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The caregiver's journey: a phenomenological study of the lived experience of leisure for caregivers in the sandwich generation who care for a parent with dementia

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THE CAREGIVERS' JOURNEY: A PHENOMENOLOGICAL STUDY OF THE
LIVED EXPERIENCE OF LEISURE FOR CAREGIVERS IN THE SANDWICH
GENERATION WHO CARE FOR A PARENT WITH DEMENTIA

by

Lisa Anne Schumacher

A thesis submitted in partial fulfillment
of the requirements for the Master of
Arts degree in Leisure Studies
in the Graduate College of
The University of Iowa

May 2010

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CERTIFICATE OF APPROVAL

MASTER'S THESIS

This is to certify that the Master's thesis of

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has been approved by the Examining Committee
for the thesis requirement for the Master of Arts
degree in Leisure Studies at the May 2010 graduation.

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To Tim,
You washed loads of laundry, changed many diapers and kissed lots of boo boos so I
could finish this. Thank you!

To Jake and Finn,
I promise we will get long term insurance!

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CHAPTER 1

EVOLUTION OF THE STUDY

Introduction

A phenomenological study was chosen to explore the lived experiences of leisure for caregivers wedged between dependent children and dependent adults with Alzheimer's Disease and Related Disorders (ADRD) because there needs to be more research about the subjective experience of balancing the constant demands of caregiving while raising a family. Phenomenology addresses the nuances of everyday experience and shows a more complete picture of the lifeworld of caregivers. For example, a quantitative study cannot adequately describe the angst of a parent missing a child's recital or championship game in order to tend to the needs of his/her own parent. Time and energy taken by caregiving reduces time and energy available for parenting. Time to one's self is virtually nonexistent. People in this role say they are so overwhelmed it affects how they perceive their effectiveness in other areas of their lives (Cada, 2000).

Therapeutic Recreation (TR) is well positioned to serve caregivers. Leisure is a tool for developing coping skills. Effective coping skills are necessary for resilience. The research literature has focused on (TR) as a service for people with illnesses and physical, developmental or psychological disabilities. There is little research in TR that specifically addresses the needs of caregivers and even less for caregivers caring for both dependent children and dependent elders. In order to help this population, there needs to be more research that highlights the lived experience for caregivers with multiple responsibilities.

Phenomenon of Interest

The phenomenon explored was the experience of caregiving by mid-life people who were simultaneously caring for an adult with ADRD and a dependent child. Informal caregiving is not a new phenomenon (Connell, 2003). The experience of caring

for dependent adults and dependent children is a relatively new phenomenon, the term “sandwich generation” was coined in the 1980’s to describe this experience. “Sandwich generation” is defined as “generation of people who are caring for their aging parents while supporting their own children” (Merriam-Webster Online, 2008). Well Point (2002) describes the sandwich generation as a generation of men and women who concurrently care for dependent children and dependent elders and who financially support elders while working and raising their own family. In this study, sandwich generation refers to middle -aged people who financially and emotionally support minor children and provide physical, emotional, financial, and/or legal assistance to adults with ADRD.

The increase in this phenomenon is due to a variety of factors. Medical advances extended life expectancy, the Baby Boomer fertility rates declined (they averaged less than 2 children) and more women are employed outside the home (Spillman and Pezzin, 2000). Additionally, fertility is often delayed until the thirties and forties increasing the potential for dual caregiving obligations (Bowers, 1987, Brody, 1981, Himes, 1992).

Socio-economic changes also transformed the function of elder care. Over the past one hundred and fifty years the country shifted from a rural economy to an urban economy and from an industrial culture to a technological culture (Connell, 2003). Women’s participation in the labor force has contributed to these shifts in economic culture. Working mothers must balance the demands of outside employment and family. Though women still outnumber men as primary caregivers (Spillman and Pezzin, 2000), men are accepting the role of hands on parent and caregiver more often. A study by Wolfson et al. (1993) found sons and daughters had an equal sense of moral obligation to assist with financial decisions, physical care and emotional support for aging parents. The study also showed men and women felt equally competent to provide all forms of care. The duties men and women accept mirror the division of labor in other aspects of family life (Kwok, 2006). Women assist with intimate activities of daily living (ADLs)

such as bathing, dressing, toileting, transferring, eating, laundry, and housework while men typically take on instrumental activities of daily living (IADLs) tasks associated with financial and legal decisions (Spillman and Pezzin, 2000; Kwok, 2006; Family Caregiver Alliance, 2008).

Nuclear families in past generations lived in close proximity and shared the responsibility for senior care (Connell, 2003). Now more people relocate for career opportunities and senior care is a long distance endeavor (Family Caregiver Alliance, 2008) or parents move closer to adult children (Petrovich, 2008; Connell, 2003) thus increasing the burden on one family. People of various ethnic groups view caregiving differently. In western culture, child care and senior care are devalued compared to paid work. Petrovich (2008) notes people of Hispanic and Asian descent assume white Americans place their elders in nursing homes because they are too busy to care for them at home. Studies have shown that African-American caregivers experience more internal satisfaction than white caregivers (Family Caregiver Alliance, 2008). Women of all ethnic groups are viewed as natural caregivers (Stoller, 1994) and are more likely to move to part-time, decline promotions and retire early (Gort et al, 2007). In addition, the study showed that work hours did not increase after caregiving responsibilities ceased. Thereby increasing the risk that women who assumed caregiving roles will live in poverty in their senior years (Wakabayashi, C. & Donato, K. M., 2003). Men's employment was not affected by caregiving.

Justification for Study

Anne Petrovich, an Associate Professor in the Department of Social Work Education at California State University published "Lessons Learned in the Sandwich" (2008) detailing her experiences as a member of the sandwich generation. She had three grown children and a nine year old daughter when her parents moved from Michigan to be nearer to her. Dr. Petrovich's mother had dementia and her father could no longer

care for her by himself due to his fragile health. Her mother was placed in a local nursing home and her father moved to her home. To complicate matters, she had just begun a tenure track position when she received the call for help from her father. The pressure of teaching, publishing and serving on committees as a new faculty member combined with the exhausting tasks of being a wife, mom and caregiver was overwhelming. Dr. Petrovich states, “No matter how many degrees you have after your name, regardless of your academic expertise...you are on your own when it comes to your own life, your own parents, your own family dynamics and your own energy level. There is no manual for coping with the end-of-life issues that grip you in their vise, squeeze you until you drop, and challenge the limits of your love and patience.” (p. 224). Even as a professional trained in elder care, she was scared and unsure that the decisions she made on behalf of her parents were correct. Though Dr. Petrovich lectured on the effects of caregiving burden, she almost died of sepsis as a result of an undiagnosed urinary tract infection because she couldn’t find the time to take herself to the doctor. . “I felt inadequate in every arena.” (p. 226).

If a Professor of Social Work ,whose specialty is elder care, doubts her choices—and that doubt permeates all aspects of her life—how can society expect people who have no experience to undertake such an important and exhausting role without assistance?

Human interest stories in the news and video clips on the internet give glimpses into the life of a caregiver in the sandwich generation. Research for ADRD caregivers, however, has focused on the objective burden related to specific activities of caregiving such as ADLs and IADLs, responsibility for making financial, health care decisions and legal decisions, and constantly adjusting the environment to ensure the safety of the care receiver. Public initiatives are created based on research that gives only a partial picture of a caregiver’s experience. TR stresses the importance of looking at the whole person, using their strengths and interests to decrease stress and frustration and maximize self determined thoughts and behaviors. Without a complete picture of a caregiver’s

experience, programs will be based on guesswork rather than accurate assessment of needs.

Context

The subjective burden of caregiving is difficult to comprehend and measure through quantitative studies. Subjective burden focuses on the emotional and psychological elements of caregiving stress. Subjective burden is analogous to pain, everyone has a different threshold and it is contingent on factors confounded by the objective burden. Subjective burden may increase due to lack of sleep, illness, somatic manifestations, and/or depression which may have been a consequence of caregiving but now magnify the caregiving obligation.

Living bereavement is a unique effect of caring for someone with ADRD and is felt to varying degrees by caregivers. In a study by Light & Lebowitz (1989) living bereavement is described as the loss of the person and relationship they knew as cognition declines. Participants in a study by Butcher et al. (2001) stated, “Then all of a sudden I am there for him but he is not there for me. He had always been there for me...It is almost like part of him has died” (p. 46). Kagan’s (2008) research shows that feeling listened to is an essential need for health. People need someone to call “with the highs and lows” of their lives (Kagan, 2008). For many people, a parent has served that role. As the disease progresses, people with ADRD are not able to “listen”—ie. hear, interpret, and comprehend complex dialogue. This change in relationship can contribute to living bereavement. Combined with dependent children, who by their very nature do not listen, and decreased time with a spouse, caregivers are not being listened to and this can have a negative impact on their health.

My encounter with caregivers as a Recreation Therapist motivated me to learn more about their experience. TR inherently focuses on the subjective and intangible aspects of an experience (Mobily, 2007). Leisure is subjective. One person may deem an

activity leisure and another person it may regard it as drudgery. A Recreation Therapist must listen and learn about a person's likes and dislikes, strengths and weaknesses, and past successes and failures to attempt to find activities to meet a person's need. In my professional experience, one common leisure thread for most people is storytelling. It affords the opportunity to be listened to. The majority of people want to tell their story, unload what causes them angst and share what provides them pleasure.

Storytelling is a way to find meaning in an experience. It is a basic human need to find meaning in one's life (Frankl, 1962). Throughout history stories have been passed down to highlight the interconnectedness of humankind and share their meaning. The goal of hermeneutic phenomenology is to explicate meaning from lived experience (van Manen, 1990; Connell, 2003; Wojnar & Swanson, 2007; Linseth & Norberg, 2004; Butcher, et al., 2001). In other words, allow people to tell their stories, interpret those stories and find meaning within those stories. The hermeneutic interview is not meant to be an intervention but research has shown that there are positive effects from the interview process (Kvale, 1983). Hermeneutics presupposes there is meaning in lived experience that is not intuitively available (Cohen & Omery, 1994). If more information were learned about everyday experience of ADRD caregivers in the sandwich generation, Recreation Therapists could develop programs to address the needs of this population. I am conscious that I must not let my experience bias the results of the study.

This study is a small step in understanding the unique experience of sandwich generation caregivers who care for a parent with ADRD. The study focuses on the subjective interpretation of this phenomenon. Through phenomenological investigation, this study will attempt to uncover the prevailing themes of the caregiver experience.

Phenomenology

Phenomenology is simultaneously a philosophical approach and a research method (Wojnar & Swanson, 2007; Connell, 2003; van Manen, 1990). Phenomenology

stems from the Greek words “phenoinomai” meaning appearance and “logos” meaning reason. As a philosophy, phenomenology is “a radical beginning, a return to philosophical questioning, a way to see the world anew as it really is rather than as it is constructed” (Caelli, 2000, p371). As a research method, phenomenology is “...the rigorous and unbiased study of things as they appear so that one might come to an essential understanding of human consciousness and experience...” (Valle & Halling, 1989, p.6).

“Phenomenology is the study of essences” (Merleau-Ponty, 1962 p. vii). Essences are the essential elements of a phenomenon, those things which makes it recognizable as such (van Manen, 1990). Phenomenology does not look for cause-effect relationships nor does it seek to generalize (Porter, 1999). It is a process of observing and analyzing “the things themselves” (Husserl, 1962) in a new way. “A good phenomenological text has the effect of making us suddenly ‘see’ something in a manner that enriches our understanding of everyday life experience” (van Manen, 1997).

This study will use a hermeneutic phenomenological human science process as outlined by Max van Manen. van Manen (1990) delineates what phenomenological human science is and what it is not. Hermeneutic phenomenology is the study of lived experience as it is immediately experienced; however, it cannot be understood until it is reflected on. Phenomenology does not attempt to generalize or create theory, rather it allows the essence of the experience to emerge from the data. It does not seek to solve problems. Phenomenology highlights what makes an experience unique. Interpretation of experiences creates a constant awareness of what it means to be human and aids in the quest to reach our full humanity. Phenomenology reveals the lifeworld through language, writing is an integral component of the phenomenological process. Writing allows the discovery of memories. How ideas are expressed can create a deeper meaning than what is written.

