The Lived Palliative Care Experiences of Community-Dwelling Older Adults with Dementia in South Western Ontario

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ABSTRACT

Palliative care is often suggested for individuals with dementia, yet there remains great uncertainty surrounding best delivery of care to individuals wishing to receive this care at home. The aim of this phenomenological study was to understand the experiences of both individuals with dementia who receive palliative care in the community, and their informal family caregivers. Hermeneutic thematic analysis of semi-structured interviews from ten participant dyads revealed key themes. The themes for older adults with dementia were: belonging at home and acceptance of terminal illness. Themes for informal caregivers were: impact of dementia, double strain and home as a source of control over care. Themes across dyads were: honouring wishes, fear of hospitalization and uncertainty. This study provides a better understanding of how community-dwelling older adults and their informal care providers experience palliative care while also managing dementia. Implications for community-based palliative care practice in South-Western Ontario are discussed.

Keywords: aging, community-dwelling, dementia, end-of-life, hermeneutic phenomenology, home-care, palliative care.
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DEDICATION

To my grandmother for continuously giving me just what I need, for reminding me that I am always fiercely protected and loved and for instilling in me the belief that we should always be brave enough to believe. Thank you for the magic.
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1 INTRODUCTION

1.1 Background and Significance

As Canada’s aging population continues to rise, so does the prevalence of dementia. Over 747,000 Canadians are currently living with Alzheimer’s disease and other dementias, and experts believe that number will increase to 1.4 million by 2031 (Alzheimer Society, 2013). Dementia has been defined as an irreversible neurological condition, which causes progressive and irreversible decline of mental capabilities (Mitchell, Kiely, & Hamel, 2004). Dementia often occurs in those age 65 or older (Alzheimer Society, 2013; Mitchell, Kiely, & Hamel, 2004).

Dementia is a terminal illness, but many people with dementia do not necessarily die from this disease. People with dementia often die due to other morbidities that co-exist with the dementia diagnosis, such as cancer and heart disease (MacDonald & Cooper, 2007) or from complications associated with other medical conditions, such as pneumonia acquired because of difficulty swallowing (World Health Organization, 2013). According to the World Health Organization (2013) the median age of survival for an individual with Alzheimer’s disease (the most common form of dementia) is 7.1 years. Persons with dementia typically have high levels of pain towards the end of their lives as they often are unable to communicate the occurrence and severity of their pain to their care providers (Torke et al., 2010). According to Craven and Wald (1975), “what people need most when they are dying is relief from distressing symptoms of disease, the security of a caring environment, sustained expert care, and assurance that they and their families will not be abandoned” (p. 1816).

Health care professionals often suggest a palliative care approach for persons with dementia, which involves focusing on the needs of the dying individual (Sampson, 2010) and spares them burdensome, painful and often futile end-of-life interventions (Munn, 2012). Palliative care has been defined as a non-curative philosophy of care that aims to improve the quality of life of persons and their families with life-threatening illness through the prevention and relief of suffering, and treatment of pain and other symptoms (WHO, 2013). Palliative care can be delivered in a variety of settings, including hospitals, nursing homes, and in the community (the homes of the individual). The palliative care philosophy uses a holistic approach which integrates the physical,
psychosocial and spiritual needs of a person to enhance the quality of life of terminally ill individuals and includes the family, in order to help them cope with the patient’s illness and in their own bereavement (WHO, 2013).

The distinctions between ‘palliative care’ and ‘end-of-life care’ are unclear within Canadian policy literature. For the purpose of this thesis the author uses the term ‘palliative’ care to refer to a broader philosophy of care, with the focus being on maximizing quality of life for the individual with terminal conditions whereas ‘end-of-life’ care focuses on death management. These definitions are consistent with the definitions provided by the World Health Organization (2013) and the Canadian Hospice Palliative Care Association (2006).

Palliative care helps individuals die with dignity (WHO, 2013). Dignity at the end-of-life occurs when individuals are capable of having control over their environment and their care plans (Franklin, Ternestedt, & Nordenfelt, 2006). For the majority of older adults, their preferred place of care is within their homes and communities (Canadian Hospice Palliative Care Association, 2006; Stajduhar & Davies, 2005).

Due to the complex care needs of those with dementia, persons with late-stage dementia are often unable to die in their place of choice (typically their own homes), due to the lack of palliative care supports available for them (MacDonald & Cooper, 2007). Dementia causes cognitive decline, which means that individuals with dementia most often have complex care needs that require special home-care services (MacDonald & Cooper, 2006). A shortage in palliative care resources has created limited access for certain population groups, such as those with dementia, (Freeman, Heckman, Naus, & Marston, 2013). As a result, approximately 70% of deaths in Canada occur in hospital, despite the wishes of individuals (Canadian Hospice Palliative Care Association, 2010; Freeman et al., 2013). While many studies suggest that palliative care is beneficial for persons who have a dementia diagnosis (for example, Murtagh, Preston, & Higginson, 2004; Sampson, 2010; and Sampson, Ritchie, Lai, Raven, & Blanchard, 2005), little is known about how family caregivers and health-care providers deliver person-centered palliative care for community-dwelling older adults who have dementia. To date, much attention has focused on palliative care in long-term care homes, yet very little work has been conducted in the community regarding those with the same condition(s) (Goodman...
et al., 2010). This is not surprising given the difficulty in predicting with accuracy the
time of potential death of an individual with dementia and the very small number of
individuals with dementia who have been able to spend their last years of life in the
community (Sampson, 2010). At present, a comprehensive understanding of community-
based palliative care delivery specific to the unique context of having a diagnosis of
dementia is notably lacking, especially in a Canadian context. What current community-
based palliative care delivery looks like from the perspective of older adults and their
care providers is not well understood.

For the few older adults with dementia able to receive palliative care at home, family
members are often the ones to take on significant caregiver roles (Hudson, Aranda, &
Kristjanson, 2004; Linderholm & Friedrichson, 2010). A Canadian study suggests that
approximately 90% of care to seniors is delivered by informal family caregivers (Smale
& Dupuis, 2004). Thus, supporting family caregivers is critical. Increased attention
should be placed on home care services and ways in which family caregivers can meet
the needs of those they are caring for in the community. Specifically, home-based
palliative care delivery has become an increasingly important area of study (Goodman et
al., 2010).

In conclusion, palliative care aims to relieve the patient's suffering and improve the
quality of living and dying (WHO, 2013). People with terminal conditions, including
dementia, need timely palliative care. The majority of literature on palliative care has
been conducted on people with oncological diagnoses, notwithstanding the fact that
Torke et al. (2010) found that of programs offering palliative care, 94% provided services
to a client with dementia. Given the increasing prevalence of those with dementia,
palliative care for terminally ill individuals with dementia is an extremely important
research area (Roger, 2006). While there has been considerable work done in the USA,
England, and Australia, there is no guidance on how to transfer this knowledge to our
Canadian health care system. There is very limited evidence-based literature which
Canadian governing bodies can use to guide the development of appropriate interventions
or services. Therefore, it is crucial that research is done in a Canadian context to identify
the requirements and current state of palliative care for those with dementia residing in
the community.
1.2 Study Purpose

The purpose of this study is to describe the lived experiences of individuals with dementia who receive palliative care in the community due to other terminal conditions, along with the experiences of their informal caregivers.

1.3 Research Questions

The following research questions had been devised to guide this study: How do community-dwelling individuals with a terminal condition, in addition to dementia, describe their experience of receiving palliative care? How do the participants’ informal caregivers experience providing care to someone with dementia who also requires palliative care?
2 LITERATURE REVIEW

2.1 Community-based Palliative Care Promotion

While initially intended to help individuals die from cancer, modern palliative care now includes a variety of terminal illnesses (Canadian Hospice Palliative Care Association, 2014). The most commonly accepted definition of palliative care comes from the World Health Organization (Canadian Hospice Palliative Care Association, 2006):

… an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual. (WHO, 2011, p.1).

Across Canada, different types of palliative care services are available including community hospices, acute in-hospital palliative care, and long-term palliative care (Hadad, 2008). Figure 1 illustrates the definition of palliative care in more detail.

Canadian evidence supports that most Canadians with a terminal condition would prefer to die in their own home surrounded by their family and family members, yet approximately 70% of Canadian deaths occur in hospital (Canadian Hospice Palliative Care Association, 2006; Stajduhar & Davies, 2005). Older people perceive the presence of friends and family and being at home as crucial for a good death (Gott, Seymour, Bellamy, Clark, & Ahmedzai, 2004). Given the wishes of terminally ill individuals, home-based palliative care has become a significant trend in Canada (Williams et al., 2001). Palliative care is a holistic approach to care that incorporates elements of pain management, psychosocial and spiritual care in order to improve the quality of life of patients and their families facing a life-threatening illness (WHO, 2011).
Figure 1: Palliative Care versus End-of-life Care

Reprinted from The Ottawa Hospital (2014): https://www.ottawahospital.on.ca/wps/portal/Base/TheHospital/ClinicalServices/DeptPgmCS/Programs/CancerProgram/AboutTheCancerProgram/OurProgramsClinics/SupportiveAndPalliativeCare/WhatIsPalliativeCare
Home-based palliative care programs provide interdisciplinary care usually encompassing palliative care physician specialists, nurses, personal support workers, and/or other family physicians (Walshe et al., 2009). Community-based palliative care services provided to people who die with, or of, dementia is associated with significant reductions in hospital emergency department use in the last year of life (Rosenwax, Spilsbury, Arendts, McNamara, & Semmens, 2015). This aligns with the wishes of family caregivers and terminally ill persons (Rosenwax, et al., 2015). The ability for an individual to die at home is dependent on the availability of community resources such as health care providers, informal caregivers, and funding (Canadian Hospice Palliative Care Association, 2006; Stajduhar & Davies, 2005). Only 16% to 30% of Canadians with a terminal illness have access to or receive community-based palliative care services, depending on where in the country they live (Canadian Institute of Health Information, 2007).

Due to the increased demand for palliative care services within the community, governing policy bodies need to ensure that dying individuals and their families have access to community-based palliative care (Matsui, 2010). A United Kingdom national initiative known as the Gold Standards Framework aims to promote quality community palliative care (King, Thomas, Martin, Bell, & Farrell, 2005). The Gold Standards Framework aims to facilitate reliable and high quality community-based palliative care through a set of guidelines, mechanisms and assessment tools aimed at helping health care professionals and other clinicians in the earlier identification of terminally-ill older adults who may need additional support (King et al. 2005). A qualitative study conducted by King et al., (2005) examined the effectiveness of this framework during its first year using nurses’ perspectives. Most participants in the study believed that the Gold Standards Framework had strengthened their ability to deliver community palliative care (King et al., 2005). No follow-up study was found.

2.2 Dementia Care

Dementia is a progressive syndrome that affects an individual’s memory, cognition, communication, swallowing, essential bodily functions and activities of daily living (Rentz, Krikorian, & Keys, 2005; World Health Organization, 2012). There are three broad stages of dementia. These are referred to as the early, middle, and late stages
Many of the dementias are described as being progressive, meaning the individual’s impairments become more severe at each stage of dementia (Mayer, 2001; Cohen-Mansfield, 1996). In the early stages of dementia individuals experience forgetfulness, slight difficulty concentrating, and difficulty finding the right words (Reisberg, Ferris, de Leon, & Crook, 1982). The middle stages of dementia are marked by a difficulty concentrating, decreased memory of recent events, difficulty socializing and a greater need of assistance to complete their daily activities (DeLeon & Reisberg, 1999; Reisberg et al., 1982). In the late stages of dementia, individuals with the condition require extensive assistance to carry out daily activities and have little memory of recent events (DeLeon & Reisberg, 1999; Reisberg et al., 1982). Personality changes, such as delusions (believing something to be true that is not), anxiety and/or agitation may occur (DeLeon & Reisberg, 1999). Eventually, individuals in this stage lose their psychomotor skills and ability to communicate DeLeon & Reisberg, 1999; Reisberg et al., 1982)

Despite being incurable, dementia has only recently received recognition for being a terminal illness (Albinsson & Strang, 2002; Blasi, Hurley, & Volicer, 2002; Torke et al., 2010). The disease trajectory of dementia is an unpredictable process (Sachs, Shega, & Cox-Hayley, 2004; Xie, Brayne, & Matthews, 2008). The end-stage of the illness varies depending on the individual and can last for as short as three years (Boersma et al., 1999; Lee & Chodosh, 2009) and as long as nine years (Klinkenberg et al., 2005; Lee & Chodosh, 2009; Volicer, Hurley, & Blasi, 2003). An individual with dementia is more likely to die from pneumonia, cardiac disease, or cerebrovascular disease than the dementia itself (Gambassi et al., 1999). People with advanced stages of dementia are also more likely to develop apraxia, dysphagia, and decreased mobile functioning that increase the risk of infection, malnutrition and other possibly fatal outcomes (Alzheimer’s Society, 2014; Barry, Parsons, Passmore, & Hughes, 2014; Cohen-Mansfield & Creedon, 2002). Health care professionals and family caregivers find it difficult to detect when someone with dementia is approaching the end-of-life (Aminoff, & Adunsky, 2005; Connolly, Sampson, & Purandare, 2012; Evans, & Goodman, 2009). This is due to the gradual loss of cognitive and physical functioning an individual with dementia experiences, coupled with a protracted disease course which includes other chronic conditions (Connolly, Sampson, & Purandare, 2012; Evans, & Goodman, 2009).
Persons in the later stages of dementia often require complete assistance with their activities of daily living, have difficulties communicating their needs and may even be mostly bedridden (Aaltonen et al., 2014; Cordner, Blass, Rabins, & Black, 2010). As such, many individuals with later-stage dementia live in long-term care (Arcand et al., 2009). Numerous studies suggest that care homes are ill-equipped to provide optimal end-of-life care for those with dementia. For example, Ryan and colleagues (2012) found that residents with dementia in long-term care facilities receive very little care interventions at the early stages of their illnesses but are given aggressive treatments towards the end of their lives. Some of these interventions include cardiopulmonary resuscitation (CPR), feeding tubes, and intravenous antibiotics (McCarthy, Addington-Hall, & Altmann, 1997). Such interventions have been found to increase pain and suffering in those with advanced dementia (McCarthy, Addington-Hall, & Altmann, 1997). These interventions are often the default action of healthcare practitioners (McCarthy & Volicer, 2009; Meeussen et al., 2012).

Older adults with dementia wishing to die at home have been found to have greater levels of pain than their nursing home counterparts (Mitchell, Morris, Park, & Fries, 2004). Shega and colleagues (2004; 2006) came to similar conclusions: persons with dementia living in the community were at greater risk of untreated pain than persons without dementia. Those with advanced dementia being cared for at home had less functional disability, more behavioural problems, and more feeding tubes at their end-of-life than those residing in nursing homes (Mitchell et al., 2004; 2009; Kuhn & Forrest, 2012; Livingston et al., 2012).

Studies have found that those with advanced dementia were less likely to have advanced care directives limiting such aggressive interventions, in comparison to those with other chronic conditions (Gandy, Roe, McClelland, & Ashton, 2011; Gessert, Forbes, & Bern-Klug, 2001). An advance directive is a legal document by which an individual records his/her wishes for future health care decisions in the event that he/she becomes unable to make those decisions (Dresser, 2001). Advance directives exist primarily to protect patients’ rights to refuse medical interventions at the end-of-life and may request a palliative philosophy to care (Winzelberg, Hanson, & Tulsky, 2005). The majority of individuals with dementia who do have an advanced care plan in place do not
have directions for care that limit aggressive interventions (Triplett et al., 2008). Typically, prompts for discussions for end-of-life care for individuals with dementia only occur after particular medical events that required aggressive interventions or changes to financial status (Hirschman, Kapo, & Karlawish, 2008). A 2008 study by Sloan and colleagues found no correlation between measures of pain and advanced care planning for those dying with dementia within long-term care. The lack of advanced directives does not address the issue of inadequate quality of life at the end-of-life for those with dementia (Dening, Jones, & Sampson, 2011).

In the absence of advanced directives family members are often called to make the end-of-life care decisions (Gessert, Forbers, & Bern-Klug, 2000). Family members agree to more aggressive care for persons with dementia significantly more often than cognitively intact older adults (Robinson et al., 2005). In a qualitative study conducted by Caron, Griffith and Arcand (2005), the researchers found mixed results regarding the quality of care family members felt their family members with advanced dementia received while residing in long-term care. Some family members believed that the care was adequate, whereas others found the care to be poor (Caron, Griffith, & Arcand, 2005). The majority of family caregivers receive little information on the anticipated course of their family member’s illness or indicators of distress to help them better care for their terminally ill family member (Cain, MacLean, & Sellick, 2004; King et al., 2005). Due to insufficient information about dementia and poor communication with health care practitioners, families feel ill-equipped to make end-of-life care decisions for persons with advanced dementia (Ahroheim et al., 2000; Campbell, & Guzman, 2004; Godwin, & Walters, 2009; Thuné-Boyle et al., 2010). Researchers have argued that if family caregivers understood the clinical course of dementia and had realistic expectations about the outcome of interventions, they would be less likely to advocate for aggressive care measures (Peacock, 2013; Rurup et al., 2006a, b).

2.3 Dementia Care in the Community: Impact on Family Caregiver

Many older persons with advanced dementia receive their end-of-life care in long-term care homes, but a large majority remain in the community with home care services and family caregivers providing care (Davies et al., 2014; Forbes, Bern-Klug, & Gessert, 2000). This reflects the wishes of many older adults who prefer to stay at home near the
end-of-life (Abelson, Gold, Woodward, O’Connor, & Hutchinson, 2004; Canadian Hospice Palliative Care Association, 2006). When persons with chronic conditions choose to receive care at home, family members take on a significant role in caregiving (Clemmer, Ward-Griffin, & Forbes, 2008). Indeed, caregivers play a critical role in all stages of caring for someone with dementia (Rabins, 1998).

The care requirements of elderly individuals with end-stage dementia can be particularly challenging for informal caregivers (Lawrence, Samsi, Murray, Harrai, & Banerjee, 2011). Caregivers of individuals with dementia have been found to experience higher levels of caregiver burden (Steadman, Tremont, & Davis, 2007) and suffer from more negative health outcomes than those caring for cancer patients (Clipp, & George, 1993) and non-dementia caregivers (Pinquart, & Sorensen, 2004).

Very little is known about the caregiver burden experiences of caregivers of individuals with dementia in Ontario (Smale & Dupuis, 2004). Caregiver burden refers to the stressors of caregiving (Etters, Goodall, & Harrison, 2008). Objective caregiver burden relates to the burden associated with the tasks required to care for the client (Jones,1996). Subjective caregiver burden relates to the extent to which the caregiver cares about performing these tasks (Jones,1996). Behavioural disturbances, impairments related to activities of daily living, and cognitive decline have been found to increase the objective burden of caregivers of individuals with dementia (Hughes et al., 2014; Savundranayagam, Montgomery, & Kosloski, 2011; Wolfs et al., 2011). Behavioural disturbances from persons with dementia are the most prominent predictive factors of subjective caregiver burden for carers to persons with dementia (Etters, Goodall, & Harrison, 2008). Studies have found that dementia-related behavioural problems, such as aggression, have a greater impact on objective and subjective burden than cognitive or functional impairment (Dunkin, & Anderson-Hanley, 1998). Objective burden increases with the increasing severity of dementia (Etters, Goodall, & Harrison, 2008; Hughes et al., 2014; Wolfs et al., 2011). Some literature reports that familial relationship ties are also associated with increased objective and subjective burden (Annerstedt, Elmstähl, Ingvad & Samuelsson, 2000; Etters, Goodall, & Harrison, 2008; Torti, Gwyther, Reed, Friedman, & Schulman, 2004). Annerstedt and colleagues (2000) found that closer kinship to the care receiver imposes a greater burden on family caregivers. Wolfs et al.
(2011) found that the relationship between the care recipient and the caregiver, gender of the caregiver, and the comorbidity of the care recipient are not predictive of objective burden.

Caregivers of individuals with dementia tend to report their health to be worse than non-caregivers (Andren, & Elmståhl, 2008; Baumgarten et al., 1992, Etters, Goodall, & Harrison, 2008). Many caregivers’ physical and mental health declines after beginning to provide care, and those caring for persons with dementia are at a significantly greater risk of morbidity (Acton, 2002). Vetter et al. (1999) found that caregivers of those with vascular dementia experience a greater burden at the start of their disease, whereas caregivers of persons with Alzheimer’s disease experience greater burden at the later stages. Other studies suggest that caregivers of persons with early onset of dementia also experience high levels of caregiver burden (Baldwin, 1994; Dunkin, & Anderson-Hanley, 1998; Razani et al., 2007). Hatada et al. (1999) suggest that caregiver burden may be greater for caregivers at the early stages of their family member’s disease as they are “not psychologically ready” for caring for an individual with dementia (p. 125). The unpredictability of dementia increases frustration and anxiety for caregivers (Beach, 1994). An increased stress burden for caregivers, such as anxiety, was found to be directly related to lower self-rated health (Savundranayagam, Montgomery, & Kosloski, 2011). Caregiver burden often increases over time for persons providing care at home (Winslow, & Carter, 1999). As caregivers learn to adapt to their caregiving demands, the burden may decrease (Almberg, Grafström, & Winblad, 1997). Increases in burden, however, often leads individuals to place their relatives with dementia in an institution (Hope, Keene, Gedling, Fairburn, & Jacoby, 1998; Potter, 1993; Savundranayagam, Montgomery, & Kosloski, 2011; Pruchno, Michaels, & Postashnik, 1997). Caregiver burden can continue even after the caregiver places his/her family member in a long-term care facility (Riddick, Cohen-Mansfield, Fleschner, & Kraft, 1992; Smale & Dupuis, 2004; Tornatore, & Grant, 2002; Winslow, & Carter, 1999). This can be explained by the concept of caregiver vigilance which refers to the continual oversight caregivers have over their care recipients’ activities, even when not with them (Mahoney et al., 2003).

In comparison to caregivers of individuals without dementia, caregivers for persons with dementia experienced a greater emotional burden (Birkel, 1987; Leinonen,
Korpisammal, Pulkkinen, & Pukuri, 2001). The communication difficulties and problem behaviours of dementia care recipients have been reported to increase emotional burden for caregivers (Fried, Bradley, O’Leary, & Byers, 2005; Kim, Chang, Rose, & Kim, 2012; Savundranayagam, Hummert, & Montgomery, 2005). The process of watching a relative gradually deteriorate is also one of the most painful experiences for family caregivers (Dupuis, 2002; Kim et al., 2012). This often leads to a phenomenon known as ambiguous loss\(^1\) where family caregivers experience great emotional distress and grief over their family member not being mentally or emotionally present in the same way as before (Dupuis, 2002).

