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The Lived Experience of Family Caregivers who Provided End-of-life Care to a Relative with Advanced Dementia

by

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Dedication

For my husband, Gregory.
Thank you for making what seemed impossible, possible!

For my children:
My son, Joshua.
You are the light of my life and all my reasons.
&
In memory of my baby daughter, Sophia.
Your brief presence in our lives provided me with an abundance of gifts, for which I am eternally grateful.

* * *

Abstract

With aging of the baby boomer population, older adults living longer, and no known cure for dementia, the prevalence of dementia in older adults will inevitably rise. Dementia is a terminal illness, although it may not be recognized as such. Family caregivers to persons with dementia provide invaluable care, often at the expense of their own health and well-being. Over the past two decades there has been an abundance of research that examines the various and complex aspects of caring for a relative with dementia. However, there is a paucity of research that has been conducted on the experiences of family caregivers providing end-of-life care. The conceptual framework that guides this research is based on the work of Martin Heidegger.

A thorough search of the literature reveals that the main themes of this end-of-life experience studied to date are the experience of grief and loss, and the manifestations of depression in family caregivers. A number of gaps in the literature remain that limit our understanding of the end-of-life care experience. The purpose of the present study is to begin to address this neglected area of research. As a result, the research question is: *"What is the meaning of the lived experience of family caregivers who provided end-of-life care for a relative who died with advanced dementia?"* This question was addressed using an interpretive phenomenology based on the work of Munhall.

The study utilized a purposeful sample of family caregivers (*n* = 11) whose relative with dementia died in the last year. Two to three in-person, unstructured interviews were completed with each participant as a way to glean an understanding of their experiences and offer opportunities for the participant to verify their end-of-life caregiving story. A total of 27 interviews were recorded and transcribed verbatim. Transcripts were hermeneutically analyzed in order to create individual narratives for each participant, reveal the essence of this experience, discuss the influence of the life worlds, consider the taken for granted, and generate an overall study narrative. These findings reveal the complex nature of the end-of-life caregiving experience with dementia.

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CHAPTER 1: Background & Rationale for the Study

Introduction

With aging of the baby boomer population, older adults living longer, and no known cure for dementia, the prevalence of dementia in older adults will inevitably rise and cause increasing demands for families and the health care system (Forbes & Neufeld, 2008). In Canada, 8% of persons 65 years and older and 35% of persons over 85 have dementia for an average of 6.7 years for women and an average of 4.6 years for men (Canadian Study of Health and Aging Working Group [CSHAWG], 2000). As many as 50% of persons with dementia live in the community with a spouse, family or close friends (CSHAWG, 1994) with 90% of the care they require provided by family and friends (Keating, Fast, Frederick, Cranswick & Perrier, 1999). Family caregivers provide invaluable care resulting in a number of consequences to their health and well-being. Despite increases in the need for services, reforms to health care (e.g., less funding for home care or fewer long-term care beds) have shifted the responsibility of care for frail and chronically ill older adults to families (Fast, 2005; Forbes & Neufeld). This may further pose significant issues specific to end-of-life care and where and how it may be carried out and by whom.

Research acknowledges the important role of family caregivers in providing end-of-life care to those with terminal illness (Andershed, 2006). However, little is known about the distinctive experience of providing end-of-life care to a relative with dementia. There are several gaps in the literature worth exploring as a way to better understand the issues and needs of these family caregivers. Thus, the present research intended to explore the experiences of family caregivers caring for a relative with dementia who is at end of life. This introductory chapter will begin with a statement of definitions salient to the study, followed by a background discussion of family caregiving to persons with dementia that includes who caregivers are, what they do, the consequences of caregiving, and their needs. The purpose and rationale for the study will be presented and the chapter will conclude with the conceptual framework that supports the present study.

Salient Definitions

The topic of this research study is family caregivers of persons with dementia at the end of life. The following definitions will guide the study: dementia, family, family caregivers, and end of life.

Dementia

Dementia is a chronic disease of the brain that results in a deterioration of thinking ability and memory to the degree that it interferes with one's ability to work, participate in social activities or relationships with others (Diamond, 2006; Feldman et al., 2008). The progressive nature of dementia can lead to an inability to make judgments, behavioural changes (e.g., agitation, aggression, or depression), changes in personality, and decreased functional ability. Dementia is an umbrella term encompassing a number of diseases (e.g., Alzheimer's Disease, Lewy Body dementia, Frontotemporal dementia or Vascular dementia) that have slightly different manifestations and consequences depending on what parts of the brain are affected. Although Alzheimer's disease is the most common form of dementia (CSHAWG, 2000; Feldman et al.) it may be limiting to focus on this or any other type of dementia alone. Thus, for purposes of this study use of the broad term *dementia* will refer to the disease process of the care recipient.

Family

Over the past 40 years the *typical* Canadian family (i.e., opposite sex two-parent family with children living in the same household) has transformed into a complex institution that may be challenging to define (Juby & Bourdais, 2006). As such, this increasing diversity (e.g., step families or gay/lesbian families, etc.) calls for a definition of family that is inclusive enough to capture the reality of the kinds of families that provide care to an older adult with dementia. Wright, Watson and Bell (as cited in Wright & Leahey, 2005) define family as, "a group of individuals who are bound by strong emotional ties, a sense of belonging, and a passion for being involved in one another's lives" (p. 60). This definition of family is consistent with the aims of the present study as it acknowledges the importance of relationship from the perspective of the individual. Further, it recognizes that family members may not be related by blood or marriage and that they may not live together in a single household.

Family Caregiving

Family caregiving may be defined as unpaid or informal care provided to a frail or chronically ill family member because they are no longer able to perform tasks themselves; these tasks may include assistance with bathing, dressing, meal preparation, housekeeping, transportation, managing finances or securing assistance from formal services (Ory, Yee, Tennstedt, & Schulz, 2000; Schulz & Martire, 2004). In addition to these physical tasks, family caregiving can also include sentiment, an emotional connection to the care receiver, and providing psychosocial support (Benner & Gordon, 1996). Specific to the context of dementia, the family caregiving role changes constantly.

Family caregiving is often assumed to be provided to an ill or frail care receiver in their home (Decima Research for Health Canada, 2002; Fast, 2005). However, family caregiving may last for years and continue after institutionalization of the care receiver (Kelley, Specht, & Mass, 2000). Family caregivers often seek continued involvement with care and a way to rebalance family caregiving within the context of long-term care (Gladstone, Dupuis, & Wexler, 2006). Time and again, families go *above and beyond* to provide this invaluable care.

End of Life

It may be impossible to in fact definitively identify how and when an individual enters the period known as the *end of life*. Although there is no accepted definition the research supports two components that are present at end of life: (a) presence of a chronic disease or impairment that persists but may also fluctuate; and (b) the resulting impairments from the disease require care provided by others (formal care providers and/or informal caregivers) and ultimately lead to death (National Institutes of Health, 2004). Undoubtedly, the presence of advanced dementia with complete dependence with activities of daily living indicates the likelihood of reduced survival for care receivers (Coventry, Grande, Richards & Todd, 2005; Mitchell et al., 2009). The advanced stage of dementia is often characterized by being unable to ambulate, having difficulty with swallowing and being unable to speak resulting in constant, 24 hour care; this stage may last for years (Volicer, 2001). Research demonstrates that increasingly high levels of suffering (e.g., pain, agitation, shortness of breath, or pressure ulcers) are associated with the end-stage of dementia (Mitchell et al.) and may indicate that the care receiver is entering their last days of life and that death is looming (Aminoff & Adunsky, 2006).

Background

Who Are Family Caregivers and What Do They Do?

To consider who is participating in family caregiving several aspects need to be considered. Gender, age of the caregiver, relationship to the care receiver and the bond (or lack of one) that exists between caregiver and care receiver are all factors that influence the caregiving experience. In general, 54% of primary family caregivers are women and 46% are men (Fast, 2005). However, for those who participate in end-of-life care there is a larger proportion of women (67%) providing this care (Fast, Niehaus, Eales & Keating, 2002). As well, women tend to do more hands on, personal care and spend more time caregiving compared to male caregivers who typically engage in home maintenance activities and transportation (Armstrong & Kits, 2001; Fast; Fast et al., 2002; Keating et al., 1999). As many as 70% of family caregivers are 45 years of age and older and one-quarter are at least 65 years of age and older (Decima Research for Health Canada, 2002).

Further, older adults that provide family caregiving may have health issues of their own, while younger family caregivers may have other obligations (e.g., employment or young children) in addition to their caregiving (Fast, Keating, Otfinowski & Derksen, 2003). Family caregivers are typically a spouse or an adult child of the person requiring assistance (Schulz & Martire, 2004) that may or may not live in the same household (Fast, 2005). When not sharing a household most caregivers live near the care recipient, with those living the closest spending more time providing care (Fast et al., 2002). It is important to acknowledge that neighbours or friends may also participate in family caregiving responsibilities (Fast; Fast et al., 2003).

Family caregiving may be difficult to conceptualize given that much of what caregivers do may be considered part of everyday activities within a family (Ory et al., 2000). For instance, making a meal and maintaining a house may be normal, necessary activities in many families. When one family member has dementia would these activities then be considered part of a caregiver's role? It seems easier, however, to view personal care (e.g., bathing or dressing) as a caregiving activity. These tasks may also be carried out by formal care providers as a way to assist both the family caregiver and the care receiver. It may be important to take into consideration how family caregivers define what they do and their role. Family caregivers may engage in caregiving because they feel it is their responsibility, they have a strong desire to do so or there is no one else available (Decima Research for Health Canada, 2002). Fast and colleagues

(2002) note that most family caregivers who provide end-of-life care have been caring for the care recipient for a year or more.

Caregiving tasks may be divided among family members, however, most commonly the majority of care is provided by one or two persons (Fast et al., 2003). Owing to the progressive nature of dementia the caregiving role changes constantly. Researchers suggest that the combination of loss, physical demands of caregiving, and psychological distress may increase the risk of compromised health to family caregivers (Fast et al., 2002; Schulz & Martire, 2004). As a result, family caregiving is often characterized as stressful and burdensome. It may be important to bear in mind that caregiving is imbedded within the context of the family. Thus, how caregivers respond to caregiving and how they perceive the personal impact of that care may be shaped by their family relationships and given situation (Fast et al., 2003; Ory et al., 2000). Caring for a family member with dementia is often referred to as a journey.

Consequences of Family Caregiving

Given the time invested and the energy required caring for a relative with dementia is not without cost or benefit to family caregivers. These consequences impact family caregiver well-being in both positive and negative ways.

Positive consequences. Commonly, researchers and health care practitioners may discuss family caregiving in a purely negative sense and do not consider its positive consequences (Berg-Weger, Rubio & Tebb, 2001; Hunt, 2003). This approach focuses on only one part of the caregiver journey and does not provide a holistic view. There may be a need to recognize and enhance the positive aspects and strengths of the caregiving experience in order to understand how best to support family caregivers and target interventions appropriately (Cohen, Colantonio, & Vernich, 2002; Louderback, 2000). Fortunately, recent research has begun to explore the coexistence of negative and positive aspects in family caregiving (Andren & Elmstahl, 2005; Heru, Ryan, & Iqbal, 2004; Sanders, 2005).

The literature reveals that positive aspects can include: (a) the reward from a reciprocal relationship, (b) a strengthened bond or feeling closer to the care receiver, (c) a sense of satisfaction with caregiving, (d) finding meaning, and (e) a sense of personal growth (Berg-Weger et al., 2001; Fast, 2005; Fast et al., 1999; Hunt, 2003; Tarlow et al., 2004). It is these positive aspects that may sustain a family caregiver in his or her role for longer than would be expected.

Reciprocity in caregiving has different meanings. In the case of dementia, caregivers cannot often be verbally thanked or acknowledged for their care from their family member. Instead, the family caregiver may feel that giving back to the care receiver for past care is sufficient (as in a parent-child relationship), or that they will get back in the future from another individual, the care they are providing now (Fast et al., 2002; Lo & Brown, 2000; Neufeld & Harrison, 1998). Satisfaction with the caregiving role may be determined by things such as a positive marital relationship (Lewis, Hepburn, Narayan, & Kirk, 2005) or being able to find purpose and pleasure in caregiving (Andren & Elmstahl, 2005). Providing care for a family member with dementia may be viewed as an opportunity for a closer relationship that might not have otherwise have been possible (Peacock et al., 2010).

Making meaning in ones' caregiving is also a positive factor for some family members. The concept of meaning was studied by Ayres (2000), who concluded that family caregivers make sense of their caregiving by finding explanations to their success or failure in the choices they make as a caregiver. Making sense of the impact that caregiving has had on their lives helps them to discover more about themselves. As a result family caregivers may also experience gains in personal growth (Netto, Goh, & Yap, 2009; Sanders, 2005). Assessment of these types of positive consequences is important when working with families who care for a relative with dementia. It is important to note that the rewards of caregiving should not be exploited as a way to have family caregivers pick up the slack when formal services are reduced or withdrawn (Fast et al., 2002).

Negative consequences. The vast majority of interventions to support family caregivers are intended to alleviate negative consequences; for the most part these interventions are unsuccessful (Acton & Kang, 2001; Peacock & Forbes, 2003). Multi-component interventions, however, do show some promise as they often address a number of caregiver and care receiver issues and may offer more individualized support (Hoskins, Coleman & McNeely, 2005). Maintaining caregiver well-being is complex at best. Well-being can be considered an umbrella term and has many dimensions, for example physical health, mental health, and financial security (George & Gwyther, 1986). Physical health of family caregivers may be compromised by disruptions in sleep or alterations in their own health (Fast et al., 1999). Mental health can be affected in a number of ways. Family caregivers' reaction to caregiving, such as anger, guilt or grief can affect their mental well-being (Fast et al.).

The most widely studied aspect of mental health related to the family caregiving experience is depression. The Canadian Study of Health and Aging (CSHAWG, 1994) found that depression was nearly twice as common in family caregivers of people with dementia compared to family caregivers of people without dementia. Depression may be a result of the responsibilities associated with caregiving and range from mild depressive symptoms to a major depressive disorder. Mignor (2000) suggests caregiver depression manifests as sleep disturbances, loss of appetite, and feelings of loneliness and worthlessness. McConaghy and Caltabiano (2005) state that family caregivers of people with dementia may under-report their feelings of depression to appear as though they are coping well to continue as primary caregivers.

A recurrent and common theme in the literature is caregiver strain, also known as burden. The experience of strain is immensely complex and difficult to measure and research. Caregiver strain may be considered as either objective (e.g., measurable disruptions) or subjective (e.g., distress or burnout) in nature. Feelings of strain may be a result of manifestations of care receiver disruptive behaviours that are commonly associated with dementia and the family caregiver's difficulty coping with those behaviours (Diwan, Hougham & Sachs, 2004; Zarit, Todd, & Zarit, 1986). Interestingly, some researchers have found that higher levels of income and education are associated with higher levels of strain in family caregivers (e.g., Diwan et al.; Montgomery, Gonyea, & Hooyman, 1985).

Often families must sacrifice financially to perform their caregiving role (Fast et al., 2002). This may be in the form of alterations in career or employment choices and paying out of pocket for formal caregiving (McKeever, 1996). Women are most likely to alter their own paid employment (thus reducing their income, benefits, and future pension) in order to meet the demands of hands-on family caregiving (Fast et al., 1999; Walker, 2005). An alteration in well-being for a family caregiver may be a result of challenges to all or only one of the dimensions of well-being. For example, a caregiver may have adequate finances to continue caring at home, but suffer emotionally as the care receiver deteriorates as a result of his or her dementia, thus well-being is negatively affected. When well-being is compromised, family caregivers can succumb to the negative consequences of caregiving.

What do Family Caregivers Need?

The issues that arise for family caregivers over the course of dementia are numerous and complex. These result in changing needs as the disease progresses and families encounter new challenges. Since caregiving may be overwhelming and consuming health care professionals may need to anticipate needs and advocate for family caregivers. Some of the most common needs of family caregivers to persons with dementia may include (a) emotional, social and formal support, (b) educational needs, and (c) being viewed as partners in care.

Emotional, social, and formal support. Steeman, De Casterle, Godderis, and Grypdonck (2006) advocate that from diagnosis onward persons with dementia and family caregivers need proactive supportive care to adjust to a diagnosis of dementia. With a lower proportion of older adults residing in long-term care homes (Cranswick & Thomas, 2005) there is a shift to family caregivers to care for longer periods of time, with increasing responsibilities. This increased responsibility means that both the care receiver and family caregivers will likely need to be better supported with multidisciplinary formal support (Hoskins et al., 2005). A way to ensure on-going and coordinated care to best meet the needs of family caregivers is to initiate an integrated continuing care model where health care, community care, and institutional care are assumed into one system (Forbes & Neufeld, 2008).

Family caregivers have many emotions and feelings to work through as their family member with dementia makes the transition from home to a long-term care setting. Formal care providers that coordinate placement to long-term care need to acknowledge this difficulty and support families appropriately. Research has shown that families desire to have a single contact person from the long-term care home who is supportive and knowledgeable about end-of-life care and the potential issues that may arise (Caron, Griffith, & Arcand, 2005; Forbes, Bern-Klug, & Gessert, 2000).

Educational needs. From early on in the journey with dementia family caregivers require knowledge and education about how their caregiving role may evolve (Coen, O’Boyle & Lawlor, 1998). Appropriate knowledge may help caregivers deal with disruptive behaviours and other consequences of dementia. The key is to tailor education to meet the needs of family caregivers and not overwhelm them. For instance, early on education may be required for how to deal with mild cognitive impairment and not how to deal with potentially aggressive behaviours that may (or may not) present further into the journey.

There is also a need for appropriate education regarding the late stage and end of life as a way to improve care provided by family caregivers and formal care providers (Mitchell, Morris, Park & Fries, 2004). Family caregivers may lack knowledge about the dying process and require staff support to make complex decisions at the end of life (Caron et al., 2005). Decision making may be so difficult that families may wish for staff to make decisions regarding procedures and interventions (Forbes et al., 2000). With adequate, sensitive education family caregivers may be able to have a more active role in caregiving and decision-making at the end of life if they so choose.

Being viewed as partners in care. Family caregivers have a vested interest in the care decisions regarding their family member with dementia. All too often caregivers feel left out of decisions about medications, treatments, or which services they have access to (Forbes et al., 2008). This lack of partnering may lead some family caregivers to forgo accessing services and interventions; this has the potential to affect them negatively. Dementia impacts a family and as such family caregivers need to be considered and supported in decisions.

Further along the journey, family caregivers should continue to be recognized as partners in providing care in the long-term care setting (Strang, Koop, Dupuis-Blanchard, Nordstrom, & Thompson, 2006). Family caregivers have expertise and knowledge about their family member that may benefit staff in order to provide individualized care (Gladstone & Wexler, 2000). This is particularly important as persons with dementia cannot often voice preferences or concerns and are functionally dependent on staff for meeting their needs. Communication between health care professionals and family caregivers is vital. For example, at the end of life, decisions to stop invasive procedures or life prolonging interventions can be difficult, families require support and education.

In summary, as dementia progresses family caregivers may have an accumulation of experiences that follow them into end-of-life care; for example, the amount and different kinds of responsibilities, the types of positive and negative consequences, and the resulting needs that arise from family caregiving. It may be important to consider the potential impact these experiences have on family caregivers to find ways to support them in carrying out their role, including up to and at the end of life.

Rationale & Significance of the Study

The purpose of the present study is to explore the lived caregiving experiences of family members caring for a relative with dementia who is at the end of life. The caregiving experience at the end of life is impacted by a number of factors given the complex issues and needs of family caregivers throughout the caregiving journey. It is important to recognize that family caregivers to persons with dementia may have unique needs compared to other types of caregivers who care for someone who is cognitively intact (Lynn, 2001; Ory et al., 2000; Schulz

& Martire, 2004). Also, it is important to bear in mind that dementia is a terminal illness (Gill, Gahbauer, Han, & Allore, 2010; Mitchell et al., 2009), although it may not be recognized as such owing to its often lengthy and slow progression (Coventry et al., 2005; Mitchell et al., 2004). It may be then that the challenges for family caregivers within the context of the end of life in dementia could inadvertently be neglected or overlooked. This may partly account for why appropriate end-of-life care is not readily available for persons with dementia in either the community or long-term care settings (Aminoff & Adunsky, 2006; Mitchell et al.).

The inevitable rise in the prevalence of dementia among older adults will cause increasing demands for families and the health care system to care for these vulnerable individuals (Forbes & Neufeld, 2008). As such, the issues with end-of-life care in dementia may continue and increase with this population and their family caregivers. While an abundance of research is available regarding the caregiving experience, its consequences, and supportive interventions early on in the journey with dementia (Peacock & Forbes, 2003) far less is known about the experiences at the end of life. Much of the research about end-of-life care focuses on diagnoses such as cancer (Coventry et al., 2005; Forbes et al., 2000). Research that considers other disease processes often includes a variety of family caregivers and may focus on one setting (e.g., long-term care). The literature reveals that the impact and experience of the end of life on dementia family caregivers has received limited empirical attention (Kim, Yeaman, & Keene, 2005; Schulz et al., 2003; Strumpf, Tuch, Stillman, Parrish & Morrison, 2004). Given the paucity of end-of-life research available that is specific to dementia care it may be beneficial to examine this context from the perspective of family caregivers.

Gleaning an understanding of the lived experience of family caregivers may point future research in directions that are salient to caregivers rather than focusing on what formal care providers or researchers deem important. This kind of understanding may have the potential to guide health care professionals in their interactions with family caregivers, lead to future areas of research that are salient to family caregivers, and aid in developing supportive interventions that address the needs of family caregivers. There may also be benefit to individual participants as they share about their end-of-life experience and have their story *heard* (Boss, 2004). As such it is advantageous to use an interpretive phenomenological approach to explore the lived experience as understood by family caregivers that takes into consideration and values the social, cultural, and historical world of the individual, as well as endeavouring to uncover what may be taken for granted in the caregiving experience. Interpretive phenomenology also moves beyond description of the lived experience to delve into the meaning of being a family caregiver.

Conceptual Framework

The study is guided ontologically and epistemologically from the work of Martin Heidegger (e.g., Heidegger, 1927/1962). The philosophical influences that inform the present research are based on what it means to care and the influence of relationship as perceived by an individual. It may be surmised that Heidegger embraced a relativist position given his belief that we cannot exist separate from our objective world; instead we are a part of it and shaped by it (Annells, 1996; Johnson, 2000). Thus, the subjective experience is valued as a means to achieve understanding. The main philosophical perspectives that are found in Heidegger's notions of ways of *being-in-the-world*, engaged agency and background, what it means to care, the experience of time, and always being towards death may lend to the understanding of the creation of meaning of the lived experience of being a family caregiver.

Heidegger and *Being-in-the-world*

A major contribution of Heidegger's philosophy is in regard to his anti-subjectivism (in the dualistic Cartesian sense) and the move away from our preoccupation with epistemology to get back to reflecting on the question of the meaning of being (Annells, 1996; Leonard, 1994; Moran, 2000). According to Heidegger, meaning is found in "the transaction between an individual and a situation so that the individual both constitutes and is constituted by the situation" (Munhall, 1989, p. 25). We become and are who we are based on the contexts of our involvement with the every-day world around us (Conroy, 2003; Guignon, 2006; Leonard). Further, our experience of *being-in-the-world* is founded on a reciprocal interdependence with others (Conroy; Moran); and this may also influence our decisions and work as they are connected with what occurs in the world (Buber, 1996). Our world is, in part, a result of our culture and language, played out in meaningful relationships and very often, is taken for granted (Johnson, 2000; Kellett, 1997).

Engaged Agency and Background

It may be important to consider Heidegger’s perspective that we experience the world as humanly embodied (Kellett, 1997; Taylor, 2006). Embodiment inevitably shapes our perceptions thereby shaping our world (Leonard, 1994). This is possible because it is through our body that we gain access to the world around us (Munhall, 1994). Engaged agency implies that we have the capacity to act in the world through our embodiment and thus our ability to make experience understandable (Taylor). Our engaged involvement in caring practices has the potential to reveal meaning that is attributed to our existence (Kellett). This experience can be understood from an intelligible context or what Taylor terms the *background*. Our background may be made up of what we take for granted but that which we are able to articulate as something that we “always knew” or had a “sense” of even if we were unaware of it (Taylor, p. 211).

Notion of Care

“The manner of [being in] relation to others is best understood under the notion of care” (Moran, 2000, p. 242). Heidegger purports that our fundamental way of *being-in-the-world* is to care (Dostal, 2006; Dreyfus, 1991; Heidegger, 1927/1962; Hoffman, 2006). Our existence entails that we are to care about others (Heidegger) such that it may be humanly impossible and socially unacceptable to not care about someone or something (Benner & Gordon, 1996). Further, it may be that we matter in terms of the things for which we care about (Leonard, 1994). To care is more than a sentiment; it is a way to interact with our significant others and nourish our relationships.

Experience of Time

Heidegger suggests that time is the basic form of all experience (Dostal, 2006). Understanding is a reciprocal activity and the present may only be understood in terms of the past and the past in terms of the present, and so on (Conroy, 2003; Kellett, 1997; Racher & Robinson, 2003). It may be useful to lose our ordinary assumptions of time and attend to considering the lived experience of time; “we might say that the present is ‘thick’ to the extent that within the present, we find both the past and the future; that is, we find all three dimensions of time.” (Dostal, p. 125). This is furthered by Heidegger’s notion of *temporality*.

Temporality does not imply that we are confined or constrained in time or even that we have a sense of time, rather “it is being ahead of ourselves in the future, drawing on our past, while being concerned with the present that constitutes our being” (Frede, 2006, p. 64). Experience is formed by what has gone on in the past and what is possible in the future (Kellett, 1997). It may be that we are extended outward in temporal dimensions so as not to be contained in a literal here and now. That is “time flows ineluctably toward the future; it is not reversible” (Dostal, 2006, p. 126). For everyone the future holds death, we are always going toward death (Heidegger, 1927/1962).

Towards Death

“Death is something distinctively impending”, it is an event that is inevitably a part of everyone’s world (Heidegger, 1927/1962, p. 294). Hoffman (2006) suggests that Heidegger viewed the anticipation of death as bringing about feelings of why life matters as we are faced with the reality that we do not live forever. Death is the most powerful meaning-giving possibility in life (Hoffman;

Johnson, 2000). “If death moves us to show concern about our life, it is because man’s ‘basic state’ is indeed care” (Hoffman, p. 228). There seems to be an inevitable connection between death, care, and *being-in-the-world*. This may have implications for family caregivers since our *being-in-the-world* is based on the past, looking at the present and anticipating the ultimate reality of the future which is death (Frede, 2006; Taylor, 1995).

In summary, clearly Heidegger provides philosophical direction for exploring the complex meaning inherent to the family caregiving journey with dementia (Kellett, 1997). How we engage in our world through caring relationships with others has the potential to reveal the meaning of our existence. By exploring the end-of-life care experience of family caregivers using the ideas of Heidegger we may better understand the ways in which being a family caregiver is meaningful; ultimately this is the aim of the present study. This foundational understanding from the perspective of the family caregiver is lacking in the current literature (as chapter 2 will demonstrate) and is needed for health care providers to question current practices and aid in developing supportive interventions for family caregivers.

CHAPTER 2: Review of the Literature

Over the past two decades there has been an abundance of research that examines the various and complex aspects of caring for a relative with dementia. The vast majority of research has been in relation to the burdensome or stressful nature of caregiving, including the effectiveness of interventions to alleviate these negative outcomes. More recently there has been acknowledgement of the positive aspects associated with caregiving, the experience of grief or multiple losses, and other factors (e.g., differences based on gender or cultural influences). This work focuses on the earlier phases of the caregiving journey with dementia. Far less research has been conducted on the experiences of family caregivers providing end-of-life care. This is somewhat perplexing given that dementia is a terminal illness (Gill et al., 2010; Mitchell et al., 2009).

The purpose of this chapter is to present the current and relevant literature regarding the experiences of family caregivers of persons with dementia at the end of life in order to identify what is known and gaps in current knowledge. To begin, the search strategies will be presented. The discussion of the literature demonstrates that caregiver experiences of grief and loss, the impact of depressive symptoms that may result from caregiving, and the burdens associated with caring for persons with dementia have been the main areas of investigation. This will be followed by a discussion of the gaps in the literature and how the present study may begin to address these. The chapter will conclude with a presentation of the research question.

