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# The Lived Experiences of Home Care Nurses Providing Palliative Care Information to Community-Dwelling Older Adults with a Terminal Illness

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A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Health and Rehabilitation Sciences

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## Abstract

For the past decade, expanding palliative care information has been one strategy for improving palliative care in Canada, yet there remain many concerns regarding the lack of information available to clients and their families. Nurses play a key role in providing information to community-dwelling clients and families. To date, however, limited research has investigated nurses' experiences of providing palliative care information in a community context. The purpose of this phenomenological study was to better understand the lived experiences of 10 home care nurses providing palliative care information to community-dwelling older adults with a terminal illness. Thematic analysis revealed eight key themes: importance of support and unity; tools for providing information; building relationships with clients; comfort level talking about death and dying; language and cultural barriers; clients' readiness to accept information; influence of the home environment; and helping clients to a good death. Implications for practice and future research are discussed.

Keywords: palliative care, information, nurses, community-dwelling, older adults, hermeneutic phenomenology.

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# Chapter 1

## 1 Introduction

### 1.1 Background and Significance

Ensuring that community-dwelling individuals with a terminal illness receive timely palliative care and the necessary information and services to ensure a good death has been the focus of numerous recent reports (Office of the Auditor General of Ontario, 2014; Carstairs, 2010; Canadian Hospice Palliative Care Association, 2009). In particular, the 2014 Annual Report of the Office of the Auditor General of Ontario reported that despite much palliative care information being available from Community Care Access Centres (CCACs), hospitals, and healthcare providers, it is not getting to the clients and their families who need it most (Office of the Auditor General of Ontario, 2014). This study attempts to address this issue by better understanding the experiences of home care nurses with palliative care caseloads in southwestern Ontario.

Older adults currently make up the fastest growing age group in Canada. In 2014, one in seven Canadians was 65 years or older, and it is estimated that this number will rise to one in four Canadians by 2031 (Statistic Canada, 2017a). Among this population, 74% of seniors reported having one or more chronic conditions, and 24% of seniors reported having three or more chronic conditions (Canadian Institute for Information, 2011b). It is estimated that chronic diseases account for about 70% of all deaths (Canadian Hospice Palliative Care Association, 2016). Palliative care is often recommended when a person is approaching death, as well as during the earlier stages of a terminal illness. Palliative care may be appropriate for various diseases such as cancer and chronic respiratory diseases, and other conditions including Parkinson's disease, multiple sclerosis, and dementia (World Health Organization, 2015).

Palliative care aims to improve the quality of life for persons with life-threatening illness and their families through prevention and relief of suffering, and pain and symptom management (World Health Organization, 2015). Palliative care is a holistic approach that aims to meet the physical, psychological, social, cultural, emotional, and spiritual needs of each person and family (Canadian Hospice Palliative Care Association,

n.d.). Palliative care may be delivered in various settings, including hospitals, residential hospices, long-term care homes, and in the homes of individuals (Hadad, 2008).

The palliative care approach gives persons and their families information and opportunities to be more engaged in care decisions, and make decisions that reflect their preferences (Bacon, 2012). Palliative care helps persons die with dignity, that is, making decisions about their own care, their environment, and death (Chochinov, 2002; Franklin, Ternstedt & Nordenfelt, 2006). Most Canadians nearing the end of life prefer to die at home surrounded by family and friends (Quality End-of-Life Care Coalition of Canada, 2008). Within home-based palliative care, it is noted that it is important to provide accurate information to persons and caregivers to enable them to make informed decisions about their care (Broback & Bertero, 2003).

Expanding information related to palliative care has been noted as one of the strategies for improving palliative care in Canada at national, provincial, and regional levels. In 2009, the Canadian Hospice Palliative Care Association released ‘Caring for Canadians at End of Life’, a document outlining a strategic plan for hospice, palliative, and end-of-life care in Canada for the next five years (Canadian Hospice Palliative Care Association, 2009). A focus on raising awareness was one of the six key strategies to advance quality palliative and end-of-life care for all Canadians. Specific activities planned to support this strategy included informing Canadians about hospice, palliative, and end-of-life care options available to them, and providing information to enable informed decision-making related to end-of-life care. In addition, plans include providing support and education for persons and their families to help them feel more confident about talking with healthcare providers about dying, bereavement and effective end-of-life care (Canadian Hospice Palliative Care Association, 2009). The Ontario Hospice Palliative Care Network noted, as a part of the network description, their ongoing support for information and education for healthcare providers, caregivers, and persons with terminal illness, along with research, and enhanced communication to improve palliative care across Ontario (Provincial End-of-Life Care Network, 2010). The South West (Ontario) Hospice Palliative Care Network plan for 2014 and 2015 also noted the development of client, family, and caregiver information and education (such as informational materials to support understanding system navigation and road maps,

healthcare consent, advance care planning, and holistic approach) as an area of focus to improve the palliative care system (South West Hospice Palliative Care Network, 2014).

Despite these strategies to improve palliative care across Canada, there are still reports of the lack of public awareness of palliative care services, and information on palliative care not getting to clients and families. It is estimated that about 95% of deaths would benefit from palliative care, yet only 16% to 30% of Canadians who die receive palliative and end-of-life care services (Carstairs, 2010; Canadian Institute for Health Information, 2007). Only 19% of Canadians surveyed believe palliative care is available to persons dying of life-threatening illnesses. Nearly half of Canadians believe that palliative care is only available to persons at the end of life regardless of their illness, and about 34% of Canadians are unsure for whom palliative care services are available (Canadian Hospice Palliative Care Association, 2013b). These reports confirm that many Canadians are still lacking in awareness and information about palliative care, limiting the benefits they may gain from palliative care services.

In the recent Annual Report of the Office of the Auditor General of Ontario (2014), the section on palliative care stated that the Ministry of Health and Long-Term Care does not yet have effective processes in place to ensure the availability of sufficient public information on palliative care services to meet the needs of persons with a life-threatening illness. One of the significant areas for improvement noted by the report was for more public awareness and information around palliative care and palliative care services. The report noted that information on palliative care was not getting into the hands of clients and families even though such information was available from Community Care Access Centres (CCAC), hospitals, and healthcare service providers, and provided through various channels including websites, verbal discussion, brochures, and newsletters. Similarly, in a report released by the Honourable Sharon Carstairs (Carstairs, 2010) on the status of palliative care in Canada, Carstairs also highlighted the current lack of awareness and education related to palliative care in Canada. In particular, Carstairs recommended that clients and family caregivers need better information and education at the time of diagnosis.

Clients and their families receiving palliative care in various settings often feel that their informational needs are not being met and want more information from service

providers (Harding et al., 2012; Washington, Meadows, Elliott & Koopman, 2011; Docherty et al., 2008; Hughes & Arber, 2008; Gore, Brophy & Greenstone, 2000; Wikes, White, & O’Riordan, 2000). Clients and their caregivers commonly report the need for more information related to pain and symptom management, disease progression, and service availability. The need for more information was also consistent across clients and their caregivers of various illnesses and conditions. In a qualitative study conducted by Kirk, Kirk, and Kristjanson (2004), clients with terminal cancer and their families enrolled in a palliative care program expressed dissatisfaction with how information was being communicated. Clients and their families wished for healthcare providers to be honest and direct in conveying information about diagnosis and prognosis, and to convey information in a way that is easy for clients and their families to understand. Some of the clients and their families wished for information to be provided in a more compassionate and empathetic manner, and for healthcare providers to offer enough time during the information discussions to be able to sit and talk. Clients and their families who perceived insufficient information reported feelings of stress, frustration and uncertainty (Kirk et al., 2004). Caregivers in other studies have reported similar experiences of feeling inadequately informed and lacking knowledge, resulting in lack of control and insecurity (Docherty et al., 2008; Funk, Allan & Stajduhar, 2009; Aoun, Kristjanson, Currow, & Hudson, 2005). It is evident from government reports and studies investigating client and caregiver perspectives that clients and their families have many unmet needs and are not receiving the palliative care information they require.

Although some attention has focused on better understanding client and family experiences related to the provision of palliative care information, limited research to date has focused on better understanding the experiences of nurses with palliative care caseloads who provide this information (Pavlish & Ceronsky, 2009; Johnston & Smith, 2006; Dunne, Sullivan, & Kernohan, 2005; Johnston, 2005). In particular, there is very limited research focused on the experiences of nurses providing palliative care in a community context (Penz & Duggleby, 2012). Nurses often work closely with clients and their families receiving palliative care, and are recognized as playing an important role in identifying and providing information to clients and their families (Laschinger, Gilbert, Smith, & Leslie, 2010). Nurses’ perspectives regarding information provision to

palliative care clients are not well understood despite their primary role in providing this information. Further research is needed to gain a better understanding of nurses' experiences in providing palliative care information to community-dwelling older adults with a terminal illness.

## 1.2 Purpose of the Study

The purpose of this study is to better understand the lived experiences of home care nurses providing palliative care information to community-dwelling older adults with a terminal illness.

## Chapter 2

### 2 Literature Review

#### 2.1 Introduction

With the growing aging population and majority of Canadians preferring to die in their home (Canadian Hospice Palliative Care Association, 2006), an increased demand for home-based palliative care from the older adult population is anticipated. Older adults receiving palliative care at home require timely and appropriate information from their healthcare providers to be able to die in their place of choice, meet their own personal care needs, make informed-decisions, and ensure dignity at the end-of-life (Moyano & Zambrano, 2011; Tomlinson, Barker, & Soden, 2012). Nurses often work closely with clients receiving palliative care and their families, and have an important role in providing this information. Nurses' experiences of providing information to those receiving palliative care are not well understood, and require further research. The purpose of this study is to gain a better understanding of the home care nurses' experiences of providing palliative care information to community-dwelling older adults with a terminal illness.

This chapter will begin with a discussion of the aging population, followed by disease trajectories and the role of palliative care. The focus will then move into a review and discussion regarding what is known to date about the experiences of nurses providing information in palliative care, and some of the unique issues to consider when providing information to older clients.

#### 2.2 The Aging Population

The proportion of older adults in the Canadian population is increasing, and the life expectancy has increased dramatically. With the large baby-boom cohort reaching the age of 65, it is estimated that by 2031, approximately one in four Canadians will be 65 years or older (Statistics Canada, 2017). Among this population, there is an increasing prevalence of older adults living with one or more chronic diseases. Cancer and heart disease were the leading causes of deaths in Canadians 65 years and over (Statistics Canada, 2017b).

Many Canadians would prefer to receive care and die in their homes (Wilson et al., 2009; Quality End-of-Life Care Coalition of Canada, 2008; Stajduhar, Allan, Cohen, & Heyland, 2008; Higginson & Sen-Gupta, 2005; Wilson, 2000). In 2004, one in four Canadians died at home (Wilson et al., 2009). According to the Canadian 2014 Harris/Decima survey, 75% preferred to die in their home (as cited in Canadian Hospice Palliative Care Association, 2013b). For older adults, receiving care at home when dying was of importance because the home was recognized as more than a physical location. Home represented familiarity, comfort, and a place to be surrounded by family and loved ones (Gott, Seymour, Bellamy, Clark, & Ahmedzai, 2004; Tang, 2003; Murray, O'Connor, Fiset, & Viola, 2003). As the aging population increases, Canadians will receive significantly more care within their homes and communities. Home-based palliative care that meets the needs of clients and their families is essential for caring and supporting older adults preferring to die at home, to manage pain and symptoms as the disease progresses, and to ensure dignity at the end-of-life.

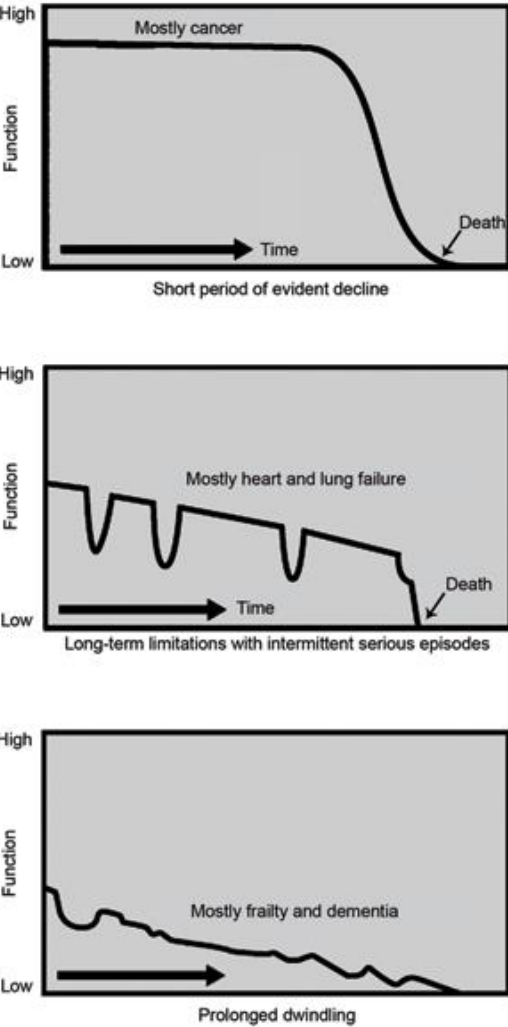
## 2.3 Palliative Care

### 2.3.1 Disease Trajectories

Disease trajectories conceptually outline broad timeframes and patterns of probable needs for individuals with progressive illnesses (Murray, Kendall, Boyd, & Sheikh, 2005). Many studies have concluded that persons with specific diseases often have common patterns of experiences, symptoms, and needs with the progression of disease (Murtagh, Preston, & Higginson, 2004; World Health Organization, 2004; Lehman, 2004; Lunney, Lynn, Foley, Lipson, & Guralnik, 2003; Glare & Christakis, 2004). Such trajectories may help clients, their families, and healthcare providers better understand how the disease is likely to progress, and proactively plan care to meet the client's various needs.

Lynn and Adamson (2003) described three typical illness trajectories for people with progressive chronic illness (Figure 1). The first trajectory entails a brief period of predictable decline, typically occurring in individuals with cancer. Due to the predictable nature of decline, there is generally time to anticipate the needs and plan for palliative care for individuals with cancer. The second trajectory, typically occurring in individuals with conditions such as chronic obstructive pulmonary disease and heart failure, entails

Figure 1: Typical Illness Trajectories for People with Progressive Chronic Illness



Lynn & Adamson (2003)



Long-term limitations with occasional serious exacerbations. Individuals will usually survive a few of these episodes but will die from an exacerbation rather suddenly. Ongoing disease management and advance-care planning are important in the care provided to these individuals (Lynn & Forlini, 2001). The third trajectory, characterized by prolonged dwindling, is typical of individuals with dementia, disabling stroke, and frailty. These individuals are likely to die at older age of neurological failure or frailty of multiple body systems; hence, support services are important in the care of these individuals (Lynn & Adamson, 2003). As cancer has a more predictable disease trajectory, there is greater understanding of the care needs associated with oncology clients and how these needs can be addressed (Murray et al., 2005). A better understanding of how the needs of individuals with illnesses of a more unpredictable nature can be met is needed, as well as a better understanding of the unique needs of an aging population.

### 2.3.2 The Role of Palliative Care During Illness

There is some confusion around the definitions and distinctions between the terms “hospice care”, “palliative care”, and “end-of-life care” in the literature. The Canadian Hospice Palliative Care Association uses the term “hospice palliative care” to refer to a specific approach to care aimed at improving the quality of life for persons living with and dying from advanced illness, and notes that hospice care and palliative care are used synonymously in Canada (Canadian Hospice Palliative Care Association, n.d.). The term “end-of-life care” is used as one component of palliative care that focuses on death management (Canadian Hospice Palliative Care Association, 2013a). The Canadian Institute for Health Information and the Canadian Cancer Society provide similar definitions and distinctions between palliative care and end-of-life care (Canadian Institute for Health Information, 2011a; Canadian Cancer Society, 2016). The World Health Organization also defines palliative care in a similar fashion; however, it does not refer to end-of-life care (World Health Organization, 2015). In contrast, the Heart and Stroke Foundation, Health Canada, and the Canadian Virtual Hospice use the terms palliative care and end-of-life care interchangeably. There is an evident lack of consensus on defining and distinguishing between hospice, palliative, and end-of-life care in the literature.

For the purposes of this research, “palliative care” will be used and defined using the World Health Organization and Canadian Hospice Palliative Care Association definitions of palliative care. Palliative care is an approach that improves the quality of life of persons and their families experiencing life-threatening illness. It focuses on the prevention and relief of suffering, the treatment of pain, symptom management, and addresses other physical, psychosocial and spiritual needs (World Health Organization, 2015). The Square of Care (Canadian Hospice Palliative Care Association, 2013a), a conceptual framework for palliative care, illustrates that assessment, information sharing, decision making, care planning, care delivery, and confirmation are six essential steps in the process of providing care and apply to the common issues faced by clients and their families (Figure 2). The goal of palliative care is to neither hasten nor prolong death, but to support the person in living as actively as possible until death. It should be person and family centered care in which the client directs and makes decisions about his or her own care (World Health Organization, 2015). Palliative care is not implemented exclusively at the end-of-life, and is made available to persons and their families throughout the illness and bereavement experiences as shown in Figure 3.

Palliative care may be delivered in various settings, including hospitals, residential hospices, long-term care homes, and in the homes of individuals residing in the community (Hadad, 2008). In Canada, there is a growing demand for home-based palliative care due to the increasing number of Canadians choosing to die at home (Canadian Hospice Palliative Care Association, 2016). Home-based palliative care is typically provided by an interdisciplinary team consisting of a variety of professionals including physicians, nurses, pharmacists, personal care workers, social workers, volunteers, and family members who work together to meet the client and his/her family’s various needs (Canadian Hospice Palliative Care Association, 2006). Although there is not always structural clarity around how palliative care services are accessed, palliative care services are typically initiated by the family physician and Community Care Access Centre. Most Canadians with life-threatening illnesses would prefer to die at home, however, about 75% of deaths in Canada continue to occur in hospital or long-term care homes (Canadian Hospice Palliative Care Association, 2006). According to the Canadian Hospice Palliative Care Association (2006), the gap between Canadians’

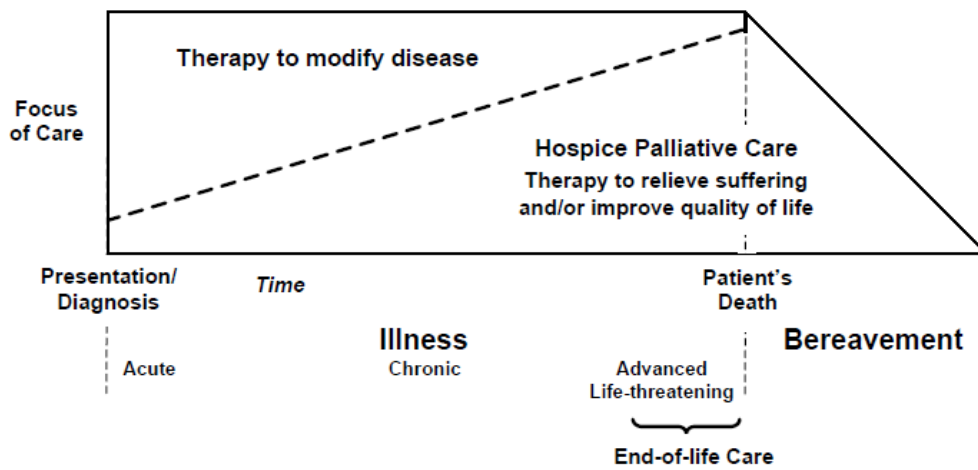
**Figure 2: Square of Care**

		Process of Providing Care					
		Assessment	Information Sharing	Decision-Making	Care Planning	Care Delivery	Confirmation
Common Issues	Disease Management						
	Physical						
	Psychological						
	Social						
	Spiritual						
	Practical						
	End of life/ Death Management						
	Loss, Grief						

**Patient and Family Care**

Canadian Hospice Palliative Care Association (2013)

**Figure 3: The Role of Hospice Palliative Care During Illness**



Canadian Hospice Palliative Care Association (2002)

preferred location of death and actual location in which most of these deaths occur is due to the lack of awareness and lack of information regarding the availability of home-based palliative care services and variation in the palliative care services provided across Canadian provinces.

To support a consistent approach to home-based palliative care services across Canada, the Canadian Hospice Palliative Care Association worked with the Canadian Home Care Association in developing the Pan-Canadian Gold Standard for Palliative Home Care (Canadian Hospice Palliative Care Association, 2006). The gold standard provides the benchmark for high quality palliative care at home through various recommendations focused on case management, nursing, palliative-specific pharmaceuticals, and personal care in palliative and end-of-life care at home (Canadian Hospice Palliative Care Association, 2006). In 2008, federal, provincial, and territorial governments completed a survey based on the Pan-Canadian Gold Standard for Palliative Home Care to produce a snapshot of palliative home care in Canada (Quality End-of-Life Care Coalition of Canada, 2008). Survey results in ‘Hospice Palliative Home Care in Canada: A Progress Report’ found that the gold standard had not been adopted widely and there were areas of home-based palliative care that were not consistently offered across all provinces in Canada (Quality End-of-Life Care Coalition of Canada, 2008; Collier, 2011).

