THE STRESS OF CAREGIVING: FACTORS IMPACTING FAMILY CAREGIVERS FOLLOWING ENTRY OF THE CARE RECIPIENT INTO A NURSING HOME

by

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But Jesus looked at them and said to them,
"With men this is impossible,
but with God all things are possible".
(Mathew 19:26)

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As I close one chapter in my life I am reminded, "Arriving at one goal is the starting point to another" (John Dewey). I will carry with me, not only the knowledge and skills I have obtained while a student at the University of Texas at Arlington, but a commitment to the social work profession reflective of that which is modeled by all throughout the social work department.

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ABSTRACT

THE STRESS OF CAREGIVING: FACTORS IMPACTING FAMILY CAREGIVERS FOLLOWING ENTRY OF THE CARE RECIPIENT INTO A NURSING HOME

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The purpose of this study was to identify stressors associated with family caregiving following entry into the nursing home of the care recipient. A cross-sectional, survey design included 129 family caregivers for care recipients located in sixteen long-term care facilities in north central Texas and Southern Oklahoma. Consistent with prior research stress related to the caregiving role did not end with the care recipient's entry into the nursing home. Utilizing a conceptual model of stress proliferation, caregiver characteristics, role captivity, constriction of participation in family activities, family conflict and work-caregiving conflict are examined in relation to perceived stress.

Multiple linear regression with forward entry indicated role captivity accounted for the majority of explained variance in perceived stress by family caregivers, followed by constriction of time for participating in family activities, caregiver income and family conflict. Caregiver uplifts (positive beliefs about oneself as a caregiver and personal growth attributed to the caregiving role) originally thought to mediate perceived stress, were eliminated from analysis as almost 100% of participants indicated a high levels of caregiver uplifts. Contextual factors examined included dual caregiving responsibilities, length of time in the caregiving role, visitation schedule and reason for placement. While these variables did not contribute to the model for perceived stress, they do offer insight into the multiple issues faced by family caregivers of loved ones who are in a long term are facility. Family caregivers identified the activities of caring in which they participated following nursing home entry, and if they felt this to be a hassle.

Understanding the multiple and complex ways family caregivers provide support to the care recipient, while at the same time recognizing the unique stressors they face as a consequence of this role provides a challenge for professionals along the continuum of healthcare. Specifically, social workers need to cultivate a knowledge base and skills that support family caregivers throughout the process of institutional care for their loved one.

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CHAPTER 1

INTRODUCTION

Caregiving is a term commonly used to reference the “act of giving care” to someone who needs assistance completing some aspect of daily activities. Informal caregiving is understood to mean the physical act of providing assistance to someone who is aged or disabled without monetary compensation, and is usually provided by family or friends of the care recipient. In addition to the physical aspect of providing assistance, this natural course of human interaction encompasses an affective or emotional component of “caring” about the individual in need. The emotional and physical components of the caregiving relationship have the potential to impact caregiver well-being throughout the term of the caregiving role.

The affective and physical components of the caregiving role when coupled with chronic life strains occurring in the lives of family caregivers create an environment challenging the caregiver’s capacity to maintain a homeostatic balance in their lives resulting in a process of stress proliferation (Pearlin, Menaghan, Lieberman, & Mullan, 1981; Pearlin, Mullen, & Semple, 1990). A desire to understand the process of family (informal) caregiver stress proliferation and associated outcomes have earned a prominent place in the research literature over the last twenty-five years. Much of this research documents the negative impact care demands have on outcomes for caregivers (Blake, Lincoln & Clark, 2003; Coverman, 1989; Frosch et al. 1997; Gaugler, Zarit, Pearlin2003; Kolakowsky, Hayner & Kishoe, 1999) while some gives credence to positive outcomes gleaned from the role of caregiver (Kellett, 1998; Raschick & Ingersoll-Dayston, 2004; Sanders, 2005). The breadth of research focuses on informal caregivers for community dwelling care recipients.

A decision to terminate care in the community and seek placement within a nursing home for the care recipient is often times identified as a manifestation of the care giving stress proliferation process (Aneshensal, Pearlin, & Schuler, 1993; Gaugler, Leach, Clay, & Newcomer, 2004; Gaugler et al. 2003; Kramer, 2000). Despite the link between caregiver stress, termination of the caregiving role in the community setting and evidence of continued involvement of family members following entry into a nursing facility little is known of caregiver outcomes once the care recipient enters a formal institution. Additionally, informal caregiving is not always initiated in a non-institutional setting. Caregiving may actually begin at the time the care recipient enters a nursing home. Perhaps the care recipient was able to function independently until illness or injury resulted in an abrupt interruption of this homeostatic state. The option to enter a facility may be abrupt, thus thrusting a family member into an informal caregiving situation at the time institutionalization occurs. The literature virtually overlooks issues faced by these family caregivers.

1.1 Background

1.1.1 Nature of Informal Caregiving

Informal caregivers, usually family or friends may be considered primary caregivers (i.e. the person who spends the most time helping) or secondary caregivers (extended members of the family providing support to primary caregivers or professional caretakers); they may provide assistance full or part time; may live with the care recipient or live separately and they may provide assistance for the care recipient who is institutionalized. National Alliance for Caregiving and AARP estimates that 21% (44.4 million) of the U.S. population provides care to friends and family ages 18 or older and who are aged or disabled (Pandya, 2005). Assistance may be provided to meet needs with instrumental activities of daily living (IADL), which includes helping with laundry, transportation, yard work or housekeeping and overseeing financial issues. A more intense level of assistance is that of activities of daily living (ADL) which encompasses physical assistance in dressing, bathing, eating, toileting, transferring from one surface to another and ambulation or mobility. Care provided for IADL tasks and ADL tasks by informal caregivers translates to an estimated $306 billion a year of “free care”, which is almost twice as much, spent on formal in home services and nursing home services combined (Arno, 2006). A typical caregiver in the United States is female (61%), approximately 46 years of age, has at least some college experience (66%), and spends an average of 20 hours or more per week providing unpaid care to someone 50 or older (Pandya, 2005).

1.1.2. Evolution of Informal Caregiving

In the 19th and 20th centuries caregiving was typically a short-term endeavor with overall life expectancy much shorter than current estimates. From 1900 through 2003 life expectancy at birth increased from 48 years to 75 years for men and 51 years to 80 years for women (Arno, 2006). Improved access to healthcare advances in medical technology and pharmacological interventions, along with overall better health before age 65 underlie decreased death rates and increased life expectancy. In recent decades medical miracles including life-sustaining mechanisms such as the ventilator or internal feeding devices have been introduced. Such advances have resulted in increased life expectancy with individuals surviving conditions that previously resulted in death, often creating the need for substantial and chronic lifetime care. Areas identified with increased survival rates include individuals with cardiovascular diseases, those suffering traumatic (TBI) and non-traumatic brain injuries and individuals who experienced spinal cord injuries. Additionally the ability to manage symptoms of chronic diseases such as Alzheimer's disease, Multiple Sclerosis, or Parkinson's disease has resulted in individuals living longer with increasing care needs. Individuals surviving catastrophic medical events often have life long disabilities and chronic conditions, along with better disease management of chronic progressive disease processes in turn impact healthcare costs, increasing governmental and third party insurance expenditures.

Thirty-five years ago fewer individuals survived heart attack or stroke, with estimates of non-institutionalize stroke survivors increasing from 1.5 million to 2.4 million between the 1970s and 1990s (American Heart Association, 2004). Many of these survivors require sustained physical, emotional and financial assistance. Accident victims who might not have survived severe physical injury in past decades now live full life expectancies but often with ongoing need for assistance. According to the Centers for Disease Control and Prevention (2006) 1.4 million individuals sustain a TBI each year in the United States, and it is estimated that 5.3 million American currently have a long-term or life long need for help to perform activities of daily living as a result of a TBI.

According to Centers for Medicare and Medicaid Services the U.S. spent approximately $2.0 trillion in healthcare costs or $6,697 per person in 2005. Since the early eighties when diagnostic related groups (DRGs) were introduced as a payment scale for Medicare, a shift from receiving care in a hospital environment to a community setting has been the focus of efforts aimed at reducing overall healthcare expenditures. As the proportion of the population aged 65 and older increase, federal actuarial projections suggest the combined Medicare and Medicaid cost could grow from approximately 7% of the gross domestic product (GDP) in 2005 to 24% of the GDP by 2080 (Manton, Gu & Lamb, 2006). Further efforts to reduce medical costs and governmental responsibility for long term care will result in increased expectations of family and friends to care for loved ones in need. The need for informal caregivers is projected to increase in the years ahead, with the population of individuals over the age of 65 expected to increase by 2.3% (Mack & Thompson, 2001).

When informal caregivers are not available, willing or able to provide sustained, intense levels of care required by the care recipient, alternatives must be sought, and placing the care recipient into a nursing facility is often the only alternative available. For persons who turned 65 in 1990, it is projected 43% will enter a nursing home at sometime before they die (Kemper & Murtaugh, 1991). The number of people age 65 and older living in nursing homes will likely double by the year 2020 and 55% of those entering a nursing home will have a total lifetime use of one year, 21% will have total lifetime use of five or more years with more women entering a nursing home and having a longer lifetime use of 5 or more years (Kemper & Murtaugh). Once seen as a form of abandonment by the family, the decision to place the care recipient in the nursing home has been demonstrated to be no more than a shift in the caregiving environment and the role of family caregiver (Gaugler, 2005; Hertzberg, Ekman, & Axelsson, 2001; Whitlatch, Schur, Noelker, Ejaz & Looman, 2001; Port, et al. 2005).

While the choice to place a loved one into a long-term care facility is often difficult and emotionally taxing for all involved, it may be the only realistic alternative available to ensure the needs and safety of the care recipient are met. Understanding how stress factors might change for the caregiver following entry into the nursing home is a first step in the development and implementation of supports to assist with this transition.

1.2 Purpose of The Study

An underlying premise of this study is that activities associated with the caregiving role, while altered, will continue following the care recipient's entry into a nursing home. Additionally family caregivers will experience stress, as well as personal growth, as a result of the caregiving relationship. Within the context of this study, "stress" will refer to the state of the caregiver, rather than the circumstances to which the caregiver is exposed. Utilizing the conceptual framework of the stress process outlined by Pearlin et al. (1990) as a model, the relationship of role captivity, multiple role conflict, family conflict, caregiver gain (which includes feelings of confidence and personal growth) to caregiver stress will be examined in family caregivers of loved ones who have entered a nursing home. Subsequent analysis will be conducted to compare perceptions of the above identified stress factors between caregivers who provided assistance to the care recipient in the community prior to nursing home entry and those who did not.

1.2.1 Research Questions

1. What are the stressors associated with family caregiving following a loved one's entry into nursing home?
2. Do family caregivers who provided assistance to the care recipient prior to entry into the nursing home experience differences in stress factors than those who did not provide assistance prior to the care recipient's entry into the nursing home?

1.2.2 Research Hypothesis

1. Family conflict will impact feelings of stress for family caregivers of care recipients in nursing homes.
2. Family caregivers (of care recipients in nursing homes) who report positive beliefs about their abilities as a caregiver will experience lower levels of stress than those who do not.
3. Family caregivers (of care recipients in nursing homes) who report more personal growth will experience lower levels of stress than those who do not.
4. Family caregivers who assisted in the care of the care recipient prior to nursing home entry will experience less multiple role conflict than family caregivers who did not provide assistance prior to the care recipient's entry into the nursing home.
5. Family caregivers who assisted in the care of the care recipient prior to nursing home entry will experience less conflict associated with advocating for and assisting the care recipient following entry into the nursing home than family caregivers who did not provide assistance prior to the care recipient's entry into the nursing facility.
6. Family caregivers who did not provide assistance to the care recipient prior to entry into the nursing home will have greater feelings of role captivity than family caregivers who did provide assistance prior to the care recipient's entry into the nursing home.

1.3 Problem Statement

While research shows caregivers remain involved with the care recipient following nursing home admission, a void exists in identifying stress factors or positive outcomes and understanding the impact these have on the overall well being of family caregivers. Positive outcomes for the care recipient often times are dependent on the caregiver's reaction to placement (Davies & Nolan, 2005; Whitlatch et al. 2001). Knowledge of the impact a care recipient's entry into a nursing home has on caregiver outcomes in relation to stress, adjustment and role transition will provide a solid foundation to build and sustain in building positive relationships between the caregiver, facility staff and care recipient.

1.4 Relevance to Social Work

The social work profession has been embedded within the field of healthcare dating back over 100 years, when in 1906 Ida M. Cannon was appointed by Dr. Richard Cabot to provide social services in outpatient clinics at Massachusetts General Hospital. Bringing the unique perspective and knowledge base of understanding the person within the environment, it was expected social work professionals would be able to address the psychosocial factors impacting patient outcomes (Cannon, 1952). The evolving continuum of healthcare has resulted in patients receiving services in a variety of settings including inpatient or outpatient hospital facilities, home health services, and various levels of residential settings where the focus is on long-term, non-acute care needs, with social workers providing services at the various junctures of this complicated system.

Unprecedented growth of the elderly population in the 21st century has heightened the awareness for what is termed “long-term care services”. The broad scope of help with daily activities for chronically ill or disabled individuals includes a range of services provided in the home (least restrictive environment) to care encompassed within the nursing home (most restrictive environment) and are deemed “long term care services”. Future social work professionals working in healthcare and social services will be increasingly involved with older individuals and their families impacting outcomes for both caregiver and care recipient across a variety of long term care settings (Kitchen & Brook, 2005; Holliman, Dziegielewski, & Priyadaishi, 2001).

Because the need to seek entry into a nursing home is often initiated during hospitalization following treatment of an acute illness or injury (primarily a fall), social workers become a primary contact for the family caregiver making faced with this decision. With physicians often times playing a major role in this decision making process, the social worker bridges the gap between the hospital environment and the natural environment of the patient by bringing the family’s voice to the healthcare team and teaching caregivers how to effectively advocate for the care recipient (Kitchen & Brook, 2005; Kolb, 2003 Nolan & Dellasega, 2000). The social worker’s focus is on resolving issues related to seeking nursing home placement for the care recipient through consultations with the patient, family and various service providers as a component of discharge planning (Auslander, 2000; Ryan & Scullion, 2000).

If care at home begins to breakdown and the caregiver seeks entry into a nursing home for the care recipient, social workers within the home health realm often become involved. Within both settings social workers potentially impact caregivers experience with the transition to a formal care setting and by working in partnership with the caregiver to ease this transition; the experience may be enhanced in a positive manner (Davies & Nolan, 2005).

Once the transition from community to institution has occurred, social workers continue to play a vital role in adjustment for both the care recipient and the caregiver. In 1990 nursing home reform legislation made the goal of enhancing the quality of life of nursing home residents a part of the national policy. Federal Law (42 CFR 483.15) requires that all skilled nursing facilities provide “medically related social services to attain or maintain the highest practical resident physical, mental and psychosocial well-being”.

Enmeshed within an orientation of systems theory, the social worker understands the interactive effects placement has on the care recipient and the caregiver, or simply stated: “what affects one, affects the other”. Despite the common myth that care recipients are admitted to nursing homes and abandoned by family caregivers, research exists that shows family members remain involved in the care recipient’s life (Gaugler, 2005; Hertzbert et al. 2000; Kolb, 2003).

Caregivers have been shown to be involved actively in the decision-making process regarding placement, and often times are the key decision maker in this process (Nolan & Dellasega, 2000). Research demonstrates that caregivers have needs of their own because they are facing the institutionalization and gradual deterioration of the care recipient (Hertzberg et al. 2000; Kellet, 1998; Davies & Nolan, 2005; Gaugler 2005). However assessment and interventions at the time of entry into a nursing home often are entirely focused on the care recipient despite the adjustment needs of the caregivers (Davies & Nolan).

It has been shown adjustment to the nursing home setting for the care recipient is impacted by the interpersonal relationship between the caregiver and resident, in addition to stressful characteristics of the nursing home (Whitlatch et al. 2001). Evidence does exist that involvement with nursing home residents by relatives can have positive effect for both relatives and residents (Davies & Nolan, 2005). Social Workers have ample opportunities to make a positive impact for both the family caregiver and the care recipient along the continuum of long term care.

CHAPTER 2

REVIEW OF THE LITERATURE

To fully understand the factors impacting caregivers within the process of stress proliferation, the concept of stress must first be described. The term “stress” has become a common term used to identify a wide range of phenomena impacting physical and psychological outcomes within human existence. Rooted in biological sciences, stress is considered a non-specific response of the body to a demand.

2.1 Stress Process

The origins of understanding the relationship between the non-physical component of being human (the mind) and physical manifestations (the body) can be traced back to the seventeenth century in the philosophical works of Descartes. In his later writings, Descartes espoused the concept related to an interaction between the human mind and the functioning of the body. While philosophical thinkers were grappling with the concepts of the psychological impacting the physical, engineering scientists, such as Robert Hooke, were evaluating differences among various structural components.

Hooke was an experimental researcher in a variety of areas in the seventeenth century, including engineering. Through his work he gave stress a technical component. The *Law of Elasticity*, refers to the “load”, which is the demand placed on the structure, “stress” is the area affected by the demand and “strain” the change in form that results from the interaction between load and stress (Cooper & Dewe, 2004; Lazarus, 1993). The theme evolving from these early works that perpetuates into the 21st century is the idea of stress being an external load or demand on a biological, social or psychological system (Lazarus).

Four consistent ideas emerge within stress research, which include the presence of a causal agent, an evaluative component by the organism, the presence or absence of coping mechanisms and a complex pattern of effects on the mind and body often referred to as the stress reaction (Lazarus, 1993). Stress proliferation process as outlined by Pearlin, Mullan & Semple (1990), incorporates these components in an effort to better understand experiences of the family caregiver. First a causal external or internal agent must be present, this is what Hooke referred to as “the load”; Lazarus (1993) considers this to be an interaction of person-environment relationship; Antonovsky (1987) suggests that a demand has been made on an organism (either from the external or internal environment or both) and given the organisms current mode of functioning it is not capable of meeting the demand.

Once the external or internal demand has been made, an evaluation by the mind or a psychological system occurs and distinguishes what is threatening or noxious from what is benign about the event (Lazarus, 1993). In his work with holocaust survivors, Aaron Antonovsky (1987) described the importance of having a sense of comprehensibility, in that demand is perceived by the individual as making cognitive sense, and a sense of manageability which is the perception that adequate resources are at one’s disposal to meet the demand thus negating the event as threatening or noxious.

Stress was originally purported to produce a linear effect on physical and psychological outcomes of individuals, however research in the 1950s began to demonstrate stress did not affect everyone in the same manner. Empirical evidence exists to demonstrate that appraisal and coping processes shape the stress reaction, and these processes are in turn influenced by variables in the environment and within the person, producing varied outcomes across populations (Antonovsky, 1987; Pearlin et al. 1981). These themes, which have emerged from stress research, serve as a map for understanding the complex and multi-dimensional aspects of the stress proliferation process for caregivers.

2.2 Caregiver Stress Proliferation

The caregiver stress proliferation process is an organizing framework conceptualized out of the many years of stress research (Lazarus, 1993; Pearlin et al. 1990). Caregiver stress is experienced when life events, chronic life strains, individual self-concepts, and coping mechanisms, along with the presence or absence of social supports come together to create an environment that challenges the individual's capacity to adapt to role of primary caregiver. Placing caregiving activities into the conceptual framework of a "process" results in a model for identifying stressors (or factors) and understanding the role each plays in the overall impact of caregiver stress. The process of caregiver stress proliferation can best be understood by examining three domains: the sources, mediators and manifestations associated with this process (Pearlin et al. 1981). Sources of stress include those factors considered to be primary stressors, which in turn lead to secondary stressors. Primary and secondary stressors are perceived to be straining or exceeding the caregiver's capacity to adequately adapt.

Primary stressors stem directly from the needs of the care recipient in terms of the nature and magnitude of care demand, thus driving the process which results in conditions, experiences and activities that become problematic for the care provider (Pearlin et al. 1990). Specifically feelings of role captivity, level of care demand reflected in assistance required by the care recipient to complete activities of daily living (ADLs) and instrumental activities of daily living (IADLs) are considered primary stress factors. In addition cognitive functioning and behavioral patterns of the care recipient have been identified as a source of primary stress for caregivers. Because primary stressors associated with care demand are likely to be both durable and intensified over time additional factors referred to as secondary stressors result (Pearlin et al. 1981; 1990). Secondary stressors include role tensions (role conflict and role strain) along with intrapsychic strains (caregiver competence and mastery).

Caregivers are not passive recipients of the stress process, but bring with them individual coping mechanisms and networks of support systems. The ability of the caregiver to modify the caregiving situation or the meaning associated with the caregiving situation has been shown to impact stress outcomes (Jansson, Nordbert & Grafström, 2001). While caregiver health has been shown to play a role at various points of the stress process, the primary focus is on concerns stress factors have ultimately on caregiver health. Potential outcomes, in addition to those related to caregiver health status, include caregiver depression and/or the decision to terminate care and seek entry into a nursing home setting.

2.3 Primary Stressors

2.3.1. Onset of Caregiving Role

The mechanism initiating the caregiving role (whether it is an immediate onset following an accident or illness or a gradual decline in the physical and cognitive ability of the care recipient) is the first factor within the proliferation stress process and has been shown to directly impact outcomes for the caregiver. Based on work by Bernice Neugarten, abrupt life transitions or unexpected events that occur "off time" in the normative life cycle is likely to be perceived as more stressful, leaving the individual no time for anticipatory coping and planning (Hagestad & Neugarten, 1985). In correlation with the concept of an abrupt entry into a caregiving role or one that occurs "off time", the age of the caregiver has been found to be associated with self-loss, with younger adult children and spouses experiencing conflicting feelings regarding what they should or would like to be doing and the demands of the caregiving role (Skaff & Pearlin, 1992). For those individuals faced with assuming the caregiving role at a time in his/her life when this is not an expected norm, a lack of identification with peers exists. With a lack of reference group, the caregiver may feel isolated thus compounding the stressful event.

Caregivers faced with an acute need to accept caregiving responsibilities, experience immediate disruption in an established role system resulting in stress factors related to role captivity, role conflict and an individual sense of mastery or control (Aneshensal et al. 1993; Gaugler, Anderson, Zarit, & Pearlin, 2004; Salive, Collins, Foley, & George, 1993). While relative few studies examine the actual impact caregiver acquisition has on caregiver stress, information may be extrapolated from research encompassing caregiver outcomes within specific diagnostic categories that would constitute an immediate and enduring need for care such as traumatic brain injury, stroke or spinal cord injury.

Caregivers of spinal cord injured persons have experienced negative effects on their lives, but the severity of the injury experienced by the care recipient is not a correlation of the negative outcome, giving some validity to the assumption that an abrupt, off-time entry into the caregiving role would have a negative impact on caregiver outcomes (Ünalan et al. 2001; Manigandan et al. 2000). Similar findings are reported for those providing assistance to stroke survivors.

It has been found that the early weeks at home following discharge from the hospital prove to be difficult with caregivers reporting they have to teach themselves the physical skills necessary to help the care recipient at home, while attempting to come to terms with dramatic changes in their own lifestyle, and that of the person for whom they are providing care (Kerr & Smith, 2001). Following a stroke in one marital partner, role responsibilities for the unaffected spouse increase and the enjoyment of performing such roles decreases (Deluane & Brown, 2001). Changes in personal plans, feeling overwhelmed, upsetting behaviors of the care recipient and feelings of confinement were reported by spouses of stroke survivors at three months and six months following the event (Blake et al. 2003). Co-resident spouses of stroke patients were shown to experience significant strain most strongly associated with caregiver mood, perceived patient Extended Activities of Daily Living (EADL) and negative affectivity (Blake & Lincoln, 2000). The best predictors of caregiver depression at onset of the caregiver role among persons providing care to a stroke survivor included lower life satisfaction, lower physical functioning, and a lack of tangible social support (Grant, Bartolucci, Elliot & Giger, 2000).

In contrast to an acute accident or illness, family caregivers often find themselves drifting into the role of primary caregiver such as when the care recipient is an aging parent or spouse, or has a progressive illness such as Alzheimer’s disease, Parkinson’s disease, or Multiple Sclerosis. When the caregiving role is assumed in small increments over a period of time individuals become well entrenched in the provision of care have been found to be less likely to place the care recipient in an institution (Gaugler, Zarit, & Pearlin, 2003). A slow integration of the caregiving role provides opportunity for the caregiver to reorganize his/her role system into a positive balance. A more balanced role system results in reports of less roles strain, more role ease, greater well-being and more positive role experiences than people with less balanced systems (Marks & MacDermid, 1996). It would be anticipated an abrupt entry into the caregiving role would potentially result in greater feelings of role captivity, as the caregiver has less time to incorporate the new role into existing schema. When faced with an immediate decision to accept caregiving responsibilities, the option to seek institutional placement may result in negative feelings of self-esteem in the caregiver when he/she is not being able or willing to provide care outside of a facility. Likewise for those who have become immersed in the caregiving role over time, adapting the role into an existing life style, may find themselves faced the need to place a care recipient into a facility when a breakdown in the caregiving environment occurs resulting feelings of failure and guilt.

