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Emily M. Hill

The University of Western Ontario

Supervisor

Dr. Marie Savundranayagam

The University of Western Ontario

Graduate Program in Health and Rehabilitation Sciences

A thesis submitted in partial fulfillment of the requirements for the degree in Master of Science

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INVESTIGATING BARRIERS TO ACCESS AND DELIVERY OF PALLIATIVE
CARE FOR PERSONS WITH DEMENTIA IN LONG TERM CARE IN LONDON,
ONTARIO

(Thesis Format: Monograph)

by

Emily Hill

Graduate Program in Health and Rehabilitation Sciences

A thesis submitted in partial fulfillment
of the requirements of the degree of
Master of Science

The School of Graduate and Postdoctoral Studies
The University of Western Ontario
London, Ontario, Canada

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Abstract

Dementia is a syndrome that is progressive, degenerative and terminal. The palliative care philosophy aims to maximize quality of life for the dying individual and has been recognized in the literature as being both beneficial and under-used in persons dying with dementia. The purpose of this study was to investigate the experiences of staff delivering palliative care to individuals with dementia to determine how care was delivered, to learn which assessment tools were used, and whether policies were affected the delivery of palliative care. Twenty-two staff participants were interviewed. Data were interpreted using phenomenological methodology. Findings yielded three themes: confusion, resource shortages, and communication difficulties. Implications for practice include the clarification of terminology surrounding palliative care, the education of families about dementia and palliative care, better resource management, and a dementia-specific model of palliative care. Fruitful areas for future research include how to implement best dementia-specific guidelines, and solutions for more efficient resource use.

Keywords: dementia, palliative care, barriers to access, long-term care

Acknowledgements

Firstly, I would like to thank my supervisor, Dr. Marie Savundranayagam for her invaluable support, guidance, and encouragement throughout this process. Secondly, I would like to thank my committee members, Dr. Zecevic and Dr. Kloseck for their help and guidance. To my family, especially my parents, and to Jayde, thank you for your unwavering support, encouragement and love. Lastly, to all of the individuals who gave their time to participate in this study, thank you.

For Ruth Hill

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Chapter 1: Background

Dementia is a progressive syndrome caused by many diseases that results in impairments in brain function, memory and cognition, communication, speech, swallowing, balance, essential bodily functions, and activities of daily living (American Psychiatric Association, 2013). Types of dementia include Alzheimer's disease (the most common form), Lewy-Body dementia, vascular dementia, and frontotemporal dementia, among other types (World Health Organization, 2012). The term "dementia" will be used to encompass all different disease types and forms of dementia.

The World Health Organization (WHO) estimates that there are currently 35.6 million people worldwide who are living with a diagnosis of dementia (WHO, 2012). According to the WHO (2012), the median age of survival for an individual with Alzheimer's disease is 7.1 years, but survival rates with a diagnosis of dementia are extremely variable. Persons with dementia often die from complications associated with the causative diseases, such as pneumonia acquired because of difficulty swallowing, or falls associated with muscle weakness and disorientation (WHO, 2012).

It is estimated that 747,000 Canadians currently are living with dementia (Alzheimer Society of Canada, 2012). This number is continuing to rise, and is expected to reach 1.4 million by 2031 (Alzheimer Society of Canada, 2012). The rise is due in part to Canada's aging population (Alzheimer Society of Canada, 2012). Dementia affects not only the individuals who have it, but also their family caregivers, and healthcare professionals working with those with the syndrome. The terminal nature of dementia, coupled with the fact that it causes cognitive decline, means that individuals in the late and end stages of the disease require complex care. Most persons with dementia spend

the last stages of their life in long-term care facilities or hospitals because they require the care of trained professionals to assist with feeding, toileting, mobility, and other activities of daily living (Houttekier, Cohen, Bilsen, Addington-Hall & Onwuteaka-Philipsen, 2010). Many persons with dementia also experience high levels of pain in the last stages of their lives, due in part to the fact that they have difficulty communicating the occurrence and levels of pain to caregivers (Torke et al., 2010). It is known that dementia is a terminal illness in which persons with dementia often require high levels of care towards the end of their lives. Thus it is important to examine what kind of care is available to persons with dementia as they progress to the end of their lives.

The World Health Organization (WHO) defines palliative care as a non-curative care approach that improves the quality of life of persons and their families with life-threatening illness through the prevention and relief of suffering, and treatment of pain and other problems (WHO, 2013). Palliative care can be implemented at all stages of an incurable or chronic illness and not just at end of life (Hadad, 2008). Palliative care can be delivered in a variety of settings, including hospitals, hospices (specialized facilities that practice only palliative care), and in the homes of the individual. In Canada, different types of palliative care are available including community and respite palliative care available in the community, hospices, acute in-hospital palliative care, and long-term palliative care (Hadad, 2008). For the purposes of this study, the term “palliative care” is used to cover all types of palliative care occurring in different settings.

Modern palliative care originated in England in the 1960’s to help individuals dying from cancer, but has now expanded to include a variety of terminal illnesses (Canadian Hospice Palliative Care Association, 2014). The first palliative care unit in

Canada opened in Winnipeg in 1976, and the movement has since spread across the country (Hadad, 2008). In Canada, the demand for palliative care services still exceeds the amount of resources available (Canadian Hospice Palliative Care Association, 2010). There is a recognized need that palliative care ought to be made available for more people, and that current shortages of palliative care resources are putting Canadian persons at a disadvantage (Freeman, Heckman, Naus & Marston, 2013).

Existing policy reports and recommendations in Canada highlight the importance of palliative care but do not address dementia specifically. Palliative care was one of the priorities addressed in the Romanow Report released in 2002, which aimed to address problems with the health care system in Canada. One of the recommendations of the report was that the Canada Health Act (CHA) be amended to allow home care, including palliative care, to be considered medically necessary, so that it would be funded publically. The CHA states that any medically necessary hospital services are to be funded, but out-patient services are not always funded under provincial health plans (Government of Canada, 1985). Palliative care in hospitals is currently funded under the CHA. Only some services are in home care covered and this varies by province. According to the report, most Canadians prefer to die at home, but this is often impossible because of the lack of palliative care resources available in the home. Romanow noted that palliative care is more cost effective and saves the health care system money. However, dementia was not addressed in the report, which is noteworthy. Romanow recommended that palliative care be expanded beyond cancer to include illnesses such as chronic obstructive pulmonary disease, amyotrophic lateral sclerosis, and acquired immune deficiency syndrome, but did not mention dementia. He also

recommended that access to palliative care in the home be restricted to people with a survival prognosis of less than 6 months, based on a referral from a physician. This is problematic for persons with dementia because such a referral is not often available, given the difficulty in predicting with accuracy the time of potential death of an individual with dementia.

Senator Sharon Carstairs released a report in 2010 discussing palliative care in Canada (Carstairs, 2010). This report highlighted gaps in the system including a lack of awareness of the benefits of palliative care, lack of consistency in terms of funding and terminology across the country, and inequitable access to palliative care for Canadian residents. In her report she also stated that 90% of Canadians who die could have benefitted from some form of palliative care. In contrast to the Romanow report, Carstairs argued against “arbitrary time limits” to be eligible for palliative care, noting that they are ineffective for diseases that do not have the typical cancer death trajectory (Carstairs, 2010). Carstairs noted significant advances in palliative care in Canada, stemming from the recommendations in the Romanow report. For example, palliative care training is now offered in all 17 medical schools across Canada. Interestingly, Carstairs also argued that palliative care could be considered an enforceable human right under the Charter of Rights and Freedoms. She reported that the unpredictable, slow death trajectory associated with dementia is becoming more prevalent in Canada, and that people with this trajectory would benefit from palliative care. Other than this reference, Carstairs did not address whether palliative care is appropriate or necessary for those with dementia, or describe any challenges in providing such care.

Palliative care is now recognized in scientific literature as being appropriate for those dying from chronic illness with terminal diagnoses including dementia (Ryan, Gardiner, Bellamy, Gott & Ingleton, 2011). People with dementia have similar needs compared to persons dying from any other disease, and ought to be able to access quality end of life care (Sampson, Ritchie, Lai, Raven & Blanchard, 2005). According to the WHO, palliative care aligns well with person-centered dementia care given its focus on the needs of the dying person. It also is beneficial for persons with dementia who are in the end stages of the disease (WHO, 2012). Given that dementia is a progressive, incurable, terminal illness, maximizing the quality of life for the person while allowing them to die without painful and possibly futile interventions (such as feeding tubes) is ostensibly a logical decision. There is evidence that persons with dementia often experience painful and futile end of life treatments, especially compared to persons with other diagnoses, such as cancer (Shega, Hougham, Stocking, Cox-Hayley & Sachs, 2003). Persons with end-stage dementia in nursing homes are known to experience low quality of life and could benefit from increased pain treatment (Cordner, Blass, Rabins & Black, 2010). Palliative care not only benefits persons with dementia by sparing them burdensome, painful and often futile end of life interventions, but it has very beneficial effects for caregivers and relatives, who often experience comfort and relief that their family member is not suffering (Munn, 2012).

The need for palliative care to improve the quality of life for persons in the end-stage of dementia has been well documented, so too have the lack of services available (Ahronheim, Morrison, Missis, Baskin & Meier, 2000; McCarty & Volicier, 2009). Access to palliative care within Canada varies considerably depending on the type of

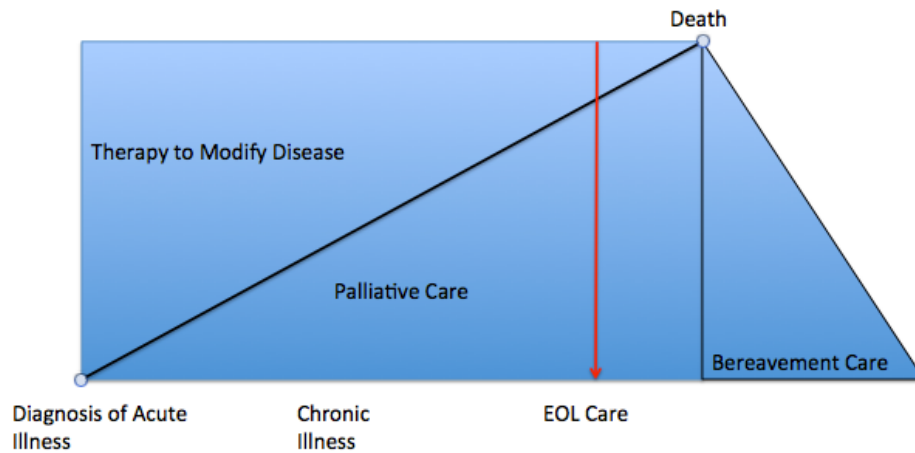
geographic location and the type of incurable chronic disease. Persons in rural areas have little or no access to palliative care (Canadian Medical Association, 2011). When persons with end-stage dementia receive palliative care, it is often sub-optimal compared to persons with other diagnoses (Mitchell et al., 2009). Persons with dementia have substantial unmet palliative care needs including elevated pain and emotional or behavioural problems (Torke et al. 2010). This is an emerging concern in the field of dementia research, and researchers are beginning to advocate for change in the palliative care needs of those with dementia (Hughes, 2010).

The definitions of and distinctions between “hospice palliative care,” “palliative care” and “end of life care” are unclear both in the literature and in practice. Health Canada states that the three terms are used interchangeably, and directs people to the Canadian Hospice Palliative Care Association (CHPCA) or to the WHO websites for further clarification. The CHPCA uses the term “hospice palliative care” as a broader term, and states that hospice palliative care is offered early in the course of the illness, often combined with other therapies that are intended to prolong life (Canadian Hospice Palliative Care Association, 2013). They also state that end of life care is focused more on “death management”, and is a part of palliative care and is not a separate entity (Canadian Hospice Palliative Care Association, 2013). The WHO provides a similar definition to the CHPCA for palliative care but does not mention end of life care (WHO, 2013). Clearly, there is confusion about the terminology and meaning within the palliative care community and scientific literature.

It is important to clarify definitions that will be used in this thesis. “End of life care” is used to describe care that occurs in the last days or weeks of life, and is primarily

focused on the management of symptoms. “Palliative care” is defined as a broader philosophy of care, which begins earlier in the disease trajectory, and is focused more on maximizing quality of life for the individual with the condition. These definitions are most consistent with those of the World Health Organization and the Canadian Hospice Palliative Care Association. The relationship between palliative care and end of life care is further explained in Figure 1 below.

Figure 1: Palliative vs. End of Life (EOL) Care



Modified from The Ottawa Hospital (2014)

Chapter 2: Literature Review

Palliative care is both beneficial and under-utilized for individuals with dementia, yet what remains unknown is what prevents persons with dementia from accessing such care. The purpose of this literature review is to identify barriers that limit access to palliative care for persons with dementia, and to explore what was being done or what could be done to improve access to palliative care for persons with dementia.

To be included in this scoping literature review, articles had to be written in English, be written after 2000, and cover dementia and at least one of the other topics: 'barriers to access' and 'palliative care'. Articles that covered all three topics were considered first, and then papers dealing with dementia and either barriers to access or palliative care were considered. The search began in January of 2013 and concluded in February of 2013. A shorter search was conducted in April of 2014 to determine if any new publications had been released, and several sources were added from this search.

The original focus of the literature review was a Canadian perspective of palliative care for individuals with dementia, especially once it became apparent that there was little Canadian research on the topic. The inclusion criteria for Canadian research were less rigorous than for non-Canadian papers. Articles that had information on any of the three topics were considered for inclusion in the literature review, as opposed to having to discuss dementia and one other topic. This was modified after the search began because of the scarcity of Canadian research that was available. It was important that every opportunity to include Canadian research in the discussion be taken because the current review was exploring palliative care for persons with dementia through a Canadian lens.

Databases searched for the scoping review were CINAHL, Scopus, PubMed, and PsycINFO. Search terms included: dementia, Alzheimer's disease, barriers, communication barriers, health services accessibility, access, perceived barriers palliative, palliative care, hospice and palliative nursing, terminal care, and end of life care. Approximately 80 resources were found among these databases, and 39 articles met the inclusion criteria and were included in this review.

Searches of the grey literature on the Internet were conducted to find current information on palliative care in Canada, because there was very limited information from this perspective in the academic literature. Websites such as the Government of Canada webpage, the Canadian Hospice Palliative Care Association webpage, and those of various community organizations were searched. Of note, there was no comprehensive location for information pertaining to palliative care access in Canada or in Ontario. Most information from Ontario was scattered and varied greatly between municipalities and Local Health Integration Network (LHIN) boundaries.

In general, the articles found were recent (2005 and later) and were from the United States, the United Kingdom or Australia. Most studies used staff (i.e., nurses, physicians, social workers, long term care home executives, etc.) as their primary research population, while a few included family members. There were no studies found that included persons with dementia as primary research participants due to the issues of incapacity to consent for persons with end-stage dementia.

During the search for information on this subject, a number of other published reviews were found. All of the existing reviews were found, with the exception of one

Canadian review. Special care was taken not to duplicate any findings from these reviews, and to find information from a Canadian perspective.