Palliative care activities are driven by a number of different values including autonomy and dignity (Canadian Hospice Palliative Care Association, 2013a). The principle of autonomy suggests that each person is an autonomous and unique individual. The concept of autonomy focuses on individual self-determination, individual rights, free will, and choice. Western understandings of autonomy are based on the writings of John Stuart Mill (1859) and Immanuel Kant (1998). Mill’s approach recognizes individual freewill, in that autonomy is described as freedom from interference from others (Woods, 2006). Similarly, Kant’s definition of autonomy is related to the concepts of liberty and freedom, which argues that individuals are due autonomy; however, they must also respect the autonomy of others (Beauchamp & Childress, 2001). In the context of palliative care, the care should be guided by the quality of life as defined by each individual, when the person and family are ready to accept it (Canadian Hospice

Palliative Care Association, 2013a). Client autonomy suggests that palliative care should allow clients to make informed choices about their care, and their choices to be respected. To enable clients to make informed choices, clients require sufficient information, knowledge, and understanding of the choices available (Wilson, Ingleton, Gott, & Gardiner, 2014).

In the palliative care approach, it is also important for care to be provided in a manner that helps maintain the sense of dignity of the individual and allows the person to die with dignity. Although the concept of dignity has been defined differently across studies and may have different meaning for each individual, common to many studies is having one's human value acknowledged, being able to make decisions about one's own process of dying, and being cared for with respect and empathy (Chochinov, 2002; Franklin et al., 2006). Mains (1994) similarly defined dignity as individuals having control over their behavior, their environment, and the way they are treated by others. Mains, however, added that the concept of dignity also includes understanding information to be able to make choices. In the palliative care context, Mains' study would suggest that to maintain the dignity of the client, it is imperative for healthcare service providers to empower clients by providing appropriate and timely information, and support to enable decisions about their care.

In addition, the healthcare system across Canada is increasingly moving towards a more person-centred model of care which aims to empower individuals to take a more active role in their own healthcare experience (Hoare, McLeod, & Joy, 2016; Brookman, Jakob, DeCicco, & Bender, 2011). A person-centred approach to care emphasizes the importance of developing an understanding of the individual, their values, relationships and environment, and refers to providing care that focuses on the needs of the individual (Brookman et al., 2011). Access to relevant and trustworthy information is important for individuals to make informed decisions about their care and feel in control of their own health (Hoare et al., 2016). Information is defined as facts and data of interest to a particular person or groups of persons, and differs from advice or suggestions (Hoare et al., 2016). For individuals and their families receiving palliative care, information provision is important to support a person-centred approach to care, and to maintain the

autonomy and dignity of the individual and his/her family as they move through the disease process.

## 2.4 Providing Information in Palliative Care

In receiving palliative care, clients rely on nurses for not only physical care, but also various types of information related to diagnosis, prognosis, purpose of palliative care, and palliative care services available (Fourie & Meyer, 2014). Clients often turn to nurses for information as they trust and find them more accessible than doctors (Neumann et al., 2011). Nurses often work closely with clients and seem to be in the best position to provide important information to support clients in maintaining their quality of life (McCaughan & McKenna, 2007) and make care decisions (Beaver, Twomey, Witham, Foy, & Luker, 2006). Nurses serve as an important link between information on palliative care, and the client and family.

Few research studies have examined the perspectives of nurses regarding the provision of information in palliative care (Johnston, 2005). Furthermore, these studies are based on nursing in formal care settings, such as hospitals and hospices, and very little is known about nurses' experiences of providing palliative care information in a community context. Nonetheless, previous studies with nurses in formal care settings illustrate that nurses play a critical role in providing information to clients requiring palliative care. In one study, Pavlish and Ceronisky (2009) conducted interviews with 33 medical center oncology nurses about their involvement in specific palliative care situations. Findings suggest five primary nursing roles: teaching, caring, coordinating, advocating, and mobilizing. Several nurses emphasized that using their knowledge to inform and prepare clients and families for informed decision making and self-care was an important responsibility. In the context of knowing the client, the nurses recognized that they had an important role and ability to use their clinical knowledge in informing clients of treatment options that matched the clients' preferences and needs. Similarly, a qualitative study conducted in the U.K. explored the perceptions of nurses in the provision of palliative care, and the concept of the expert palliative nurse (Johnston & Smith, 2006). Johnston and Smith explored the perceptions of 22 Registered Nurses from two hospices and two hospitals regarding the concept of an 'expert palliative nurse'. Nurses described *connecting* as an important element of the expert palliative nurse role,

which included being willing to listen, building rapport, spending time with clients, providing information, and supporting the client and family. Open communication and having the right information for clients was identified as part of the expert palliative nurse role by the nurses. These studies illustrate that nurses indeed perceive a role in providing information to clients in palliative care; however, these findings are specific to experiences of nurses in hospitals and hospices. Further research is needed in the home care context to better understand how home care nurses' experience their role in providing information to palliative care clients.

Palliative care nurses often provide a wide range of information including information on the disease, symptoms, prognosis, self-care, treatment and pain management (Fourie & Meyer, 2014; Davies, Contro, Larson, & Widger, 2010; Matti, McCarl, Klaer, Keane, & Chen, 2010; Wikes et al., 2000). Nurses have an important role in helping their clients make sense of the information provided to them, and being able to provide information that meets the clients' diverse needs (Fourie & Meyer, 2014). Despite having an important role in providing information, nurses working in palliative care are not always trained in palliative care, may not be prepared to face the complex, ethical concerns of fully disclosing information to clients and their families (Fourie & Meyer, 2014), and skilled in finding a balance between maintaining hope and a client's desire for information (Curtis et al., 2008).

A prominent theme found in research on nurses' experiences of providing information to palliative care clients in the community was the challenge of dealing with conflict within families. In numerous studies, nurses often found that families wanted to protect or shield clients from knowing the truth about their condition and prognosis (Griffiths, Ewing, Wilson, Connolly, & Grande, 2015; Wilson, Griffiths, Ewing, Connolly, & Grande, 2014; Arnaert & Wainwright, 2009; Dunne et al., 2005). It was challenging for nurses to provide clients with information when families requested the nurse avoid using terms such as "cancer" or "palliative" (Arnaert & Wainwright, 2009). When families or caregivers of clients wished for the nurse to withhold certain information from the client, nurses often felt difficulties at an interpersonal level and struggled to make a choice to agree with the family (Wilson et al., 2014). Nurses struggled to withhold information from clients as they felt that withholding information



from clients posed a barrier to effective symptom management, the clients' journey to acceptance, and ultimately made care planning very difficult (Wilson et al., 2014). Nurses also felt that withholding information from clients' denied their right to say their "goodbyes" and prepare for their deaths (Dunne et al., 2005). It was very challenging for nurses to provide information, particularly on the client's condition and prognosis, as they found themselves stuck between conflicting family wishes.

Palliative care nurses in the community also reported difficulties in communicating effectively with dying clients. In the Dunne et al. (2005) study, nurses felt awkward talking to clients who were dying, and were uncomfortable with the subject of death and dying. There was uncertainty in providing answers to clients' questions, and they frequently hoped that they were not asked any questions during their visits. The timing of end-of-life conversations was also found to be challenging. Nurses did not want to introduce end-of-life care discussions with palliative care clients too soon, preferring to maintain "normality" for clients as long as possible. Of equal concern for the nurses was that the information be provided with sufficient time left for the clients and their family to prepare for death (Griffiths, Ewing, et al., 2015).

In addition, palliative care nurses also often found it difficult to cope with anger and negative emotional reactions from clients and families when providing information. Nurses working in palliative care in the community found that anger was one of the most significant emotional reactions in many situations, and felt that it was very difficult and stressful for them to remain calm (Dunne et al., 2005). Dunne et al. (2005) found that it was difficult for nurses not to take the anger of the client and family personally, and most of them interpreted the anger as a personal criticism of themselves. At times, nurses experienced difficulties in having any further conversations with clients due to the clients' response to prognostic information (Griffiths, Ewing, et al., 2015). In response to anger from clients and families, nurses tended to physically distance themselves from the situation (Griffiths, Ewing, et al., 2015; Dunne et al., 2005).

In a recent study, the home environment was also found to influence nurses' experiences of providing information to clients receiving palliative care. In Griffiths, Ewing, et al. (2015), nurses reported that family members were often present during their interactions with clients in the home. Nurses found that there was a lack of privacy when

family members were present, and this made discussions regarding death with the client difficult. The presence of family members during visits changed the dynamics of interactions with clients. Clients were sometimes reluctant to talk when family members were present (Griffith, Ewing, et al., 2015). In addition, nurses reported challenges in their experiences of providing information to clients receiving palliative care in the home due to other home aspects such as television and telephone noises in the background, and presence of pets and children (Griffiths, Ewing, et al., 2015). Further research is needed to gain a deeper understanding of nurses' experiences of providing information to clients receiving palliative care at home.

An added challenge is that very little is known about nurses' perspectives regarding the provision of palliative care for older adults, especially those in advanced old age. Much of the research to date is limited to the palliative care experiences of nurses working with oncology clients in institutional settings. Very little is known about nurses' experiences with older clients with terminal illnesses other than cancer (O'Shea, 2014). One qualitative study explored the perceptions of staff nurses providing palliative care for hospitalized older adults (O'Shea, 2014). This study found that nurses experience difficulties providing palliative care information to older adults. The nurses in this study knew of the importance of honest and open communication with older clients regarding their conditions and prognosis; however, they felt hesitant and reluctant in having these difficult discussions. The nurses also often felt they did not have enough time to get to know the client, and thus were inadequate in addressing clients' end-of-life needs (O'Shea, 2014). This study did not provide further insight into nurses' experiences of providing information to older adults receiving palliative care; however, it suggests that further research in this area is needed. Although it is recognized in the literature that aging is associated with various physical and cognitive changes that may affect the way older adults process information, nurses' experiences in the O'Shea (2014) study did not discuss any unique challenges experienced in providing information to older adults.

Good communication and the provision of information is an essential element of palliative care; however, it is complex and can be complicated by age (van Vliet, Lindenberger, & van Weert, 2015). Factors to consider that are unique to older clients include physical and cognitive age-related changes and the health literacy of older adults.

Primary aging is the inevitable, progressive deterioration of cellular structures and subsequent decline in function due to increasing age (Holloszy, 2000). Age-related changes that may hinder the provision of information to older clients include visual and hearing impairments, a decline in memory, and slower processing of information. Increased sensitivity to glare, loss of low-contrast acuity, loss of accommodation and attentional visual field are examples of visual changes that may increase the difficulty of reading written information (Sadowski, 2011; Watson, 2009; Carter, 1994). Presbycusis, an age-related hearing loss, in older clients is often associated with having difficulties understanding the information during verbal communication with physicians (Veras & Mattos, 2007; Amalraj, Starkweather, Nguyen, & Naeim, 2009). Furthermore, episodic information, including the information physicians provide to their clients, and processing speed of information is subjected to age-related loss (Kessels & De Haan, 2003; Kessels, 2003; Pinguart & Duberstein, 2004). Consequently, older clients often require more time to take in, learn, and store to memory the information provided by their service providers.

An additional consideration when providing information to older clients is the health literacy of those receiving this health information. Health literacy has been defined as the degree to which individuals are able to access, process, and understand basic health information and services required to manage one's care (as cited in Institute of Medicine Committee in Health Literacy, 2004). Health literacy has been recognized as a determinant of health in Canada, and deemed critical to Canadians' capacity to manage their health. Currently, it is estimated that only one in eight adults over the age of 65 has adequate health literacy skills (Canadian Council on Learning, 2007). This is particularly significant for older adults as they are more likely to have multiple chronic conditions and increased medication use, and face a higher level of health information demands. It is important to recognize the level of health literacy an older adult has, as inadequate health literacy skills can impair an older adult's ability to understand the health information provided to him/her to make the necessary care decisions.

A common theme within the literature suggests that providing verbal and written information significantly increases the knowledge of older clients and retention of the information provided. Sadowski (2011), in her review of numerous studies, found that there are deficits with information retention when either verbal communication or written

information is used in isolation. One study found that clients only recalled about 3 of 11 pieces of information from verbal counselling alone following a physician visit (Wilson, Robinson, Blenkinsopp, & Panton, 1992). Studies also found that written material such as information leaflets often did not use type size legible for those with poor visual acuity and required a high reading level, leading to poor comprehension of the material when presented in isolation of other methods (Pettersson, 1994; Wong, 1999). Sadowski noted that when reinforcement was used in providing information to clients, for example supporting verbal counselling with written information, there was a greater impact on knowledge retention (O'Connor et al., 2009; Couldridge, Kendall, & March, 2001). The use of both verbal and written information together was found to improve the ability of older adults to understand and retain the information provided to them by their healthcare provider.

Like their younger counterparts, older adults receiving palliative care require information to meet their various needs to make important care decisions. It is, however, unclear as to the amount of information older adults desire. While some studies suggest that it is less common for older adults to want detailed information on disease progression and prognosis (Parker et al., 2007), other studies have found little differences in information needs across age groups (Jansen, van Weert, van Dulmen, Heeren, & Bensing, 2007). The lack of consensus regarding the information needs of older adults highlights the importance of assessing individual information preferences (van Vliet et al., 2015). Individual assessments can be helpful to ensure the right information is provided to meet the needs of each individual.

The use of empathetic communication by healthcare providers has been associated with effectively communicating information to older adults in palliative care. Empathetic communication includes providing reassurance about a continued relationship with the older adult, using eye contact, showing respect, understanding and support for individual, and giving enough space for the individual to explore his/her emotions (van Vliet et al., 2015). The use of empathy when providing information to clients has been found to be important in building more trusting relationships, greater client satisfaction, decreased feelings of anxiety, and better information recall (van Vliet et al., 2015). Of particular importance is that information that satisfies the emotional well-being of older

adults seems to be better memorized (Mather & Carstensen, 2005). van Vliet et al. (2015) suggest that creating a trusting environment during client-provider consultations with the use of empathetic communication is important in enhancing memory of information in older adults.

## 2.5 Conclusion

While much research has focused on client perspectives related to information needs, limited research exists regarding nurses' experiences of providing information to clients receiving palliative care. Furthermore, according to O'Shea (2014), research related to nurses' experiences in caring for older adults receiving palliative care is especially lacking. Although it is recognized that nurses play an important role in providing information to palliative care clients, their experiences have not been explored in-depth. The provision of timely and accurate information is an important component of palliative care to enable clients to make their own care decisions, and to ensure dignity at the end-of-life (Moyano & Zambrano, 2011; Tomlinson et al., 2012). In light of a growing aging population with preferences to die at home (Wilson et al., 2009), understanding the experiences of home care nurses who provide information to older adults receiving palliative care is crucial.

## Chapter 3

### 3 Methodology

Qualitative hermeneutic phenomenology was used in this study to better understand the lived experiences of home care nurses providing palliative care information to community-dwelling older adults with a terminal illness. Below is a philosophical overview of phenomenology, a description of phenomenology as a research methodology and the rationale for its use in this study, and the theoretical framework used in this study. Study design, method of data collection and analysis, quality criteria, and the various strategies used in this study to ensure study rigor are also discussed.

#### 3.1 Paradigm, Ontology, and Epistemology

In qualitative research, it is important for the researcher to locate one's research within a particular paradigm. Guba and Lincoln (1994) define a paradigm as a set of basic beliefs or assumptions about the world which provides a conceptual framework for one's study. The chosen paradigm serves as a guide for the researcher in the selection of participants, methodology, and the methods used in the study (Denzin & Lincoln, 2000), and will inform the interpretation of findings (Guba & Lincoln, 1994). Simply put, it is important for researchers to position themselves within a paradigm as this provides a rationale for why researchers do what they do. Guba and Lincoln (1994) ask three fundamental questions: the ontological question, the epistemological question, and the methodological question, to which the responses to these questions define the basic beliefs of a particular paradigm. This study was guided by an interpretivist paradigm as my beliefs about reality and my role as a researcher align with the assumptions of an interpretivist perspective.

Guba and Lincoln (1994) describe ontological questions, which ask "what is the form and nature of reality and, therefore what there is that can be known about it?" (p. 108). This study adhered to a relativist ontology, assuming multiple truths and realities exist (Schwandt, 1994). Relativists postulate that reality is constructed in the mind of the individual; it is what is perceived to be real by the individual rather than an objective singular entity (Hansen, 2004). Consistent with the ontological assumptions of a relativist, I acknowledged that the experiences of the participants in this study will be

diverse, and that the findings of this study do not claim representation of an objective singular reality.

Guba and Lincoln's (1994) epistemological questions ask "what is the nature of the relationship between the knower or would-be knower and what can be known?" (p. 108). I assumed a transactional and subjective relationship with the participants in this study, as knowledge would be co-constructed through interviews with the participants. These epistemological assumptions are consistent with the interpretivist paradigm which assumes understanding and knowledge can be brought to the surface by an interactive dialogue between the researcher and participant, where findings are co-constructed through this dialogue (Ponterotto, 2005). The goal of the dialogue was to jointly create an understanding of the lived experiences of the participant, from the point of view of those who live it day to day (Schwandt, 2000).

This study adopted an interpretivist paradigm, as my ontological and epistemological perspectives aligned with an interpretivist approach. Consistent with an interpretivist paradigm, hermeneutic phenomenology that allows co-construction of lived experiences through dialogue between the researcher and participant was chosen as the methodology for this study. Hermeneutic phenomenology was used to gain a better understanding of the lived experiences of home care nurses in providing palliative care information to community-dwelling older adults with a terminal illness.

### 3.2 Phenomenology

Phenomenology, originating as a philosophical study of our day-to-day lived experiences or phenomena, was founded in the early twentieth century (van Manen, 2014; Dowling, 2004). In particular, it was the work of Edmund Husserl and Martin Heidegger that resulted in two primary schools of phenomenology: descriptive phenomenology and interpretive phenomenology (van Manen, 2014). Husserl's (1970) descriptive phenomenology aims to study phenomena as they appear, to arrive at an understanding of human experience (Dowling, 2007; Flood, 2010; Dowling, 2004). Husserlian phenomenology focuses on understanding the lived experience from the pre-reflective descriptions of experience, without interpretations, in an attempt to capture the experience of phenomena as they appear to the consciousness (Wilcke, 2002). Husserl advocated for the use of bracketing in phenomenology, where the researcher suspends all

biases, presuppositions, and preconceptions about the phenomena under study to ensure an unbiased study (Dowling, 2007).

In existential or interpretive (hermeneutic) phenomenology, Martin Heidegger (1962), a former student of Husserl, proposed the importance of understanding the meanings of lived experiences rather than simply describing it (Flood, 2010). Heidegger's focus is ontological in nature, and emphasizes the importance of interpreting phenomena to uncover the hidden meanings of lived experiences (Dowling, 2004). In contrast to Husserl, Heidegger argues that rather than bracketing our beliefs, our preconceptions and presuppositions are an important part of the process of understanding lived experiences (Flood, 2010; Dowling, 2004).

More recently, a third school of phenomenology has emerged under the guidance of Max van Manen (Dowling, 2004). van Manen (1990) combines Husserl's descriptive phenomenology, with an emphasis on description and studying the pre-reflective experiences, with interpretation from Heidegger's interpretive phenomenology (Dowling, 2007). Like Heidegger, van Manen (1990) acknowledges the researcher's role in the research process and the influence of presuppositions on our reflections, and therefore does not suggest bracketing (Dowling, 2007; van Manen, 1990).

### 3.2.1 Why Hermeneutic Phenomenology?

Hermeneutic phenomenology aims to explore, describe, and interpret the lived experiences of individuals, and to understand the meaning of the lived experiences (Sloan & Bowe, 2014; Flood, 2010; Lopez & Willis, 2004). In hermeneutic phenomenology, the lived experience means reflecting on the ordinary day-to-day human existence as we live through it pre-reflectively, without interpreting, explaining, or theorizing it (van Manen, 2014). It incorporates elements of both descriptive and interpretive phenomenology, going beyond solely describing the lived experiences, to understanding the meaning of the experiences through an interpretive process (Dowling 2007; Lopez & Willis, 2004).