2.3.2. Role Captivity

Once a situation has occurred to trigger the need for a caregiver, the individual must determine if this is a role he/she is willing to accept. Role captivity refers to feelings that one has unwittingly become captive of an unwanted role (Pearlin et al. 1990). Placed within the stress process as a primary stressor, the potential for feelings of role captivity emerge in conjunction with the method of role acquisition and is correlated with factors related to overall caregiver stress.

The caregiver may not find the caregiving aspect difficult or initially stressful, but simply does not want to be the one responsible for meeting the needs of the care recipient. The caregiving role may be experienced as an obligation, or the caregiver may be required to withdraw from other roles in which he/she has a vested interest i.e. that of student, active community member or perhaps even employee. Some caregivers report it is just assumed they would care for their relative and no one ever asked if they wanted to or were willing (Kerr & Smith, 2001).

In one instance placement of the care recipient into a nursing home has been demonstrated to alleviate feelings of role captivity (Aneshensal et al. 1993). For caregivers of non-dementia patients, perceived stress increased with the perception of feeling trapped in the caregiving role rather than with the perception of care recipient behavior problems (Bertrand, Fredman & Saczynski, 2006).

Whether an immediate need ignites the caregiving role or it is assumed in small increments over time, it becomes necessary to address unmet needs of a disabled, elderly or ill individual. Care demands (at times used interchangeably with the term care burden) include the intensity and duration of providing assistance with instrumental activities of daily living (shopping, answering the phone, driving, bill paying etc.) and activities of daily living (toileting, bathing, dressing, eating, ambulation and transferring). A caregiver may also complete activity assistance in ways they don't even realize such as providing empathy, supervision and mental stimulation (Jansson et al. 2001).

2.3.3 IADL and ADL Functioning

Providing assistance with instrumental activities of daily living (IADLs) may be associated with the gradual onset of a caregiving role and is seen as a less intense level of assistance, while the intensity and duration of need related to assisting with activities of daily living (ADLs) directly impacts the caregiver's physical functioning, feelings of role strain, and role overload (Pearlin et al. 1990). The number of hours providing care is directly related to feelings of burden among extended family members, but has no impact on burden for spouses or adult children (Thiede Call, Finch, Huck & Kane, 1999). In a large national sample of nurses, it was found that higher informal care time commitment and increased risk for depression is especially strong among spouse caregivers (Cannuscio, et al. 2004). As would be expected, higher levels of role strain have been found to be associated with the caregiver living with the care recipient, directly relating to the physical and mental impairment of the care recipient (Williams, Dilworth-Anderson & Goodwin, 2003). Assisting the care recipient with activities of daily living has not been directly correlated to the various outcomes for the caregiver (CK Chan, PWH & Lieh-Mak, 2000) but impacts secondary stress factor such as role strain, multiple role conflict, feelings of competence and a sense of mastery (Pearlin et al. 1990).

2.3.4. Cognitive Status of Care Recipient

Cognitive deficits, or what may be termed dementia, are associated with diseases such as Alzheimer's disease, Parkinson's disease and various vascular disease processes. Dementia includes the loss of mental processing ability, including communication skills, abstract thinking, judgment and physical abilities, all which interfere with daily living. Dementia can occur gradually or following an acute illness or injury. Increased levels of intensity and time required to assist adults with dementia in ADL and IADL tasks is apparent throughout the literature (Bertrand et al. 2006; Jannson et al. 2001; Pearlin, Aneshensel, & Leblanc, 1997). In a meta-analysis conducted by Pinquart and Sörensen (2004), cognitive problems of the care recipient showed stronger associations with low subjective well being in the caregiver than did the number of months in the caregiver role and the number of caregiving tasks.

Others have reported limited support of the relationship between care recipient cognitive status and the impact on caregiver outcomes. One study found that no behavior variables including neither memory and behavior problems, nor the extent of cognitive impairment correlated with caregiver burden (Zarit, Reever & Bach-Peterson, 1980). While investigating feelings of burden in Japanese caregivers, bivariate analysis showed burden was significantly impacted by cognitive status of the care recipient, yet in a multivariate analysis this relationship evaporated (Miura, Arai & Yamaski, 2005).

Despite the differences reported throughout the literature, several problem areas are identified as specific to the care provided to care recipients with dementia, including increased need to provide supervision, potential isolation of the care giver, a decrease in the exchange relationship between caregiver and care recipient and the anticipated progressive deterioration of the care receiver (Clipp & George, 1993). First is the increased need for supervision, resulting in a lack of spare time for the caregiver. Being overwhelmed with care responsibilities was identified as a theme for those providing assistance to Alzheimer's patients (Sanders, 2005). Being overwhelmed originated from lack of sleep, growing feelings of fatigue and the development of increasing responsibilities as the disease progressed.

An additional consequence of dementia care may be that of relational depravation, which refers to the restructuring of the caregiver-care recipient relationship, stripping it of its former reciprocities. A limited ability of the care receiver to express gratitude has resulted in a decrease in associated uplifts of caregiving (Clipp & George, 1993). In a comparison study examining differences in gender and relationship to care recipient, it was found that receiving companionship from the care receiving husband had a strong association with greater caregiving rewards for wives (Raschick & Ingersoll-Dayton, 2004). To gain a deeper understanding of the interactions occurring between caregiver and care recipient who is cognitively impaired, a qualitative, observational study was undertaken with eight cohabitating couples (Jansson et al. 2001). In this study, all caregivers had undergone a transition from equal partner to caregiver and had full time responsibility for planning, decisions and assignments in the home, responsibilities once shared with the care recipient. In addition to observable tasks oriented care, the provision of mental and physical stimulation to the impaired individual, along with constant supervision and surveillance were observed. Within the intense level of caregiving observed, unimpaired spouses gained knowledge and expertise in performing the caregiving task, often serving as mediators for other family members and between various social and health care networks.

In a longitudinal study of caregivers to individuals with Alzheimer's disease, the severity of cognitive degeneration appears to have no influence upon the placement decisions (Aneshensal et al. 1993). While in some instances changes in the cognitive status of the care recipient, resulting in behavioral problems has been shown to lead to decisions to seek entry into a nursing home (Gaugler et al. 2004; Kramer, 2000; Ryan & Scullion, 2000). The latter is potentially a result in the behavior status of the care recipient and not directly tied to the cognitive decline.

2.3.5 Behavioral Status of Care Recipient

While levels of assistance provided to the care recipient in terms of activities of daily living have been shown to impact entry into a nursing home, care-recipient behavior problems demonstrate more viability in the stress process (Grant et al. 2000; Williams et al. 2003). When the care recipient manifests behavioral problems such as physical resistance during the care process, wandering which requires a constant vigil by the caregiver or verbal outbursts, the stress associated with caregiving becomes compounded. In addition when complex care demands require the physical abilities of the caregiver and time related to providing care, providing assistance with daily activities for someone who demonstrates behavioral problems such as aggressive behavior is even more difficult. The pivotal role of personality change and increased behavioral difficulties is well documented throughout the literature regarding individuals who have experienced traumatic and non-traumatic brain injuries.

A longitudinal study of individuals with traumatic brain injury and the impact behavioral changes had on the caregiver's well being demonstrated negative emotional behaviors, in particular anger, apathy and dependency caused the greatest distress of distress for caregivers (Marsh, Kersel, Havill & Sleigh, 1998). In support of the assumption within the framework of caregiver proliferation that primary stressors, being enduring over time impact other areas of the caregivers life, one study demonstrated increased number of behavioral issues in survivors of traumatic brain injury resulted in a higher number of role changes for the caregiver and loss of free time (Frosch et al. 1997; Marsh, Kersel, Havill & Sleigh, 1998). Caregivers faced reducing other occupied roles within their lives, such as student, worker, and religious participant etc. when the care recipient exhibited behavioral problems causing distress.

2.4 Secondary Stressors

Secondary stressors result as an enduring and prolonged need for care disrupts the caregiver's daily environment in terms of work, family and social life roles. Secondary stressors are examined as direct outcomes resulting from the need to assist the care recipient with IADL tasks, and ADL tasks. Additionally the cognitive status and presence or absence of behavioral problems has been shown to impact secondary stress factors. Secondary stressors include those evolving from role tension in the area of role strain and role conflict, along with changes in individual self-esteem related to the caregiving role and an individual sense of control or mastery.

2.4.1 Role Strain: Beliefs about the caregiving role

Conceptually pressure to meet care demands for the care recipient, coupled with subjective responses to the caregiving role held by the caregiver, compounded by shared social expectations, and the external evaluations of others regarding the caregiver's ability to provide adequate care results in role strain (Thomas & Biddle, 1966). Components of role strain include the caregiver's ability to provide hands on care, often times specialized, in the home, coupled with gender role expectations, and expectations of other family members leading to potential conflict.

Medical advances aimed at prolonging life have resulted in an expectation of informal caregivers to become an extension of the healthcare environment. Caregivers are often expected to provide specialized services to the care recipient such as diabetic care, special diets, and internal feedings, even in some instances administration of IV's or wound care in the home, in addition to traditional caregiving tasks related to ADL tasks. Higher levels of physical and cognitive impairment and medically fragility of the care recipient, the more specialized care expected. Individuals providing care for stroke survivors in Hong Kong reported the main problem encountered in the first weeks following release from the hospital was how to protect the care recipient from harm (WH Sit, KS Wong, Clinton, SW Li & Fong, 2004).

It has been documented throughout the caregiving research, globally that women are more likely to be in the role of primary caregiver. Additionally based on the role theory perspective and the caregiving literature, men and women may be expected to react to or cope with the caregiving role in different ways due to differences in caregiving role expectations, caregiving role satisfaction, and perception of role adequacy; role preparedness and meanings associated with the caregiving role in late life (Mui, 1995; Boeije, & Van Doorne-Huskies, 2003)

Women were found to approach caregiving from a sense of duty and become engulfed in the role, while men appear to be motivated by obligation and are more likely to set boundaries, making space for their own interests (Boeije & Van Doorne-Huskies). When vignettes were presented to participants asking for distribution of caregiving tasks among a set of adult children, daughters were more closely associated with what would be “female” task such as housekeeping and assisting with bathing (Lawrence, Goodnow, Woods & Kranatzas, 2002). Caregiving wives have reported experiencing more restriction in their personal and social activities than caregiving husbands (Bookwala & Schulz, 2000; DeLaune & Brown, 2001). A greater ‘loss of self” reported by women also tends to be associated with greater restrictions on social contacts and fewer social roles outside of the caregiver role (Skaff & Pearlin, 1992). It has been suggested that the financial burdens associated with caregiving may be more of a stressor for caregiving husbands than their female counterparts (Bookwala & Schulz).

Increased levels of role strain have been shown to have a direct impact on caregiver self esteem and feelings of mastery. The pressure of role strain may result in the care recipient choosing to terminate care in the community and move the care recipient into a formal institution. This would have a direct impact on the caregivers level of self-esteem, and feelings of mastery with one anticipating a decline in these levels as the caregiver would feel a sense of failure, not being able to meet the expectations of the caregiving role as identified by others and his/herself. The time spent assisting the care recipient to complete ADL tasks directly reduces the time available to spend in other roles for the caregiver resulting in multiple role conflict.

2.4.2 Multiple Role Conflict

Multiple role conflict occurs when competing demand from many roles is such that adequate performance of one role jeopardizes fulfillment of other roles role conflict occurs. Two opposing viewpoints, enhancement hypothesis and scarcity hypothesis, have emerged within the literature related to demands placed on the individual by multiple roles. Those subscribing to the enhancement hypothesis anticipate occupying multiple roles enhances one's energy by increasing sources of identity, self-esteem, rewards and resources available to cope with multiple demands (Marks, 1977). Some support in the literature exists for the enhancement hypothesis, caregivers report experiencing spiritual growth and increased faith as a result of the caregiving process, along with personal growth and feelings of mastery based on personal accomplishments (Sanders, 2005). Additionally support exists that outside roles have a significant negative effect on loss of self (Skaff & Pearlin, 1992). It seems the more social identities one has outside the caregiver role, the more potential sources of positive self-evaluation and positive feedback about the self.

Caregiving literature tends to provide more support for the scarcity hypothesis, which presupposes the more roles occupied; the more likely limited resources will be depleted resulting in negative consequences for health and well being of the caregiver (Goode, 1960). Based on the definition of inter-role conflict in which the person is a member of simultaneously held positions for which distinct expectations are held, caregiver role conflict results from competing demands in providing care for the care recipient and fulfilling additional roles of parent, spouse, employee or civic participant. Multiple role conflict has been documented in areas of caregiver work conflict, conflict with family roles and activity restriction in personal and social life often times leading to physical exhaustion and increased stress (Blake & Lincoln, 2000; Boeije & Van Doorne-Huskies, 2003; Coverman, 1989; Frosch et al. 1997; Horowitz, 1985).

Time conflict occurs because work and family roles are generally performed in different locations so when functioning in one role the individual is physically unable to function in the other. Conflicting reports exist as to the picture of the employed caregiver. Research findings indicate it is not simply conflicts between role of employee and caregiver that results in negative outcomes, but elements related to care recipient behaviors, and caregiver gender interacts with employment status and contributes to stress proliferation (Edwards, Zarit, Stephens &Townsend, 2002) Results of one study indicated when assuming the caregiving role, the employee did not scale back time at work and the use of flexible scheduling or scheduled time off did not provide a mediating effect on the well-being of the caregiver (Chesley & Moen, 2006).

While the association between informal caregiving and depressive symptoms is similar among women who are not employed outside the home and those employed part-time or full time (Cannuscio et.al. 2004) interference of caregiving with employment was a significant predictor of emotional strain more often for daughters than sons (Mui, 1995). Women have been found to spend more time caregiving and performing a higher number of tasks which in turn affects their concerns about reduced work effectiveness due to worry about the elder care recipient (Neal, Ingersoll-Dayton & Starrels, 1997). Work was reported as stressful for spousal caregivers of persons with spinal cord injury in Hong Kong because they had to undertake both the caregiver and employee roles at the same time (CK Chan, 2000).

The examination of caregiver outcomes related to competing demands within the family unit is reflected throughout the literature in terms of the “sandwich generation”. The aging of the population has spurred investigations into the cohort of individuals who simultaneously support or have relations with their adult children as they enter and adjust to adulthood and their parents as they deal with issues of later life (Ward & Spitze, 1998; Grundy & Henretta, 2006). Of elders with a chronic disability, 75% rely on adult children for assistance with basic activities of daily living (Caregiving in the U.S., 2004).

The results of a study comparing mid-life women in the United States and Great Britain were contradictory in nature. Providing help to one or more adult children (including monetary and momentary assistance) increased the probability of also giving help to an elderly parent or parent-in-law and vice versa; but with potential demands from 3 or more children or a child at home, women were less likely to provide help to an elder (Grundy & Henretta, 2006). In a sample of over two thousand married persons ages 40 to 59, less than one-fifth of respondents were found to be combining help to children and parents (Ward & Spitz, 1998). In a survey of Canadian caregivers, only 27% of those aged 45-64 simultaneously performed childcare and eldercare (Williams, 2005).

Because the marriage relationship is embedded within other family involvements and responsibilities, which may be impacted, concern arises as to how role overload or conflict affects marital satisfaction. However, little evidence exists to support competing demands between familial roles negatively impacts the marriage relationship (Loomis & Booth, 1995; Marks & MacDermid, 1996) with the exception that role overload results in one or both spouses feeling neglected or unfairly burdened or there is too little time and energy for joint activities

As one assumes the role of primary caregiver, less time is available to participate in activities with family, friends or the pursuit of one's own goals and enjoyment. Interference in personal and social lives appears to be stressful for all caregivers regardless of relationship, gender or situation. Activity restriction, closely tied to role captivity could be a significant contributor to decisions for seeking institutional care for the care recipient. Evidence indicating role changes and activity restrictions occurring throughout the caregiving process is ample throughout the literature.

In a study of adult children caring for aging parents the conclusion that it is not the caregiving workload that is critical in determining strain, but rather the caregiver's beliefs or perceptions about the interference between caregiving and their personal social life is supported (Mui, 1995). Individuals assuming the caregiving role for traumatic brain injury patients reported distress about loss of personal free time (Marsh et al. 1998). Greater caregiver-activity restriction significantly predicted poorer relationship quality with the care recipient and was marginally related to more depressive symptoms for husbands (Bookwala & Schulz, 2000). Higher levels of caregiving assistance, along with increased behavioral problems exhibited by the care recipient resulted in greater activity restriction for wives (Bookwala & Schulz; Deluane & Brown, 2001). One would anticipate less restriction in caregiver's activities once institutional placement occurs, however little evidence of this in the literature exists at this time.

2.4.3 Caregiver Competence

Caregivers are often asked to assume the role of healthcare provider, or act as an arm of the healthcare system. The expectation of the caregiver to provide medical care, coupled with declining health of the care recipient and or unanticipated complications may result in decline in the caregivers judgment about his/her own worth related to providing competent care. The act of providing care may result in the caregiver experiencing negative self-relevant belief, or the way he/she judges the self, experiences of being competent to cope with basic life challenges or being worthy of happiness may be eroded by the caregiving role thus contributing to increase caregiving stress.

2.4.4 Caregiver Feelings of Mastery

A sense of mastery refers to the extent the caregiver sees him/herself in control of the forces that importantly affect his/her life (Pearlin et al. 1981; 1990). Closely tied to this concept is the definition of manageability (one component of an overall sense of coherence model) proposed by Aaron Antonovsky (1987) in which feelings of high manageability is correlated with the perception that adequate resources are available to meet the demands posed by the event activating the stress. Evidence of the importance for perceived manageability is found in an investigation of primary caregivers to survivors of traumatic brain injury (Nabors, Seacat &

Rosenthal, 2002). Results indicate the importance of caregiver needs and percentage of needs met was a higher predictor of caregiver burden than family functioning, social support, race, age and household income.

In relation to mastery or manageability of the caregiving role, the caregiver encounters various health and social service professionals, coordinates medical appointments, and often must apply for social services and benefits on behalf of the care recipient potentially eroding feelings of control. In a comparison study of primary caregivers for dementing and nondementing family members in Belgian, those with a strong sense of coherence are less likely to perceive role overload (Gallagher, Wagenfeld, Baro & Haepers, 1994).

2.5 Mediators of Caregiving Stress Process

The mobilization and use of resources and coping strategies are elements crucial within the stress that can be invoked by the caregiver in behalf of his/her own defense (Pearlin et al. 1981). The behaviors, perceptions and cognitions brought into the caregiving relationship by the caregiver are often capable of altering the difficult conditions or mediating their impact. Those elements which have a potential to impact the stress process for caregivers includes social supports, and coping mechanisms, specifically the ability to modify the caregiving situation, the meaning of the caregiving situation and the ability to manage the stressful situation.

2.5.1 Social Support

Social support refers to access and use of individual, groups or organization in dealing with the needs related to caregiving activity (Pearlin et al. 1981). Support mechanisms may include external, tangible help in the form of material or financial assistance, physical assistance within the provision of care or social companionship, which may encompass reciprocal help or support. Community caregivers found to have tangible support and social companionship exhibit better psychosocial health than those who did not (WH Sit et al. 2004). Similarly, spouses of spinal cord injured patients who were found to have limited coping strategies and social support were characterized by higher levels of depression and care-giving burden than spouses with adequate or mid-range coping strategies and social support (CK Chan, 2000; CK Chan, Lee et al. 2000).

Education targeted at community caregivers regarding availability of community resources and service coordination has proven to be beneficial in reducing negative outcomes. “Powerful tools for Caregiving” is an educational program aimed at family caregivers of older adults with a goal of reducing overall negative effects related to the caregiving situation. Significant positive outcomes were found in improved self-care behaviors, emotional well-being, caregiving self-efficacy and increased knowledge and use of community services (Boise, Congleton & Shannon, 2005). In spouse caregivers of persons with spinal cord injury, higher perceived social support is associated with lower caring burden and when coupled with adequate internal coping mechanisms, they are identified as being well-adjusted (CK Chan; CK Chan, PWH L., et al. 2000). As indicated social support is an important component in mediating the negative effects of caregiver stress for the caregiver within the community, leading to the assumption that following the care recipient’s entry into the nursing facility, social support would continue to be an important component in reducing caregiver stress. Education and written information also proved to significantly reduce anxiety in caregivers of head injured individuals within 2-9 months post injury (Morris, 2001).

Similarly in a program offering support after stroke, coordination of services and education were found to be beneficial in family functioning, along with improved functional and social outcomes for the patient (Clark, Rubenach & Winsor, 2003: Lilly, Lincoln & Francis, 2003). Swanberg, Kanatzar, Mendiondo & McCoskey (2006) evaluated the usage of an employer sponsored Eldercare program for employees at the University of Kentucky and the impact this had on caregiver stress. The program provided referrals, consultations and educational material. Employees utilizing the services reported reduced stress, and decreased financial burden related to long distance care provision. In addition fewer lost workdays have been reported since the program has been initiated.

2.5.2 Ability to modify the caregiving situation

The ability of the caregiver to positively alter his/her relationship with the caregiving environment may then lessen the conditions of psychological stress is one method of problem-focused coping (Lazarus, 1993). When the caregiver experiences a successful outcome secondary to actions taken a sense of mastery or control may be positively impacted in turn interrupting the progress towards depression or institutionalization

Caregivers who have a negative orientation towards problem solving have been shown to experience increased levels of depression, anxiety and ill health (Elliott & Shewchuk, 2003; Elliott, Shewchuk & Richards, 2001). The caregiver's tendencies to impulsively and carelessly solve problems have been associated with a lower acceptance of disability in the care recipient and were predictive of the development of pressure sores in individuals with recent onset of spinal cord injuries (Elliott et al. 2000).

The ability to modify the caregiving environment is closely linked with actual and perceived available social support networks (Grant, Elliott, Giger & Bartolucci, 2001). When caregivers are not provided with the education and support to effectively problem solve, the result is potentially termination of care in the community and the seeking of entry into a nursing home for the care recipient. Once the decision to terminate care in the community results in institutionalization, the caregiver may feel they have lost control, or failed the individual thus increasing stress following placement. Some caregivers may feel a sense of relief in turning over what is perceived as complicated medical care to a professional staff, which would then result in reduced stress.

2.5.3 Ability to modify the meaning of the caregiving situation

The meaning attached to the situation is representative of the motivational component or what is identified as emotion focused coping (Lazarus, 1993).

Antonovsky (1987) refers to meaningfulness as:

> … the extent to which one feels that life makes sense emotionally, that at least some of the problems and demands posed by living are worth investing energy in, are worthy of commitment and engagement, are challenges that are welcome rather than burdens that one would much rather do without (p. 18).

Seen within stress research as a coping mechanism, the caregiver's ability to modify the meaning of the caregiving situation refers to a cognitive process of appraisal or mediation, between the demands, constraints and resources of the environment and the personal beliefs of the caregiver (Lazarus, 1993; Pearlin et al. 1990). For the aspects of depressive symptoms and caregiver self-esteem, the ability to hold positive beliefs about the caregiving situation and about the self as caregiver was found to positively impact both (Noonan & Tennstedt, 1997). Similarly in a longitudinal study of caregivers for stroke survivors, a negative orientation was a significant predictor for the development of depression, anxiety and health complaints (Elliott et al. 2001). In the realm of the caregiving literature, understanding the impact meaning placed on the caregiving role by the caregiver has in terms of outcomes can be viewed from two perspectives first filial norms and expectations and cultural or ethnic norms and expectations.

Relationship of caregiver to care recipient has been shown to alter the meaning of the caregiving situation, thus the impact on stress outcomes. Adult children providing care for a parent have been shown to experience more rewards than do spousal caregivers, attributed to the spouse viewing the caregiving role as an expected duty, while children view the parental caregiving as exceeding social expectations and thus more rewarding (Raschick & Ingersoll-Dayton, 2004). Spouses of persons with spinal cord injury were found to decrease their expectations of their injured partner's role performance, resulting in a more satisfactory rating of the spinal cord injured individual (CK Chan et al. 2000). Consistent with the theme of filial norms, values and role expectations, caregivers outside of the immediate family, or with no relation to the care recipient, reported greater feelings of burden than did spousal or adult children caregivers (Thiede Call, et al. 2004).

Understanding the meaning of caregiving from the perspective of family members' values and role expectation pertaining to later life is important in creating cultural sensitive support systems and should be a targeted area of future research development. Several studies have undertaken cross-cultural comparisons when examining reasons for nursing home entry of the care recipient. A comparison of Latina and Caucasian caregivers found nursing home admission for the care recipient was delayed longer in the Latina population with cultural values and a positive perspective attached to the caregiving role attributed to these outcomes (Gaugler, Kane, Kane & Newcomer, 2006; Mausbach, et al. 2004). When comparing nursing home admission between African Americans and Whites, it was found African Americans were half as likely to be institutionalized, with physical and cognitive impairments being leading risk factors for whites but not African Americans (Salive et al. 1993).