The older literature reviews focused primarily on establishing that palliative care was indeed appropriate for individuals with dementia (Volicer, 2005; Sampson et al., 2005). This reason for this was likely when the issue of palliative care for persons with dementia first emerged. Other reviews focused on very specific groups, such as ethnic minorities within the UK (Connolly, Sampson, & Purandare, 2012) or family caregivers providing end of life care in the home (Peacock, 2011). The current review focuses on the issue of barriers to palliative care access for individuals with dementia, but in a broad sense, and does not focus solely on family caregiver experiences.

The only literature review with a specific Canadian focus was one prepared for the Alzheimer's Society of British Columbia (Puurveen, n.d.). This review differed from the current review in that one of the inclusion criteria was that papers had to have been written before 2009, so the information in it is slightly older. Puurveen's review also did not have the specific focus on barriers to access. Purveen's literature review was not peer-reviewed, although it used very similar sources to reviews of the same topic.

There were several international reviews on this topic. The largest was the IMPACT (IMplementation of quality indicators in PAlliative Care sTudy), which is an ongoing project addressing palliative care for persons with dementia in Europe. As part of this study, Raymond et al. (2012, 2013) published two separate literature reviews addressing the views of professional and family carers, and evaluating educational incentives to improve palliative care, respectively. The first paper by Raymond and colleagues (2012) addressed the views of caregivers (both professional and family

members) who provided end of life care to those with dementia. The second paper by Raymond and colleagues (2013) was focused on the evaluation of education programs aimed at increasing the quality of palliative care being provided by staff. This second paper evaluated several Canadian education programs, but provided few details because, according to the authors, that information was not made available. Both of these reviews for the IMPACT study provide valuable insight into specific gaps in the literature (such as the need for research evaluating current palliative care initiatives) and have a much larger scope than was possible for the current review.

Barriers to Access

There were several reoccurring themes within the literature that emerged with regards to barriers to access of palliative care by persons with dementia. The five distinct themes included: disease trajectory, misconceptions in the perception of dementia, families acting as barriers to care, professional barriers, and policies or funding barriers to access.

Disease Trajectory

Dying from dementia often is an unpredictable process (Sachs, Shega & Cox-Hayley, 2004). Palliative care practices originated with cancer, which are very well studied and where cancer has a more predictable death trajectory compared with dementia (Shega & Tozer, 2009). Palliative care is certainly appropriate for individuals dying from any type of terminal illness, but the unpredictable nature of dementia makes it difficult for practitioners and families to know when palliative care is most appropriate (Thuné-Boyle, Sampson, Jones, King, Lee & Blanchard, 2010). In fact, one study found that persons with dementia often received too little support and intervention during the

early stages of their illness, but received too much care (in short, aggressive or unwarranted treatments) towards the end of their lives (Ryan et al. 2011). This could be explained by the fact that the disease progression is still not well understood. Similarly, Sachs et al. (2004) reported that the unpredictable disease trajectory and decline in dementia, coupled with the lack of reliable prognostic markers for persons with dementia, meant that healthcare professionals were less likely to refer them to palliative care. This is because they were uncertain about how much time they actually have left to live, and whether palliative care is appropriate. The clinical implications of discussing dying trajectories are important for both the person with dementia and their family (Murray, Kendall, Boyd & Sheikh, 2005).

In the case of dementia, the dying trajectory is often prolonged decline, where the individual's functioning is already relatively low, punctuated by unpredictable episodes of decline and recovery, decreasing gradually until death (Murray et al., 2005). Having an understanding of the specific trajectory likely to be associated with the dementia will help to avoid unnecessary hospital admissions at the end of life, and decrease aggressive interventions that the individual might receive (Murray et al., 2005).

Given the unpredictable dying trajectory often associated with dementia, healthcare practitioners experience notable difficulties when referring persons with dementia to palliative care. Identifying when death is imminent for a person with dementia is a challenge. Therefore, it is difficult to discern when palliative care would be beneficial. In contrast, the steady decline of the cancer trajectory makes it easier to reach consensus regarding when palliative care should start (Shega & Tozer, 2009).

The health care consequences of an ambiguous dying trajectory and uncertain time of death for persons with dementia can include unnecessary treatments and poorly timed referrals to palliative care services. For example, cardiopulmonary resuscitation (CPR), feeding tubes, and intravenous antibiotics increased pain and distress among persons with dementia, and transfers to hospitals did not provide any tangible benefits for them. These interventions are often the default action of healthcare practitioners if palliative care is not being used (Murray & Robinson, 2011). A more passive course of action was recommended for episodes of significant decline in persons with end-stage dementia (Murray & Robinson, 2011).

A better understanding of the clinical course of dementia leads to better quality palliative care. Mitchell et al. (2009) studied 323 nursing home residents with advanced dementia over 18 months, and found that pneumonia, febrile episodes, and eating problems were frequent complications that occurred in many persons. They also found that 40% of persons with dementia had “burdensome interventions”, defined as interventions that were unnecessary or stressful for these complications in the last three months of life. This ties in to the perception that dementia is not a terminal disease, and therefore persons with dementia receive aggressive interventions for complications arising from dementia. Healthcare practitioners focus on the fact that such complications can be “cured” while not recognizing that the primary diagnosis of dementia is terminal.

Perception of Dementia as Not Being a Terminal Illness

The perception that dementia is not a terminal illness (an illness that is incurable and will eventually lead to death) is still very common among persons with dementia, their families, and some healthcare professionals (Torke et al., 2010). This makes

palliative care extremely difficult to provide because of the wariness of staff and family to give up or let the person die. If palliative care is not recognized as both appropriate and beneficial, it is very unlikely that persons with dementia will ever receive it.

In the end stages of life, persons with dementia often experience other conditions caused by complications from dementia, such as eating and breathing difficulties, injuries from falls, and complications from immobility and incontinence, such as bedsores or urinary tract infections (WHO, 2012). Sachs et al. (2004) found that while families and healthcare professionals recognized that dementia is a serious progressive disease, they would categorize secondary complications arising from it such as pneumonia or urinary tract infections as the primary cause of death, and therefore the condition that required the most treatment. They also noted that the US Centre for Health Statistics did not include dementia as a rankable death until 1994. There is still debate as to whether the “final” cause of death is dementia or the complications that arise from it. This is a debate that is beyond the scope of the current review. However, for the purposes of palliative care, it is irrelevant what is determined to be the “final” cause of death. What matters is what happens prior to death. With a progressive, terminal disease, palliative care is extremely beneficial in terms of maximizing quality of life. Persons with dementia will decline and eventually die. Although the cause of death might be unclear, individuals who have dementia are no less deserving of quality palliative care. The perception that complications from advanced dementia should be treated because it is necessary to “save” the person is a significant barrier to palliative care.

Many family caregivers of persons with end stage dementia do not understand the disease or the way it progresses and did not plan for the future (Thuné-Boyle et al., 2010).

This misinformation is a significant barrier to palliative care. Lack of awareness that dementia is terminal, either on the part of the family who did not want palliative care or on the part of the healthcare professional for not offering palliative care, is a significant barrier to access palliative care for persons with end-stage dementia (Torke et al., 2010).

There is a failure on the part of medical staff to acknowledge dementia as a terminal illness, and some palliative care staff feel persons with dementia should “stay in nursing homes where they belong” (Ryan et al., 2011). Regardless of whether long term care homes are the best place for persons with dementia, it is clear that the misconceptions about terminal nature of dementia will continue to be a significant barrier to the provision of palliative care in those dying from dementia.

Families as Barriers to Palliative Care

Family members are intimately involved in the decision to undergo palliative care for persons with dementia because they often are designated as the substitute decision maker (SDM). Generally, persons in the late stages of dementia are unable to advocate for themselves, and require a family member or other designated SDM to advocate on their behalf. Thus, SDMs can sometimes act as barriers to the provision of palliative care if they do not consent on behalf of the person.

Stemming from misconceptions about the nature of dementia on the part of family caregivers, communication barriers between families and staff were a significant theme identified in the literature with regards to palliative care in persons with dementia.

Persons with SDMs who understand the clinical course of the disease and have realistic expectations for the prognosis of their family member are less likely to advocate for aggressive care at the end of life compared to proxies who have poorer understanding of

the nature of dementia (Mitchell et al., 2009). The cognitive and communicative declines associated with dementia are barriers to advance care planning, and this often results in caregiver uncertainty about what decisions to make regarding end-of-life care (Stewart, Goddard, Schiff & Hall, 2011). Ryan et al. (2011) found that planning ahead facilitated decision making around palliative care, and that a best-interest standard should be used to make decisions at end of life. A best-interest standard takes into account what healthcare professionals ascertain to be in the best interests for the person. It does not necessarily follow the person's prior expressed wishes if healthcare professionals and SDM's feel that these wishes do not serve the best interest of the incapable person at that particular time. Lastly, persons who do not have formal or informal caregivers to advocate for their needs are also much less likely to receive palliative care at end of life (Torke et al., 2010).

Family members are often uncomfortable in their roles as SDMs. This, combined with uncertainty regarding the person's wishes and misconceptions about the clinical course of dementia, can result in SDMs defaulting to aggressive treatments simply because they do not want to "give up" on their family member. This is even more likely if staff do not explain the importance of palliative care and the terminal nature of dementia, and provide support in the decision making process. Family members indicate a preference for aggressive care significantly more often than cognitively intact older adults (Volicer, 2005). For example, when writing their advance directives, nearly all persons with early dementia indicated that they would not want CPR, feeding tubes, or intravenous antibiotics in the late stages of their illness. However, their family members, when making this decision later on, had different views: 46% wanted CPR, and 52% wanted intravenous antibiotics (Volicer, 2005). Family caregivers were more comfortable

consenting to treatment than refusing treatment for their family member with dementia (Volicer, 2005). This indicates that support and education throughout the decision making process is essential if family members are going to consent to palliative care. A small number (20%) of physicians reported giving counselling to family members regarding advance care planning and end of life care (Volicer, 2005). Increasing this number could possibly result in better planning surrounding end of life care. This could decrease the stress and indecision that caregivers experience when trying to decide the best course of treatment for their family member, and would allow more respect for the wishes of the person. A discussion about advance care planning also is a good opportunity to start a discussion about palliative care, and to educate persons about the benefits of this type of care while they are still in the early stages of their disease about the benefits of this type of care.

Significant caregiver strain associated with dementia was noted repeatedly in the literature (WHO, 2012; Dutton, 2009). Palliative care programs are likely to be the most successful when they provide support for both caregivers and their relatives with dementia. According to Diwan, Hougham and Sachs (2004), successful palliative care programs provide services to family caregivers such as counselling about behavioural changes, help with navigating the healthcare system and interacting with staff, and facilitating access to community resources. If this can be achieved, it is likely that cooperation of families will result in increased use of palliative care services by persons with dementia.

Professional Barriers

Lack of communication among healthcare professionals from different disciplines, and lack of skills in communicating with persons with end-stage dementia are barriers to high quality palliative care for persons with dementia. Ryan and colleagues (2011) found that palliative care specialists had little experience with dementia and that those who specialized in dementia had little experience with palliative care. Therefore, persons with dementia would be less likely to be referred to palliative care by dementia specialists. In turn, palliative care specialists would have less knowledge about the unique needs of persons with dementia. Palliative care specialists and other staff working in similar fields in the UK reported that they had self-reported lapses in communication between disciplines, showing that more integration is needed in this area (Johnson, Chang, Daly, Harrison, Noel, Hancock and Easterbrook, 2009). It also was noted that increased communication among staff members directly contributed to better-quality palliative care for persons (Ryan et al., 2011).

Most guidelines used by hospices to assess suffering and determine approximate time of death do not accurately predict time of death in persons with dementia (Aminoff & Adunsky, 2006). Staff (typically physicians) often are reluctant to refer to palliative care because the needs of persons with dementia (especially in terms of pain management) are different from those with cancer. Moreover, hospice guidelines typically are designed with persons with cancer as their main focus (Ryan et al., 2011). Consequently, staff in hospices are unable to estimate an accurate time of death, making efficient use of resources difficult. Moreover, staff members at hospices are unable to assess properly the pain levels in persons with dementia. An assessment of symptoms, especially pain, among persons with end-stage dementia, can be challenging because

many persons with end-stage dementia are unable to communicate and have impaired cognition. Persons with dementia often die with significant unmet pain needs, and better assessment tools are needed to improve the ability of healthcare practitioners to meet those needs (Aminoff & Adunsky; 2006; Sachs et al., 2004). In general, high levels of suffering predicted lower rates of survival. Persons with dementia are likely to have pain from co-morbid conditions such as osteoarthritis, which is often not diagnosed or properly treated because of dementia-related communication impairments (Sachs et al., 2003). However, they also are less likely to receive opioids for pain relief in the final stages of life (Murray & Robinson, 2011).

A lack of knowledge and skills related to palliative care can often contribute to decreased quality of palliative care in advanced dementia (Chang et al., 2009). For example, that there were not enough guidelines for palliative care for persons with dementia, resulting in disorganized care, and frustrated staff (Davis et al., 2003). Often, staff were not well educated in palliative care, and therefore were fearful of taking any responsibility in the palliative care process, including signing off on orders for palliative care consultations (Davis et al., 2003).

Ryan and colleagues (2011) also found palliative care staff did not have enough dementia-specific skills, especially for pain assessments, because many persons with dementia are unable to communicate effectively. This makes quality palliative care more difficult to provide. Skills that were deemed significant in providing excellent palliative care included assessing needs of persons with end-stage dementia, pain and symptom management, management of dysphagia, behavioural symptom management, and knowledge and skills related to dementia as a disease (Chang et al., 2009). Staff reported

that improved education and increased resources with regards to palliative care would improve care that was available currently. Staff are eager to be educated about improving palliative care in nursing homes, and it is likely there would be significant improvements to the quality of care provided if such education were available (Hirakawa, Kuzuya & Uemura, 2009).

The majority of persons with end-stage dementia reside in long-term care facilities, because of the significant decline in function associated with the late-stages of this disease. Palliative care specialists often do not work in long term care and are perceived as “outsiders” (palliative care specialists entering the long-term care home) disrupting the dynamic within the facility. Long-term care home staff can be resistant to welcoming palliative care specialists (Gusmano, 2012). Tensions between staff would almost certainly result in negative changes in the care that persons receive, and working to better integrate these two disciplines (speciality in palliative care and specialty in dementia care) is a necessity for high-quality palliative care for individuals with dementia.

A notable barrier to access to palliative care amongst healthcare professionals is the fear of being sued for withholding or not providing enough treatment. Although such lawsuits are rare and usually unsuccessful, the fear is strong enough to prevent some frontline staff from administering effective palliative care (Gusmano, 2012).

It is clear that healthcare practitioners from all disciplines could benefit from further skills training to increase their comfort with providing palliative care for persons with end-stage dementia, and also to improve their interactions with each other. If this does not improve, lack of communication skills, and knowledge about palliative care for

persons with dementia will continue to prevent persons from accessing high-quality palliative care.

Funding and Policies as Barriers to Palliative Care

Policies and funding incentives that work against the goals of palliative care are significant barriers (Sachs et al., 2004; Shega & Tozer, 2009). According to the Canadian Medical Association (2011), the provincial jurisdictions of Ontario, Nova Scotia, and the Northwest Territories all lack policies to promote team-based palliative care. As noted above, a team approach with increased communication among staff has resulted in better quality palliative care. Most provinces in Canada cover the cost of some drugs and medical equipment, but not the entire cost. Individuals without enough funds could be prevented from accessing palliative care because of inability to pay. They would instead turn to hospital-based interventions (such as emergency departments), which are covered by provincial health plans, and cost less to the individual with dementia and their family compared to hospital care. There also are significant variations in where palliative care is offered in Canada, with rural areas having fewer resources for palliative care. Such variations limit access to palliative care (CMA, 2011).

