturally competent care providers across all settings of care.

5. To ensure that spiritual needs are met at the end of life

A related issue involves addressing spiritual needs. For some, spirituality may be expressed through ritual and religious practices (Teno, Landrum & Lynn, 1997). Yet, for others spirituality may be expressed in different ways. Thus, a broader understanding of spirituality is needed to meet existential needs of persons with dementia and their families. By remaining firmly grounded in person-centred care, providers can more effectively meet spiritual needs. Care providers must be sensitive to differences between individuals and not assume that spiritual needs can sufficiently be met through a pastoral care visit or a religious service.

6. To ensure that care providers have appropriate end of life care and dementia knowledge

In addition, as care aides provide the majority of hands-on care within residential care facilities and assisted living settings, there is an urgent need for this group of providers to have relevant education as well. However, there is also an apparent lack of dementia end of life care

in their curricula (Ersek, Kraybill & Hansberry, 1999). Thus, there is a pressing need to put systems in place where care providers will be presented with continuing education and guidance in the full spectrum of end of life care - from philosophical understandings of death and dying to pain/symptom management, psychosocial and spiritual support at the end of life (Ersek, et al., 1999; Raudonis, Kyba & Kinsey; 2003

7. To ensure that mandated assessment and monitoring processes are sensitive to end of life care needs

The MDS assessment framework appears to under-report symptoms of pain (Cohen-Mansfield, 2004). Moreover, funding that is attached to this framework rewards aggressive interventions such as the use of tube feeds (Mitchell et al., 2003) and less so, comfort care measure. As such, it is important to examine the usability of the MDS in the context of end of life care.

In a discussion about the regulatory environment of the US residential care system, Thompson and Parker-Oliver (2008) argue that while resident care and outcomes have improved since the mandatory completion of the MDS, it “does little to prompt providers regarding the needs of those at the end of life” (p.172). The MDS system has embedded ‘prompts’ that direct care planning and because they are quite sensitive, they may impose inappropriate goals for residents are declining or dying (for example, a prompt might suggest that a goal of care is to improve physical functioning). Consequently, critics of the MDS system suggest that it is geared heavily towards restorative/rehabilitative care and as the researchers argue, this leaves those nearing death inappropriately receive aggressive rehabilitative care and a denial of death persists (Miller, Teno & Mor, 2004; Johnson, 2005; Thompson & Parker-Oliver, 2008). Funding is also linked to the MDS system also favouring those receiving aggressive or rehabilitative care and again, those at the end of life do not receive the resources necessary for optimal care (Kane, 2003). Concerns about reliability and accuracy of the data have also been raised and data quality is only as good as those completing the assessment (Shin & Sherer, 2009). While research has shown that data quality and subsequent care planning is improved if the assessment is completed in conjunction with front-line staff (Taunton, Swaggerty, Smith, Lasseter & Lee 2004), if care providers do not see the value of the system, it is likely that it will be viewed as an add-on and its potential value diminished.

As the BC provincial government has mandated the use of the MDS in residential care facilities as well as the home care equivalent (RAI-HC), it is imperative to gain a better understanding of the usefulness of these assessments as end of life care planning tools. Moreover, if BC follows suit in using MDS data to inform funding and regulation, then it is

essential for these funding bodies to know exactly what information the MDS and home care assessments captures and the evident gaps in the assessments. Without this knowledge, decisions will erroneously be made and no matter what recommendations are made to improve care practice; these will only be good intentions if funding and support on an organizational/provincial level does not follow suit. Moreover, it would be wise to adapt the MDS to reflect goals of palliative care and efforts should be made to align financial incentives with the provision of palliative care – much like incentive is given to provide rehabilitative care (Sachs et al., 2004). Various health authorities have made efforts in creating pathways with MDS data that may help identify someone who may require end of life care earlier (see for example: Tait et al., 2007) as well as developing detailed care planning tools (see for example: Fraser Health Care Planning Framework).

References

- Addington-Hall, J., Fakhoury, W., McCarthy, M. (1998). Specialist palliative care in non-malignant disease. *Palliative Medicine*, 12, 417-427
- Alzheimer's Australia. (2006). Palliative Care and Dementia.
- Ahronheim, J.C., Morrison, R.S., Baskin, S.A., Morris, J., & Meier, D.E. (1996). Treatment of the dying in the acute care hospital: Advanced dementia and metastatic cancer. *Archives of Internal Medicine*, 156, 2094-2100.
- Albinsson, L., & Strang, P. (2002). A palliative approach to existential issues and death in end-stage dementia care. *Journal of Palliative Care*, 18, 168-174.
- Allen, R.S., Burgio, L.D., Fisher, S.E., Hardin, J.M., & Shuster, J.L. (2005). Behavioral characteristics of agitated nursing home residents with dementia at the end of life. *The Gerontologist*, 45, 661-666.
- Alzheimer Society of BC (2009). *Put your mind to it: Make change happen for those living with dementia*. Brochure
- Aminoff, B.Z., & Adunsky, A. (2005). Dying dementia patients: Too much suffering, too little palliation. *American Journal of Hospice and Palliative Medicine*, 22, 344-348.
- Andrews, S., McInerney, F., & Robinson, A. (2009). Realizing a palliative approach in dementia care: Strategies to facilitate aged care staff engagement in evidence-based practice. *International Psychogeriatrics*, 21, S64-S68.
- Arcand, M., Monette, J., Monette, M., Sourial, N., Fournier, L., Gore, B., & Bergman, H. (2009). Educating nursing home staff about the progression of dementia and the comfort care option: Impact on family satisfaction with end-of-life care. *Journal of the American Medical Director Association*, 10, 50-55.
- Arinzon, Z., Peisakh, & Berner, Y. (2008). Evaluation of the benefits of enteral nutrition in long-term care elderly patients. *Journal of the American Medical Directors Association*, 9, 657-662.
- Aupperle, P.M., MacPhee, E.R., Strozeski, J.E., Finn, M., & Heath, J.M. (2004). Hospice use for the patient with advanced Alzheimer's disease: The role of the geriatric psychiatrist. *American Journal of Alzheimer's Disease and Other Dementias*, 19, 94-104.