2.6 Manifestations of Caregiving Stress Process

Manifestations or outcomes that have a documented association with the stress proliferation process throughout the literature include caregiver depression, impact on overall caregiver health and the decision to terminate care and seek entry into a nursing home.

2.6.1 Caregiver Depression

The effects or outcomes associated with the caregiving role are focused on the well being of the caregivers and their physical and mental health, along with the ability to sustain themselves in their social roles. Depression has been identified as a manifestation or outcome of the stress process (Pearlin et al. 1981). Depression as a manifestation of activities associated with the caregiving role and stress factors related to these activities vary across the scope of caregiving related research. Family caregivers who provide care 36 hours or more in a week are more likely than non-caregivers to experience symptoms of depression and anxiety, with the rate for spouses being six times higher and for adult children twice as high (Cannuscio et al., 2002).

As previously indicated, very little work has been done to examine circumstances surrounding the onset of the caregiver role and the relationship to caregiver stress. Some studies have substantiated an abrupt entry into the role of caregiver is directly associated with the decision to seek entry into a nursing home, but less is known about the impact role acquisition has on caregiver depression. In a longitudinal study, Gaugler (2005) found when care began gradually, caregivers reported a decrease in depressive symptoms over a 3-year period as compared to caregivers whose experience was the result of an abrupt situation.

Additionally, cognitive and behavioral problems of the care recipient are often directly related to the decision to institutionalize and have been correlated with depression in the caregiver, with depression in caregiving wives reported more frequently than husbands (Bookwala & Schulz, 2000; Clark, 2002). Higher weekly time commitment to informal care for a spouse or parent was associated with increased risk of depressive symptoms. Women who reported high spousal care time commitment and few social ties experienced a dramatic elevation in depressive symptoms, compared to women with no spousal care responsibilities and many social ties (Cannuscio et al. 2004).

Tangible social support, life satisfaction and physical functioning were the best predictors of depression in family caregivers of stroke survivors (Grant et al. 2001). In a sample of 202 primary caregivers who accessed adult day care services for relatives with a diagnosis of dementia, no significant differences between employed and non-employed caregivers were found on depressive symptoms (Edwards et al. 2002). Examining social problem solving abilities and the emotional reactions reported by people who assumed family caregiving roles, found a negative problem orientation or one of great pessimism, lack of motivation towards problem solving or the tendency towards negative moods correlated with higher levels of depression, distress and ill health (Elliott & Schwchuck, 2003; Elliot et al. 2001).

2.6.2 Caregiver Health Status

Caregiver health status has been viewed within the perspective as a mediating factor within the process of caregiver stress and as an outcome measure. To assure congruence within the conceptual framework utilized here, caregiver health status is viewed an outcome in that elements of emotional distress are likely to surface first and if persist, they may eventually lead to a decrease in the physical well-being of the caregiver (Pearlin, et al. 1990). McCann et al. (2004) found significant relationship between caregiver's health and the initiation and continuation of caregiving activities. The caregiver who had disabilities related to activities of daily living and experienced an increase in days in which he/she was in poor physical health were less likely to continue providing care. For these individuals, the need to seek entry into a nursing facility for the care recipient would potentially result in increased feelings of guilt and decreased self-esteem in that they "failed" the person. The placement of the care recipient would not result in a change in health status of the care provider, thus would not alleviate stress for the individual. Perceived burden caused by impact on health was seen to decrease significantly (Yeh, Johnson & Wang, 2002).

2.6.3 Decision to Institutionalize

As with incidents triggering the role of caregiving, those events associated with arriving at a decision to seek nursing home entry initiates a process of stress proliferation for post placement factors (Gaugler, 2005). Several studies have examined the "transition" for caregivers from community care to institutional care. In an exploratory study of family caregivers in Ireland, admission to an institution generally followed a time of crisis (Ryan & Scullion, 2000), while in Canada it is reported waiting on bed availability can be a long wait (up to five years), only to be rushed through the admission process once the bed becomes available (Reuss, Dupuis & Whitfield, 2005). Often times the decision to seek institutional placement is made due to lack of alternative resources to support continued care in the community (Kolb, 2003).

2.7 Critique of Existing Literature

Research regarding the effects of informal caregiving has grown extensively since the mid 1990s. Current research is vast, sophisticated and informative including qualitative studies, large-scale population investigations and information gleaned from longitudinal data. While the development of caregiving research as a whole, has transitioned from exploratory to predictive, understanding of the stress process as it relates to informal care provision following entry into the nursing home of the care recipient is in its early stages with exploratory studies being undertaken in the United Kingdom (Kellett, 1998, 1999), Australia (Davies & Nolan, 2005), Canada (Reuss et al. 2005) and the United States (Kolb, 2003).

The complexity and multiplicity of the caregiving role is reflective of the various measures utilized to capture characteristics, behaviors and outcomes associated with caregiving. The inconsistent use of terms and conceptual definitions of concepts related to activities results in difficulty in gaining a true picture of outcomes across the span of the caregiving role.

One example of such differences can be found when attempting to quantify activities related to the provision of hands on assistance in areas such as toileting, eating, transferring etc. are measured by a variety of methods including self report (Cannuscio, et.al, 2002, 2004; Gaugler et al. 2003) or more formal measures such as the Katz index of ADLs status (Gaugler et al. 2004; Kramer, 2000); Family Members Activities of Daily Living Questionnaire (Heru, Ryan & Igbal, 2004) or the Functional Independent Measurement (Grant, et al. 2001; Grant, Weaver, Elliott, Bartolucci & Giger, 2003). Attempting to capture more complex phenomenon such as burden, strain, stress, and life satisfaction results in even more elusive agreement conceptually and operationally.

A comparison of two separate studies examining caregiver burden for those providing assistance to individuals with traumatic brain injury demonstrates the difficulty in operationalizing such concepts. Caregiver burden as it relates to providing ongoing assistance for individuals with brain injuries has been conceptualized and operationalized in different ways. Burden seen as the direct result of providing assistance to the individual is related to the caregiver's perceived burden resulting from the affective/behavioral and cognitive and physical dependency of the care recipient (Marsh et al. 1998) whereas burden is seen as a level of distress experienced by the caregiver in relation to changes in their lives which have resulted from caring for the brain injured individual (Williams et al. 2003).

Caregiving is a phenomenon found throughout virtually every cultural and ethnic group within the United States and countries throughout the world. The caregiving literature is reflective of this to a certain extent with research initiatives being undertaken in the United Kingdom, Japan, Taiwan, Canada, New Zealand, and Ireland along with other countries. Within the United States understanding the cultural and ethnicity impact on caregiving roles is somewhat limited.

The United States is becoming increasingly diverse, with the non-white Hispanic population being one of the fastest growing. Projections from the year 2000 to 2025 for people 65 who are Latino will increase from 1.8 million to 6.1 million; and non-Hispanic black will increase from 2.8 million to 5.6 million with a projection that by 2050 the number of people 65 and over who are black will be 8.4 million including an increase in those who are 85 an older from 0.2 million to 1.4 million (U.S. Bureau of the Census, 1997). Some researchers are becoming sensitive to potential cultural issues when considering caregiving outcomes, both positive and negative (Gaulger et al. 2006; Mausbach et al. 2004; Salive et al. 1993). While the majority of studies utilize cross-sectional designs, the importance of viewing stress within the conceptual framework as a process is substantiated in studies utilizing longitudinal designs. Following caregivers over a period of time allows for a better understanding of adaptation and integration of the caregiving role into an existing lifestyle and who stress factors over time impact the decision to ultimately seek institutional placement for the care recipient (Aneshensel et al. 1993, Gaugler et al. 2003, Kramer, 2000; Marsh et al. 1998). The literature related to caregiver stress following nursing home entry is relatively young in the development of understandings. Exploratory studies have been undertaken in the United Kingdom (Kellett, 1998 & 1999) Australia (Davies & Nolan, 2005), Canada (Reuss et al. 2005) and the United States (Kolb, 2003).

2.8 Post Nursing Home Entry: Modifying the Conceptual Framework

It has been demonstrated that upon the care recipient's entry into a nursing home the role of informal caregiver does not end, but continues in various new ways (Whitlatch et al. 2001; Port et al., 2005; Gaugler, 2005). The conceptual model outlined by Pearlin and associates throughout the literature offers the foundation for understanding factors impacting family caregivers following placement of the care recipient (Figure 1.1). As has been established, the caregiving role does not end with placement; therefore feelings of role captivity may persist as the family caregiver is faced with assuming new responsibilities of monitoring personal care, financial oversight and advocacy on behalf of the care recipient creating new categories of primary stressors. Provision of assistance with ADL and IADL tasks is shifted from the family caregiver to professional staff; the need to assure this care is safe, appropriate and meets the needs of the care recipient emerges. As a result of the new responsibilities faced by the family caregiver, conflicts between other role responsibilities may emerge, along with disagreements among family members regarding issues surrounding the placement and ongoing care for the care recipient creating secondary stressors.

Additionally, family members may choose to not accept the allocation of caregiver outside of an institution if it occurs in an acute manner, instead choosing for the care recipient to enter a facility directly from the hospital or home following injury or illness. Identifying and understanding the factors impacting caregivers at this juncture of life has been overlooked throughout the literature. While some long term studies have provided insight into the impact the method of entry into the caregiving role has on the caregiver, no distinction in the empirical literature has found regarding feelings of role captivity between long-term community caregivers following nursing home placement and those facing the caregiving role for the first time at the point of entry into the institution.

Factors such as the ability to problem solve, modify and/or give meaning to the caregiving relationship would be anticipated to continue mediate the outcomes for family caregivers. Outcomes for family caregivers following placement would potentially be represented on a continuum from decreased stress, depression and overall improved health status to higher levels of stress, depression and overall decreased health status.

Nursing home placement is often times sought secondary to the care recipient's inability to manage ADL tasks and IADL tasks independently. Once the care recipient enters the nursing home the role of the caregiver has been shown to focus more on IADL tasks while staff provide assistance with ADL tasks. Kolb (2003) found caregivers carry out tasks related to visiting, bring specific foods, managing finances, washing residents' laundry and serving as interpreters. Caregivers also act as an advocate on behalf of the care recipient, monitor the standards of care and provide expert knowledge about the care recipient to assist the professional staff in understanding the individual. A glimpse into lives of family caregivers for loved ones in long term care can be found in the results of one an exploratory study conducted in the United Kingdom revealing three themes relating to care transition from the community to a nursing home from the perspective of the caregivers (Davies & Nolan, 2004). First is that of the period of "making the best of it", which represents the period of community caregiving; "making the move" reflecting the period immediately before and after entry into the nursing facility and "making it better" as caregivers make efforts to engage staff in the homes and contribute to the life of the care recipient in an ongoing way.

Understanding the factors, both positive and negative, and the impact these have on family caregivers post placement is imperative in building an appropriate educational and support network.

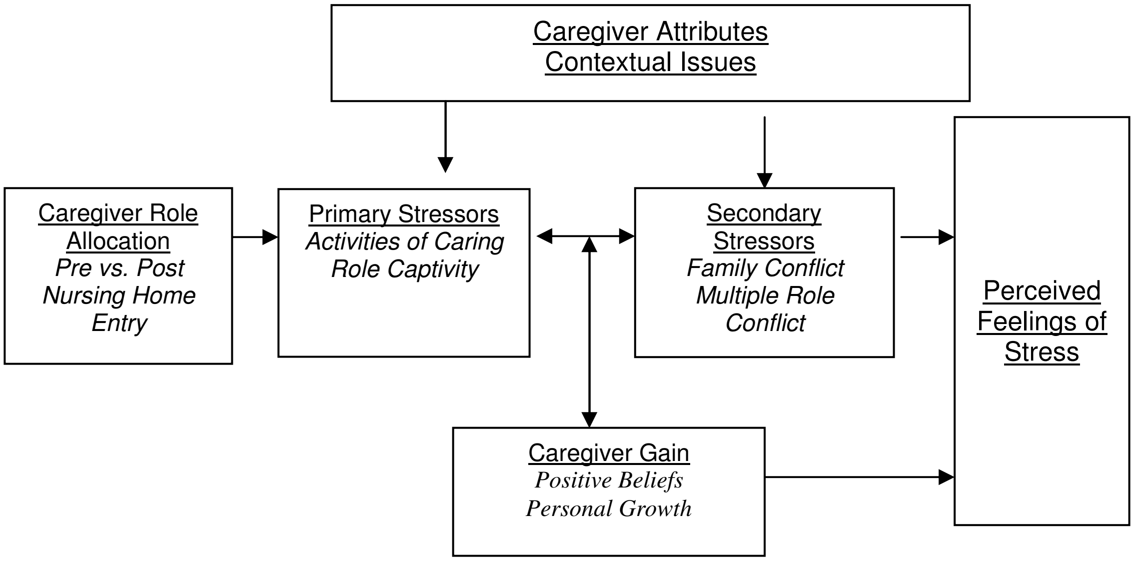

Figure 1.1 Proposed Model: Factors Impacting Family Caregivers Post Nursing Home Placement

2.8.1 Primary Stressors

Paralleling the stress proliferation process outlined for family members providing care in the community, allocation of the caregiving role and feelings of role captivity may also impact ongoing stress following the care recipient's entry into a nursing facility. There is a scarcity of research offering how the caregiver's feelings of obligation and unwanted responsibilities of caregiving are impacted by the choice to seek institutional placement. Entry into a nursing home was found to alleviate feelings of role captivity for caregivers of Alzheimer's patients (Aneshensal et al. 1993). Less physical strain for the caregiver following entry into a nursing home has been associated with more time and energy to enjoy social and recreational activities in husbands, thus potentially alleviating some feelings of role captivity (Kramer, 2000). However, in a study of caregivers from various ethnic backgrounds some indicated feelings of being trapped or being resentful of expectations placed upon them even within the nursing home setting (Kolb, 2003).

Caregiving in the community setting involves some level of direct assistance in terms of ADL tasks and IADL tasks by the caregiver for the care recipient. This may include assistance constantly throughout the day or a few hours a week. When the care recipient enters a nursing home the duties of primary caregiving in terms of ADL tasks and IADL tasks is transferred from the family member to staff at the institution. Caregivers monitoring of the standards of care for their relatives and providing feedback to staff is seen as a vital new role, while at the same time may feel inhibited in carrying out this role in fear of upsetting staff (Davies & Nolan, 2006). Once the care recipient enters the nursing home the role of the caregiver has been shown to focus more on IADL tasks while staff provide assistance with ADL tasks. Kolb (2003) found caregivers carry out tasks related to visiting, bringing specific foods, managing finances, washing residents' laundry and serving as interpreters.

2.8.2 Secondary Stressors

Family Conflict may continue or even be heightened once the care recipient enters a nursing facility. Multiple role conflict would be anticipated to be less for caregivers after the care recipient enters the nursing facility. However, for those caregivers who only accepted role of caregiver at time of nursing home placement, multiple role conflict may be intensified as they attempt to balance time and energy between immediate families needs, employment and oversight of the nursing home admission along with ongoing monitoring of the care being provided. Frequency of visits by family caregivers was negatively related to post placement role overload a finding attributed to the possibility that the transition of technical and hands on care from the caregiver to the nursing home staff freed the caregiver from providing basic ADL assistance allowing him/her to pursue more fulfilling role attributes such as socializing (Gaugler et al. 2004). Additionally the primary caregivers in this study are thought to have viewed their new role as advocate for the care recipient as empowering and satisfying, not as a source of emotional stress.

Additionally, roles will change as the caregiver is no longer responsible for meeting the ADL and IADL needs of the care recipient, but becomes responsible for seeing that others do provide care as anticipated. Role strain is morphed into another form for the caregiver who transfers primary care responsibilities (Davies & Nolan, 2004). For the caregiver who is faced with the unexpected responsibility of providing care he/she may experience role strain or role conflict in a very different manner than those who provided care in the community.

2.8.3 Mediating Components

Caregiver gain, the feelings of confidence and competence the caregiver feels as a direct result of providing assistance and oversight for the care recipient. The literature often focuses on the negative impacts of caregiving. However research has shown caregivers describe positive outcomes related to the caregiving role. Some themes related to gains identified by caregivers include learning to be more tolerant, gaining an inner sense of well being, with personal satisfaction and fulfillment (Ross, Holliman and Dixon, 2003). The caregiver may feel they have failed the care recipient, maybe didn't fulfill the promise of "I will never place you in a facility" (Kellett, 1999). The methods of coping with the decision to seek placement is found in the caregiver distancing him/herself from the responsibility for the decision, often times reaching out to others to seek validation of the decision to seek entry into the nursing home for the relative (Ryan & Scullion, 2000).

Community caregivers, or those who provided care to the recipient outside of the nursing home, have different experiences in terms of placement than those caregivers who did not. A longer duration of caregiving prior to admission to the nursing home is associated with a greater decreased burden post admission in Taiwanese families (Yeh et al. 2002; Zarit et al. 1980). It is quite evident that there is little understanding of the stress related outcomes for the caregiver following placement of a care recipient into a nursing facility. To move towards an understanding of caregiver outcomes following entry of the care recipient into a nursing home the conceptual framework of stress proliferation as outlined by Pearlin et al. (1981; 1990) for understanding outcomes related to caregiving activities within the community provides a foundation to build upon.

2.9 Conclusions

By utilizing the caregiver stress proliferation model outlined by Pearlin et al. (1990) as a foundation a consistent and stable framework for the interpretation and organization of vast findings throughout the existing literature is provided. It is this framework that also allows for assumptions to be made related to continued caregiver stress following termination of the caregiving relationship in the community and a new relationship emerges once formal placement is obtained.

The primary focus of the caregiver research up to this point has been related to outcomes associated with care provision occurring outside of a formal institution. Because caregiver stress is a process and is not composed of static elements, the assumption the process will continue, albeit in an altered form following entry of the care recipient into a formal institution. As the propensity to utilize nursing homes for ongoing care is expected to be a growing factor in the future as the population ages and life expectancies increase, understanding how the model of caregiver stress changes across caregiving environments will be essential in designing support structures.

The first step in assisting caregivers in readjustment when providing care in a community setting is terminated and institutional placement sought is to better understand how the elements related to caregiver stress differ across the environments. While the literature relating post placement stress for caregivers is in the early stages, factors identified to this point, correlate with the research for community caregiving. Three primary factors shown to affect outcomes for the caregiver in a community setting are feelings of role captivity, role conflict and role strain.

Trying to meet the needs of the care recipient in terms of time demands, quality expectations and conflicting demands of multiple roles has been documented throughout the research to result in global stress. Once the care recipient enters into a formal institution, much of the daily care demands are transitioned to professional care providers, resulting in a potential reduction in feelings of role strain and role conflict.

While decision to transition care from the community to an institution has been shown to be a direct manifestation of feelings related to role captivity, the need for continued involvement, assistance and oversight of the care recipients needs has been shown to continue. It is not anticipated the expanse of obligatory for guilt feelings will be alleviated simply by placement of the care recipient.

CHAPTER 3

THEORETICAL/CONCEPTUAL FOUNDATION

As outlined throughout the literature, role of caregiving and associated outcomes for caregivers is a mix of complicated interactions between individual caregiver and care recipient characteristics, surrounded by social factors, which result in varied outcomes for all involved. To gain an understanding of the interplay between personal and environmental characteristics for caregivers, a merging of two conceptual frameworks will be utilized. First the conceptual map for diagramming the process of caregiver stress proliferation as outlined by Pearlin et al. (1981; 1990) is employed. Concepts taken from role theory then provide the basis for understanding factors impacting the individual as he/she incorporates and carriers out activities associated with the role of caregiver.

3.1. Caregiver Stress Proliferation Model

Such as with photography, often times different filters are placed on the lens of a camera to enhance the picture obtained. The filter placed on the conceptual lens of role perspective is one of stress proliferation process. Emerging from global stress research, the caregiver stress proliferation model underscores the idea that the direct provision of care does not impact the caregiver directly, but through a wider context of “life strains” are the effects exerted (Pearlin et al. 1990). Touted as a primarily heuristic model, the stress proliferation process conceptual map lends itself to research that incorporates the unique, phenomenological experience of each individual caregiver, while providing a guide for developing empirically based research. Developed as a representation of the complex association between personal and environmental characteristics that potentially change over time the stress proliferation process model has been utilized for longitudinal, as well as cross sectional data analysis

(Bertrand et al. 2006; Bookwala & Schulz, 2000; Skaff & Pearlin, 1992; Whitlatch, et al. 2001; Williams et al. 2003).

3.2 Role Theory

The impact of providing care to someone in need is best understood through the examination of the caregiving role within the context in which the activities occur. Emerging in the early 1900's the field of role became an accepted paradigm for understanding human behavior, yet its evolution to that of an actual theory has been debated. Accepted as a heuristic approach for thinking about links between social structure and individual "role theory" does not necessarily qualifies as what defines a "theory", which is "A systematic set of interrelated statements intended to explain some aspect of social life or enrich our sense of how people conduct and find meaning in their daily lives (Rubbin & Babbie, 2002, p 2). In absence of one "grand" theory, the field of role is proposed to encompass three forms of statements: (a) as single hypothesis, (b) as sets of logically unrelated hypotheses on the same topic, and (c) as sets of logically, as well as topically, related hypotheses (Thomas & Biddle, 1966). Hypotheses outlined in this study fall into the latter category of logically, as well as topically, related. Having acknowledged concerns related to field of role or role perspective being conceptualized as a true theoretical orientation, the term "role theory" will continue to be used in the identification of the theoretical orientation for this study, as this is how it is commonly identified throughout the literature.

Role theory emerged in the writings of George Herbert Mead when he utilized concepts such as "role taking" in his works related to "socially reflexive behavior"; during the same time frame Jacob Mareno pioneered the use of role plying in psychodrama and sociodrama. In 1936 the classic work of Ralph Linton, resulted in the idea that an individuals' behavior could be construed as role performance, implying role was one linkage between individual behavior and social structure (Thomas & Biddle, 1966). Integrating role theory into the framework of the stress proliferation process, allows for an examination of the complex role of caregiving, while acknowledging caregivers as experts in the reality of their own lives.

3.3 Merging Caregiver Stress Proliferation and Role Theory

Identified as the preeminent model of the caregiving process, Pearlin et al. (1990) have utilized role theory as a backdrop for the conceptual map created to better understand the dynamic processes of the caregiving experience. The beginning of the caregiver stress process occurs with the assumption of the caregiving role. Whether by a gradual or acute onset, the need to undertake role of caregiver offers a reference point to measure changes. Role theory provides hypotheses for role allocation, or what is determined to be the processes by which roles are assigned to individuals and to the related dynamics of role entry and exit (George, 1993).

Social norms of caring for an aging parent exists globally, with the gradual decline of the aging parent, role allocation and socialization occur in a routine and predictable manner in terms of shared expectations about role behavior, timing of role entry and role exit, where as a sudden incident instigating the role of caregiver leaves little time for learning the skills and behavioral expectations. Once the role of caregiver is allocated, the direct provision of care is initiated. While it is not the direct action of providing care that impacts the individual, it is the changes in the more persistent circumstances of people's lives that act to intensify the levels of stress experience by the caregiver (Pearlin et al. 1990). In addition to role entry and role exit, language associated with role theory provides concepts that allow for the description of such circumstances as that of social position, role conflict and role strain. The role of caregiver can been seen as that of a social position, or a "designated location in the structure of society"; just as caregivers can be defined as "a set of persons sharing common attributes or treated similarly by others" (Biddle & Thomas, 1966 p 11). The role expectations of a spouse providing care to an aging or disabled partner or an adult child expected to care for his/her aging parent(s); along with ethnic or cultural expectations of individuals constitute caregiving as that of a social position as defined in role theory and should be examined within the context it occurs (Gaugler et al. 2006; McCann et al. 2004; Navaie-Waliser, et al. 2002). Guided by a "social script", the caregiver seeks to balance expectations of multiple roles in life each impacted by the care demands of the care recipient. Multiple role conflict or inter-role conflict arises because the caregiver is simultaneously a member of two or more positions in which distinct expectations are held (Biddle, 1979). Role strain results as the caregiver has difficulty fulfilling role expectations resulting from demands and rules by others, sanctions for conforming and nonconforming behavior and by the caregiver's own understanding and conception of what his/her behavior should be (Goode, 1960).

Just as an actor's performance is impacted by that of the director, other actors and audience reaction, the caregiver's "performance" may be impacted by conflict regarding beliefs about the disability or impairment of the care recipient, the amount of time and quality of attention given the care recipient by secondary caregivers and attention and acknowledgement accorded the caregiver by other family members (Pearlin et al. 1990). Caregiver self-confidence is the process of approving or disapproving his/her behavior in terms of internal standards, is highly susceptible to the acceptance and evaluations of other group members according to role theory (Thomas & Biddle, 1966). Impacted by the social norms and expectations of caregiver role allocation, enduring role strain and multiple role conflicts, caregiver self-confidence is often eroded resulting in leaving the individual susceptible to stress outcomes (Pearlin et al. 1981; 1997; 1990). The complexity of the real-life role experiences of the caregiver can best be examined within the conceptual framework outlined by Pearlin and colleagues.

