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A PHENOMENOLOGICAL EXAMINATION OF THE CAREGIVING EXPERIENCE
OF
ELDERLY SPOUSAL CAREGIVERS

by Christine Moghimi
A Dissertation
presented to the faculty of
Towson University
in partial fulfillment
of the requirements for the degree

Doctor of Science in Occupational Science
Department of Occupational Therapy and Occupational Science
Towson University
Towson, Maryland 21252
(May 2012)

TOWSON UNIVERSITY
OFFICE OF GRADUATE STUDIES
DISSERTATION APPROVAL PAGE

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Entitled: A Phenomenological Examination of the Experience of Caregiving in a Sample of Elderly Spousal Caregivers

has been approved by the thesis committee as satisfactorily completing the dissertation requirements for the degree Doctor of Science in Occupational Science

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ACKNOWLEDGEMENTS

I would like to thank Dr. Regena Stevens-Ratchford for all of her help, patience and guidance in getting me through this incredible journey. I would also like to acknowledge all of the support and advice from my peers, faculty of the Occupational Therapy/Occupational Science program and the committee members. Lastly, I would like to acknowledge my dear family for their understanding and encouragement all along the way, and most importantly, for their unwavering belief that I could do this.

ABSTRACT

A Phenomenological Examination of the Caregiving Process in a Sample of Elderly Spousal Caregivers

Christine Moghimi

Problem

Older adults with chronic illness often require extensive informal care. Informal care generally is provided by family members, and increasingly, elderly spouses. Providing care to a loved one has the potential to last for weeks, months, and in chronic illness management, even decades. The literature has shown that there can be great burden and stress in the occupation of spousal caregiving. The purpose of this study was to examine the caregiving process in a sample of informal elderly spousal caregivers caring for a chronically, medically ill spouse. In order for occupational therapists to assist elderly spouses in their caregiving occupation, they must have an in-depth knowledge and understanding of the caregiving experience.

Methodology

A qualitative phenomenological approach was utilized to provide an in-depth look at the elderly spousal caregiving process. Research questions in this study explored the culture, occupation, successful aging and occupational justice in elderly spousal caregiving.

Data was collected from a purposive sampling of five elderly spousal caregivers through a series of four long interviews that were audio taped and then transcribed. Statements were transformed into clusters of meanings. The data analysis process transformed these clusters to make a general description of the experience for each participant including a textural description, a structural description and finally a textural-structural synthesis.

Conclusion

Four themes emerged from the data: the culture of elderly spousal caregiving is one of forced self-reliance; the occupation of elderly spousal caregiving centers around concern for safety; elderly spousal caregiving challenges one's ability to age successfully and elderly spousal caregiving is an unjust occupation. Elderly spouses committed themselves to caregiving when their loved one needed help in the home. The caregiving occupation involved advocacy, multiple interactions with formal healthcare and challenges to physical and emotional capabilities. Elderly spouses learned through trial and error, were isolated and confined, and were often the sole provider of care. Clinical considerations included a population-based approach for occupational therapists with the intent of a triad approach to care: therapist, patient and caregiver.

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Chapter One

Introduction

Research problem

The Rosalyn Carter Institute for Human Development states, “There are just four kinds of people in the world: those who have been caregivers; those who are caregivers; those who will be caregivers; and those who will need caregivers (Talley, 2004, p.13). Providing care to a loved one has the potential to last for weeks, months and in chronic illness management, even decades. The literature showed that there can be great burden and stress in the occupation of elderly spousal caregiving. Such burden and stress can be due to a variety of factors including: the complex and difficult care that needs to be provided; the caregiver’s advanced age and health status; the chronic condition of the care recipient; inadequate training and education on caregiving and the constant fear that caregivers can have over the safety and health of the care recipient. The presence of caregiver burden can be devastating and can negatively impact the health of both the care recipient and the caregiver (Elliot, 1998). Many recent clinical studies showed that long-term family caregivers are at high risk for sleep-deprivation, immune system deficiency, muscle and joint problems, depression, chronic anxiety, loss of concentration and premature death (Sheehy, 2010).

The family caregiving process can be described as a set of actions, routines and functions that bring about the act of caregiving. In chronic illness management the caregiving process usually begins with an acute episode and hospitalization and includes provision of services from both formal and informal caregivers. Formal caregivers are paid for their services and they include physicians, nurses, a variety of therapists and aides. Informal caregivers provide care for no pay and are most often close family members. The purpose of hospitalization and in-patient rehabilitation is to utilize formal caregivers to help the patient regain medical stability as well as restore physical and mental function. At the end of the hospital course, when discharged to the community, it is the informal or family caregiver who is often providing most or all of the needed care and support. Family caregiving then evolves into an occupation defined as the act of providing unpaid assistance and support to family members who have physical, psychological or developmental needs (Caregiving, 2004).

If individuals who have chronic illnesses are to be successful in their recovery and rehabilitation and experience a good quality of life then caregiver burden and stress need to be lessened. By exploring further the lived experiences of family caregivers, health care practitioners, particularly occupational therapists, could broaden their understanding of the complexity of family dynamics and the caregiver occupation. Health care practitioners could then develop specific, targeted strategies to enable and support family caregivers for all that they do, increasing their quality of life as well as that of their families.

Background

A caregiver is defined as an individual who cares for and/or assists a disabled, ill or

frail family member, spouse or friend (Corradetti, 1998). The occupation of caregiving includes the physical and emotional activities that enable the care recipient to have some degree of comfort and function with greater quality of life. Currently there are 42.1 million unpaid caregivers in the United States helping adults aged 18 or older (Caregiving, 2009). Half of the current caregivers are totally new to their occupation, having provided no help at all to their care recipients prior to hospitalization (Caregiving, 2004). To the best of their ability these caregivers are carrying out the care, support and rehabilitation for ill relatives that was initiated in the hospital; providing such care activities as feeding, bathing, dressing, medication management and toileting. Many caregiving activities require more clinical skills than are usually expected of lay people, i.e., wound care; tube feeding and catheter care. As Sheehy (2010) stated, the new family caregiver is expected, overnight, to take on roles performed in the hospital by three shifts of skilled professionals: from the dietician to the IV nurse, to the visiting specialists and resident doctors. If this care was provided by government services, it would be worth approximately \$450 billion annually (Caregiving, 2009).

Much of the recent literature on caregiving has focused on the burden and stress family caregivers often experience. As the caregiving demands increase so do the risks of experiencing caregiver burden. Family caregivers who provide round-the-clock care can experience fatigue and burn out from the constant demands of meeting the care recipient's physical and emotional needs. Caregiver burden is defined here as the extent to which caregivers perceive their emotional or physical health, social life and financial status as suffering as a result of caring for their relative (Zarit, 1987). Symptoms such as decreased morale and life satisfaction, decreased immune functioning, decreased heart

rate activity, increased blood pressure levels and even mortality appear in various studies of care giver burden (Evans, 1992; Dilworth-Anderson, 2004; Given, 2004; Kurtz, 2004; and Grant, 2004). Depression is also a common measure in many family caregiver studies. Depression of the caregiver can worsen the depression of the care recipient and create poor responses in rehabilitation (Connell, 1999; Given, 2004; Kurtz, 2004 and Grant, 2002). Family caregiver needs and the burden they experience still remain poorly understood because there has been little qualitative research in the complex, multilayered phenomenon of family caregiving. No current simplistic survey instrument captures all the important dimensions and variables of the family caregiving experience (McCullagh, 2005).

Caregiver perceptions and assessment of caregiver burden have appeared in the literature in the last few years. Caregiver perceptions of their own abilities, as well as adequacy of support may influence the presence of burden. Pro-active assessment of caregiver characteristics and support networks, prior to care recipients' discharge from formal care, could also minimize the presence of burden (McCullough, 2005 and Van Exel, 2005).

Adding to family caregiver burden is the lack of thorough caregiver training and education. Some studies found that carers were dissatisfied with the lack of information and support, post-discharge, from healthcare professionals (Law, 1998). Caregiver education can often amount to a set of verbal instructions that is delivered within hours of the patient's discharge from formal care. This leaves little time for questions or practicing the skills and activities the caregiver is expected to accomplish (Wilkins, 2001). Studies show that increased healthcare information and training can lessen the

burden and increase the confidence and coping skills of caregivers for better outcomes (Bar-Tal, 2005; Curry, 2006 and Kalra, 2004).

What may explain the lack of training/education and information offered to informal caregivers by healthcare professionals is a culture clash. Culture can be defined as the set of values, concepts, practice and beliefs shared by members of a group. Family caregivers and health professionals bring different priorities and assumptions to the care of an ill person: they are both experts but in a different way. For example, the dominant medical culture today places high values on cognitive and technical mastery, technology, scientific evidence and hierarchy. Family caregiver priorities in caring for the chronically ill are often toward actions that build or sustain relationships (Levine, 2004). This clash of cultures results in lack of mutual respect and the result is often conflict and misunderstanding, adding to the burden and stress of family caregiving.

Family caregivers tend to underutilize formal health and human services that are available to them (Grant, 2004 and Care giving, 2004). Caregivers were about five times more likely to express interest in a service rather than using one (Laditka, 2001). Yet many unmet needs of carers are chronicled in the literature. These needs include social support, coping strategies, problem-solving, learning how to talk with doctors, time for self, continued participation in valued activities and interests, balancing needs of family and more specific education and training in day to day management of the care recipient (Brereton, 2000; Coradetti, 1998 and Chambers, 2001).

While there are concerns regarding caregiver stress and burden, healthcare providers also need to recognize and help build upon the positives of family caregiving. Many caregivers are motivated to help others by feelings of affection and obligation. Studies

have looked at motivations, altruism and spiritual contexts of taking care of loved ones (Lopez, 2005; Hudson, 2004 and Feeney, 2003). Caregivers have reported a sense of fulfillment in being able to manage the situation and develop a closer relationship with the care recipient and other family members (White, 2003). Caregiver satisfaction is noted to be associated with a previous affectionate relationship between caregiver and care recipient, fulfillment of the occupation of care giving by one's own initiative and the ability of the caregiver to maintain some leisure time for self (Lopez, 2005).

While the average age of a family caregiver is around forty-eight (Caregiving, 2009), many spousal caregivers today are sixty years of age and older. Aged caregivers of spouses with chronic illness can encounter particular challenges to their own health and well-being that can negatively impact their ability to provide care. For example, activities that an older spousal caregiver may engage in to keep mind and body healthy, such as exercise, social outings and routine visits to the doctor can be disrupted or diminished by the daily demands of caregiving. Such an imbalance of activity can result in poor quality of life and inability to age successfully. Rowe and Kahn (1999) defined successful aging as more than absence of disease and more than maintenance of functional capacities. Successful aging is the combination of both with an active engagement with life. Elderly spousal caregivers are at great risk for decreased physical health, depression, accidents and even death.

Many care giving studies have been funded recently by large organizations, such as the National Alliance for Caregiving with the American Association for Retired Persons (Caregiving, 2004, 2009) and the Rosalyn Carter Institute with the University of Florida (McKune, et al, 2005). These studies have presented comprehensive overviews on the current condition of family caregiving in the United

States as it affects the economy, society and culture. These types of studies utilize massive amounts of data in their presentation in order to educate society about the overwhelming demands placed on today's caregivers and the pressing need for the community to support them for the well-being of the patient, caregiver and our healthcare system.

Recognizing and providing for the occupational needs of individuals and communities as part of a fair and empowering society is the definition of occupational justice. It is vital that society enables family caregivers to flourish to their greatest potential individually and as members of their community. Occupational injustice occurs when people are disempowered, deprived, alienated or restricted (Wilcock, 2005). As a result, individuals are unable to meet basic needs, find satisfaction or experience well-being through their occupations in a society that appears not to value what they do. Many family caregivers can experience disempowerment and deprivation from not having a voice or power in navigating the healthcare system. And family caregivers can experience alienation from health experts who don't value their opinion and from a society who doesn't fully value their sacrifice and commitment to care for loved ones in the home.

Occupational therapists have made important contributions to the caregiving literature over the years (Curry, 2006; Gitlin, 2003; Crowe, 2002 and Hasselkus, 2007). The occupational therapy literature addresses the challenges for caregivers and care recipients and the provision of education, training, and skill building that can decrease burden and increase well-being (Clark, 1995; Olson, 2000 and Moghimi, 2007).

Suggestions in the literature for future research include a closer study into the type of support caregivers with different health problems and in different care giving situations need and desire (Van Exel, 2005). There is a need for a responsible strategy to support caregivers in adapting to and managing their new role and how that role is determined among family members (Connell, 2004 and Faison, 1999). Further studies should be conducted to provide more data to give a comprehensive picture of what caregivers actually do, i.e., the full range and complexity of caregiver tasks (Levine 2004). Also more qualitative work is needed to provide the depth and diversity to the experiences of spousal caregivers.

Purpose statement

The purpose of this study was to examine the caregiving process in a sample of informal older adult spousal caregivers who were caring for a chronically medically ill spouse. In the present study these care actions occurred in the home setting. The spouse that provided the care was referred to as the caregiver. Caregivers provided care to address the emotional and physical needs of chronically ill older adults. Chronically ill referred to those individuals who were frequently hospitalized and who had one or more chronic illnesses including chronic obstructive pulmonary disease (COPD), diabetes, Parkinsons, peripheral vascular disease (PVD), hypertension (HTN), multiple sclerosis, Alzheimer's disease and congestive heart failure (CHF). Because of new technologies and treatments in medicine and pharmacy most life-threatening diseases, including cancer, are now turning into chronic conditions (Sheehy, 2010). Chronic illnesses can result in impairments which are problems in body function or structure and activity limitations which are defined as difficulties encountered by an individual in executing a

task or action in which the older adult is no longer able to meet their care needs: hence they require a caregiver.

Importance of this study

As Sheehy (2010) stated, more and more the family caregiver is the backbone of our present health-care system and there is a movement in this country to increase the recognition and support for these caregivers. This movement includes advocate agencies, healthcare professions, local and state governments and the caregivers themselves. This urgency for recognition and support is witnessed in professional/research studies, multiple web sites, conferences and even articles in popular literature such as women's magazines.

In the near future, occupational therapists and occupational therapy assistants may well be functioning as caregiver trainers as the population ages and the formal healthcare system is stretched to its limit. Therefore occupational therapists need to increase their knowledge and understanding of the caregiving occupation and all that this occupation encompasses. And, due to the nature of the professional training, occupational therapists need to develop interventions that support, educate and train caregivers. These interventions will enable caregivers to become not only more equal members of the formal healthcare team but also become more successful and satisfied in caring for themselves, even as they care for others in need.

Research questions

This study was guided by the following central questions:

- 1). What were the experiences of care givers?
- 2). What was the meaning of care giving?

Sub-questions that were considered included:

- a). What was the culture of care giving?
- b). What was the occupation of care giving?
- c). How did care giving impact successful aging?
- d). What were the dimensions (extent) of occupational justice in the care giving process?

This study led to better understanding of the caregiving process, and the opportunities available for closer collaboration between informal and formal caregivers.

Chapter Two

Literature Review

Introduction

Older adults with chronic illness often require extensive informal care. This informal care generally is provided by family members. Such care giving constitutes an obligation that family members undertake in spite of having little knowledge, preparedness and support for meeting the broad range of medical, physical and emotional care that older adults with medically and psychologically complex conditions require. Family caregivers accept this often 24/7 obligation of care routines in addition to their existing occupational routines. The care routines can invoke self-sacrifice and selfless giving that is often unrecognized and unsupported by the formal health care system.

From an occupational science perspective this chapter examined the spousal caregiving occupation and its relationship to health, quality of life, social structures and policy. Occupational Science involves studying the person as an “occupational being,” exploring the nature of occupation (work, play, leisure, self-maintenance and sleep) and the processes involved in orchestrating daily activities in order to remain healthy, obtain satisfaction and achieve good quality of life (Hanna, 2002). Wilcock (1998), Yerxa (1998) and Law (1998) have established that there is a relationship between occupation, health and well-being.

The present literature review explored the complex nature of family caregiving and the related literature in order to establish a background and foundation for better

understanding of the family caregiving process and occupation as well as its effect on the health and quality of life of older spousal caregivers.

Framing the Care giving Process in the Context of Occupational Justice

Family caregivers have become the front line of support for ill and disabled relatives and friends. As Olsen (2003) noted, the introduction of PPS for hospitals and growth of managed care organizations have led to the discharge of elders “quicker and sicker” (p.49). While making an important contribution to society by supporting disabled persons at home, caregivers are experiencing significant burden while making many personal sacrifices. The National Alliance for Care giving & the American Association for Retired Persons Study of Care giving in the United States (2004) found that 29% of caregivers help with dressing; 26% help with bathing; 18% help with feeding and 16% assist with incontinence and diapers. Rabow (2004) stated that while caregivers are helping with transportation, shopping, homemaking and financial management, they are also undertaking more and more complex medical tasks. These tasks can include changing ostomy bags, caring for catheters, using feeding tubes, administering injections and providing wound care. Evans (1992) added that in most situations chronic disabilities often thrust caregivers into non-normative activities that compete with and impede the attainment of more normative social, personal and vocational roles. It is not surprising then that Grant (2004) found that caregivers experienced a loss of independence and inadequate time to manage their multiple roles and responsibilities.

Families need information and their own support services to preserve their critical role as caregivers but frequently they do not know where to turn for help. When they do seek

assistance, many community agencies cannot provide adequate supports due to funding constraints and outdated policies (Family, 2009).

Fulfilling the occupation of care giving can be a great struggle and it is work that often goes unrecognized and unappreciated in today's society. With the care giving occupation not being given the support and resources needed for success, family caregivers are experiencing occupational imbalance, occupational deprivation, occupational marginalization or occupational alienation. This terminology belongs to the concept of occupational justice which is defined as recognizing and providing for the occupational needs of individuals and communities as part of a fair and empowering society (Wilcock, 2000).

Occupational justice as a topic appeared in the occupational therapy literature in the mid-'90s. Ann Wilcock and Elizabeth Townsend blended their shared interests in occupation, well-being and social justice. Wilcock (2006) stated that occupational justice grew out of her research on the occupational foundations of human existence, while Townsend (2005) added that occupational justice also emerged from the principles of empowerment and social justice that implicitly inform practices that strive to be client-centered. Different components and research contributions of Townsend and Wilcock eventually led to their collaboration and formulation of the occupational therapy practice framework of occupational justice.

From an Occupational Science perspective it is unjust that the caregiving occupation can negatively affect the emotional, mental, physical health and well-being of the caregiver. Occupations should be health-giving, satisfying and contribute to a good quality of life not a diminished one.

The model of human occupation. The Model of Human Occupation, (MOHO) an occupational therapy practice model, introduced in the early 1980s', has a strong focus on occupation as it addresses the motivation for occupation. Much of the context of this model can be found in today's principles of occupational justice. MOHO is intended for use with any individual experiencing occupational dysfunction such as an elderly spousal caregiver who deals daily with burden and stress.

As occupational science studies the individual as an "occupational being," the Model of Human Occupation, as developed by Gary Kielhofner, is based on the assumption that occupation is a central aspect of the human experience (Miller, 1993). In the MOHO, Kielhofner seeks to account for the performance and organization of occupational behavior in everyday life through studying motivation for occupation; patterning of occupational behavior; performance skills and the influence of environment on occupational behavior. The model has four subsystems: volition, habituation, occupational performance/skill and the environment.

Kielhofner (1997) contends that occupational behavior of the human system is a central force in health, well-being, development and change, which is similar to Wilcock's (2006) notion of occupational justice: humans are occupational beings who need and want to engage in doing, becoming and belonging. When occupational dysfunction occurs it can be recognized when a person is having problems performing, organizing in their occupation and their environment failing to support and expect adaptive behavior (Kielhofner, 1997).

In his Model of Human Occupation Kielhofner (1997) examines motivation for occupation under a volitional subsystem. The volitional subsystem is motivated by the

innate urge toward exploration and mastery. This concept relates to the occupational justice practice framework as, according to Wilcock (1993), occupation is the mechanism by which individuals demonstrate the use of their capacities through achievements that are of value and worth to their society and the world. By their activities people keep demonstrating what they are, or what they hope to be. Humans, according to Wilcock (2006) need and want to engage in occupations for survival, to connect with others and to build communities.

The three areas under the volitional subsystem are personal causation, values and interests. According to Kielhofner, (Miller,1993) personal causation is the sense one has of one's ability to affect and influence one's environment; the degree to which one feels an ability to direct one's own life. Kielhofner emphasizes that values are what one feels are important or right and that a value defines what is worth doing and how one ought to perform as well as what goals or aspirations deserve one's commitment. Further, according to Kielhofner, interests are what one enjoys and prefers doing. Interests are dispositions to find pleasure and satisfaction in occupations and the self knowledge or enjoyment of occupations. These three areas pertain to what one holds as important, how effective one is acting in the world and what one finds enjoyable and interesting. Together this constitutes the content of feelings, thoughts and decisions about engaging in occupations (Miller, 1993).

Concerning volition, spousal caregiving usually is not an occupation of choice; however caregiving that evolves is an occupation created out of a call to action, as well as out of love and concern, as the spouse begins to require more and more care. Caregiving,

because of its urgent and immediate nature, is an occupation that can leave the caregiver lacking the preparation, resources and skills required to perform the job successfully. As this situation is carried out day to day, the individual's personal causation is negatively affected: they may be unable to achieve what they desire; they may under or over estimate their capacities and likelihood of success and so they may make decisions that expose them and the care recipient to danger or failure.

In regards to value, many spousal caregivers do value their new role through feelings of love and obligation toward the care recipient. However feelings of worthlessness can result when caregivers are unable to achieve impossible ideals or find that others do not value what they do. One of the more pervasive effects of taking on the caregiving occupation is disruption of interests. Many pleasurable and health-giving activities are diminished in time and importance as the tasks of caregiving fill up a daily schedule. This can have a negative impact on the physical/mental health of the caregiver.

In the volitional subsystem, Kielhofner (1997) explains humans enact their values, develop interests and fulfill beliefs in self and abilities through their chosen occupations. The Occupational Justice practice framework is based partially on Wilcock's extensive research on humans' relationship with occupation and individuals' right not only to excel in their chosen occupation with the needed resources and tools to ensure their success, but the right also to have health-giving occupations that support healthy, satisfying interests. What caregivers may be experiencing, from an occupational justice perspective, would be described as occupational imbalance and deprivation (little or no time for other interests or occupations).

According to Kielhofner (1997) the patterning of occupational behavior results in routines and lifestyles. Kielhofner contends that in order to be competent, people's occupation must be integrated into the rhythms and customs that make up their physical, social and temporal worlds. These rhythms can be viewed as regular routines that are social positions or roles with behavior expectations. These patterns of behavior and routines make up the habituation subsystem, which includes habits and roles (Kielhofner, 1997). Habits are further defined as latent appreciation tendencies acquired from previous repetitions, operating at a preconscious automatic level and influencing a wide range of behavioral patterns. Habits serve to help keep one's bearings and steer one's behavior (Miller, 1993). Together habits and roles contribute to one's ability to recognize features and situations in the environment and to behave automatically. According to Kielhofner, habits and roles are intertwined in daily life and together they organize routine behavior.

In taking on caregiving, spouses find many of their previous routines are no longer possible or effective. The act of caregiving can place important restrictions and demands on habits because it consumes time and can disrupt as well as shift the priority of daily routines and habits. Caregiving routines can become dissatisfying and prevent the caregiver from living up to their own and other's desires.

Kielhofner (1997) argues that occupational behavior reflects the roles one has internalized. The internalized role is defined as a broad awareness of a particular social identity and related obligations. Roles organize occupational behavior by influencing the manner and content of interactions with others and by requiring routine tasks. Having a

complement of roles gives one rhythm and change between these different identities and modes of participating (Kielhofner, 1997).

With the addition of a caregiving role, one may not be able to meet one's own or other's expectations for the role which leads to role strain and interpersonal conflict. Not living up to a role can affect one's sense of identity and worth, making it difficult to live up to their own and other's needs and expectations.

In Kielhofner's habituation subsystem, fulfilling habits and roles set up a pattern of daily life and routine, a rhythm that can sustain and enable an individual. As the caregiving occupation disrupts established habits and crowds out other important and valued roles, there is occupational injustice. It is in the form of marginalization which speaks to the loss of choice and decision-making power in the occupations in which caregivers participate. According to Townsend and Wilcock (2004) this loss of power is occupational alienation: the lack of opportunity and resources to enable occupational meaning and enrichment.

The performance subsystem includes skills which are the basic abilities for action. Performance refers to spontaneously doing actions required to accomplish an occupation. Kielhofner (1997) identifies three areas of skill: (a) motor (moving oneself and objects in space); (b) process skills (management and modification of procedures); and (c) communication/interaction skills (dealing with and sharing information with others). In order to perform successfully in the occupation of caregiving older adults need training, education and resources to manage the daily tasks and negotiate through and within the healthcare system. Lack of skills and abilities that so many new caregivers

bring to the occupation can render them dysfunctional and in the case of caregiving, can result in negative consequences on both caregiver and care recipient.

Finally, according to Kielhofner (1997), the environment can influence occupational behavior. The environment affords or gives opportunities for performance and it “presses” or requires particular behavior. Physical environment includes the space which the individual engages in the occupation and the objects with which the individual must interact to carry out the occupation. Social groups are collections of persons that occur with regularity and demand certain kinds of occupational behavior (Kielhofner, 1997).

In the occupation of spousal caregiving, physical space can become challenging with architectural barriers that interfere with the caregiving performance, such as too-small a bathroom or having to negotiate flights of stairs. Socially, the caregiving occupation may necessitate removal from groups where the caregiver routinely performed. This can cause frustration and devaluation for the individual.

Occupational therapy practitioners can use MOHO to organize information, guide action and provide a comprehensive view of occupational function, which includes exploration, competency and mastery (Kielhofner, 1997). To be occupationally functional can be defined as meeting society’s need for productive and playful participation and one’s own need for exploration and mastery which enhances volition, habituation and interaction with the environment (Kielhofner, 1997). To be occupationally just, the occupation of spousal caregiving should allow the caregiver to feel and be productive, efficient, trained, educated and empowered to carry out the necessary daily tasks of caregiving in a supportive society.

Social justice as a factor of occupational justice. Social justice is a very broad term, Braveman & Suarez-Balezar (2009) explained, and it encompasses several interrelated concepts such as equality, empowerment, fairness in the relationship between people and the government, equal opportunity and equal access to resources and goods. Put more simply social justice can be conceptualized as a process and a goal; where the goal is full participation of all groups with a society constructed to meet everyone's needs (Adam, Bell & Griffin, 1997). Townsend (1993) defined social justice as the belief that societies are to be governed justly; being guided by a set of ethical, moral and civic principles that are associated with fairness, empowerment and equitable access to resources. Townsend added that there is also a sharing of rights and responsibilities.

Townsend (1993) believed that the practice of occupational therapy was founded on social and political activism. Townsend contended that occupational therapy's language, ideas and practice are similar to civil rights, feminist, ethnic, gay and lesbian, disability and other social justice movements. Braveman (2009) agreed, having stated that social justice and health disparities have been integral to occupational therapy theory development, by having informed proposed practice interventions regarding the role of occupational therapy in working with communities, populations and society at large. There is increased focus and concern for occupational therapists becoming globally connected and addressing issues of injustice as well as narrowing the gap in health status caused by health disparities (Braveman & Bass-Haugen, 2009). Many goals of social justice are embedded in occupational therapy's philosophy, core competencies, recognized professional beliefs and responsibilities. Specifically, the profession advocates the belief that people are compelled to be productive members of society and

that society has a duty to enable this participation (Paul-Ward, 2009).

The features of social justice. In her work on occupational therapy and social vision Townsend (2003) presented five fundamental features of social justice. All are very applicable to occupational therapy practice and the issues of care giving in this country today. The first social justice feature is recognition that persons have power to act in this world. Social justice in this case can be viewed as a person-centered concept. Townsend (2003) explained that recognition of a person's power to act must begin with a language that conveys respect for persons and that respect can be lacking where there are cultural differences. Townsend further argued that this is why respect has to be supported by public policies and laws which recognize the equal power of persons to act. These notions of social justice are based upon the belief that persons are considered of equal worth and with equal moral right to participate in society regardless of age, socioeconomic class, race, culture, sexual orientation or disability. This notion of power to act and participate in society relates to the care giving process in that caregivers often feel powerless within the formal healthcare system and within their own community. There is a lack of resources and support from the community for caregivers who strive to enable those who are disabled to remain a part of the community (Family, 2009). An injustice to the caregiver is this powerlessness and inability to participate fully and successfully in the occupation of care giving.

The second feature of social justice is the recognition that individuals are not dependent or independent. Rather, they are interdependent. Townsend (2003) suggested that the characteristics of interdependence are determined partially by the visible environment which includes the setting, time of day or number of people present. Also

interdependence is shaped in the invisible environment which is comprised of funding mechanisms, public policies and laws which determine where ideas will prevail in interactions. Each is relying on the other to provide support, education and optimum care for the chronically ill patient. Barriers still exist that are undermining this interdependency including our society's value of individualism and the paternalistic or "expert" attitude of the healthcare system toward the family caregiver.

Interdependency also suggests that persons have the power to collaborate and become partners in sharing power. Townsend (2003) offered that a distributive concept of social justice takes the ethical stance that power ought to be shared. This implies, Townsend believed, that diverse types of "expertise" ought to be recognized as holding equal power in decision making. Distributive justice also refers to provision of resources, access to resources and economic opportunities (Braveman, 2009). Again this kind of collaboration needs to be embedded in budget processes, public policies and laws that will ensure that persons hold equal power in decision making regardless of differences in expertise and ability to participate. This type of partnership is horizontal rather than hierarchical in decision-making. Such partnerships benefit the care giving process to ensure that the caregivers' expertise is heard and respected and that power is equally shared with formal healthcare professionals in regards to decision-making for the care recipient.

The third feature that Townsend (2003) presents on social justice is that social justice can only become a reality through action and reflection in the real world. Action needs reflection to generate knowledge for decisions about the aim of action (Mezirow, 1990). And reflection needs action to implement decisions. Mezirow offers additional thoughts

on reflective discourse through his work on the concept of transformative learning.

Mezirow advised that reflective discourse is the forum for finding “one’s voice” and is a prerequisite for free, full participation. Effective participation in discourse and reflections require emotional maturity which is awareness, empathy and control. Goleman (1998) calls this emotional intelligence; knowing and managing one’s emotions, motivating oneself, recognizing emotions in others and handling relationships- as well as clear thinking. Townsend concluded in this social justice feature of the real world that action and reflection need to occur in order to produce change that is relevant to a person’s real experiences of injustice. For caregivers this may require additional education and training as well as a forum for expression.