- Australian Pain Society (2005). *Pain in residential aged care facilities: Management strategies*. Retrieved, May 4, 2007 from www.apsoc.org.au.
- Benbow, S.M., & Quinn, A. (1990). Dementia, grief and dying. *Palliative Medicine*, 4, 87-92.
- Benkendorf, R., Swor, R.A., Jackson, R., Rivera-Rivera, E.J., Demrick, A. (1997) Outcomes of cardiac arrest in the nursing home: Destiny or futility? *Prehospital Emergency Care*, 1, 68-72.
- Bern-Klug, M., Gessert, C.E, Crenner, C.W., Buenaver, M., & Skirchak, D. (2004). "Getting everyone on the same page": Nursing home physician's perspectives on end-of-life care. *Journal of Palliative Medicine*, 7, 533-544.
- Black, A.L., & Arnold, R.M. (2005). Dealing with conflict in caring for the seriously ill. *Journal of the American Medical Association*, 293, 1374-1381.
- Black, H.K. & Rubinstein, R.L. (2004). Themes of suffering in later life. *Journal of Gerontology: Social Sciences*, 59, S17-S24.
- Blasi, Z.V., Hurley, A.C., & Volicer, L. (2002). End-of-life care in dementia: A review of problems, prospects, and solutions in practice. *Journal of the American Medical Directors Association*, 3, 57-65.
- Bottrell, M., O'Sullivan, J.F., Robbins, M.A., Mitty, E.L., & Mezey, M.D. (2001). Transferring dying nursing home residents to the hospital: DON perspectives on the nurse's role in transfer decisions. *Geriatric Nursing*, 22, 313-317.
- Brandeis, G.H., Berlowitz, D.R., Coughlin, N (1998). Mortality associated with an influenza outbreak on a dementia care unit. *Alzheimer's Disease and Associated Disorders*, 12, 140-145.
- Brazil, K., & Vohra, J.U (2005). Identifying educational needs in end-of-life care for staff and families of residents in care facilities. *International Journal of Palliative Nursing*, 11, 475-481.
- British Columbian Ministry of Health (2006). *A framework for end of life care*.
- Brodaty, H., Green, A., & Koschera, A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society*, 51, 657-664.

- Brudney, D. (2009). Choosing for another: Beyond autonomy and best interests. *Hastings Centre Report*, 39, 2, 31-37.
- Calkins, M.P. (2005). Environments for late-stage dementia. *Alzheimer's Care Quarterly*, 6, 71-75.
- Campbell, M.L., & Guzman, J.A. (2004). A proactive approach to improve end-of-life care in a medical intensive care unit for patients with terminal dementia. *Critical Care Medicine*, 32, 1839-1843.
- Caron, C.D., Griffith, J., & Arcand, M. (2005). Decision making at the end of life in dementia: How family caregivers perceive their interactions with health care providers in long-term-care settings. *Journal of Applied Gerontology*, 24, 231-247.
- Carstairs, S., & Beaudoin (2000). Quality end-of-life care: The right of every Canadian: Final report of the subcommittee to update Of Life and Death. Ottawa: Standing Senate Committee on Social Affairs, Science and Technology.
- Chan, J., & Kayser-Jones, J. (2005). The experience of dying for Chinese nursing home residents: Cultural considerations. *Journal of Gerontological Nursing*, 31, 26-32.
- Chenoweth, L., King, M.T., Jeon, Y.H., Brodaty, H., Stein-Parbury, J., Norman, R., Haas, M., & Luscombe, G. (2009). Caring for aged dementia care resident study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: A cluster randomized trial. *Lancet Neurology*, 8, 317-325.
- Chibnall, J.T., Bennett, M.L., Videen, S.D., Duckro, P.N., & Miller, D.K. (2004). Identifying barriers to psychosocial care at the end of life: A physician group. *American Journal of Hospice and Palliative Care*, 21, 419-426.
- Cipher, D.J., & Clifford, A. (2004). Dementia, pain, depression, behavioural disturbances and ADLS. *International Journal of Geriatric Psychiatry*, 19, 741-748.
- Cipher, D.J., Clifford, A., & Roper, K.D. (2006). Behavioral manifestations of pain in the demented elderly. *Journal of the American Medical Directors Association*, 7, 355-365.
- Cohen-Mansfield, J. (2002) Relatives' assessment of pain in cognitively impaired nursing home residents. *Journal of Pain and Symptom Management*, 24, 562-571.

- Cohen-Mansfield, J. (2004). The adequacy of the minimum data set assessment of pain in cognitively impaired nursing home residents. *Journal of Pain and Symptom Management, 27*, 343-351.
- Daaleman, T.P., Williams, C.S., Hamilton, V.L., Zimmerman, S. (2008). Spiritual care at the end of life in long-term care. *Medical Care, 46*, 85-91.
- D'Agata, E., Mitchell, S.L. (2008). Patterns of antimicrobial use among nursing home residents with advanced dementia. *Archives of Internal Medicine, 168*, 357-362.
- Department of Health and Ageing. (2004). *Guidelines for a Palliative Approach in Residential Aged Care*. Rural Health and Palliative Care Branch, Department of Health and Aged Care, Canberra.
- Dewing, J. (2001). Care for older people with dementia in acute hospital settings. *Nursing Older People, 13*, 18-20.
- Doka, K.J. (2004). Grief and Dementia. In K.J. Doka (Ed.) *Living with grief: Alzheimer's disease* (pp. 139-153). Washington: Hospice Foundation of America.
- Dull, S.M., Graves, J.R., Larsen, M.P., Cummins, R.O. (1994). Expected death and unwanted resuscitation in the prehospital setting. *Annals of Emergency Medicine, 23*, 997-1002.
- Engel, S.E., Kiely, D.K., & Mitchell, S.L. (2006). Satisfaction with end-of-life care for nursing home residents with advanced dementia. *Journal of the American Geriatrics Society, 54*, 1567-1572.
- Ersek, M., Grant, M.M., & Kraybill, B.M. (2005). Enhancing end-of-life care in nursing homes: Palliative Care Educational Resource Team (PERT). *Journal of Palliative Medicine, 8*, 556-566.
- Ersek, M., Kraybill, B.M., Hansberry, J. (1999). Investigating the educational needs of licensed nursing staff and certified nursing assistants in nursing homes regarding end-of-life care. *American Journal of Hospice and Palliative Medicine, 16*, 573-582.
- Ersek, M., Kraybill, B.M., Hansen, N.R. (2006). Evaluation of a train-the-trainer program to enhance hospice and palliative care in nursing homes. *Journal of Hospice and Palliative Nursing, 8*, 42-49.