A handful of studies have also explored the experience of grief and other spiritual needs as they relate to caregiving for a community-dwelling individual with dementia at the end-of-life. Results from such studies highlight how the deeply personal relationship to the care receiver and inadequate social supports influence the experience of grief for family caregivers (Peacock, 2013; Walshe et al., 2009). To support family caregivers with their bereavement, scholars have suggested implementing interventions early on in the caregiving journey as a means to lessen grief after the death of a family member (Sachs et al., 2004; Peacock, 2013). For example, Shega and Cox-Hayley (2004) share that family caregivers can benefit greatly from the assistance and support a social worker or local Alzheimer’s Society can provide. Nevertheless, the benefit of providing care for a relative at home was found to exceed the issues related to grief (Lecouturier, Jacoby, Bradshaw, Lovel, & Eccles, 1999). It is important to note that the majority of studies that focused on the psychosocial and spiritual needs of terminally ill older adults residing in the community and their informal caregivers were based upon conclusions drawn from qualitative evidence, heavily influenced by researchers’ assumptions about the end-of-life

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\(^1\) Ambiguous loss is defined as a type of loss and grief that occurs while an individual with dementia is still physically present. People with dementia may experience feelings of loss over their diagnosis and mourn as their own abilities gradually change. Caregivers to persons with dementia grieve the progressive losses in the life of the person with dementia and mourn the relationship that they had with the person with dementia prior to his/her diagnosis (Dupuis, 2002).
experiences. This is problematic as it may not reflect the experiences of community-
dwelling terminally ill older adults and their informal family caregivers.

Caregivers for persons with dementia tend to withdraw from social engagement
opportunities and have limited social connections with peers (Meshefedjian, McCusker,
Bellavance, & Baumgarten, 1998; Johnson, & Troll, 1994). Due to social isolation,
caregivers to persons with dementia are more likely to report requiring more emotional
support from health care professionals in comparison to individuals with other illnesses
(Franks et al., 2000; Straw et al., 1999). Cain, MacLean and Sellick (2004) found that
health care providers typically focus their attention on the client, leaving the informal
caregiver with little support. Family caregivers of those with dementia residing in the
community found ‘family-centered’ care to be lacking (Clemmer et al., 2008) and often
feel exploited by the health care system (Luker, Austin, Caress, & Hallet, 2000;
Stajduhar, 2003). Caregivers’ unmet needs for emotional support are correlated with an
increase subjective and objective caregiver burden (Hughes et al., 2014). More social
support has been found to result in less depressive symptomology for caregivers of
individuals with dementia and lower perceived caregiver burden than those with less
support (Baumgarten et al., 1992; Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000).

Hughes et al., (2014) reason that targeted intervention programs that incorporate
emotional support for caregivers of individuals with dementia are required. For example,
support group attendance helps those caregivers to receive emotional support and acquire
effective coping skills (Kaye, & Applegate, 1993). Educational interventions are also
effective in providing caregivers with skills needed to manage the behavioural problems
of persons with dementia (Buckwalter et al., 1999; Chang, 1999) which may decrease the
depressive symptoms of caregivers (Buckwalter et al., 1999). Respite services may help
lower emotional stress and improve the caregiver-care receiver relationship
(Dziegielewski, & Ricks, 2000). Respite refers to a caregiver’s temporary rest
from caregiving duties. Zarit et al., (1998) found that caregivers using respite programs
report feelings over worry and strain.

Most of the literature on caregiver burden focuses on the emotional impacts of
caregivers of individuals with dementia (Etters, Goodall, & Harrison, 2008; Smale &
Dupuis, 2004; Pinquart, & Sörensen, 2007), but a few studies have explored the physical
effects of caregivers. Dementia-related behaviors such as aggression and agitation have been found to create more physical stress on caregivers (Hope et al., 1998). Caregivers to those with dementia are at an increased risk for developing hyperlipidemia, hyperglycemia (Davies 1996; Matsumoto et al., 2007; Papastavrou et al., 2007) and a compromised cellular immune system (Canfield, 2002; Davies 1996; Kiecolt-Glaser et al. 1995; Mills et al. 2004, Thomson et al. 2004). Increased rates of respiratory illness, elevated blood pressure and slower wound healing is associated with impaired immune function (King, Oka, & Young, 1994). Caregivers of individuals with dementia are less likely to engage in health-promoting behaviours and self-care, such as exercise, than non-caregivers (Fuller-Jonap, & Haley, 1995; Gallant, & Connell, 1997). Caregiver burden has also been related to decreased caregiver employment rates and increased financial strain that can lead to poverty risks for women (Aneshensel et al., 1995; Wakabayashi, & Donato, 2006). A declining economic well-being has been found to be correlated to poorer physical health (Wakabayashi, & Donato, 2006). The physical health effects may persist even after the death of the person with dementia (Winslow, & Carter, 1999).

The caregiver burden faced by caregivers of individuals with dementia naturally affects the health of the care recipient (Gainey, & Payne, 2006). Highly-stressed caregivers have been found to provide lower quality of care to their care recipients (Gainey, & Payne, 2006). Furthermore, a longitudinal study found that persons with dementia living with highly-stressed caregivers had more behavioural problems, agitation and a more rapid disease progression (Vitaliano, Young, Russo, Romano, & Magana-Amato, 1993).

2.4 Palliative Care for Dementia in the Community

Given the inadequate support many older adults with dementia and their family caregivers receive towards the end of the older adults’ lives, many scholars are now recommending a palliative care approach. Palliative care provides patients with relief from physical pain, as well as assistance with their psychosocial and spiritual needs, with the overall goal of improving quality of life for both the patient and the family caregivers (Jones et al., 2016; Luchins, & Hanarahan 1993; Rexach, 2012). The majority of physicians, gerontologists, and family caregivers of persons with dementia recommended care using a palliative care philosophy (Luchins, & Hanrahan, 1993). A palliative care
philosophy of care aims to improve the quality of life for terminally-ill patients and their families through the treatment of pain and other problems, and addressing the physical, psychosocial and spiritual needs of the individuals (WHO, 2012). Involvement of persons with a terminal condition, including dementia, in palliative care is said to benefit both patients and their families (Jones et al., 2016; Volicer, 1998). Only a few studies measured the efficacy of palliative care for persons with dementia. The evidence suggests a palliative care approach for persons with dementia is favoured by formal and informal carers of those with dementia (Casey 2010; Gnaedinger et al., 2008; Jordan, 2010). A systematic review by Brown, Sampson, Jones and Barron (2012) concluded that there is a lack of agreement about which prognostic indicators should be used when choosing the time to deliver palliative care for persons with dementia. Palliative care offers a better quality of life than continued medical interventions delivered as per usual curative care plans (Brown et al., 2012; Jones et al., 2016; Roger, 2006; Shega et al., 2004; van der Steen et al., 2014; Volicer, 1998).

Persons with dementia must be placed at the center of care for palliative care to be successful (Jones et al., 2016). Care providers must be educated on providing care that is unique to the needs of each individual patient (Jones et al., 2016). Given the difficulties of interviewing participants with dementia, little is known about the wishes and needs of the elderly individuals with dementia themselves. A preliminary 2004 study conducted by Shega and collaborators suggests that patients with dementia do find a palliative approach to care most desirable as illustrated by high rates of satisfaction when a palliative care approach was adopted.

Palliative care is extremely beneficial for helping those with dementia maximize their quality of life up until death (van der Steen et al., 2014). Palliative care can help those with dementia maintain some of their function and maximize their comfort (van der Steen et al., 2014). Given its focus on the individual needs of the dying person, palliative care for persons equates to person-centered dementia care (Regan, Tapley, & Jolley, 2014; Roger, 2006). The majority of the research within the field of palliative care has been conducted with participants with cancer. Patients dying with dementia have been found to have comparable needs to those of cancer patients (McCarthy, Addington-Hall, & Altman, 1997; Miller, Lima, Looze, & Mitchell, 2012). However, unlike those with
cancer, the unpredictable disease trajectory of dementia makes it difficult for healthcare professionals and families to know when palliative care is most appropriate (Dening, Greenish, Jones, Mandal, & Sampson, 2012; Evers, Purohit, Perl, Khan, & Marin, 2002; Goodman, Amador, Elmore, Machen, & Mathie, 2013). This unpredictable disease trajectory makes it difficult for caregivers to care for individuals with dementia (Harrison-Dening, Greenish Jones Mandal, & Sampson, 2012). The majority of those with dementia do not receive palliative care (Abelson et al., 2004; Gove et al., 2010). Individuals with dementia are no less deserving of palliative care than those with more predictable disease trajectories such as cancer (Bekelman et al., 2005; Schonwetter, Han, Small, Martin, Tope, & Haley, 2003).

Advocates of palliative care for patients with dementia believe that palliative care should begin right at diagnosis, with changes made to the care plan as the disease progresses and aggressive medical interventions become more and more futile (Cain, MacLean, & Sellick, 2004; Ouldred, & Bryant, 2008; Raymond, Warner, Davies, Iliffe, Manthorpe, & Ahmedzhai, 2014). Abelson et al., (2004) suggests that further research is needed to determine how much information patients with dementia would like to be given regarding their prognosis. Other researchers suggest that it is reasonable to assume that patients with dementia would be similar to those with cancer with respect to prognosis disclosure (Birtch & Draper, 2008). Knowledge of their prognosis would allow those with dementia to opt for a palliative philosophy of care sooner. In doing so, a palliative care approach would allow patients and their caregivers to establish goals of care that change with the progression of their diseases (Stajudhar, 2003; van der Steen et al., 2011; 2012). In a cross-sectional study conducted in the USA, Engel et al. (2006) found that time devoted to discussing future goals of care was associated with greater satisfaction with care for people with advanced dementia. It has been argued that establishing goals to align with one’s stage of dementia helps support the dignity of the individual and helps to control for pain (Raymond et al., 2014; Rexach, 2012; Sampson et al., 2005). Doing so also addresses the various psychosocial and spiritual needs that may arise throughout the disease trajectory (Raymond, et al., 2014; Rexach, 2012; Sampson et al., 2005).
As illustrated by van der Steen et al., (2013) in Figure 2 below, palliative care health care professionals must consider changing the care goals and priorities throughout the different stages of the disease. The goals of palliative care, including improving quality of life, maintaining function, and maximizing comfort can be considered appropriate for patients with dementia throughout their disease trajectory (van der Steen et al., 2013). Similarly, bereavement support, another goal of palliative care, must also be offered to individuals’ families following their loved one’s passing (van der Steen et al., 2013).
Figure 2: Dementia Progression Prioritization of Goals

A randomized control study by Ahronheim et al. (2000) suggests that a palliative care approach is often not practiced for individuals with dementia residing in long-term care. Long-term care staff have little knowledge about palliative care in relation to dementia (Ryan et al., 2012; Sanders, & Swails, 2009; Turjumaa, Hartikainen, Kangasniemi, & Pietila, 2014; Suh, Kil Yeon, Shah, & Lee, 2005). A study in the UK found that palliative care specialists and other chronic disease health practitioners reported gaps, needing more communication between various disciplines to better provide palliative care for individuals with dementia (Johnson et al., 2009). Staff are willing to be educated about improving palliative care for those with dementia residing in long-term care homes (Hirakawa et al., 2006). The current lack of knowledge and guidelines for palliative care for persons with dementia have been found to lead to disorganized care (Davies et al., 2014). The current practices of some long-term care homes aim to prolong life rather than improve the quality of life of individuals (Hennings, Froggatt, & Keady, 2010; Kenny, Hall, Zapart, & Davis, 2010). With no agreed-upon standard to care for the treatment of late-stage dementia, clinicians within long-term care homes face ethical and health policy dilemmas. Health policies urge physicians to provide aggressive medical interventions to extend an individual’s life (Volicer, 1998). In a study conducted in the Netherlands, researchers found that the intention to hasten death was evident in 53% of the cases, and that the action would hasten death was considered in 41% of cases involving people in nursing homes who had antibiotics withheld from them (van der Steen et al., 2005). This view that death is constrained by medical values and practices controlled by physicians is known as the medicalization of death (Connelly, 1998). With the medicalization of death in long-term care, even individuals with palliative care plans, have been found to die undignified deaths (Birtch & Draper, 2008).

2.4.1 Pain Management

Of all the components of palliative care, pain management appears to be the largest priority within dementia and palliative care research. Pain is common for people with advanced dementia (Barry et al., 2014; Davies et al., 2014). A palliative approach to home care for those with a terminal illness including dementia would make the controlling of pain and symptom management a priority (Walke, Gallo, Tinetti, & Fried,
2004; Volicer, 1998). It is difficult to assess symptoms of pain in people with dementia because of cognitive, functional and communicative issues that arise (Ahronheim et al., 2000, Aminoff, & Adunsky; 2006; Sachs et al., 2004). Unmanaged pain only causes additional suffering for terminally ill individuals with dementia (Aminoff, & Adunsky; 2006; Sachs et al., 2004). Currently, pain is often measured by self-reporting (Sampson et al., 2005) which is problematic for those with dementia. Research on the assessment of pain for people with end stage dementia is limited, particularly in home-care settings, and has focused on the ability of caregivers to predict patient pain (Shega et al., 2004; 2008). Knowledge and skills on dementia are believed to help caregivers manage pain (McCarty, & Volicer, 2009; Regan, Tapley, & Jolley, 2014). The majority of family caregivers have been found to receive little information on the anticipated course of their family member’s illness or indicators of distress to help them better care for their terminally ill family member (Cain, MacLean, & Sellick, 2004; King et al., 2005). Mitchell et al. (2004) found that older adults with dementia choosing to die at home had greater levels of pain than their nursing home counterparts. Findings from Shega and colleagues (2004; 2006) concluded that persons with dementia living in the community were at greater risk of untreated pain than persons without dementia. On the other hand, those with advanced dementia being cared for at home had less functional disability, more behavioural problems and more feeding tubes at their end-of-life than those residing in nursing homes (Mitchell et al., 2004; 2009; Kuhn & Forrest, 2012; Livingston et al., 2012). Honest discussions between health care professionals and family caregivers on pain the patient could be feeling can help caregivers address pain in those who are uncommunicative (Caron, Griffith, & Arcand, 2005).

Specialist interdisciplinary teams are necessary for community palliative care services to be delivered effectively (Abelson et al., 2004). Specialist care for people with terminal conditions have existed within Canadian home care for some time and it is believed that such care can be applied to those with dementia (Canadian Hospice Palliative Care Association, 2006; Abelson et al., 2004; Hurley, Volicer, & Blasi, 2000). Ahronheim et al. (2000) found that a palliative care research team was unable to influence the care of advanced dementia patients in the acute hospital setting. In another study, caregivers reported higher satisfaction with palliative care services when health care teams
addressed issues of patient comfort by avoiding the use of tube feeding and giving care in a specialized dementia care unit (Engel et al., 2006).

When compared to usual care, patients with dementia have been found to experience less discomfort when receiving palliative care in the community (Volicer, 1998). Community palliative care providers for persons with dementia may limit ‘curative’ medical interventions that inflict pain, such as tube feeding and cardiopulmonary resuscitation—both of which have been found to provide equivocal benefits (Jordan, 2010). Engel et al. (2006) found that the absence of tube feeding was associated with increased satisfaction with care for older people with advanced dementia. Evidence suggests that in forgoing such treatments, death is not hastened but quality of life is improved (Hughes, 2010). A palliative approach to care for people with dementia not only prevents patients from receiving unbeneficial medical treatments, but also can save the health care system valuable medical resources (Davies, Maio, Rait & Llife, 2014; Volicer, 1998).

The aforementioned evidence supporting palliative care for persons with dementia to alleviate symptoms of pain could apply to various health care settings. A study conducted by Volicer et al. (2003) provides evidence that palliative care pain management is most effective in the home. Volicer et al. (2003) conducted a retrospective study to consider the characteristics of palliative care in different settings for patients with dementia. The study concluded that when a terminally ill individual with dementia was cared for at home during their last 90 days of life, they experienced fewer symptoms of pain than those cared for in institutions. The study did not provide detailed explanations as to why pain was lessened at home. It is important to keep such studies in mind when considering the most appropriate place in which to provide palliative care (Birch & Draper, 2008).

2.4.2 Psychosocial Needs

It is sometimes believed that people with dementia only need their physical needs addressed due to their communication difficulties (Hughes, 2010). The psychological and social needs of people with dementia must not be forgotten. Palliative care fosters a holistic philosophy of care, which considers the psychological and social needs of people with dementia and their families. For people caring for those with dementia, the largest perceived psychosocial need is maintaining patient dignity (Gove et al., 2010; van der
Steen, 2010; 2011). The term ‘dignity’ was not clearly defined within the literature. Dignity is commonly used in connection with the dying process, in reference to ‘dying with dignity’. It is widely accepted that to die with dignity means to control the dying process (Gove et al., 2010; van der Steen et al., 2011). Enabling terminally ill older adults who remain at home is another way of affirming the person’s autonomy (Sampson, 2010). Palliative care is said to enable patients to be involved in decision-making more so than traditional care (Roger, 2006). Palliative care supports human dignity by continuously assessing the needs and wishes of the ill individual and their families (Sampson et al., 2005; Volicer, 1998).

Dementia diminishes the decisional capabilities of individuals so advance directives are often used for individuals to indicate their wishes for palliative care. The Alzheimer Society of Canada (2013) supports advance directives as a means for people with diagnosed dementia to exercise their right to determine their care. Scholars have found that for advanced directives to be suitable for palliative care decision-making, they must be done early on in the diagnosis while those with dementia still have their cognitive capacity intact enough to express their wishes (Gandy et al., 2011; Gessert et al., 2001). Barriers to effective communication about end-of-life issues are significant (Johnson et al., 2009; Shega et al., 2008) and are challenged by the context of dementia (Birch, & Draper, 2008). The majority of advanced directives for people with dementia do not request that palliative care be delivered in the community (Birtch & Draper, 2008). For those without advanced directives, palliative care still continues to support dying with dignity by often limiting the use of psychoactive medications and physical restraints, which are often used to treat those with dementia who become violent (Jordan, 2010; Mayer, 2001). It has been argued that the use of psychoactive medications and physical restraints reduces patients’ autonomy (Sampson et al., 2005; Sampson, Burns, & Richards, 2011).

Allowing palliative care to be delivered in one’s home supports the dignity of elders with dementia and addresses their social needs and helps to foster dignity and autonomy throughout the dying process. Despite the wishes of patients, many palliative care clients with dementia currently die in institutions (Jordan, 2010). Numerous studies suggest that some care homes are ill-equipped to provide optimal end-of-life care for those with
dementia (Klinkenberg et al., 2005; McCarthy, Addington-Hall, & Altmann, 1997; McCarthy & Volicer, 2009; Meeussen et al., 2012; Regan, Tapley, & Jolley, 2014; Ryan et al., 2012). For example, Ryan and colleagues (2012) found that persons with dementia residing in long-term care homes receive very little care interventions at the early stages of their illnesses but are given aggressive treatments towards the end of their lives. Some of these interventions include cardiopulmonary resuscitation (CPR), feeding tubes, and intravenous antibiotics, which ultimately have been found to only increase pain and suffering in those with advanced dementia (McCarthy, Addington-Hall, & Altmann, 1997). In instances where the palliative care philosophy is not being used, these interventions are often the default action of healthcare practitioners (McCarthy & Volicer, 2009; Meeussen et al., 2012).

The thought of a loved one passing away in an institutionalized setting and not in one’s home is associated with added anxiety about death for family caregivers (Klinkenberg et al., 2005; Regan, Tapley, & Jolley, 2014). Hughes (2010) argues that if people with dementia have discussed their preference for place of death earlier on in their diagnosis, it is likely that they will die in that place. Researchers are urging for the creation of policies aimed at increasing opportunities for care at home (Williams et al., 2001). Proponents of community palliative care for persons with dementia believe that giving individuals the choice about where health care is delivered is central to respecting an individual’s psychological needs and overall autonomy (Abelson et al., 2004).

A preliminary study by Shega et al. (2004) described how community palliative care was helpful for managing pain in those with terminal illnesses and for allowing patients to die at their place of choice. Allowing those with dementia to retain some control over where they die, can help enhance their quality of life. Despite the noted psychosocial benefits that follow from offering palliative care to be delivered in the community, no study acknowledged the challenges that this may cause or how such care should be delivered. Studies that argued for community-based palliative care delivery failed to address issues related to the family's ability to cope, safety and health considerations, and the availability of regulated health care professionals to provide support in homes (Goodman et al., 2010; Shega et al., 2004). Further studies are needed to support the
development of palliative care in the community for persons with dementia (Robinson et al., 2005).

As the increase in prevalence of life-threatening illnesses and push towards home care has happened in Canada, informal caregiving has gained a significant amount of attention in recent research on palliative care (Clemmer et al., 2008; Stajduhar, 2003). The intention palliative care philosophy is to care for the needs of family caregivers. Caregiving for terminally ill individuals has a profound and lasting effect on caregivers (Stajduhar, 2003). Albinsson and Strang (2002) noted that when a person is dying with dementia, the needs of informal caregivers differ from those of other conditions.

Numerous studies have reported on the consequences of the psychological stress that results from caring for palliative patients in the community (Lecouturier et al., 1999; Stajduhar, 2003). Diwan, Hougham and Sachs (2004) posit that successful palliative care programs must also provide services to family caregivers that encourage access to community resources that meet their psychological and social needs. Researchers found that caregivers have a desire for more information and overall support from health care professionals (Davies et al., 2014; Godwin & Waters, 2009; Livingston et al., 2012).

A mixed methods study by Williams and colleagues (2001), evaluating home-based palliative care in Ontario found that current non-profit agencies delivering palliative care in communities were better able to meet client satisfaction in terms “needs other than physical” (p.29). Studies conducted in long-term care have shown that informal caregivers are often not identified as rightful recipients of care (Cain et al., 2004; Lecouturier, et al., 1999). The majority of health professionals choose to prioritize the dying patient’s psychosocial needs versus their caregivers’ needs due to the limited length and frequency of visits (Oudshoorn, Ward-Griffin, & McWilliam, 2007). Community-based palliative care can support the psychosocial needs of caregivers.