The next feature Townsend (2003) discussed was the process of change and its riskiness. This change, if consistent with social justice, would transform inequality into collaborative power sharing. The risk of reflecting on injustice or powerlessness is raising fears, anxiety and resentment about unfairness. The risks of acting in real situations, Townsend explained, can range from loss of personal support to the danger of political and legal sanctions. Yet the energy that is derived from risk taking can have potential for personal liberation from fear and social liberation from inequality. Sometimes this risk-taking behavior emerges because the injustice is so great and anger builds up. Caregivers have begun to unite via some political actions, organizations and websites. The energy that is being produced is finding its way to mass media and political forums in support of the family caregiver.

The final feature of social justice is more of a spiritual concept and practice. It is recognition that persons are of equal worth. Social justice, Townsend (2003) stated, is

about inclusiveness rather than exclusiveness. Diversity is valued and inclusiveness demands unconditional respect, caring, love, trust and value regardless of a person's characteristics and contributions to everyday life. Like the other features inclusiveness would rely on a social vision that is embedded in public policies, economic patterns and laws.

Summary. Townsend (2003) concluded her work on social justice with the acknowledgement that a social vision is difficult to enact in the current practice of occupational therapy that is defined mostly by technology and medicine. Paul-Ward (2009) agreed that professional discourse on social justice suggests more critical work is still needed to sufficiently address the larger societal issues that ultimately affect occupational therapy practitioners' ability to advocate for and with clients. However, occupational therapists do increasingly recognize the need to incorporate a social justice perspective into research, curricula and practice (Paul-Ward). Townsend declared that the potential was there for occupational therapists to work toward a just society with more focus on approaches that are person- centered, interdependence-oriented, enabling and community-driven. When occupational therapy practitioners view the world with a social justice lens, the field is presented with new ways of thinking about occupation, engagement, empowerment, participation and meaning (Townsend, 2003). Occupational therapy's relationship to the care giving process can build upon the social justice potential. Family caregivers are a population in need of empowerment, respect, enabling and recognition. In practice occupational therapists can have the vision that Townsend embraced with social movements oriented toward justice for the occupation of care giving.

Social justice and occupational justice are complimentary ideas which share a common belief in the need for societies which are governed justly by a set of ethical, moral and civic principles. There are considerations in both perspectives for fairness, empowerment, and equitable access to resources and sharing of rights and responsibilities.

However, both Wilcock and Townsend did not feel that social justice went far enough in addressing occupational injustices adequately. The concept of social justice lacked a language or concept that raised awareness about the unfairness of people leading unhealthy, empty, unfulfilling lives. While social justice addresses the social relations and social conditions of life, occupational justice addresses what people do in their relationships and conditions for living.

While Townsend brought the concept of social justice to the occupational justice framework, Wilcock explored the occupational foundations of human existence which eventually led to occupational justice.

Occupational perspective of health. Wilcock (2006) provided a body of work and research that related occupation to health and well-being. Wilcock examined what health is and what it should mean to occupational therapists. Wilcock maintained that there was no better definition of health than the definition provided by the World Health Organization's (WHO) constitution established in 1946. In that constitution, WHO defined health as not only the absence of disease or infirmity but also the experience of total physical, mental and social well-being (1946). Health was recognized as a resource for life not just the objective of living. Health was a positive concept of emphasizing social and personal resources as well as physical capacities. Wilcock based her work on

this ideal and she considered three aspects of health: absence of illness; active aging and well-being.

Health: The absence of illness. Wilcock (2006) in her research of the history of health went back as far as the 5th century B.C. According to Wilcock the Athenian Greek goddess Hygeia was known not for treatment of the sick but rather represented the natural laws. Promotion of the health of the mind and body was believed to be the most important function of health care. Hygeia was a symbol of health and well-being which meant that people would not become ill as long as they lived a balanced life in a pleasant environment. Weil (2004) offered that our word “hygiene” comes from Hygeia and that Hygeia worshippers felt that clean living was the way to good health emphasizing fresh air, good diet, water, light and herbs.

Wilcock (2006) continued her historical examination of health with a discussion of the favored god of healing, Asclepius. Asclepius lived as a physician in 12th century B.C prior to becoming a deity. Asclepius and his followers disagreed with Hygeia’s notion that the promotion of mind and body in the prevention of illness was the purpose of health care. They argued that the most important function of health care was to treat disease, correct imperfections and therefore restore health (Wilcock,).

According to Wilcock (2006) Asclepius’ concept of health and not Hygea’s has been accepted through the centuries and has continued to be the dominant view in modern medicine today. As Hart (2000) noted the influence of the basic medical practices and ethics of the physician worshippers of Asclepius was strong enough to survive not only the decline of ancient Greek and Roman religions but also the adoption of Christianity. During the Renaissance Asclepius’ ancient theories relating to the physical factors that

cause illness were rediscovered and this reawakened the progress of medical science (Hart). Wilcock explained that people in general value healing science more than naturally healthy living and are fascinated with all things related to newest technologies and cures of medical science. Weil (2004) agreed and stated that the rise of scientific medicine with its great triumphs over infectious illness, its successful discoveries of vitamins and life-giving hormones and antibiotics won patients over natural healing. Throughout the first half of the 1900's technology seemed the answer to all humanity's problems including disease (Weil). Wilcock asserted that this belief in healing science, with the aid of modern technology, has fostered the idea that individuals can control their bodies as well as the environment and they expect health and wellness as a right. Wilcock contended that healing science diminishes the appreciation for the holistic nature of the WHO definition of health and as a consequence most resources today are put toward curative illness compared to resources provided for preventative medicine.

As medical science is dominant in approaches to health care today, Wilcock (2006) offered that it is the medical experts who now define for the general public what health is. According to Wilcock occupational therapists and others working within this current medical view are influenced and at times their actions controlled by the dominance of the medical model. Wilcock maintained that occupational therapists have succumbed to the pressures of modern medicine with a routine practice of activities of daily living, techniques, splints and equipment rather than a broader consideration of health in relation to occupation. Therapists offer excuses of having little time in their day and dictates from management; holistic approaches do not easily fit into the current practice or work environment. Kielhofner (1997) acknowledged that occupational therapy had, in recent

decades, adopted the reductionist viewpoint of the medical model which emphasizes the musculoskeletal and neurologic issues underlying the capacity for performance rather than the holistic view which is the foundation of occupational therapy embracing occupation and focusing on mind-body and person-environment unity. Wilcock advocated for occupational therapists to start thinking of people they work with as occupational beings rather than patients or clients.

Wilcock (2006) contended that health is so much more than just the absence of illness. If occupational therapists were to embrace an occupational perspective of health, as Wilcock suggested, then the focus of health care with social and occupational determinants would become much broader.

With this approach to healthcare Wilcock presented some key concerns for occupational therapists to consider. These concerns included living and working circumstances; lifestyles; health implications of economic and social policies; and benefits of investment in health policies. Kronenberg (2005) offered that occupational therapists must develop their roles as agents of social change, taking the profession to a new level that makes a difference to entire communities, as well as to the individuals we treat and encourage. For occupational therapists this broader focus of health care would enable whole populations such as family caregivers to benefit from interventions that seek to facilitate participation and quality of life in occupations that provide meaning, satisfaction and good health.

Health: Active aging. Wilcock (2006) taking the stance that health is more than absence of illness argued that the focus of occupational therapists should be on health maintenance and prevention. She emphasized that occupational therapists should use

individual's occupational potential to promote their health and well-being. Wilcock expressed the importance of utilizing these health approaches in keeping the aging population healthy and fit.

Wilcock's concern for active aging and continued health has been supported by the WHO and the United Nations (UN). At the first UN World Assembly on Aging in 2002, there was recognition of the accumulated wealth of knowledge and experience that makes the aged an asset rather than a liability to society. Society was urged to encourage older people to do what they can and want to do rather than telling them what they can't or shouldn't do. The WHO warned that if aging is to be a positive experience it must be accompanied by improvement in the quality of life of those who have reached or are reaching old age. Based on the UN principles for older people aimed at independence, participation, dignity, care and self-fulfillment, the WHO recommended policies and programs for the aged. These policies focused on the enablement of older people to continue to contribute to society while also preventing discriminatory action that can be counterproductive to well-being. It was also at this U.N. World Assembly that the WHO posed some important questions for society to consider:

- How do we help people remain independent and active as they age?
- How can we strengthen health promotion and prevention policies especially those directed to older people?
- How do we acknowledge and support the major role that people play as they age in caring for others? (United, 2002).

Wilcock (2005) expressed that occupational therapists already have many answers and some expertise regarding these issues. But she questioned whether the profession is active enough to advocate for active aging concerns.

To ensure that aging is a positive and healthy experience, Wilcock (2006) stated that it is imperative for occupational therapists to consider whether occupations provide older people with sufficient meaningful physical, mental and social experiences as well as opportunity to meet their unique needs. Wilcock stressed there is a need to equip older adults with ways to improve the quality of their lives in a manner that will enable them to continue to grow. Wilcock contended that there is great risk to the health and well-being of the aged when their occupations lack balance, are not health-maintaining nor satisfying. As Faber (2001) pointed out in her study on successful aging, the absence of limitations and losses does not constitute one's success at old age; instead success is measured by the way these limitations and losses are integrated into one's attitude toward old age. Successful aging is a process; the successful adaptation to physical limitations and a sense of satisfaction to the person concerned (Faber).

In her research on positive aging Rudman (2006) reviewed the literature describing the emergence and evolution of positive aging discourses using an occupational perspective. The discourses emphasized two main types of occupations for the aged: consumer-based leisure and body maintenance activities. Numerous types of occupations are not emphasized Rudman noted such as caregiving, passive and solitary leisure and volunteering. The author concluded that positive aging discourses are being shaped in

ways that limit occupational possibilities and promote occupational injustice. Continued promotion of occupations for the aged that require substantial financial, health and literacy resources is injustice (Rudman). Active aging concepts need to consider older people with the vision of a fair, ethical and moral society. This relates to social justice in that it claims people should be able to enact aspirations and use their talents as well as engage in daily life tasks regardless of difference in age or indeed of class, gender, race and income (Wilcock, 2006). Since many caregivers are aged it is critical that active aging approaches be implemented now out of grave concern for caregiver health and well-being.

Health: Physical, mental and social well-being. In examining alternative definitions to health besides the absence of illness and understanding the WHO and UN initiatives on supporting active aging, Wilcock (2006) also explored people's perceptions and experiences of well-being. Wilcock contended that people are able to resist disease and seem impervious to many problems and difficulties when they are experiencing well-being. Definitions of well-being vary. In standard dictionaries, well-being stands with words like happiness and prosperity as well as health. Within health promotion, well-being has been described as a subjective assessment of health which is less concerned with biological function than with feelings of self-esteem and a sense of belonging through social integration (Wilcock, 2006). Well-being, Orem (1985) offered, is a perceived state of harmony in all aspects of one's life. It is a state characterized by experiences of contentment, pleasure, by spiritual experiences and a sense of happiness (Orem).

In many of her writings on the subject of well-being, Wilcock (1998) referred to Blaxter's (1990) study in *Health and Lifestyle*, based on a survey conducted in the United Kingdom with a sample of 9000 adults. The study showed that, as well as the absence of disease and illness, people considered health as physical fitness, energy and vitality, social relationships, being able to function, having a reserve to combat problems and having psychosocial well-being (Blaxter).

Physical well-being is the aspect of health that receives the most attention and is the easiest to understand. Blaxter (1990) found that physical well-being is often related to fitness. Young people and men in particular associated health with physical fitness, strength and energy. Young men stressed strength, athletic prowess and the ability to play sports. Young women defined physical fitness in terms of outward appearance such as body size and complexion. Blaxter contended that there is a growing recognition that use of physical capacities has an effect on general well-being.

Mental well-being refers to the well-working and coping ability of both emotional and intellectual capacities and sometimes includes spiritual capacities (Wilcock 2006). Those attributes in combination enable individuals to find meaning in their lives, interact effectively with others, be reflective, solve problems, cope with stress and be flexible and adaptable to changes in life circumstances and demands (Wilcock, 2006).

Social well-being is less researched in terms of conventional medicine. Throughout history people have displayed a need to be part of cooperative social groups. Nutbeam's (1986) definitions of social well-being included social capital, which represents the social cohesion which exists in communities. Social capital is processes between people which establish networks, norms and social trust. Social networks are the relations and links

between individuals which may provide access to or mobilization of social support for health. Social support is defined as the assistance available to individuals and groups from within communities (Nutbeam, 1986). Social support can provide a buffer against adverse life events and living conditions and provide a positive resource for enhancing quality of life (Wilcock, 2006). Having social well-being, it has been found, enhances health by both preserving the immune system and encouraging good health habits. And socially valued activities, like worship or career, seem to have a positive correlation with health and happiness (Nutbeam, 1986).

Wilcock (2005), when asking participants of a study what situation is associated with a feeling of well-being, found that the most common response was related to occupations. Included within these occupations were leisure, achievement, rest, selfless activity, self-care and religious practices. Feelings related to engagement in occupation included confidence, energy, control, purpose and self-actualization. Wilcock expressed that enabling the experience of occupations that generate such feelings could be a type of health promotion.

What is needed in family care giving is to have that particular occupation generate feelings of well-being in that individual. Rather than stress and burden family care-giving should be an occupation of joy, selfless activity and meaning.

Health perspective of occupation. Wilcock (2005) spent much of her research on relating occupation to health. Her focus on health as the absence of illness, as being part of active aging and as the meaning of well-being supported her overall assertion that occupation is health-giving. One of the foundations underlying occupational therapy theory and practice, Law (1998) offered, is the belief that there is a relationship between

occupation and health. The uniqueness of occupational therapy lies in its focus on occupation as central in promoting and maintaining health and well being (Law).

Wilcock argued that engagement in occupation should lead to both happiness and fitness and that seeking occupational engagement is also inherent to being human and wanting to be healthy.

Wilcock (2005) asserted that humans need and want to be occupied in various ways and for various purposes. Johnson and Yerxes' (1989) agreed, having stated that individuals are most true to their humanity when engaged in occupation. Wilcock further explored this idea that she labeled occupational needs.

Occupational needs. Wilcock (2005) discussed that humans have occupational needs which are related to health. Occupations, Law (1996) agreed, meet the person's intrinsic needs for self maintenance, expression and fulfillment. These needs prompt occupation in order to overcome physiological, psychological or social discomfort, as well as to maintain the well-working of the organism through use. Humans have occupied their lives with the goal-directed pursuits necessary for their existence and well-being since the dawning of time (Christensen, 2004). Occupations can be viewed as humans' primary health mechanism. Occupations can motivate humans to provide for other basic requirements, as well as enable individuals to use their biological capacities and potential to adapt to or change different environments. Occupational engagement also can meet sociocultural expectations and in general provide opportunities for individuals to flourish. As Crabtree (1998) stated, "The nature of humans is to make meaning through occupation," (p. 205). These occupational needs for health predate medical science by several million years.

Wilcock (1998) maintained that early humans kept in good shape and kept healthy through their continuing interaction with the environment; through what they did and through being true to their species' nature. Wilcock stated that Plato discussed the notion that humans are fitted by nature for different activities because of their particular aptitudes and interests. Marx (1970) asserted that labor is our species' nature.

Wilcock (2006) summarized the occupational needs of humans by offering two central concepts. The first was that all people engage in complex and self-initiated occupations because of their species common combination of biological features, such as consciousness, cognitive capacity and language. The mind and body are not seen as separate entities but simply one and the same. It was Descartes (1954) who began the divisive trend of separating mind and soul from the body. Unfortunately many healthcare practitioners today still act and treat mind and body as if they are separate despite claiming to be holistic.

Wilcock's (2005) second concept in relation to the occupational needs of humans stated that engagement in occupation is indispensable to survival. The brain of the species has "health survival" as its primary role. Occupation's three major functions for species survival include: providing for immediate bodily needs for sustenance, self-care, shelter and safety; developing skills, social structures and technology aimed at superiority over predators and the environment and exercising and developing personal capacities to enable the organism to flourish. According to Wilcock the brain continually activates people's particular mix of characteristics and capacities through engagement in occupation. Survival of individuals is the outcome of the use of capacities within

occupations that provide for essential needs of the organism including supportive, social, ecological and material environments. The survival of healthy species also depends on a humans' capacity to live in harmony within an environment that continues to provide basic requirements and ensure the continued acquisition of these requirements.

While most people in post-industrial societies regard health from the perception of medical science, Wilcock (1998) wanted occupational therapists to focus on the natural health-giving functions of occupations just as nutritionists focus on the natural health-giving functions of foods. To do this, the meaning of occupation and health must be clear. Wilcock (1998) presented a composite of occupational therapists' definitions because of the complexity of the word, "occupation."

Definition of occupation. Occupation can be described as purposeful use of time, energy, interest and attention or a natural human phenomenon which is taken for granted because it forms the fabric of everyday lives (Wilcock, 2006). Yerxa (1989) contributed that occupation enables humans to survive, control and adapt to their world to be economically self-sufficient and to experience social relationships and approval. Gray's (1997) definition of occupation is that it is goal-directed, carries meaning, is repeatable and is perceived as doing by those engaged in it. Occupation, Law (1998) offered, is everything people do to occupy themselves, including looking after themselves, enjoying life and contributing to the social and economic fabric of their communities.

Wilcock (1998) concluded that occupation is more than doing. It is a synthesis of doing, being and becoming which is engaged in not only by individuals but also at community, national and international levels for cultural, social and political purposes. It

is the outcomes, Wilcock states, of such group occupation which have long-term but often unforeseen effects upon the health of individuals.

Definition of health. As stated previously Wilcock (2006) did not want to view health as just the absence of illness despite medical science's current trend toward that goal. Wilcock embraced the WHO (1946) definition of health mentioned earlier in this paper and she used it to tie together occupation and health. The WHO 1986 Ottawa Charter for Health Promotion stated that an individual or group must be able to identify and to realize aspirations to reach a state of well-being. Wilcock answered back that occupation is the fundamental mechanism by which people realize these aspirations, satisfy needs and cope with the environment. Health, Epp (1986) advocated, is created by caring for oneself and others, by being able to take decisions and have control over one's life circumstances and by ensuring that the society that one lives in creates conditions that allow the attainment of health by all its members.

In Blaxter's (1990) study, cited earlier in this review, there were those who defined health in various ways over the life course. Some defined health as not suffering any symptoms. Others described health as coping well with a disease or disability. Some respondents, especially the younger people, emphasized physical fitness and energy with health. Women in the study were more likely to define health in terms of their relationships with other people.

Of particular interest in Blaxter's study was the notion most frequently mentioned by older people. This notion incorporated ideas about health as being able to perform physically demanding work, social, family and community activity and to work despite an advanced age.

Wilcock (1998) concluded that from Baxter's outcomes many people do link health and occupation, perhaps not in those exact terms, but as a concept. For example, when asked about health, words such as physical fitness, energy, exercise, relationships and mental health and well-being are brought forth. Even with health and occupation defined for practitioners, Wilcock (2005) expressed concern over the deterrents towards occupation as a basis for practice for occupational therapists. One of these deterrents is the language used in most of occupational therapy's professional literature. Unfortunately, much of this language is medical-speak, rather than health or occupation for health-speak.

Summary. Wilcock (2005) stated that her interest in the profession of occupational therapy/occupational science is to have others understand the relationship between people's health and occupations at all levels of population, social and health-care planning and activity. To make her point, Wilcock refers to Ornstein & Sobel (1998) and their claim that it is the integrated functioning of the mind and body that maintains health as the brain makes numerous adjustments to perceive stability between social worlds, our mental and emotional lives and our internal physiology.

Wilcock (2005) contended that as people engage in life's occupations the integrated functioning of mind and body is called upon according to social demands; and such engagement is integral in the process of health and healing. As Siegerist (1955) noted, the brain slips into chaos and confusion unless it is constantly used for work that seems worthwhile to the individual. That is how the species has survived in relative health throughout time despite the many differences in human engagement in occupation

(Siegerist). As Meyer (1922) stated it is a person's occupation that makes life ultimately meaningful.

Wilcock (2005) stated that occupations over time and at any age will lead to either negative or positive health outcomes. Occupations that are a prerequisite to health include those that provide shelter, food, income and education; sustain resources, peace, stable eco-systems and social and occupational justice. Occupations are health giving when they provide choice, meaning, purpose, balance, challenge, freedom, creativity, growth, opportunity, satisfaction of mental, physical and social needs. But it is also true, Wilcock contends, that lack of occupation or the wrong kind of occupations can produce illness, isolation, and despair and can lead to death just as the right kind of occupation can enhance health and defer death.

Wilcock (2005) stated that she wants to see the profession of occupational therapy move in a similar direction as the World Health Organization in promoting health and well-being. Occupational health and well-being is a right for all people and a responsibility of occupational therapists. Occupational therapy should address disadvantaged communities and population groups as well as individuals with dysfunction. The outcome would be increasing participation in occupations as well as decreasing handicap. It would include taking a health promotion focus aimed at physical, mental and social well-being and occupational environments which are equitable and just.

Wilcock (1998) outlined the following to be integral to occupational therapy: being responsive to the individual's and the community's goals; facilitating all people's participation and quality of life in occupation that provides meaning and satisfaction and preventing ill-health that can be the result of occupational injustice.

Next, in this literature review, the practice framework of occupational justice was presented as the result of Townsend's and Wilcox's collaboration. The concept of occupational justice helped drive the examination of the research question of what was the occupation of caregiving? Family care giving is an occupation fulfilled by millions of people daily; not always by choice, often by necessity. Family care giving is an occupation that can be full of stress, burden and ill-health as noted in the literature. Formal healthcare, the community and public policies have yet to meet the needs of family caregivers. These unmet needs are negatively impacting the health and quality of life of the caregiver and care recipient. With the profession of occupational therapy being founded on a social vision of justice, occupational therapists need now to build upon that vision and think globally. The profession has to develop approaches that reach whole populations rather than just individuals. Occupational justice strategies of enablement and empowerment can help family caregivers successfully meet the challenges of their occupation so they can experience fulfillment and meaning in their daily lives. By applying the occupational justice framework to the family care giving occupation, occupational therapists can fulfill Townsend's vision of social justice, and Wilcock's vision of health through occupation.

Occupational justice. The concept of occupational justice grew out of research on the occupational foundations of human existence (Wilcock) and on the principles of empowerment and social justice that informs practices and strives to be client-centered (Townsend). Occupational justice implies that societies value different occupational capacities and different occupational meanings. As Abelenda (2005) explained, occupational justice is based on the premise that the role of society includes the provision

of adequate occupational opportunities for all. These occupational opportunities may also involve meaningful employment, leisure, skill development, hobbies and other forms of occupation. An occupational perspective of justice, Wilcock (2006) explained, focuses on occupational equity, occupational fairness, occupational empowerment, occupational enablement and occupational well-being. Wood (2005) stated that the concept of occupational justice gives voice to occupational therapist's implicit historical and ethical stance to address potential or real injustices. Rather than sameness, occupational equity and fairness demands respect for differences. These differences can arise in various individual capacities and different meanings derived from both personal and cultural influence (Wood). Hammell (2008) acknowledged that an engagement with occupational rights will bring occupational therapy into line with our stated belief in the relationship between occupation and human well-being, acknowledge the connection between human well-being and human rights and enable us to state what occupational therapy contributes to humanity.

Wilcock (2005) explained that occupational justice is challenged when people are not able to meet their basic requirements through what they do; not able to demonstrate their capacities and abilities nor able to express themselves through opportunities for developing potential. Occupational injustice occurs when people are disempowered, deprived, alienated or restricted. As a result, according to Wilcock, individuals are unable to meet basic needs, find satisfaction or experience well-being through their occupations in a society that appears not to value what they do.

This describes the current state of family care giving in America. Many caregivers are experiencing the disempowerment and deprivation that comes from not having a voice or

any real power in navigating the current healthcare system. Family caregivers experience alienation from the health “experts” who don’t value their opinion and from a society who doesn’t yet fully value their sacrifice and commitment to caring for loved ones in the home. The result is a care giving occupation that often brings burden, stress, and dissatisfaction to the caregiver. Health can be negatively affected and well-being diminished.

Occupationally just world. Motivating the formulation of the concept of occupational justice was a utopian vision of an occupationally just world. This is a world envisioned by Wilcock and Townsend (2004) that is governed in such a way as to enable individuals to flourish by doing what they think is the most meaningful and useful to themselves, to their families, communities and nations. Wilcock (2004) explained that people engaged in meaningful occupation make personal and community transformation possible. Such transformation can be politically and organizationally directed toward health, well-being, happiness and even survival.

An occupationally just world, for family caregivers, would be one in which there are adequate resources and financial, emotional support for the caregivers to carry out their daily care tasks. Family caregivers would receive needed training and education. There would be respite periods provided to ease the stress and burden of giving 24/7 care. Most importantly, family caregivers would be given the respect and voice they deserve; they would be equal partners with the health professionals in our healthcare system. The result would be caregivers who experience satisfaction, good health and general well-being in their occupation; there would be meaning and fulfillment and balance in their

daily lives. And finally the family caregiver would transform society to value them for who they are and what they do to make a good life for those chronically ill in America.

Occupational justice as a practice framework. Wilcock (2000) considered the fact that pairing the word occupation with the ethics and principles of justice might seem unusual. But Wilcock countered that every day life is characterized by occupation; the very broadest sense of doing, becoming, and being. Daily routines of work, play, rest, self-care and care for others results in the growth or stunting of the future potential of individuals, communities and nations.

Wilcock and Townsend (2004) both maintained that occupational justice should be considered a practice framework for occupational therapists because the profession exists to address occupational injustices. Occupational therapists' primary concerns are those who are vulnerable to injustices because their participation in occupations is restricted by injury, chronic illness, disability of different types, mental illness, incarceration, old age or other circumstances. Wood (2005) agreed, having stated that occupational justice offers occupational therapists a meaning-making system; collaboratively created and occupation-focused interventions that are valued by the people and groups who benefit from them and the occupational therapists who are rewarded in providing these interventions. Wilcock and Townsend (2004) also contended that occupational therapy's goals and objectives are linked to occupational justice. Occupational therapists strive to collaborate with clients to promote social inclusion. To accomplish this, a variety of enabling methods are used to emphasize client decision-making about their participation in occupations.

Without occupational justice Wilcock and Townsend (2004) offered that individuals, communities and the world can experience inequities which can touch the essence of living. They further suggested that while some people may find occupations that are meaningful to them, others may be relegated to a life in which they are unable to develop their occupational potential or to meet the occupational challenges of their communities.

Wilcock (2000) explained that the personal and social consequences of occupational injustice are the foundations of health and well-being for individuals and communities. What is at stake is not only the reduction of illness or disability, which could be outcomes of people finding meaningful occupation, but the promotion of an idea of health that is understood as the ability and opportunity to live, work and play in safe supportive communities in accord with the WHO 1986 mandate.

The three types of occupational justice. Wilcock and Townsend (2004) proposed three cases of occupational injustice: occupational deprivation; occupational alienation and occupational imbalance.

Occupational deprivation. Wilcock and Townsend (2004) defined occupational deprivation as a state of prolonged preclusion from engagement in occupations of necessity and/or meaning due to factors outside the control of the individual. Wilcock and Townsend acknowledge that while work is important, humans need to do more than work. Humans need the right to develop through participation in occupations for health and social inclusion. Wilcock and Townsend were most concerned, when naming occupational deprivation as a form of injustice, with those individuals who are confined or limited from participating in work. Wilcock explained that occupational deprivation

may arise too when populations have limited choice in occupations because of their isolated location, their ability or other circumstances.

Wilcock and Townsend concluded that occupational deprivation is a matter of justice because participating in a range of occupations is the day-to-day means in which individuals embody health, citizenship and social inclusion. People are denied these opportunities when deprived of occupations.

In the family care giving occupation many individuals experience deprivation of occupations due to the time and energy demands of caring for a loved one. Occupations that bring pleasure, leisure, exercise or fulfillment have to be put aside for the time being. This occupational deprivation, if long lasting, can cause stress for the individual and possible ill health.

Occupational alienation. Wilcock and Townsend (2004) described occupational alienation occurring when people experience daily life as meaningless or purposeless.

The concern here is whether choices are available for all populations to experience meaning and enrichment as they participate in occupations.

According to Wilcock and Townsend, examples of occupational alienation occur when people are physically removed from their own cultural occupations through slavery, refugee confinement or industrial policies that require them to work in demeaning jobs that pay them low wages, maybe great distances from their home or loved ones. Participation in occupations is a major force in shaping identity, so a lack of positive experiences in occupation can distort identity formation (Christiansen, 1999).

Wilcock (2004) stated that occupational alienation can also occur for people who have permanent acquired or congenital disability. Deprivation here is a consequence of social

conditions such as attitudes and policies that lead to environmental designs that fail to make them accessible for the diversity of physical, mental and cognitive abilities that exist within a population.

Family caregivers can experience occupational alienation through their care recipients. Many of the chronically disabled experience alienation and inaccessibility to occupations, that they could fulfill with some support and resources. This can add to the burden and emotional stress of care giving; witnessing the disappointments of their loved ones when they can't participate in meaningful and enriching occupations.

Occupational imbalance. A third occupational injustice is occupational imbalance. Wilcock (2004) explained that occupational imbalance is a temporal concept since it refers to allocation of time use for particular purposes. Occupational balance is based on the reasoning that human health and well-being require a variation in labor, work and leisure occupations. Occupational imbalance, Christiansen (1996) offered, occurs when a person has no time for occupations other than paid work or when family and parenting responsibilities present such a burden that there is poverty, underdevelopment of skills or decreased time for paid work. In society, occupational imbalance is witnessed when some people are over occupied and others are under-occupied.

The underemployed are at risk for ill health Wilcock (2004) stated, because they are less likely to experience sufficient mental, physical and social exercise that provides meaning and enrichment in their lives. Over-employed people are also at risk for ill health because they are too busy to look after themselves. And unemployed individuals may experience ill-health because they become over-occupied with survival.

Wilcock and Townsend (2004) stated that occupational imbalance is also used as a population-based term to identify populations that do not share in the labor and benefits of economic production. This is a cornerstone of social justice principles.

For family caregivers occupational imbalance is usually about being over-occupied. Many family caregivers were already engaged in various occupations when it became necessary to care for a loved one. The care giving occupation tends to crowd out and diminish pre-existing occupations because of the time demands and the needed multiple tasks to perform. Energy is depleted and time runs out daily to perform other meaningful and enjoyable occupations.

This occupational imbalance can begin to take a toll on health, both physically and mentally. The occupational injustice here is having individuals often involuntarily take on so much care for their loved ones that they can no longer benefit from the health-giving occupations they once chose to pursue.

The four beliefs of occupational justice. The beliefs in the theory of occupational justice are based on ideas, values and assumptions about humans as autonomous yet interdependent occupational beings whose occupations determine their health and quality of life. The first belief is that *humans are occupational beings*. Wilcock and Townsend (2004) discussed that occupational justice is grounded in the belief that humans are occupational beings. Wilcock contended that humans need and want to be occupied in various ways and for a variety of purposes.

