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I am submitting herewith a dissertation written by Lee Ann Russell Grubbs entitled "Phenomenological Inquiry of the Primary Caregiving Experience: Challenges, Rewards, and Hopes for the Future." I have examined the final paper copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Human Ecology.

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Challenges, Rewards, and Hopes for the Future

A Dissertation
Presented for the
Doctor of Philosophy Degree

The University of Tennessee, Knoxville

Lee Ann Russell Grubbs
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DEDICATION

I would like to dedicate this manuscript to my husband, Brent Grubbs, and to my mother, Richa Cox Russell, whose enduring support, patience, and love have made it possible for me to succeed and come farther in life than I had ever expected.

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In addition to the love and support of my husband, Brent Grubbs, and my mother, Richa Cox Russell, I have been blessed to be surrounded by family, friends, and faculty who have supported, influenced, and encouraged me to strive to be the best that I could be both in my academic pursuits and in my life.

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ABSTRACT

Caregiving is a process that can create both stress and gratifications within the family unit, including the extended family system. Family members assuming the primary caregiver role for individuals with either age-related fragility or cognitive impairment as a result of a traumatic brain injury experience demands, producing stress and changes within the family system. Affected by the changes within the family system, primary caregivers use a variety of coping mechanisms to adapt to conditions of impairment in the family system.

This study was conducted using the qualitative paradigm in order to understand the lived experiences of primary caregivers from the perspective of the individuals being studied. This method included the use of the long, in-depth interview as an instrument to facilitate understanding of the beliefs and experiences of the primary caregivers within the study. Two other data collection methods used in this research study were observations and field notes. The data that were included in the study came from two distinct groups of caregivers. The first set of data, focusing on caregivers to frail elders, was collected from August 2001 through July 2002 in Dr. Priscilla White Blanton's Family Caregiving Research project. The second set of data, focusing on caregivers to individuals with traumatic brain injury, was collected from caregivers identified from the Tennessee Rehabilitation Center (TRC) in Smyrna, Tennessee, and the Traumatic Brain Injury program at Fort Sanders Regional Medical Center in Knoxville, Tennessee.

The McCraken (1988) Long Qualitative Interview: Four-Part Method of Inquiry Model was used as a discovery tool for the identification of analytic categories to

determine categories, relationships, and assumptions that inform the participant's view of the world in general and notions of how these views were related to the topic of primary caregiving. This analysis process moved from specific to general and concluded with the thematic analysis of the transcribed interviews to determine how caregivers experienced the phenomenon of primary caregiving. Additionally, the Creswell (1998) Data Analysis Spiral, used in qualitative inquiry and research design, was utilized to evaluate the data in analytical circles rather than in a fixed linear approach. This analysis approach allowed the researcher to describe in detail the development of themes or dimensions, and it provided an interpretation of caregiver views of primary caregiving experiences. The Stevick-Colaizzi-Keen Data Analysis Method was used in addition to the spiral procedure to assist in analyzing the experiences of primary caregivers.

After analyzing caregiving across groups, it was concluded that families provide most of the primary care for the ill and the disabled. A second conclusion focused on the strong desire of primary caregivers to provide direct care in the context of their own homes when at all possible. A third conclusion focused not only on the issues surrounding caregiver burden, but also the impact of rewards in the caregiving process. A final conclusion was that caregivers' lives were changed extensively by caregiving processes.

After analyzing caregiving within groups, it was concluded that gender had an impact on the role of the primary caregiver. A second conclusion identified the impact of the developmental context of the family and of the caregiving experience. Finally, the need to understand the concepts of loss and grief as experienced by caregivers was revealed.

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CHAPTER 1

INTRODUCTION

Caregiving is a process that can create both stress and gratifications within the family unit, including the extended family system. As a caregiver to two frail elders, I have seen how my life was changed forever, once my role as caregiver was complete. I experienced, first hand, the stresses of one-on-one caregiving with my grandmother, and I also was a part of the caregiving process with my grandfather, both while he was in a transitional care unit and during his time in a residential hospice facility. I seek to understand the experiences of others, and I attempt to comprehend how others, like myself, cope during times of great demand. I am curious about the caregiving experiences of others, and I wonder if, when I reach fragility, someone will care for me as I cared for my grandparents.

Rationale for the Study

Family members assuming the primary caregiver role for individuals with either age-related fragility or cognitive impairment as a result of a traumatic brain injury experience demands, producing stress and changes within the family system. Affected by the changes within the family system, primary caregivers use a variety of coping mechanisms to adapt to conditions of impairment in a family member. The family system, also affected by the presence of a family member with age-related fragility or cognitive impairment as a result of a traumatic brain injury, makes adaptations in their interactions. These adaptations may take many forms. Primary caregivers, utilizing the processes of coping and adaptation, gather information to address the issues, stressors,

and rewards of the caregiving process in an attempt to maintain individual equilibrium. The maintenance of equilibrium allows for the reduction of stress, which benefits both the caregiver and the family member with age-related fragility or cognitive impairment as a result of a traumatic brain injury.

Factors Influencing Caregivers' Experiences

A study of primary caregivers, within different situations in the community, is needed to better understand the experience of providing direct care to individuals with either age-related fragility or cognitive impairment as a result of a traumatic brain injury. These two distinct groups of caregivers need to be examined and compared in order to address the issues surrounding the caregiver's life stage development, different roles and relationships that primary caregivers have in the context of the family, length of anticipated time of caregiving, and the impact of the sudden onset of a disability as compared to the lifelong development of age-related fragility.

Family caregiving is a major concern due to the stage of development during which caregivers provide direct care to frail elders. "By 2020 there will twice as many elderly needing long-term care as today. In 1970, there were twenty-one potential caregivers for each person 85 or older; by 2030, there will be only six such potential caregivers" (Carter & McGoldrick, 1999, p. 312). As average family size decreases, fewer children are seen as being available to provide care and sibling support. With more people marrying and having children later in life, those at midlife often are caring simultaneously for children and adolescents, as well as for aging parents and other relatives (Carter & McGoldrick, 1999). This is important due to the financial drain that may be the result of simultaneous college expenses for children and medical expenses for

elders. "Adult children who are past the age of retirement and facing their own declining health and resources must assume responsibilities for growing numbers of aging parents" (Carter & McGoldrick, 1999, p. 313). Therefore, the likelihood of young, middle-aged, and even elderly persons becoming a primary caregiver for one or more aging family members is rapidly increasing within society today.

Women in midlife face many demands with caregiving duties as job demands and expectations of maintaining traditional responsibilities for the home and parenting coupled with elder care responsibilities within the context of their families. "Caregiving responsibilities have been almost exclusively the domain of women, mostly daughters and daughters-in-law; three out of four primary caregivers are women. The average age for the female caregiver is 57, but one fourth of female caregivers are 65 to 74 years of age, and 10 percent are over 75 years of age" (Carter & McGoldrick, 1999, p. 313). Due to women's increased participation in work outside of the home and their income contribution for two-parent households as well as single-parent households, their rebalancing of work and family roles is necessary. However, few employers are willing to offer flexibility on the job or to begin to consider men as primary caregivers in need of time to assist in the caregiving duties within the family.

When approaching the topic of age-related fragility in the elderly, researchers and practitioners need to expand the prevalent narrow focus on an individual female caregiver to encourage the involvement of family members as a caregiving team. To meet the challenges of providing direct care to elders, caregivers in middle to late adulthood must have access to resources within their communities and must be able to gain support from a range of services. Such a range of services includes "day programs to assisted living

and commitment to full participation of the elderly, including those with disabilities in community life" (Pinkston & Linsk, 1984, p. 23). It is only through the availability of such resources that caregivers are able to cope effectively with their dual roles as primary caregivers to both children and frail elders.

When focusing on caregivers providing direct care to individuals with cognitive impairment as a result of a traumatic brain injury, the researcher must be aware that the stage of development in which these caregivers are functioning is important in understanding their experiences. Turnbull and Turnbull (1986) have focused on the phases of the family life cycle and on how these phases are related to concerns that caregivers have about a disabled family member. In general, family caregiving fulfills traditional family functions. "These family functions include: economic, domestic/health care, recreation, socialization, self-identity, affection, educational and vocational care" (Singer & Irvin, 1989, p. 17). Each of these functions can become problematic for families when they are experiencing the impact of both the disability and the demands of the stages of family development. Families during the period of the launching phase of the family life cycle are responding and adjusting to the new demands of young adult family members, who themselves are entering new stages of the life cycle. Parents' focus is on such major midlife issues as reevaluating both their marriages and careers. This focus on marriage is seen as emerging from the heavy caretaking responsibilities of young children, and this may threaten the relationship between parents as they begin to review their personal satisfaction with this relationship in the context of the family (Carter & McGoldrick, 1999).

It is at this stage in the family life cycle that children are being launched from home and families are beginning to become more aware of the impact of having to redefine family roles. Disability may precipitate the loss of the pre-disability identity of the family. This forces the family into a transition in which one of the family's main tasks is to adjust to the possibilities of further loss of past roles and established relationships. Greene (1991) identified issues for midlife caregivers providing direct care to individuals with disabilities, stating, "Caregivers begin to become more aware of personal details, and that breaks down boundaries. However, caregivers are forced to continue to give rather than receive nurturance and advice, and they may feel trapped in their roles" (p. 7). Caregivers are seen sometimes as having anger and ambivalence due to the unsteadiness of the transition periods of midlife. They begin rethinking previous commitments, and they may lack openness to address necessary changes in familial roles. During these periods of transition, feelings of indecision about the future can be eliminated by focusing on how to communicate effectively within the family unit in order to accept new familial roles.

A second area of importance in studying and comparing these two groups of caregivers is seen in the different roles and relationships that primary caregivers have in the context of the family. As more adult children have parents living into old age and more people are experiencing the impact of disability on the family, issues of filial responsibility become of increasing concern and debate. According to Schaie and Willis (2002), "Filial responsibility is the sense of personal obligation that adult children and spouses feel toward their aging parents' well-being. This may involve a sense of duty or willingness to protect and care for one's family" (p. 161). One of the most

consistent findings on attitudes toward filial roles is that "sons and daughters have very similar beliefs and attitudes toward providing care for their parents" (Schaie & Willis, 2002, p. 163). However, an even more clearly presented finding is that "daughters are much more likely than sons to actually provide care to frail elders" (p. 163). Adult daughters are seen to provide more assistance than adult sons and to help with more "hands-on, intensive, instrumental, and emotional support tasks" (p. 163). Although there now are more women working outside the home than at any other time in history, women do not appear to be reducing their caregiving activities in regard to giving primary care to frail elders. The most likely providers of support to frail elders are their spouses and, in the absence of the spouse, adult children. "Over a third of older parents who require daily assistance receive it from a spouse or an adult child" (Connidis, 2001, p. 133). In contrast, the assistance and care being provided by adult sons to frail elders "typically involves financial management advice, heavy chores and shopping" (p. 163). "Across all age-cohorts, and most life stages, men are less likely than women to be providing direct care to elders" (Schaie & Willis, 2002, p. 163).

Caregivers of individuals with cognitive impairment as a result of a traumatic brain injury are an often overlooked population when considering primary care and role adjustment within the family unit. Primary caregivers' lives may be dramatically altered by changes in family routine. Parents and spouses of persons with brain injuries may experience increased stress, role change issues, and health problems resulting from providing direct care to the individual with the traumatic brain injury (Wallace et al., 1998). "Much of the responsibility for supporting the brain injured person during the years that follow lies with informal caregivers, most usually parents or spouses" (Knight,

Devereux, & Godfrey, 1998, p. 467). In cases of severe traumatic brain injury, primary caregivers may be faced with having to cope with a person very different from the one they knew before the trauma who may exhibit a range of emotional, behavioral, and cognitive problems. Parents or spouses providing direct care to individuals with brain injury often experience a diminished social network and decreases in previous levels of social and vocational contact. This change often results in the caregiver being left with the majority of the responsibility for supporting the individual with the traumatic brain injury (Wallace et al., 1998). "The impact on the family life and relationship with the caregiver can be profound and may not diminish with time" (Knight, Devereux, & Godfrey, 1998, p. 467).

A third area of importance in describing the experiences of these two groups of caregivers is seen in length of anticipated time of caregiving. Marks, Lambert, and Choi (2002) reflected on the impact that the transition to the caregiving role and the length of time the caregiving relationship has on the primary caregiver. Women and men who become new caregivers for children or young adults with disabilities are seen as having greater increases in depressive symptoms and anger. "Women who began providing care for a child reported higher levels of hostility" (Marks, Lambert, & Choi, 2002, p. 663). Besides their increase in depressive symptoms, men in the primary caregiving relationship with a child with a disability reflected a "greater decline in happiness than men who did not take part in the caregiving process" (p. 663).

Research results reflected the impact that this type of injury has on the lives of parents of children with traumatic brain injuries. "There is a sense of dislocation to their lives that came with the need to provide support and care for a person who had changed

in many profound ways as a consequence of the TBI" (Knight, Devereux, & Godfrey, 1998, p. 476). Parents must prepare for their caregiving roles, and with this preparation, parents are seen as expressing more pessimism and concern for the future. "Parents are more concerned about future care for the person with TBI given their advancing age" (p. 476). Noting the caregiver's age is important when focusing on this distinct group of caregivers who provide care to individuals with traumatic brain injuries across the life span. These caregivers will begin providing care to individuals with traumatic brain injuries in the prime of their lives and will continue to provide care as they transition into later life. This type of care will be intense and of longer duration than any other caregiving role within the family. "Caring for a child with a long-term disability is often a life-long role for parents. Longer life expectancy makes it more likely that older mothers will be carrying out this responsibility of caregiving alone at a time in life when their own needs for support are increasing" (Connidis, 2001, p. 150).

Caregivers to frail elders, in contrast, experience differences in the duration of time spent in their roles as primary caregivers. In this caregiver group, death is a normative reality for the care recipient. Death's role in the lives of primary caregivers is complex. "Caregivers do not know for sure what death will bring until they face death as an end. Death, we say, is the end of life" (McCall, 1999, p. 63). Death represents the end of the caregiving experience for the primary caregiver to a frail elder. Family members are more likely to have seen and accepted their elders' deaths because of the suffering they witnessed as caregivers and the sense that the care recipient had lived a long life. Through the process of becoming primary caregivers to frail elders and accepting the final stage of caregiving as death, primary caregivers feel that they did their best for

their frail elder. "Caregivers whose parents had died felt that they had done the 'right thing' to be caregivers" (Merrill, 1997, p. 139).

A final area of importance in describing these two groups of caregivers is seen in the impact of the sudden onset of a disability as compared to the lifelong development of age-related fragility. Stress is a key factor to consider when focusing on the impact of the primary caregiving role within the family. Stress experienced by family caregivers of the elderly can be viewed within the context of the characteristics of the caregivers, the dyadic relationship between the caregiver and the frail elder, and the relationships with other family members. Within the caregiving relationship, primary caregivers can identify the events that they may perceive as stressful, and primary caregivers can address how they can effectively respond to these events. These responses are developed within the context of the family, as well as the orientation of the family through patterns of interaction that have been established over time. "The ways in which the family responds to the stress of caregiving may negatively or positively influence future interactions within the family" (Stephens, Crowther, Hobfoll, & Tennenbaum, 1990, p. 37).