3.4 Conceptual Definitions

3.4.1 Primary Family Caregiver

The primary family Caregiver is defined as the individual named by formal legal status such as guardianship, durable power of attorney or healthcare proxy. In absences of legal determination as primary caregiver, the individual identified by the nursing home staff as having primary decision making capacity related to the individuals care will be deemed “primary caregiver”.

3.4.2 Caregiver Stress

Family caregiver stress refers to the psychological outcomes resulting from the demand or external load placed on the individual as a direct result of meeting the physical, emotional and health needs of a aged or disabled person.

3.4.3 Role Captivity

Role Captivity refers to feelings of unwittingly becoming the captive of an unwanted role. The caregiving role is experienced as obligatory and/or inescapable and feelings of being a captive may result at the caregiver is forced withdraw from other roles in which he/she has a vested major interest and/or commitment (Pearlin et al. 1990)

3.4.4 Multiple Role Conflict

Multiple role conflict occurs when a caregiver encounters tensions as a result of incompatible roles, or what might be termed multiple-position occupancy such as when caregiver experiences incongruence between role of employee, parent, friend, spouse and expectations related to the time required for providing care. The demands on an individual’s time are too great for them to perform these roles adequately or comfortably.

3.4.5 Family Conflict

Family conflict is rooted in disagreements between the primary caregiver and other relatives of the care recipient over the amount and quality of time that is spent with the care recipient (Pearlin et al. 1990).

3.4.6 Caregiver Gain

Caregiver gain is reflected in the caregiver’s beliefs regarding the necessary competencies and challenges faced in the caregiving role and his/her ability to meet these challenges. Feelings of being competent to cope with basic life challenges or being worthy of happiness may be eroded by the caregiving role thus contributing to increased caregiving stress.

CHAPTER 4

METHODS

4.1 Sample Selection

Nursing homes in north central Texas and southern Oklahoma made up the sampling frame. Initial contact was made with representatives of all facilities located in Grayson and Fannin Counties of North Texas. Of these fifteen facilities, two administrators declined to host the study (Meadow Brook Care Center and Texoma Healthcare Center); one facility representative did not commit within the specified time frame for data collection (Homestead of Sherman) while the remaining twelve facilities hosted the study.

Administrators of three facilities in Bryan County Oklahoma were contacted, with all three agreeing to host a random mailing of the survey instrument. The facilities were chosen based on previous contacts with the facilities staff and administrators by the researcher. While the administrator of one facility (Four Seasons Nursing & Rehab Center) agreed to participate in the study by means of a mass mailing, the surveys were not placed in the mail within the specified time frame. The administrator had been provided fifty survey instruments, stamped and ready to mail, however several were received return due to insufficient postage, indicating the instruments had not been mailed until on or after May 12th when an increase in postage went into effect. Despite this factor, four caregivers completed survey instruments, added additional postage and returned them for inclusion in the study. In addition two facility representatives in the Dallas area made a request to participate in the study. One facility (Willow Bend Nursing & Rehab) hosted an information session, while Brentwood Place III, canceled the information session one day prior to the scheduled date.

Institutional Review Board (IRB) training was completed on November 19, 2007 as required by the University of Texas at Arlington (UTA) Office of Research Compliance (ORC, 2006a). Once agreement for participation from nursing facilities had been secured the protocol was submitted for IRB approval to initiate the survey process. IRB approval was received on December 14, 2007. A pilot study of the instrument was conducted on Jan. 22, 2008 with family caregivers of an Alzheimer's Support Group held at Reba McEntire Center for Rehabilitation in Denison TX. A retest of the instrument was conducted two months following the initial administration. The only changes made to the survey instrument following the pilot test were correction in spelling and grammar. Data collection for the survey began on February 15th, 2008 and continued through May 17th, 2008.

Family caregivers were solicited in a variety of ways in cooperation with nursing facility staff. Ten facilities hosted information sessions in which an invitation to participate (Appendix A) was mailed out to the primary family contact. The invitation introduced the study and offered specified dates and times to attend an information session and learn about the project and complete the questionnaire. During the information session caregivers were informed of the confidential aspect of the study and told about the purpose. They had the option of completing the survey instrument at that time or taking it with them for completion at a future time. For those who opted to take the questionnaire home, a self-addressed stamped envelop was provided allowing the completed instrument to be mailed directly to the researcher.

Six facilities opted to complete a mass mail out of the survey instrument to primary family contacts. Family caregivers identified by the facility staff to receive a survey via mail, were provided a copy of the survey instrument, including a cover letter explaining the research project and a self-addressed stamped envelope for returning the instrument to the researcher. One social worker chose to request family members to complete the survey as she came into contact with them while they were visiting their loved ones in the facility. Representatives of the Alzheimer's Associations in Grayson County were also provided information regarding the ongoing data collection. This information included ways to contact the researcher by phone or email if interested in participating, resulting in a miscellaneous category. In addition to participation of caregivers from the identified facilities, four family caregivers made direct contact via email and requested to participate. Each one was mailed the survey packet and coded as a miscellaneous facility.

4.2 Measurements

A three part self-administered questionnaire was developed specifically for this study (Appendix B). A cover letter described the purpose, anticipated completion time of the questionnaire, the voluntary aspect of participation and contact information. Information requested included basic demographic information of age, gender, relationship of the caregiver to care recipient, ethnicity, education, employment status and household income, information regarding the context of the caregiving relationship is requested.

Section II of the questionnaire consisted of both forced choice and open ended questions focused on gathering information about the care recipient in relation to why nursing home placement was sought, point of entry into the facility, length of time the care recipient had been in the facility and if this is a temporary placement and the activities of the caregiver regarding visitation schedule, distance traveled and potential participation in a support group for caregivers.

Section III contains scaled measurements designed to assess the caregivers' perceptions of his/her feelings of role captivity, caregiver gain, family conflict, and employment conflict for working caregivers, along with questions aimed at assessing constriction of family activities. A scale to capture participation and ease of assisting the care recipient following placement was incorporated, along with the Perceived Stress Scale (PSS). Each survey instrument had an attached sheet of lined paper requesting additional information the caregiver may wish to share on a voluntary basis about his/her situation.

4.2.1 Role Captivity

Feelings of role captivity or the belief that one is an unwilling participant in the role of caregiver was measured using a 3-item scale designed to capture thoughts and feelings caregivers have about assuming the caregiving role (Pearlin et.al. 1990). Caregivers are asked to indicate a level of agreement on a four-point likert scale ranging from (1) “Not at all” to (4) “Very much” about thoughts of “Wish you were free to lead a life on your own?” “Feel trapped by the care recipient’s illness”; and “Wish you could run away”. Internal consistency of the scale was evaluated using item-total analysis and Chronbach’s alpha (Table 4.1). The results indicate moderate to high levels of correlation among scale items.

The instrument has also been correlated with stress for the caregiver when providing in home care created a feeling of confinement or captivity, helping to establish construct validity (Aneshensel et al. 1993, Bertrand et al. 2006). Within the context of this study, this scale is moderately correlated with the perceived stress scale (*r*=.588, p <.001) demonstrating construct validity within this population of caregivers.

Table 4.1 Role Captivity Scale: Internal Consistency [a]

Item		Lead Own Life	Trapped by Illness	Run Away
	X(sd)	r		
Role Captivity Sum Total	5.52(2.34)	.862**	.898**	.814**
Lead Own Life	2.01(.900)	1.0	.699**	.518**
Trapped by Illness	1.98(.951)		1.0	.597**
Run Away	1.54(.868)			1.0

[a] alpha = .82 ** p < .001

4.2.2 Constriction of Family Activities

Developed specifically for this study, a four item, likert scale assessed family caregiver’s perceptions of limitations on participation in family activities because of the caregiving role. Each caregiver was asked to indicate his/her level of agreement with limitations on time they have to (1) spend with my spouse/partner, (2) spend with my children, (3) spend in family activities and (4) quiet time for myself. Responses ranged from “strongly agree” to “strongly disagree”, with higher scores indicating greater dissatisfaction. On item 1 & 2, a category for "not applicable" was added in the event the caregiver did not have a spouse/partner (or the care recipient may be the spouse) or children. These were assigned a code of 0 for purposes of further analysis, allowing for a range of 2-16 in aggregate scoring. Internal consistency was assessed by means of a total-test correlation and Chronbach's alpha (table 4.2). The measurement meets the criteria for face validity; no other forms of validity have been established at this time.

Table 4.2 Constriction Of Family Activities Scale: Internal Consistency [a]

	Time with Partner	Time with Children	Time in Family Activities	Time Alone
Item				
Constriction Total	.820**	.807**	.870**	.862**
Time with Partner		.572**	.536**	.573**
Time with Child.			.627**	.468**
Time with in Family Act.				.811**

[a] alpha = .86 p < . 001

4.2.3 Work-Caregiving Conflict

Work caregiving conflict was measured using an adaptation of the job-caregiving conflict scale, (Pearlin et al. 1990) requesting family caregivers to indicate how much they agree or disagree with statements about their work situation since the care recipient entered the home. Instructions were altered from "…the following statements about your present work situation" to "…about your work situation since the care recipient entered the nursing home". Responses range from "strongly agree" to "strongly disagree" with lower numbers indicating less conflict. Statements include: (1) I have less energy for my work; (2) I have missed too many days at work; (3) I am dissatisfied with the quality of my work; (4) I worry about the care recipient at work and (5) Phone calls about the care recipient interrupts me at work.

Assessment for internal consistency using total-test correlation and Chronbach's alpha resulted in the identification of item number 5, "calls at work" as having weak correlations with all other items in the scale. Based on these results this item was excluded from further data analysis, reducing the number of items to four, with a possible range from 4-16.

Table 4.3 Work-Caregiving Conflict Scale: Internal Consistency [a]

		Less Energy	Missed Work	Satisfaction	Worry	Calls at Work
	X(sd)	r				
Work-Stress Total	8.03(2.53)	.828**	.756**	.715**	.683**	.305*
Less Energy	2.10(0.90)	1.0	.589**	.480**	.397**	.269*
Missed Work	1.78(.739)		1.0	.471**	.271*	.274*
Satisfaction	1.82(.757)			1.0	.261*	.326*
Worry	2.35(.958)				1.0	.075
Calls at work	1.84(.808)					1.0

[a] alpha = .72 * p <.05 ** p < .001

4.2.4 Family Conflict

Caregiver's perception of the attitudes and actions of other family members towards the care recipient was assessed using a sub-scale of the Family Conflict Scale (reported alpha = .86) (Pearlin et al. 1990). This is a four-item likert scale asking caregivers to indicate level of agreement, ranging from "no disagreement" to "quite a bit of disagreement" they have with other members of the family to the following statements: (1) Don't spend enough time with the care recipient; (2) Don't do their share of caring for the care recipient; (3) Don't show enough respect for the care recipient and (4) Lack patience with the care recipient. Internal consistency of family conflict scale was established using total-item testing and Chronbach's alpha (Table 4.4). The scale has established validity in terms of face validity. No other forms of established validity have been identified.

Table 4.4 Family Conflict Scale: Internal Consistency [a]

Item		Not Enough Time	Caregiving Assist	Respect for Care Recipient	Lacks Patience
	X (*sd*)	r			
Family Conflict Total		.833**	.814**	.764**	.776**
Not Enough Time	1.93 (1.11)	1.0	.804**	.714**	.671**
Caregiving Assist	1.79 (1.06)		1.0	.663**	.652**
Respect	1.65(1.35)			1.0	.771**
Lacks Patience	1.64(1.06)				1.0

[a] alpha = .83 **p < .001 (2-tailed)

4.2.5 Activities of Caring in the Nursing Home

Adapted specifically for the purpose of this study the activities of caring scale is designed as a reflection of the Caregiving Hassles Scale (Kinney & Stephens, 1989) which was developed to focus on minor events occurring in the daily routine of caregivers providing assistance outside of a long term care facility. Postulated that stress is better measured as what are seemingly minor annoyances rather than a major tragedy (Lazarus, 1993), caregivers were asked to identify activities in which they participated and assess a level of “hassle” the activity constituted in their lives. Utilizing the same format of administration and scoring protocol, caregiving categories were changed to reflect the activities of role transition incorporated by family caregivers of nursing home residents (Kolb, 2003; Kellet, 1998). The instrument consists of eleven items representing potential activities in which a family caregiver may participate following entry of the care recipient into the nursing home. Each item is assessed separately with other caregiver, contextual, stressor, gain and perceived stress variables. A sum total score was not calculated secondary to inconsistent levels of correlations among the various items (Table 4.5).

Table 4.5 Nursing Home Activities Of Caring Scale: Internal Consistency [a]

Activity	Paper Work	Contact	Care Plan	Medical	Room Mate	Personal Care	Advocate	Personal Items	Provide Clothes	Laundry Hassle
	r									
Financial	.758**	.543**	.206	.290**	.435**	.338**	.273**	.85	.355**	.389**
Paperwork	1.0	.401**	.229	.290**	.382**	.441*	.322**	.076	.256**	.452**
Contact		1.0	.382**	.490**	.318*	.592**	.466**	.498**	.422**	.304*
Care Plan			1.0	.496**	.285	.592**	.466**	.540**	.382**	.304*
Medical				1.0	.470**	.599**	.607**	.534**	.478**	.428**
Roommate					1.0	.470**	.332*	.173	.220	.657**
Personal Care						1.0	.633**	.478**	.422**	.651**
Advocacy							1.0	.533**	.431**	.335**
Personal Items								1.0	.721**	.321*
Providing Clothes									1.0	.349**

[a] alpha= .79* p <.05 ** p<.001

No established measures of validity are available. However, activities are conceptually related to those identified by caregivers in exploratory studies (Kolb, 2003, Kellet, 1998).

4.2.6 Caregiver Gain

Positive aspects of the caregiving role is measured utilizing two, four-point likert scales reflecting positive beliefs the caregiver holds about his/her abilities, and personal growth resulting from being in the caregiving role. Positive beliefs held by the caregiver about his/her abilities are captured using the caregiving competence scale outlined by Pearlin et al. (1990). The original scale (alpha =. 74) contains the following four items: (1) Believe that you've learned how to deal with a very difficult situation; (2) Feel that all in all, you're a good caregiver; and "How: (3) competent and (4) self-confident do you feel as a caregiver?". Caregivers responded to each statement using a 4-point likert scale ranging from "Not at all" to "Very much".

Personal growth for the caregiver is captured using a four-item likert scale (alpha=. 76) designed to explore how much each caregivers has: (1) become more aware of your inner strengths; (2) become more self-confident; (3) grown as a person; and (4) learned to do things you didn't do before (Pearlin et al. 1990). Response categories range from 1-4, with one indicating "not at all" and a four "very much".

Summing the scores of all items contained in both sub-scales assesses overall care for each caregiver (alpha = .833). To assess the internal consistency of this data set, item-total Analysis was conducted with all eight indicators included to obtain a correlation matrix (Table 4.7). The item of "Believe that you have learned to deal with a very difficult situation" showed low correlation with the sum total of caregiver gain (r=. 330**, $p < 0.01$) and low correlation with all other items in the scale. This item was removed from further analysis based on low correlation. Other than face validity, no other forms of validity have been identified.

Table 4.6 Caregiver Gain Summed Scale: Internal Consistency ^{a}

	Good Caregiver	Feelings of Competence	Deal with Situation	Self-Confidence	Inner Strengths	More Self -confident	Personal Growth	Learned
Gain Total	.646(**)	.616(**)	.330(**)	.542(**)	.810(**)	.845(**)	.790(**)	.688(**)
Good Caregiver		.665(**)	.484(**)	.535(**)	.808(**)	.824(**)	.767(**)	.666(**)
Feelings of Competence			.197 (*)	.801(**)	.301(**)	.390(**)	.236(**)	.082
Deal with Situation				.148	.316(**)	.251(**)	.200(**)	.155
Self-Confidence					.174	.387(**)	.181(8)	.045
Inner Strengths						.670(**)	.713(**)	.612(**)
More Self-confident							.676(**)	.531(**)
Personal Growth								.579 (**)

^{a}alpha = .83 * p < .05, ** p< .001

4.2.7 Perceived Stress Scale

The PSS is a ten-item instrument designed to measure the degree to which situations in one's life are appraised as stressful (Cohen, Kamarck & Mermelstein, 1983). With permission of the author instructions for completion were changed from "…feelings and thoughts during the past month" to "…feelings and thoughts since the time the care recipient entered the nursing home". The PSS is reported as an outcome measure examining the experience level of stress as a function of objective stressful events, coping processes and personality factors. After reverse-scoring items 4, 5, 7, and 8, the score for the PSS is obtained by summing all item scores. Higher scores suggest greater levels of perceived stress. An item-total analysis demonstrated moderate to strong correlations between each item and the scaled total (Table 4.10 and 4.11). Item number4: "how often do you feel confident about your ability to handle your personal problems?" showed weak correlations with the other items in the scale, but it was not removed based on original construction of the scale and overall consistency with the sum total. Good construct validity has been reported, as the PSS scores were moderately related to responses on other measures of appraised stress as well as to measure of potential sources of stress as assessed by stress-event frequency (Cohen et al. 1983). This version of the PSS was studied with a national probability sample of 2388 respondents, mirroring census data for the United States, thus suggesting the generalizabiltiy of the data. The overall mean for the PSS was 13.02 (sd = 6.35); the mean for males was 12.1 (*sd* = 5.9) and the mean for females was 13.7 (*sd*= 6.6). The PSS is reported to have established good construct validity with scores moderately related to responses on other measures of appraised stress as well as to measures of potential sources of stress assessed by stress-event frequency (Cohen et al., 1983).

Table 4.7 Perceived Stress Scale: Internal Consistency

	Unexpected	Control	Nervous	Confident	Your Way	Cannot Cope	Irritations	On Top	Angered	Piling Up
Stress Total	.427**	.756**	.806**	.369**	.709**	.737**	.468**	.792**	665**	.830**
Unexpected		.403**	.416**	.111	.117	.247**	.103	.187*	.374**	.278**
Control			.682**	.062	.458**	.524**	.207*	.456**	.447**	.660**
Nervous				.085	.501**	.564**	.232**	.531**	.516**	.704**
Confident					.328**	.105	.275**	.381**	.112	.146
Going your way						.328**	.473**	.485**	.533**	.744**
Cannot Cope							.251**	.485**	.533**	.744**
Irritations								.522**	.131	.238**
On top									.451**	.559**
Angered										.556**

^{a}alpha = .87 * p < .05, ** p < .001

4.3 Data Analysis

4.3.1 Data Preparation

Analysis of date was completed using the Statistical Package for Social Sciences (SPSS 12.0). Data was initially screened and prepared for analysis based on the criteria outlined in Tabachnick and Fidell (2001) and included the following steps (1) inspecting univariate descriptive statistics for accuracy of input; (2) evaluating amount and distribution of missing data; (3) checking for nonlinearity and heteroscedascity; (4) identifying non-normal values and multivariate outliers and (5) evaluating variables for multicollinearity and singularity.

Univariate descriptive were computed for all variables and analyzed for out of range values, univariate outliers and plausible means and standard deviations. Distance between the nursing home and family caregiver's home was initially measured on an interval level in miles. Review of frequency table resulted in identification of one extreme outlier (case 129), which was deleted. Further analysis revealed that 78.0% of family caregivers lived within 25 miles of the nursing facility. This variable was then dichotomized into categories of those who lived within a distance of 25 miles or less (78.0%, *n*= 99) with those who live more than 25 miles away (22.0%, *n*=28). No other extreme outliers were identified in the remaining interval level variables (hours per week care was provided or length of time in the caregiving relationship).

Identifying and addressing issues related to normal distribution revealed four items with potential problems. First, the variable of role captivity exhibited moderate positive skewness of .814 (sd = .214) with a possible range from 3.00 to 12.00 and a mean of 5.52 (*sd* = 2.34). Following square root transformation the skweness was reduced to .485 (*sd* = .214), the mean score was 2.30 (*sd* = .48) and the possible range was from 1.73 to 3.46.

The second item displaying highly skewed results was the estimated time the caregiver has been active in the caregiving role for the care recipient. The original interval level scale resulted in substantial positive skewness of 1.165 (*sd*= .224). A Log transformation was attempted, resulting in substantial negative skewness. After further review of the cases, it was determined creating a dichotomous variable would be the best option. This resulted in the creation of the following two categories (1) provided care for five years or less (48.1%, *n*= 62) and (2) provided care more than 5 years (42.6%, *n*=55).

The next item to be addressed was the identification of number of ADL and IADL tasks (item 8b) for which assistance had been provided prior to the care recipient's nursing home entry with a possible range from 1-9 items on both subsets. Intensity of assistance was obtained by summing the total of all ADL and IADL tasks identified in each sub set. However, analysis of frequency distributions revealed the summed scores to be highly skewed for both ADL tasks (skewness =.635*, sd =.239*) and IADL tasks (skewness =-0.65, sd= .24). The summed number for ADL tasks proved to have substantial positive skewness and IADL tasks had moderate negative skewness. It was decided to collapse data into three categories for each: "no assistance"; "moderate assistance (range 1-4) and high assistance (range from 5-9). Because univariate analysis of caregiving hassles scale resulted in the identification of a non-normal distribution, with severe positive skewness, it was decided to dichotomize the variable into two categories of "hassle" and "no hassle".

The final set up variables that presented potential problems with skewness, included those of caregiver positive beliefs, personal growth and the total sum of caregiver gain. Caregiver positive beliefs scale was highly skewed in the negative direction (skewness = -0.814, *sd* .215), personal growth scale and gain total were moderately skewed in the negative direction. All variables were dichotomized into two categories representing if the family caregivers had a strong positive belief about their abilities in providing care, if they felt they had grown as a person. Total uplift scores were obtained by multiplying sub scales for positive beliefs and personal growth resulting in possible range from 1-12.

The second step in preparing data for analysis was to evaluate the amount and distribution of missing data. This analysis revealed widely dispersed, minimal missing cases across most variables (< 5%) with the exception of the variables targeted at capturing the hours of care provided to the care recipient prior to entry into the nursing home and household income.

Of the 102 family caregivers indicating they assisted the care recipient in the community, only 82.4% (n=84) quantified the hours of care each provided. List wise deletion was utilized and these 18 cases were omitted from the analysis, thus reducing the sample size for this variable. Almost one-half of the family caregivers (47.6%) reported they provided 24 hours or less per week in assistance while the care recipient was in the community, with 17.8% providing care seven days per week, twenty four hours per day. This resulted in a decision to collapse the variable into three, ordinal level categories: (1) provided care 24 hours or less; (2) provided care 25 – 167 hours and (3) provided total care (24 hours per day, 7 days per week). There were 16 missing cases for household income, which represented 12% of the entire sample. Women represented 50% (n=8) of the missing cases. Deletion of missing cases is not recommended when missing values are not randomly distributed through the data as this may cause distortions of the sample to occur (Tabachnick & Fidell, 2001). Because the data for household income is categorical, thus not being amenable to mean substitution, optimum method for addressing the issue was to estimate and impute missing values.

The process of estimation required first identifying the location of the nursing home that represented the case with the missing data: (1) Grayson County (*n*=8*)*, (2) Fannin County (*n*=3) and (3) Bryan County (*n*=5). The respective median household incomes in 2004 for Grayson County ($38,752), Fannin County ($35,434) and Bryan County ($29, 055) were imputed into the corresponding cases (Quick Facts, 2008). Analysis of data for income following estimation imputation found no change in between the median (3.00) and mode (3.00) of the original data (*n=113)* and revised data set. The mean for the original data set was 3.25(*sd*=1.35) and the revised data set is 3.22(*sd*=1.26).

No cases were identified through Mahalanobis distance as multivariate outliers with $p < .001$. Pair-wise linearity was checked using within-group scatterplots for variables of role captivity, work-caregiving stress, constriction of social activities, family conflict, and perceived stress scale. No multicollinearity is evident as seen in the Collinearity Diagnostics Table 4.8.

Table 4.8 Collinearity Diagnostics [a]

				Variance Proportions				
Model	Dim.	Eigen-value	Cond. Index	(Constant)	Role Captivity	Family Act	Caregiver Income	Family Conflict
1	1	1.979	1.000	.01	.01			
	2	.021	9.662	.99	.99			
2	1	2.893	1.000	.00	.00	.01		
	2	.087	5.760	.12	.04	.91		
	3	.020	12.048	.88	.96	.08		
3	1	3.781	1.000	.00	.00	.01	.01	
	2	.126	5.473	.01	.01	.39	.58	
	3	.074	7.157	.10	.10	.52	.34	
	4	.019	14.155	.89	.89	.08	.07	
4	1	4.708	1.000	.00	.00	.00	.01	.00
	2	.129	6.037	.01	.01	.21	.71	.03
	3	.101	6.837	.00	.00	.61	.08	.25
	4	.044	10.337	.26	.26	.10	.13	.67
		.018	16.055	.73	.73	.08	.08	.05

[a] Dependent Variable: Perceived Stress Scale

4.3.2 Analyzing the Data

Analysis of the data progressed in a systematic manner. First correlation analysis was computed to evaluate relationships between caregiver characteristics, contextual factors, caregiving stressors and perceived stress scores. Variables with correlations of at least p = .001 are considered for inclusion in the regression analysis with the exception of the item variables in Nursing Home Activities Scale which were not included secondary to the reduction of available sample size as not all caregivers participated in all activities. Next independent samples t-test and ANOVA were computed to evaluate differences on mean scores for role captivity, constriction of family activities, family conflict, work-caregiving stress and perceived stress for family caregiver contextual variables. Descriptive statistics and analysis of correlation for activities of caring post nursing home entry were conducted in terms of caregiver participation and interpretation of what participation meant. Independent samples t-tests were computed to identify differences in mean scores for caregivers who identified specific activity participation as being a hassle and those who did not on role captivity, constriction of family activities, perceived stress, family conflict and work-caregiving stress.