Literature Search Strategies

A thorough search of recent literature was undertaken between the years 1960 to 2010 using the databases of CINAHL and MEDLINE. The search terms utilized in various combinations included: family caregiving, family caregivers, dementia, end-of-life, palliative, experience, grief, and strain. Simply using the key words family caregiving and dementia resulted in more than 550 studies; very few studies addressed the end-of-life experience. An additional specific search was conducted using the search terms of dementia, family caregivers, and end-of-life for studies conducted qualitatively (e.g., phenomenology or grounded theory) that may be similar to the present study; none were identified in either database. A few empirical studies that solely examined family caregiving to a relative with dementia at the end of life were retrieved by other means (searching reference lists of caregiving articles and hand searches of pertinent journals). In all, eight publications were retrieved that examine the end-of-life experience for family caregivers to persons with dementia. These eight studies will form the core of this literature review. Where relevant, literature on family caregiving during the earlier stages of dementia or end-of-life caregiving for persons with a variety of illnesses (mixed caregivers) will be referred to in this review.

End-of-life Family Caregiving with Dementia

Currently, researchers are beginning to conduct qualitative and quantitative studies that address the experience of caregivers who care for a family member at the end of life. However, there remains more to be done to add clarity and understanding within this context, particularly for those who care for a relative with dementia (Allen, Kwak, Lokken, & Haley, 2003). Given the disease trajectory, family caregivers to persons with dementia may have unique needs and experiences compared to other types of family caregivers (Hebert & Schulz, 2006; Lynn, 2001; Ory et al., 2000). Thus, the context of end-of-life care of family caregivers to persons with dementia calls for separate investigation from other types of family caregivers to persons with a terminal illness.

Eight studies were retrieved that explore family caregivers' end-of-life care experience specific to dementia. Four of the studies report on the same sample; they are part of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study (see Wisniewski et al., 2003). Of the eight retrieved studies quantitative methodology is the most common approach (n=5); naturalistic inquiry and mixed methods account for two studies, and one utilized an ethnomethodology. All eight studies were conducted in the United States. Sample sizes range from 27 to 254 participants, with all participants being recruited from either an existing program or the long-term care home where their family member lived. Common themes of these studies were: (a) the experience of grief (n= 4), (b) guilt and burden with decision-making (n=1), (c) how symptoms of depression may or may not be resolved with death of the care receiver (n=4), and (d) how caregivers respond to the end-stage of dementia (n=1). These themes will guide the following discussion of the end-of-life experience for family caregivers to persons with dementia. See Table 1 for summaries of these eight *dementia-specific* end-of-life care experience studies.

Table 1: Study Summaries of End-of-life Caregiving for Family Members with Dementia

Source/Author	Purpose	Sample	Design	Results	Implications	Comments
Bodnar & Kiecolt-Glaser, 1994 USA	To examine the differences in levels of depression among caregivers with more time to adjust to the death of the care receiver than those recently bereaved.	*N* = 254; *n* = 98 continuing caregivers (72% female, mean age 59 years), *n* = 49 bereaved caregivers (69% female, mean age 63 years), *n* = 107 controls (79% female, mean age 63 years). 22% attrition over 4 years of study. Recruited through a variety of sources.	Longitudinal study (4 years) with structured interviews and measures completed yearly. Eight instruments were administered and included: The Hamilton Depression Rating Scale; Perceived Stress Scale; Social Support Interview; Social Network Index Interview; Impact of Events Scale; Structured Clinical Interview for DSM-III-R, (nonpatient version); Memory and Behaviors Problem Checklist; and Blessed Dementia Scale.	Compared to controls caregivers continue to show higher rates of depression and anxiety for as long as three years after bereavement. Relationships and social activities did not improve following bereavement. Time since bereavement did not hold any significant differences between caregivers. No differences in depressive scores detected between spousal and adult child caregivers.	Family caregivers require support even after death of the care receiver because of the rates of depression and continued rumination about the former caregiver role.	Lengthy follow-up time compared to other studies. Control group non-caregivers and not bereaved. All reported data quantitative. No discussion of a conceptual framework.
Boerner, Horowitz, & Schulz, 2004 USA	To examine how the positive aspects of caregiving affect adaptation to bereaveme	*n* = 217 bereaved family caregivers (from *N* = 1222), 84% female; mean age 65 years; 50% spouses,	Prospective Survey study part of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study. Standardized survey instruments with	Caregiving benefit was positively linked to grief and less correlated to depression. Caregivers who reported poorer health, more pre-death depressive symptoms, more caregiving benefit pre-death, as well as less	The positive aspects that carry caregivers through difficult times in active caring may not carry over into bereavement. The caregiver	Presents discussion regarding conceptual framework and thorough literature review. Quantitative

Source/Author	Purpose	Sample	Design	Results	Implications	Comments
	nt among older adults who cared for a family member with dementia.	50% children and other relatives; mean time of caregiving 3 years. Care receivers mean age 81 years; 46% female; moderately to severely impaired; place of death: 32% home, 40% hospital, 27% long-term care (LTC). All recruited from the REACH study.	structured questions in interviews conducted at baseline, 6, 12 and 18 months follow-up. Instruments included: Revised Memory and Behavior Problems Checklist; Center for Epidemiologic Studies – Depression scale; Mini-mental state exam; Anxiety Inventory; Social Support scale; and portions of other scales/tools. Positive aspects were assessed with 11 items, phrased as statements (developed for the REACH).	time between death and the post-death assessment were likely to show more depressive symptoms within a year following death of the care receiver. Those who were spouses were more likely to report higher levels of grief after the loss.	benefit may be in relation to having a closer relationship (as in a spouse in this study) to the care receiver, thus with their death the loss may be felt greater than those with a less close relationship. Depressive symptoms may be related to negative mental health, while grief is related to feelings of loss; thus grief and depression may be represented by different facets of bereavement. Both the negative and positive aspects of caregiving should be assessed.	responses regarding positive aspects may be limiting. Large, multi-site study focusing on feasibility of psychosocial interventions for caregivers of persons with dementia. No discussion provided if a power analysis was completed regarding the necessary sample size to detect differences.
Forbes, Bern-Klug &	To describe families	*N* = 28 family caregivers;	Descriptive, qualitative study,	Five themes resulted that indicate the	Family caregivers'	Focus on decision-

Source/Author	Purpose	Sample	Design	Results	Implications	Comments
Gessert, 2000 USA	decision-making processes, both cognitive and affective regarding end-of-life treatments for nursing home residents with moderately severe to very severe dementia.	64% female; mean age 66 years. Care receivers mean age 84 years; length of time since loss of decision-making capacity: mean 4 years. Recruited from four LTC facilities that utilize advanced directives for residents.	using naturalistic inquiry. Focus groups (n = 4) using open-ended questions (e.g., "With regard to your family member, what does quality at the end of life mean to you?"); data analyzed with content analysis.	experience of decision-making: *Emotional effect* (strongest theme that revealed the emotional burdens of decision-making with underlying guilt stemming from LTC placement; burden, guilt and sense of responsibility were unresolved with LTC placement, caregiving continued in LTC; immense pain from multiple losses; hesitant to make end-of-life decisions); *Insult-to-life stories* (the present reality of the care receiver was not consistent with the life-story family members had envisioned, personhood was shattered; caregivers' own life story changed); *Two faces of death* (death was seen as a tragedy and/or a blessing, accepted vs forbidden, acknowledged vs unacknowledged; this resulted in difficulties to	decision-making can be compared to traveling on a long, unwelcomed journey. Facing the death of the care receiver was filled with intense emotional pain and conflict. Caregivers' own peace of mind was the most significant outcome of the journey after death of the care receiver. Even though all of the care receivers were in the moderately severe to severe stages of dementia caregivers did not view death as part of the experience. This study provides an illustration of	making in the end-of-life stage rather than the experience in general. May have benefited from a grounded theory (process oriented question) approach. Argue the need for advanced directives, yet does not explore this in its entirety. No relation to the experience of grief discussed.

Source/Author	Purpose	Sample	Design	Results	Implications	Comments
				make decisions and caregivers usually wanted another's help); *End-of-life treatments* (valued quality of life, yet it seemed lost, need to preserve dignity, promote comfort and ensure good care and have peace of mind regarding decisions); and *Unrecognized dying trajectory* (caregivers unable to conceptualize the whole dying process thus made decisions with limited knowledge; desired a natural death; lack of communication with one person/consistent provider a barrier).	the unrecognized trajectory of dying.	
Hebert, Dang, & Schulz, 2006 USA	To determine the relationship between preparedness for the death and mental health in bereaved caregivers of persons	*n* = 222 bereaved family caregivers (from *N* = 1222), 84% female; mean age 63 years; 50% spouses; 50% adult children and other relatives. Care receiver	Prospective Survey study part of the REACH study. Standardized survey instruments with structured questions in interviews conducted at baseline, 6, 12 and 18 months follow-up. Instruments included: Revised Memory and	Twenty-three percent of caregivers were "not at all" prepared for the care receiver's death; those caregivers had the worst mental health (i.e., were more depressed, experienced complicated grief and had anxiety symptoms). African American caregivers, those with less education, those with	Perhaps asking about preparedness of death may serve as a screen for psychiatric morbidity. Family caregivers who have less education, have less income, are more depressed	Uses only quantitative data. Large, multi-site study focusing on feasibility of psychosocial interventions for caregivers of persons with dementia. Brief literature

Source/Author	Purpose	Sample	Design	Results	Implications	Comments
	with dementia and explore predictors of preparedness.	mean age 82 years; place of death: home 32%, hospital 41%, LTC 27%. All recruited from the REACH study.	Behavior Problems Checklist; Center for Epidemiologic Studies – Depression scale; Mini-mental state exam; Anxiety Inventory; Social Support scale; and portions of other scales/tools.	less income or those with more depressive symptoms were more likely to perceive themselves as "not at all" prepared for the death. The amount of pain the care receiver was in prior to death was positively associated with preparedness.	or are African American may be more in need of supportive interventions (authors suggest these caregivers are at risk for not receiving quality end-of-life care).	review and no mention of a conceptual framework. No discussion provided if a power analysis was completed regarding the necessary sample size to detect differences.
Meuser & Marwit, 2001 USA	To define a model of caregiver grief to aid in clinical interventions and further research.	*N* = 87 family caregivers; n = 45 adult children (93%female, mean age 52 years), n = 42 spouses (60% female, mean age 72 years). Care receivers: 67% female. Recruited from Alzheimer's Association, other memory/dementia services and by word of mouth.	Qualitative - quantitative exploratory design using focus groups (16 in total) and survey data. Focus groups divided according to relationship to and stage of dementia of the care receiver. Instruments included: Clinical Dementia Rating interview; Anticipatory Grief Scale; and Many Faces of Grief Questionnaire.	(Summarized due to extensive reporting) In the early stages of caregiving adult children exhibit more denial and focus loss about themselves than spouses, while spouses are open and accepting about the impending burdens and loss of their partner. Middle stage adult child caregivers experience anger and frustration, grief is at its highest; in contrast spouses increase in empathy and have little anger. Late stage caregiving is marked by LTC placement: adult child caregivers express	It appears that adult child caregivers express grief in a curvilinear fashion. as it peaks in the middle stage of caregiving; while spouses express grief in a linear fashion, increasing as dementia progresses. Anticipatory grief is real grief and may be equal to the intensity of death-related grief.	Utilized focus groups rather than individual interviews. Focus to develop psychometric tool (the Marwit-Meuser Caregiver Grief Inventory; 2002). Focuses on grief related to relationship and stage of dementia, including post-death experience.

Source/Author	Purpose	Sample	Design	Results	Implications	Comments
				relief and are able to reflect on their experience and feel the loss of the care receiver, while spouse caregivers experience high amounts of grief and sometimes anger and frustration with loss of the relationship. Post-death groups' findings relate to anticipatory grief; it has an ameliorating affect on post-death grief, but not over the long run.		Does not value/comment on the post-death grief experience, except for brief comments regarding anticipatory grief.
Sanders, Butcher, Swails, Power, 2009 USA	To investigate how family caregivers respond to the end stages of dementia with assistance of hospice. Part of a larger study focusing on hospice care for people with end-stage dementia.	*n* = 27 family caregivers using hospice care; 74% female; age ranged from 38-88 years; 15% spouses, 81% adult children, and 1 grandchild. 70% of care receivers lived in a nursing home, 22% in assisted living, and 7% at home with caregiver.	Exploratory qualitative study using ethnomethodology. Up to 4 semi-structured interviews were conducted with each participant starting after care receiver was admitted to hospice, then every 8-10 weeks while care receiver remained in hospice. Transcripts and notes were analyzed and coded in a constant comparative process;	Four caregiver portraits emerged relating to the way that caregivers are involved in caregiving with care receiver in hospice: (a) *disengaged caregivers* (physical and/or emotional distance between caregiver and care receiver); (b) *questioning caregivers* (asked many questions and struggled to understand dementia and changes in the care receiver); (c) *all-consumed caregivers* (pre-occupied with	These 4 portraits provide an important foundation for determining how caregivers construct their situation and ways to support them during end-of-life care. This study highlights that health care professionals cannot assume that caregivers of persons with dementia will	Multiple interviews over a 10 month period. The focus is limited to active caregivers utilizing hospice care; sample not culturally diverse.

Source/Author	Purpose	Sample	Design	Results	Implications	Comments
		Recruited by social workers from two hospice programs.	resulting themes were organized into 4 descriptive caregiver portraits. Chart reviews also conducted to collect data concerning caregiver's interactions with hospice care.	every aspect of care and the impact of this on their lives); and (d) *reconciled caregivers* (accepting and prepared for care receivers dying and death).	feel relief or will be able to reconcile their emotions with the death of the care receiver.	
Schulz et al., 2003 USA	To describe the caregiving experience of family caregivers who provided in-home care to persons with dementia during the year before the care receiver's death and to characterize the nature of caregivers' responses to	*n* = 217 bereaved family caregivers (from *N* = 1222), 84% female; mean age 65 years; 50% spouses, 50% children and other relatives; mean time of caregiving 3 years. Care receivers mean age 81 years; 46% female; moderately to severely impaired; place of death: 32% home, 40% hospital, 27% LTC.	Prospective Survey study, part of the REACH study. Standardized survey instruments with structured questions in interviews conducted at baseline, 6, 12 and 18 months follow-up. Data used from assessments done before or closest to the care receiver's death and assessments done after the death. Instruments included: Revised Memory and Behavior Problems Checklist; Center for Epidemiologic Studies – Depression scale; Mini-mental	Approximately 60% of the caregivers reported feeling like they were on duty 24 hours/day. As many as 18% left employment to caregive; 46% used formal services and 56% used informal help. Over 90% believed death was a relief to the care receiver, 72% felt it was a relief to them; 69% stated they were prepared for the death. More than 62% stated they thought the care receiver was in pain at the time of their death. More than 21% used bereavement services after the care receiver's death. Scores on the depression scale spiked at time of death and	Family caregivers are intensely involved in providing end-of-life care. Caregivers demonstrate resilience in adapting to the death of the care receiver. Those who institutionalized the care receiver did not show the same relief from depressive symptoms. It is possible that in the end stage caregivers grieve the loss of the care receiver before	Uses only quantitative data. Large, multi-site study focusing on feasibility of psychosocial interventions for caregivers of persons with dementia. Brief literature review and no mention of a conceptual framework. No discussion provided if a power analysis was completed regarding the necessary sample size to detect

Source/Author	Purpose	Sample	Design	Results	Implications	Comments
	bereavement.	All recruited from the REACH study.	state exam; Anxiety Inventory; Social Support scale; and portions of other scales/tools.	decreased to less than pre-death scores by the one year anniversary (*n*=53); almost one third had scores that could indicate risk of clinical depression. Of the *n* = 180 caregivers who institutionalized the care receiver they had a higher depression score than caregivers whose relative died. Among all caregivers depression scores after the care receiver's death declined in the first 13 weeks and continued to decline to 65 weeks.	actual death.	differences.
Schulz, Boerner, Shear, Zhang, & Gitlin, 2006 USA	To better understand why some caregivers manifest clinical levels of complicated grief post-death.	*n* = 217 bereaved family caregivers (from *N* = 1222), 84% female; mean age 65 years; 50% spouses, 50% children and other relatives; mean time of caregiving 3 years. Care receivers mean	Prospective Survey study part of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study. Standardized survey instruments with structured questions in interviews conducted at baseline, 6, 12 and 18 months follow-up. Instruments included: Revised	Twenty percent of participants exhibited clinical levels of complicated grief. These participants were those with less education, who had lower incomes, higher levels of pre- and post-death depression scores, higher levels of pre- and post-death anxiety, reported higher levels of caregiver burden pre-death or had more positive aspects of	Data suggest that reducing caregiver burden, treating depression prior to the death of the care receiver and providing supportive interventions may assist the caregiver to better manage the consequences of death. Those	Uses only quantitative data. Large, multi-site study focusing on feasibility of psychosocial interventions for caregivers of persons with dementia. Brief literature review and no mention of a conceptual

Source/Author	Purpose	Sample	Design	Results	Implications	Comments
		age 81 years; 46% female; moderately to severely impaired; place of death: 32% home, 40% hospital, 27% LTC. All recruited from the REACH study.	Memory and Behavior Problems Checklist; Center for Epidemiologic Studies – Depression scale; Mini-mental state exam; Anxiety Inventory; Social Support scale; and portions of other scales/tools.	caregiving pre-death. No socio-demographic variables were associated with complicated grief. Findings suggest that complicated grief increases during the first 15 weeks post-death, then decreases in the subsequent 6 - 12 months.	family caregivers who experience positive aspects in their caregiving may be more attached to the care receiver and may value their caregiving role more, thus may not be able to deal as well with the death of the care receiver (discussed further in Boerner et al., 2004). Interventions should be targeted to those who are at risk for complicated grief.	framework. No discussion provided if a power analysis was completed regarding the necessary sample size to detect differences.

Grief and Loss

A common theme of four of the studies was the exploration of the experience of grief and loss as they relate to dementia caregiving at the end of life. The focus on grief and loss is similar to the investigations of non-end-of-life dementia caregiving studies (e.g., Adams & Sanders, 2004; Diwan, Hougham, & Sachs, 2009; Dupuis, 2002; Frank, 2008; Loos & Bowd, 1997). The multiplicity of losses, before and after death of the care receiver, has been acknowledged as characteristic of caregiving in dementia because of the progressive nature of the disease and how it psychologically steals away the care recipient (Allen et al., 2003; Kuhn, 2001). Grief and loss is discussed in the caregiving literature in a variety of ways; for example how grief is experienced along the overall caregiving journey, as anticipatory grief, naming the loss of a relative with dementia as ambiguous loss, with a focus on after-death grief, or in terms of consequences that may resolve or lessen grief.

Grief experienced over the caregiving journey. Meuser and Marwit (2001) undertook a mixed methods exploratory study to define a model of caregiver grief along the journey with dementia. The qualitative portion of the study utilized 16 focus groups with semi-structured interview guides. Participants were grouped according to relationship to the care receiver (either spouse or adult child) and by stage of dementia (using the *Clinical Dementia Rating Interview*, see Meuser & Marwit). This included two focus groups made up of adult child or spousal caregivers of a person who already died of dementia. Much of the findings are based on the responses from the caregivers engaged in actively providing care. Results highlight how stage of disease and relationship to the care receiver may influence the experience of grief and how losses are perceived by family caregivers. For example, the changing demands of care as a result of the increasing dependence of the care receiver impact how grief is experienced. When grief was measured (using the *Anticipatory Grief Scale* and *Many Faces of Grief Questionnaire*, see Meuser & Marwit) with respect to the stage of dementia adult children seem to experience the highest levels of grief in the middle stage of dementia, whereas spouses' grief continued to rise in a linear fashion as dementia progressed. In particular, during the third and severest stage of dementia, adult children spoke of their grief as being additive across time to this stage, while spouses expressed grief as feelings of sadness and bitterness. The anticipated death of the care receiver for adult children was viewed as loss that is now finalized, associated with expressions of helplessness and the feeling that nothing more can be done; spouses on the other hand expect new manifestations of grief to come. Thus, it appears that perhaps the experience of grief is influenced by both stage of dementia and relationship to the care receiver. These valuable insights were the common themes shared within and between focus groups.

Meuser and Marwit (2001) further discuss other findings with respect to relationship to the care receiver of active caregivers. For instance, early on in the caregiving journey adult children tend to experience denial of the disease and its process and may avoid discussion of the future, whereas spouses focus attention on the care receiver and what the future will be as a result of dementia. In the last stage of the disease adult children change their focus to longing and increased empathy for their parent, and feelings of emptiness; spouses on the other hand move to feelings of guilt and regret, and struggling to live as a single person when still married to another. These qualitative findings suggest there is more to the caregiving journey than experiencing grief. In fact, Meuser and Marwit state, that at times, quantitative and qualitative findings were not mutually supportive in their study. Qualitative findings suggest complex issues at play in the caregiving experience that cannot be explained by quantitative data alone.

Further, Meuser and Marwit (2001) suggest that the perspective of the experience of bereaved caregivers “differ in meaningful ways from the experiences reported by those actively caregiving” (p. 666). However, they did not elaborate on those differences and did not present data to support this statement. This is unfortunate as a discussion of responses from these caregivers may have lent a different perspective that could add to understanding the grief experience across all stages of dementia, up to and including the death of the care receiver. Instead, the responses reported on from these two groups were with respect to the perceived effects of anticipatory grief post-death. These findings are discussed below in the review. It may be important to point out that Meuser and Marwit used a cross-sectional design (rather than a longitudinal approach) and specifically sought common experiences shared within and across focus groups in order to develop a grief inventory. The unique lived experiences of family caregiver’s grief and loss were not the focus of their study.

Studies of caregivers whose relative with dementia was not at the end-of-life suggest that grief increases as the person with dementia moves along the disease trajectory and grief scores vary with relationship between caregiver and care receiver. Adams and Sanders (2004) indicate that the experience of grief changes over the course of caregiving. Like Meuser and Marwit (2001), Adams and Sanders' mixed methods study revealed that stage of dementia influences the focus of grief and loss. In the early stage the caregivers' grief tended to focus on the loss of shared activities with the care receiver. Later, in the middle stage of dementia caregivers reported grieving the loss of their social activities and freedom as well as the changes occurring in the care receiver. In the later stage of dementia, but prior to the end-of-life stage, caregivers began to comment on their grief as if the care receiver had already died. The later the stage of dementia the more symptoms of grief were reported. The findings of this study must be interpreted cautiously given that it was a pilot study with a limited sample size; as well, data was collected using a mail-out survey with written responses to two open-ended questions about grief and loss.

Similarly, Sanders and Corley (2003) found that feelings of grief and loss for the family caregiver seem most prevalent in the later stages of dementia and are characterized by the losses accumulated during the caregiving journey. Interestingly, some of the caregivers who indicated they were not grieving were those who were providing care not out of a bond or a close relationship to the care receiver, but because no one else was available. Instead these caregivers spoke of feeling angry and enduring the losses of what active caregiving took from their own lives, rather then what dementia was doing to the care recipient. Thus, it may be important to keep in mind some family caregivers to persons with dementia may not experience grief, they may have experienced grief and moved on, or they have not started grieving yet. Because of the limited focus of the study on the experience of grief and loss there is no way to discern what else these non-grieving caregivers are in fact experiencing. This study also raises the issue that accumulated caregiving experiences may influence the latter part of the journey; this may hold significance to the end-of-life care experience. As with Adams and Sanders (2004), this study involved active caregivers and used a single mail-out survey limited to written responses to two-open ended questions with quantitative survey data. Given the subjective nature of grief and loss, in-person interviews may have been more beneficial to augment the quantitative findings. As well, a retrospective approach may shed light on the overall caregiving experience that was not possible in these studies. It may be that these actively engaged caregivers are consumed by the care they are providing and do not have time or energy to reflect on the meaning of their care.

The experience of grief has been found to vary, depending on the caregiver-care recipient relationship. Sanders, Ott, Kelber and Noonan (2008) used a mixed methods study to explore the lived experience of adult children and spouses of persons with dementia; the family caregivers included in this study were limited to those who scored high on the *Marwit-Meuser Caregiver Grief Inventory, Short Form* (see Sanders et al.). When considering relationship to the care receiver, they found spouses yearned for the past and felt more restricted compared to adult child caregivers. Adult children, on the other hand, reported more feelings of guilt around how they responded to their parent's dementia and for events that happened in the past compared to spouses. These findings are in contrast to Adams and Sanders (2004) whose results suggest the experience of grief is independent of relationship to the care receiver. Although Sanders and colleagues utilized interviews to collect their qualitative data, they were limited to a focus on the experience of grief and loss at one point in time using a semi-structured interview guide. Interestingly, they use the term *lived experience* in stating the purpose of the study, yet they did not use a phenomenological approach to explore the phenomenon of family caregiving. Nonetheless, these pre-death grief studies are valuable as they demonstrate that the experience of grief is immensely complex and may be related to stage of dementia and/or relationship to the care receiver as Meuser and Marwit (2001) propose. However these studies do not address the experiences of family caregivers to persons with dementia who are nearing end of life. Research is needed to explore this experience of caregiving and to examine how it is influenced by grief and loss.

Anticipatory grief. Research has shown that family caregivers may immediately experience loss and grief with a diagnosis of dementia; thus grieving for the care receiver may begin well before end of life or death occurs (Kuhn, 2001; Lindgren, Connelly, & Gaspar, 1999; Morgan & Laing, 1991). Kuhn regards anticipatory grief as a normal response in caregiving given the number of losses associated with dementia. The experience of anticipatory grief may vary, depending on the disease of the care recipient. For instance, persons with cancer and their caregivers may be able to work through feelings of loss together during the earlier phases of the illness. Because of the cognitive decline in persons with dementia, this opportunity for joint grieving is unlikely to be available for family caregivers.

Meuser and Marwit (2001) proposed that experiencing anticipatory grief may potentially reduce the amount of grief experienced once the care receiver with dementia dies. The quantitative findings that grief scores diminish as dementia progresses support their proposition. The qualitative findings, on the other hand, suggest something far more complex. The qualitative findings based on the responses in two focus groups of family caregivers whose relative with dementia was already deceased focus on the effects of anticipatory grief. Meuser and Marwit found varied responses among these bereaved family caregivers that did not support their initial hypothesis; for instance, anticipatory grief did not lessen after-death grief as shared by family caregivers in the long term and not at all in some cases. Further research in this area is warranted. The grief measurement tool, the *Marwit-Meuser Caregiver Grief Inventory* (see Marwit & Meuser, 2002), developed from this work has been used extensively by other researchers (e.g., Frank, 2008; Sanders & Corley, 2003) and has furthered the discourse regarding grief experienced by family caregivers to persons with dementia. The focus on the experience of grief alone however, may have narrowed the research and neglected other important end-of-life experiences.

An exploratory quantitative survey conducted by Walker and Pomeroy (1996) considered the relationship between depression and anticipatory grief among community-dwelling family caregivers to persons with dementia in the earlier stages of the disease. They suggest that family caregivers may be mistakenly diagnosed as depressed when they may, in fact, simply be grieving. Distinguishing between depression and grief is important in determining appropriate supportive interventions. This can be difficult as grief and depression share some symptoms. It is important to note that this study used a non-random sample that may limit the generalizability of the findings. While this study was limited to measures from two instruments (i.e., the *Grief Experience Inventory* and the *Beck Depression Inventory*, see Walker & Pomeroy) and did not seek the subjective responses of participants, it does raise the awareness of needing to truly understand what it is that caregivers experience given the similarities between the experiences of grief and depression (i.e., are caregivers grieving, depressed or both?). Anticipatory grief and its relation to the many losses over the caregiving journey with dementia may have implications for how end-of-life care is experienced by family caregivers. It may be beneficial to understand what is transpiring within the end-of-life context from the perspective of family caregivers themselves.

Ambiguous loss. Boss (1999; 2007) proposed the term, *ambiguous loss* to describe the type of loss that may manifest when caring for a relative with dementia. Essentially there is ambiguity about the presence of the care receiver, in other words, the care receiver is physically present, while being psychologically absent. Boss suggests that ambiguous loss occurs because there is confusion about what causes dementia and of the resulting boundary ambiguity within the family system. In a study with family caregivers to persons with dementia prior to their death Sanders and Corley (2003) found that family caregivers are experiencing ambiguous loss and that this potentially has consequences for resolving grief.