Hermeneutic phenomenology, informed by the work of Max van Manen (2014, 1997, 1990), was considered the best approach for this study as it closely aligned with the research objectives of this study, and my ontological and epistemological perspectives. Hermeneutic phenomenology aims to gain a deeper understanding of a phenomenon from those who have experienced it, and asks what an experience of a certain phenomenon is



like. It incorporates elements of descriptive and interpretive phenomenology to produce rich textual descriptions of the experience of a phenomenon and enables interpretation of meanings in the text by researchers, using the researchers' theoretical and personal knowledge (Ajjawi & Higgs, 2007). Through interviews with home care nurses, their pre-reflective experiences were obtained. According to van Manen (2014), it is important for the phenomenological interview to stay close to the experience as lived. The interview should ask questions about a specific instance, situation, person, or event, and avoid asking for interpretations, explanations, generalizations, or speculations that get away from descriptions of experience as it is lived through (van Manen, 2014). This enabled me to interpret the meanings of their experiences with personal knowledge and presuppositions.

van Manen (1990) emphasized that it is impossible to eliminate presuppositions and prior knowledge from influencing the research, hence methods such as bracketing would be inconsistent in hermeneutic phenomenology. Instead, it is by making our presuppositions explicit that we can understand how we make meaning of experiences in our day to day living. A declaration of self is included in this study to acknowledge my personal values, beliefs, and knowledge that may have influenced the interpretation of the participants' experiences.

### 3.2.2 Hermeneutic Circle

The hermeneutic circle, a key strategy in hermeneutic phenomenology, was incorporated into this study. According to Koch (1996), the hermeneutic circle is a metaphor to describe the movement between parts (data) and whole (gradual understanding of the phenomenon). In hermeneutic phenomenology, understanding and interpretation of the phenomenon emerges from the continuous interaction between the researcher, participant, text, and fore-structures, in a circular and iterative process. To engage in the hermeneutic circle, I, as a researcher, continued to go back and forth between dialogue, reflection, reading, and rereading the text, in developing meaning and understanding of the participants' experiences.

### 3.2.3 Theoretical Framework

Phenomenology does not use theory to interpret the meaning of lived experiences as it may constrain our understanding of phenomena. Theory, however, may be used if it

helps to provide a deeper understanding of human experience (van Manen, 2014). The theory of empowerment in nursing posits that if nurses are empowered within their workplace, they are, in turn, able to better empower their clients and provide better care, improving health outcomes for the clients (Laschinger et al., 2010). Considerable research on empowerment in nursing has been done and discusses the importance of structural empowerment and psychological empowerment in nursing outcomes (Laschinger et al., 2010; Laschinger, Finegan, Shamian, & Wilk, 2001; Kuokkanen & Leino-Kilpi, 2000; Laschinger, 1996).

### 3.2.3.1 Theory of Empowerment in Nursing

According to Kanter (1977, 1993), *empowerment* is defined as the ability to accomplish work in an organization, in a meaningful way. Kanter (1977) recognizes empowerment structures in organization such as opportunity and power that help empower individuals to maximize their ability to accomplish their work. *Opportunity* relates to the work conditions that promote knowledge and skills development, enabling individuals to advance within their organizations. *Power* refers to the ability to mobilize information, resources, and support to meet organizational goals. Formal power is achieved from job activities that are key in meeting organizational goals, whereas informal power is achieved through developing relationships with others in the organization and mutual cooperation to reach their goals. Information refers to access to knowledge required to complete job activities. Resources refer to access to materials, money, rewards, and time necessary to accomplish work. Support relates to sources of feedback from superiors on one's job. Greater access to these empowerment structures can result in a sense of empowerment, allowing individuals to accomplish their work in a meaningful way and achieving organizational goals (Kanter, 1977).

Spreitzer (1995) defines *empowerment* as a motivational construct, referring to how individuals experience their role in their work environment. Psychological empowerment involves meaning, competence, self-determination, and impact, which together reflect an individual's wishes and ability to shape their work role. *Meaning* refers to how the requirements of one's work role fits with their personal beliefs, values, and behaviors. *Competence*, or self-efficacy, relates to an individual's belief in their ability to successfully perform job activities with skill. *Self-determination* refers to the

individual's sense of choice in initiating and continuing work behaviors. *Impact* is the individual's perception of influence they have on the strategic, administrative, or operating outcomes at work. According to Spreitzer (1995), when all four components of psychological empowerment are experienced, individuals feel empowered and able to take an active work role.

It is important to note that there is a limitation in using only one of these empowerment theories to understand empowerment at work. According to Spreitzer (2007), the structural empowerment theory is limited to focusing on empowerment at the organizational level, whereas the psychological empowerment theory focuses solely on empowerment at the individual level. Spreitzer (2007) argues that to gain a comprehensive understanding of empowerment at work, an integration of both the structural empowerment and psychological empowerment theories is needed. By integrating the two theories, it is possible to enhance understanding of how nurses' experiences within their organization can contribute to their ability to work optimally to fulfill their work role. Empowering nurses is important as nurses will then be better able to empower their clients to make their own healthcare decisions. In the Laschinger et al. (2010) study, a model of nurse/client empowerment is suggested using the integrated empowerment theory. Laschinger et al. (2010) argues that, as a result of having greater structural and psychological empowerment in their work settings, nurses are more likely to use client empowering behaviors, such as providing relevant and timely information to clients. The use of client empowering behaviors by nurses, in turn, lead to higher levels of client empowerment and a greater sense of control.

Nurses are in a key position to provide palliative care information, identify optimal strategies as well as barriers to service provision and, within a community context, often have the flexibility to organize their day, within limits. However, for nurses to feel truly empowered, the culture of their organization (structure) is critical. If it is an empowering environment, that is, if the organization is willing to listen and collaborate with staff nurses to resolve issues identified, there is great opportunity to enhance service provision. If, on the other hand, it is a more top-down controlling environment, it is less likely that issues will be resolved. This theory will, hopefully, help

guide a better understanding of the experiences of nurses providing palliative care in a community context.

### 3.3 Quality Criteria in Qualitative Research

According to Tracy (2010), there are eight key criteria for ensuring the quality of qualitative research. These criteria include: a worthy topic, meaningful coherence, rich rigor, credibility, resonance, significant contribution, ethics, and sincerity (Tracy, 2010). Tracy's (2010) worthy topic refers to qualitative research whose research topic is "relevant, timely, significant, or evocative" (p. 840). Meaningful coherence refers to research that achieves its research purpose and uses methods that are coherent with its stated goals and paradigmatic framework. Research with rich rigor is marked by the sufficient and careful use of theoretical constructs, appropriate sample(s) and context(s), time in the field to collect significant data, data to support research findings, and data collection and analysis procedures (Tracy, 2010). Credibility refers to the trustworthiness and plausibility of the research findings. The researcher uses thick descriptions, member checking, methods of crystallization, and attends to multivocality to ensure the credibility of the research (Tracy, 2010). Resonance refers to research that is able to influence, affect, or move an audience (Tracy, 2010). Quality research also provides a significant contribution to the current state of knowledge, practice, or politics, while adhering to ethical practices in qualitative research. Sincerity can be achieved through self-reflexivity, honesty and transparency about the researcher's roles and biases in the research, and being transparent about the research process (Tracy, 2010; Seale, 1999). Tracy's (2010) eight criteria for quality qualitative research were used throughout this study to ensure rigor.

### 3.4 Study Design

#### 3.4.1 Study Sample

The purpose of this phenomenological study was to gain a better understanding of the lived experiences of home care nurses providing palliative care information to community-dwelling older adults with a terminal illness. This study focused on nurses providing home-based palliative care to clients of the South West Community Care Access Centre (CCAC) in London, Ontario.

Purposeful sampling was used in this study to gain examples of rich and detailed descriptions of the experience under study, as suggested by van Manen (2014). Ten home care nurses meeting the following inclusion criteria were eligible to participate in this study: (a) nurses currently providing palliative care information to community-dwelling older adults with a terminal illness receiving home-based palliative care through the South West CCAC, and (b) able to communicate fluently in English. Home care nurses were chosen as the target population for this study because they play an important role in providing palliative care information to clients within the South West CCAC.

Phenomenology does not strive to generalize its findings from the sample of the study to a population (van Manen, 2014). Phenomenology aims to explore what is unique and singular to a certain example of lived experience (van Manen, 2014). The goal of phenomenology is to get an experientially-rich, in-depth understanding of a phenomenon. In the literature, recommended sample sizes for phenomenological studies vary; Creswell (1998) suggests between 5 to 25 participants while Morse (1994) recommends a minimum of six participants. A sample size of 10 participants was chosen for this study. Previous studies in a similar context have shown this number to be sufficient to get an experientially-rich, deep understanding of the phenomenon of interest (Kokorelias, 2016; Vieira Zamora, 2015)

### 3.4.2 Participant Recruitment

For this study, the South West Local Health Integration Network (LHIN) Hospice Palliative Care Lead was the first point of contact and assisted in getting the support of multiple sites to recruit eligible participants. The South West CCAC was chosen for recruitment of participants because they have a list of contract service provider agencies which provide home-based palliative care services in London, Ontario. The South West CCAC London Office manager was identified as an important contact as she would be able to identify potential nurse participants who meet the inclusion criteria for this study. The South West LHIN Palliative Pain and Symptom Management Consultation Program Nurse Educator was also identified as an important contact as she is responsible for the training of home care nurses who may go on to provide services through the South West CCAC. Ethics approval was obtained from the University of Western Ontario Research Ethics Board prior to start of the study (Appendix A). Following ethics approval from the

University of Western Ontario Research Ethics Board, the researcher contacted the South West LHIN Hospice Palliative Care Lead via email. The South West LHIN Hospice Palliative Care Lead introduced the researcher to the South West CCAC London Office manager and South West LHIN Palliative Pain and Symptom Management Consultation Program Nurse Educator, then forwarded the notice of recruitment (Appendix B) and letter of information (Appendix C) to both. The manager and educator were asked to share the notice of recruitment and letter of information with their home care nurses and invite them to participate. The letter of information outlined the purpose of the study, potential risks and benefits, study procedures, and confidentiality. The notice of recruitment invited interested individuals meeting the inclusion criteria to contact the researcher for further information and participation in the study. Once contacted, the researcher answered any questions or concerns about the study and, if the participant agreed to participate, the researcher set up a time and location convenient for the participant to conduct the interviews.

Before starting the interviews, the researcher reviewed the letter of information with participants and answered any further questions participants had regarding the study. Each participant signed the consent form prior to participation in the study (Appendix C).

### 3.5 Data Collection

The aim of phenomenology is to collect examples of possible lived experiences and to reflect on the meanings embodied in these experiences. Interviews are commonly used in phenomenology to explore and gather experiential material that is rich and detailed (van Manen, 2014). In-depth semi-structured interviews were used in this study to gain a better understanding of the lived experiences of home care nurses in providing palliative care information to community-dwelling older adults with a terminal illness.

One interview was conducted with each of the 10 participants. Interviews used a face-to-face format and lasted anywhere from 30 to 60 minutes. During the interview, participants were asked to complete a short demographic questionnaire (Appendix D) prior to the beginning of the interview. A semi-structured interview guide (Appendix E) was used to guide the interview. The direction of the interviews, however, was also guided by the emerging dialogue with the participants. Open-ended questions were used to allow the participants to share their experiences in their own words (McConnell-

Henry, Chapman, & Francis, 2011; Cohen & Manion, 1989). Probing questions were also included to further clarify and better understand participants' responses. Participants were asked to reflect on their day-to-day experiences providing palliative care information to community-dwelling older adults with a terminal illness. The following are examples of questions in the interview guide:

*Please tell me what your role is in providing palliative care information to your clients.*

*What is it like to provide palliative care information to older adults in their own home?*

Interviews with the participants were audio-recorded to ensure that the participants' experiences were accurately captured. At the beginning of the interview, the researcher reassured participants that this study was voluntary, and if at any time during the interview the participant wanted the audio-recorder stopped, the researcher would stop the audio-recorder and only start again when the participant felt comfortable.

Observational notes were taken during the interview to ensure that the participants' experiences were accurately captured. Field notes and reflexive journaling were also used by the researcher after the interview to document observations of participants' behavior, reactions, and emotions during the interview, as well as the researcher's thoughts and reflections throughout the interview. The interviews were transcribed verbatim.

### 3.6 Data Analysis

Consistent with hermeneutic phenomenology, data analysis and interpretation were an iterative process (Smith, 2004). Data analysis began simultaneously with the ongoing recruitment process and interviews (Crist & Tanner, 2003; Starks & Trinidad, 2007; Wright-St. Clair, 2015). Once interviews were completed, the researcher went back to the audio-recordings of the interviews and listened to the full interview recordings several times, and made reflexive notes about initial interpretations of the participants' experiences (Bontekoe, 1996). The researcher transcribed the interviews verbatim and continued to add to the reflexive notes as the interviews were transcribed. van Manen's (2014, 1997) framework for phenomenological analysis consisting of wholistic, selective, and line-by-line analysis was used for this study.

### 3.6.1 Wholistic Analysis

After the interviews were transcribed, the researcher first engaged in a wholistic analysis of the text (van Manen, 2014, 1990; Ajjawi & Higgs, 2007). Each interview transcript, written field notes, observational notes, and reflexive notes were read and re-read carefully. Additional reflexive notes were made by the researcher, recording and describing thoughts and preliminary interpretations arising from the text as a whole. This process is referred to as *immersion* in the data (van Manen, 1997), and allowed the researcher to become familiar with the text, to gain an understanding of the text as a whole. The aim of using the immersion process was to enable the researcher to think about how preliminary findings can be used to guide subsequent interviews and to facilitate coding for further, more detailed data analysis. Appendix F provides examples of participant stories that were compiled in this phase of the analysis.

### 3.6.2 Selective Analysis

The second level of data analysis involved selective analysis of meaningful and significant words and phrases within each of the interviews that seemed essential to the experience under study (van Manen, 2014, 1990; Braun & Clarke, 2006). During this phase, the researcher circled and underlined words and phrases that best described the experiences of the participants, and identified potential emerging themes.

First and second cycle coding were completed within this phase of analysis (Saldaña, 2015). In first cycle coding, specific codes were assigned to the data. Second cycle coding was completed by clustering identified codes into categories, which were used for subsequent analyzes and emergence of themes (Saldaña, 2015). A combination of coding methods was used to complete first and second cycle coding. Initial coding, In Vivo coding, and descriptive coding were used for first cycle coding, and pattern and focused coding were used for second cycle coding.

#### 3.6.2.1 First cycle coding

Initial or open coding was used to help the researcher become familiar with the data, to breakdown the data, and to begin extracting ideas and concepts. Initial coding allowed the researcher to freely assign codes to the data, without restrictions on what should and should not be coded (Saldaña, 2015). In Vivo coding aligns with phenomenological research as it honors the voices of the participants to tell the story



(Saldaña, 2015). NVivo 11 software was used to organize the data, using the participants' language and words as codes. For example, a direct quote was used as a code to illustrate how one participant felt discussing death and dying with her clients as it best captured the participant's feelings. Lastly, descriptive coding was used to summarize the basic topic of different segments of the data, reminding the researcher of the various topics that appeared throughout the interviews (Saldaña, 2015). For example, if a participant spoke about the bond and trust formed with her clients, this was coded as "relationship with clients".

Two additional members of the research team each reviewed and independently coded three transcripts. The first researcher independently coded transcripts from participant 1, 2, and 6; the second researcher independently coded transcripts from participant 2, 3, and 5. This ensured that all research team members were in agreement with the initial codes generated. This process was also used to establish the credibility of the research findings.

### 3.6.2.2 Second cycle coding

After the completion of first cycle coding for all transcripts, codes were categorized using a combination of pattern coding and focused coding during second cycle coding. Pattern coding was used to group together similarly coded data into more meaningful clusters of information (Saldaña, 2015). For example, all the data pertaining to the use symptom assessment tools were clustered together under the category "symptom assessment". Focused coding was used to categorize first cycle codes based on thematic similarities (Saldaña, 2015). For example, first cycle codes pertaining to sources of support to provide palliative care information were clustered under the category "knowing where to turn for support". Upon completion of second cycle coding research team members reviewed all categories generated to ensure agreement before proceeding to the next level of analysis. Appendix G provides an example of the selective analysis process.

### 3.6.3 Line-by-Line (Detailed) Analysis

Following selective analysis, line-by-line or detailed analysis was used. The researcher examined every sentence or sentence cluster and asked what each of the sentences revealed about the experience being described (van Manen, 2014). Re-reading

the transcripts line-by-line helped further understanding of participants' lived experiences. Throughout this process, the researcher took note of emerging themes within each participant interview, as well as across all transcripts. Consistent with hermeneutic phenomenological research, the researcher continued to engage in the hermeneutic circle by moving back and forth between the text and emerging themes to gain a deeper understanding of the participants' experiences. The researcher worked to define the themes emerging from the participants' experiences and to refine them, ensuring that the themes captured the meaning of the participants' experiences and consensus was reached by the research team. Appendix H provides an example of the emerging themes.

Upon completion of the study, member checks were completed with each participant. Participants requested to conduct member checks by phone, and the researcher set up a time convenient for the participants. Member checking (Lincoln & Guba, 1985; Krefling, 1991; Lindlof & Taylor, 2002; Tracy, 2010) or participant feedback, a strategy in which participants confirm the interpretations of the findings, was used as a part of the analysis process to ensure accuracy of the research findings (van Manen, 2014). The researcher encouraged participants to share any additional information that may have been missed in the first interview and incorporated this information into the final analysis of participants' experiences.

### 3.7 Study Rigor: Application of Quality Criteria

#### 3.7.1 Worthy Topic, Meaningful Coherence, and Rich Rigor

This study explored a worthy topic, as it attempts to address concerns from the recent 2014 Annual Report of the Office of the Auditor General of Ontario (Office of the Auditor General of Ontario, 2014). Methods used in this study were coherent with the research question, and consistent with the proposed paradigm and methodology, demonstrating meaningful coherence. Careful selection of appropriate methodology, sample, interview procedures for data collection, and data analysis ensured rich rigor.

#### 3.7.2 Credibility

Several strategies were used to promote the credibility (Tracy, 2010) of this study's research findings. Interviews were audio-taped and transcribed verbatim by the researcher to ensure the accuracy of the data. Member checking (Lincoln & Guba, 1985;

Krefting, 1991; Lindlof & Taylor, 2002) was conducted with the participants to ensure that the research findings reflected accurate insight into the meaning of the participants' lived experiences (van Manen, 2014). A method of crystallization (Tracy, 2010; Ellingson, 2008) was used during the analysis of the transcripts, in which multiple researcher viewpoints were incorporated into the analysis and interpretation of the participants' experiences to promote credibility of the findings. The research team worked together to generate a final list of codes, finalized themes, and reviewed the findings to ensure that all researchers were in agreement. Crystallization allowed for consistency in the interpretation of participants' experiences, for different aspects of the experience to be explored, and deepened understanding. The researcher also used thick descriptions to promote the credibility of the research findings; that is, enough detail about the context and the findings of the study were provided so that other readers are able to determine the extent to which the findings of this study are applicable to their own experiences (Shenton, 2004; Tracy, 2010). Direct quotations from the participants were included to demonstrate exemplary anecdotes that support the findings of the study.

### 3.7.3 Resonance and Significant Contribution

Although the aim of this study was not to produce generalizable findings (Tracy, 2010), knowledge gained through this study can be transferable and useful in other settings or populations. The findings of this study add to the existing body of knowledge, and proposed implications may be useful to other health professionals, home care agencies, and researchers to inform future research, training, and support for home care nurses providing palliative care information.

### 3.7.4 Ethics

Ethics approval was obtained from the University of Western Ontario Research Ethics Board. Participants were informed that participation was voluntary and that they may refuse to participate, refuse to answer any questions, or withdraw from the study at any time. The participants were also informed that participant information will be used only for the purposes of this study, and any identifying personal information will be kept confidential, anonymous, and will not be disclosed in any form of presentation of the findings.

Electronic data were stored on a password-protected computer. All identifiable information was stored in locked drawers, in a locked laboratory, in a secure building on campus at all times. Identifying information was eliminated from the data and replaced with a with a code (001, 002, 003, etc.) for participant anonymity. Transcripts and audio-recordings will be kept on file for five years following data collection, then be destroyed and disposed of to protect participants' confidentiality.

### 3.7.5 Sincerity

Sincerity as an end goal was achieved through self-reflexivity, honesty, transparency, and data auditing (Tracy, 2010). Using a reflexive journal throughout the research process, the researcher noted any subjective feelings, thoughts, how meaning of experiences was understood, etc. (Tracy, 2010; Emerson, Fretz, & Shaw, 1995). The researcher promoted transparency by keeping an audit trail (Tracy, 2010; Seale, 1999), documenting how decisions were made, as well as when and how the remaining research team members were involved. A declaration of self is also included in efforts to be transparent.