The final analysis included computing multiple regression with forward entry to determine if addition of information regarding caregiver income, having been a caregiver prior to nursing home entry, feelings of role captivity, family conflict and constriction of social activities predicted variations in perceived stress scores. A second regression analysis was completed for employed caregivers, which included household income, community care provider, role captivity, family conflict, constriction of social life and work-caregiving stress.

CHAPTER 5

RESULTS

5.1 Hosting Facilities

Table 5.1 Hosting Facilities

County State	Nursing Home	Data Collection Method	Sample Size	No. Of Responses
Grayson Co. Texas	Brentwood Place	Information Session	60	3
	Homestead of Denison	Information Session	45	8
	Texoma Specialty Care	Information Session	63	5
	Whitesboro Health & Rehab	Information Session	65	5
	Hilltop Haven	Information Session	180	17
	Denison Nursing & Rehab	Random Mail out	40	16
	Sherman Healthcare Center	Information Session	61	6
Fannin Co. Tx	Mullican Care Center	Information Session	Unknown	2
	Seven Oaks Nursing & Rehab	Selected Mail Out	10	4
	Honey Grove Nursing Center	Direct Contact	Unknown	3
	Fairview Nursing & Rehab	Information Session	20	1
	Bonham Nursing & Rehab	Information Session	20	4
Dallas Co. Tx	Willow Bend Nursing	Information Session	80	3
Bryan Co. Ok	Calera Manor	Random Mail Out	35	12
	OakRidge Manor	Random Mail Out	50	32
	Four Seasons	Random Mail Out	50	4
Miscellaneous Category				4
		Total Participants		129

Initial contact was made with either the administrator or social worker at twenty-four homes within the identified area, resulting in a total of representatives of sixteen facilities agreeing to participate in the research project (see Table 5.1). Ownership of the participating facilities was primarily for-profit partnership or corporations with two being identified as non-profit (Texoma Specialty Care and Hilltop Haven) with the number of certified beds ranging from 52-179 (Appendix C).

5.1.1. Quality Indicators of Participating Nursing Facilities.

Concerns most often expressed by family caregivers when considering placement for their loved one surrounds the quality of care to be provided. One son stated about the placement of his mother:

> "…the placement of your family member is to me one of the most important things to consider. They have to be in a place that you can trust to do the best for him/her because it isn't easy to care for them".

A daughter expressed dissatisfaction with the care her mother had receive:

> "…the first nursing home was horrible, we reported…the current nursing home is wonderful and all the staff has made my job easier".

To focus on improving nursing home care throughout the United States, efforts have been focused on increased transparency with information related to specific quality indicators. The Centers for Medicare and Medicaid Services (CMS) requires data collection on regular intervals for all residents in a Medicare or Medicaid Certified Nursing home. The information is collected on the resident's health and physical functioning, mental status and general well being. Information collected and reported by nursing home staff is then reviewed by nursing home inspectors but not formally audited to ensure it is accurate.

Designed to empower consumers to make informed choices, quality nursing home public reporting began in 1998 with the nursing home compare web site and has been increasingly emphasized since 2002. Quality measures are divided into two sets to include long-stay residents and short-stay residents and include a total of 14 separate measures. Quality measures reported here have been obtained from the Centers for Medicare and Medicaid

Services Website and nine of the identified indicators that reflect issues related to the ongoing care for long stay residents (Appendix D). Data reported here reflect the time period of October 1, 2007 through December 31, 2007.

Focusing on physical functioning of long stay residents, quality indicators examined include the percent of long-stay residents whose need for help with daily activities has increased; who spend most of their time in bed or in a chair; and whose ability to move about in and around their room got worse. These numbers are obtained by examining the residents previous functioning in the past 7 days prior to an assessment date.

Information is collected and reported on the care recipient's ability to feed one-self, transfer from one chair to another, change positions while in bed and toilet without assistance. A resident's ability to perform basic activities of daily living is important in maintaining current health status and quality of life. While, a loss of functioning can be expected in elderly residents, however sudden or rapid loss of one or more of these basic skills could indicate the need for medical attention. The mean percentage of residents who declined in ADL functioning nationally is 15%, with Texas averaging 14% and Oklahoma averaging 11% of residents declining. Hosting facilities for this study reported the percentage of long-stay residents who declined in ADL functioning ranging from 7% to 24% with seven facilities in Texas reporting percentages equal to or above both the national and state averages (Appendix D).

The national average for long-stay residents who spend most of their time in bed or in chair is 11%, with Texas reporting a state average of 9% and Oklahoma of 8%. Percentages for long term residents in hosting facilities in Texas who spend most of their time in bed or in a chair range from 0% to 13%, with all but two (Denison Manor and Seven Oaks Rehab & Nursing) reporting lower percentages than the state and national average. Monitoring of this quality indicator is important because residents who spend too much time in bed or a chair, may lose the ability to perform activities of daily living, experience increased health risks such as blood clots or pressure sores and may be experiencing anxiety or depression or these mental health issues could increase. One daughter indicated concerns regarding her mother's care in the nursing home:

> "…one concern is lack of understanding of the elderlys' concern with personal modesty, as well as their coping with loss of independence".

The third quality indicator for physical functioning examines the percentage of long-stay residents whose ability to move about in and around their room got worse. The national average reflects 4% of residents got worse in their ability to move about, while the state of Texas reports 6% and Oklahoma reports 8% of residents declining in this area for the reporting period. For hosting facilities the range is from 0% to up to 20%, with seven of the facilities reporting percentages higher than both the state and national average.

The next area of quality indicators examined for purpose of facility comparison include the percent of long-stay residents who lose too much weight; who were physically restrained and who are more anxious or depressed. A loss of 5% or more of body weight in one month is usually considered unhealthy. Even residents who are on a weight loss plan for medical reasons are not expected to lose more than 5% of body weight in one month. Possible reasons for weight loss may potentially include the resident are not being fed properly, his/her medical care is not being properly managed or that the home's nutrition program is poor.

The average percent of long-stay residents reported as losing more than 5% of body weight in a month nationally is 8% with the an average of 9% for Texas and Oklahoma. Hosting facilities in Texas report percentages ranging from 0% to 15%, with eight facilities reporting percentages below the national average while only three fall below the state average. Oak Ridge Manor reported 19% of the long-stay residents losing too much weight and Four Seasons Reported 12%, both well above the state and national average.

Using physical restraints is strongly discouraged for residents in nursing homes, and should only be used when medically necessary as determined by a physician. A resident who is restrained may become weaker, agitated or physically combative. The national average for long-term residents who were physically restrained during the assessed time period is 5%, with an average of 4% for Texas and 8% for Oklahoma. Percent of long-term residents physically restrained within hosting facilities range from 0% to 11% with five reporting percentages equal to or above the national average; four Texas facilities reported percentages above the state average and Oklahoma facilities were equal to or below the state average (Appendix D).

Residents of nursing homes are at high risk for developing depression and/or anxiety for many reasons. The presence of depression and/or anxiety can directly affect quality of life while leading to other health problems, thus identification and treatment is an important role for facility staff. Nationally 14% of long-stay residents are reported as being more anxious or depressed than when last assessed, with Texas reporting a state average of 8% and 10% for Oklahoma. Two hosting facilities report percentages higher than the national and state averages (Whitesboro Health & Rehab with 16% and Texoma Specialty Care with 48%). It should be noted that Texoma Specialty Care is a non-profit home designated as one of the Eden Alternative Projects, which is a community designed to eliminate loneliness, boredom and helplessness among the residents. Four facilities report percentages equal to or less than the Texas state average (Brentwood Place, Homestead of Denison and Seven Oaks Nursing & Rehab report 3% and Hilltop Haven reports 8%).

Often associated with neglect of abuse in the nursing home, the development of pressures sores is another area focused on as a quality indicator. Tied to the activities listed above, reflecting direct care of the facility staff, and the medical condition of the care recipient the development of pressure sores may lead to other complications such as skin and wound infections. Data reported for analysis by nursing home staff include the percent of high-risk and low-risk long stay residents who have pressure sores and the percent of long stay residents who have a urinary tract infection. Nationally, 11% of high-risk long stay care recipients develop pressure sores, while 12% in Texas and 15% in Oklahoma are reported as developing pressure sores. Three hosting facilities in Texas report equal or higher percentages equal to or above both the state and national average (Texoma Specialty Care, Whitesboro Health and Rehab and Mullican Care Center. Both hosting facilities in Oklahoma report percentages well below both state and national averages.

5.2 Family Caregiver Characteristics

Table 5.2 displays sample characteristics separately for family caregivers. Reflective of the typical caregiver in the United States (Paynda, 2004), participants are primarily female (66.1%), white (91.5%), with a mean age near 60 and over one-half have some college experience (59%). Children constitute the largest group (60.5%), followed by the category of “other” (15.5%) which includes niece/nephew, friends, parents, siblings and daughter-in-laws. Spouses fall into the next group (14.0%) and a small percentage of step-children (2.3%) and grandchildren (7.0%) are represented. For purposes of analysis beyond this point relationship categories were collapsed into three: children (62.8%, *n*=81), other (15.5%, *n*=19) and spouses (14.0%, *n*=18).

Table 5.2 Family Caregiver Characteristics (*n*=129) [a]

Characteristic	% of total	n
Gender		
Female	66.1	86
Male	32.6	42
Relationship to Care Recipient		
Spouse	14.0	18
Child	60.5	78
Step-Child	2.3	3
Grandchild	7.0	9
*Other	15.5	20
Neighbor/Friends		3
Parent		2
Daughter in law		3
Sibling		5
Niece/Nephew		7
Ethnicity		
White	91.5	118
Non-White	7.8	10
African-American	3.1	4
Native American	3.1	4
Hispanic	.8	1
Pacific-Islander	.8	1
Highest Level of Education		
Junior High	3.1	4
High school	37.2	48
Some College	32.6	42
College Grad	9.3	12
Post College/Professional	17.1	22
Employment Status		
Working	50.4	65
Fulltime	41.1	12
Part-time	9.3	49
Not Working	49.7	64
Retired	38.0	49
Retired due to disability	9.0	7
Unemployed	4.7	6
Household Income		
0-15,000	11.6	15
15,001-25,000	13.2	17
25,001-50,000	27.1	35
50,001-75,000	13.2	17
Greater than 75,000	22.5	29

[a] Changing sample size reflects missing data on certain variables.

Mean stress scores for the entire sample was 15.59 (*sd* = 6.42), while females had a mean score of 16.20 (*sd* = 6.13) and males had a mean score of 14.38 (*sd* = 6.71) all higher than the reported on the normed data in which the overall means was 13.02 (*sd* = 6.35); females (13.7 (*sd* = 6.6) and males 12.1 (*sd* = 5.9) (Cohen & Williamson, 1988).

5.3 Variable Relationships with Family Caregiver Perceived Stress

Pearson's correlation coefficients were computed for ordinal and interval level variables for the purpose of establishing relationships for further evaluation (table 5.3). Twelve of the variables indicated weak to moderate levels of correlation with all but two (household income and length of time the care recipient has been in the nursing home) indicating a positive relationship with perceived stress. Feelings of role captivity had the highest level of correlation with perceive stress (.588 p <. 001) and length of time in the nursing home had the weakest (-0.185 p < .05). Variables with significant level of .001 will be included in regression analysis.

Table 5.3 Variable Relationships With Family Caregiver Perceived Stress

	Perceived Stress Scale	
Variable	n	r
Age of Family Caregiver	126	-0.096
Educational Level of Family Caregiver	126	-0.090
Household Income of Family Caregiver	111	-0.260**
Length of time in Caregiving Role	117	-0.127
Distance from Nursing Home	125	-0.054
Length of Time Care Recipient in NH	124	-0.185*
Intensity of Visits to Nursing Home	126	-0.03
Intensity of ADL assist in community	101	1.06
Intensity of IADL assist in community	100	0.153
Weekly Hours of Care Provided in Community	83	0.022
Constriction of Participating in Family Activities	123	0.453**
Role Captivity	127	0.588**
Family Conflict	125	0.304**

Table 5.3 continued

Variable	Perceived Stress Scale	
Work-Caregiving Conflict	63	0.523**
Nursing Home Activities Hassles		
Discussing Medical Concerns	112	0.298**
Providing food/personal Items	110	0.324**
Completing Paperwork	110	0.137
Acting as Primary Contact	108	0.305**
Providing Clothing	108	0.286**
Acting as an Advocate	101	0.243*
Handling Finances	93	0.336**
Monitoring Personal Care	80	0.173
Attending Care Plan Meetings	69	0.137
Overseeing Roommate Changes	64	0.161
Doing Laundry	60	0.204

p ≤ .005, ** p ≤ .001

5.4 Categorical Variables and Perceived Stress

Independent samples t-test were computed to examine potential differences in perceived stress scores for based on gender, ethnicity, choice in providing care, providing care prior to care recipients’ entry into the nursing home, providing care for another, the point of entry for the care recipient, anticipated return to the community and participation in a support group (table 5.4). A significant difference was found between those who provided care in the community prior to the care recipient’s entry into the nursing home and those who did not. Community caregivers had significantly (*t*(125) = 2.130 p < .001) higher perceived stress scores (*m*=16.23, *sd* =6.47) than non community caregivers (*m*=13.27, *sd* =5.65). Also for caregivers who provided assistance to someone in addition to the care recipient reported higher levels of perceived stress (*m*=17.21, *sd* =6.15) than those who did not (*m*=14.96, *sd*=6.46) which is a significant (*t(124)*=1.816, p <.05, one tailed).

Table 5.4 Result Of Independent Samples T-Test For Categorical Variables And Perceived Stress

	Perceived Stress Scale		
Caregiver Category	n	X(sd)	t(df)
Gender			
Male	42	14.38 (6.73)	-1.508(124)
Female	84	16.20 (6.25)	
Ethnicity			
White	117	15.73(6.48)	.826(124)
Non-White	9	13.89 (5.60)	
Choice in Providing Care			
Yes	51	14.69 (6.233)	-1.325(124)
No	75	16.23 (6.52)	
Dual- Care Provider			
Yes	38	17.21(6.15)	1.816(124)*
No	88	14.96 (6.46)	
Community Care Provider			
Yes	101	16.23 (6.47)	-2.130(125)**
No	26	13.27 (5.65)	
Anticipation of Care Recipient to Return Home			
Yes	18	17.944 (5.54)	1.720(121)
No	105	15.133 (6.54)	
Entry point for Care recipient into nursing home			
Hospital	72	16.07(6.79)	.844(124)
Home/Community Based	54	15.09(5.91)	
Participation in Support Group			
Yes	7	18.28 (3.15)	1.165(122)
No	117	15.43 (6.43)	

*p ≤ .05 (1-tailed) ** p ≤ .001 (2-tailed)

5.5 Contextual Factors

Family caregivers were asked to respond to questions relating to the context of the caregiving relationship and included such areas as type and intensity of assistance provided prior to nursing home entry, reasons for nursing home entry, providing care for someone in addition to the care recipient in the nursing home, length of time providing care for this care recipient, anticipation of the care recipient returning to the community, distance between the caregiver's home and the nursing home and how often the caregiver visits the nursing home. Additionally, family caregivers were asked if they participated in a support group for caregivers, with only 5.4% (*n*=7) indicating active participation.

5.5.1 Choice in Becoming Caregiver

Over half (59.7%, *n*=77) of the responding caregivers indicated they had no choice in the decision to become a care provider for the care recipient. For spouses, 55.6% (n=10) believe they had no choice in assuming the caregiving role. Reasons given include "if you are a spouse, it is just something you do"; "Marriage Vows", "being his wife, that is what wives and husbands vow to do". For children (including step children), 64% feel they had no choice in providing care. Reasons given include "only child", "only child close by", "it is my mother… I love her and enjoy our time together". Fifty percent (n=14) of caregivers with a relationship other than spouse or child indicate they had no choice in assuming the role of caregiver. Some reasons cited by these caregiver's include "her children are drug addicts, I am all she has"; "she has been an extended member of our family for 64 years" and "she had only one son, who is no help to her".

As would be expected, the mean score on role captivity is significantly higher for family caregivers who felt they had no choice in becoming the caregiver compared to caregivers who believe they had a choice (Table 5.2). A significant relationship exists between the mean scores on constriction of family activities for those who perceived a choice and those who did not. While there is a difference in mean scores for family conflict between caregivers who feel they had no choice in accepting the role of caregiver and those who did the difference is not significant. One daughter describes how caring for her father is very stressful because

> "… my sister lives to far to assist…my brother refuses to help which has caused great problems in our relationships, something that I always thought would never happen".

For caregivers who are employed (*n*=61), there is a significant relationship (*t* (51) = -2.32, p < .05) between believing one had a choice in accepting the role of caregiver and work-caregiving conflict. Mean score for work-caregiving conflict for employed caregivers is significantly higher (*m*=7.13, sd= *2.4)* than non-employed family caregivers (*m*=8.59, *sd*=2.53). No significant differences were identified between those caregivers who perceived a choice in accepting the caregiving role and those who did not on any of the primary care activities carried out in the nursing home

Table 5.5 Results Of Independent Samples T-Test For Perceived Choice

	Choice in Providing Care	No Choice in Providing Care	
	X(sd)	X(sd)	t(df)
Stressor			
Multiple Role Conflict			
Constriction in Activities	6.54(2.79)	8.74(3.37)	3.808(121)**
Employment -Caregiving	7.12(2.36)	8.59(2.53)	2.286 (61)*
Family Conflict	5.41(1.64)	5.64(1.64)	.761(124)
Role Captivity	2.14(0.41)	2.41(0.50)	3.27(125)*
Outcome Variable			
Perceived Stress	14.67(6.23)	16.23(6.52)	1.325(124)

* p < .05 ** p < .001

5.5.2 Community Caregivers

The majority of family caregivers participating in this study (79.1%) provided assistance to the care recipient prior to nursing home admission, and will be referred to from this point forward as community caregivers. The majority of spouses (94.4%) assisted the care recipient in the community while 82.1% of children and 65.5% of other relatives or friends provided this support before nursing home admission. Independent samples t tests comparing the mean scores of community and non-community givers for role captivity, constriction of social activities, work-caregiving stress, family conflict and perceived stress (Table 5.6). The mean scores for role captivity, constriction of social activities, work-caregiver stresses are all slightly higher for community caregivers; however none of these differences are significant.

Table 5.6 Results of Independent Samples T-test For Community Caregivers

Stressor	Community Care (n= 103)	No Community Care (n= 26)	
	X (*sd*)	X (*sd*)	*t*(df)
Role Captivity	2.32(.49)	2.21(.44)	0.86(126)
Multiple Role Conflict			
Constriction of Social Activities	8.08(3.31)	7.00(3.20)	2.13(125)
Employment -Caregiving	8.24(2.56)	7.28(2.37)	1.25(62)
Family Conflict	5.48(1.63)	5.77(1.65)	0.84(125)
Outcome Variable			
Perceived Stress	16.23(6.47)	13.27(5.65)	2.13(125)*

* $p < .05$ (2-tailed test)

Non-community caregivers have a slightly higher mean score for family conflict than community care providers, but this is not significant. Increased family conflict for non-community caregivers could be reflective of a greater expectation of support and assistance from other family members in terms of visitation and/or sharing in the caring responsibility as the care recipient entered the facility. For those caregivers who have been assisting prior to the nursing home admission, the relationships are already established and interaction patterns among family members may be set, with no expectations of change upon nursing home entry. One caregiving daughter wrote:

> "…when my brother lived closer I would be angry because he didn't help or visit mom often, but now that he has moved several hundred miles away, I realize he can't and I don't resent it as much "

There is a significant difference between the mean perceived stress score for community caregivers and non-community caregivers (Table 5.3). As compared to non-community caregivers, community caregivers have higher levels of perceived stress that may be attributed to changes within the caregiving role resulting in conflicting feelings of relief from primary caregiving responsibilities coupled with guilt that community caregiving could not continue resulting in a sense of disempowerment, loss and sadness. (Ryan & Scullion, 2000; Kellet, 1998).

Indicating a potentially abrupt ending to providing care in the community, 60.4% of community caregivers in this study indicated the care recipient entered the nursing home from a hospital setting, where as 53.8% of non-community caregivers identified the point of entry for the care recipient as being community based. Potentially tied to the higher mean scores of perceived stress for community caregivers, admission from a hospital can result in the caregivers not receiving adequate support from healthcare professionals or feeling they have no choice in the decision (Nolan & Dellasega, 2000, Ryan & Scullion, 2000).

Upon entry into the nursing home, family caregivers experience a variety of role changes and expectations. While they may not physically assist the care recipient with ADL tasks or IADL tasks, several activities of participation have been identified throughout the literature (Kellet, 1998, Kolb, 2003). Participating family caregivers were asked to indicate participation on eleven different activities. While the majority of family caregivers indicated a high level of involvement in activities of caring, slightly more of non-community caregivers (79.2%) indicated they participated in 8 or more of the listed activities, compared to 71.3% of the community caregivers. In addition to indicating participation, each family caregiver was requested to indicate if participation constituted a hassle. Independent sample t tests were computed but found no significant differences between community and non-community caregivers regarding perception that participating in any activity is a hassle.

5.5.3 Providing Dual Care

Another contextual factor of interest is related to providing dual care for another person in addition the care recipient in the nursing home. Less than one third of those responding

(30.2%, n= 39) indicated they provided additional assistance to another person. Below is the relationship of the dual care recipient to the caregiver:

Relationship of care recipient to caregiver	Percentage of Caregivers Assisting	Frequency
Spouse	11.6	15
Minor Child	6.2	8
Adult Child	3.9	5
Sibling	1.6	2
Parent	3.9	5
Other	3.1	4

As would be anticipated family caregivers providing care for another person showed a significantly higher (*t*=1.816; *df*= 124; *p* ≤ .05) perceived stress (*m*= 17.21; *sd*= 6.15) than do family caregivers not providing dual assistance (*m* = 14.96; *sd*= 6.47). One daughter stated that "…with a full time job and 2 young children at home, I have had to hire someone to take care of my father's day to day stuff in the nursing home". Those who provided care for an additional person reported slightly higher mean scores for role captivity (*m*= 5.69, *sd* = 2.19) and constriction of family activities (*m*=8.31, *sd* =3.39) than non dual care providers did on role captivity (*m* =5.48, *sd* =2.41) and constriction of family activities (*m* =7.64, *sd* =3.08), but differences were not significant (*t* (125) =477, *t (121)* =1.034). One caregiver describes feeling overwhelmed in being the primary caregiver for her sister because "… I also have a husband that is disabled and we are raising 4 grandchildren".

Dual care providers had lower mean scores on family conflict (*m* = 5.66, *sd* = 1.69) than did non-dual care providers (*m* = 5.28, *sd*= 1.48) but again the difference is not significant (*t (123)* = -.681). While work caregiving conflict also shows to be slightly lower for dual care providers (m = 7.65, *sd* = 2.62) than those caring only for the care recipient (*m* = 8.24, *sd* = 2.49) this is not a significant difference (*t (62)* = -.806*)*. Comparisons of the perceptions of dual and non-dual care providers in terms of the activities of caring post nursing home indicate differences between the two groups. Monitoring the personal care of the care recipient is perceived as more of a hassle for dual care providers (*m*=1.68; *sd*=. 81) than care providers who provide assistance for only the care recipient (*m*=1.27; *sd*=. 53) which is a significant finding (*t (107)* =3.16*; p* ≤ .05). Also, acting as a primary contact for nursing home staff is perceived as significantly (*t (106)* =2.18 p < .05) more of a hassle for dual care providers (*m*=1.71*,* sd=*.* 97) than caregivers who assist only the care recipient (*m*=1.36*, sd*=. 63). Identification as a dual or non-dual care provider did not result in any further significant differences on the remaining activities of caring.

5.5.4 Intensity of Care Provided Prior to Nursing Home Entry

The intensity of community care includes both the hours of care provided on a weekly basis, and the number of activities of daily living (ADL) and instrumental activities of daily living (IADL) assisted by the caregiver. Weekly hours of care range from 1.5 to 168, with 22.5% (*n*=23) of those providing care in the community indicating they provided assistance 168 hours *(24 hours per day, 7 days per week)* per week to the care recipient. Spouses provided more hours of assistance prior to the care recipient's entry into the nursing home (m= 100.43, sd= 73.38) when compared to children (m= 56.11, sd= 63.43) with the difference being significant (*t*=2.06; *df*= 19; *p* ≤ .05).