According to Wilcock and Townsend (2004) literature on occupational science is reporting on what occupation and lack of occupation mean to humans. Occupational science is just one of many disciplines interested in participation, activity, involvement

and community action. What the exploration of occupational justice can do, Wilcock pointed out, is unite these different interests through the concept of occupation.

2). *Humans participate in occupations as autonomous agents.* Wilcock and Townsend (2004) explained that in our need for occupation humans are individual, autonomous, active agents who have different capacities to choose and participate in occupations. This belief rests on the concept of personhood and rational will (Metz, 2000). Individuals as active agents, McGary (1999) offered, have the power to allocate resources as a means toward a visionary or ideal goal such as justice.

Wilcock and Townsend (2004) expressed that individual will and their drive to participate in occupations is a biological idea. This is because individuals possess the biological power to act and to reflect on, access and make decisions about their participation in occupations. Carlson (1995) stated that individual persons experience that occupational participation is important because it supports much of our temporal sphere of existence. Human needs and power to participate in occupation differ greatly because human bodies and minds are individually unique (Carlson).

3.) *Occupational participation is interdependent and contextual.* As Wilcock and Townsend (2004) explained, occupational participation involves interaction with other humans in a physical, social, cultural and institutional context. What occurs then, according to Wilcock, is an inter-play between nature and nurture and between individual autonomy and individual interdependence in doing things with others. This concept, Wilcock and Townsend (2004) discussed, offered the philosophical view of self and society; the self being shaped by society and society being shaped by the concentrated will of many individuals who make up society. Messick (1991) observed that

conceptions of social and occupational justice hinge on debates about the responsibility of the state to mediate in matters beyond individual control. The interdependence and contextual nature of occupations may not be obvious but individuals are dependent on what others have done before or are doing around us.

4). *Occupational participation is a determinant of health and quality of life.* This is true when health is defined, as in the WHO statement, (1946) as the ability and opportunity to live, work and play in safe, supportive communities.

Wellness is more than absence of disease. Activity is known to enhance health. And humans need to feel useful otherwise they can fail to flourish and become unhealthy. DoRozaro (1994) stated that health can be promoted through occupation but occupation does not always promote health. Participation in some occupations may be degrading or debilitating.

The four principles of occupational justice. In the four principles presented by Wilcock (2004), all outline rights, responsibilities and freedoms of enablement. The principals come from a recognition in occupational justice that individuals have occupational needs, strengths and potentials that affect our health and quality of life.

The first principle is *empowerment through occupation*. It is a belief in power sharing which refers to power exerted and accepted through horizontal collaboration and partnership (Messick, 1991). The contrast to this concept is hierarchical, patriarchal, authoritative control of power. The reasoning that links empowerment with injustice is that occupational determinants such as economic practices, policies and laws and cultural forces are also determinants of empowerment (Messick, 1991).

Empowerment has many meanings. Some use it as a term to describe the growth of our individual or group feelings of power (Wilcock, 2004). To feel empowered is to generate feelings of personal drive, motivation, purpose, confidence, identity and even joy (Rappoport, 1985). To act empowered is to believe assertively, be decisive and confident (Mann, 2001).

Empowerment through occupation might be experienced as occupational enrichment, meaningful occupation or occupational balance.

2). *Inclusive classification of occupations.* Wilcock and Townsend (2004) stated that this principle concerns the definition of the occupations themselves. Some occupations become paid work, while other occupations are considered private and unpaid. When occupations are classified hierarchically, inequalities in status and wages perpetuate a social class structure of haves and have-nots.

According to Wilcock and Townsend (2004), many people seek greater occupational enrichment, meaning a balance beyond as well as through their work. When individuals look to occupations outside work, these tend to be dismissed as unproductive, frivolous or a backdrop to what really matters which is paid work (Primeau, 1996). Those who succeed at paid work make more income and have a greater influence in society. Those who are occupationally deprived become disempowered. There is a fundamental injustice in the discrepancies of pay, privilege and status allocated to occupations.

3). *Enablement of occupational potential.* Wilcock and Townsend (2004) explained that this principle refers to approaches and conditions that might be developed to support all people individually and collectively in developing their occupational potential.

Enablement would focus on the empowerment of those who are currently disempowered

or occupationally deprived and would involve all people as participants in their decision making as well as the performance of occupations related to their lives.

Townsend (2003) advised that enablement approaches would emphasize collaborative interpersonal forms of helping along with the development of enabling policies, laws and economic practices. The development of enablement conditions would involve writing policies that attend to the empowerment of all participants or stakeholders in a particular issue. An advocate for occupational justice might envision all citizens participating to empower themselves and others to draw out their full potential as humans. Occupational justice emphasizes choice in accepting opportunities and resources that support the enablement of individuals to expand their choices.

4). *Diversity, inclusion and shared advantage in occupational participation.* Wilcock and Townsend (2004) contended that occupational justice depends on the recognition of the occupational needs and potentials of individuals who are also members of social groups. Occupational equity and fairness demand respect for differences which arise in different individual capacities and different meanings derived from both personal and cultural meanings.

An occupationally just community or nation would be socially inclusive according to Wilcock and Townsend (2004). The corollary to social inclusion is shared advantage. Everyone in an occupationally just community or nation would share the social and economic advantages of that community or nation.

These combined principles oppose social exclusion and differential privileges that create different classes of people. It would guide an occupationally just society to watch

out for individuals or groups who are excluded from choosing and participating in the typical occupations of that society.

Summary. Occupational justice, as presented by Wilcock and Townsend (2004), is a practice framework for occupational therapists that can embrace the family care giving process and positively affect the issues of burden and stress. Occupational justice can be described as holistic because it encompasses the interactive nature and complexity of people within natural and human-made environments. Occupational justice accepts that ill health can be an outcome of the inequitable distribution of power and resources and that ill health can result from factors such as the type of economy, national priorities and policies and cultural values. These underlying determinants can cause people to experience occupational deprivation, imbalance and alienation; fatigue; boredom and stress that can lead to ill health and premature death. The occupational justice approach to health aims at changing these underlying determinants.

Wilcock and Townsend (2004) through their individual work and joint approach of occupational justice asked tough questions of the profession of occupational therapy. One such query was what vision of power and justice is guiding the profession of occupational therapy as it implements client-centered practice of enabling occupation? What might occupational therapists contribute to society with a more explicit focus on occupations, collaborative process of enabling and occupational justice? Wilcock contended that with occupational therapists there needs to be a persistent focus on using occupations as both the process of therapy and as outcomes, defined in terms of occupational performance, occupational well-being and justice. Occupational therapists

also need to enable individuals to engage in doing that which will meet prerequisites of health, find meaning, purpose, satisfaction and belonging and also promote physical, mental and social well-being. Enabling involves helping others aim toward becoming what they have potential to become. To implement occupationally just programs to meet physical, mental and social health and well-being, as the American Occupational Therapy Association code of ethics requires, will take, according to Wilcock, acts of courage to challenge existing ways of delivering services and extending them to the people most in need.

Levine (2004) echoed Wilcock's (2004) call for challenging the current healthcare system. Levine advocated for family caregivers stating they are in dire need of better understanding and better tools to deal with the care of their loved one and most importantly, to deal with the diverse professional and bureaucratic cultures of health care. Levine offered that most family caregivers receive little training and it often comes from someone the caregiver knows or consults informally; not from the healthcare professionals.

Occupational therapists need the practice framework of occupational justice to advocate for policy change in America; to implement a truly family-centered approach to care. Family caregivers, as a population, should inspire occupational therapists to fight for population-based services in order to bring justice to the occupation of care giving. Justice would bring adequate and on-going training and education; support; respite care; and respect for the hard work and sacrifice of these caregivers. The care recipient's health and continued recovery is tied to the health and well-being of the caregiver. It will be through occupational justice practice that occupational therapists can expand their

reach and create an environment for their clients where family care giving is successful, meaningful and healthy for all.

The literature review now examined the culture of caregiving to provide further understanding of the conflicts and common ground between family caregivers and health professionals and the impact culture has on the present caregiving process.

The Theoretical Foundations of Caregiving

The culture of caregiving. Culture can be described as a shared understanding of a way of life which encompasses principles, values, attitudes and behaviors based on a membership in a group (Levine, 2004). This group could be family, professional discipline, institution or agency.

One could not examine the family caregiving process without considering the role of culture. As Fitzgerald (2004) stated, families are not only a cultural context, they are situated in and must function in cultural contexts.

The topic of caregiving and culture has been studied by many, including Dilworth-Anderson, (2004); Pinquart, (2005); Ayalong, (2004); Kosloski, (2002) and Manthorpe, (2007). However the focus of most of these studies on culture and caregiving has been on ethnicity, gender and race and how these factors influenced the family caregiver in areas that included stressors, resource utilization and physical health. For example, Dilworth-Anderson looked at the specific culture of African-American caregivers. She concluded that cultural beliefs and values did help to explain health outcomes. Specifically, she found that higher levels of mastery among African-American caregivers were associated with poor health outcomes primarily due to role engulfment. Pinquart

did a meta-analysis on ethnic differences in family caregiving and concluded that intervention needs do vary between ethnic groups of caregivers. Other studies have been similar: comparing ethnic groups of caregivers and suggesting strategies of easing burden and stress that were tailored to that particular culture.

Ayalong (2004) however, conducted a cultural study of caregivers that was a little different. He chose to look at the commonalities among three ethnic groups of caregivers: African-American, Caucasian and Latino. Four themes emerged from the study: tradition of family care; familial conflicts; caregiving dissonance and low levels of use of formal services. The results, Ayalong claimed, supported the existence of a culture of caregivers across ethnic affiliation. Ayalong advocated that more attention needed to be paid to the common characteristics of caregivers rather than the differences.

This aspect of commonality of culture among caregivers was embraced by Levine (2004) in her body of work. Rather than view caregivers within specific ethnic groups, Levine saw family caregivers as one informal culture versus the formal caregiving culture (health professionals). Levine believed that these two distinct cultures of caregivers was the source of present family caregiver burden and stress. As Levine stated, the culture of family caregivers (their values, priorities and relationships to the patient) frequently differs significantly from that of professionals and the result can be conflict and misunderstanding. For occupational therapists, Levine's unique approach and examination of culture is relevant because occupational therapists' interventions with family caregivers can often be influenced by their culture of work which is most likely within the formal healthcare system.

In examining the culture of caregiving Levine (2004) chose to view it from two important perspectives. First, she provided a historical review of care giving in America that offered the reader some clarity and insight on how formal and informal care giving has evolved. At one time the family was the only source of care. Today, Levine argued, the formal care system could not be sustained without the huge contributions of family care giving.

Levine (2004) also presented a perspective of caring culture that involves the integration of modern medicine with family care giving. This integration constitutes the blend of two very different cultures. Levine emphasized that “families and health professionals have distinct cultures which affect their priorities and actions in the care of an elderly or ill person” (p.1.) As Levine asserted, this concept of culture illuminates the many tensions and conflicts that can occur in health care especially those that involve family caregivers.

Historical perspective: Care giving in the nineteenth century. The historical perspective presented by Levine (2004) starts in the early nineteenth century when there was great community support for family care giving. While the care giving duration was rarely long-term due to short life expectancy, there was available to the family caregiver resources, support, extra hands if needed and even times of respite from care. All care giving responsibilities were reciprocal, defended by social expectations and religious precepts. There was respect and reverence for the family care giving model as it existed then. Institutional care at that time was only for “outsiders”; those individuals who had no family to care for them.

Into the 20th century, Levine (2004) found there had been fundamental changes in care giving. Care giving responsibility shifted and families began to rely more on the formal care giving found in medical institutions which now provided better and more sophisticated care. This perspective was supported by Olson (2003) who stated that the shift to formal care was the emergence of the powerful health care industry which considerably reduced the need for at-home medical services. Home care was replaced by hospital care and, as Olson explained, this was becoming an acceptable solution to the endless obligations of caring for the sick at home. As medical institutions assumed more and more of the families' care for loved ones, these formal caregivers also assumed an "expertise" of care that defied any family input. Soon families were being banished from the bedside and seen as interfering with the health professionals' duties.

Along with this shift to a more formalized care giving system, Levine (2004) explained, institutions began to specialize in their provision of care. There were centers for mental illness; state schools for mental retardation; sanitariums for individuals with tuberculosis and nursing homes for the frail and the elderly. These facilities were usually located far from populous areas and had limited visiting privileges and hours. According to Levine, families were encouraged to put their loved ones "away" so as to avoid the burden of care as well as to avail their family member of the opportunity for the "best care" available. For family caregivers though, Olson (2003) offered, institutionalization was a last resort and even then with much hesitation. It would occur usually after years of backbreaking labor and only after the carer was totally exhausted, too ill or too frail to continue the assistance. Levine argued that with the establishment of these facilities and protocols of care there was the disappearance of shared values, strong religious faith,

integration of the sick into the community and interlocking obligations between the sick and the healthy. In these settings, the sick faced challenges without the comfort of family and friends, while the authority of the physicians and the institutions themselves were elevated.

Care giving in the twenty-first century. In the twentieth-first century, Levine (2004) explained that the shift in care giving has returned to family and community but not completely. Late in the twentieth century and up to today many of the specialty medical institutions are closed or in the process of closing. Society now seems to feel that this type of treatment is unethical and that this kind of “expert” care and isolation from community and family does not promote well-being of the individual.

Family caregivers are now an integral part of the healthcare delivery system due to changes in resource allocation and increases in chronic disease and disability (Elliott, 1998). As the community and families take in these ill individuals there are challenges as millions of more Americans are requiring complex care at home for longer periods of time. These challenges include a national decline in birth rate meaning that smaller families and fewer adult children available to provide care. And in today’s society more women are employed outside the home and so have limited time and energy to participate as a primary caregiver. More families are dispersed geographically and struggle to provide or even arrange care giving from long distances. And finally, our society experiences more divorces and re-marriages than ever before, increasing the complexity of family relationships and the complexity of care giving decisions.

The historical perspective of the evolution of the care giving process presented by Levine (2004) and others provided important insight for understanding and examining the

current tensions and conflicts that have continued to fester between formal and informal caregivers. Both cultures have continued to develop distinctly different approaches to care without consistent collaboration that could lessen the informal care burden and create a mutually supportive partnership that would benefit both cultures. Family caregivers, Elliott (1998) argued, are now essentially operating as formal health care providers yet receiving little help from health care systems. The formal care culture has given the informal side of care little or no recognition, support or preparation which has resulted in misunderstanding, lack of confidence and ongoing conflict between the two cultures (Elliott, 1998). Families have continued to play a significant role in the modern-day care giving process, Sheehy (2010) agreed, but the fast-paced, technological and complex nature of today's formal care has perpetuated the "banishment" of the family caregiver from important aspects of the care process. The family caregivers have to learn how to talk to physicians and nurses and decode their clinical speak. As Sheehy put it, it is like being dropped into a foreign country where one doesn't know the language.

It is a clash of cultures that has continued to be interdependent in spite of the domination and expertise of the formal health care system. And it was this clash of cultures that warranted this phenomenological study of the lived experience of caregivers that was proposed.

Modern medicine vs. family caregivers. The interdependency of formal and informal care giving leads into Levine's (2004) other main perspective in her work on care giving culture which is the blending of modern medicine with the family. Levine asserted that today's health professionals do recognize families as a critical medical resource primarily for decision-making on recommended procedures and in the provision of long-term care

needed for the ill individual. Sheehy (2010) agreed with this assertion having stated that until recently, medical professionals showed scant respect for the family caregiver. The job was typically seen as custodial work best handled by low-paid domestics. However, geriatricians and many nurses and social workers now bring in the family caregiver as part of the decision-making team (Sheehy). Medical practice acknowledges the reality that patients, embedded within a network of family relationships and culture, do not interact with the healthcare system as isolated individuals. Health professionals have an increasing dependence on family members for patient care and management but this relationship is only sustainable if there is mutual respect. Levine described this mutual respect as being dependent on the recognition that the institutions of family and medicine embody distinctive conceptions of care and sets of values, all of which are valid. Family caregiving and paid caregiving are typically treated as two separate worlds Seavey (2005) offered, but in reality, the two often interface. In the worlds of advocacy and policy making however, these caregiving systems are rarely considered two parts of a complex whole. Family caregiving and paid caregiving have their own lobbyists and allies and each is addressed as if it functioned independently of the other (Seavey).

The practice of modern medicine started out as a very paternalistic system with the doctor always being right and he/she alone determining the medical course and how much information was to be disclosed to patient and families. There was no questioning this authority and expertise; families had very little say and were dictated to rather than invited to collaborate. Then came the “patient rights” movement or consumerism, where the patient began to drive the medical care with more active participation in selecting the care prescribed and being involved in most medical decision-making. In this current era

of consumerism in medicine, healthcare has adopted a marketplace mentality which is driven by being a business that deals with goods and services. Doctoring is now a product to be packaged, marketed and provided. Families and relationships are secondary and not valued. Medicine contributes to the erosion of the values of family, Levine (2004) offered, and the moral relationship between patient and other family members when medicine embraces marketplace values that then determines how it interacts with families.

So the challenge is, in the historical shifts of power and domination between medicine and families, how can the cultures blend with the well-being of all as a primary goal? In Levine's (2004) work, suggestions for improving this relationship include empowering families to make treatment decisions similar to the model of hospice and palliative care but instead applying these philosophies to those with chronic illnesses. The hospice model, adopted from Great Britain, embraces patients and their families and pulls them into the medical realm as very equal partners. In hospice and palliative care the patient and family comprise the unit of care (Finn, 1997). There is an emphasis on empowerment of patients and families. There is recognition for the need to educate and inform the family, to help with practical matters, to assist with decision-making and to establish an ongoing discussion of concerns. Hospice-type care forces many issues, such as involvement of family in decision-making; understanding the family dynamics by health providers; education of patient and family on disease process and prognosis and having resources available. This is one way to harmonize the values of medicine and family (Finn, 1997).

Levine's (2004) examination of the culture of care giving from a historical perspective up to modern day healthcare consumerism is related to this examination of the care giving process in that it makes sense of the place where caregivers find themselves today. As Levine showed, there has always been a clash of cultures between healthcare professionals and families. The pendulum has swung from one extreme of cultural practice to the other over the years. Both families and healthcare professionals are experts in their own way and what they bring to the patient in terms of values and concepts are valid but different. They share a common goal of wanting what is best for the ill individual. What Levine offered in her work is optimism that the two cultures can come together, because from a historical perspective the interdependence is greater than ever; this need for institutional expertise with the management of chronicity in the home. A large part of today's care giving process needs to be working toward greater collaboration and understanding between families and healthcare professionals. It begins with mutual respect.

Fitzgerald (2004) offered a different aspect of culture that is pertinent to care giving families and the practice of occupational therapy. Fitzgerald examined two important concepts which were family and culture. She was concerned that occupational therapists must have an understanding of these concepts to enhance their practice which claims to be client-centered and holistic. Fitzgerald identified several issues that are relevant to the profession of occupational therapy in its interaction with families. Those issues included lacking understanding of the concept of culture, confounding of culture and ethnicity, considering culture as an issue only in families from "other" cultural backgrounds,

assuming the nature of families and therapists and differing expectations between a client or family and the occupational therapist.

Family culture and occupational therapy in the caregiving process. In an examination of the concept of family Fitzgerald (2004) explained that families are key contexts and reference points for our socialization. Families help us develop an identity and model our behaviors. According to Fitzgerald through our families we learn how to “be” in the world as well as learn the beliefs, values, attitudes and customs that guide much of our lives. Most importantly we learn how to be occupational beings in and through our families. Occupational therapists have to learn to deal with families as part of their practice and, as Fitzgerald explained, culture always underpins interaction with families. That is because family is a universal institution in all cultures and human societies and while the concept of family may appear simple it is in fact very complex in day-to-day interactions. Fitzgerald stated that it is very hard to narrow our reference when working with families because of the loose definition of what constitutes a “family.”

Occupational therapists must keep in mind that family caregivers come from all ethnic, racial and cultural backgrounds. While they face the same caregiving problems and similar needs for information and support, a caregiver’s values, ways of doing things, reactions to problems and coping strategies may differ as a result of cultural influences (American, 2003).

According to Fitzgerald (2004) occupational therapists, lacking a framework, rely on two perspectives when dealing with families: their own experiences (personal, social and media) and “expert” knowledge gleaned from textbooks, workshops and policies. With a

personal perspective it is easy to allow judgment of what is normal behavior from families. In expert perspective there are rarely questions on what is learned; it is accepted as true. Therefore the “good” families meet the therapist’s ideals; bad families do not even come close and in fact will be labeled as dysfunctional, a barrier, non-compliant and incompetent. This supports Levine’s (2004) work in describing the culture clash between family caregivers and healthcare professionals and the inability to understand each other’s perspective on the patient’s care. Health professionals can invoke their values onto the families and families do not have the same power to “push back.” When that happens no one is satisfied with the interaction or the outcome (Levine).

A classic example in the occupational therapy literature regarding families is families doing the patient’s activities of daily living while the occupational therapist is advocating for the patient to be independent. Families often reinforce occupational therapists’ ideals about family by being the exact opposite, offering an oppositional contrast. The goal from the therapist’s perspective is to bring family closer to the therapist and organization’s ideal. Unfortunately the failure of occupational therapy to meet the requirements for well-being of the culturally diverse people it encounters, Iwana (2003) offered, is often constructed as a problem of the individual rather than attributed to some inadequate aspect of occupational therapy.

The seven levels of family involvement that health professionals experience as outlined by Fitzgerald (2004) starts with no family involvement; family as an informant; family as therapist’s assistance; family as a co-client; family as consultant; family as a team collaborator and finally family as director of service. Which role the family plays is determined by several factors: the organization and its approach; assumptions about

family and their role; therapists' comfort in working with families from particular cultural groups and therapists' beliefs about their role and their rights and responsibilities.

Language differences can also be a factor.

Fitzgerald (2004) successfully argued in her work that family cannot be separated from culture. Fitzgerald defined culture as the "learned, shared patterned ways of perceiving and adapting to the world around us that is characteristic of a population or society," (p.494). Fitzgerald stated that this definition helps capture some of the core ideas that most anthropologists would agree on: that culture is learned and shared; it is patterned; it belongs to societies and/or populations and it is ever changing. All humans are cultural beings; it is what makes us human.

Today occupational therapists are more likely to work with patients who have not only differing beliefs, values, attitudes and behaviors but also different definitions of the nature of work, leisure, health and self-care (Black & Wells, 2007). The problem with many occupational therapists may be that they only consider cultural issues in families they see as culturally different or ethnic. This can blind them to the cultural influences on the behavior of families because the focus is on ethnicity. They can also be blind to the cultural assumptions that they themselves bring into the interactions and their evaluations of people and events involved. Therapists must keep culture in mind when interacting with all patients and their families not just those they identify as being ethnically or culturally different (Fitzgerald, 2004).

Cultural competence of occupational therapists was in fact studied by Suarez-Balcazar (2009) and others, utilizing the Cultural Competence Assessment Instrument developed and validated by Suarez-Balcazar. There were 49 items that measured four components:

awareness, knowledge, skills and practice and application of cultural competence.

Cultural competence was measured by three dimensions: cultural awareness and knowledge; cultural skills and organizational support for multicultural practice. The results showed that the two factors that most affected how therapists rate their level of cultural competence were prior training and favorable attitudes toward cultural competence.

Summary. Examining culture and families through the works of Levine, Fitzgerald and others is essential to the study of the care giving occupation if we are to understand why the care giving occupation today is so complex, unrecognized and largely unsupported. Recognition that all parties bring their cultural contexts to care giving is a start in increasing collaboration between the family caregiver and health professional in support of the care recipient. Surpin (2004) offered that family care needs to be interwoven with the formal care system and moved toward a new model for chronic care based on this collaboration.

Caregiver burden and stress. Kielhofner (1997), with his Model of Human Occupation, described the three states of occupational dysfunction as inefficiency, incompetence and helplessness. Sources of inefficiency could be environmental constraint, disease processes or imbalanced lifestyles. Incompetence was described as major loss or limitation of skills, a failure or disruption of self-confidence and inability to routinely and adequately perform the tasks associated with the occupation. And helplessness could be defined as extreme feelings of ineffectiveness, anxiety and/or depression (Kielhofner, 1997). In the occupation of spousal caregiving, these three states of dysfunction often translated or evolved into caregiver burden and stress.

Throughout the current caregiving literature there were many studies that discussed the burden and stress experienced by those caring for a loved one (Zarit, 1987; Evans, 1992; Dilworth-Anderson, 2004; Given, 2004; Kurtz, 2004; Grant, 2004 and Sheehy, 2010). The majority of these studies were quantitative by design and offered interesting and relevant data on the emotional and physical costs that family caregivers could experience. However as McCullough (2005) stated no current simplistic survey instrument can capture all the important dimensions and variables of the caregiving experience. Levine (2004) called for more qualitative work regarding the caregiving process because there is a lack of depth and diversity that only qualitative studies can offer in exploring why burden and stress is so ever present in this particular occupation.

Occupational therapists should be concerned about the presence of burden and stress in family caregiving because it suggests missed opportunities. The occupational therapy profession with its social justice roots and now emerging occupational justice practice framework was founded on enabling others to succeed in health-giving occupations and to experience well-being. Family caregivers have not consistently been the focus of occupational therapists in regards to training, education and empowerment strategies. As a result, caregivers and care recipients (often “graduates” of occupational therapy rehabilitation programs) have experienced burden, stress and decreased quality of life.

Definition. Faison (1999) defined caregiver burden as the result of prolonged provision of physical, mental and emotional support to the patient. Caregiver burden as described by Zarit (1987) is the extent to which caregivers perceive their emotional or physical health, social life and financial status as suffering as a result of caring for their relative. The literature was divided into looking at objective caregiver burden versus

subjective caregiver burden. According to Van Exel (2004) objective burden referred to time spent on care giving, the tasks that need to be performed and the possible resulting financial problems. Subjective burden can be the psychological, social and emotional impact caregivers may experience from the objective burden of care giving (Van Exel). More specifically, Tooth (2005) stated that subjective burden is how the carer subjectively appraises the care he or she provides in terms of feelings, attitude and perceptions.

There is a debate about the importance of subjective versus objective measures of burden in care giving research studies. Many researchers felt that subjectivity was more important because people interpret their situations differently and the meaning one places on a task determines how burdensome the task is. As Noonan and Tennstedt (1997) found, caregivers' appraisal of their caregiving situation does appear to be a significant factor contributing to increasing or decreasing stress, depression and self-esteem. But it is difficult to develop interventions for caregivers on evaluations of subjectivity. Coradetti (2005) offered that objective measures give more concrete directions for developing programs to help relieve caregiver strain. Both types of measures have the same goal of helping ease the strain of family care giving by educating others on what is involved in the occupation of caregiving, and how it feels to be a caregiver.

Five burdens. Rabow (2004) looked at family caregiving at the end of life noting that families can carry significant burdens as a result of their work. Rabow described five burdens of family caregiving: time and logistics; physical tasks; financial costs; emotional burdens and mental health risks and physical health risks.

Time and logistics. Family care giving can take as little as a few hours per week but most commonly it is equivalent to a full-time job. Rabow (2004) reported that 20% of caregivers provide full time or constant care. Along with the time-consuming tasks, families typically must coordinate numerous medications, treatments, clinical and social services as well as the needs of multiple family members. This daily time crunch keeps family caregivers from participating in other occupations of leisure and pleasure. Care giving restricts time with family and friends. Over half of all family caregivers have given up vacations, leisure time and/or hobbies (Care giving, 2004). As Larels (2000) offered, caregiving can take over every spare moment making it difficult for well spouses and adult children to attend to their own needs. Family caregivers experience occupational imbalance in devoting their time almost exclusively to care giving. By doing so there is great risk to their health.

Physical tasks. Laborious care giving is often performed by people who are themselves elderly, ill or disabled. According to the National Alliance for Care giving & AARP Study of Care giving in the U.S. (2004), half of all family caregivers perform the tasks involved in activities of daily living. The study found that 29% of caregivers help with dressing; 26% help with bathing; 18% help with feeding and 16% deal with incontinence and diapers. Rabow (2004) reported that while family caregivers also help with transportation, shopping, homemaking and financial management, they are also taking on more medically technical tasks. These tasks include routinely changing colostomy bags, caring for foley catheters, managing feeding tubes, administering injections and providing wound care. Rabow explained that family caregivers often have not received training in many of these caregiving tasks, which include moving, lifting and

turning seriously ill adults. Yet they routinely perform these very strenuous physical activities on a daily basis. Stress, Zarit (1994) stated, is likely to be higher for family caregivers who have these difficult care tasks. Family caregivers have experienced occupational alienation in that they did not receive proper training and education to prepare them for such tasks. As a group, they were not included as part of the healthcare team. Therefore their occupation of care giving was not acknowledged or respected enough by healthcare professionals to receive the needed information that would help them succeed. Instead, with the daily physical toil most family caregivers experience, caregivers are at a significant risk for physical injury.

Financial costs. Family care giving creates an uncompensated financial burden for family members both in outright expenses and in lost income and benefits. In the United States Rabow (2004) reported that family care giving costs range from 3-6 billion dollars for diabetes, more than 6 billion dollars for stroke and 65 billion dollars for patients with Alzheimers disease. Rabow stated that economic disruption can be enormous. Nearly two-thirds of family caregivers work full or part-time. Over one-half make work-related changes and decisions because of family care giving responsibilities. These changes include coming to work late, leaving early, rearranging work schedules, reducing work hours and turning down promotions. 20% of family caregivers must quit work or make major life changes and 31% lose most or all of their family savings as a result of care giving. African Americans and Hispanics are likely to experience economic burden more than whites (National, 2004). As Sheehy (2010) observed, it is so difficult to see family members being ground down by the staggering costs of taking care of a loved one, long term, at home. In a study by the National Alliance of Caregivers and the American

Association of Retired Persons (2004), the two greatest predictors of caregivers' financial hardship were level of burden and whether they had a choice in taking on care giving responsibilities.

Emotional burdens and mental health risks. Family caregivers often bear an incalculable emotional burden for their work. Rabow (2004) reported common and understandable reactions to care giving include sadness, guilt, anger, resentment and a sense of inadequacy. Exhaustion, financial strain, disrupted usual activities and continuous care giving contribute to significant mental health morbidity, including anxiety and depression. A number of studies according to Rabow (2004) found that as many as one half of all caregivers experience clinical depression. Yates (1999) reported that family caregivers frequently report symptoms of depression, anxiety, feelings of helplessness, decreased morale and emotional exhaustion. Depression and anxiety are the mental health outcomes most highly studied. The rate of depression among dementia caregivers is three times higher than the general population; in non-dementia caregivers, the rate is two times higher (Rabow).