### 3.7.6 Declaration of Self

To demonstrate self-reflexivity and transparency (Tracy, 2010), my own interests in palliative care, health, and aging are provided. Living in a different country from my grandparents, I had very little interactions with older adults as a child. Only once every few years did I have the opportunity to visit, and really be able to have long conversations with my grandparents in Japan. As a result, growing up I did not have much knowledge or understanding of aging, and what it meant to be an "older adult". During my undergraduate career, I began to expose myself more to the topic of aging, and interacting with older adults. In my second year of my undergraduate degree in Health Sciences, I was introduced to the *Health Issues in Aging* course. For the first time, I learned about the various fundamental issues associated with aging, and the complex interaction of issues that influence the health and well-being of older adults. I was very much interested in learning more about health and aging after completing this course, and went on to complete various other courses related to aging such as the *Aging Body*, *Physical Activity and Exercise Guidelines for Older Adults*, *Gerontology in Practice*, *Palliative and End of Life Care*, and *Bereavement Theories and Interventions*. During

this time, I also had a great and enjoyable opportunity to volunteer at a senior exercise program and to visit retirement homes, which furthered my interests in pursuing a Master's Degree in the Health and Aging field.

My interest in palliative care was largely influenced by the *Palliative and End of Life Care* course I had taken in the fourth year of my undergraduate degree. This course helped me shape my understanding of the conceptual framework of palliative care, the various aspects of care involved in palliative care, as well as the various needs of palliative care clients and families. In addition, I recognized that coming from a family with a Japanese background, I learned through my experiences about the importance of caring for our older adults and the importance of the home. From a young age, seeing my great-grandmother being cared for by family at home, and hearing about the importance of allowing her to remain in the home with the family has definitely shaped my beliefs about caring for older adults. My beliefs in the importance of caring for older adults in the community and allowing them to remain in their homes have led me to be passionate and pursue research in palliative care in the community.

### 3.8 Conclusion

This chapter outlines the methodology, study design, participant recruitment, methods of data collection and data analysis used in this study. Hermeneutic phenomenological methodology informed by van Manen was used in this study to explore, describe, and interpret the lived experiences of home care nurses in providing palliative care information to community-dwelling older adults with a terminal illness receiving home-based palliative care. The research was rooted within an interpretivist paradigm, assuming that multiple truths and realities exist, and knowledge is co-constructed through an interactive dialogue between the researcher and participant. The quality of this study was ensured using Tracy's (2010) eight major criteria of quality in qualitative research.

## Chapter 4

### 4 Findings

The goal of this study was to better understand the lived experiences of home care nurses providing palliative care information to community-dwelling older adults with a terminal illness. An in-depth, thematic analysis of each participant's story was completed, and key themes were identified within and across participants.

Ten participants were interviewed for this study. All participants were female and were working on a full-time basis. Five of the participants were registered practical nurses and five were registered nurses. The number of years the participants worked in palliative care ranged from one year to 15 years. Nine of the participants had some type of specialist training in palliative care. Of these, four participants had completed the Comprehensive Advanced Palliative Care Education (CAPCE) program, five completed the Fundamentals of Hospice Palliative Care program, and one participant completed the Learning Essential Approaches to Palliative care (LEAP) program; all three programs were developed and offered by the Palliative Pain and Symptom Management Consultation Program of Southwestern Ontario. One participant also noted having worked 400 hours alongside an experienced palliative care nurse as part of the Health Force Ontario program. Table 1 provides additional details about the participants' socio-demographic characteristics.

Eight key themes emerged from this study: (1) importance of support and unity, (2) tools for providing information, (3) building a relationship with clients, (4) comfort level talking about death and dying, (5) language and cultural barriers, (6) clients' readiness to accept information, (7) influence of the home environment, and (8) helping your client to a good death. Several of these themes contained multiple sub-themes.

#### 4.1 Importance of support and unity

The theme 'importance of support and unity' refers to the participants' experiences of working within a multi-disciplinary team when providing information to their clients. Sub-themes include information flow, knowing where to turn for support, and balancing palliative care issues with non-palliative care client needs.

**Table 1: Socio-demographic characteristics of participants**

Characteristics	Study participants (n=10)
Gender	
Male	n=0
Female	n=10
Highest Level of Education	
Below High School	n=0
High School	n=0
College Diploma	n=4
University Bachelor's Degree	n=4
University Master's Degree	n=2
University PhD degree	n=0
Other	n=0
Type of Nurse	
Registered Practical Nurse	n=5
Registered Nurse	n=5
Nurse Practitioner	n=0
Specialist Training in Palliative Care	
Yes	n=9 <sup>1</sup> Comprehensive Advanced Palliative Care Education (n=4) The Fundamentals of Hospice Palliative Care (n=6) Learning Essential Approaches to Palliative care (n=1) Health Force Ontario (n=1) Hospice Palliative Care Ontario conference (n=1) Thanatology courses at King's University College (n=1)
No	n=1
Number of Years in General Nursing	1.5 years (n=1) 3 years (n=5) 9 years (n=1) 18 years (n=1) 20 years (n=1) 34 years (n=1)
Number of Years in Palliative Care Nursing	1 year (n=1) 1.5 years (n=1) 2.5 years (n=1) 3 years (n=4) 5-8 years (n=1) 10 years (n=1) 15 years (n=1)
Employment Status	
Full-time (> 30 hours/week)	n=10
Part-time (< 30 hours/week)	n=0
Other (contract, casual)	n=0
Number of years of providing palliative care nursing services to clients of the South West Community Care Access Centre	1 year (n=1) 1.5 years (n=2) 2.5 (n=1) 3 (n=3) 5-8 years (n=1) 10 years (n=1) 15 years (n=1)

<sup>1</sup>Some participants had more than one specialist training in palliative care

#### 4.1.1 Information flow

It became apparent from the participants' experiences that they were working within a multifaceted information system. Participants indicated that they were working in a multi-disciplinary team, usually comprised of a family physician or community palliative care physician, nurse practitioners, registered nurses, and registered practical nurses, all providing some form of palliative care information. Physicians and nurses had distinct roles, with physicians providing the primary diagnosis and prognosis. Many of the participants agreed that a large part of their role consisted of "clarifying information that the doctor has given the clients, and reinforcing information" (participant 6). Participants noted that a physician had to be the one to communicate the diagnosis and prognosis to their client, and once that was done, clients were typically referred to other professionals within the team. At this time, nurses would be able to answer questions and go over information if the client wished to do so. Participant 1 explained: "As a nurse, I can't provide a diagnosis...I can't provide a diagnosis, it has to come from the doctor. Um, but once we, that's been provided by the doctor, I can talk about it". Some participants stated they often clarified the information from the physician with their clients because clients were overwhelmed with the initial diagnosis and unable to absorb the information. Participant 8 shared:

Clients are overwhelmed in the doctor's office, and will have issues with absorbing the information then, and so they will ask lots of questions when I'm with them. All they heard was "this cancer" and that was all they heard. They don't know what was said after that. So then I will read whatever update I get from the doctor, and help reinterpret the information back to the client.

Participants indicated that their role was not limited to reinforcing information, but to introduce additional information to their clients as well. Although some of the information provided depended on the unique needs of each of their various clients, all participants expressed that it was their role to provide information related to do-not-resuscitate (DNR) orders and expected death in the home (EDITH).

Most participants indicated that there was a general flow of information between the physician, clients, and themselves. Participants explained that in an ideal situation, when a client is first admitted to the palliative care service, the client's most responsible



physician has already provided the client with information regarding diagnosis, prognosis, and what to expect. Participants stated that they would then receive an update from the physician regarding the client's condition. This enabled them to answer any questions the clients may have about their diagnosis and discuss what they would be able to do for the client, including care options. It was noted by the participants that if any physician decided to become the client's most responsible physician, they agreed to be available for contact at all times.

In some cases, participants found that they were not getting valuable information, updates, or clear instructions from physicians. Many participants expressed that it then became a challenge for them to provide information to their clients. Participant 1 stated:

...well a big challenge that we haven't talked about is just getting the information from the hospital or from the family doctor, you know, from people like that... a discharge note will go from the specialist or from the oncology to the family doctor, but it never comes to us. And sometimes there's good information in there that would be helpful for us to have.

Participant 1 further expressed her worries: "I worry about, you know, if I haven't gotten clear instructions from the doctor about something, um, you know, I'm worried about not having all the answers for them [her clients] because I haven't been given the most recent reports". She noted feeling frustrated that she would sometimes have to be "a little vague" with her clients because she did not want to give them the wrong information.

Some participants described having greater difficulties reaching family physicians compared to the palliative care physicians. "...it's really much easier to deal with the community palliative doctors than it would be say a family doctor because they're seeing patients all day, and they might not call you back" (participant 7). In another example, participant 8 stated her frustration in not being able to reach her client's family physician:

I have had, recently, a palliative client who was declining and the family doctor didn't name anybody as their secondary, and they went away on vacation. And we couldn't get in contact with anybody to get increased pain medication for this client. So CCAC had to get involved and name a secondary, on his behalf more or less so we could get pain medication and all that started. Yeah, so it was frustrating.

One participant in particular explained that the most challenging part of providing information was when “the most responsible physician has not had a frank discussion with the client” (participant 3). She went on to explain: “I don’t feel it’s my place to give them the diagnosis and the prognosis, it’s the most responsible physician. It’s, I think, their kind of job to give them the diagnosis and prognosis”. Participant 3 stressed that it was a big challenge for her when she was unable to provide her client with the information they requested because the physician had not discussed the diagnosis and prognosis. She recalled an experience with a palliative care physician which left her surprised and confused:

And the client was obviously going to die...he was going to pass away within 2 or 3 months. And the palliative physician put a very positive spin on it, I was almost, I was surprised actually. And she said “oh, no, no, no, I don’t want to admit him to the palliative unit, I just want to admit him to the palliative unit cuz I think he might be having little strokes, and I want to investigate the strokes...And it was just very...odd...it was kind of a difficult position to be in because he [the client] was not receptive to me in any way at all, CCAC was telling me we’ve got to get the DNR and EDITH done because he’s gonna die very soon, and then when I asked the physician to speak to the daughter, she turned it around and put a whole positive spin on the whole thing. And I was just...sitting there going “what is going on?” [laughs].

#### 4.1.2 Knowing where to turn for support

Colleagues, physicians, and hospices were all identified as a primary source of support. Participants described support in terms of expertise, being available for questions, and providing opportunities to decompress.

Many of the participants indicated that they turned to a colleague, quite often another nurse who was experienced and trained in palliative care, when they needed help with difficult situations. Participant 4 explained that when a family was not hearing any of the information, her colleague would make a joint visit with her to help facilitate end of life discussions with the client and family. Similarly, participant 6 explained that a joint visit with a colleague was very helpful to learn some ‘tricks and tools’ to facilitate difficult conversations that she could use with her clients in the future. Participant 2

added that the clinical lead resource practice nurse at the agency was another great resource for difficult situations.

For a number of participants, physicians were recognized as a source of support. Six out of 10 participants indicated that specialist palliative care physicians in particular were a great support with their palliative care expertise. Participant 6 stated: “Our palliative physicians especially are really fantastic. They’re the on-call group”. Agreeing, participant 7 commented: “if it’s already a community palliative doctor that’s been set up, they have pagers, they have on-call available. It’s, it’s really much easier to deal with the community palliative doctors than it would be say a family doctor”. Many participants reported positive experiences regarding the availability of the palliative care physicians. “Most of my experiences with like the palliative doctors have been fantastic. Like I’ll call them at 11 o’clock at night, and they call me back right away” (participant 8).

In addition to being available for consult, specialist palliative care physicians were great at ensuring their clients were well-informed in terms of what to expect. For example, participant 3 explained:

...they will continually at every visit, talk to the patient about end of life changes and what to expect...the palliative care physicians are usually very good...they’ll be able to have a discussion with the client but also, never kind of take away hope, if the client still has any kind of hope.

Participant 4 expressed that joint visits with the palliative care physicians helped build her confidence:

having joint visits...has really built who I am as a palliative nurse, and like I feel comfortable, confident in anything someone would ask me, and I know for the most part where to direct them if I don’t have the answer. Or I know who to reach out to. “You know, that’s a really good question, I know who I’m going to ask”, and reaching out to find out.

One participant in the study noted hospice to be a great resource for more information. When asked about the types of information she provided to her clients, participant 4 shared:

...are you talking about actual booklets, pamphlets, handouts?... we aren’t necessarily given direct access as nurses to those things. Um, what we do

sometimes get is, like I will stop by St. Joseph's Hospice and they happily give you stuff, to give out... I personally use St. Joseph's Hospice as a wonderful referral tool, um, because there are a lot of things available through them that give supportive care, you know, in all the spheres... Like not just like this is about the spiritual, the mental, emotional aspect of death and dying, that we do not have access to as nurses, like we can get social work through the LHIN for them, but that's kind of it. So St. Joseph's Hospice is really good for having those things for people.

A few participants recalled moments of having to decompress after difficult situations. In these cases, colleagues, such as their managers, were very supportive "either if it's venting or you know, crying" (participant 7). Participant 6 revealed having previously called all three managers at her office in times of stress. She shared the following example of a difficult situation:

One day I had been 6 hours, 6 and a half hours with a client because there had been miscommunication... I spent the last 6 hours of his life, keeping him comfortable and dealing with stuff. And my day that day went to 15 hours because I couldn't give away the rest of my clients. So I'd seen 2, I went to see this guy, wound up staying until he died, because we could not control everything, so it was 6 hours...the doctor was there for the first hour, and I called him 8 or 9 times in the intervening hours. And then I called and said he passed. And then I did all the stuff that we do, and then I left to my next client...The next day I went into the manager and I...she held me, and let me cry, and let me vent, and I went on with my day. Because that's what we do. (participant 6)

#### 4.1.3 Balancing palliative care issues with non-palliative care client needs

Most of the participants in this study reported having encountered unanticipated issues during their visits with their palliative care clients. In these cases, most participants found that it was a challenge balancing their time between palliative care clients and their non-palliative care clients. Participants 1 and 2 explained that it was particularly difficult when they had other time-sensitive clients to see.

I have to think about other people too, like not only palliative people...I know I have to go for another IV client, you know, that time I have to...be there [on-time]. (participant 2)

...if you walk into the home and the family is really upset or something is happening that you need to deal with, it was really hard cuz you have to rush to get to the next person. (participant 1)

Several participants also felt that the time allotted for each of their palliative care visit was not enough. Participant 5 shared: “there are times that...that you feel like maybe you’re-, you’re pushing the visit along a little bit further-, like a little bit faster than what the family may want to be moving at”. On the other hand, participant 4 explained that she felt rushed in her visits with some of her other non-palliative care clients because she would spend more time with her palliative care clients when needed. Participants 8 and 10 both explained that they do not set a time limit with their palliative care clients:

They say it’s 2 hours, but you can’t do that. You can’t do that. You have to leave the house in a safe, like your patient has to be safe. And whatever it takes. That’s me! That’s me. It’s whatever it takes. So a visit is 2 hours maximum, however, you still have to complete all your duties. (participant 10)

Some of the participants noted that sometimes they just end up working longer days to spend that extra time with their palliative care clients.

Other participants indicated that they had the ability to call their office or colleagues for help when they needed someone to cover their remaining clients. For example, participant 5 shared:

...we do have the ability to reach out to our office and say “look, I need-, you know I need these 5 patients reassigned to somebody else, this is what’s happened with my day”. Or even just sending out a global email to other nurses you know, that are working in London that day and saying “I need help, I’m on the West side. Who can help?”

Participants explained that having the ability to get a colleague to cover some of their other clients allowed them to spend more time with their palliative care clients when needed:

...sometimes stuff creeps up, and you know, stuff that you don't plan on, so you just have to call into the office and say, "look I'm running behind, can you get somebody else to cover the rest of my patients", or "can somebody take a couple of my patients so that I'm able to stay an extra hour". (participant 9)

...tracking down the family to find out what funeral home they wanted...took 3 hours. So I was there for 3 and a half hours. And again, you call your friends, you rearrange your day, you make sure everybody gets seen, but you do your job. (participant 6)

## 4.2 Tools for providing information

'Tools for providing information' refers to the various methods used to determine the timing and types of information provided to palliative care clients. This theme contained four sub-themes: guidelines/protocols, symptom assessment, starting with where the client is at, and it's very much client-driven.

### 4.2.1 Guidelines/protocols

Three out of 10 participants in this study indicated that there were written agency guidelines or protocols for providing information to palliative care clients. Of these three participants, two reported using what was called a "palliative package" (participant 2) or "care plan from the agency" (participant 9) which included a checklist of information that was to be discussed with each palliative care client. Participant 2 explained that her agency 'palliative package' contained a variety of information such as EDITH, DNR, and funeral homes for palliative care clients. Similarly, participant 9 discussed that her agency care plan included information on the EDITH program, and steps on what a family member should do if the client stopped breathing. Although the third participant (participant 7) believed there to be agency guidelines, she stated: "I don't use one anymore because I just kind of go with the flow of the visit and know what I'm doing".

Further, three different participants noted receiving verbal instructions from the CCAC to discuss the EDITH and DNR with their clients. Participant 1 claimed that "we get put in by the CCAC, and commonly CCAC will send us a note saying go out and get the DNR". Similarly, participant 3 stated: "electronic updates we will get from CCAC will say, 'nurse to go in and get DNR and EDITH completed', like they expect a death in the home...Nurse to go in and get EDITH and DNR set up". Participant 5 stated that she

provided information to her clients when needed, and sometimes that was when the CCAC asked her to get the DNR and EDITH completed.

#### 4.2.2 Symptom assessment

Many of the participants noted using symptom assessment tools in determining the timing to provide certain types of information. Participants indicated using various symptom assessment tools including the Palliative Performance Scale (PPS) and the Edmonton Symptom Assessment System (ESAS). Participant 1 used an additional tool to help “determine who is maybe in the last year of their life” (participant 1), however could not remember the name of this tool.

The PPS was used to help clients understand the likely progression of symptoms as they approach end of life. Participant 1 stated:

we use something called the PPS, which is ugh, a way we score them based on their functional status...show them the scale, and we kind of say, you know, we pay attention to things like, when you...can't eat or drink anymore cuz of your disease...

It was evident in the experiences of participant 6 that the PPS was used to help inform the family of the client's imminent death. She recalled:

Another client I walked into yesterday, the family knew I was coming, the doctor knew I was coming...I came at an odd time, there was one family member home. I walked in, and the patient...was what we call 10% [PPS], so she was imminently dying...And I said you know, you might want to call everybody because she's had 2 breaths in the last minute, and this is at-, this is very much likely at the very end. (participant 6)

Identifying clients in their final year of life was deemed an important part of advanced care planning. Participant 1 used a tool, which she could not remember the name of, to identify clients that were in the last year of their life to aid in the timing of advanced care planning conversations:

we have some tools to, that we use to kind of um, identify people who might be in the last year of their life to try to have these conversations about, like, about advanced care planning but also about like how many more interventions do you want? Like how invasive do you want the interventions to be?... Just so they can

think about it a little bit before... because we're always trying to kind of see...um...yeah. Who should we have these conversations with.

Despite noting the usefulness of this tool, participant 1 referred to the complexity of different disease trajectories to express that it was not always easy figuring out when to have end of life discussions:

...cancer, like they're fine and then they just decline. So like on the graph they just kind of decline. And then with organ failure, it's like they're fine, and then they have an exacerbation, and they go into hospitals, and they get "tuned up" we say, like their meds get changed and they get sent home. But they're a little less functional, so they can't walk as far, can't do as many things and then they go along for a while and then they have another little dip. And any one of those dips could be end of life. But because they've done it for so many times...they're not thinking that I'm at end of life, they're thinking, oh I don't feel so good, I'm gonna go into the hospital, they're gonna fix me up, and change my meds and I'm gonna come home and be fine again. So it's like, figuring out, when to have that conversation.

#### 4.2.3 Starting with where the client is at

The notion of "find[ing] out how much the client knows" (participant 3) and "start[ing] with where they're at" (participant 1) was key to many of the participants' experiences of providing information. Participant 1 stated:

we try our best to ask them what they understand of their disease and what they know, and what their doctor has told them because even if, they have been told 10, 20 times about what [is] going on, you know, you have to start with where they're at.

Similarly, participant 7 explained that it was important for her to gain an understanding of what her client already knew to determine how to proceed with information provision:

So if we're going in there for the first time, we might be talking to them about just what we as the pain and symptoms management team does, trying to get a layout of what they know...you really just have to question and probe them to see where they're at, so that you can move forward with your teaching. Because if they know nothing, you might not want to talk about a do not resuscitate and



EDITH... You'd want to talk, just about what we're there for, to help try and be a resource to them, and be part of their healthcare team to try and manage their symptoms. In comparison to if they know what's happening, and they're fully aware, sometimes I've just walked right in to asking them, towards the end of the visit, about do not resuscitates and EDITH because sometimes they're just very ready.

Some clients were found to have mistaken beliefs about end of life. Participant 5 indicated that it was crucial to find out about these mistaken beliefs to appropriately address them with the client. For example:

People asking for hydration for their family member at end of life, because dehydrating to death would be a terrible way to die. You know, that's one of those common misbeliefs that we hear a lot, and um, becoming good at fielding that really affects how they view using hydration at end of life. (participant 5)

None of the participants mentioned any fact sheets that could be handed out to clients in the home to dispel these common misbeliefs.