Table 1: Description of what Phenomenology is and is not

IS	IS NOT
Study of lived experience As we immediately experience it	An empirical science Does not generalize or develop theory
Explication of phenomena as they present themselves to consciousness Consciousness is retrospective, we cannot understand an experience until it is reflected on	Not mere speculative inquiry in the sense of unworldly reflection Concrete experiences understood through language
The study of essences That which makes the “thing” what it is	Neither mere particularity, nor sheer universality Paradoxically explicates what makes something unique and different
Description of the experiential meanings we live as we live them	Does not solve problems Meaning questions that allow for thoughtful and tactful action
Human scientific study of phenomena The systematic, explicit, self critical and intersubjective analysis of the lived world	
Attentive practice of thoughtfulness Constant awareness of what it means to live a life	
Search for what it means to be human Quest to live to our fullest potential	
A Poetizing activity Discovery of memories	

Adapted from Researching Lived Experience

Max van Manen (1990) pp. 8-13 & 21-23

Experiential context

My experiences as a Recreational Therapist at a facility for people with ADRD inspired me to learn more about the disease process and how it affects loved ones. Caregivers for someone who has ADRD have articulated that friends and family treat people with ADRD differently than those with other diseases (Upton & Reed, 2005). I felt that strain of not knowing how to interact and how to program for these individuals. I was initially overwhelmed by the residents lack of inhibition and personal space. And I

was saddened that they did not seem to possess that which made them who they were. All the memories that shaped them evaporated. The more time I spent with the residents I shifted the way I listened to them. I learned all of their life experiences were safely embedded in their being as they reclaimed the innocence of childhood. I had the privilege of knowing the people they were now—childlike and wise simultaneously—without the grief of knowing who they were prior to the disease. People’s priorities in life were apparent. The stories they told over and over demonstrated how they viewed the world, a lifetime of attitude habits were transparent. It seemed to me that people who perceived life with a negative lens, told stories of their regrets and fears and people who perceived life with a positive lens, told stories of their joys and triumphs. Family members confirmed that residents were living and coping as they always had without the benefit of accessible memory.

In my experience, residents who carried their adaptive coping mechanisms with them through the disease process had fewer behavior issues and were happier than residents who relied on maladaptive coping mechanisms. I began to wonder, if good coping skills are beneficial when you may not even remember you have them, can they be taught? Research suggests that coping skills can be learned (McClendon, et al., 2004; Hagan, et al., 1997/98). Phenomenology cannot develop strategies for coping or establish cause and effect relationships but more research aimed at understanding the lived experience of caregivers and care receivers may provide a better understanding of how coping strategies are employed. I am cognizant to bracket my experiences and curiosity from the content of this study.

CHAPTER 2

LITERATURE REVIEW

Overview

This literature review will be presented in 7 sections: 1) Overview of caregiving and ADRD, 2) Financial consequences of caregiving, 3) Therapeutic Recreation and caregiving, 4) Caregiver perceptions of leisure, 5) Leisure as a coping strategy, 6) Overview of Phenomenology, 7) Experiential context.

Caregiving and ADRD

Informal (unpaid) caregivers are at risk for a variety of stress related illnesses. Research has shown that caring for a loved one with a disability can have a negative impact on psychological and physical health (Hooyman & Kiyak, 2005; Butcher, et al., 2001; Connell, 2003; Sansoni, et al., 2004). Caregivers may develop increased blood pressure and insulin levels (Cannuscio, C. C., et al, 2002), have decreased immune function (Kiecolt, et al, 2003), and be at greater risk for cardiovascular disease (Lee, et al, 2003), 30-40% of caregivers who care for someone with ADRD suffer from depressive symptoms and other manifestations of emotional stress (Family Caregiver Alliance Website, 2007).

Dementia is a general term for diseases that impair cognitive function (Alzheimer's Disease Facts and Figures, 2007). There are 77 types of dementia (Institute for Natural Resources, 2007) this study will include participants who are caring for someone with any form of dementia. Alzheimer's Disease (AD) receives the majority of attention. AD is a degenerative neurological disorder that destroys brain cells, impairs memory, cognitive and physical functioning and is fatal (Alzheimer's Association website, 2007). Five million people are currently diagnosed with AD, by 2010, 454,000 new cases a year are expected.

Financial Consequences of Caregiving

Adult children of persons diagnosed with ADRD are often primary or secondary informal caregivers. Approximately 8.9 million people are informal caregivers for someone with ADRD (Alzheimer's Association website, 2007). Studies suggest that if these services were provided by paid staff the estimated cost would be \$23,436 per year per recipient (Harrow, et al, 2004). American businesses lose \$11-29 billion a year in productivity (Metlife Market Group, 1997). Caregivers who are employed full-time and taking care of a family member over age 65 with ADRD must adjust their work schedule and often take unpaid leave to fulfill caregiving obligations (Wakabayashi, C. & Donato, K. M., 2003) thus losing an average of \$25,494 in Social Security benefits, \$67,202 in pension benefits and \$566,433 in wage wealth, combined the loss is \$659,139 over a lifetime (Metlife Mature Market Institute, 1999). Financial strain exacerbates the stress of caregiving (Lim & Zebrack, 2004). Stress leads to immune suppression and immune suppression leads to illness (Hooyman & Kiyak, 2005) and illness leads to more stress and fatigue which can lead to collapse of caregiving (Gort et al., 2007). Given the current national economic constriction, the government cannot afford to fund long term care for the masses.

The majority of informal caregivers are women (Hooyman & Kiyak, 2005; Wakabayashi & Donato, 2003). Women in the sandwich generation are primarily middle- age. Research by Wakabayashi and Donato (2003) showed middle-aged women experience difficulty when trying to re-enter the work force after caregiving due to age discrimination and health problems brought on by the stress of caregiving. Women with lower education and limited financial security pay a high economic price as they start with less advantage and fewer support networks. Social Security benefits and pension are determined by earnings, informal caregiving can have economic repercussions later life. Goffen et al. (2007) found elders who live in poverty had twice the risk of physical and mental disabilities than elders who did not live in poverty. Helping caregivers find

resources to cope with the financial burden of caregiving now can decrease personal and national economic burden in the future.

Therapeutic Recreation and Caregiving

This study concentrates on a population not typically served by TR. The American Therapeutic Recreation Association specifies Recreation Therapy as services “to restore, remediate or rehabilitate in order to improve functioning and independence as well as reduce or eliminate the effects of illness or disability” (ATRA, 2007). The National Therapeutic Recreation Society defines Recreation Therapy as the use of “treatment, education and recreation services to help people with illnesses, disabilities and other conditions to develop and use their leisure to enhance their health, functional abilities, independence and quality of life (NTRS, 2000). Leisure Education was discussed by TR researchers (Hagan, et al., 1997/98) as a strategy to reduce caregiver stress. The premise of the study was that by improving the quality of life for caregivers, it will subsequently improve the quality of care and quality of life for care receivers. There is research in other fields that support this strategy.

“Care-recipient problematic behaviors have consistently predicted caregiver depression.” (McClendon, et al., 2004). Caregivers who experienced high level depression were at greater risk for engaging in abusive behaviors (Williamson & Shaffer, 2001). Research by Gitlin, et al. (2001) showed care receivers exhibited fewer behavior problems and slower decline in ADLs when caregivers received in-home training to increase knowledge about the disease process and methods for augmenting personal control. A study conducted in Italy (Sansoni, J., et al., 2004) focusing on ADRD caregivers suggests increased education and leisure time decreases anxiety and depression. Education and leisure increase perceived control and perceived control has a positive impact on health. “If I am not rested then I am impatient, and impatience gets impatience. I am very cognizant of the fact that it is not one person” (Butcher, et al.,

2001) Caregivers involved in programs to promote coping skills led to greater survival rates for care receivers at 5 years and at an 8 year follow-up study (Brodaty, et al., 1997).

The focus remains on serving people with the illness or disability. I contend caregivers should benefit from TR services in their own right. The current definition of health by the World Health Organization (WHO) is “a state of complete physical, mental, and social well-being, and not merely the absence of disease and infirmity” (Carter, et al., 2003). According to this definition of health, many sandwich generation caregivers of someone with ADRD are not healthy or are at risk for not being healthy in the near future. Caregivers and people adjusting to recent illnesses and disabilities must come to terms with an altered life scheme (caregivers must do it twice, as they are caregiving and when the care receiver dies). Caregivers and the latter are at risk for secondary conditions due to the stress caused by the traumatic life event. Caregivers and the latter often endure significant changes in social and financial position as a result of the life event. TR’s commitment to increasing quality of life for people at risk for psychological, physical and social challenges supports the inclusion of caregivers as a population we serve.

A qualitative study by Lee, et al., (1996) states that how a person adjusts to leisure after an injury can indicate how he/she is adjusting to the disability on the whole. This idea can be used to meet the needs of caregivers. People with a recent injury or illness find it difficult to adapt to “too much free time” caregivers must adapt to increased responsibility and not enough free time. The themes in Lee’s, et al. study (1996) are relevant for caregivers who choose to embrace healthy self care options. In *seeking continuity*, caregivers express the intent to include an activity that previously brought satisfaction; in *establishing continuity* caregivers learn how to incorporate the activity into their schedule and develop adaptations as needed. The broadening and building that results from positive feelings associated with leisure supports the caregivers ability to walk through the stages of *accommodating continuity*.

Caregiver Perceptions of Leisure

A study by Bedini (2004) indicated caregivers valued leisure and cite it as one of the “top 3 negative consequences to being a caregiver” (p. 1). The majority of participants defined leisure as “unobligated time to do as I please” (p. 6). Seventy one percent of participants responded that leisure is cherished. However, only 12% of participants indicated they protected their leisure. And 63% stated caregiving tasks hindered their ability to pursue leisure, the more dependent the care receiver the less unobligated time the caregiver had available. Only 12% of participants in this study also cared for dependent children.

A conceptual framework developed in a study by Bedini & Guinan (1996) specified 4 categories to describe caregivers feelings about their right to leisure. The categories are repressor, resenter, consolidator, and recharger. The repressor rejects the idea that leisure has value. The resenter would like more leisure time but believes caregiving responsibilities do not allow time for leisure. The consolidator recognizes the need for leisure and includes care receiver in leisure pursuits. The recharger acknowledges leisure is necessary for mental and physical health and makes time for leisure. The repressors indicated feeling financially burdened by caregiving responsibilities. Financial burden can increase feelings of anxiety and loss of personal control.

Financial burden was shown to have a negative impact on the value of leisure. Conversely, caregivers who put high value on leisure perceived less financial burden. Time away from caregiving responsibilities is essential for the caregiver (Family Caregiver Alliance Website, 2007). However, respite services are costly. If a caregiver is already feeling financially strained, the cost of respite care is prohibitive (Hagan, et al., 1997/98) further reducing perceived control.

Leisure as a Coping Strategy

Under stress, the autonomic nervous system becomes aroused and impairs concentration, perception and reasoning (Fredrickson, 1998, 2000). Autonomic arousal has physical ramifications which include increased heart rate and elevated blood pressure. Prolonged stress can lead to the aroused state as the norm, which has a negative impact on overall health. Poor health can be a catalyst for reactive depression which can lead to social isolation at a time when support is needed.

Positive emotions have been shown to calm the autonomic nervous system which enhances problem-solving abilities, widens perception, and allows for the acquisition of new skills (Fredrickson, et al., 2003). The Broaden and Build Theory developed by Fredrickson (1998) has shown that positive emotions increase intellectual resources, physical resources, social resources and psychological resources. The broadening that stems from positive emotions creates a foundation to enhance coping in future stressful situations. Because of the progressive nature of ADRD, caregivers in the sandwich generation must constantly adapt to new physical and cognitive limitations of the care receivers while adapting to ever changing emotional and financial needs of their dependent children. The Broaden and Build Theory provides a framework that endorses leisure as a conduit for developing positive emotions.

A phenomenological study by Iwasaki et al. (2005) focused on leisure as a coping strategy and classified leisure as a means of coping from two points of view: 1) the use of leisure pursuits as a means to promote coping 2) a psychosocial experience where the fundamental interpretation of leisure functions as a method to manage stress. The subjects used were from marginalized groups. Caregivers for someone with ADRD express that there is different treatment of people with ADRD than other diseases (Upton & Reed, 2005) “friends and family stop coming around because they can’t understand how to deal with the disease” (Kruse, 2006), which increases feelings of isolation.