In a mixed methods study regarding the barriers to dementia family caregiving prior to the end of life Frank (2008) found that most barriers identified by family caregivers (e.g., lack of freedom or care receiver challenging behaviours, etc) were connected to or underpinned by the experience of grief and ambiguous loss. Thus, Frank proposes that it is not so much the demands of intensive, hand-on caregiving that is at issue for family caregivers, rather it is their grief reaction. Frank highlights well the complexity of multiple losses and how family caregivers deal with and perceive them. Other considerations of importance that were not assessed in this study include the possible influences of the socio-cultural context, relationship to the care receiver or the end-of-life experience. While this study holds significance for understanding the consequences of ambiguous loss its findings are limited to linkages with the components of grief and loss as measured by the *Marwit-Meuser Caregiver Grief Inventory*.

Dupuis (2002) utilized a grounded theory to explore the experience of ambiguous loss with family caregivers to persons with dementia living in long-term care. Dupuis has furthered the theory of ambiguous loss to suggest that it is a process rather than a stable event that family caregivers experience as they deal with the deterioration of their relative. She proposes that family caregivers initially anticipate loss by considering what an unpredictable future may hold. Then they move onto the phase of progressive loss as deterioration of the care receiver becomes more apparent and end the process with acknowledged loss where the psychological loss of the care receiver is accepted. The findings of this study suggest that ambiguous loss contributes to a long and painful grieving process. Although this study was limited to adult children, the long-term care setting, and did not focus on end-of-life care experiences it has potential to inform us in regard to how ambiguous loss may be experienced with caring for a relative with dementia. Strengths of this study are the use of theoretical sampling, the author interviewed all 68 participants herself, and that the resulting theory expands the conceptualization of ambiguous loss as a process that family caregivers move through. Despite the relevance of ambiguous loss, the theoretical knowledge around it has yet to be studied among family caregivers to persons with dementia at the end of life. For instance, is ambiguous loss a key component of the experiences of family caregivers who provide end-of-life care to a relative with dementia?

After-death grief. The grief experience of family caregivers specifically after death of the care receiver with dementia has been explored in a sample taken from a randomized control trial of the REACH study (Schulz, Boerner, Shear, Zhang & Gitlin, 2006). The primary measure of grief in the REACH study was based on the *Inventory of Complicated Grief* (see, Schulz et al.). Schulz and colleagues suggest that a minority (20% of their sample) of family caregivers continue to experience *complicated grief* after death of their relative. Of the caregivers experiencing this complicated grief after death were those who had high levels of depression and strain over the course of caregiving, as well cared for a more cognitively impaired relative compared to family caregivers not reporting symptoms of complicated grief. Schulz and colleagues' findings demonstrate a connection between the experiences of depression, strain and grief and how they may impact the end-of-life experience.

Similar to Meuser and Marwit (2001), Schulz and colleagues (2006) recommend supportive interventions earlier in the caregiving journey as a means to lessen the development of complicated grief after the death of a relative with dementia. Although grieving may be a normal response to the loss of a family member, complicated grief is not. Perhaps family caregivers at risk of developing complicated grief could be identified prior to the end-of-life phase and offered supportive interventions. The REACH was a prospective study conducted over 18 months, which also has the benefit of following participants after death of the care receiver. The findings of all the included REACH studies in the review are based on the experiences of the bereaved participants. Of note however, is that multiple post-death assessments were not available for the entire sample. As well, predominantly reporting only quantitative results may be a limitation as subjective experiences that participants might have shared were not explored.

Positive experiences and the impact on grieving. Another article related to the REACH study explored how positive aspects of family caregiving may impact caregivers' adaptation to the death of their family member with dementia (e.g., Boerner, Horowitz, & Schulz, 2004). Boerner and colleagues found that the more family caregivers experienced benefits from their caregiving the more grief they experienced with the death of the care receiver. The spousal caregivers in

Boerner and colleagues' study seemed to experience more benefits from their caregiving role suggesting a closer relationship. This resulted in experiencing a greater intensity of grief when the spousal care receiver finally died. Thus, positive aspects may aid a family caregiver during active caring but do not carry over into bereavement. In the REACH study, caregiver benefit was measured by 11 items phrased as statements; responses were rated on a 5-point Likert scale in order to measure positive aspects of caregiving. Perhaps the experience of grief as related to the benefits from caregiving is more complex than their quantitative study suggests.

Contrarily to the previous discussion, the bereaved family caregivers in a qualitative study by Koop and Strang (2003) reported both negative and positive outcomes resulting from providing end-of-life care at home to a relative with advanced cancer. The bereaved caregivers in their study expressed the view that they were having an easier time dealing with their grief because they had been able to care for their loved-one at end of life. Similarly, Kruse (2004) conducted a qualitative study which found among mixed caregivers (i.e., caregivers of persons with a range of chronic conditions) that as part of letting go at the end of life family caregivers felt the need to continue to provide care and remain respectful to the dignity of their loved-one. The participants whose family member had already died at the time of the study interview shared that doing all they could to provide care eased their grieving once the care receiver died. These retrospective qualitative studies provide a different view of end-of-life caregiving that is not possible when participants are actively providing care.

Kruse's (2004) and Koop and Strang's (2003) studies highlight the potential for positive experiences with end-of-life care that is either not present or not yet noted in caregiving for persons who died of dementia. Is it possible for community-dwelling caregivers to persons with dementia to experience the same benefits? How might providing end-of-life care in long-term care be rewarding for family caregivers? Perhaps the length of time providing care is of importance in how caregiving benefits impact grieving after death of the care receiver. In Boerner and colleagues' (2004) study caregivers had been in their role for a median of three years; Koop and Strang's sample had provided care for less than a year, and Kruse offered a range of caregiving of 4 months to 10 years for her participants. The differences in experiences between cancer and dementia caregiving may also be in relation to the different trajectories of the diseases and being able to recognize the decline in care receivers. Persons dying of cancer may deteriorate in a steady progression with a short-lived terminal phase, while persons with dementia present with a prolonged gradual decline that may last for years (Hebert & Schulz, 2006). It may be that being in the caregiving role longer (as might be the case with dementia) wears on the family caregiver or that caregiving experiences earlier in the journey may impact the experience of benefits with end-of-life caregiving.

Burden and Guilt

Burden as a consequence of family caregiving is a common theme in the caregiving literature. Care for a relative with dementia is an all-consuming, demanding role that can take a toll on family caregivers over time (Ory et al., 2000). The predominance of burden as a theme in the literature may also, in part, be a result of researchers initially studying family caregiving for persons with dementia from a stress/adaptation paradigm (Farran, 1997). Feelings of guilt may manifest for a number of reasons over the caregiving journey. For instance, family caregivers may feel guilty about their inability to do more in providing care for their relative or being relieved when the care receiver finally dies (Meuser & Marwit, 2001; Schulz et al., 2003). Although guilt and burden are commonly studied in earlier parts of the caregiving journey, only a single study was retrieved for the review that explores these experiences during the end-of-life phase.

In a descriptive qualitative study Forbes and colleagues (2000) explore how family caregivers make end-of-life decisions for care of their relative with dementia in long-term care. Reports of feelings of burden and guilt by family caregivers were a major outcome of the study. Despite the focus on decision-making, this study demonstrates the lingering experience of burden and guilt from earlier in the caregiving journey that can flow into end-of-life care. Also, there appears to be little relief for the caregiver from long-term care placement of the care receiver. Family caregivers in the study found it difficult to make end-of-life decisions, coupled with being unfamiliar with the dying trajectory. This uncertainty may have negative impacts on decisions for care and is suggestive of the need for emotional and informational support for family caregivers during the end-of-life phase. It may be important to consider whether or not guilt and burden figure in the experiences of family caregivers providing care in other settings (i.e., hospital or home).

Interestingly, Forbes and colleagues (2000) do not explicitly discuss grief; loss is addressed in terms of being painful and impeding decision-making for family caregivers. This study utilized focus groups rather than individual interviews to explore how family caregivers make decisions for end-of-life care. Nonetheless, exploring the perspective of family caregivers reveals that burden and guilt are salient experiences for caregivers who have a relative dying in long-term care. This is noteworthy given the focus on much of the research with this population to date is limited to the experience of grief and loss. What other experiences might family caregivers to persons with dementia share when not limited to a semi-structured or structured research format?

Studies conducted with mixed caregivers also identify sources of caregiver burden that result from providing end-of-life care. For instance, Cain, MacLean and Sellick (2004) utilized focus groups to explore mixed family caregivers' experiences with palliative care services in the community. They found that the consuming demands associated with providing intense care at the end of life, the resulting social isolation, financial costs, and the coordination of formal care providers were all sources of tension and burden. Some of the participants in this study were caring for a family member with dementia, however how many and the data specific to them was not separated out from other types of caregivers. Individual interviews may have revealed distinctions between different types of family caregivers that a focus group may not. Most participants were actively engaged in providing end-of-life care at the time of the study. These findings are overwhelmingly negative unlike those of Koop and Strang (2003) whose participants reported providing end-of-life care for a relative with advanced cancer at home to be both a positive and negative experience. Perhaps a retrospective approach affords a completed picture of the caregiving experience that actively caring family caregivers cannot yet appreciate. It may also be important to listen for positive experiences as well as the negative experiences that family caregivers share.

Forbes and colleagues (2000) also indicate the presence of feelings of ambivalence as family caregivers approach the death of their relative. Ambivalence manifests at the end of life when death occurs with feelings of sadness and possibly regret, while also experiencing relief at letting go of the care receiver and the suffering they have endured. Ambivalent feelings can be distressing to family caregivers. These findings are similar to the results of a qualitative descriptive study by Goodridge, Bond, Cameron, and McKean (2005) that included mixed family caregivers to institutionalized care receivers at the end of life. They found participants shared ambivalent feelings as death of the care receiver was approaching. These contradictory feelings were upsetting to the caregiver and caused turmoil in their family relationships. Other studies note family caregivers express relief with the death of the care receiver, while having other conflicting feelings (e.g., Schulz et al., 2003). However, studies may not necessarily name those feelings as being ambivalent. It may be of value to further explore if ambivalent feelings figure prominently in the end-of-life experiences of family caregivers to persons with dementia.

Depression

Caregivers to persons with dementia have been found to have higher levels of depression than caregivers of persons who are cognitively intact (Canadian Institute for Health Information, 2010; Neundorfer et al., 2001). Depression as an outcome of providing care to a relative with dementia and ways to alleviate it are the focus of much of the family caregiving research (Peacock & Forbes, 2003). Not surprisingly, assessment of depressive symptoms is the focus of half (*n* = 4) the studies included in the present review.

In an earlier article of the REACH study Schulz and colleagues (2003) discovered that family caregivers to persons with dementia experience high levels of depressive symptoms (as measured by the *Center for Epidemiologic Studies Depression Scale*, see Schulz et al.) while providing end-of-life care to their relative. More than half of the caregivers in their study admitted their relative to long-term care prior to death. Despite the potential relief from 24 hour care that institutionalization provides, those whose relative with dementia died in long-term care did not have the same relief from depression as those caregivers who provided end-of-life care at home. Is it possible that the benefit of seeing caregiving through to the end-of-life at home provides relief from depressive symptoms? Or might there be societal pressures at play here? For instance, the health care system may impose expectations on family caregivers to maintain their relative at home and when this is not the case perhaps caregivers feel a sense of failure.

Other findings from the REACH study revealed that increased levels of depression may lead to complicated grief after the death of a relative with dementia (Schulz et al., 2006). As well as caregivers who were unprepared for the death of their relative, despite experiencing grief all throughout their caregiving were more depressed than those caregivers who reported being prepared for the death (Hebert, Dang & Schultz, 2006). Boerner and colleagues' (2004) examination of the REACH study data indicate that the benefits of caregiving have little to do with influencing depressive symptoms after death of the care receiver. There appears to be a connection (causal or otherwise) between grief and depression and how this impacts the end-of-life experience for family caregivers that warrants further investigation.

Levels of depression after death of a relative with dementia were measured by Bodnar and Kiecolt-Glaser (1994). In this study depressive symptomology was assessed using the *Hamilton Depression Rating Scale* (see Bodnar & Kiecolt-Glaser); this tool was one of eight different measures posed to participants. Their quantitative longitudinal study reveals that family caregivers continue to exhibit higher rates of depression compared to a non-caregiving control group for up to three years after death of the care receiver. This appears in contrast to Schulz and colleagues (2003) who found depressive symptoms declined in the first 13 weeks after death of the care receiver and continued to decline up to 65 weeks post-death. Both studies indicate that long-term care placement of the care receiver does not appear to bring relief from depressive symptoms. These findings are similar to Forbes and colleagues (2000) who also noted the lack of relief for family caregivers with long-term care placement of the care receiver at the end of life. Perhaps there are added challenges with long-term care placement that family caregivers in the community do not face.

Further, Bodnar and Kiecolt-Glaser (1994) found that other lingering effects from the negative outcomes of caregiving (e.g., social isolation) do not seem to resolve even up to three years post death. Experiences or measures of grief were not completed nor was place of death indicated for comparison in this study; this is unfortunate as it may have revealed further insights regarding the relationship between depression and grief. The main implication of this study is that family caregivers also require support after the caregiving journey ends. The structured quantitative approaches of Bodnar and Kiecolt-Glaser and the REACH study (Boerner et al., 2004; Hebert et al., 2006; Schulz et al., 2003 & 2006) may have limited the exploration of complex experiences that may not be entirely amendable to quantification. Unfortunately, the unique and subjective experience is neglected. The collection of data from the same sample over multiple points of time is a strength of both the REACH and Bodnar and Kiecolt-Glaser's studies.

Response to the End Stage

The response of family caregivers to the end stage of their relative's dementia was studied using an ethnomethodology by Sanders, Butcher, Swails, and Power (2009). They report on a sample of 27 active family caregivers from a larger project that focused on hospice care for persons with end-stage dementia.

The transcripts of four semi-structured interviews with each participant were analyzed and coded to reveal themes that related to how the caregivers responded to their relative's end-stage. Themes were organized into four distinct caregiver portraits, (a) disengaged caregivers, (b) questioning caregivers, (c) all-consumed caregivers, and (d) reconciled caregivers. These portraits were based on how caregivers construct their experiences. For instance, disengaged and reconciled caregivers were ready for their relative's death, but for different reasons; disengaged caregivers may have been covering up for difficult past relationships, while reconciled caregivers found closure to a close relationship with the care receiver. Questioning and all-consumed caregivers were very involved in the care of their relative and this came at a price. Similar to Meuser and Marwit (2001), these caregivers experienced more burden, anxiety and grief as the care receiver approached death. A strength of this study was continued contact and multiple interviews with participants over a 10 month period. However, the sample is limited to caregivers who were accessing hospice care and were of European American descent.

In summary, it may be difficult to disentangle what is occurring at the end of life for family caregivers based on the limited studies cited above. The vast majority of the studies were based on the researchers' assumptions about the end-of-life experience for family caregivers to persons with dementia. The control required of quantitative approaches (e.g., distance between the researcher and participant, structured or semi-structured interviews, or quantification of variables) may limit understanding of a phenomenon. It is often those unique and subjective elements in qualitative research that have the potential to reveal deeper understanding. Narrowing the focus of qualitative approaches to one concept (e.g., the experience of grief) may not allow participants to share other experiences that are important to them. As well, of note is that all the retrieved studies recruited participants from existing programs or long-term care homes. Family caregivers not accessing formal or support services may have differing experiences; these individuals also warrant attention, although they may be harder to locate.

While the studies retrieved for this review provide valuable insights, the differing methodologies, lack of the subjective experience, and narrow focus of studies prove challenging to synthesizing the overall end-of-life caregiving experience; too many gaps continue to exist that limit our understanding. What is known is that (a) the end-of-life experience is found to be difficult and burdensome for many caregivers; (b) some caregivers may experience positive outcomes from providing end-of-life care that do not carry over into bereavement; (c) guilt, burden, grief and depression may not be resolved with either long-term care placement of the care receiver or their death; (d) the experience of grief is impacted by relationship to the care receiver and the stage of dementia; and (e) that family caregivers require support at the end-of-life and post-death. Clearly, the effect of end-of-life care on the family caregivers to persons with dementia has not been explored sufficiently (Allen et al., 2003).

Gaps in the Literature

The review of knowledge regarding family caregiving to persons with dementia reveals a lack of published research focusing on the personal experience of end-of-life care. Specific gaps in the literature as identified in the above review include: (a) exploring the potential differences in end-of-life experience based on place of death; (b) further exploration of the positive and negative aspects to providing end-of-life care within the context of dementia; (c) in what ways might gender, relationship to the care receiver, or the socio-cultural beliefs of the caregiver impact the end-of-life experience; (d) exploring the roles family caregivers undertake and how that may impact their experience with end-of-life care; (e) how ambiguous loss or ambivalent feelings may or may not influence the end-of-life experience; (f) how family caregivers can be supported as they provide end-of-life care; and (g) what past experiences impact the end-of-life care experience. It is evident that a great deal remains to be done to conceptualize the experience of end-of-life caregiving in dementia. However, an exploratory study of the caregiving experience of family caregivers of persons with dementia at the end of life is needed as foundational for other studies in this area.

Research Aims

The purpose of this study is to explore the lived experience of end-of-life care to a relative who died with dementia in order to better understand what family caregivers experience at the end of the caregiving journey. Given the complexity of the end-of-life caregiving experience it is important to consider the perspective of the family caregiver to further our understanding. Rigorous qualitative research is needed to add to the conceptualization of the end-of-life caregiving experience in dementia. A phenomenological approach facilitates the exploration of the end-of-life caregiving experience from the perspective of family caregivers. This allows for a rich and meaningful description of the experience and offers further understanding with interpretation of the findings.

The present study begins to address the gaps in the current knowledge by exploring the end-of-life experience from the stories of family caregivers themselves, without being driven by the assumptions or biases of the researcher. Going directly to the persons who had the experience can reveal the nature, the meaning, and the "whatness of [an] experience" (Munhall, 2007a, p. 191). Interpretive phenomenology explores a phenomenon with the people who live the experience, values and acknowledges the socio-cultural and historical contexts in which individuals exist, and seeks understanding from the deepest level of what it means to be a human being (Benner, 1994; Munhall). Using a heterogeneous purposive sample of family caregivers provided a variety of perspectives regarding end-of-life care in dementia that may broaden the understanding of the end-of-life caregiving experience. Another advantage of interpretive phenomenology is that it calls us to explore the taken for granted or hidden experiences and bring them out to develop a fuller understanding of the phenomenon. Although a single study cannot address all of the gaps in the literature, it can begin to point us in future directions that are salient to family caregivers and help to build a sound knowledge base.

Research Question

Given the state of the current knowledge and purpose of the research the question for the present study was: *"What is the meaning of the lived experience of family caregivers who provided end-of-life care for a relative who died with advanced dementia?"* The study focused on those who cared for a relative who died with dementia in the last year. This retrospective approach provided a complete perspective of the caregiving journey and allowed family caregivers time to reflect on their end-of-life experiences without the constraints that active caregiving may impose.

CHAPTER 3: Research Method & Design

The phenomenon of interest is the meaning of the lived experience of family caregiving within the context of end-of-life care to a relative with dementia. Interpretive phenomenology is an appropriate approach for the exploration of the research question: *"What is the meaning of the lived experience of family caregivers who provided end-of-life care for a relative who died with advanced dementia?"* Phenomenology values the perspective of the family caregiver in order to gain an understanding of the lived experience of providing end-of-life care. This understanding is currently lacking in the literature. Family caregivers were recruited from a variety of sources to include as many perspectives as possible regarding end-of-life caregiving. In-depth interviews with a purposive sample of family caregivers of persons who died of dementia were conducted in order to develop a narrative that captures their unique and common experiences. Other phenomenological material will be considered to enrich and broaden the study narrative to move beyond description of the experience to delve deeper to the meaning of family caregiving at the end of life. The results of the study will enable a critique of current health care practices, increase our capacity for care and compassion with family caregivers, and raise awareness of what may be taken for granted or what was not known about the end of the caregiving journey.

Research Method – Interpretive Phenomenology

"Phenomenology takes us ... to a gazed perspective where we give, reflect, and attempt to understand ..."

(Munhall, 1994, p. 4)

Phenomenology is commonly referred to as the study of the *lived experience* (Munhall, 2007a) and may be considered a philosophy and methodology (Dowling, 2007; Munhall, 1989). Research that employs interpretive phenomenology (which may also be known as hermeneutic phenomenology or hermeneutics) strives to understand and interpret phenomena (Laverty, 2003). In other words, the aim of interpretive phenomenology is to let things show themselves and seek after meaning which may be hidden (Benner, 1994; Heidegger, 1927/1962; Moran, 2000). As a result, interpretive phenomenology calls researchers to reflect on data with an open attitude that interprets the lived experience from the perspective of the individual in a deeper way to establish meaning (Annells, 1996; Bergum, 1989; Munhall, 1994). What makes phenomenology unique from other qualitative methods is that it requires immersion in philosophical literature and looking at the phenomenon of interest with a phenomenological lens (Munhall, 1994; 2007a).

Heidegger (1927/1962) opined that there is no way to prescribe a specific direction to answer questions of the meaning of *being*. Munhall (1994) speculates: “The [phenomenological] ‘method’ is to be as unrestricted and creative as possible in an intense search to understand human experience” (p. 92). As such, there are no set procedures to conducting phenomenology; this may be because phenomenology is not so much a method as it is a methodological approach. Yet, Heidegger does informally offer direction on how to proceed *phenomenologically* (i.e., the need for reflection, fusion of past/present/future, etc.) based on his various notions related to *being-in-the-world* (Annells, 1996;

Conroy, 2003; Johnson, 2000). Heidegger believes that human beings have the capacity to reflect upon experience in a way that may reveal meaning and make it known to others (Kellett, 1997).

Guiding the methodological approach for this study was Patricia Munhall's interpretation of Heidegger's phenomenology. Patricia Munhall, a nurse researcher, discusses the process of an approach to interpretive phenomenology in detail based on her years of research and academic experience (e.g., Munhall, 1994; 2007a). Munhall acknowledges the influence of Heidegger on her approach and writes in a coherent manner that resonates with my thoughts and values. Further, Munhall desires to move the conduct of phenomenology forward as a means to demonstrate its relevance to nursing. As a result, her work influenced and guided much of the phenomenological approach described below.

As the purpose of the present study was to explore the lived experience of caregiving at the end of life, it was advantageous to focus on those family caregivers who had completed their journey with dementia. By studying the end-of-life care experience when it is completed allowed for authentic meaning to reveal itself without interrupting participants while *in* their experience (Munhall, 1994). Thus, this interpretive phenomenology was a retrospective study that explored the lived experience of caring for a relative with dementia at the end of life. Heidegger suggests that we have the capacity to and values reflection on meaning of *being-in-the-world* (1927/1969) and so a retrospective approach was appropriate using his philosophy.

Research Design

Setting and Sample

The setting for this study was in a small urban center of Western Canada where I live. Remaining within a manageable geographical area was desirable as multiple interviews with participants were required (Porter, 1999). Purposive sampling was employed as a means to include participants who had experienced the phenomenon of interest and desired to and could articulately tell their story (Loiselle et al., 2004; Starks & Trinidad, 2007). There are no rigid rules concerning specific numbers of participants rather the resulting data (does it explore the phenomenon sufficiently?) determined the adequate number (Munhall, 2007a; Starks & Trinidad). Further, a heterogeneous sample was desirable to capture diverse experiences of the phenomenon of family caregiving at the end of life in dementia in order to deepen our understanding.

Inclusion and exclusion criteria. The focus of the study called for a purposive sample of participants who cared for a relative who died with advanced dementia or some consequence of it (e.g., infection) in the last year. It was necessary that these participants be willing to share their story of caregiving at the end of life (Munhall, 2007a). It was helpful to wait a few months after the death of their family member since family caregivers required time to sort out initial responsibilities, while waiting longer than a year could have reduced recall of events (Addington-Hall & McPherson, 2001). Although care receivers had other co-morbitities it was important to focus on those who predominantly suffered with dementia, as their family caregivers may have had differering experiences compared to caring for a relative with another terminal illness (Hebert & Schultz, 2006; Lynn, 2001).

Participants for the study needed to be 18 years of age and older in order to give informed consent. Also, including adults of any age was necessary given that spousal caregivers may be advanced in age (i.e., beyond 65 years) and should still have an opportunity to participate if they desired. Participants had to have the ability to read and speak English in order to share their story and provide consent to participate. Appendix A contains a sample of the written consent form with the *other* data release forms (adapted from the University of Saskatchewan's Health Research Ethics Board, available at www.usask.ca/research/ethics). As well, see Appendix B for the demographic information that was collected of each participant.

Recruitment. Participants were recruited from a variety of sources in order to attempt to achieve a heterogeneous sample. Family caregivers whose relative with dementia died in a long-term care home were easily identifiable as staff had knowledge about which family caregivers were appropriate for the study (Moss, Braunschweig & Rubenstein, 2002). I partnered with a care community in Saskatoon, namely LutherCare Communities. They willingly facilitated access to family caregivers on my behalf**.** The special care home within their care communities has 129 beds for older adults and has approximately 4 deaths per month; the majority of residents have some form of dementia (M. Cooper, Director of Nursing, personal communication, March 4, 2009). After receiving ethics approval, I met with the social worker who was willing to assist with recruitment. The social worker contacted families on my behalf and asked their permission for me to telephone the family. The names and telephone numbers of those who provided consent to be contacted were shared with me as they became available. I then contacted those family members who consented. A total of six families were contacted by the Social Worker and all agreed to participate in the study.

In order to achieve variability, family caregivers of relatives who died in hospital or at home were also sought out. I attempted to locate these types of families through advertising with the other residences affiliated with LutherCare Communities. This was done using a poster (see Appendix C) on the announcements board and by offering a small tea (that was held in the centre) for a presentation of the proposed study to residents who might be interested. LutherCare Communities has a resident's tower with 195 suites for independent seniors and an assisted living residence with 15 residences for older adults requiring assistance with the activities of daily living. It was hoped some of these residents had cared for a family member with dementia who died in some place other than the long-term care home. I was able to recruit one suitable participant in this process. Appendix D contains a copy of the letter of support from V. Hauck, Chief Executive Officer of LutherCare Communities.

Further, I pursued contact with family caregivers through advertisements with the Saskatoon Council on Aging. The council is a resource agency that is a community-based, voluntary organization that functions to promote the health and independence of older adults. They willingly advertised the research poster (see

Appendix C) in their office. This resulted in a number of inquiries, including non-family caregivers sharing this information with potential participants. This resulted in two participants contacting me to be included in my study.

As well, I undertook snowball sampling with the initial eight participants. By asking initial participants for the names of other individuals with the same characteristics who may agree to be in the study is known as snowball sampling (Munhall, 2007b). I asked that the participants share my contact information with these other people so that they may contact me if interested in also participating in the study. This resulted in two additional participants.

Data Generation

In-depth interviews (or *discussions*) that allow the participant to share their story formed the main data gathering technique with participants in this phenomenology (Bergum, 1989; Morse & Richards, 2002; Munhall, 1994, 2007a; Wuest, 2007). According to Heidegger "discourse brings the matter out into the open, lets it be seen" (Moran, 2000, p. 29). At least two in-depth, open-ended, audiotaped interviews were completed with each participant. Data generation, with respect to participants, flowed in this way:

1. Contact with participant, agreed upon a convenient time and comfortable place to meet.
2. Initial face-to-face audiotaped interview was conducted in the home or office of the participant to obtain written informed consent, collect demographic information, and begin the telling of the end-of-life caregiving story (approximately 1-3 hours long).

3. Interview was then transcribed verbatim by either me or a hired transcriptionist, with field and personal notes completed.
4. I occasionally debriefed with my co-supervisors about the interview process and how I was affected by the participant's story; this was done after the first participant and then with any participant that proved challenging.
5. I prepared the data from the initial interview in a draft narrative summation with consideration for the context of the situation and potential meanings. I then arranged for the second interview.
6. The second face-to-face audiotaped interview (approximately one hour in length) allowed the participant to share further reflections and for verification of the draft individual study narrative. Field and personal notes were again completed.
7. After second interviews were completed with all participants (i.e., the phenomenon had been explored sufficiently) an overall study narrative was prepared that considered the meaning of the experience across narratives. A third and final interview was arranged with a select group of (four) articulate participants.
8. The third face-to-face audiotaped interview allowed for deeper questioning related to the life worlds (approximately one hour in length). The overall narrative in its initial stages was shared with two of the participants to check for accuracy of meaning of the end-of-life care experience.