In advocating for community-based palliative care, it is important to consider the results of an ethnographic study conducted by Stajduhar (2003). This study found that despite informal caregivers reporting caring for their terminally ill family member in the home to be favourable, the transition of palliative care services from hospital to home left many informal caregivers to feeling exploited by the health care system (Stajduhar, 2003). According to Cain, MacLean, and Sellick (2004) the psychological needs of
informal caregivers is crucial for health care providers and policy makers to consider given that psychological strain is the leading reason for the use of formal care services. Community-based palliative care has the potential to support the psychosocial needs of caregivers, but some caregivers have felt that the current provision of care does not adequately meet their needs (Kenny et al., 2010; Lecouturier et al., 1999; Oudshoorn et al., 2007). For instance, caregivers often do not have a familiar home support worker that they trust (Stajduhar, 2003). Family caregivers have reported feeling exploited or pressured to keep their family member home as a result of community health care reforms (Stajduhar, 2003). The current approach to home care in Canada causes pressures on nurses to limit their time with clients and thus, may limit the amount of care provided to informal caregivers (Oudshoorn, Ward-Griffin, & McWilliams, 2007). Luker et al. (2000) theorize that high-quality palliative care can only be developed once a health care provider knows the extent of the needs of their patients and his/her family. The researchers believe that community palliative care delivery must give nurses the appropriate amount of time to know their clients and their family and aim to provide more than the physical aspects of care (Luker et al., 2000). A model theorizing how to best support the psychosocial needs of family caregivers to terminally ill individuals has not been established. More studies are needed to test effective ways to support the psychological and social needs of caregiver (and terminally ill individuals) within community palliative care services.

2.4.3 Spiritual Needs

The limited literature on the spiritual palliative care needs of palliative care clients with dementia focuses almost exclusively on family caregivers. The diagnosis of terminal illness has been found to prompt feelings of loss in the patient themselves and their family caregivers (Roger, 2006). A literature review by Davies, Maio, Rait, and Llife (2014) found that many family caregivers were not able to think about the death and dying process of their relative with dementia. In a Delphi study by van der Steen et al. (2014), the authors recommended that spiritual care be implemented into any successful community-based palliative care program if requested by the client or caregiver, especially in terms of bereavement. In spite of this, a focus on the spiritual needs of families and patients with dementia facing a terminal illness has been poorly researched.
Caregivers of those with dementia need support in facing the prospect of death, prior to the death of their family member (Albinsson & Strang, 2002). The findings from various studies examining caregiver experiences with caring for a family member at end-of-life in the home showed that informal caregivers are faced with the burden of inadequate support regarding their feelings on death, fear, and isolation (Albinsson & Strang, 2002; Diwan et al., 2004). A cross-sectional study by Kenny and colleagues (2010) concluded that health care providers caring for palliative clients in the home need to be aware of the vulnerable position of caregivers in order to best support their overall needs. van der Steen et al. (2014) suggest that support resources in caregiving for persons with dementia should include the involvement of sources that support spiritual well-being at times of fear and loss. A palliative approach to dementia care would support their spiritual needs by allowing family members to access bereavement supports that differ from bereavement following cancer (Albinsson & Strang, 2002; 2003). People with dementia and their caregivers have been thought to benefit from such spiritual support (van der Steen et al., 2014). An approach to quality end-of-life care for those with dementia must go beyond the biomedical model to support spiritual care (Small, Froggatt, & Downs, 2007). No study explicitly examined the process of bereavement experiences by family caregivers of persons with dementia, using the palliative care philosophy. Some believe that palliative care would best support the spiritual needs of patients and caregivers (Davies, Maio, Rait, & Llife, 2014; Roger, 2006). The lack of research focusing specifically on the spiritual needs of community-dwelling palliative care clients and their family members represents an important gap in the current literature.

2.5 The Control Theory of Aging

Upholding a person’s wellbeing and dignity is at the core of the palliative care literature. A common theme among this literature is the lack of control held at the end-of-life by terminally ill patients and their families (Redding, 2000). Theorist Schulz (2006) posits that a perceived sense of personal control is a critical determinant of an older adult’s physical and psychological wellbeing. Believing that one is in control over his/her own life is understood to be the most important defense against experiences of distress (Mirowsky & Ross, 1986). The mere belief that one has control over undesirable or uncontrollable events is said to lessen the negative consequences of the event (Redding,
Circumstances that deprive people of control in their lives, such as an incurable illness, increases a sense of distress (Mirowsky & Ross, 1986; Redding, 2000).

Having a sense of control is vital to coping with the uncertainty of a disease (Burgess, 1994; Redding, 2000). Caruso-Herman (1989) identified that a loss of control is the primary concern of dying persons. Scholars believe one of the most stressful development events in an individual’s life is when they are faced with a terminal illness (Paton, 1996). Individuals make an effort to regain control as a reaction to the loss of control that comes from a terminal illness (Burgess, 1994). The palliative care philosophy creates opportunities to address individuals’ wishes and help them maintain a sense of control. This aligns with the Institute of Medicine (1997)’s definition of a dignified death, which is one that reflects an individual’s wishes. According to Hunt (1994), prior to the acceptance of palliative care, terminal care failed to address individual choice and control. As Hunt (1994) stated, the palliative care model “stressed the importance of patients being involved in decisions about their quality of life” (p.131). Achieving a sense of control has been identified as one of the five domains of quality end-of-life care as proposed by Singer, Martin, and Kelner (1999).

Mesler (1995) states that the principle of increasing patient control at the end-of-life highlights the concept of autonomy in medicine. Respect for the ethical principle of autonomy is thus a special concern for the control theory of aging. Efforts to reform decision-making for terminally ill individuals has largely focused on promoting patient autonomy to control treatment decisions (Winzelberg et al., 2005). In its dominant understanding in Western Societies, autonomy refers to freedom from external restraint and the ability to make decisions about his/her own preferences, values, beliefs and choices (Schulz, 2006).

Respecting the autonomy of patients is a large ethical concern in diseases like dementia, where cognition and decision making are compromised (Schulz, 2006). Under the theory of control, caregivers and health care professionals should address dying individuals’ preferences for care as they are now (if they have the cognitive capacity to express such wishes) or the way their wishes were expressed in the past (such as those mentioned in advance directives) (Dresser, 2001; Schulz, 2006). There is the underlying assumption that all health care professions ought to respect the autonomy of their
patients. There is also the assumption that individuals should make decisions about their health care for as long as possible. The traditional definition of autonomy does not incorporate effects on families (Winzelberg et al., 2005). Studies have indicated that individuals consider the potential effect of their health care decisions not only on themselves but also on their family members (Winzelberg et al., 2005). This indicates that health care decisions may not always reflect the exact wishes of the individual. Autonomy in older age is a complex challenge that involves more than acknowledging the rights of a person at specific time in their lives and urges for autonomous decision making across the life span (Schulz, 2006).

Autonomy and the upholding of patient choice are emphasized as essential components of palliative care delivery models world-wide (Lau & O’connor, 2012). The World Health Organization report on palliative care affirms that “however complex a person’s problems or uncertain their future may be, autonomy is a key human right and maintaining this must be a core ethical value” (Davies & Higginson, 2004, p. 18). Redding (2000) argues that the only person who can inform health care professionals regarding what they need and want at the end-of-life is the dying patient. Patients should be at the core of all palliative care research and practice, to best ensure that suggestions for care delivery support their autonomous wishes.

2.6 Conclusions and Guidelines for Future Practice and Research

While there is much literature conducted on palliative care, there is a lack of literature related to community-based palliative care for individuals with dementia. This can be because the majority of deaths in Canada occur in hospital (Canadian Hospice Palliative Care Association, 2010; Freeman et al., 2013). As a systematic review by Sampson et al. (2006) demonstrated, the general information available within this field is ambiguous regarding the efficacy of a palliative model of care in dementia (p.31). Despite significant gaps in the literature, the importance of providing appropriate palliative care to address individuals with dementia and conducting research in this area were reinforced by all of the included studies. It is only through future research in this area that improvements with regard to the potential to increase the quality of life for terminally ill patients suffering from dementia can be made (Birkh & Draper, 2008). Palliative care for persons with dementia is a relatively new and emerging field within the greater body of policy and
research. Studies focusing on palliative care for persons with dementia in home care settings have been relatively neglected. The care of those who are terminally ill and choosing to die in their own home has received little attention, especially when considering the research on patients without cancer. There is an opportunity to use what is currently known about palliative care and community-based care as a starting point for future studies.

Further studies, particularly ones with rigorous methods and strong evidence, are needed to help service providers ensure that palliative care for community-dwelling individuals with dementia is appropriate to meet this population’s unique needs. It has been suggested that qualitative research would be helpful for understanding the experiences of palliative care in home-based settings for those with dementia (Goodman et al., 2010). Terminally ill individuals and their family caregivers themselves must be the sources of information to fully understand the experiences of care at the end-of-life (Godwin & Waters, 2009). Further research in this area will help guide improvements for palliative care for those with dementia choosing to die at home, which has the potential to increase their quality of life and reduce the use of non-beneficial medical resources. Above all, future research will help terminally ill individuals with dementia die at their place of choice with a dignified death.

2.7 Study Rationale and Objectives

Much work remains to be done in the area of community-based palliative care for older adults with dementia (Goodman et al., 2010). This study presents a phenomenological study of the lived palliative care experiences of community-dwelling older adults with dementia and their informal caregivers. While types of dementia include Alzheimer’s disease, vascular dementia, frontotemporal dementia and other kinds (WHO, 2012), the term ‘dementia’ will be used throughout this thesis to encompass all different disease types and forms of early-stage dementia. This study focused on individuals with early-stage dementia as the majority of individuals at this stage are still able to communicate well. The purpose of this study is to enhance understanding of the experiences of this group of individuals. This understanding is needed to help advance the quality of care within the community-based healthcare system. This study aims to describe the experiences of individuals with dementia who receive palliative care in the
community and the experiences of their informal family caregivers. As older adults’ voices are infrequently heard within the literature on community-based health care, this work will complement the work of others done on end-of-life care for people with dementia (for example, Hughes, 2005; Volicer, 2013, van der Steen et al., 2013).

This study may result in a better understanding of how older adults and their care teams are managing multiple chronic conditions coexisting with dementia within the community. Understanding common experiences can help to guide future research on interventions, policy changes and future best practices.

2.8 The Present Study

2.8.1 Study Purpose

The purpose of this study is to describe the lived experiences of individuals with dementia who receive palliative care in the community due to other terminal conditions, along with the experiences of their informal caregivers.

2.8.2 Research Questions

The following research questions had been devised to guide this study: How do community-dwelling individuals with a terminal condition, in addition to dementia, describe their experience of receiving palliative care? How do the participants’ informal care providers experience providing care to someone with dementia who also requires palliative care?
3 METHODOLOGY

A qualitative research design guided by a hermeneutic phenomenology methodology was employed in this study to examine the lived palliative care experiences of older adults with dementia and their family caregivers. Below is a brief overview of phenomenology as both a philosophical method of understanding phenomena and as a research methodology. A rationale for this methodology is also provided. The study design, method of analyzing data, credibility of the study and the different measures of quality criteria employed throughout the study are discussed.

3.1 Phenomenology

Phenomenology, as a philosophical approach of understanding phenomena, was formally introduced by Edmund Husserl at the start of the twentieth-century (Dowling, 2007). Husserl rooted this philosophical thought deep in the works of other philosophers such as Kant and Hegel, with the desire to convert philosophy into a science (Guignon, 2006). Through Husserl’s (1931) work, came about the first branch of phenomenology known as phenomenological reductionism or descriptive (eidetic) phenomenology. For Husserl, converting a philosophy into a science meant directing attention towards the meanings of experiences (Guignon, 2006). The scientific investigation of uncovering meaning is only considered valid when the information has been gathered through rich descriptions of experience, allowing for an understanding of the essence of the experience (Moustakas, 1994). According to Dowling (2007), this method of phenomenology aims to understand lived experiences exactly as they appear without the researcher’s preconceived notions, biases, or interpretations. This detachment from the observer or researcher’s prior knowledge of the phenomenon is known as bracketing (Carpenter, 2007; Wilding & Whiteford, 2005).

Martin Heidegger, a former pupil of Husserl’s, extended on the concept of phenomenology as a method. Unlike Husserl, Heidegger focused on the ontological interpretation of the meaning of lived experiences (Dowling, 2007). Heidegger (1962) posited that human beings should not be viewed as objects, but rather as persons whose actions and understandings form a comprehensive set of self. Heidegger’s early thoughts became what is known as existential phenomenology or interpretive (hermeneutic) phenomenology (Dowling, 2007). For Heidegger, phenomenology requires extending the
study of the lived experience from simply describing phenomena to understanding it via an interpretative process (Dowling, 2007). Heidegger (1962) argued that because human beings actively participate in their understanding of the world, individuals cannot bracket their understandings and interpretations of experiences, as proposed by Husserl (Downling, 2007; Flood, 2010). Heidegger (1962) believed that researchers are unable to put aside their own beliefs about the phenomenon under investigation and throughout the phenomenological exploration.

Hans-Georg Gadamer, a student of Heidegger, further advanced interpretive (hermeneutic) phenomenology as a method, by extending Heidegger’s work into more practical applications (Gadamer, 2004; Polkinghorne, 1983; 1989). Gadamer believed that since interpretation is an always evolving process, a definitive interpretation of a lived experience is likely to never occur (Annells, 1996a; Gadamer, 2004). However, Gadamer (2004) introduced two important elements into phenomenological methodology: prejudgment and universality (Dowling, 2007). Prejudgment encourages the researcher to be aware of his/her own prior knowledge of the experience, and use this as an aid in interpreting the data (Dowling, 2007; Gadamer, 2004). Conversely, the concept of universality holds that the meanings of the lived experience are understood through a joint collaboration between the researcher and participants from where a co-construction of interpretation is derived (Dowling, 2007; Flood, 2010).

Relatively recently, a third branch of phenomenology, guided by Max van Manen, is beginning to emerge known as the Dutch school of phenomenology (Dowling, 2004). van Manen’s methodology is a combination of both descriptive and interpretive phenomenology (Dowling, 2007; van Manen, 1990,1997). van Manen does not suggest bracketing (Husserl, 1931) and instead, believes that external knowledge is needed in developing an understanding of the phenomenon being investigated (Dowling, 2007; van Manen, 1990,1997).

3.1.1 Why Hermeneutic Phenomenology?

In all schools of thought, Rossman and Rallis (1998) describe the goal of all phenomenological research as to “seek to understand the lived experience of a small number of people” (p.68). Hermeneutic phenomenology is believed the most appropriate methodology for this study as it is well suited to answer questions regarding humans’
experiences, concerns and issues (Benner, 1994). This methodology will help provide a better understanding of the significance people give to their experiences and issues within their experiences (Benner, 1994).

Given that the primary goal of this study was to encapsulate the full meaning of participants’ experiences, using their own words, and to interpret the meaning of their experiences, a hermeneutic phenomenology methodology informed by Heidegger (1962) was selected. A hermeneutic phenomenological methodology was appropriate for this study because it enables the researcher to “understand the meaning that participants attribute to those actions – their thoughts, feelings, beliefs, values, and assumptive worlds” (Rudestam & Newton, 2001, p. 57), but also allows the researcher to make sense of the meaning that participants make of that experience. The concepts of Heideggerian hermeneutic phenomenology also ensured that participants were situated in their everyday activities and realities with emphasis on their concern regarding their day-to-day life (Benner, 1994; Mackey, 2005). This is important for the study because there is little research which examines the lived experience of those with a terminal condition, in addition to dementia and tries to make sense of the experiences to improve their conditions. Through Heideggerian phenomenological inquiry, the study subjects become co-researchers of the study through the process of interviewing (Rudestam & Newton, 2001). In wanting to understand the participants, the researcher required the privilege of listening to their experiences and then only afterwards, attempted to reveal meanings within these stories (Plager, 1994; Ray, 1994).

In accordance with Heideggerian hermeneutic phenomenology, the researcher came to the study with some pre-understanding of palliative care in the community (within South Western Ontario) and with some experience working with individuals with dementia, and other chronic conditions. The hermeneutic circle put forward by Heidegger enabled the researcher to interpret the meaning of participants "in a careful and detailed manner" (Packer, 1985, p. 1082), while also shedding light on the importance their experiences have in practice. Taylor (1993) concludes that phenomenology also has the potential to generate knowledge for practice from practice. The data made available through this research can initiate a pathway for persons with dementia receiving palliative care to
have with their needs and wishes known, in their own words and from their own experiences.

3.1.2 Key Concepts in Heideggarian Hermeneutic Phenomenology

Heideggerian hermeneutic phenomenology is a research method based on the philosophy of Heidegger, with the aims of uncovering lived experiences from the perspective of the individual(s) experiencing the phenomenon, the meaning of the human experiences, and how the researcher and individuals interpret those experiences (Flood, 2010; Laverty, 2008; Streubert, & Carpenter, 2011). Hermeneutic phenomenology aims to incorporate both a description and an interpretation of a lived experience (Dowling, 2007) in order to attribute meaning to this phenomenon (Flood, 2010; Laverty, 2008).

In Heideggerian hermeneutic phenomenology, "phenomenological description as a method lies in interpretation" (Heidegger, 1962, p.61). This is because the methodology stems from the belief that all human beings have a prior understanding of the phenomenon being investigated, due to previous knowledge, history and backgrounds, which cannot be detached from the analysis of phenomenon (Dowling, 2007; Heidegger, 1962). According to Heidegger (1962), this prior understanding will unavoidably influence the construction of the meaning of the phenomenon. Heidegger (1962) distinguishes three interrelated modes of interpretation of the lived experiences, known as "fore-having", "fore-sight" and "fore-conception" (p. 191). These three modes are an important component of Heideggerian hermeneutic phenomenology known as the hermeneutic circle, or the “fore-structure” (Heidegger, 1962, p. 191). The hermeneutic circle is the framework from which all interpretation is constructed in order to increase the understanding of the lived experience (Bontekoe, 1996; Heidegger, 1962; Plager, 1994). This hermeneutic circle of understanding is an ever expanding, circular cycle of understanding and interpretation (Gadamer, 2004).

Plager (1994, p. 72) describes the hermeneutic circle as follows:

*Fore-having*: Coming into an experience (or situation) with a familiarity of background practices that ensures an interpretation is possible.

*Fore-sight*: Our backgrounds provide us with a point of view from which we can make an interpretation.
Fore-conception: Our backgrounds cause us to have some expectations of what we might anticipate in an interpretation.
Figure 3: The Hermeneutic Circle (adapted from Bontekoe, 1996, p. 4)
The hermeneutic circle relies on the process of continuously examining the whole essence of the experience of a phenomenon to the specific parts of the experience, to ultimately come to an understanding of the data shared by the researcher and participants (Mulhall, 2013).

3.2 Paradigm, Ontology and Epistemology

As Heideggarian hermeneutic phenomenology situates participants within the context of their realities (Laverty, 2008), this study was guided by an interpretivist-constructivist paradigm (Guba & Lincoln, 1994). This paradigmatic lens was most fitting to this research project as it supports Heidegger’s (1962) belief that human beings’ experiences are situated and formed through their involvement in their daily activities, relationships and environments. The constructivist paradigm supported the use of multiple informant types in this study as it encourages the use of multiple perspectives and realities. In line with the interpretivist-constructivist paradigm, this study adopted a relativist ontology and a subjectivist epistemology. In taking the viewpoints of a interpretivist - constructivist, the researcher assumed relative and constructed realities throughout this study (Guba & Lincoln, 1994). This stance maintains that humans construct meaning as they engage with the world they are interpreting (Crotty, 1998).

3.3 Quality Criteria in Qualitative Research

Several authors, such as Koch (1996), have argued that the criteria used to ensure quality in qualitative research should be consistent with the methodological basis of the research. In support of this view, the following criteria of rigor and trustworthiness was used in this phenomenological study.

3.3.1 Rigour

Ensuring quality in phenomenology research requires the rigorous use of methods of data collection and analysis consistent with phenomenology methodology and transparency in documenting these methods, the challenges of the research process and findings (Lincoln, & Guba, 2000; Tracy, 2010). According to Tracy (2010), a study that employs rich rigour is also careful to include adequate sample numbers and appropriate contexts. Transferability of these findings is also an important indicator of quality in qualitative research (Hammersley, 1992; Seale, 1999).
A key component of ensuring transparency in phenomenology is the use of self-reflexivity. Reflexivity refers to the conscious decision of the researcher to be self-aware of his/her values, biases and understandings throughout the duration of the research experience (Strauss & Corbin, 1998; Tracy, 2010). A reflexive journal was kept throughout the research process that allowed the researcher to acknowledge her own influences on the data and provide evidence of the decision-making processes made throughout the study (Clayton & Thorne, 2000). Memos and thoughts from discussions with my academic advisory committee throughout the entire thesis project were also included in this journal. For example, during the early stages of this project, I wrote about my emerging understanding of phenomenology methodologies and reflected on the changes that were made to the research design. The journal writing enabled me to articulate my ideas about conceptual frameworks for analysis of the data and led me eventually to adopt an interpretivist-constructivist framework. During the process of data analysis, I was able to write about initial concepts or thoughts I had about the transcripts or notes from discussions of potential themes I had with my supervisor.

Self-reflexivity is inherently embedded within the process of the hermeneutic circle (Bontekoe, 1996). By acknowledging the researcher’s own familiarity with the palliative care literature and her academic and social background, the researcher was able to engage in the hermeneutic circle. The use of the hermeneutic circle in analyzing the data contributed to the rigour of the study.

Rigour was also maintained through the congruency between the adopted paradigm and chosen methods and the use of participant dyads in data collection. The use of two sources of data collection provide multiple constructions of the phenomena. This enhanced the richness of the data (Denzin & Lincoln, 2000).

3.3.2 Trustworthiness

Trustworthiness goes hand-in-hand with rigour in qualitative research. According to Streubert and Carpenter (1995) trustworthiness can also be achieved through the researcher’s accurate representation of the participants’ experiences. The trustworthiness of the findings of the research was illustrated through the use of rich description and participant quotes. Doing so ensured that the voices of the participants and the researcher were evident in the analysis of the understanding of the phenomenon. This ultimately
enhanced the authenticity of the data (Lincoln, & Guba, 2000). Trustworthiness was also demonstrated through the use of audiotaping, verbatim transcription of interviews and member checking to ensure accuracy and authenticity of the data (Lincoln, & Guba, 1985; Tracy, 2010).