When a condition is long term or chronic, the dimension of time becomes a central reference point. "The family and each of its members face the formidable challenge of focusing simultaneously on the present and the future, on mastering the practical and emotional tasks of the immediate situation while charting a course for dealing with the complexities and uncertainties in an unknown future" (Rolland, 1994, p. 101). Families providing care to an individual with cognitive impairment as a result of a traumatic brain injury are faced with a sudden crisis, which includes the initial period of readjustment and coping after the injury has been identified through a diagnosis and or

treatment. These families, unlike families providing care for frail elders, are placed into an alternate phase of life that will extend throughout a lifetime. The onset of a traumatic brain injury within an individual family member forces an immediate focus on change of family roles. "Crisis is painful and may debilitate the family. The length of the debilitation may vary from hours to years" (Boss, 2002, p. 66). "Family crisis is caused by such severe stress that the family cannot function; it is immobilized. When a crisis occurs, the family hits bottom and then, it is hoped, reaches a turning point. This is the point at which the recovery process begins" (Boss, 2002, p.70). It is with recovery that time becomes such a critical element. It is partially the time of onset and the suddenness of the onset of a disability that creates the family crisis.

A description of primary caregivers' experiences as they provide care for individuals with either age-related fragility or cognitive impairment as a result of a traumatic brain injury makes an important contribution to the substantive areas of family studies, geriatrics, disability and rehabilitation, and to professionals who work with families who are providing primary care to individuals within the family unit. Primary caregiving to individuals with either age-related fragility or cognitive impairment as a result of a traumatic brain injury is provided by different individuals within the family unit (Rolland, 1994). However, most care of individuals with either age-related fragility or cognitive impairment as a result of a traumatic brain injury is provided by a spouse, adult child, or parent. A review of the literature reflects an emphasis on some of the critical issues surrounding the caregiving roles experienced by the primary caregiver to individuals with either age-related fragility or cognitive impairment as a result of a traumatic brain injury. These critical issues include (a) adjusting to changing family

roles, (b) decision-making processes by primary caregivers for frail elders, and (c) coping with stress as a primary caregiver. Each of these critical issues must be addressed to ensure that primary caregivers adjust to their new and ongoing roles of primary caregiving with success (Briggs, 1998; Brody, 1990; Ingersoll-Dayton, Neal, & Hammer, 2001; Merrill, 1997; Piercy, 2001). In order to objectively study the essence of primary caregiving experiences of those caring for either individuals with age-related fragility or individuals having a cognitive impairment due to a traumatic brain injury, the research chose in this study to describe the phenomenon of primary caregiving by obtaining from primary caregivers their verbal descriptions and perceptions of their caregiving experiences. An essential structure of the primary caregiving experience was extracted from these descriptions by phenomenological analysis.

With the increase of both life expectancy and numbers of individuals with disabilities in the United States and around the world, it is necessary to focus on the needs of individuals with age-related fragility and cognitive impairment due to a traumatic brain injury. Research in the areas of family studies, geriatrics, and disability and rehabilitation have focused on the needs of primary caregivers providing direct care to either individuals with age-related fragility or individuals having a cognitive impairment as a result of a traumatic brain injury. However, a comparison study of these two groups of caregivers has not been conducted and is needed in order to better understand the roles of primary caregivers and how the caregiving role impacts on the experiences of the individual providing direct care. This study describes these two groups of primary caregivers. It focuses on their experiences, and it has brought their voices to a research project that explored caregiving across two different contexts.

Purpose of the Study

The purpose of this phenomenological study was to describe the caregiving experience for the primary caregivers of an individual with either age-related fragility or cognitive impairment as a result of traumatic brain injury. This purpose was met by capturing the meanings of the lived experiences of primary caregivers who were involved daily in the direct care of an individual.

By focusing on the descriptions of the lived experiences of primary caregivers to an individual with either age-related fragility or cognitive impairment as a result of traumatic brain injury, this research study sought to reflect the true essence of the individual primary caregiver's experiences and how these experiences had impacted his or her life and family. The use of the primary caregiver as the unit of analysis in a phenomenological study approach (Creswell, 1998, Boyatzis, 1998) allowed for qualitative analysis by considering common themes that emerged from the interviews conducted with primary caregivers. The goal of this research study was to capture the overall meanings given to the challenges and rewards of the primary caregiving experiences.

Research Question and Topical Questions for the Study

Through the process of extracting significant statements from the raw data within the analysis of interviews, I sought to understand the essential structure or essence of the primary caregiving experience. Furthermore, I sought understanding and insight regarding answers to the following main research question and topical questions focusing on primary caregiving to an individual with age-related fragility or cognitive impairment as a result of a traumatic brain injury. The main research question for this research study

was: Given the experiences of situational crises producing stress and changes within the family system, what is the impact of the primary caregiving role on the primary caregiver within the family unit? Because there were few studies exploring a broad range of caregiving effects on the primary caregiver, a phenomenological study devoted to understanding the primary caregiver's lived experiences focused on both broad issue and more specific topical questions.

Issue Questions

1. What does it mean to be a primary caregiver within the family unit?
2. How have caregiving decisions affected your family unit?
3. How are caregiving decisions made by the primary caregivers with the family?
4. What is the method for conflict resolution by the primary caregiver in the family unit?
5. How has the role of primary caregiver altered your life?
6. What coping mechanisms are important to relieve stress in primary caregivers within the family unit?

Topical Questions

1. What do primary caregivers do within the family unit?
2. What do primary caregivers not do within the family unit?
3. Describe what you feel defines a "good" caregiver?
4. What is difficult/easy about the caregiving relationship within the family?
5. How/When did you first become a primary caregiver to a frail elder or an individual with cognitive impairment due to a traumatic brain injury?

6. What would you express to others is important about the family's role in the caregiving relationship?

Comparative Questions

1. Do you feel that there are rewards to your role as a caregiver?
2. When do you see your time as a caregiver ending?
3. How do you feel that caregiving has impacted on your future?
4. What is important for others to know about your caregiving experience?

Importance of the Topic

The concept of caregiver is utilized often throughout scholarly literature. The impact of caregiving roles in American society, as described in current scholarly literature, has been viewed in the varied contexts of education, employment, and health care. With increasing life expectancies, long-term care for individuals with either age-related fragility or cognitive impairment as a result of traumatic brain injury has emerged as a process through which important familial, social, and financial issues must be addressed in society today. Long-term care involves diverse issues of health, personal care, and social services for people who need assistance with their activities of daily living as a result of chronic physical or functional disability with subsequent loss of the ability to function independently. Of the 7.3 million individuals currently needing long-term care, 5.7 million live at home or in small community residential settings. Only 1.6 million live in nursing homes or other long-term care institutions (Kane & Kane, 1987; U.S. General Accounting Office [GAO], 1996). In long-term care processes, the care of more than 67% of frail elders, regardless of severity or of disability, depends exclusively

on family and friends for long-term care services (National Academy on Aging, 1997; Mui, Choi, & Monk, 1998).

In both the family studies and disability literatures, caring for individuals with either age-related fragility or cognitive impairment as a result of traumatic brain injury has been described as stressful and at times overwhelming for some primary caregivers in these family systems (Boss, 1999; Dell Orto & Power, 2000; Merrill, 1997). A review of the caregiving literature revealed that primary caregivers deal with a variety of critical issues throughout the caregiving process.

Although stress has been documented in scholarly literature, not all caregivers report high levels of stress. Noelker and Wallace (1985) found that a sizable portion of caregivers reported little or minimal levels of caregiver stress and that caregiving can enhance family relationships. Adult children are seen as trying to provide for their parents out of duty, love, or a combination of both, and the caregiving relationship can be positive to family relationships (Adams, 1996; Stephens, Crowther, Hobfoll, & Tennenbaum, 1990).

Several studies have suggested that the nature of caregivers is influenced by the pre-existing quality of family relationships (Noelker & Townsend, 1987; Townsend & Noelker, 1987). Reinvolvement with parents may release long buried hostilities. Some resolution of long standing differences may be necessary to overcoming barriers that prevent children from letting parents do for themselves. Greater respect and connectedness between the primary caregiver and the individual may be fostered through an awareness on the part of caregivers that care recipients may see themselves as autonomous and may resent at times interference from the primary caregiver. As their

dependency grows, respect for the prestige and self-direction of the care recipient must be primary to the caregiver if the relationship is to be mutually satisfying. This task may seem difficult at times to the primary caregiver. However, barriers may be overcome, allowing a more comfortable role adjustment and personal connectedness to take place (Haggan, 1998). The process of caregiving may become an enjoyable collaborative endeavor for the adult and for the individual with either age-related fragility or cognitive impairment as a result of traumatic brain injury. Such collaboration leads to feelings of belonging (Haggan, 1998). "Adult children may be encouraged to share any persistent thoughts or feelings that, until now, they had not planned to share. Bringing up something that is not significant enough to bring up at this stage in life may be significantly rewarding to the primary caregiver and to the individual" (McCubbin, Sussman, & Patterson, 1983, p. 65). This communication between the primary caregiver and the care recipient allowed for explorations of their feelings and "clearing up" misunderstandings within their relationships. "Without addressing any 'uncomfortable topics,' closure to a lifelong relationship may sadly never occur" (Haggan, 1998, p. 341).

Family Studies

Research in the family studies literature has focused most often on the needs of the family. It reflects the need for support for families experiencing high levels of stress and also a better understanding of role structures within the family unit (Aneshensel, Pearlin, Mullan, Zarit, & Whitlach, 1995; Boss, 1988). Family studies literature addresses life span development and theories of human development. It is important, when studying the role of primary caregivers, to understand their developmental context at the time that the role of primary caregiver is assumed. Adult children and aging

parents are seen as simultaneously encountering developmental challenges unique to their life stage while trying to relate to one another. Middle-aged children are seen as struggling to gain a sense of productivity while their elderly parents concurrently are striving to find meaning both in how they are living and how they view death. If neither fulfills the challenge of respective developmental tasks, various feelings may arise: Middle-aged people feel a discrepancy between goals of young adulthood and the reality of what has been accomplished, resulting in feelings of stagnation; the elderly person who fails to achieve a sense of life being worthwhile and does not come to terms with death, may end up experiencing feelings of despair, hopelessness, guilt, resentment, and self-disgust (Erikson, 1963). When a remaining parent dies, there is recognition that, in line with normal development, there no longer exists a buffer to one's own death (Thomas, 2000).

Geriatrics

Geriatrics has scholarly work that tends to focus more on the care recipient, with less emphasis given to the role of the primary caregiver in the caring relationship. In long-term care processes, the care of more than 67% of all individuals with either age-related fragility or cognitive impairment due to a traumatic brain injury depends primarily on family and much less often friends for long-term care (Mui, Choi, & Monk, 1998; National Academy on Aging, 1997). It is crucial to understand both the process of aging and/or the impact of a disability and the necessary role adaptations that must take place in order to be adaptive in the caregiving process.

An emotionally complex set of circumstances arise out of seeing one's elderly parents in never before experienced vulnerable positions. This forced perceptual

redefinition of parent and child is often difficult. Outsiders ignorant of the parent-child relationship dynamics prior to parental decline often foster guilt and create a sense of shame in the adult child for not always wanting to provide direct care for the elderly parent. According to Haggan (1998), "Adult children having difficulty setting limits allowing for personal pursuits and self-nurturance are candidates for stress and burnout" (p. 336). Support from others is key to overcoming adversity related to fatigue felt due to the demands of being a primary caregiver to a frail elder, and it begins with the recognition and communication of personal needs.

Regardless of the age of the frail elder, it is difficult for the caregiver when a parent in advanced stages of life becomes increasingly dependent. Literature in the area of geriatrics reflects on the difficulties of caregiving within American society. "A reflection of our society's strong value for independence is found in aging persons' most often reported fear of becoming a burden on others" (Haggan, 1998, p. 339). Elders within the community strive to remain as self-sufficient as possible. Elders find that, with increasing age, they are less meaningful to others, particularly because they are no longer actively fulfilling their previous social and occupational roles (Shulman & Sperry, 1992). Difficulties for elders may involve a diminished sense of belonging and a resulting loss of self-significance. "Older persons, no longer commanding respect for the knowledge of the times, become irrelevant" (Haggan, 1998, p. 339). O'Connell (1992) noted that a lack of sense of purpose within elders has a "detrimental impact on their self-worth, belonging, healing and humor" (p. 451). Helping elders to find a strong sense of purpose significantly impacts on the well-being of both the elder and the primary caregiver. It is through such efforts that primary caregivers find that elders, "who have

often enormous amounts of knowledge, experience, history, wisdom, and advice to offer younger people, will often share their rich past and experience" (Haggan, 1998, p. 339).

Disability and Rehabilitation

The body of literature focusing on disability and rehabilitation is limited in illustrating the impact that an individual with a traumatic brain injury has on both the family unit and the primary caregiver within the family. Past programs for individuals with disabilities have focused more on physical rehabilitation rather than on comprehensive rehabilitation to assist in the development of the independent living skills necessary to allow these individuals to function as independently as possible within society. There has been a gradual recognition that this lack of focus on independence has caused individuals with traumatic brain injuries to have limited experiences and opportunities to develop independence. Services received by individuals with traumatic brain injury are most effective when they enable them to regain independence, self-determination, and productive participation in society (Humes, Szymanski & Hohensil, 1989). Such services, when provided, increase the ability of the individual with a traumatic brain injury to experience positive growth and assist the individual in learning how to positively interact with others in the family unit.

When focusing on family members, one needs to address the primary caregiving issues surrounding disability. Emotional issues such as guilt, self-punishment, or anger need to be discussed when focusing on caregiving within the family unit (Hulnick & Hulnick, 1989). Family members may feel responsible for the individual's altered condition and may have a negative focus on outcomes in the future for the individual with the traumatic brain injury. During this emotional time for both the family and the

individual with a traumatic brain injury, communication issues and caregiving choices become a priority. The primary caregiver may emphasize either withdrawing from or reaching out to family members for assistance. Support systems play a critical role in the assistance of a primary caregiver with the process of caregiving to an individual with a traumatic brain injury. Without support networks, primary caregivers do not have the positive outlets needed to ensure effective management of caregiving demands.

The basis of any relationship is acceptance of the individual's right to existence, importance, and value (Brill, 1995). When focusing on literature in the area of disability and rehabilitation, researchers need to begin to emphasize the issues surrounding the primary caregiver of the individual with a traumatic brain injury. Understanding the role of the primary caregiver in the direct care relationship is essential to developing acceptance within the family unit. As a result, primary caregivers will be equipped to assume the uniqueness of their caregiving roles to an individual with a traumatic brain injury within the family unit.

Theoretical Foundations

Professionals working with families must consider that family systems are not isolated systems. Families deal with stresses in a variety of contexts. The external context is made up of those elements over which the family has little or no control. Elements of the external context include culture, history, economics, maturation, and genetic inheritance. The internal context is made up of those elements that a family is able to control. Elements of the internal contexts for family stress are defined as the family's structure, its psychological defenses, and its philosophical considerations (Boss, 1988). When focusing on primary caregivers involved in the direct care of an individual

with either age-related fragility or cognitive impairment as a result of traumatic brain injury, family stress theory and symbolic interactionism provide a lens for understanding aspects of the caregiving process. These theories place emphases on the needs of the family unit and the interpretation and meaning that primary caregivers bring to the experience of providing direct care to an individual with either age-related fragility or cognitive impairment as a result of a traumatic brain injury.