#### 4.2.4 It's very much client-driven

Participants described their experiences of information provision by using phrases such as "what you need from me right here, right now" (participant 5), "it's [on] a need-to-know basis" (participant 1), and "it's very much client-driven" (participant 6).

Participant 1 expressed that her clients were often not seeking out certain information until they were faced with a situation where the information became more relevant. In one example, she explained that despite information being available, she found that her clients were not reading some of the information:

we just tend to find that people don't read it...you know, even if it's there, they're not really...I know that the CCAC, they have a whole booklet about dying at home, and you know, it's there, but they're not really...reading it?...And maybe, I find, if people aren't reading that kind of thing, or doing that kind of stuff, it's because we've maybe given it to them too late? You know, at a certain point, it's very intense for families, like the clients not reading it cuz they're too sick and dying, and the families are just overwhelmed with their caregiving and their all the other more immediate things. (participant 1)

She further explained:

...if they don't need to know it...at that moment, then they aren't seeking out the information. But when they are faced with their, um, their family member dying, and they want to know what it's like at those last hours, then they're more...[they're] more receptive. (participant 1)

Agreeing, participant 7 explained that "sometimes you just need to wait for people to hit that...point in their disease, that they realize that...there's no coming back from this".

Several participants indicated that they took cues from the client in providing information. Participant 7 stated that "you pick up on the openness of the client in determining when to bring up information" or "it might just be whenever it comes up". Participant 1 acknowledged that she still struggled with finding the right timing to deliver the information, and that it would be ideal if there was an opening from the client to talk about the DNR and EDITH. Participant 6 noted that her focus regarding information was different every day for each client, and "usually we don't focus on it, unless the client wants to focus on it".

All participants agreed that they try to provide their clients with all the information their clients want, but some expressed facing barriers to providing some of this information. Participant 8 noted the lack of written resources, such as brochures or pamphlets, to provide to her clients, while participant 1 explained her limitations with physical copies of information: "but for us, limitations are, we are out of our car, and the specificity of some of this information is like, we can't carry the paperwork for all of the different things we might see in a day". In addition, four of the 10 participants noted that although a lot of information is available online or electronically, many of their clients do not have a computer, a smartphone, or the internet-skills to use this online information.

I have a lot of clients who don't have a computer, so suddenly all that information is not available [laughs]. That's definitely a huge challenge, that the elderly do not-, most of them don't have computers. They barely have phones [laughs].  
(participant 8)

### 4.3 Building a relationship with clients

The theme 'building a relationship with clients' refers to how the participants' relationships with their clients influenced their experiences of information provision.

Within this theme, four sub-themes emerged: establishing the relationship first, growing an attachment to your client, I've never met this person before, and some clients like to hear from the physician.

#### 4.3.1 Establishing the relationship first

For some participants in this study, it was important to establish a nurse-client relationship with their clients prior to providing any palliative care information.

Participants used terms such as “rapport” (participant 9), “bond” (participant 8), and “trust” (participants 5, participant 9) to describe their relationship. Participant 9 expressed that building a relationship meant that her client had trust in her as a nurse, and “they believe what we say”. For participant 8, forming a bond enabled her client to talk more openly. Participant 7 explained that due to the nature of the information provided, it was important for her to gain an understanding of her client: “you really need to get to know your clients, and what symptoms are debilitating them...you just, you get to really know them, because it's personal, and very intimate because they're entering the last path of their journey in life”. Participants 1 and 3 stated that they develop a relationship with their client prior to bringing up discussions about a DNR order: “Timing of information also depends on the relationship built with the client. After it is established, I will let the client know about the DNR and ask them about their thoughts and feelings” and “on the first visit, I won't start to talk about a DNR. I'll just try and get to meet them, develop a relationship, and then in subsequent visits, we will bring up the topic of the DNR and other issues”.

One participant in particular stressed the importance of having a nurse that was a “good fit” (participant 6) for the client. Participant 6 explained that if she was not a good fit for a client, she would advocate to get a different nurse in with that client:

I tell them right off the bat, if I'm not a good fit for you, you let me know...I want you to have the best nurse for you, and I may not be it. So if you find that I'm not a good fit, just tell me or just call the office...I want you to be supported as best as you can, and if that means a different nurse, then that's fine...And I know some of the other nurses, so you know their approach is different, so you say we can try this person instead.

### 4.3.2 Growing an attachment to your client

While it was important for participants to develop a relationship with their clients, participants felt that there were difficulties and challenges associated with growing “an attachment” (participant 9). For participant 7, it was difficult for her learn about her client’s goals knowing that they would be unattainable. She explained:

The most challenging part is whether or not you get attached [laughs] to them...if there are goals that they want to attain before they die, that can be really heart wrenching because some of them are unrealistic goals because you know that they’re not gonna live that long, to see their you know, daughter get married or something like that (participant 7)

Some participants expressed that it was harder connecting with certain clients and seeing their own family members in a particular client’s situation. As participant 1 explained:

some clients just get to you more than others. You just see your family members or your friends, or whoever, or yourself in their situation more than other people... You just connect with them more. Um, and if you have to have a difficult conversation about, like, dying, then those conversations are just harder.

Participant 9 shared a similar experience:

I had a patient who passed away in May, and it was the day before she passed away that we completed the EDITH and the do not resuscitate form...She was just not believing that this was the end for her. And she, I don’t know, she just was hopeful that there was something else that could help her...that situation really hit me hard, because the lady was the same age as my mom, and my mom was in the hospital for a bit of time. She’s okay, but, it just kind of hit home. Like that could be my mom going through that situation, right?

Participants expressed that it was difficult to bring up certain conversations with their client when they had been with them for a long time. Participant 9 stated, “sometimes you, just grow an attachment, and it’s hard to keep those professional boundaries, right? Because you get so close to your patients after you see them for so long right?”. Participant 4 recalled the moment when a client she had been with for a while suddenly received a palliative diagnosis:

the ones you've had for three years, four years, that have suddenly become palliative. It's harder to see them go down, when you realize that a year ago, he would walk from Cherryhill, through Costco, all the way back up to Beaverbrook by Farm Boy. And he goes "I get a little winded", and I'm like "I would be winded doing that!" [laughs]. And all the sudden he has a stroke, and now his cancer's in his brain, and it's...you're like "wow, didn't see that coming."

#### 4.3.3 I've never met this person before

A few of the participants in this study provided examples of having to provide palliative care information to a person they had never met before. In particular, participants described having difficulties in providing information when they were not the primary nurse. Participant 2 explained that without knowing a client well enough, it was difficult to meet their informational needs:

If I know the client well, I can readily provide information, but when I am seeing a client for the first time, [am] not the primary nurse, and the client suddenly asks questions, I do not have enough time to go back to see the client's information to be able to answer some of their questions.

In the experiences of participant 8, she explained that she felt "a little awkward" having been suddenly sent out to see a client for another nurse that called in sick or took a vacation. She expressed: "you have to go by the book, and see what's going on, and it's just you're getting thrown right into the middle of something" (participant 8). Participant 8 stressed that she felt it was important for there to be a nurse-client relationship in place prior to having difficult conversations with a client: "Just because they have that extra trusting bond. And it's not as awkward for them, you know". She added: "I really wished that we had just a small team, and that team, you know, that it was made so that they were always working, you know, not so that they [clients] were left with some random person on their day off".

Participant 1 shared that it would make more sense for a family doctor to have end of life discussions with a client since they tend to have had a longer relationship together:

And it is hard because we go out to have these end of life discussions, but frankly, like I've met, I've never met this person before, and I'm having to have this

conversation whereas they've probably seen their family doctor for years and years and years. And so, it really makes more sense to, um, have the family doctors have those conversations. But it doesn't really happen?

She shared her dislike of being told to "go get it [DNR]" (participant 1) from clients she had never met before, rather than being asked to find out about the client's wishes:

so we get put in by the CCAC, and commonly CCAC will send us a note saying go out and get the DNR- like as if it's a task, right?... Not like a bigger conversation about what this person wants... And so my pet peeve is, I just hate that language, like "go get it" ... It should say "go discuss with the client what they want at end of life and let us know". (participant 1)

#### 4.3.4 Some clients like to hear from the physician

Regardless of the relationship and trust developed, some participants found moments where their clients just "like to hear things from a physician" (participant 3). Participants explained that some clients were not open to having discussions about their diagnosis, prognosis, palliative, and end of life care with nurses, and were more accepting of the information if it came from a physician. "When doctors tell them the truth, they are more accepting of the information than from the nurses" (participant 2). Agreeing, participant 9 stated:

Sometimes what happens is, the patient is not really open to listening to what the nurses have to say about palliative care and end of life care... the nurses will call and say "look, you need to have this conversation with this patient because they're not hearing it from us" ... they [clients] tend to want confirmation from their doctor in terms of palliative care and end of life care.

Participant 3 felt that she, as a nurse, did not have the "same kind of authority as a physician". She found that the information she was providing her clients "doesn't carry the same weight" (participant 3) as the information from a physician. She described her experiences as follows:

...they like to hear things from a physician. Like a nurse can tell them something, but if a physician comes in and tells them the exact same thing, then like that is the word. It carries a lot more, I guess confidence, if they hear it from a physician... Where if they hear it from the nurse, it's just like "oh well, the nurse

said this, and the nurse said that, but I'm gonna ask my doctor about that first".

You know, before I take it from the nurse. (participant 3)

Similarly, participant 10 referred to a nurse as being less experienced compared to a physician from a client's point of view. She gave an example of a joint visit with a physician to discuss end-of-life options with a client:

...we had to speak in regards to a DNR or an expected passing in the home, we would have [name of doctor A] come in with us, and we would do a joint visit, as he would be explaining that they were end of life. We would go through what the options were, so that the patient didn't feel that it was come[ing] from the nurse, who is less experienced, right? (participant 10)

#### 4.4 Comfort level talking about death and dying

When asked about how comfortable participants felt having conversations around death and dying with their clients, the majority of participants felt comfortable providing death and dying information. Participant 3 shared:

I don't have any problems talking about death, or DNRs, or setting up EDITH or funeral arrangements...sometimes people will share with you more information than you need to. Like they'll share with you what type of funeral they'd like to have, and where it's going to be, and whether they're going to be cremated, or just what they're going to do. And they share more information than you actually need, but it doesn't bother me to talk about any of that.

Participant 5 also felt comfortable and confident discussing any type of information with her clients because she knew where to reach out to if she needed help. Participant 4 stated: "Well I'm a Christian so I believe in when people pass away, that they're at peace, so I don't have a problem with talking about death".

Some of the participants explained that they had become comfortable gradually. Participant 7 explained that she had become comfortable with the topic as it was something that she has gotten used to doing, and "it's something that I'm doing every day, or most days that I work". Participant 6 had the unique experience of having lived at home with her mother-in-law until she died. This helped her see what her clients and their families were going through, and helped her become comfortable having conversations about death and dying. She explained that when she first started this job, "there were

things where you're kind of going like 'oh my god, what am I doing? And who said I was going to be able to do this for somebody'" (participant 6), however, having been through a similar experience with her mother-in-law "it gives you a better perspective of...you're able to identify a little bit better with what they're [her client and family] going through, and what they're dealing with" (participant 6). Similarly, participant 10 expressed that she is now comfortable in talking about end of life with her clients, but had a tough time when she first started working in palliative care. She stated:

Initially, probably. Like when I first started palliative care, I did. I had a rough-, I had to go in, and it was my first patient, and I had to, you know, bring up the DNR and EDITH, and I had no idea. And I was alone, and I had a really hard time. (participant 10)

Becoming comfortable in discussing death and dying with clients was an ongoing "process" (participant 1) for a number of participants. Participant 1 stated that she was now comfortable in talking about death and dying with her clients, however, still has moments of discomfort:

...it's one of those things where you think you are [comfortable] and then you go in and all of the sudden for whatever reason...they're [clients] asking you these questions, and you're like "ah..." [laugh]. So it always like catches you every so often [laugh].

Agreeing, participant 9 explained that over the past few years, her confidence has grown in approaching these conversations with her clients. She found, however, that every situation is different. She noted that certain factors such as "my rapport with a patient, how long I've been with them...what their diagnosis is, and whether or not they're willing, or open to talking about these topics" (participant 9) influenced how comfortable she felt in bringing up certain information.

Not all participants felt comfortable in approaching topics related to death and dying with their clients. Two of the participants in this study made it very clear that they felt uncomfortable talking about death and dying with their clients, and particularly worried about hurting their clients by bringing it up with them. In the case of participant 2, she explained: "But some like, emotional, very depth [deep] discussion, it's...it's hard, but we try...Because we have to be...very careful what to tell, it might hurt them..."



Participant 2 expressed that her discomfort was something she did not want her clients to see:

Like, I would say like, um...hold my emotion, don't want to show that you know, that it's very uncomfortable...I'm uncomfortable, but I try to talk about it. But it's really like, with the dying people, like talking about their death is like always always challenging.

Similarly, participant 8 shared:

Definitely not comfortable with any of it! Because I care for the client, I don't want to have that talk with them, but you know, it is one of those necessary planning talks. And that's usually kind of how I try and start my conversation, is you know, "I wish I didn't have to have this conversation, but..." [laughs], just in case...definitely just...anxiety a little bit. How to bring it up to them, you know, how to bring it up in a normal conversation and not come off offensive, especially if they're still holding onto hope, you know? It's quite a challenge.

In most of the participants' experiences, previous training in palliative care and having taken palliative care education programs was identified as very helpful. Nine out of 10 participants in this study reported taking either the Comprehensive Advanced Palliative Care Education (CAPCE) program or the Fundamentals of Hospice Palliative Care program, and felt that the education programs were extremely helpful. For example, having taken the CAPCE, participant 1 stated that the program was helpful in teaching her how to communicate the DNR, CPR status, and difficult conversations with her clients. For participant 9, the Fundamentals of Hospice Palliative Care program was helpful as it reiterated the tact in presenting various conversations to clients, but found that much of the program was a repeat of what she learned in nursing school. There were some differences in whether the education programs were a mandatory part of employment for the participants; however, most participants indicated that these programs were only recommended through their respective home care agencies. Participant 10, who had not taken any palliative care education programs, expressed her desire to do so in the future, noting that the education programs "would definitely help me with the conversational part a lot".

In the case of participant 5, her previous training in palliative care had really

helped to prepare her to provide palliative care information to her clients. Participant 5 highlighted her unique experience of learning under a palliative care team through the Health Force Ontario program. She explained how helpful the 400 hours she spent with another palliative care nurse was because it “helps you learn about how to talk to people, how to talk about death and dying, and what are the things people worry about” (participant 5).

## 4.5 Language and cultural barriers

Several participants reported experiencing language and cultural barriers when providing palliative care information to their clients. The participants felt that providing information to their clients was a challenge when their clients did not speak English. For participant 6, she expressed that “sometimes that creates almost a barrier to the rapport that you need to build”.

Many of the participants often relied on the client’s English-speaking family members to translate the information for the client; however, some of the participants felt that there were challenges associated with relying on a family member to translate. Participant 8 noted, “the difficulty is setting up a time with the family to translate when I go in for a visit. There can sometimes be misunderstandings when family is trying to simplify things for the client and relaying the information”. During the interview, participant 5 recalled what she was taught in nursing school regarding language barriers:

...we’re taught in nursing school, um that when there is a language barrier that you’re not supposed to use a family member as an interpreter. Because sometimes things don’t get communicated properly, things aren’t communicated accurately, and sometimes some family members leave something out because they don’t feel that this is something mom needs to know.

Despite this, she explained that she too, often has to rely on a family member or Google translate to translate information for her clients due to the lack of access to an interpreter on her regular visits. Participant 5 explained:

But when we’re in the home, I don’t have access to an interpreter, at any given point. You know, like if we are doing a care conference, so they’ll have the doctor, the nurse practitioner, the care coordinator, nursing. We will bring in an interpreter then. But as far as at my regular visits, I don’t have that. I’m relying

on, you know, google translate, um, I'm relying on a family member. We had one lady, where is she from?... I think she was from Tibet, I want to say, and nobody in the house spoke English except the grandson who was occasionally there. And it was like sign language almost that we were using... (participant 5)

Four of the participants noted having set up an interpreter through the CCAC when there was a language barrier with their client. For participant 5, access to an interpreter was limited to when there was a care conference with her client. In contrast, participant 6 stressed the importance of having an interpreter present at her visits when she was providing information regarding any legal documents, such as the DNR and EDITH. However, she recognized that "you have to be very aware of maybe this person doesn't understand what I'm saying" (participant 6) for the day-to-day communication with her clients. Participants 8 and 10 both stated that interpreters were available through the CCAC whenever needed; however, participant 8 added that it can be a challenge to schedule a visit with an interpreter: "It's hard to get them to get the same time as you though [laughs]... You got to call like the beginning of the morning, and then set it for the afternoon, and that part can be a bit of a challenge".

Cultural differences in beliefs on death and dying was identified as another challenge. Participant 2 recalled that having been an immigrant herself, she did not know about cremation services until having been asked by one of her clients. She further expressed that it was difficult to ensure that she was being sensitive of the various cultural differences, meanwhile trying to have certain conversations such as the DNR and EDITH. She explained:

Some culture, people even don't...like [the] sound [of] the term death or something...we have to be very very sensitive, like diligent about...those people. Um, so it's hard...say you know that she's dying or he's dying, very close, but then family still not ready yet to you know, talk about or do the EDITH, DNR... [I feel] like I cannot help. I don't know what to do, you know? (participant 2)

Similarly, participant 4 explained that it was a challenge to figure out what she could and should not say to her client from different cultural backgrounds:

...figure out what you need to do, what you should not say...may not bring up the DNR the first day because you're gonna go and research [the client's cultural

beliefs on death and dying] ...Certain-, well it's like with the MAID program right? The medically assisted in death. I just found that out, that if you should choose that, it goes "suicide" on your death certificate... Certain cultures you don't even mention that. Because then you're going to hell in a hand basket, right away.

## 4.6 Clients' readiness to accept information

Clients' readiness to accept information significantly impacted participants' ability to provide palliative care information. Participants shared experiences related to denial, and conflicting wishes between clients and their families, leading to various levels of acceptance of palliative care information.

### 4.6.1 Denial

All participants in this study indicated having an experience with a client in denial about their situation and not wanting any palliative care information. Many of the participants recalled experiences of being immediately shut down by their clients when trying to provide them with information: "you go in to have the conversation and they they're like 'no'" (participant 1); "I've had people who say 'no, we're not talking about this at all'" (participant 7). Participants 1 and 3 both described the experience as: "It's kind of like if you talk about it, it's going to happen. But if you ignore it and don't talk about it, it won't happen" (participant 3). Participant 9 described her client's resistance as holding onto hope. She shared:

I had a patient who passed away in May, and it was the day before she passed away that we completed the EDITH and the do not resuscitate form. She was just not believing that this was the end for her. And she, I don't know, she just was hopeful that there was something else that could help her. (participant 9)

Participants explained that it was a challenge when a client was in denial as it often meant the client did not want to hear the information from them. Participant 1 explained:

Sometimes I go in wanting to have a big conversation about where they're at and give them all this information, and they do not want to hear it... they tell you (a) you've been here too long [laugh] cuz it wears them out right? And (b) I don't want to talk about it or hear it. And so that's a challenge sometimes, cuz they need

the information so they can make the decisions about, you know, do you want to stay at home to die, do you want to go to hospice, you know, if you do, we need to sign a DNR.

Similarly, participant 2 expressed that it was a challenge for her when a client was in denial and she could see that the client was declining. Although she had information readily available for her client, the client refused the information and would not talk about it.

Participant 6 noted that some clients were never going to accept that they were dying and would never be receptive to receiving palliative care information. She explained that she could only revisit the information once in a while and could not force it upon her clients. She stated: “You can’t push people into these things. It just doesn’t work. And then sometimes it’s gonna be a coroner’s case because of it. And you have to understand that, and be okay with that” (participant 6). She shared an example of a client who was not receptive to discussing a DNR:

The person is dying. 90 plus years old. Absolutely is the full code. “You are gonna bring me back. I’m gonna go for as long as I can.”. And you want to just bang your head against the wall because you know at the end, they will call 911. Chances are, they’re gonna break her ribs, it’s gonna be a catastrophe for the family...if she survives the ordeal, she will be in a persistent vegetative state, in intensive care, and then they will discuss about pulling the plug. She doesn’t want to be supported with machines. But she’s absolutely a full code, and it doesn’t matter how many ways you say it and put it. (participant 6)

Participants 7 and 8 also noted, “we don’t talk about it” (participant 7) and “I don’t try to push...it’s just something we come back to later” (participant 8).