3.4 Methods

3.4.1 Sampling Strategy

Purposive sampling was used to recruit participants. Purposeful sampling is useful in phenomenological research as it helps ensure useful and rich data by confirming that all participants experienced the phenomenon under study, and are willing to talk about the experiences to the interviewer (Plager, 1994; Suri, 2011). Purposeful samples tend to be small (Suri, 2011). This study recruited 10 participant dyads, consistent with Creswell’s (2013) recommendation that a phenomenological study requires a minimum of 10 participants in order to make assertions regarding the phenomenon of interest. Saturation is a key component of the phenomenological approach. Sampling officially ended when interpretations of the participants’ experiences were clear and additional participants did not reveal novel findings or meanings (Crist & Tanner, 2003).

3.4.2 Recruitment

In Ontario, Canada, Community Care Access Centres (CCACs) arrange access to service care providers for all in-home services including palliative home support services. The 14 CCACs across Ontario use case management to coordinate the care services (Aronson, Denton, & Zeytinoglu, 2004). The researcher worked collaboratively with palliative care providers from the community healthcare organization CarePartners, as contracted by the South West CCAC London office, to recruit ten participant dyads for this study. The palliative care providers were briefed on research study objectives and on inclusion/exclusion criteria for study participants. Using a telephone script developed by the researcher (Appendix A), palliative care providers contacted potential participants who they believed met the inclusion criteria and briefly described the study to them. Interested participants were given the researcher’s contact information and were asked to contact her regarding the study. Those who contacted the researcher and agreed to be involved in the study had their questions answered and, if they remained interested in participating, had an interview time set up. At the time of the first interview, the
researcher reviewed the letter of information (Appendix B and Appendix C) with the participants and outlined the study in detail before beginning the interview. At this time the researcher also answered any additional questions that participants had about the study, and had the participants sign the consent form (or in the case of older adult participants with limited capabilities, had a proxy decision maker do so).

3.4.3 Inclusion/Exclusion Criteria

To be eligible to participate in this study, older individuals must have been aged 65 years or older and had to: (a) have one or more terminal conditions for which they have chosen a palliative care treatment option for; (b) receiving palliative care in the community through a formal health care system for a minimum of 3 months; (c) be receiving care from an informal caregiver; (d) have a diagnosis of early-stage dementia disease as classified by a Mini-Mental State Examination score of 20 to 24 as administered by a health care professional; and (e) be able to provide informed consent or have a substitute proxy-decision maker to provide informed consent. All individuals must also have had an informal caregiver willing to participate in this study.

For family caregivers to be eligible to participate in this study, they had to: (a) be directly involved in providing palliative care to the older adult participant; (b) not be employed within the field of primary health care; and (c) be able to provide informed consent. All individuals must also have had an older adult participant willing to participate in this study.

Participants who were unable to communicate and/or understand English (including those with severe forms of dementia) were excluded. Participants who could not be interviewed in London, St. Thomas or Oxford, Ontario or by telephone were excluded from this sample. Participants who did not consent to having the interviews audio-taped were also excluded. No other criteria were used to allow for a diverse sample in regards to experiences and characteristics.

3.4.4 Ethical Considerations

Throughout this study, careful consideration was given to the welfare of all involved. Ethical practice is of utmost importance in all qualitative research regardless of paradigm or methodology (Tracy, 2010). Ethics approval to conduct this investigation was obtained by Western University Health Science Research Ethics Board (REB) (Appendix D). A
written letter of information was given to each participant outlining the study and consent was obtained from all participants prior to their interview. Prior to the initial interview, individuals were encouraged to ask questions regarding the study. Participants were reminded that their participation was voluntary and that they could withdraw from the study at any time with no penalty. Participants had the option of declining to answer any interview question. Given the sensitive nature of the interviews, and the possibility of the interviews triggering memories and emotions, contact information for free bereavement services in London, Ontario, were available to all participants at the end of each interview (Appendix E).

All participant names were changed to pseudonyms and identifying information was eliminated from the data for the purpose of participant anonymity. Confidentiality was also preserved by omitting salient details about participants, including specific age and location within the community in the findings, as these might have implied their identity and made them recognizable to those in the community reading this thesis.

3.5 Data Collection

Data were collected through audio-recorded semi-structured individual interviews with ten older adults and their caregivers. All interviews were conducted in person in the participants’ homes, by video conference, or by telephone (13 interviews in home, 1 interview using video-calling, 6 interviews by telephone). Participants were interviewed individually. All the demographic questionnaires were completed in person. For participants interviewed in person, caregiver participants completed the demographic questionnaires when the older adult participants were being interviewed. Older adult participants were often nearby when the caregiver participants were being interviewed, but not directly in the room.

Phone interviews were used with some of the participants due their preferences. The researcher asked that participants be interviewed independently, but had no way of verifying this was done for phone interviews. The absence of visual cues during the standard-telephone interviews compromised the ability to obtain non-verbal data from these interviews and perhaps may result in a poorer interpretation of the responses. According to Novick (2008), there is a lack of evidence indicating that phone interview use in qualitative research produces lower quality data than traditional face-to-face
interviews. Phone interviews may have allowed participants to be more forthcoming in disclosing sensitive information. It is likely that the sample size would have been significantly smaller if interviews were not to take place over the phone.

The researcher developed a semi-structured interview guide (Appendix F & Appendix G) to facilitate an in-depth exploration of the experiences of receiving palliative care in the community and caring for a family member who is receiving this care. The use of a semi-structured interview guide, with open-ended questions, was selected to encourage the participant to speak freely, while ensuring key topics were discussed (Dilley, 2004). The interview guide for older adult participants consisted of seven open-ended questions. Interview probes were used to gain a deeper understanding of their answers to the initial seven questions.

The following seven questions were asked of older adult participants:

1. What is it like to live with multiple chronic conditions?
2. How do you experience community health care services in your everyday life?
3. Are there any differences in how you experience care throughout your days today, compared to a typical day before you began receiving palliative care services?
4. Can you describe what palliative care means to you?
5. Can you help me understand how you came to choose home-based palliative care?
6. Are there any additional services that would be useful to you?
7. Is there anything else you would like to share about your experiences?

Given that participants in the palliative stages of their disease often experience difficulties communicating for longer periods of time, interviews were conducted in longer length with the informal caregiver to gather more sufficient data. An interview guide of eight open-ended questions was developed for the older adult participants.

The following eight questions were asked of family caregiver participants:

1. What are your experiences providing care to someone who is terminally ill and residing in the community?
2. Are there any differences in your caregiving experiences today, compared to a typical day before palliative care services were required?
3. What is the most challenging part about being a caregiver to someone who is terminally ill? What is the most rewarding part of your experience?

4. What is your definition of palliative care as it relates to caregiving for someone with dementia who also has a terminal illness?

5. How does the experience of providing palliative care for someone with dementia change your needs?

6. Can you help me understand how you or the person you are caring for decided to choose home-based palliative care?

7. Are there any additional services that would be useful to you?

8. Is there anything else you would like to share regarding your experiences as a caregiver for someone with dementia requiring palliative care?

The length of the interviews and the time spent with each informant type (the older adult and the caregiver) was contingent on the older adults’ ability and the caregivers’ wishes at the time of the interview. Interviews averaged about half an hour for older adult participants and about 45 minutes in length for caregiver participants.

In addition to the interviews, each caregiver participant completed a socio-demographic questionnaire (Appendix H). For the caregiver participants interviewed via telephone, the researcher read out the questions of the demographic questionnaire and recorded their answers prior to the start of the actual interview. In qualitative research, the participant socio-demographic questionnaire is designed to provide background information regarding participant characteristics and to describe the qualitative sample (Creswell, 2013).

Field notes were written after each interview. These field notes were kept in a reflexive journal and contained comments on the researcher’s theoretical, methodological and personal thoughts about the interview (Polit & Beck, 2008). Examples of field notes included incidences of crying or other extreme emotion, interruptions in the interviews, and the authors’ personal reflection on the interview. Notes of what was said before or after the interview were also recorded. These field notes were used to help better understand the participants, in addition to the demographic questionnaire.

All of the digitally-recorded interviews were then transcribed verbatim by the researcher.
3.6 Data Analysis

Hermeneutic phenomenology was used to understand the meaning of the lived experiences of older adults with dementia receiving palliative care in the community. The goal of analysis was to use the researcher’s preconceived understanding of the phenomenon of community-based palliative care for people with dementia along with the information generated from interviews with participants and data obtained from other relevant sources, to identify participants’ meaning.

The process of hermeneutic phenomenological analysis is iterative (Diekelmann, & Magnussen-Ironsie, 1998). Data collection and analysis occurred simultaneously (Annells, 1996a, b). The analysis of participant data was guided by Diekelmann, Allen and Tanner’s (1989) multi-stage hermeneutic interpretative analysis process. Diekelmann, Allen and Tanner’s (1989) describe their hermeneutic method as Heideggerian in nature. The Diekelmann, Allen and Tanner (1989) approach was particularly suited to this study as the sample consisted of dyads and the method aims to find emergent themes amongst different sets of data.

The Diekelmann, Allen and Tanner (1989) method of analysis involves seven interpretive steps: (1) reading all of the transcripts for all the interviews to obtain an overall understanding; (2) writing interpretive summaries and coding for emerging themes (Appendix I); (3) analyzing all transcripts as a group to identify codes/themes by first analyzing the older adult with dementia interviews all together, then the informal caregiver interviews; (4) returning to the transcripts and participants to clarify disagreements the research team had in interpretation and writing a composite analysis for each text; (5) analyzing across dyads by comparing and contrasting all transcripts to identify and describing shared practices and common meanings between the informal caregiver interviews and the older adult participant interviews; (6) identifying links between the themes, using patterns; and (7) eliciting responses and suggestions on a final draft of themes and patterns from the interpretive research team (the thesis advisory committee members) (Diekelmann, Allen, & Tanner; 1989 in Profetto-McGrath, Polit, & Beck, 2010, p. 330.).
3.6.1 Composite Analysis of the Text

Throughout the entire data analysis process, the individual transcripts and audio-tapes were revisited numerous times. This helped to further immerse the researcher into the hermeneutic circle (Diekelmann et al., 1989). An iterative process was used with multiple rounds of refining the codes until a final coding list was established for the older adult interviews and the caregiver interviews. Careful journaling about any emerging themes or ideas was used to maintain an audit trail. The primary researcher took the lead in the identification of codes at this time. The academic committee members either supported the analysis or offered constructive criticism. All transcripts were then analyzed by the researcher and at least one other academic committee member.

As per Diekelmann, Allen and Tanner’s (1989) suggestion, the researchers then returned to the transcripts to clarify any disagreements of the codes. This helped to solidify a final coding list for each of the individual analyses, and supported inter-coder agreement (Miles, Huberman, & Saldaña, 2014). Following this step, feedback was given from the academic committee to refine the initial coding list that was entered into the Excel spreadsheet. The researcher used this coding list to code all the transcripts using NVivo 11 Software©. Using the final coding list and the discussion of possible themes that the researchers saw to emerge, the primary researcher then wrote an interpretive summary of each interview (Diekelmann & Magnussen-Irons, 1998).

To further enhance the validity of the analysis of nine dyad transcripts, member checks were used. The researcher was unable to get in contact with one of the participant dyads, despite trying to call numerous times over a three-week period. All member checking occurred via telephone. The researcher called the caregiver participant and presented a summary of the main topics discussed in the interview. The researcher then asked if the summary was an accurate portrayal of their experiences. The older adult’s construction of their lived experience was mediated through their caregiver. All of the summaries were reported to be accurate. Participants were also encouraged to share anything that they would like to further add to their interviews; however, none of the participants did so. These member checks ensured an accurate portrayal of participant experiences and helped to establish study rigour (Guba & Lincoln, 1994; Koch, 1996; Tracy, 2010). Following the member-checking process, the researcher discussed all
possible emergent themes for the older adult experiences and the caregiver experiences with the academic committee to further deepen the understanding of the text.

3.6.2 Discovery of Constitutive Patterns

Through hermeneutic circles of interpretation and shared dialogues, the researcher then sought out constitutive patterns connecting relational themes across the dyads. All transcripts were compared to one another in an iterative process. Diekelmann, Allen and Tanner (1989) recommend following the same process outlined above for all transcripts to identify and describe the shared meanings that emerge between them all to analyze the dyads. To do so, the researcher read each transcript line-by-line and entered all of the codes from each transcript into NVivo 11 Software©.

The use of NVivo 11 Software© allowed the researcher to uncover constitutive patterns that showed relationships across themes among all the interviews. According to Diekelmann and Magnussen-Ironsides, (1998), the discovery of a constitutive pattern forms the highest level of hermeneutic analysis. An identified pattern is considered constitutive when it gives actual content to describe a person’s way of being in the world (Diekelmann &Magnussen-Ironsides, 1998). Constitutive patterns were identified as codes and elements of the data that could be clustered together through similarity and regularity and therefore captured different essences of the data. The reflective notes taken throughout the data analysis were also reexamined at this time to add another layer of depth to the analysis. Emerging patterns were discussed with the academic committee. Once agreement was found, these patterns became the themes that describe the shared participants’ experiences. A final report was written with the themes supported by verbatim quotes.

3.7. Credibility of the Analysis

Diekelmann, Allen and Tanner’s (1989) multi-step process for analyzing data using a combination of analysis techniques helped to deepen the understanding of participants’ experiences (Cohen & Omery, 1994; Lincoln & Guba, 1985). Madison (1988) proposed a list of criteria for evaluating the credibility of phenomenological research. While Madison (1988) believed that researchers should use good judgment rather than rules to guide a rigorous research process, some of the proposed criteria were used to assess the
merit of the data analysis of this study. Among those identified criteria recommended by Madison were:

3.7.1 Comprehensiveness

Comprehensiveness adapted from Madison (1988) refers to interpreting the interviews by taking into account the researcher’s and participants’ thoughts as a whole, and not ignoring any thoughts of the researchers. This was demonstrated in the data analysis phase through the use of the reflective journal notes and memos.

3.7.2 Thoroughness

A good interpretation of the data must be based upon data that were gathered to fully represent the various dimensions of the phenomenon and must answer all of the questions posed within the interviews (Madison, 1988). In this study, data collection ceased only when saturation was reached and the rich data fully described (1) the experience of receiving palliative care services for older adults who also have a dementia diagnosis, and (2) the experiences of their family caregivers. Thoroughness of findings was also ensured through audio-recording and verbatim transcription of each interview to ensure accuracy. Authenticity of the rich data was addressed by making every effort to capture the perspectives of participants in their own words (Patton, 2002).

3.7.3 Agreement

Other researchers or readers of this study must be able to follow how the researchers of this study came to the interpretation (Madison, 1988). Agreement was strengthened through simultaneous coding and discussion with the academic advisory committee members (Miles et al., 2014). To achieve this, the research team worked closely together to ensure that all co-investigators, including the contacted participants (through member checking), were in agreement with the endorsed interpretations of the phenomenon, which also ensured rigour was maintained.

3.8 Situational Ethics

While procedural ethics was obtained at The University of Western Ontario before the study commenced (Appendix D), additional ethical steps were taken throughout the research process (Tracy, 2010). This is known as situational ethics (Tracy, 2010) and ensured that at all points of contact with potential participants and recruitment gatekeepers (the palliative care providers) were conducted in an ethical manner. This
study contained a highly vulnerable population. All efforts were made to protect the older adult participants and the caregiver participants. For example, all participants were reminded that they could decline answering any questions that they did not wish to answer. Participants were also encouraged to ask questions at the start, throughout, and after the interviews had concluded. During the interviews, special attention was placed on the older adult participants. If participants began showing signs of difficulty in participating in the interviews, they were offered to take a break from the interview or the interview was ended. This occurred with one older adult participant. The participant began crying during the interview and asked that the interview be paused. The researcher turned off the recorders until the participant indicated that she wanted to continue. Confidentiality and anonymity were used throughout the study.

3.9 Reporting

Results from this study will be shared with the Nurse Manager and nurses of the South West branch of CarePartners who aided in recruiting for this study. One study caregiver participant also asked for a lay summary of the report. These will be presented upon completion of the thesis.

3.10 Declaration of Self

In the aim of being a transparent author, it is important that readers are made aware of my standpoint (Tracy, 2010). I am physically and mentally healthy. Unlike my caregiver participants, I have not yet encountered providing care to a family member with dementia nor have I been in close contact with someone who has suffered from dementia. On the other hand, I grew up in close contact with a family member who had multiple comorbidities and watched family members serve as her primary informal caregivers. Much like my participants, I have experience with the challenges of caregiving for someone during the later stages of their diseases.

I am educated. I have an undergraduate degree in Gerontology from McMaster University. I have a tendency to focus on the most marginalized individuals throughout my studies. I always struggled with the idea that the provision of care in one case often is applied to other cases, especially when considering marginalized groups of individuals. There was no way to suspend my past experiences and past knowledge as I proceeded with my study. As a Gerontology student, I was trained to always focus on 'person-
centered care’, as the gold standard. Others may not have found the same results as I found.

I entered the Masters of Science program at The University of Western Ontario knowing that I wanted to look at a project dealing with those with dementia. It is less challenging for me to be open minded about dementia care than it is with palliative care because I have no personal experience with it. I struggled to recognize the ways in which this study is a personal topic to me and how my past personal and academic experiences make me gravitate towards certain ideologies.

The primary reason that this is a personal topic for me is due to my ongoing interest in trying to improve the circumstances of end-of-life care for marginalized older adults, so that everyone can achieve dying with dignity, in however they define it. The germ of this particular interest started during the final year of my undergraduate degree, during an ethics course discussing the ‘Dying with Dignity’ Movement. For the final course project, we had to write an ethical debate about whether or not physician-assisted suicide is ethical. Having always been interested in those with compromised autonomy, I found the assignment difficult. My interest in autonomy influences my choice to focus on those with cognitive impairment and compromised autonomy.

While the proposed study is rightfully different from the one I just described, my focus on preserving and upholding the autonomy for those with limited capabilities remains. Thinking reflexively, it is crucial for the future readers of my work to know why and how I approach this research. I am admitting that it is clear that I approached this project assuming that there are areas of our current palliative care delivery system that need improvement for those who utilize services with cognitive impairment. I made a conscious effort to not influence participants’ responses during interviews.

3.11 Conclusion

The purpose of this study was to better understand the lived palliative care experiences of community-dwelling older adults with dementia and their informal family caregivers. The primary aim of this study was to ensure that the experiences of these individuals become known and that their voices be heard. Thus, the study utilized terminally-ill individuals with dementia and their primary informal caregiver as the only sources of data, collected through semi-structured interviews. Consistent with the study goals, this
study employed a Heideggarian hermeneutic phenomenological methodology that is
grounded in an interpretivist-constructivist paradigm informed by the work of Heidegger
(1996) and Diekelmann, Allen and Tanner’s (1989) multi-stage hermeneutic
interpretative analysis process. The quality of the research study was ensured by
upholding rigour and trustworthiness, as guided by qualitative methodologists such as
Tracy (2010). The credibility of the analysis was confirmed through Madison’s (1988)
criteria for comprehensiveness, thoroughness and agreement.
4 FINDINGS

The goal of this hermeneutic phenomenological study was to understand the lived experiences of community-dwelling older adults with dementia who receive palliative care in the community. Another goal was to understand the lived experiences of their informal family caregivers. An in-depth analysis of each participant’s story and a holistic analysis of all findings were completed.

A total of twenty participants were interviewed for this study, consisting of ten older adult participant/informal caregiver dyads. All older adult participants were in the early stages of dementia and all were also receiving community-based palliative care for another terminal illness. All participants were interviewed individually, although their family members were often nearby. Participants came from London, St. Thomas, Elgin County and Oxford County. Details about the participants’ socio-demographic background can be found in Appendix J. The community-based palliative care service use of the participants is described in Appendix K. In a conscious effort to keep all identifying characteristics of the participants confidential, this study did not analyze the participant’s experiences in the context of their conditions and all interview data presented in this thesis do not have any identifying information.

4.1 Emergent Themes

Hermeneutic thematic analysis of the semi-structured interviews from the ten participant dyads revealed key themes. The themes for older adults with dementia were belonging at home and acceptance of the terminal illness. The themes for informal caregivers were impact of dementia, double strain and home as a source of control over care. The themes across the dyads were honouring wishes, fear of hospitalization, and uncertainty.

4.2 The Lived Experiences of the Older Adults with Dementia

Receiving palliative care at home was at the center of the older adults’ experiences. The older adults wanted to die at home as the home was a source of comfort, familiarity, and security. The themes of belonging at home and acceptance of the terminal illness encapsulate their experience.
4.2.1. Belonging at Home

“This is where I belong” (Older Adult Participant 1)

Older adult participants described their homes as the place where they “belong”. All of the participants indicated that receiving palliative care at home was very important to them and a key goal, in terms of care, was for them to be able to stay in their homes for as long as possible. Older adult participants were extremely grateful to have ability to receive care in the community. All participants, except one, wished to die at home. All participants wished to receive care in their homes.

Participants described their homes as a place of comfort, familiarity and their preferred place to receive their palliative care. Older adult participants’ reasons for feeling as though they belonged at home, went beyond the physical location of the place to receive palliative care. This theme includes the subtheme of family as home and familiarity.

In receiving their care in their homes, older adult participants described having a sense of control over whom they were surrounded with when they were to die. Older adults described that receiving palliative care services at home allowed them to be surrounded by those they recognize and love. Given their dementia diagnosis, older adult participants found being around those they recognize to be extremely important. They stated that being around their family members provided them with a greater sense of safety and comfort.

… in the hospital I felt sick because I was around sick people, strangers. At home, my wife is healthy so I feel healthy except for when the nurses come. They remind me I’m sick. I want to be home safe around her (Older Adult Participant 8).

The notion of being surrounded by their family members was key to defining why the home was the preferred place of the older adults to receive palliative care. When asked why receiving palliative care in the home and remaining at home was so important to her, Older Adult Participant 9 explained:

I belong here. This is my house. My family is here (Older Adult Participant 9).

Older adults often compared their experiences to that of being in a hospital surrounded by strangers.
I would rather die now than spend the time in the hospital……I don’t know those people. They’re strangers. Here my wife is. My pictures are here. My life was here. I just wish we started this early and that I didn’t waste time in the hospital with strangers (Older Adult Participant 5).

[Home] is where I belong. I don’t belong in a hospital with the strangers. I belong at home. This is my house. This is where my family is (Older Adult Participant 8).