IADL tasks are identified as the area in which most assistance was provided, with 98% of all family caregivers (*n=100*) reporting they provided assistance with a range of 1-9 activities, while only 64.7% (*n*= 66) reported assisting with any ADL tasks. Spouses provided more assistance with both ADL (*m*=4.23*, sd*=3.08) and IADL tasks (*m*= 7.44, *sd*= 1.56) than children (ADL: *m*=2.86, *sd*=2.93; IADL: *m*=6.30, *sd*=2.45). The difference in mean number of IADL assistance between spouse and children is significant (*t*=(36.24) =2.31, p < .05) whereas the difference in mean number of ADL is not (*t*(79) = 1.78). The number of ADL tasks or IADL tasks was not correlated with mean scores for role captivity, constriction of social activities, work-caregiving stress, family conflict or perceived stress for family caregivers.

5.5.5 Duration of Care & Length of Time In Nursing Home

A higher percentage of caregivers who are children (70.4%, *n*=38) have been providing assistance for five or more years, compared to others (22.2% *n*=12) and spouses (7.4%, *n*=4). Conceptually two potential outcomes for caregivers are present throughout the literature. First is the perspective that caregiving over time results in widespread and continuing erosion of a caregiver's resources and well-being (Blake & Lincoln, 2003; Bookwala & Schulz, 2000; Edwards et al. 2002). The second concept is one of adaptation, suggesting that caregiving demands are stronger at the beginning but subjective stress recedes secondary to the caregiver learning how to do new tasks in the course of the demands associate with the illness (Lawton, Moss, Hoffman & Perkinson, 2000).

The length of time family caregivers within this study have been assisting the care recipient does not appear to have a substantial impact on feelings of role captivity, multiple role conflict, family conflict or perceived stress (Table 5.4). No significant differences were found between the two groups perceiving participation in any of the eleven post nursing home activities as being a hassle.

Table 5.7 Results Of Independent Samples T-Test For Duration Of Care

Stressor	Less than Five Years of Caregiving	More than Five Years of Caregiving	
	X(sd)	X(sd)	t(df)
Role Captivity	2.33 (0.55)	2.25(0.44)	.860(114)
Multiple Role Conflict			
Constriction of Social Activities	8.12(3.60)	7.56(3.13)	.884(110)
Employment -Caregiving	8.55(2.99)	7.68(2.27)	1.24(56)
Family Conflict	5.44(1.66))	1.68(1.61)	-0.79(113)
Outcome Variable			
Perceived Stress	16.06(6.83)	14.45(5.70)	1.37(113)

The largest percentage (43.4%, *n* = 56) of care recipients has been in the nursing home for 1-5 years, with 20% (*n*=26) having been there for six months or less. Of those entering in the most recent six months, 57.7% (n= 15) entered for the purpose or receiving therapy and 46% (n= 12) of those who are anticipated to return to the community. Employed family caregivers of care recipients who had been in the nursing home more than five years had a lower mean score on work-caregiving stress (m = 6.31, sd =2.06) than caregivers of care recipients who had been in the facility six months or less (m = 9.47, sd = 2.90) which is a significant difference (f (3, 57) = 4.12, $p < .05$). It would seem as the role of family caregiver within a nursing home evolves over time, work roles become more integrated and create less conflict. No other significant differences are identified in relation to feelings of role captivity, constriction of family activities, family conflict or perceived stress (Table 5.8).

Table 5.8 ANOVA For Length Of Time In Nursing Home

	1-180 days	6 months – 1yr	1-5 years	>5 yrs	
Stressor					
	X(sd)				f(df)
Role Captivity	2.43(.568)	2.21 (.0.43)	2.36 (0.48)	2.10(.039)	2.42(3,121)
Multiple Role Conflict					
Constriction of Family Act.	8.63(3.62)	8.67 (3.77)	7.78(3.02)	6.39(3.03)	2.36(3,117)
Employment –Caregiving	9.47 (2.90)*	7.75 (2.43)	8.16(2.19)	6.31(2.06)*	4.12(3,57)
Family Conflict	5.08 (1.62)	5.48 (1.66)	5.64 (2.19)	6.00(1.76)	1.38(3,120)
Outcome Variable					
Perceived Stress	17.36 (6.01)	16.10 (7.09)	15.57(6.62)	13.39(5.69)	1.57(3,120)

* $p < .05$

5.5.6. Point of Entry & Reason for Placement

Over one-half of the care recipients entered the facility from the hospital (57.4%, n=74) the remaining entered the facility directly from home (34.1%, n=44) or another community based setting (7.8%, n= 10). The mean perceived stress score for caregivers when the care recipient entered the facility from the hospital (m= 16.07, sd= 6.8) was higher than the mean perceived stress score for caregivers when the care recipient came from home or other community setting (*m*=15.09, *sd*= 5.9) however this difference was not significant (*t*(124) = .894).

The decision to enter a nursing home from the hospital is most often identified as the need for therapy, physician recommendation, and cost of care at home. First the majority of care recipients entering the facility from the hospital (57%, *n*=39) in need of therapy differs significantly (X^2 (2) = 20.63, $p < .05$) for those who directly admitted from home or other community setting (14.8%, *n*=8). Admitting from the hospital on the recommendation of a physician (63.5%, *n*= 47) occurs more often than when the care recipients comes to the facility from home or a community setting (56.3%, *n*=72) but this is not a significant finding (X^2 (1) = 3.76). The cost of care at home was also identified as a reason for the care recipient to enter a nursing home from the hospital (29.7%, *n*=22) and is significantly different (X^2 (1) =3.87, $p < .05$) from care recipients whose point of entry is home or community setting (14.8%, *n*=8).

Additional reasons for entering a nursing home identified for care recipients coming from the hospital include physical disabilities (70.3%*, n*=52), the care recipient being confused/forgetful (17.3%, *n*= 35) and lack of resources (17.6%*, 13).* Whereas, those coming from home identify physical disabilities (68.5%, *n*=37), being confused/forgetful (53.7%, *n*=29) and lack of resources (11.1%, *n*=6). These differences were not significant. Additionally, the point of entry had no significant impacts on mean scores of caregivers for role captivity, constriction of social activities, employment-caregiving conflict or family conflict (Table 5.9).

Table 5.9 Results Of Independent Samples T-Test for Point of Entry

Stressor	Entry from Hospital	Entry form Home/Community	
	X(sd)	X(sd)	t(df)
Role Captivity	2.30(.51)	2.30(.44)	-0.06(125)
Multiple Role Conflict			
Constriction of Family Act.	7.96(3.42)	7.64(5.90)	0.844(124)
Employment –Caregiving	8.31(2.77)	7.75(2.22)	0.875(61)
Family Conflict	5.38(1.67)	5.81(1.55)	-1.46(124)
Outcome Variable			
Perceived Stress	16.07(6.79	15.09(5.90)	0.844(124)

5.5.7. Temp vs. Long-Term Placement

Entry into a nursing facility is not always correlated with the care recipient needing to remain on a long-term basis. Many individuals enter a facility after an accident or illness to received skilled care and therapies, then returning to a community living setting. Fourteen percent (14%, *n =18)*) of family caregivers anticipate the care recipient to return to the community. For family caregivers who perceive entry into a nursing home as temporary for the care recipient 13.9% (n=13) also provided care when the care recipient lived in the community and 15.812 (n=5) don't feel they had a choice in accepting the role of caregiver. The top three reasons for the care recipient to have entered the nursing home (caregivers could identify more than one reason) on an anticipated short-term basis is for therapy (61.1%, n=11), physical disabilities (56.7%, n=12) and physician recommendation (50%, n=9). Fifty percent of family caregivers who anticipate their loved one to return home visit the nursing home on a daily basis as compared to 26.2% of caregivers for long term care recipients. An independent samples *t* test comparing the mean scores of caregivers who anticipate the care recipient to return home and those who don't found a significant difference between the means of the two groups for work place stress (t(*5*9) = 2.94 p < .05). The mean for those anticipating a temporary stay was significantly higher (*m*=10.10, *sd* = 2.38) than the mean of those who consider the placement long term (*m=7.65*, *sd*= 2.42). Means scores between the groups for social life constriction, family conflict, role captivity, and perceived stress were not significantly different (Table 5.10).

Table 5.10 Results of Independent Samples T-test For Placement Status

	Temporary Placement	Long-Term Placement	
	X(sd)	X(sd)	t(df)
Stressor			
Role Captivity	2.45(0.60)	2.28 (0.42)	1.34(122)
Multiple Role Conflict			
Constriction of Family Act.	9.24(3.34)	7.60(3.24)	1.91(119)
Employment -Caregiving	10.01(2.38)	7.65(2.42)	-2.94(59)*
Family Conflict	5.55 (1.85)	5.58(1.61)	-0.60(121)
Outcome Variable			
Perceived Stress	17.94(5.54)	15.13(6.54)	1.72 (121)

* p < .05

5.5.8 Visitation Schedule and Distance from Nursing Home

Most family caregivers in this study visit the care recipient 1-3X weekly (38%, *n*=49), with 30.2% (n*=39)* visit on a daily basis. Visiting more often results in greater participation in the care by family caregivers with 75% of those who visit daily assist in a range of 8-11 activities while only 61% of those who visit 1X a month or less participate in the same level of activities of caring. The care recipient's spouse is more likely to visit on a daily basis than are children or friends and extended family. Caregivers who report visiting one time a month or less also report significantly higher mean scores for family conflict than do those who visit 1-3X weekly (table 5.11). Slightly more family caregivers who visit 1X month or less are employed (57.1%) compared to those who visit 1-3x weekly (51%). It is unclear if increased family conflict may result in a decline in the visitation schedule or if a decline in the visitation schedule impacts feelings of family conflict.

Table 5.11 ANOVA For Visitation Schedule

	Daily	1-3X Weekly	4-6 X Weekly	< 1X month	
	X(sd)				f(df)
Stressor					
Role Captivity	2.34(.47)	2.30(.48)	2.49(.49)	2.14(.46)	.11(3,123)
Multiple Role Conflict					
Constriction of Family Act.	7.64(3.40)	7.43(3.24)	8.81(2.86)	7.78(1.97)	1.04(3,119)
Employment -Caregiving	7.58(2.63)	8.16(2.49)	8.90(3.08)	7.75(1.58)	.679(3,59)
Family Conflict	5.76(1.77)	5.22(1.40)*	5.31(1.64)	6.57(1.69)*	2.99(3,122)
Outcome Variable					
Perceived Stress	15.76(6.10)	15.41(6.77)	17.07(6.93)	13.50(4.78)	1.21(3,128)

$p < .05$

Family caregivers who reside within twenty five miles visit more often than do family caregivers who live away from the facility more than twenty five miles. Of those residing within 25 miles of the facility, 37.4 %(*n*=37) visit daily compared to 3.6% (*n*=1) of those residing a distance of more than 25 miles. However, 50% (n=14) of those who live the farther distance do visit 1-3 times weekly, with 35.7% visiting one time a month or less.

Table 5.12 Results of Independent Samples T-test for Distance From Nursing Home

	25 miles or less	Greater than 25miles	
	X(sd)	X(sd)	t(df)
Stressor			
Multiple Role Conflict			
Social Life Constriction	7.78(3.31)	7.89 (3.35)	-0.163(120)
Employment -Caregiving	7.81(2.57)	8.71(2.33)	-1.18(60)

Table 5.12 Continued

	25 miles or less	Greater than 25miles	
	X(sd)	X(sd)	t(df)
Family Conflict	5.58(1.59)	5.43(1.77)	.423(123)
Role Captivity	2.30(0.47)	2.29(.53)	.138(124)
Outcome Variable			
Perceived Stress	15.79(6.57)	14.96(5.97)	0.60(123)

5.6 Mediators

While family caregivers must deal with the negative aspects of caregiving, positive outcomes can also be identified. Family caregivers may initially feel doubt about their abilities to assist the care recipient; entry into a nursing facility may be overwhelming in terms of understanding the process, paperwork and financial implications. However, it has been shown that family caregivers my eventually feel a sense of accomplishment in their ability to resolve issues of concern (Sanders, 2005). It is also been found that the ability to hold positive beliefs about the caregiving situation and oneself as a caregiver can impact depression in a positive manner (Noonan & Tennstedt, 1992).

Virtually all-family caregivers within this study identified positive benefits that ware forthcoming from caregiving activities. All caregivers responding to these items (*n*=127) indicated strong positive beliefs about their ability as a good caregiver, being competent and self-confident in dealing with the ups and downs of the situation. Additionally 98% (n=126) believe they have become very much aware of increasing inner strengths, more self-confidence, growing as a person and learning to do things they couldn't do before. While it is positive that family caregivers recognize gains received from accepting and assisting with the difficulty of caring for a loved one, this removes caregiver gain as a variable in this study. Because the appraisal set of caregiver gain did not demonstrate a significant effect this single result is of interest primarily as a possible topic for future investigation.

5.7 Activities of Caring: Post Nursing Home Entry

As the environment of care is that of a nursing home, primary care activities differ from activities of assistance provided in the community by family caregivers, including less "hands on" assistance and more peripheral support (Kolb, 2003). Participation in activities of caring post nursing home entry varied widely across the sample of family caregivers (Table 5. 13). The majority of family caregivers participated in discussing medical concerns, acting as a primary contact, providing clothing and completing paperwork. Where as the least amount participated in areas of washing laundry and overseeing roommate changes. While participation in activities is one dimension of the caregiving responsibilities, perception of the activity being inconvenient or a hassle is the second dimension.

Table 5.13 Summary For Post Nursing Home Activities (n=129) [a]

Activity being completed by family caregiver	Percent of total carrying out activity	Percent caregivers competing activity who see it as a hassle
Discuss Medical Concerns with Staff	94.6 (n=122)	27.2 (n=31)
Act as a Primary Contact for Resident	90.7 (n=117)	34.5 (n=38)
Providing Clothing	89.9 (n=116)	30.9 (n=34)
Complete Required Paperwork	88.4 (n=114)	52.7 (n=59)
Provide food & personal items	88.4 (n=114)	30.6 (n=34)
Act as an advocate	81.4 (n=105)	32.0 (n=33)
Make Financial Arrangements	76.0 (n=98)	63.2 (n=60)
Oversee Personal Care	62.8 (n=81)	43.2 (n=35)
Attend Care Plan Meetings	57.4 (n=74)	22.9 (n=16)
Oversee roommate changes	48.1 (n=62)	38.5 (n=25)
Wash resident's laundry	47.3 (n=61)	34.4 (n=21)

[a] Changing sample size reflects missing data on certain variables

5.7.1 Discussing Medical Concerns

Discussing medical concerns is the activity in which most family caregivers participated. Identifying this activity as a hassle correlated with perceived stress (*r*=. 298, *p* < .001), constriction of family activities (*r* = .249, *p* = .001), work-caregiver stress (*r*= .426, *p* <. 001) and role captivity (*r* = .223, *p* < .001). Women (30.8%) more often than men (20.0%) identified this activity as a hassle, as did spouses (33.3%, *n* = 5) more often than children (27.4%, *n* = 20) and others (24.0%, *n* = 6). If the care recipient is anticipated to return to the community, 86.7% (n = 13) family caregivers are more likely to feel discussing medical concerns is not a hassle as compared to 62.0% (*n* = 57) of family caregivers who anticipate the care recipient to remain long term

5.7.2 Acting as Primary Contact

Being the primary contact for the resident and feeling this is a hassle is correlated with mean scores on perceived stress (*r*=. 305, *p*< .001), constriction of social activities (*r* = .326, *p* < .001), family conflict (*r*= .353, *p* < .001) and role captivity (*r* = .355, *p*, >05). One daughter described being a primary contact as … "always being on alert for phone calls, hoping something doesn't happen to her. It is kind of like ongoing state of anxiety, hoping nothing happens". The majority of family caregivers who have been providing assistance for five years or less (70.9%, *n* = 39) don't feel acting as a primary contact is a hassle, compared to 55.6% (*n*= 25) who have provided assistance greater than five years. A spouse (21.4%, *n* = 3) is less likely to feel, acting as primary contact, is a hassle when compared to children (35.2%, *n* =25) and others (40.0%, *n* =10).

5.7.3 Providing Clothing

The third most participated in activity is that of providing clothes for the care recipient and is correlated with perceived stress (*r*= 286, *p* < .001) and constriction of social activities (*r* = .345, *p* < .001). Providing clothing is believed as more of a hassle for caregivers who do not anticipate the care recipient to return to the community (33.3%, *n* = 31) compared to caregivers of care recipients expected to return to the community (15.4%, *n* = 2). Extended family caregivers are more likely to feel providing clothes is a hassle (41.7%, *n* =10) when compared to children (31.0%, *n* = 22) and spouses (14.3%, *n* = 2). Women (35.5%, *n* =27) are more likely than men (21.2%, *n* = 7) to feel providing clothes is hassle, as well as employed family caregivers (35.7%, *n* = 20) when compared to unemployed (28.9%, *n* = 14). If the care recipient has been in the nursing home for five years or more, 39.6% (*n* = 19) of family caregivers feel it is a hassle to provide clothes, where as only 24.1% (*n* =13) do if the care recipient has been in the facility less than 5 years

5.7.4 Completing Paperwork

It is the policy of most facilities to have the primary caregiver to accept and carry out the responsibility of completing required paperwork, especially at admission to the facility. Within this study population, a large percentage of family caregivers (88.4%, n= 114) participated in the completion of required paperwork and 52.7% of them deemed this to being a hassle.

No correlation is found between determining the completion of paperwork as being a hassle and role captivity, constriction of family activities, family conflict, perceived stress or work-caregiving stress. Children feel that completing paperwork is a hassle (59.5%, *n* = 44) more often than others (39.1%, *n* = 9) and spouses (35.7%, *n* = 5). Caregivers of care recipients who have been in the facility for more than 5 years are more likely to feel completing paperwork is a hassle (68.8%, *n* = 33) as compared to those who have been in the facility less than 5 years (42.65, *n* = 23). Correlations between completion of paperwork being perceived as a hassle and time in nursing home (*r* = .240, *p* <. 05) and distance from nursing home (*r* = .212, *p* < .05) are also identified.

5.7.5 Providing Food and Personal Items

Correlation is noted between feelings that providing food and personal items is a hassle with role captivity ($r = .190$, $p < .05$), perceived stress ($r = .324$, $p < .001$) and constriction of family activities ($r = .284$, $p < .001$).

5.5.6 Acting as an Advocate

Seeing advocating for the care recipient as a hassle is correlated with perceived stress ($r= .243$, $p < .05$), constriction of social activities ($r = .263$, $p < .001$), work-caregiver stress ($r = .323$, $p < .001$) and role captivity ($r= .230$, $p < .001$). Men are less likely to view advocating as a hassle (28.6%, $n = 10$) when compared to women (33.8%, $n = 23$). Children are less likely to believe advocating for the care recipient is a hassle, (27.3%, $n =18$) when compared to spouses (28.6%, $n =4$) and other relatives/friends (47.8%, $n =11$). Financial hassles are correlated with perceived stress scores ($r = .336$, $p <. 001$), and role captivity ($r = .222$, $p = <. 05$).

5.5.7 Making Financial Arrangements

Making financial arrangements is seen as creating the most hassle for family caregivers; with 76 % of those identifying this as a task in which they participated as being a hassle. Of those completing financial arrangements, most (87.6%, $n=85$) don't anticipate their loved one to return to the community. Care recipients who are anticipated to return to the community may be in the facility under Medicare to receive therapy, thus negating the need for financial arrangement to be made. Admission to a facility and ongoing care does require completion of paperwork

5.7.8 Overseeing Personal Care

No correlations between deeming the monitoring of personal care or attending care plan meetings as a hassle and any other variable are found. However, spouses (60%, $n =6$) are more likely to feel monitoring of personal care is a hassle than other friends/relatives (44.45, $n=8$) and children (39.2%, $n=21$). Additionally, 46.2% ($n=18$) of employed caregivers feel monitoring personal care is a hassle; where as 40.5% (*n* =17) of unemployed caregivers identify this as being a hassle.

5.7.9 Attending Care Plan Meetings

Just over one-half (57%, n =74) of participating family caregivers attended care plan meetings and of those attending, only 12.4% identified this as being a hassle. Family caregivers of those who had been in the nursing home 180 days or less were less likely to view participation in care plan meetings as a hassle (11.1%, *n* =1), when compared to those who's loved one had been in the nursing home five or more years (28%, *n* =4). Employed family caregivers who attended care plan meetings were more likely to view this as being a hassle (28.6%, n=8) when compared to unemployed family caregivers who attended the meetings (19%, *n*= 8). No real differences were observed in terms of relationship to care recipient, visitation schedule, or distance from the nursing home when comparing perceptions of attending the meetings as being a hassle.

5.7.10 Overseeing Roommate Changes and Washing Care Recipient's Laundry

As progress is made within nursing home settings, private rooms are becoming more common, which may result in the lower numbers being reported here. Additionally doing the care recipient's laundry is a service that all facilities provide, however losing clothes is often a consequence and family caregivers often want to take on this responsibility to prevent the loss of clothing items. The only correlation between the hassles of overseeing a roommate is that of work-caregiving stress (r = .453, p < .05). Females are much more likely to view overseeing roommate changes as a hassle (72.0%, *n* =18) when compared to males (35.0%, *n*=7). Doing the residents laundry and perceiving this to be a hassle is correlated with work-caregiving stress (r = .512, p < .001) and role captivity *(r = .387, p* <. 001). Only minimal variations are seen between groups of family caregivers who deem doing the residents laundry as a hassle and those who do not. No correlations between identifying any of the post nursing home activities as a hassle and caregiver characteristics, such as age, race, relationship, or duration of care are found. Independent samples t-tests comparing the mean scores of role captivity, constriction of family activities and perceived stress for caregivers who identified the activities as a hassle and those who did not, resulted in significant differences for the two groups across all activities (Table 5.14).

Table 5.14 Results of Independent Samples T-test for Role Captivity; Perceived Stress and Constriction of Family Activities for Nursing Home Activities

	Role Captivity		Perceived Stress		Constriction of Family Acts	
Activity						
	X (sd)	t(df)	X (sd)	t(df)	X(sd)	t(df)
Financial Hassle						
No Hassle	2.15(.47)	-2.181(92)*	12.23(6.01)	-3.408(99)**	_____	_____
Hassle	2.38(.48)		16.61(5.93)			
Contact Hassle						
No Hassle	2.19(.47)	0.393(107)***	13.97(6.09)	-3.92 (106) **	7.20(2.80)	-3.529104)**
Hassle	2.53(.45)		18.10(6.48)		9.40(3.51)	
Medical Discuss						
No Hassle	2.24(.47)	-0.241(111)*	14.10(6.28)	-3.271(110)**	7.47(2.91)	-2.676(108)*
Hassle	2.49(.50)		18.32(5.65)		9.26(3.71)	
Advocacy Hassle						
No Hassle	2.22(.47)	2.361(100)*	14.20(6.24)	-2.491 (99)*	7.429(2.97)	-2.699(98)*
Hassle	2.46(.46)		17.53(6.26)		9.219(3.41)	
Personal Items						
No Hassle	2.26	2.01(108)*	13.89 (6.12)	-3.56(108)**	_____	_____
Hassle	2.46		18.44(6.33)			
Laundry Hassle						
No Hassle	2.15(.43)	2.945(58)***	_____	_____	_____	_____
Hassle	2.57(.56)					
Clothing Provide						
No Hassle	_____	_____	13.92 (6.22)	-3.070(106) **	9.50(2.83)	-3.73(103)***
Hassle			17.88(6.26)		7.15(3.09)	

* p< .05, ** *p* < . 001 ****p* < .000

Independent samples t-test were computed comparing mean scores on work-caregiving conflict of those who deemed overseeing roommate changes, advocating for care recipients and discussing medical concerns as a hassle and those who did not. The mean of those believing overseeing roommate changes are a hassle (*m*=9.15, *sd* = 1.95) was significantly higher (*t* (29) = -2.737, p = .010), than those who do not perceive this activity to be a hassle (*m*= 7.05, *sd* = 2.21). Caregivers who perceive advocating for the care recipient as a hassle have a mean score of (*m*=9.39, *sd* = 2.50) for work-caregiver stress that is significantly higher (*t* (49) = -2.388, *p* = .021) than the mean score for those who do not feel it is a hassle (*m* =7.75, *sd* =2.34). Just as those who identify the need to discuss medical issues with staff as being a hassle have a mean score of 9.94 (*sd*= 2.11), which is significantly higher (*t* (58) = -3.592, *p* = .001) than those who do not (*m= 7.52, sd* = 2.37). Caregivers, who perceive discussing medical concerns with staff as a hassle, have higher mean scores on family conflict (*m*= 6.34, *sd* =1.54) which is significantly different (*t* (108) = -3.915, *p* = .000) than those who do not perceive this activity to be a hassle (*m*= 5.15, *sd*=1.49)

5.8 Regression Analysis

Table 5.15 Summary of Multiple Regression Analysis with Forward Entry for Variables Predicting Perceived Stress For All Family Caregivers (*N=116)*

Predictor	Δ R^2	ΔF	B	SE B	β	R^2	Adj R^2	F
Model 1	.371	70.20***						
Constant			-3.089	2.255				
Role Captivity			8.030	.958	.609			
Model 2	.042	8.53**						
Constant			-3.471	2.191				
Role Captivity			6.682	1.038	.507			
Activity Const.			.441	.151	.230			
Model 3	.032	6.85**						
Constant			-.897	2.354				
Role Captivity			6.678	1.013	.507			
Activity Constriction			.487	.148	.254			
Caregiver Income			-.911	.348	-.182			
Model 4	.022	4.88*						
Constant			-3.227	2.545				
Role Captivity			6.280	1.013	.476			
Activity Restriction			.453	.147	.236			
Caregiver Income			-.858	.343	-.171			
Family Conflict			.603	.273	.155			
						0.47	0.45	25.54(4,116)***

* p < .05, ** p < .001, *** p < .000

Pearson's correlations were computed between caregiver's perceived stress and all demographic variables and contextual variables. A significant negative correlation (r = -0.260, p <. 05) was found between household income and caregiver perceived stress. No other demographic or contextual variables were associated with perceived stress. With the exception of those who provided care in the community and those who did not, T-tests and analysis of variance revealed no differences between men and women, ethnic groups, or other caregiving relationships. However, caregiving stressors were significantly related to perceived stress scores for family caregivers.