#### 4.6.2 Differing wishes

All participants also reported having been in a situation where there were conflicts between the wishes of their client and the client’s family. Participants often expressed that it was challenging and difficult to navigate between differing desires for information. “...we definitely deal with, is dysfunctional families that don’t agree and that kind of thing, so if you’re dealing with that then yes. There’s definitely [a] challenge”

(participant 1). Participant 5, in particular, noted the importance of respecting the wishes of both the client and family. She noted, however, that it was difficult to find a balance:

You know, like sometimes what the patient's wishes are, aren't necessarily the wishes of the family members. So, as the nurse for that patient, how do I promote their right to autonomy? And at the same time, not break relationship with their care providers, because recognizing their role is very important too, and their wishes are important as well. Um, and that can be really hard. (participant 5)

In some cases, although family members wanted palliative care information, the client was not receptive to talking to about the information. Participant 3 noted that this was the most frequent case. She explained: "the family's ready to move forward, and the client is 'no, I'm not signing that, I don't want to hear about any of this'" (participant 3). Participant 3 recalled one particular instance:

I even had one client say to his wife, "you come in here and sit down at this table because you're the one who wanted this visit. I did not want this visit". And he was very resistant to me, did not want to talk about anything, did not want to sign the DNR, didn't even want to talk about any end of life thing at all.

Participant 3 expressed that it was difficult when there was a mismatch between the client and family's desire for information.

In other cases, despite the client's acceptance of their situation and readiness for palliative care information, the family was not receptive or ready to hear the information. Participant 2 recalled an experience with one client who was ready to complete the paperwork to die at home, however, her husband and daughter did not want this. She explained that she felt very uncomfortable that her client wanted the information, yet her family did not even want to hear the term palliative. Participant 9 found it difficult to provide information especially when family members who were not ready to hear the information were present in the room. She explained that a client who is comfortable with talking about their condition may not "want to talk about it in front of their son or daughter, because they're not emotionally there" (participant 9). Participants found that there was a relatively equal portion of clients who were more accepting of palliative care information compared to their family, and clients who were in denial.

Participant 4 described an experience of sibling rivalry and being “caught in the middle”. She expressed that differing opinions and arguments were a challenge to being able to provide information to her client:

Sibling rivalry about yes or no. Whether we should tell mom this, or tell dad that, let’s not tell her that. Let’s not tell them that. Well, the other one says yes, let’s tell them that, they need to know. And then you’re kind of caught in the middle. I remember one place, I went “Woah. Everybody stop!” ...they needed to stop arguing, the client was still sitting there. I don’t care if you’ve been doing that your whole entire life, you’re not gonna do it today, at least when I’m here.  
(participant 4)

Sharing a similar experience, participant 5 recalled that it unfortunately took some time before the disagreement was resolved:

...there was kind of a very elderly mother, and she was 103 years old. And two daughters that were involved that had differing opinions on care at end of life...having to navigate the two sisters, who both had joint POA, um, became challenging...you had to be very creative in how you spoke and both of them had very different personalities, so you had to kind of you know, reach both of them where they were at, to let them see “hey, we’re all a team, we’re all on team mom, and we all have a role to play, and let’s keep bringing it back to mom, let’s keep bringing it back to her, what’s she dealing with, how can we make this better” and helping them see, you know, especially the one that didn’t feel that we should be using medications for mom to keep her comfortable. And unfortunately, we had to kind of let it get to the point where she was very uncomfortable, and she finally saw it, so that we can finally begin giving her good care.

## 4.7 Influence of the home environment

Influence of the home environment refers to factors such as the physical environment (living in the community in one’s own home) and the client’s sense of comfort. Two sub-themes emerged within this theme: distractions, and home is the comfort zone.

### 4.7.1 Distractions

Some of the participants in this study expressed that there were certain distractions in the physical environment when providing information to their client.

Sources of distractions included televisions, family members coming and going, and family conflict. For participant 9, the distractions were not something she could not overcome: “Um...it’s nothing that can’t be overcome, but there’s always TVs on, and I try and ask my patients, you know, do you mind if we turn down the tv while we talk for a little bit?”. Other participants found distractions to be a challenge to providing information:

Yeah, there’s always lots of distractions. I find that some clients don’t want to talk about it when their family is around. Um, they’ll say like let’s wait and talk about this later kind of thing. They really don’t want to have that upsetting conversation in front of their family, they want to kind of keep their image? So to speak? So that can be a challenge. (participant 8)

...my patient and her husband had a massive fist fight in front of me. And I had to call the police. (participant 10)

#### 4.7.2 Home is the comfort zone

Several participants felt that their clients were very relaxed and comfortable when the information was provided within their home. Participants described the home as being their client’s “own environment” (participant 1), “familiar environment” (participant 10), and “comfort zone...their safe spot” (participant 6). Participant 9 noted that quite often her clients would more readily ask her questions when they were in the home because they were relaxed and comfortable. Three of the participants felt their clients were better able to absorb the information in their familiar and comfortable home environment. Participant 10 particularly expressed: “it’s a familiar environment for the client, they’re more comfortable, it’s more environment for the caregiver family, they’re there, don’t feel as burnt-out from having to go back and forth to the hospital or have that hospital sense”.

A number of participants revealed that providing information in a client’s home environment also led to some unique challenges. For example, it was not uncommon for clients, not wanting to hear about palliative care, to ask their nurse to leave their home and not come back. Participant 1 expressed: “they’re much more likely to tell you to leave [laughs] cuz you’re in their home, and they don’t want to talk about it”. Similarly, participant 3 explained it as being in “their [her client’s] environment”, and therefore



“they can ask you to leave if they want you to leave and not talk about it”. She recalled an example of when she felt her client was more in control of her visit than she was:

I’ve had an elderly man who was definitely, definitely a difficult case [laughs].

And he basically told me to leave. He did not want to talk about anything. He did not want to talk about end of life, he did not want to talk about dying, and he basically said “okay, you can go now, and you can leave the home and don’t come back.” [laughs]. (participant 3)

## 4.8 Helping your client to a good death

For all the participants in this study, the most rewarding part of their experiences was centered around being able to support their clients in having a “good death” (participant 7). Participants felt they had the ability to help their clients and family all have a better understanding of what was happening and could help them make their own informed decisions about their care. For example, participant 1 explained:

The most rewarding part is being able to empower clients to have more control over a time when they don’t have a lot of control. And being able to tell them something and it eases their mind, they feel they can handle this one thing in front of them because they have the knowledge and understand a bit better what is going on with them.

Agreeing, participants 3 and 4 stated: “I would say hopefully, the most rewarding part is that everybody is on the same page and they all understand what’s going to happen” and “the family is fully aware about what’ going on”.

Some participants noted the most rewarding part of their experience was knowing that they were able to help take away some of the client’s and family’s worries and stress. Participant 5 stated that it was just rewarding knowing that she had the ability to “make a crappy situation a little better”. She explained:

I know that I give good care, I know that I’m a good palliative nurse. And that when you walk in, and you see a family that’s stressed out and feels like they have to figure out everything, and this is so much and so overwhelming, and you sit down and say “hey, hey. I’m here. I’m gonna do this for you. You don’t got to worry about this stuff anymore.” you know? You’ve been going on four-hour sleep at night for the last week and a half. Guess what? We’re gonna bring in care,

we're gonna make sure you sleep through the night. You know, these symptoms that you're seeing that's causing so much stress, we're gonna use medications to bring those down. We're gonna have everything all fixed, like we're gonna make this better. And we do have that ability to make it better...And that when you actually see family members, like, you go to pronounce a death, and they hug you and say "thank you so much. You made this so good". You know, that's the best part of it. (participant 5)

Overall, participants expressed that seeing their client enjoy the end of their life as best they could was a rewarding aspect of their experience.

Definitely the clients. Um, they're just amazing, and you know, making them laugh, and making them enjoy, you know, the last bit of their time you know. (participant 8)

...their comfort. And their acceptance. And you can actually see that they're relieved and they are enjoying the end of their life as best as they possibly can. And that they've passed away, the way they have seen. It's very comfortable, very calming, it's not stressful, very peaceful. And then I know I did a good job. (participant 10)

## 4.9 Conclusion

In conclusion, participants in this study provided an in-depth description of their experiences as home care nurses providing palliative care information to community-dwelling older adults with a terminal illness. Eight key themes emerged from their experiences: importance of support and unity, tools for providing information, building a relationship with clients, comfort level talking about death and dying, language and cultural barriers, clients' readiness to accept information, influence of the home environment, and helping your client to a good death. The implications of these findings are discussed in the following chapter.

## Chapter 5

### 5 Discussion

The purpose of this study was to better understand the lived experiences of home care nurses providing palliative care information to community-dwelling older adults with a terminal illness. This chapter will discuss the central themes and their respective subthemes of this study, in relation to the current literature. The study limitations and directions for future research will also be discussed. Finally, implications for practice will be presented.

#### 5.1 Importance of support and unity

The multi-disciplinary teams in which the participants of this study worked significantly influenced the participants' experiences of information provision. Participants' challenges in providing information to clients often stemmed from challenges with communication involving family physicians, such as not being provided updates on the client, difficulties reaching the doctor, and the most responsible physician not having had a frank discussion with the client. More open communication between healthcare providers is needed to ensure clients receive timely and accurate palliative care information. There are also contextual challenges to consider, particularly when providing palliative care in a community setting. Given the diverse caseloads and different settings in which care is provided by family physicians, it may be understandable that nurses experience greater challenges in communicating with family physicians than they do communicating with specialist community palliative care physicians who see only palliative care clients.

Communication with family physicians and getting support when needed has been reported to be a source of stress for nurses providing palliative care in the community (Wilkes & Beale, 2001). Participants in this study similarly felt frustrated with the lack of communication from family physicians because they often needed further instructions or updates on the client's condition to provide the required information to their clients. The lack of information often led to providing vague information to clients, and the inability to answer clients' questions. Participants noted that family doctors were unlikely to call

participants back right away because of their workload and having to see other clients all day.

On the other hand, participants also found that members of the multi-disciplinary team were a major source of support. Specialist community palliative care physicians and nurse colleagues were often available to provide expertise and consult when participants encountered difficult situations with their clients, and provided support by conducting joint visits. Participants also felt supported by their managers who provided opportunities for them to decompress. In the literature, there have been conflicting findings regarding support for nurses providing palliative care in the community. In the Wilkes and Beale (2001) study, nurses providing in-home palliative care were supported in many ways, including informal support from peers to debrief, formal bi-weekly meetings with colleagues to discuss concerns, and bereavement counselling services. In contrast, in studies by Wallerstedt and Andershed (2007) and Penz and Duggleby (2012), nurses felt poorly supported in providing palliative care. In particular, there was insufficient support from managers in addressing the physical and mental health needs of nurses (Wallerstedt & Andershed, 2007), and a lack of opportunities for nurses to debrief and/or discuss concerns and difficulties (Penz & Duggleby, 2012). This often led to participants feeling that their needs were unimportant. Burt, Shipman, Addington-Hall, and White (2007) found that while there were no formal support services in place for nurses providing palliative care in the community, colleagues often acted as the main source of practical and emotional support for the nurses. Despite the availability of this informal support, nurses felt that additional formal support, such as clinical supervision from specialist palliative care colleagues, would be of immense help in difficult situations. Findings from these studies illustrate the lack of universal formal support for nurses providing palliative care in a community context.

Challenges in balancing palliative care issues with other non-palliative care clients on the caseload were evident in the participants' experiences. Participants often found that there were unpredictable and time-consuming issues that required their attention when visiting their clients. The unpredictable nature of these demands by palliative care clients often complicated planning of caseloads, and left nurses with very little time for other tasks. When unanticipated palliative care issues arose, many of the

participants indicated that they were able to contact their colleagues to see if someone was available to attend to their other clients, and that these colleagues were a great source of support.

When visits with palliative care clients required prolonged involvement, participants often noted having to work longer days to complete the rest of their duties. When colleagues were unable to cover the remaining non-palliative care clients, participants felt rushed during their time with these other clients and felt they were compromising their care needs. Other authors have found similar findings in which nurses were juggling many roles in their day, having to provide care for their generalist caseload as well as palliative care clients (Burt et al., 2008; Wilkes & Beale, 2001). Time was a significant stressor for these nurses. Consistent with the findings of the present study, Burt et al. (2008) found that nurses often prioritized spending time with palliative care clients, therefore spent less time with non-palliative care clients on their caseload, often rushing to provide the care that was needed. At times, nurses were unable to spend the extra time with their palliative care clients, which left them feeling frustrated. Participants in the present study also found it difficult to spend additional time dealing with palliative care issues when they had other time-sensitive clients to see. In these situations, visits with palliative care clients may have been moving at a faster pace than what clients and families may have wanted.

## 5.2 Tools for providing information

Methods used to determine the timing and type of information provided to clients varied across participants. Very few participants indicated that agency guidelines were available, and no strict agency protocols were in place for participants to follow. The lack of agency guidelines or protocols often caused participants to rely on symptom assessment tools, and at times, observation of clients' cues to time and deliver information to their clients. In a study by Reinke, Shannon, Engelberg, Young, and Curtis (2010), nurses caring for clients with life-threatening illnesses reported similar approaches to providing information to meet clients' needs. This study found that nurses often assess what the client already knows about his/her disease or prognosis, and follow the client's lead to determine the client's and family's information needs and desires. Inconsistencies in how the type and timing of information is determined among

participants suggest that clients receive inconsistent palliative care information. Potential consequences of inconsistent information may be that information is provided to clients far too late, and provides limited client choice.

Similar findings related to variations in the availability of care protocols were found in the literature. For example, Brazil et al. (2009) assessed the level of coordination between services in south-central Ontario, Canada to support palliative cancer clients. These researchers found a lack of organization and cohesiveness among service programs in the planning and delivery of supportive cancer care services for persons receiving palliative care. Program administrators and direct care providers, including nurses, indicated a lack of collaboration and coordination among service programs, suggesting inconsistencies in how palliative care clients are cared for across programs. While the program administrators and direct care providers identified a service brokerage agency for service provision (the CCAC), inconsistencies in care for palliative care clients remained. In the present study, participants' experiences suggest that the lack of guidelines affect timing and the type of information that is provided to their clients. Participants seemed to be aware of bits and pieces of various palliative care information; however, because of the lack of guidelines and formal agency information packages including key palliative care information, information provision was largely dependent on the nurses' knowledge and ability to pick up on client needs. Three of the 10 participants, representing two different service provider agencies contracted by the South West CCAC, reported that a formal palliative care package with guidelines was available in their agency. Interestingly, their colleagues (7 participants) equally representing the same two organizations reported their agencies did not have a formal palliative care information package with guidelines. This is consistent with the findings of the 2014 Annual Report of the Office of the Auditor General of Ontario (Office of the Auditor General of Ontario, 2014). It seems information does exist; however, some nurses are not aware of this, thus possibly leading to inconsistencies when providing palliative care information to clients in their homes. Ultimately, it appeared that if a client is lucky enough to get an experienced nurse, he/she will receive good and timely information. Alternatively, if the nurse is new or inexperienced, the provision of timely, quality information is more 'hit or miss'. This has implications for staff education and training.

Additional agency-supported education or a formal peer mentoring program may help support nurses new to the palliative care specialty.

In an analysis of the evolution of hospice palliative care in seven provinces in Canada, Williams et al. (2010) identified that a lack of standardization for service provision in the Canada Health Act has partially resulted in uneven prioritization of palliative care across regions and provinces. Morrison (2017) and Williams et al. (2010) noted that while community-based palliative care organizations such as the Canadian Hospice Palliative Care Association have created national guidelines and recommendations for hospice palliative care, there is yet to be a comprehensive national policy on palliative care in Canada. Lack of standardization may provide room for inconsistencies in information provision across healthcare providers, and a lack of policy provides little guidance for information provision in palliative care. Therefore, standardizing agency guidelines or protocols for information provision, using guidelines for hospice palliative care from the Canadian Hospice Palliative Care Association (2013), may help to improve quality of client care and increase consistency across providers and settings.

### 5.3 Building a relationship with clients

Building a trusting relationship with the client was at the foundation of providing palliative care information according to current study participants. Participants expressed the importance of establishing a relationship with their client to provide timely and helpful information, especially due to the very personal and intimate nature of the information being provided. Participants noted that they were also able to be more open with their clients if a trusting relationship existed. These findings were consistent with the findings of Keall, Clayton, and Butow (2014) and Strang, Henoch, Danielson, Browall, and Melin-Johansson (2014), who found that building a relationship based on trust facilitated effective communication between the nurse and the client, and allowed in-depth conversations concerning spiritual and existential issues. Participants found that in building a relationship with their client, clients came to trust their nurse to talk more openly about their needs.

When participants faced a situation in which they were having to fill in for another nurse on their time off, participants found difficulties in providing palliative care

information because the trusting relationship with the client was not there. There were also concerns regarding continuity of care, with participants feeling that they did not know enough about the clients to answer their questions, and felt awkward having to bring up difficult end-of-life conversations with a client they had never met before. Participants' experiences from the present study support the findings from Luker, Austin, Caress, and Hallett (2000), revealing that a nurse must truly know and understand the client to provide care that meets the unique needs of the individual client. To meet the informational needs of palliative care clients and provide good quality care, continuity of care needs to be considered, and nurses who know the client should be providing the information to him/her.

Participants in this study found themselves occasionally forming special relationships with certain clients. These relationships were described by the participants as an attachment, connection, and closeness with the client, and often prompted difficulties and heart-wrench for nurses in having end-of-life conversations. Wallerstedt and Andershed (2007) found similar findings in their study with nurses caring for dying clients. Their study found that feelings of inadequacy, frustration, sorrow, or loss emerged when a client died, and there was additional burden on the nurse when a relationship with a client ended abruptly. Nurses were at some risk in identifying with the client when they felt deeply moved; special closeness and understanding of a client may contribute to difficulties in letting go, and these nurses were more likely to take their work home with them.

#### 5.4 Comfort level talking about death and dying

Nurses' personal discomfort in death has been found to prevent effective communication between the nurse and client (Tay, Ang, & Hegney, 2012). Nurses' lack of knowledge and skills in addressing topics such as prognosis, existential issues, and end-of-life care were often projected into fear and reduced self-confidence in addressing the client's palliative care needs (Zamanzadeh et al., 2014). Some studies have reported that community nurses have difficulties communicating with dying clients (Dunne et al., 2005; Buckman, 1998; Wilkinson, 1991). Dunne et al. (2005) found that many nurses felt awkward talking to clients who were dying, were uncomfortable with having conversations about death and dying, and consequently hoped that clients did not ask



about death. While two of the participants in this study expressed being uncomfortable talking about death with their clients, the majority of participants in this study felt comfortable discussing death and dying issues with their clients. Interestingly, these findings contrast with the death-denying culture in Western societies (Aries, 197).

While most of the participants had previous training in palliative care, participants noted that they had taken the training programs mostly out of personal interest. The programs were not a mandatory component of employment, but they were, however, recommended through their home care agencies. Many of the participants who were comfortable with discussing death and dying noted that education and training in palliative care, as well as previous experience with death had helped them feel more comfortable talking about death. These findings were consistent with other authors who found that even short courses in death education could reduce death anxiety in nurses, and professional experience and learning from more experienced staff helped nurses feel more comfortable in having end-of-life conversations with their clients (Halliday & Boughton, 2008; Peters et al., 2013; Nia, Lehto, Ebadi, & Peyrovi, 2016; Lange, Thom, & Kline, 2008; Clarke & Ross, 2006). The one participant in this study without any palliative care training noted that she felt uncomfortable with discussions on death and dying, and felt that the training would help her in end-of-life conversations with her clients. This participant noted that she planned to complete some sort of palliative care training program in the near future. The emphasis participants placed on the usefulness of the training programs indicates the benefit of training for all nurses working with palliative care clients.

## 5.5 Language and cultural barriers

In the literature, researchers have found that interactions between nurses and clients were limited and strained when there was a language difference between them (Zamanzadeh et al., 2014; McCarthy, Cassidy, Graham, & Tuohy, 2013; Kai, Beavan, & Faull, 2011; Richardson, Thomas, & Richardson, 2006). For several participants in this study, providing information was a challenge when a client had limited fluency in English. One participant in the study felt that language barriers also created obstacles to building a rapport with her client, which is consistent with the findings of Luker et al. (2000). In Luker et al. (2000), community nurses expressed that ‘getting to know the

patient' was hampered as a result of language barriers, leading to feelings of disempowerment and discontent with the quality of care they are able to provide to the client. In situations where there was a language barrier, many of the participants in this study largely relied on family members to translate information to the client. In having to rely on family, some participants in this study expressed concerns about how accurately the information was being communicated to the client. They recognized the possibility that family members may withhold some of the information, and that information was not being interpreted accurately in family members' attempts to simplify the information for the client. Other authors report similar findings with nurses expressing unease and concerns about relying on family for interpretations (Owens & Randhawa, 2004; Gerrish, Chau, Sobowale, & Birks, 2004; Gerrish, 2001). The study by Gerrish et al. (2004) revealed that, regardless of concerns with reliance on family members for interpretation of information, many nurses may resign themselves to using family members for interpretation due to factors such limited availability of formal interpreters.