Most of the older adult participants reported that they had wanted their family members to provide the majority of their care and that this was only possible if they were to receive community-based palliative care services.

Well now people come to my house so I don’t have to go to them. But now my daughter can do everything for me instead of them. Because I am home (Older Adult Participant 10).

Older adult participants were grateful that community-health palliative care professionals were able to enter their homes and assist their family members with providing care to them. Older Adult Participant 9 said the following about the community health-care providers:

Hmm, I like it when they come. They help out my sister. They never hurt me. I feel better when they leave. They are very nice. I….I … they are very nice. And I like that they come to help her (Older Adult Participant 9).

Another meaning and reason to why participants wished to die at home was that the home provided a sense of familiarity and thus, comfort to the older adult participants. The presence of personal possessions and the familiarity of the surroundings was highlighted as being important for the older adult participants to be around. Spending some of their final days at home seemed to prompt familiar and important memories, such as raising their families in the home. The familiar environment of their home also allowed the older adults to be more independent.

I raised my babies here. My daughter has her babies here. I need to be home with my family. My stuff is here (Older Adult Participant 2).

I wish I came home sooner. I didn’t like it there. But we couldn’t. I couldn’t. I don’t know. I have dementia so I don’t know everything…. But I do know some things. I know…well I know a lot. I really like this. I like that when I’m home I can remember where we keep the cups so I can even get my own water (Older Adult Participant 7).
4.2.2 Acceptance of The Terminal Illness

All older adult participants acknowledged that they were dying. Throughout the interviews older adult participants would mention that they were dying, sometimes multiple times, even though none of the interview questions discussed death directly. An example of this comes from an interview with Older Adult Participant 5:

Well it means I am dying and there is nothing nobody can do to stop it. And so, right now, when my heart stops because I am in a hospital…or I mean not in the hospital, they won’t be able to stop me from dying so I just will. And I’m okay with that. I said so. My wife said so. It won’t be today or you know, it could be. It may not be this year. So with palliative care I can…I can feel I can stay like this for years...here at home (Older Adult Participant 5).

Participants described that once they came to terms with the fact that their conditions were incurable and a palliative care plan was in place, they were able to better accept the care provided to them by health care professionals and their informal family caregivers.

And I like to be in control, but other than that, you know what, the services that I get at my house, I can’t complain. It, it is wonderful. And they seem to go out of their way and they seem to be caring and professional. I know I need them because I am dying and it’s palliative. And they are quite helpful, so to be honest with you. I have no complaints… for this situation because I can’t do it for myself anymore (Older Adult Participant 1).

Older adult participants mentioned that by receiving palliative care in their own homes and communities as opposed to being in an institution they felt less ill. This helped them to accept their terminal illness. Accepting their terminal illness assisted them in living with a higher quality of life. Many of the participants believed that they would get sicker if they were to re-enter an institution, particularly a hospital.

In addition to feeling less ill, older adult participants described being less fearful of death now that they are receiving palliative care services in their home. This also aided in their acceptance of their prognosis. Older adult participants credited the presence of the community-based palliative care specialists as one of the largest reasons for lessening their fear of death. They described that having a health care professional visit and educate them on the status of their condition(s) made them less fearful of the future. The following excerpt from the interview with Older Adult Participant 6 describes how the
presence of a community-health nurse assisted her with accepting her illness by lessening her fear of death:

But I like it when they come. They explain things. And I am less scared because …when I forget they tell me it’s okay and they are like doctors, right so it makes me less scared. I love not having to go to the hospital as much. Or… well before I would have problems breathing but not want to go to the hospital, so I would just wait and then an ambulance would come maybe two or three days later, but now I know they are coming so I’m less scared that I’m just going to die. I know when she comes she will check or she will tell my husband or son things are getting bad and when I should expect to go. The nurses make me feel less scared of death (Older Adult Participant 6).

4.3 The Lived Experiences of the Informal Family Caregivers

The informal caregiver participants in this study described their experiences of providing care to their terminally ill family member with dementia in the community as a sense of duty, love and obligation. The informal caregiver interviews revealed three themes: the impact of dementia-related impairment, double strain, and the home as a source of control and personalized care.

4.3.1 Impact of Dementia

When asked about the role dementia plays, if any, in the experience of providing palliative care to a family member at home, Caregiver Participant 6 responded with “Well I just want to say I think it is easier if they have cancer”. Nine of the ten caregiver participants described that the added diagnosis of dementia made providing palliative care in the community to someone who is terminally ill harder. Furthermore, when asked if there was any community-resource or added service that would make the experience of providing care easier for themselves, as informal caregivers, Caregiver Participant 5 responded with, “take the dementia disease away”. It was clear that the impact of dementia made the experience of providing palliative care in the community unique to these individuals. This theme was further broken down into three subthemes: home-bound, lack of knowledge, and finances.

Perhaps one of the biggest changes experienced by participants was the experience of becoming home-bound. Statements, such as “We’re both stuck at home” (from Older Adult Participant 9) and “I’m home basically 24/7, pretty much” (from Caregiver Participant 5) highlight the change experienced by the participants. The informal caregiver participants believed that they spent the majority of their time alone because the
dementia diagnosis made it difficult for them to leave their loved one alone or take them out.

But before it was different. She could do things. She could remember. She wasn’t living here. I would only have to go to visit her to care for her. To a point. She could do things. She would eat. She could take care of herself. She wasn’t having to bug me…. Because of the dementia I can’t leave her to go out at all (Caregiver Participant 10).

The arrival of a health care professional to their home was acknowledged by caregiving participants as an opportunity to be temporarily relieved of their caregiving duties. One participant explained that due to their family member’s dementia diagnosis, they felt uncomfortable to leave their family member home alone during this time. Caregiver Participant 5 explained that sometimes without her present the Personal Service Workers are unable to perform the required care activities:

Like, he won’t let them do it at all. Um…. Well I don’t, I don’t mind doing it. But it is quite time consuming. It is like you have to live two lives- their’s and your own. ….You can’t communicate with them always. You can’t get them to understand what they have to do and what you have to do to help them even when others are there to do it (Caregiver Participant 5).

The inability to have a break from their caregiving situation was a major obstacle in the life of the caregivers. The caregivers longed for time alone and yearned for the opportunity to spend more time outside the house. Caregivers felt that they were unable to take time for themselves as they described caring for someone with dementia, “…pretty much like having a young child around that you have to watch 24/7” (Caregiver Participant 8).

Caregiver participants felt that they lacked knowledge about dementia. Caregiver participants felt that the community-based palliative care specialists also lacked knowledge of dementia at the end-of-life, and did not fully understand the behaviours typical of someone with dementia. As a result, the caregiver participants were unable to receive information about dementia from the health care providers.

You know, just to talk to some other people who are going through the same thing in their lives. Just because I don’t know what I am doing is good enough, or if what I am doing is normal compared to other spouses, so you know, it would be nice to talk to other people going through the same thing and who maybe know about dementia, because really I don’t know if the staff know. They can’t figure it out either (Caregiver Participant 3).
Without this knowledge, caregiver participants felt guilty for neglecting the dementia-portion of the family member’s health conditions.

…he was probably, you know, he was probably coming down with Alzheimer’s for years before I really knew because of the cancer. I just assumed he was violent because of that sometimes. I just thought, that was what is happening to him, I did not think dementia. I didn’t know (Caregiver Participant 9).

Several participants experienced a change in financial status or experienced a financial burden due to their family member’s dementia diagnosis. Caregiver participants expressed the inability of them to remain in full-time employment because “it is pretty much 24-hour care” (Caregiver Participant 8). For many of the informal caregivers there was no other family and community supports available to help them take care of their family member. Caregivers discussed the high costs associated with caring for someone with dementia, given that there were limited resources and support in the community to assist them with taking any respite from their caregiving duties. As one caregiver described:

That is another thing. It is expensive. It is expensive to care for someone who, you know, has dementia and all those needs. Dementia makes it more expensive. But the other stuff is expensive too (Caregiver Participant 7).

With almost any mention of financial burden, participants were quick to express that they were thankful for the services that they receive through the CCAC and the fact that this care was largely covered by the government.

4.3.2 Double Strain

Several informal caregiver participants reported experiencing great stress due to providing care for someone with a terminal illness and dementia. “I am much weaker. As a person. I am more tired. It has taken a lot out of me.”, was the response Caregiver Participant 1 stated when asked how his life has changed since beginning to be a caregiver to someone with dementia who is receiving palliative care services in the community.

The informal caregiver participants in this study described that the added complexity of having their terminally-ill family member also having dementia caused them to experience two co-existing types of burden. First these caregivers had to deal with all the emotional and physical challenges of caring for an individual throughout the dying
process. Secondly, informal family caregivers had the added pressures of caregiving for someone with dementia. Two subthemes reflect the consequences of double strain: physical and emotional strain.

Due to the added challenges of caring for someone with dementia, family caregivers reported being physically exhausted by their caregiving ongoing duties. As a result of this exhaustion, the physical health of many participants was affected in a variety of ways, including a lack of sleep, as expressed by the following caregiving participant:

I find that, um…when you’re doing this 24 hours a day and you just get a person who comes in maybe twice a day for 3 minutes, it just isn’t enough… So I just don’t have the time to sleep. I am not sleeping at all. Between that and the laundry and it is just some of the same thing. So I guess that. But I mean, I wouldn’t change anything to have my mum at home. But I just need to sleep. It is hard…but I would ask for more but I cannot qualify for more. It is pretty much just the same thing (Caregiver Participant 10).

Additional respite time was considered vital to help the caregivers sustain their ability to provide care to their family members. Caregivers prioritized respite care despite the high costs of using respite services. As Caregiver Participant 7 articulated:

Well, during my 4-hour respite, I try to do things for myself. I will go and get a massage and or I’ll, you know, get a pedicure. So I think that, that makes me cope with it a little better, I think. Yeah. I have no choice. I…I really have to go and have my respite or I couldn’t do this. I have to do that. Every three months. But yeah, that does cost a lot of money (Caregiver Participant 7).

Caregivers struggled with having to leave their family member so that they could receive some respite. Caregivers described concern over taking their family members to a Day-Away program or a long-term care home to receive temporary respite due to concerns over their family members’ dementia-related behaviours. Caregivers sought out respite when they could at home, such as when their family member was asleep.

And some days, he may sleep. Like some days if he is in pain, he will sleep for most of the day. And that isn’t bad for me. That is my respite care then so I don’t have to take him somewhere. That is when I will sit down and read a book, take a break. (Caregiver Participant 5)

The caregivers described not being prepared for the emotional impact of caring for their dying family member with dementia. Caregivers described their concern for the welfare of their loved one as stressful. This emotional stress was caused by many things, including, their worries about leaving their care receiver alone and about his or her safety
and their concern over their care receiver’s present levels of pain. All of the caregivers in this study identified as being the primary informal caregiver and described caregiving with little support from extended family, or additional services in the community. This resulted in the caregivers being emotionally exhausted.

When my brother was here visiting with his family to [Location], I had some help and was able to let go of the emotional stress of her previous diagnosis but that was 2 years ago. And then my mother’s sister is in Toronto and I have a brother who is in [Location] for 6 months out of the year. Cousins who are in [Location] … See, so it is just me. It is very hard to get any type of additional help. This makes it worse. No one asks if I am okay. I find it to be a very long and lonely road. Like I don’t even get to talk a lot. Like I don’t even know if people think I have much to say. So I would say, more emotional support. Having family and friends is very important. And I don’t have that. I’m exhausted…emotionally (Caregiver Participant 10).

Moreover, caregiver participants described being concerned over the lack of time they have with their family member. Caregivers described being concerned over time for two reasons: their family member’s dementia resulting in a declining ability to communicate due to the disease and time in terms of their prognosis due to their terminal condition. As one participant described:

Um…yeah…the lack of time, yeah. But also time to go out. I mean it can really go both ways. Time is definitely one of those things. The lack of time with him. You know, you know he is going to die. You know he is going to get worse with dementia too. You know there is nothing to make it better. So you know, you just kind of always have to wonder now how much time do you have so I took him home. Because you always have to wonder about time in death but also before he gets bad enough that all forms of communication is cut off between us. (Caregiver Participant 8).

An additional form of emotional stress for the caregiver participants was the guilt they felt for not being able to separate the dementia diagnosis from the terminal illness. Dementia, co-existing with another terminal condition made caregiver participants feel frustrated at their inability to best care for both conditions. In the example of Caregiver Participant 10, she described recognizing that having dementia complicates the feeding of patients, yet did not know if her family member’s eating habits were due to the dementia or a result of her jugular bleeding. She described feeling guilty for not even knowing where to turn to find information to help her care for her family member. As
aforementioned, participants felt that they did not have the knowledge on how to best care for persons with dementia. Caregiver Participant 10 described her experience with feeling this way:

So there is always lots of confrontation and questioning and guilt....

Like...like...like I said it is very, very hard. But not so much...like I said, it is very hard to figure out what is causing her not want to eat- is it the jugular, the dementia, the cancer? Or the stroke? It is just all very frustrating. I cannot figure it out.

And she had a mini stroke, maybe that maybe caused the dementia so she doesn’t even want to eat anymore. So because of the stroke...well now, it is always question, question, question, “Is it the jugular or is it the blood clot or is it the dementia?” Do I read up on dementia and eating or the jugular or what? Where do I go to look for information? I feel bad that I can’t just look it up.

4.3.3 Home as a Source of Control Over Care

While participants experienced a “double strain” over their responsibilities to care for an individual who has a dementia diagnosis and another terminal condition, they perceived that receiving palliative care services at home allowed them to have a better sense of control over the quality of care their family member receives. A sub-theme of this theme is personalized care.

Some informal caregivers described control in terms of being able to have more authority over their family member’s care plans at home. One caregiver described community-based palliative care in the following way:

Well, for the patient...well for the patient it provides...it provides um, comfort and trust and most important dignity to be around those they recognize. For the caregiver...it...it is just the ability to spend time with the patient...control, too ... ugh...better interactions with the patient. It is more hands on care now. In a certain way, you have much more control over the care plan than compared to the hospital (Caregiver Participant 6).

The caregivers found it easier to provide care to their family members at home because they could easily see them. For example, they do not have to drive to visit their relative during set visiting hours like they would have to if their family member was still in an institution. As Caregiver Participant 7 shared:

And then she went and developed the Alzheimer’s. She ... Then they kind of just went and put her in a little room...And that kind of really bothered me. And it was like for them. Like just because she is not there in her brain doesn’t mean
she isn’t important. So we decided to just say “okay, I’ll quit my job and I’ll take her home”. So…um…yeah. I’ve been doing it for three years now. So I can see her when I want. Not when they say.

*Interviewer: And so do you think the care that she receives now at home for the community health organizations and with you is better than when she was in the retirement home?*

Yeah. One hundred per cent. I control it here (Caregiver Participant 7).

Informal caregiver participants believed that they could provide their family member with better care at home than they would receive elsewhere. Informal caregivers believed this was because they could personalize their family member’s care at home. They also believed that the community-based palliative care providers offered an individualized and more personalized approach. Informal caregivers described long-term care homes as being unable to provide personalized care. For example:

But they [Long-term Care Home] can’t give him individual care. There are just too many...And so, I think he gets a better quality here. A better quality of life, too, than if he was in a nursing home. (Caregiver Participant 5)

And you can react to the patient’s needs…um…I would assume quicker. Than...than...and I would just assume you are able to understand the needs better as a family caregiver than at a hospital where doctors do all this. And that is not to say that the staff within a hospital are incapable or not able to provide care…but it is just more…personal at home. (Caregiver Participant 6)

Some of the caregivers recommended improvements be made to the CCAC's current model of care delivery in South Western Ontario. The caregivers believed that the allotted time given to each informal family caregiver for respite care and the amount of physical care provided to the care recipient be modified depending on the situation. Participants were concerned over who would care for their family member when they are unable to do so and did not qualify for extra care from the CCAC. The caregiver participants reported using informal supports, such as support from friends or neighbours, in situations when they could not access additional care from the CCAC and were unable to provide care themselves.

For example, Caregiver Participant 5 described a time when she required surgery but was unable to access more health care services from the CCAC. She was required to as her daughter for help:
I just recently had two surgeries in one week. And that was the 12th and 14th of February. I had a trabeculectomy on my eye and I had a carpal tunnel surgery on my left hand. And it got really bad. And I had to get my daughter to come and stay. I couldn’t get anyone else to come. To stay like 24 hours. I still had to look after him…And I wasn’t able to…And so, she…she stayed with me for three or four days, while she even could. But I mean, it made it really hard to do those things. And recovery. And as soon as I was able to do anything at all… I mean I was washing him with one hand. (Laughing)

Caregiver Participant 7 described a comparable situation. In her interview, Caregiver Participant 7 described a time when son required a consultation for an emergency surgery and she had to seek help from a neighbour who was also an informal caregiver, as she was not able to change her appointment time with the personal support worker (PSW) she receives through the CCAC.

…to see if he needed surgery on his arm. And now I was like ‘oh no, now what?’ And so I had someone in the community stay with my mother-in-law. Because when I called the PSWs and they said they could only give me that time. But it wasn’t during my appointment that I needed her to come and help me. So there’s the lady in the community who did the same thing I am but with her husband….So I said I kind of feel bad that this lady in the community is coming here, I said ‘during your respite time’ but then she said ‘yeah but I don’t have anybody’….Um…and then it kind of feels bad that you know there isn’t a system in place to deal with these kinds of emergencies.

4.4 Emergent Themes Across Dyads

While the experiences of the older adult participants receiving palliative care services in the community and the experiences of their informal family caregivers who help facilitate this care differ, three shared themes emerged out of their lived experiences. The shared themes are honouring wishes, fear of hospitalization, and uncertainty.

4.4.1 Honouring Wishes

Older adult participants’ desire to remain at home for as long as possible, and caregiver participants’ wishes to keep their family member home for as long as possible were apparent across all the interviews. Older adult participants felt that their end-of-life wishes to receive care at home were being honoured. Each older adult participant said that their wish to have this care be delivered at home was extremely important to them and their family.

Yeah. That I won’t get better or they won’t try to keep me alive with a machine. So then as soon as I found that out, I said “take me home”. But I couldn’t just go
home. So they said they’d send someone once a week. And that’s it. This is what I wanted and because of my wife and the people who come I can. This is what I want. My wish is to be here. I got my wish (Older Adult Participant 5).

Similarly, caregiver participants perceived receiving community-based palliative care services and taking on a caregiving role for their family member was a way of honouring end-of-life wishes. Informal caregiver participants discussed doing anything possible to ensure that their family members’ wishes were granted including quitting their jobs, relocating, and/or sacrificing their own family. To all the caregivers, having their family members’ wishes honoured was worth these sacrifices. The caregivers reported that grieving would be more difficult with the added burden of guilt over not letting their family member receive care in the community, as per their wishes.

And I think that for me, this all makes it easier for when she does die because I will be able to look back and be proud knowing that I did everything to grant her, her wishes, support her life, support the quality and I won’t have any regrets. Right? I will never have to be like “oh I wish I did more for my mom, I wish I did this or that”. Right? I never will have to. I will know that I did everything. (Caregiver Participant 10)

4.4.2 Fear of Hospitalization

All of the older adult participants mentioned being in a hospital prior to receiving palliative care services in the community. The older adults did not want to return to the hospital after receiving care in the community. Some reported that they would rather die sooner than receive care in a hospital.

I want to die at home. I would rather die than go to the hospital again. Like when they cut my…my…my foot…Yes. I felt so bad there. I wanted to die. They just came in. They just said things. Again to my daughter (Older Adult Participant 7).

At the hospital, I thought I was going to die. But at home even if I am sicker or you know I can die. But I am at home. I want to be home even if I die sooner here (Older Adult Participant 10).

The older adult participants were more fearful about returning to the hospital because they did not want to be away from their families or homes. Caregiver participants were also worried about their family member returning to the hospital, but for different reasons. The caregiver participants believed that the care they could provide at home to their family members, in conjunction with the help from the community palliative care
specialists, was better to than the care that could be provided in an institution. Almost all of the caregivers interviewed mentioned poor treatment outcomes after their family member had been in either a hospital.

I go away. Well I put her away. And she always comes back with bed sores. She’s dehydrated. She lost weight. And then it takes me about a month to get her back to where I usually have her (laughing). Because when I have her at home, she has never had a bed sore from me. Never. Ever. (Caregiver Participant 7)

Caregiver participants were fearful that hospitals took away their family member’s dignity.

I don’t think they understand that, doing that takes away his dignity. Or what. (Caregiver Participant 5).

I just know they couldn’t look after [Older Adult Participant 9] like the way I could. The way she is sometimes. They would have to give her more pills. They sedate her. Its undignified. (Caregiver Participant 9).

4.4.3 Uncertainty

While the care provided by the CCAC met their needs now, both older adult participants and caregiver participants described being anxious about what the future held. Due to the unpredictability of the dementia disease trajectory, older adult participants were fearful that their diagnosis would progress to the point, where the services provided by the CCAC would not be enough for them to continue to receive all their care at home. One older adult participant described his concern as such:

Well, I can’t do things for myself much. Like I can’t even take my pills. My wife has to hand them to me. It’s not because I can’t. It’s just to make sure I don’t forget. Because if I forget, then I can get really bad. But one day I may forget more. And well, when that happens, if I am even alive well then maybe I have to go somewhere. Dementia makes it hard for me to know (Older Adult Participant 8).

Informal caregivers also discussed the uncertainty of the future. Caregivers largely described how they might not have been able to attend to their family member’s wishes to remain in the home later as their condition progresses, particularly their diagnosis of dementia. They discussed they may have to put their loved one in an institution despite their wishes if they are unable to care for them. As one participant explained:
I have no intentions of ever putting him in a nursing home. I think that unless it got to the point where I absolutely have to because he gets violent. (Caregiver Participant 5).

The caregiver participants in this study found themselves acknowledging that the terminal condition may take their family member’s life prior to the dementia diagnosis getting worse. Caregiver participants felt that if it was just the terminal condition they would have to worry about, there would be less concern about the uncertainty of their family member passing away at home.

Because of the dementia. It is really also means that people cannot catch things earlier. So people actually get worse. You don’t know they are in pain. They hurt. People with dementia…

We just don’t know what is happening. I think that it needs to become …well…something that is becoming more and more present in society and it is becoming scary. It’s scary thinking that one day maybe she’ll be so bad that I can’t take care of her. I want to. I pray that the cancer gets me to that point where the dementia gets bad enough that I can worry about it. It’s hard. I am lucky to do this right now. (Caregiver Participant 10).