- Fabiszewski, K.J., Volicer, B., & Volicer, L. (1990). Effects of antibiotic treatment on outcome of fever in institutionalized Alzheimer patients. *Journal of the American Medical Association, 263*, 3168-3172.
- Ferrell, B.A., Ferrell, B.R., & Osterweil, D. (1990). Pain in the nursing home. *Journal of the American Geriatrics Society, 38*, 409-414.
- Ferrell, B.A., Ferrell, B.R., & Rivera, L. (1995). Pain in cognitively impaired nursing home patients. *Journal of Pain and Symptom Management, 10*, 591-598.
- Ferrell, B., Virani, R., & Grant, M. (1999). Analysis of symptom assessment and management content in nursing textbooks. *Journal of Palliative Medicine, 2*, 161-172.
- Finucane, T.E., Christmas, C., & Leff, B.A. (2007). Tube feeding in dementia: How incentives undermine health care quality and patient safety. *Journal of the American Medical Directors Association, 8*, 4, 205-208.
- Finucane, T.E., Christmas, C., Travis, K. (1999). Tube feeding in patients with advanced dementia. *Journal of the American Medical Association, 28*, 14, 1365-1370.
- Finucane, T.E., & Harper, G.M. (1999). Attempting resuscitation in nursing homes: Policy considerations. *Journal of the American Geriatrics Society, 47*, 10, 1261-1264.
- Fisher, R., Ross, M.M., & MacLean, M.J. (2000). Guide to end-of-life care for seniors. Toronto, ON: University of Toronto.
- Forbes-Thompson, S., & Gessert, C.E. (2005). End of life in nursing homes: Connections between structure, process, and outcomes. *Journal of Palliative Medicine, 8*, 545-555.
- Forbes-Thompson, S., & Gessert, C.E. (2006). Nursing homes and suffering: Part of the problem or part of the solution? *Journal of Applied Gerontology, 25*, 234-251.
- Forbes, S., Bern-Klug, M., & Gessert, C.E. (2000). End-of-life decision making for nursing home residents with dementia. *Journal of Nursing Scholarship, 32*, 251-258.
- Fox, P., Solomon, P., Raina, P. & Jadad, A. (2004). Barriers and facilitators in pain management in long-term care institutions: A qualitative study. *Canadian Journal on Aging, 23*, (3), 268-280.
- Froggatt, K. (2001). Life and death in English nursing homes: Sequestration or transition? *Ageing and Society, 21*, 319-332.

- Froggatt, K. (2005). Choice over care at the end of life: Implications of the End of Life Care Initiative for older people in care homes. *Journal of Research in Nursing, 10*, 189-202.
- Fried, T.R., Gillick, M.R., & Liptsitz, L.A. (1997). Short-term functional outcomes of long-term care residents with pneumonia treated with and without hospital transfer. *Journal of the American Geriatrics Society, 45*, 302-306.
- Ganguili, M., & Rodriguez, E.G. (1999). Reporting of dementia on death certificates: A community study. *Journal of the American Geriatrics Society, 47* (7), 842-849.
- Gaugler, J.E., Andersen, K.A., Zarit, S.H., & Pearlin, L.I. (2004). Family involvement in nursing homes: Effects on stress and well-being. *Aging and Mental Health, 8*, 65-75.
- Gessert C.E., Forbes, S., Bern-Klug, M. (2000-2001). Planning end-of-life care for patients with dementia: Roles of families and health professionals. *Omega, 42*, 273-291.
- Gillick, M.R. (2000). Rethinking the role of tube-feeding in patients with advanced dementia. *New England Journal of Medicine, 342*, 206-210.
- Gillick, M.R., & Volandes, A.E. (2008). The standard of caring: Why do we still use feeding tubes in patients with advanced dementia. *Journal of the American Medical Directors Association, 9*, 5, 364-367.
- Gjerdingen, D.K., Neff, J.A., Wong, M., & Chaloner, K. (1999). Older persons' opinions about life-sustaining procedures in the face of dementia. *Archives of Family Medicine, 8*, 421-425.
- Goodridge, D., Bond, J.B., Cameron, C., & McKean, E. (2005). End-of-life care in a nursing home: A study of family, nurse and health care aide perspectives. *International Journal of Palliative Nursing, 11*, 5, 226-232.
- Graham, J.E., Rockwood, K., Beattie, B.L., Eastwood, R., Gauthier, S., Tuokko, H., & McDowell, I. (1997). Prevalence and severity of cognitive impairment with and without dementia in an elderly population. *The Lancet, 349*, 1793-1796.
- Hall, P., Schroder, C., & Weaver, L. (2002). The last 48 hours of life in long-term care: A focused chart audit. *Journal of the American Geriatric Society, 50*, 501-506.
- Hallberg, I.R. (2006). Palliative care as a framework for older people's long-term care. *International Journal of Palliative Nursing, 12*, 224-229.