Participants indicated that although interpreters were available through the Community Care Access Centre (CCAC), access to interpreters was often limited and difficult to obtain, and therefore they had to rely on family members on most occasions. Availability of interpreters was often limited to care conferences, leaving participants with no support during their regular visits with a client. Similarly, Gerrish (2001) found that despite the availability of interpreting services for nurses in the community, nurses rarely utilized interpreters due to difficult access. Nurses indicated that there was insufficient time to book an interpreter in advance, as the nature of their visits were often unpredictable and urgent. When faced with a lack of human translator available during visits, participants resorted to Google translate, a web-based translation tool. This, however, raises concerns regarding security of private and sensitive medical information, miscommunication, and how accurately medical information is translated using web-based translation tools. Although there are concerns with using web-based translation tools, it may currently be the most accessible and convenient mode of communication when language is a barrier.

The participants also found challenges in providing palliative care information when there were cultural differences in beliefs on death and dying. Participants expressed

difficulty in being sensitive to the various cultural differences and avoiding terms such as ‘death’ and ‘palliative’ while having to discuss do-not-resuscitate orders with the client and family. Cultural differences between the nurse and client were often found to hinder effective nurse-client interactions due to differing perceptions on death and end-of-life care (Aslakson et al., 2012; Helft, Chamness, Terry & Uhrich, 2014; Zheng, Guo, Dong, & Owens, 2015). While participants in the present study did not indicate avoiding conversations related to death and dying because of their client’s culture, one participant shared feelings of helplessness and uncertainty in providing information in a culturally sensitive manner.

## 5.6 Clients’ readiness to accept information

Denial was a common theme among all participants in the present study. All participants reported facing clients who were in denial about prognosis, and that often lead to difficulties in providing the client with timely palliative care information. Participants often experienced resistance to conversation from their clients. In particular, clients resisted conversations related to prognosis and end-of-life, which was difficult for participants as they watched their clients approaching the end of life. Participants noted that palliative care information could not be forced upon clients who did not want the information. This was a challenge for participants as they felt the information was necessary for the clients to make informed decisions about their care. Wilkes & Beale (2001) reported similar findings in their study. The stress of coping with a client’s denial of their prognosis often hindered communication with the client (Tay et al., 2012), leading to less than optimal palliative care (Wilson et al., 2014) and other deleterious consequences for the client and family, including a lack of knowledge and control (Parker et al., 2007; Raftery & Willard, 2010).

Studies with nurses caring for dying clients have commonly reported encounters with incongruent client and family wishes (Griffiths, Ewing, et al., 2015; Wilson et al., 2014; Dunne et al., 2005; Hudson, Aranda, & Kristjanson, 2004). This was true for the participants in the present study as well, where differences in the desire for palliative care information between the client and family members was a common experience. Participants explained that there was a mix of cases where the family was more receptive to palliative care information compared to the client, and the family struggled more to

accept the client's prognosis even though the client was ready to talk about palliative care information. Other times there were conflicting opinions among family members regarding care decisions. Participants expressed that all three situations posed challenges in being able to provide optimal palliative care and end-of-life care.

In palliative care, nurses must be responsive to the needs of both clients and families, which becomes difficult when the client and family members have conflicting needs. Negotiating families struggling to accept the client's prognosis is a common and challenging situation for nurses. In a study by Wilson et al. (2014), it was found that this situation often placed extra demands on the nurses' time and took the focus of care away from the client. Nurses indicated that denial within families led to unwillingness to consider palliative options, and prevented preparation for end-of-life. Similarly, participants found it difficult to navigate between differing desires for information when family members were often unaccepting of the client's prognosis and unreceptive to palliative care information while the client themselves had accepted their prognosis. Participants struggled with finding a balance in respecting the wishes of both the client and family, and often felt discomfort in these situations, which sometimes led to a delay in providing the required palliative care information. Penz and Duggleby (2012) note concerns of negative emotional outcomes for nurses, dealing with ongoing stressors such as complex family dynamics. Other studies have found that the cumulative effects of various stressors, such as difficulty controlling symptoms, being immersed in complex family dynamics, and ensuring adequate support for clients and families are of concern for nurses providing palliative care in the community, leading to increased risk of compassion fatigue and burnout (Abendroth & Flannery, 200; Holland & Neimeyer, 2005; Keidel, 2002).

Truth-telling has been found to be a complex dilemma for many nurses providing palliative care. Nurses often build trusting relationships with family, in which the family may trust that the nurse will not cause harm to the client by disclosing information that the client's life is limited (Brewin & Sparshott, 1996). Nurses, however, may feel they are in breach of their code of conduct by failing to provide information to their clients (Vivian, 2006). Costello (2000) found that nurses often experience discomfort and fear engaging in conversations with their clients when asked to withhold information from

them. Discomfort may lead to feelings of powerlessness, and lead to an uncomfortable relationship with the client (Georges, Grypdonck, Casterle, & Dierckx, 2002). Other authors have found that family members often wanted the nurse to withhold information from the client to protect the client from getting hurt (Griffiths, Ewing, et al., 2015; Wilson et al., 2014; Dunne et al., 2005). Nurses were often faced with the dilemma of making a choice between withholding information at the request of family and the client's right to know. Such dilemma was particularly experienced by community nurses where family members are usually in control of the home environment, and where there may be no opportunity for the nurse within the home to speak with the client in privacy (Luker et al., 2000). Despite wanting to provide clients with information to meet their needs, nurses were afraid of risking being refused access to the home and no longer being able to provide care to the client. Interestingly, most participants in the current study did not share experiences of facing this dilemma. Only one participant shared an experience of being 'caught in the middle' of sibling rivalry related to withholding information from the client. Despite requests to withhold information from the client, the participant shared that she felt it was important to be there for her client, and provide her with the information she desired. When information is withheld, client's acceptance of prognosis may be delayed, leading to reduced client choice, and limited consideration of palliative options and preparation for end-of-life (Wilson et al., 2014).

## 5.7 Influence of the home environment

For some of the participants, the home environment occasionally presented barriers to providing information to a client. Televisions and presence of family members were distractions to providing information for participants in this study, although distractions in the home were generally noted as being minor, and easily overcome. Griffiths, Wilson, Ewing, Connolly, and Grande (2015) reported similar findings in which fairly minor distractions such as televisions were the greatest challenge in the home, with nurses feeling confident in being able to control the home setting. In contrast to these findings, other authors found that certain aspects of the home posed difficulties for nurses, making the home environment sometimes less than ideal for providing information. Television in the background, pets, telephone ringing, presence of family members and young children in the home often made conversations with clients difficult for nurses (Griffiths, Ewing,

et al., 2015; Keall et al., 2014; Wilson et al., 2014). In addition to the lack of privacy with the presence of family members in the home, Griffiths, Ewing, et al. (2015) found that the presence of family members changed the dynamics of interactions where the client became reluctant to speak when family members were present. In this study, only one participant shared similar experiences where her clients became resistant to having conversations in the presence of family. The participant found that it was a challenge to provide information when the client kept delaying their conversations when family was present.

Consistent with the findings of Gott, Seymour, Bellamy, Clark, and Ahmedzai 's (2004) that the home represented a place of familiarity, autonomy, security, and comfort for older adults, participants in this study recognized the significance of the home for their clients. Despite the distractions in the home, several of the participants expressed that the client's home was a supportive environment for them to provide information because clients were comfortable, relaxed, and in control. Participants felt that it helped clients absorb the information provided to them. In other cases, however, some of the participants revealed that because their client was more in control, participants were more likely to be told to leave the home if the client did not want to hear the information. A unique finding of this study was that participants felt they had little control over the environment. They found that providing care in the personal home environment of the client created a unique barrier that, in some cases, impacted their ability to provide information. If a client asked them to leave, they felt they had no choice but to do so. These findings contrast the findings in the Bertero (2002) study which found that nurses providing palliative care in the home described feelings of having control over the caring situation. The feeling of having control over caring situations was necessary for nurses to be able to supervise the care of clients and families (Bertero, 2002).

## 5.8 Helping your clients to a good death

Although the challenges in providing palliative care information were evident in the participants' experiences, the rewarding aspects of their experience contributed to feelings of job satisfaction. Many of the participants in this study were proud of their ability to empower clients and families to make informed decisions about their care, and felt satisfied with their work when they saw that the client and family members all

understood what was going to happen at end-of-life. Ultimately, seeing that the client enjoyed his/her end-of-life and had a smooth transition to a good death helped the participants feel rewarded in their experiences, and continue to work in community palliative care despite the challenges. Similar findings were reported by Penz and Duggleby (2012) in which the rewarding aspects of the community nurses' work, such as feeling valued and respected, helped them deal with the negative impacts of their daily challenges and sustain them in their practice. The positive and rewarding aspects of the participants' experiences may have acted as a buffer against the various challenges participants faced in providing palliative care information, and contributed to their resilience (Penz & Duggleby, 2012).

Of the eight key themes which emerged, four themes appear to pose significantly more barriers to providing palliative care information in a community context. There is a clearly identified need for formal agency guidelines and protocols to guide the timing and type of information provided to ensure consistency across agencies and settings. It appears these guidelines do exist; however, nurses may not be aware of their existence, suggesting a need for agency-supported education and training related to available information. A formal package of information, perhaps divided into three key sections, may be helpful. The first section could consist of all the legal documents requiring signatures, such as the DNR and EDITH; the second section could include a list of all the useful tools for symptom assessment and measuring the progressive decline of palliative care clients; and the third section could include a list of frequently asked questions, fact sheets (myth-busters), and list of available resources. Secondly, access to interpreters needs to be resolved given the common language and cultural barriers identified by study participants. While convenient, using family members to relay information creates additional challenges and potential conflicts, while the use of Google Translate raises issues of accuracy of information and translation related to a highly sensitive topic and vulnerable population. Thirdly, client and family readiness to accept information requires significant consideration. Denial and conflicting client and family wishes were common in this study. Targeted education and training to provide nurses with strategies to deal with this would be helpful. The fourth barrier, a unique contribution of this study, is the challenge of providing care in a client's home environment. While very empowering for

clients, providing care in the personal home of the client leaves the nurses at a disadvantage, especially when they are asked to leave the client's home in the face of denial and family conflict. It is important that service provider agencies work with their nurses to strategize ways of dealing with this issue when it occurs.

Kanter's (1977, 1993) structural empowerment theory, which recognizes the ability to mobilize resources to accomplish goals and opportunities related to work conditions that promote knowledge and skill development, along with Spreitzer's (1995) notion of psychological empowerment seem particularly relevant to helping overcome the barriers to information provision identified in this study. Nurses experience these challenges first hand and, in this study, have identified priority areas for improvement. Numerous opportunities have been identified for nurses to work with their service provider agencies to facilitate positive change in key areas affecting the provision of information. While the culture of organizations, such as the CCAC or service provider agencies, and whether these organizations endorse an empowering work environment to aid in problem identification and resolution was not the focus of this study, it is important that future studies explore organizational culture. It may be that this turns out to be a very important factor impacting the optimal provision of information, and ultimately, uptake of the information by the client.

Numerous other community agencies are investigating how to provide better information to their clients. The Multiple Sclerosis (MS) Society (Hoare, McLeod & Joy, 2016), for example, has explored in detail how providing information can improve the lives of individuals with MS. The MS Society, MS Trust, along with multiple stakeholders used change theory and outcome measurement framework approach to (a) document client/consumer journeys, (b) highlight the role of information in empowering clients and answering questions, and (c) "prioritize key outcomes, and provide practical tools for measuring whether these outcomes are being achieved" (Hoare, McLeod & Joy, 2016). The MS Society 'Information Provision for People with Multiple Sclerosis' framework may provide a useful guide for the development of an information model for palliative care and a good focus for future research.



## 5.9 Limitations of the study

While this study offers insight into the experiences of home care nurses providing palliative care information to community-dwelling older adults with a terminal illness, the findings of this study are limited by several factors. All participants were employed by service provider agencies contracted out by the South West CCAC; therefore, the sample may not be representative of home care nurses employed outside of these agencies. It is important that further research include home care nurses employed by private service provider agencies and other agencies. In addition, despite numerous efforts to recruit participants from all three service provider agencies contracted by the South West CCAC serving the London, Ontario area, the researcher was unable to recruit from one of the three agencies due to major restructuring of the CCACs and LHINs. The current study also did not investigate differences between the two service provider agencies. Further investigation into the differences of home care nurses' experiences employed by these two different services provider agencies may provide a better understanding of agency-specific challenges.

Although race and ethnicity were not a focus for this study, the majority of the participants were Caucasian, and their experiences may not be representative of individuals of other races and cultures. It is important to conduct further research with individuals of other cultures to understand if their experiences are similar to the findings of this study. In addition, there were no male participants in this study and therefore the findings of the current study may be more representative of the female home care nurses' experiences of providing palliative care information to community-dwelling older adults with a terminal illness. Furthermore, participants were either a registered practical nurse or a registered nurse; therefore, findings of this study may not be representative of nurse practitioners. As the current study did not compare the participants' experiences based on type of nursing position, it would be interesting to explore similarities and differences in the experiences between registered practical nurses, registered nurses, and nurse practitioners.

Due to the nature of a hermeneutic phenomenological study, the findings of this study are not intended to be generalizable to all home care nurses providing palliative care information to community-dwelling older adults with a terminal illness. As a

researcher with an interpretivist perspective, I acknowledge the potential for diverse understandings and interpretations of the experiences of the participants in this study.

## 5.10 Implications for practice

The findings of the study offer a number of interesting and unique insights into the home care nurses' experiences of providing palliative care information to older adults with a terminal illness that are useful to consider in future training and support for home care nurses. Firstly, study findings highlight the importance of providing all home care nurses with training in communication with palliative care clients and families, and the information and resources available to them. Training should focus on preparing nurses to feel comfortable and confident in providing information on diverse topics, and provide nurses with the knowledge and skills necessary to provide timely and accurate palliative care information to their clients and families. Secondly, it would be helpful for each service provider agency to have a pool of nurses specifically trained in palliative care to draw from, to act as substitute nurses in situations requiring replacement of regular nurses.

Communication training is necessary for all nurses working with palliative care clients and families. Due to the death-denying culture in Western societies (Aries, 1976), it would be helpful to allow nurses to explore their feelings towards death and caring for the dying, and become comfortable with discussing topics around death and dying with their clients. Although most participants in this study had completed some sort of palliative care training, many of them indicated that training was not a mandatory component of employment. Participants found that palliative care training had helped them become more comfortable in providing information and talking about death, and yet some nurses who work with palliative care clients do not complete any palliative care training. Training in communication of palliative care information should be a priority for all nurses working with palliative care clients and families, and should begin prior to caring for palliative care clients with new nurses. This would ensure that all nurses are well-prepared and comfortable with the information they are providing their clients.

This study highlighted the importance of standardized guidelines for information provision, available for all nurses across service provider agencies. It also highlighted that most participants were unaware of these guidelines. Most participants indicated

having to rely on their own techniques such as observing clients for cues or waiting for an opening from the client to provide palliative care information. Participants often relied on their own abilities to pick up on what their clients needed or desired in terms of information, and the appropriate time to discuss it, resulting in inconsistencies across clients and families. Training related to palliative care information and resources available to nurses, and how to best use these resources is necessary. Guidelines should be used by nurses in addition to cues and guidance from clients and families to support a person-centred approach to information provision.

One of the prominent challenges expressed by participants was suddenly having to be sent out as a substitute nurse for another nurse on their vacation or sick days, to provide information to a client they had never met before. To ensure continuity of care and to continue to meet the informational needs of palliative care clients and families, it is recommended to create a team of nurses specifically trained in palliative care that can fill-in as substitute nurses when needed. If this team had greater access to client information such as background and medical history, with their specialized training in palliative care, these nurses may be able to better meet the informational needs of clients and families when their primary nurse is away. This team may help to prevent the stress of having to repeat the same information to different nurses for clients and families, as well as reduce the burden of regular nurses having to provide information to clients they had never met before.

### 5.11 Directions for future research

The findings of this study offer several avenues for future research. Additional research involving diverse palliative care settings is recommended to gain a better understanding of the home care nurses' experiences of providing palliative care information in older adults' home environments in a community context.

Rural community nurses face different challenges and sources of stress from caring for palliative care clients in the home in comparison to urban community nurses; therefore, it would be beneficial to explore the experiences of home care nurses providing palliative care information in rural and remote communities. Vast distances between clients, lack of financial resources for after-hours services, a sense of isolation being long distances from support, and caring for clients with pre-existing friendships have often

been cited as major stressors by rural community nurses working with palliative care clients in the home (Wilkes & Beale, 2001). Future studies using comparative research methods to investigate how experiences of information provision are similar or different for home care nurses in urban and rural communities are recommended to make recommendations on mechanisms for support of nurses in their respective environments.

With technological developments in video and telephonic interpretation, barriers to interpreting services are more easily overcome in healthcare settings, and offer another interesting avenue of research. Developments in videoconferencing, call centers, and the internet, have allowed resources to be shared across networks of providers and organizations, overcoming barriers to interpreting services (Masland, Lou, & Snowden, 2010). Future research investigating the impact and feasibility of implementing communication technologies is urgently needed to ameliorate challenges with language barriers and access to interpreters.

This study highlighted the unique challenges posed by providing palliative care information in the home. Participants identified issues of control, and lack of control for both clients and nurses. Additional research focusing more closely on the impact of the home environment on the nurses' ability to provide information in the home is needed. It is also recommended that future research explore nurses' sense of control and the power dynamics of the nurse-client relationship in providing palliative care in the home environment.

Consistent with the theory of empowerment (Kanter, 1977, 1993; Spreitzer, 1995), it would be helpful to investigate how nurses experience their role in their work environment and the culture of service provider agencies. This is critical to determine whether empowerment structures exist within these organizations to overcome the barriers identified by nurses in this study, and to maximize the nurses' ability to accomplish their work, in this case, providing palliative care information in a community context.

As the aging population increases and many Canadians prefer to die in their homes, the demand for home-based palliative care will increase. Clients and families require palliative care information to make informed decisions about care, have control over their own health, and end their life with dignity. Nurses work closely with the clients and

families in the home, and have a key role in providing palliative care information that meet the needs of clients and families; however, it is evident that nurses experience certain challenges and barriers to providing palliative care information in the home environment. It is necessary for future research to look closely at the provision of palliative care in a community context. Exploring the context in which nurses provide palliative care information to clients and family in home will help to develop a more comprehensive understanding of their challenges and barriers, and how nurses can be better supported in providing information to clients and families in the home.

## 5.12 Conclusion

Information is a vital component of palliative care for informed decision making and dignity at end-of-life; however, palliative care information is not making it into the hands of individuals and families who need it (Office of the Auditor General of Ontario, 2014). Nurses work closely with clients and families receiving palliative care in the home, and have an important role in providing palliative care information that meet the needs of their clients and families. This hermeneutical phenomenological study provided a better understanding of the home care nurses' experiences of providing palliative care information to community-dwelling older adults with a terminal illness. Participants established trusting relationships with their clients and families, and followed cues from clients and families to provide information that they needed and desired. While participants in this study felt that it was rewarding to be able to help their clients have a good death through the information they provided and found that colleagues were a great source of support in their experiences of providing information, participants faced several challenges and difficulties in providing information clients and families in the home environment. Many participants faced challenges in communication within the multi-disciplinary team they worked in, experienced language and cultural barriers that posed challenges to providing information to clients and families, and met with denial from clients and/or families. Clients and families had more control over the caring situation in the home environment, and participants were more likely to be told to leave the home when the information was unwelcome. Some participants also noted that it was uncomfortable to talk about death and dying with their clients and families. It is hoped that the findings of this study highlight areas in which home care nurses can be better

supported in their experiences of providing palliative care information to community-dwelling older adults with a terminal illness.

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# Appendices

## Appendix A: Ethics Approval Form



### Western University Health Science Research Ethics Board HSREB Delegated Initial Approval Notice

**Principal Investigator:** Dr. Marita Klooseck

**Department & Institution:** Schulich School of Medicine and Dentistry\Geriatric Medicine, Western University

**Review Type:** Delegated

**HSREB File Number:** 108692

**Study Title:** The lived experiences of home care nurses providing palliative care information to community-dwelling older adults with a terminal illness.