4.5 Conclusion

In conclusion, participants in this study provided an in-depth understanding of the experiences of individuals with dementia and their informal caregivers who are receiving palliative care in their homes within South-Western Ontario. All of the participants in this study were grateful for the services provided to them by the CCAC and were satisfied with the care provided in-home. Many caregiver participants felt they would not have been able to honour their family member’s wish to die at home if community-based palliative care services were not available to them. Similarly, older adult participants were relieved that such services allowed them to stay in their homes and with their families for as long as possible. Caregiver participants identified sources of strain, such as the challenge of balancing the demands of caring for someone with dementia and caring for someone with a terminal illness, as key to their experiences. The interviews also revealed the combined experiences of having a fear of hospitalization and a deep worry about uncertainty of the future. Caregiver participants and older adult participants described wanting to be able to be home for as long as possible, but recognize that because of the unpredictable trajectory of dementia, they may not be able to do so.
5 DISCUSSION

The purpose of this study was to better understand the lived experiences of community-dwelling individuals across South-Western Ontario who were receiving palliative care services due to a terminal illness, in addition to having a dementia diagnosis. This study explored the experiences of these patients and the experiences of their family caregivers.

This thesis chapter will discuss the central themes of this study, including their relation to the current literature. The study limitations and strengths will also be discussed. Recommendations and implications for future practice and research directions will also be presented.

5.1 The Older Adult Participants’ Experiences

All the older adult participants in this study described feeling as though they ‘belonged’ at home and that being home made it easier for them to accept their terminal illness. Several other authors also found that most individuals prefer to die at home with their family members present and in a familiar surrounding, with the majority of care being provided by their willing family (Canadian Hospice Palliative Care Association, 2006; Stajduhar & Davies, 2005; Wilson et al., 2009). Stephen (1991) states that dying persons and their relatives should be asked about what they consider to be a good death. This present study reiterated these findings, revealing that dying at home, with their family members present is what makes a good death for the older adult participants.

Older adult participants had a particular bias towards dying at home that might have been due to patients’ personal investment in attaining this end-of-life goal. Older adult participants in this study had others involved in their care—both professional and informal carers—presumably allowing the mobilization of resources to fulfil this wish to die at home. The influence of social factors and ethnicity on place of death, however, can also explain why these particular individuals were more likely to be able to pass away at home. For example, Koffman et al. (2004) found that many people from ethnic minorities feel they are not provided with enough choice about where they are able to pass away, unlike the Caucasian participants in this study.

Consistent with the findings of Gott et al. (2004), the home for all the older adults represented more than a physical space; it was also symbolic of their family, familiarity,
and memories. Older adults described their homes as places where they raised their children and grandchildren, were able to spend quality time with their family members and friends and were able to do a better job at remembering their surroundings, given their dementia diagnosis. It is therefore important to move beyond thinking of the home as the preferred place of death for simply the physical location. Gott et al. (2004) suggest that understanding the reasoning behind why older adults prefer to receive their palliative care at home provides an opportunity to help older adults unable to receive palliative care at home incorporate items, such as familiar objects or family photos into institutional settings, ultimately making them a more “homely”, enjoyable place to be (p. 465).

Individuals with dementia are rarely given a terminal diagnosis and often there is a lack of understanding about the terminal nature of dementia (Sampson, 2010). People with dementia are less likely to be referred to palliative care teams, as it is not seen as a terminal condition until the late stages (Ahronheim et al., 2000). This raises greater issues for individuals with dementia but no other terminal illness as dementia is often not viewed a terminal illness. These individuals may not receive palliative care, which aims to provide comfort for the terminally ill, until death is perceived as imminent (Sachs et al., 2004). A critical first step to enrolling in palliative care is to identify a patient as terminal, as this represents a barrier for people with dementia (Sachs et al., 2004). Individuals with dementia often pass away from other conditions than dementia itself, making it difficult for families and clinicians to view dementia as the sole proximate cause of death for individuals with dementia. None of the older adults in this study identified dementia as the condition taking priority in terms of care.

The term palliative care carries a stigma for patients and their caregivers, who regard it as synonymous with impending death (Zimmermann et al., 2016). Researchers have argued that palliative care should be discussed early on in the dementia disease trajectory. This may ensure that patients would receive a full spectrum of supportive care, offered to improve their quality of life from the moment of diagnosis through the course of illness (Cherny, 2009; Volicer, 2005; Zimmermann et al., 2016). Professionals and family members have difficulty viewing dementia as a terminal illness, and research suggests some clinicians are reluctance to discuss palliative care at the early stages of the illness because of the stigmatization associated with palliative care (Sachs et al., 2004). Public
education is critical for addressing the appropriateness of a palliative care approach for persons with dementia, and lessening the stigma associated with palliative care. Clinicians are also urged to integrate palliative care into routine dementia care. As Zimmermann et al. (2016) argue, stigma around palliative care will persist if palliative care is recommended at the late stages of disease trajectories, after curative or life-prolonging treatments are deemed ineffective or undesired. Snow and colleagues (2009) discovered that physicians referring patients frequently for palliative care helped individuals be better aware of the options that resulted in better patient outcomes across a variety of measures.

Given this body of research, patients with early stage dementia may not receive the care they want or the opportunity to receive their care in the place they want to die. All participants in this study were referred to palliative care due to their other terminal condition and not their dementia diagnosis. It is a great possibility that these participants would not have been able to access palliative home care services if they did not have an additional terminal illness. Prognostic indicators, such as functional dependency and recurrent hospitalizations have been developed to help identify individuals with dementia and other terminal conditions who may require palliative care (Sachs et al., 2004). It is recommended that clinicians use these indicators for when palliative care would be appropriate.

The Canadian Hospice Palliative Care Association (2013) states that there is a large prevailing myth in Canadian society that palliative care accelerates death, often perceived as being due to foregoing treatments. This means that the goals of palliative care remain unclear for many Canadians. For individuals with early stage dementia and their family members being told about palliative care early on in their disease trajectory may be troubling. This option may not be well-received if it is associated with an early-death. In this study, all older adult participants were aware of their limited life expectancy and acknowledged that they were dying. Some participants described their condition as being incurable, whereas others simply described that they were approaching death. None of the participants described a hope of being cured. This suggests that older adults with mild forms of dementia are similar to those without dementia in that they are intellectually
aware and accepting of their terminal condition(s) and are able to adjust their attitudes and ultimately, their lives accordingly.

According to the 2014 Annual Report of the Office of the Auditor General of Ontario (Ministry of Health and Long-Term Care, 2014) there are no minimum palliative care specific education requirements for physicians or nurses providing this care. To date, this still remains true. A lack of knowledge related to palliative care has been found to contribute to decreased quality of palliative care for those with dementia (Chang et al., 2009). Previous research, such as that conducted by Sachs et al. (2004) have argued for the need for more dementia-specific training for health care professionals. These authors assert that implementing these changes will improve the delivery of palliative care to individuals with dementia and raise awareness about dementia in the wider community. The goals of palliative care require a professional readiness of clinicians to allow their patients to make decisions that reflect their wishes. Research has shown that when patients have the knowledge and access to palliative care, their perceptions of the dying process changes and they are more likely to consider a palliative approach to care (Volicer, 2005). If physicians are not educated on palliative care, those with dementia who may require these services are at a disadvantage.

5.2 The Family Caregivers’ Experiences

All the family caregivers in this study identified the impact of dementia, the ‘double strain’ they felt and their need to maintain control as being central to their experiences. Ory and colleagues (1999) found that caregiving has greater effects on caregivers of individuals with dementia than caregivers for individuals without dementia in a variety of important domains of living, including social isolation and finances. Results of this study also support previous research findings stating that there is an associated burden with informally caring for a palliative family member at home (Hudson, Aranda, & Kristjanson, 2004; Linderholm & Friedrichsen, 2010; Stajduhar, 2003).

Findings from a study conducted by Smale and Dupuis (2004) found that caregivers of patients with dementia overwhelmingly reported impacts to their social lives. Such impacts included participating less often in social activities and lessening their involvement in group and other organized activities (Smale & Dupuis, 2004). The caregivers in the present study experienced objective burden because they felt that the
demands of caregiving resulted in them being unable to leave their homes and continue social relationships. Studies have found that as dementia progresses, caregivers give up activities to spend more time providing care to their family members (Meshefedjian et al., 1998). The close ties to one’s family member with dementia may impose a greater stress burden on family caregivers (Annerstedt et al., 2000). Similar to the findings of Mahoney et al. (2003), the caregivers in this study were concerned for the wellbeing of their care recipient even when they were not performing specific caregiving tasks. Spouses have been known to justify their caregiving burden in terms of role obligation, whereas adult children may believe that their caregiving responsibilities are unfair (Smale & Dupuis, 2004). Male caregivers may be able to keep a greater emotional distance from their caregiving tasks whereas female caregivers may feel greater feelings of guilt when not providing care (Kaye & Applegate, 1993).

Gott et al. (2012) posited that community health care professionals’ inadequate training about late-stage dementia may reinforce the tendency to give responsibility to others. This often places additional burden on family caregivers. All of the family caregiver participants believed that the palliative health care specialists who helped them deliver palliative care to their family member lacked dementia-specific knowledge and thus, they too, did not have the proper information about dementia. The participants in this study experienced similar feelings to caregiver participants in other studies who felt they were unprepared for their caregiving duties and responsibilities to those at the end-of-life (Bee, Barnes, & Luker, 2000; Stajduhar, 2003; Stajduhar & Davies, 2005). Staff who are untrained or uninformed about palliative care for individuals with dementia represent a significant barrier to accessing palliative care (Ryan et al., 2011). Helping patients and their families understand the nature of illness and prognosis is a crucial aspect of palliative care (Volicer, 2005).

All of the caregiver participants felt that the community palliative care workers were often aware of palliative care for individuals with dementia, but were not trained in how to deliver it. This is consistent with findings of previous studies (Hirakawa, Kuzuya, & Uemura, 2009; Volicer, 2005). Educational interventions have been found to be effective in providing caregivers with greater knowledge on how to manage behavioural problems for persons with dementia (Buckwalter et al., 1999; Chang, 1999). This increase in
knowledge can decrease caregiver burden related to dementia-related problems (Smale & Dupuis, 2004).

A review article by Chang (1999) indicated that most caregiver intervention studies use support programs or respite care to help homebound caregivers. Informal caregivers need to be relieved from their caregiving duties occasionally in order to restore and encourage their ability to continue caring for their family members (Smale & Dupuis, 2004; Schulz & Williamson, 1991). Individuals with supportive social relationships are happier, healthier and report less caregiver burden than those who are socially isolated (Schulz et al., 2003). The costs of respite care were identified by most of the family caregiver participants as a barrier to seeking support. In Canada, patients and their family caregivers bear the financial costs associated with palliative home care (Canadian Hospice Palliative Care Association, 2006). In a 2014 study conducted with Ontario caregivers of individuals with dementia, researchers found that almost half of caregivers described monthly expenses to be greater now that they were caregiving for someone with dementia (Smale & Dupuis, 2004).

Due to a lack of adequate support, all participants in the current study reported being physically exhausted and in dire need of additional respite time, although they could not afford it. This finding echoes the conclusions of prior research that indicate feelings of deteriorating health were the most significant predictor for caregiver burnout when caring for someone with a terminal illness (Almberg, Grafström, & Winblad, 1997). The caregivers in this study were in a unique situation as they were caring for someone with dementia who also had a terminal illness. The caregivers had to emotionally deal with coming to terms with their family member’s terminal diagnosis as well as their diagnosis of dementia. Proot and collaborators (2003) postulated that caring for a terminally ill individual at home requires balancing between dealing with their caregiver duties and coping with their family member’s terminal illness. As the caregivers in this study described, the care demands required of them are onerous and the emotional stresses are high as they grieve their family member’s impending death and face an uncertain future. Prior research has found many family members do not identify themselves as requiring support, focusing instead on the dying individual, hindering their acceptance of obtaining support (Stajduhar, 2003). Unmet caregiver needs can lead to prolonged grief, increased
use of health services, caregiver burden and decreased quality of life (Stajduhar, 2003). Woods, Beaver and Luker (2000) concluded that palliative care health professionals did not acknowledge the needs of the family caregivers in palliative care. As the palliative philosophy of care involves supporting the best possible quality of life for patients and their families, additional support is needed for caregivers. Earlier studies explain how informal caregivers receive little practical assistance to support them in their palliative caregiving duties (Cain et al., 2004; Keefe, 2011). Little is known about the most effective intervention for supporting family members providing palliative care.

Participants had the added challenge of caring for someone with dementia, leading to a ‘double strain’. Caring for individuals with dementia creates special challenges with respect to communication barriers, pain control and the need for vigilant care (Schulz et al., 2003). Consistent with findings in other studies (Smale & Dupuis, 2004), this study found that caring for individuals with dementia was physically exhausting and full of emotional and financial burdens for caregivers. An important policy question is how to best develop interventions that maximize the well-being of caregivers of individuals with dementia as well as the comfort of the individual with dementia for whom they are providing care.

All of the older adults in this study explained that being able to care for their family member at home gave them a better sense of control over their situation. In accordance to the control theory of aging, these participants sought to obtain control of their experiences by controlling the place they receive their palliative care. The mere belief that one has control over uncontrollable events is linked with ease of coping with an undesirable circumstance easier, such as a terminal illness (Redding, 2000). Individuals exposed to stress and illness cope better and exhibit better physical health if they feel they have control (Redding, 2000). Studies describe the importance of maintaining control by patients or their appointed surrogates at the end-of-life (Redding, 2000).

Caregivers in this study described doing absolutely everything they could for their family member and that the care at home was more personalized than it would have been in an institution. Caregivers were concerned about the care their family members would receive in an institution. Caregiver participants in this study had a particular bias against long-term care homes. Many researchers have found that families experience feelings of
guilt when placing a relative with dementia in a long-term care facility (Forbes et al., 2000; Schulz et al., 2004; Stajduhar, 2003). Thus, caregiver participants in this study may have had a bias against long-term care homes as an emotional response to their fear that they may not be able to continue to care for their family member at home. Family members often fault long-term care facilities as residents with dementia continue their decline towards greater frailty as a result of the underlying disease processes (Schulz et al., 2004). Many family members may have unrealistic expectations of long-term care facilities if they do not have a comprehensive understanding of dementia (Schulz et al., 2004). Additionally, family members may have expectations of care that are beyond the reasonable capabilities of a long-term care home (Schulz et al., 2004).

Caregivers often described long-term care as being impersonal and did not take into consideration the unique needs of their family members. The need for personalized palliative care for persons with dementia has received scant scientific research. It is likely that by providing as much personalized care as they possibly could, caregiver participants felt that they were gaining as much control as they could. Singer, Martin and Kelner (1999) identified that achieving a sense of control was one of the domains of quality end-of-life care. Participants in this study were able to achieve this sense of control in providing the majority of care to their family member.

According to the control theory of aging, maintaining a sense of control helped decrease the family caregiver’s vulnerability and provide better care for their family members (Redding, 2000). The control theory of aging explains that having a personal sense of control, such as controlling the care provided to their family member, served as an important psychological resource that helped the caregiver participants compensate for their inability to control the health status of their loved ones. Proot et al. (2003) suggest that having a sense of control protects caregivers against exhaustion and burnout. Caregivers who experience significant amounts of caregiver burden describe experiencing a sense of loss over the caregiving situation (Smale & Dupuis, 2004).

Singer, Martin and Kelner (1999) also found that individuals at the end-of-life want their family member to retain as much control over their care plans as possible. Caregivers in this study used strategies to maintain a sense of control in otherwise uncontrollable circumstances.
5.3 The Combined Older Adult and Family Caregivers’ Experiences

The older adult participants’ and the family caregiver participants’ experiences each revealed unique themes. They also shared three similar themes (honouring wishes, fear of hospitalization and uncertainty), although how they interpreted these themes differed.

The support received by the CCAC enabled the caregivers in this study to honour their family member’s wish to receive their palliative care in their own homes. The older adults were worried that they may not be able to continue to receive palliative care in their homes if their dementia progressed. The majority of individuals with dementia die in institutions and often spend their last days in long-term care homes (Ryan et al., 2011).

Persons with dementia typically receive less pain relief and fewer medical services that could help improve their quality of life at the end-of-life (McCarthy, Addington-Hall, & Altmann, 1997; Hirakawa et al., 2006). Previous findings indicate that, as their illness progresses, individuals with dementia experience agitation, fear and confusion, pain that is often not communicated, and several other mental problems (Cohen-Mansfield, 1996). The unpredictable, slow death trajectory associated with dementia makes it difficult for health care professionals to optimally care for those with end-stage dementia (Torke et al., 2010).

While the older adults in this study were aware of their imminent death, they described living with great uncertainty as to whether or not they would be able to continue to receive their care at home as their dementia progressed. In this study all older adults were in the early stages of dementia and caregivers acknowledged that their family member’s terminal illness would likely kill them before they were confronted with this difficult decision. Family caregivers believe that they are obligated to provide care at home out of a sense of love and duty, despite feeling ambivalent (Stajduhar, 2003). Consistent with other studies, the primary motivator for providing care at home for caregivers was related to poor experiences with acute and long-term care (Stajduhar, 2003). This suggests that improvements to palliative care are needed in these settings, as the majority of those with dementia do pass away in institutions.

The experience of caregiving at the end-of-life has been described as fundamentally uncertain by other researchers, in part due to unpredictable disease trajectories (Stajduhar, 2003). Forbes et al. (2000) and Stajduhar (2003) found that caregivers felt a
sense of failure when the person with dementia was placed into long-term care. Family carers are unprepared to make effective decisions about end-of-life care for persons with dementia when their family member enters long-term care due to a lack of available information (Stajduhar, 2003). Other studies have concluded that being uncertain was one of the largest barriers to providing quality end-of-life care for people with dementia (Harrison-Dening et al., 2012). A variety of interventions need to be incorporated in each specific client’s care plan to meet the diverse needs of caregivers and terminally-ill individuals wishing to receive palliative care in the community for as long as possible (Proot et al., 2004; Sampson, 2010). Palliative care policies for people with dementia have yet to incorporate interventions that address the challenges that dying with dementia in the community poses, such as pain-management (Downs et al., 2006). Flexible palliative care plans are instrumental in addressing the changing needs of terminally ill individuals and their families (Proot et al., 2004). For example, as the principle goal of palliative care is to relieve the suffering of patients and their families, when death becomes more imminent, terminally-ill individuals may require more aggressive palliation (Rome, Luminais, Bourgeois, & Blais, 2011). Receiving adequate pain and symptom management is one of the domains of quality end-of-life care put forth by Singer, Martin and Kelner (1999). As treatment intensifies, additional support should be provided to a dying patient's family (Rome et al., 2011).

When asked how community-based palliative care services were initiated, the majority of the older adults stated that they had expressed their wishes to their family member(s). None of the older adult participants described requesting palliative care. Caregiver participants described learning about home-based palliative care services only after trying to care for their family member without these services at home and through a Registered Social Worker at a hospital. The family caregivers then asked their family members if they wanted a palliative care plan, to which the older adult participants agreed to.

None of the participants in this study described having an advanced directive in place. This raises questions regarding what would happen if the older adults were at a later stage of their dementia when communication is difficult and individuals are unable to state their wishes or consent to a palliative treatment plan. As Hirschman et al. (2008) found, prompts for discussions about end-of-life care wishes for patients with dementia often
included medical events or changes to financial status. The older adult participants in this study may not have felt the need to put such a plan into place at this early point in their diagnosis. Advanced care planning represents an opportunity for people with dementia to discuss their wishes for end-of-life with their carers while they still have the cognition to do so. Clinicians should strive to avoid what a terminally-ill individual may consider an inappropriate prolongation of dying, as the prolongation of death has been identified as an important domain of quality end-of-life care by Singer, Martin and Kelner (1999).

Advanced care planning may help to ensure that future care will be centered around the terminally-ill individual’s wishes rather than the assumptions made by health care professionals or even family members. In the absence of advanced care plans, end-of-life decision making for people with dementia are usually shaped by religious beliefs, professional training, family understanding of palliative care and perspectives of other patients (Luchins & Hanrahan, 1993). These may not necessarily be the wishes of the individuals themselves (Luchins & Hanrahan, 1993; Rurup et al., 2006b). Mezey et al. (2000) found that family caregivers with a greater sense of caregiver burden were more likely to consent to life-sustaining treatment. Some of the participants in this study described feeling as if they required more information about dementia to make more informed decisions about their family member’s end-of-life care. Family caregivers are often unprepared for decision-making at the end-of-life for people with dementia (Forbes et al., 2000; Hirschman et al., 2004; Smale & Dupuis, 2004). Having an advanced care plan in place early, prior to the dementia progressing may make things easier on family and caregivers and enable them to better honour their family member’s wishes.

5.4 Limitations of the Study

This study had several limitations. All participants received their home care services from organizations contracted out by the CCAC. The sample may not be representative of individuals who receive palliative care support services from elsewhere. It is important to conduct further research with individuals who do not use services provided by the CCAC to understand their experiences with community-based palliative care. All participants in this study were in the early stages of dementia and all were able to answer the researcher’s questions. It is important that future research explores the experiences of
individuals in mid and late stages of dementia, as well as the experiences of their caregivers.

Ethnicity was not a focus of this study. All participants were Caucasian and these experiences may not be representative of individuals from other cultures. The study did not compare participant experiences on the basis of severity or total number of chronic conditions. It is important for future research to investigate the role different conditions, diseases and severity of conditions have on the experiences of older adults living with dementia and their caregivers.

This study was also constrained by the circumstances of the participants. While some caregivers were able to talk in great lengths, others were not able to due to other time commitments and caregiving duties. Some older adult participants were only free to be interviewed in the late afternoon, which may have impacted their answers due to ‘Sundown Syndrome’. Sundown syndrome, also known as ‘sundowning’, affects individuals with dementia and is marked by a worsening confusion and agitation in the later afternoon and evening in comparison to symptoms earlier in the day (Khachiyants, Trinkle, Son, & Kim, 2011). Three older adults requested that the interview be cut short due to fatigue. Two of the family caregivers completed the study with a nurse or personal service worker present, which may have influenced the answers of the participant.

5.5 Implications for Practice

The current study offers some insights that are useful to consider in the future development of community-based palliative care services for individuals with dementia. The findings of this study can help government organizations, health care commissioners and palliative care professionals improve on their services by providing them with insight into what caregivers need to best care for terminally ill individuals at home. This study contributes to the greater, and growing, body of evidence-based research highlighting particular aspects of community-based palliative care that warrants attention and improvements.