A multiple linear regression, with forward entry was calculated to predict family caregivers' level of perceived stress based on household income, providing care in the community prior to nursing home entry, feelings of role captivity, family conflict and constriction of social activities. The sample size of *n*=116, satisfies the requirement for a medium effect size with five predictors based on the new rule of thumb proposed by Green (1991). A significant regression equation was found (F (4, 116) = 25.54, p <. 000) with an adjusted R^2 of .45. All variables with the exception of providing community care prior to nursing home placement resulted in a significant increase in the percentage of variance explained. Examination of beta coefficients indicates role captivity accounted for the majority of the explained variance followed by constriction of family activities, caregiver income and family conflict. For employed family caregivers, work-caregiver stress was added into the above model, reducing the available sample size to n = 62 (which falls one below the recommended sample size for medium effect with two predictors according to Green, 1991). A significant regression equation was found (F (2, 60) = 33.980, p < .000) with R^2 = .531 and adjusted R^2 = .515 (Table 5.15). Caregiver income and constriction of social activities no longer contributed significantly to the model.

Table 5.16 Summary of Multiple Regression Analysis With Forward Entry For Variables Predicting Perceived Stress In Employed Family Caregivers (*n* =61)

Predictor	ΔR^2	ΔF	B	SE B	β	R^2	Adj R^2	F
Model 1	.472	54.546***						
Constant			-5.195	2.950				
Role Captivity			9.065	1.227	.687			
Model 2	.059	7.554**						
Constant			-6.922	2.873				
Role Captivity			7.474	1.302	.566			
Work-Caregiving Conflict			.679	.247	.271			
						.531	.515	33.980 (2, 62)***

** p < .01, *** p < .000

5.9 Hypothesis

5.9.1 Hypothesis #1

Family conflict represented in this study reflected the family caregivers' perception of other family members' interactions with the care recipient. The hypothesis that family caregivers perceived conflict in areas of the amount of time other family members spent with the care recipient or shared in the responsibilities of care provision, along with subjective perceptions of others treatment of the care recipient would impact feelings of stress for those acting as primary family caregivers was supported. A moderate correlation (r=0.523, p≤ .001) between family conflict and perceived stress was identified. An independent samples *t*-test comparing the mean scores of perceived stress for family caregivers who perceived family conflict and those who did not found a significant difference between the means of the two groups ($t(68) = 2.18$, p <.05). The mean of the family caregivers who perceived conflict was significantly higher (*m*=17.12, *sd*= 6.58) than the mean of family caregivers who did not perceive conflict (*m*=13.22, *sd*=6.19).

5.9.2 Hypothesis #2

Family caregivers (of care recipients in nursing homes) who report positive beliefs about themselves, as caregivers will experience lower levels of stress than those who do not.

All caregivers reported feelings of self-gain, thus reducing the variance for this item. This hypothesis was not supported.

5.9.3 Hypothesis # 3

Family caregivers (of care recipients in nursing homes) who report greater feelings of personal growth will experience lower levels of stress than those who report lower feelings of personal growth. All caregivers reported high feelings of personal growth, thus reducing the variability of this time. This hypothesis was not supported.

5.9.4 Hypothesis # 4

Family caregivers who assisted in the care of the care recipient prior to nursing home entry will experience less multiple role conflict than family caregivers who did not provide assistance prior to the care recipient's entry into the nursing home. Multiple role conflict was conceptualized as interference with employment related tasks and constriction of social life in terms of spending time with family or alone participating in activities for leisure. Thus role conflict has two components, work related stress and constriction of family activities.

This hypothesis was not support. While community caregivers reported higher levels of feeling constricted in family activities (m= 8.09, sd= 3.23) than those who had not provided assistance (m = 6.92, sd = 3.29), the difference is not significant (t (122) = -1.593). Additionally for employed caregivers (n=63), those who provided assistance in the community report greater work-caregiving conflict (m = 8.23, sd = 2.53) than did non-community caregivers (m = 7.23, sd = 2.45) again the difference is not significant (t (62) = -1.283).

5.9.5 Hypothesis # 5

Family caregivers who assisted in the care of the care recipient prior to nursing home entry will experience less conflict associated with advocating for and assisting the care recipient following entry into the nursing home than family caregivers who did not provide assistance prior to the care recipient's entry into the nursing facility. This hypothesis was not support, in that no significant differences were found between those who provided assistance in the community and those who did not, when identifying participation in activities of caring as a hassle.

5.9.6 Hypothesis # 6

It was hypothesized that family caregivers who had provided assistance to the care recipient in the community would experience less feelings of role captivity following nursing home placement, where as those individuals who accepted the caregiving role at the time entry occurred, would have greater feelings of role captivity. An independent samples *t*-test comparing the mean scores on role conflict of family caregivers who provided care in the community and those who did not resulted in a slightly higher mean for community care providers (*m*=2.32, *sd*=0.49) and those who did not assist prior to entry of the care recipient into a nursing home (*m*=2.23, *sd*=0.44), but this difference was not significant (*t* (123) = .861).

CHAPTER 6

DISCUSSION

The results of this study contribute to the growing body of knowledge regarding family caregivers of care recipients in long-term care facilities. It has been demonstrated throughout the literature that family caregivers continue to provide physical, emotional and financial support, oversight of formal care, and act as advocates for the care recipient following nursing home entry (Davies & Nolan, 2004, 2005; Gaugler et al. 2004; Hertzberg et al. 2001; Kellett, 1998; Kolb, 2003; Reuss et al. 2005; Whitlach, et al. 2001). Consistent with prior research family caregivers participating in this study continued to actively participate in the ongoing care of the care recipient and the stress related to this role did not end with nursing home placement (Kramer, 2000; Whitlatch et al. 2001).

Perceived stress was associated with a variety of sources including whether or not they had a choice in assuming the caregiving role, feelings of role captivity, family conflict, constriction of time for participating in family activities and continued involvement with activities of caring within the nursing home environment. Additionally, employed family caregivers also experienced stress as a result of work-caregiving conflicts. Aspects associated with perceived stress of family caregivers spanned the domains outlined in the proposed model (figure 1.1) found in chapter two. Caregiver attributes, role allocation, contextual factors, along with primary and secondary stressors were shown to impact perceived stress scores.

6.1 Hypothesis Support

6.1.1 Hypothesis #1

Hypothesis 1 stated that family conflict would impact feelings of stress for family caregivers of care recipients in nursing homes. This hypothesis was soundly supported. Family caregivers who reported conflict in the amount of time other family members spent with the care recipient or shared in the responsibilities of care provision, along with subjective perceptions of other family members treatment of the care recipient experienced significantly higher mean scores of perceived stress than did those who reported no family conflict. Family, being the initial environment of care, tends to have deeply rooted beliefs and expectations regarding ongoing care for the aging members and those who will assume this responsibility. The family unit faces a multitude of changes with the onset of caregiving while attempting to balance already established familial and social-roles.

It is traditional, as well as more efficient, to have one family member identified as the primary caregiver for the care recipient in the nursing home. As one member of the family is called upon to support the declining member, other family members may resist in taking part of the caregiving, as they do not wish to forfeit their independence increasing or creating conflict (Sayger, Homrich, & Horne, 2000). Consistent with other research, family conflict, disagreements and hardships have been found to directly impact caregiver well-being (Scharlach, Li & Dalvi, 2006).

In a qualitative study designed to assess an individuals future plans regarding formal care, the decision to not rely on family members for care was associated with family conflict (Roberto, Allen & Blieszner, 2001). Additional support for this hypothesis is seen in the positive correlation between of the constriction of time available to participate in activities with family members and perceived stress. Perceived limitations in time available to spend with a partner or spouse, children, family activities or simply having time alone was positively correlated with perceived stress. Family caregivers, who feel the caregiving role constrains them in terms of other activities and may in turn feel other family members, are not providing adequate support to the care recipient or to them as a primary caregiver. While caregivers who visit the care recipient more often report less family conflict than do caregivers who visit the least, it is unclear if increased family conflict may result in a declined in the visitation schedule or if a decline in the visitation schedule impacts feelings of family conflict. This data provides a limited glimpse into a potential area of concern when working with family caregivers and an area to be addressed prior to the care recipient's entry into the nursing home and throughout the time in the institution.

6.1.2 Hypothesis 2 & 3

Hypothesis 2 and 3 encompassed beliefs about potential mediation of caregiver uplifts on perceived stress. Hypothesis 2 stated family caregivers (of care recipients in nursing homes) who report positive beliefs about their abilities as a caregiver, will experience lower levels of stress than those who do not report positive beliefs. Hypothesis 3 espoused family caregivers (of care recipients in nursing homes) who report more personal growth will experience lower levels of stress than those who do not report feelings of personal growth. Neither hypothesis was supported. Mediating components of caregiver uplifts were eliminated as almost all caregivers responding indicated they held strong positive beliefs about their ability to as a caregiver and that they had grown as a person. Despite holding positive beliefs about the caregiving role and oneself as a caregiver, this held no apparent association with feeling trapped in the caregiving role, a similar finding in other research (Noonan & Tennstedt, 1997), as a large percentage of participating caregivers reported feelings of role captivity which in turn contributed the most to perceived feelings of stress. Additionally, both positive and negative effects of the caregiving role have been demonstrated to co-exist and found here (Sanders, 2005).

6.1.3 Hypothesis # 4

Family caregivers who assisted in the care of the care recipient prior to nursing home entry will experience less multiple role conflict than family caregivers who did not provide assistance prior to the care recipient's entry into the nursing home**.** Multiple role conflict was conceptualized as interference with employment related tasks and perceptions of limited time available to participate in family activities or pursue "alone time" secondary to activities related to the caregiving role. Findings from one study (Heru et al. 2004) found that if caregiving can be carried out without affecting quality of life, caregiving can be perceived as more rewarding than burdensome. As community caregivers transferred primary care responsibilities to facility staff, it would be anticipated that conflict with employment related activities and time available to spend in family activities or pursing alone time would lessen. Whereas non-community caregivers who were just beginning to integrate the caregiving role into an already balanced lifestyle would experience greater conflicts in these areas as they attempt to integrate the new responsibilities related to providing care. This hypothesis was not supported.

While findings were not significant for differences in mean scores of constriction of time for participating in family activities or employment caregiving conflict, community caregivers reported higher levels of conflict in both categories. One possible explanation would be as community caregivers exchanged the primary responsibilities of providing care for the new roles related to caregiving activities in the nursing home an upset in the balance of activities occur. As the transition between community caregiving and institutional care occurs, family caregivers may feel they need to spend more time with the care recipient following placement and provide more oversight of the care being provided by staff than caregivers who had not already incorporated the caregiving role into their lifestyle.

Some evidence exists that as the caregiving role becomes integrated into the lives of family caregivers participation in family activities increases. Family caregivers within this study who have been providing care less than five years report more time constriction for participating in family activities when compared to those who have been providing care more than five years. Also, as the length of time the care recipient is in the nursing home increases, time constriction for participation in family activities decreases.

For employed family caregivers, work-caregiving conflict was found to be higher during the first six months of placement, gradually declining over time, indicative of an integration of the role of employee and caregiver. If the care recipient was considered to be in the nursing home temporarily, work-caregiving conflict was higher for family caregivers than if the care recipient was anticipated to remain long-term.

Examination of work-caregiving conflicts and participation in activities of caring post placement revealed potential effects on quality of life. Caregivers who participated in and identified activities of overseeing roommate changes, advocating for the care recipient and the need to discuss medical concerns with staff as a hassle had higher mean scores of work-caregiving conflict than those family caregivers who don't feel these activities to be a hassle. If employee responsibilities are interrupted secondary to these above activities of caring, this may produce the feeling of participation being a hassle.

6.1.4 Hypothesis # 5

It was hypothesized that there would be a difference between community caregivers and those assuming the role of family caregiver at time of the care recipient's entry into the facility in relation to participating in activities of caring and conflict associated with this participation. It was felt that simply identifying the type of activities in which a family caregiver participates is not sufficient, but an attempt should be made to understand what participation means for each caregiver. The data did not support this hypothesis. It seems activities of caring in the nursing home environment present the same challenges for participating family caregivers regardless of their status as a veteran or novice caregiver. One reason for not seeing less conflict for community caregivers is that changes in the caregiving environment from community to institution may result in new roles that the family caregiver is unprepared to carry out, or transferring primary care of the care recipient to others may erode a sense of control he/she once held.

6.1.5 Hypothesis # 6

It was hypothesized that family caregivers who had provided assistance to the care recipient in the community would experience less feelings of role captivity following nursing home placement of the care recipient, whereas those who assumed the role of caregiver at the time nursing home entry occurred, would have greater feelings of role captivity**.** This perspective was not supported in this population of family caregivers. With entry of the care recipient into a long term care facility, it would be anticipated community caregivers would potentially experience a decrease in the time commitment and primary responsibilities associated with meeting the ADL and IADL needs of their loved one. The reduction in responsibilities would potentially be correlated with reduced feelings of being trapped in the caregiving role. Family caregivers whose role has been initiated with the care recipient's admission to the nursing home would experience new demands on their time and an increase in responsibilities related to care oversight resulting in potential feelings of being trapped in the role of caregiving. Feelings of role captivity did gradually decrease as the length of time the care recipient was in the nursing home increased, however this was not a significant finding. Over the past eighteen years, nursing home reform has focused on enhancing the quality of life of nursing home care recipients with increasing involvement of family caregivers at the center of this movement. While research indicates continued family involvement has beneficial effects for the care recipient (Whitlach et al. 2004) this increased involvement may do little to alleviate the caregiver's feelings of entrapment in the caregiving role, thus not reducing overall perceived stress.

In addition to impacting perceived stress, feelings of role captivity positively correlated with family conflict, time constriction in participating in family activities, and feeling that participating in certain activities on behalf of the care recipient are a hassle (i.e. the need to discuss medical concerns with staff, advocating for the care recipient, handling finances, acting as a primary contact and providing personal items as well as doing the care recipient's laundry).

The importance of feeling one had a choice in accepting the role of caregiver also impacts caregiving-work conflict among employed family caregivers. Those who feel they had a choice in assuming caregiving responsibilities reported lower levels of caregiving-work conflict.

6.2 Theoretical Support and Ties

Drawing upon the components of the general stress process model as outlined by Pearlin et al. (1981) and utilizing concepts associated with role theory, factors impacting family caregivers of care recipients in nursing homes may be best understood within a general systems conceptual orientation as seen in Figure 2.2. Moving away from a process model, which insinuates linear relationships occurring in a temporal-spatial manner, envisioning the family caregiver at the center of interactions among various other systems allows for a clearer picture of interactions between various systems and the role of family caregiver.

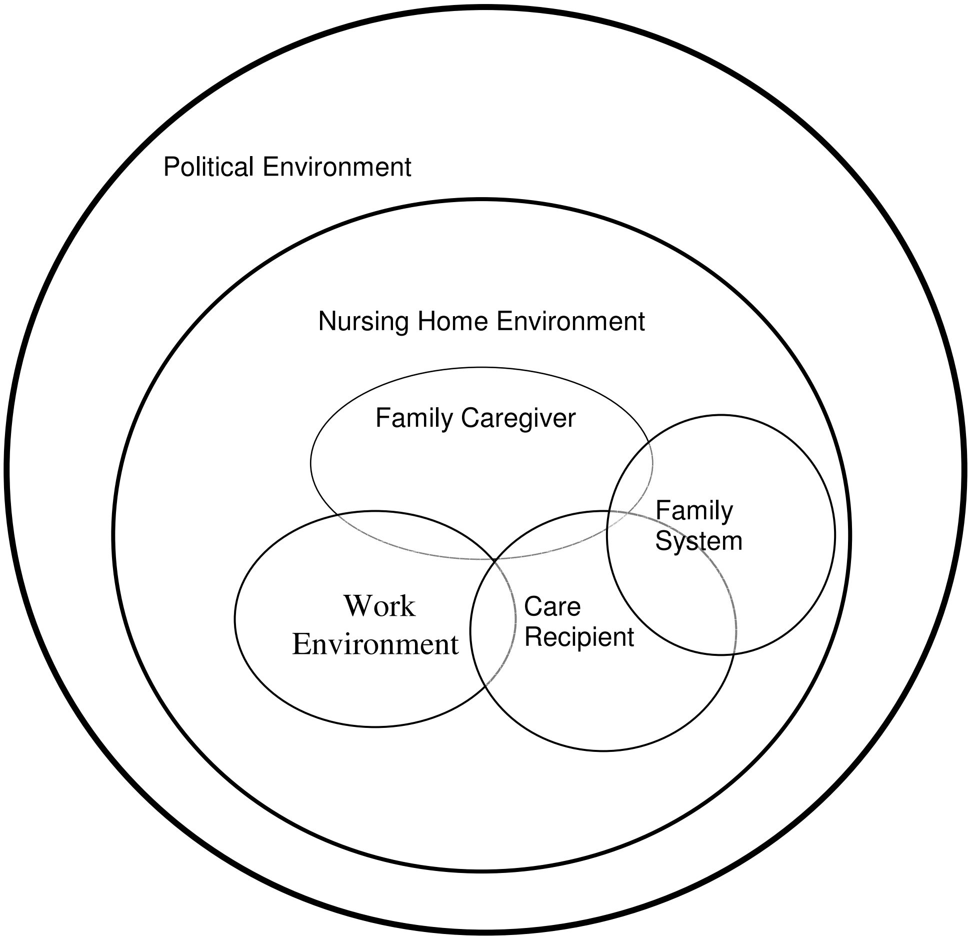

Figure 2.2 Conceptual Framework for Understanding Factors Impacting Family Caregivers

This perspective will allow for support and interventions to move beyond an individual perspective increasing the likelihood of positive outcomes for not only the family caregiver, but also the care recipient and nursing home staff. Placing the family caregiver into a larger ecological system requires an acknowledgement

First, the family caregiver is impacted by the macro political and financial environment governing policies for long term care. Making financial arrangements and completing required paperwork were identified as being a hassle by the highest percentage of family caregivers. This could potentially be related to the complexities of the financial reimbursement system among Medicare, Medicaid, third party insurances and/or long term care insurance underwriters and government regulations regarding not only admission to a facility, but the ongoing care of the care recipient (Miller, Booth & Mor, 2008). With projections that combined Medicare and Medicaid costs could grow from 7% of the GDP in 2005 to 24% by 2080, further reductions in funding for long term care may be expected, in turn creating a more complex and restrictive system of reimbursement. Just as the care recipient is a component of the nursing home environment, family caregivers too impact and are impacted by this system. One study found that relatives of the care recipient saw their personal contributions as an important component for ensuring the best care for the care recipient (Davies & Nolan, 2005).

Examining feelings of care recipient's relatives in relation to the nursing home environment, found limited or poor communication by staff resulted in negative emotions for the relatives, in addition they felt it was their responsibility to establish communication with the staff and it was not always welcomed (Hertzbert, 2001). Perceived stress for this population of family caregivers correlated with discussing medical concerns with staff, acting as a primary contact and acting as an advocate for the care recipient, all three which are tied to communication skills of both the caregiver and the staff. In addition it has been found that family members of the care recipient have the potential and often the desire to contribute to the larger community within the home through activities which enhance the social environment and engage care recipients other than their own relative in social activities (Davies & Nolan, 2005).

Understanding the caregiver within the context of the family system, and the larger ecological environment is imperative for supporting and assisting family caregivers as they in turn provide support and assistance for those members in need. Both family conflict and constriction of time for participating in family activities made a positive contribution to perceived stress for family caregivers.

Family centered approaches that parallel recommendations for management of chronic diseases (Weihs, et al. 2002) and would be beneficial in the realm of long term institutional care include (1) psycho-educational interventions to facilitate knowledge of the aging process, manifestations of chronic disease as well as improving an understanding of the nursing home environment and what institutional care for a love one means for multiple family members; (2) modified psycho-educational interventions to strengthen and improve family relationships in terms of quality and functioning; (3) family therapy and (4) reconfiguration of the healthcare team.

Care recipient characteristics is one area not addressed within this study, but throughout the literature it has been documented that cognitive deficits and negative behavioral manifestations of the care recipient impact family caregivers in the community (Bertrand et al. 2006, Jannson et al. 2001, Pearlin et al. 1997, Zarit et al. 1980; Clipp & George, 1993; Marsh et al. 1988; Grant et al. 2000). For employed family caregivers, conflicting demands between employment and caregiving need to be considered.

6.3 Limitations of The Study

Several limitations to these data require findings to be viewed with caution. While the sample was drawn from a variety of sources, it was a self-selected group. It is impossible to know how many family caregivers were told about the study by staff or other means and did not choose to participate. While efforts were made to assure participants of the confidential nature of the study and those findings specific to facilities would not be directly reported back to representatives of each facility, it is possible responses to questions were biased in ways that might be seen as favorable to their situation, as well as the nursing home.

Additionally, low representation across the majority of facilities does not allow for a comparison among family caregivers based on facility characteristics and quality indicators. The crosses sectional design overlooks temporal and contextual fluctuations, instead identifying common themes or structures, which are then presumed to be stable (Lazaurs, 1990). Because the survey design is one of self-administration, participants must have been literate to take part and there is room for misunderstanding of questions. Potential discussion of the questionnaire may have occurred among caregivers within the same facilities.

It is also important to note limitations of the study's generalizability to the larger population of family caregivers. This sample consisted of caregivers who remained involved in the care of their loved ones in facilities in predominantly urban facilities, with limited minority or ethnic representation. Many of the instruments used in this study lack established validity.

6.4 Implications for Social Work

Social workers, who are key members of treatment teams along the continuum of healthcare, are in a strong position to impact outcomes for family caregivers. Therefore it is imperative social workers employed throughout healthcare have a knowledge base and understanding of not only the immediate environment in which he/she is employed, but also characteristics of other environments in which the family caregiver will interact. In an effort to provide a seamless transition between community and long-term care environments, social workers in acute or chronic care hospitals, rehab facilities, and home health settings can provide education regarding inherent stresses associated with the nursing home environment and potential roles the family caregiver will likely continue to carryout. Educating family caregivers regarding what to expect during the admission process, especially regarding financial issues may serve to reduce perceived stress.

For social workers employed in long-term care, continued involvement of family caregivers must be acknowledged, which in turn should lead to identifying interventions designed to impact perceived stress. For those caregivers who are employed, it is important that social workers discuss options as to when and how the best way contact might be made when needing to discuss care recipient issues. In addition, employed caregivers may be present in the evenings or on weekends when primary nursing or therapy staff is unavailable. The long-term care social worker can provide continuity in terms of communication regarding the care recipient's status by flexing work hours to be available at these times.

As the family caregiver often continues to feel "trapped" in the role of caregiver, the long-term care social worker can utilize techniques such as cognitive reframing to assist in changing individual perceptions of the role of caregiver. Additionally working to identify the level and types of interaction desired by family caregivers will serve to return a sense of choice and control into their lives, potentially reducing feelings of role captivity.

Understanding the care recipient is a member of a larger family system, and that potential conflict within this system may result in perceived stress for the primary family caregiver is important for social workers not only in long term care, but at all points along the healthcare continuum. Social workers can adopt themes similar to those outlined for improved management of chronic diseases (Weihs, et al. 2002), which could potentially lessen negative impacts on the primary family caregiver. First, the social worker can work with the primary family caregiver to mobilize the care recipient's natural support system by increasing mutually supportive interactions among various family members, and friends with the purpose of relieving the responsibility of one person in overseeing the ongoing needs of the care recipient and potentially reducing feelings of role captivity. To achieve this first objective, the social worker might need to intervene in the family system with a goal of minimizing interfamilial hostility and criticisms surrounding care decisions being made by the primary caregiver.