When there is a shortage of resources (as is often the case in publically funded healthcare in Canada), healthcare professionals often feel that it is better to use these limited resources for persons with cancer because cancer has a more predictable death trajectory, and therefore resources can be used more efficiently (Ryan et al., 2011). There was a distinct sense among staff that resources were being “wasted” on persons with dementia because of the assumption that they could not benefit from support as efficiently as persons with cancer or other individuals with more predictable dying

trajectories (Sachs et al., 2004; Ryan et al., 2011). Funding policies for nursing homes often work against the goals of palliative care (Shega & Tozer, 2009). Less funding is earned when residents die, and the facility bears most of the cost of end of life care when residents die in the long term care home. Consequently, long term care home staff often advocate for more aggressive treatments to “save” residents and not let them die, or seek to transfer residents to hospital for the final stages of their illness to avoid having high rates of resident deaths in the nursing home. This practice works against the goals of palliative care, and is a barrier to the provision of higher quality care.

The criteria for hospice eligibility often are not accurate for predicting mortality for persons with dementia. Therefore, persons with dementia are often not deemed eligible for hospice care when they could, in fact, benefit from it (Aminoff & Andusky, 2006). The requirement of a 6 month terminal diagnosis to be eligible for hospice care (common in the US) makes palliative care access difficult because of the difficulty of predicting time of death when the primary diagnosis of the person is dementia (McCarty & Volcier, 2009). According to staff involved in a study by Torke and colleagues (2010), staff felt that policies which made reimbursement for palliative care more difficult for persons with dementia than persons without dementia as the biggest barrier to palliative care access. Based on the literature review I conducted I was unable to determine if there is a specific requirement for persons with dementia to access publically funded palliative care in Canada.

There is a lack of consensus in the scientific literature about what constitutes “futile” treatments. With respect to palliative care are, futile treatments are unnecessary, painful, and do not provide any benefit in terms of increasing quality of life. There is

generally a consensus that so-called futile treatments are not appropriate for persons with any diagnosis. However, it is difficult to establish coherent guidelines for practitioners to follow if there is no consensus on when a treatment ceases to be beneficial (Gusmano, 2012). Therefore, there is no established standard of care, and increased confusion and uncertainty from healthcare practitioners about the best course of action. Clearer guidelines regarding futile treatments would result in greater continuity of care for persons with dementia and could likely aid in reducing the rates of unnecessary procedures.

There are no well-established protocols and is no consensus among professionals with respect to palliative care for persons with dementia. It is clear that while this issue is no longer obscure in the literature, there is still a lack of consensus among professionals working in the field. For example, Mitchell (2007) used the case study of a 93-year-old man with advanced dementia and eating problems to illustrate that there is still very little consensus on the best course of treatment for those with dementia. According to Mitchell, the use of feeding tubes for someone with end stage dementia is not supported in the literature because it is not effective. However, there was significant disagreement among physicians about whether the 93-year-old man should receive a feeding tube in this case (Mitchell, 2007). Indeed, it is clear that there is still controversy about the use of feeding tubes for persons with late-stage dementia (Shega et al., 2003a). I did not exclude articles on artificial nutrition and hydration for persons with dementia in the current literature review. However, an analysis of the pros and cons of artificial nutrition and hydration is beyond the scope of the review.

Policies working against the goals of palliative care can be considered the most significant barrier for persons with end-stage dementia and their families. Even if all the other barriers discussed above were eliminated, policies limiting the use and effectiveness of palliative care would prohibit access. Persons with dementia need to be allowed to access palliative care services in order for the services to be effective.

Promising Studies

There are some promising pilot studies and innovative programs in the field of palliative care for persons with dementia, which are discussed to some length in the literature (Kuhn & Forrest, 2012). For example, Shega and colleagues (2003b) have started the Palliative Excellence in Alzheimer's Care Efforts (PEACE) program in Chicago. This program aims to improve end of life care for persons with dementia. It recognizes that persons with dementia often are disadvantaged when it comes to palliative care, and do not access it as often as individuals without dementia. It also aims to reduce barriers to access by advocating for increased palliative care enrolment and increased awareness. However, the program is still in its early stages (Shega et al., 2003b). The PEACE Program was noted in the literature as being a uniquely successful model that should be expanded, but to date, no published literature indicates whether this has taken place.

Similarly, Dutton (2009) discussed a pilot study in the UK where a community-based end of life care nurse is partnered with a dementia services team. This program aims to relieve caregiver burden for family members caring for community-dwelling persons with late-stage dementia. The program aims to increase the quality of life for

persons dying at home. It also aims to achieve this by increasing support for family caregivers in the home, instead of moving the person with dementia to a different setting (such as long term care or a hospital). The program is in the very early stages, and no published literature discusses the impact of this program and whether it is successful (Dutton, 2009).

Carlson, Lim and Meier (2011) discuss what they perceive to be the three most successful models for providing non-hospice palliative care in nursing homes. This study is promising because it offers some concrete suggestions, such as eliminating economic and regulatory disincentives for palliative care, establishing a licensing program for palliative care units, and investing in a palliative care workforce. However, this study is mostly specific to the American healthcare system. Each model is specific enough to the American healthcare system that it would be difficult to apply them as separate entities outside of that context. In addition, there was no published literature available about either the long-term effects of these models or whether the authors implemented it outside of the area where the study was conducted.

Lastly, the IMPACT project is very relevant and current to this topic. This project is a four year research initiative based in Europe aimed at improving palliative care for persons with dementia and cancer (IMPACT, 2011). This project has already produced several relevant articles on this subject (Raymond et al., 2012; Raymond et al., 2013; Davies et al., 2014) and will be important to monitor as more findings emerge. In particular, Davies et al. (2014) published a study very relevant to this topic. They found that staff delivering palliative care to individuals with dementia in the UK were confused about guidelines for providing this care. In particular, they were confused about how they

should be followed. Some staff found these guidelines to be too restrictive, and others found them to not give enough direction. This might indicate that confusion around how and when to deliver palliative care is a widespread problem.

The Present Study

Evidence in the published literature suggests that palliative care is beneficial for persons with dementia but it remains under-utilized among this population. However, barriers that have contributed to preventing more widespread use of palliative care among persons with dementia include the unpredictable disease trajectory, perceptions that dementia is not terminal, families being unreceptive to the idea of palliative care, lack of professional knowledge about palliative care, and policies or funding incentives as barriers. The only barrier that is not expected to change for the foreseeable future is the unpredictable disease trajectory of dementia, because this is an inherent issue with the disease. However, the other barriers are possible to amend with education or policy changes (Aminoff & Adunsky, 2006).

Although the need for and barriers to accessing palliative care among persons with dementia are well-documented, there is a dearth of research from a Canadian perspective. Most information is from the United States, United Kingdom, and Australia. With regards to policies acting as barriers, not much is known specific to Canadian policies, and because they are unique, information about American (or other) trends cannot be applied here. What remain unknown are the barriers to access to palliative care and the efforts, if any, that have been undertaken to address the barriers in Canada. Specifically, there is a lack of consensus regarding the transition to palliative care for persons with dementia, especially regarding when it is appropriate and the ideal setting

for delivering palliative care. Stemming from this, I noted in the published literature a lack of prognostic measures for individuals with dementia (Gusmano, 2012).

There remain large gaps in knowledge in this field, even though some areas of palliative care for individuals with dementia are well researched, such as what barriers exist. While pilot studies are a step in the right direction, more information is needed about how these studies have fared, and about best-practices for increasing participation in palliative care, instead of discussing the general need for improvement in this area. In addition, there are very few large-scale studies showing best practices for what is actually effective in terms of increasing participation in palliative care for persons with dementia. The IMPACT project is one of the first in this area, and it is still in the early stages. The need for palliative care in dementia has been well documented, as are the barriers (IMPACT, 2011). There is a need for more scholarly articles discussing interventions, policy changes, and best practices, to improve this issue, instead of solely reporting on current trends (van der Steen, 2012).

The purpose of the present study is to develop an understanding of how palliative care is delivered to persons with dementia in Southwestern (SW) Ontario. Such information will provide a basis for research about interventions, policy changes and future best practices. The primary research question investigates how palliative care is delivered to persons with dementia in long-term care facilities located in SW Ontario. Specifically, (a) are there established protocols to guide this transition and (b) are there assessment tools and measurements to determine objectively if and when palliative care would be appropriate for a person in the late stages of dementia? The secondary research question examines the role of current policies on access to palliative care in Ontario.

Specifically, what policies or funding incentives in Ontario enable or prohibit individuals with dementia from accessing beneficial palliative care? The findings have a potential to inform policy recommendations.

There is a dearth of information about palliative care for individuals with dementia. Specifically, there is very little information about best practices, timing, and education for professionals and families about the benefits of palliative care for persons with dementia. Therefore, the present study focused on the experiences of staff delivering palliative care to individuals with dementia to gain a better understanding of the current state of the field, as this information was not readily available. The issue of barriers to access to care was of particular interest. The literature review revealed that there were a number of factors prohibiting good-quality palliative care from being delivered to individuals with dementia, but it was not known if these same barriers were all present at a local level. Additionally, assessing policy barriers through staff perspectives would be an excellent starting point to initiate change within the system. This was the reason for the focus on the experiences of staff members, as they were likely to experience these barriers firsthand in delivering care.

Chapter 3: Method

This study is based on a transcendental phenomenological approach throughout the research process. This chapter will include an overview of phenomenology and a rationale for its use in the study. Additionally, this chapter includes a description of the inclusion and exclusion criteria for this study, recruitment of participants, data collection, information about the participants themselves, and a description of how the data were analyzed.

This study is based on transcendental phenomenology based on Moustakas' (1994) description. This method seeks to understand the experience of the individual, in this case, the experience of individual long-term care staff providing palliative care to persons with dementia. Moustakas' approach involves collecting qualitative data through in-depth interviews and analysing the data for themes that capture the experience for the individual participating in the research. Moustakas' design is based on the post-positivist approach of Husserl (1901), which seeks to obtain an objective interpretation of the data. Moustakas' approach includes constant comparative method throughout the data collection and analysis process, and categories and themes are deduced from the information collected. The method of constant comparison involves repeated comparisons among pieces or groups of data. For example, the researcher might compare two different interviews, or two different responses to a specific question, to see how they differ and are similar (Thorne, 2000). The purpose of the constant comparison method in transcendental phenomenology is to learn about an experience or phenomenon from someone who has experienced it without actually experiencing it oneself (Thorne, 2000). It is an inductive process, moving from specific findings to more general ones as more

data are collected and compared. The research team used this method throughout the data collection and analysis processes.

Moustakas' transcendental phenomenology, advocates the systematic elimination of bias or presupposition, and suggests approaching the research from a state of "freshness and openness" (Moustakas, 1994 p. 41). Transcendental phenomenology utilizes only information that appears before the researcher, and is therefore objective and systematic because of this (Moustakas, 1994). Moustakas also emphasizes the importance of the researcher being aware of his or her "self" when conducting phenomenological research. It is important to acknowledge the role that the individual researcher plays in the research process, including contributions that the self might make to the research, consciously or unconsciously. Moustakas (1994) discusses the importance of bracketing, or putting aside all presumptions about a phenomenon, in order to see the true essence of the phenomenon in question. It was important to engage bracketing throughout the research process, but particularly during the data collection process, when interacting with participants. I, the researcher, had personal experience with a family member having dementia, and I therefore made a conscious effort to put aside any prior knowledge or feelings I had about the issue before each interview, to ensure that the questions I was asking of the participants were as unbiased as they could possibly be. I used the interview guide to help with this, and also checked in with other members of the research team (who were aware of my personal connection to dementia) periodically to ensure that they were satisfied with the questions I was asking. This was a challenging process, in one instance, a participant did guess that I had personal experience with seeing someone in the end stages of dementia, and did ask some personal questions. We had a short

discussion about how my personal connection to this topic made the research more meaningful to me, and then I followed with the next question on the interview guide. While it is not possible to completely remove one's personal history from the research process, every effort was made to ensure that the two overlapped as little as possible.

Phenomenology was the most appropriate methodology because the purpose of this study was to understand the experience of staff providing palliative care. Since there was very little known about this topic, grounded theory would have been inappropriate, because the researchers were not seeking to create or to modify an existing theory, but to explore this topic in as much detail as possible.

Inclusion and Exclusion Criteria

To be eligible to participate in this study, individuals had to (a) work in long-term care facilities, (b) be directly or indirectly involved in providing palliative care to persons with dementia, and (c) be able to provide informed consent. The inclusion criteria were broad because the research team was looking for a cross-section of many different staff with different levels of responsibility and from different professions. Exclusion criteria were individuals who did not work in long-term care or who did not provide palliative care to persons with dementia in the facility. One facility was included that did not provide palliative care for individuals with dementia because it was not apparent until the interview took place that the facility did not provide this care, and the participant was not aware that the care they were providing was not palliative care. The research team felt that this was an important finding and included the facility in the sample.

Recruitment

The research team aimed recruit staff members from a variety of disciplines for this study. This diverse sample was chosen in order to examine a number of different experiences. A snowball sampling method was used to recruit participants. Several gatekeepers were used initially to recruit participants, including contacts from previous research and individuals who were recommended to the research team by others in the long-term care community. Once data collection had begun, it became apparent that there was a small community of healthcare professionals from different facilities who shared knowledge with each other about best-practices in palliative care. Many individuals were recruited from this pool. The initial goal was to recruit participants from various professions including, but not limited to: personal support workers (PSWs), registered practical nurses, registered nurses, nurse practitioners, pharmacists, social workers, members of the chaplaincy, home administrators, physicians, recreation therapists, and palliative care volunteers. Volunteers were included because in certain facilities, volunteers were trained in basic palliative care techniques and spent large amounts of time with the dying individual, particularly if the individual did not have family members present. Thus, it was felt that volunteers could be included with staff as they comprised part of the care team.

Long term care homes were chosen as the optimal location for data collection because most individuals who are in the end stages of dementia have significant care needs and reside there. It was felt that staff from this environment would be an excellent sample from which to draw from when recruiting for this study.

Ethics approval for this study was obtained from Western University's Research Ethics Board (Appendix A). Participants were contacted with by the researcher an email

inviting them to participate in the study. The email invitation included the Letter of Information (Appendix B), which outlined the study aims and procedures. At the first meeting between the researcher and the participant, each participant was asked to sign a form indicating they gave informed consent to participate in the study (Appendix C). There was a separate consent check box to indicate permission to be audio recorded during the interview. Participants were still eligible to participate even if they did not agree to be recorded. The researcher explained the goals of the study, and reviewed the procedures that ensured confidentiality. Participants were assured that any information they divulged would be used only for research purposes, and any personal information that could identify them would be removed from the final document. They were also told that they could withdraw from the study at any time, and did not have to answer any questions with which they were uncomfortable. Once the researcher was satisfied that the participant understood these and written consent had been provided, the interviews were allowed to proceed.