This study demonstrated the importance of respite care for home-bound caregivers. Providing more respite periods for informal caregivers and access to extra personnel, especially at night, would help support the physical and psychological health of caregivers. In turn, this would ensure that they are better able to support the wishes of
their family member by allowing them to remain at home for as long as possible. The alleviation of burden and the ability to strengthen relationship with loved ones are fundamental in achieving a quality end-of-life (Singer, Martin & Kelner, 1999). The Ontario government has recognized that community-based palliative care is a cost-effective strategy to current hospital-based palliative care unit spending (Ministry of Long-Term Care, 2014). It is acknowledged that there are limited resources available (including financial and human resources) to provide additional respite time and care for family caregivers caring for their family members at home (Ministry of Long-Term Care, 2014). One possible solution is for the CCAC to lessen the day-time visits of willing caregivers and allocate those hours for additional respite or night care.

As Ontario hospices are largely expected to generate large portions of their revenue through fundraising or donations and the majority of individuals pay for additional palliative care services out-of-pocket (Ministry of Long-Term Care, 2014), a possible solution is to create a non-profit organization that focuses on peer-support for caregivers of those receiving palliative care, with trained volunteers who may be able to provide this additional respite time. To date, this does not exist in South-Western Ontario.

Support group opportunities for informal caregivers are also recommended. Nearly all of the participants mentioned that greater emotional support was required, and that support groups would be beneficial. Many of the caregiver participants mentioned not being able to attend the available support groups because they are unable to leave their family member unattended. Providing individuals with more respite opportunities so that they are able to attend support groups or creating a long-term telephone or teleconference support group, is recommended. These support groups should be facilitated by a clinical social worker or registered health care professional knowledgeable about palliative care and dementia.

It is also important that family caregivers are well educated on their family member’s medical conditions. Caregiver participants expressed a longing for more education and information about the conditions of their family member, especially in terms of the dementia diagnosis, and the medical care plan followed by the home-based health care providers. Educating palliative care providers on dementia will allow them to better educate family caregivers. It is important that health care providers are also trained on
how to best deliver this knowledge as medical jargon has been frequently cited as a
barrier to adequate understanding about palliative care plans (Northouse & Northouse,
1998). A combination of additional education and caregiver support may help family
members sustain and fulfill their caregiving duties and support them in ensuring they are
able to keep their family members at home.

Another policy recommendation involves making greater attempts to have fewer
health care professionals visit the family and patient and instead have more continuity of
staff. Older adult participants mentioned being confused by the many different staff
members who enter their homes. Caregiver participants mentioned their family member
being more reluctant to accept the care provided by an unfamiliar face. Both wished that
the majority of home visits be conducted by staff members familiar to them. Family
caregivers also requested regular visits from physicians, even when no medical issues
seem apparent. Family caregivers believed doing so would help avoid any unnecessary
visits to medical clinics and hospitals and would provide them with reassurance that their
family member is receiving suitable care. It is also recommended that home care staff
members make more of an effort to communicate with older adult participants with
dementia, as older adult participants described feeling as if their care providers did not
engage them in conversations about their care plans.

The prevalent belief that a person with mild forms of dementia cannot be involved in
health care decisions or give their preferences for care must be eliminated. It is vital that
people with dementia are fully engaged in their health care plans for as long as they can.
If community-based services for persons with dementia are to remain effective, they must
encourage user feedback taken directly from the individuals with dementia receiving
these services.

The terminology used when discussing the palliative philosophy of care should be
clarified throughout the continuum of medical care. Interviews revealed much confusion
and some incorrect assumptions about what the palliative philosophy of care entails. In
the absence of a clear understanding of palliative care, participants of this study found
their own ways of defining palliative care, by comparing palliative care to end-of-life
care. Participants may have developed a misunderstanding about palliative care from
health care professionals. Better awareness of what palliative care does and does not
entail will help ensure patients and their families are able to make appropriate decisions regarding their care plans. This includes the possibility of an early initiation of palliative care and not just solely reserving the palliative philosophy of care to individuals nearing death.

Health care providers offering palliative care services are encouraged to educate referring providers and their patients on what the palliative care philosophy entails early in the dementia disease trajectory. In the absence of clear medical guidelines as to when to best deliver palliative care to individuals with dementia, it is recommended that palliative care discussions be integrated into health care practices. In doing so, individuals will better understand the palliative care philosophy and will have the ability to differentiate between palliative care and end-of-life care. This will allow individuals and their family members to make informed decisions appropriate to their needs and wishes. Individuals diagnosed with dementia wishing to opt for a palliative care plan will be better able to access palliative care services earlier.

5.6 Future Research Recommendations

This study examined the experiences of individuals receiving community palliative care services in South-Western Ontario while also having a dementia diagnosis. While there is a growing body of research identifying the challenges of providing quality palliative care for a person with dementia, the available studies are largely conducted in institutional long-term care settings, as many patients die in these settings (Houttekier et al., 2010). There is a need for community-based research that identifies the characteristics needed to facilitate optimal care for those choosing to die at home.

Future studies with larger sample sizes across larger geographical regions are necessary to make recommendations for future best practice guidelines and service delivery models. More specifically, it is recommended that a longitudinal study be used to explore how family caregivers continue to experience palliative care services in the community, from start to end. This will allow researchers to explore how experiences differ as individuals move through the various stages of dementia and how caregiving needs change. While it is difficult to interview individuals in more advanced stages of dementia, it would still be useful to include them in such a study in order to learn more about their decisions and wishes at the start of the care process and use this to compare it
to their actual outcomes later in the trajectory. Doing so will allow researchers to gather information about how the disease trajectory impacts palliative care delivery in community-based settings over time.

As persons with dementia often receive too little, if any, palliative care support in the early stages of their illnesses (Ryan et al. 2012), discovering novel and innovative strategies to reach individuals early on in their experiences of receiving palliative care services is suggested. One suggestion for future research would be to pair researchers with health service providers and social workers in institutionalized settings where the discussion of community-based palliative care is said to often begin, in order to recruit participants into the process as soon as possible. Similarly, it would be helpful for researchers to connect with personal support workers, or public health nurses who may come in close contact with more isolated individuals who may not know about palliative care services. Likewise, it would be beneficial to explore private health care agencies that deliver palliative care services for individuals with dementia.

It would be beneficial to use comparative research methods to explore how palliative care experiences for patients with dementia at home is similar or different to individuals in hospices, in long-term care homes and in hospitals. It is also recommended that future research continues to include people with early-stages of dementia, given that it is these individuals who are receiving the care and subsequently, whose opinions, wishes and experiences, arguably, matter most. This study highlighted the feasibility of including participants with dementia in qualitative research. This novel contribution identified the experiences of older adults with dementia who are receiving palliative care in the community by using first-hand accounts as sources of data. This provides some evidence that people with dementia are suitable for participation in future qualitative research initiatives. People with dementia can and should be involved in future studies surrounding palliative care, as long as researchers take the appropriate steps to adapt their methods to allow for active participation.

5.7 Conclusion

The number of Canadians with dementia in need of palliative care is increasing as the expected number of those affected by dementia continues to grow and older adults live longer. One of the most common wishes of terminally ill older adults is to die in their
homes and communities. There is a need to better understand the delivery of palliative health care services in community settings for older adults with dementia. More specifically, there is a need to better understand the complex experiences of older adults with dementia who are receiving these palliative care services and the experiences of their informal family caregivers who provide the majority of their in-home care. Little research exists which explores such issues.

This interpretive phenomenological study described the lived experiences of ten older adults with dementia who are currently receiving palliative care in South-Western Ontario and the experiences of their informal family caregivers. The findings of this study highlight the unique experiences of living with dementia and another terminal illness at the end-of-life, as well as the challenges of caring for someone with these conditions. All participants were grateful for the care provided by the CCAC and believed that receiving palliative care services in the home would not be possible without the community-based palliative care professionals. Caregiver participants described the physical and psychological hardships of caring for someone who is receiving palliative care for a terminal diagnosis, and who also has dementia. Family caregivers also reported that caring for their family member at the end-of-life has many rewards. While overall the experiences of these individuals were positive, the findings of this study suggest the need for improvements in community-based palliative care delivery for people with dementia.
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Appendix A: Telephone Script for Case Managers

Hello _________, I would like to talk to you about a study being conducted to better understand the experiences of those receiving palliative care services in the community due to a terminal condition in addition to dementia. The study is being conducted by a Master of Science in Health and Rehabilitation Sciences student, Kristina Kokorelias, in collaboration with Dr. Kloseck from Western University. The study will explore the personal experiences of elderly individuals receiving care and their informal, family caregivers and what it is like to receive palliative care in the community with a dementia diagnosis. Kristina would like to interview older adult participants and their care providers along with a representative of the Community-Care Access Centre. It is also the hope that a Case Manager from the CCAC will assist in the recruiting of participants, given their knowledge of those who may best meet inclusion criteria. If you are interested in assisting with this study, I am happy to send you a letter of information that outlines the study in more depth and you can contact one of the researchers if you would like to be a participant in the study. Thank-you for your time.
Appendix B: Letter of Information & Consent (Older Adults with Dementia)

Project Title: The Lived Palliative Care Experiences of Community-Dwelling Older Adults with Dementia in South Western Ontario

Principal Investigator:
Dr. Marita Kloseck
address
e-mail
phone number

Student Researcher:
Kristina Kokorelias
address
e-mail
phone number

Letter of Information
Older Adult Participants
You are being invited to participate in a Master’s level thesis project within the Faculty of Health Sciences at Western. This research study investigates how you are experiencing palliative care being delivered to you in your home in order to better understand you needs. This letter will provide you (and/or your proxy decision maker) with the information required to make an informed decision regarding participating in this research study. This letter will also describe to you why this study is being conducted and what your participation in the study will entail. Please take your time to read the whole letter carefully and feel free to ask any questions that you have. You will be given a copy of this letter of information and consent form to keep, for your records, once the papers have been signed.

1. **Purpose of this Study**

   The purpose of this study is to better understand the experience of receiving palliative care in the community while also having a diagnosis of dementia.

2. **Number of Participants**

   There will be 10 participants in this study. Participants will include individuals who are receiving palliative care along with their informal family care provider.

3. **Who is Eligible to Participate?**

   To participate, you must be over the age of 65, able to speak English, have a diagnosis of a terminal condition for which you are receiving community-based palliative care for at least three (3) months, and have a diagnosis of early-stage dementia. You must also have an informal caregiver with whom you live with, or see regularly, who is willing to participate in this study. You must be able to provide informed consent or have a substitute proxy-decision maker to provide informed consent. Lastly, participants need to be from London, Ontario and the surrounding area.

   Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, end data collection interviews before they are finished or withdraw completely from the study at any time.
caregiver willing to participate are not eligible to participate in this study. Participants who cannot be interviewed in London, Ontario and unable to be interviewed via telephone are also not eligible.

4. Study Procedures

As a participant in this study, you will be asked to complete an interview, which will be audio-recorded with your consent. Your informal caregiver may be present for the interviews. Interviews will take place at your home or at a place where you feel most comfortable. If participants cannot be interviewed in person, telephone interviews may be used. Interviews will last approximately 30-45 minutes each session and will consist of open-ended questions of for you to answer. These questions will ask about your experience of receiving palliative care in the community. The researcher may also ask you to meet for a second time if she requires a better understanding of your experience.

5. Possible Risks and Harms

There are no known physical risks to your participation in this study. However, discussion of your recent experiences and conditions may bring up extreme emotions. Similarly, you may find it difficult to communicate your answers with the researcher. A list of support services available in London, Ontario, that are free of charge, will be provided to you.

6. Possible Benefits

You may not directly benefit from participating in this study. If you agree to participate, you will be sharing information that may improve the quality of palliative care services provided in the community. Once the study has been completed, it is hoped that the findings of this study will guide policy changes and future best practices for palliative care for people with dementia and also to help inform the design of a community-based, dementia-specific model of palliative care within South Western Ontario.

7. Compensation

You will not be compensated for your participation in this research.
9. 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 delivery of care. Should you withdraw from this study, all data collected from your interviews will be destroyed and will not be analyzed.

10. Confidentiality

All data collected will remain confidential and accessible only to the investigators of this study. If the results are published, your name will not be used and changed into a pseudonym. No identifying information will be linked to the data for the purpose of anonymity. All data will be stored in a locked desk in the Sam Katz Community Health and Aging Research Unit at Western University, which can only be accessed by members of the research team. Computer files will be password protected. Non-identifiable data will be kept for 5 years after the study is completed and then will be shredded and destroyed to remain confidentiality. If you choose to withdraw from this study, your data will be removed and destroyed immediately. While we will do our best to protect your information there is no guarantee that we will be able to do so. Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

11. Contacts for Further Information

If you require any further information regarding this research project or your participation in the study you may contact the Principal Investigator, Dr. Marita Kloseck phone number, email: email or the student researcher, Kristina Kokorelias phone number, email: 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 (519) 661-3036, email: ethics@uwo.ca.
12. **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 the study results, please contact the student researcher, Kristina Kokorelias (*phone number*, email: *email* or please provide your name and contact number on a piece of paper separate from the Consent Form.

13. **Consent**

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

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

Project Title: The Lived Palliative Care Experiences of Community-Dwelling Older Adults with Dementia in South Western Ontario

Study Investigator’s Name: Dr. Marita Kloseck, PhD, Faculty of Health Sciences, Western University

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

Participant’s Name (please print): ___________________________________________

Participant’s Signature or Proxy: _____________________________________________

Date: ____________________________________________________________________

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

Legally Authorized Representative (if applicable) Print: ______________________

Legally Authorized Representative (if applicable) Sign: ________________________

Legally Authorized Representative (if applicable) Date: ________________________

Person Obtaining Informed Consent (please print): ___________________________

Signature: __________________________

Date: ____________________________

Page 6 of 6 Version Date: 10/17/2015 Participant Initials___
Appendix C: Letter of Information & Consent (Family Caregivers)

**Project Title:** The Lived Palliative Care Experiences of Community-Dwelling Older Adults with Dementia in South Western Ontario

**Principal Investigator:**
Dr. Marita Kloseck
*address*
*phone number*
*email*

**Student Researcher:**
Kristina Kokorelias
*address*
*phone number*
*email*

Participant Initials____
Letter of Information

Informal Family Caregiver Participants

You are being invited to participate in a Master’s level thesis project within the Faculty of Health Sciences at Western. This research study investigates how you are experiencing palliative care being delivered to you in your home in order to better understand your needs. This letter will provide you (and/or your proxy decision maker) with the information required to make an informed decision regarding participating in this research study. This letter will also describe to you why this study is being conducted and what your participation in the study will entail. Please take your time to read the whole letter carefully and feel free to ask any questions that you have. You will be given a copy of this letter of information and consent form to keep, for your records, once the papers have been signed.

1. Purpose of this Study

The purpose of this study is to better understand the experience of receiving palliative care in the community while also having a diagnosis of dementia.

2. Number of Participants

There will be 10 participants in this study. Participants will include individuals who are receiving palliative care along with their informal family care provider.

3. Who is Eligible to Participate?

To participate, you must be over the age of 18 and able to read and speak English. Participants who are directly involved in providing and/or managing palliative care needs for a family member or friend, with whom they live, and who are not employed in health care are eligible to participate. Participants must be able to provide consent. Lastly, participants need to be from London, Ontario and the surrounding area.

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, end data collection interviews before they are finished or withdraw completely from the study at any time.
4. **Exclusion Criteria**

Participants who are unable to understand English, unable to communicate (including those with severe forms of dementia) and those without an informal caregiver willing to participate are not eligible to participate in this study. Participants who cannot be interviewed in London, Ontario and unable to be interviewed via telephone are also not eligible.

5. **Study Procedures**

As a participant in this study, you will be asked to complete an interview, which will be audio-recorded with your consent. Your family member may be present for the interviews. Interviews will take place at your home, or at a place where you feel most comfortable. If participants cannot be interviewed in person, telephone interviews may be used. Interviews will last approximately 30-45 minutes each session and will consist of open-ended questions you to answer. These questions will ask about your experience of providing care to someone who is receiving palliative care in the community. The researcher may ask you to meet for a second time if she requires a better understanding of your experience.

6. **Possible Risks and Harms**

There are no known physical risks to your participation in this study. However, discussion of your recent experiences and the conditions of your family member may bring up extreme emotions. Similarly, you may find it difficult to communicate your answers with the researcher. A list of support services available in London, Ontario, that are free of charge, will be provided to you.

7. **Possible Benefits**

You may not directly benefit from participating in this study. If you agree to participate, you will be sharing information that may improve the quality of palliative care services provided in the community. Once the study has been completed, it is hoped that the findings of this study will guide policy changes and future best practices for palliative care for people with dementia and also to help inform the design of a community-based, dementia-specific model of palliative care within South Western Ontario.
8. **Compensation**

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

9. **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 delivery of care. Should you withdraw from this study, all data collected from your interviews will be destroyed and will not be analyzed.

10. **Confidentiality**

All data collected will remain confidential and accessible only to the investigators of this study. If the results are published, your name will not be used and changed into a pseudonym. No identifying information will be linked to the data for the purpose of anonymity. All data will be stored in a locked desk in the Sam Katz Community Health and Aging Research Unit at Western University, which can only be accessed by members of the research team. Computer files will be password protected. Non-identifiable data will be kept for 5 years after the study is completed and then will be shredded and destroyed to remain confidentiality. If you choose to withdraw from this study, your data will be removed and destroyed immediately. While we will do our best to protect your information there is no guarantee that we will be able to do so. Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

9. **Contacts for Further Information**

If you require any further information regarding this research project or your participation in the study you may contact the Principal Investigator, Dr. Marita Kloseck phone number, email: email or the student researcher, Kristina Kokorelias phone number, email: 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 (519) 661-3036, email: ethics@uwo.ca.
10. 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 the study results, please contact the student researcher, Kristina Kokorelias phone number, email: email or please provide your name and contact number on a piece of paper separate from the Consent Form.

11. Consent

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

This letter is yours to keep for future reference.
Consent Form

Project Title: The Lived Palliative Care Experiences of Community-Dwelling Older Adults with Dementia in South Western Ontario

Study Investigator’s Name: Dr. Marita Kloseck, PhD, Faculty of Health Sciences, Western University

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

Participant’s Name (please print): ___________________________________________

Participant’s Signature: _________________________________________________

Date: _________________________________________________________________

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

☐

Signature:

_____________________________________________________

Date: 

_____________________________________________________

Participant Initials: _____
Appendix D: Ethics Approval Form

Research Ethics

Western University Health Science Research Ethics Board
HSREB Full Board Initial Approval Notice

Principal Investigator: Dr. Marita Klouche
Department & Institution: Schulich School of Medicine and Dentistry/Medicine-Dept of Western University

Review Type: Full Board
HSREB File Number: 107194
Study Title: The Lived Palliative Care Experiences for Community-Dwelling Older Adults with Dementia in South Western Ontario
Sponsor:

HSREB Initial Approval Date: December 10, 2015
HSREB Expiry Date: December 10, 2016

Documents Approved and/or Received for Information:

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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 (TCP52), 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

Ethics Officer to Contact for Further Information: Jilka Bashe / Nicole Kamii / Grace Kelly / Miss Mekhalfi / Nabil Taha

This is an official document. Please retain the original in your files.

Western University, Research, Support Services Bldg, Rm 5150
London, ON, Canada N6G 1L9 t. 519.661.3036 f. 519.850.2456 www.uwo.ca/researchEthics

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Appendix E: End-of-Life Care Support Services

Describing your experiences of receiving palliative care or describing the experiences of your family member may cause emotions to surface. Please find services below that you can access in London, Ontario that are free of charge. Please remember that there is no timeline on receiving support to meet your emotional, spiritual and practical needs.

**London and District Distress Centre:**
A confidential telephone to support for seniors and their caregivers to assist with:
- problem solving skills
- crisis intervention
- referral to other agencies as appropriate

**Hospice of London**
Bereavement support programs that are offered at Hospice of London include:
- Volunteer Visiting Program
- “Walking with Friends” Bereavement walking group
- Mindfulness for Healing
- Massage Therapy
- Reflexology
- Healing Touch and Bereavement Support
- Reiki
Appendix F: Semi-Structured Interview Guide (Older Adult Participants)

Semi Structured Interview Guide

(Older Adult Participants)

Today is ____________at ______________and I will be interviewing participant ____________.

To start, I will be asking you questions about your experience with receiving care in the community.

1. I wonder if as we begin if you could tell me a bit about your experiences in living with more than one condition at a time. What is it like to live with multiple chronic conditions?

   Probe: Of these conditions, do you think one takes priority in terms of care? What takes priority? What are the challenges you face living with more than one condition at a time? Where does the dementia diagnosis come in?

2. How do you experience community health care services in your everyday life?

   Probe: Who is currently involved in providing care to you? Are there any doctors or specialists you see regularly? Or any other in-home services you receive? How is your care coordinated between all your care providers?

3. Are there any differences in how you experience care throughout your days today, compared to a typical day before you began receiving palliative care services?

   Probe: Is this experience different than you expected? Is it the same? How do you feel regarding your experiences related to both the dementia and palliative care services you receive? What is working well? What is not working so well? If you could change one thing, what would you change?

Thank you very much for sharing. Now I’d like to ask some questions about your perceptions about palliative care.

4. Can you please describe what palliative care means to you?
Probe: Are there any palliative care or other resources that you need or would like that you currently don’t have? What do you like most about the services you receive? What do you like least?

5. Can you help me understand how you came to choose home-based palliative care?

Probe: What informed your decision? What were your expectations? Have your views about home-based palliative care changed since you began receiving your care? What is different from what you thought it would be?

6. Considering your current experience with community palliative care so far, are there any additional services or help of any kind that would be useful to you?

7. Is there anything else that you would like to share about your experiences? Anything that stands out for you about receiving care in the community? Anything you liked? Anything you wish could be done differently?

THANK YOU.
Appendix G: Semi-Structured Interview Guide  (Family Caregiver Participants)

Semi Structured Interview Guide

(Caregivers)

Today is _______________ at ______________ and I will be interviewing participant ______________, caregiver to _________________.

To start, I will be asking you questions about your experience with providing care to someone with a terminal condition in the community.

1. I wonder if as we begin if you could tell me a bit about your experiences providing care to someone who is terminally ill and residing in the community. What is your role in this care?