- Hanrahan, P. & Luchins, D.J. (1995). Feasible criteria for enrolling end-stage dementia patients in home hospice care. *Hospice Journal*, 10, 47-54.
- Hanrahan, P., Raymond, M., McGowan, E., & Luchins, D.J. (1999). Criteria for enrolling patients in hospice: A replication. *American Journal of Hospice and Palliative Care*, 16, 1, 395-400.
- Hanson, L.C., Reynolds, K.S., Henderson, M., & Pickard, C.G. (2005). A quality improvement intervention to increase palliative care in nursing homes. *Journal of Palliative Medicine*, 8, 576-584.
- Herr, K., Bjoro, K., & Decker, S. (2006). Tools for assessment of pain in nonverbal older adults with dementia: A state-of-the-science review. *Journal of Pain and Symptom Management*, 31, 170-192.
- Herr, K., Coyne, P.J., Key, T., McCaffery, M., Merkel, S., Pelosi-Kelly, J., & Wild, L. (2006). Pain assessment in the nonverbal patient: position statement with clinical practice recommendations. *Pain Management Nursing*, 7, 44-52.
- Hicks, M.H., & Lam, M.S. (1999). Decision-making within the social course of dementia: Accounts by Chinese-American caregivers. *Culture, Medicine and Psychiatry*, 23, 415-452.
- Hirschman, K.B., Kapo, J., & Karlawish, J.H.T. (2008). Identifying the factors that facilitate or hinder advance planning by persons with dementia. *Alzheimer Disease and Associated Disorders*, 22, 293-298.
- Holmes, H.M., Sachs, G.A., Shega, J.W., Houghman, G.W., Cox-Hayley, D., & William, D. (2008). Integrating palliative medicine into the care of persons with advanced dementia: Identifying appropriate medication use. *Journal of the American Geriatrics Society*, 56, 1306-1311.
- Hughes, J.C., Jolley, D., Jordan, A., & Sampson, E.L. (2007). Palliative care in dementia: Issues and evidence. *Advances in Psychiatric Treatment*, 13, 251-260.
- Hung, L. (2008). The dining experience of persons with dementia. Master's thesis. Simon Fraser University.
- Hurely, A.C., Volicer, B.J., Volicer, L. (1996). Effect of fever-management strategy on the progression of dementia of the Alzheimer type. *Alzheimer Disease and Associated Disorders*, 10, (1), 5-10.

- Husebo, B.S., Strand, L.S., Moe-Nilssen R., Borge-Husebo, S., Aarsland, D., Ljunggren, A.E. (2008). Who suffers most? Dementia and pain in nursing home patients: A cross-sectional study. *Journal of the American Medical Directors Association, 9*, 427-433.
- Janssens, J.P. & Krause, K.H. (2004). Pneumonia in the very old. *Lancet Infectious Diseases, 4*, 112-124.
- Jennings, B. (2004). Alzheimer's disease and the quality of life. In K.J. Doka (ed.). *Living with Grief: Alzheimer's disease*, pp. 257-258. New York: Springer.
- Johnson, S.H. (2005). Making room for dying. End of life care in nursing homes: Improving end of life care: why has it been so difficult. *Hastings Centre Report, Special report, 35, 6*, S37-S41.
- Kalish, R.A. (1985). *Death, grief and caring relationships*. Monterey, CA: Brooks-Cole Publishing Co.
- Kane, R.A. (2003). Definition, measurement, and correlates of quality of life in nursing homes: Towards a reasonable practice, research, and policy agenda. *The Gerontologist, 43*, 28-36.
- Kaufman, S.R. (2005). *And a time to die: How American hospitals shape the end of life*. Chicago: University of Chicago Press.
- Kayser-Jones, J. (1989). The impact of the environment on the quality of care in nursing homes. A socio-psychological perspective. *Holistic Nursing Practice, 5*, 29-38.
- Kayser-Jones, J. (1997). Inadequate staffing at mealtime: Implications for nursing and health policy. *Journal of Gerontological Nursing, 23*, 14-21.
- Kayser-Jones, J. (2002). The experience of dying: An ethnographic nursing home study. *The Gerontologist, 42 (Special Issue III)*, 11-19.
- Kayser-Jones, J., Schell, E., Lyons, W., Kris, A.E., Chan, J., Beard, R.L. (2003). Factors that influence end-of-life care in nursing homes: The physical environment, inadequate staffing, and lack of supervision. *The Gerontologist, 43, (Special Issue II)*, 76-84.
- Kayser-Jones, J., Schell, E., Porter, C., Barbaccia, J., & Shaw, H. (1999). Factors contributing to dehydration in nursing homes: Inadequate staffing and lack of professional supervision. *Journal of the American Geriatrics Society, 47*, 1187-1194.

- Keay, T.J. (1999). Palliative care in the nursing home. *Generations*, 23, 96-98.
- Keay, T.J., Alexander, C., McNally, K., Crusse, E., & Eger, R.E. (2003). Nursing home physician educational intervention improves end-of-life outcomes. *Journal of Palliative Medicine*, 6, 2, 205-213.
- Keene, J., Hope, T., Fairburn, C., & Jacoby, R. (2001). Death and dementia. *International Journal of Geriatric Psychiatry*, 16, 969-974.
- Kiely, D.K., Mitchell, S.L., Marlow, A., Murphy, K.M., & Morris, J.N. (2001). Racial and state differences in the designation of advance directives in nursing home residents. *Journal of the American Geriatrics Society*, 49, 1346-1352.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham, UK: Open University Press.
- Komaromy, C. (2000). The sight and sound of death. The management of dead bodies in residential and nursing homes for older people. *Mortality*, 5, (3), 299-315.
- Komaromy, C. (2001). The performance of the hour of death. In J. Hockey & D. Clark (Eds.) *Palliative care for older people in care homes*. Buckingham, UK: Open University Press, p.p. 138-150.
- Komaromy, C., Sidell, M., & Katz, J. (2000). The quality of terminal care in residential and nursing homes. *International Journal of Palliative Nursing*, 6, (4), 192-200.
- Kovach, C.R., Noonan, P.E., Griifie, J., Muchka, S., & Weissman, D.E. (2001). Use if the assessment of discomfort in dementia protocol. *Applied Nursing Research*, 14, 193-200.
- Kovach, C.R., Weissman, D.E., Griffie, J., Matson, S., & Muchka, S. (1999). Assessment and treatment of discomfort for people with late-stage dementia. *Journal of Pain and Symptom Management*, 18, (6), 412-419.
- Kovach, C.W., Wilson, S.A., & Noonan, P.E. (1996). The effects of hospice interventions on behaviours, discomfort, and physical complications of end stage dementia nursing home residents. *American Journal of Alzheimer's Disease and Related Disorders*, 11, 7-15.
- Kunin, J. (2003). Withholding artificial feeding from the severely demented: Merciful or immoral? Contrasts between secular and Jewish perspectives. *Journal of Medical Ethics*, 29, 208-212.

- Kuo, S., Rhodes, R.L., Mitchell, S.L., More, V., & Teno, J.M. (2009). Natural history of feeding-tube use in nursing home residents with advanced dementia. *Journal of the American Medical Directors Association, 10*, 264-270.
- Kwak, J., & Haley, W.E. (2005). Current research findings on end-of-life decision making among racially or ethnically diverse groups. *The Gerontologist, 45*, 634-641.
- Leong, I.Y., & Nuo, T.H. (2007). Prevalence of pain in nursing home residents with different cognitive and communicative abilities. *The Clinical Journal of Pain, 23*, 119-127.
- Lewis, L. (2001). Toward a good death in the nursing home, pain management, and hospice are key. *Caring for the Ages, 24*, 24-28.
- Li, I. (2002). Feeding tubes in patients with severe dementia. *American Family Physician, 65*, 1605-1610.
- Lloyd-Williams, M., & Payne, S. (2002). Can multidisciplinary guidelines improve the palliation of symptoms in the terminal phase of dementia? *International Journal of Palliative Nursing, 8*, 370-375.
- Lorenz, K.A., Lynn, J., Dy, S.M., Shugarman, L.R., Wilkinson, A., Mularski, R.A., Morton, S.C., Hughes, R.G., Hilton, L.K., Maglione, M., Rhodes, S.L., Rolon, C., Sun, V.C., & Shekelle, P.G. (2008). Evidence for improving palliative care at the end of life: A systematic review. *Annals of Internal Medicine, 148*, 147-159.
- Luchins, D.J., & Hanrahan, P. (1993). What is appropriate health care for end-stage dementia? *Journal of the American Geriatrics Society, 41*, 25-30.
- Luchins, D.J., Hanrahan, P., & Murphy, K. (1997). Criteria for enrolling dementia patients in hospice. *Journal of the American Medical Association, 289*, 18, 2387-2392.
- Lynn, J. (2001). Serving patients who may die soon and their families. *Journal of the American Medical Association, 285*, 925-932.
- Lynn, J. (2008). Reliable comfort and meaningfulness. *British Medical Journal, 336*, 958-959.
- Lynn, J., West, J., Haussman, S., Gifford, D., Nelson, R., McGann, P., Bergstrom, N., & Ryan, J.A. (2007). Collaborative clinical quality improvement for pressure ulcers in nursing homes. *Journal of the American Geriatric Society, 55*, 1663-1669.

- Maas, M.L., Reed, D., Park, M., Specht, J.P., Schutte, D., Kelley, L.S., Swanson, E.A., Trip-Reimer, T., Buckwalter, K.C. (2004). Outcomes of family involvement in care intervention for caregiver of individuals with dementia. *Nursing Research*, 53, 2, 76-86.
- McCloskey, R. (2004). Caring for patients with dementia in an acute care environment. *Geriatric Nursing*, 25, 139-144.
- McCormick, T.R., & Conley, B.J. (1995). Patients' perspectives on dying and on the care of dying patients. *Western Journal of Medicine*, 163, 236-243.
- McMahon, M.M., Hurley, D.L., Kamath, P.S., & Mueller, P.S. (2005). Medical and ethical aspects of long-term enteral tube feeding. *Mayo Clinic Proceedings*, 80, 1461-1476.
- Meier, D.E., Ahronheim, J.C., Morris, J., Baskin-Lyons, S., & Morrison, R.S. (2001). High short-term mortality in hospitalized patients with advanced dementia: Lack of benefit of tube feeding. *Archives of Internal Medicine*, 161, 594-599.
- Menec, V., Lix, L., Steinbach, C., Ekuma, O., Sirski, M., Dahl, M., & Soodeen, R.A. (2004). Patterns of Health Care Use and Cost at the End of Life. Winnipeg, MB: Manitoba Centre of Health Policy. Retrieved, October 15 2005, from www.umanitoba.ca/centres/mch/reports/pdfs/end_of_life.pdf
- 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 and Medical Sciences*, 64A, 395-402.
- Mezey, M., Kluger, M., Maislin, G., Mittleman, M. (1996). Life-sustaining treatment decisions by spouses of patients with Alzheimer's disease. *Journal of the American Geriatrics Society*, 44, 144-150.
- Mezey, M., Neveloff Dubler, N., Mitty, E., & Aizer Brody, A. (2002). What impact do settings and transitions have on the quality of life at the end of life and the quality of the dying process? *The Gerontologist*, 42 (Special Issue III), 54-67.
- Mentes, J.C., Teer, J., & Cadogan, M.P (2004). The pain experience of cognitively impaired nursing home residents: the perceptions of family members and certified nursing assistants. *Pain Management in Nursing*, 5, 3, 118-125.
- Michel, J.P., Pautex, S., Zekry, D., Zulian, G., & Gold, G. (2002). End-of-life care of persons with dementia. *Journal of Gerontology, Medical Sciences*, 57A, M640-M644.

- Mitchell, S.L., Berkowitz, R.E., Lawson, F.M., & Lipsitz, L.A. (2000). A cross-national survey of tube-feeding decisions in cognitively impaired older persons. *Journal of the American Geriatric Society, 48*, 391-397.
- Mitchell, S.L., Buchanan, J.L., Littlehale, S., & Hamel, M.B. (2003). Tube-feeding versus hand-feeding nursing home residents with advanced dementia: A cost comparison. *Journal of the American Medical Directors Association, 4*, 27-33.
- Mitchell, S.L. & Kiely, D.K. (2001). A cross-national comparison of institutionalized tube-fed older persons. *Journal of the American Medical Directors Association, 2*, 10-14.
- Mitchell, S.L., Kiely, D.K., & Hamel, M.B. (2004). Dying with advanced dementia in the nursing home. *Archives of Internal Medicine, 164*, 321-326.
- Mitchell, S.L., & Lawson, F.M. (1999). Decision-making for long-term tube-feeding in cognitively impaired elderly people. *Canadian Medical Association Journal, 160* (2), 1705-1709.
- Mitchell, S.L., Morris, J.N., Park, P.S., & Fries, B.E. (2004). Terminal care for persons with advanced dementia in the nursing home and home care settings. *Journal of Palliative Medicine, 7*, 6, 808-816.
- Mitchell, S.L., Teno, J.M., Miller, S.C., & Mor, V. (2005). A national study of the location of death for older persons with dementia. *Journal of the American Geriatric Society, 53*, 299-305.
- Mitchell, S.L., Teno, J.M., Roy, J., Kabumoto, G., & Mor, V. (2003). Clinical and organizational factors associated with feeding tube use among nursing home residents with advanced cognitive impairment. *Journal of the American Medical Association, 290*, 73-80.
- Mockus-Parks, S., Haines, C., Foreman, D., McKinstry, E., & Maxwell, T.L. (2005). Evaluation of an educational program for long-term care nursing assistants. *Journal of the American Medical Directors Association, 6*, 61-65.
- Molony, S.L., Kobayashi, M., Holleran, E.A., Mezey, M. (2005). Assessing pain as a fifth vital sign in long-term care facilities: Recommendations from the field. *Journal of Gerontological Nursing, 31* (3), 16-24.
- Moorman, S.M., Hauser, R.M. & Carr, D. (2009). Do older adults know their spouses' end-of-life treatment preferences? *Research on Aging, 31*, 463-491.

- Morrison, R.S., Magaziner, J., Gilbert, M., Koval, K.J., McLaughlin, M.A., Orosz, G., Strauss, E., & Siu, A.L. (2003). Relationship between pain and opioid analgesics on the development of delirium following hip fractures. *Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 58, M76-M81.
- Morrison, R.S., & Siu, A.L. (2000). A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fractures. *Journal of Pain and Symptom Management*, 19, 4, 240-248.
- Monteleoni, C & Clark, E. (2004). Using rapid-cycle quality improvement methodology to reduce feeding tubes in patients with advanced dementia. A before and after study. *British Medical Journal*, 329, 491-494.
- Mor, V., Intrator, O., Fries, B.E., Phillips, C., Teno, J., Hiris, J., Hawes, C., & Morris, J. (1997). Changes in hospitalization associated with introducing the Resident Assessment Instrument. *Journal of the American Geriatrics Society*, 45, 1002-1010.
- Morris, J., & Volicer, L. (2001). Nutritional management of individuals with Alzheimer's disease and other progressive dementias. *Nutrition in Clinical Care*, 4, 148-155.
- Motiwala, S.S., Coyte, P.C. (2006). Predictors of place of death for seniors in Ontario: A population-based cohort analysis. *Canadian Journal on Aging*, 25, 363-371.
- Mylotte, J.P., Naughton, B., Saludades, C., Maszarovics, Z. (1998). Validation and application of the Pneumonia Prognosis index to nursing home residents with pneumonia. *Journal of the American Geriatrics Society*, 46, 1538-1544.
- Naughton, B.J., Mylotte, J.M., Tayara, A. (2001). Outcomes of nursing home-acquired pneumonia: Derivation and application of a practical model to predict 30-day mortality. *Journal of the American Geriatrics Society*, 48, 1292-1299.
- Nolan, M., Grant, G., & Nolan, J. (1995). Busy doing nothing: Activity and interaction levels amongst differing populations of elderly. *Journal of Advanced Nursing*, 22, 528-538.
- Oneschuk, D., & Bruera, E. (1998). Access to palliative medicine training for Canadian family medicine residents. *Palliative Medicine*, 12, 23-27.
- Orchard, H. (2001). Spiritual care in care homes: Perceptions and practices. In J. Hockey & D. Clark (Eds.) *Palliative care for older people in care homes*. Buckingham, UK: Open University Press p.p. 66-85.

- Ory, M.G., Hoffman, R.R., Yee, J.L., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *The Gerontologist, 39*, 177-185.
- Parker, D., & McLeod, A. (2001). Assessment of need in care homes. In J. Hockey & D. Clark (Eds.) *Palliative care for older people in care homes*. Buckingham, UK: Open University Press p.p. 34-51.
- Parker-Oliver, D., Porock, D., & Zweig, S. (2004). End-of-life care in U.S. nursing homes: A review of the evidence. *Journal of the American Medical Directors Association, 5*, 147-155.
- Peck, A., Cohen, C.E., & Mulvihill, M.N. (1990). Long-term enteral feeding of aged demented nursing home patients. *Journal of the American Geriatrics Society of America, 38*, 1195-1198.
- Perrin, T. (1997b). Occupational need in severe dementia: a descriptive study. *Journal of Advanced Nursing, 25*, 934-941.
- Pisani, M.A., Redlich, C.A., McNicoll, L., Ely, E.W., Friedkin, R.J., & Inouye, S.K. (2005). Short-term outcomes in older intensive care unit patients with dementia. *Critical Care Medicine, 33*, 6, 1371-1376.
- Powers, B.A. (2000). Everyday ethics. *American Journal of Alzheimer's Disease and Other Dementias, 15*, 143-151.
- Powers, B.A., & Watson, N.M. (2008). Meaning and practice of palliative care for nursing home residents with dementia at end of life. *American Journal of Alzheimer's Disease and Other Dementias, 23*, 3, 319-325. Retrieved March 3, 2009, from <http://aja.sagepub.com>.
- Post, S.G. (1995). *The moral challenge of Alzheimer Disease*. Baltimore: John Hopkins University Press.
- Pregliasco, F., Mensi, C., Serpilli, W., Speccher, L., Masella, P., & Belloni, A. (2001). Immunogenicity and safety of three commercial influenza vaccines in institutionalized elderly. *Aging, 13*, 38-43.
- Proctor, W.R. & Hirdes, J.P. (2001). Pain and cognitive status among nursing home residents in Canada. *Journal of Pain Research and Management, 6*, 3, 119-125

- Raudonis, B.M., Kyba, F.C.N., & Kinsey, T.A. (2002). Long-term care nurses' knowledge of end of life care. *Geriatric Nursing, 23*, 6, 296-301.
- Robison, J., Curry, L., Gruman, C., Porter, M., Henderson, C.R Jnr., & Pillemer, K. (2007). Partners in caregiving in a special care environment: Cooperative communication between staff and families on dementia units. *The Gerontologist, 47*, 4, 504-515.
- Sachs, G.A., Shega, J.W., & Cox-Hayley, D. (2004). Barriers to excellent end-of-life care for patients with dementia. *Journal of General Internal Medicine, 19*, 1057-1063.
- Saliba, D., Kington, R., Buchanan, J., Bell, R., Wang, M., Lee, M., Herbst, M., Lee, D., Sur, D., & Rubenstein, L. (2000). Appropriateness of the decision to transfer nursing facility residents to the hospital. *Journal of the American Geriatrics Society, 48*, 154-163.
- Sampson, E.L., Gould, V., Lee, D., & Blanchard, M.R. (2006). Differences in care received by patients with and without dementia who died during acute hospital admission: A retrospective case note study. *Age and Ageing, 35*, 187-189.
- Sanders, D.S., Careter, M.J., D'Silva, J., James, G., Bolton, R.P., Bardhan, K.D. (2000). Survival analysis in percutaneous endoscopic gastroenterology feeding: A worse outcome in patients with dementia. *American Journal of Gastroenterology, 95*, 6, 1472-1475.
- Shin, J.H., & Sherer, Y. (2009). Advantages and disadvantages of using MDS data in nursing research. *Journal of Advanced Nursing, 35*, 7-17.
- Schulz, R., Mendelssohn, A.B., Hayley, W.E., Mahoney, D., Allen, R.S., Zhang, S., Thompson, L., & Belle, S.H. (2003). End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *New England Journal of Medicine, 349*, 1936-1942.
- Schulz, R., Boerner, K., Shear, K., Zhang, S., & Gitlin, L.N. (2006). Predictors of complicated grief among dementia caregivers: A prospective study of bereavement. *American Journal of Geriatric Psychiatry, 14*, 650-658.
- Shega, J.W., Levin, A., Hougham, G.W., et al., (2003). Palliative Excellence in Alzheimer Care Effort (PEACE): A program description. *Journal of Palliative Medicine, 6*, 315-320.
- Simmons, S.F., Keeler, E., MPhil, X.Z., Hickey, K.A., Sato, H., & Schnelle, J.F. (2008). Prevention of unintentional weight loss in nursing home residents: A controlled trial of feeding assistance. *Journal of the American Geriatrics Society, 56*, 1466-1473.

- Simmons, S.F., Osterweil, D., & Schnelle, J.F. (2001). Improving food intake in nursing home residents with feeding assistance: A staffing analysis. *Journal of Gerontology: Series A. Biological Sciences and Medical Sciences*, 56, 12, M790-794.
- Sloane, P.D., Zimmerman, S., Hanson, L., Mitchell, M., Riedel, Leo, C., & Custis-Buie, V. (2003). End-of-life care in assisted living and related residential care settings: Comparison with nursing homes. *Journal of the American Geriatrics Society*, 51, 1587-1594.
- Sloane, P.D., Zimmerman, S., Williams, C.S., & Hanson, L.C. (2008). Dying with dementia in long-term care. *The Gerontologist*, 48, 6, 741-751.
- Small, N. (2007). Living well until you die: Quality of care and quality of life in palliative and dementia care. *Annals of the New York Academy of Sciences*, 1114, 194-203.
- Small, N., Froggatt, K., & Downes, M. (2007). *Living and dying with dementia: Dialogues about palliative care*. Oxford: Oxford University Press.
- Stone, R. (2003). Selecting a model or choosing your own culture. *Journal of Social Work in Long Term Care*, 2, (3/4), 411-412.
- Sweeting, H., & Gilhooly, M. (1997). Dementia and the phenomenon of social death. *Sociology of Health and Illness*, 1, 93-117.
- Sydner, Y.M., & Fjellstrom, C (2005). Food provision and the meal situation in elderly care: Outcomes in different social contexts. *Journal of Human Nutrition and Dietetics*, 18, 1, 45-52.
- Tait, J., Howley, S., Porterfield, P., Turris, M., & Blois, B. (2007). *The next CHES move: Integrating RAI 2.0 outputs into the palliative care planning process*. Poster Presentation, CIHI RAI Conference: Edmonton AB.
- Taunton, R.L., Swagerty, D.L., Smith, B., Lasseter, J.A., & Lee, R.H. (2004). Care planning for nursing home residents: Incorporating the Minimum Data Set requirements into practice. *Journal of Gerontological Nursing*, 30, 40-49.
- Teno, J (1998). Looking beyond the "form" to complex interventions needed to improve end-of-life care. *Journal of the American Geriatrics Society*, 46, 1170-1171.

- Teno, J.M., Clarridge, B.R., Casey, V., Welch, L.C., Wetle, T., Shield, R., & Mor, V. (2004). Family perspectives on end-of-life care at the last place of care. *Journal of the American Medical Association, 29*, 88-93.
- Teno, J.M., Landrum, K., & Lynn, J. (1997). Defining and measuring outcomes in end-stage dementia. *Alzheimer Disease and Associated Disorders, 2*, 25-29.
- Thomas, B.M., Starr, J.M., & Whalley, L.J. (1997). Death certification in treated cases of presenile Alzheimer's disease and vascular dementia in Scotland. *Age and Aging, 26*, 401-406.
- Thompson, G.N., Menec, V.H., Chochinov, H.M., & McClement, S.E. (2008). Family satisfaction with care of a dying loved one in nursing homes: What makes the difference? *Journal of Gerontological Nursing, 34*, 12, 37-44.
- Thompson, S., & Parker-Oliver, D. (2008). A new model for long-term care: Balancing palliative and restorative delivery. *Journal of Housing for the Elderly, 22*, 169-194. Retrieved, March 25, 2009 from www.informaworld.com.
- Travis, S.S., Bernard, M., Dixon, S., McAuley, W.J., Loving, G., & McClanahan, L. (2002). Obstacles to palliation and end-of-life care in a long-term care facility. *The Gerontologist, 42*, (3) 342-349.
- Travis, S.S., Loving, G., McClanahan, L., & Bernard, M. (2001). Hospitalization patterns and palliation in the last year of life among residents in long-term care. *The Gerontologist, 41*, 153-160.
- Triplett, P., Black, B.S., Phillips, H., Richardson-Fahrendorf, S., Schwartz, J., Angelino, A.F., Anderson, D., & Rabins, P.V. (2008). Content of advanced directives for individuals with advanced dementia. *Journal of Aging and Health, 20*, 583-596.
- Tseng, W.S., & Streltzer, J. (2004). Introduction: Culture and psychiatry. In, W.S. Tseng & J. Streltzer (Eds.) *Cultural Competence in Psychiatry*, pp. 1-20. Arlington, VA: American Psychiatric Publications.
- Van der Steen, J.T., Gijsberts, M.J.H.E., Muller, M.T., Deliens, L., & Volicer, L. (2009). Evaluations of end of life with dementia by families in Dutch and U.S. nursing homes. *International Psychogeriatrics, 21*, 321-329.

- Van der Steen, J.T., Ooms, M.E., Mehr, D.R., Van der Wal, G., & Ribbe, M.W. (2002). Severe dementia and adverse outcomes of nursing home-acquired pneumonia: Evidence for mediation by functional and pathophysiological decline. *Journal of the American Geriatrics Society, 50*, 439-448.
- Volandes, A.E., Paasche-Orlow, M., Gillick, M.R., Cook, E.F., Shaykevich, S., Abbo, E.D., & Lehmann, L. (2008). Health literacy, not race predicts end-of-life care preferences. *Journal of Palliative Medicine, 11*, 754-762.
- Volicer, L., Brandeis, G.H., & Hurley, A.C. (1998). Infections in Advanced Dementia. In L. Volicer & A.C. Hurley (eds.). *Hospice care in patients with advanced progressive dementia*, pp. 29-47. New York: Springer.
- Volicer, L., Hurley, A.C., & Blasi, Z.V. (2001). Scales for evaluation of end of life care in dementia. *Alzheimer's Disease and Associated Disorders, 15*, 194-200.
- Volicer, L., Hurley, A.C., & Blasi, Z.V. (2003). Characteristics of dementia end-of-life care across care settings. *American Journal of Hospice and Palliative Medicine, 20*, 191-200.
- Voordouw, B.C., van der Linden, P.D., Simonian, S., van der Lei, J., Sturkenboom, M.C., & Sticker, B.H. (2003). Influenza vaccination in community-dwelling elderly: Impact on mortality and influenza-associated morbidity. *Archives of Internal Medicine, 163*, 1089-1094.
- Watcherman, M., Kiely, D.K., & Mitchell, S.L (2008). Reporting dementia on the death certificates of nursing home residents dying with end-stage dementia. *Journal of the American Medical Association, 300* (22), 2608-2610.
- Whittaker, E., Kernohan, W.G., Hasson, F., Howards, V., McLaughlin, D. (2007). Palliative care in nursing homes: Exploring care assistants' knowledge. *International Journal of Older People Nursing, 2*, 36-44.
- Wilkinson, A., & Lynn, J. (2005). Caregiving for advanced chronic illness patients. *Techniques in Regional Anesthesia and Pain Management, 9*, 122-132.
- Witucki, J.M., & Twibell, R.S. (1997). The effect of sensory stimulation activities on the psychological well being of patients with advanced Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias, 12*, 1, 10-15.

- Wolf-Klein, G., Pekmezaris, R., Chin, L., & Weiner, J. (2007) Conceptualizing Alzheimer's disease as a terminal medical illness. *American Journal of Hospice and Palliative Medicine*, 24, 77-82.
- Won, A., Lapane, K., Gambassi G., Bernabei, R., Mor, V., & Lipsitz, L. (1999) Correlates and management of non-malignant pain in the nursing home. *Journal of the American Geriatrics Society*, 47, 936-942.
- Yoneyama, T., Yoshida, M., Ohrui, T., & Mukaiyama, H. (2005). Oral care reduces pneumonia in older patients in nursing homes. *Journal of the American Geriatrics Society*, 50, 430-433.
- Young, J. (2002). Artificial Nutrition in older people with dementia: Moral and ethical dilemmas. *Nursing Older People*, 14,
- Zieber, C.G., Hagen, B., Armstrong-Esther, C., & Aho, M. (2005). Pain and agitation in long-term care residents with dementia: Use of the Pittsburgh agitation scale. *International Journal of Palliative Nursing*, 11 (2), 71-78.
- Zimmerman, S., Sloane, P.D., Hanson, L., Mitchell, C.M., & Shy, A. (2003). Staff perceptions of end-of-life care in long-term care. *Journal of the American Medical Directors Association*, 4, (1), 23-26.
- Zweig, S.C. (1997). Cardiopulmonary resuscitation and do-not-resuscitate orders in nursing homes. *Archives of Family Medicine*, 6, 5, 424-429.