People participate in leisure activities that address the type of stress they are experiencing, thus people choose different leisure pursuits for different stress experiences (Patterson & Coleman, 1996). The activity the caregiver chooses is not as important as the control the caregiver has over the choice of activity (Iso-Ahola, S. E., 1980). Freedom is an essential element of leisure (Bedini, 2004). Leisure can be a means of empowerment, caregivers have stated that they feel inadequate in all areas of their life (Petrovich, 2008). Leisure can be a “break from always giving and being busy caring for the needs of others...and a way to feel normal...a way to forget pain...a way to focus on what you can do versus what you can’t do...how I escape...”(Iwasaki, 2005).

Overview of Phenomenology

Hegel’s Phenomenology of Mind, also known as Phenomenology of Spirit due to the dual meaning of the German word “geist”, launched the movement known as phenomenology (Connell, 2003). He believed the mind’s perception of reality changed according to what one understands as the truth. Plato’s “allegory of the cave” illustrates how appearances can be mistaken for reality (Hunnicut, 2007). Hegel did not, however, “pursue the development of this concept as a philosophy or a methodology” (Connell, 2003, p.33).

Phenomenology evolved with the works of Husserl and Heidegger. Husserl focused on “the things themselves” (van Manen, 1990), the experiences of everyday life that make life important. Husserl’s view of phenomenology is to describe the taken-for-granted attitude or experience of the lifeworld. To understand the lived experience as it is not as a collection of pre-conceptions. Human beings are “of” this world, even though it may be difficult sometimes, humans can “bracket” their pre-conceptions and presuppositions to study the natural world and the structures of the world (van Manen, 1990).

Heidegger, a student of Husserl, developed Hermeneutic Phenomenology. His concept of Phenomenology is ontological (van Manen, 1990) the study of the Being itself (van Manen, 1990; Connell, 2003). He asks “What is the experience like for you?” “Hermeneutics is the theory and practice of interpretation...it is necessary when there is possibility for misunderstanding” (van Manen, 1990, p. 179). The process of interpretation reveals meanings not immediately apparent. We give significance to a lived experience as we interpret its meaning (van Manen, 1990).

Hermeneutic phenomenology searches for the meaning of an experience through textual interpretation (Lindseth & Norberg, 2004). Once an experience is named it has been transformed (van Manen, 1990). The hermeneutic experience acknowledges the reader and the researcher approach the text from their own personal history and the strength of a rigorous phenomenological study is the ability to follow the path of the researcher and understand how the interpretation could have been made (Koch, 1994).

CHAPTER 3 METHODOLOGY

Method of Inquiry

Caregiving is a universally lived experience, people have been caring for each other throughout history. The concept of informal caregiving for elders while caring for dependent children without the benefit of a tribe or extended family has altered the experience of caregiving over the past century. The increase in the aging population along with the decrease in available caregivers, delayed fertility and vast geographic distance within family of origin has created a difficult dynamic for people who accept the caregiving role. The prevalence of AD/DRD among elders further complicates the caregiving experience. The purpose of this study is to increase our understanding of the lived experience of leisure for caregivers in the sandwich generation who care for a parent with AD/DRD. Hermeneutic Phenomenology was chosen to investigate the everyday experience and lifeworld of caregivers. The researcher wanted to uncover and interpret the meaning of leisure within the caregiving experience.

Phenomenology uses inductive research methods to comprehend universally-lived experiences (van Manen, 1990). A phenomenological researcher acknowledges the “whole might be quite different than the sum of its parts” (Omery, 1983). The researcher analyzes and interprets lived experiences to find essential themes and the themes taken together allow meaning of the experience to emerge as a whole (van Manen, 1990).

Rationale

Phenomenology as a philosophy grew in Western culture as a reaction to the notion human behavior can be controlled by scientific method. B.F Skinner’s character in Walden II states “I like walking in the rain” to illustrate that it is rational to be irrational. Human behavior cannot always be predicted and boiled down to quantifiable data and logical terms. The Social Sciences adopted phenomenology as a method to gain

a more comprehensive understanding of the human experience. “Phenomenology has been used to examine areas that previously have not been amenable to traditional forms of scientific research...” (Omery, 1983). Traditional methods of scientific research have fallen short in TR (Mobily, 2007) because they cannot grasp the subjective nature of leisure. Leisure cannot successfully be quantified because it is experienced uniquely from person to person. Phenomenology addresses the concept that a person’s life world shapes the interpretation of an experience.

Hermeneutic phenomenology as a method blends art and science. The process of developing a proposal, finding accessible and eligible participants, following the guidelines of ethical research, and staying true to the goals and philosophy of the researcher’s profession represent the rigor of the scientific method. Interpreting the lived experiences of the participants to ensure they encompass the grammatical and psychological axes requires the researcher to “hear” and “see” beyond the given words. Tone of voice, body language and silences are relevant and essential for hermeneutic interpretation. “Composing linguistic transformations is not a mechanical procedure. Rather, it is a creative hermeneutic process.” (van Manen, 1990, p. 96)

“When TR specialists construct environments that are at once fun and beneficial they have crafted the most elegant expression of TR, its science and its art.” (Mobily, 2007, p. 23) TR specialists tire of defending their position as a legitimate professional in the rehabilitation therapies but we continue to try to express our modality in traditional scientific terms. “Once we start trying to explain TR in the language of other therapies then we run into trouble. TR has allowed others to dictate the terms of our explanation...the profession needs to embrace its uniqueness...” (Mobily, 2007, p. 20). Hermeneutic phenomenology offers a research method which grants the TR researcher the opportunity to present rigorous research in our own language using the greatest assets of our field—listening and creative interpretation.

Outcome

The purpose of this hermeneutical phenomenological study is to uncover the essence of how leisure is experienced by caregivers of a parent with ADRD while parenting a dependent child. The knowledge learned from this study can demonstrate the need for TR professionals to serve this population. Listening to the lived experience of sandwich generation caregivers may reveal areas of concern and moments of insight that may lead to new programming to increase the quality of life during this stressful time. “We must have a good clear picture of the qualities of the world before we can attempt to explain it, let alone predict or modify it” (Gubrium & Holstein, 1997 as quoted by Connell, 2003). The results of this study can guide TR professionals in the development of programs and generate new research questions to gather more information for a population not consistently served by TR.

Human Science Method

Hermeneutics is derived from the Greek word *hermeneuin*, which means “to interpret” (Pehler, 2003; Moran, 2000). A German theologian, Friedrich Schleiermacher, formulated a dual axes approach to interpretation, the grammatical axes and the psychological axes (Pehler, 2003; Moran, 2000; Chan, 2001). The first axes pertains to language, the interpretation must stay true to the linguistic style of the time period. The second axes pertains to the author’s frame of reference, his/her historical, social and cultural experiences that create the lived experience (Pehler, 2003; Chan, 2001; Moran, 2000). Wilhelm Dilthey incorporated Schleiermacher’s dual axes hermeneutic approach in social science research (Pehler, 2003; Moran, 2000). Heidegger studied Dilthey’s work and blended hermeneutics with phenomenology.

Hermeneutic phenomenology in Heidegger’s view studied phenomenology as *dasein* or “being in the world” (Pehler, 2003; Wojnar & Swanson, 2007). This concept emphasizes a person’s experience cannot exist outside the context of their values, family

traditions, political views, relationship with nature, spiritual beliefs and individual history (Wojnar & Swanson, 2007). *Dasein* applies to the researcher as well as participants. “Hermeneutic phenomenology is grounded in the belief that the researcher and the participants come to the investigation with fore-structures of understanding shaped by their respective backgrounds, and in the process of interaction and interpretation, they cogenerate an understanding of the phenomenon being studied” (Wojnar & Swanson, 2007, p, 175). This resonates in TR as Mobily (2007) states, “...it is impossible to separate the beneficial changes associated with leisure experiences from the experiencing itself” (p, 21).

“The human science researcher is a scholar-author who must be able to maintain an almost unreasonable faith in the power of language to make intelligible and understandable what seems to lie beyond language” (van Manen, 2007, pp. xvii-xviii). According to van Manen, writing and re-writing is essential for understanding the phenomenon. Writing is not separate from the research, it is an integral part of the process (van Manen, 1990). A researcher conducting a phenomenological study cannot merely calculate the results of an experiment with the traditional scientific method. The researcher must address his/her experience with the phenomenon, insights gleaned from the interviews, listen to the interviews over and over, reread the transcripts, and re-contact participants to ensure their interviews accurately articulated what they intended. Then all of that information must be integrated into a cohesive and coherent text. “Writing is a valuable tool for integration...” (Cameron, 2001). Again, this process mirrors TR, “...TR is an iterative process...” (Mobily, 2007, p.22).

Sample

Purposive sampling was used for this study. Participants were selected based on their experience with the phenomenon. Information about the study was presented in the

Alzheimer's Association newsletter, in the neurology department and the Noon News of a Midwestern university hospital. All participants met the following inclusion criteria:

- Dependent adult has some form of dementia
- Dependent adult is a parent of the caregiver
- Participant may be primary or secondary caregiver
- Caregiver must assist with any of the following: legal matters (financial or health decisions), ADLs, IADLs, transporting to and from appointments
- Lives with caregiver, lives near caregiver, care-receiver lives long distance but does not have the capacity to make informed and appropriate decisions, is in a formal care facility and caregiver has power of attorney
- Caregiver has 1 or more dependent children under 18 living in same residence
- Caregiver may or may not be employed
- Caregiver may be male or female

Recruitment

Information about this study was presented in the Alzheimer's Association newsletter, in the neurology department and Noon News of the university hospital. The researcher was also interviewed by a local radio station to introduce the study.

“Consent to participate” forms were emailed to participants. When participants agreed to participate they were emailed an “Informed Consent” document. The IRB did not require signatures for either form.

Analysis of the data began after the first interview. van Manen does not indicate a specific sample size for his method, 6-12 is typical (Haase, 1987).

Research Procedures

van Manen outlines a methodological structure to conduct phenomenological research. Although he provides a list of “steps”, van Manen believes the “method of

phenomenology is that there is no method” (van Manen, 1990, p. 30). The following is a visual representation of van Manen’s methodological structure.

Table 2: Methodological Structure for Phenomenology

Turning to the Nature of the Lived Experience	Existential Investigation	Phenomenological Reflection	Phenomenological Writing
1.Orienting to the phenomenon	4.Exploring the phenomenon: gathering data	6.Conducting thematic analysis	8.Attending to the speaking of language
2.Formulating the phenomenological question	a.Using personal experience as a starting point	a.Uncovering thematic aspects in lifeworld descriptions	9.Varying the examples
3.Explicating assumptions and pre-understandings	b.Tracing etymological sources	b.Isolating thematic statements	10.Writing
	c.Searching idiomatic phrases	c.Composing linguistic transformations	11.Rewriting: (A) to (D) etc.
	d.Obtaining experiential descriptions from subjects	d.Gleaning thematic descriptions from artistic sources	
	e.Locating experiential descriptions in literature, art, etc.	7.Determining essential themes	
	5. Consulting phenomenological literature		

Adapted from *Practicing Phenomenological Writing* (1984, p. 42)

A. Turning to the Nature of the Lived Experience

Lived experience is an experience that occurs in a person’s lifeworld before he/she has reflected on, or named the experience (van Manen, 1990). To understand and find meaning in the experience requires the experience be reflected on and interpreted.

1. Orienting to the Phenomenon

The researcher must identify an interest in understanding the experience of the phenomenon being explored. My orientation to caregiving is as a Recreation Therapist. I detailed my experiences with the phenomenon in a field journal.

2. Formulating the Phenomenological Question

The researcher develops the phenomenological question as a process of “living” and “becoming” the question (van Manen, 1990). The questions we ask of our participants must be connected to our lives and experiences. My interest in sandwich generation caregivers of someone with ADRD evolved with my professional relationship with ADRD caregivers, my personal relationship with my aunt as an ASRD caregiver, and my concerns about being an older parent. I began to wonder what it would be like to care for my aging parents and raise my son. What is your experience of time for yourself as you care for a parent with dementia while raising a family emerged as the phenomenological question.

3. Explicating Assumptions and Pre-Understandings

Quantitative research dictates the researcher leave his/her relationship with the investigation behind. van Manen (1984), however, states the researcher should “make explicit understandings, beliefs, biases, assumptions, presuppositions, and theories [not to forget them], but rather to turn this knowledge against itself...exposing its shallow or concealing character” (p. 46) This position reasons that a researcher is not able to completely bracket pre-conceptions because they invariably re-enter reflective thought. Again, all presuppositions were detailed in a field journal.

B. Existential Investigation

4. Exploring the phenomenon: gathering data

“All recollections of experiences, reflections on experiences, descriptions of experiences, taped interviews about experiences, or transcribed conversations about

experiences are already *transformations* of those experiences” (van Manen, 1990, p. 54).

van Manen offers 4 paths for accessing minimally adulterated experiences.

a. Using Personal Experience as a Starting Point

As *my* experiences become *your* experiences the researcher may find clues to orient oneself to the phenomenon (van Manen, 1990). Because experiences may be shared as potential human experiences, “...phenomenological descriptions have a universal (intersubjective) character” (van Manen, 1990, p. 58). My professional and personal experience with ADRD caregivers gives me an elementary understanding of the caregiving experience while my role as a parent inspires me to learn about the experience of those who must assume dual roles.

b. Tracing Etymological Sources

Human nature has evolved over the course of history and language has evolved as well. The original meaning of words may not be the way our culture understands them today. For example, the original meaning of *care* encompassed “...worries, trouble, anxiety, lament on the one side, and charitableness, love attentiveness, beneficence on the other side” (van Manen, 1990, p. 58). This is particularly relevant to this study when understanding the subjective nature of caregiving. Words that will be reviewed are: caregiver, dementia and stress.

c. Searching Idiomatic Phrases

Just as word meanings evolve, idiomatic phrases evolve—and “...they are born out of lived experience” (van Manen, 1990, p. 60). In this study the origin of “sandwich generation” will be explored. There may be nuances from the original meaning lost over the past two decades and there may be new meanings developing as a new generation become classified as “the sandwich generation”.

d. Obtaining Experiential Descriptions from Subjects

“We gather other people’s experiences because they allow us to become more experienced ourselves” (van Manen, 1990, p. 62). The crux of phenomenology is that the

researcher and the participants become partners in the process of understanding the lived experience. van Manen offers several ideas on how to collect experiential descriptions from participants: interviewing; protocol writing; observing; lay literature; art; and phenomenological literature. This study will utilize interviews as the method for data collection.

The interview is aimed at 1) gathering and exploring narrative material to develop a comprehensive understanding of the phenomenon of interest, 2) developing a conversational relationship with the interviewee to understand the meaning of the experience. It is important to remember, in the phenomenological interview, the interviewer (researcher) and the interviewee (participant) are partners in the process of discovery. Thus, formulating good questions before the interview is essential to ensure clarity throughout the interview (van Manen, 1990). The interview is a delicate balance between asking appropriate open-ended questions and allowing silences to help the participant proceed with their story.

“There are four existential that may prove especially helpful as guides for reflection in the research process: *lived space (spatiality)*, *lived body (corporeality)*, *lived time (temporality)*, and *lived human relation (relationality or communality)*” (van Manen, 1990, p. 107). Understanding these four lifeworld existentials and incorporating them in the interview will help create a thorough and flowing interview.

Lived space (spatiality) is pre-verbal and typically not reflected on, however, it is the space that affects how we feel. Standing near Ground Zero may elicit feelings of vulnerability while standing in front of the Statue of Liberty may elicit feelings of community and gratitude for those that came before us. “We feel a special sorrow for the homeless because we sense that there is deeper tragedy involved than merely not having a roof over one’s head” (van Manen, 1990, p. 102). Lived space in the context of caregiving may involve a change in the way it feels to “come home”. Home may no

longer be the place to rest and feel content but a place of constant uncertainty and never ending responsibility.

Lived body (corporeality) refers to the fact that we are always physically in the world, our bodies are inescapable (van Manen, 1990). This is particularly salient for caregivers as they reframe their parent's physical presence. Care-receivers may be physically present and emotionally unrecognizable to the caregiver. The caregiver is responsible for caring for the physical needs of the care-receiver while the caregiver's "bodily space" may become numb or neglected.

Lived time (temporality) is subjective (van Manen, 1990). "When a man sits with a pretty girl for an hour, it seems like a minute. But let him sit on a hot stove for a minute—and it's longer than any hour. That's relativity" (Einstein). In other words, lived experience affects how time is perceived. Sandwich generation caregivers battle against objective (clock) time to do all that needs to be done, which alters how they experience time spent with parents and children.

"*Lived other (relationality)* is the lived relation we maintain with others in the interpersonal space that we share with them" (van Manen, 1990, p. 104). A caregiver's relationality constantly shifts with the progression of ADRD. This is one of the most difficult components of caregiving (Butcher, 2001). As cognition declines and dependence increases the relationship between parent and child is forever changed.

These four lifeworld existential guided the interview process. Examples of these questions are in Appendix G. The researcher utilized open-ended questions to foster a conversational style interview. The goal of an informal interview was to establish trust and build a rapport with the interviewee and create an atmosphere amenable to self disclosure (Kvale, 1983).

5. Consulting phenomenological literature

The researcher searched CINAHL, Academic Search Elite, and PsychNet

databases for phenomenological studies. The phrase “dementia family caregivers in the Sandwich Generation” was used initially. When no matches were found, the researcher used the phrase “dementia family caregivers”.

C. Phenomenological Reflection

6. Conducting thematic analysis

a. Uncovering thematic aspects in lifeworld descriptions

Theme provides focus, meaning, and a point to lived experience. “Themes are the stars that make up the universes of meaning we live through. By the light of these themes we can navigate and explores such universes” (van Manen, 1990, p. 90).

b. Isolating thematic statements

There are three approaches that can be used in uncovering thematic aspects in lifeworld descriptions: wholistic, selective and detailed (van Manen, 1990). This study will use the selective approach. The researcher will listen to the interviews and read transcripts and search for statements that are essential in revealing participants experience of leisure.

c. Composing linguistic transformations

“Composing linguistic transformations is not a mechanical procedure. Rather, it is a creative, hermeneutic process” (van Manen, 1990, p. 96). The researcher will develop creative expressions for articulating themes.

d. Gleaning thematic descriptions from artistic sources

The researcher will study sources of art that may reflect thematic elements of this study. Art renders a unique perspective because “the artist recreates experiences by transcending them” (van Manen, 1990, p. 97).

7. Determining essential themes

Essential themes are those that speak to the shared experience of the phenomenon and without them the phenomenon would be altered. These questions must be asked, “Is

this phenomenon still the same if we imaginatively change or delete this theme from the phenomenon? Does the phenomenon without this theme lose its fundamental meaning?” (van Manen, 1990, p. 107).

D. Phenomenological Writing

8. Attending to the speaking of language

A dual axes approach to interpretation allows the researcher to stay true to the nature of the participants’ intent. The axes are the grammatical axis and the psychological axis (Pehler, 2003; Moran, 2000; Chan, 2001). The first axis pertains to language, the interpretation must stay true to the linguistic style of the participants. The second axis pertains to the author’s frame of reference, his/her historical, social and cultural experiences that create the lived experience (Pehler, 2003; Chan, 2001; Moran, 2000).

9. Varying the examples

“...a phenomenological description is an example composed of examples” (van Manen, 1990, p. 122). In order to understand a lived experience and make it somehow tangible, the phenomenologist must use a variety of examples so that the reader can become immersed in the phenomenon. This makes aspects of the phenomenon accessible to the real world.

10. Writing

“...writing brings clarity and passion to the act of living” (Cameron, 2001, p.4). Writing is an act of understanding. As the phenomenologist translates the participants’ experiences into shared themes, the phenomenologist has a clearer understanding of the phenomenon.

11. Rewriting: A to D etc.

“...the process of writing and rewriting...is more reminiscent of the artistic activity of creating an art object that has to be approached again and again...going back

and forth between the parts and the whole in order to arrive at a finely crafted piece that often reflects the personal ‘signature’ of the author” (van Manen, 1990, p. 132). The art of phenomenology is that it allows the researcher to craft scientifically rigorous research in a style that reflects the author’s orientation to the world.

Interviews

The researcher gathered experiential description through face-to-face interviews. Interviews lasted approximately 1-2 hours. The interviews took place in the participant’s home , office or over a web camera. Each interview was audio taped and later transcribed for data analysis. Information about demographics was collected at the end of the interview.

The initial phenomenological question was—What is your experience of time for yourself as you care for your parent with dementia while raising a family? Subsequent questions that focus on spatiality, corporeality, temporality, and relationality may include, but are not limited to: Can you describe how your experience of time for yourself changed when you first accepted the role of caregiver? Can you describe your experience when your caregiving obligations and your parental responsibilities conflict with time you have planned for yourself? Can you describe how you feel about the control you have over your life as a caregiver? Can you describe how you feel about balancing your parent’s needs and your child’s needs? Can you describe how you feel about caring for your own needs? These questions are also listed in Appendix A. Probes will be offered as a means to clarify participant descriptions and I will be respectful of silences as they may allow the participant to generate meaning and new understanding. NVivo will be used to conduct thematic analysis (which will be detailed in a later section).

Standards for Evaluation

Evaluation of qualitative data differs from that of quantitative data, the standards, however, are as rigorous (Connell, 2003). Establishing trustworthiness is the foundation

of sound qualitative research (Koch, 1994). The traditional scientific method mandates the researcher's personal experience does not influence the data. The premise of phenomenology is personal experience, it grew as a way to understand human behavior that cannot be explained through detached experimentation. Hermeneutics is a dialogue between the researcher and the text and between the reader and the interpretations (Koch, 1994). It is understood that the researcher and the reader approach the material with unique personal experiences, preconceptions and prejudices, therefore, their analyses may vary (Koch, 1994). Unlike quantitative research, differing analyses do not render the study defunct. Rigorous qualitative research must show the process by which the researcher developed his/her interpretations so the reader can comprehend how the interpretations were created (Koch, 1994; Connell, 2003).

The criteria for establishing trustworthiness are credibility, transferability and dependability. Credibility is the counterpart of internal validity (Koch, 1994; Connell, 2003). While phenomenology does not seek to uncover cause/effect relationships, the researcher must understand how his/her interactions and reactions to events affect analysis of the data. A field journal is used by the researcher to capture the interactions and reactions to maintain self awareness as the study proceeds (Koch, 1994; Connell, 2003; Guba & Lincoln, 1989). Consulting participants to ensure interpretations reflect their intent is another method of constructing credibility (Koch, 1994; Connell, 2003).

Transferability corresponds to external validity in quantitative research (Koch, 1994). Guba & Lincoln use the idiom "fittingness" when findings can be understood outside the context of the current study (Porter, 1999; Koch, 1994; Connell, 2003). In other words, the reader should be able to transfer the information gleaned from the study and find it meaningful and applicable to their own experience.

Dependability is akin to reliability (Koch, 1994). Guba & Lincoln (1985) recommend auditability to establish consistency of the data. Consistency of the data is ensured when another researcher can follow the decision trail in the study and interpret

the data in a similar manner, the interpretation does not have to be exact, but it should not be contradictory (Koch, 1994; Sandelowski, 1986). Building a path for other researchers and readers to follow allows for the discussion of theoretical, methodological and analytic choices through the course of the study (Koch, 1994). When credibility, transferability, and dependability are achieved confirmability is established (Guba & Lincoln, 1989; Koch, 1994; Connell, 2003). Confirmability demonstrates the manner and method with which decisions were made throughout the study.

CHAPTER 4 PRESENTATION OF FINDINGS

Data Analysis

The purpose of the research method was to explicate a deeper understanding of the lived experience of leisure while caring for a parent with dementia and concurrently caring for the needs of a minor dependent child or children. This chapter presents the findings of this inquiry and will include: 1) a description of the natural setting where the study occurred, 2) a description of the pertinent characteristics of the participants, 3) characteristics of the research design, 4) participants' stories, 5) presentation of the essential themes, and 6) a hermeneutic summary of the essential themes.

Natural Setting

The interviews were conducted by the researcher in Iowa City, Iowa April through August 2009. The semi-structured interview utilized promotes a conversation between the participant and researcher. For the comfort of the participant, he/she chose the setting of the interview. Two interviews were conducted in private offices where the participants were employed, one interview was conducted in a participant's kitchen, one interview was conducted on a participant's back porch overlooking her acreage, and two interviews were conducted over a web camera. Three of the six participants live in Iowa City, 1 participant lives in Norway, Iowa, and 2 participants live in a rural area near South Bend, Indiana.

Pertinent Characteristics of the Participants

Two participants were referred to the researcher, three participants responded to information posted about the study in the Noon News at the University of Iowa Hospital and one participant responded to information about the study in the regional Alzheimer's Association newsletter. One participant who was referred to the researcher was a friend

of both parties and was familiar with the researcher's study. The other participant was referred by his wife, who was also a participant in the study.

The participants' ages ranged from 37 to 54 years. Two participants were in their thirties, two participants were in their forties and two participants were in their fifties. All participants lived in their own home with spouses and at least one dependent child. Three participants lived with their dependent parent. Two of the participants were married to each other.

All participants completed some post secondary education. One participant did not earn a degree, one participant earned a Bachelor's degree and completed some work at the graduate level, one participant earned two Bachelor's degrees, one participant earned a Master's degree, one participant earned two Bachelors' degrees and a Master's degree, and one participant earned a Doctorate. The time devoted to education affected two of the participants' dedication to their career. All participants worked outside the home and indicated that work offered an escape from the pressures at home and/or a support network.

Characteristics of the Research Design

Purposive sampling was used for this study. The participants were selected based on their experience with the phenomenon. Initially the researcher intended to present information about the study at support groups held through the regional Alzheimer's Association, but due to an unfortunate experience with a previous student, this branch of the Alzheimer's Association no longer allowed graduate students to present information regarding their studies. The Alzheimer's Association did allow the researcher to submit information about the study in their monthly newsletter and one participant responded to that query. The researcher posted information and requests to participate through the local Elder Services and the Neurology Department at a Midwestern hospital. No participants responded to those queries. The researcher was interviewed at a local radio

station regarding this study and participants were requested, however, no people responded. Information about the study was submitted to the Noon News at the University of Iowa Hospital. The Noon News is a daily publication of the hospital; it highlights important news of the day, posts activities of the day, and gives information about research studies conducted throughout the hospital and university. Three participants responded to that information. The first four participants were located in or near Iowa City. The above mentioned efforts of the researcher yielded only four participants.

The sample size of a phenomenological study can range from 6-10 participants (Haase, 1987). The thesis committee of the researcher required at least 6 participants for the study to comply with the requirements for graduation. A friend of the researcher, who was familiar with the study, knew of someone who met the inclusion criteria through another friend. The participant was initially contacted via email by her friend and asked permission for the researcher to contact her. This participant lived in Indiana. Travel was not feasible, so the interview was conducted over a web camera and audio taped. The mother of this participant lived with her family and her husband was the primary caregiver of both the children and his mother in law while the participant worked. The researcher requested the participant ask the husband if he was willing to participate in the research. He agreed and his interview was also conducted over the web camera.

The participants were asked to describe their experience of time for self while simultaneously caring for a parent with dementia and a dependent child or children. The interviews were audio taped. The researcher listened to all interviews immediately following the interview and reflections were recorded in a field journal. A person was hired to transcribe the interviews. The researcher listened to all interviews again before looking at the transcript to gain a general understanding of experiences. Then interviews were listened to while reading the transcript. Information was highlighted on the transcripts during that read through. Transcripts were reread without the audio and notes

were made in the margins to begin thematic analysis. Transcripts were reread several more times. The researcher felt there was always something new to learn. van Manen (1990) states that all interpretations are interpretations of an interpretation. Each time new information was gleaned from the transcript, a new interpretation of the whole emerged.

The analysis was completed using QSR NUD*IST N Vivo 8 (1999) software designed for qualitative research. NVivo 8 allows the researcher to manage “narrative data by coding, indexing passages of text, labeling categories of text, and retrieving the labeled passages across all cases” (Richards & Richards, 1994 as cited in Butcher, et al., 2002). Initially, the researcher developed one hundred and fourteen nodes as a starting point for “uncovering thematic aspects in lifeworld descriptions” (van Manen, 1990). All references within each node were reread within the context of the interview to ensure they were in the correct node. The one hundred and fourteen nodes were synthesized to isolate thematic statements. A member of the researcher’s thesis committee reviewed the original one hundred and fourteen nodes and then the synthesized thematic statements. The references in each thematic statement were again reread within the context of the whole interview to uncover essential themes. Six essential themes emerged from the data and the researcher “composed linguistic transformations” to arrive at a poetic rendering of the essential themes. The essential themes are *reconciling life transitions, succumbing to infinite obligations, time shifts, constructing a foundation, revisit control, and freedom to recreate*. Each essential theme and the thematic statements that compose the themes will be presented with descriptive expressions directly from the participants. Table 3 identifies each essential theme and the thematic statements that compose the essential theme. The number of passages refers to the descriptive expressions from interviews. And the percentage of cases reflects the percent of participants that had a descriptive expression present in the thematic statement or the essential theme.

Table 3: Frequencies and Percentages of Thematic Statements and Essential Themes

Essential Themes	Thematic Statement	Number of Passages	Percentage of Cases
Reconciling life transitions		150	100
	Discovering memory loss	13	83.33
	Integrating parent demands with family needs	75	100
	Juggling multiple life challenges	21	83.33
	Balancing guilt and grief	41	83.33
Succumbing to infinite obligations		101	100
	Crushing time and emotional pressure	88	100
	Acknowledging inequities	13	83.33
Time shifts		94	100
	Nursing home alters time	14	50
	Longing for spontaneity	8	66.66
	Evaluating time for self care	72	100
Constructing a foundation		56	100
	Partners grant a reprieve	9	50
	Garnering support	47	100
Revisit control		69	100
	Positive power	11	100
	Humor as a stabilizer	20	83.33
	Balanced perspective	38	100
Freedom to recreate		71	100
	Yearning for old leisure	9	66.66
	Structured relief	14	100
	Modifying leisure	47	100
Total		541	

Participants' Stories

TR and Phenomenology both use stories as a journey of discovery through a partnership between therapist and patient and researcher and participant. A conversational interview is the method for revealing the stories. Studs Terkel was a masterful interviewer and describes the power of the interview on *Speaking of Faith* (2008).

She never heard herself talking, or in this case, thinking as well as talking. And suddenly she said something on the microphone...she puts her hand to her mouth and "Oh, my God." And I said, "What?" And she says, "I never knew I felt that way before." Well, that's a great moment. She's saying, "I never knew I felt that way before." It's suddenly a discovery she's made as well as I'm making one. So it's as though we're both on a journey in a way.

The phenomenologist and the recreational therapist understand the importance of cogenerating meaning within an experience. The themes that emerged from the data can best be comprehended through each participant's story. Pseudonyms were created to protect confidentiality.

Chloe

Chloe was fifty four years old and had two bachelors degrees, one in education and one in nursing. She was the primary caregiver for her mother-in-law, Kate, who at the time of the interview lived in a nursing home. "I am more like a daughter to her probably than a daughter-in-law..." She assumed power of attorney for health care because, as a nurse, all involved felt she could make the most informed decisions.. At the beginning of her caregiving journey, she cooked meals and did laundry for Kate while she was in assisted living. As her illness progressed, Chloe assumed more ADL responsibilities. While Kate was on the waiting list for a nursing home that Chloe researched and felt comfortable with, Kate fell and broke her hip and was placed in the only nursing home that would accept her. Chloe felt this nursing home was inadequate plus it was a half hour drive from her home. She struggled with losing control of the

quality of care she gave Kate. Chloe stated that caregiving was mentally and physically exhausting. She worried that she may eventually have to care for her husband if it is hereditary and she worried that her children will have to take care of her. She did not want her children to feel this burden.

Guilt played a large role in Chloe's experience and it effected the time she allowed for herself. She admitted that she had a "wake up call" at her last physical when her cholesterol and blood sugar were elevated. At the time of the interview, she had just begun to exercise more. Throughout the process of the interview, Chloe discovered that she did take some self care moments. She strategically planned to relax and socialize during her quarterly conference for work. She continued to stay connected with her best friend in California and claimed talking was her method of coping. When her daughter noticed that she always had something positive to say, Chloe realized that she created a positive spin on life every day to bring herself up.

Abby

Abby was 51 years old and has a Masters degree in Nursing. She was the primary caregiver for her father, Stan, who at the time of the interview, lived in a nursing home that he chose. "...at the nursing home, they all love him because he is just fun..." Stan typically had a very good sense of humor any loss of humor was a barometer that something was awry. Prior to placement, he frequently called Abby in the middle of the night and expected her to come right over. Often she would go over immediately but when she did not she stated she "would feel guilty for not going over and helping...It just kind of weighed on me..." She said that caregiving was a "huge time commitment" and it required a lot of "emotional time."

At the beginning of the interview Abby maintained that she had very little time for herself and the time she took was "at the end of things." As the interview unfolded, Abby revealed that even through the hardest part of her caregiving experience she

preserved her Friday “cards and dinner” night with her husband and friends, her Tuesday golf outing, and walking her dog. When Abby realized that she did carve out time for herself along the way, she believed it would have “impacted her stress level” more and she might have felt “a little grudge against the time and what you’re losing ‘cause of it” if she had not made the choice to continue taking time for herself.

Ellie

Ellie was 49 years old and a Physicians Assistant. She was the primary caregiver for her mother, Tessa, who lives with Ellie, her husband and two sons. Ellie worked part-time and her husband, Ted, cared for her mother while she is at work. Ellie lived in a rural area near Iowa City and the interview took place on her back porch overlooking her acreage while her youngest son watched TV and her mom sat on the couch. Her mom had Crohn’s Disease and had an accident while the researcher was there which Ellie handled gracefully and her son hopped right up to help. She worried about the example she was setting for her children. Ellie insisted that she “can easily take care of her...it’s not like she needs two people to help her transfer, it’s not like she needs IV fluids...” Ellie confessed that taking care of her mom was not nearly as difficult as surviving the Physician’s Assistant program. Then she had absolutely no time for herself.

Ellie claimed she had one “perk”, the one thing she allowed herself to do was get her hair cut every five to six weeks. She believed she missed spontaneity most. In the middle of the interview while talking about spontaneity, a hummingbird flew by and Ellie got visibly excited and shouted “a hummingbird, a hummingbird.” She didn’t miss a beat, “it’s a spontaneous thing, like I’m driving by, there’s a yard sale, I’ll stop for five or ten minutes” and continued to say that finding treasures at yard sales was leisure for her. The interviewer asked if having that outlet filled a need for control and Ellie said, “Maybe it does. I hadn’t thought about that.”

Sophie

Sophie was 47 years old and was a clerk at a hospital. She took some college level classes but had not completed a degree. Sophie was a secondary caregiver for her mom, Alli, at the time of the interview, Alli has since passed away. Sophie commuted an hour each way when her mom first needed assistance. At that time she was a single mom and “the stringent time” of having to feed her mom and get her ready for bed took its toll on her. She felt guilt about not being there for her daughters when they needed her and guilt about not being there for her mom. When she reached her limit, she confessed to her sister that she was burnt out. “...it was hard to complain to somebody who is doing twice as much as you are, that you’re burnt out but I also wasn’t afraid to say I am.” At that point, they placed Alli in the nursing home affiliated with the hospital where Sophie’s sister worked. Sophie believed her control was in her attitude, “where my control is, is that we have the potential to make the best or the worst out of the situation. We have to make those choices every day.”

Sophie’s sister, Jenna a Recreational Therapist, was their mom’s primary caregiver. Sophie affirmed that she and her sister relied on social support and humor to pull them through the toughest parts of their respective journeys. “...my sister did things for herself too, I mean we were lucky that both of us [knew] our friendships were important...” One summer Sophie’s son was deployed to Iraq at the same time Jenna’s daughter was hospitalized and developed short term memory problems. With their usual dry humor, Jenna reported to Sophie, “Two people with brain damage is not easy to deal with all day long...it’s like ‘50 First Dates’!”

Leah

Leah was 37, had her PhD and accepted a faculty position one year prior to this interview. Leah’s mom, Jeanne, lived with her, her husband, Zach, and their two

daughters. Zach was a stay at home dad for several years and assumed some responsibility for Jeanne's care as well. He is also a participant in this study.

Leah was a self proclaimed introvert and believed the hardest part of being a parent, caregiver, and teacher was that she was "always surrounded." At the beginning of the interview, Leah said that she didn't take any time for herself. She felt she had to work to make up for the "hole" she put her family in to earn her degree. She revealed that work was like a "retreat" "I can work on the computer and I can have music, this is kind of a nice space to be by myself..." As the interview progressed, she stated that she "crashed" when she couldn't take it anymore. The interviewer asked what a "crash" looked like. Leah said a crash was watching TV and letting her mind "go somewhere else" and not "being productive" "...I love a good laugh...watching Funniest Home Videos..." She also believed laughing helped alleviate pressure and helped keep an optimistic attitude.