Second, utilizing a strengths perspective, the social worker can identify ways for family caregivers to cope with inherent stresses related to caring for someone in a nursing home by incorporating them as viable and active members of the treatment team. Family caregivers feel they have gained a great deal from the caregiving role and have confidence in their abilities as a caregiver. By utilizing the knowledge they have gained in relation to providing ongoing care for the care recipient, the care provided by staff at the facility can be enhanced and the family caregiver is seen as contributing member of the treatment team potentially reducing stress associated with overseeing care or acting as an advocate for the care recipient.

In addition, social workers across the healthcare continuum should utilize their unique knowledge base and skills to provide education and training for other direct care staff with a focus on incorporating the family caregiver into the care recipient's assessment process. By incorporating strengths and needs of the family caregiver into a plan of care, social workers can take the lead in transforming continued caregiving within a facility from a "care recipient perspective" to a "family centered perspective" impacting outcomes for both the care recipient and the family caregiver in a positive direction.

6.5 Future Research

Future research designed to capture the experience of the family caregiver following entry of the care recipient into a nursing home and to develop strategies aimed at reducing stress associated with the caregiving role must include several components. Associated with feelings of role captivity is a lack of choice in accepting the caregiving role, often identified as familial obligation, while at the same time caregiver gains in terms of increased competence and confidence as a result of the caregiving role is apparent. Further exploration of the relationship between familial responsibilities and caregiver uplifts would be beneficial.

As feelings of role captivity continue to contribute to perceived stress for family caregivers, future research should include efforts designed to develop an understanding of expectations held by the family caregiver about the roles to be carried out following nursing home placement. Moving beyond the enumeration of activities carried out by family caregivers and gaining an in-depth understanding of the perceptions held about the legitimacy of such roles is important for designing and implementing support systems following placement of a loved one in a nursing home. Within each of the areas identified for further examination, it is important to include cultural and ethnic influences for all involved in entry of a loved one into a nursing home.

While contextual factors surrounding entry of the care recipient into the facility and ongoing activities for the caregiver did not have a significant impact on the family caregivers within this study it is important to not disregard these issues in future research. One example would be to move beyond the frequency of visits or distances the caregiver travels and examine the quality of activities that occur during each visit. In addition, it is necessary to explore the roles each member of a care recipient's family might play in the life of the care recipient once they have entered the nursing home and how these roles intertwine and relate to stress for all involved.

Additionally it is important to link measurements for quality of care to outcomes not only for the care recipient, but the family caregiver. Development and implementation of best practices to meet the ongoing physical and mental health needs of the care recipient should further reduce stress for the caregiver by alleviating concerns regarding the safety and well being of their loved one whose care they have turned over to others. Utilization of technology for purposes of enhancing the long-term care experience for both the care recipient and family caregiver(s) is also an important area for research development. Only minimal efforts have been made to develop technological applications targeted at aging individuals, and virtually none have addressed issues for those in nursing homes. One concept, though controversial is the "granny cam" or an equivalent to the nanny cam, which are hidden cameras placed for purpose of monitoring care of a vulnerable individuals. In 2001, Texas became the first and only state enacting a law permitting a care recipient or the care recipient's guardian to monitor the room of the resident through the use of electronic monitoring devices (Kohi, 2003).

Technology for connection which helps older adults stay in contact with family and friends is one focus of a newly created Center for Aging Services Technologies (CAST) which brings together leaders from university research labs, technology, health, and consumer product companies; long term care facilities and governmental organization agencies (Bodoff, 2003). While the focus of this group is to utilize technology to promote independence for the elderly in the community, it is important to not eliminate uses in nursing home settings. Other examples to build upon for those in nursing homes includes an "internet boot camp" in which care recipients were taught and/or assisted in keeping in touch with family via email (Scollin & Couture, 2007) and the use of tele-medicine which utilizes video phones to improve communication between nursing home residents and family members (Oliver, Demiris, & Denset, 2006).

Current statistics project a dramatic increase in the use of nursing homes in the future, with the number of people age 65 and older living in a nursing home doubling by the year 2020. For each person in a nursing home, there are family caregivers who are also impacted by aspects of this care environment. Identifying potential positive and negative outcomes, while developing strategies to support and enhance this experience is necessary for the overall well being of the family caregiver.

6.6 Summary and Conclusions

As with other research, family caregivers participating in this study demonstrated ongoing involvement with the care recipient following entry into a nursing home. Moving from a process-oriented framework to an ecological systems model provides a clearer depiction of the complex interactions between family caregiver and various environments.

In contrast to individual attributes (with the exception of caregiver income) or contextual factors of the placement, perceived stress scores of family caregivers were primarily impacted by feelings of role captivity, constriction of time for participating in family activities and family conflict, with perceived stress of employed caregivers being influenced by role captivity and work-caregiving conflict. Excluding caregiver income, each of the remaining factors should be considered pliable and when placed within a family centered paradigm, the potential for developing intervention strategies aimed at enhancing the long term care experience of all involved could be realized. Improving the experience of family caregivers for care recipients in the nursing home, will no doubt improve the experience for current and future care recipients also. Caregivers of today are care recipients of tomorrow. One family caregiver wrote:

> “For Christmas, I put a copy of my long term care insurance in my son’s stocking with a note saying, find a good nursing home visit when you can and don’t feel guilty”.

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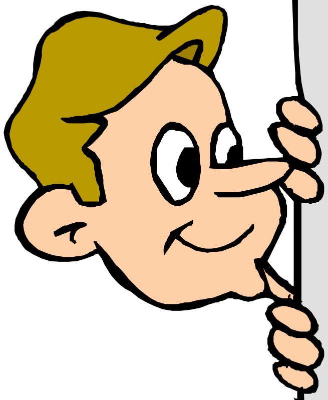
APPENDIX A

CAREGIVER INVITATION

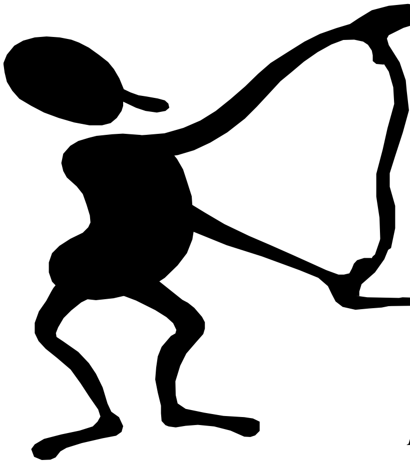
In an effort to better understand the stress factors experienced by primary caregivers after a loved one enters a nursing home:



You are being invited to participate in a research study: *The Stress of Caregiving: Factors Impacting primary Caregivers Following the Care Recipient's Entry into a Nursing Facility.*

An information session to learn more about this study will be held at the following location.

(Snacks will be Served!!)



Location:

Time:

Date:

If you are unable to attend, but are interested in completing the survey, please contact Rebecca Judd at 903-815-0169 or rjudd_uta_05@msn.com to have the instrument mailed to you.

APPENDIX B

SURVEY INSTRUMENT

Dear Caregiver

Providing ongoing care for a loved one is known to be a stressful endeavor. It is widely understood that making the decision to place a loved one into a long-term care facility is difficult and the need for care assistance is not totally alleviated upon nursing home admission. In an effort to better understand stress factors for the primary care provider following the placement of the care recipient into a nursing home, you are being asked to participate in a research study.

The purpose of this study is to gain an understanding of stress factors that occur following placement of a care recipient into a long-term care facility. The attached questionnaire has been designed to capture information about your role in providing care to the care recipient and perceived stress factors.

The questionnaire is divided into three sections:

Section I:	General information about you as the caregiver and the caregiver situation
Section II:	This section asks about things related to the care recipient's entry into the nursing facility.
Section II:	This section asks you to think about your caregiving experience after the care recipient entered the nursing home

It is anticipated the completion of the questionnaire will take approximately 20-25 minutes.

Every attempt will be made to see that your study results are kept confidential. A copy of the records from this study will be stored in the office of Dr. Rycraft, #211 E. School of Social Work, University of Texas at Arlington for at least three (3) years after the end of the research. The results of this study may be published and/or presented at meetings without naming you as a subject. Although your rights and privacy will be maintained, the Secretary of the Department of Health and Human Services, the UTA IRB (Institutional Review Board), the FDA (if applicable), and personnel particular to this research (individual or department) have access to the study records.

If you have any questions, problems or research related concerns at any time you may call Rebecca Judd @ (903) 416-1005 or Dr. Joan Rycraft @ (817)272-5225. You may call the Chairman of the Institutional Review Board at 817-272-1125 for any questions you may have about your rights as a research participant.

Participation in this research is voluntary. By completing and returning the questionnaire you confirm that you are freely and voluntarily choosing to participate in this research project.

Sincerely
Rebecca Judd

SECTION I: CAREGIVER INFORMATION

1. How old were you on your last birthday? ______________

2. What is your gender? ( ) Female ( ) Male

3. What is your relationship to the care recipient?

( ) Spouse ( ) Life Partner ( ) Child ( ) Step-Child

( ) Grandchild ( ) Other (please specify): ________________

4. What is your race or ethnic background?

( ) White ( ) African-American ( ) Native-American ( ) Hispanic

( ) Pacific-Islander ( ) Other

5. What is the highest educational level you achieved?

( ) Grade School (grades 1-6) ( ) Junior High (grades 7-8)

( ) High School (grades 9-11) ( ) High School Graduate

( ) Some College (1-3 years) ( ) College Graduate

( ) Post College/Professional Ed.

6. What is your employment status?

( ) Employed Full-Time ( ) Employed Part-Time ( ) Retired

( ) Retired due to disability ( ) Unemployed

7. What is your annual household income?

( ) 0- $ 15,000 ( ) $15,001 - $25,000 ( ) $25,001-$50,000

( ) $50,001- $75, 000 ( ) Greater than $75, 001

8. Did you provide assistance for the care recipient before he/she entered the nursing home?

( ) Yes ( ) No

8a. If yes how many hours a week did you provide assistance?____________________

8b. If yes, please indicate all the areas you assisted:

( ) Use of Telephone
( ) Dressing and Undressing
( ) Cleaning teeth or dentures
( ) Doing housework
( ) Toileting
( ) Handling Finances

( ) Getting in and out of bed
( ) Walking
( ) Preparing Meals
( ) Doing home repairs
( ) Taking medications
( ) Shopping for groceries

( ) Bathing or Showering
( ) Fixing hair or shaving
( ) Eating
( ) Walking up stairs
( ) Doing Laundry
( ) Transportation

9. How long have you been a caregiver for this care recipient? __________________

10. Do you feel you had a choice in taking on the responsibility for providing care to the care recipient?

( ) Yes ( ) No

If no, please explain:____

____
_

11. Do you provide care for any other person (s)? Yes ( ) No ( )

11a. If yes, what is the relationship of this person to you?

Spouse ( ) Minor Child(ren) ( ) Adult Child ( ) Sibling ( )

Parent ( ) Other: ( ) *Please specify*: ___________

SECTION II: PLACEMENT DECISIONS

12. Please indicate the reason the care recipient entered the nursing home?
(*Check all that apply)*

(   ) Unable to live alone due to confusion and/or forgetfulness
(   ) To receive physical, occupational and/or speech therapy
(   ) Recommendation of physician
(   ) Unable to afford cost of care in the home
(   ) Lack of available community resources to provide in home assistance
(   ) Unable to live alone due to lack of physical abilities to care for him/herself
( ) Other:____

13. Did the care recipient enter the nursing home from:

( ) The Hospital ( ) Home ( ) Assisted Living ( ) Other: __________

14. Is it anticipated the care recipient will leave the nursing home and return to the community to live?

Yes ( ) No ( )

15. How long has the care recipient been in a nursing home: ____

(   ) 1-30 days (   ) 31-60 days (   ) 61-90 days (   ) 91-120 days

(   ) 121-150 days (   ) 151-180 days

(   ) More than 6 months but less than 1 year

(   ) More than 1 year but less than 5 years (   ) More than 5 years

16. How often are you able to visit the care recipient in the nursing home?

( ) Daily ( ) 1-3 times a week ( ) 4-6 times a week

( ) 1-2 times a month ( ) other: ___________________

17. How far away is the nursing home from your home? _________________

18. Do you participate in a support group for caregivers? (   ) Yes (   ) No

SECTION 3: PROVIDING CARE

RC. Here are some thoughts and feelings that people sometimes have about themselves as caregivers. How much does each statement describe your thoughts about your caregiving?

RC1. Wish you were free to lead a life on your own?

_____ 1. Not at all
_____ 2. Just a little
_____ 3. Somewhat
_____ 4. Very much

RC2. Feel trapped by the care recipient's illness?

_____ 1. Not at all
_____ 2. Just a little
_____ 3. Somewhat
_____ 4. Very much

RC3. Wish you could run away?

_____ 1. Not at all
_____ 2. Just a little
_____ 3. Somewhat
_____ 4. Very much

CC1. Believe that you have learned to deal with a very difficult situation?

_____ 1. Not at all
_____ 2. Just a little
_____ 3. Somewhat
_____ 4. Very much

CC2. Feel that in all, you're a good caregiver?

_____ 1. Not at all
_____ 2. Just a little
_____ 3. Somewhat
_____ 4. Very much

CC**.** Think now of the daily ups and downs that you face as a caregiver; the job you are doing as caregiver and the ways you deal with the difficulties. Putting all these things together:

CC3. How competent do you feel?

_____ 1. Not at all
_____ 2. Just a little
_____ 3. Somewhat
_____ 4. Very much

CC4. How self-confident do you feel?

_____ 1. Not at all
_____ 2. Just a little
_____ 3. Somewhat
_____ 4. Very much

CC. Sometimes people can also learn things about themselves taking care of someone. What about you? *How much have you:*

CC5. Become more aware of your inner strengths?

_____ 1. Not at all
_____ 2. Just a little
_____ 3. Somewhat
_____ 4. Very much

CC6. Become more self-confident?

_____ 1. Not at all
_____ 2. Just a little
_____ 3. Somewhat
_____ 4. Very much

CC7. Grown as a person?

_____ 1. Not at all
_____ 2. Just a little
_____ 3. Somewhat
_____ 4. Very much

CC8. Learned to do things you didn't do before?

_____ 1. Not at all
_____ 2. Just a little
_____ 3. Somewhat
_____ 4. Very much

FC. Family members may differ among themselves in the way they deal with a relative who is ill. Thinking of all your relatives, how much disagreement have you had with anyone in your family because of the following issues:

FC1. Because he/she does not spend enough time with the care recipient?

_____ 1. No disagreement
_____ 2. Just a little disagreement
_____ 3. Some disagreement
_____ 4. Quite a bit of disagreement

FC2. Because he/she does not share in caring for the care recipient?

_____ 1. No disagreement
_____ 2. Just a little disagreement
_____ 3. Some disagreement
_____ 4. Quite a bit of disagreement

FC3. Because he/she does not show enough respect for the care recipient?

_____ 1. No disagreement
_____ 2. Just a little disagreement
_____ 3. Some disagreement
_____ 4. Quite a bit of disagreement

FC4. Because he/she lacks patience with the care recipient?

_____ 1. No disagreement
_____ 2. Just a little disagreement
_____ 3. Some disagreement
_____ 4. Quite a bit of disagreement

WS. From your own experience, how much do you agree or disagree with the following statements about your work situation since the care recipient entered the nursing facility?

WS0. _________ I do not work

WS1. I have less energy for my work.
_____ 1. Strongly Disagree
_____ 2. Disagree
_____ 3. Agree
_____ 4. Strongly Agree

WS2. I have missed too many days at work.
_____ 1. Strongly Disagree
_____ 2. Disagree
_____ 3. Agree
_____ 4. Strongly Agree

WS3. I am dissatisfied with the quality of my work
_____ 1. Strongly Disagree
_____ 2. Disagree
_____ 3. Agree
_____ 4. Strongly Agree

WS4. I worry about the care recipient while at work.
_____ 1. Strongly Disagree
_____ 2. Disagree
_____ 3. Agree
_____ 4. Strongly Agree

WS5. Phone calls about the care recipient interrupts my work.
_____ 1. Strongly Disagree
_____ 2. Disagree
_____ 3. Agree
_____ 4. Strongly Agree

FRC. Caregivers often experience conflict between completing caregiving activities and spending time with family. Consider the following statement and indicate your level of agreement or disagreement regarding your time since the care recipient entered the nursing home.

FRC1. My caregiving activities interfere with the time I have to spend with my spouse/partner
_____ 1. Strongly Disagree
_____ 2. Disagree
_____ 3. Agree
_____ 4. Strongly Agree
_____ 5. N/A

FRC2. My caregiving activities interfere with the time I have to spend with my children.
_____ 1. Strongly Disagree
_____ 2. Disagree
_____ 3. Agree
_____ 4. Strongly Agree
_____ 5. N/A

FRC3. My caregiving activities interfere with the time I spend in family activities
_____ 1. Strongly Disagree
_____ 2. Disagree
_____ 3. Agree
_____ 4. Strongly Agree

FRC4. My caregiving activities interfere with quiet time for myself.
_____ 1. Strongly Disagree
_____ 2. Disagree
_____ 3. Agree
_____ 4. Strongly Agree

CB. Once a care recipient has entered a nursing facility the role for the caregiver often times changes. This section lists things you might do for the care recipient while he/she is in the nursing home. You will find some of these things are a hassle, while others are not. For each item, indicate if you have done the activity by checking yes or no. If you check "No', go on to the next item. If you check "Yes", indicate how much of a hassle it was for you to complete.

	Did It Happen		If yes, how much of a hassle?			
	No	Yes	It wasn't	Somewhat	Quite a bit	A great deal
1. Made financial arrangements for the care recipient to enter the nursing home.						
2. Complete required paperwork						
3. Act as primary contact for nursing home staff						
4. Attend care plan meetings						
5. Discuss medical concerns with staff						
6. Oversee room/roommate changes						
7. Monitor personal care i.e. bathing, toileting, feeding, dressing						
8. Act as advocate for care recipient						
9. Bring food/ personal items for care recipient						
10. Provide clothing for care recipient						
11. Wash care recipient's laundry						

CS. The questions in this scale ask you about your feelings and thoughts since the care recipient entered the nursing home. In each case, please indicate by writing a number in the space :

HOW OFTEN you felt or thought a certain way after the care recipient entered a nursing facility?

0=Never 1=Almost Never2=Sometimes 3= Fairly Often 4= Very Often

CS1. _____ How often have you been upset because of something that happened unexpectedly?

CS2. _____ How often have you felt you are unable to control the important things in your life?

CS3. _____ How often have you felt nervous and “stressed”?

CS4. _____ How often do you feel confident about your ability to handle your personal problems?

CS5. _____ How often do you feel things are going your way?

CS6. ____ How often do you find that you cannot cope with all the things you have to do?

CS7. _____ How often are you able to control irritations in your life?

CS8. _____ How often do you feel you are on top of things?

CS9. _____ How often are you angered because of things that are outside of your control?

CS10 _____ How often do you feel difficulties are piling up so high that you cannot overcome them?

I want to thank you for your time and willingness to participate in this survey. Without you, this research project would not be possible.

Sincerely
Rebecca Judd
PHD candidate
University of Texas at Arlington
School of Social Work

Additional Information

If you want to add any additional information you think might be helpful in understanding your situation as at caregiver, please feel free to do so….

APPENDIX C

PARTICIPATING NURSING HOMES

Participating Nursing Homes

Participating Nursing Homes

County State	Home	Ownership	Date of Last Inspection	Certified Beds	No. Residents
Grayson Co. Texas					
	Sherman Healthcare Center	For-Profit Corporation	06/28/2007	107	72
	Texoma Specialty Care	Non-Profit Partnership	05/25/2007	136	85
	Denison Manor	For Profit Partnership	06/29/2007	71	46
	Brentwood Place	For Profit Partnership	04/27/2007	52	42
	Whitesboro Health & Rehab	For Profit Corporation	12/14/2007	100	80
	Hilltop Haven	Non-profit Church Related	10/19/2007	179	174
	Homestead of Denison	For-Profit Partnership	07/19/2007	132	111
Fannin Co. Texas					
	Honey Grove Nursing Home	For-Profit Corporation	04/16/2007	102	91
	Seven Oaks Nursing Home	For-Profit Partnership	03/23/2007	108	62
	Mullican Care Center	For-Profit Corporation	07/12/2007	119	111
	Fairview Nursing & Rehab LP	For-Profit Partnership	05/18/2007	81	30
	Bonham Nursing Centers	For-Profit Partnership	09/28/2007	65	41
Bryan Co. Oklahoma					
	Calera Manor LLC	For-Profit Corporation	02/14/2007	82	8
	Oak Ridge Manor	For-Profit Corporation	02/14/2007	104	90
Dallas Co. Texas					
	Willow Bend Nursing & Rehab	For-Profit Corporation	11/30/2007	162	73

APPENDIX D

QUALITY INDICATORS FOR HOST FACILITIES

Quality Indicators For Host Facilities*

Nursing Facility**	Percent of Long-Stay Residents whose need for help with daily activities has increased.	Percent of Long-Stay Residents who spend most of their time in bed or in a chair	Percent of Long Stay Residents whose ability to move about in and around their room got worse
Brentwood Place	Not available	Not available	0%
Denison Nursing & Rehab	Not available	13%	Not available
Homestead of Denison	17%	8%	6%
Texoma Specialty Care	15%	7%	20%
Whitesboro Health & Rehab	24%	1%	14%
Sherman Healthcare Center	22%	8%	9%
Hilltop Haven	18%	4%	15%
Bonham Nursing & Rehab Center	Not Available	9%	Not Available
Mullican Care Center	7%	3%	10%
Seven Oaks Nursing & Rehab	11%	11%	6%
Honey Grove Nursing Center	14%	0%	8%
Willow Bend Nursing & Rehab	18%	5%	15%
Oak Ridge Manor	19%	7%	10%
Four Seasons Nursing Center	2%	Not available	12%

* Information obtained from Nursing Home Care at Medicare.gov
** Information not available for Calera Manor or Fairview Nursing & Rehab

Nursing Facility**	Percent of High-Risk Long Stay Residents who have Pressure Sores	Percent of low-risk Long Stay Residents who have Pressure Sores	Percent of Long Stay Residents with a urinary tract infection
Brentwood Place	Not available	Not available	0%
Denison Nursing & Rehab	Not available	Not available	5%
Homestead of Denison	3%	0%	10%
Texoma Specialty Care	13%	3%	6%
Whitesboro Health & Rehab	18%	0%	17%
Sherman Healthcare Center	Not Available	0%	10%
Hilltop Haven	6%	3%	3%
Bonham Nursing & Rehab Center	Not Available	Not available	9%
Mullican Care Center	12%	0%	9%
Seven Oaks Nursing & Rehab	3%	Not available	0%
Honey Grove Nursing Center	5%	Not available	9%
Brentwood Place III	10%	3%	6%
Oak Ridge Manor	9%	3%	6%
Four Seasons Nursing & Rehab Center	13%	5%	16%

** Information not available for Calera Manor or Fairview Nursing & Rehab

**Nursing Facility	Percent of Long-Stay Residents who lose too much weight	Percent of Long-Stay Residents who were Physically Restrained	Percent of Long Stay Residents who are more anxious or Depressed
Brentwood Place	Not available	3%	3%
Denison Nursing & Rehab	0%	3%	10%
Homestead of Denison	6%	5%	3%
Texoma Specialty Care	15%	5%	48%
Whitesboro Health & Rehab	11%	1%	16%
Sherman Healthcare Center	7%	0%	10%
Hilltop Haven	3%	0%	8%
Bonham Nursing & Rehab Center	Not Available	0%	9%
Mullican Care Center	4%	1%	12%
Seven Oaks Nursing & Rehab	7%	5%	3%
Honey Grove Nursing Center	7%	0%	12%
Willow Bend Nursing & Rehab	6%	6%	9%
Oak Ridge Manor	19%	7%	29%
Four Seasons Nursing & Rehab	12%	8%	16%

** Information not available for Calera Manor or Fairview Nursing & Rehab

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BIOGRAPHICAL INFORMATION

Rebecca Judd has been a practicing social worker for the past eighteen years and has worked across the healthcare continuum. She has spent the past thirteen years in the role of social worker for Reba McEntire Center for Rehabilitation in Denison Texas. In this role she has provided support services to patients and families as they recover from an acute illness or injury. Prior to this position, she has worked in a variety of long term care settings and along the way developed a passion for working with elderly and their caregivers.

In addition to this work, Rebecca is an item writer for the Association of Social Work Board Examiners; a volunteer with the Alzheimer's Association in Grayson County and has served on the Elder Rights Panel in Association with the Texoma Council of Governments. She acted as a volunteer guardian from 2000-2002 within the cooperative program between AARP and Texoma Council of Governments. To assist those individuals who live Grayson County Texas and have no health insurance, Rebecca volunteered with the Grayson Volunteer Health Clinic from 2003-2006.

Rebecca lives with her husband, Charles and their two cats (Pepper and Tom) in Whitewright, Tx. They have one daughter, Charlotte. Following graduation, Rebecca has accepted a position as an Assistant Professor for Texas A&M University in Commerce. She will be teaching in the graduate social work program and working towards building a curriculum in aging studies.