Descriptions of sleep quality by current and bereaved caregivers of individuals with advanced cancer

by

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Abstract

End of life care for individuals with advanced cancer has moved from the clinical setting to the home setting. Family members thus have taken on the role of caregivers and must cope with the responsibilities and challenges of providing care. In order to support caregivers in this role, healthcare professionals need to understand the experience of caregivers. An important part of this role is a decline in sleep quality. The research question for this study was: how do current and bereaved primary caregivers of individuals with advanced cancer describe their experience of sleep quality in the context of caregiving? Using an interpretive description approach, interviews with ten current and bereaved caregivers were analyzed. Four themes related to sleep quality were identified: a) integrating caregiving with pre-caregiving activities, b) changes in sleep quality due to caregiving activities (being available; worried and afraid), c) really tired, and d) powering through. A novel finding of this study, "powering through," explains how caregivers are able to persevere in their caregiving role despite the challenges of caregiving and marked declines in sleep quality.

Preface

This thesis is an original work by Danielle Gagnon. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, “Exploration of the relationships among caregiver situation, sleep, adaptive capacity, and fatigue in family members providing care to those with advanced cancer”, NO. Pro00037302, 2017-06-02.

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Chapter 1: Statement of the Problem

There has been a move toward home–based palliative care in Canada. This movement is associated with the restructuring of health care in Canada (Dumont et al., 2006; Guerriere, et al., 2010) and with the desire of individuals with advanced disease to be cared for and to die at home (Kristjanson et al., 2004; Stajduhar, 2003). Most of the care in home-based palliative care is provided by family and friends (hereafter referred to as caregivers) (Romanow, 2002). Hence it is essential to understand whether, in fact, caregivers are able to provide the care required, and to understand the impact of caregiving on them (Keating, Otfinowski, Wenger, Fast, & Derksen, 2003).

The task of providing care for individuals with advanced disease at home is challenging. Caregiving is both intensive and extensive, as it involves the responsibility for meeting the majority of physical and emotional needs of the person who is dying (Stajduhar, Allan, Cohen, & Heyland, 2008). The responsibilities are complex and varied, and frequently include medical management, extra housework, monitoring and emotional support, and making funeral arrangements. Duties can be very time consuming (Cho, Dodd, Lee, Padilla, & Slaughter, 2006), and may eventually require care around the clock, seven days a week and over many months (Stajduhar, Martin, Barwich, & Fyles, 2008). It is no wonder that caregivers experience a feeling of constantly being “on call (Carter & Chang, 2000). Caregivers have been found to be at high risk for negative outcomes due to their extensive roles and responsibilities (Family Caregiver Alliance, n.d.; Nissen, Trevino, Lange, & Prigerson, 2016; Williams & Bakitas, 2012).

In this study, I chose to focus on caregivers of individuals with advanced cancer. In Canada, over two hundred thousand people are diagnosed with cancer yearly (Canadian Cancer Society, 2016). Further, per year there are close to 80000 deaths: mortality rates of cancer are approximately 1 in 4 Canadians (Canadian Cancer Society, 2016). The Canadian Cancer Society (2010) highlights that a majority of persons with end-stage cancer would prefer to die at home. Despite this more than 45% deaths occur in hospital. Lack of support for informal caregivers, given the challenges of providing care could help to explain the discrepancy between preference and actuality.

The challenges faced by caregivers of individuals with advanced cancer are compounded by the trajectory of cancer. Persons with advanced cancer typically function relatively well prior to the final phase of their illness, during which sudden and rapid changes are likely to occur (Lynn, 2001). During this final phase, caregivers must often learn new skills and adapt to rapidly changing conditions. These new challenges come at a time when caregivers have often been providing care for long periods of time. During caregiving sleep is typically interrupted, truncated, and fitful, contributing to poor sleep quality. Caregivers typically average four or fewer than four hours of sleep per night (Bramwell, Mackenzie, Laschinger, & Cameron, 1995; Holing, 1986; Kristjanson et al., 2004; Stajduhar, Martin, Barwich, & Fyles, 2008), which is far below the recommendation of seven to nine hours of sleep recommended per night for adults for healthy functioning (National Sleep Foundation, 2015). This decline in amount of sleep is particularly problematic when the caregiving is prolonged because it may limit the caregiver’s ability to undertake the complex tasks required (Carter, Mikan, & Simpson, 2009; Tononi & Cirelli, 2006).

There is some evidence that declines in sleep quality in caregivers could also contribute to negative health outcomes for caregivers across physical and mental health domains, which could then impair day-to-day functioning, productivity, the ability to provide care, and bereavement (Belenky et al., 2003; Zammit, Weiner, Damato, Sillup, & McMillian, 1999). Specific negative outcomes associated with declines in sleep quality include tiredness, loss of concentration, low pain threshold, nervousness, irrational thoughts, loss of appetite, and constipation (Hayashino et al., 2010), as well as exhaustion, fatigue, and anxiety (Hudson, Thomas, Trauer, Remedios, & Clarke, 2011), sleeplessness, weight loss, burnout, social isolation, general deterioration in health, considerable burden, and distress (Aoun, Kristjanson, Currow, & Hudson, 2005; Dumont et al, 2006; McCorkle, & Pasacreta, 2001), financial hardship (Emanuel, Fairclough, Slutsman, & Emanuel, 2000), and increased mortality (Schulz and Beach, 1999).

The literature, in sum, provides evidence that caregivers of palliative patients experience a number of negative outcomes, and that poor sleep quality may play a key role in their development. There is limited research on sleep quality in caregivers in general and cancer caregivers specifically, and hence limited guidance for health care providers about how best to support these individuals.

Based on my clinical experience, I decided to focus this study on sleep quality in caregivers of individuals with advanced cancer because I thought reduced sleep quality could be at the root of many of the negative health outcomes of caregiving noted above and in my practice. This observation has been supported by some studies. For example, Aslan, Sanisoglu, Akyol, and Yetkin (2009), Carney et al. (2011), Carter (2002); Chang, Tsai, Chang, & Tsao (2007), Gibbins, McCoubrie, Kendrick, Senior-Smith, Davies, and

Hanks (2009), and Hearson and McClement (2007) all found that caregivers reported changes to sleep quality, which had negative associations with quality of life, physical health, depression, and grief. The aim of this study is to extend the exploration of sleep quality in caregivers of individuals with advanced cancer by examining this issue from the standpoint of the caregivers themselves. The provision of supportive services based on the needs of the caregivers could reduce the risk of physical and mental health problems among caregivers.

Purpose and Research Question

The purpose of this study was to describe the experience of primary caregivers of individuals with advanced cancer regarding links between sleep quality and caregiving. My research question was: How do current and bereaved primary caregivers of individuals with advanced cancer describe their experience of sleep quality in the context of caregiving?

Conceptual Definitions

Sleep quality. Sleep quality is a frequently used term in the literature but is poorly defined. For the purposes of this study, I used the definition developed by Buysse, Reynolds, Monk, Berman, and Kupfer (1989). Buysse et al. define sleep quality as a function of the following domains: "subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, and daytime dysfunction" (p.193). Relatively little is known about the nature of sleep quality in caregivers, and so I wanted a definition that included a broad range of dimensions of sleep quality.

Primary caregiver. A primary caregiver may be a blood relative, family member, or a friend. Primary caregivers are generally at least 15 years old or more and provide help or care to a person with a long-term health condition or a physical or mental disability, or with problems related to aging (Turcotte, 2013)

Advanced cancer. The National Cancer Institute (n.d.) defines "Advanced cancer" as a cancer that cannot be cured or controlled (www.cancer.gov/dictionary).

Palliative care. WHO (2008) defines Palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual".

Chapter 2: Review of the Literature

The exploration of sleep quality in primary caregivers of individuals who have advanced cancer and who are at the end of life has been limited in health-related literature. This literature review is focused on studies published between 1998 and 2016. Some studies prior to 1998 were included if they are considered seminal studies in the field of caregiving and sleep quality. I searched CINAHL, OVID, Medline, and Scopus. Search terms included “caregiver or caregivers or carer or carers”, “end-of-life or palliative or terminal”, and “sleep, or sleep quality, or sleep deprivation”.

In this chapter, I first discuss the empirical literature regarding the nature of sleep, and the implications of poor sleep quality. Subsequently, I discuss the literature regarding caregiver characteristics (perceived stress, age, sex, and chronic illnesses) and their relationships to sleep quality in caregivers of ill family members. Finally, I summarize gaps in the literature on sleep quality in the context of caregiving that my study was designed to address.

The Nature of Sleep

Description of Sleep Processes

Carskadon and Dement (2005, 2011) provide specific details about the key characteristics of sleep. Sleep is comprised of two distinct types of sleep: non-rapid eye-movement (NREM) and rapid eye movement (REM). NREM and REM sleep alternate cyclically. Sleep scientists have used electroencephalography (EEG) to study the electrical activity of NREM and have characterized it as slow wave, high voltage brain waves associated with low physiological activity and muscle tone, while REM is fast frequency, low voltage brain waves, REM is typically associated with dreaming.

In adults, sleep initiates in NREM sleep followed by a REM phase. The entire cycle takes place over a period approximately 120 minutes. The cycle of NREM and REM sleep repeat themselves four to six times throughout the duration of sleep with the earlier cycles exhibiting a greater concentration of NREM sleep and with the longer REM cycles occurring closer to awakening. Higher arousal thresholds occur with each subsequent stage as slow wave sleep decreases and REM sleep increases.

The sleep cycle is managed by three physiological processes—homeostasis, circadian rhythm, and ultradian processes (Zisapel, 2007). Within the context of sleep theory, homeostasis, sometimes referred to as the S-process of sleep, refers to the individual's drive to acquire sleep, which increases with sleep deprivation and decreases with sleep (Zisapel, 2007). Circadian rhythm, referred to, as the C-process, which will be further described in detail below, is the body's internal regulatory process that determines onset and termination of sleep. The ultradian process occurs during sleep and regulates the alteration between NREM and REM phases during sleep (Kunz & Herrmann, 2000). Zisapel explains that the S and C processes are responsible for sleep consolidation, a process of obtaining sleep in a single nightly session, and both can be altered by arousal levels and stress. Sleep consolidation is important for maximizing the restorative function of sleep and enhancing memory and learning outcomes (Carter, 2005). Constant disruptions that occur as a result to changes in the physiological process responsible for regulating sleep, namely those involved with circadian rhythm deterioration, decreases an individual's ability to obtain positive sleep related outcomes. While both the S-process and the C-process are important and relevant for managing sleep, circadian rhythm disruptions have a more significant impact on sleep consolidation (Monteleone & Maj, 2008), and would therefore have a greater impact on family caregivers who are already vulnerable to disruptions to sleep, and thus circadian rhythm disruptions will be the focus of the discussion to follow.

Circadian rhythm. Andrew and Benbadis (2005) define circadian rhythm as the "…manifestation of an endogenous oscillatory signal with near 24-hour periodicity that occurs in synchrony with the 24-hour periodicities in the physical environment" (p. 85). This signal governs the body through a series of inputs and outputs that peak and trough depending on a positive or negative feedback system. Circadian rhythm, also referred to as the "internal biological clock", is responsible for physiological and behavioral processes, such as sleep, that have an intrinsic 24-hour rhythm.

Circadian rhythm is regulated by a group of neurons located in the hypothalamus called the suprachiasmatic nucleus (SCN) and pacemaker cells that exist throughout the body (Beersma & Gordijn, 2007). Beersma and Gordijn explain that the SCN coordinates the function of pacemaker cell but pacemaker cells when separated from the SCN also have their own intrinsic 24-hour rhythm.

Synchronization of the SCN to the external environment happens by a process defined as entrainment, and keeps functions within the body on a 24-hour schedule. Light is thought to have the greatest influence over this process, especially as it relates to the sleep/wake cycle. Entrainment also may be influenced by other factors such as environmental temperature, stress, presence of others, health state, and hormones, in particular melatonin (Beersma & Gordijn, 2007).

Disruption of circadian rhythm, either through pathophysiological processes or environmental influences, may decrease the consolidation of sleep. Ziaspel (2007) explains that increased arousal, through stress or anxiety, can impede the functioning of circadian rhythm potentially leading to sleep disturbance and frequent night-time disruptions. Frequent nighttime sleep disruptions have major health implications, including immunological and endocrine dysfunction (Okun, 2011), and metabolic disorders and chronic inflammation (Bixler, 2009). More recently Rahman, Burton, Galbraith, Lloyd, and Vollmer-Conna (2011) found that when circadian rhythms are disrupted, individuals experience fatigue, poor concentration, and sleep abnormalities.

Monteleone and Maj (2008) report that circadian rhythm plays a large part in managing dramatic fluctuations that occur in the external environment, which could include caregiving. Alterations to circadian rhythm have been linked to an increased incidence of mood disorders (Monteleone & Maj, 2008). The link between circadian rhythm disturbance and the development of mood disorders is important as it may help to explain the connection between poor sleep quality and the onset of depression (Carter, 2002).

The role of caregiving may contribute to fluctuations of circadian rhythm, leading to disruptions of sleep consolidation. Carney et al. (2011) noted that family caregivers of oncology patients were awakened about 18 times each night, each episode of awakening lasting 3-4 minutes each night. These authors compared caregivers and their care recipients sleep through the use of subjective and objective measures of sleep and found that this dyad exhibited nighttime disruptions at twice the rate of the general population. In addition to the role of caregiving (i.e. being awakened during the night to provide care), the caregiver may also be awakened by worry, and may have difficulty sleeping due to napping throughout the day. This level of sleep disruption has the potential to influence circadian rhythm and could lead to serious health implications.

Functions of sleep: Learning and restoration of system function. A significant portion of every day is spent in sleep. Sleep fulfills a necessary role for functioning and well-being. Chen and Kushida (2005) and Nelson (2007) argue persuasively that one of the primary functions of sleep is to restore system function through CNS restoration. CNS restoration allows for memory consolidation, which is necessary for learning to take place (Krueger, Obal & Fang, 1999; Krueger, Obal, Kapas, & Fang, 1995; Siegel, 2005).

While precise mechanisms are not entirely understood, memory consolidation has been linked with learning through neuronal plasticity (Payne, 2011; Walker, 2010). Krueger, Obal, Kapas, and Fang, (1995) and Krueger, Obal and Fang (1999) describe how brain development (neuronal plasticity) occurs through the establishment of neuronal connections. Neuronal functioning is designed to regulate the inputs and outputs of the brain and enhance learning. Neuronal connections are best established in REM sleep.

NREM sleep has also been found to enhance learning (Tononi & Cirelli, 2006). Synaptic connectivity in the thalamocortical areas of the brain increases during waking and decreases during sleep. Changes in brain functioning during periods of sleep support the idea that sleep is connected to learning.

Studies on sleep loss provide insight into the valuable role sleep has on cognition. In instances of reduced sleep, cognitive processes including attention, memory, and problem solving have been noted to decline (Hearson & McClement, 2007). Chee and Chuah (2008) found that sleep deprivation had a negative influence on learning, including: memory (long, short, and working), emotional responses, decision-making, and monitoring of appropriate behavioural responses. These findings suggest that caregivers who experience sleep loss may have difficulty processing new information, learning new skills, and retain information required to provide care to their ill family member.

Acquiring the necessary information to respond to the challenges associated with caregiving requires learning. Impaired learning ability influences the ability of the caregiver to acquire the necessary skills needed to provide care. Contemporary caregiving is a multi-faceted role and requires the highly advanced care ranging from performing technical skills (i.e. wound care, pain management) to providing psychosocial support in the home (Potter, Deshields, Kuhrik, Kuhrik, O'Neill, & Rihanek, 2010). Additionally, caregivers need to respond to rapid changes in patient symptoms, particularly as the care recipient nears end-of-life. If the caregiver does not obtain adequate sleep quality, the ability of the caregiver to learn new skills and adapt to changing conditions of caregiving, and the care of the care recipient, may be compromised.

Short-term sleep loss and poor sleep quality has effects on multiple domains of health, which are further exacerbated in occurrences of chronic sleep deprivation. Sleep loss for caregivers can occur over a lengthy period, and as such it is important to note the effects of chronic sleep loss, such as increased mortality (Ancoli-Israel, 2009; Dew et al., 2003; Espiritu, 2008; Garcia, 2008) and morbidity. Processes related to loss of sleep that are also related to illness development include impairments in glucose metabolism, immune function, well-being, and bereavement processes and increases in hypertension, falls, anxiety, and depression (Atienza, Henderson, Wilcox, & King, 2001; Belenky et al., 2003; Kryger, Roth, & Dement, 2005; Rausch, Baker, and Boonmee, 2007; Zammit, Weiner, Damato, Sillup, & McMillian, 1999).

Many of the adverse health outcomes associated with reduced sleep, such as anxiety, depression, and declines in physical and mental health, are also associated with family caregiving (Dumont et al., 2006; Gladstone, Dupuis, & Wexler, 2006). Poor sleep among caregivers may be a key factor in the development of these negative outcomes.

Sleep Quality

Defining Sleep Quality

Poor sleep is a function of both declines in quantity and quality. Negative health outcomes may be associated with declines in both sleep quality or sleep quantity. The terms “sleep quality,” “sleep disturbance,” and “sleep deprivation” are used interchangeably in the literature. Definitions of sleep disturbance are most prevalent. Hearson and McClement (2007) define sleep disturbance as any change in a person’s normal sleep pattern that alters both quantity and quality of sleep. Rausch, Baker, and Boonmee (2007) combine the concepts of quality and quantity in their definition of sleep disturbance and define sleep disturbance as a disruption in at least in one of four areas: ability to fall asleep, quality of sleep, early-morning waking, and inadequate rest leading to daytime sleepiness.

Buysse, Reynolds, Monk, Berman, and Kupfer (1989) offer their own definition of sleep quality. These authors developed scales that measure key aspects of sleep, which together comprise the Pittsburgh Sleep Quality Index (PSQI). The PSQI has been used throughout the caregiving literature to measure sleep quality. For this reason, I used the definition developed by Buysse et al. in this study.

Caregivers and Sleep Quality

According to the National Caregiver Profile Survey (Decima Research, 2002) the typical caregiver in Canada is aged 65 years or older, is female, and has one or more chronic illnesses. Caregivers are at risk for poor sleep quality given their age and sex, and any chronic illnesses they may have. In this section, I will outline the research linking sleep quality, age, sex, chronic illness, and chronic illness and then discuss the additional challenges to sleep quality posed by caregiving.

Age, sex, gender, and sleep quality. Sex and gender roles are associated with differences in sleep quality. First, it is important to stipulate what I mean by sex and gender. Sex refers to the biological differences between men and women whereas gender refers to the psychosocial roles that typically define men and women in North American culture.

The relationship between sex and sleep quality, referred to as sexual dimorphism, has been clearly established. Research using objective measures of sleep quality, including polysomnographic and actigraphy measures, indicate that overall women exhibit more effective sleep patterns than do men (Lee, 2011). Women have been found, in stable circumstances, to be better able to maintain adequate levels of both slow wave sleep and REM sleep than are men (Avidan, 2005).

Furthermore, subjective measures of sleep quality indicate that men report more naps during the day, and also report more experiences of lighter and more disturbed sleep than do women (Lee, 2011). In comparison women report longer sleep duration and shorter sleep-onset latency. These findings suggest that, in normal circumstances, women typically exhibit better sleep quality than men.

It is also true, however, that gender roles influence the various tasks assumed by women and men, and contribute to sleep disturbances mainly through the experience of stress (Brody, 2004; Strang, 2001;Yee & Schulz, 2000), and this may be why female caregivers report a greater decline in sleep quality than do male caregivers. Based on the perception that caregiving is an extension of housework, which has traditionally been assumed as women's work, women take on the majority of caregiving responsibilities (Strang, 2001). Females typically take on more hands-on tasks and personal care relative to their male counterparts (Brody, 2004; Strang, 2001; Yee & Schulz, 2000). Strang adds that women are socialized to care for others and to place others' needs above their own. Consequently, women may be less likely to seek out assistance and others may be less likely to offer to help. Yee and Schulz (2000) and Brody (2004) support the argument that gender influences the types of responsibilities assumed. These authors found that men are more involved in intermittent tasks, such as care management and transportation, are more proactive in finding resources, and are more likely to ask for assistance than women. Brody noted that the differences in types of tasks have an impact on sleep because men create a network of care that often provides more support.

In sum, the different roles and tasks that women perform means that females caregivers typically providing more direct and intimate care and are less able to access support than their male counterparts. Perception of stress may also be different for a woman than a man, and this could contribute to increased experiences of stress and declines in sleep quality (Yee & Schulz, 2000).

Although it is not completely clear in the literature, the decline in sleep quality in women, as a result of increased stress, may be linked to the development of insomnia.

Edinger and Means (2005) and Sutton, Moldfosky, and Badley (2001) support the argument that women are at an increased risk of developing insomnia in response to stress. Development of insomnia related to the presence of stress is in part due to changes in sleep architecture (Lee, 2011).

Another explanation for the vulnerability of women to insomnia in the presence of stress is the connection between stress and depression. Lee (2011) explains that sleep changes noted in woman who are experiencing stress may contribute to increased risk of developing Major Depressive Disorder (MDD). There is strong evidence that women and in fact people in general, who report MDD experience sleep-related disturbances. Buysse (2008) explains that the development of depressive symptoms is one of the strongest risk factors identified with insomnia.

The role of stress in the development of insomnia and in the development of depression has implications for the female caregiver. Developing insomnia or depression threatens the caregivers' ability to provide care until death and threatens the well-being of the caregiver.

Age and sleep quality. Age has typically been thought to have negative consequences on sleep quality. I previously discussed the importance of circadian rhythm in the sleep process especially its role in sleep consolidation. Age has been linked with declines in circadian rhythm in older adults, and thus may contribute to declines in sleep quality in caregivers. Changes in circadian rhythm function may be a factor in altering sleep patterns and contribute to the assumption that sleep inevitably declines as we age (Van Someren, 2000). Two possible changes to the typical rhythm that may contribute to sleep declines are: 1) an advance in the cycle leading to early daytime sleepiness and, 2) a decreased amplitude of the circadian rhythms making it harder for an individual to regulate their cycle to a 'normal' sleep pattern (Van Someren, 2000).

Dampened circadian rhythm amplitude, in the older adult changes the normally diurnal pattern evident in younger adults, to one that runs more "freely" and is less constrained by the typical 24-hour period (Bliwise, 2005). Sleep cycles that are less habituated could potentially lead to increased sleepiness in the daytime, leading to daytime naps. Daytime naps further alter normal 24-hour cyclical patterns that are generally common to a healthy sleep cycle (Mistlberger, & Rusak, 2005).

Caregivers are vulnerable to changes in circadian rhythm functioning both as a result of age related changes and as a result of stress associated with caregiving that can also impact sleep consolidation. Furthermore, caregiving that requires frequent night-time awakenings can alter entrainment of the circadian rhythm both through sleep fragmentation and the need to re-coop lost sleep through daytime naps.

Chronic illness and sleep quality. Chronic illnesses that developed in the older adult have been noted to contribute to declines in sleep quality. The illness process may contribute to declines in sleep quality beyond those associated with aging (Ancoli-Israel, 2009; Espiritu, 2008). Wolkove, Elkholy, Baltzan, and Palayew (2007) explain that physical and mental illnesses can contribute to difficulty falling or staying asleep. Ancoli-Israel and Espiritu further assert that in the absence of illness, healthy older individuals may experience only minimal changes to sleep and report overall good sleep quality.

Garcia (2008) describes the reciprocal relationship between sleep and illness: "Any physical illness that causes the patient discomfort can affect sleep, and the severity of the disease will naturally have a greater impact. Conversely, poor sleep quality secondary to sleep disorders has been shown to have effects on various chronic disorders (p.28)". Therefore, it should not be assumed that sleep problems in the older adults are attributable to the aging process alone, and that older adults will, as a rule, experience poor sleep quality. However, if these older adults have chronic illnesses, they are at risk for disruptions in the normal sleep cycle due to complications of disease process, insomnia and depression (Gooneratne & Vitiello, 2014).

The issue of illness is relevant in this study because almost 75% of older persons have at least one chronic condition and many have multiple conditions (AHRQ, 2002), many of which emerge for the person around 65 years of age. Caregivers have been noted to have one or more chronic illnesses while providing care, which has implications for the caregivers' ability to obtain good sleep quality even when relieved of caregiving duties.

Caregiving and Sleep Quality

There is a small but growing body of literature about the relationship between caregiving and sleep quality. This relationship is thought to be due to the additional challenges related to caregiving (Stenberg, Ruland & Miaskowski, 2010). The nature of these challenges and their implications have been described over the last two decades by various researchers. Stenberg, Ruland, and Miaskowski (2010) conducted a systematic review of the literature identifying the impacts of caring for a patient with cancer. Using 192 titles, 164 of which were research-based, the authors examined burdens and types of problems experienced by caregivers and the language the caregivers used to communicate those problems. Stenberg et al. categorized the implications of providing care into broad categories: physical health, social problems, the need for information, emotional problems and reactions, and the burden of caregiving responsibilities. They found that compromised sleep quality was a significant consequence across multiple domains of health and wellness among those providing end of life care to an individual with advanced cancer.

In an Australian study, Morris, Thorndike, Ritterband, Glozier, Dunn, and Chambers (2015) measured sleep quality changes in caregivers of individuals with cancer. Using the insomnia severity scale they found that out of 234 caregivers 60% reported insomnia, which they defined as sleep onset latency, frequent waking, waking too early, and/or deficits in daytime functioning due to lack of sleep. Thirty percent of their sample indicated moderate to severe insomnia.

Both direct and indirect caregiving may compromise sleep quality. Indirect caregiving, such as worrying about the health of one’s family member and the ability to care for that individual, may contribute to emotional distress and lead to increased sleep latency, a component of sleep quality. Direct caregiving duties such as having to wake in the night to provide care to the care recipient could exacerbate any pre-existing sleep challenges or initiate sleep pattern alterations. The work related to direct and indirect caregiving likely increases over time as the care recipient approaches death. When caregiving must be sustained over time, the risk of adverse health outcomes for caregivers associated with compromised sleep quality may increase.

A European study by Gibbins, McCoubrie, Kendrick, Senior-Smith, Davies, and Hanks (2009) highlights some of the indirect and direct aspects of caregiving on sleep quality. Using a prospective observational descriptive design, they comparing sleeping patterns of 60 caregivers of individuals with advanced cancer, and found that despite measuring fairly standard durations of nocturnal sleep, there were high levels of sleep fragmentation and movement among caregivers. Two areas of particular concern for both the care recipient and caregiver were difficulty falling asleep and frequent awakenings during the night. For caregivers, the causes of frequent night awakenings were going to the toilet, being disturbed by the care recipient, and worry. Both patients and caregivers who reported poor sleep quality reported experiences of significantly higher anxiety and increased pain. This study demonstrates the disruptions to sleep quality that caregivers experience and links them to the negative outcomes (increased pain and anxiety) that could adversely impact functioning of the caregiver.

Declines in sleep quality are echoed in studies investigating the outcomes and experiences of caregivers. Authors of both quantitative and qualitative research studies have found that the sleep quality of caregivers is compromised by their responsibilities to their family member. Researchers Aslan, Sanisoglu, Akyol, and Yetkin (2009) provide a quantitative investigation of sleep quality in Turkish family caregivers of cancer patients. They had more participants (n=90), than did Bramwell et al. (1995) (n=37) in the study discussed previously, and they used the PSQI rather than a retrospective self-report approach. They found that the participants' average score was 8.19 on the PSQI. A score greater than five indicates a moderate decline in sleep quality (Swore Fletcher, Dodd, Schumacher, & Miaskowski, 2008). An interesting finding of this study was that when the caregivers were asked the reasons for their decline in sleep quality, emotional distress was cited as the main cause. There are some limitations in this research, including the use of a subjective measure of sleep quality, lack of control of extraneous variables such as depression that could potentially have impacted assessment of sleep, and homogeneity of participants. It is, however, important to listen to the perceptions of the caregivers, the impact on caregiving that they ascribe to sleep quality, and the emotional distress that contributes to the declines in sleep quality.

Arber and Venn's (2011) qualitative study findings echo the quantitative findings of Aslan, Sanisoglu, Akyol, and Yetkin (2009). Themes of sleep quality decline emerged in Arber and Venn's study of caregivers of 62 individuals across a variety of illnesses. Caregivers reported their sleep was disturbed due to a number of factors such as direct care at night, anticipation of providing care at night, monitoring and surveillance, wandering and disruptive night-time behavior by the care recipient, and emotional labor. Additionally, participants indicated that the impact of caregiving on sleep quality carried on after the conclusion of caregiving.

Another qualitative study explored the needs and challenges of informal caregiving at home. Harding, Epiphaniou, Hamilton, Bridger, Robinson, Beynon, and Higginson (2012) carried out a qualitative study of 20 informal caregivers of at home palliative individuals. This study echoed the findings of others in that sleep quality declines were identified as an experience of providing care.

Lee, Yiin, Lin, and Lu (2015) explored the factors that may explain sleep quality declines in caregivers. In a descriptive, cross-sectional study of 172 caregivers, objective and subjective measures of sleep were collected. Their aim was to identify predetermining, precipitating, and perpetuating factors related to sleep quality declines in Taiwanese caregivers of those with advanced cancer. They found that …"female caregivers, caregivers with greater fatigue, higher levels of depression, more caregiver burdens, or more than 16 hours per day spent in caregiving tasks had poorer sleep quality" (p.1636).

Perceptions of stress related to caregiving. Each caregiver is faced with unique challenges and individual perceptions of those challenges. There are numerous potential factors such as relationship with the care recipient, stage of illness, caregiver personality, financial situation, and level of social support, that have the potential to impact the perception of stress while providing care (Bevens & Sternberg, 2012).

Perceived stress is a concept that acknowledges individual perception in appraising events as stressful or not stressful (Cohen, Kamarack, & Mermelstein, 1983). Perceived stress is related to a process of appraisal and an important aspect of stress response theory (Hill, 1958; Lazarus & Folkman, 1984). It is relevant to the unique and challenging experiences that caregivers face because some authors describe caregiving as a source of stress for caregivers, which results in negative physiological, affective, behavioural, and cognitive outcomes (Brazil, Thaband, Foster, and Bedard, 2009; Carter & Acton, 2006; Yee & Schulz, 2000). Yee and Schulz (2000) found that female caregivers reported greater burden in relation to caregiving than did than male caregivers, perhaps related to gender roles. Burden is a related concept to perceived stress and reports of burden are strongly related to increased stress (Bevens & Sternberg, 2012).

Stenberg, Cvancarova, Ekstedt, Olsson, and Ruland (2014), and Lee, Yiin, Lu, Chao (2015) explored links between burden and sleep quality. Stenberg et al. studied the early caregiving trajectory of caregivers and found high levels of depressive symptoms and reduced sleep quality, but low to moderate levels of burden. Factors associated with increase perception of burden were being female, time and being unemployed. Perceptions of burden increased significantly at 6 months after the initiation of the care recipients' first radiation treatment. Lee, Yiin, Lu, Chao (2015) also investigated the relationship between burden and sleep quality and found that in a sample of 176 caregivers burden explained 56% of the variance in sleep quality ($p<.01$).

There is some literature in other populations linking perceived stress with sleep quality. In a cross sectional analysis study of 350 individuals with cardiovascular disease, Kashani, Eliasson, and Vernalis (2012) reported that increased perceived stress was correlated with declines in sleep quality. In their high-stress population, sleep was approximately twenty minutes less per night. Although it may not seem significant, obtaining twenty minutes less sleep per night may contribute to sleep debt (Van Dongen, Rogers, & Dinges, 2003), which is the cumulative amount of sleep lost over time with respect to the daily needs of an individual, and which can contribute to chronic sleep deprivation and increased negative outcomes.

Impact of Reduced Sleep Quality on Caregivers' Health

Some researchers have investigated outcomes associated with caregiving in persons providing care to family members with advanced cancer. Pawl, Lee, Clark, and Sherwood (2013) investigated declines in sleep quantity (reduced minutes of sleep) and health-related outcomes in caregivers of individuals with primary malignant brain tumors. Early in the caregiving trajectory, they found that while declines in sleep quality, changes in cognitive/behavioral and social domains of health, and depressive symptoms were evident, physiological changes associated with declines health were not yet present.

Sleep quality and depression. The majority of research investigating the consequences of sleep quality disturbance in caregivers focuses on the relationship between sleep quality and measures of depression. Carter and Chang (2000) and Carter (2002, 2003, 2005, 2006) conducted a number of studies linking poor sleep quality and depression. They found that moderate to severe sleep problems were also associated with an increase in anxiety and depression, lowered quality of life, diminished emotional well-being, and less patience in challenging situations.

Sleep quality and fatigue. Authors of a cross sectional study (n=125) found that chronic stress and poor sleep quality, which are important aspects of caregiving, played a role in the development of fatigue (Teel & Press, 1999); Both chronic stress and poor sleep quality were closely tied to the direct and indirect effects of caregiving and the need for care recipient institutionalization.

Fatigue can be immobilizing. Dittner, Wessely, and Brown (2004) assert that… "fatigue can be a major source of disablement and is often reported by patients as being amongst their most severe and distressing symptoms" (p. 157). If fatigue impedes functioning in the caregiver, as in the person with cancer, then fatigue could limit the ability of the caregiver to provide quality care and impede their ability to function and navigate the challenges of caregiving without ill effect. Preliminary investigations of caregivers have suggested that caregivers do report fatigue as a result of caregiving. Teel and Press (1999) did a comparative study regarding fatigue, energy level, and difficulty sleeping in which they compared spouses of those who provided care for persons with cancer, Alzheimer's disease, or Parkinson's disease, and non-caregivers. The authors found that caregivers in comparison to non-caregivers, reported increased amounts of fatigue, decreased energy levels, and increased difficulty sleeping. Differences between groups of caregivers on measures of fatigue, energy level, and ability to sleep were minimal despite variations in the mental and physical status of the care recipient and the duration of caregiving.

Carlsson (2009) found that caregivers of individuals with end stage renal failure, reported significant general, mental, and physical fatigue, even though their sleep was fairly stable. The study suggested that when fatigue of the care recipient increases, the fatigue of the caregivers seems to increase. Passik and Kirsh (2005) used 25 couples to compare caregivers fatigue with that of spouse. In their investigation the impact of care recipient fatigue on caregivers and determined care recipient fatigue was associated with that adverse outcomes for the caregiver including a perceived increase in burden, increased fatigue, poor energy, less engagement in work and social activities, and worse dyadic adjustment.

Sleep quality and bereavement. Literature in the domain of bereavement and caregiving note that sleep declines contribute to the development of complicated grief (Carter, 2005). Complicated grief is defined as symptoms of grief that are (a) to be distinct from bereavement-related depression and anxiety, and (b) to predict long-term functional impairments (Prigerson et al., 1995). In Carter's descriptive qualitative study of 9 adult bereaved caregivers, she found that the process of navigating the tasks of bereavement was impaired in individuals with poor sleep quality, which lead to further changes in sleep and depressive symptoms. Participants in Carter's study were asked to describe their experience during the caregiving period retrospectively therefore, identifying exact measurable impacts of caregiving on sleep was not possible. However, the open-ended questions asked of the participants provided some evidence of the impact of caregiving on the development of nightmares, on sleep latency, on sudden waking after sleep onset, and of the impact of the loss of the family member on sleep quality. Furthermore, participants' Pittsburg Sleep Quality Index scores revealed moderate sleep disturbances particularly in the areas of latency, duration, and efficiency. Taken together, these findings suggest that there may be a link between alterations in sleep quality and poor health outcomes

Results similar to those described above were also reported by Carter, Mikan and Simpson (2009), who described a longitudinal descriptive intervention study, of 11 caregivers, aimed at improving sleep through two home-based cognitive interventions. Sleep quality was measured using PSQI and actigraphy. The authors found that participants were experiencing significant sleep quality declines prior to the intervention. Insomnia in bereaved caregivers, perhaps developed during the caregiving period, persisted for longer than a year, much longer than reported for bereaved non-caregivers, placing bereaved caregivers at a greater risk for depression and complicated grief. The goals of the intervention were to reduce insomnia and depression and to increase daytime energy. The study was limited by the lack of a control group and by not having a baseline for sleep quality levels while subjects were caregiving. However, the study provides initial information about the impact of sleep on health outcomes of caregivers.

Sleep quality and quality of life. Quality of life has become an important measure of personal well-being, and hence is an outcome of interest in caregiving literature. Historically quality of life had been closely linked with life satisfaction but as Anderson and Burckhardt (1999) explain quality of life is broader than life satisfaction and the conceptual definition needs to include 3 key components. The authors state: 1) quality of life can only be understood from the perspective of the individual, 2) quality of life can be labeled as global happiness or satisfaction but overall is comprised of multiple components, and 3) the difference between one's expectations and current experiences is a critical attribute. Two of the available studies linking sleep quality and health outcomes were conducted outside of North America (Wei-Chung Chang, Tsai, Chang and Tsao, 2007; Cora, Partinico, Munafo, and Palomba, 2011). The other two studies (Swore Fletcher, et al., 2008; Willette-Murphy et al., 2009) were conducted in the USA. Each of the above studies found a decline in a physical or psychological domain in the presence of declines in sleep. Further, Wei-Chung Chang, Tsai, Chang and Tsao found a negative significant correlation between sleep and quality of life. The authors of these studies reported similar findings despite the differing origins of the settings in which the data were collected.

Wei-Chung Chang, Tsai, Chang and Tsao (2007) investigated the connection between sleep quality and quality of life as a health outcome. Using a sample of 61 caregivers, sleep quality and quality of life were measured using the PSQI and the World Health Organization Questionnaire Quality of Life: BREF-Taiwan version (WHO-QOL-BREF-TAIWAN). A unique aspect of this study is that of the 61 participants, 50 were male. This study provides an initial look at the impact of caregiving on the sleep quality of male caregivers providing care for individuals with breast cancer. Measures were only taken once but authors found a significant relationship between moderate declines in sleep quality and declines in quality of life, even in situations where care recipients were experiencing less severe symptoms. Interestingly, although the PSQI scores for caregivers who had support in providing care showed moderate sleep quality disturbances, their subjective reports of sleep quality declines were significantly less than those caregivers who did not have someone to share caregiving responsibilities. It was not clear whether the participants had been or were suffering from a prior sleep disorder or a chronic illness that may have impacted the relationship between poor sleep and lowered quality of life, but these authors provided some initial information about a possible impact of reduced sleep quality on quality of life.

Like Wei-Chung Chang, Tsai, Chang and Tsao (2007), Swore-Fletcher et al. (2008) also examined the relationship between sleep and quality of life. Though the authors were interested in the relationships among levels of depression, anxiety, pain, sleep disturbance, and fatigue on functional status and quality of life, they found that 36% of caregivers of individuals awaiting the initiation of radiation therapy exhibited clinically meaningful declines in sleep quality. The authors used the self-report General Sleep Disturbance Scale (GSDS) rather than the more commonly used PSQI, but results indicated that even during the early stages of caregiving, caregivers experienced sleep quality declines. Importantly, depression was found to have a greater impact than sleep quality on functional status and quality of life. However, as discussed previously those with depression may be experiencing stress and poor sleep quality. Despite the limitations of the study (small sample, participants were caregivers of care-recipients in early-stage of illness only), the findings suggest a link between compromised sleep-quality and reductions in functional status and quality of life. Although the early stage of illness and single measurement period may not capture the full extent of the impact that providing care has on sleep quality, the initial findings suggest that if caregivers' sleep quality is disturbed in the early phases of illness, the caregivers could potentially experience further declines over time, and that collectively these declines could have a negative impact on caregivers' quality of life and functional status.

Speculation and emerging evidence have linked the process of caregiving to sleep quality declines. However, research that incorporates a control group within a longitudinal design would provide more information about causal relationships between caregiving and sleep quality. For example, Cora, Partinico, Munafo, and Palomba (2011) implemented an age- and sex-matched control, unlike any of the other studies discussed above, of 20 caregivers and 20 age matched controls, to establish the influence of caregiving on health outcomes. The goal of the study was to investigate the development of cardiovascular risk factors (increased heart rate and increased blood pressure) in caregivers, with an additional goal of determining how length of caregiving further contributed to the development of these risk factors. Although, the authors did not find significant elevation of heart rate and blood pressure between the caregivers and the comparison group they did report elevated heart rates for those caregivers providing care for longer than six months, which could increase long-term chances of developing heart-related illness. Like the other studies discussed above, the authors reported a relationship between higher psychological distress and lowered sleep quality. Seventy percent of caregivers reported insomnia while only twenty-five percent of non-caregivers reported insomnia. Unfortunately, the study sample was small. A longer assessment period with repeated measurements would have helped to clarify the impact of providing caregiving changes over time. This study again highlights that caregivers' sleep quality is lower than sleep quality in non-caregivers.

Interventions for improving poor health outcomes associated with caregiving. There are a few studies documenting intervention studies in which the goal was to address the poor health outcomes associated with caregiving. With a sample of 38 inactive and 30 active caregivers, Willette-Murphy et al. (2009) investigated whether physical activity could reduce the number of negative outcomes reported by caregivers. The outcome variables included sleep patterns, psychological symptoms, and daytime function. Sleep was measured for 48 hours using actigraphy, a sleep log, and two sleep scales (the PSQI and the GSDS). Although the authors did not find clinically significant differences between sleep quality in the physically active and non-active groups, the authors found that non-active caregivers generally reported more difficulty falling asleep, less total sleep time; lower scores on the attentional function assessment, and increased daytime sleep than active caregivers. Again, limitations including the use of only one self-report measure of physical activity, the small sample size, and the short duration of the study make these findings difficult to interpret.

Gaps in Knowledge about Sleep Quality in Caregivers of Individuals with Advanced Cancer

The gaps in knowledge about sleep quality in caregivers of individuals with advanced cancer are primarily related to methodological issues. These issues include the lack of control/comparison groups or other strategies to control extraneous variables that impact sleep, sample homogeneity (generally white, middle-class women), small sample sizes, reliance on descriptive and bivariate analyses, and use of cross-sectional designs with limited use of longitudinal designs. Lee, Cho, Miaskowski, and Dodd (2004) note that much of the investigation surrounding caregiver sleep deprivation has been focused on the early phase of diagnosis and has not examined the implications of sleep deprivation throughout the disease trajectory from diagnosis through to bereavement. They advise the use of prospective designs in future studies, which could help to tease apart causal links between sleep and health outcomes, so that the implications of alterations in sleep patterns on the ability to navigate the course of caregiving and the long-term health outcomes can be examined more closely.

Of more concern however, is the fact that the majority of the studies were quantitative in nature, without first establishing a solid description of the experiences of caregiving and sleep quality. I identified only three (Arber & Venn 2011; Carter 2005; Harding et al., 2012) and one study with both a qualitative and a quantitative component (Carter, 2002). This is a significant issue, as there may be some key connections between sleep quality and caregiving that have not yet been identified or fully described. I designed my study to address this gap.

Chapter 3: Methods

In this chapter I present the objectives, design, selection of participants, criteria for selection, selection procedures, data collection, analysis, strategies undertaken to ensure rigor, and ethical considerations.

I initially proposed a study with a prospective mixed methods design for the purpose of exploring relationships among sleep quality, perceived stress, adaptive capacity and fatigue in current and bereaved caregivers. Due to unforeseen difficulties with participant recruitment, I refined the research question and redesigned the study as a qualitative study using an Interpretive Description (Thorne, 2016) design. Because a similar interview approach was used in both the original proposed study and the redesigned study, I have included qualitative data obtained in both studies.

Objective

The objective of this study was to explore how current and bereaved caregivers of individuals with advanced cancer describe their sleep quality in the context of caregiving.

Design

Interpretive description was selected as the design for this study because the research question came from clinical practice and interpretive description provides a strategy for studying research questions that are clinically rooted (Thorne, 2016). Interpretive description is "… a non-categorical methodological approach to developing clinical understanding" (Hunt, 2009, p. 1285). Interpretive description stems from clinical practice and seeks to answer clinical practice questions that may not be readily answered by traditional qualitative methodologies (Hunt, 2009, p.1285). Thorne, Reimer

Kirkham, and O'Flynn-Magee (2004) explain that interpretive descriptions studies are often

> "…smaller scale qualitative investigation of a clinical phenomenon of interest to the discipline for the purpose of capturing the themes and patterns within the subjective perceptions and generating an interpretive description capable of informing clinical understanding." (p. 3).

The goal of a study was to find patterns and relationships within descriptions provided by study participants (Thorne, 2016). Thorne explains that clinical experience is a useful place to start orientating research because it provides a context for the creation of a theoretical scaffold that can then be challenged and refined through the collection and interpretation of data. Thus, starting with my initial ideas about the connections between caregiving and sleep quality, I used informed questioning and reflective and critical examination, as described by Thorne et al. (2004) to create an interpretive account of patterns and relationships between sleep quality and caregiving from the standpoint of caregivers.

A second reason for using interpretive description was that the research on sleep quality in caregivers is limited and so there may be aspects of the phenomenon that are not yet identified or understood well enough to formulate testable hypotheses. Hunt (2009) asserts that interpretive description is a useful design in such areas that have yet to be fully evaluated in a rigorous fashion. As detailed in chapter two, research on sleep quality and primary caregivers has been limited. A better understanding of perceived connections between sleep quality and caregiving from the perspective of caregivers, could be used to develop nursing interventions to support these caregivers.

Interpretive description has three core philosophical assumptions. These assumptions are:

1. There are multiple constructed realities that can be studied only holistically. Thus, reality is complex, contextual, constructed, and ultimately subjective.
2. The inquirer and the "object" of inquiry interact to influence one another; indeed, the knower and known are inseparable.
3. No *a priori* theory could possibly encompass the multiple realities that are likely to be encountered; rather, theory must emerge or be grounded in the data (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004; Thorne, 2008, 2009, 2016).

These philosophical underpinnings acknowledge the constructed and contextual nature of human experience and allow for shared realities (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997). In studies using an interpretive description design, these shared realities become articulated as patterns and relationships in the data, and can then be used to shape the practice of nursing (Hunt, 2009, Thorne, Reimer Kirkham, & MacDonald-Emes, 1997).

Interpretive description requires the researcher to orient him or herself in clinical practice and available research, which provide the foundation for the construction of the theoretical scaffold. This allows for what Thorne (2016) describes as the analytic framework; the platform on which to build the study. This approach is different than other designs where a formal conceptual framework provides the platform for the study. The analytic framework in interpretive description provides a rationale for the anticipated boundaries of the study, and makes the theoretical assumptions, biases, and preconceptions that will drive design decisions explicit (Thorne et al., 2016). As the research progresses the researcher challenges and refines the theoretical scaffold, and in so doing, develops an answer to the research question.

At the outset of my study, I hypothesized that caregiving had a major impact on the sleep quality of caregivers. The theoretical scaffold was based on clinical experience and the literature about the mechanisms of sleep and the roles of caregiving discussed in chapter 2. I used interview data from study participants to challenge and refine original ideas and to co-construct a description of the connections between sleep quality and caregiving with the participants.

Selection of Participants

The sample for the study was obtained using both purposive and theoretical sampling (Mason, 2010). Mason explains that purposive sampling is a process of identifying which participants are likely to provide the richest data related to the research question. The initial purposive approach to sampling was to recruit individuals who could provide accounts of caregiving with a particular focus on sleep quality.

As the study progressed, I also used theoretical sampling. Theoretical sampling is a process of sampling individuals who may have a potentially different account to offer with respect to topic under investigation (Thorne, 2016). I derived a theoretical sample from bereaved caregivers, as I thought that their ability to reflect back on the caregiving experience might allow them to see connections between sleep quality and caregiving that were not apparent to caregivers still in the midst of caregiving.

The sample size in studies using an interpretive description is determined by the ability of the participants to describe their experience. Thorne (2016) has expressed concerns about some of the common language that has been used to determine sample size in qualitative studies, and has noted that “interpretive description can be conducted on samples of almost any size” (p. 103). She argues against Morse’s minimum guideline of -10 participants for qualitative studies, explaining that Morse’s sample size may be too limiting to ensure data sufficiency. Thorne (2016) also suggests that terms such as saturation and redundancy presume that one could get to a point where nothing new could be learned, which may not be true. Therefore, Thorne (2016) encourages recruitment until the data are sufficient to provide an initial description of the phenomenon under investigation.

Criteria for Selection

I recruited individuals who were current or bereaved primary caregivers of individuals with advanced cancer. Eligibility criteria included: a) at least 18 years of age, b) able to read, write, and understand English, and c) living with/ lived with the care recipient. In order to obtain data that were still relatively recent, an additional criterion for bereaved caregivers was that the death of the person with advanced cancer had occurred within the past six months.

Selection Procedure

Recruitment took place over a period of two years. Participants were initially recruited through the Psychosocial and Spiritual Resources unit at the Cross Cancer Institute in Edmonton, Alberta and online via the Canadian Hospice and Palliative Care Association websites. Following ethics approval from the Health Research Ethics Board at the University of Alberta, I gave an overview of my study to staff at the Psychosocial and Spiritual Resources unit and provided them with copies of the information sheet (see Appendix A), which they agreed to hand out to clients who met inclusion criteria.

Individuals interested in hearing about the study were asked to sign the information sheet and give their phone number, and then leave this information in a box provided. I planned to collect the information sheets and contacted the potential participants by phone, and obtained written informed consent from those interested in participating (see Appendix A for consent). I was not given any information about the number of individuals who received written information about the study, but no participants were recruited using this approach.

A link about the study was also placed on the Canadian Hospice and Palliative Care website. Individuals clicked on the link if interested in hearing more about the study. The link took them to a short description of the study and my email address. Individuals interested in hearing more about the study were asked to email me.
Two individuals responded to the ad and were sent a consent form. I arranged a screening interview with these individuals to ensure that inclusion criteria were met. One individual signed a consent form and participated in the study but the other was not able to schedule an appointment for a screening interview, and thus did not continue in the study.

To expand the possible participant pool, I attend two caregiver support groups in Calgary where I was able to provide an overview of my study to six individuals. Some individuals were interested in the study but indicated they were very busy and would contact me if things settled for them enough to be able to participate in the study; I never heard further from anyone from the Calgary site.

After discussing further possible strategies to generate participation I contacted the Edmonton Multiple Myeloma Support group. It was suggested that the support group might be a viable recruitment source as the members were active and engaged in other relevant research. I presented my study at two meetings, which included both individuals with Myeloma and caregivers of individuals with Myeloma. About 40 people were at each meeting. Four caregivers attending those meetings agreed to participate in my study. Two other caregivers initially expressed interest in the study but did not sign consent forms.

The remaining 5 participants in my study were recruited through snowball sampling. Colleagues who were aware of the study provided information to individuals who they knew were caregivers for family members and obtained permission from the caregivers for me to contact them.

Data Collection

Data collection appointments were scheduled with individuals who met the eligibility criteria, based on the information obtained in the screening interview. I met face-to-face with participants living in the Edmonton area and met with those outside the Edmonton area by phone. Initially, I had planned to use face-to-face technology for interviews with participants I could not interview in person, but participants said they were not comfortable with face-to-face technology and preferred to use the telephone. Demographic data (age, sex, and marital status of both caregiver and care recipient, relationship of caregiver to care recipient, caregiver chronic illnesses) were collected to describe the sample (see Appendix B for data demographic data collection form).

Conversations began by asking caregivers to describe what their caregiving experience was like, using open-ended guiding questions to facilitate the interview (see

Appendix C for guiding questions). Qualitative data were collected first, followed by collection of information to describe the sample. Two interviews were conducted with each participant. Six of the participants were contacted for a third time to clarify some of the points that they brought up in their previous interviews. Interviews varied in length from 30 minutes to an hour. Subsequent interviews were used to clarify unclear points in the initial interview. All interviews were transcribed to facilitate analysis, and data collection and analysis occurred concurrently.

Data Analysis

Data analysis in interpretative description is an inductive process whereby the researcher reads and re-reads the interviews to identify patterns and relationships across participants and then considers how that knowledge could be applied to improving some aspect of clinical nursing. The process of analysis started with the first interview and continued throughout the entire study.

Thorne (2016) encourages a process for making sense of the data by moving from pieces to patterns and then from patterns to relationships, using Morse's (1994) four cognitive processes to guide the conceptualization that Interpretative Description requires. Morse describes four sequential cognitive processes of comprehending, synthesizing, theorizing, and re-contextualizing (Morse, 1994). Comprehending began with consideration of the data in its raw form. I wrote detailed notes about the data that I thought might be part of a pattern. After each interview, I wrote field notes about links I saw between sleep quality and caregiving. Richards and Morse (2007) and Mayan (2009) encourage use of field notes during this step to capture observations related to incidents and perceptions arising from the interviews. I engaged in synthesis by considering each interview in relation to the previous interviews (if any) with a given participant, and with all other participants. The results from each interview were used to guide future interviews. I highlighted words and sentences in my field notes that linked interviews and wrote more field notes about how these links fit with the question. Once bereaved caregivers were added, I compared their data to that of current caregivers so that I could identify similarities and differences.

As I identified patterns in the data I sought to move deeper into the theoretical phase of the analysis, with the goal of finding relationships among the patterns I had identified. Both my supervisor and I read the first three interviews and discussed them. Complex findings were discussed and discrepancies in our findings were acknowledged. Discussions of the discrepancies allowed for a fuller interpretation of the findings and were used to refine my ongoing analysis. I was the only coder for subsequent interviews, but I discussed my work on an ongoing basis with my committee, with particular emphasis on the identification of relationships within the data.

I located relationships by identifying key words and phrases across participants and by writing detailed descriptions that showed how these words and phrases linked patterns and created relationships. As I moved closer to identifying relationships I ensured that I was asking myself questions to support my ideas as encouraged by Thorne (2016). These questions included what I heard during the interviews, and what was mentioned in the texts from the interviews. The aim was to construct a tentative description of the data as a whole (Thorne, 2016).

Within Interpretative Description findings are

> …not simply the reporting of first credible set of patterns. Rather, findings reflect an interpretive maneuver within which you consider what the pieces might mean, individually and in relations to one another, what various processes, structures, or schemes might illuminate about those relationships, and what order and sequence of presentation might most effectively lead the eventual reader toward a kind of knowing that was not possible prior to your study (p. 163).

During the theoretical phase of my analysis, I also spent a significant amount of time thinking about my findings, talking about them with other healthcare professionals, and conducting new searches of the literature on topics that emerged in my analysis but that were not part of my original literature review. I also reviewed the results of my analysis and located them within the context of what was known from other studies and what was still unknown, despite my work.

Finally, to understand the results in the context of nursing I used a process of re-contextualizing. Re-contextualization is a process honed by Morse (1994) to locate the themes generated in the findings in the context of established knowledge (Iwelunmor, Newsome, & Airhihenbuwa, 2013). Morse describes re-contextualizing as a process where one highlights findings that "support established knowledge/theory, and (that) claim clearly new contributions" (p.34). The re-contextualization of my findings is discussed in Chapter 5.

Rigor

Rigor is an important consideration in all forms of research. Thorne (2016) describes epistemological integrity, representative credibility, analytic logic, and interpretive authority as the standards for ensuring that products of interpretive description are credible and trustworthy. These criteria components ensure that assumptions, claims, reasoning of the researcher, and that the results revealed are in essence ‘valid’. Achieving credibility results from careful attention in the analytic course through an iterative process of reflecting on the data and asking oneself what is being heard that helps to answer the research question. Meetings of my supervisory committee were held to further ensure that the processes used for analysis were transparent and logical. At every step, I was challenged to show my evidence in the data for conclusions I drew. I engaged in a process of making notes after interviews, coding with meaning units, highlighting thematic similarities, keeping a section of quotable quotes, and making sense of the patterns through iterative reasoning. These approaches led to a series of analytic notes and discussions, which contributed to interpretations of the data. From an epistemological perspective, who a person is influences the results of their analysis. Hence my role as a nurse and as a psychologist has influenced interpretations of the data. It was essential to make the analysis clear by using quotes to support conclusions so although readers may not agree with the analysis they could follow my thinking and see how I arrive at conclusions. To ensure credibility initial analysis was checked with study participants in subsequent interviews, and thus ensure that I had accurately understood and described their experience.

Ethical Considerations

The research study conformed to the University of Alberta’s ethical guidelines for research with individuals and was approved by it, and by the Canadian Hospice and Palliative Care Program before commencement of the study. Participants were given all the necessary information to decide whether to consent to participation and were able to withdraw from the study without penalty at any point. Additionally, throughout the study if at any time was concerned about the health status of the participant I was prepared to discuss options for follow-up. I put in place procedures to ensure participant privacy. Data were stored in a locked filing cabinet. The research was carried out with the least amount of inconvenience to participants as possible given their already stressful situation; I collected the data in either the participant’s home or on the phone. Caregivers were given a letter of thanks for participating along with a $50 honorarium. I planned that if an event should occur, such as death of care recipient or the transfer of care recipient to hospice, the participant would be invited to remain as a participant if they so chose, and would be reminded that were free to withdraw at any point in the study with no questions asked. The one participant whose care recipient died during the study chose to remain in the study.

Summary

This study was conducted using interpretive description, as developed by Thorne (2016). Both purposive and theoretical sampling were used and all participants were interviewed at least twice. Data analysis took place from the outset of study and occurred through the use of journaling, reflection, and discussion. Steps taken to ensure rigor included careful use of the analytical process and discussion with my supervisory committee (Thorne, Reimer Kirkham, & O’Flynn-Magee, 2004).

Chapter 4: Results

In this section I describe the sample and findings of this study. Data were analyzed using the three-step process initially developed by Morse (1994) and endorsed by Thorne for studies designed using Interpretive Description (2016). Hence, I began by analyzing the data from current caregivers in the first two steps in the analytic process (comprehending and synthesizing) I described in chapter 3. This process resulted in the identification of patterns. Finally, in the third step of that analytic process, theorizing, I used my data from bereaved caregivers to check for patterns that may not have been apparent to or experienced by current caregivers, and used data from both current and bereaved caregivers to look for relationships among the patterns I identified.

Sample

The sample (n=10) included six individuals who were currently providing care at the time of the interviews, (one man and five women), and 4 individuals (all women) who had provided care in the past 6 months. Five of the current caregivers were providing care for their spouse and one of the current caregivers was providing care for her mother. Two of the bereaved caregivers were providing care for their spouses, one of the bereaved caregivers was providing care for her mother, and the final bereaved caregiver was providing care for her brother. Four current caregivers were recruited from the multiple myeloma support group in Edmonton, one current caregiver was recruited by use of internet advertisement, and one current caregiver was recruited using snowball sampling. The four bereaved caregivers were recruited using snowball sampling. All participants were Canadians, and ranged in age from 39 to 80 years old. Only one caregiver reported a chronic illness; she had arthritis.

Five of the ten study participants were former and current practicing nurses, which provides an interesting context for the study findings. Although not explicitly discussed, these participants likely had both internal and external resources acquired in the course of their professional education and clinical work that helped them navigate the caregiving role. Their ability to “cope” as discussed later may extend from the fact that these caregivers had an ability to manage that other caregivers may not have and may have influenced these caregivers’ decisions to participate in this study.

Steps 1 and 2: Comprehending and Synthesizing:

The goals of this part of the analysis were to find patterns in the descriptions of sleep quality provided by individuals who were currently caregiving. Current caregivers’ accounts of their experiences were generally described in relation to the illness/wellness phase of their family member. These accounts were accompanied by a description of the caregivers’ roles, which caregivers described as” just doing what had to be done”. Three patterns were identified within these descriptions of caregiving. These patterns are presented below.

Integrating Caregiving with Pre-caregiving Activities

Participant’s goals for daily life seemed to revolve around blending caregiving and enjoyable activities that had been part of their lives prior to caregiving. One participant explained the interaction between her personal life and her caregiving role by saying, “you just sort of live your life around it [cancer]…You just plan things differently. That is one thing that I didn't let him do or myself, was just cocoon in the house. We go out and we do things. I mean, every Thursday we go dancing”. Another participant spoke about the need to keep experiencing good things in life despite the illness, "…I mean he wanted to do these things (travel and spend time with friends) and I wanted to do them, because of what he had, too. You know I wanted him, us to enjoy as much as we could". Engagement in enjoyable activities occurred despite tiredness. Participants seemed able to pushed aside feelings of tiredness in order to do the work of caregiving. One participant said, "So, you try not to dwell on it (being tired)." Another participant who admitted that sleep had been altered said, "yeah, so, I suppose it truly changed my pattern, but I don't feel impacted by it." And another when speaking about providing care said "…I could still do what I needed to do." Another participant stated, "You sleep you know, wherever it's convenient, you know, because when they don't sleep well, well you don't sleep well, so you but you still wanna, you know, see what's going on, you know. You have a responsibility, in other words".

This finding suggests that at the time the data were collected, there was no reduction in sleep quality, based on the definition developed by Buysse et al. (1989), as participants did not report any daytime dysfunction, were able to find energy to continue activities they enjoyed prior to taking on the caregiving role, and were able to incorporate the additional work of caregiving. This finding is a very interesting finding as further exploration of participants' experiences revealed the presence of both increased sleep disturbance and increased sleep latency, two factors that one would expect to contribute to declines in sleep quality based on the definition of sleep quality used in this study (Buysse et al., 1989).

Throughout the interviews the participants described declines in both the duration and depth of their sleep, which they related to their caregiving role. These declines constitute sleep disturbance, which is a formal dimension of sleep quality as defined by

Buyse et al. (1989). Declines in duration and depth of sleep that were directly related to the role of caregiving resulted from having to provide care or having to wake in an instant if their family member needed assistance. Changes that were indirectly related to caregiving related to the caregivers' feelings and thoughts about the situation and about their family member's impending death.

Being available: Direct effects of caregiving. Caregivers explained that they reduced the depth of their sleep because they wanted to arouse easily and be available quickly if needed to perform caregiving duties. As one caregiver explained "I didn't sleep well because you're, got one you know, you got one ear open to see if everything's okay, so you don't get your sleep" And yet another stated "It (caregiving) does 'cuz you when he was sleeping with me, of course, it's very much interrupted because he was interrupting it. When I wasn't sleeping with him, lots of time I'd sleep in the living room because it was close to the bedroom. It (caregiving) definitely interacts with your sleep." Proximity to care recipient changed sleep. One caregiver who had an opportunity for respite reported that she got sleep, but explained that it was "not great sleep…because you weren't responsible for them". One caregiver described that she would have to help her partner to the bathroom if needed to go in the middle of the night. She captured the effects of this on her sleep by stating

> But I wasn't comfortable with him getting up in the middle of the night to go to the bathroom without me being there. Because he fell quite a few times. And you wake up, and he wakes up, anybody wakes up in the middle of the night, anybody's disoriented. And if you really have to go, then you jump out of bed. And so I would, I would, not sleep well because I'm waiting, listening for him to

> want to get up.

Having to sleep at times with partial attentiveness, “one ear open”, to be available in case the caregiver has to wake to provide assistance has consequences for sleep quality. Declines can be seen as a result of the impacts on the dimension of sleep disturbance. In this study, caregivers describe experiences of having to be ready and available. Having to wake within the normal sleeping hours is a disturbance. Repeated disturbances to sleep contribute to a decline in sleep quality.

Worried and afraid: Indirect effects of caregiving. Issues, such as anxiety and fear, which were not directly related to caregiving, had an equal if not greater impact on sleep quality. Being afraid tends to emerge at night before bed when one is quiet and contemplating the day and reflection on life. One caregiver who was asked about the challenges faced while being a caregiver stated,

> …sleep and anxiety. Yeah, I think that. Yeah, I think it was partly because it was a constant role, I wanted to be there for him. There were other people, we did have breaks. But I dealt with the worry, I think it's the worry. How is this gonna unfold? You never know. And not knowing the ending. So I think there is worry about that. Part of your worry is this could go on for two weeks, how am I going to manage.”

Another participant reported:

> For maybe three or four months, I don't think I slept. Just because for one, she was in my bed, and I was sleeping on the couch. But, the bigger reason is because I constantly worried about her getting up. And if I'd hear her move, and then I'd

> worry about her falling. And you know, there was so much worry attached with it, and worried if she was needing the medication or something.

Other participants commented that they would often checked on their family member to see if they were alive and breathing. One commented on watching the covers to see whether they were rising and falling, which would indicate that her husband was breathing, while another would always stop by her husband's bed after going to the washroom to make sure he was still alive. The one male caregiver echoed this behaviour and said he watched to ensure that his wife was alive when she was on a particular medication stating, "I think I noticed, yes, because you're awake. When she was taking, [a medication] anyway, she would almost stop breathing. Her breathing would change and she would start breathing in on her own, right, and it's almost like you were getting chest pains (matching her breaths) and so, yeah, you wake up and then you, you wait to see that everything settles down again."

Participants noted there were times that fears would surface as they were about to go to sleep and when they would wake in the night. Fears related to the reality of the situation and impending death of their family member. Participants noted that there were times where these fears influenced their sleep quality. One caregiver explained:

> ...the way it effects the sleep is that then you start thinking and it's difficult to go back to sleep. So, that is where the loss of sleep comes in, rather than-- most of the time I don't have too much trouble falling asleep unless it's been a really rough day. But yeah. I think that that's where the lack of sleep comes in. Anxiety or some of the racing thoughts or trying to process a lot of things. When you wake

> up, it kind of catches you and they are quite weighty. So you would find that that probably, if anything, is what impacts your ability to sleep well to a large extent.

Still another participant stated that sleep was compromised

> during the night, during the night mostly. That's when it hits. If I wake up and, and can't get sleep. Your mind just, you get an unquiet mind and it, you know. Then you kind of jump ahead and say what if this, what if that. Well that's when if I don't get back to sleep, then I think of all kinds of things that I'm going to possibly be faced with.

Another participant said: “It's that worry and then at times it's the direct care-giving, but it seems like the, the worry and the planning seems to trump even the direct care-giving”.

Caregivers’ fears and worries contributed to sleep latency, which is the time it takes to fall asleep. Increased sleep latency is another component of sleep quality in the definition developed by Buyse et al. (1989). When sleep latency increases, sleep quality declines.

Really Tired

Participants all identified times they felt “really tired.” In addition to increased sleep disturbance and sleep latency, participants identified some other factors that they said contributed to feeling “really tired,” including a lack of understanding about what to do, depression, and uncertainty. For example, one participant said, “I'm trained to do that [Nursing]. I have lots of experience doing it but it's really different with, with a loved one as opposed to the public…So it's um, you know it's been challenging, and interesting, and at times extremely exhausting because (I) don't know what I'm doing.” Another participant said, “You know what? All along I hadn't (noticed that my sleep was impacted) because I was so exhausted at the end of the day and probably a bit depressed. I just always slept well”.

The uncertainty of caregiving made it difficult to work out a plan for managing declines in sleep quality. As one caregiver stated, “I wondered how long, I was gonna have to continue to do this…Like I still felt like I could, do what I needed to do. I know that I had periods of exhaustion, but I remembering thinking many times...I'm exhausted, knock it off, think about what she (my mom) is going through".

“Really tired” summarized the paradoxical nature of the caregiving experience. Although caregiving was challenging, it also provided new opportunities and insights valued by participants. For example, one participant said, “It's just such an amazing learning opportunity. Even though some of the learning has been just totally, ugh, horrid. Right? It's like really, I'm not sure I want to learn this... Yeah, and also, I mean, it's fatigue. I mean, I'm just, it really does impact on your life, so. You really have to just care for yourself, and, and be aware of your limitations.

Step 3: Theorizing

The first part of step 3 (Theorizing) involved analyzing the data gathered from bereaved caregivers and comparing the patterns to those identified in the data from current caregivers. I thought bereaved caregivers might be able to add a more finely-grained description of the declines in their sleep quality by reflecting on the entire caregiving experience. While the patterns in the current and bereaved caregivers were similar, the accounts provided by the bereaved caregivers were indeed more detailed, and the links between direct effects of caregiving and declines in sleep quality were generally clearer.

One bereaved caregiver explained, “I could tell that my sleep was compromised a bit, yeah it (caregiving) affected me. It affected my sleep for sure because I would just sleep on the edge, it would be superficial sleep because she'd (participant’s mother) need help to get to the bathroom so as soon as I'd hear that name being called! So, lots of interruption, in my sleep. I just know I didn't get good quality”. This was a sentiment echoed by most bereaved caregivers. One participant said, “I don't think I slept at all when she started to get very ill and I needed to be there more and more. No, I didn't sleep at all”.

Bereaved caregivers’ accounts suggested that current caregivers may minimize the effects that caregiving had on daily life. Bereaved caregivers emphasized how hard it was to be a caregiver and described how tired they felt at times, but how they still kept going despite any ill effects experienced. One bereaved caregiver said, “I just knew I was just sorta (going through the motions) but I don't know if I remember feeling really tired like, I know I wasn't sleeping.” Being tired was something that was always present but was pushed to the side. Bereaved caregivers explained that there were seldom opportunities to reflect on what they themselves were experiencing when they were in the midst of caregiving. Nevertheless, these caregivers generally reported positive feelings about having provided care to a family member at the end of their life.

> I did most of the nights. You know, at times you're tired and stuff but with more time evolving you forget about that. I think it's kind of like what we remember now. What I remember now is of course the times with him, and the conversations with him, and being there. At the time, we were really tired. Yeah,

> so but I think what you forget as time goes on how tired you were. I remember more of the positive part of it all.

Relationship between Patterns

The central part of the third step in the analytic process is finding relationships among the identified patterns. When considering the patterns identified in the data of current caregiver's and bereaved caregivers, I found one relationship that I think linked the experiences of caregiving and sleep quality—powering through. Powering through resulted from a decision that caregivers made to "keep going." The reasons for the decision to power through were not completely clear, but seemed rooted in the participants' view that caregiving was an important aspect of their relationship with their ill family member. The data from current caregivers showed that learning to power through begins early in the caregiving experience when caregivers found ways to incorporate activities they enjoyed prior to taking on the caregiving role. Involvement in these activities seemed to help generate the energy required for caregiving. As the length of time as a caregiver increased and sleep disturbance and sleep latency continued, data from both current and bereaved caregivers showed that new insights emerged about the importance of caregiving and that these insights provided the energy to continue caregiving. Hence, powering through developed over the course of caregiving and was used by caregivers to navigate work of caregiving.

Powering Through

Throughout the interviews many of the participants described carrying on and meeting the challenges of caregiving, adapting as needed. "Powering through" was about not having the time to be tired. A participant explained, "And I know, sometimes I'd wake up in the morning and I'd think oh, I'm so tired. I'm tired. But then I would just [keep going].

One caregiver captured the concept of "powering through" by stating, "So, you try not to dwell on it and some mornings I have to push myself," while another stated, "just let go of all this stuff that you can't do anything about right now, cuz you don't have that time, energy, wherewithal. You got bigger fish to fry, just let it go."

Having the worry and fears of a family member with a late stage diagnosis of cancer, there was little time for caregivers to think about themselves. Being tired was something that was always present but that was pushed to the side. One participant noted, "I knew what was coming ahead. You gotta face the music. What are you gonna do? You know, this is coming. You know? It was very tough, sure. Had me a few cries and carry on".

Another caregiver said, "Well, I lost weight. That was one thing, because I was so busy. I didn't sleep well because you're, got one you know, you got one ear open to see if everything's okay, so you don't get your sleep. You don't eat properly". Another participant indicated she willed herself to not even let herself get sick so that she wouldn't let her husband down if he needed her, saying "….You know, lots of times somebody would say, you haven't been sick for awhile and I'd say, I can't. I just can't". Caregivers indicated that they had a role to fulfill and they would strive to do so for the well-being of the care recipient. As one participant explained:

> I had constant thoughts of how I had to power through. I think that it just felt as though this was my life and nothing else really mattered. I also knew that this is where I needed to be, and I wanted to make life for her as

> comfortable as possible, and that required me to be on my game. She was the priority always. I also remember thinking that this (care giving) could go on for an extended period of time, but that was so much better than the alternative, not having her...so that just helped me to power through.

Another caregiver summarized “powering through” by saying,

> When I was caring for my mom I knew she was dying and there was no other job that mattered. I had to make sure she was taking her meds, eating, was comfortable, etc. She became confused so I had to be with her all the time. It was like there was nothing else on the agenda. Everyone else in my life kids included had to understand that this was all that took priority at the time. I would spend time researching her illness and the process of death. I would spend all my time looking for the next symptom and stage and making sure I was ready for it and that I could address her needs. It was an emotion, physical and mental test trying to prepare her and myself for her death. I definitely had to leave work, friends and family to be there for her during this time. People can push through and do anything when they are faced with no other alternative. I feel I was able to power through because of all the love she gave me. I loved her and I owed her this.

Hence, participants seemed to view the tiredness associated with caregiving as unimportant in relation to the larger meaning of the whole experience of caregiving. When reflecting back on caregiving, descriptions of tiredness seldom featured as a prominent element of the experience. Rather, participants described the positive aspects of caregiving. One participant who was the caregiver for her brother explained,

> I did most of the nights. You know, at times you're tired and stuff but with more time evolving you forget about that. I think it's kind of like what we remember now. What I remember now is of course the times with him, and the conversations with him, and being there. At the time, we were really tired. Yeah, so but I think what you forget as time goes on how tired you were. I remember more of the positive part of it all. There were other responsibilities to take care of and plans to make.

Answering the Research Question

Current and bereaved caregivers acknowledged declines in sleep quality related to increased sleep disturbance and sleep latency that were associated with providing care. The decline in sleep quality was associated with needing to be available to provide care and with fears and worries about providing care for a person with advanced cancer who was expected to die shortly. Participants described a profound sense of tiredness that was associated with declines in sleep quality and other factors such as depression, a lack of understanding about what they were actually supposed to do, and the uncertainty associated with the length of time for which caregiving would be required. There was a paradoxical relationship embedded within the caregiving experience between the tiredness and sheer volume of work associated with caregiving and the positive meaning participants ascribed to caregiving. “Powering through” describes a strategy used by caregivers to manage their caregiving role. It involved pushing forward and concentrating on the needs of the person for whom they were providing care.

Summary

Three patterns that described the connections between sleep quality and caregiving were identified in the data from current caregivers of individuals with advanced cancer: integrating caregiving with pre-caregiving activities, changes in sleep quality, and really tired. These patterns were further developed by integrating experiences of bereaved caregivers. “Powering through” was identified as the overarching relationship among these patterns.

Chapter Five: Discussion

Introduction

Interpretive Description is not about claiming “truth” but going beyond merely describing or explaining findings to offer interpretations within the context of theoretical and research literature, while recognizing limitations and tentative nature of the findings (Thorne, 2016). In studies designed using interpretive description, this phase is called re-contextualization, which is defined as the process by which abstract concepts are considered from the perspective of current theoretical work by others. Thus, in this section I will focus on the main findings of my study and their integration with existing theoretical and research literature.

Re-contextualizing the Findings

The purpose of this study was to explore the experience of primary caregivers of individuals with advanced cancer regarding links between sleep quality and caregiving. The data in this study supported the existence of a connection between caregiving and sleep quality. Current and bereaved caregivers reported declines in sleep quality, which were influenced directly and indirectly by caregiving. Despite declines in sleep quality, however, caregivers were able to “power through” and to continue providing care for their family member.

In this chapter, I discuss my findings in relation to the literature detailed in Chapter 2 and literature related to new findings from my research. Participants in this study reported declines in sleep quality. These findings are similar to the findings reported by others. Links between reduced sleep quality, increased stress, and a profound tiredness among caregivers have been studied by many research teams (Arber & Venn, 2011; Aslan, Sanisoglu, Akyol, &Yetkin, 2009; Bevens & Sternberg, 2012; Brazil, Thabane, Foster, &Bedard, 2009; Carter, 2000, 2002, 2003, 2005, & 2006; Carlsson, 2009; Carter & Chang, 2000; Carter, Mikan & Simpson, 2009; Cora, Partinico, Munafo, & Palomba, 2011; Gibbins, Carter & Acton, 2006; McCoubrie, Kendrick, Senior-Smith, Davies, & Hanks, 2009; Lee, Yiin, Lin, & Lu, 2015; Lee, Yiin, Lu, Chao, 2015; Morris, Thorndike, Ritterband, Glozier, Dunn, & Chambers, 2015; Passik, & Kirsh, 2005; Pawl, Lee, Clark, & Sherwood, 2013; Teel & Press, 1999; Stenberg, Cvancarova, Ekstedt, Olsson, & Ruland, 2014; Stenberg, Ruland, & Miaskowski, 2010; Swore Fletcher, et al., 2008; Wei-Chung Chang, Tsai, Chang & Tsao, 2007; Willette-Murphy et al., 2009; Yee & Schulz, 2000).

Qualitative studies have highlighted the experiences of providing care. The studies by Arber and Venn, 2011; Carter, 2002; Carter, 2005; and Harding et al., 2012 illustrated caregiver challenges with respect to declines in sleep quality. In the studies by Arber and Venn, and Carter 2002 and 2005, the focus was on exploring the negative outcomes of sleep quality declines. In Harding et al., the focus was on the exploration of needs and challenges of being a caregiver and declines in sleep quality were noted. The findings of this study added to what is known about the relationship between caregiving and sleep quality by providing a more complete description of the contributions of increased sleep disturbance and sleep latency to declines in the sleep quality of caregivers. This study also provided a description of “powering through,” a strategy participants used to continue caregiving despite declines in sleep quality.

Perception and Appraisal of Caregiving

One of the key findings in this study was the importance of appraisal and perception of the experience of being a caregiver. Although participants were clear about the extensive nature of caregiving, they did not describe it as stressful. This finding may be viewed by some as surprising. When viewed from the standpoint of theoretical work on perception and appraisal, however, this result is easier to understand. Lazarus and Folkman (1984), defined perception as the environment and the person's awareness of it, and defined appraisal as the processes that evaluate the perceived environment. Given existing studies in the caregiving literature (Bevans & Sternberg, 2012; Lee, Yiin, Lu, & Chao, 2015; Stenberg, Cvancarova, Ekstedt, Olsson, & Ruland, 2014; Yee & Schulz, 2000), one might expect participants to describe caregiving as stressful and burdensome, but they did not do so, even when they had been providing care for long periods of time. In fact, they talked at length about enjoyment received by integrating caregiving with pre-caregiving activities. One possible reason that participants did not report caregiving as stressful was that they appraised caregiving differently than the caregivers in other studies. Caregivers who were finding caregiving stressful may have opted to not participate in this study.

Many groups have studied the role of perception and appraisal of events as they related to the stress response. Cohen, Kamarack, and, Mermelstein (1983); Hill (1958); and Lazarus, and Folkman (1984) all noted that appraisal of an event is more significant than the event itself, when considering perceived stress and individual coping. How one perceives and appraises a stressor influences how one responds to that stressor (Hill, 1958, Lazarus & Folkman, 1984). Increased stress and increased perceived burden in caregiving has been identified by others. The research by Brazil, Thaband, Foster, and Bedard, 2009; Carter and Acton, 2006; and Yee and Schulz, 2000 discussed in chapter 2 supported a working hypothesis that caregivers would be more stressed. Thus, I expected more data about the stressful nature of caregiving. Interestingly, participants in this study did not speak about the stress they were experiencing as a result of caregiving. One possibility for this interesting finding is that these particular caregivers may have appraised the role of caregiver as a stressor but determined that they had the resources to deal with the stressor (Bigatti, Steiner, & Miller, 2012). I think, however, that the explanation for this outcome can be better explained by the more recent work of Folkman (1997) and Folkman and Moskowitz (2000), who explore the meaning-based aspect of coping: positive affect outcomes. The caregivers in this study spoke about integrating the caregiving role with their pre-caregiving lives and spoke about the things they were learning and new insights caregiving provided, which shaped the meaning of the caregiving experience for them.

The findings of this study underscore the potential roles of perception and appraisal as mediators of the stress response in the context of caregiving. While anxiety and fear were present in the results of the current study, these negative emotions seemed to be buffered by caregivers' appraisals of caregiving as a "gift," and a sense that despite the hardships, it was "worth it."

Integrating Pre-Caregiving Activities

Participants in this study all talked about trying to incorporate pre-caregiving activities into daily life. Interestingly, the kinds of activities most frequently identified were health behaviours such as regular exercise and socializing with friends. Links between positive appraisal of stressful events and behaviours that promote health warrant further investigation. In this study the health behaviours followed the positive appraisal, but it might also be true that health behaviours facilitate positive appraisal. Regardless of the relationship between health behaviours and appraisal, recent findings support the importance of maintaining normal health behaviours during the caregiving experience. For example, Ross, Yamg, Klagholz, Wehrlen, and Bevans (2016) found that, if caregivers of individuals who had undergone stem cell transplants continued to engage in healthy behaviours, they were less likely to report declines in sleep quality or fatigue, and Goldzweig, Merims, Ganon, Peretz, and Baider (2012) found that fatigue was predicted by limited engagement in health promoting behaviors. Although participants in this study reported increases in sleep disturbance and sleep latency, and were "really tired," engagement in health behaviours may have helped to provide the energy that made "powering through" and continued caregiving possible.

Caregiving and Sleep Quality

Caregivers in this study were aware of declines in their sleep quality and linked these declines to their caregiving responsibilities. When asked directly about sleep, participants reported that at times they were very tired and could describe declines in their sleep quality. These findings are congruent with those of other authors who have reported that sleep quality is compromised by caregiving (Arber and Venn, 2011; Aoun, Kristjanson, Currow, & Hudson, 2005; Dumont et al, 2006; McCorkle, & Pasacreta, 2001 Morris, Thorndike, Ritterband, Glozier, Dunn & Chambers, 2015; Pawl, Lee, Clark, & Sherwood, 2013).

Even though participants did not perceive the decline in sleep quality as stressful, it is important to note that a number of research teams have identified links between reduced sleep quality and negative health outcomes such as depression, fatigue, complicated bereavement, and declines in quality of life. For example, Carter and Chang (2000) and Carter (2002, 2003, 2005, 2006) found that reduced sleep quality contributed to mood changes. Carter (2005) and Carter, Mikan, and Simpson (2009) found that reduced sleep quality during caregiving was correlated with intensified grief symptoms in the bereavement phase. Finally, researchers studying quality of life and health outcomes have identified declines in quality of life and health in the presence of declines in sleep quality (Cora Partinico, Munafo, & Palomba, 2011; Swore Fletcher, et al., 2008; Wei-Chung Chang, Tsai, Chang, &, Tsao, 2007; Willette-Murphy et al., 2009). The negative health outcomes associated with reduced sleep quality should not be ignored, and will be discussed in more detail under implications for practice in Chapter 6.

Really Tired

Participants linked reductions in sleep quality to a profound tiredness that had many of the characteristics reported by other groups who have studied fatigue (Carlsson, 2009; Olson, 2007; Olson, Krawchuk, & Quddusi, 2007; Olson, Turner, Courneya, Field, Man, Cree, & Hanson, 2008; Passik & Kirsh 2005; Teel & Press, 1999). Interestingly, Carlsson (2009,) Passik and Kirsh (2005), and Teel and Press (1999), found that caregivers reported higher levels of fatigue compared to non-caregivers, even when sleep quality was considered relatively stable. The findings in this study were similar to those of the above authors. Although participants described their tiredness as significant, it was not always associated with perceived declines in sleep quality.

Although “ Really tired” is the language used by the caregivers the descriptions of “really tired” fit closely with descriptions of fatigue in the literature. There are many definitions of fatigue, which vary depending on the cause of fatigue. For the purposes of my discussion here, I have used the standard definition of fatigue that includes two primary manifestations—a sense of tiredness that is out of proportion to the amount of energy expended, and that is unrelieved by rest (Wagner & Cella, 2004). There were many descriptions from participants in this study about an overwhelming and unpredictable lack of energy, but none related to whether rest relieved the availability of energy.

Building on the above definition, Olson and colleagues (2007, 2008) used stress theory (McEwen, 2006, 2007, 2008; Selye, 1984;) to develop a framework for understanding causes of fatigue and to establish links between fatigue and the decreased ability to adapt to stress. Participants in this study demonstrated several of the causes of decreased ability to adapt to stress identified by Olson and colleagues, most notably, increased anxiety and a decline in sleep quality.

It is important to note that declines in sleep quality, and fatigue have been linked with depression (Carter, 2002, 2003, & 2005). Participants in this study identified depression as one possible contributor to “really tired.” Whether they met diagnostic criteria for depression was beyond the scope of this study.

There are a few studies on fatigue in caregivers of individuals with advanced cancer. Chen, Chiou, YU, Lee, Liao, Hsieh, Jhang, and Lai (2016) found that caregiver fatigue was correlated with negative health outcomes and with an increased need for supportive care for caregivers. Jensen and Given (1991) found that fatigue in caregivers was present when care recipients' schedules were more demanding, and that fatigue reduced the abilities of caregivers to meet the needs of their care recipient. Caregivers without support, particularly when the duration of care giving is long, may be at increased risk of fatigue.

In this study, the ill family members of all bereaved participants were transferred to a hospital setting at end of life. The reasons for transfer to hospital were not clear and warrant further study. Caregiver fatigue may have been one of the reasons for transfer to hospital.

There have been some studies of fatigue in caregivers in other populations. Choi, Tate, Hoffman, Schulz, Ren, Donahoe, and Givens (2014) studied fatigue in caregivers of individuals in intensive care units. They determined that fatigue contributed to negative outcomes including increased depressive symptoms, caregiver burden, health risk behaviours, and patient symptom intensity, as well as reduced sleep quality. While being a caregiver in an ICU is a different experience, the impact of fatigue may be similar.

Based on these studies, caregivers who perceive the challenges of caregiving as more difficult and distressing may be less able to adapt to the stressors associated with caregiving and be more at risk for fatigue and other poor health outcomes associated with stress. Participants in this study did not perceive caregiving as distressing, but they described being "really tired" and reported some poor health outcomes such as anxiety and depressive symptoms. The health outcomes associated with caregiving warrant further research.

Powering Through: A Novel Finding

"Powering through," as described in this study, has not been identified in research on caregivers of palliative patients to date. "Powering through" is the ability to persevere with caregiving responsibilities despite declines in sleep quality. There are some studies of concepts similar to "powering through" in other populations. For example, Kruse (2006) explored the meaning of perseverance for caregivers of individual with Alzheimers. She defined perseverance as "…very calculated and deliberate actions to continue doing the hard work that needed to be done regardless of any obstacles that appeared" (p.342). One of the participant's in Kruses' study described perseverance as "time-you can't plan ahead, you just hang on and trust that you're not going to fall. You can function when you have to" (p. 342). Ultimately, Kruse found that the overarching theme presented by the participants was that individual's struggled cautiously through challenge by relying on others and focusing on the future. "Powering through" seems similar to Kruses' interpretation of perseverance, in that caregivers in this study found ways to endure despite challenges. "Powering through" could be differentiated from perseverance, however, by its roots in the meaning of providing care for a dying family member.

"Powering through" is a concept that links well with adaptation. "Powering through" could be viewed as evidence that despite declines in sleep quality, caregivers are able to adapt and meet the challenges of caregiving. Facilitators of "powering through" warrant further investigation. The time and energy spent on "powering through" may be one reason why caregivers have little time for reflection until the bereavement period.

Limitations of the Study

This study had some limitations. Caregiving responsibilities may have limited the involvement of individuals who would otherwise have liked to participate and whose experiences may have been different from those who participated. A longitudinal study that extended further into the bereavement phase may have enhanced the exploration of the relationships between caregiving and sleep quality.

Results of qualitative studies are not generalizable to a demographically defined population. They should, however, fit well with the experiences of others who have similar experiences. In this study, there was only one male caregiver and so it is difficult to say how well his experience reflected the experience of other male caregivers. There were nine female caregivers in this study and their descriptions were remarkably consistent. The description they provided would be expected to fit well with the experiences of other female caregivers who were not in the study.

About half the sample is comprised of bereaved caregivers, and one might expect their experience to be different from current caregivers given the impact of grief and loss, but this was not the case. The bereaved caregivers' descriptions were very similar to those of current caregivers, perhaps because they were recently bereaved, but they were more detailed.

There is a growing body of literature on modes of interviewing. In a study of prison guards and prisoners, Sturges and Hanrahan (2004) found that there was no difference in the data obtained from face-to-face and phone interviews. In a study of women who had terminated a pregnancy following diagnosis of fetal anomaly in which data were collected by face-to-face interview, phone, and e-mail, however, McCoyd and Schwaber-

Kerson (2006) found that the e-mail data were more richly nuanced. In this study, some caregivers (current caregivers n=2, bereaved caregivers n=3) were interviewed by phone. A comparison of the data from face-to-face and phone interviews showed no substantial differences.

There are potentially some other factors that may have had an impact on the experience of individuals providing end of life care, such as family dynamics, health status of caregiver, and relationship with the ill family member. These factors were beyond the scope of this study.

Summary

Literature both past and present continues to demonstrate that caregivers of individuals with cancer experience reduced sleep quality. To a large extent the findings from this study fit well with existing literature. “Powering through”, the theme that linked the patterns identified in this study, however, has not been reported in caregivers of palliative patients before. The capacity to “power through” suggests that the caregivers in this study were able to adapt to caregiving and provide the care required, despite reductions in sleep quality.

Chapter 6

In this chapter, the implications of this study for education, practice research and policy are discussed.

Education

In chapter 2, the process by which sleep takes place and the many ways in which it is fundamental to health were described. In this study, this process was explored in relation to caregivers of individuals with advanced cancer, but one could easily imagine many other situations across the life span in which sleep quality of caregivers may be compromised. This point is especially important given the increased reliance on caregivers in the home in the Canadian health care system. For this reason it is critical that nursing education programs provide basic content on the physiology of sleep and on strategies for promoting sleep. Buysse et al., (2003) found that there was minimal sleep-related curriculum in medical and nursing educational programs. While there may be shifts in the understanding and integration of sleep-related issues in nursing education (Lee et al., 2004), the importance of helping nurses understand their role in assessing and intervening in the domain of sleep remains important.

There is also a need for more education on the nature of caregiving and the implications of being a caregiver. The caregiving role is socially constructed, and thus, it is deeply rooted within the cultures where it is found. Over the course of their lives, most individuals are likely to find themselves in caregiving roles–caring for a parent, a friend, a spouse, or a child. As discussed at several point in this dissertation, caregiving has the potential to adversely affect health outcomes of the caregiver. Nursing students should therefore be taught to include assessments of caregivers in their health histories in order to increase early identification of potential declines in health status. Grant and Ferrell (2012) emphasize the nurses' role in caring for caregivers. For nurses to appreciate the extent of their involvement educational programs need to highlight the nature of the caregiving role, and learn ways in which they can support caregivers.

The study by Harding et al., 2012 exploring the needs of caregivers, those participants identified the need to be prepared, the need to be visible to healthcare professionals, and the need for illness specificity. All three needs were directly associated with healthcare professionals and one could argue with nursing staff. Nurses are front line staff who will encounter patients and their caregivers over and over. Educating nurses regarding the needs of caregivers and how to meet those needs could reduce negative outcomes that have been associated with caregiving.

This study highlights that caregivers want to continue to live as fully as possible while providing care. They incorporate pre-caregiving activities and "power through" despite declines in sleep quality. Educating nurses about some caregiver's desire to continue to provide care despite personal impacts may help nurses approach caregiver assessments with more than a what-can-I-help-you-with-attitude.

Practice

Culpepper (2002) explained that, in society, there is a general ignorance about sleep-related concerns and their impact on health, and that this ignorance contributes to hesitation in discussing sleep-related problems with health care providers, for fear that they will be labeled as having a psychiatric problem or exhibiting drug-seeking behaviors. In 1999 Engstrom and colleagues found that individuals with insomnia generally did not seek help, despite the common occurrence of insomnia, because either they believed that nothing could be done, or they did not think health care providers would address the problem. Saddichha (2012) explains that insomnia is largely under-recognized, under-diagnosed, and under-treated and that 30% of all adults complain of occasional insomnia. Insomnia assessments need to be implemented more regularly in practice especially in those populations, such as caregiving, where the focus may be more on the care recipient.

Supportive nursing actions are critical when individuals are in potentially stressful situations. (Lee et al., 2004, p. 126). Caregiver contacts with the health care providers are opportunities for nurses to explore sleep patterns and share important information about sleep (Colten & Altevogt, 2006), and provide basic information about ways to protect sleep. Haponik and Camp (1994) assert that "those who receive sleep-related education are more likely to ask individuals about past or current sleep problems" (p. 184). With that in mind, nurses who have been educated in the area of sleep are "…in a unique position to contribute to new knowledge about sleep and health promotion, monitor sleep habits, and disseminate information about sleep to patients (Lee et al., 2004, p.132).

Because caregivers don't always have the time to sleep, or have to sleep with "one foot on the floor," their ability to advocate for themselves and their care recipients may be limited. Nurses thus have a unique opportunity to support caregivers by advocating for them, and thus help them to "power through". Hebert, Moore, and Rooney (2011) explored the role of nurse advocacy in end of life care. They explain that the nurse-client relationship is the foundation of advocacy, with advocacy being a function of information and support where the nurse sees the client, in this case the caregiver, as

"…uniquely human, with individual strengths and beliefs, and uses this understanding to intervene on the client's behalf.

Advocating for the meeting of caregiver needs rather than simply offering to help remove caregiving from the caregiver may better serve the needs of the caregivers as discussed above. Caregivers in this study exuded a sense of meaning in their role and one that would not be given up easily. "Powering through" is not merely about sticking with something because there were no other options but a choice. Nurses need to practice supporting clients where they are at and with what they want to achieve, especially in a situation such as caregiving that could be objectively defined as a stressful situation but one that is also deeply meaningful to individuals.

Research

In chapter 2, I identified some of the methodological problems in the research on sleep and caregivers. The main problems were recruitment difficulty, limited longitudinal research, and small sample sizes.

It was difficult to recruit participants for this study. Individuals who consented to participate in this study did so for a number of personal reasons and their contribution was invaluable. However, there are likely many more caregivers who were not able or willing to participate. It is possible that these individuals may be finding caregiving stressful, and so it is particularly important to understand their experiences. There is a growing interest in involving individuals from any given population in the design of studies about them. In the interest of designing a study that best accommodates the unique needs of caregivers and increase participation one could add a pre-study phase during which, two to three individuals from the study population were invited to help refine the research questions and design the study.

Longitudinal research is needed within the caregiver population. “Powering through” was a unique finding of this study. More research is needed to understanding how individuals power through over the course of the caregiving experience, and this can only be obtained through longitudinal research.

In future studies, researchers should explore the relationships among length of time caregiving, sleep quality, health outcomes, and the ability to integrate pre-caregiving with caregiving activities. Relationships between the kinds of activities selected and various outcomes such as the ability to undertake caregiving over long periods, and caregivers’ health outcomes are urgently needed.

There is also a need for research to investigate how an individual’s created meaning of caregiving impact a caregiver’s ability to provide care. This research could be tied in with examination of how a caregiver appraises and copes with their situation and corresponding health behaviors.

Policy

Policy implications cannot be drawn from this study, given its limited scope, but when combined with other studies in this some area, some implications for nursing become clear. Arabi, Rafii, Cheraghi, and Ghiyasvandian (2014) explain the influence nurses exert in policy change

> …their values, professional ethics, advocacy skills, and experiences, nurse leaders have unique and valuable views toward health policies. There has been increasing growth toward nurses’ presence, role, and influence in health policies during

> recent decades. Nurses are expected to identify the issues deliberately and work with other decision makers to advance health care policies (p. 315).

With respect to caregiving, the literature supports the need to develop health policy that supports caregivers, particularly those who are older. The Canadian Medical Association (2015) detailed the needs of seniors with respect to healthcare, particularly, the need to enhance care of caregivers. As there continues to be an increased shift to home care versus hospital, particularly at the end of life, policy that supports the caregiver is a must. The nature of this support should be elaborated collaboratively with caregivers.

Summary

The education, practice, research, and policy domains all provide opportunities to build on the results of this study and advance knowledge about the relationships between sleep quality and caregiving. This work has the potential to significantly improve health outcomes.

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Appendix A-Information Letter, Informed Consent, Web Advertisement

Study Title: Exploration of the relationships among caregiver situation, sleep, adaptive capacity of family members providing care to those with advanced cancer

Supervisors:	Research Investigator:
Dr. Karin Olson Professor Faculty of Nursing	Danielle Gagnon
Office: 4-359 ECHA Edmonton, AB, T6G 1C9	University of Alberta
xxx-xxx-xxxx xxxxx.xxxxx@ualberta.ca	xxx-xxx-xxxx xxxxxxx@ualberta.ca

I thank you for your interest in this research project. You have been provided the following information as you indicated interest in this research due to your role as a caregiver of an individual who has advanced cancer and is no longer receiving treatment with intent to cure. I invite you to participate in this research as a way for health professionals to improve the services that are available to caregivers.

I am doing this study as part of my PhD program. The results will be presented at conferences and in journals but all information that could personally identify participants will be removed.

Purpose

Family caregivers provide invaluable care to individuals with cancer. Health professionals have a duty to provide support for caregivers. Providing quality support can only happen if health professionals are aware of the experiences of caregivers and what assistance would best serve this population. Sleep patterns of caregivers are not completely understood. The focus of this research is to gather a better understanding of the sleep patterns of family caregivers.

Study Procedures

The study is designed to gather a broad range of information. The study will consist of 1-2 interviews and completion of a brief questionnaire. An interview time will be scheduled which will take approximately 60 minutes. If there is a need for a follow up interview one will be scheduled at your convenience for a shorter duration. You will also be asked to complete a brief questionnaire at the time of the interview, which will take about 20 minutes.

Benefits

I appreciate that this particular subject may be accompanied by difficult emotional challenges. Agreeing to participate in this research will allow healthcare professionals to better understand the experience of the caregiver. Knowledge of this experience will allow healthcare professionals to better support those individuals who are providing care to ill family members. Additionally, you will be given an honorarium of $50 at the end of the study to thank you for your participation. This gift will be given as thanks at the end of the study, if for some reason you are not able to complete all the parties of this study, you will still be given your gift in appreciation for your efforts.

Risk

At this time no specific risks to taking part in this study have been identified. You may find some of the questions distressing. In addition to being a nurse, I am a certified psychologist and if will assist you in obtaining any additional psychological support you may require, at no cost to you.

Voluntary Participation

Consent to participate in this research is completely voluntary. Should you wish to withdraw at any time you may do so with no questions asked.

Confidentiality and Anonymity

I will store the information I receive from you in a locked filing cabinet at the University of Alberta and on a computer that is password protected. Only my supervisory committee members and I will have access to your information. All data will be kept for five years after the study is finished, and then will be discarded in a way that does not identify you.

All of your information will be identified by your study number only. A list linking your name and your study number will be stored separately. I plan to present my findings at conferences and in professional journals. All information that could identify participants will be removed from these presentations.

There is a potential that the data collected for this study may be used as foundation for further research in this area. If so, ethics approval will be first sought from the appropriate Research ethics Board.

Further Information

If you should need any additional information or further clarification please do not hesitate to contact Danielle Gagnon by phone at (xxx) xxx-xxxx or e-mail at xxxxxxx@ualberta.ca

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics board at the University of Alberta. For questions regarding participant's rights and ethical conduct of research, contact the Research Ethics Office at 780-492-2615

Information Letter and Informed Consent

Study Title: Exploration of the relationships among caregiver situation, sleep, adaptive capacity, and fatigue in family members providing care to those with advanced cancer

Supervisor:	Research Investigator:
Dr. Karin Olson Professor Faculty of Nursing	Danielle Gagnon
Office: 4-359 ECHA Edmonton, AB, T6G 1C9	University of Alberta
xxx-xxx-xxxx xxxxx.xxxxx@ualberta.ca	xxx-xxx-xxxx xxxxxxx@ualberta.ca

I thank you for your interest in this research project. You have been provided the following information as you indicated interest in this research due to your role as the primary caregiver of a family member who recently died as a result of a cancer diagnosis.

I am doing this study as part of my PhD program. The results will be presented at conferences and in journals but all information that could personally identify participants will be removed.

Purpose

Family caregivers provide invaluable care to individuals with cancer. Health professionals have a duty to provide support for caregivers. Providing quality support can only happen if health professionals are aware of the experiences of caregivers and what assistance would best serve this population. Sleep patterns of caregivers are not completely understood. The focus of this research is to gather a better understanding of the sleep patterns of family caregivers.

Study Procedures

The study is designed to gather a broad range of information. The study will consist of 1-2 interviews and completion of a brief questionnaire. An interview time will be scheduled which will take approximately 60 minutes. If there is a need for a follow up interview one will be scheduled at your convenience for a shorter duration. You will also be asked to complete a brief questionnaire at the time of the interview, which will take about 20 minutes to complete.

Benefits

I appreciate that this particular subject may be accompanied by difficult emotional challenges. Agreeing to participate in this research will allow healthcare professionals to better understand the experience of the caregiver. Knowledge of this experience will allow healthcare professionals to better support those individuals who are providing care to ill family members. Additionally, you will be given an honorarium of $50 at the end of the study to thank you for taking part in the study. If for some reason you are not able to complete all parts of the study, you will still be given your gift in appreciation for your efforts.

Risk

At this time no specific risks to taking part in this study have been identified. You may find some of the questions distressing. In addition to being a nurse, I am a certified psychologist and if will assist you in obtaining any additional psychological support you may require, at no cost to you.

Voluntary Participation

Consent to participate in this research is completely voluntary. Should you wish to withdraw at any time you may do so with no questions asked.

Confidentiality and Anonymity

I will store the information I receive from you in a locked filing cabinet at the University of Alberta and on a computer that is password protected. Only my supervisory committee members and I will have access to your information. All data will be kept for five years after the study is finished, and then will be discarded in a way that does not identify you.

All of your information will be identified by your study number only. A list linking your name and your study number will be stored separately. I plan to present my findings at conferences and in professional journals. All information that could identify participants will be removed from these presentations.

There is a potential that the data collected for this study may be used as foundation for further research in this area. If so, ethics approval will be first sought from the appropriate Research ethics Board.

Further Information

If you should need any additional information or further clarification please do not hesitate to contact Danielle Gagnon by phone at (xxx) xxx-xxxx or e-mail at xxxxxxx@ualberta.ca

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics board at the University of Alberta. For questions regarding participant's rights and ethical conduct of research, contact the Research Ethics Office at 780-492-2615

CONSENT

Title of Study: Exploration of the relationships among caregiver situation, sleep, adaptive capacity, and fatigue in family members providing care to those with advanced cancer

Principal Investigator(s): Danielle Gagnon **Phone Number(s): xxx-xxx-xxxx**

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 benefits and risks 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 are free to leave the study at any time,
☐ ☐
without having to give a reason and without affecting your (future medical care/employment, or without penalty)
☐ ☐

Has the issue of confidentiality been explained to you?
☐ ☐

Do you understand who will have access to your study records?
☐ ☐

(Do you want the investigator(s) to inform your family doctor that you are
☐ ☐
participating in this research study? If so, give his/her name __________________)

Who explained this study to you?
____

I agree to take part in this study:

Signature of Research Participant
____

(Printed Name) _________________________________
Date_____________________________

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

Signature of Investigator or Designee_______________________________

Date ______________________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

Letter of Invitation

RESEARCH CONTACT

Danielle Gagnon
Faculty of Nursing
University of Alberta
xxxxxxx@ualberta.ca
xxx-xxx-xxxx

BACKGROUND

Family caregivers provide invaluable care to individuals who require or required end-of-life care and who prefer or preferred to remain at home. Health professionals are interested in gaining a better understanding of the present and past experiences of caregivers so that they can provide the best possible support. One particular area that needs to be explored more is the sleep of family caregivers. The goal of this research is to obtain a better understanding of sleep in family caregivers. In the long term, I plan to develop ways to support family caregivers who are experiencing problems with their sleep. In appreciation for your participation in this research, you will be given a cash gift in the amount of $50 at the end of the study.

If you are:

- at least 18 years of age
- able to read, write, and understand English
- the primary caregiver for a person in your family who lives with you and has advanced cancer and is no longer receiving treatment with intent to cure **OR/**
- a bereaved caregiver who provided primary care for a family member during the end-stages of the illness
- willing to fill out a brief questionnaire and meet for 1-2 interviews that will take approximately 30-60 minutes of your time.

Name____

Phone Number____

Best time to call____

Is it okay to leave a message_____________________________________

Signature____

Web Advertisement

Researchers at the University of Alberta want to find ways to explore the impact of sleep problems in family caregivers who are providing or provided care for those individuals with advanced cancer.

Research is always voluntary!

Would the study be a good fit for me?
This study might be a good fit for you if:

- The primary family caregiver of an individual with advanced cancer/or a bereaved caregiver who provided primary care for a family member during the end-stages of the illness
- Over the age of 18
- Live with the care recipient
- Read, write, and understand English

What would happen if I took part in the study?
If you decide to take part in the search study, you would:

- Meet with the researcher in person or by phone, for a short time, once a month for three months
- Fill out questionnaires and answer a few questions
- a cash gift in the amount of $50

If you are interested in hearing more about this study, please contact Danielle Gagnon at xxxxxxx@ualberta.ca or at xxx-xxx-xxxx

Appendix B- General Information – Caregiver and Care Recipient

1. Relationship of care recipient to caregiver. You are caring for your…

☐ Husband/wife

☐ Parent

☐ Parent-in-law

☐ Daughter/son

☐ Sister/brother

☐ Other (please specify) ___________

2. Marital Status – caregiver

☐ Married

☐ Widowed

☐ Never married

☐ Divorced

☐ Common-law

☐ Other (please specify) ______________

3. Marital Status – care recipient

☐ Married

☐ Widowed

☐ Never married

☐ Divorced

☐ Common-law

☐ Other (please specify) ____________

4. Caregiver age _____________

5. Care recipient age _____________

6. Caregiver sex

☐ Male

7. Care recipient sex

☐ Male

☐ Female	☐ Female

8. Do you have chronic health problems? ☐ Yes ☐ No

If yes what are they?

Appendix C- Guiding Qualitative Interview Questions

Please tell me about your experience as a primary caregiver?

If sleep mentioned:

Please describe one or two instances in which your caregiving influenced your sleep.

If sleep not mentioned:

Some people have indicated that caregiving had an influence on their sleep. Did you notice this? If so, please describe.

Can you tell me about your experience as a caregiver?

How would you describe your role as a caregiver?

Is there anything particular about your experience as a caregiver that stands out for you?

Have you noted any particular challenges in being a caregiver?

Personally, have you noted any implications as a result of being a caregiver?

If sleep mentioned:

Please describe one or two instances in which your caregiving influenced your sleep.

If sleep not mentioned:

Some people have indicated that caregiving had an influence on their sleep. Did you notice this? If so, please describe.

Can you tell me how you have managed any challenges experienced as a caregiver?