There is a relationship between the participants and researcher involved in phenomenology that called for close contact over a lengthy period of time (Munhall, 1994). This was because a respectful relationship is ethically necessary and needed for participants to share their stories. I maintained telephone contact with participants and was flexible with meeting times to accommodate them; I was sensitive to their emotions and reminded them of elements of confidentiality when necessary. Merleau-Ponty suggests that a researcher should approach participants from the perspective of a *perpetual-learner* (Thomas, 2005). This was done by my choosing to keep an open mind and, as Munhall (1994; 2007a) suggests, a willingness to listen from an *unknowing* stance. The following is a detailed discussion of procedures and issues regarding the above data gathering process with participants.

Interview setting. The place of the interview was in the participant's home and in one case a participant's office. Participants were informed and reminded that they could end an interview or leave the study at any time. As noted above, more than one interview was required so as to check meaning and seek clarification with participants regarding interpretations (Conroy, 2003; Munhall, 2007a; Walter, 1995). First and second interviews were completed with all 11 participants, with one participant requiring a third interview to complete her individual narrative. A total of four third interviews were done with a purposive sample of participants who were the most articulate and insightful in their sharing. A total of 27 interviews make up the majority of the study data.

Process. During the initial contact between myself and the participant, the purpose of the study was clarified and a convenient time for the first interview was set. The first interview involved obtaining written informed consent, collecting demographic information, and hearing the story of end-of-life caregiving from the participant; personal and field notes were collected after the end of the interview. Subsequent interviews included discussion about new insights or additions to the previous interview and personal and field notes were collected. All interviews were audiotaped with permission of the participant; one participant was made uncomfortable by the presence of the recorder so her interviews were not audiotaped.

In order to allow participants to tell their stories and talk about their experience an open-ended unstructured interview approach was utilized (Mayan, 2001; Munhall, 2007a). The participant's stories were heard in their *voice* with no direction imposed by me (Benner, 1994; Conroy, 2003; Johnson, 2000). It was vital to create an open and inviting relationship with participants such that their story of caregiving flowed freely. The first interview began with a very broad question (e.g., "What was it like to care for your dying relative?") to initiate description of the participant's experience. Participants were reminded that there is no right or wrong way to share their story; it is their personal experience, interpretations and meaning that is sought after and valued (Munhall). In order to glean meaning of the caregiving experience it was occasionally necessary to add more probing questions, albeit sparingly. For instance, asking "How were you feeling?" or "What did that do for you?" were used to help the participant to move beyond description. To draw out what seemed to be hidden it was useful for me to ask for clarification, offer reflective observations, or restate what had been said (Conroy).

It was important to think of the interview as a conversation and avoid leading questions that might have imposed structure on the participant's story (Johnson, 2000; Munhall, 1994; 2007a). Allowing for moments of silence and reflection were necessary, although uncomfortable at times. Listening is an art in phenomenology (Munhall, 2007a). Going back to participants for a second interview allowed them an opportunity to add more *reflected on* material to the previous interview and to answer the closing question of: "Might there be anything more you would like to share?" (Munhall, 2007a). Returning to participants allowed for the possibility to reveal deeper layers of meaning and offered a *second chance* at understanding (Benner, 1994). Attending to both what participants said and what was left unsaid is important in interpretive phenomenology (Gadamer, 1975/2004) and I did my best to ensure this occurred. All transcript data was hand coded; interview tapes were listened to many times and transcripts re-read over and over to be as thorough as possible.

Other sources of data. "Phenomenology is not only the language of words but also the language of semiotics, the symbols and signs in our environment that 'speak' to us and tell us what is going on in the environment" (Munhall, 2007a, p. 186). A gathering of other materials, such as art, poetry, or letters can also convey meaning and deepen understanding of an experience. Art has the potential to offer a representation of an experience in that it offers "wondrous connections to the human spirit and the telling of what it means to be human" (Munhall, 1994, p. 115). Thus, I invited participants to share a drawing, photograph, poem, diary entry or anything else that helped the participants to find meaning in their end-of-life care experience. Three women and two men (all spouses) shared photo's of when their spouse was well and one gentleman shared a book that helped him with his grief process.

In addition to rich interview data or participant art, data was also found in philosophical and phenomenological literature (Morse & Richards, 2002). This literature was necessary for a phenomenological approach. As such, ongoing reading of philosophers work (e.g., Heidegger, 1927/1969; Gadamer, 1975/2004; Taylor, 1989, etc.) was essential. Other ways to enhance reflection included looking for description of the phenomenon in other sources such as literature, poetry or art (Conroy, 2003; Munhall, 2007a). Munhall suggests that researchers be sensitive to the presence of material that is important to the study, that eventually a researcher begins to "[see] it everywhere" (p. 168). It was imperative that these kinds of insights and connections be added to data to deepen understanding of the phenomenon. Any material that enriched the understanding of the phenomenon was included given my aim was "for a full-of-meaning-and-detail narrative of the experience" (Munhall, p. 183). Reflecting on a wide variety of resources assisted me to find out what makes up the phenomenon (Morse & Field, 1995). Philosophical *data* is included within each participant narrative and other findings as means to aid in interpretation and understanding of the end-of-life care experience.

Data Analysis

In phenomenology, analysis or interpretation is not a single step completed at a particular time nor is it a linear process (Laverty, 2003). Instead, analysis (of many sources of *material*) was on-going and concurrent; it is a constant part of the inquiry once there was a realization that phenomenology was the way to explore the phenomenon I longed to understand (Munhall, 2007a). There was a constant going back and forth; pausing to reflect and reflecting further when thoughts changed or new insights were discovered (Benner, 1994; Munhall). This took many months and many drafts of writing to complete.

Existential investigation. Existential inquiry demands that I be attentive to and reflective of the world around the participant and me (Munhall, 2007a). It was particularly important that I be aware of and give considerable thought to my own assumptions and biases as these were essential to and embedded within the interpretive process (Laverty, 2003). See Appendix E for a paper that reflects my personal experience, assumptions, and biases related to end-of-life care and dementia. Further, a number of things occurred that lent to the process of analysis; for example, (a) preparing a literature review of the current knowledge and gaps in the research; (b) reading philosophical texts; (c) undertaking self-reflection in what lead to the desire to study the phenomenon; (d) seeking and recognizing the phenomenon in other resources (poetry, art, novels, films); (e) recording reflections and personal experiences in a personal journal; and (f) writing a personal reflection chapter for the present dissertation (see Chapter 5). As interviews were completed they became additional sources of the experience of the phenomenon with each participant providing their story as one perspective. The challenge then was to write the existential material that had been gathered with attention to the contexts in which the participants and I found ourselves (Munhall).

Contextual processing. Recall, that Heidegger proposes we are always in the *world*, influenced by our history, culture, and social contexts (Leonard, 1994). It was important to engage in processing what was occurring for the participant and their resulting experiences based on what their world provided or limited (Munhall, 2007a). This is because the situated context in which the participant found them self had influence upon the meaning of experience (Johnson, 2000; Morse & Richards, 2002).

In interpretive phenomenology it is important to assess the four existential life worlds in order to understand further what perspective the participant comes from and how that context might influence meaning (Munhall, 2007a). The existential life worlds are: (a) *spatiality* or the environment or space in which we live; (b) *corporeality* refers to the body and may also be referred to as embodiment; (c) *temporality* or the perception of *time* in which we are living; and (d) *relationality* or the world of relations to others (Morse & Field, 1995; Munhall; van Manen, 1990). The life worlds are in unity and interconnected. The significance of each life world to the experience of end-of-life care within the context of dementia will be discussed in detail in the findings chapter (see Chapter 4). Without consideration of the participants' situated context meaning of a phenomenon would be incomplete (Munhall, 1994). Thus, I became aware of and acknowledged these dimensions and their potential for influence on meaning and experience.

Write participant phenomenological narratives. It was essential to capture each participant's story in such a way as to communicate an understanding of the situated context married with the existential material (Munhall, 2007a). I carefully chose from the long spoken narrative to create a narrative summation that reflected the central meaning that had been communicated. This was achieved after re-listening to the audio recording, dwelling on the transcript and memories of the interview process, while contemplating the meanings that were communicated by the participant. Other data collected (photographs and writings) from participants were also considered. I reflected on the meaning the other data communicated and integrated it into the narrative (Munhall, 1994). Benner (1994) advised that I must be patient with the text and imaginatively ponder the participant's situation.

Meaning presented in the narrative cannot be acontextual or ahistorical; "interpretation of the interaction of the situated context in which individuals find themselves while in experience" provided a holistic interpretation of the experience (Munhall, 2007a, p. 198). Thus, the meaning of the experience for the participant was integrated with the life worlds. It was through this integration that authentic meaning was discovered. I reported meaning that acknowledged the individual experience rather than a synthesis of meanings. It was also important to ponder what was concealed (Mackey, 2005) and to highlight these aspects to reveal meaning that may be taken for granted (Carmen, 2006). As a novice researcher it was important for me to seek guidance from second readers (e.g., my co-supervisors) to independently analyze the individual narratives after being provided with a copy of the participant's transcript (Conroy, 2003). This activity was also useful in order to consider the hidden or obscure meanings.

I then returned to each participant with their individual narrative summation and to check for accurate interpretation of the participant's lived experience. Participants were invited to comment on his or her written narrative and could add or delete anything they wished. No narrative was rejected out right, instead occasionally a word or phrase was clarified or a salient event was added to the narrative. I found it useful to continuously examine my personal biases and prejudices and reflect further so that the narrative was a mirror of the participant's story (Munhall, 2007a; Walter, 1995). Put together, the participant narratives add to our understanding of the phenomenon.

Write a narrative of the meaning for the study. It is important to remember that phenomenology is not interested in generalizations or focusing solely on the similarities of participants (Morse & Richards, 2002; Munhall, 2007a). Further, the narrative of the study is not intended to be reduced to a homogeneous work where *one person* is a synthesis of many. Each participant's story is valued as a unique perspective on the phenomenon. I strived to accurately reflect the participants' voices (Benner, 1994). The group of participants certainly shared similar meanings of the experience; however it was just as important to call attention to and acknowledge the differences among participants (Munhall). So, although categorizing findings in the study's narrative according to common themes may be useful to capturing the experience of a group of people, Munhall cautions that researchers not be bound by themes alone as there may be the risk that individual contexts are lost. Thus, instead of generating themes, the four life worlds were thoroughly explored to further examine the phenomenon.

It took much time and deep consideration to complete the study narrative. Writing and rewriting the narrative were essential to reflecting about the phenomenon in order to develop insights (Morse & Richards, 2002). The result was a summary of the major interpretations found in the participants' narratives and was supported by direct quotes from participants (Munhall, 2007a). It was important to return again and again to the earlier steps of the process (in a circular way) to ensure wholeness of the study (Munhall). There was engagement in cycles of understanding, interpreting, and critique as I moved from the parts to the whole of the text (Benner, 1994). The study narrative underwent independent analysis by second readers (i.e., my co-supervisors) to verify that the research had met the intents of the study (Conroy, 2003). This summary was then given to two of the participants (in the third interview) to seek clarification and accuracy of the writing of the experience (Munhall). I reminded the participants that the summary contains many stories and is not only a detailed account of their individual story. Also, there was a need to bear in mind that interpretation can never be complete (Johnson, 2000; Koch, 1996) and that we are always seeking understanding (Gadamer, 1975/2004). Both participants agreed with the study narrative and felt that it resonated in some ways with their experience.

It is imperative that the resulting data from the study be presented in such a way as to reach as many interested persons as possible. With thorough writing and sharing “Excellent phenomenology touches us [as if to declare] ‘that’s it!’” (Morse, 1992, p. 91).

Trustworthiness of the Data

It was important to utilize verification strategies to shape and direct the development of the research in order to ensure rigor of the study (Morse, Barret, Mayan, Olson & Spiers, 2002). Sandelowski (1986) suggests incorporating procedures to maintain credibility, auditability, fittingness, and confirmability as a means to achieve rigour in qualitative research. However, specific to interpretive methods confirmability (i.e., neutrality or objectivity) may not be desirable because ultimately I am also part of the findings (Morse et al.); knowledge was co-constructed between the participants and me. I needed to remain neutral and not lead the participant in sharing their story, however I could not be neutral with respect to the findings as might be the case in other qualitative methods. The following is a discussion of the various verification strategies that were undertaken in order to address the factors of credibility, auditability and fittingness, as well as post-hoc criterion.

Purposive sampling. Fittingness is the external validity of qualitative methods such that participant’s stories are representative of the phenomenon (Sandelowski, 1986). In order to achieve fittingness of the data it was necessary to utilize a sample of participants that could articulately illuminate the phenomenon being studied, thus purposive sampling was used to attract individuals who were capable and willing to reveal their story. It was also important to remain true to the data that the findings are derived from and check for representativeness of the data as a whole. The participants affirmed that the narrative‘s representation of the meaning of the experience resonated with them (Munhall, 1994).

Confirmation. Credibility or truth value was maintained through adhering to the text of the interview transcript and returning to participants for confirmation of the interpretations made of the data. It is the participants themselves who were able to indicate if the interpretation captured their story and the meaning it holds for them (Munhall, 1994). Prolonged contact with participants and validating interpretations with them was necessary for both credibility and fittingness (Sandelowski, 1986). I conducted all interviews and provided an audit trail to ensure consistency over the research process.

Audit trail, memos, and field notes. With the exception of one participant, all interviews were recorded on audio tape and transcribed verbatim. Recordings were transcribed by me or an individual typist who agreed to maintain confidentiality. Each transcript was checked and cleaned by me as soon after the interview as possible. Additional comments regarding pauses or non-verbal feedback were also added to the transcript during this time. This was helpful later in the analysis process to help identify what was unsaid or taken for granted (Conroy, 2003). For the one participant who refused to be recorded copious notes were made of the three interviews with the participant verifying quotes as accurate.

Since phenomenology is an emerging process it was vital to record any and all changes and decisions throughout the study (Conroy, 2003; Koch, 1996). An audit trail using memos was necessary to ensure consistency and auditability of the findings (Sandelowski, 1986). Field notes aided in tracking the research process and in the interpretation of the data. This was important to the reflective process required in interpretive phenomenology (Conroy). Field notes of observations and perceptions of the interview provided an opportunity for reflection and augmented the interview data; these activities also helped to enhance credibility (Koch; Sandelowski). Field notes included a description of the setting in which the interview took place, as well as my reflections, interpretations, hunches, and moments of confusion about what happened with the interview (Mayan, 2001). Field notes were completed as soon as possible after each interview.

Journaling and researcher sensitivity. I kept a personal journal of the research process separate from the data. This journal included struggles I encountered, personal reactions to the interviews, and insights relevant to the research. Munhall (2007a) suggests that this personal journal be considered a *phenomenological journal* in that it "situates [the researcher] in the life-world of [the] study" (p. 193). Heidegger values the beliefs of the researcher and proposes that he/she be aware of and reflects on their own *being-in-the-world* (Wimpenny & Gass, 2000). Thus, it was important I check and track understandings and reflections that the study process brought up (Munhall; Walter, 1995) and was useful for me as I engaged in further interviews. Writing in such a personal way added to a broader view of the experience, provided an avenue for personal growth, and demonstrated how the research process changed my understanding (see Chapter 5). Personal journaling and recognizing how I was influenced by and influenced participants was also a means to maintain credibility of the study (Koch, 1996; Sandelowski, 1986). Occasionally debriefing between me and my co-supervisors after interviews was also of value.

Post-hoc 'R's.' Research from a phenomenological perspective also requires criteria to ensure that the research remains consistent with its aim. Thus, Munhall (1994) proposes a number of concepts as criteria for assessing the rigour of phenomenology. These include: (a) resonance, (b) recognisability, (c) raised consciousness, (d) reasonableness, (e) representativeness, (f) readability, (g) relevance, (h) revelations, and (i) responsibility. *Resonance* is a criterion that indicates that the interpretation of the meaning of the phenomenon resonates or rings true with the participants. Clear and articulate writing of the participant narratives and the study narrative was required for this to occur. Similar to resonance is the criterion of *recognizability*. Recognizability is the detection of aspects of an experience by individuals who read the study, but who may not have had the experience themselves. During three recent presentations of the preliminary findings of this study I received feedback (in the form of nods or verbally) from conference participants that suggested recognisability. This recognition may raise their awareness of things that the reader may not have considered before; this is the criterion of *raised consciousness*. Questioning our beliefs and re-evaluating what we think we know of an experience is the aim of phenomenology and should raise consciousness (Koch, 1996). *Reasonableness*, as a criterion should answer the question of "why?" for any of the decisions made throughout the study; for example, does the interpretation of the phenomenon seem plausible? The reasoning process used throughout the study was supported by rationale and is available for evaluation by others (Munhall).

Repesentativeness is a criterion that ensures that the study represents the various aspects of the lived experience. A broad variety of perspectives was necessary and it should be evident that all avenues that aid in our understanding have been considered; for instance including other materials that the participants deem meaningful. Preparing the study to read like an interesting conversation so that it is understandable by a variety of people meets the criteria of *readability*. It is necessary that the study have *relevance*. The study was relevant to my interests as well as serving the people being studied. The criterion of *revelations* reminded me that a deeper level of understanding can be achieved when we have also considered what was concealed or simply taken for granted. Paying close attention to what was said and not said in interviews with participants was necessary to reveal what may be concealed (Koch, 1996). These revelations were presented in the narratives for each participant and in the study narrative as well. Lastly, *responsibility* ensured that I was aware of my ethical commitment to participants and the stories they shared. This required me to be sensitive to participant's stories and remain true to the meaning of the phenomenon as presented by them. As well, data was transcribed and stored in an ethical manner (Munhall, 1994).

Many of these criterions were assessed when the study was underway and after it was completed in some cases. Remaining true to the participants' stories, returning to them for verification, responding to comments by others about the study narrative, and remaining sensitive to the ethical considerations throughout the process all aided in the rigour of this phenomenological study.

Dissemination

It is possible that outcomes of the study could be used for development of end-of-life care policies, increase our capacity for care and compassion with family caregivers, and raise awareness of what may be taken for granted or what was not known about the end of the caregiving journey (Munhall, 2007a). Munhall further suggests that the descriptions and interpretations from phenomenology also be stated in a way to critique current practices in the hopes of offering them as direction for change. In this way the study has a mandate to act on participant's stories in an attempt to improve end-of-life care for persons with dementia and their family caregivers.

The outcomes of the study will be shared in a number of ways; as Morse (1992) states, "The power of phenomenology is in the sharing" (p. 91). Poster and oral presentations will be of benefit to a variety of individuals that may be affected by the outcomes of the study. For example, presenting at an Alzheimer's Society conference may reach a variety of individuals, including the kinds of family caregivers who participated in the study. While scientific conferences (e.g., Canadian Association on Gerontology) may provide opportunities to share with formal caregivers, other researchers, and policy-makers. Presentations to nursing students and peers in other formats (e.g., research days, graduate student seminars, or Geriatric Grand rounds within the health region) will be sought. Publications in peer-reviewed journals are also imperative. It is important to share the findings of the study with as wide an audience as possible. In addition, publications that discuss the process of the study (e.g., the relevance of interpretive phenomenology as a methodology to the study of experiences with family caregiving) will be considered. These are useful to describe the challenges and successes of the research process so as to benefit future researchers who may undertake an interpretive phenomenological study.

Ethical Considerations

This study received ethical approval from the University of Alberta's Health Research Ethics Board; as well as, the University of Saskatchewan's Health Research Ethics Board as I was a resident of Saskatchewan and the study was conducted in my home province. The Saskatoon Health Region also granted ethical approval given that I was to partner with the long-term care home within the health region.

The study involved working with vulnerable participants. Although bereaved family caregivers may be vulnerable this should not preclude them from participating in research (Dean & McClement, 2002). It was important to be sensitive to the needs and emotions of participants as they shared their stories. It was occasionally distressing for some family caregivers to talk about their experiences as their stories brought up unpleasant, unresolved, or difficult feelings. It was important for me to recognize when it was difficult for a participant to continue in the study (Munhall, 2007a). I shared a list of resources (see Appendix F) available in Saskatoon with each participant at the first interview, including the contact information of a grief counsellor if necessary for any of the participants (see support letter from Dr. Phil Carverhill, a registered psychologist, Appendix G). However, the process of telling their stories was cathartic and relieving for some of the participants as it offered a way to have their end-of-life experiences valued and heard by others (Boss, 2004).

As indicated earlier, participants were informed that they may withdraw from the study at any time and refuse to answer any question if they chose. I provided compensation to participants in the form of a small gift for the time it took to participate in the study. Ten of the participants chose a donation to the Alzheimer’s Society and one chose a $20 gift card to Tim Horton’s. It was important that compensation not appear as being coercive (Horowitz, Ladden, & Moriarty, 2002).

I was cognizant of the responsibility I had to the participants who shared their stories. The research interviews provided an opportunity to share a deeply personal experience and with that sharing the participant may be changed; just as I was changed in the process. It was useful for me to debrief occasionally with my co-supervisors to discuss the research process and how it was affecting me.

Bergum (1989) suggests that researchers have a life-long ethical commitment that extends beyond signing the consent form and the time it takes to conduct the study. Procedures that ensure confidentiality were discussed with each participant. For example, participants were made aware that code numbers will identify their recorded interviews and transcripts. In addition, recordings, transcripts, memos, notes and code lists were kept separate from personal and demographic information and the signed consent forms. All documents will be kept in locked cabinets for a maximum of five years and be destroyed thereafter. In reports of the study findings pseudonyms will be used to avoid identification of the participant. It was important to collectively write the participants' stories within the study narrative in such a way that they may recognize themselves in the narrative but that others could not recognize them (Bergum; Munhall, 2007a). In addition, care was taken to recognize that interpretation would always be qualified. It was therefore essential to use memos, keep a rigorous audit trail, and appeal to my co-supervisors and the participants to guard against gross misrepresentation (Conroy, 2003).

CHAPTER 4: Findings & Discussion

The purpose of this chapter is to share the findings of the study. This chapter will flow from the parts to the whole in order to develop an understanding of the end-of-life care experience for family caregivers to persons with advanced dementia. Although data generation and analysis did not necessarily follow a linear path it is helpful to present the data in this way so as to build towards the overall common narrative. The chapter will begin with the context of where the study unfolded. Following this is a presentation of each participant's narrative. Among the narratives are threads (or essences) that tie the experience together; these essences will be discussed. The findings then move toward a detailed discussion of the life worlds as they are informed by the narratives and essences. By moving back and forth among these parts an overall common narrative was developed and will be presented at the end of the chapter. Please note that supporting quotes from philosophical sources are in italics.

Context

All of the participants for this study lived in Saskatoon and were three or more months bereaved at the time of our first meeting. Among the participants are four wives, three husbands, three adult daughters, and one adult son. Every one of of the spouses remained widowed at the time of our meetings and all seven of them were retired; their ages ranged from 65 – 89 years old. Three of the adult children were married, one was widowed, and all worked either full or part-time; their ages ranged from 49 – 63 years old. To varying degrees, each of the participants undertook hands-on care and/or advocated for formal care to be provided to their relative with dementia.

The care receivers (ages ranged from 63 – 89 years) all had a confirmed diagnosis of some form of dementia and died in a long-term care home within a year of the start of the study. Ten of the care receivers died in various facilities within Saskatoon; the eleventh care receiver died in a home on the east coast of Canada. Thus, the focus of this study is end-of-life care within the context of long-term care. Care receivers were admitted to long-term care homes because of the progressive cognitive decline dementia imposed, their increased need for personal care, and the inability of the caregiver to continue providing intense care. Safety issues, incontinence, and wandering were also reasons for admission. Length of residency in the long-term care home was from as short as 10 days to as long as 4 years. Much of the family caregiving that was undertaken in the long-term care setting involved feeding their relative. This was particularly true for most spouses who established routines around mealtimes. Continuing to provide personal care (e.g., shaving, toileting, etc.) was allowed for some participants and discouraged for others. Becoming bedridden and not taking anything by mouth were the main signals of the end of life for the vast majority of care receivers.

Despite the focus of the present study on end-of-life care, the majority of participants began their discussion with a detail of events that lead up to the diagnosis of dementia, the cognitive and physical decline in their relative, and their relative’s eventual admission to long-term care. The interview transcripts are full of rich discussion of the overall journey with dementia; this is telling. As well, the photo's that spouses shared helped complete the context that participants came from when telling their stories. It is evident that the end-of-life piece is but one small part of the whole journey with dementia and it holds varying significance to different people. I suspect that this *testimony* to the whole journey, as Frank (1995) refers to this type of storytelling, are my participants' way to bear witness to their relative's life and illness. This testimony is reflected in Merleau-Ponty's (1962/2002) comment, "*Past time is wholly collected up and grasped in the present... I have my actual present seen as the future of the past*" (p. 80).

Participant Narratives

An individual narrative was developed for each participant after the first interview. I returned to each participant with their narrative and asked for feedback and comments as to whether I had in fact captured what had transpired for them during the end-of-life phase of caring for their relative with dementia. By using verbatim quotes from the transcripts I attempted to use their words to guide how their story unfolded. Bear in mind, many of the transcripts were complete stories of the whole journey with dementia; to remain true to the intent of the present study I focused on the end-of-life phase and supported it with experiences that may have occurred in the past if that was warranted to develop the end-of-life care narrative for each participant.

While there are many similarities among the participant's narratives there is also a uniqueness to each experience that should be given voice. These narratives are a result of my writing with any additions participants felt was necessary to further their story. I encouraged participants to alter, add, or delete anything in their narratives that they did not agree with or felt was missing. I did not have a single participant who rejected his or her story out right. Instead, when necessary small additions or clarifications were made at the request of a participant. This usually meant changing a particular word or commenting on something significant to the participant. Dale is a good example, he requested that I comment that his wife would ask for him to take her home when he would go to feed her in the long-term care home; this was something very important to him that I had not thought meant all that much to his end-of-life care experience. Pseudonyms have been used and I will present the narratives in the order of the interviews.

Lois

Lois (65 years old) is a newly retired professional, lives in her own home, and has two grown daughters who live in opposite ends of the country. I was very fortunate to have Lois as my first participant. She was articulate and generous with her sharing. This may have come from her past experience as a research participant and in relation to her work as a support group leader for caregivers. It was important to Lois that I know who her husband was apart from his dementia. She was thankful for the opportunity to share her story and make sense of losing her husband to this "horrendous disease." Here is her story:

Lois shared a great deal about Bill, this was very important for her to do. She provided *his story* very eloquently – "he was an amazing man." This story revealed three Bill's: (a) Pre-Alzheimer's Disease (AD) Bill (the scientist), (b) early/mid AD Bill (at home to long-term care), and (c) End-of-Life Bill (of the last 2.5 weeks). Lois speaks of *tipping* or breaking points – when Bill can no longer be at home alone, when he must go into long-term care, and when the end was coming. She intuitively knows her husband and what is going on for him. Being there and providing comfort was very important all through his living in the long-term care home, including at the end of life.

Lois also mentions a number of times that Alzheimer's disease is a "horrendous disease" and she shares about her concerns at possibly passing this onto her daughters. This weighs heavily at times for her and her daughters (i.e., *should* they have children of their own?). Their grief has flowed over all the stages of dementia and new/different grief work is ahead with the 1 year anniversary having passed. A recently added grief for Lois is the loss of her puppy.

Lois is (tentatively) thankful that the end (the last 2 days really) were quick for Bill, it "was the best thing...I couldn't wish him back." There are other times she would have liked more time: "like in other ways it would've been nice if it had been a long progressing [dementia] that you have 10-15 years of half decent life..." further, "you always feel that there could be a magic wand and he'll come back..." Understandably, there is this residual ambivalence about his death.

Further, Lois talks of having time to "get my head around it..." Yet, "I just couldn't believe, especially that he went so quickly..." It seems that Bill's death was expected/anticipated and yet it was still shocking to have it all transpire over such a short time.

It would seem that Bill came full circle with his disease as Lois and her daughter were able to donate his brain for dementia research – "he is a scientist at the end..." Perhaps, she too has come full circle and uses her fresh and relevant experience to help other family caregivers – she uses this unwanted role as a positive opportunity. "There is only *one* form of liberation for those who are ... suffering *{grieving}*: to elevate suffering to the level of one's own perspective and to transform it into an aid for one's way of seeing." (Rilke, 2005, p. 112-113).

There is a song by James Blunt (*Carry you Home*, 2007) that captures the heart of Lois and Bill's journey:

As strong as you were, tender you go.
I'm watching you breathing for the last time.
A song for your heart, but when it is quiet,

I know what it means and I'll carry you home.
I'll carry you home.

Jane

Jane was my second participant and probably my most challenging. She is an active 84 year old woman who plays tennis twice a week. Jane was approached by another researcher who noticed my poster at the Council on Aging. So, when we spoke on the telephone I was not sure she was ready to talk with me, but she insisted she wanted to tell me her story. As she spoke I noted contradictions in her story (e.g., how long she had been away on vacation the week or month prior to her husband's death) and I sensed her struggling to tell me the feelings that arose from her experience. Jane had had serious family crises prior to husband's death and I am sure that impacted and perhaps resulted in confusion about how she might be feeling during those few years. I did my best to be succinct and delicate with her story so as to honour where she was at during the time we met; here is her story:

Jane and Jim were married for 62 years and shared a rich life together. Jane talked candidly about the last couple of years with her husband Jim. Many times Jane states: "it was very hard." Jane suggests briefly that perhaps she and her family were in denial about Jim dying. This may have been influenced by and related to their other recent losses and challenges (for example: son-in-law's suicide, daughter's health crisis). It would be impossible to separate these experiences from the past to what was going on in the present and what was inevitable in the future - Jim dying.

The *moves* that Jim had to make in his last months weigh heavily on Jane - the move from the home they shared into the (private) care home 4 blocks away and the final move to the long-term care home. Among these moves Jane wishes Jim had *simply* returned home. Except that, given his care needs, this would not have been a simple move. Nonetheless, end-of-life care, according to Jane, is best done at “home... with someone who cares about them when they die.” The constraints and issues in long-term care cannot seem to provide this kind of caring environment. In fact, as Jane describes, the environment was so unpleasant it made it difficult for her to remain there and just *be with* Jim. It appears that in many ways, both large and small that the health care system let Jane and Jim down.

Interestingly, Jane pointed out that her mother believed that life was about, ‘caring for the people that cross your path.’ I think this belief has significance for Jane as well. Caring for others is principal to Jane’s life; in particular, supporting her daughter. Her present grief work, as Jane states, “leaves you with a ton of guilt” may be related to not being able to actualize the end-of-life care she so desired for Jim. Despite these feelings Jane is left with the task of carving out a new identity as a single woman; she had not planned for this. “*Death, in itself, is not wonderful. It is terrible. But how we see our death and the death of others we know and love can be transforming. It takes time. But it is possible*.” (Nouwen, 2001, p. 151).

In conclusion, Jane pointed out three significant things that occurred around the time of Jim’s death: (a) Jim died on her father’s birthday, (b) a friend lost her dog Toby that day, Jim had a dog named Toby as a child, and (c) a good friend called the morning Jim died with a feeling that Jane needed her. These fortunate coincidences seem to comfort Jane and provide some meaning to the day Jim died.

Charles

Charles (73years old) is a retired dentist and has recently moved into a senior’s high rise although, he stated he is “not really ready for what it has to offer yet.” I was thankful to have Charles as a participant. I think our conversations were as much for him as for my research. Making sense of the way his wife died gave him a deeper perspective on what that time meant to him; this was made possible by sharing with someone who was virtually a stranger to him. Both he and his wife had careers and excelled in their chosen professions; they had no children together. Charles viewed his care as a way to maintain his wife's dignified independence, to enable her to do as much for herself as possible because so much of their married life they were independent of each other. As he spoke I could see he was negotiating what to say and how to say it, he was concerned about details and exact dates. This is his story:

" I hold this to be the highest task of a bond between two people: that each should stand guard over the solitude of the other." (Rilke, 1975/2004, p. 33). Charles's married life with his wife Claire, including their journey with dementia, may well be reflected in this statement by Rilke. All during their long marriage, Charles recognized and honoured Claire's need for independence. The day she passed away seems to be no exception.

Charles shared a great deal about the impact of dementia on his wife. The most painful consequence being "Claire felt so very bad [in] the fact that she lost her independence," "her independency... this is exactly [what] this damn disease took ... away from her." He seems to downplay his role as her caregiver, yet together they managed her dementia very well and "didn't change [their] lifestyle all that much... went on holidays... to the symphony" and the theatre. His most concentrated caregiving took place in the last 8 weeks or so of Claire's life. Interestingly, Charles comments that " I didn't find it a chore... I didn't think of it as a burden" to provide this care; instead he "found it natural."

Particular dates hold importance related to the loss that accompanies them. These significant losses are condensed in the last months of Claire's life, as if: "[a] little parade of endless miseries" played out before Charles (Rodriguez, 1917). These include:

- June 5th - Claire's 75th birthday. The inability to dress herself begins close to this time, this is when "[the] business of the clothing really started to go downhill.";

- August 5th - a family reunion down south. Claire loses the ability to feed herself properly, “that was the first time she had a problem with the food... getting it to her mouth.” As well, Charles states: “from then on things went downhill very quickly.”;
- September 19/20th – Charles seeks assistance from the social worker to manage Claire’s behaviours; Claire subsequently enters long term care for a respite bed. Admitting her to care symbolizes the end of so many important things, among them – his caregiving and their life together. He states, “the day I had to sign the papers... that was my hardest day”;
- October 21 - Claire passes away, on her terms, gracefully and independently.

Claire declined very quickly between August to October, like “a precipitous fall.” Charles states: “It went so fast I didn’t have time to think about feeling sorry for myself.” Charles alludes to the fact that the last month of Claire’s life must have included “*somebody upstairs* looking after us.” This seems to give him comfort, despite the swiftness of her decline and eventual death. Feelings of ambivalence linger however, Charles is “thankful [Claire] went the way she did, for her and for [him]...”

Rose

Rose is an 81 year old widow who lives in a senior’s high rise. Her son lives nearby and she sees her three grown grandchildren regularly. Rose was very eager to share with me however, she was made uncomfortable by the presence of the digital recorder, thus our conversations are not recorded and any quotes I have included have been verified as accurate by her. Rose married optimism with her despair and sprinkled in a great deal of humour as she spoke with me. Rose suffers from mild memory loss related to damage from a cancer surgery on her neck many years ago, so I heard many of her musings more than once over our 3 meetings. This is her story:

Rose and her husband, Bob, shared a life together that most people would probably envy. When we love another, perhaps as Rose and Bob did, we take a *beautiful risk* – "*a risk worth taking. For when, in spite of the risk, a gift is given and received, both giver and receiver experience a miracle of unmerited grace, the kind that makes all the difference in life.*" (Olthuis, 1997, p. 149). It seems their risk paid off and Rose is left with lovely memories of the long life they shared. Working hard and raising their son provided them with a life rich in love and friendship. Rose states: "we had a good life, we had a good marriage."

The difficulties they had to face came later in life; she with cancer, Bob with dementia. It seems that these circumstances provided an opportunity to care for and love one another in a deeper way than previously. They "had many good years, with a few bad ones." The *bad ones* were a result of Bob's dementia and its consequences, particularly when he could no longer speak. The inability to communicate meaningfully with Bob was devastating to Rose. Rose is angry and bitter with how much dementia stole from her and her husband. She states: "Bob was the last person that should have gotten this terrible disease, he was such a good guy." Further, Rose believes dementia causes, "suffering for the family."

Bob was admitted to long-term care for the last two years or so of his life. Rose faithfully visited Bob, everyday, feeding him, talking with him. This was necessary for her to do even though he no longer recognized her. Bob began to sleep more and get up less often. So much so that the only way Rose knows he entered the last days of his life is by the fact he was no longer eating. This end-of-life phase lasted for about 5 days, Rose states: "they were a loss." Owing to Rose' physical limitations she was not able to be with Bob when he passed away. By the time she was able to get there she states, "he was already cold." She believes the staff did the best they could in caring for Bob.

Rose tries to make meaning of her experience by sharing with other wives in similar situations to her own; looking at the positives in life and not dwelling on the negative. Now that Rose has taken time to reflect on her life from the last three years, the years she refers to as "the *bad ones*," she is able to start to find comfort in memories of Bob from the "*good times*" or those years before his dementia. Perhaps, where Rose is at now in her life, moving forward and cherishing memories, may be reflected in the song: "*To Where You Are*" (Groban, 2002):

As my heart holds you
Just one beat away
I cherish all you gave me everyday
'Cause you are my
Forever love...

Alice

Alice is an independent 78 year old who lives in the same bungalow that she and her husband shared for almost 50 years. Alice was my fifth participant and unique to her is that there was no warning of her husband's death, no hours or days of preparation to say good-bye. She has three grown sons and they all unconditionally supported her as she cared for her husband, before and after his death. Her optimism is contagious. Unlike many of the other participants she is kind to herself; in other words, she does not dwell on what *should have happened* or that some how she could have done more. I feel very privileged to have met her. Here is her story:

Alice's journey with her husband Roger and his dementia is a mixture of opportunity and suffering. Upon first meeting Alice, she shares that within Roger's dementia and his death she has choices – she may choose to be angry, resentful, and bitter or she may choose to accept things as they are and move on with optimism; Alice consciously and readily chooses the latter.

Roger was diagnosed with vascular dementia in March of 2007, although there were signs of his dementia prior to seeking a diagnosis. I sense that Alice was sustained in their journey with dementia by Roger’s ability to acknowledge her caregiving and his expressions of gratitude for all she did. Roger continued to enjoy the pleasures in life, for example a game of cards with family or lunch with Grandchildren, despite the toll dementia took on him. Alice and Roger managed together in their home quite well until January 2009. This is when “things really started showing, [especially] his physical decline...” The next six months were a challenge for both Alice and Roger. Alice was active in caring for her husband and engaged others to assist her to keep Roger at home for as long as possible. One of the most difficult tasks was lifting Roger in order to carry out his personal care. Both Alice and Roger were concerned for her health (related to the consequences of the lack of sleep or the lifting of a grown man), thus Alice made the (unwanted) choice to have Roger admitted to a long-term care home. The facility was welcoming and supportive; this was important to Alice and her family because Roger was so reluctant to move.

Alice shared with me a piece of writing that talked about passages and constant changes, that *“your whole life is filled with losses... The question is not how to avoid loss... but how to choose it as... an exodus to greater life and freedom.”* (Nouwen, 2005, p. 95). It may be that when a spouse develops dementia that losses seem more tangible, more readily apparent versus the losses that may result from healthy aging. It is apparent that Alice used the losses she experienced to find meaning and purpose rather than dwell on the negative. The greatest loss for Alice was when Roger dies; she had no warning, it was unexpected, thus she was not present for him when he passed away. And yet, she was so thankful he died peacefully in his sleep, she stated: “that is what I treasure...” In the time since Roger’s death, Alice has been negotiating a new identity and dealing with her loneliness with courage and hopefulness.

Leona

Leona (63 years old) was an intriguing lady. Leona shared a home with her husband and has three grown children. She was very comfortable sharing about her experience and I did not once feel as though she was at all upset by talking about the death of her mother. She readily shared about her closeness to God and how prayer and faith sustained her and her mother over the caregiving journey. It seemed appropriate then to begin her story with comments from Mother Teresa:

> *"Death can be something beautiful. It is like going home. He who dies in God goes home even though we naturally miss the person who has gone. But it is something beautiful. That person has gone home to God."*
>
> (Mother Teresa, 1997, p. 141)

Leona's mother struggled for almost 11 years with dementia. Leona and her family knew something was wrong with their mother when they attended their grandmother's funeral. Shortly before that time, her mother was over-prescribed a drug that tipped her into a dementia, Leona states, "So really, we lost our mom just like that." Within that next year after her grandmother's death Leona's father also died. That was not easy for her mother, "she never got over it... She was always unhappy after." The last 6-7 years of her mother's life were spent as a resident in a long-term care home close to Leona. As happens with many families when a parent becomes ill, there was some conflict that resulted from her mother's move to the city where Leona lived. During the last week of her mother's life the family was able to come together and support their mother to have a good death, Leona states: "I can honestly say we all felt blessed when she actually died..."

It seems, the many losses that occurred over the 11 years were the focus of Leona's grief work. Watching her mother struggle with, "being an invalid... having somebody [else] look after her... [and] all the stuff that you lose in the last few years..." was difficult. Perhaps the loss that holds the most significance was how her mother changed from being "bubbly and friendly" to a woman who no longer wanted to participate in activities and was "depressed." Leona states, "she had such a different personality" further, "I didn't feel like she was my mom for a long time." So, when her mother *physically* died it came as a relief, "I haven't had too hard a time with grieving part, because I wanted her to be with Dad and I wanted her to be in heaven."

As Leona spoke about her mother's death it was evident that this was a welcome event, "I just felt at peace knowing that she was with the Lord..." In the days leading up to her mother's death Leona prayed with her mother and helped her to make peace with God; this may have been as much a benefit for Leona as it was for her mother.

Rudy

Rudy looked much younger than his stated 85 years. He lives in the apartment he and his wife moved into approximately 15 years previous. Although he misses his wife terribly, he has been able to move on and enjoy what life has left to offer him. He took pleasure in simply sharing a cup of coffee with me and assisting me with my research. I enjoyed looking at his many pictures of his vacations with both his wife and those more recently with his adult children. Despite the toll dementia took on his wife he could grasp even the smallest pleasure in a situation, his complete journey with his wife entailed many good times. Many times I wondered how he was able to hold onto those good memories and what made him different from so many other people (i.e., those who see the glass as have empty). He cried after he read what I had written for his story:

August 2, 2002 holds a special significance for Rudy. Not only was it the wedding day of his youngest son or that it was his and Helen's own 55th wedding anniversary, but it was also the day he knew "something was different" with his wife. It was then "a series of things over the next few years" that slowly took Helen away.

In 2005 while away on a vacation with his children Helen was cared for in a respite bed. During that time she fell and Rudy was not able to take her back home, “so she just stayed there.” Surprisingly, Rudy does not share any feelings of guilt about this unplanned move. Caring for Helen at home progressed to constant supervision because Rudy was not sure if she would wander away or accidentally hurt herself. Rudy states, it was “just like being in jail and then you are free.” After Helen moved he states he found it hard “seeing my wife deteriorate over four years... it was a sad situation.” Rudy shares that the last 2 weeks were particularly hard on Helen, as if “everything seemed to go all at once...” Something that comforts him from this difficult time was the fact that Helen continued to recognize him and acknowledge his presence. Rudy was not ready for the Helen to die; so much of his daily life was occupied with going to see Helen (and many of the other residents she lived with):

I want so much for you to stay
But I know to say, ‘Goodbye.’
Thank you for your love
Now I offer love to you
And in the echo of my heart
I will forever miss you.
(Davidson, 1998)

Although it is hard for Rudy to talk about losing Helen, he focuses on the “good times” and the small pleasures they enjoyed together; like going for walks everyday or eating ice cream. The good times in their long 62 year marriage are not limited to before Helen’s illness. In some ways Rudy is unique from other participants as he could see the good and humour about the time he and Helen shared together all throughout their journey with dementia. Rudy’s story is amazingly full of grace and contentment.

Rudy often visits the long-term care home where Helen lived and died and sits on the bench donated in Helen’s name to the facility after her death. His children and grandchildren support him and he feels fortunate that he has them to help him through this time.

Laurie

Much like Lois, Laurie (49 years old) was a very articulate and organized participant. Laurie had a folder with details and information (about dementia and caregiving) ready to share with me when we had our first interview. She is the second youngest daughter from a large family and took on the care of both her parents lovingly and willingly in their final years. It had been almost a year since her mother's death when we first spoke and our conversations brought up feelings that she had left unattended for some months. The amount of detail and depth that Laurie shared made it somewhat difficult to write her story. It was a challenge to be true to everything she shared with me. Here is what Laurie and I created as her story:

Laurie was extremely organized in the care of her mother. She was proactive in the unfolding of events, rather than reactive; for instance, she completed issues such as power of attorney or updating her mother's will while her mother was still able to participate. This meant Laurie was able to carry out her mother's actual wishes rather than what she thought her mother would have wanted. "If things wouldn't have been done in the orderly fashion that they were, we would have probably run into a lot of difficulties." So this means, "get your ducks in a row" and "forward think." Further, Laurie has used this valuable experience to guide and support others through written materials (that she has readily shared with me).

Laurie journeyed with her mother for almost 10 years with Alzheimer's Disease; she states, "I was able to walk with my mom through this experience." Laurie articulately explained how her mother declined: "we would have good weeks, we then had good days, we then had good parts of days, we then had good hours." Over the years Laurie grieved losing the mother she relied on and looked to for mentorship and support. In essence, she became a parent to her mother. With her mother's eventual move to a private care home and then onto a long-term care home meant Laurie had less of a *mother role*: "after I initiated care from others what happened I became the daughter again... So I could take her for tea and take her for ice cream..." It was important that her mother receive care that was sensitive to who her mother was as a person, "they still did her hair and they still made her look nice and we tried to emphasize... that she was a full person, a whole person."

The day before her mother died Laurie spent the day pampering and just *being with* her. Given the close connection Laurie had with her mother, she had a sense that the end was near, "I just didn't have a good feeling because she just wasn't like she was a couple of weeks before." This connection is further evidenced by her mother's acknowledgement of her despite her mother being semi-conscious during her final day, "I think I was given a gift just to be able to look after her, but also because she was capable of communicating with me the way she did." Laurie's mother's dying was swift; by the first evening she passed away:

> It was a very peaceful death and she didn't suffer. It was just one of those things that it was time, it was just really time for her to go. We were with her, she wasn't alone, and I think that you take comfort in that knowing that you were there and for me I was there all along. It sort of gives you closure to know that she didn't suffer and that they handled her with dignity.

Perhaps her mother's death may be echoed in Mother Teresa's (2001) statement: *"Death can be something beautiful."* (p. 141).

As with other participants Laurie comments on feelings of ambivalence, "You have mixed emotions once death does occur... it's a feeling of relief in a way, [and] the feeling of loss, feeling of sadness, feeling of anger."

Interestingly, Laurie is extremely thankful to have had the opportunity to care for her mother, she states, "I was given a gift. It was a tough one to unpack, but I think that I did the best I could with what I had to work with..." I believe Rilke (1986) may capture in a way how Laurie could willingly undertake the care of her mother: *"Perhaps everything terrible is in its deepest being something helpless that wants help from us."* Through the offering of help maybe we are able to overcome what is terrible (in this case Alzheimer's Disease) and view this help as something meaningful to engage in, to view it as an opportunity; or in Laurie's case see it as "a gift."

Dale

Dale is an 89 year old gentleman, who at the mere mention of his wife's name would weep openly. These emotional moments lead him to believe that he would "not be a good subject" for my research. On the contrary, he shared a great deal and I admire his devotion to and love for his wife. Dale has such a unique sense of humour and views unpleasant situations from a positive vantage point. Together he and I laughed and cried as he shared about his journey with his wife's dementia and her eventual death. This is their story:

Dale met Peggy while in university; Peggy was his sister's roommate in nursing school. They shared a long and happy life and were married 64 years; Dale states, "we had a pretty good life together." As with most people who develop dementia, Peggy began to have some difficulties with her memory. Dale talks about needing to assist Peggy with her baking and cooking because the recipes were not *turning out*; through that process he humorously states, "I learned something about cooking myself." Peggy was diagnosed with Alzheimer's Disease in 1997. Over the next nine years Dale and Peggy managed her dementia and eventually moved to a retirement community to give Dale a sense of safety with regard to Peggy's wandering. Dale points out, "she never really did get hard to get along with and I found that amazing."

When Dale had a stroke in 2006 their son moved Peggy into a long-term care home where she lived until she died in late 2009. This was a difficult move for Dale, one that he had been avoiding despite his son's insistence; he states, "my son figured it was very stressful for me and I must admit it was, but it wasn't all that bad..." Dale acknowledges that considering the limitations imposed by his stroke he could no longer care for Peggy as he had been. So, he eventually moved next door to Peggy's long-term care home because, "I needed to be able to get over there everyday" to be with her and feed her lunch and supper.

Watching Peggy decline over the next 3 years was hard for Dale, "I found it very difficult to see her getting weaker and less responsive... because she was really an outstanding person." The most difficult part of his care was when Peggy would ask, "when are you going to take me home?" Those words are etched in his mind and bring him to tears the moment he recalls them.

Dale shares a poem in Peggy's funeral card that sums up his feelings "*In tears [I] saw you sinking, [I] watched you fade away. You suffered much in silence. You fought so hard to stay.*" (Graham, n. d.). During the last week of Peggy's life Dale and his son took turns sitting with her; his son was present when she passed away. Dale is appreciative of the care Peggy received in the long-term care home and is thankful for their son's support. The funeral card poem further speaks to Dale's feelings in those final days, *"So when [I] saw you sleeping, So peaceful, free from pain; [I] could not wish you back, to suffer that again."* (Graham). Yet despite Peggy's decline, Dale is not ready to say good-bye to Peggy... *"It is so quiet and peaceful now and my heart aches for the days when she was with me."* (Heinrichs, 2000, p. 112).

Grace

Grace was my tenth participant. She is 52 years old and has two grown daughters. I completely realized just how small the world is when I met Grace – we are both nurses and inevitably have colleagues in common. I felt it necessary to assure her that what we spoke of would remain between the two of us. The fact Grace is a nurse influenced her experience and provided a perspective of end-of-life care from the vantage point of both an informal and formal caregiver. She has kept herself busy in the months since her mother died and talking with me revived her grieving; I struggled with the amount of emotion with which she shared her story. As a result, I did not meet Grace for a third time, instead I left it up to her if she wanted to discuss anything further. I respectfully share her story:

Grace shared openly about her mom's last few years with dementia. The last two years Grace saw her mom struggle with her loss of abilities, recognizing family, and having quality of life. It seems this steady decline was marked by the death of Grace's father from cancer. Although her dementia had advanced by this time, Grace's mom understood that her husband had died; Grace states this is when, "she seemed to withdraw, she didn't have much contact with us" after that.

Grace's end-of-life care experience included being confronted with decisions to extend her Mom's life given her mother had developed aspiration pneumonia; she had unexpectedly been taken to hospital from her care home. Grace had to make decisions rather quickly about whether to aggressively treat her Mom's pneumonia or not. This was a difficult decision to make for a number of reasons: (a) she had not had an opportunity to consult with her siblings about decisions, (b) her mother had had little quality of life in the recent months; (c) her mother was likely to aspirate again due to her inability to swallow effectively; (d) the care home could not manage intravenous antibiotics, and (e) the hospital was not a particularly welcoming environment. In the end, Grace and her siblings are glad they made the decision to not admit their mother to hospital and to instead take her *home* to die. This was a difficult time, one that Grace was not wholly prepared for, regardless of her mother's decline and well advanced dementia.

Over the course of five days Grace's mom stopped taking anything by mouth, including the antibiotics prescribed for the pneumonia, and slipped into a semi-conscious state. During the final evening Grace and her sister sensed the end was only a matter of hours. Those last hours were filled with, "listening to the sounds of dying." Grace generously told her mom "it is okay to go, Dad's waiting for you." Her mother passed away in the early hours of the morning with many of her family close by. Grace also washed and prepared her mother's body after death. Since it was a chilly morning Grace and her sister purposely chose a warm and cozy walking suit to dress their mother in; Grace shares that this is because her mom was, “still with us, she’s still there.” When asked about why she prepared her mother’s body, she states: “It was all I could do, I was happy to do it.” Remen (2000) suggests that “*death seems to... be the ultimate mystery that gives life its meaning and even its value.”* (p. 340). Essentially, what matters is to care, as fully and completely as possible; in Grace’s case caring extended beyond her mother’s living and dying to include after her death. She shared that her mother’s death brought her closer to her siblings and her own daughters. Perhaps her mother’s death brought deeper meaning to relationships she already valued. This may be similar to Nouwen (2005), as he believes, *“death lays bare what really matters”* (p. 183).

Tom

Tom (50 years old) was my final participant. Tom works part-time as a carpenter so that he can be at home to equally share with his wife in the care of his three young daughters. He is unlike anyone I have ever met before. His analysis and insight into what is going on for him and around him lead me to wonder if he was some how related to Martin Heidegger himself. The caregiving he offered his father was done over great distances – emotionally and geographically. Hands-on active and intense caregiving was done weeks at a time, a few times a year. I cannot imagine the strength it took to provide this care to a man who was not a supportive father, yet required a great deal from the only son willing to offer care. Most importantly, none of Tom’s care would have been possible without the support of his wife and his in-laws that allowed him to be away from his young family for extended periods of time. His story appropriately begins with a quote from Rilke:

> *Our instinct should not be to desire consolation over a loss but rather to develop a deep and painful curiosity to explore this loss completely, to*

> *experience the peculiarity, the singularity, and the effects of this loss in our life.*
>
> (Rilke, 2005, p. 109).

Tom shared about his caregiving and the loss of his father in a way that allows him to consider what it means to be human - what it means to be *Tom*. Just as Rilke suggests, Tom is attempting to explore the effect *this* loss has had on his life. Alzheimer's Disease altered his father and his relationship with his father; as a result it forced Tom to consider, "what we [are] able to give to another human." During our discussion Tom often went back and forth to the analogy of sailing and how it informs his journey in life, as well as his father's life journey. Although I am not a sailor I followed much of how Tom described how a boat is supported and set on course. Following Tom's notion of the ocean I have wondered what is it about the ocean that supports a boat, what is beneath the surface? All throughout his caregiving Tom wondered about the man his father was and what drove him as an individual. I sense there were many parts of Tom's father that were taken for granted or inaccessible, namely what lay beneath the surface of the water. Also, what is it that lay beneath the surface for Tom that enables him to provide care and discover what it means to be human?

Tom's challenge in deciding to provide care to his father was influenced by reconciling his childhood experience with the needs of the present. "I guess you're bookended; you know you have kids on one end of your shelf and your parents on the other end." Tom would not be able to travel the thousands of miles to care for his father if not for the support of his family in Saskatoon; his wife respected what Tom needed to do. Of significance to Tom is the fact that his father was able to provide care to others in very trying and difficult situations (e.g., as a child to his own mother with arthritis and as an adult to his wife who became bedridden the last 7 years of her life); Tom states, "Dad was quite a caregiver." If his father could spend his life giving and caring for others, then so could Tom.

Tom's end-of-life care provided him opportunity to peer deeper into the man who was his father. Tom describes his father as "very much removed and absent" in his parenting and as a Grandfather; yet I think Tom accepts that his father was a product of his environment and the hard life he had (essentially those things that lay beneath the surface of the water...). Tom seemed to deepen his relationship with his father by choosing a relationship that required a great deal of Tom; he states, “I was drawn closer as Dad needed more.” Olthuis (1997) declares: “*Empowered through the giving/receiving experience, a positive spiral of mutuality begins to take shape in which we are inspired to recognize, reach out, and yield more often and in deepening ways”* (p. 147). Tom certainly was able to recognize and reach out to his father in many ways to meet his needs for care and in doing so received gifts in return.

Tom is grateful for the caring legacy his father left him, even if it was not directly to Tom as a child. The lessons Tom gleaned from his father were borne out in actions and not through words. Some of these lessons enabled Tom to: (a) care for his wife after invasive brain surgery, (b) be an example to his own children about what it means to give over to the needs of another human being, and (c) in essence learn more about him. He states:

> My caring for [my dad] and my time learning more about him and wanting to learn more about the relationship with him helped me understand that perhaps he didn’t have the tools to do that, didn’t have the interest and the ability, but he had the interest and the ability to be there for somebody else when they needed and that was his gift, and it was something that made me much fuller as a human and to understand my children deeper and what gifts they have and understand myself deeper and [know] more about myself.

Being able to care for his father in his father’s own home was of the utmost importance to Tom. Family is the best source of care when a person is in need because in a long term care home, “you know that they are not going to get what they need... which is a loved-one.” Tom openly talks about his father essentially dying the day he entered the long term care home; he tries to resolve some of this by acknowledging that his father is safe, well fed, and most importantly, can see the ocean from his new home.

The time his father spent in long term care seems like the most difficult for Tom. Owing to poor weather Tom is not able to be with his father in his last hours or attend his funeral. Some of this may have been made more difficult by Tom's brother's reluctance to be with their father in his final hours. And yet, Tom is able to find closure when he and his family travel out east to inter his father's ashes a few months later. He returns with some of his father's ashes to places his father loved and felt at home. This is a responsibility that Tom feels is necessary to finish his father's journey; this is also for Tom. Tom's caregiving and his father's death allowed him to go "through the full range of what it means to be human..." Perhaps, if we are open to it, that is what caring and death may provide us.