Data Collection

Data collection occurred at nine long term care homes in London, ON. Interviews were conducted in private or semi-private settings within the facility, at a location of choice for the participant, or over the telephone. However, phone interviews were conducted for a small number of participants ($N = 3$) for whom phone contact was the only convenient method of data collection. Interviews took place between September of 2013 and February of 2014.

Interviews were conducted primarily one-on-one with participants, but one two-on-one interview was conducted at the request of the participants because of time

constraints. Interviews lasted from 15 to 45 minutes. Participants were given the option of adding follow-up thoughts or queries to the researcher via email after the interview was completed. Interviews were recorded using a digital recorder, if the participant gave consent for this, and if they did not, notes were made by the researcher during the interview. All but two participants agreed to be audio recorded for their interviews. Interviews used a semi-structured format. The researcher was prepared with specific questions and prompts (Appendix D), but if the participant strayed off topic, questions were modified to accommodate this. Participants also had the option of viewing the interview guide ahead of time, so that they could prepare answers and shorten the length of time needed for the actual interview. Because of the wide spectrum of professions represented within the sample, several questions remained broad enough so that they would pertain to all individuals within the sample. A conscious effort was made during the creation of the interview guide to include only questions that could be answered feasibly by all participants. However, several participants stated that they did not have the knowledge or experience to answer certain questions. For example, participants with less decision-making authority over care (such as PSWs or volunteers) were less able to answer questions about policies because they were not familiar with them.

In addition to the interview, each participant completed a two page demographic questionnaire (Appendix E) of general questions, in order to decrease time needed for the actual interview. The questionnaire was usually done before the interview began. Questions focused on the specifics of the participant's job, for example, how many residents and other staff they typically worked with, what training they had received, and what hours they worked.

Interviews were audio recorded and then transcribed verbatim by the researcher or by a research assistant. If the participant did not consent to be recorded, notes were made during and after the interview. Field notes also were made by the researcher after the interview, documenting what occurred outside of the interview itself, including body language, emotions noted by the researcher, or irregularities in the interview.

Participants

In total, 22 participants were interviewed for this study. Participants came from nine different facilities in SW Ontario. All of these facilities were publically funded, with the exception of one, which was private. The facilities differed in size, with the largest having several hundred residents (Table 1). Participants ranged in age from 23 to 67 years, although 4 participants declined to disclose their age. Most had been working in their positions for between 10 and 20 years, but ranged from working for only a few months to being in their position for 42 years. There were 3 male staff members in the sample, and the remaining 19 were women. The sample was comprised of nine registered nurses, three personal support workers, two social workers, one physician, one pharmacist, one nurse practitioner, one chaplain, one recreation therapist, one registered practical nurse, one palliative care volunteer, and one volunteer coordinator (Table 2). Several of the registered nurses had additional roles within their facility; such as being involved with palliative care committees or being a director of care. The decision was made by the research team to keep all other identifying characteristics of the participants confidential. Due to the fact that a small sample size was used, and many professions were represented by only one person, the research team was conscious that they might be easily identified if specific information about their gender, age or facility association was

revealed. Thus, all interview data presented in this thesis do not have any identifying information.

Standards of Evaluation

The researcher, aided by a team of advisors, used several techniques to ensure credibility and confirmability, based on the standards established by Lincoln and Guba (1985). These techniques included: triangulation, bracketing, and achieving saturation of the data.

The research team, comprised of one student (myself) and three faculty members, used triangulation (having multiple individuals analyse the same information) to ensure accuracy of the conclusions drawn from the data. Each member of the team coded a different transcript to establish an initial code list. Next, using that list, the team coded the same transcript to ensure that there was a shared understanding of the definitions of each code, and that this list yielded similar results when used by different researchers. It took three rounds of coding to establish a list of codes that was agreed upon. This final list was used for the remainder of the analysis process. Using triangulation to maximize confirmability helps to ensure that the findings were not biased or influenced by the personal beliefs of one individual researcher. It is impossible to ensure that this is done completely, but having the input of multiple researchers certainly minimizes the extent that outside biases enter the conclusions drawn.

The researcher engaged in bracketing throughout the research process, attempting to approach the research process from a fresh, open perspective and attempting to set aside any presuppositions. This process is imperfect and it is impossible to remove all personal bias from research. The researcher also acknowledged her own personal biases

and perspectives at the beginning of the analysis process, and made a conscious effort to work outside of those. One particular bias that was present was the fact that a literature review had been done before the data collection process began, and the researcher had prior knowledge of the topic from the information found in the literature. I, as the researcher, made an effort to be aware of any assumptions I had about this topic that I had learned from the literature. It would not be possible to remove oneself from this prior knowledge because this knowledge was essential to the creation of the research questions in this study.

The researcher continued to collect data until she felt that saturation had been achieved, meaning that there was no more information to be learned from the population of this study. By the end of the study, most of the participants were expressing the same themes, and very little new information was uncovered. The researcher felt that due to this, it was appropriate to cease data collection.

Another technique proposed by Lincoln and Guba (1985) is member checking, which entails having the participants review the data to ensure that it is accurate. Due to difficulties maintaining contact with participants, the research team was not able to engage in member checking because no participant indicated that they were interested in reviewing the transcripts of their interviews to ensure accuracy. The researcher asked if they were satisfied with the information they had given at the conclusion of each interview, and all participants indicated that this was the case. The researcher also followed up with an email thanking them and inviting any further comments or questions, and no participant responded.

The research team evaluated the quality of the research process to ensure that it was consistent with the population being studied, and that these findings would be as transferable as possible outside of the research population. And effort was made to include a sample that consisted of a broad range of professions, experience levels, and from different facilities. This proved to be difficult, because participants were difficult to recruit due to time constraints, but the final sample included a variety of the professions identified above.

Analysis

The text of four of the transcribed interviews was coded by the researcher and a research team comprised of three individuals. Each member of the research team coded a different transcript. The research team engaged in open coding, reading through the transcripts broadly to see what emerged, and creating codes from this process. Once the draft list was established, each member of the research team coded a different transcript using the draft list. The research team met several times to compare different transcripts coded by the same list to ensure that the findings were similar and to come to consensus about the final code list. A copy of the code final list can be seen in Appendix F.

NVivo software, edition 10 was used during the analysis process to aid in organizing the information. The researcher and advisory team first engaged in open coding, looking line by line for any and all codes that emerged. This was the stage where the draft list was created. After this, the researcher engaged in axial coding, and began to refine the codes into a more comprehensive list, combining similar ideas under similar codes, and providing definitions for each. At this point, the codes (15 codes and 12 subcodes) were organized using the aid of NVivo software. From there, the researcher

engaged in selective coding, grouping similar sub-themes together, and making connections between them. From the selective coding process, three distinct themes emerged from the data: confusion, lack of resources, and communication problems (see Figure 2).

Tables

Table 1. *Description of Facilities*

Facility	Approximate Number of Beds	Type of Funding	Number of Participants
101	250	Public	4
102	400	Public	1
103	250	Public	2
104	125	Public	1
105	150	Public	10
106	75	Public	1
107	200	Public	1
108	50	Private	2

Table 2. *Participant Information*

Category	Percentage
Role	
RN	41.0
PSW	14.0
RPN	9.0
Social Worker	9.0
Pharmacist	4.5
Volunteer	4.5
Volunteer Coordinator	4.5
Physician	4.5
Recreation Therapist	4.5
Chaplain	4.5
Palliative Care Education	
No Education	9.0
Education	91.0
Gender	
Men	14.0
Women	86.0
Length at Facility	
0-5 years	18.0
6-10 years	9.0
11-15 years	14.0
16+ years	27.0
No response	32.0
Number of Residents Responsible For	
Less than 100	68.0
100-199	23.0
200+	9.0

Chapter 4: Findings

The research aims for the study were to investigate what palliative care looked like as it was being delivered in long-term care, whether there were any assessment tools to help guide the initiation of palliative care, and whether there were any policies or funding incentives that facilitated or prohibited the delivery of palliative care.

The first question posed to each participant during their interview was about their role in delivering palliative care to individuals with dementia. The responses were varied, given the number of different professions that were represented in the sample. In general, the registered nurses (RNs) stated that they were responsible for symptom management and overseeing the personal support workers (PSWs), who in turn were responsible for the direct care of the resident, including turning, bathing, and mouth care. Registered practical nurses (RPNs) fell between RNs and PSWs in terms of responsibility; they did more hands-on care, but were not responsible for overseeing any other staff. RNs and PSWs provided the majority of the medical care at end of life. RNs in particular took a leadership role in making many of the care decisions at end of life such as contacting the physician to request specific medications and educating the family of the resident about the dying process. The physician had limited involvement in daily care and relied on the nursing staff for updates because of high resident caseload both within and outside the facility.

Other staff members who were involved in providing non-medical palliative care included social workers, members of the spiritual care team, palliative care volunteers, and recreation therapists. Their roles varied slightly by profession, but in general, they focused more on the emotions and psychological well-being of both the resident and their

family members. For example, the role of the chaplain was to provide spiritual and psychological counsel as the resident neared death. Most stated that their role was to provide a comforting presence at the end of life. Analyses of the interview data, guided by a phenomenological approach, revealed the following three themes. These themes included confusion with the distinction between end of life care and palliative care, resource shortages, and communication difficulties.

Confusion

A significant finding during the course of this study was the issue of confusion, which in turn was broken into three sub-themes: confusion in terminology, confusion in initiation and lack of guidelines. Participants were confused about the distinction in terminology between palliative care and end of life care and when palliative care should be initiated. The lack of guidelines to aid decision making at end of life contributed to the confusion.

Confusion in Terminology

Most staff members who were interviewed used the two terms (palliative and end of life care) interchangeably, and did not appear to know the difference between the two. End of life care refers to symptom focused care that is delivered in the last few days or weeks of life (Canadian Hospice Palliative Care Association, 2013). Palliative care refers to person centered care that is focused on maximizing quality of life and is delivered earlier in the course of the illness (Canadian Hospice Palliative Care Association, 2013; WHO, 2013). However, the interview data revealed that the designation of “palliative” in long-term care appeared to mean that the individual was at end of life. Despite the fact that many staff agreed that “everyone who is in this facility is palliative according to the

definition of palliative” (1-101), no one received the designation of “palliative” until they were no longer able to eat, drink, and get out of bed. Residents usually died within a few days of this designation. Thus, many staff were confusing the terms “palliative care” with “end of life care”. According to some participants, this confusion was problematic because residents were not able to access many resources until they had the palliative distinction.

The confusion about terminology permeated staff members’ belief about pain relief at end of life. On some occasions, nurses were afraid of giving the prescribed dose of pain medication because they were concerned about the side effects it might cause, and that they might be blamed for speeding up the dying process. As a result, staff would often delay palliative measures like these until they were certain of the necessity of such measures. They usually would become certain that end of life care was necessary when the individual stopped eating and drinking, and had decreased consciousness and mobility.

One participant was particularly troubled by the fact that palliative care often started at a very late stage in the illness. Due to the fact that additional pain medications were made available with the palliative designation, the participant reported that residents who did not get an early palliative designation had untreated pain until they were at end of life. The following excerpt reveals this view.

Most frequently, it [palliative care] is way too late. That’s what I find in long-term care, it’s way too late. You know, it might even be a day or two. Which is unfortunate because they’ve [residents] been in that state and could have been given these symptom management medications for much longer, but it takes so

long for them [staff] to do that because it's so difficult to prognosticate at end of life, you see. (1-101).

Confusion in Initiation of Palliative Care

Participants felt uncertain in initiating palliative care because of the uncertainty in the palliative vs. end of life distinction. Nurses mostly shared this confusion because they were often the ones making decisions about continuing treatments and beginning palliative care. Staff participants (usually nurses) were unsure about when to initiate end of life care, and expressed a desire for more guidelines to aid them in making that decision. In addition, they were unsure about when to stop treating certain ailments. For example, if a resident had a urinary tract infection, and the family asked the staff for guidance in determining whether to treat it or not, staff were unsure when the decision to stop such treatment should be made. In addition, the issue of when to stop nutrition and hydration did not appear to have a clear solution, because there were cases where residents would stop eating for periods of time, and then begin again. Staff were not sure when it was appropriate to stop trying to help residents eat.

Indeed, it appeared that the entire philosophy of care shifted after the palliative designation. As stated earlier, the "palliative designation" is a term that staff used to mean the initiation of what they felt was palliative care. It usually occurred in the last few days or weeks of the resident's life. Prior to the palliative distinction, there appeared to be more of a focus on curative care, and less emphasis on pain management. Once the resident was deemed palliative, the philosophy of care changed to be more person-centered, to treat symptoms that they experienced, and to provide a calm, reassuring environment for them as they died. Most participants agreed that keeping residents as

comfortable as possible was a priority, and this was achieved through medication, psychological support, spending one-on-one time with them, and giving them a comfortable, quiet room where their family or other visitors could spend time with them, if they wished. One participant summed it up as follows:

You're managing the symptoms that the resident has, whether it's pain relief, are they agitated, are they short of breath, are they nauseated and vomiting. We can tell, as people are, if their physical condition is deteriorating, are they eating less, are they in bed more, are they sleeping less, are they not interested in activities, this tells us where we're heading with somebody's condition. (1-103)

Several participants explained their philosophy around pain management at end of life, stating that being pain-free was the most important goal. One participant stated: "I know that we're excellent at delivering pain control. I'd probably err on the side of too much. Some of the nurses worry about addiction, you know, but who cares. There's only one way out" (7-105). It is noteworthy that this shift in priorities is so sudden, especially given the lack of reliable assessments and established guidelines to determine when palliative care should be initiated.

This dramatic shift in philosophy also appeared in areas besides pain management, such as visits from volunteers and family members. One participant pointed out that most individuals with dementia were marginalized before they reached end of life, and that once they were at end of life, it "evened the playing field" (10-105). The palliative designation appeared to change the entire way that the resident was viewed. This staff member stated that both staff and other residents often avoided residents who had dementia, particularly ones who resided in the specialized dementia unit.

I find that over the years people with dementia sometimes are marginalized even before they become palliative, and that's a challenge because residents who are say physically frail but cognitively intact don't understand why people with dementia are the way they are. I know one dementia care unit I worked on, not here but at another home, people [staff, family members, volunteers, other residents] were afraid of coming to the dementia care unit...but then I find once they [residents] do become palliative, it's "oh, well you show up now". Where I worked, there was a huge volunteer base for palliative care, which was great, but we need volunteers for when they had dementia and could use a distraction. (10-105)

Participants expressed that often, staff and other residents did not understand that behaviours such as exit-seeking, confusion, and agitation were typical of someone with dementia, and were not reflective of the individual. This meant that persons with dementia had very little meaningful contact with other residents who were often afraid of interacting with them. The staff member felt frustrated that residents received no extra support at a time when they had greater awareness and ability to appreciate that someone was spending time with them. In contrast, when they were deemed palliative and were usually unresponsive with diminished consciousness, residents with dementia had access to volunteers who would sit with them, and family members were contacted and encouraged to spend more time with the resident as they died. Additionally, staff would make extra efforts to ensure that they were comfortable and not alone.

Lack of Guidelines for Dementia-Specific Palliative Care Initiation and Delivery

An important research aim for this study was to determine if there were any assessment tools or guidelines to aid in the delivery of palliative care for individuals with dementia, specifically to guide when initiation should occur. Given the inherent communication difficulties with residents with dementia, it was important for the research team to know more about how these decisions were made. The information that was received from the participants was extremely varied. No dementia-specific palliative care assessment tools were mandated for use by the province or any other governing body.

Participants from three facilities reported using the Palliative Performance Scale (PPS). The PPS is a 10-point scale outlining typical changes (in mobility, evidence and level of disease, ability to care for self, intake of food and fluid, and level of consciousness) that people undergo as they move from 100% (disease-free) to 0% (deceased) (Anderson, Downing, Hill, Casorso & Lerch, 1996). Of the facilities that used the PPS, none of them had a specific threshold on the scale that indicated when palliative care should be initiated; instead, they used it mostly as an educational tool for families to show them what the dying process might look like.

The reasons staff gave for not using assessment tools were that many were copyrighted, and they did not have the money to pay for the rights to their use, or that they were unaware of any assessment tools that would be useful for them. One staff member disclosed that their facility used the PPS without paying for it, and acknowledged that this was not an optimal situation. One facility used only assessment tools that were available for free, such as the Abbey Pain Scale. The Abbey Pain Scale is a checklist with six sections (vocalization, facial expression, change in body language,

behavioural change, physiological change, physical changes) used to assess pain in individuals with dementia, using a variety of different indicators to do so (Abbey, De Bellis, Piller, Esterman, Giles, Parker, & Lowcay, n.d.). Others used the Registered Nurses Association of Ontario (RNAO) best practice guidelines for end of life, but these are not specific to dementia or to long-term care, according to the nurses. Most facilities did not use any specific assessment tools to guide palliative care initiation. This meant that palliative care initiation differed from facility to facility.

The majority of staff responsible for initiating palliative care used their own experience and professional judgement to determine when palliative care was best initiated. Usually, RNs made the decision to initiate palliative care. Most said the assessments were based on common sense. One participant, who was an experienced nurse, explained “When they’re done, they’re done. We just know.” (9-105). Usually, when a resident with dementia stopped eating and drinking, the RN made the decision to contact the physician and request that the resident be designated palliative. They also made assessments based on abnormal vital signs, behaviours out of the ordinary for that individual, and obvious distress on the part of the resident.

Non-verbal cues are super important with people with dementia, especially in palliative care...people are especially non-verbal at that time. So you’ve got to kind of read them and guess what they need. And I think a lot of that comes down to the nursing staff, they’ve worked with them for however long they’ve been here, they know them pretty well. (1-106).

Most staff expressed a desire for more guidelines to aid end of life decision making. Many RNs expressed the desire for more research into best practices in this area

because they were uncertain in the decisions that they were making. Several participants reported that sharing knowledge and best practices with people working in other facilities helped eliminate some of this uncertainty. In fact, some staff had formed a palliative care community of practice, comprised of individuals from different facilities and disciplines who met four times per year and discussed best practices and other issues they were facing in end of life care. This group was not specific to dementia, but most members did have significant experience working with individuals with dementia because of their experience in long-term care.

It was important to understand what happened when someone with dementia died, and whether the process was different from that of someone who did not have dementia, with respect to assessment tools and guidelines for care. Staff were asked these questions specifically, and asked if there was anything different they needed to do when caring for someone dying with dementia. Most staff agreed that individuals with dementia would lose mobility, lose interest in eating and drinking, and then begin to lose consciousness, until they eventually died. One participant referred to this as “getting the dwindles” (1-101) because the process was often lengthy and unpredictable. Palliative care was usually initiated when there was a significant change in the resident’s medical status, including a dramatic decrease in food or fluid intake, mobility, or level of consciousness. Usually, the nurses would notice this change and notify the family and the physician, and designate the resident as palliative.

With the exception of a few staff members belonging to the palliative care community of practice (mentioned above), knowledge was not often shared among staff across and within facilities. Consequently, each facility operated independently by

creating their own palliative care approaches, because of the absence of formal guidelines. The community of practice was an excellent start to combat this problem, and all who were involved shared that sentiment.

The need for dementia specific guidelines was related to the unique complications that individuals dying with dementia presented to staff. Individuals with dementia did not always follow a predictable dying trajectory, and instead “dwindled” slowly until death. This meant it was difficult for staff to allocate certain resources, such as the palliative care room. For example, if two residents were nearing death at the same time, it was difficult to determine who should be placed in the palliative care room. In addition, staff noted that they still had to combat the misconception that dementia was not a terminal disease, both from other staff and from families. According to participants, staff and family members who held this belief were less likely to appreciate the merits of palliative care for someone with dementia, and would be less likely to request it.

Dementia-specific palliative care was very rarely done in long-term care because palliative care was initiated so late in the dying process. At this stage, as noted above, participants reported that the needs of the resident with dementia are not that different than the needs of any other individual who is dying. Where the difference lies is in the care that residents with dementia received before the “end of life” stage. One participant expressed a different view to the approach of palliative care this way:

I think if we talked about palliative care as being a philosophy of care, not a type of care, I think there’s a misunderstanding that palliative care is only for people who are dying. It’s a problem we don’t acknowledge, that chronic disease is not curable. And it will end in death. And really, what we’re doing with chronic

disease is treating the symptoms, which is palliative care. But people don't see it that way; it's not explained to them that way. Where it should be explained that...it's a chronic disease, which means that it's life limiting, and yes, we have medications that can manage the symptoms, but that's not curative, really, that's a palliative treatment. People don't see it that way, but that's exactly the way it is. (1-101).

According to the beliefs of this participant, everyone who was living in long-term care would be palliative, and would require a dramatic shift in the philosophy of the care they were getting. During the course of this study, many participants acknowledged the irreversible decline that occurred with dementia, and many also noted that almost everyone who entered long-term care would die there. However, there was still the sense that they were not "dying" until they were at end of life, and for that reason, the philosophy of the care they were receiving was not true to the definition of palliative care.

Resource Shortages

The second major theme that emerged involved resource shortages. Every facility that participated lacked resources either in terms of physical resources and equipment, or in terms of staff shortages. Nearly every participant expressed a need for more staff, with more time available to provide care. Good quality palliative care is inherently more time-intensive because communication difficulties make needs assessments difficult, and because of the extra time spent reassuring the resident and providing a calming environment. This does not align well with the task-oriented nature of care in most long-

term care facilities. Many participants, as illustrated by three quotations, expressed this sentiment:

I very much believe that hearing and touch are the last things to go in dementia, and usually they respond positively to gentle touch and stuff, so I find sometimes that the biggest barrier that I see from a staff point of view is the staff just want to go in and do their thing and get out because [in] long term care we're so time-crunched, that they don't often take that extra time to give that little TLC [tender loving care], and I think that sometimes just prevents the palliative care experience from being a positive one. (1-102)

They don't have enough staff to do what they're doing. It's amazing, the work that they have to do. And it's all task-focused, and palliative care is not task-focused, it's person-focused. (1-101).

The challenge is having the time and staff available to figure out what those individual needs are for the person, and then meeting them. So typically if it means you're dealing with agitation, you could give them a medication, or you could give them one-on-one. But one-on-one isn't an option, even though that would be ideal, when somebody's dying, to be in the presence of someone else. So I would say it's not so much that there's a strategy that's being missed, but we're under resourced to have the time to be able to figure out what unique strategies work for each person and meet them. (1-105).

Participants felt that not having enough staff contributed to a poor experience for the individual receiving palliative care. Some participants, particularly ones doing more hands-on care, also were personally affected by this shortage.

You have some staff take it really hard, really we have staff members that will cry, literally, if they have to leave the room to go attend to a call bell or something, you know, these people are family. We come here, we spend 8, 9 hours a day with them, so they become a part of us, right? So it is hard, it would be an ideal thing for the government to... implement more staff, so that when people are dying, they have staff members there, because I said before, some family members choose not to be there (3-105).

Facilities also lacked the resources to fund a variety of staff members, particularly social workers, chaplains, recreation therapists and other staff who address psychosocial care needs. Many staff members from these professions had had their hours cut, and often they were responsible for extremely large numbers of residents. It appeared that these areas were the first to be cut when there was a shortage. One staff member felt that this was because administration did not know what his job consisted of, and how much of a benefit he provided to residents. He explained that nurses and PSWs were seen as essential staff by administrators, but that other disciplines were not, and they were the first to go if there were budgetary constraints.

Another area where the resource shortage was noted was in the area of staff training in palliative care. Most staff were not trained formally in palliative care techniques during their education, and relied on work experience and training provided outside the facility. Most participants had taken some form of basic training, but indicated that this was not the case for all coworkers. According to the participants, the facility often did not have the funds available to pay for the extra training so it was usually funded through grants or private donations.

Discussions on resource shortages were consistently accompanied by recommendations to improve the delivery of palliative care. For example, staff participants expressed a desire for the implementation of more alternative therapies, such as music therapy, art therapy, and massage therapy, even if it was on a limited basis. However, they stated that this was likely going to be challenging to accomplish because there were not enough resources. Many also expressed desire to create a room or rooms designated specifically for palliative care, or to improve existing ones. However, while most staff expressed this sentiment, many also were realistic in their views that this was unlikely to happen.

Anything in long-term care as I've come to realize...it seems that everything is a money thing. If we had more money, we'd have more staff, and the staff would be able to spend more time with individual residents, and people would be happy. But as with most things government or public, money's always going to be an issue. I think if you were to give us like twice as much money, we'd still use more, you know? (1-106)

When collecting data for this study, it became apparent that there were many inconsistencies between facilities. Some facilities seemed to be more progressive than others in terms of the development of their palliative care program, the knowledge of staff, and the staff perception of success. What appeared to be working for these facilities was multi-factorial. Firstly, staff were trained in palliative care, and were adept at recognizing the needs of the residents with whom they worked. Most staff had taken the Center to Advance Palliative Care (CAPC) course, which is an American organization dedicated to increasing the availability of palliative care services (CAPC, 2014).

Additionally, staff felt confident in their skills but were willing to evaluate their own performances, and to learn from mistakes that they made.

What works well...is the staff are well trained, quite well, from the day these people enter here, and we recognize the challenge...we're working at building a strong team. Recognizing we have a very active palliative care team here, and with this recent education, we want to continue to build that. So we still have gaps, we still have issues, we still have concerns sometimes that happen with families...but we're really working and we identify [those concerns]. (2-105)

Secondly, dying residents also had access to palliative care volunteers, if the facility had any. In some facilities, they also were moved to a private room. Some facilities had specific palliative rooms, which had extra beds for family members when they visited. Staff would treat symptoms that the resident was experiencing, and provide support to the family if they were present. PSWs, in addition to turning and changing the resident, provided extra support such as making sure their lips were not chapped, and other basic mouth care. Most facilities had some kind of designation to let others know the status of the resident, such as placing a butterfly on the door of the room. This allowed staff and other residents to be respectful of the needs of the dying resident and their family. Most facilities also had a palliative care cart that was brought in for the dying resident, which included things like soothing lotions, extra soft sheets and nightclothes, music, and some resources for the family, including information about what to expect at the time of death, and contact information for local funeral homes, and other similar organizations.

I think the way we deliver care here, we are the best...this is a family-oriented facility, and if I had my parents in this world still, I would not hesitate to bring them here to die. Never. It's emotional, it's a necessary thing when someone's dying, and you don't get that in the hospital, you don't know the nurses. I've watched people that I love die in the hospital and the atmosphere is not the same...we're really good at delivering palliative care here, and I'm really proud to say that. (7-105)

Having the management and administration of the facility committed to the goals of palliative care also was an important facilitator to success, according to the participants' responses. Supportive administrations were more willing to allocate a certain amount of money for resources such as a palliative care room, and training volunteers and staff in specialized palliative care. They were also more understanding of the need to spend some extra time with individuals who were dying.

Management has been very supportive of this committee and the palliative care and end of life care for residents. This is their home, so you are not going to send them somewhere else for palliative care, because I think long-term care does it best...they want to have the residents here to die because they're like family and we're very familiar with them, and for supportive families, they're needing us as well at that time. (1-103)

When staff were able to focus less on completing tasks and were responsible for fewer residents, they were able to have more meaningful interactions with the residents for whom they were caring. Participants noted that having the time available to not rush through care tasks was valuable and necessary, and decreased the need for

pharmaceutical interventions to control behaviour, particularly for residents with dementia.

We are resident-first, not task-oriented...if the resident needs something now, then we leave the task and go to the resident, and as registered staff, it's not just about pushing the pills, and doing the dressings and catheters and whatever, we also have the time to do one-on-one...they get to know us very well, they don't know who we are, they don't know what our names are, but they know that we are the people that are kind to them, and help them, and we have that trust, so you get the decreased behaviours and all that as well. (2-108)

Challenges in Communication

The third theme, communication throughout the palliative care process, was difficult for staff, and presented as a barrier or challenge to care. There were three types of communication channels that staff identified as problematic: staff-resident communication, staff-co-worker communication, and staff-family communication.

Staff-Resident Communication

Communication difficulties on the part of individuals with dementia are an inherent change that occurs as their cognitive abilities decline throughout the course of the disease. Staff indicated that individuals with dementia who were unable to express themselves verbally might communicate by aggressive behaviour towards staff, family, and other residents, despite the best efforts of staff to prevent this. Staff also felt uncertain about whether they were meeting the needs of residents because of the lack of meaningful communication they were able to have with them.

They're not able to verbalize that they're in pain. If they're more restless, we'd spend more time trying to be the detective and their care, knowing that we have to be the one telling if they're in pain, and then lots of them are not able to verbalize that information. (3-105)

Staff-Staff Communication

Staff also felt that communication among each other was sometimes difficult, and that a lack of communication among staff made it more difficult to provide good care. In particular, communication among staff of different disciplines was challenging. Nurses indicated that, at times, they did not have enough communication with physicians who were prescribing drugs and designating residents as palliative, because physicians often worked in several different facilities, and had many residents under their care. Other members of the palliative care team, like volunteers, social workers, chaplains and recreation therapists also felt excluded from the process at times. One participant explained her dismay at finding out that a resident had died, and that no one from her team had been called to help. She felt that she could have contributed meaningfully, but no one had thought to include her.

In addition, staff at facilities that had no formal palliative care committee expressed frustration in making end of life decisions because there was no protocol to guide them and no one to take the lead in decision-making. Another problem of communication between staff was the increasing number of part-time and casual staff employed in long-term care. As noted previously, participants described having a personal relationship with the residents with dementia as a facilitator to good quality care, and this relationship was not as strong with part-time or casual staff. Often, new staff

switched between floors or units, and sometimes even facilities, and did not get to know the residents or their co-workers well. One participant also observed that part-time staff were less likely to be trained in palliative care techniques because they did not permanently or consistently work on one a particular unit.

Staff-Family Communication

Study participants reported that communication between staff and family was a challenge. Families, especially ones who were uninformed about the dying process, could become aggressive, irrational, and distressed as their family member died. This made it difficult for staff to collaboratively make care decisions. Staff also noted that sometimes families were unable to let go of their loved one, and wanted to try as many treatment options as possible, or as one participant put it: “wanted the book thrown at them” (4-105). Staff had difficulty accommodating these requests, knowing that the interventions were futile. Communication between staff and family also was made difficult when families had information based on anecdotal evidence or unreliable internet sources. Staff had difficulty convincing them that these interventions would not produce the results they were expecting, and family members were frustrated that their wishes were not followed. This could lead to conflict over decision-making. Staff also reported that some families would not follow the wishes listed on their relative’s advance directive, and as discussed above, staff felt that they had to comply with family requests, especially if the family was insistent or aggressive.