Family Stress Theory

Hill (1958) formulated his theory ABC-X model to describe the process resulting in family stress. This framework focuses on three concepts: (1) A-the provoking event or stressor; (2) B-the family's resources or strengths at the time of the event; and (3) C-the meaning attached to the event by the family. These three variables form the foundation of family stress theory today. Boss (1988) reflected on Hill's work and addressed the need to evaluate family stress by focusing on the crises created or the outcome of the interaction of A, B, and C. The outcome may result in continuous degrees of stress or families may move into a state of crisis. Family crisis is brought about by such severe stress that the family cannot function. "The family becomes immobilized" (Boss, 1988, p. 54). Crisis is sometimes reflected in the primary caregiving role of an individual providing direct care to either an individual with age-related fragility or cognitive impairment as a result of a traumatic brain injury. Boss (1988) stated that when "crisis happens, the family "hits bottom" and then one hopes (the family) reaches a turning point" (p. 54). At this turning point, the recovery process may begin, and the family unit may be stronger than when the crisis first occurred.

When providing direct care to either an individual with age-related fragility or cognitive impairment as a result of a traumatic brain injury, both nonvolitional stressor events and the accumulation of the stressor events may cause great turmoil within the family unit. Boss (1988) described nonvolitional stressor events as, "those events that are thrust upon the family" (p. 43). These types of stressors originate outside the context of the family, and are not a result of action by individual family members. With this type of stressor, the family has no control over the occurrence of the event. A second type of stressor event that impacts on the role of the primary caregiver within the family unit is accumulation stressor events. Boss (1988) reflected on the notion of accumulation of stressor events as a "phenomenon in which several stressor events or situations occur at the same time or in a quick sequence, thus compounding the degree of pressure on the family" (p. 45). These types of stressors impact the roles primary caregivers have within the family unit. Individuals, within the family unit, do not prepare to have an individual sustain a traumatic brain injury, nor do they prepare to provide direct, ongoing care to an individual with age-related fragility. Both of these situations involving primary caregivers are unplanned, thrust relatively suddenly upon the family, and may cause disequilibrium within the family unit and with family roles, due to the lack of control over these two areas of stress.

When focusing on family stress theory and primary caregivers, an understanding of the meaning that the family places on the stresses within the context of the family is crucial. The perceptions of the events, by the family, is important in explaining why, given the same or similar stressor events, some families can manage the resulting stress of providing direct care as a primary caregiver effectively, while others go into a stage of

crisis. Families are different in their coping strategies, and in the ways in which stressors are dealt with in the family unit. The family perception of the event or situation will influence greatly the degree of stress felt by the family, and the positive or negative impact that stressor event will have on the outcome.

Symbolic Interactionism

Due to the importance of the perception of an event, symbolic interactionism places emphasis on the needs of the family unit, and on the interpretation and meaning that primary caregivers bring to the experience of providing direct care to an individual. According to Boss (1988), symbolic interaction focuses on interaction within a family and on symbols of that interaction. Symbolic interaction places an emphasis on the concept of role. People carve out roles relative to each other in the process of social interaction (Winton, 1995). The results of this process of interaction are that the family constructs a symbolic reality based on shared meanings and role expectations inside the family unit (Boss, 1988; Winton, 1995). These shared meanings between family members are not only influenced by family members, but are also influenced by the world outside of the family unit: the community, broader society and cultural norms. "The interpretations of the objects and stressor events in their environment have no preconceived ideas placed upon the individual family members as to how to define or interpret themselves or others" (Winton, 1995, p.131).

The most relevant concept discussed by Mead (1934) underlying the role of a primary caregiver is the concept of definition of the situation. The definition of the situation is one of the most useful and meaningful concepts within the social sciences. This term reflects on the way in which individuals define a situation and how that

definition will affect the action that they take in relation to that situation (Winton, 1995). It is important to state that symbolic interactionists do not exclude the impact of norms and role expectations that are placed on the individual within the family unit. However, the individual is seen as not automatically conforming to these norms and expectations of others within the family system. Symbolic interactionists believe that people construct their own actions. Individuals act the way they do by making indications to themselves (Blumer, 1969; Winton, 1995). "These indications include defining the situation and giving meaning to objects and people within the situation, assessing alternative courses of action that are available options of response, and anticipating consequences for all alternatives considered" (Winton, 1995, p.135). This role-taking sequence, within symbolic interactionism, is critical when focusing on the role of the primary caregiver. Within these caregiver roles, definition of the situation is crucial in addressing the necessary outcomes to assist the individual to remain as independent and self-reliant as possible within the context of the family. When focusing on symbolic interactionism, people are seen as having a choice. "People have a choice-autonomy over their own lives" (Winton, 1995, p. 136). However, the primary caregiver has the difficult task of having to address the needs of the individual and to anticipate the future consequence of all alternatives considered. The choices made, by the primary caregiver in the role of direct care provider, no longer impact solely the individual with age-related fragility or cognitive impairment as a result of a traumatic brain injury. These choices impact the lives of each individual member of the family unit, and change the roles and relationships within the family forever.

Definition of Terms

The following terms will be used throughout this research study and are operationally defined for clarity and understanding.

Adaptation	Families are viewed as living organisms that respond to their environment. The behavior traits of the family are examined to see how these traits helped families respond or better meet their familial needs (Nichols & Schwartz, 1998, p. 112)
Age-related fragility	Any condition that causes mental or physical deterioration due to the normal aging process. (Rolland, 1994, p. 226).
Ambivalence	The focusing on contrasting impulses in the psyche. This is understood to indicate a conflict between positive and negative feelings toward a person or set of ideas (Boss, 1988, p. 61)
Boundary Ambiguity	This term means not knowing who is in and who is out of the family (Boss, 1988, p. 73).
Caregiver	This is one who by choice, through delegation, or by training and job description, assists in helping individuals in meeting their needs. (Mc Call, 1999, p. 90)

Caregiver burden	The extensive range of negative phenomena with caring for an individual (Dell Orto & Power, 2000, p. 62).
Catastrophe	This is an event which is sudden, unexpected, often life-threatening and due to the circumstances render the survivors feeling an extreme sense of helplessness (Figley, 1983, p. 16).
Community resources	Resources and services established outside the home within the family's community setting. These include medical care, rehabilitation, respite, transportation, housing, institutional, and financial entitlement services. This, also, includes potential support from friends, neighbors, self-help groups, religious or other community group. (Rolland, 1994, p. 283).
Coping	A cognitive activity incorporating (a) an assessment of impending harm and (b) an assessment of the consequences of any coping action. (Boss, 1988, p. 57).
Coping behaviors	Defined as (a) direct action behaviors, an attack or escape from threat, which is used to change a

	stressed relation with one's physical or social environment, and (b) intrapsychic forms of coping, which are defense mechanisms, used to reduce emotional arousal rather than to change the situation. (Boss, 1988, p. 57).
Disability	Any physical or mental impairment that limits a major activity. It may be partial or complete. (Thomas, 1997, p. 551)
Disequilibrium	An unsteady state; an unbalanced state. (Selye, 1978, p. 64).
Equilibrium	A steady state; a state of balance. (Selye, 1978, p. 64).
Family members	Each family member has a specific role to play in the system, and other family members depend on him or her to play that role. There are, also, important emotional dependencies between each individual within the family unit. (Schaie & Willis, 2002, p. 130).
Family system	As a system moving through time, the family has different properties from those of all other systems. Unlike all other organizations, families incorporate

	new members only by birth, adoption, commitment, or marriage, and members can only leave by death. (Carter & Mc Goldrick, 1999, p. 2).
Family unit	The context of significant emotional relationships whether by blood, adoption, marriage or commitment.(Carter & Mc Goldrick, 1999, p. 4).
Family	The family is a continuing system of interacting personalities bound together by shared rituals and rules even more than by biology (Boss, 1988, p. 12).
Formal Care	This is the support that is provided by private or public service agencies at the local, state or national level (Briggs, 1988, p. 23)
Frail elder	The problems of diminishing independence and the related fears of dependency that haunt most individuals as they reach old age. This, also, is described as the dysfunctions that accompany the normal aging process (Schaie & Willis, 2002, p. 78).

Informal Care	This is care, which is provided primarily by family, but may include help from friends, neighbors, and church members (Briggs, 1998, p. 24)
Primary Caregiver	This is the key person responsible for the care of the individual (Briggs, 1998, p. 28)
Rehabilitation	The processes of treatment and education that help disabled individuals to attain maximum function, a sense of well-being, and a personally satisfying level of independence (Thomas, 1997, p.1653).
Social contacts	The family is open in that its members interact not only with each other, but also with extra-familial systems in a constant exchange of information, energy, and material (Nichols & Schwartz, 1998, p. 457).
Stress	The state manifested by a specific syndrome, which consists of all the nonspecifically-induced changes within a biologic system (Selye, 1978, p. 64).
Stressor	The stress-producing stimulus. (Selye, 1978, p. 64).
Stressor Event	This is an occurrence that is of significant magnitude to provoke change in the family system (Boss, 1988, p. 12).

Symbolic Interactionism	This is the meaning that things have for human beings central in their own right. (Blumer, 1969, p. 29).
Traumatic brain injury	This refers to the disruption of brain structure and/or function from the sudden application of physical force, usually involving a blow to the head or penetration of the skull by a foreign object. (Eisenberg, Glueckauf, & Zaretsky, 1999, p. 98).

CHAPTER 2

LITERATURE REVIEW

In the family studies and disability literature, caring for a frail elder or an individual with a traumatic brain injury has been described as stressful and at times overwhelming for the primary caregivers in these familial systems (Boss, 1999; Dell Orto & Power, 2000; Merrill, 1997). In American society, mass media have created a focus on concern for the well-being of individuals who are caring for family members with impairments. In addition, scholarly literature reflects a need for education, support, and concern for the well-being of primary caregivers (Kane & Kane, 1987; Mc Call, 1999; Singer & Irvin, 1989).

A review of the caregiving literature revealed that primary caregivers struggle with a variety of critical issues throughout the caregiving process. These critical issues include (a) adjusting to changing family roles (Knight et al., 1998; Moen et al., 2000; Moules & Chandler, 1999; Wallace et al., 1998); (b) decision making processes by primary caregivers (Lefley, 1996; Perry & O'Connor, 2002; Piercy & Chapman, 2001), and (c) coping with stress as a primary caregiver (Aneshensel et al., 1995; Figley, 1983; Ingersoll-Dayton, Neal, & Hammer, 2001). These issues are viewed most clearly through the application of theory from the family studies and disability scholarly literature.

Theoretical Considerations

A number of theoretical perspectives provide useful lens for understanding caregiving. A combination of family systems theory, symbolic interactionism, and stress

theory provides a theoretical basis for understanding the phenomena of primary caregiving within the family.

Family Systems Theory

Family systems theory emphasizes interaction and context; individual behavior is viewed within the context in which it occurs. Systems theory states that the system is greater than the sum of its parts. From this perspective, function and dysfunction are defined relative to the fit among individual and family, their social context, and the psychosocial demands of the situation (Boss, 1988; Rolland, 1994). This perspective is useful when focusing on the role of the primary caregiver within the context of the family. The system of the family is seen as having multiple components. However, it is not the components that make this theory of value when focusing on primary caregivers. This perspective places emphasis on the pattern of relationships among the components and on how these patterns are affected by changing conditions (Thomas, 2000). "A change in the condition of one component does not leave the other components untouched. Instead, change in any component affects other components and their interrelationships in either large or small ways" (Thomas, 2000, p. 537). This tenet of systems theory is of importance when addressing the issues surrounding primary caregiving to frail elders or individuals with traumatic brain injury. A change in the conditions of components in the family system results in changes in the roles and results also in changes in relationships within that system. Therefore, changes in the roles and relationships of a primary caregiver will affect all areas both within the caregiver's life and also their family system. Both caregivers and care-recipients begin the caregiving process with a history of interactions, which may facilitate and/or impede the caregiving

relationship. "Family life is characterized by change and, at the same time, there is a continuity of relationships that can assist or inhibit adjustment to these changes" (Anderson & Sabatelli, 1995, p. 256). It is within family systems that individuals "develop and negotiate mutually acceptable caregiver/care-receiver relationships successfully" (p. 256).

"In well-structured and differentiated family systems, patterns of interaction support the developmental needs and agendas of the various generations" (Anderson & Sabatelli, 1995, p. 255). Whether the caregiver has a relatively open family system or closed family system also affects the impact that the caregiving process creates. "A closed system is rather like an island community in which no existing component (residents or facilities) ever leaves and no new components (residents or facilities) ever enter" (Thomas, 2000, p. 538). A relatively closed family system can create or exacerbate stress for caregivers. Individuals within this "closed" system have needs for resources both inside and outside of the family. In such family systems, useful resources may not be accessed. Thus, caregivers have few options for physical and mental restoration from the demands of their role as direct care providers. "An open system, on the other hand, is one in which components can change from time to time, so that occasionally new residents and facilities may arrive or old ones may leave. The entrance or exit of components alters the patterning of the system, thereby affecting development in ofttimes significant ways" (Thomas, 2000, p. 538). A relatively open family system allows the primary caregiver to obtain resources and services outside of the family. It allows the caregiver to experience change in a more positive manner since it is not experienced as threatening by the family. Within this open system, family members can

access useful resources from inside and outside of the context of the family system. However, due to the constancy of change in an open system, the family must become more resilient to pressure or stress that may be created by change.

"It has been suggested that many family systems problems emerge from the inability of the family system to manage its emotional climate as well as other basic tasks (identity, boundary, maintenance) when under stress" (Anderson & Sabatelli, 1995, p. 256). Within poorly differentiated systems, there is a tendency for family members to "(1) fuse under stress, thereby limiting the choice and effectiveness of coping strategies; (2) establish dysfunctional exchanges characterized by rigidly complementary relationships that restrict and limit the behavior of family members; or (3) establish cross-generational coalitions and triangles that split the family systems and under some circumstances, project blame onto the a family scapegoat" (p. 257). These types of relationships and patterns in the family system may be found in the relationships between frail adults and their children, between spouses, and individuals with traumatic brain injury and their parents.

Symbolic Interactionism

Symbolic interactionism is a perspective that is relevant to understanding the experiences of primary caregivers. Symbolic interactionism focuses on the individual, on the individual's interactions and roles, and on how society and social situations influence human behavior. In focusing on interaction, human beings are seen as "active participants and not as passive participants" (Charon, 1998, p. 27). Individuals are seen as interacting with their environments and interacting with the society of which they are a part. "Interaction is an ongoing activity; it means that human actors act in relation to the

acts of another; they take one another's acts into account as they act" (p. 27). These interactions mean that individuals are not only influenced by others, but that influence is bidirectional. Therefore, a more dynamic individual is seen as emerging from these interactions, "rather than an actor merely responding to others in their environment" (p. 27). Social interaction, interaction with the self, and the definition or interpretation of the situation are three important concepts from symbolic interactionism. "The position of symbolic interactionism is the meanings that things have for human beings are central in their own right. To ignore the meaning of things toward the person is seen as falsifying the behavior under study" (Blumer, 1969, p. 3). Meaning is a central element in the caregiving process. Meaning can be seen also as internal or what Blumer (1969) termed "psychical accretion"(p. 4). This psychical accretion is "treated as being an expression that constitutes element's of the person's psyche; feeling, ideas, sensations, memories, motives, and attitudes" (p. 5). This focus on meaning is crucial in understanding variation in the "lived experiences" of caregivers. To understand the "lived experiences" of caregivers, individuals conducting research in this area must understand the meaning that caregivers have evolved from their interactions as direct care providers within their homes and within their communities.

Stress Theory and Caregiving

Family stress theory conceptualizes the stress level of the family as being qualitatively different from the sum of the individual stress levels of the family members. (Billings & Moo, 1984; Boss, 1988). This perspective emphasizes the demands placed on primary caregivers, with a focus on the stress created by processes of direct care to frail elders and individuals with traumatic brain injury.

Family Stress

According to Boss (2002), the "internal context of the family is composed of three dimensions: the structural, the psychological, and the philosophical" (Boss, 2002, p. 44). The structural context refers to, "the form and function of the family boundaries, role assignments, and rules regarding who is within and who is outside these boundaries" (Boss, 2002, p. 44). When a boundary within the family is ambiguous, there is a lack of clarity in the structural context of the family and the occurrence of stress within the family is amplified. "Boundary ambiguity is seen as "not knowing who is in or out of the family" (Boss, 1988, p. 73). When there is ambiguity regarding a family member's physical and emotional presence or absence in the family system, it results in "ambiguous loss" (Boss, 1999). There are two kinds of high boundary ambiguity and both have been associated with family stress. Types of ambiguity are, "outcomes of a situation of incongruence between physical and psychological presence in the family" (Boss, 2002, p. 95). The first type of boundary ambiguity is seen in physical absence with psychological presence (Boss, 1988; Boss, 1999; Boss, 2002). Physical presence is determined by the actual bodily presence of an individual within the family system. Psychological presence is the presence of a physically absent family member in an individual's mind, both in a cognitive and emotional manner. This type of boundary ambiguity is greatest when there is a lack of clear facts surrounding the individual's physical whereabouts. Certainly the experiences of families who lost members in the terrorists' attacks on the World Trade towers are a very clear example of the effects of this type of boundary ambiguity. "Grieving and restructuring are not possible: so the family is held in limbo" (Boss, 1988, p. 74).

The second type of high boundary ambiguity is seen when physical presence is experienced along with psychological absence. The family is physically intact, but one member is emotionally and psychologically unavailable to the family system. The main point in this type of ambiguity is that the family member is physically present but his or her mind is somewhere else (Boss, 1988). Examples of this type of ambiguity include, "families having a member in a coma or chronically ill, Alzheimer's disease, and other forms of dementia"(Boss, 1988, p. 74). Boss (2002) described this situation as "leaving without saying good-bye." This type of high boundary ambiguity reflects the impact that the structural context and the experience of ambiguous loss may have on families providing care to frail elders and individuals with traumatic brain injury.

When viewing the concept of boundary ambiguity in the context of family stress theory, it must be noted that boundary ambiguity influences both the individual as well as the perceptions and meanings constructed by families. Therefore, family boundary ambiguity may result from two distinct situations. According to Boss (1988), these two distinct situations are "(a) one in which the facts surrounding the event are unclear (e.g. Alzheimer's disease), or (b) one in which the facts surrounding the event are clear, but for some reason the family ignores or denies them (e.g. illness)" (p. 77). What is of importance when focusing on these two situations is the perception of the event. According to Boss (1988), "It does not matter whether the ambiguity results from unavailable facts surrounding the events or from the family's distortion of those facts; it is the family's perception of the event or situation that is the critical variable in determining the existence and degree of the boundary ambiguity" (p. 77). The family's

perception of the event gives that event its own meaning and reality within the experiences of the family.

It is important, also, when focusing on the perceptions and meanings of the caregiving relationship, to understand that high boundary ambiguity is not always negative in its effects. Sometimes, caregivers will manage to "make peace with the ambiguity of living with a partially absent or present person" (Boss, 2002, p. 101). This is important when focusing on the role of primary caregivers to frail elders and individuals with traumatic brain injury. There needs to be an acceptance within the context of the family that care recipients are at times physically present, but psychologically absent in the ways their family experienced them before cognitive impairment occurred. The family makes the choice to move forward by accepting changed roles and relationships within the family system. It is with this acceptance that families learn to manage the ambiguity effectively.

There have been critiques within scholarly literature concerning the family stress theory model as applied to family caregiving. Connidis (2001) and Piercy and Chapman (2001) have reflected on this theory's focus on the negative consequences of change as a part of the larger phenomenon of looking at the family and the relationships within the family.

There is an embedded assumption in family stress theory that all members of a family share similar, if not the same, experiences within the context of their family. Connidis (2001) reflected on the impact that this focus has when using family stress theory to examine families. "The impact of change is assessed in relation to the family rather than from the point of view of different family members" (p. 12). Therefore, the

coexistence of both positive and negative sentiments and the competing demands of familial relationships may be the basis for ambivalent intergenerational ties (Connidis, 2001; Luescher & Pillemer, 1998).

A second critique of this perspective was offered by Piercy and Chapman (2001) in their qualitative study of 43 members of 15 families. Caregiver role adoption was influenced not only by the stresses within the context of the family, but also by (a) expectations of themselves and others, (b) family rules about caring for others, (c) religious training and spiritual experiences, (d) role modeling, and (e) role-making processes. Results suggested that most families transmitted values about care by means of expectations, religious beliefs, family rules, or interactions of these components. Each of these areas is important when addressing the use of family stress theory within the context of family. This incorporation of family values and meaning is important because family stress theory as applied to family caregiving lacks a focus on the positive incorporation of coping strategies as well as positive outlooks on the concept of stress within the context of the family. Family members have an ability to support and nurture one another even in times of crisis and stress. It is with this support that families manage stress, tension, and conflict in ways that maintain cohesion and support the individual throughout the caregivng process.

Elements of stress theory will be utilized in this review of literature and will include Boss's (1988, 1999, 2002) concept of ambiguous loss in relation to the notion of boundary ambiguity; Billings and Moo's (1984) conceptual schema of individual stress that demonstrates the impact of events that affect a person's morale and functioning while in a primary caregiver role; Carter and Mc Goldrick's (1999) concepts of vertical

and horizontal stress associated with the anxiety of the primary caregiver role over time; and Hill's (1958) ABC-X model of family stress. These theoretical concepts help to construct the interpretations that will be made in this review, and will be of assistance perhaps in understanding the data that will be collected in the research project.

Individual Stress

One model of stress that has been noted throughout the disability literature was developed by Billings and Moo (Briggs, 1998; Connidis, 2001; McCubbin, Sussman, & Patterson, 1983; Singer & Irvin, 1989). Individuals experience stress at different levels of intensity. As illustrated in Figure 1, their model of individual stress demonstrates how events affect a person's morale and functioning and how individuals can react very differently to similar events. This model illustrates that the effects of the environmental stressors are determined, in part, by resources available for dealing with challenging events, and, in part, by the way that individuals appraise and cope with stressors. Therefore, the resources, appraisal and coping responses, and the nature of the stressors all combine to determine an individual's morale and functioning under difficult circumstances. (Billings & Moo, 1984, p. 5-6).

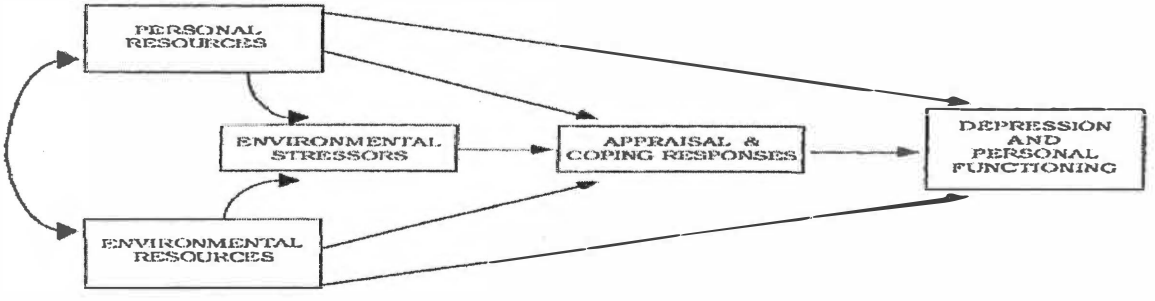


Figure 1. Model of Individual Stress and Functioning
Source: Singer, G. S., & Irvin, L. K. (1989). *Support for caregiving families: Enabling positive adaptation to disability.* Baltimore: Paul H. Brookes Publishing Company.

According to Billings and Moo (1984), individual reactions to stressors are not only a matter of appraisal, but also depend on resource availability. These resources include personal skills, social support, informal services, formal services, and money. One of the most influential resources seen in this model of individual stress is that of social support. "Social support is seen as a buffering mechanism for many stressful events" (Billings & Moo, 1984, p. 6). People having greater support are impacted less negatively by stressors than individuals who are more isolated. A second area noted in this model is the environmental stressor or event. Stress, according to Billings and Moo (1984), is tied to physical and emotional reactions. To understand stress, in the context of this model, individuals need to identify which events are stressors and whether or not exposure to these unpleasant events leads to physical or emotional problems. (Billings & Moo, 1984, p. 7). Identification of these events has great impact as the individual moves into the different areas of the model. A third area noted in the model is the structural component of appraisal and coping resources. This component of the model places emphasis on whether or not an event acts as a stressor, and to what extent it does so. This is determined partly by the attributions of the individual about the event. These interpretations of events result from the long history that individuals have with trying to interpret the events around them, and by interpreting the meaning that comes from the personal experiences of the event. Therefore, appraisal is a key component when focusing on the individual stressors of primary caregivers. A fourth area seen within this model is with coping skills. According to Billings and Moo (1984), coping skills are the methods of response to events, which become stressors and cause some distress. Coping skills are classified in three ways; emotion focused coping, problem-focused coping, and

passive coping. Billings and Moo (1984) stated that coping skills should be emphasized because these skills can be taught and learned by individuals. "These skills have proven to be effective in alleviating a wide range of stress to include headaches, depression, hypertension, generalized anxiety, and gastrointestinal problems." (Billings & Moo, 1984, p. 10). The final area in this model focuses on personal function. It is important to understand that the interactions of stressors, appraisals, resources, and coping skills have either primarily positive or negative effects on the personal functioning of the primary caregiver (Billings & Moo, 1984, p. 13). Stress can be positive or negative in terms of how one responds to change. The perception of stress by primary caregivers allows the caregivers to either cope with the stressor event or to decline into negative personal functioning. (Cicirelli, 1992; Merrill, 1997; Moules & Chandler, 1999).

It is important to understand the need of the primary caregiver to have assistance from social support resources and familial support networks. Through this network and assistance, primary caregivers can deal with individual stressors in a positive manner and achieve success within the individual stress model.

Vertical and Horizontal Stressors

According to Carter and McGoldrick (1999), in order to understand how individuals evolve, their lives within a social and familial context must be explored as roles change for the individual within the context of the family. It is imperative, when a researcher focuses on the family to examine what Carter and McGoldrick (1999) termed the vertical and horizontal stressors that impact these individuals. Both vertical and horizontal stressors create change. As illustrated in Figure 2, each stressor can be

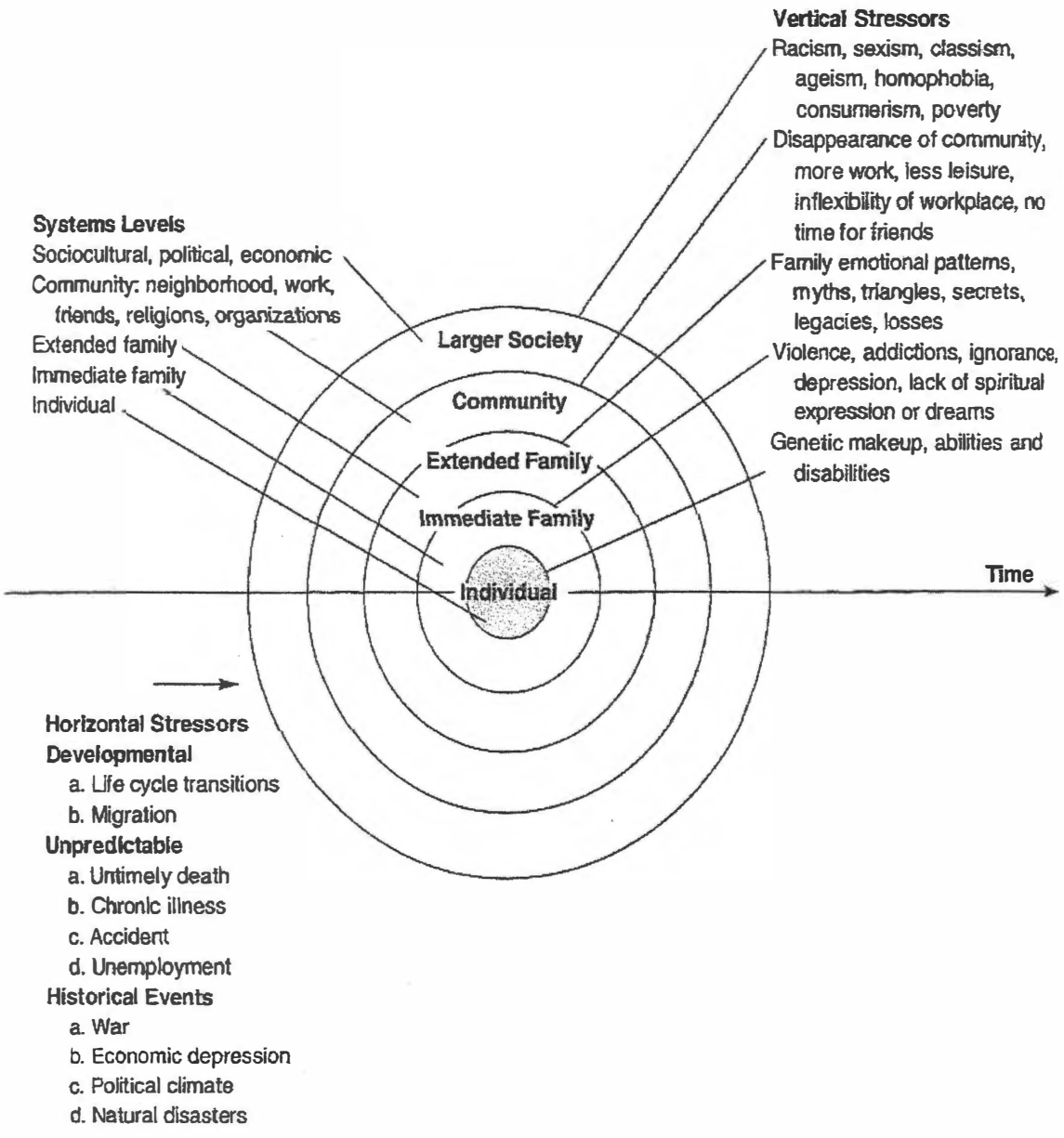


Figure 2: Flow of Stress Through the Family

Source: Carter, B., & McGoldrick, M. (1999). *The expanded family life cycle: Individual, family and social perspectives* (3rd ed.). Boston: Allyn and Bacon.

represented schematically along two time dimensions: one which brings past and present issues to bear reciprocally on all other levels (the vertical axis) and one which is developmental and unfolding (the horizontal axis). "For the individual the vertical axis includes biological heritage and intricate programming of behaviors with one's given temperament, possible congenital disability, and genetic makeup" (Carter & McGoldrick, 1999, p. 5). " The horizontal axis relates to the individual's emotional, cognitive, interpersonal, and physical development over the life span within a specific historical context"(p. 5). According to Carter and McGoldrick (1999), the vertical axis includes family history and the patterns of relating and functioning that are transmitted across generations. It includes all the family attitudes, taboos, expectations, labels, and loaded issues that individuals grow up within the context of the family. The horizontal axis at the family level describes the family as it moves through time, coping with the changes and transitions of the family's life cycle. "This includes both predictable developmental stresses and unpredictable events that may disrupt the life cycle process, such as chronic illness or disabling condition." (pp. 5-6). To understand how individuals evolve, their lives must be examined within the context of both the family and the larger culture, with their past and present properties, which are constantly changing over time. Carter and McGoldrick (1999) stated, "Over time the individual's inherent qualities can become either crystallized into rigid behaviors or elaborated into broader more flexible repertoires. Certain individual stages may be more difficult to master, depending on one's innate characteristics and the influence of the environment" (p. 5).

According to Carter and McGoldrick, (1999), at the sociocultural level, the vertical axis includes cultural and societal history, cultural stereotypes, patterns of power,

social hierarchies, and beliefs which have been passed down through the generations. "The horizontal axis relates to the community connections or lack of community connections, current events, and social policy as it affects the family and the individuals within the family unit" (p. 7). Stress within this model is seen as an impact of either the horizontal or vertical axis.

> Given enough stress of the horizontal axis, any individual will appear extremely dysfunctional. Even as small horizontal stress on a family in which the vertical axis is full of intense stress will create great disruption in the system. The anxiety engendered on the vertical and horizontal axes where they converge and the interaction of the various systems and how they work together to support or impede one another are the key determinants of how well the family will manage its transitions through life. (Carter & McGoldrick, 1999, p. 7).

This model has implications when focusing on primary caregivers of frail elders and individuals with traumatic brain injuries. According to Merrill (1997), each family is unique and experiences life differently. Family members have unique histories with each other. Some families will experience negative impacts of the primary caregiver role, and other families will experience positive impacts of the primary caregiver role. The care recipient, primary family caregiver, and other caregivers may experience their roles as caregivers in different ways due to their roles within a social and familial context (Carter & McGoldrick, 1999; Rosenthal, Griffith, Bond, & Miller, 1990; Rosswurm, 1998). Describing the roles of primary caregivers is one way that researchers may begin to understand the direct impact that this experience has on primary caregivers in caregiving relationships. It is with this understanding that professionals may begin to focus on strategies adopted by primary caregivers that assist them in managing caregiving demand effectively.

Pathways to Caregiver Roles

Intergenerational Relationships

A review of the literature suggests that changes in the roles of primary caregivers of frail elders and individuals with traumatic brain injury have a tremendous impact on every aspect of the primary caregivers' lives. Scholarly literature reveals variance both within groups and within individuals over time as they are providing primary care to frail elders and individuals with traumatic brain injury. Family legacies across generations influence greatly the meaning of caregiving processes.

Bengtson (1996) focused on the impact that caregiving processes have across time in his longitudinal study of intergenerational relationships. This study of family members from 300 third and fourth generation families focused on the patterns of interactions, support, and conflicts in family intergenerational relationships over time. These intergenerational ties were described as being founded primarily on solidarity or conflict within the context of intergenerational relationships. Solidarity is seen as having six analytic dimensions: "(a) associational (type and frequency of interaction and activities), (b) structural (factors such as geographic distance that influence the extent of interaction), (c) functional (exchange of assistance and support, especially instrumental help), (d) affectional (sentiments and feelings), (e) consensual (agreement between generations on opinions and values), and (f) normative (the extent to which family members share expectations of family life)" (Connidis, 2001, p. 117).

The concept of solidarity and studies surrounding this concept have encouraged theoretical thinking and have indicated that there is a multi-dimensional nature of intergenerational relationships. However, "there has been an ongoing concern about the

solidarity perspective and its tendency to minimize family diversity and to treat problematic and conflictual features of intergenerational relationships as simply the absence of solidarity" (Connidis, 2001, p. 118). Recently, applications of the solidarity perspective have tried to incorporate notions of paradox and conflict in family ties. "Indeed, one of the ultimate paradoxes of intergenerational relations is the fact that that solidarity and conflict coexist. Explorations of conflict have been primarily at the level of interpersonal relations-asking parents and children about their differences, disagreements, and disappointments with each other" (Connidis, 2001, p. 118). This focus on incorporation of conflict within normal assumptions of solidarity places limits on "examining conflict itself as a root to understanding intergenerational relationships" (p. 118).

Another approach to intergenerational relationships emphasizes problems and conflict in families. This approach "focuses on the problems created for children, and sometimes, parents by caring for older parents" (p. 118). Some literature has termed this approach a conflict perspective when, in fact, most of this perspective is not directly related with conflict beyond the level of interpersonal relationships (Connidis, 2001).

"Recently, the concept of ambivalence was explored as a way to address the coexistence of solidarity and conflict, rather than emphasizing one or the other as the overriding feature of intergenerational relationships" (Connidis, 2001, p. 118). Intergenerational ambivalence refers to "contradictions in parent-child ties, and these contradictions apply at both the psychological (primarily subjective) and sociological (institutional resources and requirements) levels" (p. 118). Because intergenerational ties are ambivalent, these ties must be negotiated in the context of family relations.

Therefore, when focusing on intergenerational issues, the study of the intergenerational relationships must "address how social structural forces and individual interests create the contradictions and conflicts that family members must work out in their encounters with one another" (Connidis, 2001, p. 119).

Intergenerational relationships are not going to remain static over time. These types of relationships are seen as ever-changing and evolving over time. Family members must respond to changes over the life span, "interacting in a social world of conflicting or contradictory interests and structural arrangements. Emphasizing the ambivalent nature of family ties encourages us to consider both sides of the solidarity-conflict coin" (p. 119).

Pyke and Bengtson (1996) continued research in the area of intergenerational relationships with a focus on collectivist and individualistic family systems and the process of family eldercare. They reflected on the increasing need for family eldercare and the lack of qualitative research focusing on family caregiving. In order to begin to address the needs of family caregivers, their qualitative study addressed "concerns surrounding ideological principles and theories that guide the ways in which families organize and maintain ties among their members, define tasks and obligations, and identify and respond to crises, such as sickness and fragility" (Pyke & Bengtson, 1996, p. 134). They found that families were either primarily collectivist or individualistic in their approach to family caregiving. "Collectivist families are more likely to feel that their emotional needs are met by the family, which provides a sense of continuity, belongingness, and identity. In these families, emphasis is placed on kinship ties and

familial responsibilities, which take precedence over other roles and obligations" (Pyke & Bengtson, 1996, p. 382).

Individualistic families, on the other hand, "emphasize independence, self-reliance, autonomy, self-fulfillment, personal achievement, loose kinship ties, and friendships with similar others" (p. 382). Family relationships are more voluntary, and there is less emphasis placed on duty to the family and more emphasis placed on the importance of self-sufficiency. Individualistic families "minimized the caregiving, provided less hands-on physical care and relied instead on formal supports such as residential facilities and formal help" (p. 383). They did not abandon their care recipient, but rather managed finances and caregiving arrangements. Individualistic caregivers regarded the amount of care required as too overwhelming. In contrast, collectivistic families assumed direct care responsibilities even when the role as a primary caregiver was demanding. Collectivists reported strong commitment to caregiving despite competing demands on their time and health. Collectivist families were describe as families likely "to employ caregiving as a means of constructing family solidarity, at times leading family members to provide more care than required to elderly parents, particularly to healthy elders with relatively few needs" (p. 387).

Intergenerational relationships, family contact, and family affect are important in understanding the experiences of primary caregivers. Measuring the amount of contact between family members of different generations has been a substantive focus of research. Much of the research on parent-child relationships has addressed the need to focus on the potential for support by examining the extent to which children and parents engage in supportive exchanges with one another. The helping flow from parent to child

is seen as a crucial component in the caregiving relationship making the focus on support exchange essential in understanding the experience of primary caregivers. Similarly, the construct of affect is directly related to the perceptions of the caregiving experience. Any relationship has a certain degree of affect, whether positive, negative, or neutral. The affect dimension of the family relations is multidimensional in nature and may allow the "lived" experiences to be explained by an understanding of the "mutual respect and sentiment among group members and their self-expressions of love, respect, admiration, and recognition that each member of the family has worth" (Manger, Bengtson, & Landry, 1988, p. 75).

Demographics of Caregiving

Age, Gender and Family Roles of Caregivers

Society creates and maintains certain expectations of roles for women and men within families. Women in families often are responsible for upholding the traditions and rituals of their families. Men are expected to be the financial providers and to be more emotionally detached in their caring networks (Robinson & Howard-Hamilton, 2000). "Women are expected to assume total responsibility for maintaining family relationships and connections" (p. 214). If they do not assume this role and no one else fills in the gap, the connections in the family unit start to loosen. The socialization of women to take on the caretaking role is passed from one generation to the next. "These positions maintain a female's position as responsible for family ties while at the same time, they maintain a man's position as a stranger to the family whose value is defined through monetary means" (p. 214). Therefore, it is important when focusing on the primary caregiver

within the context of the family, to understand the impact that gender and the age of the caregiver have on the caregiving experience.

Gender influences roles of family members relative to caregiving processes. Typically, the responsibilities of caregiver roles fall mostly upon a single person (Ceserta, Lund, Wright & Redburn, 1987). Most often, the role of primary caregiver is assumed by the female, a wife or daughter (Barber & Pasley, 1995; Mui, Choi, & Monk, 1998; Rolland, 1994). While males do provide care, men generally do not assume the primary caregiver role, unless a wife, a daughter, or daughter-in-law is unavailable. Men tend to take on the role of secondary caregiver and participate mostly through indirect care by financial and managerial contributions (Carter & McGoldrick, 1999; Mace, Whitehouse & Smith, 1993; Merrill, 1997). Changes in familial roles in many areas occur as caregiving processes evolve. A discussion of these changes for families providing care to frail elders and families providing care for individuals with traumatic brain injury is offered.

The average age of a primary caregiver to a frail elder is 46 years. "More than one in five caregivers are under the age of 35, close to four in 10 are 35-45 years of age, about one in four are 50-64 years of age, and around 12 percent are 65 and older. Asian and Hispanic caregivers are younger than whites, with average ages of 39 and 40, respectively, compared with 47 years of age for whites. More than one-third of Asian and Hispanic caregivers are under the age of 35, compared with just over one in five white caregivers" (The National Alliance for Caregiving, 1997, retrieved Oct. 17, 2002 from http://www. caregiving.org).

There are also generational differences in caregiving roles. While spouses may prefer to take on the role as a primary caregiver, their advancing age and poor health may limit their abilities. Adult children, on the other hand, often juggle the competing demands of their nuclear families, their careers, and the caregiver role. Therefore, when a spouse is available to provide care, adult children usually choose to assume the role as a secondary caregiver (Mace, Whitehouse & Smith, 1993).

Marks, Lambert, and Choi (2002) address issues surrounding gender and the impact of the primary caregiving role. They found that taking on the role of primary caregiver for a biological parent in the household was associated with more hostility, a decline in happiness, less autonomy, and less personal growth for women. Men providing care to a biological parent in their households reported less personal mastery and less self-acceptance, but did not provide as much direct hands-on care for the frail elder. In terms of gender, women who were in-home caregivers for parents experienced significantly more hostility and more decline in happiness than men who were in-home parent caregivers. When focusing on providing direct care for a parent-in-law, the feelings of hostility and frustration toward the caregiving role were not as apparent. Instead, men who reported this type of caregiving activity reported a significantly higher level of purpose in life and more positive relationship with others. The males in this study supported frail elders through financial resources and through the use of outside support services within the community.

Much of the responsibility for supporting the brain injured person during the years that follow a traumatic injury lies with informal caregivers, usually spouses or parents (Knight, Devereux, & Godfrey, 1998). In cases of severe TBI, relatives may be faced

abruptly with the prospect of coping with a person very different from the one they knew before the trauma, who may exhibit a variety of new emotional, behavioral, and cognitive problems. Knight, Devereux and Godfrey (1998) examined the gender of primary caregivers to individuals sustaining traumatic brain injuries. Their sample of 52 primary caregivers was comprised of 43 female caregivers and 9 male caregivers. Twenty-nine of these primary caregivers were parents of the individual with the TBI, 17 were spouses, and 6 were other relatives. Direct care was being provided to both males and females sustaining traumatic brain injuries. For males there was a mean age of 25 years for care recipients, and an average time since injury was 5.71 years; for females there was a mean age of 32 years and an average time of 6 years since onset of injury. The majority of these TBI cases had been sustained in automobile accidents (63%) with further accidents resulting from pedestrian or bicycle accidents involving a motor vehicle (17%). This study found that "most (caregiving) individuals were parents and the majority were women; as might be expected, there were more males than females amongst the persons with TBI" (p. 475).

When focusing on family roles of primary caregivers, the needs of women in the "sandwich" generation must be addressed. Historically, caregiving was not defined as a crisis, but was part of the family life cycle, rather than an abrupt entrance into a new role.

> The profound changes in our social structure have propelled parent caring into the area of adult life crisis. Notice of the adult's predicament of simultaneously caring for children and parents has also become a sign of wider community commitment to social and economic justice. Such societal recognition moves the problem from an individual focus to a social issue involving both the person and society's structures. (Bengtson, 1996, p. 147)

The socialization of many women toward family issues often conflicts with career decision making in that career can be perceived as a liability for a woman. Essentially, roles within the family are segregated "with women the main duties are childrearing and primary care provider" (Robison & Howard-Hamilton, 2000, p. 238). Therefore, the experiences of women as direct care providers will be extremely different due to this impact of the "sandwiching" of their roles within the context of the family. It is important when viewing family roles to note the impact that the responsibility for primary care has on every aspect of the female's life. The primary caregiving role, when focusing on female caregivers, must be viewed holistically. If there are changes in roles and relationships in one area of female primary caregivers' lives, these changes will impact every other aspect of their lives.

Education and Income of Caregivers

Status has social meaning within society. Being poor in American society is a status that carries with it certain meanings and discourses. Therefore, education and income are two important indicators and/or predictors of socio-economic status of caregivers. Although noteworthy changes regarding the distribution of women has occurred in the labor force, more positive changes must occur in order to address the concerns and needs of the individuals in roles as primary caregivers in the context of the family. "For instance, women workers with 4 or more years of college average about the same income as men who have much less education--1 to 3 years of high school" (Robinson & Howard-Hamilton, 2000, p. 232). As of 1992, women constituted 46% of the labor force, whereas men were 54%. It has been estimated that, by the year 2005,

women will compose 48% of the labor force, and men 52% (Robinson & Howard-Hamilton, 2000).

Education is an important component when focusing on the primary caregiving experience. Nine percent of primary caregivers have less than a high school education, 35% of caregivers are high school graduates, 23% have some college education, and 29% are college graduates or have a post graduate education, and 4% have some technical schooling. The more education an individual obtains, the greater the possibility for better employment positions with better benefits. Highly educated individuals have a greater chance of obtaining work leave or for obtaining the time away from their jobs that is necessary when providing care for an individual within the context of the family. Although many occupations are growing in the context of labor force development, "workers who have the most education have the highest earnings and the lowest unemployment rates" (Robinson & Howard-Hamilton, 2000, p. 232). College graduates, at this time in history, are not guaranteed employment. "However, for this group, the unemployment rates in 1992 were 3.2% and the median dollar earning were $46, 000" (p. 234). Also, according to Steinberg (1994), 74% of college graduates were in the labor force full time, and 11% worked part time, or fewer than 35 hours per week (p.12).

Overall, earnings rise with education for a variety of reasons. According to Steinberg (1994), "Many highly paid occupations, such as physician and lawyer are open only to workers with education beyond the undergraduate level of education. To some, however, advanced degree holders earn more just because they are older, and incomes rise with age as expertise grows and makes workers more valued to employers" (p. 21). Therefore, regarding the economic well-being of primary caregivers, the median annual

household income of caregivers is $35,000. Caregivers have a relatively evenly distributed income range; 36% have household incomes under $25,000, 35% have incomes of $25,000 to $49,999, and 29% received $50,000 or more in household incomes.

When focusing on the experiences of primary caregivers researchers must understand the impact that economic well-being may have on the services and resources that an individual may access within the community. According to Haggan (1998), "Financial security may have come for the first time in an individual's life and yet pressures to support frail elders and individuals with disabilities can generate considerable life dissatisfaction and turmoil" (p. 342). Primary caregivers need to be able to access economic resources since they can use these resources to obtain support services within the community. Without financial resources, individuals providing direct care to frail elders and individuals with traumatic brain injury cannot access valued support services necessary to emerge out of their roles as primary caregivers with success.

Labor Force Participation and Caring

Because women are so prominent as providers of primary care, their increased involvement in the labor force prompts concerns about how these competing demands surrounding care can be managed. "Women's paid work changes the way in which caring is carried out but it does not change the likelihood of caring" (Connidis, 2001, p. 140). Labor force participants begin conflicting demands by identifying needs and ensuring that some of these needs can be met by others. Therefore, those who receive care from employed women receive just as much care. Close to two of three caregivers

are working; 52% are working full-time, 12% are working part time, 16% are retired, and 20% are not employed (National Alliance for Caregiving, 1997, retrieved Oct. 17, 2002 from http://www. caregiving.org). "Employed women and housewives provide similar levels of care with shopping, transportation, household maintenance, emotional support and service management, but traditional hands-on care is most usual among housewives" (Connidis, 2001, p. 140). This "caregiver picture" becomes even more complicated when one considers the impact between hours at work and hours providing care. Among those who worked up to 18 hours per week, hours of care increased with hours of work (Connidis, 2001; Doty et al., 1998).

In a study conducted by Wagner (1997) of working caregivers, results demonstrated an increase in the number of hours spent in caregiving per week. "In 1987, 36% of the working caregivers reported spending 8 hours or less in caregiving; in 1997, 52% reported this level of activity" (Wagner, 1997, p. 2). The effects of primary caregiving were seen as a paradox within the study. "More than half of the employed caregivers (52%) in 1997 reported that they were required to leave work early, arrive late, or take time off as a result of caregiving. However, they wanted to remain caregivers within their homes and communities" (p. 2). Wagner (1997, p. 3) suggested that, if the 1997 percentage in caregiver demands continues to rise, then "there will be an additional 9% increase in needs of primary caregivers within the next 10 years, and there will be between 11 and 15.6 million employed caregivers in the U.S.".

The National Alliance for Caregiving (1997) also addressed the need to evaluate the effects of providing care by focusing on both the level and intensity of the direct care being provided by primary caregivers and how they impact labor force participation. The

major purpose of this study was to understand how the level of demand presented by the caregiving situation and the amount of time that the caregiver spent in direct care provision impacted on the caregivers' lives. Within this study, each caregiver was classified into one of five levels of caregiving. Level one was the lowest level in caregiving demand or intensity and level 5 was the highest level of demand or intensity. Within each of these levels there was a range of activities and a number of hours that each individual spent in the caregiving situation. As the levels increased, so did the responsibility or demand of the primary caregiver. Level one caregivers were seen as providing no assistance with personal care activities, and typically they provided care for a maximum of 8 hours per week. In contrast, level five caregivers assisted with at least two personal care activities and provided care for more than 40 hours per week. Level five caregivers are much more likely to be at least 65 years old than other caregivers; 30%, in contrast with only 10 % of level one caregivers (National Alliance for Caregiving, 1997, retrieved Oct. 17, 2002 from http://www. caregiving.org). It is important to understand that the level of care provided by the primary caregiver impacts on employment status and workforce participation. Those caregivers providing level 5 care are more likely to be retired (32%) than caregivers of any other level. This suggests that the people providing this type of direct care may themselves be older and requiring more care (National Alliance for Caregiving, 1997, retrieved Oct. 17, 2002 from http://www. caregiving.org).

Wallace et al. (1998) reflected on the changing roles of the primary caregivers of individuals with traumatic brain injury. This study of 211 individuals found that 30% of caregivers reported working less hours as a result of caring for the injured individual,

whereas 43% indicated that their participation in leisure activities had declined since taking on the primary caregiving duties to the individual with the traumatic brain injury. When focusing on overall role and life change, 66.7% of the primary caregivers experienced at least some difficulty in conducting activities as a direct result of the care being provided to the injured individual. The caregivers' perceptions of their family members' cognitive deficits had a significant relationship to the extent to which they felt their lives had changed following assumptions of the role of primary caregiver.

With the increases in primary caregivers in the workplace, some employers have begun to assist employees with care responsibilities. Rearranging schedules is the most common tactic for combining work and care. However, managers, professionals, and clerks are almost twice as likely to use this approach as caregivers in other job positions (Connidis, 2001) "There were, however, increases in the number of employed caregivers who reported negative workplace impacts as a result of providing direct care to a family member" (Wagner, 1997, p. 4). Regardless of the positive or negative reports by primary caregivers concerning the workplace, it is clear that the workplace will likely need to accommodate the schedules and situations of primary caregivers in the future.

Caregiver Stress and Coping

Caregiver Stress

Research has revealed that emotional stress and strain are by far the most pervasive and negative effects of caregiving (Aneshensel, Pearlin, Mullan, Zarit, & Whitlach, 1995; Brody, 1990; Merrill, 1997). However, not everyone deals with the same extent of these effects. Caregivers who are most affected by these stresses include women, older caregivers, and those who live with the elderly individual (Brody, 1990;

Ingersoll-Dayton, Neal, & Hammer, 2001; Moen, Robison & McClain, 1995). Family members who care for individuals with disabilities or degenerative conditions have higher rates of stress, as do those who have hands-on primary physical caregiving responsibilities (Merrill, 1997). It is important to understand stress in the context of the caregiving relationship. Stress is not related to the length of time as a primary caregiver. However, stress is seen as being related to the caregiver's perceptions of their experiences as direct care providers.

A range of negative phenomena with primary caregiving to individuals with brain injury has been called caregiver burden (Dell Orto & Power, 2000, pp. 62-63). According to Dell Orto and Power (2000) the amount of burden a family member experiences can depend on age, gender, coping styles, and view of the situation. There are two types of burden discussed by Dell Orto and Power (2000). These two types of stress were termed objective and subjective burden. "Objective burden is understood as problems encountered by the injured. Subjective burden is the perceived stress by the primary caregiver, or the amount of psychological strain on the primary caregiver" (Dell Orto & Power, 2000, p. 62).

Research has focused on the areas of physical and emotional burdens associated with the role of the primary caregiver (Mc Call, 1999; Merrill, 1997; Mui, Choi & Monk, 1998; Singer & Irvin, 1989). However, Schaie and Willis (2002) took a different focus on the roles of the primary caregiver and the impact that these roles have on caregiver burden. Schaie and Willis (2002) focused on the emotional response of loneliness in the frail elder population. Next to physical dependency, loneliness is seen to be one of the greatest fears of frail elders. Loneliness, according to Schaie and Willis (2002), is a

dependency issue because with increasing age, the individuals upon whom the frail elder depends upon for emotional and physical support are members of their families. "Persons growing older have a decrease in frequency of personal interactions with friends and an increase with family members" (p. 89). As frail elders age, they are increasingly limited to the emotional and physical care provided to them by their primary caregivers. According to Schaie and Willis (2002), "This is just one more "burden" that their existence puts on their beloved family" (p. 89).

There were also stressors associated with caregiving when focusing on individuals with traumatic brain injury. At any time, at any place, and under any circumstances, individuals may be involved in a catastrophe. "A catastrophe is an event which is sudden, unexpected, often life-threatening and due to the circumstances renders the survivors feeling an extreme sense of helplessness" (Figley, 1983). When focusing on traumatic brain injury, the role of a catastrophe must be addressed by focusing on the individual within the context of the family unit. According to Figley (1983), the family has a central role to play at the point of a catastrophic event and how it is experienced. Family, friends, and spouses can detect when the brain injured individual has not recovered physically and emotionally from the accident or injury. The injured individual may feel more at ease talking about the event with family members. In the case of a traumatic brain injury, the primary caregiver will play a critical role of support. The family system will be affected also by the occurrence of this catastrophic event and the changes that this event will create within the system. Various family rules, roles, and responsibilities will change due to the presence of the individual with the traumatic brain injury.

Just as there have been descriptions of the physical and emotional stressors surrounding primary caregivers to frail elders, there has been literature focusing on the impact of stressors on primary caregivers to individuals with traumatic brain injury. Following the family's immediate emotional response when an individual has sustained a head injury, there is a developmental stage model that is used in understanding the emotional reaction and burden of the new role of primary caregiver to an individual with a traumatic brain injury. According to Dell Orto and Power (2000), the primary caregiver will exhibit differential adaptation patterns following the injury to the individual with a traumatic brain injury. Dell Orto and Power (2000) suggested phases that are common within families and within individual caregivers of traumatic brain injured individuals. These phases include shock, denial, grief, gradual realization, and reorientation. Shock begins with the onset of the traumatic brain injury event. Shock has a sudden and extensive effect on the lives of the individual family members. Within this first phase there are apparent feelings of helplessness, numbness, confusion, and feelings of being overwhelmed. A second phase seen after injury is denial. With little understanding that the individual with the traumatic brain injury may be impaired, family members deny any implications of the trauma regarding permanent physical, emotional, or intellectual limitations. At this time, according to Dell Orto and Power (2000), denial may serve as a coping mechanism and will not necessarily result in negative effects. As family members begin to understand that the injured individual family member is not going to be the same as prior to the injury, issues of blame, guilt, and depression can emerge. "Family members begin to understand that their lives have changed forever" (Dell Orto & Power, 2000, p. 62). With the family's understanding of the effects of trauma on the individual

with the traumatic brain injury, individual family members begin to focus gradually on meeting caregiver demands, role reallocation, and perhaps evaluating family finances. This is the most intense time period following the injury. During this time of reorientation, the individual lives of family members may be difficult. The family may attempt to reintegrate the individual with the traumatic brain injury into the family unit, involving all aspects of social and household activities. Each of the different adaptive themes can be illustrated below in Figure 3.

Stress is part of caregiving, and caregiving is a part of the everyday lives of many individuals within society today. The term stress implies that all aspects of caring for a frail elder or an individual with a traumatic brain injury create demands and sometimes the resources for meeting these demands are not marshaled easily. As mentioned previously, caregiving and the stresses associated with caregiving are experienced differently by each individual primary caregiver. When focusing on the lived experiences of primary caregivers, it is crucial to evaluate and to understand the impact that family support networks and the primary caregiver's access to community resources has on successful caregiver outcomes. It is important to understand that primary caregivers will utilize different coping mechanisms as they attempt to adjust to their new

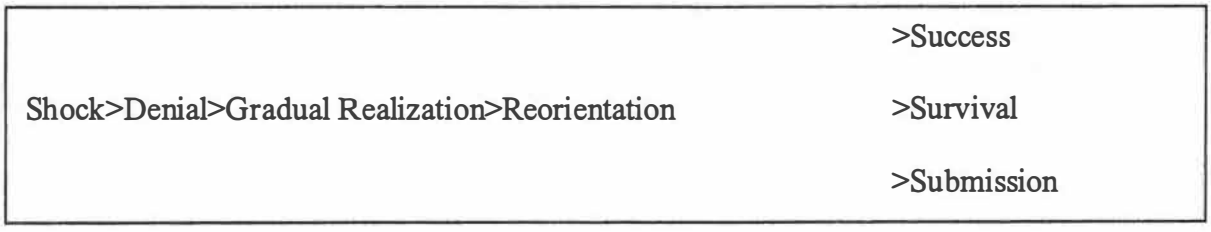


Figure 3: Themes of Emotional Burden

Source: Dell Orto, A.E. & Power, P.W. (2000). *Brain injury and the family: A life and living perspective* (2nd ed.). London: CRC Press.

roles as direct care providers to individuals with age related fragility and individuals with cognitive impairment as a result of a traumatic brain injury. Individuals who appear to adapt to the primary caregiver role with success utilize available support services and familial support networks to ensure that they have the resources necessary to sustain them in times of emotional burden associated with their new roles as a primary caregivers within their homes and communities.

Caregiver Coping

There has been a great deal of research concerned with caregiver distress which suggests that there is a need to focus on identifying factors that may contribute to the successful coping strategies of individuals within the primary caregiving role (Connidis, 2001; Haggan, 1998; Hillier & Barrow, 1999; Papalia, Camp, & Feldman, 1996). "Coping is a response to the demands of specific stressful current situations, and coping techniques and abilities vary from person to person" (Hillier & Barrow, 1999, p. 274). These variations in coping need attention and explanation in order to understand how some caregivers emerge out of the caregiver role with a sense of mastery, while others simply try to survive and experience at times feelings of victimization.

According to Ingersoll-Dayton, Neal, and Hammer (2001), benefits of caregiving off-set the stress and coping perspective characterizing caregiving as an experience that is rewarding as well as stressful. In this study of 17 focus groups and 624 couples, participants addressed stress in the primary caregiver role. Participants reported what seemed at times as overwhelming demands: multiple demands of employment, demands of caring for children, and demands of caring for their aging parents. Despite the demands and stress, there were descriptions of benefits from caregiving. Specifically,

there was a description of the benefits from the reciprocal nature of the caregiving relationship. Emotional support from the frail elder was experienced in terms of enjoying companionship with their parent. Helpful advice was another form of reward that individuals within this study received from interaction with their frail elders. The receipt of tangible kinds of help, financial assistance, assistance with child care, and help with household tasks were related more frequently to reports of less stress. However, receiving these types of assistance from frail elders were associated with stronger feelings of dependency, indebtedness, or guilt. Overall, this study emphasized the need to address the stresses within the caregiving relationship as mutual and to understand that caregiving relationships range from conflictual to rewarding.

Burdens of caregiving have been well documented and researchers continue to study what kind of coping strategies might be most helpful to direct care providers within their communities. One type of coping strategy used by primary caregivers is seen in psychosocial interventions. These types of interventions for caregivers are seen typically in "individual counseling, family counseling, support groups, educational groups, problem-solving groups for the caregiver and patient, social worker visits, and family consultants" (Hillier & Barrow, 1999, p. 275). Support groups are typically available in larger communities and also from individual mental health counselors. Support groups are seen as one of the most common strategies used by primary caregivers for caregiver coping. Counselors for both individuals and families may be helpful also for families that have the financial resources to access these services directly within their communities. However, some families may not have the financial resources available for such services, or the caregiver may be suffering from a poor relationship with the care

recipient. For these primary caregivers, "emotional distancing may be the only stress-management technique that would alleviate guilt and despair" (p. 275).

In contrast to the findings by Hillier and Barrow (1999), The National Alliance for Caregiving (1997) has suggested other coping strategies that may assist caregivers in coping with the strains and stress of primary caregiving. Caregivers are seen as coping with the stresses of caregiving primarily through their personal resources and/or informal networks. The most common coping mechanisms noted are prayer (74%), talking with friends or relatives (66%), exercising (38%), and hobbies (36%). There were relatively small percentages of individuals who obtained help from counselors or other professionals (16%), or used medications (7%). Overall, prayer was seen as the most common way of coping with the everyday stresses of the primary caregiving experience (National Alliance for Caregiving, 1997, retrieved Oct. 17, 2002 from http://www.caregiving.org).

Respite care services were addressed also within scholarly literature as a more effective coping resource than psychosocial interventions. "Respite care can mean placement of the dependent individual in a nursing home for two weeks or so, or it may involve bringing a hired home care worker into the home for one to two weeks or more while the caregiver goes on vacation" (Hillier & Barrow, 1999, p. 275). Time off for the caregiver is also important when focusing on respite care. Intervention and respite care should not be measured by its alleviation of caregiver distress only. Other important outcomes have been found: improved functioning of the dependent elder, reduced use of hospital days, and improvements in patient mortality. Overall, respite benefits not only the primary caregiver, but the care recipient as well.

One of the most important coping strategies for the caregiver is seen in the need to address concerns surrounding the evolving role as a primary caregiver. Moules and Chandler (1999) conducted a study of spouses as primary caregivers to individuals with traumatic brain injury to address their needs as direct care providers. This study of 22 individuals (at least 12 months post-catastrophic injury) focused on the issues surrounding the coping with stress by primary caregivers of individuals with traumatic brain injury. The individual care provided impacted on the independence, future expectations, and personal relationships of the primary caregiver. Stress-producing change were noted in the areas of altering the primary caregiver's lifestyle due to the care of the individual with traumatic brain injury; concerns about the future roles of the caregiver with regard to the individual with traumatic brain injury across time; and the ability of the individual caregiver to address adequately his or her own needs in the evolving caregiving role. The findings suggested that, when the primary caregiver perceived support from health and social services, stressors experienced in the caregiving process were lowered. However, it was important to note that health and social services cannot take away the distress created by brain injury but could offer support once needs were identified by the primary caregiver.

When focusing on family resources, effective management skills and interpersonal skills may lead to more successful coping with the demands of primary caregivers. "These resources include: problem solving and behavioral management skills; negotiation and communication skills in working with professionals; informal social support, including other family members; and generic community support" (Singer & Irvin, 1989, p. 31). It is important when focusing on coping mechanisms to understand

that individuals use different strategies at different times in their roles as primary care providers. It is only by understanding the uniqueness of the individual, and the uniqueness of the individual's method of coping with the demands in their roles as primary caregivers that researchers may begin to understand the "lived experiences" of these individuals.

Rewards of Primary Caregiving

Gifts of Primary Caregiving

Caregivers sometimes feel burdened, overwhelmed, and stressed. Yet, caregivers are not alone in their experiences. Connie Goldman (2002) addresses the need for caregivers to understand that they are not alone in their experiences. "One of the things that I've realized is that I'm part of a group called caregivers, and that there are millions of us" (Goldman, 2002, p. 4). This author reflects on the impact of the primary caregiver role. She stated that the primary caregiver role is "often a role that we take on willingly because we love the person and because we feel it's our duty, and yet we don't see it as a job, necessarily, and it really is"(Goldman, 2002, p. 4). Most often, individuals become primary caregivers through unforeseen circumstances. Individuals take on the role as a primary caregiver because all too often there are no acceptable alternatives. However, some individuals do not understand the "gifts" that will be received from their experience as a primary care provider.

Along with an awareness that a cure might not be possible and as caregivers begin to accept what can not be controlled or changed, many caregivers learn something deeply meaningful and profoundly spiritual about themselves or in relation to the care recipient throughout the caregiving experience. Caregivers bring with them a sense of loyalty that

can only be fully understood by focusing on the caregiving experience. Through the caregiving experience caregivers expand "their vision, touch new depths of compassion and gratitude, and reassess their priorities" (Goldman, 2002, p. 5).

"The literature on the benefits of caregiving augments the stress and coping perspectives by characterizing caregiving as an experience that is rewarding as well as stressful" (Ingersoll-Dayton, Neal, & Hammer, 2001, p. 284). Hinrichsen, Hernandez, and Pollack (1992) addressed benefits that were discovered from individuals' roles as primary caregivers. These benefits were seen in "enhanced relationships with elders, improved family relationships, and a sense of gratification associated with being helpful" (p. 489). Walker and Allen's study (1991) also addressed caregiver relationships and described their findings on a continuum ranging from conflictual to rewarding. "The rewarding caregiving relationships were characterized by dyadic exchanges between the daughters and mothers that were mutually beneficial" (p. 392). This beneficial, dyadic exchange allowed for parent and child to interact with an open communication style, and allowed for open discussion surrounding the needs of the frail elder. What was discovered in the context of the "rewards" of caregiving was that there was "a sense of satisfaction derived from repaying the elder for previous care, there was an enjoyment from spending time together with the elder, and there was an appreciation for help provided to the elder" (Ingersoll-Dayton, Neal, & Hammer, 2001, p. 284).

Scholarly literature addresses the need to understand the rewards of the primary caregiving experiences of individuals providing direct care to family members sustaining traumatic brain injuries. Knight, Devereux, and Godfrey (1998) reflected on the positive aspects of the primary caregiving experience. Their study of 52 primary caregivers to

individuals with traumatic brain injury underscored the need to understand caregiving not only as a stressful situation, but one that has distinct rewards. This study presented several positive comments from these primary caregivers regarding their experiences. "There were positive expressions of resolution in the face of adversity, and the conviction that caregiving can be uplifting" (Knight, Devereux, & Godfrey, 1998, p. 476). Several women in this study reported that their relationship with their spouse had actually improved as a consequence of their caregiving experience. There were increasingly meaningful interactions that came out of the experience of providing direct care to an individual sustaining a traumatic brain injury. "Several parents stated that caregiving had been positive for them because it offered a sense of family unity and focus" (p. 476). This positive attitude was reflected in the ways in which these caregivers often enjoyed their work as direct care providers, and in how they reflected on their primary caregiving roles as "both a sense of achievement and a pleasure" (p. 476).

The National Alliance for Caregiving (1997) reported some rewards from their study of over 1,000 primary caregivers in the United States. Overall, the greatest reward of caregiving was understanding and knowing that the care recipient has received quality care. Personal satisfaction for the caregiver was reflected in knowing that the individual is doing a good deed and that the care recipient is appreciative and happy with their level of care. Also, caregivers reported that their rewards came from watching the care recipient's health improve, family loyalty, "giving back," fulfilling family obligations, and spending time together. Overall, primary caregivers were seen as using positive words to reflect on their caregiving experiences. These types of words include happy,

helpful, thankful, grateful, enjoyable, and loving (National Alliance for Caregiving, 1997, retrieved Oct. 17, 2002 from http://www. caregiving.org).

It is by focusing on the rewards of the caregiving experience that researchers may begin to understand how caregivers internalize their experiences. Caregiving can be a gift in disguise. It can be an experience that will move caregivers toward a more meaningful connection with themselves and with those to whom they are providing direct care. It is only by addressing the rewards and gifts of the primary caregiving relationship that a voice may be given to the lived experiences of primary caregivers.

Synthesis of Perspectives

With growing numbers of elderly and individuals with disabilities, primary caregiving members are increasing and the demands of providing direct care to a frail elder or to an individual with cognitive impairment as a result of a traumatic brain injury are being experienced by growing numbers of families. There are both similarities and differences when focusing on these two distinct perspectives on primary care providers. It is by understanding these similarities and differences that these two perspectives in scholarly work can be compared and contrasted.

Similarities

There are three major similarities between these two perspectives on primary caregivers. The first similarity is seen in the policy shifts that encourage community living and in part are reducing the costs of providing services to both elders and the disabled within the community. This lack of funding has increased pressures on primary caregivers to provide long-term care for these individuals within the community. There has also been less funding for community programs and agencies providing services to

caregiving families. "There is no longer a guarantee of supportive benefits within the community to assist with caregiver responsibilities" (Connidis, 2001, p. 152). All too often caregivers must fight for resources in order to provide the best care possible to the individual within the community.

A second similarity is seen in the descriptions of individual primary caregivers across perspectives. Caregivers across care contexts have a greater likelihood of being female, and carrying out the direct responsibilities for hands-on care in spite of her personal needs for intervention, care, and at times support. "The longer life expectancy of women makes it more likely that they will be carrying out this responsibility alone at a time in life when their own needs for support may be increasing" (Connidis, 2001, p. 151).

The final area of similarity is seen with what is now being termed the sandwich generation. This term refers to the caregiver being sandwiched between competing demands of work, children and elders or the disabled. This sandwiching is important when focusing on the roles of primary caregivers because it allows researchers to begin to understand how primary caregivers cope and adapt to their new and ongoing roles as direct care providers. Also, this area of similarity allows research to focus in the areas of support, both in the quantity and the quality of the support as articulated by caregivers themselves.

Differences

There are three distinct areas of difference between these two contexts of primary caregivers. The first difference is seen in the length and duration of care for the care recipient. When focusing on primary caregivers to frail elders, frail elders are often

receiving some type of support from either spouses or adult children. In contrast to this somewhat more temporary caregiving situation of adult children caring for their parents, providing care for an individual with a traumatic brain injury is often a life-long role for spouses and/or parents. This is an ongoing process that will be concluded only by the death of the individual caregiver. This area of difference is important because it allows the stresses and rewards of the caregiving situation to be considered in the context of time. It is by understanding the length of time and impact of the caregiving relationship that will allow researchers to understand the lived experience of primary caregivers.

A second difference is seen in the stress levels of caregivers. When focusing on adult children caring for frail elders, there has been wide variation of stress levels in this caregiving relationship. As addressed in the National Alliance for Caregiving (1997), the levels of care begin with the level one (lowest demand and intensity) and end with level five (highest demand and intensity). In contrast, caregivers to individuals with traumatic brain injuries are mostly at level five in terms of demand and intensity of care. These caregivers are seen as in a state of non-normative stress that may lead to a crisis within the context of the family. There is no gradual progression through caregiving intensity levels, but there is an understanding that a catastrophic event has occurred and that the life of the family has been changed in that instant forever.

A third difference seen between these two contexts is the relationship between the individual primary caregiver and the care recipient. Within the group of primary caregivers to frail elders, the caregiver is most often a spouse or an adult child. These caregivers are providing direct and ongoing care to an individual that is in the oldest stages of adulthood and life. In contrast, spousal and parental caregivers to individuals

with traumatic brain injury are providing care to individuals in the early stages of adulthood.

Future researchers must begin to direct attention to the "lived experiences" of primary caregivers providing direct care to frail elders and individuals with cognitive impairment as a result of a traumatic brain injury. Research needs to direct attention to the perceptions and meanings of the caregiving experience as expressed by the caregivers themselves. This review of literature has focused on the theoretical considerations/frameworks associated with primary caregiving, the pathways to caregiver roles, demographic profiles of caregiving, caregiver support, and the stresses and rewards associated with the role as a primary caregiver. Each of the areas lends support to the need for further research in areas focusing on the "lived" experiences of primary caregivers. The present study will focus on the primary caregiving experience as described by the caregivers themselves. Perhaps this study will be able to provide a "voice" to the most important issues and concerns, challenges and rewards, the individual, and the social support resources needed as addressed by primary caregivers within society.

CHAPTER 3

METHOD

"Qualitative research begins with the assumption that human behavior is made up of thoughtful, meaningful responses to stimuli in the world" (Taylor, 1994, p. 266). The meaning of experience to an individual will influence greatly on the way in which that individual will respond. "Meaning is not static; rather meaning itself is always a process of interpretation and refinement" (Taylor, 1994, p. 266). Meaning will change as time passes, when objects appear in different settings, or as individuals change within their environments. The world is dynamic and changing, as people are constantly interpreting, reinterpreting, and making meaningful responses to the world itself. However, there is order and pattern to be found in individuals' behaviors due to the ordering and patterning that is intrinsic to human perception. Therefore, truth is regarded as relative and specific to time and space. "What is true today may not be true tomorrow or 10 years from now; and what is true for one group of people in one setting may not be true for another group in a different setting" (Taylor, 1994, p. 267).

Blumer (1969) stated that "human beings act toward things on the basis of meanings that things have for them" (p. 2). Things are perceived to include everything that human beings may interact with in their worlds: physical objects, other human beings, institutions, activities of others, guiding ideals, and situations. According to Blumer, meanings of objects or "things" for human beings are derived from the interactions that they have with others and through reflection within the self. Therefore, meaning is seen as not inherent to an object or thing, but rather as a matter of human

perception. Meaning is derived from the interactions that individuals have with the world around them (Blumer, 1969; Taylor, 1994; Morrison, 2002). Blumer's view of meaning is termed as symbolic interactionism. Symbolic interactionism includes "seeing people as active, interpreting individuals who construct worlds of meanings and who act upon the world rather than allowing the world to act upon them" (Morrison, 2002, p. 17).

The way in which qualitative researchers go about investigating a certain topic or question is guided by the assumptions that meaning (a) is both individual and shared, (b) comes from interactions with others, and (c) is contextual. These assumptions are important when investigating the roles of primary caregivers within the family. Meaning is the central concept in understanding the experiences of the primary caregiver to an individual with age-related fragility or cognitive impairment due to a traumatic brain injury. "It can refer to research about persons' lives, stories, behaviors, but also about organizational functioning, social movements, or interactional relationships" (Strauss & Corbin, 1990, p. 17).

The common goal of qualitative research methods is to understand the world from the perspectives of the individuals being studied. Qualitative researchers hold a belief that they have a certain view of the world that may be different from the views held by the groups they wish to study. It is for this reason that qualitative researchers must suspend their own interpretations of what things mean and rely on their observations of and conversations with the research participants whom they interview. Researchers do not distance themselves from their participants and their meanings. Qualitative researchers stay close to the phenomenon and try to form a greater understanding of that phenomenon based on the interpretations of individual participants and how those

participants interpret the world around them. Therefore, understanding the participant's world and experience can come about only by "collecting and observing data in the forms that are natural to the participants"(Taylor, 1994, p. 268). Qualitative researchers gather verbal and nonverbal data that are said to be valid, real, rich, deep, and thick (Morrison, 2002).