In summary, the above narratives reflect the experience that is found when caring for a family member with dementia who is at the end of life. The participants are as much alike as they are different. End-of-life care entails a great deal of effort, both physically (as in the case of Rose or Laurie), mentally (Tom is a good example), and emotionally (for instance Grace or Dale). By telling their story about their end-of-life care gives participants an opportunity to reflect on that time in their lives and to delve into what that care meant to them. By revealing their story as part of a research project furthers that meaning in a way to bear witness and share with others what end-of-life care may hold. In this way they continue their care and extend it to others long after their relative has died. Perhaps this speaks to Heidegger's (1927/1962) notion that to care is our most fundamental way of being in the world.

By moving from the parts to the whole, back and forth, and everywhere in between I am able to offer a diverse and rich interpretation of the end-of-life care experience and assist the voice of my participants. Among these parts, these participant narratives, are threads that can help weave together an overall narrative. To bring together these many narratives into one interpretive narrative means acknowledging the essence(s) of the story while honouring the unique experiences as well. What follows is a discussion of these essences and their significance to the end-of-life care experience.

Essences

Essences are elements related to the ideal or true meaning of the lived experience; they reveal the essential nature and significance of the experience in a new way. Van Manen (1990) states that essence means "*the inner essential nature of a thing, the true being of a thing.... Essence is that what makes a thing what it is*" (p. 177).

From dwelling with and analyzing the data two essences are revealed: *being-with* and *being-there.* These essences permeate many of the experiences and situations along the way to the death of a relative with dementia. It may be important to recognize that there is a shifting back and forth between the two essences and that on occasion they occur together, as might be the case in the final days of end-of-life caregiving.

Being-with

Being-with may occur anywhere at any time as a caregiver senses and feels with their relative; it is not a physical presence. This sensing and feeling is borne out of an intense caring, concern, and love for another. Buber (1970) shares that, "*love itself cannot abide in a direct relation; it endures*" (p. 147). *Being-with* is all part of the caregiving journey – end-of-life care is no different; instead this intense caregiving phase may reawaken a need to feel and sense – it is *a closeness* to their dying relative. Further, some caregivers sense their relative even after they have died. Some talk about feeling their family member still in the room or with them later on during bereavement. This is particularly true for caregivers who believe in an afterlife.

Being-with is essential to the end-of-life care experience because this may be all that remains of their connection to their dying relative. Likely communication has been limited for a number of years and caregivers may no longer be recognized by their relative. This *being-with* is how caregivers can love and support their relative in the absence of reciprocal communication and recognition.

Being-there

Being-there was the need that some caregivers feel to physically be present at death, offering comfort care, keeping a vigil during the last days and hours, or washing the body after death. Nouwen (2005) explains that, "*to care for the dying means to make them live their dying as a way to gather around them*" (p. 185). Caregivers were basically accompanying their relative at the end of their life. This physical accompaniment may rise out of the need to *be-with*. A caregiver's dying relative is unable to verbalize their needs and discomforts and as a result caregivers feel a need to be present to ensure that comfort care is provided. Many caregivers were very dedicated in their hands-on caregiving, even after their relative entered long-term care; *being-there* allows them an opportunity to complete the final leg of the journey. When they are not physically *there* they: (a) are glad another family member is, (b) are comforted that their relative was at peace at the time of death, or (c) have guilt to work through for not *being-there*. *Being-there* is significant because, "*Being present to each other is what really matters*." (Nouwen, 2005, p. 171).

From these essences then it is possible to delve deeper into the many layers of the end-of-life care experience. In an effort to be coherent and comprehensive detailed findings will be discussed according to the life worlds (these make up the situated context as indicated in Chapter 3). By doing this I am able to process my participants' experience and lend meaning to their perspectives without being limited to themes that reflect common experiences alone.

Life Worlds

Life worlds are where we find ourselves in experience; namely spatiality, temporality, corporeality, and relationality. They are all interwoven, together they essentially make up our (single) *lifeworld*. One cannot be discussed without consideration of other life worlds. While they may be differentiated it is impossible to separate them (van Manen, 1990). Having a grasp of the life worlds aids in our understanding of how a person experiences their world (Munhall, 2007a); it helps provide us with the necessary context of experience. These life worlds were intricately woven throughout the participant narratives. The following is a detailed discussion of each life world with supporting quotes from participants as a means to pull together and further explicate the end-of-life care experience with dementia.

Spatiality

When considering lived space we often think of it as a place of home. A quote from Nouwen (2005) begins this section:

> *The first and most obvious quality of a home is its intimacy... We express a longing for that intimate place that offers us a sense of belonging... The word 'home' continues to carry with it a warm love and remains one the most evocative symbols for happiness*.
>
> (p. 146-147).

In a sense spatiality, "*is the existential theme that refers us to the world or landscape in which human beings move and find themselves at home*" (van Manen, 1990, p. 102). Spatiality is felt space; the space where we find ourselves in experience impacts the way we feel (van Manen). It is not related so much to the concrete nature of space, but has to do with the feeling and sense of where we find ourselves. Of Heidegger's many discussions spatiality seems to be the most confusing (Dreyfus, 1991).

With the present study long-term care homes were the place of death of all the participants' relatives, thus it is necessary to consider how that space felt to the participants. Participants had many reactions to the physical and social space in long-term care. Some participants felt welcomed, some viewed this place as being necessary for the sake of safety for their relative, while others viewed it as a failure of their own home. As a result, participants experienced the lived space differently and this had a profound effect on how they felt during the end of life.

A welcoming space. For the participants that viewed the space in long-term care as a welcoming place they were positive about many aspects and felt it as a new home for their relative. Dale shared about his wife's new home, the "staff over there were very accommodating and I think they gave her good care." Another husband, Rudy, talked of how staff would accommodate what he needed for his wife,

> The head nurse... she just did everything for me, just beautiful. If I had something she'd sure make sure it was possible, she was very good that way. They all were excellent. And then the girls that looked after Helen they were just marvellous really.

Despite Rudy's requests to do things for his wife he still felt welcomed rather than as a hindrance or a family member wanting too much. Lois was reluctant to place her husband in a long-term care home, however she felt included and welcomed to continue to care for her husband as much as she liked. She stated,

> This was Bill's home. This was where he was... I just felt like I was part of the whole thing when I went there. So no, I never felt like I was just visiting and I was just supposed to sit and talk and then go away. That was never part of it.

A few participants spoke of long-term care as a necessary move in order to keep their relative safe. Laurie, an adult daughter, acknowledged the deficits in long-term care homes yet accepted that it was necessary for her mom, she stated,

> It was a tough one. It wasn't her home. It wasn't a place that [Mom] would choose to be. It's not a place that I would have liked her to have to go, but I really didn't have a choice.

Yet, Laurie mentioned, "at this place my mom had the freedom to move around, to walk, to carry her doll, to eat her lunch, to wear her shirt on backwards and nobody was going to care. It didn't matter." Interestingly, while Laurie's mother was dying she felt it important to not transfer her mother to a hospital for life-prolonging interventions, she stated, "it's important to leave her at this place that we call her 'home'. Funny that the word home comes into this." Munhall (2007a) ponders how space can feel differently at different times as was the case with Laurie, "*Our environment... can assume different meanings for different experiences*" (p. 194).

Welcoming by the staff of the long-term care home can be for many reasons. For instance, family caregivers may be welcomed in long-term care because of the lack of staff. Having family there to assist with care eases the load of the formal care providers. Lois pointed out:

> The staff they don't have time to check the label on everything and say, 'oh, that's so-and-so's shirt. That should be here.' So, I think caregivers are more than welcome. You know if you would go and you would help feed your person that was huge for them and they really did appreciate it.

An unwelcoming space. On the other hand, some participants did not feel welcomed and could not view long-term care as a new home, but rather as a *failure of their home*. Those who could not accept it as a new home believe caregiving should be done in the community with family, not giving over your relative to others. When talking of how she would have changed her husband's end-of-life care Jane stated:

> I would have somebody living-in. I think that's how they used to do it...

> Then I could have had someone here to help him because the lucky people in the end of life would have been the ones who had large families. Then no one person would be burdened with something they couldn't handle.... I don't think people should be warehoused. We [had] no intention of warehousing Jim in a nursing home and that's where he ended his life.

Tom, an adult son, talked of how difficult it was to have placed his father in a long-term care home because of what the space had and didn't have to offer:

> So you visit the home and you smell the home…And you see the people shuffle and there [are] wheelchairs everywhere and there's locks on doors and there are exit signs, and it's not a home. But it has to be that. So at that point you realize that, you think, 'oh, if I was living here [in the province of his father], you know, you could, you know, maybe it could be different.' But I'm not living here so I can't think about that. But you go through the guilt. You know, because of, you know, feeling that you could be more for them because you know that they are not going to get what they need - which is a loved-one.

The perceived lack of welcoming in the long-term care space was troublesome for Jane and Tom. It appeared as though Tom and Jane are expressing feelings of burden and guilt similar to those expressed by the participants in Forbes and colleagues' (2000) study with family caregivers to persons with severe dementia dying in long-term care; these feelings impacted Tom and Jane's end-of-life experience in negative ways.

With a change in the caregiving environment (i.e., from home to long-term care) for some participants there was a feeling of being an outsider now that others are providing the hands-on care to their relative. This is illustrated well by Tom as he related to the physical separation from his father:

> You go out and you leave and the door behind you locks. All you could see was his new pyjamas and his eye in the door, that cracked double door and you are left with that... It was the hardest thing and the most difficult day of my life.

This relates to the cultural and social convention of lived space. Small and colleagues (2007) comment on the fact that persons with dementia are often hidden away, segregated to a separate area and that this is viewed as necessary and socially acceptable. This has implications for the end of life as well and perhaps the view that death is able to be denied or seen as a failure. Of all the participants, Tom and Jane seemed to consider their relative's death as a failure (of their relationship to their relative or of the environment).

Return to relationship. Yet, other participants felt this shifting of care in a new environment allowed them, to a degree, to return to their previous relationship with the care receiver. This is evident in Laurie's case, "after I initiated care from others what happened [was] I became the daughter again." Spouses talked of this as well, Rudy shared that once his wife was in long-term care that "I didn't have to, you know, be on guard all the time which again was freedom within myself... but I looked forward to going up there every day to visit [my wife]." Also Lois talked about feeling like a wife again rather than her husband’s caregiver:

> It was like that when I would go to visit Bill and I know we couldn't communicate, but we would go for walks and I would talk.... And it was just, towards the end it was worse in some ways, but in some ways it was better. Because the nitty-gritty of the wet beds and not being able to eat and the difficulty of doing everything... right now is all taken over in the end. And I can go back to just remembering why I care for this person.

Thus, the space offered by long-term care could also mean a renewed relationship between caregiver and care receiver.

The physical space. Participants spoke of the physical environment of long-term care. This is because “*we experience ourselves as situated* here *along with things around us*.” (Blattner, 2006, p. 76). For example, Laurie warned of the odours in a long-term care home: “take comfort that other people smell those smells, too, and are you there to take in the smell? No, you’re there to see your Mom.” Further Lois commented, “they certainly made it medically-oriented... very much like a hospital rather than a home.” Jane is one example of a participant who struggled with the physical make up of the long-term care home that her husband died in; she shared,

> I would come to see him in the afternoon for an hour or so every day. In the beginning there was a man sleeping on his bed, there was always at least one or two wheelchairs in his room and they started taking out all the pictures that we had put up. I complained about it but he was never moved to [an]other room... his room should not even have been used

> because it was so bad. I never got anywhere complaining about it. It is very depressing. I found it very hard to go over there.

Even in her husband's final days Jane found it difficult to physically be in the building.

Similar to the findings of this study, DeMiglio and Williams (2008) discuss at length the significance that people attach to space. As people, like the participants in the current study, reflect on their sense of space they may form opinions based on the present or their past experience, whether the environment offers services to maintain quality of life, and/or the social and physical environment of space. It is possible to form relationships to spaces outside of our own home; as presented above. There are many issues and elements (such as viewing long-term care as a home, feelings of failure of ones' own home, or what the physical and social space offered) that influence that sense of lived space by the study participants and how that may have impacted the end-of-life care experience. These issues and elements further supported or detracted from participants' ability in *being-with* and/or *being-there* for their relative.

Temporality

To set the stage for discussing the sense of time it may be helpful to consider a quote from Rankin (1999): "*When you thought about life, you thought of it as chunks of time, but really it was a series of connected moments, any of which could change you completely*" (p. 147). The traditional sense of time, as in hours or days, does not apply when we consider temporality. It may also be important to bear in mind that families have a shared time, a shared family history where occasions (those *connected moments* Rankin talks about) are experienced together (van Manen, 1990); as may be the case with death of a relative. Many participants recalled significant events as if they occurred yesterday and it impacted them in the present; there is much clarity and feeling in describing these events as if *"each moment of time calls all the others to witness*" (Merleau-Ponty, 1962/2002, p. 79).

Sensing time. Participants spoke of time in varying degrees of intensity and awareness. As some of them entered the final leg of their journey with dementia they had a sense of wondering when this will all end. Alice shared that as her husband entered the long-term care home, "I just thought this was going on and on" further, "I was preparing for the long haul." Alice's husband unexpectedly died 10 days later. She commented that she didn't have the gift of time to say good-bye as the other participants had.

For participants who were aware of their relative entering the final days of life they spoke of it as sensing a change, for example, Lois stated, "something was different" or Rudy who stated that he and his children, "knew it wasn't going to be long." In the final days time was of the utmost importance because time with their relative was now limited. During the last days of keeping vigil Lois talked about feeling as though, "you think... that it is never going to end." While Charles, a husband, commented, "the days weren't very long for me or even the nights. Thank goodness I, you know, I was able to sleep." With more specificity, Laurie spoke of her sense of time while her mother lay dying in this way, "So, during the time when she was frothing at the mouth, I mean that couldn't have gone by faster." Laurie further stated, "time at some instances stood still, however in some moments I wish I could hold onto [it]. Like the time I was saying goodbye to her.... The time that I was with my family with her was very meaningful." There is a dichotomy here – time may be viewed as an eternity or time melts away and it is experienced differently by everyone.

The right time, the wrong time. Found among the stories is a relation to the *right time* or *wrong time* for the death of their relative. In some ways this difference is borne out of the differences in relationship to the care receiver; in other words some spouses and adult children seemed to view time of death differently. Some of the spouses wanted more time in that they were not yet ready. This is exemplified in statements like: "you are never really ready, ever" (Rose) or "you always feel that there could be a magic wand and he'll come back" (Lois). That is not to say that spouses did not want the suffering of their spouse to end, they certainly did, what is happening may have had more to do with continuing their own identity as a spouse.

The adult children in the current study seemed to view their parent's death as the right time for the suffering to end. Many of the child participants spoke about losing their parent long before the end-of-life phase even occurred; for instance, Leona stated with her mother's dementia diagnosis, "So really, we lost our mom just like that." And for Tom, as his father entered a long-term care home eight months prior to his death: "his life had ended, you know his death at that point of [being my] dad was at that moment." It seems as though these children are speaking of the social death of their parent (Small et al., 2007) and that makes the physical death the next logical, and perhaps, accepted occurrence. With death adult children were thoughtful of their parent as whole again and being reunited with their spouse. For instance Grace, an adult daughter, shared, “I think of her as... she's at peace and she is with my dad. And I think of her as a whole person again, she's back to her old self” or as Leona, another adult daughter, affirmed, “[Mom] would be so happy to have her body back, to have her strength or whatever, to be young again.” These feelings may lend to adult children’s perception that their parent’s death as occurring at the right time.

The discussion of temporality reveals that chronological time is not of significance. Instead, participants felt and sensed time to varying degrees, particularly during the final days and hours of their relative’s life. *Being-with* became more and more significant as death of their relative was approaching. The time spent at the bedside (or the inability to spend time) influenced how participants could actualize *being-there* for their relative. The feeling of the right or wrong time for death clearly impacts participants regarding their end-of-life care experience, as well as their bereavement experience.

Corporeality

Corporeality or our embodied experience may be introduced by this quote from Olthuis (1997): “*I myself am my body. The body as a whole functions as a sensorium, a senser, a knower, a perceiver, a digester*” (p. 137). How we experience the world around us is done through our body; we cannot escape the “*fact that we are always bodily on the world*” (van Manen, 1990, p. 103). We reveal things about ourselves through our bodily presence, but we may also conceal elements at the same time. It is important to consider the connectedness of embodiment to the end-of-life care experience.

Physical manifestations. Participants physically felt their own suffering and guilt, through tension and fatigue. Connection of this is heard in the crying and emotion that participants expressed with me. One gentleman, Dale, could not say his wife's name without crying; he felt her loss deeply. Speaking about the losses associated with dementia brought out deep feelings for some of the participants. Rudy described it like "re-opening an old wound" further, "then at night well, that was the worst part because I couldn't sleep... I was going downhill myself. Losing weight... it was just a turmoil really."

During the last few days, when end-of-life care was most intense many participants spoke about feeling fatigued from the constant vigilance. Leona stated, "we had lots of time. We were there constantly, almost. We would take shifts and stay with her and we were totally, totally physically exhausted, just exhausted. But we were so happy to be able to be there." Laurie talked about the physical manifestations while sitting at her mother's bedside the final day:

> Physically I felt weakened. My arms felt really heavy. I knew the end was near, I just knew it. And so I had a... like a thickness. I kept feeling it thick in my stomach... I know my heart rate was up.

The lack of control or wondering what is the right thing to do also added to the intense feelings that some caregivers experienced; for example Lois shared, "it's just this constant anxiety. And you're always wondering if you are doing the right things and this causes physical manifestations too, its not just in your head, it's your whole being when you are *questioning*." Rudy emotionally shared how he felt lost during the last day with his wife, "I just didn't know what to do, but there was nothing I could do."

The consuming feelings, emotionally and physically, that participants speak of above may be related to the notion of 'total pain' (Saunders, 1978). Dementia is not the only source of suffering limited to the care receiver, instead there is an amalgamation of sensations and feelings that are extended out to the caregivers as well that consumes them in their experience. It is important to note that grieving and suffering are appropriate responses to what is occurring with end-of-life care for these family caregivers.

Gathering strength. There were two participants, both spouses who actually did not feel the same exhaustion and heaviness that the other participants so readily talked about. During his wife's last days Charles stated, "my [blood pressure] was better than it is today, my diabetes was under control.... Physically I can't say there was anything. Mentally, I don't know if there was or not." Alice spoke about a "feeling of euphoria" days before her husband died. This helped her to gather the strength to go and visit with her husband, she stated, "then I was ready to go back there twice a day and that's all I needed to, you know recharge the batteries or whatever." It may be important to note that both Charles and Alice had their spouse in long-term care for a very short period of time before their death, 30 days and 10 days respectively; they cared in their own home for years prior to that.

In summary, corporeality brings attention to how experience flows and is expressed through our bodies. The physical manifestations of end-of-life care was experienced very deeply by some participants and not at all with others. As apparent in the other life worlds, *being-with* and *being-there* was impacted by participants' bodily experience. The ability to cope with what was occurring at the end of life and the energy level required to endure the final days influenced how *being-with* and *being-there* might be carried out by participants.

Relationality

The final life world, relationality, is introduced with a quote by Rilke (1986) who acknowledges the significance of how relationship with others influences our *being-in-the-world*: "*Only someone who is ready for everything, who doesn't exclude any experience, even the most incomprehensible, will live the relationship with another person as something alive and will himself sound the depths of his own being*" (p. 90). Relationality is "*the lived relation we maintain with others in the interpersonal space that we share with them*" (van Manen, 1990, p. 104). The quality and intensity of our relationships with others can colour how we experience life. Not surprisingly, relationships are intimately interconnected to all the other life worlds.

Relationship to others presents, perhaps, as the most significant life world within the end-of-life care experience with dementia; support from others or lack of it is influential to the end-of-life experience. There are many layers of relationships to consider: (a) caregiver and care receiver, (b) caregiver and other family members, (c) caregiver and long-term care staff, and (d) caregiver and friends or significant others. It is within this life world that *being-with* and *being-there* really surface.

Caregiver and care receiver. The relationship between caregiver and care receiver within the context of dementia is ever evolving and changing given the impairments the care receiver experiences. A few participants were clear about how their relative changed and that it was as if there were different people before them as the disease progressed to death. Laurie commented, “you lose them at different stages and you continue to lose them right up to the end” or Lois commented about this when she stated, “My Bill [i.e., the man she married] had gone years before and had just kind of.... Tiny little bits of him just disappeared.” It seems as though Laurie and Lois are perhaps touching on how ambiguous loss may arise with the social losses resulting from the progression of dementia (Boss, 1999; 2007). Yet, they speak of these losses in resolved terms rather than as causing distress; it could be that the physical death of the care receiver leads to resolving issues around possible ambiguous loss from earlier in the journey with dementia.

A strained relationship between caregiver and care receiver is difficult to reconcile at the end of life when dementia is involved given that caregivers lose the ability to communicate with their relative. Tom shared a great deal about caring for his father despite not receiving fatherly love growing up; he stated, “he had a hard life, and I think that crystallized him so that that would be my experience with him growing up, a person that was very, very hard.” Tom found the ability to provide care to his father because, “regardless of what they [his parents] were for you, you know, growing up they were doing what they were taught to do, and I had been taught different in my life, that we don't treat people that way."

On the other hand, the needs that arise as a result of dementia may offer a way to further deepen an already close relationship. For example, Laurie commented on being able to care for her mom as being "given a gift. It was a tough one to unpack, but I think that I, I did the best I could with what I had to work with."

Caregiver and other family members. Relationships between a family are complex. Tensions among families may interfere with the end-of-life care experience in some cases. For instance, Tom stated: "[My brother] felt it was important we start to look into a facility for [our father]. Which I found very hard to do because of what the [long-term care] home is about for Dad... I know what homes are about." With his brother as power of attorney Tom was not included in decisions regarding his father's care or living arrangements; this further impacted his powerlessness during the end of life of his father. Leona talked about the day before her mother slipped into a coma, she stated,

> [Mom] got upset at [my sister]. I was really shocked with that.... So maybe [my sister] said [unpleasant] stuff... I don't know. Maybe that's why [my sister] resents me? Because she thinks I was Mom's pet or something. I don't know? She still, we still don't have a very good [relationship].... No communication.

On the other hand, some participants described getting closer to their family as a result of their completed journey. Laurie in particular talked about this; she stated: “we have a special closeness that didn’t exist in the same way throughout the journey with the disease and the death.... We have a special connection... now which is really, really nice.” Further, Grace, an adult daughter, echoed a similar result, “I think it got us close, us closer together... there was quite a few of us there. It was very nice to have family all together, to be able to be there together to share that.”

Some participants managed bereavement with the support from their family; for instance Lois, stated while talking about the time since her husband died, “I’ve got a bunch of good family around me. Some of it makes all the difference.” Rudy acknowledged his relationship with his children and grandchildren during his bereavement, “the only thing I find for myself I find it very lonely.... Family kind of support me in that respect, but they can only do so much.”

Caregiver and long-term care staff. Interacting with staff from the long-term care home or from the hospital in some cases held significance for participants. Many participants talked of being supported and welcomed to do whatever is necessary at the end of life. For example, Charles stated, “the staff were, you know, I think were fantastic” or Rudy, “you know they looked after her pretty good, so it was nice to have that kind of care.” Laurie was particularly struck by the support from the nurse on duty the evening her mother passed away:

> It wasn’t ten minutes and she was in the room and she said that I had asked her to come in and explain to the family what exactly was going on and that time was not something [we had a lot of], as far as Mom being around.... So that was wonderful. That person was just fantastic.

Only a few participants however, spoke about run-ins with staff in order to secure comfort care. Grace especially had an unpleasant experience at the beginning of her mother’s final days when she was admitted to hospital from the long-term care home. Grace shared: “the doc who came in was a little bit aggressive I thought and not very sensitive, but he basically was pushing us to, you know, just to make that decision not to provide any care for her.” Not surprisingly Grace and her family opted to have her mother transferred back to the long-term care home to pass away in a more supportive environment.

Caregiver and friends or significant others. The final layer of relationship is between caregivers and friends or other significant people. Many of the participants spoke of people outside of their family that assisted them during the final days of their relative’s life. A few participants mentioned how funeral home personnel were kind and accommodating; as noted in these comments, “the funeral attendants were very good” (Laurie) or “the funeral home out there was just excellent” (Rudy). Lois spoke of her close group of friends, “I think it has to be my friends. Yes, the staff were good, but they [her friends] respected my request to just leave us be.... It was those really good friends that got me through it.” This support was important for Lois because it allowed her to spare her daughters from dealing with the physical death of their father.

Another example was Alice, a wife, who was supported by her *church family*, she stated, "I felt a real support from the church and the church friends as if I was being kind of carried along with their thoughts and prayers... I felt strength from that." Alice was able to call her Pastor to accompany her to see her husband moments after he had died in the middle of the night; this was significant to her end-of-life care experience. Laurie also spoke of being able to have guidance and support from her family Priest, she stated, "he came and gave my mom a blessing... [name of Priest] was a special person to my mom, it was important for him to be there and he was very supportive of me and my sister."

It is impossible to exist without relation to others. The presence of dementia in a relative is something that inevitably calls family caregivers to encounter others in order to provide care. Buber (1970) proposes that in order to be fully human requires encountering another; he states "*the concentration and fusion into a whole being can never be accomplished by me, can never be accomplished without me. I require a You to become; becoming I, I say You. All actual life is encounter*" (p. 62). As presented above, the participants in the current study encountered many relationships as a result of journeying with their relative. These relationships impacted them and their end-of-life care experience in varying ways and continue to impact them after the death of their relative.

By far, participants spoke of most relationships as being positive and they were grateful to have the support from many different types of relationships (e.g., with family, long-term care staff, or significant others). The ability of some participants to offer care, love, and support to their relative in the final days of life enabled them to fully engage in *being-with* and *being-there* and this influenced their end-of-life care experience positively; those that had challenging relationships were less able to have a positive experience.

By discussing the life worlds and the dichotomies among them lends to a deeper understanding of the end-of-life care experience to a relative with dementia. By exploring the spectrum of feelings reveals all the places participants might find themselves in experience. For instance, (a) spatiality provided a sense of feeling like an outsider or an insider in providing care; (b) temporality assumed an eternity or as time melting way quickly; (c) corporeality revealed feelings of exhaustion or euphoria; and (d) relationality was felt as a closeness to others or in tension filled relationships. Woven throughout the life worlds are the essences that bring to light the end-of-life care experience and make it what it is – a sensing feeling and a need to be present in any shape or form with their relative as they are dying or being distressed when barriers precluded that from happening.

Taken for Granted's

To fully explore an experience it is important to be attentive to what is concealed or taken for granted; this is necessary to be true to the philosophy of phenomenology (Munhall, 2007a). *"We must assume our existence as* broadly *as we in any way can; everything, even the unheard-of, must be possible in it"* (Rilke, 1975, p. 118); with this quote Rilke is suggesting that we explore all possibilities that make up our being, including the concealed. The above life worlds discussion explored how the end-of-life care experience appeared to participants. This section explores what was concealed or unapparent.

There were occurrences that influenced the end-of-life care experience that were not so obvious to the participants nor were they commented on at length, yet were still vital to their experience. These concealed or unapparent elements are presented in order to reveal them and bring the unique and taken for granted to the surface. These include, but are not limited to: (a) existing power inequities within the long-term care home, (b) socio-cultural expectations to continue caregiving, (c) fleeting moments of normalcy, and (d) permeating ambivalence.

Existing Power Inequities within the Long-term Care Home

A few participants spoke of having little power to make choices within the context of long-term care. Jane, in particular, could not let go of the fact that she could not choose which home her husband would go to live (and eventually die); this negatively impacted her end-of-life care experience a great deal. Jane shared:

> He would have been perfect at [desired facility]. So I went over there a couple of times and kept hoping they would call him.... They always told me he was "at the top of the list. At the top of the list." I was over there twice and he was never called. Unfortunately, it was [unwanted facility] that there was a bed for him.

It is common practice to not have a choice with regard to which long-term care home a relative is placed; families are expected to take the first *bed* that comes available.

Other power inequities may be present in the segregation of care receivers or set care routines. Tom was a good example of this as he mentioned "the door behind you locks. All you could see...[was] his eye in the door that cracked double door." Tom was acknowledging that he now had little power over what was going to happen on the other side of the locked door. This holds significance for what is expected of family caregivers in the long-term care environment.