Zach

Zach was 39 and has completed some graduate level work. He was married to Leah and lived with his mother in law, Jeanne, and cared for her when he was a stay at home dad. Zach was the general contractor for the home they built to include living space for Jeanne. He was cognizant of emotional, social as well as physical boundaries as he designed the house. He said "...I want to make sure that I'm not always here, so that she felt like it was her house too...[she can have] space and freedom...without me interfering as well."

Zach, stated at the beginning of the interview that he took time for himself and "was not the type of person to feel guilty" about it. "At first I was definitely uptight about things that happened...I started coping with...stress...I walked it off, with the kids usually." He also incorporated sports and social activities into his job. He says what he missed most was spontaneity and travel.

Table 4 : Demographic Information

	EDUCATION	ETHNICITY	AGE
CHLOE	2 Bachelor's degrees	Caucasian	54
ABBY	Master's degree	Caucasian	51
ELLIE	Master's degree	Caucasian	49
SOPHIE	Post-secondary classes/ no degree	Caucasian	47
LEAH	Doctorate degree	Caucasian	37
ZACH	Graduate classes/no degree	Caucasian	39

Presentation of Essential Themes

Reconciling life transitions

Reconciling life transitions is settling into a rhythm of ambiguity. At the beginning of the caregiving journey the uncertainty is overwhelming “it weighs on you... the stress of what’s the next step...”

There are four thematic statements that compose the essential theme “reconciling life transitions”. They are 1) discovering memory loss, 2) Integrating parent demands with family needs, 3) juggling multiple life challenges, 4) balancing guilt and grief.

Discovering memory loss makes the illness tangible and portends future challenges. Leah reflects on a moment when she recognized a new challenge for her mom.

The other day she was outside ... Mom ...couldn't, quite look at the outside of the house and know what room that represented on the inside. I was actually surprised that she wasn't able to do that...

Sometimes the caregiver is forced to deal with the loss almost immediately. Sophie recalls the rapid decline of her mom, “Her Dementia started more with losing words. So she'd know that she wanted to tell you something but she couldn't get words out and she was so frustrated ... so she became non-communicative very very quickly.”

Integrating parent demands with family needs merges the all consuming uncertainty of dementia and the all consuming responsibility of parenting.

...that was when it was really, really stressful ...you felt so rushed... If there was one extra thing that happened, which when you're taking care of people with Dementia there's always one extra thing that happens. So your best-laid plan of I'm going to go and get this done and then I'll be home at nine o'clock, just doesn't happen...

For caregivers who live with the care receiver, it alters the family dynamic as well. Leah asserts “by having her along we aren't acting as...a regular family... changes ... the way that my husband and I talk to each other...”

Juggling multiple life challenges illustrates the awareness that life continues to present obstacles outside the caregiving role and amplifies time and emotional strain. Abby balanced caring for her father with dementia when her mother in law was diagnosed with dementia “...she has more significant dementia than my dad...”

Chloe was caring for her mother-in-law when her own mom, who lived out of state developed health problems.

“...since November she's had two surgeries and another admission for a broken shoulder ... that admission she developed pneumonia and was in ICU and I was back down there again...”

Balancing guilt and grief reveals the incessant efflux of emotions that compound exhaustion. Guilt manifested itself in many ways-- guilt of not being there for their children, guilt for the type of care they were providing, guilt about what they were teaching their children, and guilt for failing a spouse. Sophie explains the guilt of not being there for her children “I think that the guilt was that I wasn't here with the girls.

That was horrible guilt...” Chloe articulates the reason she chose nursing home placement rather than in home care, “It’d be way more exhausting than it is to feel guilty and worry about her being there.”

Ellie contemplates the example she is setting for her own children.

“...sometimes it's almost like a ball and chain and then I think, "What am I teaching my kids... I want them to have the freedom to live their life without feeling obligated to take care of me some day. And sometimes I wonder how strong a message I'm sending in that regard.”

Chloe said that she felt guilty because she was failing her husband. She just didn’t have the energy to talk to her husband about anything more than what needed to be done for the day.

A harsh component of dementia is the loss of the essence of the person, the characteristics that make them recognizable to loved ones. Sophie gives an example of what she and her family did so that there was the appearance that her mom participated in her son’s wedding.

“...And so for Patrick's we did not have her and that just about broke my heart. But what we did was...the kids came and put their tux and dress on and we took some pictures. And I know that she doesn't know what we know, but we have those pictures so, that helps.”

Succumbing to infinite obligations

Succumbing to infinite obligations is the unwilling acceptance that your life has been preempted by never ending responsibilities. The participants described a feeling of being overwhelmed by the constancy of the dual roles of caregiving and parenting.

I was a single mom at the time... they really needed me here and then it would be my night to go shower mom and put her to bed... I'd cry sometimes all the way there and then I'd get there and Mom would be sitting there, facing the wall ...and then on the way home you'd cry because...how could I think that I didn't need to be there.

There are two thematic statements that compose the essential theme “succumbing to infinite obligations”. They are 1) crushing time and emotional pressure, 2) acknowledging inequities.

Crushing time and emotional pressure magnifies the punishing reality of losing the parent you knew, losing time with your children, and losing the energy to care for yourself. The repetitive nature of dementia took its toll on participants and it affected how much time they were able to spend with their children and how much energy was left for them. Leah described herself as an introvert and “always being surrounded” was particularly difficult especially when she had to constantly repeat herself.

“I get home and I feel bad 'cause I know my Mom hasn't had much conversation...she asks the same thing over and over again and then she'll tell me the same thing over and over and over again.. I try not to get frustrated with that...on top of not wanting to be verbal I have to repeat the same thing ... come on, I didn't like saying it the first time.

Acknowledging inequities is acquiescing to the challenges of the role you accepted while longing for the apparent simple life of those around you. Many participants expressed the feeling of “life not being fair”.

...this was so not fair that her whole Junior High and High School she had a mom that was torn taking care of her grandma...nobody ever said life was fair... I was resentful ... and I don't even know who at.

All of the participants had siblings. If the caregiver did not feel their sibling helped enough, it exacerbated the sense of unequal burden, “...I'm located here it impacted me more than my brothers. So I wish they'd have helped out more...”

Time shifts

Time shifts as you begin to extricate yourself from unhealthy habits and create new opportunities. “...I'm not afraid to admit it. I am burnt out, I am doing more than I can do and we've got to change something.”

There are three thematic statements that compose the essential theme “time shifts”. They are 1) nursing home alters time, 2) longing for spontaneity, 3) evaluating self care

Nursing home alters time juxtaposes the fear of relinquishing control and the freedom of relinquishing control. Three of the six participants had a parent in a skilled nursing facility. They hoped it might relieve some of the caregiving burden but they feared not being in control of their care. “When she got to the nursing home my control totally disappeared.” However, if they became comfortable with the placement, it did relieve some of the participant’s time and emotional angst.

“...the better we feel about her care, the easier it is to take that guilt off and to go and to want to be there...I did notice a huge difference once we moved her. Just a huge stress relief that if something happened and I couldn't go today; she was going to be OK.”

Longing for spontaneity reveals a loss of control over time and the ability to participate in activities of choice. “...it really cuts down on the spontaneity... Let's go for a pizza tonight or a movie tonight. Well we can't, we don't have a sitter for Grandma.” Ellie “stole” moments of spontaneity, “it's a spontaneous thing, like I'm driving by, there's a yard sale, I'll stop for five or ten minutes.”

Evaluating self care occurs when you seize a moment for reflection and command change. Sophie recounts how sometimes you had no choice but to take care of yourself.

“Well I was so stressed that sometimes physically you just have to, like maybe my taking care of myself was going for a walk just because you had so much anxiety you had to do something, if you didn't move you would jump out of your skin... I just had to.

Constructing a foundation

Constructing a foundation forms the structure necessary to reestablish control over your life. Ellie believed she has control over her life because she had flexible people that provided respite when she needed it. “...I feel like I still have pretty good

control.... I...have Helen or Bonnie [from church]...that could come...and they are very flexible...”

There are two thematic statements that compose the essential element “constructing a foundation”. They are 1) partners grant a reprieve, 2) garnering support.

Partners grant a reprieve illustrates the importance of having a companion to shoulder a portion of the caregiving burden to enable self care. Sophie was a single mom at the beginning of her caregiving journey and she stated that she leaned on her partner a lot “I don’t know why he didn’t run kicking and screaming...the man is an angel...he was just there to help...He really helped keep our family healthy and whole.” The people who had the support of a spouse or partner noted that they would not be able to do it without them. Ellie states,

“I really couldn't do it without George, my husband. There is no way I could do it without him. He'll take care of Mom on days that I'm gone...he cooks, he cleans, he gives baths, he reads...”

Garnering support is consciously forming a network that allows control to emerge. As participants yield to the long term nature of the caregiving role, they realized they needed to reach out for social support.

“I have a couple different support groups and ...keeping those friendships strong have been important to me on every level... as far as being able to get through it... they fill in for everything and as far as when life does get overwhelming, they're the first people that are here to pitch in...”

Revisit control

The ability to *revisit control* evolves as you take inventory of internal strength amid challenges. Zach compared his current challenges with previous challenges and realized he had endured something more difficult and weathered it. “...after a while I really had to just pull back and look at the big picture ... when [my wife] was... doing her dissertation and working at the same time ... I think that was more stressful than anything having to do with Mom...”

There are three thematic statements that compose the essential theme “revisit control”. They are 1) positive power, 2) humor as a stabilizer, 3) balanced perspective.

Positive power creates a tether for buoyancy in turbulent times. Chloe explained to her daughter’s query of how she is able to always stay positive “...if you say negatives all the time you're going to bring yourself down... so I try to... think up a positive everyday that will bring me back up...”

Humor as a stabilizer describes the ethereal nature of laughter it diffuses angst and augments solace. Zach shares “...if you can't laugh at it... it would be depressing.” Many participants reflected on the most difficult times while caregiving and expressed that a good sense of humor “pulled them through.”

Interviewer: “How helpful is humor?”

Sophie: “Oh my goodness. I can't even imagine where we would be without it... I'm laughing about it no matter what.”

Interviewer:” Were you able to do that even during that tough year?”

Sophie: “Some, and that actually is what kept me going.”

Balanced perspective emanates from emotional distance and inspires contentment. Ellie explained, “...when I'm at work I love being at work, I love my work...when I'm at home...I love being home...” Sophie described the serenity she experienced from realizing what her mother would have chosen if she were able, “She'd have told us to go home even if she wanted us there...so.. knowing that, really takes some of the pressure off...”

Freedom to recreate

The *freedom to recreate* embraces the liberty to reinvent the caregiving journey and incorporate time for self. Sophie describes how taking time for herself helps ease the burden of caregiving.

I was driving a couple weeks ago to go feed my mom lunch and that same group of friends called and said...come on we are

going to Mt. Vernon...[it] took me a minute and I thought...there's somebody there that will feed her and she'll be perfectly fine...And I went to Mt. Vernon and met them and had lunch...then went and saw my mom. And... that really make a huge difference. It makes a difference on burn out..."

There are three thematic statements that compose the essential theme "freedom to recreate." They are 1) yearning for old leisure, 2) structured relief, 3) modifying leisure.

Yearning for old leisure replays the memory of freedom embedded in leisure.

Zach wistfully recalls an old activity "I miss travel, we traveled a lot before and it's just something that we haven't been able to do..." Leah would like the freedom to just do "everyday things." "...just sitting reading books for fun, I really miss that....going out with friends or entertaining... or just walking..."

Structured relief is time taken to generate renewed energy. Abby describes how she would feel if she did not take time for herself.

"...it would've impacted stress level...then you start feeling a little grudge against the time and what you're losing 'cause of it. You're doing it because it's the right thing to do and you want to do it but when it starts... making you not able to do the things that you find pleasure in then I think it just makes it more of a burden and your attitude about it wouldn't be as positive."

Modifying leisure amalgamates the importance of the freedom from control and the importance of the freedom to control. The dual roles of parenting and caregiving seize a lot of time and energy, when participants are able to reclaim some portion of their time and control how that time is spent they express a sense of freedom. "... it's planning to put ourselves in the position where we get to go and be a little freer..."

Hermeneutic Summary of the Essential Themes

Caregivers in the Sandwich Generation who care for a parent with dementia experienced leisure as "reconciling life transitions while succumbing to infinite obligations and managing time shifts to constructing a foundation that enables you to revisit control and embrace the freedom to recreate". The essential themes individually offer a small glimpse into the experience of sandwich generation caregiving. To

comprehend the nuances of the lived experience the themes must be interpreted together. The phenomenological researcher acknowledges that the “whole might be quite different than the sum of its parts” (Omery, 1983).