Wyngaarten (2002) added that quality time between care recipient and caregiver may suffer with too much care. Marital and sexual relationships between caregiver and care recipient can be negatively affected especially when spouses take over roles normally accomplished by the care receiver. Often the family caregiver has concerns about overprotecting the care receiver while preventing their resumption of certain roles. Sheehy (2010) agreed and stated that one of the biggest problems with both caregiver and care receiver is the lack of honest communication. Feelings that may be considered

unthinkable or unacceptable go unspoken. They can then fester and be expressed later in angry outbursts (Sheehy).

Health risks for caregivers. Family caregivers tend to put the needs of the care recipient above their own, minimizing the severity of their own problems and forgoing or delaying their own health care. Rabow (2004) reported that care giving is associated with poor sleep and even increased cancer risk. Family caregivers frequently exhibit behaviors that can negatively affect the immune system such as loss of sleep, poor nutrition and lack of attention to their own personal care. As routine functions like walking and eating or moving around without constant fear of falling become consistently problematic, the demands of caregiving can become all consuming (Sheehy, 2010). Family caregivers are less likely to engage in preventative health behaviors. They may miss appointments and fail to stay in bed when ill. Rabow points out that family caregivers are at more risk for ill health if they have poor baseline health or limited education or if there is significant loss of social or leisure time.

Assessments of caregiver burden and stress. Much of the care giving burden and stress literature comes from the results of assessment studies. There are a multitude of caregiver assessments with a wide variety of outcome measures (Bradley, 2003; Bugge, 1999; Chen, 2004; Clark, 2004; Kurtz, 2004; Daly, 1998; Van Excel, 2005 and Hartke, 2006). The majority of these assessments focus on the burden that occurred post-discharge from the hospital. For example, Bradley (2003) looked at needs of family caregivers from home health nurses' point of view. A two-page caregiver assessment tool was developed by the authors for this study. Fifty-one family caregivers with an

average age of seventy-one took the assessment. The results showed that approximately half of the caregivers reported poor or fair health. In addition, 33% reported their health had declined during the past six months. The typical caregiver in this study devoted thirteen hours per day to being a caregiver. In another study, Bugge (1999) looked at caregivers of stroke patients. Caregiver strain was measured using the Caregiver Strain Index (CSI) with 232 participants. The results of this study showed that caregiver strain is a complex and multi-layered concept. More time helping and less time spent with the patient increased the strain. Caregivers admitted to feeling strain in the early months of post-stroke and this only increased with time.

There are many caregiver assessments utilized in studies including the Screen for Caregiver Burden (Coradetti, 2005); the Caregiver Stress Appraisal (Abe, 2006); the Caregiver Strain Index (Bugge, 1999); the Caregiver Burden Inventory (Delasiega, 2002); the Burden Interview (Faison, 2004) and the Caregiver Reaction Assessment (Chen, 2004). Nearly all the multiple versions of caregiver burden scales ask questions regarding caregiver's stress that can result from the caregiver's lack of social support, economic aspects, negative feelings, increased activities of care or the relationship with the care recipient.

A common finding from the care giving assessments is that caregivers often feel that their roles are undervalued by professional carers. Although healthcare professionals and family caregivers have the same broad goals for the patient, the relationship between them is often strained, sometimes hostile. As Ziff (2000) explained it, families are often criticized by healthcare professionals when they are too involved or when they are not involved enough. Family caregivers often will state that they feel excluded from the care

process and that they have difficulty obtaining needed information or adequate instruction.

In the majority of caregiver assessment results caregivers are constantly searching for support and information. Chambers (2001) believed that the source of most caregiver anxiety, frustration and stress are from a lack of both. It seems unfair for health professionals to expect carers to have the necessary knowledge and skills to care for their ill relative without some form of support. Chambers explained that family carers need practical advice, information and education if they are to cope effectively with the demands of caring.

Summary. If you search for care giving information on any research site, the literature is usually full of statistics and data that outline the burden and stress that family caregivers are experiencing. This literature can overwhelm the reader. As Levine (2004) stated, there is a need for more research on care giving that would provide data in giving a comprehensive picture of what caregivers actually do in this and other domains. Levine also called for more qualitative work rather than quantitative assessments in order to provide the depth and diversity to the experiences of family caregivers and professionals as they encounter each other.

The occupation of family caregiving cannot be defined just by its burden and stress. There is joy and meaning in caregiving.

Caregiver rewards. There are far fewer in-depth studies found in the literature that focus on the positive aspects of family care giving. According to Lopez (2005), caregiver satisfaction is more than the absence of pathology. Care giving satisfaction is rather the perceived subjective gain and rewards and the experience of personal growth.

Some research however has explored the positive and rewarding aspects and the meaning family caregivers find in caregiving (Hinricksen 1992; Kramer 1997; Farran 1997; Lopez 2005; Cohen 2002; Hudson 2004 and Feeney 2003). Cohen found in his study that 70% of caregivers had positive feelings toward at least one aspect of caregiving. Cohen believed that a carer's positive feelings about caregiving could serve as a buffer against negative consequences for both caregiver and care recipient. They were less likely to report depression, burden or poor health (Cohen, 2002). Feeney studied 194 couples giving them an assessment to measure motivation for caring for a partner and an assessment to measure motivations for not providing support to a partner. Feeney found several factors that motivated caregivers including, love and concern; enjoyment of helping; feelings of obligation and caregiver feeling capable.

Lopez (2005) also examined the factors associated with the positive aspects of caring for elderly and dependent relatives. Utilizing the Caregiver Satisfaction Scale on 111 family caregivers Lopez discovered four factors that correlated with caregiver satisfaction: previous affectionate relationship; own initiative as caregiver; venting as a coping strategy and working outside of the home.

Previous affectionate relationship. Caregivers who had a better previous relationship with cared relatives reported higher satisfaction with care giving. Lopez (2005) contended that this may be due to the fact that having and enjoying a good longstanding relationship with their relative makes it easier to find positive features about their role as caregiver, despite the burden. It is always easier, according to Lopez, to cope with the problems of care giving when there is a loving relationship present. Lopez

also added that having a previous affectionate relationship can help to understand the caregiver's role as an act of reciprocity.

Own initiative caregiver. Lopez (2005) stated that when a caregiver chooses his/her care giving occupation as a free and personal option then it seemed easier for that individual to find satisfaction in the caregiver role. This means that caregivers are neither pressured by family imposition nor choosing to become caregivers because they were the only person available.

Less use of venting as a coping strategy. Lopez (2005) expressed that venting unpleasant or negative feelings does not help one to enjoy the experience of care giving. Lopez emphasized that while venting may appear to be a useful coping strategy, it actually tends to reinforce the unpleasant feelings of the caregivers. When caregivers discuss with others how bad they feel, those they confide in only reinforce these negative feelings. Lopez stated that this only contributes to maintaining the difficulty in solving problems or even finding enjoyment in being a caregiver.

Not working outside the home. Lopez (2005) stated that working outside the home, while being a primary caregiver, is associated with less caregiver satisfaction. Lopez presented that a possible explanation was that working in two different places resulted in a clash of roles because neither role could be ideally performed. Also in working outside the home, spare time was notably reduced, struggles at the work site increased and time incompatibility could be very stressful.

Summary. Given the dominance of research on negative outcomes of care giving, one wonders if health professionals are advising caregivers of the potential positive elements of the role. Knowing the degree of a family caregiver's positive feelings can help

determine risk factors and needs. There are some satisfaction scales available to utilize pre-discharge. Tapping into these positive characteristics of individual caregivers is another path for occupational therapists to relieve caregiver stress and burden by maximizing the caregiver's strengths and positive outlook.

As the literature review moves forward to examine successful aging, occupational therapists must keep in mind the particular challenges of aging spousal caregivers. Culture shifts, navigating the enormous and complex healthcare system and taking on the additional burden and stress in caring for a chronically ill spouse can be absolutely overwhelming to the young and middle-aged; while to the aged caregiver, these factors could be detrimental to their health and even life-threatening.

Caregiving and aging well: Successful aging. Back in 1987, the term “successful aging” became popular due to Rowe and Kahn’s published view in the *Science* journal that it was possible to reach advanced age free of age-associated disease and without experiencing significant physiological deterioration (Masoro, 2001). A modified definition by Guralnik (1989) defined successful aging as those who exhibit minimal (rather than no) disease and disability or who exhibit high levels of physical functioning. Other researchers like Manton (1991) defined successful aging as minimal interruption of usual function although minimal signs and symptoms of chronic disease may be present.

Rowe and Kahn in 1999 re-defined successful aging as having three main components: low probability of disease and disease-related disability; high cognitive and physical function capacity and active engagement with life. According to Rowe and Kahn, successful aging is more than absence of disease and more than maintenance of

functional capacities. Successful aging is the combination of both with an active engagement with life that represents the concept of successful aging.

According to Faber (2001) two main perspectives regarding successful aging exist: one that looks at successful aging as a state of being (it can be objectively measured) and one that views successful aging as a process of continuous adaptation. Faber considers Rowe & Kahn's most recent view as the positive extreme of normal aging. Other researchers similarly describe successful aging as the elite of healthy persons or "robust" aging. Yet others, like Faber, see successful aging as successful adaptation of the individual to changes during the aging process. Keith (1990) defined it as reaching individual goals or experiencing individual feelings of well-being.

In Faber's study (2007) data was obtained from 599 participants aged 85 + years in Leiden, the Netherlands. All participants were classified as successful or unsuccessful at aging based on optimal scores for physical, social and psycho-cognitive functioning and on feelings of well-being using validated quantitative instruments. Qualitative in-depth interviews on the perspectives of elderly persons regarding successful aging were held with a representative group of 27 participants. In total, only 10% of the participants satisfied all the criteria and could be classified as successfully aged. Qualitative interviews showed that most elderly persons viewed success as a process of adaptation rather than a state of being. Well-being and social function were more valued than physical and psycho-cognitive function. Using this perspective many more persons could be considered to be aging successfully.

To age successfully according to Rowe & Kahn (1999) one had to meet all three of their criteria making it likely, according to Faber (2001), that only a few of the elderly

would qualify and actually many in number would be excluded from aging successfully due to the presence of chronic illness. “Successful” as a term can imply a contest of sorts where one could be found to lose and therefore be “unsuccessful.” Alternative terms used by researchers more recently now include healthy aging, aging well, effective aging and positive aging (Faber, 2001).

Positive Aging. Rudman (2006) examined the literature on the emergence and evolution of positive aging discourses and was concerned that occupational possibilities were being limited for the aged therefore promoting occupational injustice. Positive aging discourses, Tulle & Winton (1999) offered, are often characterized by a dissociation of aging and disease, an emphasis on postponing old age, a stress on individual responsibility and a focus on activity.

In dissociating aging and disease positive aging discourses re-frame physical and psychological problems that were once considered part of normal aging itself; now these problems are considered resulting from clinical pathology, lifestyle choices or ageism. This view creates a distance between normal or positive aging and pathological or negative aging Rudman (2006) feared. It suggested to the aged that pathology can now be fought through lifestyle choices and medical advances.

Also current discourses on positive aging tend to extend mid-life and push old age into deep old age (Rudman, 2006). Mid-life is an ever-extendible, flexible place of youthful and self-fulfilling life while oldness is to be feared and avoided.

Now it seems that aging has become an individual responsibility controlled by certain proactive behaviors according to Rowe & Kahn (1999). Successful aging is dependent upon individual choices and behaviors and can be attained through good choices and a lot

of effort. And this includes a large amount of productive activity which is “the route to happiness and longevity; to live otherwise is tantamount to a death wish” (McHugh, 2000, p. 112).

With these views on positive aging the discourses have increasingly emphasized two main types of occupations for the aged: consumer-based leisure and body maintenance activities. Both require substantial health, financial resources and a high degree of literacy, which Rudman (2006) linked to occupational injustice. Those older individuals who do not have the financial, health and literacy resources may be excluded from many types of occupations and therefore feel alienated, marginalized and deprived, especially those who do experience severe disability and dependency in later life.

Rudman (2006) concluded her review of positive aging discourses by calling for occupational therapists to recognize diversity in aging persons and enable wider range of possibilities for occupations in later life. Aging individuals are not a homogeneous group; in fact there are differences in gender, cultural background, social class and health, as well as differences in their occupational preferences and needs. There needs to be a change in discourses regarding positive aging at the level of local and national government policy in order to empower aging persons to participate in occupations of their choice.

Successful aging and chronic illness. Kane (2003) stated that the contribution of medical care to successful aging may be found in better management of chronic diseases.

Kane expressed that chronic disease care seems to be the critical issue of the moment because it represents both the current and future reality.

It is a major change for health care Kane (2003) explained, to shift from acute care-oriented practice to more effectively addressing chronic care. With this shift the role of the patient becomes more central. Patients experience chronic illness twenty-four hours a day, seven days a week. Kane expressed that infrequent contacts with the health care system cannot provide the care needed. Patients need to take more control of their health and respond to changing circumstances effectively and successfully. Lorig (1999) agreed, having stated that traditional patient education strategies based on telling patients what to do need to be revisited. The goal is no longer compliance but rather active participation. Patients need both motivation and skills to manage their chronic illness (Lorig).

Another critical need in chronic care emphasized by Kane (2003) is an effective information system that can pick up changes in clinical status. There is also a need for partnerships between medical specialists and nurse practitioners. Specialists can focus on the organ of their interest while the nurse practitioners address the whole person.

In chronic care, Kane (2003) asserted, care is emphasized over cure. A major accomplishment in the context of chronic disease management is preventing exacerbations which can be damaging to patients and costly to society. Shifting the emphasis from cure to care puts great focus on preventing the transition from disease to dysfunction. Kane expressed that this goal is compatible with successful aging.

Strawbridge (2003) looked at successful aging and chronic disease by asking 889 older persons to classify themselves as aging successfully or not. Strawbridge stated that past studies showed that when older persons have been asked what is important in old age

physical functioning is often no more important than socialization, education or community ties. Strawbridge offered that despite Rowe and Kahn's assertion that successful aging is the result of prevention of disease and disability, successful aging could occur in the presence of chronic illness. Strawbridge also expressed that there is evidence that disease and disability control many other aspects of life for older people, such as frequency of activities outside the home, mental health and socialization. Strawbridge suggested that older persons who succeed at aging in spite of chronic disease might be considered the exception.

In his study Strawbridge looked at several questions. These questions included, what proportion of older persons describe themselves as aging successfully? ;what characteristics do these persons have?; how strongly do chronic conditions affect self-rated successful aging? and what prior factors predict subsequent self-rated successful aging?

Self-rating on aging successfully. The results of this question were 50/50 with strongly agreeing and disagreeing. Chronic conditions did influence the answer according to Strawbridge (2003). Two-thirds of those with no chronic conditions rated themselves as aging successfully. With those older people who had one, two and three or more chronic conditions the proportion of those aging successfully dropped to 47.5%, 36.4% and 27.4% respectively. Mobility impairment was also a factor in this study. Strawbridge reported that only 17% of those with mobility issues rated themselves as aging successfully. Strawbridge offered that chronic conditions and symptoms still were not the whole story. Those with no chronic conditions (one-third) still rated themselves as not aging successfully while many with chronic conditions stated they were.

Activities in old age. In the study Strawbridge (2003) stated that women scored higher in activities that involved spirituality, being involved with friends, being in groups and doing good things for others. Men scored higher in describing themselves as athletic and enjoying intimacy. The results indicated that those aging successfully were more involved in a wide variety of activities.

Predictors of successful aging. Strawbridge (2003) showed that the study found that not smoking, being physically active, avoiding obesity, protecting hearing and having good social relationships increased the chances of aging successfully. Strawbridge suggested that each of these factors could reduce the possibility of developing chronic conditions while promoting other health benefits. Faber (2001) added that in her study, successful aging was seen as a process; the successful adaptation to any physical limitations that an individual might have.

Strawbridge (2003) concluded that Rowe and Kahn were correct overall in that avoiding disease and disability are very important components of successful aging. Yet, Strawbridge offered there were still one-third of the subjects with chronic conditions that still rated themselves as aging successfully. Strawbridge suggested that truly understanding what it means to age successfully has to do with understanding why some chronically ill rate themselves as successfully aging while others who are healthy do not. Strawbridge also asserted that successful aging is more than just an individual affair. There needs to be public policies that promote health behaviors and social activism in communities for older people.

Successful aging and caregiving. With longer life spans there comes for the elderly increased dependence on others for tasks they used to be able to perform independently.

As the population of older people expands, so does the population of caregivers, often family members. And this fact has, according to Pearlin (2001), contributed to the intensified effort by professionals and service providers to come up with interventions designed to alleviate the pain and suffering experienced by both caregiver and care recipient. As Hilton (2009) stated the family caregiver is in an ideal position to provide additional insights into the meaning of successful aging in that their everyday lives are profoundly affected by caring for an older adult.

Pearlin (2001) was interested in role disruption with healthy aging and care giving. Pearlin offered that spousal caregivers are often forced to restructure their various established roles and activities in order to accommodate the demands of care giving. Cheung (2004) agreed and added that spousal caregivers have lived through the loss of the partners they once knew and gained changed people to care for. Pearlin expressed that conflicting obligations and roles are not easily reconciled. For many people, Pearlin explained, taking on the additional role of caregiver reverberates unfavorably across the entire range of their other roles.

Pearlin (2001) also considered the stressors that are involved in aging caregivers. Pearlin defined stressors in the care giving context as hardships, demands, frustrations, threats or other conditions that challenge people's adaptive capacities. Pearlin argued that exposure to one set of stressors often leads to other stressors. These stressors can then affect health outcomes. Pearlin explained that health outcomes are assessed by a variety of indicators of both psychological well-being and physical health. According to Vellone (2007) worries about the future, disease progression and stress were factors that lessened the quality of life of caregivers.

Pearlin (2001) then introduced moderators, a component of the stress process that is made up of personal and social resources such as coping mechanisms, social supports and certain self-concepts that regulate or govern the effects of stressors on health outcome. Pearlin explained that moderators are among the constructs used to explain the health differences in people exposed to similar stressors.

Pearlin's (2001) study interviewed 125 adult spousal caregivers to patients with Alzheimer's disease. In looking at role disruption Pearlin found that disruption of people's lives increased significantly once they are involved as caregivers. The demands of caregiving on time and energy reach into multiple corners of people's lives. This is described by Pearlin as stress proliferation.

Pearlin's (2001) look at health consequences in care giving found that women, more than men, experienced depressive affect. Pearlin stated that this was due primarily to role disruption. Also Pearlin found that those most engaged in care giving activities tended to rate their health negatively.

Pearlin (2001) concluded that care giving forces individuals to restructure their lives and roles. He explained that this can be a painful process especially when it involves separation from strong commitments that are part of self-identity. To get rid of or reduce these commitments can bring on feelings of loss and conflict. Yet Pearlin presented that if caregivers resist changes to their routine or ordinary activities, they may feel a sense of letting down a loved one. Pearlin asserted that this conflict of roles and emotions must have an adverse effect on well-being. As Moen (1994) contended, caregiving is more accurately appreciated as the beginning of a process that encompasses many components

capable of affecting people across a substantial arc of their life course, impacting on aging successfully.

Literature Review Summary

The intent of this literature review was to present to the reader the very multi-layered, complex occupation that is family caregiving today. With an increase in chronic illness, shorter-stay hospitalizations and fewer community resources, the demand for family caregiving in the home will continue to rise. And with an aging population that is living longer and producing smaller families, that family caregiver will more and more likely be, in the near future and beyond, an aged spouse challenged with caring for self and loved one. The challenge of future studies of family caregiving will be to gain more insight and understanding of the carers' daily activities in order to better provide training, education and support to this very needed occupation. Exploring elderly spousal caregiving through the occupational science lens of occupation, culture, occupational justice and successful aging can offer new insights for the literature.

Occupation of caregiving. In the literature review, the Model of Human Occupation (MOHO) was introduced. MOHO is an occupational therapy practice model, developed in the early 1980's by Kielhofner, and was presented as a method in which to view the occupation of caregiving.

In the MOHO model, three primary systems exist, of volition, habits and performance. The literature review examined each system and its application to the occupation of elderly spousal caregivers. In utilizing this practice model, some concerns that arose for the occupation of these elderly spousal caregivers were their ability to pursue interests in the midst of their caregiving; their ability to sustain any set habits or routines once taking

on the caregiving role; their ability to perform demanding caregiving tasks with perhaps little or no training and their ability to carry out spousal caregiving in a physical environment that may not support their efforts.

What the proposed study examined was the caregivers' perspective of their daily caring activities, any existing training for their present caregiving performance, the type and amount of care provided every day and any habits and routine that were effective for them.

Culture and care giving. What the literature review showed with caregiving and culture is that there is a divide between formal healthcare professionals and family caregivers. Both of these groups brought their own beliefs, attitudes and values to patient care. Collaboration did exist, but not consistently. The literature proved this with numerous studies on family caregiver stress and burden and unmet needs. Too often there was lack of mutual respect between formal and informal caregivers as evidenced by the dearth of training and education programs for caregivers and caregivers' feelings of alienation and lack of support from the formal healthcare system.

The other aspect of culture and caregiving in the literature review was that each family unit, as a care unit, comprised its own unique culture. Culture was not just race, gender or ethnicity. It was more complex than that and each family brought their own culture to the caregiving occupation as well as to each and every interaction with the formal healthcare system. Sometimes this family culture conflicted with the formal healthcare professional's decisions and goals for the care recipient. Occupational therapists and other health professionals are challenged to examine their own culture and bias as they interact with these family caregivers.

What wasn't well known about these two perspectives on culture and caregiving and what the proposed study further examined was: the elderly spousal caregiver's perspective on their involvement in the management of the care recipient's acute illness episodes in the hospital setting; the elderly spousal caregiver's perspective on how the formal healthcare system responded to their efforts at patient advocacy and ways in which the family culture enhanced and/or hindered the elderly spousal caregiver's occupation.

Occupational justice. The examination of Townsend's social justice and Wilcock's research into health and occupation was not only a review of occupational therapy's professional beliefs and values but an introduction to the emerging practice framework of occupational justice. The theory of occupational justice is relatively new and its application to occupational therapy practice still evolving so there are opportunities to contribute to the body of research already in existence especially with the family caregiving population. What Wilcock, Townsend and others emphasized in the literature review was that humans need and desire occupation to survive and prosper and that occupations should be healthy, successful, active, and have meaning for that individual. If not, there is occupational injustice and the possible occupational deprivation, alienation and imbalance can have negative consequences not only for the individual caregiver and their care recipient, but for the population of caregivers and even society as a whole. Occupational therapists are challenged to think and practice more globally beyond just the individual patient to whole populations, such as caregivers, who could benefit from their expertise in occupation. What the proposed study examined in elderly spousal caregivers was: the type and amount of training and preparation for caregiving that the

caregivers received; the ability or inability of the caregivers to balance daily occupations/activity with the occupation of caregiving; how the community/society had supported their caregiving efforts and if family caregivers identified themselves to others as caregivers.

Successful aging. And finally in the review of the literature in successful aging, chronic illness has changed the definition of what it means to age successfully. Presence of disease doesn't necessarily mean decreased quality of life or well-being. Living well and adapting to chronic illness is acceptable to many elderly individuals. And yet, as the literature showed, society may feel differently. Public programs and policies are currently structured to promote an ideal of successful aging that advocates for individual responsibility in avoiding disease, staying physically and cognitively active and being socially engaged. Unless one has the financial, health and literary resources that are needed, successful aging can be very difficult for an individual to attain. For the elderly spousal caregivers it is even a more precarious situation as they have to manage their health as well as the care recipient's health in, at times, very difficult situations. What the proposed study examined was: how family caregivers monitored their own mental and physical health; how family caregivers maintained active engagement with life while caregiving and how elderly spousal caregivers gained confidence and empowerment in their occupation of caregiving.

Chapter Three

Methodology

Introduction

Informal caregiving is on the rise in this country. Currently, there are 42.1 million unpaid caregivers in the United States, helping adults aged 18 or older (Caregiving, 2009). As individuals age and live longer with chronic illness, there is increased reliance on a loved one to care for them at home. Such care covers a wide spectrum of activities: from running errands and arranging doctor visits to managing wounds, changing diapers and providing 24/7 supervision. In fact many caregiving activities today require more clinical skills than are usually expected of lay people. If this care was provided by government services it would be worth approximately \$450 billion annually (Caregiving, 2009).

Many of the recent studies on caregiving have been quantitative in nature and have focused on the burden and stress that caregivers experience because informal caregiving, while rewarding and fulfilling to some, can also be an emotionally and physically exhausting occupation to many. Often spousal caregivers, aged themselves, are trying to cope with their own health issues and physical limitations while challenged daily to provide the support and care needed by their loved one. These challenges are compounded by inadequate training, lack of guidance and support from the formal healthcare system.

In an environment where public policies limit accessible and affordable family support for care services and an aging population, there is a growing number of occupational therapists and occupational therapist assistants that will be serving as caregiver trainers. It is critical then that occupational therapy practitioners increase their understanding of the family and the caregivers' lived experiences; hear their stories and their descriptions of the meaning of caregiving in order to develop strategies of support and guidance.

The purpose of this study was to describe the caregiving process in a group/sample of elderly spouses caring for their husbands/wives who have chronic, medical illnesses. The researcher sought comprehensive stories from the research participants (based on their knowledge and participation in caregiving) that described the nature and meaning of providing care to a loved one, and the impact caregiving had on their everyday lived experience.

This chapter describes a phenomenological methodology that examined the lived experiences of elderly spousal caregivers and the meaning of their caregiving experience. First this chapter describes the phenomenological research design and rationale. The researcher role and trustworthiness are elaborated. Next, the setting for this study, sampling procedures and the participants are described. Then the study instruments and their development are explained. The orientation and the procedures for obtaining informed consent are described. Next, the data collection and management procedures are explained. Finally, the phenomenological data analysis procedures are described.

Research Design and Rationale

Qualitative Methodology. The present investigation used a qualitative methodology. There is a need for more qualitative analyses in the area of caregiving in order to provide rich and in-depth descriptions of the experiences of family caregivers, not otherwise available (Levine, 2004). A phenomenological approach, a form of qualitative methodology, examined the lived experiences of the care giving process in a purposeful sample of five elderly spousal caregivers.

Phenomenological procedures allowed in-depth examination of the caregiving experience and meanings not experimentally examined or measured, in terms of quantity, amount, intensity or frequency (Lincoln 2000). The study design stressed the socially constructed notions of caregiving and their reality. The situational constraints that shape the understanding of the care giving experience were also examined. This study sought in depth and rich descriptions of the caregiving experience that determined how the process of caregiving was created and given meaning (Lincoln, 2000). In this examination the caregivers were the “experiencers” and were placed in the position of expert, while the investigator was in the position of learner. This qualitative process was a collaborative dialogue between the participant and the investigator (Wilding 2003).

The strength of using a phenomenological strategy in studying the experiences of caregivers was that their own words and own behaviors were the main data source. Qualitative inquiry is useful when studying families because of the focus on meanings, interpretations, interactions and the subjective experiences of the family members (Levine, 2004).

In keeping with qualitative procedures (Creswell, 1998; Lincoln, 2000; Moustakas, 1994; Miles & Huberman, 1994), this research study took place in a natural setting ; methods were utilized that were interactive and humanistic and social phenomenon was viewed holistically.

In terms of a specific qualitative approach, the present study used a phenomenological method that emphasized an inductive, descriptive research process to examine the nature and meaning of experiences involved in caregiving. The task was to investigate and describe all phenomena associated with the caregiving process including human experience. The phenomenological procedures offered a way of systematically studying and learning about caregiving phenomenon that were typically difficult to observe or name (Wilding, 2003).

Phenomenology: Background and procedures. Phenomenology was first described by Immanuel Kant in 1764, as the study of phenomena or things. Phenomenology developed as a reaction to the reductionistic approach in science, which tended to explore factors in isolation and in abstract fashion (Jasper, 1994). Husserl (1859-1938) is generally acknowledged as the founding father of phenomenology. He argued that phenomenon cannot be separated from the experience of them. Further, Husserl (as cited in Jasper, 1994), emphasized that the way to access phenomenon is through pre-reflective descriptions of it, in the person's own words.

The phenomenological approach involved a return to experience and was used in this study of caregiving in order to obtain comprehensive descriptions that provided the basis for a reflective structural analysis that portrayed the essences of the experience (Moustakas, 1994). The goal of a phenomenological approach is to determine what an

experience means for persons who have had the experience and are able to provide a comprehensive description of it. The understanding of meaningful concrete relations implicit in the original description of experience in the context of a particular situation is the primary target of phenomenological knowledge (Moustakas, 1994).

Phenomenology shares a common belief with the 20th century European philosophical movement, which contends that perception is original awareness of the appearance of phenomena in experience (Donalek, 2004). Perception is defined as access to truth and the foundation of all knowledge; perception gives one access to experience the world as it is given, prior to any analysis of it (Donalek, 2004). In caregiving, it is the perception of the caregivers of their own lived experience which will be key in understanding the caregiving experience. Phenomenology recognizes that meanings are given in perception and modified in analysis (Donalek, 2004).

In phenomenology, perception is the primary source of knowledge (Moustakas, 1994) and that source cannot be doubted. Intentions united with sensations equals perceptions. With every perception, one experiences the thing perceived as one-sided; while at the same time apprehending and experiencing the thing as a whole object. Gururtsch (as cited in Moustakas 1994) observed that throughout the perceptual process, the thing in question appears under a multiplicity of varying aspects, which are not only compatible with but also fit into one another. No one or even multiple perceptions ever exhausts the possibilities of knowing and experiencing. New perceptions always hold the possibility of contributing knowledge regarding any object.

This study's phenomenological procedures sought to understand, describe and interpret the human behavior that is inherent in the care giving experience and as stated earlier,

emphasized the perspectives of the persons being studied (Finlay, 1999). In so doing, the phenomenology method is assumed to be grounded in the belief that truth can be found in lived experience. Hence, phenomenological procedures are well-suited to holistic questions of meaning that spring from an experience such as caregiving (La Vasseur, 2003).

Role of the researcher. The role of the researcher in utilizing the phenomenology method, according to Jasper (1994), is to be an objective observer, remote from the subjects being studied and from the research topic itself. The researcher is also focused on applying rigorous techniques to avoid influencing both the collection and interpretation of data. The features of the phenomenology method demonstrate a genuine attempt to ensure that conclusions that are reached come from the data, and not from the interpretation imposed by the researcher.

In phenomenological studies, the investigator always abstains from making suppositions and focuses on a specific topic in a fresh, naïve way (Moustakas, 1994). The investigator constructs a question or problem to guide the study and derives findings that will hopefully provide the basis for further research and reflection.

Husserl (as cited in Moustakas, 1994) referred to the freedom from suppositions as the epoche, which is a Greek word meaning to stay away from or abstain. In epoche the idea is to set aside pre-judgments, biases and pre-conceived ideas about things. There is the process of invalidity, inhibiting and disqualifying all commitments with reference to previous knowledge and experience (Moustakas, 1994). The world is placed out of action while remaining bracketed. However, the world in the bracket has been cleared of

ordinary thought and is present as a phenomenon to be gazed upon, to be known freshly and naively, through a “purified” consciousness (Moustakas, 1994).

Moustakas (1994) regarded epoche as a preparation for deriving new knowledge: setting aside prejudices, predispositions, etc., while allowing things, events and people to enter anew into consciousness and regard them again as if for the first time. The process of epoche, Moustakas (1994) agrees, requires unusual sustained attention, concentration and presence. The thing of study must be delimited in distinction from every other thing, and have a definite identity, a presence that marks it as an entity. We allow a phenomenon to be just what it is and come to know it as it presents itself (Moustakas, 1994).

Although epoche and/or bracketing are rarely perfectly achieved, the energy, attention and work involved in self-reflection and dialogue significantly reduces the influence of preconceived thoughts, judgments and biases. Practiced wisely and with determination to let go of our prejudices, Moustakas believed that the actual nature and essence of things will be disclosed more fully and will reveal themselves and lead to knowledge and truth (Moustakas, 1994).

For this study of caregiving, the phenomenological approach was the most appropriate of all the qualitative methods. Phenomenology allows exploration of rich, multi-faceted, intangible and dynamic phenomenon, such as being, occupation and everyday aspects of life (Wilding, 2005). Phenomenology is a good approach because meaning presents itself in experience, and this is very compatible with the philosophy of occupational therapy.

Setting

The setting was in the homes of the participants and their care recipients. The home was chosen for the convenience of the participants and the desire to conduct the research in the most natural setting of elderly spousal informal caregiving.

Sampling Procedure

The study used purposive criterion sampling procedures (Creswell, 1998) to select a purposive sample of five informal heterogeneous spousal caregivers living in the community. Purposive sampling is defined as deliberate selection of individuals by the researcher based on certain, pre-defined criteria (Creswell, 1998). Purposive criteria sampling is the choice if one wants to select “information-rich” cases for study in-depth.

The following inclusion criteria was used to select volunteers for the study.

Participants were:

1. caregivers of care recipients who had complex medical conditions that result in physical and/or mental limitations that required caregiving to maintain their health, well-being and function, and to continue to participate in life to some degree.
2. caregivers who provided the primary care in the home for at least six months.
3. caregivers who were responsible for at least 10-15 hours of hands-on-care per week.
4. caregivers who are between the ages of 60-85 years of age.
5. caregivers who were willing and able to communicate their perception of their own caregiving experiences.

Participants were identified through peer healthcare team members (i.e. social worker, physical therapist, occupational therapist, speech therapist) and use of fliers in the community. Volunteers were solicited via a discussion and a written statement outlining the name of the research study, the purpose and what would be required of the participant (see appendices A-C).

Participants

The five participants in this study were in the age group of 63-77 years old. There were four women and one man. All of the participants were Caucasian. Educational levels ranged from high school graduate to Masters degree. Every participant had at least one adult child living in the local area. The participants lived in their current homes from 10-37 years.

All of the participants assisted in the provision of activities of daily living for their care recipients. Out of ten identified activities three participants were involved in providing 90% of the listed ADLs; one participant provided 80%; and one did 70%.

Community resource utilization was poor among four of the five participants. Out of ten named resources, 3 participants utilized 10%; and 1 participant utilized 20%. Only one participant utilized 50% of the listed community resources.

In leisure activity participation only two of the five participants engaged in a leisure pursuit on a regular basis, while three of the five rated leisure as very important.

For both physical and emotional states of health at the time of the interview, the participants' self-ratings ranged from fair to excellent with the majority falling in the category of "good."

The following are brief vignettes of each participant highlighting what caregiving meant to them, and the kind of stories they had to offer this study:

Participant One (J.) was a 65 year old white male, who was a high school graduate. He was currently retired but worked in information technology.

J. applied some of his work characteristics to his caregiving. He cared for his wife who had multiple sclerosis. He ran a very organized household, with a daily, precise schedule that centered around his wife's care. He was a very strong advocate for his wife, and when she had hospitalizations or stays in rehab facilities, he was ever present, and very much in control of her care. J. prided himself on being self-taught on her disease and prognosis. He kept up with the recent health studies and literature regarding multiple sclerosis. He would brag that he often knew more than the doctors did.

Participant Two (M.) was a 77 year old white female, with a tenth grade education. She was a full-time homemaker. M. had a background of caring. She grew up in a family of seven siblings where everyone helped raise each other, as her mother had to work long hours. M. commented on how the community where she grew up was very close-knit, neighborly, and everyone pitched in to help each other through hard times or crises.

M. was very empathetic toward her spouse, keenly aware of and sympathizing with his physical and mental losses as well as his struggle to cope with the role reversal this caregiving occupation had created. She described her spouse as frustrated and angry at his general diminishment and her authority over him, and she worked hard every day to build up his ego.

Participant Three (G.) was a 76 year old white female with some college education. She worked in the activities department of a retirement community. G. used her background in activities to engage her husband in creative tasks that kept his mind and body working. She took a lot of pride in that. She expressed that she enjoyed doing activities with him because prior to the onset of his Alzheimer's disease they rarely did things together, even taking separate vacations.

G. was a fierce advocate for her spouse. She often disagreed with physicians' recommendations for his care and she simply didn't follow them. She felt strongly about protecting his dignity and treated him as humanely as possible and that often put her at odds with the formal healthcare system.

Participant Four (P.) was a 63 year old female, white, who has two years of college. She still worked part-time in human resources.

P. had a strong sense of dignity for her spouse. She went to great lengths to keep him immaculate, clean, with pressed clothes. She even kept his memberships to certain organizations current because she believed that was what he wanted her to do. She got overwhelmed by the fact that she was making decisions for him and didn't know what he wanted or what he would do. It was important to her that she do right by him and that she also preserved the essence of him, despite the ravages of his Alzheimer's disease.

Participant Five (B.) was a 66 year old white female with a Masters degree in social work. Being familiar with healthcare, B. prided herself on being a very outspoken advocate for her husband, in the hospital and other facilities. She was not afraid to confront other care providers and she made sure there were always some family members present with him 24/7.

B. expressed a lot of disappointment in family for their lack of help and lack of understanding of what she was going through. It was important to B. that she maintained a social life and she did to a limited extent. She utilized paid help to get her out of the house. Because her stress and her lack of patience were so difficult for her to handle, she expressed her need to get out and scream loud and often as a release. Her spouse had Parkinsons and beginning of dementia and her constant vigilance over him to keep him safe, as well as his inability to interact with her as he once did, caused her a lot of tension and sadness.

Instrumentation

Typically, in the phenomenology investigation, the long interview is the method through which data is collected on the topic and questions. The phenomenology interview involves an informal, interactive process and utilizes open-ended comments and questions. A guide developed in advance is helpful but the researcher needs to be prepared to vary, alter it or not use it at all when the participant shares the full story of his or her experience (Moustakas, 1994).

The central questions of this research study were, what is the caregiving experience? And what is the meaning of caregiving? The goal was to find comprehensive stories from the research participants (based on their knowledge and participation in caregiving) that described the nature and meaning of providing care to a loved one and the impact caregiving had on their everyday lived experience.

Interview guide. Topical questions (Creswell, 1998) were the actual interview guide and these questions were based on the components of the literature review. Content validity of an interview guide is essential. Content validity is considered the most basic

form by which an instrument is validated (DePoy, 1994). Ideally content validity is achieved through specification of the full domain of a concept through a thorough literature search and by adequate representation of domains through the construction of specific items (DePoy, 1994).

Content validity of this interview guide was obtained through submission of the constructed questions for review by several qualitative research experts familiar with occupational therapy and caregiving. With feedback, the questions were revised in order to maximize the capability of achieving good understanding of the lived experience of caregiving. The completed interview guide was also pilot tested with three-five participants to help determine the guide's relevance, and ease in use.

The Moghimi Care giving Interview Guide. This interview guide had four content areas: culture of the caregiving process; occupational justice in caregiving; the occupation of caregiving; and successful aging with care giving. The culture section was designed to gather data on interactions with formal caregivers and examine informal caregivers' perceptions of care within the healthcare system. The occupational justice section was designed to gather data on the informal caregivers' perceptions of their preparation for caregiving; their ability to manage their time and maintain their health and well-being as well as information regarding the caregivers' perceptions of available community resources for caregiving. The care giving occupation section was designed to gather information on the caregivers lived experiences of caregiving, eliciting descriptions of what the caregivers did on a daily basis as well as descriptions of the demands and rewards of caregiving. The caregiving occupation section also asked the caregiver to describe how the process of caregiving evolved. And finally, the section on

successful aging was designed to explore the impact of the caregiving process on the ability to age well and asked the caregiver how caregiving has affected their quality of life; description of activities they engage in to educate themselves and keep active and descriptions of their social network. See appendix D for a copy of **The Moghimi Care giving Interview Guide**.

The Moghimi Care giving Interview Guide was pilot tested with seven individuals. Results were that minimal details and stories were elicited from participants so it was decided that the questions needed to be expanded. Therefore four separate interview guides were then developed. The four interviews focused more in-depth on the four content areas found within the original interview guide: culture, occupational justice, occupation of caregiving and successful aging. The questions in each interview were focused on eliciting stories; details of day-to-day caregiving activities and descriptions of challenges and rewards. Participants were encouraged to speak about particular experiences located in time and space, during which they felt directly connected to the caregiving phenomena. These interviews were pilot tested with one-two participants. See appendix E for copies of interviews numbered two-five.

The Care giving Demographic Questionnaire. There was also a questionnaire given to all participants that covered basic demographics as well as some questions regarding health, utilization of resources and leisure activities. See Appendix F for **The Caregiving Demographic Questionnaire**.

Data Collection and Management

The process of collecting information involved primarily in-depth interviews. The important point was to describe the meaning of a small number of individuals who have experienced the phenomenon. Interviews were audio-taped, and then transcribed.

Interview Protocol. The first interview was to establish rapport, complete the Demographic Questionnaire and explain the process of the next four interviews to come. At the completion of each interview, the researcher composed field notes in a journal writing down overall impressions and any unusual or outstanding responses that needed to be remembered. These field notes also served as a “bracketing” technique; writing down thoughts, responses and decision-making processes that could be acknowledged while certain biases, pre-judgments and preconceived ideas regarding caregiving could then be set aside. After reflecting, a contact summary form was utilized to summarize the major points that came across in the interview regarding the four contextual areas: occupational justice, culture, occupation of caregiving and successful aging. Within 24-48 hours the interview was transcribed and “proofing” the interview took place by reading the transcript again alongside the source audiotape. Upon the completion of the transcription an appointment was made with the caregiver to have a telephone conversation with them in order to summarize and verify the previous interview. An introduction to the next interview was then introduced and scheduled.

Organization of data begins when the researcher places the transcribed interviews before him or her and studies the material through the methods and procedures of phenomenological analysis (Moustakas, 1994).

Using the computer for qualitative coding helped to organize the large amount of data from the study. *A Practical Guide in Doing Qualitative Research by Computer* by Hahn, (2008) emphasized coding by Levels One, Two and Three and while not directly corresponding with any existing method, this computer coding process fit nicely with Moustaka's (1994) Modification of the Stevick-Calarizzi-Keene Method in regards to data reduction; horizontalization and grouping data into meaning units.

Level One coding is about initial open coding where large quantities of raw qualitative data are focused and labeled. This process was completed in this study by taking every participant transcript text and saving it to a code document file in Word. Paragraph breaks were created every time a different person started speaking, for example the interviewer. Each code document was then formatted with a row counters column, a column for Level One code descriptions and then a column that held the transcript. (The row counter allowed identification of the location of each Level One code and its accompanying data). Once the format was set, then it was time for the researcher to read, think, identify/create Level One codes and memos. How this was accomplished was that the formatted code document was read through: when a passage appeared that was relevant to answering this caregiving study's research questions, then a code description was written in the middle column. In general, a Level One code is just a thought captured in a phrase that can help answer research questions. Level One codes are meant to be created rapidly without undue deliberation or an immediate attempt at duplication or categorization. In this study of spousal caregiving, the question that was asked in the Level One coding process was, can the data that inspired the code be used to support a theme that helps answer the research questions?

Along with the Level One codes, memos were also created. These memos were used to identify facts, events or any other ideas that were deemed important to the study. Memos provided descriptive scaffolding for the study. According to Miles and Huberman (1994), memos are conceptual in content. They tie different pieces of data together in a cluster or they show that a particular piece of data is an instance of a general concept. Memo use in this study was a rapid way of capturing thought processes that occurred all the way through data collection, data reduction, conclusion drawing and final write-up. The memos were placed in the same column as the Level One codes and were then formatted into a table of contents at the end of each transcript. At the conclusion of this process this study had 381 Level One codes and numerous memos per participant.

Data Analysis

The purpose of data analysis in phenomenology is to preserve the uniqueness of each lived experience of the phenomenon while permitting an understanding of the phenomenon itself (Banones, 1989). The next step following Level One coding was Level Two coding with the goal of bringing order to the free-form chaos of Level One codes. The purpose of Level Two coding was to create categories from groups of Level One codes by utilizing observations, ideas and perceptions. Level One codes and the data immediately associated with those codes were drawn into a central data depository during Level Two coding.

In order to complete Level Two coding, Level One code phrases were copied from the middle column of the Word code document to a blank row in the Level One column in an Excel spreadsheet. Then the text data associated with the Level One code was copied and placed in the raw text data column in Excel. A binomial identifier was created that

related the record to a specific code document and row number in that document. This identification process allowed the researcher to more easily locate specific information in the coded document. To create new Level Two codes, the new code name was typed in a new row in the Level Two column. Each new level Two code was copied onto a column that lists Unique Level Two code names. As the researcher went through this process with each Level One code the basic questions asked were, did the data fit into an existing Level Two category or did the data represent a new Level Two category? And if a new Level Two category was to be created what should it be called? Level Two codes were then created. In this study, from a total of 381 Level One codes, 47 Level Two codes were created.

As with Level Two coding, Level Three coding focused on a many-to-few relationship. The goal was to find multiple Level Two codes for almost every Level Three code group. This meant that the Level Three code descriptions had to be broad enough to encompass multiple Level Two codes.

Level Three coding was completed away from the computer. Described by Hahn (2008) as “old school” research, Level Three coding is done with scissors, paper clips and a long table. The steps of Level Three coding included: organizing the Level Two groupings; printing the entire code sheet; cutting the printed reports to keep Level Two groupings intact and placing all the Level Two code sheets on a large surface (table or floor). The goal then was to find multiple Level Two codes that could be grouped together to support coherent themes. The Level Three groupings took shape as small piles of Level Two code sheets. After creating some viable Level Three code groups, pieces of scrap paper were used to write down names for each of the Level Three code

groups. These tentative names were placed on top of each pile. These piles were revised often, throughout days or even weeks, to review, reflect and to change things around as a result. The final Level Three codes became the Meaning Units.

After tentatively deciding on the meaning units, one other tactic for generating meaning was employed and that was counting. In qualitative studies, according to Miles and Huberman (1994), numbers tend to get ignored. Qualitative research often takes pride in going beyond how much there is of something, to tell about its essential qualities. However, when a pattern or theme is being identified, something is being isolated that happens a number of times and it consistently happens in a specific way. The “number of times” and consistency judgments are based on counting. Miles and Huberman state that there are three good reasons to resort to numbers: a) to see what you have b) to verify a hypothesis and c) to keep analytically honest.

In utilizing a quantitative counting method, four tables were created, for each topic area of the study: occupational justice, caregiving culture, occupation of caregiving and successful aging. Under each topic area, the relevant meaning units from Level Three coding were listed. Across the top of the grid were listed participant one through five. The number of responses per participant per meaning code were written and tallied. High number of responses corresponded with number of participants who experienced that meaning unit. The stronger (higher) numbers helped to validate the selection of that meaning unit; weaker (smaller) numbers were either combined, blended with a stronger meaning unit as appropriate or just not used.

At the conclusion of Level 3 data analysis, meaning units were identified and grouped under the four categories of the caregiving experience: occupational justice, culture, occupation and successful aging.

Starting with Participant One and the first category of occupational justice, the search began for what occupational justice meant for that participant and the quotes that would support particular ideas about occupational justice. Participant One's transcripts were reviewed several times to ensure all relevant quotes were captured and placed under the appropriate meaning units of occupational justice. Once placed, each quote of Participant One was reviewed and then memoed. Memoing, in this part of the study, according to Denzin and Lincoln (2000), can aid in linking analytic interpretation with empirical reality. The raw data is brought into these memos so that those connections can be maintained and examined directly. Through memo writing, one can elaborate processes, assumptions and actions that are subsumed under the codes. Memo writing leads to exploration of the codes; thus the codes take on substance as well as a structure for sorting data.

Once the quotes and memos of Participant One were in place for each meaning unit under occupational justice, phenomenological analysis began with an **individual textural description** of the experiences for Participant One. Individual textural descriptions describe the nature and focus of the experience for that participant utilizing the verbatim examples and memos from the transcribed interview. Participant One had an individual textural description for each of the meaning units under occupational justice, which equaled four.

After the individual textural descriptions were written for Participant One, **individual structural description** was constructed on Participant One's experience of occupational justice in caregiving. Moustakas (1994) describes the individual structural description as providing a vivid account of the underlying dynamics of the experience, the themes and qualities that account for "how" feelings and thoughts connected to that particular experience are aroused.

This process in examining occupational justice in caregiving was repeated for the rest of the participants: reviewing relevant quotes from the transcripts; placing the quotes under the appropriate meaning units; memoing; constructing individual textural descriptions, and completing an individual structural description.

When all the participants were reviewed for their experiences with occupational justice, then a **composite textural description** was constructed. A composite textural description is composed from the total group of individual textural descriptions. The invariant meanings and themes of every co-researcher are studied in depicting the group as a whole (Moustakas, 1994).

Following the composite textural description, a **composite structural description** was composed. The composite structural description is a way of understanding how the participants as a group experience what they experience. A composite structural description is constructed from the individual structural descriptions of each research participant and the use of imaginative variation. The task of Imaginative Variation is to seek all possible meanings and divergent perspectives with the aim of arriving at structural descriptions of the experience and the underlying and precipitating factors that account for what is being experienced. The question asked is how did the experience of

the phenomena come to be what it is? The uncovering of the essences and focusing on pure possibilities is central to the imaginative variation process. In this place of the process the structures of the experience are revealed: these are the conditions that must exist for something to appear. It is the methodic procedure through which we raise our knowledge from the level of facts to the sphere of “ideas.” The thrust is away from facts and measurable entities and toward meanings and essences. Through imaginative variation, the researcher understands that there is not a single inroad to truth, but countless possibilities (Moustakas, 1994). The steps of imaginative variation include:

- 1). systematic varying of the possible structural meanings that underlie the textural meanings- reading through and analyzing each participant’s textural description.
- 2). recognizing the underlying themes or contexts that account for the emergence of the phenomenon- looking for commonalities and shared experiences, shared opinions of the phenomenon.
- 3). consider the universal structures that precipitate feelings and thoughts with reference to the phenomenon, such as the structure of time, space, bodily concerns, materiality, causality, relations to self or relation to others- conceding the commonalities and shared experiences in reference to the caregiving experience, their relation to their spouse, their level of activities and their emotional state.
- 4). Searching for exemplifications that vividly illustrate the invariant structural themes and facilitate the development of a structural description of the phenomenon- look for the strong statements.

The composite structural description, as Moustakas describes, is a way of understanding how the co-researchers as a group experience what they experience.

The final step of Moustakas phenomenological model was the integration of the composite textural and composite structural descriptions with the goal of providing a synthesis of the meanings and essences of the experience. This integration is called the **textural-structural synthesis**. This synthesis gives practical expression to the concept of intentionality, of outward meaning and inward consciousness. And at the conclusion of this synthesis, themes emerged that addressed the study's research questions.

For each of the four content areas of the caregiving experience, all of these steps were repeated across participants so that per participant there were organized quotes and memos, textural descriptions, and a structural description of their experience with that content area. Per content area there were all the quotes and memos from all participants, the composite textural description, the composite structural description and the textural-structural synthesis with the resulting themes.

With phenomenology there was significant methodology to investigate the care giving process to gain knowledge of this lived experience from a state of pure consciousness. Moustakas (1994) encouraged the researcher to see naively and freely again, to value the conscious experience, respect one's senses and move toward the inter-subjective knowing of things, people and every day experiences. Phenomenology offered the opportunity to research and relate caregivers' stories to those who could positively affect their quality of life.

Chapter Four

Results

Introduction

As stated in Chapter One the study reported here examined the lived experience and the meaning of the caregiving process of elderly spousal caregivers. A qualitative phenomenological approach was used to examine the caregiving process of five elderly spousal caregivers. A series of interviews was conducted with each of the five participants. The caregiving process was examined from the following four theoretical perspectives: culture, occupation, successful aging and occupational justice. The following research questions were answered by four themes that emerged from the analysis of the data. The questions were: a) What is the culture of caregiving? b) What is the occupation of elderly spousal caregiving? c) How does caregiving impact the ability to successfully age? and d) What are the dimensions of occupational justice in the caregiving process? The answering themes were: a) The culture of elderly spousal caregivers is one of forced self-reliance, b) The occupation of elderly spousal caregiving centers around concern for keeping the care recipient safe, c) Elderly spousal caregiving challenges the ability to age successfully and 4) Elderly spousal caregiving is an unjust occupation.

This chapter is the result of phenomenological inquiry of the caregiving experience for five elderly spousal caregivers. The data presented is the outcome of a systematic and

methodological exploration of what appears to the subject and the manner of its appearing, with the specific goal of describing and elucidating the nature of the phenomenon of elderly spousal caregiving as an essentially human experience.

This chapter is organized by the identified themes with a presentation of the relevant data, its relationship to the study and individual participant experiences. (Numbered participants will be indicated at the end of each quote).

Theme 1: The Culture of Elderly Spousal Caregivers Is One of Forced Self-Reliance

The culture of elderly spousal caregiving entails forced self-reliance for two reasons: (a) there is a culture clash with formal healthcare and (b) family are not always willing and/or available to provide the needed assistance.

A culture clash with formal healthcare exists because both families and health professionals have distinct cultures which affect their priorities and actions in the care of an elderly, ill person. From the formal healthcare provider's perspective, elderly spousal caregivers often bring their particular standards of care to their spouse's bedside. In their daily occupation of caring in the home, these elderly spouses have established routines and care habits. Their routines and care habits are often time-based and performed in a specific manner that is familiar and acceptable to the caregiver and care recipient. These established routines and care habits may not assimilate easily into a healthcare facility's schedule nor a healthcare provider's job tasks. One participant described the discrepancy between her care in the home and what she found in a facility:

They put the patients on, like, pads. They don't diaper them because it is easier for them to let him go all over the pad and then just clean it up. The problem is you don't want to do that. And I don't blame him. It is not acceptable. I don't care what your standard operating procedure is (P.#5).

These elderly spousal caregivers expressed their difficulty in giving healthcare professionals control over the care of their loved ones. The spouses described being disheartened by what they deemed sub-standard or inadequate care in healthcare facilities, such as incontinent care management, inadequate meals, inattentiveness of staff and medication management. As a result, these elderly spousal caregivers often chose to provide hours of hands-on care during their loved ones stay in healthcare facilities. This was done to ensure that care was performed up to their standards. They chose to do this care instead of taking a respite from caregiving while their loved one was in a healthcare facility. One participant described how she never left her spouse's side: "Well when he got operated on his back I stayed, actually stayed at the hospital with him. I slept in the room and everything" (P.# 2).

Besides control of care and standards of care the culture clash between formal and informal caregivers is also formed around mistrust. This mistrust is borne from these elderly spouses' perspectives that the formal healthcare provider does not possess adequate knowledge of the care recipient, and worse, doesn't take the time to learn more. One participant described a healthcare visit that was devoid of curiosity, compassion and time:

Throughout her illness I have consistently found healthcare professionals who were incompetent, who were less caring than they should be, who are too busy to give you the time you deserve and need. You see a healthcare provider, depending on who it is, for 15 minutes twice a year or whatever the schedule may be, and they miss things too easily; they just don't give you what you really need. They don't ask about your house, they don't know who you live with. And they just send you out with a prescription and you are done (P.#1).

Another participant shared a similar experience with a doctor visit in that it was quick

and lacking care:

Dr. says hello, how are you and charges me \$100.00. I wrote a letter and said that is not what I consider a doctor appointment or a check-up from the doctor. He did not check his walk, his gait, did not take blood pressure, he didn't do anything (P.#3).

In the culture clash with formal healthcare, these elderly spousal caregivers' perspective is that they hold the most knowledge of the patient and that they have made the effort to train and educate themselves about the diagnosis and prognosis far beyond what they hear from the formal healthcare providers. One participant expressed how he felt he had to step in and learn about his wife's care and condition because the professionals have let him down:

Now I train the doctors and nurses. And that shouldn't be the case. I don't have a college degree. I have no formal medical training at all. But it is the case. I wind up taking charge. Because the professionals do a lousy job. They do an inadequate job. Maybe they are just pressed for time. But they don't do an adequate job (P.#1).

Another participant experienced this clash of knowledge of the care recipient in a patronizing exchange in a healthcare facility, where she was initially disregarded until the care recipient proved to be too difficult for the healthcare professionals to handle:

Emergency rooms, things like that are just terrible for people that have dementia because the staff and its..no matter how clearly you say it they don't believe you. Because they look at him and they think: oh he is fine, but he is not fine. They insist on asking him questions and trying to put him through stuff and he would give them nonsense answers. Well you have to keep pushing to say I need to stay with him and he can't really go off for a test by himself. He doesn't understand. And they don't want to accept that. They just think you are overprotective or something. And then when they got exasperated, then they would say could you help us with this? (P.#4).

Other participants described similar situations in which the healthcare personnel only utilized them as a resource of last resort. When the participants were finally consulted, regarding their spouse's condition or care, they explained that they felt that they were not

necessarily heard nor did their opinions seem to matter. This disregard of the spousal caregivers' opinions are reflected in this following passage:

When I take him to the family doctor, he says he should get out and walk/exercise. I said, you don't understand, my husband's feet don't work right and he can't walk, and when he walks any distances his back kills him. I said he is getting to the point where I would like to have an electric chair for him to get around. The doctor says no, he doesn't need it. He wants him to get the walker, which he has; but I said what you don't understand is he can't walk far and it hurts his back so bad. The doctor fights me for that, and I get very angry with the doctor (P.#2).

This same participant expressed similar feelings when her spouse was hospitalized. Her husband's healthcare providers disregarded her concerns about his behavior, and therefore they did not address her feeling that something was wrong:

They were giving him medication for pain, and I said something is wrong with him. He is hallucinating, and I felt like the drugs they were giving him for pain were too strong. Because actually he was hallucinating and when they gave him medication to come home, I actually had to rush him back to the hospital that same night because he couldn't breathe (P.#2).

The cultures of formal healthcare and elderly spousal caregivers shared a common concern for the health and well-being of the care recipient. However their approaches to this end widely differed and these differences, from the perspectives of the participants, were exacerbated by mistrust, miscommunication and lack of respect. These elderly spousal caregivers expressed that they did not receive the needed assistance and support from formal healthcare providers.

Lack of family involvement. Experiencing alienation and perceived diminishment of their role from the formal healthcare system, these elderly spousal caregivers often turned to family members as a possible resource for assistance in caregiving. Yet family, even if they were geographically close, were not always a reliable source of help.

These elderly spousal caregivers had expectations of family members when they visited. The caregivers hoped to receive some kind of hands-on assistance whenever family was present. Instead the participants experienced very little initiative and a sense of helplessness from family members. These participants described this behavior as a lack of the family members' understanding of their caregiving demands and stress. One participant described her response to the family's lack of understanding and lack of support in the following manner:

The best thing is to figure out how you are going to manage it and not be counting on other things or other people because you can't. I just found I was better off if I just figured that I was going to be the one and how was I going to do it with what I had. I mean family is a good example. They are afraid of being alone with that person. They don't know what to do, and they would tend to not do anything except relay the message: I think he is restless, I think he might want this...I thought they could be more helpful (P. #4).

These elderly spousal caregivers reported that their reality was not their children's reality. The children were not involved in the day-to-day care so they could not relate to their mother's or father's world. Their lack of understanding turned family concerns into criticism as they witnessed how the elderly spouse struggled with care. Regarding one such unwelcomed critique, a participant stated, "My caregiving has strained relations sometimes with the children. You know, you are taking on too much, you shouldn't be doing it and then they get mad at me for doing too much" (P.#5).

Along with this lack of understanding and the criticism of their parent's caregiving situation, some family members, these participants explained, exhibited denial of the care recipient's declining health as well as the true nature of their increasing caregiving needs. This denial was illustrated during a mother-daughter interchange regarding her father's caregiving:

I can get down. So my daughter, it is hard to explain to her. You know. She will say why don't we do this? I try to explain to her how much her father is deteriorating. She can't see that. But I said that you have to see him every day...and I say I can't take Daddy out. I don't think she believes that her father is really that sick and that he is deteriorating that much. She doesn't come over a lot (P. #3).

These elderly spousal caregivers recounted experiences with various family members who offered little time or commitment toward helping with caregiving. Although these caregivers were disappointed in their family members' behavior, these caregivers themselves offered that their family members were too busy, and that such a request for help, at times, was too much to ask from them. One participant expressed the situation this way, "Well the people who are close to me are busy. They don't have the time. And that includes my children. And actually, I would feel like I was imposing on them" (P. #2). Further, these participants also rationalized that their children had their own lives so they could not really be expected to help them with caregiving. This rationalization was demonstrated in the following description:

One daughter always works night shift. And has a lot of time some days and at other days has no time. And the other daughter works up to the last minute every day and every couple weekends she has to work Saturday and Sunday 8-hour days. She is a single mom- has a 6 year old. She has to find care for him or take him wherever she goes. And getting to bed early because he goes to school. So her time is pretty limited (P.#1).

Participants described even more disappointment in their children or other family members when they made empty promises, or hesitated to offer help, after having stated that they would be there or they would do this and that. For whatever reason, this help never materialized. One participant described her physician son's reluctance to help:

I don't get it. I mean we have one son who is a physician. So when a medical problem comes up I call him. Well he told one of the other kids

that he is not his father's doctor. And then I thought well you know, damn it, you are the only doctor in the family. And this may not be your specialty but you got an understanding that I don't have (P. #5).

Another participant described his disappointment in his family's lack of support:

If you need help let me know. I say okay and they leave. They don't mean I will give up my golf game to come help you. They don't mean I will take off a day from work to come help you. If you need help you have to tell us. So I say I sure would appreciate it if someone could come in and sit with her for a couple of hours so I could wash the car and she said cleaning the car is not on the list. It is not a priority. But you see that is what I needed (P.#1).

One participant offered some insight into her family's lack of involvement in terms of her reluctance to ask for such help:

I was not good at telling people what I needed. So I would just like, downplay that. You are not sure how receptive the person is going to be in helping anyway. But that was one part of it that I was not good at, and so like sometimes when I could have really used a break, I didn't go around screaming my head off saying oh my god somebody has got to help me. I usually don't try to get help from someone else unless I really can't do it (P. #4).

Ultimately, for these particular caregivers, turning to family for assistance and support was a disappointment. Although there were many reasons and excuses from both caregivers and family members these spousal caregivers tended to be the only provider of care in the home. And at the end of the participant's caregiving day, the reality was that formal healthcare providers did not present adequate help, and family members did not fulfill their needs. So the culture of these elderly spousal caregivers had become one of forced self reliance in that the caregivers rely on themselves as the sole care provider in their home, for learning the necessary information and techniques in order to provide optimum care to their loved one.

A Culture of Forced Reliance: Other Cultural Beliefs and Values in

Elderly Spousal Caregiving. The culture of elderly spousal caregiving, besides forced self-reliance, embodied loving obligation, experiences of joy and a tradition of caring. Loving obligation is a value and/or belief in spouses taking care of each other out of love, gratitude and commitment. Experiences of joy reflect the spousal caregiver's ability to embrace the positive aspects of their chosen occupation of caring despite the burden. All of the participants had a tradition of caring for family members that they relayed with a sense of pride and accomplishment, as well as a belief that this background was helpful in bringing specific skills and abilities to their current caregiving situation.

Loving obligation. The culture of elderly spousal caregiving is where the caregiving process begins; a deep sense of obligation and desire to take care of one's spouse. Loving obligation was expressed by these participants in two ways: a sense of commitment and as a feeling of gratitude.

Commitment. With their spouse getting sick and in need of caregiving, the participants expressed genuine surprise that any other option other than their assumption of the caregiving role would have even been considered. As a spouse and life partner, the participants described their commitment to their loved one as being present in sickness as well as in health. They described themselves as immediately stepping up to the role when illness struck and not considering any other alternatives for care. One participant explained her decision-making when the time came to provide care for her husband:

Well I didn't think otherwise. I mean of course you would do that for your spouse. To me it was the natural thing to do. I just wanted to take care of him. He needed help and of course it would be me. If your spouse doesn't do it you are in pretty bad shape (P.#4).

There existed among these elderly spousal caregivers such a large feeling of love and happiness towards a life shared and enjoyed with their spouse that they considered provision of care as part of their life commitment. One participant described her caregiving commitment as a moral obligation, the right thing to do:

Well if it is the people you love, it is, I think it is not only an obligation to do it. I think you do it out of love for him, the care of the person which when it is your family, it is not an obligation really. It is just something you should do. And I think you should do it. To me if you don't, if someone is in need and you can't do that, I don't want to live with that later. Something happens to that person, you regret when I could have done it (P.#2).

Gratitude. Feelings of loving obligation can also come from gratitude. These participants expressed feelings of gratitude for all that their spouses had provided them throughout the years: the hours worked; the raising of a family; the provision of basic life needs and more. There seemed to be a strong need and desire among these elderly spousal caregivers to return that generosity with care. One participant expressed this desire:

I have had a wonderful life. And I am very lucky. And I appreciate. He has worked very hard for his family. All his life. And he deserves to be taken care of. Course he is a very good person. He sacrificed a lot. So he deserves the best care. To take care of him all he had done for us all his life, you know, its like being able to give back, you know? (P.#2).

Another participant offered similar feelings of appreciation for a good life:

But it was just..I didn't even think about it, taking care of him. I mean you just don't think about it, these things. It is not like that. He took care of me most of our married life. And then it was just a natural step to be his caregiver (P.#3).

Loving obligation was really these elderly spouses' way of stating their determination to care for their ailing spouse. These participants were determined to provide care despite their own advanced age, health issues, lack of resources, training or help. It is important for health professionals to know how deeply embedded this sense of commitment is for elderly spouses. Formal healthcare providers need to put forth more effort into preparing these spouses to provide the care that they want to give successfully and safely.

Experiences of joy. Another cultural belief that these elderly spousal caregivers brought to the caregiving process was that there can be joy in caregiving. In the interview process, among the many recitations of daily caregiving burden and stress, there were also a variety of stories offered by the participants that brought smiles, laughter and good memories. To seek and successfully find positive aspects of caring for a loved one, who is declining in function and is in need of so much care, speaks to the love and commitment of elderly spousal caregivers.

Joy can be found in just the feeling of fulfillment; giving of oneself to help someone they love. One participant described her caregiving role as one that brought her positive self-esteem and satisfaction:

I think caregiving gives you self-worth. Certainly it gives you self-worth. Because it makes you feel like you are here for a reason: you are doing something good even though it is not something material-wise, you know what I mean? You can give money and you can give things but to give yourself is so much more gratifying to me and it stays with you too. Where if you give them a material thing or money it is gone, that is it. I think it just stays with you. If you give it out of love it stays. Absolutely worth it (P.#2).

For another participant, her spouses' illness changed him in ways not expected, such as now enjoying music and singing, which she had always loved. It was a delight for her to share these moments:

He also never liked music, he never would sing. It was just, sort of a family joke. But suddenly he liked music. Sometimes I could get him to clap to the time. And that is one of my happiest times. Because it is something we can share. He loves music and I love music and we can sit there and sing (P.#3).

One participant found and appreciated the strangers who came around to help spontaneously. For her, it was a very positive aspect to a difficult situation:

But I tell you, there are so many wonderful people in the world, like people would come, you would be in the parking lot when we had difficulty getting him out of the car and all of a sudden somebody would come over and say 'oh I have seen this before. Why don't you let me try?' Because sometimes with the different person, then they do it. Lots of people did this. And they would help with you know, holding the door, I mean like all kinds of things (P.#4).

The joyous moments that these elderly spousal caregivers experienced were precious few, but those moments seemed to have sustained them through their daily obligations of care.

Tradition of caring. For this generation of caregivers, it is not unusual to find some background or previous experience in caregiving. Many of today's elderly spousal caregivers grew up in multi-generational households and lived a tradition of family taking care of family. Thus many of the participants had themselves cared for family members, such as siblings, parents, aunts and uncles prior to their current spousal caregiving. Having this kind of background helped the participants in two ways. First, the experience of caring and the development of particular skills contributed to the participants' preparation in caring for their spouse today. Secondly, being raised in this tradition of

caring helped to reinforce and reassure the participants in their commitment and obligation to spousal caregiving.

One participant had a strong family history of caring; she grew up with it. She felt that caregiving was natural to her because she is a woman:

Well growing up, I came from a large family. A family of seven. One took care of the other one. And as you know, when you are growing up and maternal instinct....you are, that comes natural from a woman taking care of babies, taking care of people, it's a natural instinct. So its there, you just develop it. I mean its all there. And it just come naturally. I mean you take care of people, of children with colds and flus, you know. Coming home with their operations, my daughter; I had to take care of her, she had a gall bladder removed. And she had a child and she was more of a child herself so I helped her with that to take care of him, and more or less, when you come from a big family in the era that we came from, you take care of each other growing up (P.#2).

Another participant had experience of caregiving early on in his childhood and he described the lessons of family caring that he learned at such a young age:

When I grew up I had a sister who was a year and a half younger than me. She was very disabled. She had an extreme, extreme case of scoliosis. And was very disfigured and very disabled. She died early. She died some years back. So I grew up not only having to look after her, of course, there were times when I didn't physically care for her but helped look out for her welfare. The kids at school who were playing around made fun of her. So I got used to the culture of a family with a disabled family member (P.#1).

Difficult and challenging family illnesses were dealt with by some of these participants who had to overcome their fears and stress to provide the care that was needed. One participant described caring for her sibling who had a life-threatening illness:

He (brother) had throat cancer and I had to put the tube in the hole in the throat and pump, you know, the lungs. That frightened me because I didn't know what I was doing. They showed me and when I put that tube

in his throat sometimes he would make noises and I thought I was killing him you know. I am not a nurse. I am not a doctor. You know. But the lady that came, the nurse, she came and she said let me see what you are doing and I showed her and she said that you are doing fine. And she sort of gave me encouragement that I was doing it right, you know. She never came back (P. #2).

Many of these participants have put themselves in very challenging, stressful situations in order to provide care to loved ones. In the recounting of their experiences there seemed to be no hesitation in choices made, including the choice of now caring for their spouse. Tradition of caring speaks to the strong value system these participants had of being there for family, whatever the personal cost.

Within a culture, there is a set of beliefs, values and practices that define how that culture interacts with the world. The elderly spousal caregiving process, as defined in this study, started with culture. Feelings of loving obligation and gratitude led these participants to care for their spouse. A background of caring gave them some experience, skills and reassurance that the choice they made was right for them. An ability to seek and experience joyful occasions in the midst of 24/7 caregiving sustained them. However, in this study, what was evident in the elderly spousal caregiving culture is that with a presence of a culture clash with formal healthcare, and family not consistently available, the spouse assumed nearly the entire responsibility of care provision. The only one to count on was themselves, and that made the occupation of caregiving so much more difficult.

Theme 2: The Occupation of Elderly Spousal Caregiving Centers around Concern for Keeping the Care Recipient Safe

The occupation of caregiving was described in this study as the act of providing unpaid assistance and support to family members who have physical, psychological or developmental needs. The participants in this study provided direct basic care tasks such as dressing, bathing, toileting and mobilizing their spouse. Dressing tasks involved both upper and lower body either while the care recipient lay in bed or was sitting in a chair or at edge of bed, if able. Bathing was accomplished either at sinkside, or in shower stall. Toileting involved transfers to the toilet, managing clothing, hygiene and incontinence management if needed. Mobilization of the care recipient involved bed mobility, assistance to stand, and managing any mobile adaptive device. As their caregiving had continued over time and as the care recipients declined in their function, these participants' occupational performance skills, in addition to basic care provision, became focused toward minimizing any perceived safety risk or hazard.

The participants described this safety concern as a significant stressor and at times overwhelming, because their everyday activities centered around the provision of a consistently safe environment. As one participant stated, "If you can't have him safe, I mean that is scary. You can't do enough to keep them safe" (P.#4). All of the participants in this study expressed worry and fear over keeping their loved ones safe from harm. "I still don't trust the safety aspect. Lot of chances for error. And even more there is the chance that what my wife could do yesterday she can't do today. It is a constant vigilance for her safety" (P.#1).

Concern for safety: Falls. One of the most common safety issues with the aged is falls. All of the caregivers in this study had care recipients who had experienced falls, with some being quite serious. These elderly spousal caregivers' confidence in their

ability to keep their loved one safe was affected once a fall occurred, because the fear of falling again was so strong, as it was, unfortunately, so likely. The experience of one participant illustrated this scenario:

Because he can't have the operation I asked his doctor, I said he cannot seem to get his feet coordinated to walk and he will actually likely stumble over his own feet. And he falls. Well he has had two falls, bad falls. Christmas time he fell and hurt himself and to the point that he couldn't do anything. I had to do everything for him and then right after that, or month and a half later he fell again. He fell backwards and he really fell hard. He hit a cement ornament and he went completely flat on his back. And he had a bruise that was huge and it hurt him really bad. I got him up. I was at the point where I was going to call the ambulance because he is heavy you know, dead weight. So I was trying to get him up and I got him in the back door and there is like two steps into the kitchen and I dragged him up there (P.#4).

Falls can be frightening occurrences because, for both the aged care recipient and aged spousal caregiver, the risk of injury can be significant. One participant shared a lapse in her judgment that seemed excusable due to the late hour, yet the result for her was traumatizing:

He is dangerous to himself. The fall on Saturday occurred. He had gotten up early in the morning about four times telling me that we have to find the suitcase with the china and the silver in it, in Norfolk. Before we leave Norfolk, before we pack up and leave. We are not in Norfolk. So then, finally I had to prove it. See that is something I knew I would have to do; can't talk him out of it. I kept saying you are dreaming, you are dreaming. No I am not. No I am not. So I must have been up for hours. From 4-6:30. So I got him back in bed and the bar that I usually keep across the bed, you know, I figured now where is he going to go. Dumb thing to think. Because I fell asleep. Never heard him get up out of bed. He got out of bed, without the walker into the kitchen and tried to make himself breakfast and wound up on the floor. So we went to Patient First. He mangled his ear. Terrible. He got it all stitched up (P.#5).

With falls in the home, these elderly spousal caregivers could not always be close enough nor strong enough to provide the hands-on support in time to prevent the fall. The daily physical handling of the care recipient placed these participants at risk for their own falls and injuries. These caregivers described being put in difficult situations, often being the only one available to provide the care in the home, yet also being physically challenged themselves to meet the needs of their spouse. A participant shared a situation that taxed his physical ability to transfer his wife:

She is not good at all. She is just getting so hard to handle. I had to give her supper and then into the chair. Dropped her twice. She had to take a step and she just can't take a step to transfer sometimes and you just have to twist her and put her. She wasn't on the floor. I can't pick her up off the floor. She just went sideways down on the bed near her chair. She hasn't been good for a couple of days. She gets better and today not so good (P.#1).

Another participant described similar struggles in transferring her spouse when she literally used her body as an assistive device:

And then all of a sudden even to get him into the wheelchair, you know I have to lift him, get him on my shoulders and get him out too you know. It's very tiring. I am just the right height when I get him up that he can put his arms across me. I am a crutch to help him balance himself (P.#2).

Participants described falls outside the home as even more frightening, because of being among strangers in an uncontrolled, possibly unsafe environment. A participant shared one such experience that brought forth many emotions besides the fear, including embarrassment and frustration:

There was a curb, or step down. Well when he stepped down he went back, and he scraped his arm up and the people came out of the restaurant and helped me to help him up because its difficult. Even though he is not that big, he is dead weight, when you are trying to pick him up. So I got him up. He was quite upset about that. And he got really nervous. I had asked him to stand there and wait by my side but he still thinks he can do

things by himself. And I agree with that, he wants his independence, but at this point, he can't do it. And that is what I have difficulty getting through to him. You can't do it anymore, you need help. Because if I would just have his arm and steadied him he wouldn't have fallen. But I live in fear of him falling (P.#2).

For these participants falls were a huge safety concern and contributed to their tendency to stay very close to home while infrequently venturing outside. Participants expressed a perception that in the home, there existed for them some control over the environment that helped them keep the care recipient safer. Staying close to home also offered the participants the best opportunity to closely watch over the care recipient.

A participant offered that it was specifically the fear of falls that kept her close to home. She described feeling anxious just leaving her spouse even momentarily to do something out in the yard:

But I can't go out as much as I like because of him. I am afraid. I could never leave him. I could never go out and leave him. No I cannot. I would be afraid to leave him because he falls. For one thing he doesn't listen when I say 'don't go out in that room' because of the steps. Stay. If you are going to go out there, stay. I take my trash out at the end of the road. I will say stay there, don't leave. I have to go in a panic taking the trash out. Because he doesn't listen to me. He will think he can do it. He is getting to the point where he falls and I am afraid to leave him now. It is getting to the point where you can't leave him (P.#2).

Concern for Safety: Unsafe Behavior. Beyond the fear of falls, another safety concern that these elderly spousal caregivers had to contend with was the unpredictable and unsafe behavior of the care recipient. According to these participants, such behavior required constant vigilance, meaning night and day. These participants described this vigilance as stressful and exhausting. One participant referred to her experience as never-ending:

Taking care of him is stressful. Terribly stressful, because its 24/7, or 36 hour days. You know you always have to be aware and alert and listening. To see if he is alright. One day he woke up at 4am and was sitting in the chair, all dressed up, what is going on? Ready to go. You have to be vigilant at all times. Very aware (P.#3).

Occurrences of unsafe behavior were not uncommon, especially when these elderly spouses were alone in providing care. The participants described having to stay a step ahead of the care recipient in order to keep him or her safe. Despite rigorous planning however, things happened. One participant shared a frightening event that she could not have predicted:

He was taking 12 or 13 medications and he never bothered with them anymore because I did it. I came home from work and he had opened all the bottles and flushed all the contents down the toilet. Of all the medications. I said well why did you do that? He said well because I am not taking these anymore. And then I thought, my god he could have just...supposed he had done the opposite and taken them? Then what? Then I had to put them somewhere else. I had to take all the knobs off the stove; couldn't keep them on here because I was afraid. I mean when you start having many, many, many of these things, then you say, you know, I can't do this. I had to put away all of his tools and stuff because I was afraid of that; I had to put away you know, like carving knives and stuff. Keep thinking what might he do (P.#4).

Vigilance that required 24/7 really was an impossibility for anyone, much less an aged caregiver. Once an unsafe behavior was experienced, these participants described the fear they had that it would be repeated, possibly with a bad outcome. One participant described her frustration in having to keep up with her spouse in regards to his impulsive, unsafe actions:

I was afraid that I couldn't keep him safe anymore. I couldn't keep him safe. I couldn't get him up the stairs or down the stairs easily. And then of course if he would get up during the night, trying to get down by himself. Sometimes I slept OK. I had sides for the bed. So I put them up and that usually worked; when he would stir I would usually wake up. Once when I woke up he was

sitting there looking at me. The rails were up. He got out of there. I don't know how he did it. He was just sitting right there and he is smiling. Look at me and smiling. I went panic-stricken. How did he get up? You know I worry about that. He would slip out of the house and he did that on me a few times. He would be walking around at night (P. #4).

The elderly spousal caregivers in this study expressed great worry and concern over keeping their loved ones safe from harm. The participants described how they increased the demands on themselves both physically and mentally, by decreasing their sleep, providing more physical assist and by putting great thought and planning into everyday activities as ways of staying ahead of potentially unsafe situations. Some participants also made the choice of narrowing their world of caregiving in a physical sense by staying close to home in order to better control their caregiving environment. These sacrifices were made in order to lessen the chances of harm coming to their spouse under their watch.

Concern for Safety: Other Aspects of the Occupation of Caregiving. As these participants experienced the occupation of caregiving, they demonstrated the components found in all occupations, which are performance skills, personal causation as well as a set of habits and routines of caregiving. Performance skills are those skills which are the basic abilities for action. For elderly spousal caregivers, their performance skills of providing basic daily care soon got expanded and directed at trying to keep the care recipient safe. Personal causation is the sense one has of one's ability to affect and influence one's environment. Personal causation in the occupation of elderly spousal caregiving took on the essence of being an advocate for the care recipient. Habits and routines set up a pattern of daily life and a rhythm that can sustain and enable an individual to carry out their activities. Habits and routines were disrupted in these elderly

spouses' caregiving occupation due to an overwhelming number of tasks with little time. It became necessary for these participants to not only forgo some of their habits but also to be flexible with their routines while learning how to prioritize.

Advocacy. A major role that these elderly spouses played in their caregiving occupation was that of being an advocate for their spouse. Advocacy became a major role in their occupation of caregiving because of the frequent hospitalizations and medical visits that occurred with their spouses' chronic illness. These participants advocated with formal healthcare professionals and anyone else who attempted to dictate or influence care being provided to their spouse. These participants expressed that such advocacy was a necessity because individuals, such as their spouse, could feel powerless in the formal healthcare system. This sense of powerlessness was illustrated in one participant's description of why advocacy was needed with her spouse:

I think every patient needs an activist caregiver. I think everyone needs someone to speak up for them because they can't speak for themselves. Everyone needs an advocate. Well it is the same for instance, even when you go to the doctor and you are well, it is always good to have somebody else with you. It is another pair of ears, maybe taking notes. Because sometimes when you are under stress, you don't remember. And in this case, the patient cannot speak for themselves. And they need somebody to speak up for them (P.#3).

Some participants demonstrated their advocacy by staying by their spouses' side through multiple hospitalizations. One participant not only stayed with her spouse but she also advocated for his needs of a quiet and calm atmosphere:

I never left him at the hospital. He didn't cooperate at the hospital. He was probably at his worst behavior because it was so unfamiliar. Yeah and all that stuff. People bothering him, so I remember a couple of times, what I would do, it kind of worked good with him because I would take him to a lobby and sit on the sofa with him and one place near the

elevator and he would see the people come and go and we would sit there and he would be more content. But you can't keep him in a hospital bed and have him understand that (P.#4).

Another participant took his advocacy to a higher level by actually confronting healthcare workers, even doctors when in disagreement over his spouse's care. He explained why:

I don't trust what medicine she gets in hospitals or nursing homes. I know what works for her and what doesn't work. There are other things I don't know if they will work or not and I do let people try those things. I was open. But I had to stay in control and I feel whenever someone has had a long chronic illness or disability, they have to enlist a family member or friend to be an advocate. If they get down, they are going to wind up being kicked and shoved into a corner. I normally bring up my point, make my argument. Sometimes I concede the point. Sometimes I have to be extremely forceful. It depends on what the situation is. But always, whether I concede my point or force my point it's for the betterment of the patient. And that's the way you gotta be. It's like being the parent. When I am representing my wife's wishes in interviews with healthcare matters, it's like going to PTA meetings. I have no medical education but when she is being treated I literally have to jump in front of her and say stop. Because I am the advocate here (P.#1).

For these elderly spousal caregivers, being an advocate had its challenges. Advocacy required assertiveness, persistence, energy and a strong belief not only in oneself but in one's provision of care. Being an advocate for their loved one did give the participants opportunity to have some impact on the world around them (personal causation); to protect their spouse while educating and training others on what they the caregiver provided on a daily basis and how they lived.

Flexibility and Prioritization. These participants each had their own particular way of providing care, their own standards and their own unique daily schedules. In time, these participants reported, they all had to incorporate flexibility and prioritization into their set

routines and habits in order to accomplish anything in a given day of spousal caregiving. These elderly spousal caregivers reported that it was hard to plan on anything. Schedules would change suddenly. Appointments would come up and then the day became very difficult because these types of disruptions meant that certain other tasks would not be accomplished in a timely manner. Things piled up and that created stress. One participant shared how disruptions affected her day:

You don't really plan your day. You just take it as it comes. One day at a time, one hour at a time. Take it as it comes. It is all you can do. You do what you have to do. You can't really plan ahead because you don't know what is going to happen (P.#3).

Another participant had a rigid daily schedule, and he shared how one little change to that schedule affected his plans, his whole day and how he dealt with it:

It is full, but most of my typical daily schedule, the whole thing can move up or down. We don't have to have lunch at one, we don't have to have supper at six. So sometimes something would happen because of something and we have to shift. For example tomorrow her aide will be having to leave early for an appointment which means she has to come early. So tomorrow morning, I don't have the luxury of going back to sleep for a ½ hour. The alarm goes off and I will stay up. So I can take care of her and get her to breakfast about ½ hour ahead of schedule. If there is a change in the schedule, like a dental appointment or something, then the whole day has to be changed to evolve around that (P.#1)

Another participant admitted that it was really the care recipient that dictated the daily schedule overall. This was a common trend among the rest of the participants and this participant explained why this was so in her caregiving: "Everyday I more or less go along with his time schedule because he gets agitated you know, so I just stop whatever I have to do and do that. Actually it revolves around him and what he wants to do" (P.#2).

One participant gave up trying to catch up with tasks left undone. He attended to priorities and over time taught himself to live in that way because realistically for him there was nothing else he could do. He shared how only the priorities now got his attention and energy:

Things are not balanced. It is priority driven. My strategy is do the things that must be done, put off the things that don't have to be done, but try and work some of that in, if you can. I think that is all you have to do. I am behind in so much it is not funny. I haven't done my taxes from last year yet. Paperwork, the housecleaning, all kinds of things, just wind up taking a back seat. Most of my strategies are need-based. Needs to be done so you do it. From there until now, it is just been a question of what is on your list and what is most important to do first. It is a question of you becoming okay with it after awhile (P.#1).

In the occupation of caregiving, these elderly spouses struggled. The role of an advocate brought fulfillment and purpose to the participants. Yet in dealing with chronic illness management and multiple hospitalizations, the spousal caregivers described getting worn down having to present a strong force and voice so often with formal healthcare providers and others. Habits and routines exist so that the caregiving day can run smoothly but instead the participants found their day disrupted for a variety of reasons. These elderly spousal caregivers expressed that they had little choice but to be flexible and respond to priorities in order to get through the day. Meanwhile, the many other needed tasks had to be set aside, where they piled up and caused stress. Finally, for these participants, the occupation of caregiving became consumed with their concern for safety. Their efforts to keep their spouse safe eventually dominated their daily activities, their planning and even their thoughts. 24/7 vigilance is not possible for one person, yet it was attempted on a daily basis by the participants, at great potential physical, mental

and emotional cost. This put these caregivers at risk for poor health and decreased well-being.

Theme Three: Elderly Spousal Caregiving Challenges One's Ability to Age Successfully

To age successfully is to accomplish a general state of life contentment and fulfillment that is a combination of functional status, health, social, psychological and environmental factors. The participants acknowledged that the occupation of elderly spousal caregiving had provided experiences that had increased their knowledge, enhanced cognitive skills, increased their self-worth and helped them achieve a feeling of fulfillment as they cared for their spouse. One participant expressed the good of his caregiving accomplishments as well as the continuing challenges:

I am confident in my abilities and knowing most of the time what I need to do. But there is always something new to learn. There is always a new medicine to investigate. There is always a new physical need to provide. I need to learn new things. I consistently feel like I have to rise to new plateaus of confidence and accomplishments as the situation changes from year to year, sometimes within a day (P. #1).

Some of these participants also described their efforts to seek and undertake activities outside the occupation of caregiving that contributed to their well-being, increased their engagement with life or improved their health. So while these participants expressed some awareness of successful aging, they also voiced their concern about their own quality of life in the midst of caregiving. One participant described her fear of the stress of caregiving: "It doesn't happen a lot (getting sick), but it does happen and I think when you get stressed you can get physically ill from the stress. And sometimes I am afraid of that" (P.#3). Because these participants were the sole providers of care for their spouse

and were often isolated and confined to their home due to their concern for the safety of the care recipient, these elderly spousal caregivers were challenged in their abilities to age successfully.

Well-being: utilizing resources. Well-being in successful aging includes complex physical, mental and social well-being not merely the absence of disease or infirmity. These participants described their attempts to pursue well-being activities in the midst of their caregiving through utilization of resources including support groups, paid help, respite care and adult day care. One participant described her positive experience with a support group. She enjoyed giving advice and receiving it:

They have a care group. So other wives and husbands who needed help could get together and talk. I go. Well, I think it is neat to know that other people are going through the same thing. And you sort of help each other. I understand what you are going through and I just need that support. I really think it is important to share because you can draw from others' strengths on how did you deal with such and such situation or if the other person is frustrated maybe you can help them deal with their frustrations (P.#3).

Another participant described utilizing a support group where he embraced his identity as a caregiver and reached out to others in support:

I didn't realize there was a concept called caregiving. But now I do and I have been in touch from time to time with caregiver groups and organizations and things. I am comfortable about being a caregiver and sharing with others or I wouldn't be talking to you. At some self-help groups I have sometimes taken caregivers aside and told them a thing or two (P.#1).

Yet another participant described a disappointing experience with a support group. It failed to meet her expectations or needs:

I went to their support group one time and it was just absolutely awful. Because it was only a small number of people, but the facilitator just let these people go on and on with whining. She didn't control it at all, there wasn't any structure to it other than...and it was more stressful to sit there than it would have been

to not. So I never did that again (P.#4).

In pursuit of resources one participant shared his experience with a course that offered the basics of caregiving and how to care for self as well. He took this course some years ago, and he expressed that nothing like this exists now. He stated that this particular course was one of the best things he did for himself and the family:

From her first doctor, he recommended an American Red Cross program that offered caregiver sessions. It was one night a week for eight weeks for caregivers only. Patients were not allowed. When I started my daughter who was twelve went with me. They went over everything from bed bathing to taking temperatures. Some of the caretakers had been doing it for a long time; others were new like us. But that was a big help. It was eight weeks in a row. At the end of the 7th session, they announced there wasn't a meeting next week. And we wanted another meeting. And the planner said there is not another meeting next week because it is your night out. She said you have proven that you can schedule one night a week for seven weeks and do something for yourself. Next week do whatever you did before to provide care for your patient, but take the night off. That gave me more preparation than any other single thing (P.#1).

Respite care as a resource was not mentioned often among these participants. One participant utilized respite care briefly, but she described the decision as very difficult:

And by then I had taken him I would say two or three times for like a weekend to a respite facility. It felt terrible, awful. The first time I took him, I took him for two or three days and I cried the whole time. It was awful. Because it is hard- you don't feel good about it. You can't feel good about it. I couldn't take advantage of it. A couple of times we used it (P.#4).

These participants shared that their abilities and willingness to partake in well-being types of resources were limited. Some of the constraints were financial; other participants did not value the available services while still others were just not aware of their existence in the community.

Well-being: coping strategies. In successful aging for elderly spousal caregiving, pursuing well-being was not only about utilizing resources, but also about employing coping strategies into their day. These participants shared a wide variety of coping techniques including reading, pet care, music, gardening and chocolate. One participant indicated that candy therapy as a quick intervention helped her with negative feelings and thoughts:

That you know if you are really, really, really upset, whatever your favorite candy is, get it, in a miniature. It is M & Ms and I will eat six M & Ms. First of all it is a cognitive therapy because you intervene right in when you are having all these bad thoughts with something you like. Chocolate (P.#5).

Having a pet helped another participant relax and participate in something completely different from his caregiving tasks:

I love the dog. During my free times we go out to the backyard and play or sit and watch the birds. He is at my feet most of the time. It is good to have a dog around. It gives you a little bit of change of pace (P.#1).

One participant coped with her caregiving by maintaining a large, beautiful backyard garden:

The house and yard. It is very tranquil. You can sit out on the deck and it is wonderful, peaceful. And it helps me absolutely. Always has. To get outside, for me and work in the garden for 2-3 hours is like giving me a tranquilizer you know. Because it gives me peace. And it fulfills my needs. Because what it does it gives you the exercise, it is peaceful and the state of mind, it empties your mind. It takes the stress out and empties your mind (P.#2).

Even the relatively small act of reading brought this same participant some joy and peaceful moments:

I read. I like books and I like the fact that I can read a book. It takes me out of reality, into the book. It frees your mind of what is going on in reality. You can go into that book. Watching TV is not like reading a

book, you know what I mean? I have always liked to read (P.#2).

The coping strategies described by these participants were small moments in these participants' caregiving lives where there was, for a short while, some peace, tranquility and positive thoughts. These participants' descriptions of these moments were indicative to how meaningful they were to them in terms of providing a break from the stress and reality of caregiving.

Engagement with life. In contrast to well-being pursuits, these participants described few opportunities to engage with life in the context of pursuing leisure, social and work activities. A few participants described their efforts to keep up with some planned social activities such as lunches and game nights as one participant shared:

I play scrabble one night a week. So. It's a point of making yourself do it. Because I am exhausted and I don't want to play scrabble. I don't. I am too tired. But they all come here. So we sit and we laugh like four silly women. And we only get two games in three hours. That is how much we are fooling around. So it's a very, very good thing. My next neighbor is one of the gals that I play with. So when it's at her house we have it here. When its at my house we have it here. When its away from here I don't go (P.#5).

Another participant valued her social life tremendously and made every effort she could to meet up with friends:

I have to socialize. I can't imagine anything worse than being home by yourself and not having anybody to talk with. I go out to lunch a lot so sometimes I will take him with me. And I will tell him to just sit there. He is really good natured. So he will sit there. I tell him you don't need to say a word, and he will nod (P.#3).

Few of these participants had any regular social or leisure pursuits they could share.

These elderly spousal caregivers described an occupation of caregiving that tended to crowd out opportunities for leisure and took away the energy required to engage in pleasurable activities.

Negative impact on health. Successfully aging in terms of maintaining good health was extremely challenging for these elderly spousal caregivers. As one participant shared, “Well I think the biggest complaint that I probably had was being, you couldn’t like go exercise. To take him for a walk even was a problem, big problem. So you couldn’t get any real exercise” (P.#4). Nearly all these participants suffered from some ill health that they associated with their caregiving occupation. One participant shared his struggles with his health and lack of follow-up:

No question it (caregiving) has affected it (health). I am limping now on a bad knee. I have had one knee operation. I need the other one operated on. I am years behind on a colonoscopy. I don’t know how to do these things. Without someone caring for my wife in my absence or putting her in respite care which is out of pocket, which I can ill-afford (P.#1).

Another participant described her fear of future illness and what that would mean for her spouse:

I live in fear that if I am ever sick what is going to happen to him. You know what I mean. I am 77 years old and it’s a great possibility that I am going to get sick. And he could never take care of me. He can’t even take care of himself. But that is my greatest fear; what am I going to do? (P.#2).

This same participant admitted to neglecting her own health and appointments because of her caregiving occupation. “No I don’t take care of myself. I should go to the dentist and I have an appointment and I think ok he (spouse) is not feeling good today. Well then, I don’t go. I put it off” (P. #2).

Another participant described confronting a serious health issue that she believed was caused by the stress of caregiving:

It was during the early time that I got breast cancer. It was a lumpectomy. I had to go every day for six weeks of radiation. That was a stressful time because I was doing that. The only one in my family who had breast cancer, and the only thing I can think of is the stress. And I don’t know how that

happens but I think that is what it was. I wasn't aware of neglecting myself. The stress was great. Breast cancer. That was not a why me. That was telling me I need to watch out for myself. And the caregiver has to take care of themselves. And that was his way of saying take care of yourself (P.#3).

For these participants, elderly spousal caregiving was not good for their health. While the occupation could be challenging physically, mentally and emotionally, these participants also shared their lack of follow-up on medical and dental appointments, as well as delayed procedures due to the obligations of caregiving. Access to regular exercise was difficult for them. The participants acknowledged their overall lack of good health practices, but in their caregiving occupation they were most often home alone with a sick spouse so, as one participant put it, one did what one could do.

The idea that successful aging and elderly spousal caregiving could be incongruent at times is a matter of justice. That these elderly caregivers had to sacrifice their own health and well-being in order to provide care to their spouse was specifically an occupational injustice. In-home caregiving of the elderly saves the government and therefore society billions of dollars per year. However there continues to be lack of resources, support and concern for elderly spousal caregivers' quality of life and ability to age successfully.

Theme Four: Elderly Spousal Caregiving is an Unjust Occupation

The concept of occupational justice is that people are occupational beings out of need for survival, for health, for meeting obligations as well as for finding meaning and purpose. Occupational justice occurs when individuals engaged in life occupations are able to experience positive health and well being. Occupational justice for elderly spousal caregivers is the provision of training and education in caregiving techniques including activities of daily living, medical management, physical and emotional

management. Training and education can empower caregivers to succeed in their caregiving occupation by having them feel in control of their lives and having confidence in their caregiving and problem-solving abilities. Occupational justice is also about elderly spouses having the ability to participate in diverse occupations, to have some balance in their lives, besides the caregiving. And finally, occupational justice for these elderly spousal caregivers is having an occupation that brings health and wellness and satisfaction, not burden and stress. For lack of all of these components of occupational justice, the occupation of elderly spousal caregiving is an unjust occupation.

Training and education. All of the participants in this study describe a lack of needed training and education in regards to caring for their spouses. As one participant shared, “At the hospital, nothing was given to me to educate me. Even after the diagnosis. A few comments here and there from a couple of the doctors. But nobody said come to the room I want to talk to you for a half-hour” (P. #1). Most of these participants agreed that even the very basics would have been welcomed, such as learning how to move their spouse, positioning them in bed, taking a temperature, guiding them while they walk. One participant expressed how much a little education would have meant to her:

I think if you had somebody to go over with his condition and his lifting him and his limitations, sometimes it is like in the hospital when you have a person in bed, the nurse knows how to change that bed without getting that patient out. She rolls him to one side. If you have some help and some techniques it would be helpful; someone to go through it with you. I think if a caregiver would come by and say this would be helpful for you to do with him or do that, anything would be helpful. And any kind of equipment that is out there. I don’t know. I am interested in that too, you know. Any kind of equipment that would help him (P #2).

There were expressed expectations, from these elderly spousal caregivers, that formal healthcare professionals would make the effort to prepare them for caring for their spouse in the home. Participants complained that formal classes were not offered; training was not conducted and little or no referrals to community resources took place. As one participant shared, this lack of education and training forced the participants to teach themselves and rely heavily on trial and error:

Yeah the medical profession should work harder at setting up courses, instruction, classes something when one becomes a caregiver and the person who needs the care has a specific diagnosis. I had to learn a lot myself. I had to go out and dig for some of it. I try to keep up with what I could. I just follow my gut (P. #1).

Another participant expressed similar disappointment in this lack of preparation as a caregiver:

I think you don't have expertise in...you know, to lift someone, um when people are unsteady, how to guide them as they are walking, you know those kinds of things. You know, that is sort of, it is like a trial and error, when you haven't done it. It is difficult, like how do you get them up a step when they can't do it. How do you get them out of the bathtub? All of those kinds of things that I didn't feel prepared to do well. I felt like we were limping along (P.#4).

There were many opportunities to train and educate elderly spousal caregivers due to the fact that with caring for a chronic illness, these participants experienced multiple hospitalizations with their care recipients that exposed them to so many health professionals who could help them. Yet so few did. This reality led one participant to wonder how a caregiver could ever feel empowered in their occupation without any preparation and guidance from those with experience:

Some occupations you train for it because someone else knows what you are running up against. Somebody who is already a lawyer trains

you to be a lawyer. They know exactly what you will be faced with; they know what is going to happen in court; they know how judge and jury are going to react. Whatever training you get, as a computer programmer, doctor, is been done by someone who has been there before. And the scope of this experience is fairly small. An attorney doesn't go into court and constantly get hit with something he has never seen before. With the caregiver it is just the opposite. You never know what you are going to come up against. There are people who don't know how to give care. There are husbands and fathers who simply never have taken a temperature in their life. Or position in bed. How do you move somebody who can't move without hurting them? Non-specific caregiver instruction I think would help a lot of people (P. #1).

All of the participants expressed disappointment and discouragement at the lack of caregiver training and education. Their stories revealed a void of information and techniques that could have assisted them mentally, physically and emotionally in their caregiving role. Instead, these elderly spousal caregivers had to rely on their own trial and error methods which made their occupation so much more stressful.

Availability of resources. Occupational justice is not only about the individual but also about communities flourishing and supporting one another in their occupational needs. Family caregiving at one time involved communities of neighbors, churches and towns that lent support to those in need with food, visits and respite care. In the present time, that kind of help is infrequent. One participant shared her memories about the community support she grew up with and of others rallying around to help:

When I was growing up, you knew everybody, your neighbor. You knew all the names and all about them and everything and they did help each other. If somebody was sick they sent food. If somebody died, everybody took food to that house. And that is gone, it is gone. And it sad; I miss that kind of help (P. #2).

Community help is one kind of resource. Participants also struggled with lack of financial issues. As one participant expressed:

From a financial standpoint a lot of community resources are geared toward people with small incomes and assets. We don't qualify. My income is now a fraction of what it once was but I still have income and I have assets. So I don't meet some programs. Financial support would be nice; everything I ever planned for has been turned down because I make too much. It takes money to care for her (P.#1).

Another participant shared her financial struggles:

Because the financial outlays are horrific. They have been absolutely unbelievable. People say I don't want to use the money I was going to leave to my kids. I say that is great but if somebody gets sick, honey you are not going to have anything to leave your children. Oh that is so expensive (P. #5).

The lack of financial resources has meant for some the giving up on hopes and dreams they had as a couple. One participant explained:

We just have to throw all our plans out the window. Our hope and dreams that we had to spend money that we should have been able to spend on something else. All of our time and money now is directed to day-to-day needs and care and nothing towards the dreams or anything like that. I guess it is certainly disappointing for her sake as well as mine that we can't do some of the things that we love to do (P.#1).

Another needed resource identified by these participants was adequate and safe physical space in which to provide care for their spouse. Most of the participants were caregiving in a physical environment that challenged their ability to perform their daily caregiving tasks successfully. Many of the homes contained common obstacles to physically handling someone such as flights of stairs and small bathrooms. As a result, safety concerns were exacerbated and barriers to optimum care were created as the care recipient declined in health and ability. One participant described his environmental difficulties:

The house is helpful but there are still a couple of obstacles. The biggest obstacle is that her stair lift glide and her wheelchair are not close enough to

either end of the stairs. I have to park her wheelchair to get her on the stair glide and take her out. And to do that she has to stand and somehow or other I have to hold her up while she takes about three steps sideways and she can't step sideways. But we have to do it anyway. I sure wish that that whole area there was constructed differently so that the stair glide and wheelchair could be right beside each other. That is an issue. She thought we could circumvent that by putting an outside elevator off the porch. That is about \$15,000, and I could only find funding for about \$5000.00. So I did not do it (P. #1).

Another participant shared her struggles with stairs:

The worst was he could not...he had difficulty with stairs. Couldn't lift his legs. So that made it difficult. But if he can't do them, he can't do them. That was horrible. If I could have put a bathroom,... a full bathroom down here he could have just stayed there. There was no way to do it. To expand the powder room would affect the structural integrity of the house. And there was no other spot to insert one. We could have added another room but that was big deal. If I didn't have to get him up and down stairs to keep him clean and all that it would have been much easier (P.#3).

These participants tended to find the cost prohibitive when considering renovating their houses to ease the burden of caregiving. Eventually they abandoned their plans and just put up with the environmental barriers that confronted them daily.

Having experienced occupational injustice, these elderly spousal caregivers become self-reliant and self-taught out of necessity. While there was a certain pride and earnest effort described by these participants to learn on their own, there remained a knowledge gap that became filled with their trials and errors. This was a very difficult way for these elderly spouses to learn the occupation of caregiving as they struggled with day-to-day care. The occupational injustice to them was in their expressed belief of how much better caregivers they could have been if early on, training, education and resources had been provided to them.

Occupational injustice: Occupational imbalance. Occupational imbalance is an aspect of occupational justice based on the reasoning that human health and well-being requires a variation in labor, work, and leisure occupations. For these elderly spousal caregivers, occupational imbalance was about being over-occupied: the caregiving occupation tended to crowd out and diminish pre-existing occupations because of the time demands and the needed multiple tasks to perform. This state of imbalance was common among these participants and the result of this imbalance usually meant a loss of leisure and social activities. As one participant shared: “All of these activities (leisure) have come to a halt. Because he (spouse) can’t go out. He is more or less house-bound” (P. #2).

Imbalance with leisure. All of these participants experienced a loss of their leisure activities. They expressed a yearning for those activities that once brought fun, relaxation, interest and stimulation into their lives and that contributed to their physical, mental health and well-being. One participant expressed how he has little or no time for true leisure or social activities:

I would kill to ride a motorcycle again. I don’t get any recreation. If there is a train show in Timonium I can’t go. If my son-in-law wants me to go with him on Friday night to a boxing match, and he has asked me to do that, I can’t go (P. #1).

Another participant shared how she no longer attended her weekly yoga class that was just one hour a week. This particular activity she described as having helped relieve her stress both physically and mentally:

Well I used to do the yoga classes. I did those once a week. I think they are mentally and physically great. I just love them. I do miss that. Just one hour a week, but it did so much for me. But mentally it does something for you mentally too. I had an instructor, who at the end she played heavenly

music and she would go through this system where she starts at your head and you go down and let yourself go and relax and it does, it just empties everything, all the stress out of you. It is so relaxing I felt like I could lay there for about a half hour and let her go on (P.#2).

Imbalance with social activities. For most of these participants there was a decline in social gatherings or outings. This included time spent with friends and other family members. One participant described her difficulty in going out:

The whole social life changes. People with dementia do not do well in groups or crowds. So that kind of stuff was out. So he couldn't deal with that very well at all. And even, we like to go out to dinner and stuff. That became extremely problematic. He couldn't figure out what he wanted to eat. You would order for him or even if he ordered he would say he didn't order that, then he would order something else. He couldn't go to the men's room alone and that was a problem if I didn't have someone with us who could go (P.#4).

For these elderly spouses, caregiving affected their social life in several ways. For example the participants shared that getting the spouse out of the house physically could be so difficult that it seemed not worth the effort; and some participants, even when given the opportunity to go out alone, would choose not to leave their spouse behind. One of the participants used to have regular outings with her friend that she no longer could do:

I miss going out with my friend. She misses it too. Every Wednesday we went out antiquing. We used to do it every week. Go all around and eat lunch, you know. And having girl talk you know and being just with the girls. And sitting down with no worries. It was relaxing to be able to get out. I miss that a great deal...a great deal. But I could never leave him. I could never go out and leave him (P.#2).

These elderly spousal caregivers described occupational imbalance, with its loss of social and leisure activities as life-changing. But as one participant noted, there was no real time to mourn this life change because one was so busy with care and worry. She described her feelings this way:

Once he couldn't go out to dinner and things like that, you just don't do it because there is no way to fit it in. I didn't want to leave him extra. It just wouldn't work. So I think you just end up losing that whole part of your life where you would be doing things that you would enjoy. Because you are so consumed by the rest of what you are doing every minute, you are not thinking gee, I wish I were going to the movies tonight. You're not. You are just so consumed by what you are doing. Yeah I missed the leisure activities but you are so concerned. You don't have time to think about that or energy to think about that (P. #4).

Some occupational imbalance is expected to be experienced with elderly spousal caregiving. In assuming an occupation as physically and mentally demanding as caregiving, other occupations that were inhabited by these participants had to be somewhat diminished or stopped altogether. Yet these participants described an extreme imbalance in their lives, with very little or no leisure/social activity. They all shared that so much of what they had enjoyed doing and being prior to spousal caregiving was gone from their present lives; replaced with all of the caregiving duties and worry and stress that they described feeling daily. Such imbalance can lead only to increased burden and stress and feeling overwhelmed.

Occupational injustice: Feeling overwhelmed. According to occupational justice principles, occupation should be health-giving. In other words, engagement in occupation should promote and maintain health, well-being and lead to happiness and fitness. Unfortunately, without training, education, resources and balance the caregiving occupation can be overwhelming. For elderly spousal caregivers it is a matter of just having so much put upon them. As one participant explained, "And the thing is again, it's because it creeps up on you . So you don't see yourself as stretched out. This is your normal" (P. #5).

Physical. These participants described an occupation of caregiving that had physical demands that were getting harder and harder, whether it was performing transfers, positioning in bed or helping their spouse take a step. There was also the physical handling required in the daily tasks of dressing, bathing and toileting. There were the messes to clean up, from incontinence for example, and there was the inconsistent, unpredictable ability of their spouse to perform at a certain physical level day to day, depending on their disease process. One participant described how the physical burden of caregiving contributed greatly to her feeling overwhelmed:

He likes a bath not a shower so and then it gets really hard to sometimes get him out. I mean one day I had to go get my neighbor because I couldn't get him out. He wasn't helping at all. You know you need a little bit of help or it is very difficult (P.#4).

Dealing with incontinence can be overwhelming and physically taxing. One participant shared how he quantified the time that it added to the day, to deal with the clean-up:

There are times of incontinence but her bowel problem is still quite worse where she gives us two minutes or less and if it takes you three minutes to get there, to handle her, it is too late. Then it takes you forty-five minutes to clean up. Sometimes she will have a bowel movement before I get there while she is only part-way down on the toilet. Then you have to get together the appropriate supplies to deal with the situation and clean her or the floor and/or whatever. So that is a very unpleasant interruption that can add forty-five minutes to the day at any time at all (P.#1).

Another participant also shared her struggle with incontinence:

The big thing for him was when he got incontinent. That is a difficult time. Doing laundry in the middle of the night is not my idea of fun. And he would wear the depends during the day but he wouldn't wear them at night. That is the worst time (P.#3).

Dealing with physical tasks was a real vulnerability for these elderly spousal caregivers. Their ability to physically handle their spouse could not always be consistent nor reliable if the care recipient's physical function fluctuated day-to-day. There were also the physical demands of basic care, clean up and care for oneself. The occupational injustice of such a situation is that often it is this inability to meet the physical demands of care that dictate the decision to place a loved one in a facility.

Emotional. All of these participants discussed a time when they were feeling low in mood, sad, lonely and frustrated in the course of their caregiving. One participant summed up his very intense feelings in regards to his current caregiving situation:

If somebody came up to me on the street and said to me starting tomorrow your wife will never be able to walk again and will lose all bowel and bladder control, and will not be able to cut up her meat or sign her name, what are you going to do? I would probably say I would shoot myself (P. #1).

Another participant shared the lack of preparation for the emotion stress she experienced:

Well, they explained to me medically what he is going through and how to handle it. But emotionally I have more or less had to figure that out by myself, you know. They didn't really touch on that, no (P. #2).

This same participant described periods of feeling very sad and becoming tearful. She chose to keep the sadness to herself; she would not share it with her spouse:

There are times when I feel down you know. I can get down. And sometimes I have my cries. But I go to myself to have my cries because if he would ever see me crying it would upset him so much. And he would think it is all his fault. And I would never want him to think that. So I don't do that in front of him. So I go to my room. To be by myself (P. #2).

Another participant described her need to get away from her caregiving situation:

Let me say that the bathroom is my sanctuary. It is the only place that I can go and close the door and just have quiet. So there are times. I just

need quiet time. I don't need to be around somebody all of the time, to talk to all the time. And I notice that he sits here and watches my every move. Everything I do he watches and you know you get tired of that after awhile (P.#3).

These elderly spouses expressed that caregiving from an emotional aspect required a lot of patience. In managing chronic illness, patience could eventually be in short supply.

One participant shared her struggle:

It's very hard on your patience. And I have talked to many wives who have said you lose your patience and then you feel bad. It takes a lot of patience because you are losing him and the emotional challenge is the big thing. I don't know what can prepare you to have more patience. And what trains you for that, you know? I don't know what. And it's really hard. If you talked to most caregivers I bet you most of them felt anger at losing their patience (P.#3).

Another participant shared her experience of losing her control that became a coping strategy:

Cause I have got to scream. Well I do. You know. Cause I don't want to scream at him because he acts so stupid but he doesn't know it. It feels so bad. But sometimes you just have to let yourself blow it out. Cry. I say get in the car, go on the beltway and scream your head out. Scream, cry, just don't close your eyes. It is cathartic. It works (P. #5).

The emotional burden of caregiving is not always obvious to others, but it can be just as devastating as the physical burden. These participants described emotions that were intense and they experienced them as they were having to witness the slow deterioration of their loved one. This occupational injustice, of lack of emotional outreach and support to these elderly spousal caregivers, left these participants in a very vulnerable situation where stress and sadness can make way for their own declining health.

Conclusion

These elderly spouses wanted to be competent and successful caregivers, but they were not sufficiently empowered to do so. Their loving obligation and devotion toward their spouse brought them into the caregiving occupation when chronic illness and debility made spousal caregiving necessary. The caregiving occupation tended to be physically and mentally challenging for these elderly spouses, with the most difficult challenge being that of keeping the care recipient safe. Striving to keep their loved one safe required 24/7 vigilance and that led to major changes in the caregiver's life; mainly that of making their world smaller in order to better control the environment and the activities within. And as their world shrunk, these elderly spousal caregivers were challenged to age successfully in the absence of social, leisure and healthful activities that they had once enjoyed. The occupation of elderly spousal caregiving is one of injustice. Without the proper education, training and resources, these caregivers struggled through trial and error methods in order to provide the needed care to their spouses. The toll of being overwhelmed could be great for these elderly spousal caregivers as it manifested itself in their experiences of stress, loneliness, and sadness. Occupational injustice puts these caregivers at great risk for their own acquisition of ill health and their possible inability to care much longer for their loved one.

Chapter Five

Discussion

Introduction

This chapter will review and summarize the dissertation research, identify the main methods used to conduct this study and discuss the implications of the findings.

Recommendations for further research will also be included.

Purpose statement

The purpose of this study was to examine the caregiving process in a sample of informal elderly spousal caregivers, caring for a chronically medically ill spouse. The study set out to discover for these elderly spouses, the meaning of caregiving; the culture of caregiving; the occupation of caregiving; the impact of caregiving on successful aging, and the dimensions of occupational justice in the caregiving experience. In order for occupational therapists to assist elderly spouses in their caregiving occupation, they must have an in-depth understanding of the caregivers' needs, concerns and motivations.

Review of the methodology

The methodology employed in this study was a qualitative phenomenological approach. A qualitative design was chosen to enable the collection of data that could capture the personal and unique experiences of elderly spousal carers through their own accounts. The aim of this study was to capture the richness of the caregiving phenomenon as it manifested to the subject who experienced it. Phenomenology is a research method that enables study and interpretation of the world of everyday life.

Phenomenological inquiry entails the systematic and methodological exploration of what appears to the subject and the manner of its appearing, with the explicit goal of describing and elucidating the nature of the phenomenon as an essentially human experience.

Research questions for this study explored the meaning of the elderly spouse's caregiving lived experience. Data was collected from a purposive sampling of five elderly spousal caregivers through a series of four long interviews each that were audio taped and then transcribed. Also a demographic survey was utilized to gather additional information. Data management techniques included utilization of a computer program for qualitative coding to help organize the large amount of data from the study. Statements were transformed into clusters of meanings. The data analysis process transformed these clusters to make a general description of the experience for each participant; a textural description of what was experienced and a structural description of how it was experienced. Finally a textural-structural synthesis was constructed on each of the data component areas: culture, occupation, successful aging and occupational justice. Synthesis is an intuitive integration of the apparent and the hidden as represented by the textural and structural accounts respectively. The textural-structural synthesis is an integration of the composite textural and composite structural descriptions of the five participants and provides a synthesis of the meanings and essences of the experience of elderly spousal caregiving. Textural-structural synthesis aims to evoke a phenomenological reverberation- the very 'aha' we give when we finally describe what is of the essence. The combining of textural and structural accounts gave practical expression to the concept of intentionality, the inextricable intertwining of outward meaning and inward consciousness (Moustakas, 1994).

Summary of the Results

Culture. In the culture of elderly spousal caregiving, the participants described a loving obligation toward one's spouse that was a very strong motivator for their provision of care. The participants also experienced a culture clash with formal healthcare, as well as lack of family help and concern. It became necessary for these elderly spousal caregivers to be self-reliant.

The experience of loving obligation, as told by the participants was based on recognition and appreciation of the care recipients' sacrifices, hard work and generosity over a lifetime. There was gratitude expressed by the participants regarding their ability to fulfill this caregiver role and to payback their loved one. In their interactions with formal healthcare, participants described situations of feeling diminished, being ignored, being rushed through their medical appointments and not being valued for their knowledge of the patient and his/her condition. Turning to family for assistance and resources was equally frustrating. The elderly spousal caregivers expressed disappointment in lack of family help and concern as well as discouragement at the misunderstandings and lack of appreciation family exhibited toward their caregiving role. Between the culture clash with healthcare professionals and the absence of consistent family assistance, the elderly spousal caregivers were left with little or no help or resources.

Occupation. In the occupation of elderly spousal caregiving, advocacy emerged as a strong role for the participants in their provision of care for a loved one. The participants also shared that set habits and routines, which can bring comfort and order to an occupation, were often disrupted and replaced by daily priorities and the care recipient's

ever changing wants and needs. Finally, the data showed that in the occupation of caregiving, these elderly spouses spent much of their time focusing their skills and concerns on keeping the care recipient safe.

The participants explained that the reason for their advocacy was that their care recipients could not adequately speak up for themselves. They described their actions as protective in nature and they became their spouse's voice as they attempted to navigate through the formal healthcare system. In lieu of established habits and routines, the participants described having to be flexible and prioritize their daily tasks, because there wasn't enough time to do it all. They explained how ordinary tasks piled up, waiting for their attention as they attended to the more pressing priorities of caregiving. These priorities were often medical issues, appointments, incontinence episodes, etc. Finally, the participants shared how their occupation has evolved into worries and concerns over care-recipient safety. The performance skills of the elderly spousal caregiver that were devoted to daily basic care, were expanded to encompass all the safety issues that arose as the care recipient declined in function. With the safety concerns growing, the elderly spousal caregivers described feelings of reluctance, in leaving the care recipient alone or with anyone else. For them, it seemed safer to provide care in place (home) rather than risk leaving the house. In the home, the elderly spouses expressed that they felt that they had more control over the environment and therefore had more opportunity to lessen the safety risks.

Successful aging. Successful aging was a concept with which the participants in this study struggled. They identified some well-being pursuits and coping strategies, but most of their stories on this topic revolved around both struggles to engage in life activities and

negative health consequences that they attributed to their caregiving occupation. For these elderly spouses, caregiving challenged their ability to age successfully.

The participants described personal coping strategies that were individual and enacted only occasionally. Pursuit of some outside resources included support groups and respite care that the participants identified as having contributed to their well-being. But the emphasis of their stories were descriptions of the void in their lives, once filled with social pursuits that brought them enrichment, stimulation and pleasure. The participants also acknowledged their lack of good health practices such as keeping up with their medical appointments, exercising and getting adequate sleep. Nearly all of the participants described somewhat serious past or pending medical issues since their caregiving began. What the participants did not identify were some of the skills and abilities inherent in their provision of caregiving that can contribute positively to their cognitive, physical and emotional status.

Occupational justice. This study concluded with the concept of occupational injustice. Occupational injustice occurs when people are disempowered, deprived, alienated or restricted. The participants described an occupation of imbalance; nearly all of their time devoted to caring and no time for leisure and social activities. They described feelings of being overwhelmed with the caregiving tasks; the responsibilities and the emotions involved in witnessing the deterioration of their loved one. And the elderly spousal caregivers expressed anger and disappointment in the lack of caregiver education, training and resources. These elderly spousal caregivers experienced occupational injustice.

The participant's stories of imbalance of their daily activities described, most often, all of the past activities they no longer engaged in due to lack of time: activities such as going out with friends, weekly yoga class, attending auto shows and going out to dinner. Either the participants did not have the time, or it was too much effort and energy to get care recipient out of the house, or it was concern for safety that kept them homebound. The participants' feelings of being overwhelmed were more often mental or emotional anguish such as loneliness, sadness and fear. Finally, all of these elderly spousal caregivers told stories over the lack of even the most basic training in caregiving skills, as well as little or no education in their spouses' diagnosis and prognosis. Lack of resources included financial, social, equipment, etc. Without occupational justice, the occupation of caregiving remains one of great struggles.

Discussion of the Results

This qualitative study explored the caregiving experience of five elderly caregivers caring for their spouses with chronic illness. Four contextual areas of elderly spousal caregiving were explored: culture, occupation of caregiving, successful aging and occupational justice. Four themes emerged from the interview data. These four themes intertwined throughout the study and built upon each other in description of the caregiving experience.

Forced self-reliance (Theme 1). One major finding of this study was that the culture of elderly spousal caregiving was one of forced self reliance, due primarily to culture clash with formal healthcare and lack of family involvement. Forced self-reliance meant that the elderly spousal caregiver had no choice but to be the sole provider of care most of the time. Loving obligation, an additional finding in elderly spousal caregiving

culture, offered some insight into how stepping up to the great responsibilities of nurturing and caring for a loved one could possibly contribute to a self-imposed state of self-reliance.

The culture clash between formal healthcare and elderly spousal caregivers was really a shared responsibility of both parties. The participants' stories of their experiences with formal healthcare included feelings of disappointment, anger and frustration. For example, "I have consistently found healthcare professionals who were incompetent, who were less caring than they should be, who are too busy to give you the time you deserve and need" (P #1). This culture clash supports Levine's (2005) work on the cultures of caregiving where she concluded that family caregivers and healthcare professionals bring different priorities and assumptions to the care of an ill person. In managing chronic illness, these elderly spousal caregivers and formal healthcare providers had established responsibilities and standards of care they brought to the care recipient. Over the years, with each hospitalization, each doctor visit or emergency room visit, the participants described experiences and interactions where they felt their care standards and responsibilities were disregarded or challenged by formal health care providers. Acting upon their loving obligation to their spouses, these participants brought, to each of these formal healthcare interactions, a sense of protectiveness and advocacy for the care recipient as was previously described in Chapter Four. It is unknown, with this study's limitations, how these acts of protectiveness and advocacy were received and interpreted by formal healthcare providers. Levine's observation offered that much of the topic of family care-giving in the medical and nursing literature, if it is mentioned at all, is limited to either platitudes or portrays families as impediments to professionals doing their job

efficiently and authoritatively. In this culture clash, these participants experienced lack of understanding, miscommunication and lack of mutual respect from the very individuals needed to provide the most help and guidance. As a result of these interactions, elderly spousal caregivers felt not only diminished in their caregiving role, but also lacked trust in the healthcare system. The participants came to the conclusion that they would have to rely on themselves to provide the care they deemed was necessary and appropriate for their loved one.