**HSREB Initial Approval Date:** February 15, 2017

**HSREB Expiry Date:** August 31, 2017

**Documents Approved and/or Received for Information:**

Document Name	Comments	Version Date
Western University Protocol	Received 2017/01/09	
Letter of Information & Consent	Appendix E	2017/01/04
Advertisement	Appendix D	2017/01/04
Data Collection Form/Case Report Form	Appendix C- Semi-Structured Interview	2016/10/31
Data Collection Form/Case Report Form	Appendix B- Demographic Questionnaire	2016/10/31

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above named study, as of the HSREB Initial Approval Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice Practices (ICH E6 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

\_\_\_\_\_  
Ethics Officer, on behalf of Dr. Joseph Gilbert, HSREB Chair

EO: Erika Basile \_\_\_ Nicole Kaniki  Grace Kelly \_\_\_ Katelyn Harris \_\_\_ Nicola Morphet \_\_\_ Karen Gopaul \_\_\_



## Appendix B: Notice of Recruitment



Health and Rehabilitation Sciences

### **Notice of Recruitment for Home Care Nurses**

You are being invited to participate in a research study conducted by a Master of Science in Health and Rehabilitation student, Katharine Fuchigami, in collaboration with Dr. Marita Kloseck from the University of Western Ontario. The **purpose of the study is to gain a better understanding of the experiences of home care nurses providing palliative care information to community-dwelling older adults with a terminal illness.**

If you agree to participate, you will be asked to complete a **short demographic questionnaire and individual interview**, about 30-60 minutes in length. Interviews will be held at a time and location of your choice and convenience. You will be asked to share your experiences of providing palliative care information to older adults with a terminal illness receiving palliative care at home. The researcher may ask you to meet for a second time if she requires a better understanding of your experience.

**Please feel free to contact Katharine Fuchigami by email at (email) or by telephone at (phone number) , or Dr. Marita Kloseck at (email) if you have any questions about the study. If you are interested in participating in the study, I will send you a letter of information outlining the study in further detail, and you can contact me if you would like to be a participant in the study.**

## Appendix C: Letter of Information and Consent Form



Health and Rehabilitation Sciences

**Project Title:** The lived experiences of home care nurses providing palliative care information to community-dwelling older adults with a terminal illness.

**Principal Investigator:**

Dr. Marita Kloseck, PhD

Address

Phone number

Email

**Co-Investigator:**

Katharine Fuchigami, BSc, MSc Candidate

Address

Phone number

Email

### Letter of Information

#### **Invitation to Participate**

You are being invited to participate in this research study as we hope that you can help us better understand your experiences of providing palliative care information to older-adults with a terminal illness receiving palliative care at home.

#### **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 study.

## **Purpose of this Study**

The purpose of this study is to better understand the experiences of home care nurses in providing palliative care information to community-dwelling older adults with a terminal illness. Nurses work closely with clients and their families, and have an important role to play in identifying and providing information that meet the needs of clients and their families. Nurses can empower clients and families by providing them with the information that meet their needs, therefore it is important to understand the experiences of nurses providing this information.

## **Inclusion Criteria**

To participate, you must be a nurse currently providing palliative care information to community dwelling older adults with a terminal illness receiving home-based palliative care through the South West CCAC. You must also be able to communicate fluently in English to participate in this study.

## **Study Procedures**

If you agree to participate, you will be asked to complete a short demographic survey to provide us with your general background information, and take part in an interview, which will be audio-recorded with your consent to ensure accurate transcription of the interviews. If at any time during the interview you do not want to be audio-recorded, please advise the researcher. It is anticipated that the interview will take about 45 minutes, at a location and time of your choice. The interviews will be conducted by Katharine Fuchigami who will ask you open-ended questions about your day-to-day experiences of providing palliative care information to older adults with a terminal illness receiving palliative care at home. The researcher may ask you to meet for a second time if she requires a better understanding of your experience.

For this study, we will be interviewing a total of 10 participants, nurses that provide palliative care information to community-dwelling older adults with a terminal illness receiving home-based palliative care from the South West Community Care Access Centre.

### **Possible Risks and Harms**

There are no known or anticipated risks or discomforts associated with participating in this study.

### **Possible Benefits**

You may not directly benefit from participating in this study but the information gathered may provide benefits to society which include increased knowledge regarding the experiences of home care nurses in providing palliative care information to older adults with a terminal illness receiving palliative care in the home. In addition, we hope that the information gathered in this study can be used by other researchers, health care providers, or policy makers to improve provision of palliative care information to community-dwelling older adults with a terminal illness receiving palliative care.

### **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.

### **Confidentiality**

All data collected will remain confidential and accessible only to the investigators of this study. Electronic data and audio-recorded interviews will be stored using Western's secure network, and only members of the research team will have access to this information using their unique UWO IDs. Hard copy information will be stored in a locked storing cabinet, in a locked research lab at Western University. Identifying information will not be used in the audio-recorded interviews and will be removed during transcription for anonymity. 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. Electronic and paper data will be kept for 5 years after the study is completed, and then will be shredded and destroyed. Representatives of The University of Western Ontario Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

**Contacts for Further Information**

If you require any further information regarding this research project or your participation in the study you may contact the student researcher Katharine Fuchigami (phone number), (email)

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 (phone number), (email)

**Publication**

If the results of the study are published, your name will not be used. No identifying information will be linked to the data. If you would like to receive a copy of any potential study results, please provide your name and contact number to the student researcher, Katharine Fuchigami, on a piece of paper separate from the Consent Form.

**Consent**

If you are interested in participating in this study, you will be asked to sign the written consent form. You do not waive any legal rights by signing the consent form.

*This letter is yours to keep for future reference.*

**Consent Form**

**Project Title:** The lived experiences of home care nurses providing palliative care information to community-dwelling older adults with a terminal illness.

**Study Investigator's Name:**

Dr. Marita Kloseck, PhD, University of Western Ontario

Katharine Fuchigami, University of Western Ontario

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. (Please check box)

## Appendix D: Demographic Questionnaire



Health and Rehabilitation Sciences

### Demographic Questionnaire

1. Are you:     male         female
  
2. What is the highest level of education you have completed?
  - Below high school
  - High school
  - College diploma
  - University Bachelor's degree
  - University Master's degree
  - University PhD degree
  - Other (please specify: \_\_\_\_\_)
  
3. Are you a:
  - Registered Practical Nurse
  - Registered Nurse
  - Nurse Practitioner
  
4. Do you have specialist training in palliative care?
  - Yes (please specify: \_\_\_\_\_)
  - No

5. How long have you been in general nursing? \_\_\_\_\_year(s).
6. How long have you been in palliative care nursing? \_\_\_\_\_year(s).
7. What is your employment status?
- Full-time (more than 30 hours/week)
- Part-time (less than 30 hours/week)
- Other (contract, casual)
8. How long have you been providing palliative care nursing services through the South West Community Care Access Centre? \_\_\_\_\_.

Participant ID: \_\_\_\_\_.

Date: \_\_\_\_\_.



## Appendix E: Semi-structured Interview Guide



Health and Rehabilitation Sciences

### Interview Guide

“Thank you very much for agreeing to participate in our research study. As you are aware, my goal in this study is to get a better understanding of the lived experiences of home care nurses providing palliative care information to community-dwelling older adults with a terminal illness receiving palliative care. I would like to assure you that your participation in this study is completely voluntary, and you may decline to answer a question or withdraw from the study at any time without any consequences. As described in the Letter of Information, the interview today will be audio-recorded to ensure that I capture your feedback accurately. You may ask for the audio-recorder to be turned off at any time if you would like to share something that you do not want to be recorded.”

“Do you have any questions before we begin the interview?”

**\*\*\*TURN ON THE AUDIO-RECORDER\*\*\***

Today is \_\_\_\_\_ at \_\_\_\_\_ and I will be interviewing participant \_\_\_\_\_.

**Icebreaker to start:** To start, can you please tell me a bit about your role in providing palliative home care? Why is palliative care provided to your clients- generally what illnesses are you providing palliative care for?

1. Can you tell me what your role is in providing palliative care information to your clients?

Probe: -What are you in charge of?

-Are you mainly responsible for providing the information to your clients?

If not, who is?

Next, I would like you tell me about your experiences of providing palliative care information to older adults.

2. First, can you walk me through an example of providing palliative care information to your clients? Try to think back to a particular instance, from the point you walked into your client's home.

Probe: -Who was present at the time you provided the information?

-What kinds of information on palliative care did you provide?

-Did you follow any guidelines to help assess the type of information you provide to your clients? What do these guidelines look like? If not, how did you decide what types of information to provide to your clients?

-In what ways/forms did you provide information? Was it provided in a similar manner as how information is provided to your younger clients?

-Does that work for the older adults receiving this information?

-Was there a certain amount of time set aside for you to provide information to your clients? Can you give me an example of where this time fits into your work schedule?

-How much time do you typically spend on providing information to your clients? Was that enough time to provide the information to your clients?

- How does providing palliative care information to your clients make you feel?

-Do you always feel comfortable/confident/prepared when you provide palliative care information to your clients? If not, can you give me an example of when you didn't feel comfortable?

-Are there any supports for you if you are having difficulties providing information to your clients? If so, what are they?

3. What is it like to provide palliative care information to older adults with a terminal illness?

Probe: -Are there any differences in how you experience providing palliative care information to your older clients, compared to younger clients?

4. The Auditor General report (2014) on palliative care noted that although information on palliative care was available from CCACs, healthcare providers, brochures, etc., the information was not getting into the hands of clients and families. If any, can you describe your experiences of facing barriers in providing palliative care information to your clients?

Probe: -Have you experienced any barriers related to the home environment?  
-What is it like to provide palliative care information in your client's home?

5. What is the most challenging part of providing palliative care information to older adults with a terminal illness? What is the most rewarding part of your experience?

Thank you for taking the time to talk to me today. Is there anything else you would like to share about your experience of providing palliative care information to community-dwelling older adults with a terminal illness? Did I miss anything?

**\*\*\*STOP AUDIO-RECORDER\*\*\***

“Again, thank you very much for your participation in this study.”

## Appendix F: Wholistic Analysis Participant Stories

Participant 001	<p>Registered nurse. Most of her clients have cancer. Age is just a number and her experiences of providing information to older clients depend on the individual. Uses her relationship with her clients to teach and provide information. Finds it important to start by asking her clients what they know, and start with where they are at. Clients absorb more of the information in the home because it is their own environment, but is more likely to tell her to leave their home if they do not want to hear anything. Being comfortable talking about death is a process. Can be difficult when she has connected with her clients. Most challenging when there is a lack of response and communication from family doctors. Finding the right moment to provide some of the information is somewhat still a struggle.</p>
Participant 002	<p>Registered nurse. Majority of her clients have cancer. Provides information on hospice options, options to stay at home, funeral homes, and cremation services. Uses a Palliative Package, observation and the Palliative Performance Scale to determine the types of information to provide to her clients. Can be difficult to find enough time to provide information to her clients. Talking about death and having emotional, in-depth discussions with her clients is challenging and uncomfortable. Other challenges include language barriers, a client and/or family in denial, and cultural differences. Support from supervisor, colleagues specialized in palliative care, and palliative care doctors in challenging situations.</p>

Participant 003	<p>Registered nurse. Many of the clients have cancer, some congestive heart failure, renal failure, COPD, and other chronic illnesses. Assesses the amount of information a client was given by their doctor to determine the types of information to provide to the client. Provides information about DNR and EDITH. Important to constantly reinforce issues and information. Is comfortable to talk about any type of information including death, DNR, and EDITH. Finds that her older clients prefer to hear much of the information from a physician rather than a nurse. Have met with blatant resistance from her older clients to talk about death and dying. Clients have more control of the situation in their home, and will tell her to leave. Most challenging when the most responsible physician has not had a frank discussion about diagnosis and prognosis with a client. Support from clinical lead recourse practice nurse in challenging situations.</p>
Participant 004	<p>Registered practical nurse. Most clients have cancer. Uses observation, takes cues from the client, and asks a lot of questions to determine when and how much information to provide to her clients. Is comfortable to talk about death and dying with her clients. Older clients tend to be more receptive of the information and talking about death. Provides information in pieces because client's get information overload and can handle so much. Will spend more time with clients when providing information, and may feel rushed with her other clients she needs to see. Challenges include cultural differences, seeing long-term clients decline, and family conflict. Support from colleagues experienced with palliative care to come in for a joint visit.</p>

Participant 005	<p>Registered practical nurse. Most clients have cancer, some with ALS, MS, Alzheimer’s disease, dementia, and general aging clients. Information provided is very individualized. Uses observation and asks a lot of questions to her clients to determine the types of information to provide. Builds a relationship with her clients. Feels responsible to assess and provide the client with information about what they can expect as changes happen. Older clients are not wanting much information if they have received a terminal diagnosis. Difficult to provide information to her older clients that live alone. Language barriers are increasing. Challenging when the client’s wishes are not necessarily the wishes of the family members. Biggest challenge to properly assess the client’s ability to take in information, and meeting them where they are at. Support from colleagues, nurse practitioners, and palliative care physicians in challenging situations. Health Force Ontario program helpful in training her to be able to provide information to clients.</p>
Participant 006	<p>Registered practical nurse. Most clients have cancer, some with ALS, advanced senile dementia, Alzheimer’s disease, and pulmonary fibrosis. Role is to reinforce and clarify the information that was provided to her clients by their doctor. Is now comfortable to provide any type of information to her clients. Experiences of providing information is not dependent on the client’s age, but more experience-related. Uses observation and takes cues from the client to provide information that is important for the client. Important to meet clients where they are at, and being aware of where they are coming from. Clients absorb information well in the home, where they are safe and relaxed. Challenges include language barriers, and cultural barriers. Support from her family, managers, and doctors in challenging situations.</p>

Participant 007	<p>Registered nurse. Most clients have cancer, some with COPD, ALS, and general aging clients. Feels it is important to question and probe to get an understanding of what the client knows to determine the timing and types of information to provide. Has a primary role in providing information to her clients as she is their primary contact and sees them most often. There must be a level of trust with the client. Does not feel uncomfortable providing any type of information to her clients now. Older clients are most likely to be receptive of discussing the DNR and EDITH. Can feel rushed depending on what else must be done that day. Most challenging when she gets attached to the client, or sees the client has unattainable goals. Support from her family, managers, and doctors in challenging situations. Sometimes deals with conflict and challenging situations by forgetting about it.</p>
Participant 008	<p>Registered practical nurse. Various clients, some with cancer, pneumonia, chronic ulcers. Provides information about DNR, EDITH, and the services that can be provided to the clients. Most of the information is provided verbally. Wishes she had more pamphlets to provide to her clients. Uses observation to determine the types of information to provide to her clients. Not comfortable. A little bit of anxiety in how to bring up information, and how to not come off offensive. Feels awkward to fill in on another nurse's time off, to be sent out to see a client they have never met. Other challenges include language barriers, and when family members are around. Relies on her relationship with her clients to bring up information. Older clients are at the accepting stage, open to discuss DNR, EDITH, and end of life. Support from other nurses trained and experiences with palliative care, managers, and care coordinators.</p>

Participant 009	<p>Registered nurse. Most clients have cancer, and some with congestive heart failure. Introduces the DNR and EDITH, and provides information on services available to the clients. Sometimes clients are not open to listening to what the nurses have to say about palliative care and end of life care. Often answering questions from clients in the home where they are comfortable. Finds that her clients trust her, they have built a relationship and rapport. Now comfortable at providing information to her clients. Comfort level does depend on rapport with her client, how long she has been with them, and the client's openness to discuss the information. Finds that older clients are more reserved about talking about death and dying. Most challenging when you develop an attachment with the client. Support from care coordinators, clinical practice nurse, and palliative coach.</p>
Participant 010	<p>Registered practical nurse. Majority of clients have cancer, some with COPD, ALS, and end stage liver disease. Uses observation to determine the types of information to provide her clients. Information provided includes the DNR, EDITH, and comfort measures. The home is a supportive environment, and clients feel comfortable in their home. Challenges include language barriers, and different levels of understanding. Some families are not supportive of the client in the home, or get angry about what they have to understand. Sometimes experiences friction working with general practitioners. Some days become longer than planned, and got very taxing. CAPCE program a great asset in preparing her to be able to provide information to her clients. Support from case managers in challenging situations.</p>



### Appendix G: Sample of Selective Analysis

Categories	Codes
Knowing where to turn for support	Managers
	CCAC; care coordinators
	nurses experienced and trained with palliative care
	Palliative doctors
	St. Joseph's Hospice
	Good team
	Nurse practitioners
	Joint visits with palliative physicians and nurse practitioners
	Colleagues
	Other nurses
	Clinical lead resources practice nurse
	Community palliative doctors

### Appendix H: Sample of Emerging Themes

Emerging Themes	Categories	Examples of Codes	Examples of Participant Quotes
Client's readiness to accept information	Denial	<p>Does not want to hear it</p> <p>Will not talk about it</p> <p>Resistance</p> <p>Refusal</p> <p>Not receptive</p> <p>Shut down by client</p> <p>Not ready to accept information</p>	<p>“I’ve had people who say ‘no, we’re not talking about this at all’”</p> <p>“There are always those people, but they tend to just don’t want any, they don’t want to talk about it, they don’t want to like, they don’t face it, that they don’t think about it, that it won’t happen, almost?”</p> <p>“It’s kind of like if you talk about it, it’s going to happen. But if you ignore it and don’t talk about it, it won’t happen.”</p> <p>“Some clients are not receptive of information, and you can't force them”</p> <p>“She was just not believing that this was the end for her. And she, I don’t know, she just was hopeful that there was something else that could help her.”</p> <p>“Sometimes I go in wanting to have a big conversation about where they’re at and give them all this information, and they do not want to hear it.”</p> <p>“they don’t accept that this is the time”</p>
	Differing wishes	<p>Conflict</p> <p>Differing desires for information</p>	<p>“The families understood. The family knew. They were good, they were really great actually, but she was just like in denial the whole time.”</p>

		<p>Dysfunctional families</p> <p>Finding a balance</p> <p>Respecting wishes of the client and family</p> <p>Family is ready to move forward but the client is not</p> <p>Mismatch in desires for information</p> <p>The client is ready to move on, but the family is not</p> <p>Sibling rivalry</p> <p>Differing opinions</p> <p>Arguments</p> <p>Caught in the middle</p> <p>Disagreement</p>	<p>“You know, like sometimes what the patient’s wishes are, aren’t necessarily the wishes of the family members. So, as the nurse for that patient, how do I promote their right to autonomy? And at the same time, not break relationship with their care providers, because recognizing their role is very important too, and their wishes are important as well. Um, and that can be really hard”</p> <p>“I have a client, like, she’s cognitively aware, everything, she wants to do all the paperwork done, everything when she’s able to do...But husband, no. Her son won’t even want to listen like, to hear the term palliative. It’s so challenging”</p> <p>“Yeah, it is difficult. And I’ve had, I’ve had more of the client that doesn’t want the information or doesn’t want to talk about it, and the family that does. The family does, and the family’s ready to move forward, and the client is ‘no, I’m not signing that, I don’t want to hear about any of this’.”</p> <p>“Sibling rivalry about yes or no. Whether we should tell mom this, or tell dad that, let’s not tell her that. Let’s not tell them that. Well, the other one says yes, let’s tell them that, they need to know. And then you’re kind of caught in the middle.”</p>
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# Curriculum Vitae

## **Katharine Fuchigami**

### **EDUCATION**

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Master of Science, Health and Rehabilitation Sciences, Health and Aging  
The University of Western Ontario, London, Ontario  
*2015-present*

Bachelor of Health Sciences (Honors Specialization in Health Sciences)  
The University of Western Ontario, London, Ontario  
2011-2015

### **RELATED WORK EXPERIENCE**

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Teaching Assistant- HS 2711  
The University of Western Ontario  
January 2017-April 2017

Teaching Assistant- HS 2711  
The University of Western Ontario  
January 2016-April 2016

### **PUBLICATIONS**

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Sibalija, J., Ciminsky, M. L., Fuchigami, K., He, M. H., Chen, Y., Trevithick, J., Bickerton, G., & Zecevic, A. (2016). Potential implications of mail delivery conversion on older adults' risk of falls in the winter. *WURJ: Health and Natural Sciences*, 8(1).

### **PRESENTATIONS**

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Fuchigami, K., Kloseck, M., Savundranayagam, M. Y., & Fitzsimmons, D. (2018, February). *The lived experiences of home care nurses providing palliative care information to community-dwelling older adults with a terminal illness*. Poster session presented at the Health and Rehabilitation Sciences Graduate Research Conference. The University of Western Ontario, London, ON.

Fuchigami, K., Kloseck, M., Savundranayagam, M. Y., & Fitzsimmons, D. (2017, May). *The lived experiences of home care nurses providing palliative care information to community-dwelling older adults with a terminal illness*. Oral presentation at the Canadian Association of Gerontology- Student Connection, New Researchers Club. The University of Western Ontario, London, ON. (presentation by Fuchigami).

Sibalija, J., Ciminsky, M. L., Fuchigami, K., He, M. H., Chen, Y., Trevithick, J., Bickerton, G., & Zecevic, A. (2015, April). *How will the conversion to community*

*mailboxes influence seniors' risk of falls in the winter?* Poster session presented at the 34<sup>th</sup> annual conference of the Ontario Gerontology Association, Toronto, ON.

#### **AWARDS AND SCHOLARSHIPS**

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Best Poster Presentation. "The lived experiences of home care nurses providing palliative care information to community-dwelling older adults with a terminal illness". Health and Rehabilitation Sciences Graduate Research Conference. The University of Western Ontario, February 2018.

Western Graduate Research Scholarship- 2015/2016

Western Scholarship of Excellence- 2011