While there is a chronological flow in the way the researcher presented the essential themes, they are intertwined and in motion. Each theme can be understood at a moment in the caregiving experience and then be brought back into the whole as a new development or challenge is presented.

CHAPTER 5

DISCUSSION OF FINDINGS

The phenomenon of interest in this study is the lived experience of sandwich generation caregivers who care for a parent with dementia. This chapter will present: 1) an overview of the study, 2) a discussion of the relevance and significance of the study, 3) a comparison with recent literature, 4) implications for practice and research in TR, and 5) personal reflections.

Overview

Phenomenology was chosen as the methodology for this study because it provides a deeper understanding of the subjective experience of leisure within the context of caregiving. Hermeneutic Phenomenology attempts to describe an experience in terms of how it appears while understanding that all experiences are interpreted (van Manen, 1990). It is unique from other methodologies in that it does not seek to develop generalizations about a phenomenon but rather gain a more comprehensive view of how the phenomenon is experienced as a whole.

The structure for describing the lived experience is derived from thematic analysis of the interviews and transcripts, field notes and in reflective writing. Each participant viewed the experience of caring for their parent and children within the framework of their values, history, and family dynamic while the researcher came to the investigation with fore-structures shaped by her own background and in the process of interaction and interpretation, the participants and the researcher developed a shared understanding of the phenomenon (Wojnar & Swanson, 2007). The credibility of phenomenology is in the recognition that “your story” resonates in “my story” (van Manen, 1990).).The hermeneutic circle creates a conceptual structure for articulating the preconceptions and prejudgments of the researcher to ensure rigor in the study (Koch, 1994).

The process of phenomenological reflection is retrospective rather than introspective (van Manen, 1990). This means a lived experience must be reflected on in order to be understood. Thematic analysis focuses on allowing themes to emerge from the data, uncovering essences that make the nature of the phenomenon is what it is and without it, it ceases to be (Merleau-Ponty, 1962). Phenomenological reflection facilitates recognition of how a phenomenon is experienced in our lifeworld (van Manen, 1990).

The participants in this study spoke of their experiences as they reflected on them. Merleau-Ponty describes speaking as the discovery of what he was thinking (Merleau-Ponty, 1973, as cited in van Manen, 1990). As participants reflected on the caregiving experience, they discovered how each part of the experience affected the whole experience and the whole experience was more than just each part taken together. The researcher must adopt the same technique of looking at how the sum of the experience informs the whole and reflectively how the whole informs individual aspects of the experience (Omery, 1983)

All of the study participants volunteered to take part in this study and wanted to share their story. It was a homogeneous group, all participants had access to someone who worked in health care in their family, they all had some post secondary education, and they all were able to find financial resources so they were not required to assume any financial burden. This created limitations within the study because it does not reflect the lifeworld of people who are not familiar with the health care system, who lack educational resources which may inhibit their ability to navigate and feel confident within the health care system, and who do not have the financial resources to aid in caring for their family.

Relevance and Significance of the Study

The findings of this study suggest that leisure is important to caregivers. TR is a vehicle to introduce the health benefits of leisure to caregivers in the Sandwich

Generation. TR has long attempted to use quantitative data to develop evidence based practice to guide the profession (Mobily, 2007). The adoption of this technique has not lead to acceptance by our rehabilitation counterparts, occupational therapy and physical therapy, nor has it lead to an increase in funding (Mobily, 2007). Mobily (2007) contends that using quantitative methodology for an inherently subjective experience will always fall short. Hermeneutic Phenomenology, like TR, is simultaneously an art and a science. Using Hermeneutic Phenomenology allows TR to express itself in the meaningful language of its discipline.

TR is described as a person-centered profession which gives people the opportunity to experience a sense of control and freedom (Pedlar, et al., 2001). A study by Iso-Ahola (1980) suggests that the activity a person participates in is not nearly as important as the control in choosing the activity. The semi-structured interview used to collect data for a phenomenological study generates a similar person-centered focus and allows the participant control in guiding the interview. Additionally, phenomenology and TR create an experience where the researcher and participant and the therapist and patient are partners in the process of discovery.

Leisure, historically, was once a modality where people fostered a view of how to interpret the world (Goodale & Godbey, 1988; as cited in Hunnicutt, 2007). Hermeneutic phenomenology is a modality where people foster a view of how to interpret a lived experience. "At the root of patient focused care is the recognition that such care is not a technique but a way of thinking" (Pedlar, et al., 2001). Hermeneutic phenomenology is a natural method to express the lived experience of leisure because as thoughts are articulated new insights are revealed (van Manen, 1990). New insights continue to enhance interpretation.

In the researcher's quest, very few phenomenological studies were found in TR literature and no phenomenological studies were found that focused specifically on dementia caregivers in the sandwich generation. This study explicates a deeper

understanding of the lived experience of leisure for caregivers in the sandwich generation who care for a parent with dementia and offers TR a methodology that mirrors its philosophy and practice.

Comparison with Recent Literature

The researcher searched CINAHL, Academic Search Elite, and Psych Info databases for phenomenological studies. The phrase “dementia family caregivers in the Sandwich Generation” was used initially. When no matches were found, the researcher used the phrase “dementia family caregivers. Literature found addressing the Sandwich Generation was primarily quantitative or anecdotal and no studies were found that specifically focused on dementia family caregivers in the Sandwich Generation.

Dementia caregivers in the Sandwich Generation have emerged due to a shift in demographics (Spillman & Pezzin, 2000) and an increase in the rate of dementia (Family Caregiver Alliance website, 2008). There is an abundance of literature that studies dementia family caregivers and all of it concurs that caring for a person with dementia can take a toll on the caregivers’ health (Butcher, H. 2002; Family Caregiver Alliance website, 2008; McClendon, M. et al., 2004; Quinn, C., 2008; Vellone, E. et al., 2007). Literature pertaining to Sandwich Generation caregivers also suggests the dual roles can have a negative impact on the caregivers’ health (Johnson, G., 2008; Riley, L. & Bowen, C., 2005; Williams, C., 2004; Kwok, H., 2006; Petrovich, A. 2008; Chassin, L. et al., 2010). “Multigenerational Caregiving and Well-Being: The Myth of the Beleaguered Sandwich Generation” (Loomis, L. & Booth, A., 1995) was the only article found that disputed the suggestion that caregivers in the Sandwich Generation were at risk for health problems. The research used a 12 year longitudinal study of *Marital Instability Over the Life Course* by Booth, et al. (1991) the results of the study suggest that because there was not a decrease in marital quality, psychological well-being, financial resources, or satisfaction with leisure time in a large national sample Sandwich Generation caregivers’

well-being is not jeopardized. There has been no replication of this study and no other studies support this finding.

Themes from a study by Iwasaki, et al. (2005) using phenomenology as the analytical framework resonated in this study. “Building on strengths and resilience: leisure as a stress survival strategy” (2005) identified “*creation of a leisure space, leisure palliative coping, and leisure as balance*” as themes to understand the experience of using leisure as a method for managing stress. The themes connected and overlapped with themes from the current study. “*Creation of a leisure space*” explains that people designate physical or psychological distance from stress. A participant articulated leisure was an opportunity to escape “always giving” (p.91). This is similar to “*structured relief*” in which time is taken to generate and renew energy away from the care-receiver. “*Leisure palliative coping*” and “*leisure as balance*” emphasize the importance of leisure as a means to create a “*balanced perspective*” and promote “*positive power*”.

Caregivers of a person with Alzheimer’s Disease defined quality of life as being “serene and tranquil”, having “freedom” and “general well-being” and noted that “independence” and “more help” would improve quality of life for them (Vellone, et al., 2007, pp. 225-226). This is consistent with the themes that emerged in the current study. Serenity and tranquility are difficult to grasp in “*reconciling life transitions*” due to the adjustment of constant uncertainty. Serenity and tranquility were described in contrast to life before caregiving. Before caregiving, they felt tranquil and serene but have not felt so since assuming the caregiving role as a result of the constant worry caused by the illness. Freedom in the Vellone, et al. study (2007) encompassed more than the freedom to do “leisure activities or things for themselves” (p.226), it incorporated having a free mind, free from the guilt of leaving the care receiver behind. The description of freedom as a measure of quality of life overlaps with the thematic statements “*balancing guilt and grief*” and “*crushing time and emotional pressure*” where the freedom to take time for self without guilt is impeded. The caregivers in this study were spouses, adult children, family

members or friends. The lack of homogeneity was cited as a limitation of the study. The homogenous population of the current study can be considered a strength.

Quinn, et al. (2008) studied the lived experience of caregiving for a spouse or partner in the early stages of dementia. The early stages comprise an important juncture in which to develop coping skills (McKee, et al., 1997; Quinn, 2008). Motenko (1989) suggested caregivers' angst has more to do with the upheaval in their own lives than with the disease itself and this is more pronounced in the early stages of the caregiving journey when time adaptations peak. The essential themes in the Quinn, et al. (2008) study emerged as "*Don't know what that is; Changes in the relationship; Doing the best we can and It's not all plain sailing.*" Descriptive expressions echo sentiments in the current study, for example, "There's been a change in roles..." "I'm real responsible for everything that happens..." (p. 772) which correspond with responses in "*crushing time and emotional pressure.*" Within the sub-themes "*You cope in different ways*" and "*Support*" contain participant statements that are comparable to those in "*Humor as a stabilizer*" and "*Garnering support*" such as "We often laugh about the silly things he has done..." "...you realize that you are not alone." (p. 773). Participants' access to social services was cited as a limitation of this study which is also a limitation of the current study as it does not represent the experiences of persons who do not have access or are unaware of available resources.

Butcher, et al. (2001) included spouses, adult children and siblings in their research of the lived experiences of dementia family caregivers. The interviews came from secondary analysis from a previous longitudinal study. There were eight Essential Structural Elements (the nomenclature of van Kaam (1966)) that emerged from the interviews—*Enduring stress and frustration, Immersed in caregiving, finding meaning and joy, Integrating ADRD into our lives, Moving with continuous change, Preserving integrity, Gathering support, and Suffering through the losses.* There are overlapping elements in the themes of the current study and this study. The overwhelming emotional

expectations and time commitments and the constant weighing on the mind represented in “*Enduring stress and frustration*” ring in “*Reconciling life transitions and Succumbing to infinite obligations*” of the present study.

It is hard, working seven days a week, twenty-four hours around the clock for three or four months without time off. Just kind of stressed out...it is always in the back of your mind..”
(Butcher, et al., 2001, p. 45)

“*Moving with continuous change*” also resonates in “*Reconciling life transitions*” . “You never know when it’s going to happen, when you are going to take the next big slide.” (Butcher, et al., 2001, p. 48). “*Constructing a foundation*” resounds in “*Gathering support*” “There are a lot of people here and they are all willing to help” (Butcher, et al., 2001, p. 48).

Humor as a stabilizer is supported in a study by Miller (UMMC, 2009) which suggests that laughter is beneficial for heart health. The research studied the effect of emotions on the endothelium. The endothelium has a primary role in regulating blood flow, effects blood vessel tone, controls coagulation and blood thickening and releases chemicals that respond to injuries and infection (UMMC, 2009). Compromised endothelium impacts the development of cardiovascular disease and caregivers are at greater risk for cardiovascular disease (Lee, et al, 2003). One group of participants were shown movies that were meant to be funny like “King Pin” (MGM, 1996) and one group of participants was shown the movie “Saving Private Ryan” (DreamWorks, 1998) which was meant to cause distress. On average, laughter produced a 22% increase in blood flow and emotional distress produced a 35% decrease in blood flow. Increased blood flow is a factor in maintaining healthy endothelium. Miller states (UMMC, 2009), “At the very least, laughter offsets the impact of mental stress, which is harmful to the endothelium.”

Implications for Research and Practice in Therapeutic
Recreation

A phenomenological study by Lindsey, (1996) “Health within Illness: experiences of chronically ill/disabled people” focuses on a person’s capabilities rather than deficits. While this research does not investigate the same population as the current study, the researcher found a structure to guide the implications for research and practice in TR. TR’s fundamental philosophy is to concentrate on strengths instead of weaknesses. Focusing on assets fosters a sense of control. “...an internal locus of control is positively related to well-being.” (Green, S., p. 24).

Aspects of control emerged in all themes in the present study. In “*Reconciling life transitions* and *Succumbing to infinite obligations*” the overwhelming expression was a loss of control. In “*Time shifts* and *Constructing a foundation*” remnants of personal control surface. In “*Revisit control* and *freedom to recreate*” the ability to retrieve control helps alleviate pressure in the caregiving role. Leisure is both a means and an end (Mobily, 2007). for achieving a sense of control.

Hunnicut (2007) describes leisure as a sphere to establish serenity, leisure is an “opportunity to escape the maddening crowd, to find tranquility...” (p. 12). Vellone’s, et al. (2007) study indicated serenity and tranquility were elements of quality of life that caregivers no longer had as a result of caregiving. Participants in the current study expressed leisure as a method of “escape”, a “way to relieve stress” and a “break from responsibility.” It was revealed throughout the course of each interview that most did not allow or appreciate how essential time for self was for their own health at the beginning stages of their role as caregiver.

Guilt (Vellone, E., et al., 2007; Quinn, et al., 2008; Salin & AStedt-Kurki, 2007) and the feeling that obligations were too copious often impeded participants’ ability to create time for self. The study by Quinn, et al. (2008) elucidates the benefit of developing good coping skills at the beginning of the caregiving journey. Coping skills

help buffer the effects of stress. TR offers a modality in which to introduce leisure as a means of coping.

Research suggests (Fitzsimmons, S., 2006; Beadini, 2002; Beadini & Guinan, 1996) caregivers want more leisure, however, they do not self identify and they “try to quietly do what they can”(Beadini, 2002, p.29). A participant in this study stated she wished there was a “place to go” that told her what to do like the American Academy of Pediatrics does for children so she didn’t waste so much time. “...caregivers often receive little information or support at the time of initial diagnosis, either about the condition or the resources available to them...” (Quinn, et al., 2008, p. 769). One component of TR is leisure education. An important goal of leisure education is to help people learn what resources are available. Making TR accessible in the early stages of caregiving can have a positive long term affect on caregivers’ health and well-being by introducing leisure as a tool to improve coping skills and leisure education as a method for locating existing resources.

Implications for TR practice include two important elements. First, TR professionals must recognize the time pressure for this population. Beadini (2002) suggests parallel recreation opportunities for caregivers and care receivers. Sandwich Generation caregivers need recreation opportunities for their children as well. Second, the constant uncertainty of the disease combined with time pressure inhibits a sense of control for caregivers. TR professionals should emphasize breaks that help establish personal control. The Broaden and Build Theory of Positive Emotions (Fredrickson, 1998, 2001, 2003) asserts positive emotions help build intellectual, physical, social and psychological resources. Leisure is an avenue for creating positive emotions and the positive emotions will help strengthen personal resources which may facilitate a sense of control.

Personal Reflections

Shortly after I finished the sixth interview for this study, I experienced complications with my pregnancy and my son, Finn, was born eight weeks early. This happened during my oldest son's, Jake, first week of Kindergarten. I was not prepared for the intense guilt, fear and exhaustion that came with trying to juggle the needs of a fragile baby and a son navigating a new adventure. Everything in my life was put on hold for the last six months, including this project, so I could just be a mom.

Petrovich (2008) explained that when she had to make difficult decisions regarding her father's care, she looked to her fellow social workers to keep her true to her father's wishes. I worked as a Recreation Therapist in the hospital with moms who had babies in the NICU, it is a humbling experience to be the patient instead of the therapist. My TR friend checked on me and encouraged me to come to activities. I, initially, did not have the energy. The things that did help me cope were walking Jake to school and laughing along the way, sleeping in my own bed, long hot showers, holding Finn, listening to podcasts on my iPod to drown out the beeps and alarms of the NICU, and eating loads of chocolate. All activities I consider leisure. When I garnered the energy to attend an activity in the NICU, I met my friend Jennifer. We have helped each other through many meltdown days over the last six months. Like Anne Petrovich, I depended on TR, my profession, to pull me through the most difficult experience of my life.

The experience of having to balance the needs of my fragile baby and my oldest son, undoubtedly influenced the descriptive expressions I chose and the way I interpreted the data for this study. It is not possible to separate one's history, values and experiences (Gadamer, 1976; Koch, 1994). As I conducted the data analysis, Dr. Butcher reviewed the thematic statements and themes to ensure I stayed true to the intent of the descriptive expressions.

APPENDIX A

IRB APPROVAL MEMO

IRB ID #: 200902744

To: Lisa Schumacher

From: IRB-02 DHHS Registration # IRB00000100,
Univ of Iowa, DHHS Federalwide Assurance # FWA00003007

Re: THE CAREGIVER'S JOURNEY: A PHENOMENOLOGICAL STUDY OF THE
LIVED EXPERIENCE OF LEISURE FOR SANDWICH GENERATION
CAREGIVERS WHO CARE FOR A PARENT WITH DEMENTIA

Approval Date: 03/22/09

Next IRB Approval

Due Before: 03/22/10

Type of Application:	Type of Application Review:	Approved for Populations:
<input checked="" type="checkbox"/> New Project	<input type="checkbox"/> Full Board:	<input type="checkbox"/> Children
<input type="checkbox"/> Continuing Review	Meeting Date:	<input type="checkbox"/> Prisoners
<input type="checkbox"/> Modification	<input checked="" type="checkbox"/> Expedited	<input type="checkbox"/> Pregnant Women, Fetuses, Neonates
<input type="checkbox"/> Exempt		

Source of Support:

This approval has been electronically signed by IRB Chair:

Janet Karen Williams, PHD

03/22/09 0526

APPENDIX B

POSTER

RESEARCH STUDY

A researcher in the UI Department of Leisure Studies is conducting a study about caregivers in the "Sandwich Generation".

Are you a caregiver for a parent with dementia?

Do you also have a minor child who lives with you?

If you would like to participate in my study,
your involvement will consist of
an interview at a
location convenient for you
to talk about your experience.

Please contact me at: lisa-schumacher@uiowa.edu
or 319-400-0628

APPENDIX C

SCRIPT

Phone/email Script to Determine Eligibility

Hello _____. Thank you for your time. In order to determine if you are eligible to participate in this study, I need to ask you a couple of questions.

1. Do you have a parent who is diagnosed with some form of dementia?

Yes

No

2. Are you responsible for helping that parent with activities such as:

Yes No

_____ _____ **Grocery Shopping**

_____ _____ **Laundry**

_____ _____ **Taking medications**

_____ _____ **Making health care decisions**

_____ _____ **Making financial decisions**

_____ _____ **Eating**

_____ _____ **Bathing**

_____ _____ **Providing (or arranging for) transportation
to appointments**

3. Do you have a minor child who is dependent on you?

EXCLUDED - I am sorry but based on this information you would not be eligible for our study. We are looking for (GIVE REASON FOR EXCLUSION). Thank you for your interest in the study.

ELIGIBLE - Based on this information you are eligible for the study. I will mail you the consent information for this study. Please review this form for additional information and a more detailed description of the study. We can schedule a time for me to meet with you now or, if you prefer, you can contact me after you have reviewed the consent information and we will schedule the time then. My contact information is in the consent form.

May I have your mailing address (e-mail address) to send you the consent document.

Name

Date

ADDRESS:

DATE FORM MAILED:

APPENDIX D

GROUP PRESENTATION

Hello.

I am a graduate student in Recreational Therapy at the University of Iowa. I am doing a study on the experiences of caregivers, specifically, caregivers who are caring for a parent with dementia as well as a minor child.

I want to learn about your day to day experiences. I understand that people in your situation have very little time to spare. If you agree to participate, all that will be asked of you is to talk to me about your experience. The conversation will be informal and at a place and time of your choosing. I do not expect it to take more than an hour to two hours.

Your participation is voluntary. Your responses and information will be kept confidential.

The goal of this study is to learn more about the unique experiences of “sandwich generation” caregivers so more can be done to help you.

I have brought “Consent to be Contacted” forms. If you would like to be contacted to learn more about the study, please fill out the form and leave it in the envelope provided.

Thank you for your time.

APPENDIX E

CONSENT TO CONTACT FORM

CONSENT TO CONTACT

I _____ give Lisa Schumacher
permission to contact me about the “The Caregiver’s Journey” study.

I understand this does not obligate me to participate in the study. By providing my name
and contact information, I agree to be contacted by the researcher to learn:

- about the details of the study
- if I qualify for the study

Name

Date

APPENDIX F

INFORMED CONSENT DOCUMENT

Project Title: The Caregiver's Journey: A Phenomenological Study of the Lived Experience of Leisure for Sandwich Generation Caregivers Who Care for a Parent With Dementia

Principal Investigator: Lisa A P Schumacher, BS, CTRS

I invite you to participate in a research study. The purpose of this research study is to gain a better understanding of how leisure is experienced by sandwich generation caregivers of someone with dementia. This study is a small step in understanding the unique experience of sandwich generation caregivers who care for a parent with AD/DRD.

I am inviting you to be in this study because you are a caregiver for a parent who is diagnosed with dementia and also have a dependent child in your residence. Approximately 10 people will take part in this study at the University of Iowa.

If you agree to be in this study, your involvement will consist of a single interview that will last approximately one to two hours. I will schedule the interview at a time and place that is mutually convenient. You may be contacted by phone after the interview with questions to ensure that I accurately interpreted the information gained in the interview. The follow up phone call may last 5 minutes to 15 depending on the amount of information that needs clarification.

During the interview I will ask you to describe your experience of time for yourself, as you care for your parent with dementia, while raising a family. I will audiotape the interview. The audiotapes will help the researcher capture your responses and will only

be used for research purposes. The audio recording will be identified by an ID number and will not contain any personal identifying information about you. All audio tapes and the transcriptions will be destroyed after the study. You may be in the study without agreeing to the audio recordings. I will ask you at the start of the interview and before starting the recorder whether or not you agree to the recording

You are free to skip any questions that you would prefer not to answer during the interview and the follow-up phone call.

We will keep the information you provide confidential, however federal regulatory agencies and the University of Iowa Institutional Review Board (a committee that reviews and approves research studies) may inspect and copy records pertaining to this research. To help protect your confidentiality all forms will be kept in a locked file cabinet.. The audio tapes and the transcriptions will be locked in the same filing system. All study computer data will be kept in password protected computer files. We will use a false name and not your real name to identify your study information. Your study name will not be linked to your real name. All information will be destroyed at the end of the study. No identifiable quotations will be used in any papers or reports of this study. If we write a report about this study we will do so in such a way that you cannot be identified.

You may be uncomfortable talking about your experiences as a caregiver and parent with the researcher. You may skip any questions you do not wish to answer and you may end the interview at any time You will not benefit personally from being in this study. However we hope that others may benefit in the future from what we learn as a result of this study.

You will not have any costs for being in this research study. You will not be paid for being in this research study.

Taking part in this research study is completely voluntary. If you decide not to be in this study, or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify.

We encourage you to ask questions. If you have any questions about the research study itself or to report a research related problem, please contact: Lisa A P Schumacher at (319)335-3372, or email lisa-schumacher@uiowa.edu or Rich MacNeil at (319)335-9179, or email richard-macneil@uiowa.edu.

If you have questions about the rights of research subjects, please contact the Human Subjects Office, 300 College of Medicine Administration Building, The University of Iowa, Iowa City, IA 52242, (319) 335-6564, or e-mail irb@uiowa.edu. To offer input about your experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above.

If you agree to be in the study, please contact Lisa A P Schumacher at lisa-schumacher@uiowa.edu.

APPENDIX G

QUESTIONS TO GUIDE THE INTERVIEW

- Can you please tell me how long you have been a caregiver and how you chose to take on that role?
- Is there anything you do to escape the pressure from all of this responsibility?
- What is your experience of time for yourself as you care for a parent with dementia while raising a family?
- If your attitude about time for yourself has changed since you became a caregiver, please describe the change.
- Please describe your experience when your caregiving obligations and your parental responsibilities conflict with time you have planned for yourself.
- Please describe how you feel about the control you have over your life as a caregiver.
- Please describe how you feel about balancing your parent's needs and your child's needs.
- Please describe how you feel about caring for your own needs. How does your body react if you do not?
- Is there any activity you do that allows you to be spontaneous?
- Do you have anyone that you can laugh with?
- Is there anyone in a similar situation that you can talk with? Is there anything I have forgotten that you would like other caregivers to know?

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