Socio-cultural Expectations to Continue Caregiving

There is a socio-cultural expectation of family caregivers to continue to provide care, albeit on the terms set out by the long-term care staff. As noted previously, Lois commented on feeling welcomed in the long-term care environment; some of this was based on the shortage of staff. Specifically Lois stated:

> I very much felt that I was part of the staff. I felt that they really needed the [family] caregivers to continue to do a lot for the people, again, because their staff was so short. I mean, a dementia ward is, is bizarre.

Feeding their relative was the most common form of care done by the participants, for instance Lois stated:

> They tried their best, but if you've got ten people that need to be fed at a meal, if you can have one or two [family] caregivers it really, really helps, and… I mean, a lot of caregivers want to do it anyway, so it was a win-win situation.

Lois is not questioning this expectation and instead considers it a *win-win situation*. While feeding a care receiver was encouraged sometimes other personal care was discouraged despite the participant's desire to assist. Grace, a registered nurse, often wanted to assist with transfers and personal care because her mother was fearful and would call out during those situations. Grace stated:

> It is hard to be there because of those care duties and you want to help and you know how to do it, but it was necessary, they don't want you to, generally they prefer that you, [they] ask you to leave the room.... So you know you want to help and they don't particularly want you too. But as a family member I think it is your right. I wanted to be present but that was a bit of a struggle.

Grace was painfully aware that her mother was not getting all the care she needed; like other participants, Grace occasionally found her mother “very soaking wet” because she was not “changed often enough.... She was always developing diaper rash sort of because, you know, she wasn’t being changed.” The expectation to provide care or not be allowed to provide care was partially determined by the power inequities in the long-term care environment. In general, participants were content with the care their relative received however, I believe they also did not want to *rock the boat* or question too much when care was insufficient.

Fleeting Moments of Normalcy

Occasionally participants commented about doing things with their relative regardless of the presence of dementia; these things seemed to make them feel as if everything was *normal*, even if it was only for a moment. Rudy for instance spoke of going for walks or enjoying an ice cream cone with his wife, these were things they had always done together; he stated, “I took her out very often. I’d take her myself and bring her home and we’d sit around here and have an ice cream cone.” During the last days of Helen’s life Rudy still walked with her, but this time with her in a wheelchair; when Helen would not eat ice cream offered to her, Rudy knew the end was coming.

Another participant (Laurie) was adamant that her mother be considered a whole person and included in activities regardless of her ability to participate:

> They still did her hair and they still made her look nice and we still tried to emphasize, you know, that she was a full person, a whole person. Things like that I tried to continue for her for as long as I felt was necessary. I always, always wanted my mom to be included.

Moreover, Laurie mentioned that as her mother lay dying, in an unconscious state, she looked like any other dying person that her mother's dementia had basically now ceased; Laurie stated, "It was different. At the end, it was like her again. It was like her. Whereas before, it was the condition." Right up to the end some participants were looking for the normal in order to make sense of their journey. I wonder if looking for normalcy was somehow a denial of the dementia. Further, was it that this was the wrong time for his or her relative to die?

Permeating Ambivalence

Participants rarely expressed one type of feeling, instead they experienced a range of emotions, sometimes all the way to the complete opposite; this presented as ambivalence about what was occurring. "*Every feeling has its place in a polar tension; it derives its color and meaning not from itself alone but also from its polar opposite; every feeling is conditioned by its opposite*." (Buber, 1970, p. 129). Charles, in particular, named his feelings as "probably ambivalent, really" he went further and stated: "I was torn, torn between these feelings – I am not wanting to give up and yet wanting her to go." These opposite feelings were most often surrounding the impending death of their relative, for example Laurie talked of feeling sad while at the same time feeling relieved that her mother was moving on to something better through death:

> It's almost like there's a relief, too, because you know, like, I knew the end was near, so it was kind of... it was with huge sadness, but… I know my sister hates when I say this, but she was going to a better place so she could regain her self, if you believe in a life after. That she would become whole again.

Having these opposing feelings did not seem to distress participants and they spoke matter of fact about them. This is in contrast to Forbes and colleagues (2000) who found that ambivalent feelings to be distressing to active family caregivers (to the point that it impaired their ability to make end-of-life care decisions).

Through presenting these concealed or unapparent elements we might begin to critique current practice and move forward to assist family caregivers to finish the journey with dementia in a more positive way. It may be important to consider: when is seeking assistance from family members to provide hands-on care for their benefit or for the benefit of the staff? Are feelings of sentiment and concern for their relative exploited to further a family caregiver's involvement in care? How do long-term care staff provide care for residents that is reflective of the care receiver's personhood? Or, are family caregivers allowed to express conflicting feelings and be free of judgement? In order to construct an overall narrative it was necessary to incorporate many of these concealed experiences with those found within the life worlds so as to be a reflection of what my participants shared with me.

Overall Narrative

The following is an amalgamation of the many experiences that my 11 participants shared; also, inevitably, it is about me and some of the experiences I have had both as a Granddaughter and as a nurse. I introduce a small family that is dealing with the dying of their wife and mother with advanced dementia. It is a simple, yet detailed narrative that attempts to capture what it is like to lose a family member with dementia. Woven in this narrative are some of the common as well as some of the unique experiences of my participants. Two of my participants were given the opportunity to read this narrative and offer comments. I was affirmed in my endeavour as both of them cried and easily identified with either George or Sheila.

Being-With, Being-There

Martha with George & Sheila

George and his daughter Sheila reluctantly drive away from the long-term care home. Today, George's wife, Martha, moved there in order to be cared for 24 hours a day. George cannot stop looking at the closed door that separates him from his wife. He is unsure how his legs are able to carry him away from her. Sheila is relieved that her mother will be safe and under constant supervision, but she too finds it excruciating to ignore Martha's pleas to go with them. Gnawing at both of them is the question: *Are we doing the right thing?* Sheila looks over at her dad and sees how much he has aged in the last 2 years and wonders how he has managed for so long to take such good care of her mother. Neither George nor Sheila tells the other what a horrible day this is. This is the day they stopped caring for Martha in the house she and George lived, loved, and raised Sheila for more than 50 years.

Except that you cannot stop caring even with a loved-one in a *home.* They decorate Martha's room with the things she treasures – her bedspread, the picture of Sheila as a baby, their anniversary photo, and a sea shell from their loved vacation home. George visits everyday and continues to feed and walk with Martha. It is almost like they are husband and wife again instead of *caregiver* and *care receiver*. At night though, in the house, all alone, he can hear Martha's footsteps and gets up to see if she has gotten away on him again. After a moment he realizes where she is and returns to bed. A new day arrives and he is able to go and see her in her new home.

Sheila too visits her mother often. She looks for details that tell her that her mom is well cared for and content – is her hair done, is she wearing lipstick? She also looks for her mother's recognition of her because she knows that will go soon. Already her mother does not recognize objects or remember how to dress herself. But she can still walk and that is something they can do together, as if her mother is normal, is free from this disease that is slowly stealing her away.

Unfortunately, it does not take long for Martha to wear *depends* pads instead of being toileted and even worse, to begin to have falls. Martha does not know how to use the call light and cannot wait for someone to come and help her up; she needs to get up when *she is ready* to get up. George and Sheila do all they can to keep Martha walking because that is all they have left of the *old Martha*. So, walks continue but with Martha in a wheelchair. As Martha sits in her wheelchair she still gets a twinkle in her eye when George arrives, she smiles at his teasing, but her verbal replies have been long forgotten. That does not stop George and Sheila from talking with and sometimes answering for Martha.

Sheila recognizes the downhill decline in her mother more so than George does. Is it because she does not see her mother each and every day or is it because George does not want to face what is inevitably approaching? Perhaps it is a little of both. This downhill decline is what happens when you put a loved-one in a home...

Martha begins to sleep more and eat less. George feeds her, he pleads with Martha to take the Ensure and pureed foods. Sheila has taken to coming at night and bathing her mother in bed, applying lotion and massaging her, talking to her about what a wonderful childhood she had. Sheila is silently thankful she can do this for her mother; she knows it is only a matter of time now. Sheila does not dare tell her dad that she is giving her mother permission to die. Sheila wonders if her mother is confused by their different approaches to caring – as Sheila provides care as a way to say goodbye and as George cares in order to hang onto Martha no matter what her state of being.

It seems almost out of the blue when the nurse on night duty calls Sheila and tells her that her mother's had a "bad night" - maybe she should come and see her? Maybe Sheila should bring in George? Together, in the early morning hours, George and Sheila sit by Martha, listening for life (breaths) and death (absence of breathing). The staff brings George and Sheila coffee and toast. Sheila tells her dad to go home and rest, that she will call if there is any change. George does not hear her, he is in a fog, his beloved is dying and he is simply not ready. His mind races with thoughts that if Martha were still at home this would not be happening. A few hours later Martha opens her eyes and turns her head, George moves close to her bed, smiles at her, Martha reaches up and touches his face, she too weakly smiles. Sheila notices what has just happened and she goes to the bed, but Martha has already closed her eyes and becomes unconscious again. Now neither of them wants to leave in case they miss another moment like that. But there isn't one.

Eventually, Sheila and George begin to take turns sitting with Martha. Sheila makes sure someone else is with her father, so he is not alone if her mother dies before she can get back to the home. Sheila tries to count how many days it has been since the last time her mother was awake. It is hard to tell. Time melts away and an hour seems to last only a moment. They wonder: *How much longer will it be now?* After 5 days of constant *being-with* and *being-there* Sheila *knows* something is different. She calls her aunt to go and get George to bring him back, even though he only left the home 2 hours before. Martha makes gurgling noises, she appears to struggle with her breaths, but in a way she looks peaceful. Her breaths come slow and infrequent; Sheila wonders a few times: *Was that the last one?* Sheila holds her mother's hand and rests her head on the bed. She is thinking that it is okay for her mother to go, to be free of a body she doesn't recognize and would never want. "Just let go mom. Dad and I will be fine. You had a good life..." George arrives and sits on the other side of the bed holding Martha's other hand. He is weeping quietly, he knows she is not coming back; he wants her suffering to be over. He is consumed with a sadness deep in his heart that she is finally leaving him. George ponders all the things he is losing: Martha will not walk with him on the beach again, in the spring they will not plant their garden, and there will be no talks over tea and the newspaper at breakfast... Sheila reaches over and holds her father's hand – they are a complete circle and love passes between the three of them. George and Sheila realize that Martha has not taken a breath for some time, but they do not call the nurse to confirm what they already know; the serene look on Martha's still face tells them she has died.

"Come on dad, go with Aunt May, I'll get mom ready." George is lead away; he is unsure where he is supposed to go or what is supposed to be happening now. Staff members come and hug him, they cry with him and say, "I am so sorry. Martha was one of my *favourites*." With the help of the nurse, Sheila baths her mom for the last time; they dress her in her favourite ruffled blouse and grey slacks because Sheila thinks her mom would have liked that. With the air still filled with the smell of lotion, Sheila watches as the funeral home takes her mother away. Sheila is ready for the next part of the journey and she will make sure that George is ready too.

Limitations

Findings from this research are applicable only to the participants of the study as findings from a phenomenology are the result of interaction between the researcher and the participants within a given context. Thus, it may be possible that others would perceive this work differently and present different insights or understandings. However, findings may resonate with other family caregivers to persons with advanced dementia at the end of life. I have taken steps to acknowledge and explore my own preconceptions and biases concerning end-of-life care in dementia (e.g., see Appendix E or Chapter 5). I have also fully explored the context in which the participants lived their experiences, remained as true to the original transcripts as possible, returned to participants for verification of their narratives, and offered interpretations that supported participants in their own unique experience.

Participants resided in one urban center and care receivers died in a variety of long-term care homes. As relationships were important in this study, findings may have differed if the place of death was not in a long-term care home. Efforts were made to include family caregivers whose relative died in some place other than long-term care, but with a small urban centre and the rarity of death for people with dementia in their own homes or hospital this was not possible.

The social worker who recruited for the study indicated that she contacted family caregivers whom she felt would agree to participate and that she was comfortable with. Perhaps other family caregivers who the social worker did not feel as comfortable with would have provided a different perspective. Not all participants were recruited through the social worker nor did all the care receivers live and die in LutherCare Home, however the social worker's selective recruitment of family members whom she made a personal connection with may be viewed as a limitation. All of the participants indicated that they willingly took on the care of their relative. Thus, their end-of-life care experience may differ from family caregivers who are far more reluctant to provide care or do so not out of love, but of obligation. Despite the limitations to the present study, the participants and researcher were able to generate a rich understanding of the complex end-of-life care experience with dementia and offer possibilities as to where practice and future research may lead in order to support family caregivers.

CHAPTER 5: Self-reflection

A significant element to conducting an interpretive phenomenology is the involvement of the researcher as a co-creator of knowledge with the participants. When I set out to complete a doctoral degree being this involved with my participants and the outcomes of my research were not my ambition; in fact, I believe I was avoiding that closeness in favour of something more anonymous as might be possible with a quantitative study. I am not sure what that says about me as a person, however I do know I am uncomfortable with vulnerability. Alas, this phenomenological study found me and as a result I have grown and changed more than I could have imagined. Death and dying are not easy topics to explore, at least not for me anyway. And yet, this exploration has given me opportunities to discover things I may not have considered otherwise. Rilke (2005, p. 120) writes:

"To understand our *being here* as one side of being in its entirety and to exhaust it passionately, this would be the demand placed on us by death."

Experiencing the death of someone close has been the focus of my research. The deaths of my participants' relatives has called me to look deeper into who I am.

By reading many of Rilke's (e.g., 1986; 2005) letters and writings it is evident that he is a person who embraces solitude and discovery of self. In order to do this he suggests writing, allowing for poems to come out of immersing oneself in their world. That is exactly what this chapter is all about, it is a "*dear natural possession, a piece of [my] life, a voice from it*" (Rilke, 1986, p. 9). Admittedly, I find it challenging to write where I have been, where I am going, and everything that falls in between. My biggest concern is doing justice to what my participants so willingly shared with me. This weighs heavily on me and I am always cognizant of honouring them and their family member in the most meaningful of ways.

For many months now things I have read, music I have heard, situations I have witnessed, or the smell of particular odours have all led me back to what I am researching; I cannot escape recognizing my participants or parts of their experiences in the life that goes on around me. As a result I have begun to see the world differently. There is no doubt that Munhall (2007a) was correct – to study an experience you must live it. I suppose that is inevitable. It is also something which can be embraced and lived to the fullest or left to erupt in small ways with the hopes of catching ones' attention. For instance, I found common threads (the essences) among the individual narratives that were creeping into my writing before I had acknowledged them as essential to the end-of-life care experience. Had I not embraced this research experience and allowed it into my life I may have missed that important *eureka*.

I found I entered waves of consciousness of the experience depending on who I had interviewed recently. Many participants touched me very deeply, while others were more difficult to get a sense of who they were. So many times I have found myself returning to the events surrounding my grandfather's death with dementia and how that impacted my grandmother. As I listened to my participants' stories I found myself reshaping or reorganizing what it might have been like for my grandmother – how is she different or the same from the people I was meeting some 30 years later? My participant Rose stirred many of these memories for me. Rose struck me as a woman who was much like my own grandmother and her experience echoed many of the feelings I thought my grandmother experienced. I felt her story very deeply and was physically and emotionally drained after our meetings. Rose was so hurt by her husband's death and I felt like I wanted to make things better for her, but at a loss as to how to do that. Not to mention that was neither my place nor the purpose of our encounters. Nonetheless, I recall vividly feeling like that with my own grandmother – being at a loss as to how to comfort her and lessen her anger. What I have realized is just how important that time in our family was and that my grandfather's (unpleasant) death was not in vain. Without this experience I am not sure I would be here today, researching this very phenomenon.

Dale was another participant that remains in my thoughts now, long after our interviews. This sweet and gentle man seemed so vulnerable, both physically (he appeared quite frail) and emotionally (by weeping openly in front of me). I was surprised by his keen interest in me and how I might further my research (e.g., he suggested publishing in a journal that would get me many "citation hits"). His humour, interests, and approach to life resemble some of the important males in my life (e.g., my grandfather and favourite uncle) who I miss dearly or cannot see often enough. I felt his loneliness deeply.

Other participants had differing impacts on me that were not quite as strong as Rose and Dale. I think that was in relation to my ability to view what our meetings were about and to simply *get the job done* with empathy and attentiveness. These other participants did not remind so much of my own situation or relationship to my Grandparents. That is not to say I was not touched by them, I most certainly was, but my reaction was of gratitude and admiration. Many times I left interviews wondering, ‘could I do that much for another person?’ I feel honoured to have heard such a variety of stories that I know I can draw upon in my future encounters with other family caregivers and perhaps understand them a little better or interact in a way that is more supportive.

In the findings chapter I introduced Frank’s (1995) notion that what my participants were doing was offering a testimony in order to bear witness to who their relative’s were; I further Frank’s idea in that “*part of what turns stories into testimony is the call made upon another person to receive that testimony*” (p. 143). By receiving my participants stories I have an obligation to continue their stories and give them voice. I am privileged to be able to take what I have gleaned from my participants and use it to improve my nursing practice, my future research, and the way I live.

“*But telling does not come easy, and neither does listening*” (Frank, 1995, p. xii). I know that by speaking with me many participants re-lived unpleasant memories. Perhaps this is a necessary venture for people to grieve and move on, but I do not relish the idea that I was the source of their upset. And with all honesty, many times I felt dark and depressed from some of my meetings. This has not been an easy road emotionally for me. To recover from those dark times I have taken to looking at what I do have and cherishing those relationships that impact my life in a fruitful and positive way.

The vast majority of my participants lovingly and willingly devoted a great deal of time and care to their relative, some for as long as 12 years. I found myself replacing the term "relative" with *loved-one* because the care receivers in my research were very much loved. Yet, I am also reminded of the many families I have encountered at different times in my nursing practice that I can honestly say did not feel a sense of love for what was happening to their relative and what they were required to do about it. In other words, many of these families from my past cared *for* their relative rather than *about* them. For me to impose this notion of a loved-one on a family who does not share that sentiment would be wrong and perhaps destructive in our encounter. Nonetheless, I am made aware that everyone's situation and experience is unique and families must be met where they *are at,* at any given time. Not everyone is relieved or reconciled when their relative dies.

Strangely, another realization of mine has come from what I have been referring to as the place where care receivers lived and died. I think in a detached way I have always referred to long-term care buildings as *facilities*, and yet these are *homes*. People live and die there, they wake and eat, and share good times and bad with a community of others who they often refer to as family. I wonder if I have been disrespectful in my assumption about these types of structures. I suspect I perpetuated the medical-like environment that so many long-term care homes have despite their efforts to be more home-like.

Another bold realization for me is that I cannot escape the fact that death is fundamentally a part of life. *"I find myself increasingly compelled to agree ...*

with this Everything where life and death incessantly penetrate and merge with each other" (Rilke, 2005, p. 122). Rilke suggests that we can become more knowledgeable about life because we have experienced the suffering death of someone we love. This loss means we move "*deeper and more [to the] interior of life so that we will grow out of it all the more fertile*" (p. 122). There are lessons, sometimes painful lessons, to be learned and used to improve our lives if we are open to them. At the risk of sounding cliché, some of the lessons I have gleaned from my research and my participants are: (a) to enjoy the present and the gifts in front of you, (b) to accept and reach out to people where they are in experience (be they relieved or uncomfortable) and give them the freedom to express their views on their terms, and (c) that silence speaks volumes and that no one need remain silent.

CHAPTER 6: Conclusions & Implications

This dissertation research has explored the deep and rich experience of what it means to care for a relative dying with advanced dementia. What is clear from this study is that family caregiving continues in many forms within the long-term care environment from admission to after death of the care receiver. Utilizing Munhall's (1994; 2007a) approach in this endeavour gave focus on generating individual and common narratives, as well as capturing the unique and concealed found in lived experience.

The 11 participant narratives make known the varied nature of the last part of the journey with dementia. This study emphasizes that family caregiving is completed amidst many relationships. Some participants felt welcomed and free to undertake their end-of-life care as they saw fit, while other participants struggled with what was going on around them and could not fulfill what they felt was necessary for end-of-life care. These diverse experiences are influenced by how the participants lived their experience through the life worlds. By dwelling and moving back and forth between the participant narratives and life worlds an overall narrative was developed to capture the common and unique experiences of family caregivers during the end of life. This overall narrative draws attention to the essential nature of end-of-life care for a relative with dementia – namely, that *being-with* and *being-there* are pivotal to the experience.

The cognitive decline and the lengthy process associated with dementia impacts the end-of-life care experience of family caregivers in ways that other terminal illnesses do not. Giving voice to the personal loss the 11 participants in this study experienced is necessary to inform those who work most closely with these types of families. In the end, I hope this work lends understanding with regard to this complex end-of-life care experience. The following is a discussion of what to consider when working with family caregivers to persons with advanced dementia and how other research may continue to deepen our understanding.

Implications for Practice

This research has the potential to inform health care practitioners, particularly those who work in long-term care. This is important because of the relationship staff have with families, often built up over many years, but in some instances over much less time. Long-term care staff have the opportunity to begin to make up for what the physical environment may be lacking (i.e., that it is not the caregiver's own home). It was apparent that some staff members were vital to the experience of participants, while others were viewed as detrimental. It is necessary to consider the cultural aspects of the physical and social environment during end-of-life care. Further, what are the socio-cultural expectations of family caregivers in providing end-of-life care? In what ways are family caregivers supported to provide the end-of-life care they feel is necessary?

Family caregivers may not always understand the dying process and require support to work through what their relative may or may not be experiencing in their final days. As many of the narratives demonstrate when a person with dementia becomes bedridden and stops eating and drinking this is often distressful to family caregivers; yet it is a natural process to death. Health care practitioners might want to look for opportunities to share about what is naturally occurring and why.

It may be important to consider how total pain or suffering impacts the family caregiver. When health care professionals are able to acknowledge this they may be better able to support family caregivers to work through all the varied and complex feelings that may arise as their relative is dying. Moreover, support may be necessary into bereavement. Grief and suffering are natural reactions to the death of a relative and need not be viewed as needing to be fixed, rather family caregivers may require support to move through and allow those feelings to flow. It may be of benefit to make grief education a priority for health care providers. It is vital that health care practitioners understand that family caregivers be met where they are at in their experience and freely allow them to express their needs and concerns in order to assist them to help their relative to die peacefully.

Not all participants expressed relief when their relative died. To assume family caregivers will be relieved with the *final* physical death of their relative would be a disservice to them. Perhaps those who struggle the most at the time of death of their relative are those that require assistance immediately, while others who appear relieved may require support further into bereavement. Perhaps spouses with little or no family (e.g., adult children) may be at more risk for complicated grief and require assistance more so than those with supportive family around them.

Need for Continued Research

This study has identified key areas for further research. Given that this study was broad in scope and aimed at providing a foundational understanding of the end-of-life care experience for family caregivers to persons with advanced dementia, further research is warranted to confirm or contrast the findings. Of note, is how other places of death might impact the end-of-life care experience for family caregivers. This study highlights how space influences the end-of-life care experience, it may be that family caregivers will view other spaces (e.g., home, hospital, or hospice) in more or less favourable ways. How might their feelings of control be impacted? How might they arrive at decisions for care in other environments?

As this study demonstrates, relationships to staff and other significant persons (e.g., clergy or funeral home personnel) influence the end-of-life care experience. Further, research might begin to consider how others support family caregivers in order to complete their journey with dementia and into bereavement. What other supports are significant and why?

Some areas of interest generated from this work are in regard to the differences in gender and relationship to the care receiver. Women and men react to and take on differing responsibilities throughout the caregiving journey and this may have implications for the end-of-life care experience that requires further consideration. This research revealed the significance of caregiving roles at the end of life. Thus, it may be valuable to explore the role reversal prior to death of a parent as this appeared significant to adult children, while role changes after the death of a spouse seemed important to the spouses within this study. In some instances in the present study, spouses viewed death of their spouse differently than adult children viewed death of their parent. Moreover, a study that explores reactions to death of a relative with dementia among multiple members from a single family may be useful to further shed light on relationships and the end-of-life care experience. On the other hand, it may also be useful to consider narrowing a study to focus on only adult children or spouses in order to delve deeper into how relationship impacts end-of-life care. Perhaps an investigation of differences in experience among wives and husbands is warranted to further reveal gender and relationship issues and their impacts. How might the marital relationship prior to the dementia onset (be it intimate or conflicted) impact end-of-life care?

Conceivably approaching family caregivers who are actively providing care during the end of life may reveal other aspects to this experience left unattended in a retrospective approach. This would require the researcher to be empathetic and sensitive to what might be going on for a family caregiver during the difficult end-of-life stage. One area that may be worth exploring with active family caregivers to persons with dementia is the potential for or the impact of ambiguous loss and how it influences the end-of-life care experience. In the present study, ambiguous loss was not raised as an issue with bereaved family caregivers.

This study demonstrates the value of undertaking a retrospective approach to explore the end-of-life care experience with dementia. This enabled participants to reflect on their complete experience and explore what end-of-life care meant within their whole journey. This broad understanding may point to other methodologies to further explore what is happening in this context. For example, a grounded theory approach may be beneficial to explore the process family caregivers underwent as they experienced letting go of their relative with dementia over time, before and after death. Other processes might include how family caregivers negotiated care needs with formal care providers, or how they make decisions related to hospitalization and invasive procedures during end-of-life care.

It is significant to note that the retrospective qualitative approach in the present study made it difficult to compare to the vast majority of available literature presented in Chapter 2. With the exception of Forbes and colleagues (2000), the structured focus of the other two studies utilizing qualitative data (i,e., Meuser & Marwit, 2001; Sanders et al., 2009) did not offer insights comparable to the foundational and broad findings of the present study. There is not necessarily an expectation to have similar findings with different styles of research.

In conclusion, it may be worthwhile to explore in more detail the essences that were revealed in the study. *Being-with* and *being-there* could serve as providing a structured approach to continue research with bereaved family caregivers. It is important to continue to explore this end-of-life care experience and discover ways to support family caregivers adequately and appropriately.

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Appendix A

UNIVERSITY OF ALBERTA

Informed Consent Form Information Sheet

You are invited to take part in a research project entitled: *The Lived Experience of Family Caregivers who provided End-of-life Care to a Relative with Dementia.* Please read this form carefully, and feel free to ask questions.

Researcher:

Shelley Peacock, PhD candidate, Faculty of Nursing, University of Alberta
Tel: (306) 978 4410, email: speacock@ualberta.ca

Principle Investigators/Co-supervisors:

Dr. Wendy Duggleby, College of Nursing, University of Saskatchewan
Tel: (306) 966 8527, email: wendy.duggleby@usask.ca
Dr. Priscilla Koop, Faculty of Nursing, University of Alberta
Tel: (780) 492 2962, email: priscilla.koop@ualberta.ca

Purpose and Procedure:

This study aims to explore what it was like to care for a relative who died with advanced dementia. I want to learn about family caregiver's experiences of end-of-life care and what providing that care meant to them. Family caregivers may be spouses, a sibling, adult children or a friend of the person who died.

I am looking for up to 10 people. You will be asked to share about your experiences caring for a relative who died with dementia. We will meet for three interviews. All interviews will be audiotaped with your consent. The audio tapes will then be transcribed. The first interview may last about 2 hours. It is meant to be a discussion to share your story. The other two (no more than 1 hour long) will occur at a later time. They are to check that I have summarized your caregiving story accurately. This process will help me with the analysis for my study. If you like, you are also invited to share a photo or other written material that you feel supports your story. This may be included in the study summary.

These interviews will be held at a time and place that is fitting to you. Findings from the study will include direct quotes to support a story that summarizes all participants' experiences. The data from this study will be published and presented at conferences.

Potential Benefits:

The findings from this research may not impact you directly. However, your story may assist policy makers and researchers who work with family caregivers like you.

Potential Risks:

There are no known risks to being in the study. However, if the sharing of your story is upsetting you may end the interview at any time. You will be given a list of support resources. I have also arranged for a grief counsellor to take new clients if you would like someone to talk with; this will be at your expense.

Storage of Data:
The data collected will be kept in a locked cabinet at the University of Alberta, in Dr. Koop's private office. After five years the data will be destroyed. The contact information sheets will be stored separate from the interview data.

Confidentiality:
Your identity will be kept confidential. Your actual words may be used, but not your name. The study data may be used again in another study with approval from an ethics board. All information will be held private except when professional codes of ethics or the law requires reporting.

Reimbursement of expenses: You will be given a $20.00 gift card for your time. This will be at the first interview. If you choose not to finish the study you may still keep the gift card. When necessary, parking fees will be paid for you.

Right to Withdraw:
It is your choice to be part of the study. You may choose not to answer a question. You may ask that the tape recorder be turned off at anytime. What you share will be kept private and discussed only with the research team. You may withdraw from the research project for any reason, at any time, without penalty. If you do withdraw from the study at any time, anything you shared will be destroyed at your request. Consent to participate will be obtained at each interview.

Questions:
If you have any questions concerning the research project, please feel free to ask at any point. You are also free to contact the researchers at the numbers provided if you have other questions. This research project has been approved on ethical grounds by the University of Alberta Health Research Ethics Board on [November 10, 2009] and the University of Saskatchewan's Health Research Ethics Board on [November 23, 2009]. Any questions regarding your rights as a participant may be addressed to the University of Saskatchewan's committee through the Ethics Office (966-2084). Out of town persons may call collect.

(Created from: www.usask.ca/research/ethics_review/guidelines.php)

Informed Consent

Part 1 (to be completed by the Principal Investigator)

Title of project: *The Lived Experience of Family Caregivers who provided End-of-life Care to a Relative with Advanced Dementia*

Principal Investigator:

Wendy Duggleby, RN, PhD, College of Nursing, University of Saskatchewan; (306) 966 8527

Co-Investigators:

Shelley Peacock, PhD candidate, Faculty of Nursing, University of Alberta; (306) 978 4410

Priscilla Koop, RN, PhD, Faculty of Nursing, University of Alberta; (780) 492 2962

Part 2 (to be completed by the research participant)

	Yes	**No**
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the risks and benefits involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you can withdraw at any time from the study without having to give a reason?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your records?	☐	☐
Do you understand that the interview will be audiotaped?	☐	☐
Do you authorize that your records be used for another research project following the submission of a new research proposal to an ethic review board and received approval?	☐	☐

This study was explained to me by ________________________________

I agree to take part in this study: YES☐ NO☐

Signature of the research participant Date

Printed Name

I believe that the person signing this consent form understands what is involved in the study and voluntarily agrees to participate.

Signature of the Investigator or Designee Date

The information sheet must be attached to this consent form and a copy given to the participant.

UNIVERSITY OF ALBERTA

Photograph/*Other* Data Release Form {reading level 8.5}

I, ______________________________, have provided Shelley Peacock with a copy of ______________________ {photograph, drawing, poem, or other writing} as part of my sharing in her research project. I hereby authorize release of this item to Shelley Peacock. It may be used in the manner described in the Consent Form. I have received a copy of this Photograph/Other Data Release form for my own records.

____

____

(Name of Participant) (Date)

____

____

(Signature of Participant) (Signature of Researcher)

(Created from: www.usask.ca/research/ethics_review/guidelines.php)

Appendix B

Participant Demographic Information

1. What is your relationship to the person with dementia whom you cared for? (E.g., husband or wife; sister, brother; child, etc)

   ____

2. What is your age? ______ years old
3. What is your gender? *female *male
4. What is your marital status? (Please check one)

   *married/common law *separated

   *divorced

   *widowed *single (never married)

5. Which of the following categories best describes you at present? (Please check one)

   *employed full-time *employed part-time

   *retired

   *full-time homemaker *unemployed

   *other (please specify) ________________________

6. How old was your relative with dementia when they died? ______ years old
7. What was the gender of the relative you cared for? *female *male
8. Had your relative been formally diagnosed with dementia (e.g., Alzheimer's Disease, Lewy Body dementia, Frontotemporal dementia, Vascular dementia or other)?

   *yes *no

9. Where was the place of death of your relative with dementia? (Please check one)

   *at home *hospital *long-term care facility

   *other (please specify) ________________________

10. Did you use health care services (e.g., home care, palliative care) to assist you with your end-of-life care? *yes *no

Appendix C

Sample Advertisement

Research on the Experiences of End-of-life Care to a Relative with Dementia

If you are:

- Willing to talk about your experiences of caring for a relative who died with advanced dementia
- Someone whose relative died within the last year
- 18 years of age or older

I would like to talk with you about your experiences as a caregiver. I am a registered nurse from Saskatoon and a graduate student in the Faculty of Nursing at the University of Alberta.
You will receive a small gift ($20 gift card) for participation in the study.

If you would like to take part or have any questions please contact
Shelley Peacock, at (306) 978 4410 or speacock@ualberta.ca
{Co-supervisors for this research project: Dr. Wendy Duggleby, College of Nursing University of Saskatchewan, (306) 966 6237 or wendy.duggleby@usask.ca; Dr. Priscilla Koop, Faculty of Nursing, University of Alberta, (780) 492 2962 or priscilla.koop@ualberta.ca}

Appendix D

Letter of Support

From Vivienne Hauck, CEO Luther Care Community, Saskatoon, SK

LUTHERCARE
COMMUNITIES

April 8, 2009

Shelley Peacock
474 Anglin Crt
Saskatoon, SK S7J 5G1

Dear Ms. Peacock,

This letter is in follow-up to your contact with Marilyn Cooper (Director of Nursing, March 4, 2009), Walt Greaser (Vice President of Health Services, March 18, 2009), and our telephone conversation of March 30, 2009. Please accept this letter in support of assisting you to recruit participants for your proposed research study entitled *The Lived Experience of Family Caregivers who provided End-of-Life Care to a Relative with Dementia.*

Once we have received a copy of the ethical approval by the University of Saskatchewan and the Saskatoon Health Region, LutherCare Communities would be willing to assist with recruitment of family caregivers who meet your study's criteria. This would include contacting family caregivers on your behalf who had a relative die of dementia in the last year in Luther Special Care Home. As well, we would advertise your study with a post on our bulletin board and arrange for a brief presentation to recruit other family caregivers for your study with the residents living in Luther Tower.

Given our aging population and the increase in the number of persons with dementia, this is a worthwhile study. We are happy to support your research project with our aging population because it is crucial that we contribute to the quality of care for family caregivers dealing with end-of-life issues.

Sincerely,

Vivienne Hauck
CEO

1212 Osler St. ▪ Saskatoon, SK S7N 0T9 ▪ Ph. (306) 664-0300 Fx. (306) 664-0311 ▪ www.luthercare.com

Appendix E

Personal Reflection Paper

A Good-bye without Leaving and Finally Letting Go

On occasion, we are afforded opportunities to explore parts of our life in detailed and reflective ways. It may be after such reflection that we realize just how influential certain experiences are on our lives. Such is the case with the circumstances surrounding my Grandfather's dementia and eventual death. With its many challenges and opportunities the journey with dementia from diagnosis to end-of-life is often a demanding path for families. The purpose of this paper is to explore the experience of losing a family member to dementia using an interpretive phenomenological approach. It is my hope that in sharing this story that it will deepen my understanding of end-of-life family caregiving and that it may resonate with others as to what they too might experience. The following is my personal story with exploration of themes that arise. The paper will conclude with some closing remarks pertaining to my experience.

Weaving the Story: Analyzing the Experience

A Changing World

The last time I visited my Grandparents was to celebrate my eleventh birthday in November. Usually my Grandparents were attentive, loving and patient with my twin sister and I. Visits with them were carefree and happy. However, this last visit was very different from the other birthdays we had spent with them. Things had changed in their cozy apartment. Even at the age of eleven I could feel the tension and unease in the air. My Grandfather was withdrawn, my grandmother was tired and on edge. Oddly, there was a bell hanging on the front door handle and a sheet and blanket folded neatly with a pillow on the end of the couch. My grandfather could not take us for ice cream, as was our usual custom, and we were forbidden to talk about his car. My grandmother was worried we would upset my grandfather, so we had to be quiet and stay out of the way. Like many times before I sat quietly holding my grandfather's hand, examining his veins and thin skin, amazed at how much bigger his hands were than mine. Usually he told me stories while we held hands, but he didn't seem to want to this time. I had never seen his beautiful blue eyes so sad and empty before.

Years later, I am still very aware of the sadness and confusion I experienced during that final visit with my grandfather. I was uneasy. Life had become so different for my grandparents in the short time since we had last seen them a few months prior. It seems evident from the above introduction to my grandparents' story that there were many changes going on in their lives and in their world. Multiple changes were evident in my grandfather, there were changes in my grandmother as well and ultimately, their relationship was changing too. Our visit with them revealed what had been happening. It seems the changes in my grandfather meant he was less available to my grandmother. Because of dementia, he was withdrawing into a world where others could not be a part.

The changes in my grandparents' relationship meant changes to their *world* as Heidegger (1927/1962) viewed. Our world is, in part, a result of our culture and language, played out in meaningful relationships and very often, is taken for granted. We and the world are in a reciprocal relationship, in other words, our decisions and work are connected with what occurs in the world (Buber, 1996). For my grandmother, caregiving was her world. All her life my Grandmother was a caregiver; to her mother, ill brother, and in raising her children. This cultural role was a natural acquisition in her relationship to my grandfather and one may wonder if my grandmother ever thought she had a choice to be a caregiver or not. Who we are and what we do is rooted in our relationship to others and by what our world constitutes (Leonard, 1994). My grandmother's caregiving skills may have been unnoticed or taken for granted and yet those abilities are what created her possibilities and the condition of her world.

Armson (2007), in a poem she wrote about her husband, invites us to consider the world of a family member with dementia and to offer support. It is difficult to witness the changes occurring in someone with dementia; it is even more difficult to understand what is transpiring. There may be the desire to remember them as they once were and not take their current actions as who they really are or what they may become. Armson writes:

> So all we can do for Grandpa
> Is try to understand
> That Grandpa loves you very much
> So take his wrinkled hand.

Suffering-With Love

My Grandfather was admitted to a long term care facility just after Christmas that year and passed away the following spring. To my surprise my grandmother didn't cry at his funeral, rather she seemed angry and resentful. When I asked her why, she told me she had done all her crying during the night, laying there on the couch in the living room, listening for him, worried he would get up and wander away. As an eleven year old, I didn't understand why she cried so much before he died, all alone, without her family's support. I wondered why my Grandfather would want to 'wander away' anyway. But I did not ask any more questions then.

My grandfather's funeral was the first funeral I had ever attended. Owing to our young age, my mother insisted that my twin sister and I stay close to her and my grandmother during the service. This proximity provided me the opportunity to see and sense what my grandmother was experiencing in those moments while we said good-bye to my much-loved grandfather. What I did not realize then was that my grandmother had set off on her good-bye long before the funeral; in other words, even before my grandfather's actual death my grandmother began her journey of grieving. What is less clear is why she chose to grieve alone, without support from her family. Perhaps my grandmother was ashamed of my grandfather's odd behaviours or embarrassed that he was going "crazy". It is possible that part of her silence also stemmed from the busy lives that her two sons led (would they have time for her?). It could have also reflected her wish, perhaps, to protect or not impose on my own family - a family experiencing a chaotic time with the recent separation of my parents. It may be that my grandmother longed for her family to offer help instead of her needing to ask or simply that this was her duty, as a wife, to provide care alone. Possibly other family members may have avoided providing support for fear of experiencing a similar situation themselves or of needing to give more than they wished if they offered to help. I believe that we all would have rallied and assisted my grandparents, but for reasons of her own my grandmother chose to grieve and caregive alone. How many other family caregivers experience this?

My grandmother may also have experienced a loss of hope. Duggleby (2008) speculates that family caregivers to persons with dementia will enter into relationship with others (other caregivers, health care professionals or family) in search of or affirmation of hope about their caregiving situation; however, without supportive relationships family caregivers may experience despair and remain alone in their suffering. It appears as though the despair my grandmother experienced, no doubt owing in large part to my grandfather's disruptive behaviours, may have lead to feelings of anger and resentment. She had been robbed of her beloved husband. I believe my grandmother felt alone and the burden of caregiving was too heavy to carry on her own despite her natural drive to do so.

There were likely rewards in how well my grandmother managed all that was going on with my grandfather's dementia. Often positive consequences or the rewarding aspects of caregiving are hard to recognize during the very intensive phases of care. It may be that those positive consequences are what kept my grandmother in her role for the length of time that she was able to manage. Interestingly, Hansen (1979) explores the pain and joy that may exist in human relationships and concludes that one may be the cause of the other. Relationships are rarely either negative or positive. Rather, relationships may have balance, where pain and joy exist simultaneously (Hansen). It may have been painful for my grandmother to lose my grandfather to dementia; however, his dementia also presented an opportunity for her to care for him in ways that may not have been otherwise possible. She may also have been aware that this would be her last gift to him, a way to honour the love they had shared for so many years.

It remains that my grandmother *suffered-with* my grandfather. Suffering-with calls us to act empathetically on behalf of others and by doing so we are in essence, doing for ourselves (Olthuis, 1997). In many ways my grandmother became my grandfather's protector because he could no longer remain safe on his own. His vulnerability allowed her to rise to his needs in ways he would not have allowed had he been well. At the same time, this created a difficult situation for her, its own form of suffering, since she had to take measures that he could not understand but that he would challenge on many occasions. Her caregiving may also have been as much for herself as it was for my grandfather; she might have recognized that she may have future needs for care. My grandmother's ability to suffer-with my grandfather may have been borne out of the love they cultivated after many years of being together in a reciprocal relationship. Her caregiving may in part have been a result of, "Love [being] the excessive gift that keeps on giving" (Olthuis, p. 149).

Creatively Giving of Herself and to Herself

It was not until I was much older that I learned some of what my grandmother went through during my Grandfather's last, difficult months. Although not formally diagnosed, my Grandfather had dementia. I believe I was also right in sensing her to be angry and resentful at his funeral. Their time together cut short by a disease that stole my Grandfather away from her, without her consent. The bell on the door was there to warn my grandmother should my grandfather get up and wander out the door. She began sleeping on the couch at night because she was restless and tense; I suspect she was also worried he would hear her sobbing. We could not talk about the car because my grandmother had my uncle disable it and hide the ignition key so that my grandfather would not be able to drive anywhere. My grandfather was angry at his loss of independence and knew my grandmother did "something with the keys." My grandfather became unusually quiet, he was suspicious of my grandmother and what she was 'doing' to him...

I wonder what transpired over the years between my grandfather's death and my grandmother's ability to finally share about his last months with me. She may have gained a clearer perspective or deeper insights as to what happened during that time. Undoubtedly, my grandmother's feelings of anger and frustration were less raw and apparent years later. I vividly recall while speaking of this time with my grandfather that she had no expectation of anyone really understanding what she endured. My grandmother did not want praise or admiration for her caregiving; rather, I believe she did not want to be a *burden* to others in the same way as my Grandfather had been. It is sad to think she may not have wanted anyone to give that much of them for her benefit.

The imagination and creativity that my grandmother used to protect my grandfather is not unlike the lengths that many other family caregivers go to ensure dignity and safety of their family member with dementia. It may be through these creative actions that many family caregivers find meaning and experience satisfaction with their caregiving role (Peacock et al., 2009). The perception of intrinsic value in caregiving, although rewarding, may also lead to being vulnerable to self-sacrifice (Pask, 2005). Family caregivers give of themselves in amazing and complex ways, often resulting in detriment to their own health and well-being. It may be that my grandmother had insight into her own needs at that time and admitted my grandfather into long-term care before her own health was adversely affected.

Letting Go

...My grandfather's wandering, agitation and occasional violent outbursts became more than my grandmother could manage on her own and she made the difficult decision to place him in a nearby long-term care facility. Initially, she faithfully visited every day, feeling immense guilt for placing him there and giving the majority of his care over to others. Because of his agitated behaviours and a lack of understanding regarding dementia at that time my grandfather was restrained in a wheelchair out in the hall. As people passed by he would ask them for a knife so he could free himself and get out. It is hard to imagine the serene and gentle man I had known all my life acting so strangely and aggressively. My grandmother began visiting every other day because he no longer recognized her or his two sons most of the time; unfortunately her visits seemed to not bring him comfort. It was also extremely difficult for her to see the man she had been married to for 45 years turn into someone she no longer recognized. His disease progressed until he was bedridden and he eventually died, all alone in the middle of the night March 17, 1982.

Given my grandfather's disruptive behaviours my grandmother was more than justified in securing 24 hour care for him. However, despite how difficult caring for him had become, I do not believe she was able to forgive herself for giving over his care. She seemed critical of herself; as if in some way she had let him (and herself, perhaps) down. I imagine my grandmother would not have thought disparagingly of another caregiver in the same or similar situation. Peering from outside the situation, it is easy to comprehend why my grandmother needed to institutionalize my grandfather and, as her family, we were thankful she had this option and made the decision. To see my grandfather deteriorating so quickly after being placed in long-term care may have added to the losses my grandmother had already endured. The physical loss of his presence in their home was alleviated, to a degree, by visiting every day, but how does one deal with the loss of your spouse recognizing you? How is one able to let go of another when not ready to do so, when you have not moved on from the earlier losses?

The motion picture *Away From Her* (Iron, Urdl, Weiss & Polley, 2006) depicts eloquently just how difficult it is to let a loved-one go as dementia progresses. Letting go of someone takes time and may be difficult to accept, if ever. In the movie *Grant* (Gordon Pinsent) tells his story about the love of his wife *Fiona* (Julie Christie) to anyone who will listen; simply that he never wanted to be 'away from her' from the moment they met. However, Grant has no choice because Fiona's dementia is stealing her away from him. It may be that my grandmother telling me her story about losing my grandfather provided her with some perspective, allowed her to check her experiences and feelings with others as a means to come to terms with my grandfather dying the way he did.

It appears as though there are conflicting feelings occurring in this part of my grandparents' story. Connidis and McMullin (2002) suggest that ambivalence is a set of contradictions that can manifest within relationship and as such may result in motivation to take action. Buber (1996) furthers this by proposing that relationships are "the fusion of opposite feelings" (p. 130). It may be that we do not become aware of opposing feelings until circumstances change and our world is altered. In the case of caregiving, ambivalence can be present in many of the phases along the journey from diagnosis to end-of-life care in dementia. The relationship between caregiver and care receiver with dementia may generate some level of ambivalence given the increasing demands for care that results in an ever-changing environment. For example, ambivalence may have been present for my grandmother in her desire to continue to provide care to her husband, while at the same time feeling strained and burdened by that responsibility. It appears as though there may also be ambivalence with my grandmother's decision to place my grandfather in long-term care. There was potential relief from the physical demands of 24 hour caregiving, while feeling guilty about giving the majority of hands-on care over to others.

Further, it may be that my grandmother's lack of tears after the death of my grandfather also included feelings of relief that suffering was now over for him and she could now finish her good-bye. It seems as though my grandmother *silenced* her feelings. It may not be uncommon that at the end of life when death occurs, there is sadness and regret, while also experiencing relief at letting go of the person. These feelings may also be further related to what Hansen (1979) proposes about pain and joy in relationships. It did not change the fact that these may have been a source of ambivalence as well. This must have been a confusing time for my grandmother.

Caring to the end and what meaning that held for my grandmother may also be worth considering. It may be important to wonder how my grandfather's death impacted my grandmother's view of her own life and eventual death. Hoffman (2006) speculates on Heidegger's views of the essential connection between care and death. Heidegger (1927/1962) suggests that the most fundamental way of being-in-the-world is to care for other people. Through her caring my grandmother may have found her identity in a process she could no more understand than she could control to prevent it. She also may have realized what mattered to her in life and this may have helped her to face death - her own possibly and that of my grandfather. Further, it may be that "life matters only because [we are] aware that it can be snatched away ... by the power of death" (Hoffman, p. 227).

Dwelling in the Negative Spaces

In life there are experiences that may seem invisible or taken for granted. Those same experiences may provide a profound influence on our being in the world without our full comprehension. Those are the experiences that dwell in the negative space, waiting to be acknowledged. Less obvious and yet equally important experiences in my grandmother's life may have included loneliness, lingering grief, and the importance of relationship. Loneliness and lingering grief may be further explored by considering the notion of ambiguous loss. It may be important to consider the influence of relationship in her story given that relationship is foundational to all that family caregiving entails.

Ambiguous loss. The work of Boss (1999, 2007) may help to explain some of what is occurring in this situation regarding loneliness and lingering grief. The concept of ambiguous loss is a term to define loss that cannot be resolved or remains uncertain. Boss (1999) proposes that ambiguous loss occurs with dementia because there is confusion about what causes the disease and of the resulting boundary ambiguity within the family (i.e., who is in the family and who is out). In my Grandparent's case it appears as a "good-bye without leaving" (Boss, 2007, p. 105). This is further compounded by a constant re-negotiation of caregiving roles and my Grandfather's diminishing abilities. Intense grieving and experiencing loss may be a natural part of dementia and as such may need to be recognized and not assumed to be amended or prevented.

During the intense phase of my Grandfather's care, ambiguous loss may have been an issue for my grandmother. The caregiving situation can make it difficult to resolve psychologically losing a family member, while still needing to provide care to someone physically present. Perhaps this may have contributed to feelings of ambivalence for my grandmother and if left unresolved these could have adversely affected her own health if she had remained providing 24 hour care. Although it may be difficult to completely resolve ambiguous loss, naming the distress family caregivers are experiencing may be of benefit (Boss, 1999). As private as my grandmother was I am not sure how accepting she would have been to such a label; again she may have felt her duty as a caregiver was to be done at whatever cost, regardless of what it may or may not have done to her own well-being. Could these beliefs pertaining to duty lead to feelings of loneliness?

It may be important to note that her caregiving was not my grandmother's only source of ambiguous loss during that time. As mentioned, my parents had separated earlier that year, just prior to the intense, final phase of my grandfather's dementia. Our family struggled with this new and unknown situation and I know it saddened both my grandparents immensely to see my mother (and her children) in such pain. It is very likely that in the back of my grandmother's mind, she was wondering if my father was really still a part of our family, despite being physically present. I wonder how the stress of that (ambiguous) loss impacted her ability to carry on with what life was presenting her in her own marital relationship.

Relationship. Another pervasive, albeit not so obvious theme is that of relationship. I believe this story illustrates just how important relationship is to living one's life (Leonard, 1994; Olthuis, 1997) and essentially that "We are always in relation with others" (Conroy, 2003, p. 9). Most importantly, our world is made up of meaningful relationships and this determines our potential and opportunities (Leonard). Family caregiving is based within the family context, within *relationship*. The strength or lack of strength in relationships may have an influence on the quality and the amount of care provided, as well as if and when caregivers discover meaning within their role.

Buber (1996) proposes that with entering into relationship we are chosen and choosing, that at once the relationship is both passive and active. Similarly, this seems the case with providing care to a family member with dementia. For example, when dementia confronts a married couple it is as if they are chosen and presented with an opportunity to choose to explore their relationship in a deeper, meaningful way. If we truly regard the *Other* with value and worth, does it not behove us to act on their behalf whether the circumstances were chosen by us or not? Levinas (1985) would argue that we must act on behalf of the Other and suggest we take action to care for those in need.

Olthuis (1997) suggests that aspects of ourselves come alive and grow or die as we move in and out of relationship with others. Further, our identities are based on connection with others. Unfortunately, my grandfather's disease did not enable him to engage with my grandmother more fully; instead he seemed to pull away. On the other hand, my grandmother found gifts and opportunity to honour the needs of my grandfather. Olthuis refers to the notion of mutuality and describes it as a dance "in which ... the differing gifts and needs of each person are honoured, recognized, and often met" (p. 147). Although not consciously, it may be that my grandfather met my grandmother's desire to provide care, while she responded to his gifts and needs resulting from his dementia. Thus, the two continued the dance of mutuality, particularly during this difficult stage in their relationship. The mutuality present (or lack of it) earlier in their marriage may have prepared my Grandparents for how they would encounter this final phase of their relationship. Relationship in my Grandparents' story may be summed up by Buber (1996). He suggests, "Man becomes an I through a You" (Buber, p. 80).

Like many family caregivers, I believe my grandmother discovered and optimized her way in the world through her caregiving relationships.

Closing Remarks

> You learn and you learn;
> With every goodbye, you learn.
> (Shoffstall, n.d.)

This was a strangely difficult paper to write. I came to realize this story was as much my own as it was my Grandparents'. As discussed, my Grandparents' experience and mine may be described in the following ways: (a) a changing world, (b) suffering-with love, (c) creatively giving of herself and to herself, (d) letting go, and (e) dwelling in the negative spaces (i.e., ambiguous loss and relationship). While these reflect *our* experience, the journey with dementia is a story that has many authors all leading to the same ending. This story is offered from our perspective, with understanding that it may be different from the story others would tell. In addition, there is always room for further insights with interpretive phenomenology.

I have come to realize that this family experience has shaped much of who I am and what I have become (i.e., studying caring within the context of dementia and family). The relationship with my grandmother (based on the culture and values within our family) has in no small way influenced my view of the world, as well as my ways of *knowing* and *being* in this world. Although this was a sad time I recognize what opportunities this experience offered my grandmother and I. Caring for others through meaningful relationship is the essence of life and dying. Without caring what does life hold for us? Death is an inevitable part of life and we are not able to control its time or circumstances (Hoffman, 2006). However, I believe no one should die as my grandfather did and that morally we, as health care providers, are obligated to ease that experience for families in any way possible.

Utilizing a phenomenological approach to exploring stories like my Grandparents, could possibly further the much needed discourse regarding end-of-life care within the context of dementia. To conclude, it may be important to reflect and to be open to gleaning insight about those who have entered and left our lives.

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Appendix F

Resources Sheet for Family Caregivers

Family Caregiver Resources in Saskatoon

- **Dr. Phil Carverhill**

Psychologist, accepting new clients for grief counselling
617C Main St.
Saskatoon SK
Tel: (306) 665 6242

- **Alzheimer's Society of Saskatchewan**

Educational and support information
Saskatoon Office
1405 Faulkner Cres. (Oliver Lodge)
Saskatoon SK
Tel: (306) 683 6322 (call for office hours)
E-mail: saskatoon@alzheimer.sk.ca

- **A New Adventure … A Grieving Journey**

Adult grief and loss support group
Acadia Drive Funeral Home
915 Acadia Dr.
Saskatoon SK
Tel: (306) 955 1600

- **Caregiver Network Inc.**

Internet resources for family caregivers
http://www.caregiver.ca

- **Saskatoon Community contact for the widowed**

Non-denominational, self-help group
ST. John's Anglican Parish Hall
816 Spadina Cres. E
Saskatoon SK
Tel: (306) 956 1417

- **Saskatoon Crisis Intervention Service (24 hours)**

Tel: (306) 933 6200

- **Saskatoon Health Region Adult Mental Health Services**

Tel: (306) 655 7950

- **Saskatoon Informal Caregiver Centre**

Educational and support information
301 - 506 25th St. E (Saskatoon Council on Aging)
Saskatoon SK
Tel: (306) 652 4411

- **W.A. Edwards Family Centre – Grief & Loss Resources**

Lending Library provides books and articles as well as audio and video tapes

333 - 4th Ave. N
Saskatoon SK
Tel: (306) 244 5577

Appendix G

Support Letter, Dr. Phil Carverhill

Prairie
Therapists
&Trainers

Shelley Peacock, RN, B.Sc.
474 Anglin Court

Saskatoon, SK

S7J 5G1

June 14, 2009

Dear Ms. Peacock,

This letter is to confirm my support for your doctoral project entitled: The Lived Experience of Family Caregivers who provided End-of-life Care to a Relative with Advanced Dementia.

I understand that this letter will form part of your submission to the Ethics Committee at the University of Alberta, where you are completing your doctoral studies in nursing. As per our discussions I am prepared to serve in the role of an independent community-based psychologist should any of your research participants experience distress related to their participation in the study. If such a need arises I would normally be able to make arrangements for a face-to-face counselling session to take place within 24-48 hours of initial contact. I also understand that you will provide your participants with information about other mental health resources in the Saskatoon area (e.g., Adult Mental Health, Crisis Line). I am well familiar with issues that may arise out of qualitative research interviews as well as grief and bereavement issues in particular.

I can be reached at the number listed below and messages may also be left either with Fran or on my office voicemail. I wish you every success in this important area of research.

Sincerely,

Philip A. Carverhill, Ph.D.

Registered Doctoral Psychologist

Clinical Instructor

College of Medicine

University of Saskatchewan

Adjunct Professor

Department of Psychology

College of Graduate Studies and Research

University of Saskatchewan

Adjunct Faculty

St. Stephen's College

University of Alberta