Another major finding, in examining the theme of forced self-reliance in the culture of elderly spousal caregiving, was that there was no guarantee of family help and involvement, regardless of close relationships and close proximity. This finding supported Wolff's (2006) work in which he found that spouses were the most likely type of caregiver to serve as the sole care provider and also the most likely to provide assistance with the greatest frequency and intensity. These participants expressed a mixture of disappointment and acceptance regarding lack of their family support and understanding. On the one hand, these participants told stories of the helplessness their family members displayed when visiting or attempting to provide assistance, which often resulted in creating more work for the spousal caregiver. There was also expressed anger and frustration from these participants when family members made promises to help and then did not keep those promises. Yet, the same participants would then rationalize their family members' unavailability with statements such as "they are too busy with their own lives and problems," and "I would never want to bother them." From these diverse accounts of family interactions, these participants explained, they experienced a disconnection with family members whom they felt either did not or could not understand

and appreciate their daily caregiving struggles and responsibilities. This finding supports Sheehy (2010) in her advocating for organized family meetings at the very start of care, once it was recognized that the caregivers would be facing a chronic condition and a long term of care provision. Family meetings would also bring to the forefront recognition that, specifically, elderly spousal caregiving has the capacity to create an intense, personal and caring relationship between the caregiver and care recipient. This loving obligation, Feeney (2003) described, is an altruistic motivator that comes about because of genuine concern caregivers have for the welfare of their partners. They are totally committed to the care and needs of their loved one. This kind of intimate and caring relationship with spouses could be interpreted by family members as one of inclusion and self-reliance. Their help may not be needed or welcomed. In this study none of the participants had such a meeting with family members. As a result of lack of help and understanding from their loved ones these participants remained reliant on themselves to carry out the commitment of care they had made to their spouses.

Concern over safety (Theme 2). In this study, elderly spouses' concern and worry over care recipient safety was a major focus in their occupation of caregiving. Concern for safety was due to several factors including having to care for sick and frail spouses, elderly spousal caregivers' forced self-reliance and disrupted daily habits and routines. This discussion will also include the observation that as a result of this concern for safety, these elderly spousal caregivers led a life of isolation and confinement.

In this occupation of elderly spousal caregiving, the worry over care recipient safety was all-consuming. These participants' stories frequently mentioned the concepts of caregiving as being 24/7 with constant vigilance. These caregivers were worried about

their loved ones and their worry was non-stop. This notion of worrying supports the findings of Cheung and Hocking (2004) who looked at caring as worrying with spousal caregivers. The authors recognized that carers of partners who suffer from chronic disease of unpredictable illness trajectories face many responsibilities and challenges that cause them to worry, especially when their partners' ability to perform daily activities deteriorates as the illness progresses. Cheung and Hocking point out that the concept of worry and concern for care recipient safety does provide insight into the very pragmatic issues that spousal caregivers face everyday. This finding of worry and concern for safety can perhaps help those outside the caregiving world understand a little better what these elderly spousal caregivers are dealt.

Elderly spousal caregivers' culture of forced self-reliance was another factor that contributed to their increased concern over care recipient safety. In these circumstances, where the caregivers were elderly themselves and most often the sole providers of increasingly intense, challenging care, there were greater opportunities for unsafe events to occur. These participants shared stories of how situations of direct hands-on care or even being in close proximity to the care recipient did not prevent falls or unsafe behavior. Keeping a frail, elderly spouse completely safe really required either more than one person, or an individual who was rested and relaxed and not making the attempt to maintain a constant 24/7 vigil over their loved one.

The disrupted habits and routines of these elderly spousal caregivers also offered opportunities for unsafe behavior to occur. In elderly spousal caregiving, these participants offered, many habits and routines were set aside in order to attend to priorities of care. These participants described having to be flexible and having to go

along with whatever was the priority, that moment, that day. This supports Grant's (2004) study that concluded worry over safety may not only be confined to direct caregiving activities, but also to changes in established patterns of daily living. There are reasons that individuals have routine or usual roles and responsibilities because these routines, roles and responsibilities facilitate adaptation and provide comfort because of their familiarity. For these elderly spousal caregivers, the rather frequent disruptions to a planned, orderly day resulted in other important tasks being pushed aside, piling up and creating stress. The performance of daily caregiving tasks under these kinds of conditions, of being under stress and being outside the daily comfort zone of routine while having to respond to priorities of care, contributed to these participants' difficulty in managing unsafe situations for their loved ones.

The result of elderly spousal caregivers' concern over safety was isolation and confinement. The participants' stories revealed that their decisions to forgo social outings and leisure pursuits were either because the struggle to get their loved ones out of the house safely was just too difficult or they insisted on staying home with their loved one in order to keep him/her safe. Being, for the most part, the sole providers of care, the most effective way for these participants to ensure their loved ones' safety was to narrow their world to the home and provide caring in place. This gradual, daily caregiving life of isolation and confinement had all kinds of implications for these participants and their care recipients including negative impact on well-being and general health.

Challenged to age successfully (Theme 3). This study looked at components of successful aging with elderly spousal caregivers that included the concepts of well-being, engagement with life and health. The two previous themes of forced self-reliance and

concern for care recipient safety, which contributed to a caregiving life of isolation and confinement, offered some considerations as to the impact these issues had on elderly caregivers' ability to age successfully.

Well-being as a component of successful aging had a strong positive presence in elderly spousal caregiving. One important way well-being was experienced by these participants was through their loving obligation and commitment to caregiving. Phrases expressed by these participants, such as "feeling good about oneself," "being the right thing to do," and "having a purpose in life," were interwoven in their stories of how they became their spouse's caregiver. This finding supports Lopez's (2005) contention that caregivers who attend to a relative by their own decision and not because it is imposed upon them find more satisfaction when fulfilling their role. This finding also supports Feeney's (2003) work in which he discovered that individuals who are involved in a satisfying relationship would be motivated by a genuine concern for the welfare of their partners and that they would derive a sense of personal fulfillment from caring for their partners. Other pursuits of well-being that the participants engaged in included support groups, respite care and their own personal coping strategies. Per their descriptions, these activities brought to these participants feelings of affirmation, validation, stress relief and personal growth. These elderly spousal caregivers may not have been able to engage in many outside activities that could have brought them well-being, but the choice itself, to be their spouses' caregivers, did bring great feelings of joy, accomplishment and personal satisfaction.

Forced self-reliance created opportunities for successful aging. Presented in the first theme of this discussion, forced self reliance put these elderly spousal caregivers in a

very difficult situation in their caregiving: as often being the only providers of care. However, forced self reliance did offer some growth experiences for these elderly spousal caregivers in the context of their successful aging. On their own, with little support, guidance or physical help, these participants engaged in problem-solving a variety of caregiving situations including: negotiating and advocating with formal healthcare providers over care for their loved ones and needed resources; providing daily physical and emotional care; prioritizing tasks throughout their day; anticipating, planning for and responding to safety issues. All of these activities required these participants' cognitive, physical and emotional skills and these skills were challenged to grow as their care recipients declined in function. Interestingly in the interviews, these participants did not identify these particular activities as being components that contributed to their ability to age successfully. Yet these skills and personal strengths were showcased in these elderly spousal caregivers' various stories regarding their care provision. And these participants' presentations at the series of interviews for this study also reflected, as a group, their highly insightful, creative, strong and resourceful qualities. Moen (1994) supports this finding of the positives of challenges in caregiving in his contention that caregiving is more accurately appreciated as the beginning of a process that encompasses many components capable of affecting people across a substantial arc of their life course, impacting both positively and negatively on aging successfully.

In a negative aspect of successful aging, elderly spousal caregivers were restricted in their ability to engage with life. These participants' stories told of once active social lives with their spouses that were now severely restricted for a variety of reasons including lack of time, lack of energy, being the sole provider of care and concern for safety. This

finding of lack of engagement with life supported Connell's (1999) work where she found that the demands of providing full-time care limit available time and energy. Therefore, she concluded, the act of caregiving is likely to reduce the opportunities for engaging in a variety of leisure activities that augment quality of life and contribute to varied and rewarding social relationships and experiences. These elderly spousal caregivers expressed in their stories keen awareness of what they were missing in terms of sacrificing once cherished activities for the sake of caregiving. Their descriptions of past engagements resounded with a sense of loss and yearning. This finding supports the work of Pearlin (2001) when she discussed the reduction of social commitments as bringing on feelings of loss and conflict. If the caregiver begins to resist changes to their caregiving routine or ordinary daily activities, because of missed social opportunities, they may feel a sense of letting down their loved one. This conflict of roles and emotions can have an adverse effect on genuine well-being and therefore successful aging.

Elderly spousal caregivers had negative health experiences that they attributed to their caregiving occupation. These participants' difficulty in maintaining their health was described by them as being an important factor in their inability to age successfully. Nearly all of these elderly spousal caregivers described negative health experiences that ranged from simple lack of regular exercise to breast cancer. These participants told stories of their challenges to maintain good health that included their inability to keep medical and dental appointments as well as pursue wellness activities. These findings support Connell's (1999) work in that she found caregivers were in poorer physical health than age-matched controls and that the carers frequently attributed their health problems to the demands of their caregiving responsibilities. Sheehy (2010) also found

in her work that caregivers were at a high risk for sleep deprivation, immune system deficiency, depression, chronic anxiety, loss of concentration and even premature death. Some of the elderly spousal caregivers expressed great fear that their health would deteriorate more rapidly than that of the care recipient and they worried about what would happen then to their loved one. The negative health consequences for these elderly spousal caregivers gave an impression that in the occupation of caregiving, caregivers sacrifice their own health for the health of their loved one. That is not to say that this was a conscious decision on the part of these participants but rather, neglect of the caregiver's health was due to their very focused efforts and concerns toward the caregivers recipient's health issues. This kind of outcome was a significant finding of injustice of the caregiving occupation.

An unjust occupation (Theme 4). Elderly spouses experienced injustice in their occupation of caregiving due to lack of needed training, education and resources; imbalance of daily activities and feelings of being overwhelmed. The managing of chronic illness by individuals versus society will also be discussed as a factor of occupational injustice in elderly spousal caregiving.

These elderly spousal caregivers did not receive adequate caregiver training, education or resources from formal healthcare providers. These participants shared stories of how their occupation of caregiving was made more difficult because of all the unknowns. This finding supports the works of numerous authors and their studies. Hudson (2004) found, for example, that for some caregivers, the most challenging aspects of their role were related to inadequate health professional support. The caregivers were disturbed by poor continuity, inadequate information, limited respite and lack of system management

education. Brereton (2000) also found carers engaging in 'seeking' activities in order to ensure that they felt confident and safe to provide care and that they understood the likely future demands they may have to face. Rather than being facilitated by professional care providers, these carers' efforts often went unnoticed or were overlooked, leaving the carers feeling that they were going it alone. This feeling of aloneness in their occupation was shared by these elderly spousal caregivers. They used the term 'trial and error' frequently in their descriptions of providing care without really knowing what they were doing. There was no one to teach them. From an occupational justice perspective, Wilcock (2004) would have said that in utilizing trial and error methods, the injustice is that these elderly spousal caregivers were unable to demonstrate their true capacities and abilities. Wilcock would also explain that these caregivers lacked the empowerment to facilitate adaptation to their new caregiving role. Without empowerment there can be no feeling of 'mastery' which Schumacher (2000) described as a positive view of one's ability and behavior during the caregiving process. From mastery would come the feeling of self-efficacy, which is the caregiver's confidence regarding how well he or she is managing the problem and disabilities for the care receiver. Providing care well was vitally important to these participants. These elderly spouses expressed, many times, their desire to be better caregivers by developing their competency, knowledge and skills in their caregiving occupation. The occupational injustice to these elderly spousal caregivers was that they were not given the proper tools and resources that would have enabled them to have full engagement in this meaningful occupation of caring for their spouse. The result was many lost opportunities for these caregivers to actually thrive in their occupation. As Greenberger (2003) noted, self-confident caregivers and those

empowered by health professionals will tend to be more active health-wise, more assertive in reaching out for guidance and more likely to put that guidance into practice.

Elderly spousal caregivers experienced extreme imbalance in their caregiving occupation. These participants' stories told of very little or no time for leisure pursuits, social activities, or time for self on any given day. This occupational imbalance, a form of occupational injustice, came from lack of secondary assistance in care, lack of resources and fear of leaving the care recipient alone due to concern over safety. Wilcock (2004) described such occupational imbalance for caregivers as being over-employed, leaving them at high risk for ill health as a result of being too busy to look after themselves. One of the tenets of occupational justice is the right of individuals to benefit from diverse participation in occupations. Human health and well-being requires a variation in labor, work and leisure occupations. And indeed, these participants expressed their needs to fulfill and experience other roles and occupations that were just as meaningful and enriching as caregiving. These other roles and occupations would have brought balance to their lives. Such balance would have allowed for more health-giving routines and increased these participants' social inclusion and that could only have led to a more positive effect on their caregiving occupation.

These elderly spousal caregivers expressed feelings of being overwhelmed as a result of occupational imbalance. Feeling overwhelmed was described by these participants as gradual and insidious; for example, "The thing is again, it is because it creeps up on you. You don't see yourself as stretched out. This is your new normal." This finding was in contrast to the concept of burden and stress found in so much of the caregiving literature. These elderly spousal caregivers did not express or seem to identify with the physical and

mental aspects of burden and stress. Rather their stories described more of their emotional struggles with the weight of their caregiving responsibilities over time for a loved one (wanting to do everything right and well) and the resulting emotional feelings expressed as loneliness, sadness and helplessness. The overwhelming responsibility supports Schumacher's (2000) contention that this is a big issue with elderly spouses attempting to provide care unassisted in a situation often requiring more clinical skill than should be expected of lay people. Yet one of the reasons why these caregivers may not have identified so much with the experiences of great burden and stress, so often seen in the caregiving literature, was because of the loving obligation that brought them to the caregiving role in the first place. This supports Lopez's (2005) finding that when being a caregiver was a free and personal option, it was easier to discover more satisfaction in the performance of their roles. Finding meaning in caregiving enabled these elderly spousal caregivers to transcend the difficulties of their situation. This supports Wilcock's (2004) contention that in the delicate balance of caregivers being satisfied in doing their role, yet feeling overwhelmed in taking on such a huge responsibility, the occupational injustice is in not providing the support and resources to facilitate adaptation.

These elderly spousal caregivers have experienced occupational injustice in their caregiving occupation primarily because they have attempted to manage chronic illness mostly on their own. This supports Sheehy's (2010) finding in her work that our healthcare system has no affordable solution for chronic illness caregiving except round trips to the emergency room and frequent readmissions to the hospital all of which the participants in this study experienced many times. Only very short term help is available for the chronically ill at home. Shuttling the care recipient in and out of acute care

hospitals at the sign of any new symptom or unrelieved pain is debilitating for the patient and defeating for the caregiver. If true occupational justice were to be enacted for these elderly spousal caregivers it would begin with the view that chronic, frail aged people are a societal responsibility and not an individual one.

Conclusion

Elderly spouses in this study committed to their caregiving occupation when their loved one needed their help with care in the home. Described as loving obligation, this commitment to care for someone with a chronic illness was a long road. The caregiving occupation demanded advocacy, multiple interactions with formal healthcare providers and facilities and challenges to physical, mental and emotional states. What loving obligation had done was contributed to the well-being of the caregivers, having provided them with some satisfaction and fulfillment in their care of a loved one, while having helped them transcend some of the harshest burdens of caregiving that can abound in chronic illness management in the home.

Elderly spouses in this study were isolated and confined, primarily due to their concern and worries for care recipient safety. They were often on their own, forced to be self-reliant as the sole provider of care. The situation created for them the necessity of having to learn through trial and error, which increased the occurrence of unsafe events, which they were trying so hard to prevent. Isolation and confinement restricted the caregivers from participating in other roles and occupations, decreasing their opportunities to age successfully.

Finally, elderly spouses experienced occupational injustice through the lack of empowerment, which would have helped them achieve mastery in their provision of care,

and given them self-efficacy: the confidence to do it well. Just imagine assuming an occupation with no preparation, no resources and no balance: an occupation of 24/7 care with little or no relief. Love and commitment kept these elderly caregivers going, but at a cost of health and general well-being. With chronic illness on the rise in this country, this scenario for elderly spousal caregivers could be playing over and over again.

That is why occupational therapists and the rest of formal healthcare need to have a goal that frail, elderly, chronically ill people should be viewed as a societal rather than as an individual responsibility. Having that view is a way to incorporate more support for these elderly spousal caregivers in their good work. An occupational therapy caregiving model of practice is a good step toward that goal.

Clinical Implications

The results of this study offer an opportunity for occupational therapists to devise interventions for elderly caregivers that will be meaningful and practical; interventions that take the profession back to its roots of advocating for the belief that people are compelled to be productive members of society and that society has a duty to enable this participation. At this time in our present healthcare situation, who could be more valued as a productive member of society than the elderly spousal caregiver, providing care for years in the home, and saving the government billions of dollars annually?

Occupational therapists should consider a model of practice with elderly spousal caregivers based on the findings of this study and others. Acknowledging that caregivers are not usually the occupational therapists' direct clients, but rather extensions of the patients on caseload, this model of practice would be a triad approach of care involving patient, caregiver and occupational therapist.

Considerations for this model would be inclusion of an elderly spousal caregiver job description, a caregiver assessment, treatment goals early on in care of patients that incorporate specific caregiver training techniques, active aging approaches and empowerment strategies.

A generic job description for elderly spousal caregiving would have the capacity to be tailored to the specific individual. A job description would be a formal way of recognizing that caregiving is a viable occupation that includes all of the components of the MOHO model that occupational therapists are familiar with: volition, habits and routines and performance skills. Like any occupation, elderly spousal caregiving requires formal preparation and training. Caregiver training in the presence of their loved one, conducted by occupational therapists and other healthcare providers should be comprehensive and include the very basics of care and any specialized techniques the care recipient would require, keeping in mind that the caregiver may be the sole provider of care in their home.

A brief caregiver assessment would give the occupational therapist valuable information on capabilities of that individual, resources available to them and most importantly, the carer's perspective and understanding of their caregiving role.

Active aging approaches would first recognize what the experience has been so far for the elderly spousal caregiver in their realm of successful aging, acknowledging their loving obligation and commitment to care while also guiding the carer with strategies to continue participating in well-being, engagement with life and health-related activities that are within the scope of their caregiving occupation.

Finally the data showed that elderly spousal caregivers need to be empowered in their occupation. The above components of a model of practice should help, but occupational therapists can also take the lead as formal healthcare providers in incorporating elderly spousal caregivers more as part of the care team, when it comes to decisions of care and treatments. These caregivers need guidance in understanding the healthcare system, its various levels, its language and what drives the decisions that are made concerning their loved one. As occupational therapists draw caregivers more into their arena of practice, it is hoped that other healthcare providers will follow.

Future Studies.

Future research into elderly spousal caregiving should continue to be qualitative in nature, as our body of knowledge is so enriched by participants' descriptions and stories of their experiences. From the results of this study, it would be useful for health professionals to pursue research on the families of elderly spousal caregivers. There is a need to further explore the family members' perceptions and experiences of their parents' caregiving process as well as their perspective of their involvement or lack thereof in the daily caregiving tasks for their parent.

For the participants of this study, as well as for health professionals, it would also be informative to study formal caregivers' perceptions of informal caregivers. In particular, how the informal caregivers' role of patient advocate is interpreted and received by the health professionals in caring for the chronically ill spouse.

There is much yet to learn about elderly spousal caregiving in order for occupational therapists and occupational therapy assistants to effectively assist this population in their very vital occupation of caregiving.

APPENDICES

Appendix A

INFORMED CONSENT FORM

Towson University Occupational Therapy and Occupational Science Department and faculty are conducting a research study on care giving. We want to examine the experiences of caregivers in the home, caring for a chronically medically ill family member. We hope to better understand all that is involved in providing such care. This information will be used to train and educate occupational therapists and other health care professionals on how to better approach and assist caregivers. Your role in this project will consist of allowing 1-3 one-hour interview sessions, to be conducted in a location of your choice, and completing a short survey. You will be compensated for your time.

Participation in this study is voluntary. All information will remain strictly confidential. Although the descriptions and findings may be published, your identity will not be revealed at any time. You are at liberty to withdraw your consent to the study and discontinue participation at any time without prejudice. If you have any questions, please feel free to call 410-780-7306 and ask for Christine Moghimi, or contact Dr. Patricia Alt, Chairperson of the Institutional Review Board for the Protection of Human Participants at Towson University at 410-704-2236. **(This project has been reviewed by the IRB for the Protection of Human Participants at Towson University).**

I _____ affirm that I have read and understood the

above statement and have had all of my questions answered.

Date: _____

Signature: _____

Witness: _____

**** (Should there be situations where the participant's safety and well-being are at risk, the researcher may have to break confidentiality) ****

**EXEMPTION NUMBER: 10-0X14**

To: Christine Moghimi
From: Institutional Review Board for the Protection of Human
Subjects, Gerald Jerome *GJ/WRP*
Date: Wednesday, August 26, 2009
RE: Application for Approval of Research Involving the Use of
Human Participants

Office of University
Research Services

Towson University
8000 York Road
Towson, MD 21252-0001

t. 410 704-2336
f. 410 704-4494

Thank you for submitting an application for approval of the research titled,
*The care giving process: a phenomenological examination of the meaning
of caregiving in a sample of community-dwelling caregivers.*

to the Institutional Review Board for the Protection of Human Participants
(IRB) at Towson University.

Your research is exempt from general Human Participants requirements
according to 45 CFR 46.101(b)(2). No further review of this project is
required from year to year provided it does not deviate from the submitted
research design.

If you substantially change your research project or your survey
instrument, please notify the Board immediately.

We wish you every success in your research project.

CC: Dr. Regena Stevens-Ratchford
File

Appendix C

LOOKING FOR CAREGIVERS...FOR A STUDY ON THE CAREGIVING EXPERIENCE

Towson University Occupational Therapy Doctoral Student and Faculty are conducting a
research study on the caregiving experience

If the following characteristics describe you.....

- Between the ages of 60 and 85
- Primary caregiver to a spouse with at least 1-2 chronic illnesses
- Providing care in the home for at least 6 months
- Are willing and able to describe your experience about caregiving for a loved one

Then you can help us understand the caregiving experience!!!!

Volunteers will need to meet with a researcher for up to 5 interviews, each approximately 1 hour in length. The interviews will include questions on how you became a caregiver; what do you do as a caregiver; and how has the experience of caregiving affected you and your family

If interested in volunteering, please contact:

Christine Moghimi, MAS, OTR

Department of Occupational Therapy & Occupational Science

Towson University

410-780-7306

Appendix D

The Moghimi Care giving Interview Guide.

Section 1: The Culture of the Care giving Process.

- 1) Tell me about your interactions with healthcare professionals and your participation in decisions and plans made for the care of your loved one.
- 2) How did the treatment team show respect for your needs/wants as a family?
- 3) What types of differences or similarities were there, between your opinion on care and the healthcare professionals' opinion?

Section II: Occupational Justice in the Care giving Process.

- 1) What preparation did you have for becoming a caregiver?
- 2) What personal, social, leisure, and productive activities have been affected since you have taken on the role of caregiver?
- 3) What kind of community resources have you been aware of and able to utilize?
- 4) How has caregiving affected your health and well-being?
- 5) How do you manage your time for caregiving and your time for participating in your other occupations/activities?

Section III: The Care giving Occupation.

- 1) How did you become a caregiver- what was the process?
- 2) What are the challenges of caregiving? Tell me about the feelings regarding the challenges of caregiving; tell me about the emotional impact of your experiences as a caregiver.
- 3) What does it mean to be a caregiver?

Section IV: Successful Aging and Care giving.

- 1) How do you monitor your physical health?
- 2) Describe activities you engage in to keep mentally alert and active.
- 3) What social activities do you engage in that are outside of the home?
- 4) How would you describe your feelings of self-confidence and empowerment to Accomplish the activities in your life?

Appendix E

Study of the Care giving Process

1st interview- the details of daily caregiving for your spouse.

Definition of caregiving: *is the act of providing unpaid assistance and support to family members or acquaintances who have physical, psychological or developmental needs.*

Preparation for the interview- via telephone conversation.

“ I am next going to want to talk to you about a day of caregiving. I want to get a clear picture of what it is like for you and I am trying to get all of the details. In preparation for our next interview, I would like you to think about all that you do every day in providing care for your spouse; the challenges; how you chose the routine you have; what types of things help you or hinder you.”

Questions:

- 1) Describe/share all of the care activities you provide on a typical day. What does the day look like? (*motivation for occupation*)
- 2) Tell me about the days that don't go smoothly and why?
- 3) How did you decide to set up your day this way? Who or what dictates the day's activities; the timing of these activities? (*values, patterning of occup. Behavior*)
- 4) How did you learn to do these activities? (*skilled performance*)
- 5) How does the social and physical environment help or hinder you in your caregiving activities? (*knowledge of capacity-one's present and potential capacities*)
- 6) How do you make time for yourself or other obligations/household tasks?
- 7) How do you feel about the amount and type of care you provide every day?
- 8) Can you describe the strategies you use to cope with your caregiving role?

Sources for the questions:

- a. Conceptual Foundations of Occupational Therapy by Gary Kielhofner; chapter 10: The Model of Human Occupation
- b. Chapter 2 of defense proposal- Literature Review
- c. The Not-So-Golden Years-Care giving, The Frail Elderly, and the Long-Term Care Establishment, by Lauren Katz Olson (2003). Chapter 3: The Domestic Sphere: Family Caregivers
- d. Care giving in the U.S. by the National Alliance for Care giving and the AARP (2004)

Study of the Care giving Process

2nd interview: questions regarding culture and its influence on caregiving

Definition of culture: *the set of attitudes, values, concepts, practices and beliefs shared by the members of a group.*

Preparation for the interview, via telephone conversation:

“ For our next interview, I would like to ask you questions regarding your perspective of being a caregiver, based on your family values, traditions and roles. In preparation, maybe you can think about your family culture and how that has influenced your decision to be a caregiver; the kind of caregiving you provide; and your coping strategies. (by culture I mean the beliefs and values about how caregiving is done).

Questions:

- 1) Tell me about your attitude and your family’s attitude regarding caring for a loved one in the home. Do you have any family role model for this particular activity? Was it an expectation? Are you respected for what you do?
- 2) How do you feel about utilizing outside support and help versus utilizing those who are close to you?
- 3) What do you value about caregiving? What is important to you about being a caregiver?
- 4) What are your standards of practice as a caregiver? What are you expecting from yourself and your care on a daily basis?
- 5) What is your view of illness in terms of your approach to caregiving?

Sources for the questions:

- a. Care giving Awareness Through Resources and Education for Professionals by the American Society on Aging
- b. Dilworth-Anderson (2004)
- c. Kosloski (2002)

Study of the Care giving Process

3rd interview- occupational justice

Definition of Occupational Justice: *recognizing and providing for the occupational needs of individuals and communities as part of a fair and empowering society; enabling everyone to flourish to their greatest potential individually or as members of communities.*

Preparation for the interview, via telephone conversation

“On our next interview, I want to explore with you the impact caregiving has had on your other activities that you do for fun, relaxation, education, etc. I want to know how you cope with the busyness of your life now and how that has affected your general health and well-being.”

Questions:

- 1) Explain to me the kinds of activities you used to participate in prior to becoming a caregiver. What interested you? What types of activities did you look forward to doing?
- 2) In taking on caregiving tasks, tell me what activities or tasks did you have to give up, or spend less time on? How has that affected you on a daily basis?
- 3) What kind of teaching, demonstration or counseling do you think would have helped better prepare you for your caregiving role?
- 4) What support/help would make your caregiving better?
- 5) Tell me about how you find balance and maintain a sense of control over caregiving and your life?
- 6) Tell me about how you manage life's demands (home, finances, shopping) in the midst of caregiving. What happens when things get to be too much? What happens when you get overwhelmed?
- 7) Do you have any feelings of injustice or unfairness? Tell why or why not.
- 8) How comfortable are you in sharing with others your role as a caregiver, your challenges and needs?

Sources for the questions:

- a. Literature Review- chapter two
- b. Occupational Justice and Client Centered Practice: A dialogue in progress.
(Townsend and Wilcock, 2004)

A Study of the Care giving Process

4th interview- Successful Aging

Definition of well-being: *complex, physical, mental and social well-being, not merely the absence of disease or infirmity.*

Definition of quality of life: *general state of life contentment and fulfillment that is a combination of functional status, health, social and psychological and environmental factors.*

Definition of life satisfaction: *state of well-being.*

Preparation for the interview, via telephone conversation:

“In our last interview, I would like to discuss with you how caregiving has affected your ability to age successfully. What we mean by successful aging is when individuals experience continued good health, high mental and physical function and they are involved in social, productive, and leisure activities.”

Questions:

- 1) How has caregiving affected your physical spiritual and mental well-being? How has it affected your quality of life/life satisfaction?
- 2) Describe the activities you engage in to keep your mind active.
- 3) Describe the activities you engage in to educate yourself.
- 4) Tell me about your social network? How do you stay socially connected and keep in touch with others? How does caregiving affect these relationships?

Sources for the Questions:

- a. Literature review- Chapter 2
- b. Information from Dr Regena
- c. Rowe and Kahn, 1999- S-R, 2008, Wicks, 2006; Lennartsen & Silverstein, Hilton, 2009.

Appendix F

CAREGIVERS DEMOGRAPHIC QUESTIONNAIRE

Subject Number____

1.) Gender: Male__Female__

2.) Race:

__Caucasian

__African-American

__Hispanic/Latino

__Asian/Pacific Islander

__Native American/Alaskan Native

__Other: specify_____

3.) Highest Level of Education:

__No formal education

__Elementary school: grade__

__Middle school: grade__

__High school: grade__

__Vocational training

__College: # of years__

__Some graduate school: # of years__

__Graduate degree: type of degree_____

4.) Date of birth_____

5.) Number of children/stepchildren____

Ages:_____Locations:_____

—

6.) Number of grandchildren/step-grandchildren____

Ages:_____Locations:_____

7.) Number and gender of siblings_____

Ages:_____Locations:_____

—

8.) How long have you lived in your current home?_____

9.) What types of home management activities are you responsible for? /Days per week?

- ☐ lawn care__
- ☐ managing finances__
- ☐ house cleaning__
- ☐ home repairs__
- ☐ meal preparations__
- ☐ grocery shopping__
- ☐ laundry__
- ☐ pet care__

10.) How many hours of care do you provide per day? _____

11.) What Activities of Daily Living do you assist with?

- ☐ bathing
- ☐ dressing
- ☐ feeding
- ☐ toileting
- ☐ grooming/hygiene
- ☐ transfers
- ☐ errands/appointments
- ☐ functional mobility
- ☐ medical care
- ☐ medication management

12.) As a caregiver have you ever utilized community resources? Yes__No__
If yes, what types of resources have you utilized?

- ☐ financial help
- ☐ formal caregiver training
- ☐ transportation services
- ☐ meals on wheels
- ☐ support groups
- ☐ adult day care
- ☐ respite services
- ☐ religious community
- ☐ friends
- ☐ family members

- 13.) Rate the financial hardship of caregiving on a scale of 0 (no hardship) to 10 (major/severe hardship)
- 14.) How many leisure and other activities are you involved in per week? ____
- 15.) Choose the statement which best describes how you feel about leisure:
- __leisure activities are unimportant to me
 - __leisure activities are somewhat important to me
 - __leisure activities are very important to me
- 16.) How do you rate your physical health at this time?
- __poor
 - __fair
 - __good
 - __excellent
- 17.) How do you rate your emotional health at this time?
- __poor
 - __fair
 - __good
 - __excellent

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