Mummy and Daddy make their wishes known, but Tommy and Johnny, they don’t want to see Daddy die, so even though they know those are their wishes, and even though the staff know those are their wishes, it’s very difficult for staff,

even physicians, because they fear repercussions if they don't do what they're told, or what they're asked to. There are big issues with that. It [the advance directive] is supposed to be [binding] you see, but it's not, in reality...I mean nurses can talk about it with the family, but when you get families who are aggressive, I mean legally aggressive, they give in. (1-101).

Participants reported that this kind of conflict is particularly problematic because the individual who is dying is removed from the decision-making process. Although participants reported that situations where families became unreasonable were relatively rare, such situations were highly salient and distressing for all involved. One participant felt that the solution to this was more education for families.

I would have more conversations with families at end of life, more realistic conversations. That means when you're talking with the family, that you actually talk about death and dying, and that you don't sugar coat it, because I think that's what happens, we're afraid to tell people the truth, which is: they're going to die. (1-101)

A factor that was seen as a facilitator for palliative care was proactively educating families and the general public about the dying process, the nature of dementia, and what services were provided in the facility at end of life. Most participants felt that there was a lack of knowledge from the general public about the dying process. One participant stated: "It's not like the movies, you know. Being born and dying take a lot of work" (1-105). Staff also felt that families were more likely to request that residents be moved to the hospital if they were not aware of what care could be given within the facility. Participants stated that a better relationship could be fostered with the family if there is a

discussion about the dying process with the family during the admission interview. Specifically, participants expressed that it was imperative that long term care home staff explain in detail what care could be given and discuss the wishes of the resident, including advance directives. Having the family aware of the realities of the dying process greatly reduced their anxiety when these changes actually occurred. For example, when the resident stopped eating and drinking, families could become very concerned about dehydration and malnutrition, and request feeding tubes and artificial hydration. In reality, as explained by the staff, these changes were a normal part of the dying process, and usually meant that the resident was no longer able to gain nourishment by consuming food because their organs were failing. At this point, a feeding tube likely would be futile and distressing for the resident. Having the family be aware of this issue before it occurred meant that they were much less likely to become distressed in the moment, and request such interventions. This also improved family/staff interactions, as both parties were much calmer and cooperative.

Every participant who was interviewed stated that an open relationship with the family was crucial in providing a positive care experience. This is especially relevant for residents dying with dementia, who are unable to make their own care decisions. Participants expressed that having a family-oriented facility was the best approach, and staff worked hard to create this, both during and after the dying process. For example, one facility would leave a rose and a card of condolence from the staff in the room of the resident so that the room did not feel empty when the family was collecting the resident's belongings. Many facilities also held semi-annual memorial services, attended by staff and family members, celebrating the lives of recently deceased residents.

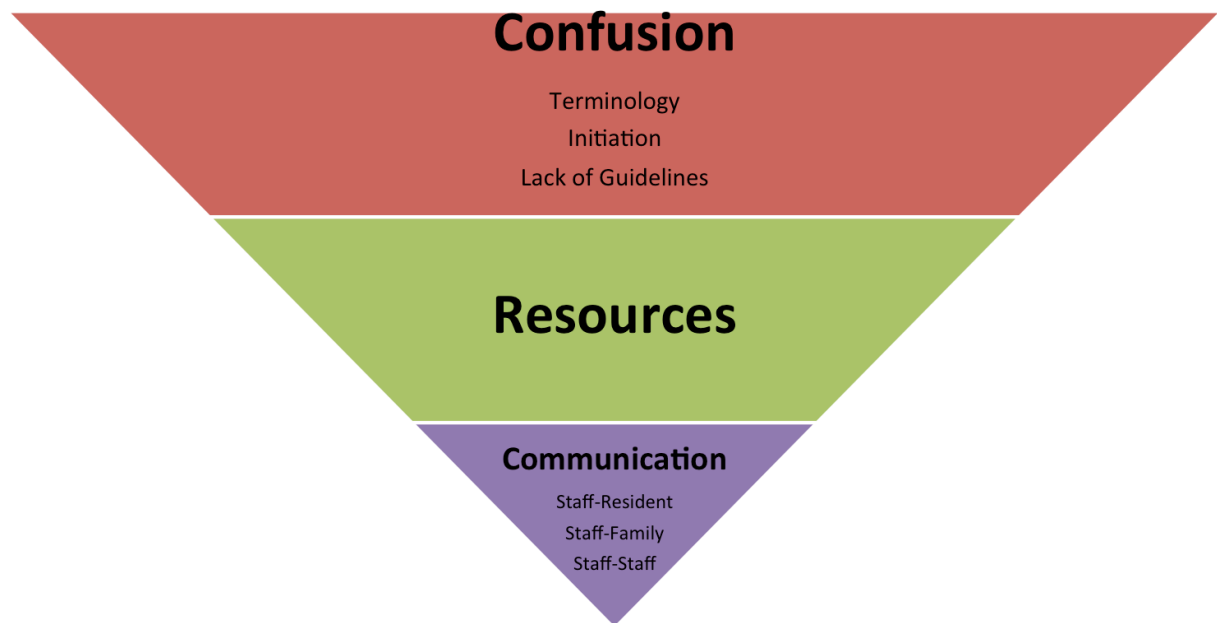
When staff utilized a team approach to care, with open communication and shared goals, palliative care was felt by participants to be far more successful. Staff had goals for each resident they worked with, and expressed a sense of success when these were accomplished. As a team, they worked to ensure that each resident had the best death possible, and that the family was supported in their grief. This approach extended beyond medical staff as well. All staff members, including housekeeping and dietary managers, were made aware that a resident was dying. This meant that extra meals could be provided for families, and extra beds or chairs could be brought in if there were large numbers of family members present. When a team approach was utilized, it also reduced emotional stress on staff, because they were able to deal collectively with the grief of losing someone for whom they had cared. This emotional support was invaluable, and was felt by all staff to result in better quality care for the resident.

In summary, three main of themes emerged from a phenomenological analyses of the interview data. These themes were: confusion, resource shortages, and communication difficulties. Confusion was centered on an inconsistency in terminology and a poor understanding of what palliative care entailed, and when it should be initiated. Confusion was compounded by a lack of guidance or assessment tools to aid in the initiation and delivery of palliative care. Resource shortages were in the form of training for staff and volunteers in palliative care, not enough money to fund non-medical staff, staff not having enough time to deliver good quality palliative care, and facilities lacking resources for specific palliative care aids such as designated palliative care rooms. Lastly, communication difficulties acted as a challenge to delivering good-quality palliative care. Communication between staff and residents was challenging because residents were often

unable to communicate their needs and staff did not have the extra time to spend deciphering them. Communication among staff could be challenging if other staff were not trained in palliative care or did not have good knowledge of the residents. Lastly, staff communication with families often was difficult because families were unaware of the nature of dementia and what palliative care entailed, and could lead to conflict around decision making. In collecting data for this study, it was clear that most facilities shared experiences described in the themes discussed above.

The relationships among the three themes are summarized below (Figure 2). Confusion, the most prevalent theme, encompassed all other themes. If there was confusion about what palliative care entailed, and how and when it ought to be delivered, then good quality care would be difficult to provide, even if resources were available and communication was clear. Next, if there was clarity on how and when palliative care should be delivered, but there were no resources available, it would still compromise the quality of care that the resident received. Lastly, even if the first two conditions were met, palliative care could still not be of optimal quality if communication was poor between staff and residents, family members, and coworkers.

Figure 2: Themes



While some facilities experienced unique challenges and delivered palliative care in different ways, these themes were representative of a majority of the facilities that participated. These themes give insight into the delivery of palliative care in long-term care facilities. Implications of these findings are explored further in the discussion.

Chapter 5: Discussion

This section will begin with a summary of the findings of this study. It will then discuss how these findings compare to the existing literature both in terms of similarities and unique contributions. This section includes the limitations and strengths of the study. Finally, this section addresses implications for practice, especially in terms of how the findings can be used to improve the delivery of palliative care for persons with dementia in long-term care settings.

The aims of this study were to investigate how palliative care was delivered for individuals with dementia, what assessment tools were used to aid in the delivery of care, and whether there were any policy or funding incentives that enabled or prevented palliative care from being delivered to individuals with dementia. Three distinct themes emerged following an analysis of the interview data: confusion, lack of resources, and communication problems.

Confusion

The first theme, “confusion” was the most prevalent, and persisted throughout all of the interview data. Participants were confused about two specific issues: terminology of palliative care, and how and when palliative care should be initiated. The distinction between “palliative” and “end of life” care, as noted earlier, was not well understood by most participants. This resulted in most individuals with dementia receiving inconsistent care. The confusion about when palliative care should be initiated also meant that individuals with dementia received care that was inconsistent, and often far too late. Guidelines to help deliver care were limited and often misunderstood by staff due to the uncertainty about what palliative care entailed. This confusion about how and when to

deliver palliative care affected all the other themes that were uncovered in the interviews. If staff were confused about what care they were delivering and how it should be delivered, resources could not be used effectively, and communication with staff, residents and family was more difficult.

Similar findings related to the theme of confusion were found in the literature. For example, Davies et al. (2014) discussed a theme they called “the ambivalence towards the systemization of palliative care”. This ambivalence was towards the changes required to implement palliative care for individuals within a system had not previously had this capacity. Many staff from their study had similar feelings to participants from this study regarding palliative care for persons with dementia: that it was disorganized. Davies and colleagues (2014) conducted their study in the UK, and found that there was confusion on the part of staff working in the field with respect to the guidelines. Some staff indicated that guidelines were too strict and could interfere with care, whereas others indicated that there were too few guidelines and that care was chaotic as a result. In our study, staff felt that there were too few guidelines, and none expressed any frustration with regards to guidelines being too strict.

In the literature, a significant barrier to palliative care for individuals with dementia were policies within facilities, or laid out by a regulatory body, that worked against the goals of palliative care (Sachs et al., 2004; Shega & Tozer, 2009). For example, American hospices providing specialized palliative care sometimes face fines and audits if it is found that they give care to individuals without 6-month terminal diagnosis (Shega & Tozer, 2009). Individuals with dementia rarely are given a 6-month terminal diagnosis because of the unpredictable nature of dementia. This attitude also

reflects a lack of understanding of the goals of palliative care and the terminal nature of dementia (Davis et al., 2003). If having individuals with dementia die in the facility is seen as a failure of care, and thus worthy of a funding cut, no one in that facility will embrace the philosophies of person-centred palliative care.

Encouragingly, the policies listed above were not replicated in the present study. Most participants did not report any policies explicitly preventing palliative care. There did not appear to be any policies directly working against the goals of palliative care, with the exception of one facility. This facility had an unofficial policy that any resident who was dying be transferred to a hospital. This facility did not appear to be prepared to deal with residents dying in their care, but did provide limited palliative care in the earlier stages of the illness. This facility had not been open for very long prior to their participation in the study, which might be why they were unequipped to provide end of life and late-stage palliative care.

While there were no policies that prohibited palliative care delivery in long term care homes, policies to aid in care delivery were also scarce. In the Ontario Long-Term Care Homes Act, which governs most of the facilities in this study, there is only a passing mention of end of life care, and palliative care is not mentioned at all. It states: "every licensee of a long-term care home shall ensure that every resident receives end-of-life care when required in a manner that meets their needs" (Government of Ontario, 2007). This provides very little guidance for what palliative or end of life care should entail, who should deliver it, and when it should begin. In addition, earlier versions of the act included references specifically to palliative care, but appear to have been subsequently removed from the current version that is available. This shows that palliative care has

become an even smaller priority for the government, if they did indeed change the act to reflect that palliative care is no longer a requirement to provide to individuals living in long term care homes. The Long-Term Care Homes Act also states that staff who provide direct care to residents should be trained in pain management, but does not state that they must be trained to provide end of life or palliative care. This shows a lack of support from the government regarding the implementation of palliative care in long term care homes.

Resource Shortages

The shortage of resources was one theme that had many implications on the care that individuals with dementia received. For example, resource shortages meant that staff members were not always trained specifically in how to deliver palliative care. In addition, most facilities did not have enough staff numbers to meet the extra time demands required of palliative care. Staff were overworked trying to deliver palliative care, which requires more time and resources than non-palliative care, in addition to looking after the other residents in the home.

Staff who were untrained or uninformed about palliative care for individuals with dementia represent a significant barrier to accessing palliative care (Ryan et al., 2011). Staff would not know to advocate for palliative care if they were not aware of its benefits. Fortunately, all of the participants in the current study were aware that palliative care was beneficial for individuals with dementia. In addition, previous findings indicate that workers were often aware of palliative care for individuals with dementia, but were not trained in how to deliver it (Hirakawa, Kuzuya & Uemura, 2009). This finding was much more prevalent in the present study.

Most participants in this study had received some kind of formal palliative care training, but all participants indicated that it was not the norm for all staff in the facilities. It is likely that individuals who knew more about palliative care were the ones interested in participating in this study, and could explain this apparent deviation from the norm. It is encouraging to note that although staff felt that they were under-trained, they did recognize the need for more training, and were committed to finding more resources for this training.

Participants in the current study stated that the unpredictable nature of the dying trajectory associated with dementia made it difficult to allocate resources, plan for the initiation of palliative care, and determine when palliative care should be initiated. This was similar to the findings by Thuné-Boyle and colleagues (2010) and Murray and Robinson (2011), who found that the disease trajectory associated with dementia was challenging because it meant scarce resources were more difficult to allocate because of the increased difficulty in predicting needs and time of death for individuals with dementia. Previous findings indicate that individuals with dementia often decline very slowly, with brief periods of increased health (Sachs et al., 2004). Some remained at the same low state for many months, while others followed a more general downward trend. Participants in this study stated that it was very difficult to determine how long someone with dementia had left to live, except in the very late stages of the disease. In the last few days, nurses stated that they were able to predict with high accuracy how long the resident had left to live. Participants stated that individuals with dementia, in the very last days, had very similar needs to individuals with other diagnoses as they died. The differences in needs for individuals with dementia appeared earlier in the course of their

illness, where they had very unique needs and challenges due to their cognitive impairments.

Communication

Communication difficulties were prevalent among staff, between staff and families, and between staff and residents. These communication problems led to disagreement, uncertainty and stress amongst staff members. Participants reported that communication with other staff members who were not trained in palliative care was often difficult, because there were uncertainties in terms of terminology and how care should be managed. Communication with families who were in the process of grieving the loss of their relative also was challenging, especially if families were resistant to the idea of palliative care or unaware of what the dying process would entail.

Communication with residents was challenging because residents often were unable to verbalize their needs and were confused, agitated, and fearful as they approached death.

Participants indicated that communication difficulties due to cognitive impairments associated with late-stage dementia made it more difficult to provide palliative care. They stated that they had difficulty assessing the needs and pain levels of the residents in their care. These findings are similar to existing work by Aminoff and Adunsky (2006) and Sachs and colleagues (2004), who found that persons with dementia often have difficulty communicating pain to their caregivers, and that this often resulted in them dying with unmet pain needs. The fact that staff are unaware of, or unable to use existing guidelines and assessment tools to aid in this process, exacerbates the problem (Herr, 2011).