   Probe: What are the challenges you face in providing this care? Can you please share your experiences as to what it is like to provide both palliative care and care for someone who has dementia? Does the dementia make it more difficult to provide the palliative care that is needed? If so, how is it more difficult? What are your biggest challenges? If you could change one thing that would make it easier for you, what would you change?

2. Are there any differences in your caregiving experiences today, compared to a typical day before palliative care services were required?

   Probe: What changes in your life have you experienced since becoming a caregiver for someone who is terminally ill who also has dementia? Is this experience different than you expected? How do you feel about the community health services you receive?

3. Considering the whole experience of caregiving, what is the most challenging part of being a caregiver for someone who is terminally ill? What is the most rewarding part of your experience?

   Probe: What about the challenges of caring for someone who is terminally ill with dementia?
Moving on, I’d like to ask some questions specific to the palliative care needs of someone with dementia.

4. What is your experience of palliative care as it relates to caregiving for someone with dementia who also has a terminal illness?

   Probe: Are there any special issues that need to be considered in providing palliative care to someone with dementia? Are there any services that you wish were available to you that you currently don’t have? What do you like most about the services and supports available to you? What do you like least?

5. How does the experience of providing palliative care for someone with dementia change your needs?

   Probe: In your opinion, how does having dementia affect the palliative care needs of someone who is terminally ill? How does caring for someone with both dementia and a terminal illness change your caregiver support needs? Do you perceive your experience with caring for someone with dementia to be different from caring for someone who is terminally ill without a cognitive impairment?

Thank you very much for sharing. Now to conclude, I’d like to ask some questions about your general perceptions about community-based palliative care.

6. Can you help me understand how you or the person you are caring for decided to choose home-based palliative care?

   Probe: How important is it for you or the person you are caring for to remain at home? Why is it important? Have your views about home-based palliative care changed? If so, why? Is anything different than you thought it would be?

7. Considering your current experience with community palliative care so far, are there any additional services or help of any kind that would be useful to you?

8. Is there anything else you would like to share regarding your experiences as a caregiver for someone with dementia requiring palliative care? Anything that stands out for you about receiving care in the community? Anything you liked? Anything you wish had been done differently?

**THANK YOU.**
Appendix H: Socio-Demographic Questionnaire

The Lived Palliative Care Experiences for Community-Dwelling Older Adults with Dementia in South Western Ontario

Demographic Questionnaire

Please answer the questions below. All information will be kept confidential and participation is strictly voluntary. You may choose not to answer certain questions. You may also withdraw from the entire study at any time. If you have any questions or concerns, please contact the primary investigator, Dr. Marita Kloseck.

Telephone: __________________________________________________________

1. Are you: _______ male    _______ female  

2. Is your family member one: _______ male    _______ female  

3. Age groups (check one):

   _______ <26          _______ 46-65
   _______ 26-35        _______ 66-75
   _______ 36-45        _______ >75

4. Are you the sole informal care provider for your family member:

   _______ Yes
   _______ No (If so, please state who else is involved: __________________________)

5. How long have you been providing care for your family member (check one):

   _______ <2 years         _______ >7 years
   _______ 2-4 years        _______ 5-6 years
6. What is your employment status (check one):
   _______ employed full-time         _______ employed part-time
   _______ volunteer work            _______ unemployed
   _______ retired                    _______ other

Version Date: 10/17/2015

7. What is the highest level of education you have completed?
   _______ less than high school
   _______ high school (9-12 years)
   _______ college (diploma) or university (Bachelor's degree)
   _______ university with advanced degree (Master's, PhD, or MD)
   _______ other education (please specify: __________________________)

8. Do you currently live (check one):
   _______ by yourself
   _______ with your spouse or partner
   _______ with another member of your family (e.g. child, grandchild)
   _______ with a friend or roommate
   _______ or with someone other than mentioned above (please specify:
   __________________________________________________________________)

9. Where does your family member currently live (check one):
   _______ alone
   _______ with spouse or partner
   _______ with you (caregiver)
   _______ with another member of your family (e.g. child, grandchild)
   _______ with a friend or roommate
   _______ or with someone other than mentioned above (please specify:
   __________________________________________________________________)

10. Please list the conditions that your family member has been diagnosed with.

11. How long ago was your family member diagnosed with dementia?
   _______ <1 year           _______ > 4 years
   _______ 1-2 years
12. How long ago did you/your family member begin seeking support from the CCAC?

________ <1 year             ________ > 4 years
________ 1-2 years
________ 3-4 years

13. If you receive any other support besides from the CCAC, please list them below. If not, please skip to 13.

14. Are you satisfied with the services you receive to assist you in providing care to your family member?

1 _____________ 2 _____________ 3 _____________ 4 _____________ 5
extremely satisfied    somewhat satisfied    dissatisfied

15. How satisfied with your own health are you?

1 _____________ 2 _____________ 3 _____________ 4 _____________ 5
extremely satisfied    somewhat satisfied    dissatisfied
Appendix I: Interpretive Summaries of the Participants

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<th>Older Adult Participant</th>
<th>Caregiver Participant</th>
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<tr>
<td><strong>1</strong> Male. Interview took place in caregiver’s home. Lives in a bungalow alone. Never been married. No children. Distance from majority of family, asides from his two cousins and their mother and spouses. Has not told any other family members about his conditions. Youngest participant, at sixty-five. Severe troubles breathing, many instances of coughing during the interview. Carries around an oxygen tank, but relies on no other assistive devices. Has not been able to work in the past ten years due to his condition and spends his day with his dogs. Still drives. Very independent, prefers to do everything alone. Receives care from a Personal Support Worker twice a week and a nurse when needed. Has been receiving care from the CCAC for a year. Was diagnosed with a mild form of dementia a year ago and has one additional chronic condition.</td>
<td>Male. Interview took place in participant’s home. Married with two children in their twenties who no longer live at home, but whom he visits twice a month. Did not share too much, was brief with answers. Owns his own business, works long hours, very few days off. Changes his work schedule to care for his cousin when need be. Smoker and does not take much time for self, yet rated himself as healthy despite this. Has a large extended family, but only receives some assistance from his brother in terms of caring for his cousin. Provides some care to his aging mother as well. Has to travel far to visit mother and his care dependent. Strong social circle – family and friends. Very strong connections with family. Resilient, good coping skills. Satisfied with the services provided by the CCAC.</td>
</tr>
<tr>
<td><strong>2</strong> Female. Interview took place in her home that she shares with her daughter and her children. Widowed. Only employed part time prior to retirement after her children went to high school, was a stay at home mom prior. Two adult children. Six grandchildren, two grandchildren with whom she lives with. Diagnosed with breast cancer years ago, prior to her dementia diagnosis. Long history of being engaged in the church community. Very strong social connections with both immediate and distant family, lots of familial support, if needed. Described by caregiver as not being accepted of palliative care treatment route. Receives care from a Personal Support Worker or a nurse once a week. She has been receiving care from the CCAC for three years. Was diagnosed with a mild form of frontal temporal dementia three years ago and has two other chronic conditions.</td>
<td>Female. Interview took place in participant’s home as mother was sleeping. Lives with her husband and two small children. Was an elementary school teacher, but has not worked since her children were born. Was mother’s caregiver during her previous bought with cancer as well. Very engaged within the community-volunteers at children’s school. Strong connections with immediate and extended family, yet is the only caregiver for her mother. Kept referring to the fact that she wasn’t a health care professional, but wishes she was to provide better care. Struggles to find a balance between caring for her mother and caring for her children. Identifies as home bound. Satisfied with the services provided by the CCAC and her own health, but believes she now takes on more of the caregiving role compared to when her mother was not palliative.</td>
</tr>
</tbody>
</table>
3 Male. Interview took place in the participant’s home which he shares with his wife and children. Has two children in their early twenties. Is being tested for schizophrenia in the upcoming weeks following our interview. No longer able to drive. Strong connections with immediate family. Social connectedness is desired, feelings of loneliness when home alone and hence, enjoys the visits from Personal Service Workers and Nurses. Is home during the day alone, while wife works. No longer is able to leave home unless accompanied by someone. Avant watcher of various news channels on TV and frequently discussed world events during our interactions. Two dogs. Described by wife as a ‘very sweet man’. Is aware he is passing away. Receives care from a Personal Support Worker once a week and a nurse only visits every 3-4 weeks. He has been receiving care from the CCAC for one-two years. Was diagnosed with a mild form of frontal temporal dementia one year ago and has two other chronic conditions.

Female. Interview took place in a coffee shop. Lives with her husband and two children. Youngest caregiver participant. Described having a very close relationship with her immediate family, but is the sole caregiver to her husband. Mentioned reaching out to various community health resources like the Alzheimer’s Society to get as much information and education as possible, but feels she doesn’t receive a lot of support from the palliative care home services. Volunteers with the Diabetes foundation. Works part time as an administrative assistant. Has many hobbies. Also referred to the fact that she wasn’t a health care professional. Requests support groups. Very friendly. Struggles with the emotional aspects of caregiving. Satisfied with the services provided by the CCAC and her own health.

4 Female. Interview took place via Face-time telephone call. Widowed. Lives with her daughter and two young grandchildren and has been for many years. Has a long history of depression beginning in adolescence. Originally from Nicaragua and traveled there frequently prior to her illnesses. Was educated in France. Only immediate family is in Canada and thus, has a strong relationship with her only child, grandchildren and her husband. Still very active in the community and goes to church with her daughter each week. Unlike the other participants, she indicated that she would like to receive her care at home, but is afraid of actually dying at home because of the impact it would have on her child and grandchildren. Lived in a retirement home for 6 months prior to terminal prognosis, when she moved back in with her daughter. Has a cleaning service that comes in biweekly, but no other receives no community support. Receives care from a Personal Support Worker once a week. She has been receiving care from the CCAC for 8 months. Was diagnosed with a mild form of Lewy Body dementia a year ago and has three other chronic conditions.

Female. Interview took place in participant’s home. Mother to young children. Very active social life. Very physically active. Some familial support. Was very emotional during interview- says it’s very difficult to watch her mother be so ill. Claims she is grieving her mother. Describes having a very close relationship with mother. Admits to not using many of the available services due to personal choice. Struggles to find work-life balance and had to quit her job to provide care. Quit job to be home more often, only works occasional shifts as a receptionist. Mentioned the home being accessible to her mother. Requests support groups. Satisfied with the services provided by the CCAC and her own health.

5 Male. Interview took place via telephone. Lives in an apartment building with wife. Has a daughter and Female. Interview took place via telephone. Lives only with husband. Has two adult children but does not see
<p>| <strong>6</strong> | Female. Interview took place in the participant’s home. Lives with spouse and oldest son. Three adult children and four grandchildren. Has been living with a rare condition for the majority of her life. Spouse does the majority of the caregiver and assists with all activities of daily living. Very limited independence, is able to be mobile, but only with help. Uses a walker or relies on spouse for help. Spouse and children accompany all doctors visits due to language barriers at times. Does not engage within the community and hasn’t in the past four years. Very strong connections with family, all grandchildren and children visit almost weekly. Family is extremely important to her. Very positive person. Has to visit the hospital for oxygen every 3-6 weeks. Was very reluctant to receive home care. Receives care from a nurse once a week. She has been receiving care from the CCAC for 1-2 years. Was diagnosed with Vascular dementia less than a year ago and has two other chronic conditions. Male. Interview took place in a building where he was having a business meeting. Lives with father and mother. Single. Never left home to care for his mother, despite having properties. In his early-fifties. Claims to have a high-stress, high-demand job. Travels frequently for work and thus relies on his father to provide care to his mother. Stressed the emotional aspect to caregiving as being the most difficult. Focused highly on the governmental costs associated with caring for someone terminally ill both at the institutional level and with home-care. Very active lifestyle. Has many hobbies. Has strong connections with family. Very large circle of friends with whom he socializes with often. Provides all transportation for his parents and accompanying them to all medical visits. Is very organized, records and files all notes he takes at medical appointments. Very busy individual and thus did not have much time to be discuss experiences. Extremely satisfied with the services provided by the CCAC and his own health. |
| <strong>7</strong> | Female. Interview took place over the telephone. Lives with son, daughter-in-law and their children, as well as her spouse. Very little familial support outside of those she lives with. Not many visitors to the home. No longer mobile, but described by self and caregiver as healthy. Has been home bound for the past three years and thus, does not engage in the community. Was very active in volunteering in a them often. Identifies as home bound. Cared for her own mother prior to her death. Very involved and integrated in community and with friends, but wishes she was able to go out more- most of her socializing is via telephone or visits to her home. Identifies as home bound. Recently had two surgeries, but still rated her health as high. Is caring for her spouse as she recovers from her surgeries. Strong familial connections, lots of familial support from daughter, if needed. Uses external respite care every three months, but cut down on it due to the cost. Wishes she was able to get more care. Satisfied with the services provided by the CCAC and her own health. | Female. Interview took place via telephone. Lives with her husband’s two parents, husband and two adolescent children. Also cares for father-in-law. Identifies as home bound. Wishes she was able to engage with the community more-specifically volunteer and take her children out. Quit her job three years ago to care for mother-in-law. Receives the most community health care services- three visits a day from a Personal |</p>
<table>
<thead>
<tr>
<th>ID</th>
<th>Gender</th>
<th>Interview Setting</th>
<th>Living Situation</th>
<th>Health Status</th>
<th>Caregiving Experience</th>
<th>Financial Strain</th>
<th>Educational Needs</th>
<th>Community Health Services</th>
<th>Other Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Female</td>
<td>At home</td>
<td>Lives with sister</td>
<td>One elder sister visits every few months. Blindness and recently become wheel-chair bound but relies on no other assistive devices.</td>
<td>Unusually active in the church community prior to illness and wishes she could return to church. Strong reliance on faith.</td>
<td>Receives care from a Personal Support Worker once a day and twice a week for an over-night-stay and a nurse once a week. Has been receiving care from the CCAC for 2 years. Was diagnosed with mild form of dementia 1-2 years ago and has one additional chronic condition.</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>8</td>
<td>Male</td>
<td>Apartment</td>
<td>Shares with wife</td>
<td>No children. Never married. Oldest of all the participants and has the most number of conditions.</td>
<td>Active in the church community prior to illness and wishes she could return to church. Strong reliance on faith.</td>
<td>Receives care from a Personal Support Worker for a short period three times a day and a nurse once every 2-4 weeks. Once a week a Personal Support Worker visits for three hours to provide respite care to the caregiver and she goes to an Adult Day Program for a night when her caregiver every three months. She has been receiving care from the CCAC for 2 years. Was diagnosed with Alzheimer’s Disease less than a year ago and has one other chronic condition.</td>
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<tr>
<td>9</td>
<td>Female</td>
<td>Phone interview</td>
<td>Shares with sister and brother-in-law. No children. Never married. Oldest of all the caregivers.</td>
<td>Active in the church community prior to illness and wishes she could return to church. Strong reliance on faith.</td>
<td>Receives care from a Personal Support Worker for a short period three times a day and a nurse once every 2-4 weeks. Once a week a Personal Support Worker visits for three hours to provide respite care to the caregiver and she goes to an Adult Day Program for a night when her caregiver every three months. She has been receiving care from the CCAC for 2 years. Was diagnosed with mild form of dementia 1-2 years ago and has one additional chronic condition.</td>
<td>Receives care from a Personal Support Worker and once a week from a nurse. All socializing is via telephone. Lack of familial support and thus relies on the community health services.</td>
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<tr>
<td></td>
<td>CCAC for two years. Was diagnosed with a mild form of dementia a year ago and has four other chronic conditions.</td>
<td>request it. Satisfied with the services provided by the CCAC and with her own health.</td>
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<tr>
<td>10</td>
<td>Female. Interview took place at her home that she shares with her daughter. Recently widowed. Has adult four children and five grandchildren. Has been battling an incurable chronic condition for eight years, but recently was deemed palliative. Given a prognosis of less than a year. Has no other familial support outside from her daughter who is her primary caregiver. Receives care from a Personal Support Worker twice a day for a needle and a nurse once every two weeks. Has been receiving care from the CCAC for less than a year. Was diagnosed with a mild form of dementia a year ago and has one other chronic condition.</td>
<td>Female. Interview took place at home. Lives with her mother. Never married, no children. Has two dogs that she considers her only source of companionship. Recently relocated to London from an urban city in Ontario due to financial issues that arose once she quit her job to become her mother’s primary caregiver. Estranged relationship with one sibling and receives minimal familial support from her other two siblings. Is receiving temporary respite care between 11pm-7am one night per week to assist with issues of exhaustion related to caregiving. Wishes for more respite care and emotional support. Satisfied with the services provided by the CCAC and with her own health.</td>
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</tr>
</tbody>
</table>
Appendix J: Socio-Demographic Characteristics of Participants

Older Adult Participant Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Study Participants (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Older Adult Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>60 % (n=6)</td>
</tr>
<tr>
<td>Male</td>
<td>40% (n=4)</td>
</tr>
<tr>
<td><strong>Older Adult Living Arrangements</strong></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>10% (n=1)</td>
</tr>
<tr>
<td>With Caregiver</td>
<td>90% (n=9)</td>
</tr>
<tr>
<td><strong>Time of Dementia Diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>&lt; 1 y year ago</td>
<td>20% (n=2)</td>
</tr>
<tr>
<td>1-2 years ago</td>
<td>70 % (n=7)</td>
</tr>
<tr>
<td>3-4 years ago</td>
<td>10% (n=1)</td>
</tr>
<tr>
<td><strong>Number of Chronic Conditions Older Adult Participant Has (including dementia)</strong></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>40% (n=4)</td>
</tr>
<tr>
<td>3</td>
<td>40% (n=4)</td>
</tr>
<tr>
<td>4</td>
<td>10% (n=1)</td>
</tr>
<tr>
<td>5+</td>
<td>10% (n=1)</td>
</tr>
<tr>
<td><strong>Terminal Conditions of Older Adults</strong></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>50% (n=5)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>30% (n=3)*</td>
</tr>
<tr>
<td>Chronic Obstructive Pulmonary Disease (COPD)</td>
<td></td>
</tr>
<tr>
<td>Congestive Heart Failure</td>
<td></td>
</tr>
<tr>
<td>*Terminal-phase diabetes as identified from CCAC nurses</td>
<td></td>
</tr>
<tr>
<td><strong>This individual has congestive heart failure and terminal-phase diabetes</strong></td>
<td></td>
</tr>
</tbody>
</table>

Informal Caregiver Participant Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Study Participants (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>80% (n=8)</td>
</tr>
<tr>
<td></td>
<td>Male</td>
</tr>
<tr>
<td>-------------------------</td>
<td>--------------------</td>
</tr>
<tr>
<td><strong>Caregiver Age</strong></td>
<td>36-45</td>
</tr>
<tr>
<td></td>
<td>46-65</td>
</tr>
<tr>
<td></td>
<td>66-77</td>
</tr>
<tr>
<td><strong>Number of Years as Caregiver</strong></td>
<td>&lt; 2 years</td>
</tr>
<tr>
<td></td>
<td>2-4 years</td>
</tr>
<tr>
<td></td>
<td>5-6 years</td>
</tr>
<tr>
<td></td>
<td>&gt;7 years</td>
</tr>
<tr>
<td><strong>Caregiver Relationship to Older Adult</strong></td>
<td>Spouse</td>
</tr>
<tr>
<td></td>
<td>Child/Child-in-Law</td>
</tr>
<tr>
<td></td>
<td>Cousin</td>
</tr>
<tr>
<td></td>
<td>Sibling</td>
</tr>
<tr>
<td><strong>Caregiver Employment Status</strong></td>
<td>Employed Full-Time</td>
</tr>
<tr>
<td></td>
<td>Employed Part-Time</td>
</tr>
<tr>
<td></td>
<td>Volunteer Work</td>
</tr>
<tr>
<td></td>
<td>Unemployed</td>
</tr>
<tr>
<td></td>
<td>Retired</td>
</tr>
<tr>
<td><strong>Caregiver Highest Level of Education</strong></td>
<td>High School (9-12 years)</td>
</tr>
<tr>
<td></td>
<td>College (Diploma) or University (Bachelor’s degree)</td>
</tr>
<tr>
<td><strong>Caregiver Living Arrangements</strong></td>
<td>With Spouse or Partner</td>
</tr>
<tr>
<td></td>
<td>With Another Family Member (e.g: child, grandchild)</td>
</tr>
</tbody>
</table>
## Appendix K: Community-Based Palliative Care Service Use of Participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Study Participants (n=9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Years Using Support From the CCAC</td>
<td>1 year (range: &lt;1-3-4)</td>
</tr>
<tr>
<td>Additional Supports Outside of CCAC</td>
<td>Yes 10% (n=1); Private Nurse 90% (n=9)</td>
</tr>
<tr>
<td>Caregiver Satisfaction with Services</td>
<td></td>
</tr>
<tr>
<td>Extremely Satisfied</td>
<td>20% (n=2)</td>
</tr>
<tr>
<td>Satisfied</td>
<td>70% (n=7)</td>
</tr>
<tr>
<td>Somewhat Satisfied</td>
<td>10% (n=1)</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td></td>
</tr>
<tr>
<td>Extremely Dissatisfied</td>
<td></td>
</tr>
<tr>
<td>Caregiver Satisfaction with Own Health Status</td>
<td></td>
</tr>
<tr>
<td>Extremely Satisfied</td>
<td>60% (n=6)</td>
</tr>
<tr>
<td>Satisfied</td>
<td>40% (n=4)</td>
</tr>
</tbody>
</table>
Curriculum Vitae

Name: Kristina Marie Kokorelias

Post-secondary Education and Degrees:
The University of Western Ontario
London, Ontario, Canada
2014-2016 MSc (anticipated)
McMaster University
Hamilton, Ontario, Canada
2010-2014 B.A.

Post-secondary Certificates:
University Learning and Teaching
The University of London Ontario
London, Ontario, Canada
2016

Leadership and Management in the Not-For-Profit Sector
Mohawk College
Hamilton, Ontario, Canada
2014

Honours and Awards:
The Audrey Evelyn Mepham Award in Gereontology
2014
The Karl Kinanen Alumni Prize in Gereontology
2014

Related Work Experience
Teaching Assistant
The University of Western Ontario
2014-2016

Communications Assistant
Alzheimer Society London and Middlesex
2014-2016

Research Assistant
Aging, Community and Health Research Unit
McMaster University
2013-2014

Teaching Assistant
McMaster University
2013-2014

Conference Publications:

Publications: