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Sleep Deficit, Fatigue, and Health in Family Caregivers of Persons with Dementia Awaiting Placement

by

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“This is dedicated to the one I love …”

Thank you Jason for your love and support, with you by my side I feel as though I can do anything I can dream of! I look forward to a lifetime of adventure and growth while holding your hand. TMD.

Thank you Marcus, Brooke, Valerie and Olivia
For being the world’s most awesome kids while I learned to juggle and balance.

Thank you Dr. Priscilla Koop, for being my sage advisor through this journey, your gentle guidance during my own stress and adaptation will never be forgotten. I look forward to many more projects with you as my trusted colleague.

Abstract

Sleep, fatigue, and health have been extensively explored in family caregivers of persons with dementia (PWD). However, no published studies have looked at these variables during the time of awaiting placement, an important period of family caregiving. In this study, 41 family caregivers of PWD were interviewed following placement of their care recipient on the waitlist (T_1), immediately prior to admission (T_2) and following admission to long-term care (T_3). Correlation and hierarchical regression were utilized to explore the relationships among these key variables. We found that sleep deficit, fatigue, and health were interrelated at T_1 and T_2, and fatigue and health were related at T_3. Sleep deficit predicted poor health at T_3. We found that sleep deficit predicted fatigue at each of the three time points. Nurses need to pay special attention to the sleep needs of family caregivers of persons with dementia who are awaiting placement.

Keywords: family caregiving, dementia, sleep, fatigue, health, awaiting placement

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CHAPTER 1 – INTRODUCTION AND PROBLEM STATEMENT

In 2005, Statistics Canada released a report stating that the age of Canada's population is increasing and will likely do so at a moderate rate until after 2056 (Bélanger, Martel, & Caron-Malenfont). The long-range projections for the next 50 years show that the proportion of seniors will rise from 13% to greater than 25% (Bélanger, et al., 2005). This trend, where the older proportion of the population outweighs the younger age groups, is referred to as the aging of a population and is currently being felt in most developed countries worldwide. In addition, Statistics Canada projects that the age of the average Canadian requiring health care will also rise (Bélanger, et al., 2005).

The aging of Canada's population is a factor in the increasing prevalence of all types of dementia; individuals are living longer and therefore have a greater chance of developing diseases that manifest in older age (Alzheimer's Association, 2010). In fact, it is predicted that dementia prevalence will reach previously unseen levels with the aging of the "baby boomer" generation (Alzheimer's Association, 2010). A new study of epidemiological data including prevalence of the disease and economic costs for dementia care was published in June 2009 by the Alzheimer's Society of Canada titled: *Rising Tide – The Impact of Dementia on Canadians*. Results indicate that one in eleven Canadians over the age of 65 has some form of dementia, with a higher prevalence among women. They also report that as of 2009 there are approximately 500,000 individuals in Canada who have some type of dementia; a number that is predicted to rise in the next generation to reach 1 to 1.3 million Canadians (Alzheimer Society of Canada, 2009).

Dementia

Dementia is an umbrella term for a set of progressive neurodegenerative diseases that can be classified by type or severity. A diagnosis of dementia, according to the DSM-IV criteria, can be considered if an individual develops cognitive impairment that represents a significant decline in their previous functional level (American Psychiatric Association, 2000). In order to meet the criteria for a diagnosis of dementia, their impairment must include problems with memory, and at least one of aphasia, which is language disturbance, apraxia, which is motor disturbance, agnosia, which is identification or recognition disturbance, and a decline in executive function, which would be the ability to plan, organize, sequence, and abstract (American Psychiatric Association, 2000).

The most common types of dementia are Alzheimer's dementia, vascular dementia, dementia with lewy bodies, frontotemporal dementia, and mixed dementia. Although there are differing etiologic mechanisms at the root of each subset of dementia, overall the prognosis remains the same; dementia is a terminal illness in which individuals require progressively increased assistance as they move through mild, moderate, and severe stages of the disease.

Along with functional changes, individuals with dementia are also at risk for sleep disorders. Sleep changes occur as a part of normal healthy aging, as a result of various physical or mental health conditions, as a result of a primary sleep disorder, as a result of poor sleep hygiene, or as a combination of these four groupings (Vitiello & Borson, 2001). In addition there is a positive correlation between sleep disturbances and severity of dementia (Bliwise, Hughes, McMahon, & Kutner, 1995). The reasons for increased sleep disturbance in this population are unclear but there is some evidence that individuals with dementia have some damage in the suprachiasmic nucleus (SCN) that initiates and maintains sleep. Damage in this area affects the ability to synchronize neuronal impulses and the release of hormones such as melatonin, which are important contributors to the sleep process.

The sleep patterns of people with dementia may also be affected by neuropsychiatric symptoms such as wandering, restlessness, and disinhibition that are associated with dementia. These above mentioned behaviours belong to a spectrum of symptoms also known as the behavioural and psychological symptoms of dementia (BPSD). BPSD can affect how a person with dementia sleeps. This factor can affect the setting in which dementia care is delivered. Because a formal diagnosis of dementia is usually made in the early to moderate stages of the disease, it is common for individuals with mild, moderate, and occasionally moderate to severe dementia to be living in the community, with family members or friends/neighbors who take on an informal caregiving role. It is believed by some that this community-based setting is associated with a greater sense of autonomy, dignity, and increased quality of life for persons requiring increased support or care, and has been reported to be the preferred choice of many Albertans (Alberta Health and Wellness, 2008).

Caring for Individuals with Dementia in the Community

Maintaining seniors with dementia in the community requires the support of committed individuals. In this study these individuals will be referred to as family caregivers (FCGs), but are also known in health care literature as carers, informal caregivers, or family and friend caregivers. Family caregivers may be required for individuals in a variety of circumstances, such as for individuals with physical or mental disabilities, chronic illness, or cancer diagnosis; however this paper refers to family caregiving in the context of dementia care. These family caregivers provide support and assistance for individuals with dementia in areas such as providing transportation, assisting with financial tasks, socialization, and activities of daily living such as bathing, toileting, and feeding.

Family caregivers have been examined in the literature in a variety of ways. Some of the issues that have been explored include; motives for providing care, benefits and burdens associated with the caregiving role, physical and mental health in caregivers, and exploration of coping and decision making in caregiving. Much research has been done in this area, and done specifically with the family caregivers of individuals with Alzheimer's dementia. It is generally accepted that caregiving can be rewarding for family caregivers (Sanders, 2005), however there are also physical, emotional, and financial costs associated with providing informal care. (Wilkinson & Lynn, 2005)

Disease trajectories affect the experiences and needs of family caregivers. Wilkinson and Lynn propose three distinct trajectories of advanced illness; the cancer trajectory, the organ system failure trajectory, or the dementia/frailty trajectory (2005). The cancer trajectory, is characterized by a disease process that is long and stable but ends with a rapid decline near the end of life (Wilkinson & Lynn, 2005). Caregivers for these individuals may view the disease process and therefore their caregiving role as having a finite end, but their caregiving experience may be quite light for a long time, with an intense period of caregiving required in the terminal stage. Individuals in the organs system failure trajectory may experience long periods of stable disease management interspersed by periods of disease exacerbation (Wilkinson & Lynn, 2005). As such, the caregiving role may be necessary from time to time, but care recipients may regain their health at or close to their previous level and no longer require the caregiver's assistance at the same level as during the exacerbation. Individuals in the dementia/frailty trajectory experience a slow decline, eventually leading to the end of life phase (Wilkinson & Lynn, 2005). Therefore the need for the family caregiver role is present and required for a long period of time. Some of the many demands and stressors felt by FCGs associated with caring for an individual with dementia include: changes in physical, psychological and financial responsibilities, feelings of worry, grief, and loss over the care recipients' declining health, role changes, as well as the physical changes that accompany normal aging. As the needs of the care recipient increase gradually, they eventually exceed caregiver resources. In some literature this phenomenon is referred to as caregiver burden.

As dementia progresses, functional limitations increase for the individual with dementia and the manifestations of late-moderate or severe disease can become more challenging for the caregiver. Family caregivers experience an increase in physical workload as the person with dementia experiences a decline in motor and functional ability and thus becomes less able to manage their activities of daily living. The psychological stress of providing care also increases as the care recipient may become socially or culturally inappropriate or unpredictable.

Fatigue is a common problem among caregivers (Matsuda, 2001). When compared to non-caregivers, FCG reported greater fatigue, lower energy levels, more difficulty sleeping, lower quality sleep, and more emotional exhaustion (Matsuda, 2001; Sato, Kanda, Anan, & Watanuki, 2002; Teel & Press, 1999b).

Family caregivers also report difficulty sleep problems, which may lead to caregiver burden. Fatigue and difficulty sleeping decrease the ability of the family caregiver to provide the care required by the care recipient. Along with the changes that occur as a part of normal healthy aging, such as increased fragmentation of sleep, decreased sleep efficiency, shifts in sleep onset and waking (Buckley & Schatzberg, 2005), caregivers' sleep can also be disrupted as a result of various physical or mental health conditions, a primary sleep disorder, poor sleep hygiene, or a combination of these factors (Vitiello & Borson, 2001), and the added responsibilities of caregiving, which may lead to sleep disrupted by worry and concern. The sleep of family caregivers may also be disturbed by the actions or needs of the care recipient, such as nighttime awakenings or wandering behaviour.

When the caregiving requirement for a person with dementia outstrip the personal and community resources available to their caregiver, formalized long-term care in an institutional setting may become the most appropriate option. This decision can be difficult for the family caregiver to make. Relinquishing caregiving responsibilities is often seen as an undesirable option and so FCG may try to continue providing care until they are overwhelmed (Skodol Wilson, 1989).

The decision to institutionalize may be immediately precipitated by a serious event such as an injury, illness, or incident - or may be a more gradual decision made over time. Some of the factors that may lead to the decision to institutionalize include the presence of BPSD (Aarsland et al., 2007; Finkel, Costa e Silva, Cohen, Miller, & Sartorius, 1996; Finkel, 2003) or decreased care recipient independence (Cohen-Mansfield & Wirtz, 2009).

Family caregiver characteristics may also predict the decision to institutionalize. Caregivers who report high levels of distress or hopelessness (De Vugt, Stevens et al., 2005; Gaugler, Yu, Krichbaum, & Wyman, 2009), those who report fear and anxiety related to their own safety (Liken, 2001), and those who perceived a lack of family support (Liken, 2001), or those who report physical or psychological exhaustion (Liken, 2001) were more likely to move towards institutionalizing their care recipient.

McLennon, Habermann, and Davis, 2010 found two themes in their study about decision-making regarding institutionalization; “anticipating the inevitable” and “reaching the limit”. The decision to institutionalize often happens when the care recipient’s needs outweigh the resources of the family caregiver (Schulz et al., 2004). An important resource available to family caregivers is sleep, and sleep disruption has been identified as a factor in the decision to institutionalize (McCurry et al., 1999; Wilcox & King, 1999; Hope, Keene, Gedling, Fairburn, & Jacob, 1998; Pollak, Perlick, Alexopoulos, & Gonzales, 1994; Pollak & Perlick, 1991).

Currently in Alberta, waiting for placement in a long-term care residence can involve a lengthy process of assessment for the most appropriate care setting, and then queuing according to urgency of need. In some cases, this process can take more than 12 months, a fact which may not be known to the FCG before they begin the process of getting their care recipient on the waiting list. Historically, individuals on the waitlist who were in the community setting had priority for LTC beds because they were viewed as having fewer supports available to them. However with the recent push to decrease emergency waits and utilize acute care beds more appropriately, individuals waiting in the hospitals currently receive priority placement.

This period of waiting for placement may be a time of great stress for the caregiver. The FCG has provided care for the care recipient for as long as they felt they were able, and then went through the difficult process of deciding to pursue institutionalization for their care recipient only to find out they have to continue providing care until a space open up. As a Nurse Practitioner with experience in seniors' clinics, community, and LTC, I recognize the valuable service that family caregivers provide. While working in the clinic and community setting I frequently called on family caregivers to provide current information about my patients and to carry out the interventions and treatments I prescribed. My experience in the LTC setting revealed to me that the placement process was stressful for both the caregiver and care recipient. As a result of these experiences, I am passionate about family caregivers' health while they are awaiting placement of their care recipient.

The health of the FCG in the caring dyad is as important as the health of the care recipient. As the institutionalized care system currently stands, family caregivers are required to provide intermediate level care to those individuals who are not ready for formalized settings. Health care practitioners need to support the health of caregivers and recognize what may be subtle clues that mark a decline in FCG health.

Conceptual Frameworks and Definitions

Stress.

Hans Selye, who many believe is the grandfather of stress theory, proposes that an individual's ability or inability to adapt to stressors has a physical effect on the body that can be measured physiologically. Selye hypothesized that health is a measure of the efficiency of an individual's homeostatic mechanisms.

Selye defines stress as "the nonspecific response of the body to any demand placed upon it" (Selye, 1974). Selye hypothesizes that the adaptation to stressors is accomplished through the hypothalamic-pituitary-adrenocortical axis (HPA axis) by means of a generalized adaptation syndrome (GAS). He proposes that the GAS is broken into three stages; alarm, resistance, and exhaustion, and individuals move fluidly back and forth between them depending on the degree of stress experienced. Selye hypothesizes that individuals in the first stage of GAS were coping in a healthy way, but that chronic activation of the HPA axis was associated with a move to the ‘resistance’ stage of GAS, which may become a chronic state. The HPA axis is one of the pathways by which the body can express stress as a physical response. Selye believes that it was the forward progression along the GAS pathway and chronic activation of the HPA axis that causes enlargement of adrenal glands, atrophy of lymph organs, and gastrointestinal bleeding. These reactions have since been attributed in part to HPA axis activation which supports Selye’s belief that physical and mental illness can be the result of prolonged stress (Goldstein & Kopin, 2007).

It has been hypothesized that HPA-axis activity increases with normal healthy aging (Buckley & Schatzberg, 2005). It is thought that structural and functional changes in the hippocampus are related to these changes, which cause disinhibition of the HPA axis – and therefore there is HPA axis hyperactivity as an inherent part of aging. This has negative implications for the family caregivers, especially for those who are in the later half of their life.

Many of the experiences of family caregivers can be viewed as stressors. Looking at this situation in the context of Selye’s physiologic stress model, family caregivers may experience physiologic changes in response to the chronic stress of providing care. As hypothesized by Selye, individuals may not recognize when they are shifting through the stages of GAS. As the care recipient’s condition declines, family caregivers call on their resources, both internal and external, to help them adapt. For family caregivers who are constantly adapting to their changing roles, the shift between the healthy adaptation that occurs in the alarm phase of GAS and the unhealthy phases of resistance or exhaustion may go by unrecognized.

Caregiving can be viewed as a balancing act, where individuals must carefully balance between giving enough to care recipients to meet their needs, but not so much that the caregiver's own resources are depleted (Lowder, Buzney, Buzo, & Loue, 2005). A tipping in the balance of this caregiving homeostasis may be what prompts caregivers to think seriously about institutionalization. The decision to institutionalize their care recipient is a difficult one for caregivers to make, and one that is inherently stressful due to the multitude of factors that are present in any given situation.

When caregivers recognize that institutionalization is required, they may have expended key resources and have shifted, or be shifting into the resistance phase of GAS. This may be evidenced by increased caregiver fatigue or a decline in health. The relationships among fatigue, sleep, and health are important in the context of stress and adaptation for the unique timeframe of waiting for placement, where individuals must continue to be caregivers while they may be struggling to adapt to the increasing needs of the care recipient.

Fatigue.

Fatigue is an important factor to investigate in family caregivers because it interferes with quality of life, decreases functional capacity, and may limit an individual's ability to fulfill their role responsibilities (however it is that they perceive them to be). Caregiving is hard work, both physically and psychologically and it stands to reason that this complex role is associated with fatigue on many levels and to different degrees dependent on the circumstance and situation.

One issue in studying fatigue is the use of the word in everyday language. The term fatigue is well known, and is typically used by individuals to describe feeling tired or worn out. Clinically however, fatigue needs an objectively measurable definition. The Fatigue Adaptation Model (FAM) is congruent with Selye's physiologic stress theory, and posits that fatigue is a response to an individual's stressors (Olson, 2007). The movement between the three distinct phases in FAM (tired / fatigued / exhausted) occurs as the individual either adapts or does not adapt to the stressors they are experiencing. How an individual perceives their situation and their ability to cope mediates their stress response (Olson, 2007). At this point the FAM has been used primarily to explore cancer patient populations but one can hypothesize that the model is also useful in the family caregiving population.

In the Fatigue Adaptation Model caregiver tiredness could be seen as the normal response to the stressors they are experiencing. Fatigue occurs when an individual's response to stressors requires a significant energy output As energy is depleted they move to the resistance phase and then the exhaustion phase of GAS. This progression to resistance and exhaustion may place them at increased risk for compromised health.

Sleep deficit.

In this study I am particularly interested in the role that sleep plays in FCG fatigue and health. Sleep is a universal phenomenon in the life of all human beings, most of whom experience a sleep-wake pattern that is tied to the Earth's day-night pattern and regulated by their individual circadian system. A widely accepted belief is that adults require approximately eight hours of sleep per night to maintain good health and functional ability; however sleep requirements are quite individualized. Why individuals require sleep is a puzzle that has no definitive answer in the literature. The consequences of sleep disturbances include memory loss, short attention span, loss of speech fluency, decreased flexibility in thinking, depression, and attenuated growth (Norman & Haywood, 2005).

There are two main hypotheses for the purpose of sleep in humans; sleep is a mechanism for energy conservation, and/or sleep is required for processing and storing the information collected through the senses during wakefulness. The first of these theories is plausible, as the body has a metabolic decrease in energy use of 5 to 15% during sleeping hours (Ravussin, Lillioja, & Anderson, 1986). However, other current trends in sleep theory include sleep as a form of memory reinforcement, where neural circuits that process information during wakefulness are temporarily used to process and store data (Kavanau, 2002) or sleep as a function of cell repair due to neurotransmitter synthesis and the release of growth hormone. It is also possible that a combination of these purposes and many other purposes compel us to sleep.

Although theories about why we sleep vary, it is well accepted by healthcare professionals, researchers, and lay persons alike that sleep is a requirement for a healthy life. There are various ways to measure sleep such as polysomnography or actigraphy however these methods aren't easily available in the community setting and may not reflect actual sleep time or an individual's sense of sleep sufficiency. A caregiver who lies still in their bed for 8 hours but does not sleep, or one who sleeps lightly may not feel as though they get enough sleep due to their caregiving responsibilities or worries.

Health.

Health is a complex concept and can be difficult to measure, as people can have individual definitions of what health entails. In the health care literature, there are many conceptualizations of health and equally as many ways of measuring it. For this study, J. Ralph Audy's (1971) conceptualization of health, which focuses on an individual's ability to rally from a variety of physical, psychological and social stressors.

Along with the ability to adapt to the stressors an individual faces, Audy posits that healthy individuals are resilient to a certain degree as well. Audy proposes that individuals are constantly balancing adaptation to and protection from insults, and that health is actually a marker of an individual's ability to maintain homeostasis. Audy's definition of health further divides into four distinct categories; physiologic health, immunological health, psychological health, and social health. The hypothesis is that an insult that affects one kind of health is also likely to have effects on the other domains of health.

Family caregivers for persons with dementia epitomize this theory. When individuals reach the point in their caregiving trajectory where they are considering moving the care recipient to a formalized setting, they may have a deficit in one or more of those before mentioned health categories. It is possible that the FCG may have underlying acute or chronic disease that that may or may not be directly related to their caregiving status but whose management has been affected because of the caregiving role; ie: treatment delays related to lack of respite, or apathy towards their own health due to depression/isolation. It is because of these factors that caregivers may not be as resilient to illness as those who are not in the caregiving role.

Care recipient functional status.

The following working definitions are adaptations of the Functional Assessment Staging (FAST) scale (Reisberg, 1986) which is one of the tools available to clinicians and experts in the field of dementia. According to FAST, individuals with mild dementia may have problems functioning in demanding occupational or social settings or they may have problems performing complex tasks of daily life such as managing finances or planning events (also known as the instrumental tasks of daily living or IADLs). Those with moderate dementia may also have problems with self care, such as choosing appropriate clothing for the season, or independently initiating or performing personal hygiene. Individuals with moderate to severe dementia require a caregiver for tasks related to activities of daily living (ADLs) such as dressing, bathing, and toileting, as well as complete management of IADLs. Severe dementia is marked by reduction in communication skills and physical ability. Persons with advanced stages of dementia may only be able to speak single words or short phrases in the early stages of severe dementia and decline to one or two single words in the later stage of severe dementia. Physical ability also declines in severe dementia where individuals lose their ability to ambulate, and eventually are unable to sit up, smile, or support the weight of their head.

Summary Statement

As the population ages, and the need for family caregivers in the community to provide assistance for those with dementia continues, it is important to understand the relationships among fatigue, sleep and health in this population. Relationships among sleep, health, and quality of life are well supported in current literature. Fatigue and problems with sleep are common issues for family caregivers for a multitude of reasons. A better understanding of these factors and the relationships among them and health outcomes could better guide individual care planning as well as the development of the community-based services for family caregivers in this area. There is a need for pragmatically designed tools that could be used by health care providers to measure these factors in the community setting. Simple scales that measure general fatigue, level of sleep deficit, and global heath and functional status of the care recipient could provide health care providers with important information about the well-being of the caregiver while the care recipient is awaiting placement without imposing the burden of intrusive and time consuming testing.

CHAPTER 2 – REVIEW OF THE LITERATURE

Family caregivers of persons with dementia are the focus of a growing field of research. However, little has been published about the period of time that has been called “awaiting placement”. Specifically, this period of time begins when the care recipient is placed on the waitlist for formalized care outside of the home, and ends when a space becomes available and the CR is institutionalized. At some point prior to this time the caregiver has become aware that they can no longer meet the care recipient’s needs.

Strang, Koop, Dupuis-Blanchard, Nordstrom, Thompson (2006) published the results of their mixed methods study that looked exactly at this point in time. Examination of the qualitative data revealed four common themes that were reported by the family caregivers during the awaiting placement period. The themes that emerged were “crisis as an initiator”, “synchronicity”, “control”, and “reciprocity”. Often caregivers stated that the period was initiated by a crisis, examples of which may be an acute illness for the caregiver or care recipient, a fall or injury, or unsafe behavior such as wandering or aggression. Caregivers also reported the fear of a “looming crisis” that could occur at any time. Along the synchronicity theme, caregivers described feeling that their readiness for care recipient institutionalization wasn’t timed well with the system. Either a space was available when the care recipient did not require it, or there was no available space when the caregiver felt it was time for institutionalization. The theme of control was identified from caregiver statements describing the effort required to remain in control of their caregiving or of feeling that they had lost control of the situation. Reciprocity was the final theme identified during the awaiting placement period and was identified though caregiver reports of congruent or mismatched expectations between the caregiving/care receiving dyad.

These four themes are important in the context of understanding the caregiver's experience of waiting placement. For health care practitioners, it is also important to understand aspects of the caregiver's health in this uncertain and demanding period of time in the trajectory of providing care. Sleep and fatigue may be important early indicators of impending declines in the health of FCGs to look at when assessing the health of a caregiver/care recipient dyad in the community setting. A better understanding of the relationships between fatigue, sleep and caregiver health may provide useful knowledge for health care providers to better provide care or develop services to better support those who are awaiting placement. Quantitative data on the variables fatigue, sleep deficit, and self-rated health were collected in this study however those data had yet to be analyzed prior to this study.

Only two other studies were found that looked at this unique period of time. However neither study explored fatigue, sleep, nor directly looked at health. (Reuss, Dupuis, & Whitfield, 2005) looked retrospectively at the waiting period and explored the experience of transition to formalized care through the caregivers perspective. Their findings supported (Strang et al., 2006) reports that caregivers in this period experience ambiguity during the waiting period, and further they report that caregivers expressed anxiety related to the timeline uncertainty.

The other publication came from the longitudinal study “Resources for Enhancing Alzheimer’s Caregiver Health” or (REACH study) (Schulz et al., 2004). This study described caregiver health and well-being before waitlist placement to a point past long term care placement however did not publish details of the waiting placement period, and looked at variables only as they had changed from the pre institutionalization period to the post institutionalization period.

The awaiting placement period in the caregiving trajectory is an important one to look at, because it is a time of transition for the caregiver/care recipient dyad. In pre awaiting placement, the caregiver manages their role independently with community supports and maintains some degree of control in their day-to-day life. At some point caregivers recognize that the needs of the care recipient outweigh the resources that are available to them and they make the decision to institutionalize. It stands to reason that this decision making process may take a long time for many caregivers, and caregivers may not anticipate that the awaiting placement period can take more than 12 months. During these months the caregiver likely has little to no idea when a space will open up for their care recipient and no control over the placement process. Family caregivers may experience heightened vulnerability and require extra supports. Health care practitioners have nearly no published data to draw on for this population at this point in the caregiving trajectory and therefore the awaiting placement period needs to become a priority research topic.

The Key Variables

Previous work in family caregiving has identified that caregivers are typically female, over the age of 60 and caring for a parent, spouse, or close relative/friend (Costa, Sanvitto, Turazzini,& Silvestri, 2000, and Dahlberg, Demack, & Bambra, 2007). Although not all caregivers fall into these categories it is an important factor to consider. As caregivers age they are more likely to have health concerns of their own which may be exacerbated or neglected due to the caregivers' responsibilities. Also, this population may have fewer personal resources, such as a hearty social support network, or an income. Another thing to consider is the relationship between caregiver and care recipient. Family caregivers may have relied on their care recipient in the past as a parent or spouse and now has to navigate a change in role.

Fatigue in family caregivers of persons with dementia.

No published studies were found describing fatigue in the FCG of PWD while waiting for placement in an institutional setting. In fact, fatigue in FCG of PWD has been scantily published. We know that being a family caregiver is a big role in which there are many responsibilities and challenges. Therefore it makes sense that caregivers may experience fatigue at different points and to different degrees during their role. Clark (2002) found that nearly a third of participants in their study of caregiver hardiness reported fatigue, and that providing care for someone with memory or behavior issues was associated with the highest levels of fatigue. Another study found that caregivers who felt the lowest levels of mastery in their caregiving role reported the highest levels of both physical and emotional fatigue (Roepke et al., 2009).

Although fatigue in FCG of PWD research is scant, there is a greater body of research in the area of fatigue and FCG of persons with cancer (PWCa). Similarities in fatigue measurements of the two populations on this variable have been found in previous studies (Teel & Press, 1999) Associations between increased fatigue in FCG of PWCa and age, perceived burden, income (Gaston-Johansson, Lachica, Fall-Dickson, & Kennedy, 2004), gender, working status (Gaugler et al., 2008), FCG anxiety, FCG perceived support (Fletcher, Schumacher, Dodd, Paul, Cooper, Lee, West, Aouizerat, Swift, Wara, & Miaskowski, 2009a) have been reported in the literature. Another emerging area of research is the possibility of the role of genetic variation in FCGs and the link between fatigue and proinflammatory cytokines as discussed in the above 'health' section (Miaskowski, Dodd, Lee, West, Paul, Cooper, et al., 2010).

What we don't know is the level of fatigue perceived by the family caregivers of persons with dementia who are awaiting placement. We also don't know how fatigue changes during this period. These data have been collected in the Coping While Waiting Placement study (Strang et al., 2006) but not previously analyzed.

Sleep in family caregivers of persons with dementia.

There have been no published studies that look at sleep in FCGs of PWD specifically during the period of awaiting placement. However we know that sleep disturbances are not uncommon for FCG of PWD. Reports of sleep disturbance in family caregivers vary from 50% to nearly 70% (Ferrara et al., 2008; Creese, Bédard, Brazil, & Chambers, 2008; McCurry, Gibbons, Logsdon, Vitiello, & Teri, 2005) in the current literature and can occur as often as three nights or more each week (McCurry et al., 2005). These studies likely include caregivers who are in the awaiting placement period of their caregiving trajectory, however this time period was not explicitly reported on.

It is not surprising that FCG of PWD have disrupted sleep in the context of a 24hr/day caregiving role. In comparison with non-caregivers, FCGs of PWD spend more time trying to fall asleep (Castro et al., 2009), sleep less (Teel & Press, 1999b), have more frequent disturbances (Castro et al., 2009), and report lower quality sleep (Creese et al., 2008). They also report greater night-to-night variability in their sleep however this is not always captured in objective studies such as polysomnography (Rowe, McCrae, Campbell, Benito, & Cheng, 2008a). It has also been reported that FCG of PWD have greater difficulty sleeping when compared to individuals with chronic pain (LoGiudice et al., 1998).

There are likely many variables (such as increased worry or concern over caregiving role or disruption caused by care recipient behavior) that play a part in the disruption of sleep experienced by FCGs. Depression (Ferrara et al., 2008; Rowe, McCrae, Campbell, Benito, & Cheng, 2008; Beaudreau et al., 2008; Creese et al., 2008), stress (Kochar, Fredman, Stone, & Cauley, 2007), and perception of burden (Allegri et al., 2006) in the caregiver have been associated with sleep problems.

It is now well known that sleep patterns undergo many changes over the lifespan (Ohayon, Carskadon, Guilleminault, & Vitiello, 2004) .These age-related changes are important in the caregiving population because Canada's caregivers are aging in conjunction with the rest of the population .Seniors' ability to initiate and maintain sleep is decreased and total sleep time is shorter, shallower, and more disrupted than in younger individuals (Espiritu, 2008) .These changes are clinically relevant because poor initiation and maintenance of sleep is associated with increased rates of illness and death in the elderly population (Espiritu, 2008) .To that same end, it is found that health and longevity can also be predicted by a senior's duration of sleep, with both too much and too little sleep being a health risk factor (Espiritu, 2008)

The sleep changes that occur as part of the normal aging process are related to timing of sleep and sleep architecture .The nocturnal sleep phase occurs earlier in the evening and a more habitual sleep schedule was noted in older persons (Ohayon, Carskadon, Guilleminault, & Vitiello, 2004) .The architecture of sleep shows great changes over an individual's life span with different aspects leveling out at different times in development .In seniors, Stage 1 and 2 of non-REM sleep increase while the proportion of stage 3 and 4 (or slow-wave) sleep decreases (Ohayon et al., 2004) .Proportion of REM sleep also declines as we age, but has stabilized sometime in mid-adulthood (Ohayon et al., 2004) .

Currently there is no published research that looks at any measure of sleep during the awaiting placement time period. Health care practitioners need to know if caregivers are at risk for greater sleep difficulties as they wait for their care recipient to be institutionalized. It would be important for health care practitioners to have an understanding of how prevalent and to what level family caregivers have problems with sleep during this time of waiting. Sleep is an important aspect of life, and disrupted sleep may lead to decreased quality of life, or a decline in health or function.

The aforementioned “Coping While Waiting Placement” (Strang et al., 2006) study calculated sleep deficit data by subtracting hours of actual sleep from the hours of needed sleep. These data could be analyzed to obtain an average baseline sleep deficit score as well as changes in scores along the awaiting placement timeframe.

Health in family caregivers of persons with dementia.

There were no published studies found that directly relate to the health of FCG of PWD during the time of waiting for long-term care placement, however there have been many studies of health during the period of providing care, as well as the period after the care recipient has been institutionalized. The literature is clear that providing care for an individual with dementia affects both the psychological and physiological health of the caregiver.

Psychological health.

The emotional health and depression in family caregivers of persons with dementia have been explored in the empirical literature. Much of the early literature in this area looked at “caregiver burden” or “burnout” and explored the difficult or more negative aspects of the caregiving role. Other studies recognize that some family caregivers may also have positive experiences (Farran, Keane-

Hagerty, Salloway, Kupferer, & Wilken, 1991; Cohen, Colantonio, & Vernich, 2002). One study found that nearly one third of FCGs of PWD report both positive and negative feelings towards their caregiving role (Sanders, 2005). Some of the benefits of providing care include a sense of spiritual or personal growth and an increased sense of mastery, while some of the stressful parts of their role were related to their worries and concerns, balancing multiple demands, and feeling overwhelmed by their duties (Sanders, 2005).

Family caregivers report higher levels of emotional stress and burden than their non-caregiving counterparts (Son et al., 2007; Sanders, 2005; Kim & Knight, 2008). FCGs with the highest levels of stress also report the poorest health and physical function and were more likely to report symptoms of depression (Lu & Wykle, 2007).

Prevalence of depressive symptoms varies in the literature and has been reported in as many as one third of family caregivers of PWD (Taylor, Kuchibhatla, & Ostbye, 2008; Yaffe et al., 2002). These numbers may vary due to the type of family caregiver that was being studied or the point in time during the caregiving trajectory the data were recorded. FCGs of PWD who have been in the caregiving role for many years or who are caring for an individual who requires a large amount of assistance exhibit more anxiety and depressive symptoms in comparison to other caregivers (Ferrara et al., 2008). Providing care for persons with BPSD was also associated with lower mental health (Hooker et al., 2002). Of course there are many other factors that put an individual at risk for depression that are not limited to but also occur in FCGs of PWD, such as chronic health issues, low socioeconomic status, and low social supports. Depression impacts the day to day function of affected individuals, decreases quality of life, and for FCGs, may even decrease their ability to fulfill the caregiving role.

Health behaviors.

There is debate about the general health of FCGs compared to non FCGs. One review of the literature reported only weak associations between caregiving status and various markers of physical health (Schulz, O'Brien, Bookwala, & Fleissner, 1995) However a more recent meta-analysis reported in comparison to non-caregiving counterparts, FCGs reported more health problems (Vitaliano, Zhang, & Scanlan, 2003). Some explanations for the different findings include differences in how they collected data for their studies, what they measured, and how they worded their research instruments. Other studies have shown that FCGs of PWD exhibit decreased self-care behaviours (Son et al., 2007), more emergency room visits and acute care admissions (Schubert et al., 2008; Dwolatzky, 2006; Son et al., 2007), and increased mortality (Christakis & Allison, 2006; Dwolatzky, 2006; Schulz & Beach, 1999). These finding support the hypothesis that family caregiving of persons with dementia has a negative effect on an individual’s general health.

Stress and health.

The “stress hormone” cortisol plays a role in many physiologic processes and can be measured in the blood or saliva of an individual. It has been shown that serum cortisol levels are elevated in FCG of PWD, and to a greater degree if the care recipient had BPSD (De Vugt et al., 2005; Wahbeh, Kishiyama, Zajdel,

& Oken, 2008). Caregivers who had elevated stress markers also were more likely to rate their health more negatively, (Son et al., 2007) exhibit signs of depression, and have a decreased level of functioning(Lu & Wykle, 2007). It is hypothesized that in this population chronic stress causes a release of cytokines which in turn cause changes in the immune system (Damjanovic, Yang, Glaser, Kiecolt-Glaser, Nguyen, Laskowski, Zou, Beversdorf, & Weng, 2007; Gouin, Hantsoo, & Kiecolt-Glaser, 2008; Mausbach et al., 2008). Salivary cortisol is also elevated from normal levels in FCGs of persons with dementia and this may account for increased gingival symptoms and incidence of periodontitis that has been reported (Gallagher et al., 2008; Hilgert, Hugo, Bandeira, & Bozzetti, 2006; Vitaliano, Persson, Kiyak, Saini, & Echeverria, 2005).

Immune health.

Family caregivers of persons with dementia have decreased immune function and report more sick days than non-caregivers, a finding that increases if the care recipient has BPSD or the caregiver is socially isolated (Kiecolt-Glaser et al., 2003). FCGs of PWD also exhibit a decreased inflammatory response (von Känel et al., 2006; Redwine et al., 2004) despite increased proinflammatory marker production (Damjanovic, Yang, Glaser, Kiecolt-Glaser, Nguyen, Laskowski, Zou, Beversdorf, & Weng, 2007; Kiecolt-Glaser et al., 2003; Lutgendorf et al., 1999). FCGs of PWD have been reported to have decreased antibody response (Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, & Sheridan, 1996; Li et al., 2007) and decreased ability to produce mature immune cells (Redwine et al., 2004; Damjanovic, Yang, Glaser, Kiecolt-Glaser, Nguyen, Laskowski, Zou, Beversdorf, & Weng, 2007) and those who exhibit elevated stress markers also heal wounds at a slower rate (Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1995). These changes in immune system could explain why some FCGs are less resilient to illness.

Cardiovascular health.

As well as changes to their immune system, FCGs of PWD also have increased incidence of cardiovascular diseases. A prospective 6 year study found that FCG of PWD were more likely to become hypertensive than non-caregiving controls (Shaw et al., 1999) or have coronary heart disease (Vitaliano et al., 2002). These findings were supported by a later study which compared FCGs to non-caregiving controls using the Frammingham CHD risk score tool (von Kanel et al., 2008). Another study reported that older men in FCG roles were more likely to have metabolic syndrome (which they describe as HTN, obesity, and disturbances in serum insulin, glucose, and/or lipid levels), and that FCGs were more likely to increased d-dimer (Aschbacher et al., 2005) or coagulation abnormalities (von Kanel et al., 2006).

Cognitive health.

There is growing evidence that FCGs of PWD also are at a greater risk of developing cognitive dysfunction than non-caregiving counterparts. Early studies looked at general measures of cognitive functioning and found that FCGs scored lower than those not in caregiving roles (Caswell et al., 2003; Lee, Kawachi, & Grodstein, 2004). In a prospective study family caregivers of PWD who were matched to non FCGs of the same age and baseline cognitive function exhibit more cognitive decline when followed for two years, especially when metabolic risk factors (such as abdominal obesity, high cholesterol, increased BP, or blood glucose issues) are present (Vitaliano et al., 2005; Vitaliano et al., 2009). A relationship is also seen between the caregivers' ability to perform in verbal memory tasks and FCGs perception of their ability to provide competent care (de Vugt et al., 2006). In regards to the trajectory of FCG cognitive decline a recent study has shown that FCGs exhibit a faster decline in cognition when compared to non-caregivers (Vitaliano et al., 2009).

Much of the research being published in this area is highly detailed and requires invasive testing, and while specific tests of serum and salivary markers of stress are important to help researchers tease out causes and associations to further build the foundation of knowledge, they are not as useful for front-line health care providers. Perhaps more general measures such as self-rated health are more valuable when planning the care of specific caregiver/care recipient dyads.

There were no published studies found that looked at self-rated health in family caregivers during the period of awaiting placement. These data were collected during the "Coping While Waiting Placement" (Strang et al., 2006) study but have not previously been analyzed.

Fatigue and sleep in family caregivers of persons with dementia.

Again there seems to be a common sense connection between fatigue and sleep in that one might expect a linear, negative relationship between the two variables. However, this relationship has received very little attention in the research literature. 14% of FCG of PWD report problems with sleep initiation, 51% report decreased ability to stay asleep, and 22% experience nighttime awakenings (McCurry & Teri, 1995). In this study the researchers state that 34% reported fatigue however no mention was made as to the relationship between the sleep difficulties and fatigue (McCurry & Teri, 1995). This is also true of other studies focusing on sleep disruptions and FCG fatigue (Ferrara et al., 2008; Rowe, McCrae, Campbell, Benito, & Cheng, 2008).

We know that fatigue has been better studied in the cancer research and a few studies have looked at both fatigue and sleep. (Fletcher, Schumacher, Dodd, Paul, Cooper, Lee, West, Aouizerat, Swift, Wara, & Miaskowski, 2009) found that the timing of fatigue predicted different variables in the caregiving situation. For example, evening fatigue was predictive of sleep disturbance whereas morning fatigue was predictive of FCG anxiety and perceived support from family members (Fletcher, Schumacher, Dodd, Paul, Cooper, Lee, West, Aouizerat, Swift, Wara, & Miaskowski, 2009). An earlier study however showed that morning fatigue in this population was associated with poor sleep quality (Sato et al., 2002). These differences in findings highlight the complexity of fatigue and its relationship with sleep.

In a more general FCG population in Japan, Tsukasaki and colleagues (2006) looked at the relationship between sleep and fatigue. They used results from FCG report and actigraphy to break caregivers into four groups with distinct sleep patterns; those who do not awaken at night, those who awaken to use the bathroom, those who have a scheduled awakening to provide care for the care recipient, and those who have unscheduled awakenings for care recipient needs.

What they found was that the caregivers with the worst fatigue profiles were those who did not awaken at night. This group of caregivers exhibited greater anxiety and depression and “chronic fatigue symptoms” (no definition published) and they also provided the largest number of hours of care during the day. The caregivers who experienced unscheduled awakenings to provide care for their care recipient had the next worst fatigue profile, reporting feeling like they did not sleep well, reduced mental energy, and increased general fatigue. Again, these findings speak to the complexity of the relationship between fatigue and sleep.

No research has been published in the awaiting placement population for these two variables, and so there are many important questions that remain unanswered. Do the FCGs of PWD who report a sleep deficit also report the highest levels of fatigue? If there is a relationship there, how strong is it? There is a common sense connection here but no published literature to support it. We also don’t know the nature of the relationship between fatigue and health. If fatigue is related to the perception of health in FCGs, what is the nature of this relationship?

Fatigue and health in family caregivers of persons with dementia.

Fatigue occurs in a variety of health conditions such as cancer (Mendoza et al., 1999; Richardson, 1995), post stroke (Ingles, Eskes, & Phillips, 1999) , liver disease (Huet, Deslauriers, Tran, Faucher, & Charbonneau, 2000), rheumatoid arthritis (Tack, 1990), and COPD (Breslin et al., 1998) to name a few. Fatigue is a well-accepted and much reported symptom of metabolic/endocrine changes such as anemia, diabetes, thyroid imbalance, and menopause. Self-care factors such as nutrition and sleep hygiene may also exacerbate or cause fatigue.

Another aspect of fatigue is as it relates to emotional distress. It has been reported that FCGs of disabled adults who reported increased fatigue also had increased depressive symptoms (Clark, 2002). This supports the hypothesis that many different health alterations or immune system activations can lead to an individual reporting fatigue. The relationship between fatigue and health has been best published for the cancer patient population. Individuals with cancer frequently report that fatigue is the worst or one of the worst symptoms they experience and that all aspects of their life, such as physical, mental, social, and economic aspects, are affected by fatigue (Curt et al., 2000).

Not much is known about the relationship between fatigue and health as it relates to family caregivers of persons with dementia at any time during the trajectory of care. However it would be especially important for health care practitioners to have a sense of how these two factors relate to each other during the awaiting placement period.

Sleep and health in family caregivers of persons with dementia.

There is a common sense connection between sleep and health that has been supported in the literature. We know in the general population of seniors that poor sleep is associated with increased frailty (Ensrud et al., 2009). We also know that sleep patterns undergo many changes over the lifespan (Ohayon, Carskadon, Guilleminault, & Vitiello, 2004). As they age, seniors are less able to initiate and maintain sleep, and total sleep time is shorter, shallower, and more disrupted than in younger individuals (Espiritu, 2008). These changes are clinically relevant because poor initiation and maintenance of sleep is associated with increased rates of illness and death in the elderly population (Espiritu, 2008). To that same end, it is found that health and longevity can also be predicted by an individuals' duration of sleep, with both too much and too little sleep being a health risk factor (Espiritu, 2008).

Other changes that occur as part of the normal aging process are the timing of sleep and sleep architecture. The nocturnal sleep phase occurs earlier in the evening and a more habitual sleep schedule was noted in older persons (Ohayon, Carskadon, Guilleminault, & Vitiello, 2004). The architecture of sleep shows great changes over an individual's life span with different aspects leveling out at different times in development. In seniors, Stages 1 and 2 of non-REM sleep increase while the proportion of Stages 3 and 4 (or slow-wave) sleep decreases (Ohayon et al., 2004). Proportion of REM sleep also declines as we age, but stabilize sometime in mid-adulthood (Ohayon et al., 2004). The significance of this is that individuals will spend a smaller proportion of total sleep time in the restorative later stages of sleep.

McEwen hypothesized that sleep deprivation contributes to and accentuates the deterioration of the brain and body (2006). This happens through the process of allostasis, which is the body's process of maintaining homeostasis through mediators such as the sympathetic and parasympathetic nervous system and inflammatory verses non-inflammatory pathways (McEwen, 2006). The changes in glucose levels, the production of free radicals, and the increase in oxidative stress that occur in the brain as the body attempts to maintain homeostasis after sleep deprivation can be deleterious to health and exacerbate conditions such as diabetes and cognitive impairment (McEwen, 2006).

We also know that there is an association between sleep and depression (McCurry & Teri, 1995) and that FCG depression is associated with use of nighttime medications (McCurry & Teri, 1995). In other measures of health we know that disturbed sleep is associated with an increase in body mass index (BMI) in older adults (Patel et al., 2008; Watson, Buchwald, Vitiello, Noonan, & Goldberg, 2010)and that FCGs who get more sleep exhibit better physical functioning (Spira et al., 2010).

There are cardiovascular changes that occur when FCGs have disrupted sleep. Individuals who are awakened after initial sleep onset have increases in coagulation (Mausbach et al., 2006) , individuals who had reduced sleep had higher blood pressure readings (Tsukasaki et al., 2006) and many cardiovascular biomarkers for artherosclerosis are associated with sleep disturbances in FCGS of PWD (von Känel et al., 2010).

Individuals who have disrupted sleep exhibit changes in their circadian rhythms and are at a greater risk of dying from any cause (Tranah et al., 2010). Another analysis from the same study showed that older men with alterations to their rest/activity rhythms had higher mortality rates compared with those who described normal sleep patterns, especially when looking at CVD related events (Paudel et al., 2010).

Summary and Statement of Purpose

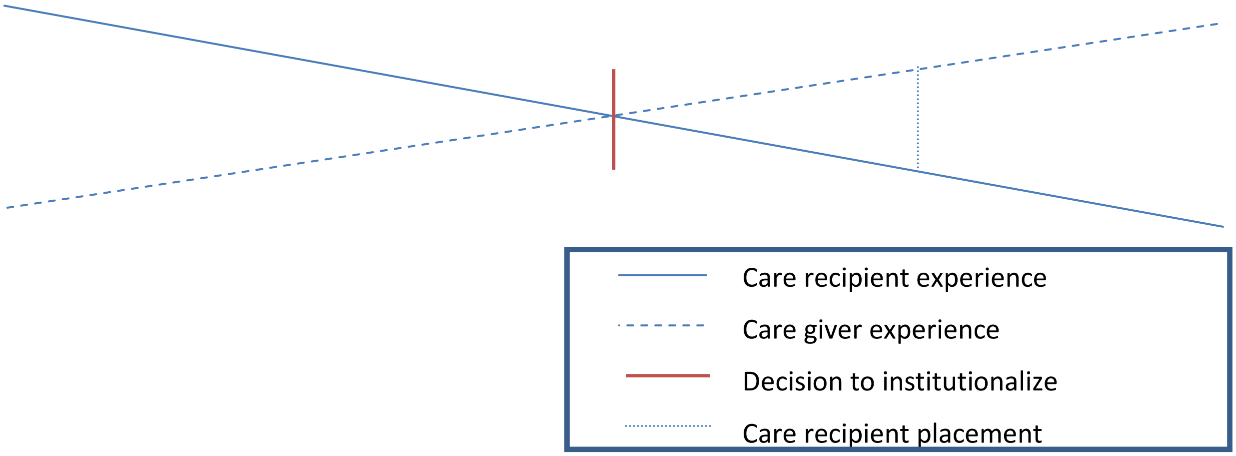
There is much that is yet to be studied for the family caregivers of persons with dementia who are in the awaiting placement for their care recipient. We know that caregivers report fatigue, disruptions of their sleep, and changes in their health that they feel are related to their caregiving duties. We know that fatigue and poor sleep are reported more frequently and that health is subjectively rated and objectively measured worse in comparisons of caregivers and non-caregivers. We know that these variables are complex and multifactorial - and largely unexplored for caregivers at this time period.

This research project has been designed to look at the relationships among caregiver reported fatigue, sleep deficit, and health at the time of awaiting placement for institutionalized care for the care recipient. Using multiple regressions a causal or predictive relationship may also be found between the variables. This information will better inform health care practitioners and guide decision making and program planning for this vulnerable population at a time when they likely need a great amount of support from the health care system.

My theory is that as the care recipient's function declines due to the dementia process the caregiver gradually needs to increases the amount of time, energy, and resources required to maintain the care recipient in the community setting. At some point, the caregiver may recognize that the resources available to them are outweighed by the needs of the care recipient and they make the difficult decision to explore an institutional setting. The period of time between waitlist placement and the care recipient moving into formalized care has not been well studied, however it is an import period in the caregiving trajectory. This research project is designed to explore the variables of gender, age, functional status of the care recipient, the nature of the relationship between the caregiver and care recipient, fatigue, sleep deficit, and care recipient perceived health during this largely unexplored time period.

Figure 1

Conceptualization of Family Caregiver/Care recipient



Research Questions

This project will look at the relationships among fatigue, sleep deficit, and health in family caregivers of persons with dementia who are living in the community while waiting for placement in a long-term care setting.

1. What are the relationships among family caregiver gender, age, fatigue, sleep deficit, perceived health, care recipient functional status (spouse or not spouse), and caregiving relationship?
   - 1.a. Do these relationships change over time?
2. Do caregiver gender, care recipient functional status, or caregiving relationship predict caregiver sleep deficit?
3. Do caregiver age and caregiver sleep deficit predict caregiver fatigue?
4. Do caregiver age and caregiver sleep deficit predict caregiver perceived health?

CHAPTER 3 – METHODS

Design

This quantitative study is a secondary analysis of data collected from the larger mixed methods study “Coping While Waiting Placement for Caregivers of Persons with Dementia” (Strang, Koop, Nordstrom, & Thompson, 2003). This study used correlation to explore relationships among care recipient functional status, caregiver sleep deficit, caregiver fatigue, and caregiver self-rated health at each of three time points (at placement on a waiting list for LTC, just prior to admission to LTC and immediately following admission). We also used multiple regression analysis to determine FCG health could be predicted by caregiver age or gender, level of caregiver fatigue or sleep deficit, or care recipient level of function. Understanding the relationships among these variables and their predictive capacity may be useful to heath care professionals planning supportive interventions for dementia patients and their family caregivers as well as planning further research in this area.

Setting and Sample

The population studied was family caregivers who are living in the community, and who have just placed their care recipient with dementia on the Capital Care waitlist for placement in a long-term care setting in Edmonton, Alberta, Canada. Forty-one individuals participated in the original study (n=41), and it will be their data that I will analyze. All participants understood and spoke

English and were living in Edmonton or the surrounding area at the time of the study. The participants were enrolled in the study at approximately at the same phase in their caregiving trajectory, when the decision to institutionalize the care recipient had been made, and they were providing care while the care recipient was awaiting placement (see figure A, red line).

All forty-one participants were interviewed at least once. Of those, twenty-seven caregivers were interviewed twice and ten were interviewed three or more times. Slightly more than half of the caregivers were the adult children of the care recipient (n=21; 51.2%). The rest of the participants reported that they were caring for their spouses (n=14; 34.1%) or “others” (n=6; 14.6%). The majority of caregiving participants were married or in a common-law relationship (n=30; 75.0%). Six caregivers stated they were never married (14.6%), two were divorced (4.9%), and one was widowed (2.4%).

Female caregivers (n=30; 73.2%) outnumbered males (n=10; 24.4%). The average age was 60.4 (±16.2) years with a range of 26 to 88. The gender split was closer to equal in the care recipients; there were 22 female care recipients (53.7%) and 18 males (43.9%). The care recipients were older than the caregivers with an average age of 83.9 years (±9.7) and ranging from 58 to 97. A summary table of demographic data that has been split into the caregiving groups is seen below in table 1.

Table 1

Demographic Data

	FCG – Parent or older generation	FCG – spouse or same generation	Care Recipient
Age	52.1 years (SD 10.2, 35 to 69)	71.9 years (SD 15.9, 26 to 88)	81.2 years (SD 9.71, 58 to 97)
Female Gender	17 participants 68.0% of FCG parent at T_1 43.6% of all FCGs at T_1	11 participants 78.6% of FCG parent at T_1 28.2% of all FCGs at T_1	19 care recipients 51.3% of all CR at T_1
Male Gender	8 participants 32.0% of FCG parent at T_1 20.5% of all FCGs at T_1	3 participants 21.4% of FCG parent at T_1 7.7% of all FCGs at T_1	18 care recipients 48.7% of all CR at T_1

Variables and their Management

The original study utilized both qualitative and quantitative methodologies to provide a greater understanding of the caregivers' experience while they wait for their CR to be placed in long-term care. For this study I limited my analysis to the quantitative data on fatigue, sleep, health, and demographic data. The tools used include; demographic data about the caregiver/ care recipient dyad along with key variables associated with being a FCG, and the Functional Dementia Scale (Moore, Bobula, Short, & Mischel, 1983) (see Appendix A). The qualitative data collected as a part of the original study was not used in this project, nor were the data from the Multi-Dimensional Caregiver Burden Inventory (MCBI) (Novak & Guest, 1989), or the Caregiver Reaction Assessment Scale (CRA) (Given et al., 1992). Please see Appendix A for a copy of the tools that were originally distributed to the participants.

Care recipient functional status scale.

The Functional Dementia Scale (FDS) was designed for use by family caregivers in the community setting (Moore, Bobula, Short, Mischel, 1983). The tool was designed to be short and straightforward to minimize the completion burden for FCGs but also a reliable, valid and functional means of distinguishing functional limitations associated with dementia. An increased FDS score is indicative of a care recipient with decreased function. With respect to reliability, the authors report a Cronbach's alpha of 0.90 for internal consistency and test retest correlation of 0.88. For validity, the FDS correlates well with SET test and SPMSQ ($p>0.05$), which are widely used (Moore, Bobula, Short, & Micshel, 1983).

Fatigue scale.

Generally speaking, the definition of fatigue used in this study is not just "tiredness" but "tiredness with a decline in normal function" as per Olson's Fatigue Assessment Model (FAM). FAM is based on Hans Selye's Stress Model, which views fatigue along a continuum from tired to fatigued and then to exhausted.

To measure fatigue levels, participants were asked, “Generally, how fatigued do you feel?” (Question 27), and their responses were recorded on a ladder-type scale from zero to ten, with zero being “not at all” and ten being “a great deal”. Using this subjective measure is thought to evoke a general sense of fatigue that encompasses the multi-factorial aspects that an individual is experiencing. The responses are at the ratio level of analysis because there is a possibility of “0” fatigue and participants are presumed to see the scale numbers as equidistant from each other.

This numeric ladder scale measures intensity of an individual’s subjective fatigue. Validity of the numeric ladder scale for fatigue may be difficult to establish. However, Piper (2004) states that 0-10 numeric rating scales (such as the one used in this study) correlate well with other similar scales that look at intensity of fatigue as well as with the multidimensional Piper Fatigue Scale-Revised which has “consistently good reliability and validity estimates across different patient and cultural samples” (p.552)

Reliability for this fatigue instrument can be construed to be similar to that of the ladder-type scale to measure health. The reliability of a research tool is the measure of extent to which an instrument’s results are consistent and repeatable. This self-rated fatigue measurement scale has demonstrated stability because individuals will use the same criteria to rate their fatigue when asked to do so over and over again. Therefore, as long as their perception of fatigue hasn’t changed, their response should remain the same when asked repeatedly to rate it.

Sleep sufficiency – the sleep deficit equation.

No studies of sleep deficit were found in the current literature however this author proposes it is a good measure of sleep sufficiency in this population. Participants were asked, “About how many hours of sleep do you need on a daily basis?” (Appendix A - question 32) and their responses were recorded numerically as hours of sleep at night and hours of sleep in naps. Participants were then asked, “About how many hours of sleep do you get these days on a daily basis?” (Appendix A - Question 33). Responses were again recorded as a nominal representation of hours at night and hours in naps. By subtracting the actual daily hours of sleep from the participants’ self-stated required hours of sleep, the participants “sleep deficit” will be calculated.

This measurement can be seen to have stability. This is because the individual will use their own set of criteria to define “About how many hours of sleep do you need on a daily basis” and measure their own hours of sleep in the same way each time they are asked. This measure has face validity because it seems on the surface to be an appropriate way of measuring sleep deficit, and appears to work in a pragmatic sense.

Health scale.

Health can be measured either subjectively or objectively. Measuring health objectively can be time consuming, invasive, and not necessarily accurate.

Using subjective measures the researchers presume that the individual will consider all of the factors that have an influence on their health and take them into account when giving their answers. These would include variables such as physical, psychosocial, and environmental factors. While some believe this measure is an adequate measure of health, other researchers feel that a more complete view of the complex variable of health can only be revealed with multiple questions.

In this study, health was subjectively measured using a self-rated, single item numeric ladder-type scale. Participants were asked, “Generally, how good is your health?” (Question 24) and their responses were measured on a scale of zero to ten with anchor points at zero meaning “very poor” and ten meaning “excellent”.

The collected data for this question is considered to be at an interval level, because the participants are presumed to view the provided choices as equidistant from each other - for example, the difference between 2 and 3 would be the same as the difference between 6 and 7. Although it would be nice to classify this data as ratio, in this instance the choice of “0” does not mean the absence of health but rather “very poor health”.

This self-rated health measurement scale has demonstrated stability because individuals will use the same criteria to rate their health when asked to do so over and over again. Therefore, as long as their perception of their own health hasn’t changed, their response should remain the same when asked repeatedly to rate it.

Validity is the extent to which an instrument measures what it is supposed to measure. Self-rated health correlates with other measures of health which provides construct validity. Self-rated health has been shown to correlate with other measures of health such as use of health care and mortality rates (Adams, 1993, & Mossey & Shapiro, 1982). This health scale has concurrent validity.

Research Procedure

Access to setting.

This proposed study is an analysis of secondary data from a larger mixed methods study, and so access to a clinical setting is not necessary. Participants were recruited from the Central Assessment and Placement (CAPS) waiting list for the Capital Care Group of institutions.

Selection of Respondents.

Inclusion criteria included being the primary family caregiver of a person with dementia, having the ability to speak and understand the English language, and living in Edmonton or surrounding area. The CAPS support staff and a research assistant for the study regularly reviewed this list and identified those who would be applicable for the study.

Approach and follow-up procedures.

CAPS personnel used a prepared script to inform caregivers about the study, and to request permission to release their name and phone number to the research assistant. The research assistant contacted those who had given permission to give more information. The initial meeting with the caregiver was done in a timely manner so that data could be collected close to the initial time of wait-list placement.

Protection of human rights.

Informed consent was collected from all of the participants when they enrolled in the original study. It was explained that if secondary analysis of the collected data were going to occur, consent would not be re-collected from the participants, however ethical approval would be sought for any subsequent analyses. Identifying information had been removed from the data collection documents and was not required for this study. As a secondary analysis of data was no direct or indirect contact made with the participants and therefore the risk of harm was deemed to be non-existent. Ethics approval was sought and received.

Data collection procedures.

Demographic data were collected during the first interview that took place at the time of wait-list placement. At this time caregivers were asked to fill out a questionnaire to collect demographic variables as well as the Functional Dementia Scale. Caregivers also participated in a semi-structured interview with a research assistant related to their caregiving experience. These interviews and the questionnaires (with the exception of the demographic questionnaire) were repeated at three to four month intervals until the care recipient had been placed in long-term care. A final interview and completion of questionnaires took place within two to three months of placement.

Data cleaning.

The data from the original study were unavailable in electronic format, so they were re-entered and cleaned of any errors.

Analysis.

All demographic characteristics such as caregiver age and gender, and the Functional Dementia Scale score, and the variables self-rated health, fatigue, and sleep deficit were analyzed for measures of central tendency and dispersion. Fatigue, sleep deficit, and health are interval or ratio level variables, so the measure of central tendency that was calculated is the mean; the measures of dispersion were range and standard deviation. As part of univariate analysis I also performed ANOVA on each of the 4 key variables; sleep deficit, fatigue, health, and care recipient functional status. The purpose of the ANOVA was to determine if the means of the variables changed significantly over the three time periods.

For the first research question, “ What are the relationships among family caregiver gender, age, fatigue, sleep deficit, perceived health, care recipient functional status (spouse or not spouse), and caregiving relationship?”, a correlation matrix was calculated. For question 1.a. “Do these relationships change over time?” I utilized a repeated measures t-test.

For the second, third and fourth research questions a multiple regression equation was calculated. Specifically, for question two “Do caregiver gender, care recipient functional status, or caregiving relationship predict caregiver sleep deficit?” I utilized the equation FCG Sleep Deficit = A+ $B_{\text{FCG gender}}$ (FCG gender) + $B_{\text{CR FS}}$ (CR FS) + $B_{\text{CG Relationship}}$ (CG Relationship). For question three “Do caregiver age and caregiver sleep deficit predict caregiver fatigue?” I utilized the following equation FCG Fatigue = A+ $B_{\text{FCG age}}$ (FCG age) + $B_{\text{FCG SD}}$ (FCG SD). Finally for question four “Do caregiver age and caregiver sleep deficit predict caregiver perceived health?” I utilized the equation FCG Perceived Health = A+ $B_{\text{FCG age}}$ (FCG age) + $B_{\text{FCG SD}}$ (FCG SD).

Generally, sample size is calculated using the equation $n \geq 50+8m$ (where *m* equals the number of independent variables). This means that for the second question, I would require 62 participants. As I only have 41 cases in my data set, there is an increased risk of committing a type 2 error whereby a significant relationship that exists may be missed because of low power. Because of this issue, this project must be viewed as exploratory and further research in this area will be required.

SPSS v. 18 was utilized to perform the data analysis. The data were reentered into the SPSS program from the original participant questionnaires that had been stripped of their identifying data. Data were checked for accuracy by a research assistant who was independent to this project. There was minor cleaning of the data required prior to beginning the analysis.

CHAPTER 4 – RESULTS

The key findings of this study will be presented, beginning with a description of the study participants. This section will focus on the demographic characteristics and main variables FCG fatigue, FCG health, FCG sleep deficit, and CR functional status, including how they change over time. The remaining discussion will be structured according to the research questions. Prior to presenting the results of the study, the re-assignment of time points will be described.

Description of Sample

Assignment of time points.

Forty-two individuals volunteered to participate in the original study. Of these, two withdrew before the first interview. Forty caregivers participated in their first interview shortly after their care recipient's name was placed on the Capital Care waitlist for placement in a long-term care facility. Twenty-nine participants had a second interview (an average of 122 days after the first interview), eleven were interviewed a third time (an average of 247 days after the first interview), two were interviewed a fourth time (an average of 381 days after the first interview), and one participant was interviewed a fifth time (433 days after their first interview).

For this secondary analysis, the data were regrouped into three interview times; time one (T_1) was the first interview done with the FCG immediately after placing their care recipient on the waitlist for placement, time two (T_2) is the final interview before the care recipient was placed in long term care, and time three

(T_3) includes the data collected at the final interview after the care recipient of the caregiving dyad was institutionalized. This recoding of interview times ensured that the FCGs were at similar points in their caregiving trajectory at each time point.

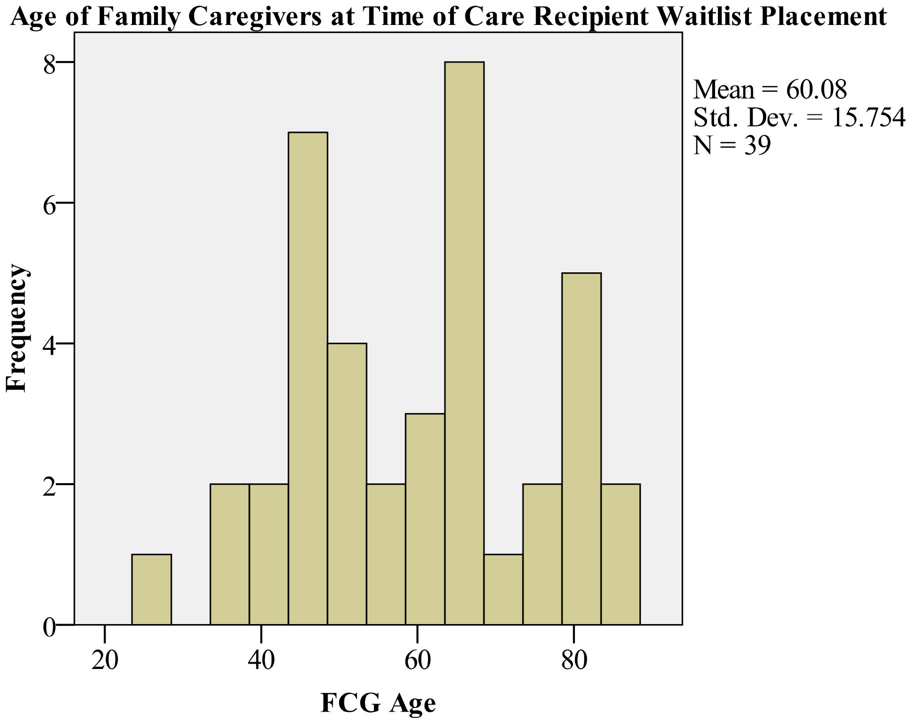
One FCG did not complete questions related to two or more variables and was excluded from further analysis. Thirty-nine participants were interviewed at T_1, twenty were interviewed at T_2, and eighteen were interviewed at T_3. All other missing data were handled by pairwise deletion on an analysis-by-analysis basis.

Age of family caregivers and care recipients.

The mean age of the FCGs was 60.1 years (15.8 SD), with a median of 60 years and a mode of 68 years, with the youngest FCG being 26 and the oldest being 88 years. The data were close to multimodal, with peaks in the 40s, 60s and 80s (see histogram next page).

Table 2

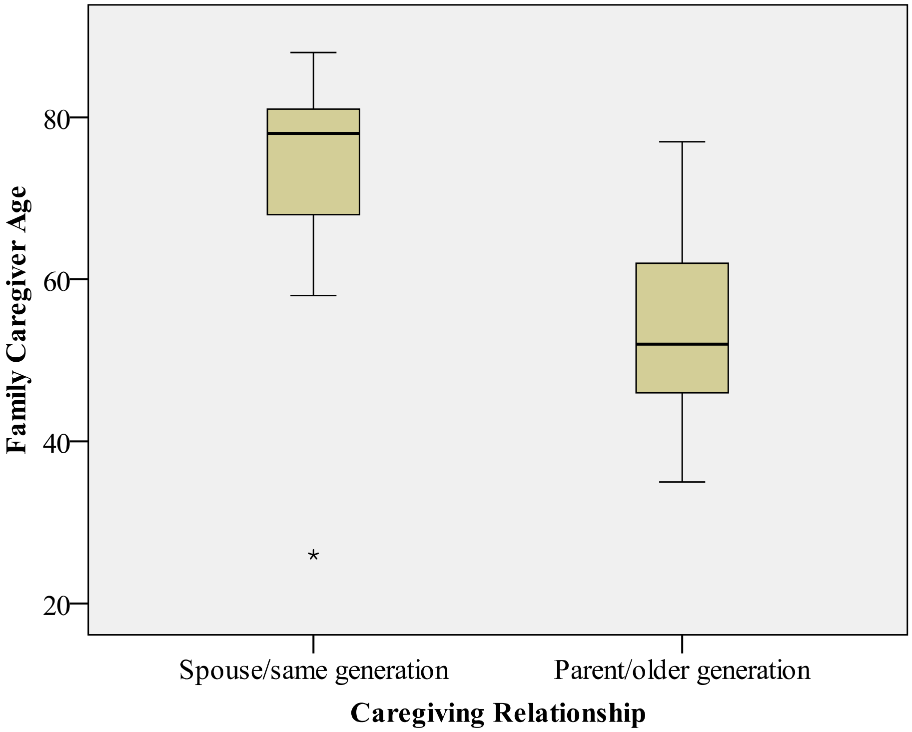
Age of Family Caregivers



I was curious about these multiple peaks and so I split the data by the caregiving relationship variable and found that typically those FCGs who were caring for spouses or persons of the same generation were older than those FCGs who were caring for parents or persons of an older generation, which is what we would expect to see (see box and whiskers plot below). The outlier in the FCG of spouse group is case number 8, a 26 year old caregiver. An independent t-test confirmed my suspicions that these are in fact two significantly distinct groups in regards to spread of age t (78)=6.549, p=0.000.

Table 3

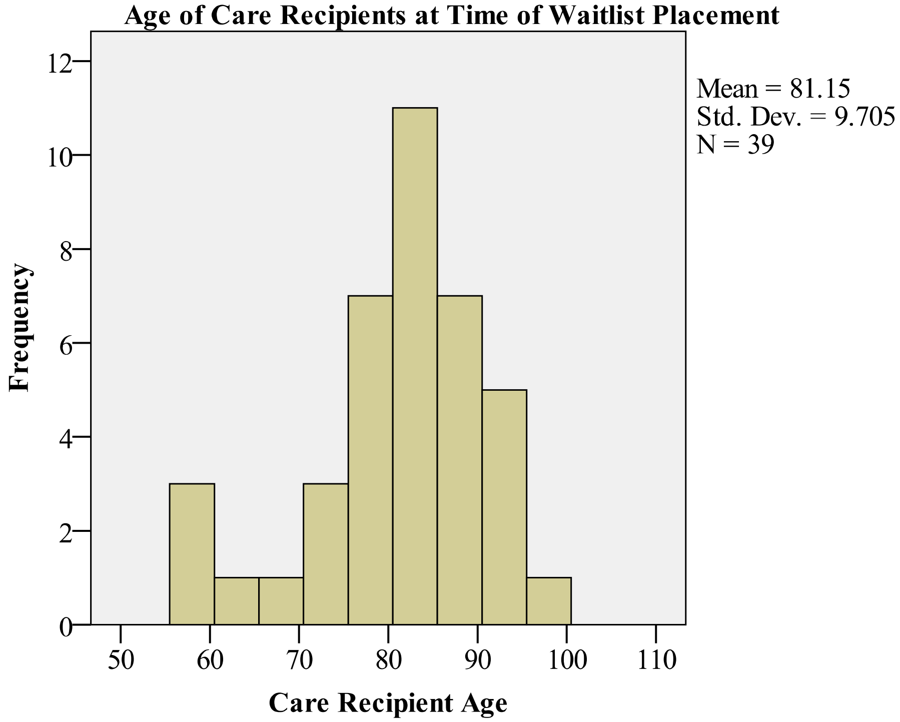
Box Plot - Age of Family Caregivers by Caregiving Relationship



Looking at the care recipients I found that the mean age for these participants was 81.15 years (SD 9.705) with a median of 82.0 years, and a mode of 83 years. The youngest care recipient was 58 years of age and the oldest was 97 years (see histogram below). This age range makes sense as dementia is a disease of later life. It is interesting to note that there is a skew to the left and a tiny "blip" in the below histogram that may indicate a few of the participants may have had early onset dementia.

Table 4

Histogram - Age of Care Recipients



Gender of family caregivers and care recipients.

Gender in this sample was similar to that which has been previously reported in FCG research. 71.8% of FCGs were female and 28.2% were male. The gender of the care recipients was split more evenly, with 51.3% of care recipients being female and 48.7% being male. When the sample was again split into the two caregiving relationship categories the FCG gender data remained about the same proportion (68% female for those caring for parents or older generations, and 78.6% female for those caring for spouses or same generation).

Care recipient gender ratios changed when the sample was split by care recipient relationship (care recipients who were parents or older than the FCG were 72.0% female, and care recipients who were spouses or same generation as their caregiver were 14.3% female). These finding suggest is that male care recipients are more likely to be cared for by wives or females of their own generation, and female care recipients are more likely to be cared for by daughters or women of a younger generation.

Number of days on waitlist.

When we entered the data into SPSS we recoded the interview numbers into three time periods; T_1 was shortly after waitlist placement, T_2 was the last interview before the care recipient was placed in long-term care, and T_3 was the final interview after care recipient placement. The average number of days between T_1 and T_2 was 144 days (SD = 64.9). The range was 62 to 368 days. The average number of days between T_1 and T_3 was 218 days (SD = 100.6) with a range of 90 to 433 days. As interviews were conducted every 3 to 4 months, these data can only be seen as rough estimates of time between placement on a waitlist and admission to LTC.

Univariate Analysis of the Variables

Fatigue.

Fatigue was measured using a ladder type scale from 0 to 10, with lower score indicating that the FCG perceived they had lower levels of fatigue. At all three time points, Kolmogorov-Smirnov tests of normality are non-significant, indicating that the data does not significantly differ from normality and can therefore be treated as though they are normally distributed for the following analysis.

Table 5

Descriptive Data – Family Caregiver Fatigue at Three Time Periods

Fatigue	Level of Measurement	Mean	Median	Mode	SD	Range
T_1 n=37	Continuous	5.86	6.0	5 and 8	2.679	10(0-10)
T_2 n=18	Continuous	5.22	5.0	5	3.021	10(0-10)
T_3 n=18	Continuous	4.89	5.0	3	2.349	8(1-9)

Mean fatigue scores decrease over the three time periods as illustrated in the box plot below, however these changes were not statistically significant. It should also be noted that range also slightly decreases, and there were no outliers.

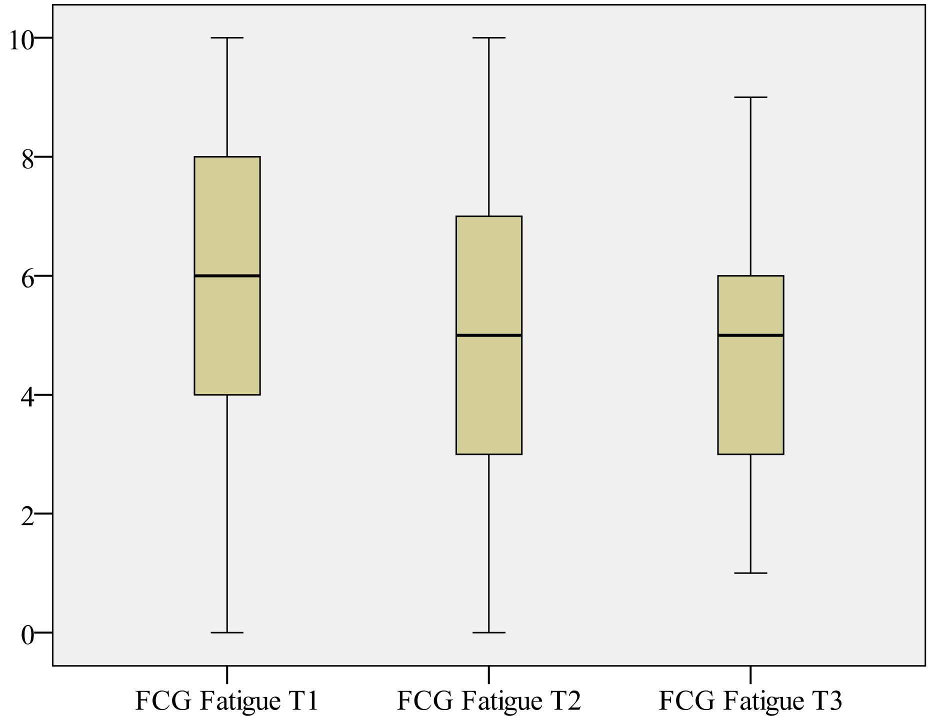
Mean FCG fatigue scores were 5.86 at T_1, 5.22 at T_2 and 4.89 at T_3. Results of the repeated measures ANOVA indicate that mean fatigue scores did not significantly differ between the three interview times.

Since I expected that fatigue levels would increase between T_1 and T_2, I wondered if the care recipients of the most fatigued FCGs were perhaps being admitted early, leaving the FCGs who were coping better and therefore perhaps less fatigued. To check this, I ran the descriptive analysis again with just the eight cases that were interviewed at each of the three time points and found mean scores of 4.63 at T_1, 3.75 at T_2, and 4.25 at T_3. Mean fatigue score in the eight participants who were interviewed at all three time periods decreased slightly at

T_2 and then increased again for T_3, however these scores are not significantly different from the scores using the full data set and so for all subsequent calculations pairwise deletion was employed and the full data set was analyzed.

Table 6

Box Plot – Family Caregiver Fatigue Scores at Three Time Periods



Sleep deficit.

For the original study, participants were asked to report how much sleep they felt they needed and how much they actually got, the majority of answers were reported in hours and partial hours. To obtain the sleep deficit scores for this analysis the responses were recoded into minutes, and then the number of minutes of sleep a caregiver typically got in a 24 hour period was subtracted from the number of minutes they felt they needed in a 24 hour period.

FCGs reported an average sleep deficit at T_1 of about one hour 20 minute sleep deficit. This increased to about one hour and 35 minute at T_2 and then decreased to about an hour at T_3, when the care recipient had been placed in LTC (81.97 at T1, 94.72 at T_2 and 57.94 at T_3). Kolmogorov-Smirnov tests of normality for FCG sleep deficit are significant at T_1 and T_2 and not significant at T_3 (D(37)=0.225, p=0.000 at T_1, D(18)=0.207, p=0.040 at T_2, and D=(17)=0.194, p=0.090 at T_3) indicating that the data is not normally distributed at T_1 and T_2, and is normally distributed at T_3, so non parametric methods of analysis were used for this variable.

Table 7

Descriptive Data – Family Caregiver Sleep Deficit

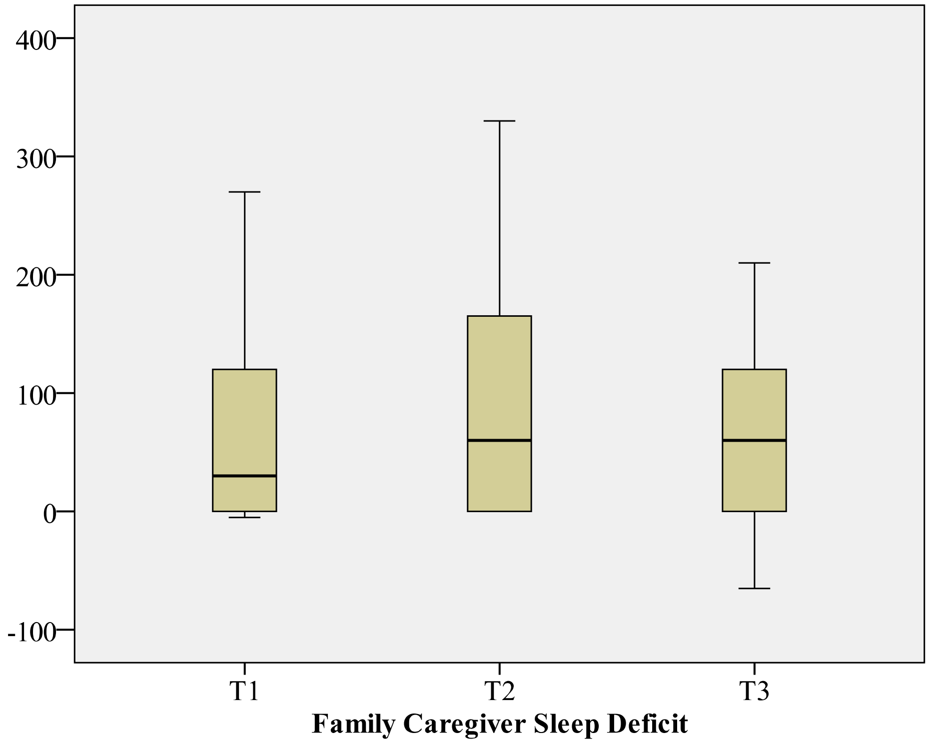
Sleep Deficit	Level of Measurement	Mean	Median	Mode	SD	Range
T_1 n=37	Continuous	81.97	30.0	0	93.106	275(-5-270)
T_2 n=18	Continuous	94.72	60.0	0	104.184	330(0-330)
T_3 n=17	Continuous	57.94	60.0	60	67.200	275(-65-210)

In regards to change over time, mean sleep deficit scores increased at T_2 then decreased below T_1 scores at T_3. At T_1, T_2 and T_3 data has a severe skew to the right (0.751 at T_1, 0.881 at T_2, 0.310 at T_3). This suggests that many of the responses were actually below the mean. However the participants whose sleep deficit was above the mean were more extreme scores.

Results of the repeated measures ANOVA suggest that mean sleep deficit scores were not significantly different between the three interview times F=(2,18)=0.160, p=0.853.

Table 8

Box Plot – Family Caregiver Sleep Deficit Score over Three Time Periods



Health.

Health was measured using a ladder type scale from 0 to 10, with lower scores indicating that the FCG perceived they had lower levels of Health. Kolmogorov-Smirnov tests of normality for FCG health indicate a normal distribution at T_1 and T_3 however a leptokurtic distribution at T_2 (D(18)=0.149, p=0.200), therefore, non parametric methods of analysis are required to analyze this variable. Generally speaking, FCGs rated their health about a seven to eight out of ten, which means they felt their health was good. It should also be noted that range is stable from T_1 to T_2 and increases at T_3, which means there was a greater variation in responses at T_3.

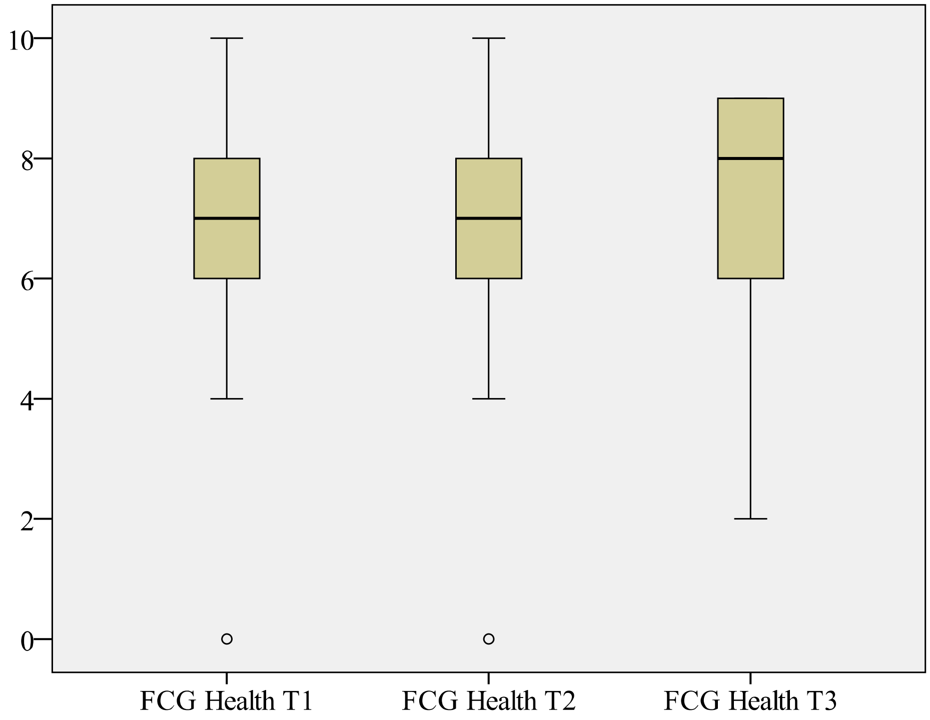
Table 9

Descriptive Data – Family Caregiver Health

Health	Level of Measurement	Mean	Median	Mode	SD	Range
T_1 n=37	Continuous	6.95	7.0	7	1.792	10(0-10)
T_2 n=18	Continuous	6.78	7.0	8	1.874	10(0-10)
T_3 n=18	Continuous	7.33	8.0	9	1.767	7(2-9)

Table 10

Box Plot – Family Caregiver Health at Three Time Periods



Mean health scores decreased slightly at T_2 then increased above T_1 scores at T_3, just after the care recipient had been admitted. Results of the repeated measures ANOVA suggest that mean health scores did not significantly differ between the three interview times F=(2,18)=0.351, p=0.709.

Care recipient functional status.

Care recipient function was measured using the Functional Dementia Scale (FDS) (Moore, Bobula, Short, & Mischel, 1983) at all three time points. The range of possible scores is 20 to 80, with a higher score indicating lower function. A normally functioning person would score a 20/80 on the FDS.

Table 11

Descriptive Data – Care Recipient Functional Status

CRFS	Level of Measurement	Mean	Median	Mode	SD	Range
T_1 n=36	Continuous	43.78	43.0	37	10.532	51(23-74)
T_2 n=20	Continuous	47.10	46	41	10.078	44(31-75)
T_3 n=16	Continuous	50.50	50.0	44*	7.685	26(41-67)

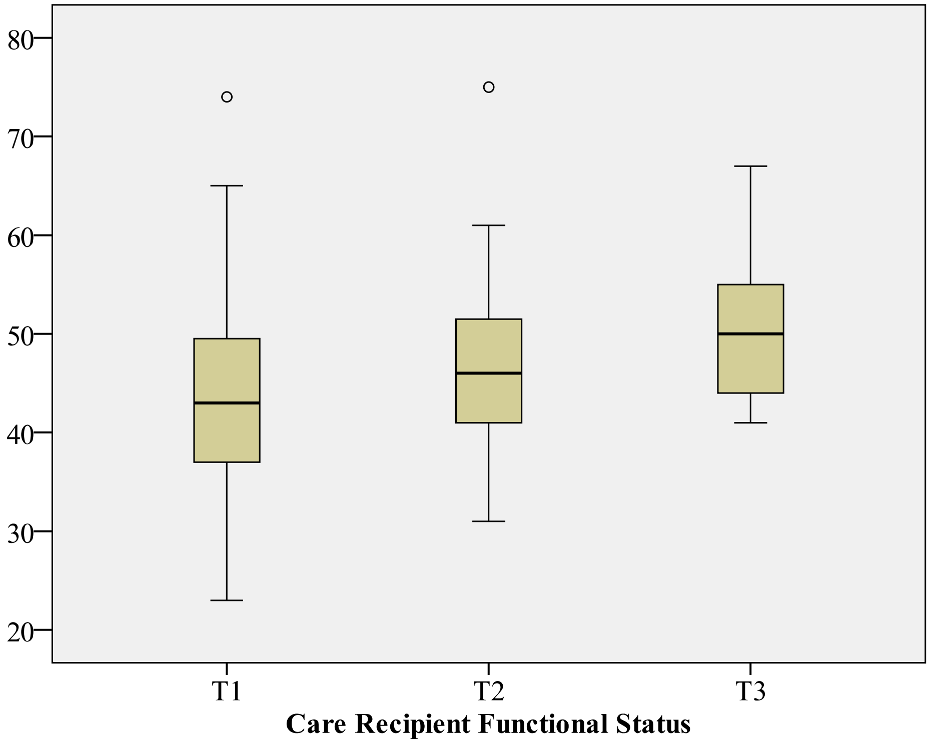
Kolmogorov-Smirnov tests of normality for FCG care recipient functional status are not significant at any of the three time points, suggesting that the data can be treated as normally distributed. The average care recipient in this study scored 43.78/80 at T_1 indicating a decline in function from the normal. At T_2 care recipients' average score increased about three points and then another three points at T_3, indicating a steady decline in function. These differences are statistically significant (t (19)=-2.261, p=0.036 for T_1 to T_2 and t(13)=-2.519, p=0.026 for T_1 to T_3).

Mean care recipient functional status scores were 40.11 at T_1, 45.33 at T_2 and 50.44 at T_3. Results of the repeated measures ANOVA suggest that mean care recipient functional status scores did significantly differ between the three interview times when comparing them overall F=(2,16)=4.233, p=0.033.

However, in post hoc comparisons (Bonferroni), results indicated that mean care recipient functional status at time of waitlist placement did not significantly differ between the T_1 and T_2 (40.11 vs. 45.33), p=0.169, nor did care recipient function at waitlist placement differ from level of care recipient function post CR placement (40.11 vs. 50.44), p=0.162.

Table 12

Box Plot – Comparison of Care Recipient Status over Three Time Periods



Summary of Univariate Analysis

In summary, mean fatigue scores appear to indicate a slight decline in the level of fatigue over the time periods; however this change was not statistically significant. FCG sleep deficit scores were not normally distributed at T_1 and T_2 and normally distributed at T_3. The scores appear to increase from T_1 to T_2 and then decrease at T_3 however these changes were not statistically significant. FCG health scores were normally distributed at T_1 and T_2 and not normally distributed at T_3. Health scores appear to decrease slightly from T_1 to T_2 and then increase from T_2 to T_3 however these changes are not statistically significant. Care recipient functional status scores are normally distributed at T_1 and T_2 and not normally distributed at T_3. These scores appear to increase from T_1 to T_2 and T_2 to T_3 however the changes were not statistically significant.

The remaining description of results in this chapter will be organized according to the research questions that were set out in chapter 3. Because of the size of the sample and the distribution of these four key variables non-parametric techniques was used for the following analyses

What are the Relationships among Family Caregiver Gender, Age, Fatigue, Sleep Deficit, Perceived Health, Care Recipient Functional Status, and Caregiving Relationship? How do the Relationships Change over Time?

The first research question of this study addresses the relationships among demographic variables such as FCG gender, age, and relationship with the care recipient; the functional status of the care recipient; and the three main variables of this study, fatigue, sleep deficit, and perceived health. The statistical analysis procedures and their rationale will be presented first, followed by the results at each of the three data collection points set out at the beginning of this chapter. The second aspect of this part of the analysis addresses how the relationships among these variables changed over time. Consequently, the similarities and differences among these relationships over the three time periods will be discussed.

Analysis procedures.

A Spearman's rho (r_s) correlation analysis was conducted to determine the presence and direction of the relationships among FCG gender, FCG age, FCG fatigue, FCG sleep deficit, FCG perceived health, care recipient functional status, and the nature of the caregiving relationship (FCG caring for parent or person of older generation, or FCG caring for spouse or person of same generation) at T_1, T_2, and at T_3. Non-parametric analysis was used because some of the data violate the parametric assumptions. The alpha cut off was set at 0.05 (representing the level of error we are willing to accept) and two-tailed tests were used because there hasn't been previous empirical work done in the area to suggest a direction to the relationship, although one could argue that the direction could be inferred with common sense. .Using a one tailed test in this circumstance would increase the likelihood of finding a significant relationship among the variables.

Findings.

As can be seen in Table 1, when the FCGs had put their care recipient on the waitlist for placement in long term care, significant correlations were found between FCG gender and fatigue as well as between FCG gender and FCG sleep deficit, indicating that female caregivers reported higher levels of fatigue and higher sleep deficits. On the other hand, no significant relationships were found between gender and age, self-reported health, care recipient function or caregiving relationship, suggesting that female caregivers were not relatively older, less healthy or of a different caregiving generation than male caregivers. Nor were the care recipients of female caregivers more or less functional than those of male caregivers.

As would be expected, FCG age and care giving relationship (1=spouse, 2=parent) were significantly related, indicating that spouse caregivers (or those caring for someone of their own generation) were significantly older than parent caregivers (or those caring for someone of an older generation). It is interesting to note that FCG age was not significantly related to any of the other key variables such as fatigue, sleep deficit, or health.

Not surprisingly, FCG fatigue and FCG sleep deficit were significantly correlated, as was FCG fatigue and FCG health, and FCG fatigue and CR function. What this suggests is that those caregivers who reported higher levels of fatigue also reported higher levels of sleep deficit, poorer health, and lower care recipient function. There was no relationship found between FCG fatigue and caregiving relationship, suggesting that fatigue levels were similar for FCGs caring for their spouses or parents.

A significant relationship was found between FCG sleep deficit and FCG health and FCG sleep deficit and caregiving relationship. Previously in this section we mentioned that FCG sleep deficit and FCG gender we significantly correlated as was FCG sleep deficit and FCG fatigue. What this means is that those caregivers who reported the highest levels of sleep deficit were more likely to be female and report higher levels of fatigue, also these caregivers reported the poorest health, and were more likely to be caring for a spouse. There were no relationships found between FCG sleep deficit and FCG age or FCG sleep deficit and CR function. This is an interesting finding as well, suggesting that FCG sleep deficit occurred at all age ranges and CR function levels.

FCG health was correlated with CR function and as previously mentioned with FCG fatigue and FCG sleep deficit. What this means is that those FCGs who reported the lowest levels of health also reported having a care recipient with lower functional status, higher levels of fatigue, and higher sleep deficit. No relationships were found between FCG health and FCG gender, FCG health and FCG age, or FCG health and caregiving relationship. That suggests that FCGs who reported lower levels of health were no more likely to be male than female, were not of any specific age range, and were no more likely to be caring for a spouse than a parent.

Care recipient function was correlated with FCG fatigue and FCG health as previously reported. This means that care recipients with lower functional status were more likely to have a caregiver who reported higher levels of fatigue and poorer health. There were no relationships found between CR function and FCG gender, FCG age, FCG sleep deficit, or caregiving relationship. It’s not surprising that care recipient function is not correlated with FCG gender, FCG age, or caregiving relationship, however it is interesting that those care recipients with lower function did not necessarily have caregivers who reported sleep deficit.

The final set of significant correlations at this time period are between caregiving relationship and FCG age, and caregiving relationship and FCG sleep deficit. What this means is that those caregivers who were caring for spouses were more likely to be older and to report having a sleep deficit. Interestingly, there were no significantly correlated relationships between caregiving relationship and FCG gender, caregiving relationship and FCG fatigue, caregiving relationship and FCG health, or caregiving relationship and CR function.

Table 13

Relationships Among Key Variables at T1

First interview after care recipient placed on institutional waitlist

			FCG Gender	FCG Age	FCG Fatigue	FCG Sleep Deficit	FCG Health	CR Function	FCG Rel
Spearman's rho	FCG Gender	CorrCoeff	1.000	-.147	.428**	.425**	-.258	.128	-.113
		Sig. (2-tail)	.	.372	.008	.009	.124	.455	.495
		N	39	39	37	37	37	36	39
	FCG Age	CorrCoeff		1.000	.024	.300	-.152	.064	-.599**
		Sig. (2-tail)		.	.889	.072	.370	.712	.000
		N		39	37	37	37	36	39
	FCG Fatigue	CorrCoeff			1.000	.566**	-.640**	.368*	-.321
		Sig. (2-tail)			.	.000	.000	.027	.053
		N			37	37	37	36	37
	FCG Sleep Deficit	CorrCoeff				1.000	-.411*	.222	-.586**
		Sig. (2-tail)				.	.011	.193	.000
		N				37	37	36	37
	FCG Health	CorrCoeff					1.000	-.440**	.305
		Sig. (2-tail)					.	.007	.067
		N					37	36	37
	CR Function	CorrCoeff						1.000	-.106
		Sig. (2-tail)						.	.539
		N						36	36
	FCG Rel	CorrCoeff							1.000
		Sig. (2-tail)							.
		N							39

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

At time 2, the care recipient was nearing placement in a long-term care setting, although caregivers may not have been notified. Fewer significant relationships were found between key variables, as illustrated in table 13. Gender was not significantly related to any other variables at T_2, suggesting that male and female caregivers were likely to be experiencing similar levels of fatigue and sleep deficit, unlike the differences that were apparent at T_1. As at T_1, there were no significant relationships found between gender and any of the other variables at T_2.

There was a significant relationship between family caregiver relationship and caregiver age, which is straightforward. The oldest caregivers were those who were caring for spouses. It is interesting to note that age was not correlated with FCG fatigue, sleep deficit, health, or care recipient function.

There is a significant relationship between caregiving relationship and FCG sleep deficit at T_2, and this relationship is stronger at T_2 than at T_1. There were no significant correlations between the caregiving relationship and FCG gender, FCG fatigue, FCG health, or care recipient function. These findings suggest that the spouse caregivers were more likely to report a sleep deficit than the caregivers who were caring for a parent, but that the gender mix, FCG fatigue, FCG health and care recipient function were similar for both groups of caregivers.

At T_2, FCG fatigue and FCG sleep deficit were significantly related, as were FCG fatigue and FCG health. There were no significant relationships between FCG fatigue and care recipient function, FCG age or gender, or the nature of the caregiving relationship. What this means is that the caregivers who reported the highest levels of fatigue were also those who reported the highest sleep deficits and the lowest levels of health. However, those FCGs who were caring for individuals with lower function were not necessarily the FCGs who reported being the most fatigued.

As previously mentioned, FCG sleep deficit was related to the caregiving relationship, and also to FCG fatigue at T_2. There was also a relationship between FCG sleep deficit and FCG health. There were no correlations found between FCG sleep deficit and gender or age, and no relationship between FCG sleep deficit and care recipient function. What this means is that the FCGs who reported the highest levels of sleep deficit were more likely to be caring for a spouse, and report higher levels of fatigue, and lower levels of health. This also means that sleep deficit occurred in FCG regardless of the FCG age, gender, or the care recipient's functional status.

To recap the FCG health relationships at T_2, there was a correlation between FCG health and FCG fatigue, as well as FCG health and FCG sleep deficit. There were no significant relationships between FCG health and care giving relationship, FCG age or gender, or care recipient function. What this means is that FCGs who reported the lowest levels of health were also those who reported higher levels of fatigue and higher sleep deficits. This being said, those FCG with the lowest reported health were just as likely to come from either gender grouping, age, or caregiving relationship. Lower levels of health were reported by those caring for individuals who were at all ability levels, not just those with the lowest function.

There were no new correlations when comparing T_1 to T_2 although a few relationships that were significant at T_1 were no longer found to be related at T_2. FCG gender was associated with fatigue and sleep deficit at T_1 but not at T_2. Also at T_1 there was a relationship between care recipient function and FCG fatigue as well as with FCG health, but this relationship was not found at T_2.

Table 14

Relationships Among Variables at T2

Last interview before care recipient placement

			FCG Rel	FCG Gender	CG Age	FCG Fatigue T_2	FCG Sleep Def T_2	FCG Health T_2	CR Function T_2
Spearman's rho	FCG Rel	Corr Coeff	1.000	-.113	-.599**	-.323	-.681**	.179	-.091
		Sig. (2-tail)	.	.495	.000	.191	.002	.478	.702
		N	39	39	39	18	18	18	20
	FCG Gender	CorrCoeff		1.000	-.147	.438	.446	-.104	-.142
		Sig. (2-tail)		.	.372	.069	.064	.681	.549
		N		39	39	18	18	18	20
	CG Age	Corr Coeff			1.000	.080	.102	.112	.186
		Sig. (2-tail)			.	.752	.688	.659	.432
		N			39	18	18	18	20
	FCG Fatigue T_2	CorrCoeff				1.000	.705**	-.660**	.143
		Sig. (2-tail)				.	.001	.003	.570
		N				18	18	18	18
	FCG Sleep Def T_2	CorrCoeff					1.000	-.505*	-.119
		Sig. (2-tail)					.	.032	.639
		N					18	18	18
	FCG Health T_2	CorrCoeff						1.000	-.177
		Sig. (2-tail)						.	.482
		N						18	18
	CR Function T_2	CorrCoeff							1.000
		Sig. (2-tail)							.
		N							20

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

After the care recipient has been placed in long term care (T_3) the only relationships that remain significant are between FCG age and caregiving relationship, and between FCG fatigue and FCG health, suggesting that FCGs who reported the highest levels of fatigue also reported the lowest levels of health. For this time period it is also interesting to note where there are no relationships.(see table 14) In comparison with time $_2$ there are no longer significant relationships among sleep deficit and caregiving relationship, FCG fatigue, or FCG health.

Table 15

Relationships Among Variables at T_3

Post placement in institutionalized care

			FCG Rel	FCG Gender	CG Age	FCG Fatigue T_3	FCG Sleep Def T_3	FCG Health T_3	CR Function T_3
Spearman's rho	FCG Rel	CorrCoeff	1.000	-.113	$-.599^{**}$	-.266	.014	.358	.331
		Sig. (2-tail)	.	.495	.000	.287	.956	.159	.211
		N	39	39	39	18	17	17	16
	FCG Gender	CorrCoeff		1.000	-.147	.311	.112	.000	.439
		Sig. (2-tail)		.	.372	.209	.668	1.000	.089
		N		39	39	18	17	17	16
	CG Age	CorrCoeff			1.000	.217	.259	-.291	-.291
		Sig. (2-tail)			.	.388	.316	.257	.274
		N			39	18	17	17	16
	FCG Fatigue T_3	CorrCoeff				1.000	.432	$-.664^{**}$	.481
		Sig. (2-tail)				.	.083	.004	.059
		N				18	17	17	16
	FCG Sleep Def T_3	CorrCoeff					1.000	-.256	.088
		Sig. (2-tail)					.	.338	.747
		N					17	16	16
	FCG Health T_3	CorrCoeff						1.000	.098
		Sig. (2-tail)						.	.728
		N						17	15
	CR Function T_3	CorrCoeff							1.000
		Sig. (2-tail)							.
		N							16

**. Correlation is significant at the 0.01 level (2-tailed).

Do Caregiver Gender, Care Recipient Functional Status, or Caregiving Relationship Predict Caregiver Sleep Deficit

The second question of this study addressed whether or not caregivers' sleep deficits can be predicted by the caregiver's gender or relationship with the care recipient, or by the care recipient's functional status. The statistical analysis procedures and their rationale will be presented first, followed by the results at each time point.

Analysis Procedure.

This question was best answered using a hierarchical regression technique because we wanted to know if and how much the variables stated influenced FCG sleep deficit. Hierarchical regression requires that you choose in which order you will do the calculation and this order was decided after careful consideration of the previous work done in this field.

Findings.

In this hierarchical multiple regression analysis, potential predictors of sleep deficit at T_1 (time of waitlist placement) were entered into three blocks. FCG gender was put into the first block and accounted for 17.9% of the variance (R_2=0.179, p=0.011). The second block included gender and caregiving relationship and accounted for 46.5% of the variance (R_2=0.465, p=0.000). The third and final block included FCG gender, caregiving relationship (parent or spouse), and CR function which was not found to significantly account for the variance in sleep deficit at T_1 (R_2=0.510, p=0.102) (See Table 15). The final model indicated that being female and of the same generation as the care recipient (ie: spouse caregiver) predicted increases in sleep deficit among FCGs (gender β=0.322, p=0.017 and caregiving relationship β= -0.516, p=0.00). Care recipient function is not a predictor of sleep deficit (β= 0.216, p=0.102). The calculated F score, F (3,34)=10.760, p=0.000, indicates that a linear model is a good fit for this data. The calculated regression equation is Sleep Deficit = 43.360 + 0.322 (gender) – 0.516 (caregiving relationship).

Table 16

Hierarchical regression of FCG gender, caregiving relationship, and CR function at T1 on FCG sleep deficit at T1

Variables	**FCG Sleep Deficit**	**FCG Gender**	**CG Relation**	**CR Function**	***B***	***β***	***sr^2***
FCG Gender	0.423				66.482	0.32	0.179
Caregiving Relation	-0.586	-0.129			-98.315		0.287
CR Function	0.333	0.158	-0.129		1.917		0.045
Intercept					43.36		
Means	83.66	1.71	1.60	43.63			R^2=0.510
Standard Deviations	94.671	0.458	0.497	10.647		Adjusted	R^2=0.463
							R=0.714

The same analysis was done with the data collected at T_2 and T_3. At T_2, FCG gender accounted for 16.8% of the variance (R_2=0.168, p=0.042). The second block included gender and caregiving relationship and accounted for 40.0% of the variance (R_2=0.400, p=0.008. The third and final block included

FCG gender, caregiving relationship (parent or spouse), and CR function which was not found to significantly account for the variance in sleep deficit at T_1 (R_2=0.426, p=0.334). The final model indicated that caregiving relationship is a negative predictor of sleep deficit (β= -0.492, p=0.08). At this time gender is not a significant predictor of sleep deficit (β= 0.342, p=0.054) and neither is care recipient function (β= 0.164, p=0.334) (see Table 16). The calculated F score, F(3,24)=5.204, p=0.008, indicates that a linear model is a good fit for this data. The calculated regression equation is Sleep Deficit = 65.543 – 0.492 (caregiving relationship).

Table 17

Hierarchical regression of FCG gender, caregiving relationship, and CR function at T_2 on FCG sleep deficit at T_2

Variables	**FCG Sleep Deficit**	**FCG Gender**	**CG Relation**	**CR Function**	***B***	***β***	***sr²***
FCG Gender	0.410				63.6	0.342	0.168
Caregiving Relation	-0.540	-0.157			-94.1	-0.49	0.232
CR Function	0.127	0.059	-0.035		1.58	0.16	0.027
Intercept					65.54		
Means	85.40	1.64	1.68	46.72			R^2=0.426
Standard Deviations	91.06	0.49	0.48	9.46		Adjusted	R^2=0.344
							R=0.653

At T_3 there were no significant predictors of sleep deficit F(3,8)=0.348, p=0.793.

These results indicate that being a female FCG or caring for a spouse or care recipient from your own generation predicts having a sleep deficit and that care recipient function does not appear to predict sleep deficit at the time of waitlist placement. However at the last interview before care recipient placement, only caregiving relationship predicts sleep deficit.

Do Caregiver Age and Caregiver Sleep Deficit Predict Caregiver Fatigue?

Analysis Procedures

In the next hierarchical multiple regression analysis, potential predictors of FCG Fatigue were entered into two blocks and separate analyses were run for each of the three time points. We chose the order of the regression based on previous research published in the area.

Table 18

Hierarchical regression of FCG age or FCG sleep deficit at T_1 on FCG fatigue at T_1

Variables	**FCG Fatigue**	**FCG Age**	**FCG Sleep Deficit**	***B***	***β***	***sr*^{2} (incremental)**
FCG Age	0.007			-0.024	-0.15	0.00
FCG Sleep Deficit	0.518	0.278		0.016	0.56	0.29
Intercept				6.017		
Means	5.86	60.08	81.97			R^2=0.29
Standard Deviations	91.06	0.49	0.48		Adjusted	R^2=0.25
						R=0.54

Findings.

At T_1, FCG age was put into the first block and did not significantly account for the variance in fatigue (R_2=0.000, p=0.965). The second block included age and caregiver sleep deficit and accounted for 28.9% of the variance (R_2=0.148, p=0.001). The final model indicated that FCG age is not a predictor of Fatigue (β= -0.078, p=0.319) however FCG sleep deficit is a positive predictor of Fatigue (β= 0.559, p=0.001) at the time of waitlist placement (see Table 17). The calculated F score, F (2,38)=7.299, p=0.002, indicates that a linear model is a good fit for this data. The calculated regression equation for T_1 is FCG Fatigue = 6.017 + 0.559 (Sleep Deficit).

Table 19

Hierarchical regression of FCG age or FCG sleep deficit at T_2 on FCG fatigue at T_2

Variables	**FCG Fatigue**	**FCG Age**	**FCG Sleep Deficit**	***B***	***β***	***sr*^{2} (incremental)**
FCG Age	0.021			0.00	0.003	0.00
FCG Sleep Deficit	0.598	0.030		0.017	0.598	0.358
Intercept				3.553		
Means	5.22	60.08	94.72			R^2=0.36
Standard Deviations	2.020	15.754	69.684		Adjusted	R^2=0.32
						R=0.598

At T_2 FCG age did not significantly account for variance in FCG fatigue (R_2=0.000, p=0.898) however FCG sleep deficit accounted for 35.8% of the variance in fatigue (R_2=0.358, p=0.000). The final model indicates that FCG sleep deficit is a positive predictor of Fatigue (β= 0.598, p=0.000) at the last interview before care recipient placement. The calculated F score, F(2,38)=10.039, p=0.000 indicates that a linear model is a good fit for this data. The calculated regression equation for T_2 is FCG fatigue = 3.553 + 0.598(Sleep Deficit).

At T_3 FCG age did not significantly account for variance in FCG fatigue (R_2=0.021, p=0.373) however FCG sleep deficit accounted for 12.9% of the variance in fatigue (R_2=0.129, p=0.042). The final model indicates that FCG sleep deficit is a positive predictor of Fatigue (β= 0.598, p=0.000) at the interview post care recipient placement. What this means is that age was not found to predict FCG fatigue at any of the time points measured although sleep deficit did predict fatigue. The calculated F score, F(2,38)=2.662, p=0.084 indicates that a linear model is not a good fit for this data and so this could mean that this relationship is non-linear.

Do Caregiver Age and Caregiver Sleep Deficit Predict Caregiver Perceived Health?

Analysis procedures.

In the last hierarchical multiple regression analysis, potential predictors of FCG Health were entered into two blocks. We chose the order of the regression based on previous research done in the field.

Findings.

FCG age was put into the first block and did not significantly account for the variance in FCG health at the time of waitlist placement (R_2=0.007, p=0.620). The second block included the age and FCG Sleep Deficit and also did not account for the variance (R_2=0.095, p=0.069). The final model indicated that neither age (β= -0.004, p=0.981) nor sleep deficit (β= -0.310, p=0.069) are predictors for FCG health at the time of waitlist placement (T_1). The calculated F score, F(2,38)=1.893, p=0.165, indicates that a linear model is not a good fit for this data, meaning the relationship may be non-linear.

At T_2 FCG age did not significantly account for variance in FCG health (R_2=0.004, p=0.695) however FCG sleep deficit accounted for 15.5% of the variance in fatigue (R_2=0.155, p=0.016). The final model indicates that FCG age is not a significant predictor for FCG health (β= 0.076, p=0.622) however FCG sleep deficit is (β= -0.388, p=0.016) at the last interview before care recipient placement. The calculated F score, F(2,38)=3.293, p=0.049 indicates that a linear model is a good fit for this data. The calculated regression equation for T_2 is FCG health = 7.152 – 0.388 (Sleep Deficit).

Table 20

Hierarchical regression of FCG age or FCG sleep deficit at T_2 on FCG health at T_2

Variables	**FCG Health**	**FCG Age**	**FCG Sleep Deficit**	***B***	***β***	***sr^2* (incremental)**
FCG Age	0.021			0.00	0.003	0.00
FCG Sleep Deficit	0.598	0.030		0.017	0.598	0.358
Intercept				3.553		
Means	5.22	60.08	94.72			R^2=0.36
Standard Deviations	2.020	15.754	69.684		Adjusted	R^2=0.32
						R=0.598

At T_3 FCG age did not significantly account for variance in FCG fatigue (R_2=0.021, p=0.373) however FCG sleep deficit accounted for 12.9% of the variance in fatigue (R_2=0.129, p=0.042). The final model indicates that FCG sleep deficit is a positive predictor of Fatigue (β= 0.598, p=0.000) at the interview post care recipient placement. The calculated F score, F(2,38)=2.662, p=0.084 indicates that a linear model is not a good fit for this data. The calculated regression equation for T_3 is FCG fatigue = 3.740 + 0.335 (Sleep Deficit).

These results indicate that neither age nor fatigue appears to predict FCG health at T_1 and T_3 however at T_2, increased FCG fatigue is predictive of poorer health.

CHAPTER 5 – DISCUSSION

Discussion of Major Findings

After univariate analysis we found that our sample was similar to that of other caregiving groups that are in the current literature, in regards to variables such as fatigue and sleep deficit, and different in other areas such as self-rated health. Many of our caregivers reported fatigue at some level, with the average caregiver reporting moderate fatigue. This is congruent with Clark's study in which one third of caregivers reported fatigue (2002). Previous studies in this area report sleep problems at a rate of 50 to 70% which is similar to our findings (Ferrara et al., 2008; Creese, Bédard, Brazil, & Chambers, 2008; McCurry, Gibbons, Logsdon, Vitiello, & Teri, 2005). In regards to health may of our participants rated their health as good, while much of the caregiving literature reports on the poor health status of their participants (Vitaliano, Zhang, & Scanlan, 2003 & Christakis, & Alison, 2006, Son et al., 2007).

The results of this study suggest that there are relationships among FCG age, gender, fatigue, sleep deficit, health, caregiving relationship, and care recipient functional status. We did not find significant changes in the variables fatigue, sleep deficit, health, and care recipient function over the three time periods. We found that being female and being a spouse caregiver (or same generation caregiver) predicts higher values of sleep deficit at T_1 and being a spouse caregiver also predicts higher values of sleep deficit at T_2. We found that higher values of sleep deficit predict increased fatigue at each of the three time periods. We found that higher values of sleep deficit predict decreased health at T_2.

Relationships among Variables at Three Time Periods

At the time of waitlist placement we found there were significant relationships among many of the variables. There are relationships between sleep deficit, fatigue and health, and for the most part these relationships are straight forward but they have never been empirically shown before, and so these findings are exciting.

From previous work we know that being a FCG of PWD is associated with sleep disturbances (Castro et al., 2009, Teel & Press, 1999) and that caregivers often feel fatigued (Clark, 2002), and we know that FCGs are a greater risk of having poor health (Vitaliano, Zhang, & Scanlan, 2003) however, the strength of those relationships has not been empirically explored. My expectation was that there would be a strong relationship between these main variables – that as the care recipients declined in function caregivers would perhaps begin accruing a sleep deficit, they would feel more fatigue, and that their health would be poorer. The relationship is there but it is not perfectly linear, and part of that is related to the complexity of the situation and the variability of caregiving relationships.

No new relationships appeared over the next two time periods. At T_2, which was the last interview before CR placement, only the relationships among the three main variables remained and at T_3, the post placement interview, only the relationship among fatigue and health remained. I find this very interesting because my hypothesis was that the relationships would get stronger over time. Our findings may be reflective of the actual situation, perhaps the relationships among variables disappear as time wears on. One possibility is that there may be other factors that we didn't include in this study that become more important as the caregiving dyad move through the process of awaiting placement. It also may be that these relationships become harder to detect due to the small participant number at T_2 and T_3.

Relationships with sleep deficit.

I am also quite surprised that the relationships among sleep deficit and fatigue and health weren't stronger. I think this comes primarily from flaws in the sleep deficit measurement tool. The wide range of responses from participants for the sleep deficit questions could be due to unrecorded differences or changes in dyad sleeping arrangements, care recipient symptoms, or preexisting FCG sleep issues to name a few. A more in depth questionnaire that collected information about where the FCG and CR slept, whether or not the care recipient awakened during the night, and whether or not the FCG had a preexisting difficulties with sleep might have been helpful to get a more full sense of why we found such varied responses.

It may be that the tool was too simple to capture useful data. We asked how many hours of sleep the FCGs got however we didn't ask if it was all in one stretch or if it was interrupted, which of course would be significantly different experiences. An example of this lies in case #17 where the caregiver felt they needed eight hours sleep per night however they were only getting seven hours with a one hour nap. Following the a priori definition of sleep deficit set out in chapter 3, this participant was recorded as having a sleep deficit score of zero. However, this individual can't really be considered to be getting the sleep they feel they require, and may not feel as well rested as someone who received the full eight hours, especially if the seven hours they got were interrupted. The simplicity of this tool was so appealing because it was logical and did not require expensive and time consuming assessments, however in hindsight it may have too general.

It is interesting that there were no significant changes in sleep deficit over the three time periods. Again the small sample size may explain this finding, or the fact that those with the greatest sleep deficit were unable to continue with the study. To explore that hypothesis I ran the descriptive again with just the eight subjects who responded to the sleep deficit questions at each of the three time periods and found that the mean sleep deficits were not significantly different.

The relationship between sleep deficit and being a female FCG is significant because there is very little published research that compares sleep issues in male verses female caregivers. Our study suggests that nearly 18% of the sleep deficit reported by FCGs at the time of waitlist placement can be accounted for by being female. Being female and caring for a spouse accounts for nearly 47% of the variance in sleep deficit scores reported by caregivers. At the last interview before care recipient placement being female is no longer predictive of sleep deficit however caring for a spouse continues to account for nearly 40% of the variance in sleep deficit scores. At T_3, after the care recipient has been placed in long term care there are no significant predictors of sleep deficit.

Our study also suggests there is a positive relationship between sleep deficit and fatigue at both T_1 and T_2 which makes sense even though those results are not necessarily well published in the caregiving literature. That relationship does not carry forward into the T_3 time period which could signify changes due to the end of the formal caregiving relationship however previous studies suggest that FCGs continue in their role after the care recipient has been placed in long term care. It may also be the power to detect this relationship was not there due to the small sample size.

We detected a negative relationship between sleep deficit and health at T_1 and T_2 which was not detected at T_3. This further supports the large body of publications that suggest that caregivers who have sleep disturbances or sleep issues are not as healthy as the ones who do not. The findings at T_3 may represent the possibility that once the care recipient was placed the caregivers sleep issues resolved, however previous research suggests that problems sleeping continue past institutionalization and the cessation of the formal caregiving relationship, and so this finding is curious. Perhaps non-significance in this instance is a function again of the small sample size.

Relationships with fatigue.

Fatigue also had a large range over the three time periods, at T_1 and T_2 we had participants who reported 0/10 fatigue and some who reported 10/10. Although mean fatigue scores did not significantly differ over the three time periods there was definitely a trend towards a smaller range which is interesting. Also, the actual mean fatigue scores dropped slightly over the three time periods and so we looked at the eight participants who reported fatigue scores at each of the three interview times and found that fatigue dropped slightly at T_2 and then rose again at T_3. This small drop in reported fatigue may be because FCGs felt like there was an end in sight after placing their CR on the waitlist for placement or it could be changes in CR activity levels or behaviours at T_2. The slight rise at T_3 may be because of the change in caregiving responsibilities that come with care recipient institutionalization or because now that the FCG isn't providing care any longer they recognize how fatigued they were. It is important to keep in mind that these changes in the mean were not significant, however that may be related to the small sample size.

The relationship between fatigue and gender, and fatigue and age, has been shown in other research in this population (Gaston-Johansson, et al., 2004 & Gaugler et al., 2008). In our study, the caregivers with the highest reported levels of fatigue were: women, provided care for spouses or persons of the same generation as themselves, reported higher sleep deficits, reported lower health scores, and were caring for a care recipient with lower function. These relationships among fatigue and sleep deficit, and fatigue and FCG health continued into T_2, as well as the relationship between sleep deficit and health. Finally, the only relationship that remained significant throughout each of the time periods was FCG fatigue levels and FCG self-rated health.

Although our study supports the hypothesis that sleep deficit and fatigue are related, previous studies have shown that FCGs with the highest levels of fatigue are often the ones who are not disturbed at night (Tsukasaki et al., 2006). The relationships among fatigue and the above mentioned variables are indicative of the complex and multifactoral nature of fatigue in this population.

Relationships with health.

FCG health while actively providing care for the care recipient or during the months following the care recipient's placement in an institutionalized setting has been fairly well explored in previous research. From this research we know that providing care for someone with dementia has a negative effect on the health of caregivers (Vitaliano, Zhang, & Scanlan, 2003). In this study we found that mean health scores stayed fairly steady throughout the three time periods. FCGs rated their health approximately 7/10 which would indicate that for the most part they viewed themselves to have fair to good health. There is a small dip in the mean scores at T_2 which may represent a tiring or wearing down of the FCGs however this finding was not significant.

Looking at the relationships with health and the other variables we found that initially the mean scores for FCG health were correlated with fatigue, sleep deficit, and lower care recipient function. At T_2 sleep deficit and fatigue were still correlated with FCG health, and at T_3 only the relationship between fatigue and health was maintained. In regards to predicting health, the only significant predictor was sleep deficit which accounted for ~16% of the variation in FCG health and this was only true at T_2. Previous research done supports the relationship between health and sleep issues in the aged population (Ensrud et al., 2009), and that persons with disrupted sleep have a higher mortality rate than those without sleep issues (Tranah et al., 2010). The findings from this study add more information to this complex relationship between health and sleep for caregivers.

Predicting sleep deficit.

Our finding suggest that being female and caring for a spouse predicts FCG sleep deficit at the time of waitlist placement however care recipient function does not. At T_2 caring for a spouse continues to be a predictor of sleep deficit however gender no longer does. At the final interview after CR placement none of these variables is a predictor of sleep deficit. Perhaps this reflects that care recipients are easier to care for as their functional status declines, or there are fewer sleep disruptions. This may also be a reflection of the previously mentioned limitations of the tool or of an inadequate sample size. Exploring how caregivers perceived their sleep adequacy would be a crucial next step for this body of knowledge.

Predicting fatigue.

It follows common sense to me that in our study sleep deficit predicted fatigue at each of our three time points. It is not unreasonable to think that those caregivers who were not getting the amount of sleep that they felt they needed would have greater perceived fatigue levels. I was surprised to see that age did not predict fatigue, and in hindsight I would like to know if caregiving relationship predicted fatigue, because that would speak to the complex relationships among caring for a spouse – these results suggest that being older doesn't predispose you to having fatigue, but having a sleep deficit does. And we know that caring for a spouse predicts sleep deficit so it would be interesting to look at that relationship a bit further. Are caregivers who are living with their care recipient more likely to experience sleep deficit and then fatigue? Are those caregivers who share a bed with their care recipients more likely to have sleep deficit and thereby fatigue? We saw in this study that there was a relationship between being female and having fatigue and being female and having sleep deficit so it would be interesting to quantify this relationship, I wonder if adding gender into the regression equation has an effect on the FCGs fatigue level. Another area that could be explored is in the area of sleep adequacy and fatigue.

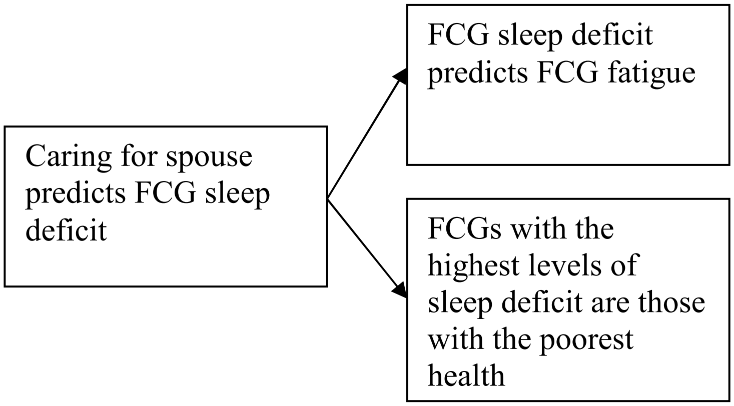
The predictive relationship between fatigue and sleep deficit is not as straight forward as might be thought on first examination. Our study showed that sleep deficit predicted fatigue, but there have been studies that support the hypothesis that fatigue predicts sleep problems (Fletcher et al., 2009). This leads me to believe that a linear framework for this relationship may not be appropriate. Perhaps if you are fatigued you don't sleep as well and if you don't sleep as well you are fatigued, in which case you can't use one to predict another. It is so important that we continue to research possible predictors of fatigue as studies have shown that fatigue is often rated as one of the worst symptoms individuals experience (Curt et al., 2000).

Predicting health.

At the time of waitlist placement and at the final interview post CR placement our study did not detect any predictors of FCG health, and we found that sleep deficit was only a small predictor of health at T_2. It would be interesting to know if a different sleep measurement tool would be a stronger predictor – because there is much previous research (as outlined in Chapter 2) that supports the relationship between sleep and health. We didn't explore whether fatigue was a predictor of health which I think would be a valuable study.

Figure 2

Possible New Conceptualization



Although other studies have explored fatigue in various caregiving populations as described in chapter two, this study is an introductory look at fatigue and its relationship with self-perceived health, sleep deficit, and care recipient functional status in FCG of PWD while awaiting placement.

Theoretical Findings

Our original theory was that as the care recipient's function declined we would see an increase in FCG sleep deficit and fatigue and a decrease in self-rated health and that the relationship would be linear. However, after analysis of this data I hypothesize that perhaps this relationship isn't as linear as I first believed it to be.

It seems that there is some improvement in fatigue and health from the time of waitlist placement to the last interview before placement. I hypothesize this could be related to many factors. It is possible that the process of putting their CR on the waitlist may have spurred on changes in FCGs. They may have felt more in control of the situation post waitlist placement, because they had made the decision to place their CR in an institution and then had the knowledge that there was going to be an end to their caregiving role. Another possibility is that FCGs may have felt better about the situation and felt it was more manageable after telling their story to the placement coordinator and being able to process the journey they had been on. There may also have been teaching done by the placement coordinator in regards to management strategies, or there may have just been reassurances given that they had been doing a good job or recognition that they had been in a tough situation.

Changes in the care recipient may have also been responsible for the small increase in health and fatigue seen at T_2. The data suggests that the CR function decreased over the three time periods however that doesn't necessarily suggest that the FCG had increased burden. As the CRs condition declined they may have had less disruptive behaviors such as aggression or wandering. Another possibility is that the assessment led to changes in treatments or medications. Another possibility is that the caregiving environment may have changed as well over the three time periods, The assessment process may have triggered referrals for supports such as initiation or increases in home care or day respite programs.

Measurement Issues

The measurement tools that were chosen for this study were designed to be simple and straightforward and easy to use for our caregivers. Using ladder type scales to measure fatigue and health has construct validity and demonstrated validity. It worked well to get a general sense of how the FCGs viewed their health and fatigue however it lacks the objectivity of different measurement scales such as physical exam findings. However I think that in reproducing this study the ease of use and low burden of these scales outweigh the lack of detail they provide.

The functional dementia scale (Moore, Bobula, Short, & Mischel, 1983) appears to have worked well to describe the functional trajectory typically associated with dementia. As expected from previous work in the area, we found that as the trajectory of caregiving continued, the functional status of the care recipient declined at a fairly linear rate, although we were unable to declare a statistically significant difference between the three time periods.

The findings from the sleep deficit equation seem to be the “least perfect” of the measurements taken. The data collected were not normally distributed and I believe that many of our “non-findings” were due to this combined with our small number of participants. If this study is to be reproduced I think a better measure of sleep will need to be devised. It would be useful to know if nightly sleep was continuous or disturbed. As stated earlier, sleeping for eight hours but being disturbed every 30 minutes is not the same as a solid eight hours of sleep. It would be interesting to add a dichotomous question such as “Does caregiving affect your sleep”. Of course a more detailed analysis of sleep also increases participant burden so changes in questions would have to be thoughtfully considered.

Summary and Recommendations for Further Research

Summary of findings.

It is possible that the changes in sleep deficit, fatigue, and health over the three interview points would be significant if they were examined in a larger study. However, even in this small pilot study there are relationships among sleep deficit, fatigue, and health in the FCG population during this time period. Those FCGs who are fatigued have the lowest health over each of the three time periods. Sleep deficit significantly predicts fatigue at each of the three time periods, and caring for a spouse or person of your own generation predicts sleep deficit. We also found that sleep deficit partially accounts for FCG health while the care recipient is awaiting placement.

Limitations of the study.

I feel the two biggest limitations of this study are the sleep measurement tool and the small number of participants. With this study being a secondary analysis of previously collected data we accept what was collected and work within its limitations. This study provides valuable insight into the variables and we wouldn't have known that this sleep deficit equation didn't work until we tried it. Our small participant number definitely affected our ability to determine significance. When this project is done on a larger scale I would expect to see significance in the changes in sleep, fatigue, and health over the three time periods.

Clinical implications of the findings.

Clinical recommendations that I would make from the findings of this study are around the importance of FCG health during this transitional period. Clinicians are already aware that FCG health is important and I believe this study provides further illumination to this unique time period for the caregiver/care recipient dyad. Healthcare professionals need to be assessing for sleep issues and signs of fatigue in the FCGs who are under their care, especially among same-generation caregivers. Programs need to be developed and implemented that provide education and resources for FCGs in the area of sleep hygiene and fatigue prevention.

Recommendations for further research.

I propose that a few minor changes in tools need to be made before this study is reproduced. A smaller and more focused questionnaire could be made to focus on these three important variables. The database could be pared down to reduce burden, including only the age and gender of FCGs and their care recipients. I believe the ladder type scale for health, and fatigue is adequate to measure these variables. For sleep I would ask only about sleep at night, and not include naps in the sleep deficit equation. I would also include a specification regarding continuous or interrupted sleep, because I believe they are two different experiences.

Future studies in this area could explore the predictors of sleep deficit in this population. Previous research has suggested that FCG frequently report sleep difficulties (Castro et al., 2009) and that there are relationships between sleep issues and burden (Allegri et al., 2006), stress (Kochar, Fredman, Stone, & Cauley, 2007), and depression (Creese, et al., 2008) but there is no published literature that explores which variables predict sleep problems. These would be important factors to explore so that further programs and interventions could be developed for this population.

In our study sleep deficit accounted for less than 20% of the variation in FCG health and so further work can be done to explore the other predicting factors that are as of yet unpublished. Exploring stress, burden and depression further may give health care providers more insight into the experience of providing care while waiting for care recipient placement.

Conclusion

This pilot study is the beginning of a very exciting new area to explore in the realm of family caregiving for persons with dementia. As our population continues to age and prevalence of dementia continues to grow it will become more and more important for health care providers to support FCGs and ensure their health remains a priority for those involved in program development and community funding. Sleep and fatigue are important factors to consider when providing care for caregivers and there is still so much to explore.

Appendix A

General Information – Caregiver and Care Recipient

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

☐ Husband/wife
☐ Parent
☐ Parent-in-law
☐ Aunt/uncle
☐ 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
☐ Female

7. Care recipient sex

☐ Male
☐ Female

8. Religion (care giver)

☐ Catholic
☐ Protestant
☐ Jewish
☐ Muslim
☐ Other (please specify) ______________

9. Religion (care recipient)

☐ Catholic
☐ Protestant
☐ Jewish
☐ Muslim
☐ Other (please specify) ______________

10. Highest level of education completed (caregiver)

☐ Elementary school or less
☐ Some high school
☐ High school graduate
☐ Some college or trade school
☐ Diploma from college or trade school
☐ Attended university
☐ University degree

11. Highest level of education completed (care recipient)

☐ Elementary school or less
☐ Some high school
☐ High school graduate
☐ Some college or trade school
☐ Diploma from college or trade school
☐ Attended university
☐ University degree

☐ Post-graduate degree

12. Ethnic background (caregiver)

☐ English
☐ French
☐ Aboriginal
☐ Asian
☐ Eastern European
☐ Western European
☐ Middle Eastern
☐ Other (please specify) _____________
____

☐ Post-graduate degree

13. Ethnic background (care recipient)

☐ English
☐ French
☐ Aboriginal
☐ Asian
☐ Eastern European
☐ Western European
☐ Middle Eastern
☐ Other (please specify) _____________
____

14. Caregiver occupation

☐ Clerical
☐ Labourer
☐ Retired
☐ Management
☐ Professional
☐ Home-maker
☐ Other (please specify) _____________
____

15. Care recipient occupation (former)

☐ Clerical
☐ Labourer
☐ Retired
☐ Management
☐ Professional
☐ Home-maker
☐ Other (please specify) _____________
____

16. Current employment status (caregiver)

☐ full-time
☐ part-time
☐ paid leave
☐ unpaid leave
☐ retired
☐ not employed
☐ other (please specify) ______________
☐ ________________________________

17. Has employment status changed as a result of caregiving role? θ Yes θ No
If yes, what was previous employment status? __________________________________

18. Family Income

☐ below $20,000/year
☐ $21,000 - $30,000/year
☐ $31,000 - $40,000/year
☐ $41,000 – $50,000/year
☐ $51,000 - $60,000/year
☐ $61,000 - $70,000/year
☐ $71,000 - $80,000/year
☐ more than $80,000/year

19. Number of persons depending on family income? _____ adults _____ children

20. Has family income changed as a result of illness? θ Yes θ No
If yes, in what way? ____

21. For how long have you been a caregiver? ___________ years

22. About how many hours per week to you spend in caregiving? __________

23. Are there other family members/non-professionals involved in caregiving?

☐ No
☐ Yes If yes, how many other caregivers are there? __________
About how many hours of caregiving per week in total do these caregivers provide? __________

24. Generally, how good is your health?

Very poor Excellent
0 1 2 3 4 5 6 7 8 9 10

Comments:

25. Generally, how much does your health interfere with caregiving?

Not at all A great deal
0 1 2 3 4 5 6 7 8 9 10

Comments:

26. Generally, how much does your caregiving interfere with your health?

Not at all A great deal
0 1 2 3 4 5 6 7 8 9 10

Comments:

27. Generally, how fatigued do you feel?

Not at all A great deal
0 1 2 3 4 5 6 7 8 9 10

Comments:

28. What are the 3 most difficult problems of caring for your family member? Please list them here:
1. ____
2. ____
3. ____

29. Re: Problem #1. How difficult is this problem for you?

Easy Extremely difficult
to manage to manage
0 1 2 3 4 5 6 7 8 9 10

Comments:

30. Re: Problem #2. How difficult is this problem for you?

Easy Extremely difficult
to manage to manage
0 1 2 3 4 5 6 7 8 9 10

Comments:

31. Re: Problem #3. How difficult is this problem for you?

Easy Extremely difficult
to manage to manage
0 1 2 3 4 5 6 7 8 9 10

Comments:

32. About how many hours of sleep do you need on a daily basis?
__________ at night __________ in naps

33. About how many hours of sleep do you get these days on a daily basis?
_____________ at night __________ in naps

34. What services are you currently using to help with caregiving? How helpful are these services to you? (0 not helpful to 5 extremely helpful)

Home-care home support

☐ home-maker services __________ hours/week (average) How helpful? ____
☐ bath assist __________ hours/week (average) How helpful? ____
☐ sitter/ in-home respite services _________ hours/week (average) How helpful? ____
☐ other _____________________ _______ hours/week (average) How helpful? ____

Professional services

☐ social work __________ hours/week (average) How helpful? ____
☐ nursing __________ hours/week (average) How helpful? ____
☐ physiotherapy __________ hours/week (average) How helpful? ____
☐ occupational therapy __________ hours/week (average) How helpful? ____
☐ other _____________________ _______ hours/week (average) How helpful? ____

Community support services

☐ adult day program __________ hours/week (average) How helpful? ____
☐ CHOICE __________ hours/week (average) How helpful? ____
☐ Respite admission __________ hours/week (average) How helpful? ____
☐ other _____________________ _______ hours/week (average) How helpful? ____

Which of these services is/are most helpful for you (list up to 3 services)?

☐ ____
☐ ____
☐ ____

35. During the past three months, how many times have you and your care recipient gone to see the doctor for health problems?
Caregiver __________ Care recipient __________

Comments:

36. How many times have you or your care recipient had to use emergency services during the previous 3 months (e.g. hospital emergency department, ambulance, police)? Please comment on what type of services were required and the circumstances under which they were required.

37. Please estimate the total amount of money spent *and not refunded* on each of the following items during your family member's illness

$ ____________ drugs
$ ____________ patient care supplies
$ ____________ equipment (walker, wheelchair, hospital bed, commode)
$ ____________ personnel (home care aides, nursing staff, home-makers, sitters)
$ ____________ other (please specify) _______________________________________
$ ____________ other (please specify) _______________________________________
$ ____________ other (please specify) _______________________________________

38. What changes in the health care system would you recommend to help you and your family member at this time?

Functional Dementia Scale

Patient

____

Observer

____

Relation to the Patient

____

Location ____________________________________ **Date**

____

Rating Scale: ***1 – None or little of the time***
2 – Some of the time
3 – Good part of the time
4 – Most or all of the time

CIRCLE ONE RATING FOR EACH ITEM:

1. Has difficulty in completing simple tasks on own, e.g. dressing, bathing.
   1 2 3 4
2. Spends time either sitting or in apparently purposeless activity.
   1 2 3 4
3. Wanders at night or needs to be restrained to prevent wandering.
   1 2 3 4
4. Hears things that are not there.
   1 2 3 4
5. Requires supervision or assistance in eating.
   1 2 3 4
6. Loses things.
   1 2 3 4
7. Appearance is disorderly if left to own devices.
   1 2 3 4
8. Moans.
   1 2 3 4
9. Cannot control bowel function
   1 2 3 4

10. Threatens to harm others.
    1 2 3 4
11. Cannot control bladder function
    1 2 3 4
12. Needs to be watched so doesn't injure self, e.g. careless smoking,
    1 2 3 4 leaving the stove on, falling.
13. Destructive of materials around him/her, e.g. breaks furniture,
    1 2 3 4 throws food, tears up magazines.
14. Shouts or yells.
15. Accuses others of doing him/her bodily harm or stealing his/her
    1 2 3 4 possessions when you are sure the accusations are not true.
16. In unaware of limitations imposed by illness.
    1 2 3 4
17. Becomes confused and does not know where he/she is.
    1 2 3 4
18. Has trouble remembering.
    1 2 3 4
19. Has sudden changes of mood, e.g. gets upset, angered, or cries easily
    1 2 3 4
20. If left alone, wanders aimlessly during the day or needs to be restrained
    1 2 3 4 to prevent wandering.

TOTAL SCORE ____________

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