The perception that dementia was not a terminal illness was indicated in the literature as being an old attitude, that was slowly changing within the healthcare profession, but one that still existed within the healthcare community (Torke et al., 2010). This view was a significant barrier to palliative care. If staff or family members were under the impression that dementia was something that could be cured, and would not eventually cause the individual to die, they were not open to the ideas or philosophies of palliative care (Torke et al., 2010). This view was not very prevalent in the findings of this study. No staff members who were interviewed held this belief, although a few indicated that they had encountered it from other staff in their careers. Staff also indicated that some families who they worked with held this view, but that most changed their minds and were open to palliative care if they were educated by the staff about dementia and palliative care. Staff also noted that there is a prevalent attitude in North America of being afraid to talk about death, and that this likely contributed to an attitude (albeit rare) of fear and denial amongst staff and family members alike.

According to the participants in this study, family members could sometimes represent a barrier to care if they did not consent to their relative receiving palliative care. However, this barrier was not as significant in this study as it is described in the literature, where findings indicated that families often do not consent to palliative care, and that because they often are substitute decision makers, they have the final say about whether this care would occur. In the literature, family members represented a significant barrier to whether palliative care was initiated if they were not receptive to the idea of palliative care (Volicer, 2005; Davies et al., 2014).

Davies et al. (2014) found very similar findings to this study in terms of themes. Their study examined the experiences of staff in several countries in Europe delivering palliative care to persons with dementia. Like the current findings, Davies and colleagues (2014) found that communication between staff and staff, staff and residents, and staff and families was a barrier to good quality care. In fact, their study had very similar findings overall, including two themes that were almost identical: communication, and funding difficulties (or resource shortages). They found five distinct themes: communication difficulties, variation in integration of services, difficulties in funding palliative care, problematic processes of care, and time constraints. Their study was published after the literature review, and after the data collection had begun for this study. The fact that their findings are similar to the ones in the current study demonstrate that specialized palliative care for persons with dementia remains a problem internationally and one that transcends any differences between health systems here in Canada and in Europe.

Limitations and Strengths of the Study

This study was limited by several factors. This sample came from the same city, and data were collected primarily through snowball sampling. Many participants were recruited from a small community of practice that already existed. Consequently, many participants had already shared knowledge about palliative care delivery with each other. Therefore, the sample may not be representative of the larger population of long-term care staff. Because participants were recruited via snowball sampling, it also is possible that there are many facilities that do not provide palliative care at all, and where its staff would not think the study was relevant. Indeed, the research team had their requests for

participation ignored by many facilities, and it is possible that the staff felt they were ineligible if they did not provide palliative care. The one facility that participated that had the policy to send residents to the hospital to die was not part of the palliative care community of practice. This could indicate that other facilities in the area that did not belong to the community of practice had similar views.

A potential reason for staff being hesitant about participating was fear of disclosing information that could lead to staff, residents or family members getting into trouble. Some participants still expressed fear over revealing information or getting into trouble with their employers even though confidentiality measures were explained both in the letter of information provided at initial contact and when informed consent was obtained prior to the interview. This was a problem with one facility in particular, where the administration of the facility was initially supportive but then became very resistant to the study, and discouraged staff from participating. Reasons for this were not made clear to the research team, but participants did indicate that the facility had come under new management, which could have perhaps been a contributing factor.

This difficulty in recruiting participants also meant that several facilities had only one participant. This did not provide the depth of information that the research team had originally intended. Despite many attempts to recruit more participants from these facilities, individuals did not respond. It was felt that it was more important to include the views of those who did participate, even if they were the only one from their facility, as opposed to excluding a large portion of the sample by including only facilities with more than one participant.

Another limitation to this study was that some professions were only represented by only one participant. It is difficult to know what the norm is for profession with a single participant without interviewing more participants. Lastly, this study was limited by time constraints of staff. While some participants were able to talk as long as they wished, many were not due to heavy workloads. The interviews were conducted primarily in the long-term care facilities to be most convenient for the participants. Thus, participants frequently used their break time to complete the interviews, which resulted in short interviews. In addition, many staff members were worried about leaving their units for long periods of time, and sometimes had to leave the interview to deal with a problem on their unit. This limitation would have been difficult to minimize, as nearly all participants wanted to be interviewed at their place of work where it was most convenient for them. It is likely that the sample size would have been significantly smaller if interviews were moved outside of the facility in order to allot more time per person. The research team also took steps to ensure that time was well used. Often, the researcher sent the demographic questionnaire and a summary of the interview questions ahead of the interview time so that the participant had time to prepare before the interview began.

Despite the limitations listed above, there are several strengths of this study. This study used a broad sample of participants, from a large variety of disciplines and facilities, which was advantageous because it provided a broad and more complete picture of how palliative care is currently delivered to individuals with dementia in long-term care. In targeting many different professions, the research team was able to gain a greater understanding of the whole picture of palliative care, and how it was delivered in

long-term care facilities. This study also explored an area that was not well researched, and will be able to make a contribution to the large knowledge gap that exists.

Implications for Practice

The findings of the study showed in great detail areas where improvements in palliative care for persons with dementia can be made. Firstly, more training for staff and families will be beneficial. Education and training of the general public about dementia and palliative care is important. Specifically, training should aim to increase awareness about dementia and the dying process to ensure that individuals with dementia have the opportunity to access high-quality palliative care, and to provide staff with the knowledge and tools to make decisions regarding initiation of palliative care. Secondly, terminology regarding palliative care should be clarified, to create a greater collective understanding of the goals of palliative care. Thirdly, palliative care resources should also be spread over a longer period in an individual's life, rather than concentrated at the very end of it, and there need to be new solutions address resource and staff shortages. Lastly, a model of palliative care that is specific for individuals with dementia who reside in long-term care facilities is needed.

Training/Education

It is necessary to improve the training for staff members dealing with individuals with dementia. For clarification, training refers to practical skills learned outside of a formal educational program (e.g. a degree or diploma) and education refers to learning that occurs within a formal educational institution. Both are necessary to develop skills in palliative care. The participants who took part in this study all noted that they encountered both coworkers and families of residents who were unaware of the benefits

of palliative care for individuals with dementia. Most staff who work in long term care do not get formal palliative care education during the course of their professional learning. This seems inconsistent, since most individuals who enter long term care will die in their facility; it ought to be a priority to educate the staff working in this environment in palliative care. Training staff would also be an excellent starting point, because they could in turn provide this information to their coworkers, and also to families. If resources are only available to train a limited number of people, it is best to educate frontline staff first.

Clarification of Terminology

A major implication for practice comes from the most prevalent theme that emerged from the data. The confusion around the distinction between palliative and end of life care appeared to have significant implications for the care that individuals with dementia received in long term care. To the study participants, “palliative” meant the last few days that someone was alive. Consequently, palliative care was not given until this point, and usually consisted of symptom management care, with occasional holistic care measures if the facility or the family had the resources. Before individuals with dementia were deemed to be at end of life, the philosophy of their care was less person-centered, with less emphasis on maximizing their quality of life. Thus, improvements in the clarity of terminology are necessary in the short term.

There is a need for a greater understanding of what palliative care means, specifically for individuals with dementia. As palliative care is currently being delivered in SW Ontario long term care homes, most are delivering symptom focused, short-term care at end of life. As established earlier, dementia is a slow, unpredictable disease that

impacts nearly every aspect of the person's life. Palliative care, by its true definition, is appropriate and necessary for individuals dying with dementia, but the current system is not providing it. Symptom focused care in the last few days of life is not sufficient for an illness that can last years. Facilities are not meeting the needs of individuals with dementia by providing palliative care when individuals are at the very last stages of their illness. As was noted in the findings, the current state of palliative care for individuals with dementia marginalizes individuals with dementia until they are in the last days or weeks of their illness, at which point the focus of their care shifts to become more person centered. A clear, precise definition of exactly what palliative care entails, and ideally some guidelines about when it should be initiated, would help clarify the confusion and inconsistency that is presently occurring in long-term care.

Long-Term Model of Care

The philosophical shift in priorities at end of life towards a more person-centred approach is encouraging, but again, appears to be happening late in the dying process, and varies widely because there are no guidelines to support this transition. Thus, the second implication of the findings is that more concrete guidelines are necessary to support a longer-term model that captures the WHO definition of palliative care (WHO, 2013). Instead of focusing heavily on managing only the last few days of the individual's life, the findings highlight the need to redistribute these resources over the lifespan of the individual with dementia. As noted by several participants, many of the resources being used for individuals dying with dementia come too late in the process. Resources such as palliative care volunteers, massage therapy, music and art therapy, and chaplaincy visits could be spread out so that the individual with dementia was able to enjoy them for a

longer period of their life. If these interventions are indeed beneficial, then it seems logical to utilize them while the resident is still active and able to interact with their surroundings. As one member of the research team noted, this model of care is similar to a retirement party. No one pays much attention to the individual until they are on their way out, and then many resources are put towards a very short period of time. Spreading this “party” out over the individual’s life would mean that their quality of life was improved over a longer period of time, rather than concentrating heavily on the end of their life.

There are still many misunderstandings in the general population about dementia and about palliative care. In particular, people are afraid to talk about death openly. According to participants in this study, even healthcare professionals, are afraid or uneasy about directly informing their clients that they will die. Western society is very focused on curative treatments, and often, this means that palliative care is seen as a failure to “beat” a disease. Families are often afraid to have open conversations about death with their relatives. This means that even when someone with dementia makes their wishes known in an advance directive, their substitute decisions makers are afraid of letting them go and are afraid to consent to palliative measures. As noted by participants, this denial of the reality of death can lead to conflict with staff, and often results in the advance directive being ignored.

Another way that this fear of discussions around death could be improved is to have a more matter of fact approach to death and dying, from the moment someone is diagnosed with a disease such as dementia. For example, on the Alzheimer’s Society of Canada website, there are many pages of useful information about what to expect when

one is diagnosed with dementia, and how to cope with day to day living, grief, and other difficulties associated with dementia, but they avoid using the language “terminal” and “death” (Alzheimer’s Society of Canada, 2013). They state that dementia is not curable and that it is a progressive disease, but nowhere is it spelled out that dementia will eventually lead to death, in the absence of another cause of death. Similarly, staff expressed that they were often afraid to be direct with family members when discussing the progression of the disease, instead choosing to focus on positives, and, as one participant indicated, “sugar-coating it” (1-101). A solution to this issue could be to have better education for families and individuals with dementia before the late stages of the disease about what the end stages might encompass, to prepare everyone involved and allow for a more collaborative advanced directive, that families feel more comfortable following.

Certainly, it will take a societal shift to change the denial of death that exists in our culture, and this will not happen quickly. However, better education about palliative care and the terminal nature of dementia is a fruitful starting point.

The study findings have several implications for family involvement. Families are often present at end of life, but are not trained to deal with many of the issues that occur. It would help reduce the burden on staff if families were able to spend time with their relative with dementia for longer periods in the dying process. However, this would require a substantial societal shift. Currently, time allotted from work to care for a dying relative is very limited. Currently, the maximum time that anyone is eligible to take off work under the Compassionate Care Benefit is 6 weeks, and that is only if the relative they are caring for is likely to die within 26 weeks (Government of Canada, 2014).

Dementia involves a lengthy and unpredictable decline, and could mean an extensive burden on family members, especially if it is not known that the individual will die within the 26 week timeline. In addition, this solution would not be feasible for individuals who had no relatives able to care for them. Thus, it is important to reorganize how staff and volunteers manage their time in supporting individuals with dementia as they die.

Palliative care volunteers could perhaps be utilized in different ways. Giving volunteers basic training about dementia and having them visit residents with dementia before they are at end of life, and are more able to appreciate an interaction with someone, might be a step towards improving the marginalization that occurs. Likely, this would be possible with a large volunteer pool and funds available to train those volunteers. Participants mentioned that using a team based approach was a facilitator to good-quality palliative care; incorporating volunteers into this team could improve care and help keep costs lower.

A consistent theme expressed by participants was the lack of resources available in long-term care. It is important to look for different strategies to address resource shortage in palliative care because dementia is likely to become more prevalent as the population ages (Alzheimer's Society of Canada, 2012). In a publically funded system, it is unlikely that there will ever be enough resources to satisfy the needs of everyone completely. However, it is useful to note the areas that staff felt were most in need of funds. There are areas where small changes could make big impacts, and improve the experience of all involved. For example, one change could be to have a team of individuals trained in specifically palliative care who were on call throughout the facility. This team could share the extra burden of end of life care with the regular staff and to

reduce the emotional and physical strain on them. This would not be a perfect solution, and a team that floated throughout the facility would be unlikely to have the personal knowledge and relationship with the dying individual. However, it would still be a better alternative than leaving them alone to die, especially if resources to train all staff are limited. Training a smaller, more specialized group of staff might be a better use of limited resources. It would also likely help with staff burnout and may result in greater job satisfaction. This was alluded to by several participants, most of whom also indicated that they used a team approach in their work, and felt satisfied with the care they were giving to individuals dying with dementia.

It's not one of my favourite things to do, palliative care, because I know we're going to lose somebody, and we're attached to them. But I always feel pretty good [when we care for them], and I always say to the women I work with, "I'm so, so, proud." I'm very thankful I've worked here; this had been my lifelong career. I've been here, in my 30th year now, and that tells you something in itself, eh? (7-105).

Finally, the findings have implications for developing a comprehensive model of palliative care that is specific to persons with dementia. The study findings indicate that the care required for someone dying with dementia was not substantively different from the care required for someone with any other diagnosis. At end of life, staff focused primarily on symptom management, and most residents had similar needs in their last days. This study demonstrated that most long term facilities do end of life care very well. Where the difference lies is in the care they get earlier in their illness. It is also essential that there is some way of determining that such a model is being implemented. Some form of accountability or reporting is necessary.

Individuals with dementia do not receive palliative care in long term care homes. They receive end of life care in their last days, which is necessary, but not the same thing as palliative care. As it exists, the philosophy of palliative care was developed from cancer, which has a vastly different illness course than dementia. One of the major implications of the findings is that the uniqueness of dementia needs to be incorporated in the delivery of palliative care. Individuals with dementia experience agitation, fear and confusion, pain that they are unable to communicate, and other significant mental problems as their illness progresses (Cohen-Mansfield, 1996). Long term care does an excellent job of treating the physical symptoms of dementia, but not the psychological ones. Certainly, person-centered care, which includes incorporating the residents' life histories and preference in care, is lacking for individuals with dementia until they are in the last days of their life.

Early discussions about death could facilitate planning with regards to where an individual with dementia will spend their last days. Currently, long-term care homes have lengthy wait lists, and private home care is not always financially feasible for everyone. If the individual with dementia declines suddenly and family members are unable to care for them at home, they often end up using the services of emergency departments and walk-in clinics, as they are covered under provincial health plans and therefore more affordable.

It has been noted throughout this study that the confusion around terminology is contributing to this problem, but this is not the only reason that this problem exists. Given their communication impairments, residents with dementia are unable to advocate for themselves in the later stages of their illness. Some family members do not spend enough

time in the facility to be aware of the specific needs of the resident. Staff members are over-worked and under-resourced, and do not have the luxury of providing person-centered care to individuals with dementia for long periods of time. As it is, staff encounter significant challenges in providing person-centered end of life care, even for short periods of time. In the future, the model of care that is currently being used to provide palliative care for individuals with dementia in long-term care will be unsustainable.

Future Directions

Due to the significant dearth of information available on this topic in the literature, there are several avenues for future research. This study was a qualitative investigation covering a small geographic area. Future studies with larger sample sizes that cover larger geographic regions are needed in order to make recommendations for best practices.

Specifically, future studies are needed to test the efficacy of existing assessment tools, and develop strategies to maximize the efficiency of resource use at end of life. Staff in this study expressed the difficulty of initiating palliative care and uncertainty around pain assessments for individuals with dementia, and expressed a desire for more assessment tools and guidelines to aid in this delivery. It is apparent in the literature that pain assessment tools for individuals with dementia do exist (Herr, 2011). There is literature available listing many different types of pain assessments specific for individuals with dementia, and it is problematic that staff are unaware and/or are not using those tools. Future studies are necessary to examine how information is shared to practitioners working within this field, and also to determine which of the many pain

assessments for individuals with dementia can best aid in decision making regarding palliative care initiation. Currently, palliative care training being offered in the region where this study took place does not include a focus on dementia.

This study also focused solely on the experience of staff providing palliative care to individuals with dementia. As noted above, family members are a significant factor in end of life care for individuals with dementia. It is important to consider their perspectives in this matter. While not the goal of this study, future studies looking at the experience of families in dealing with palliative care for individuals with dementia would provide valuable insight into their important perspective. There have been studies looking at family experiences of palliative care with dementia (Diwan, Hougham & Sachs, 2004, Dutton, 2009, & Volicer, 2005). However, it will be important to track how families continue to experience the palliative care process as this topic continues to evolve and as changes are made to how care is delivered to individuals with dementia. While it is difficult to obtain informed consent and learn much from individuals in the late stages of dementia, it would also be useful to learn more about their decision making before they are incapable, and whether these decisions are respected. A longitudinal study following individuals with dementia from before the entrance into long-term care until after their death would be challenging, but would provide a new perspective on this issue from the individuals for whom the issue of palliative care in dementia matters the most. It would also provide information about how the dying trajectory of dementia is understood by those delivering care, and how this trajectory impacts care delivery, over time.

Individuals with dementia require more resources for their care because they have more complex needs. As the population ages and numbers of older adults with dementia

continue to increase in long-term care, the need for more resources will become even more pronounced. The focus on quality of life for individuals with dementia comes too late in the care process. It is necessary to create a dementia-specific model of palliative care for individuals living in long term care that is followed industry-wide. It is necessary to create this model because the literature has overwhelmingly pointed out the benefits of palliative care for individuals dying with dementia. It would greatly improve the experience of everyone involved in the process if it was known that the dying individual had been given the best possible opportunity for a high quality of life, for as long as was possible.

In summary, this study shows that there are still many areas of improvement required in the field of palliative care for persons with dementia. From the findings of this study, it is clear that there is much confusion surrounding what palliative care is, and how and when it should be delivered. In addition, there are no formalized structures in place to aid this, which results in stress on the staff who are trying to deliver this care. Lastly, families, staff and residents all face challenges in communication with regards to palliative care.

Recommendations based on the findings of this study include increasing training for individuals delivering palliative care to those with dementia. In addition, increasing awareness of dementia and palliative care in the general population could help to improve communication and decision-making at end of life. It is important to clarify the terminology in this field, specifically the distinction between end of life and palliative care. Resource shortages need to be addressed, and palliative care needs to be initiated earlier in the course of the disease, as opposed to in the last few days of life. Finally, a

dementia specific model of palliative care to address the unique needs of individuals with dementia before they reach end of life is necessary to ensure that individuals with dementia receive the best care possible.

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Appendices

Appendix A: Ethics Approval Form



Research Ethics

Use of Human Participants - Ethics Approval Notice

Principal Investigator: Dr. Marie Savundranayagam
File Number: 104048
Review Level: Full Board
Approved Local Adult Participants: 40
Approved Local Minor Participants: 0
Protocol Title: Investigating Barriers to Access and Delivery of End of Life Care for Persons with Dementia in Ontario.
Department & Institution: Health Sciences, Western University
Sponsor:
Ethics Approval Date: September 11, 2013 Expiry Date: August 31, 2014

Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
Western University Protocol		2013/07/12
Other	Interview Questions	2013/08/27
Other	Sign Up Sheet/Email Script	2013/08/27
Revised Letter of Information & Consent	Letter of Information	2013/08/27
Revised Letter of Information & Consent	Consent Form	2013/08/27
Response to Board Recommendations	Outline of all the changes that have been made.	2013/08/27
Instruments	Demographic Questionnaire	2013/08/27

This is to notify you that The University of Western Ontario Research Ethics Board for Non-Medical Research Involving Human Subjects (NMREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the applicable laws and regulations of Ontario has granted approval to the above named research study on the approval date noted above.

This approval shall remain valid until the expiry date noted above assuming timely and acceptable responses to the NMREB's periodic requests for surveillance and monitoring information.

Members of the NMREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussions related to, nor vote on, such studies when they are presented to the NMREB.

The Chair of the NMREB is Dr. Riley Hinson. The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 0000941.

August 2013

Project Title: Investigating Barriers to Access and Delivery of End of Life Care for Persons with Dementia in Ontario.

Principal Investigator:
Marie Savundranayagam, PhD, Western University

Letter of Information

1. Invitation to Participate

You are being invited to participate in this research study investigating how end of life care is accessed by and delivered to persons with dementia in Ontario because you work with persons who have dementia, and have valuable insight into this topic.

2. Purpose of the Letter

The purpose of this letter is to provide you with information required for you to make an informed decision regarding participation in this research.

3. Purpose of this Study

The purpose of this study is to learn more about how persons with dementia transition to end of life care in Ontario, and how such care is delivered. In addition, we would like to learn about specific policies or practice guidelines that might be relevant to persons with dementia accessing end of life care.

4. Inclusion Criteria

Individuals who work directly or indirectly with persons with dementia in a long term care facility are eligible to participate in this study.

5. Exclusion Criteria

Individuals who do not work with persons who have dementia in a long term care facility are not eligible to participate in this study.

6. Study Procedures

If you agree to participate, you will be asked to complete a face-to-face interview with the research team at a location of your choice. It is anticipated that the entire task will take approximately 30 minutes over one session. There will also be an option for email follow-up and clarification after the initial interview, if this is more convenient for you. There will be a total of 7-10 participants participating from your facility. In total, our study will be interviewing people at five different facilities, with a total of 35 participants.

7. Possible Risks and Harms

There are no known or anticipated risks or discomforts associated with participating in this study. Participation in this study will not affect your employment status.

8. Possible Benefits

You may not directly benefit from participating in this study, but information gathered may provide benefits to society as a whole which include increased knowledge regarding beneficial end of life care for individuals who have dementia. Also, you may see benefits from the information we gather with regards to improved care in the patients you work with, once the study has been completed. The findings of the study will inform the development of a decision support tool that assists health professionals in assessing whether a person with dementia could benefit from palliative care.

9. Compensation

You will not be compensated for your participation in this research.

10. Voluntary Participation

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on your future employment.

11. Confidentiality

All data collected will remain confidential and accessible only to the investigators of this study. If the results are published, your name will not be used. If you choose to withdraw from this study, your data will be removed and destroyed from our database. Interviews may be audio recorded, these recordings will be kept confidential, and you are still eligible to participate in the study if you do not wish to be recorded.

12. Contacts for Further Information

If you require any further information regarding this research project or your participation in the study you may contact the Principal Investigator, Dr. Marie Savundranayagam, or the student researcher, Emily Hill.

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Research Ethics (519) 661-3036, email: ethics@uwo.ca.

13. Publication

If the results of the study are published, your name will not be used. If you would like to receive a copy of any potential study results, please provide your name and contact number on a piece of paper separate from the Consent Form.

14. Consent

If you choose to participate, you will be asked to sign a written consent form indicating this.

This letter is yours to keep for future reference.



Consent Form

Project Title: Investigating Barriers to Access and Delivery of End of Life Care for Persons with Dementia in Ontario.

Study Investigator's Name: Dr. Marie Savundranayagam, PhD, Western University

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Participant's Name (please print): _____

Participant's Signature: _____

Date: _____

Person Obtaining Informed Consent (please print): _____

Signature: _____

Date: _____

I agree to be audio recorded during my interview. (Check box below)

(Please note you are still eligible to participate in this study if you do not wish to be audio recorded).

Appendix D: Interview Guide

Interview Questions

Palliative care delivery for persons with dementia in long-term care settings

- Can you tell if someone who has dementia is nearing the end of their life?
What does this look like?
- What does palliative care look like (or entail) for someone who is dying with dementia?
- What is unique about caring for someone with end-stage dementia in a long-term care facility?
- Have you ever had experience with palliative care in the course of your professional career? Prompt: did you receive training, what was this experience like for you?

Assessment tools and measurements

- Are there any guidelines you follow to help assess whether palliative care should be delivered, or to help deliver the care?
- Do you think that persons with dementia would benefit from palliative care?
Prompt: how would you know if it was beneficial? Do you have any measure to determine if it is benefiting the patient?

Policies and funding incentives

- What policies or funding incentives enable individuals with dementia from accessing palliative care in your organization?
- What policies or funding incentives prohibit persons with dementia from accessing palliative care?
- What would make it easier for you to provide palliative care for people with end-stage dementia?

Appendix E: Demographic Questionnaire

Demographic Questionnaire

Please answer the questions below. All information will be kept confidential, and participation is strictly voluntary. Should you choose not to answer certain questions, you may do so. You are free to withdraw at any time. If you have any questions, contact the principal investigator, Dr. Marie Savundranayagam

1. What is your current role at this facility? (circle one)
 - a. Personal Support Worker
 - b. Registered Nurse
 - c. Volunteer
 - d. Social Worker
 - e. Director of Care
 - f. Facility Manager
 - g. Other (specify) _____
2. How long have you been working at or involved with this facility? _____
3. What shift (if applicable) do you usually work? (Circle one)
 - a. Day
 - b. Evening
 - c. Night
 - d. Other
4. How many residents are you responsible for? _____
 - a. Of these, approximately how many residents have dementia or related conditions? _____
5. Have you ever received any training in palliative or end-of-life care?

-
- a. Yes
 - b. No

6. How many other staff do you work with during the course of your daily duties?

7. What is your age? _____

Appendix F: Code List

Major Code	Subcode	Descriptor
1. Dementia		Anything referring to the nature of the disease of dementia, not an individual who has dementia (see "resident" code below)
	1.2 Specific traits	Traits/symptoms related to dementia at end of life (e.g. agitation)
2. Residents		Individuals with dementia who reside in the facility. Used when talking about the person rather than their disease
3. End of Life		The specific stage of the illness they are at, different from "palliative care" (see below)
	3.1 Place of Death	Physical location e.g. hospital, long term care facility, home
4. Palliative Care		Care that is given at end of life stage
	4.1 Facilitator	Something that aids in the delivery of PC e.g. administration being supportive of palliative care initiatives
	4.2 Barrier	Something that prohibits the delivery of PC e.g. families refusing to give consent to palliative care measures
	4.3 Challenge	Something that makes it more difficult, but doesn't necessarily prohibit PC, e.g. lack of money to support palliative care
	4.4 Desire for Improvement	Specific things staff are planning or would like to plan to improve care, e.g. utilizing music therapy, having a specific palliative care room
	4.5 Initiation	When/how palliative care begins
	4.6 Benefits of	e.g. increased quality of life
	4.7 Components	Components of palliative care as expressed by staff. Also includes resources needed to deliver care, including physical and monetary ones.
	4.9 Medication	Generally delivered at end of life as part of palliative care,

		usually for comfort measures, but can include other medications as well, e.g. Haldol delivered to help with agitation
5. Staff		People who work in long-term care, no specific profession
	5.1 Training/Education	In palliative care, formal or informal
6. Family		Often acting as a substitute decision maker or informal caregiver, sometimes very involved at end of life
	6.1 Education	Raising the awareness of family members about the dementia, the dying process, or anything related to palliative care. Usually done by staff.
7. Advance Care Planning		Written or verbal wishes by the person with dementia (when capable) or their family (if incapable) specifying what kinds of care they would prefer at throughout their illness, including end of life care. Varying degrees of specificity
8. Guidelines		To aid care, not as strict as policies set out by MOH
9. Policies		Stricter rules that must be followed, usually put in place by MOH or facility administration
10. QOL		Quality of Life, the general well-being of the person who is dying with dementia, physical, psychological, and spiritual
11. Resources		Physical e.g. beds, personnel e.g. staff members, and time resources are all included in this
12. What do you do?		This is people's individual roles as staff. Varies depending on profession of staff member, e.g. social worker, recreation therapist, nurse, etc.
13. Assessment Tools		Tools used by staff to determine a) pain levels/needs of resident or b) when palliative care is appropriate (e.g. Palliative Performance Scale)
14. Fear/Uncertainty		Fear or uncertainty about a question, how much the interviewee is allowed to reveal, present in the interview but not explicitly said (e.g. a request to turn off the recorder)
15. Communication		Communication between staff and other staff, staff and families, or staff and residents

Curriculum Vitae

Curriculum Vitae: Emily M. Hill

Education

- 2017 **University of Western Ontario, Faculty of Law, London, Canada**
Accepted to complete Juris Doctor (J.D.) Degree beginning September 2014
- 2014 **University of Western Ontario, Faculty of Health Sciences, London, Canada**
Candidate for Master's of Science in Health and Aging
- Advisor: Dr. Marie Savundranayagam
 - Thesis title: Investigating Barriers to Access and Delivery of End of Life Care for Persons with Dementia in Ontario
 - Courses taken:
 - Topics In Health and Aging
 - Qualitative Research Methods
 - Introduction to Research in Health Sciences
- 2012 **University of Western Ontario, Faculty of Health Sciences, London, Canada**
Bachelor of Health Science, Honours Specialization In Health Sciences, Minor In Ethics
- Dean's Honour List

Conference Presentations

Hill, E. M., Savundranayagam, M., Kloseck, M. & Zecevic, A. (November 2014). Investigating Barriers to Access and Delivery of End of Life Care for Persons with Dementia. To be presented at the Gerontological Society of America's 67th Annual Scientific Meeting, Washington, DC, USA

Hill, E. M., Savundranayagam, M., Kloseck, M. & Zecevic, A. (October 2014). Investigating Barriers to Access and Delivery of End of Life Care for Persons with Dementia. To be presented at the Canadian Association of Gerontology Annual Conference, Landscapes of Aging, Niagara Falls, ON

Hill, E. M., Savundranayagam, M., Kloseck, M. & Zecevic, A. (February 2014) Investigating Barriers to Access and Delivery of End of Life Care for Persons with Dementia. Presented at the Ontario Long Term Care Association Applied Research Day 2014 Toronto, ON

Hill, E. M., Savundranayagam, M., Kloseck, M. & Zecevic, A. (February 2014) Investigating Barriers to Access and Delivery of End of Life Care for Persons with Dementia. Presented at the Aging, Rehabilitation and Geriatric Care/Faculty of Health Sciences Symposium, Lawson Research Institute/Western University 2014

Guest Lectures

Hill, E. M., Savundranayagam, M., Kloseck, M. & Zecevic, A. (February 2014) Investigating Barriers to Access and Delivery of End of Life Care for Persons with Dementia. Presented at the Health and Aging Field Seminar, Western University.