Included in this chapter on methodology are the descriptions of (a) processes of inquiry that will be used in this research study, (b) a rationale for the research design, (c) the purpose and methodologies used in the Family Caregiving Research Project with Dr. Priscilla Blanton, principal investigator, from which part of the data will be extracted, and (d) procedures used in conducting this study focusing on two groups of primary caregivers: (a) caregivers to individuals with age-related fragility and (b) caregivers to individuals with a cognitive impairment as a result of a traumatic brain injury.

Research Process

The approach used within this study included the four-step inquiry process described by McCraken (1988). This method included the use of the long, in-depth interview as an approach to facilitate understanding of the beliefs and experiences of the primary caregivers within the study. This long, qualitative interview process is illustrated in Figure 4. The first step of the long-interview approach, identified within the model as a review of analytic categories and interview design, included an extensive review of the literature and development of the research questions to be addressed within the interview process. The second step, identified within the model as review of cultural categories and interview design, allowed the researcher a more detailed and systematic appreciation for personal experiences with the topic of caregiving.

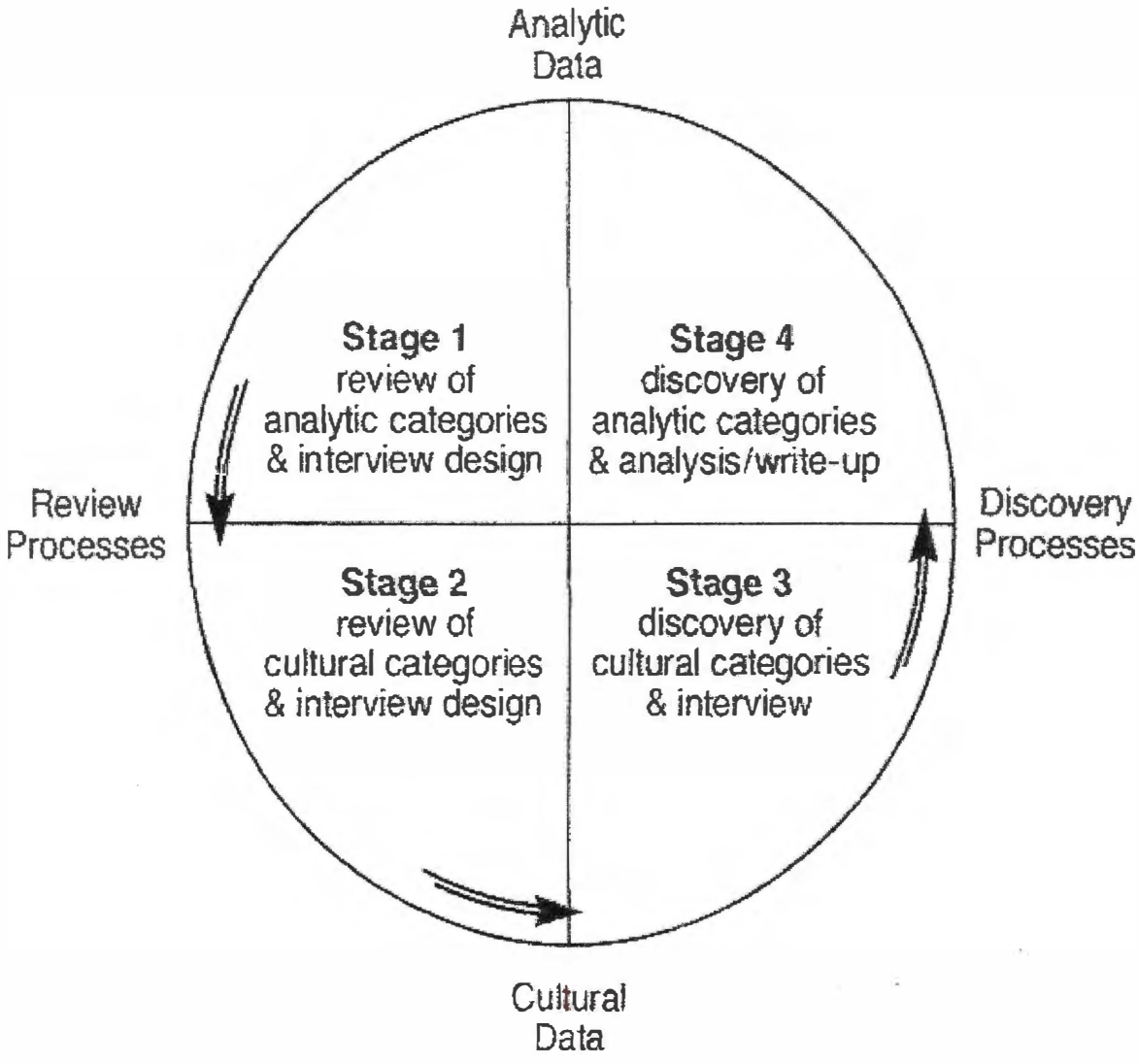


Figure 4: Long-Qualitative Interview: Four Part Method of Inquiry
Source: McCraken, G. (1988). *The long interview.* Newbury Park: Sage Publications.

This step allowed the researcher to begin the process of using the self as an instrument of inquiry and included immersion into the fields of caregiving to individuals with age-related fragility or cognitive impairment as a result of a traumatic brain injury, as well as bracketing of personal experiences related to primary caregiving. The third step of this process, identified within the model as the cultural categories and interview, included development of topical questions to guide the interview process. These questions allowed the researcher to obtain descriptive details of the individual's lived experiences. This step included collecting data in the forms of audio-taped interviews and subjective field notes based on observations before, during, and after the interview process has been completed. The fourth and final step identified within the model as discovery of analytic categories and analysis/write-up suggested the need for analysis of interview data to determine categories, relationships, and assumptions that inform the participant's view of the world in general and notions of how these views are related to the topic of primary caregiving to individuals with age-related fragility or cognitive impairment due to a traumatic brain injury (McCraken, 1988). This analysis process moved from specific to general. It concluded with the thematic analysis of transcribed interviews to see how caregivers experienced the phenomenon of primary caregiving. The final step within this interview process called for the careful verbatim transcription of the interview data. Working with the data in this form, the researcher identified themes from the interviews.

Phenomenology Defined

The term phenomenology has become so widely used that its meaning is at times unclear. Sometimes phenomenology is viewed as a paradigm, sometimes as a philosophy or a perspective, and it is sometimes even viewed as being synonymous with

qualitative methods or naturalistic inquiry (Creswell, 1998; Patton, 1990; Seidman, 1991). Phenomenological approaches are all of these things, and they focus on one primary goal: "What is the structure and essence of experience of this phenomenon for these people? The phenomenon being experienced may be an emotion such as loneliness or anger. It may be a relationship, marriage, or a job. The phenomenon may even be a program, organization, or culture" (Patton, 1990, p. 69). No matter what the phenomenon may be, it is important that the researcher understand the context in which the phenomenon is occurring, and how the individual experiencing the phenomenon expresses his or her understanding of the event.

According to Patton (1990), there are two implications that often are derived out of the phenomenological approach to research. The first implication of what is important to know is how people experience given situations and what interpretations they make of the world. "A phenomenological study describes the meaning of the lived experiences for several individuals about a central concept or the phenomenon" (Creswell, 1998, p. 51). The second implication for this approach is methodological. According to Patton (1990), the only way to understand what another person experiences is to experience it for ourselves. Phenomenologists try to interpret the experiences of others based on the verbal descriptions given by the individual experiencing the phenomenon. However, they are respectful of the fact that they may only interpret the event and how this event is impacting on this individual. This process is a source of much confusion regarding phenomenology.

> A phenomenological perspective can mean either or both (a) a focus on what people experience and how they interpret the world (in which case one can use interviews without actually experiencing the phenomenon) or (b) a methodological mandate to actually experience the phenomenon being

> investigated by the researcher (in which case participant observation would be appropriate and necessary) (Patton, 1990, p. 70).

There is a final area of phenomenology that makes it different from any other approach within qualitative research. Phenomenology explores the structures of the human consciousness in human experiences (Polkinghorne, 1989). The assumption underlying phenomenological methods is that there is an essential, invariate structure (essence) or structures that are shared experiences. These essences are the core meanings that are experienced through a shared phenomenon or experience. It is crucial to understand the importance of the concept essence to phenomenological research, because this concept is the defining characteristic of a purely phenomenological study. "Researchers using this method search for the essence or the central underlying meaning of the experience and emphasize the intentionality of consciousness where experiences contain both the outward appearance and inward consciousness based on memory, image and meaning" (Creswell, 1998, p. 52). Reality is seen as being based on the interpretation related to one's consciousness regarding the experience. Therefore, the experiences of different individuals must be explored, analyzed, and compared to identify the essence of the phenomenon.

Utilization of the Phenomenological Approach

The rationale for selecting the phenomenological approach was influenced by two factors. First, the purpose of this study was to explore the impact of the primary caregiving experience on individuals providing direct care to individuals with age-related fragility or cognitive impairment as a result of a traumatic brain injury. Second, this study was a comparison study of two distinct groups needing care, and research

necessitates a full understanding of the essence of the experiences of caregiving from the perspectives of the both groups of primary caregivers themselves.

Lauer and Handel (1977) supported the use of phenomenological approaches in working with human behaviors and external phenomenon and pointed out that Blumer stated three premises that provide insight into the importance of the use of phenomenological theory to understand the roles involved in primary caregiving:

> First, humans behave on the basis of meaning. Human behavior cannot be understood as merely the responses to stimuli or external to the individual. Rather behavior is a function of the meaning attributed to the objects, situations, and the anticipated consequences of the behavior. Second, meaning arises out of interaction. The meaning of an object or situation is not inherent; meaning is not an external phenomenon, which is imposed on the individual. Rather meaning emerges from the interaction process. Third, the use of meaning for guiding behavior occurs through a process of interpretation. Blumer states two steps in the interpretive process. The first indicates that one interacts with oneself, indicating to oneself the relevant meaning. The second involves the selective and creative use of the various meanings of an object, which one has indicated. Interpretation, then, becomes a matter of handling meanings. (Lauer & Handel, 1977, p. 304).

With the primary interest of this study focusing on comprehension and understanding of the experiences of primary caregivers, it was desired that the present research study provide a contribution to the understanding of (a) the experiences perceived by the caregivers themselves and (b) what support systems and resources are necessary to ensure that the primary caregiver is given the assistance necessary to come out of the primary caregiving role with adaptation. This study has the potential to assist family members as they begin to take on roles as primary caregivers within the future.

Individual as the Unit of Analysis

Qualitative methodologies are rooted deeply within the individual's perception of the event and ideologies related to their interactions with others. According to Gergen

and Gergen (2000), to focus research on the individual's experiences, feelings, identity, suffering, or life story is to presume the primacy of the individual and his or her perceptions of the world around them. Therefore, it is essential that the first step in a phenomenological study be to select the individual as the unit of analysis, and Creswell (1998) has suggested the inclusion of long interviews with up to 10 people when using the phenomenological tradition of inquiry in the research process. Part of the rationale for using the individual as the unit of analysis is the prevalence of previous research on caregiving to either an individual with age-related fragility or cognitive impairment as a result of a traumatic brain injury in which the individual was also the unit of analysis (Barber, & Pasley, 1995; Brody, 1990; Taylor & Bogdan, 1989). This similarity allowed the integration of the results with previous research in the area of caregiving. This integration allowed the researcher to find gaps or areas that had not been focused on in previous research. Overall, it was the experiences of primary caregivers that were the phenomena of interest.

According to Pietersma (2000), the phenomenological approach includes considerable attention to the verbal descriptions of the phenomenon given by the participants themselves. "The material itself takes on meaning and form. The meaning is constructed before our eyes" (p. 130). Meaning cannot be separated from the object nor can it be separated from the interpretation of the object by the individual. Therefore, the unit of analysis being the individual was a logical choice in order to more fully understand the meaning and interpretation of the lived experiences of primary caregivers as relayed by their verbal descriptions during the interview process.

Procedures

Seidman (1985) stated, "We simply cannot understand phenomena without considering culture both as a cause and as a way of explaining such phenomena" (p. 311). The reflective process of the researcher who is observing the phenomenon and who is actively listening to what the individual is saying regarding that phenomenon, is crucial to the process of interpreting and understanding the data (Marshall & Rossman, 1989). The long interview is seen as a tool that gives researchers the ability to see the content and patterns of individuals within their daily lives, and it is the most common method used in collecting qualitative data. McCraken (1988) encouraged the use of in-depth interviewing because "this method can take us into the mental world of the individual, to glimpse at the categories and logic by which he or she sees the world" (p. 9). The long interview allows the researcher the ability to step into the mind of another person, and to see and experience the world as they understand it.

Based on the importance of understanding the experiences of others, in-depth interviewing was the primary data collection method used within this research study. Two other data collection methods used within this research study were informal observations and field notes. Writing down observations regarding the interview and the environment surrounding the interview process and making field notes reflecting personal reactions, or reflective noting, were conducted at the conclusion of each interview session. In addition to these three techniques, the researcher drew on her reactions to her experiences as a primary caregiver. These experiences were bracketed in order to more fully understand personal bias surrounding the topic of primary caregiving. These subjective reactions to field and personal experiences in caregiving are bracketed in detail

in Appendix A. Although these bracketed experiences were not directly related to the data, they were, as expected, part of the interpretive process of analyzing the data.

Data that were included within the study came from two contexts of caregivers. The first wave of data, focusing on caregivers to frail elders, was collected from August 2001 through July 2002 in Dr. Priscilla Blanton's Family Caregiving Research project, which is summarized in the next section of this chapter. The second wave of data, focusing on caregivers to individuals with traumatic brain injuries was collected September 2002 through February 2003 from individuals identified through two separate programs. The first contact was with Ms. Cindy Murdock-Elliott at the Tennessee Rehabilitation Center (TRC) in Smyrna, Tennessee. Ms. Murdock-Elliott is the director of the Traumatic Brain Injury program at the center and agreed to provide participants in her program with the information regarding this research study. The second contact was with Ms. Patty Cruze at the Brain Injury Center at Fort Sanders Regional Medical Center, Knoxville, Tennessee. Ms. Cruze is the brain injury services coordinator with Fort Sanders Regional Medical Center. She agreed to allow the researcher to speak at a support group meeting and to place information in the local support group monthly newsletter concerning the need for participants for this research study.

Recruitment of Participants

Participants for the project included primary caregivers involved in the caregiving process to either individuals with age-related fragility or cognitive impairment as a result of a traumatic brain injury. A one-half page summary of this research project was developed in order to assist individuals in understanding the research project and to see if they were interested in participating. For the first wave of data, participants from Dr.

Blanton's caregiving project were secured through a snowball sample within the community. This process involved interviewing one individual providing care to a frail elder and then obtaining from this interviewee the names of others in the community (friend, neighbor, relative) that might be willing to discuss their caregiving experience with the researcher. For the second wave of data, Ms. Murdock-Elliott at TRC and Ms. Patty Cruz at Fort Sanders Regional Medical Center worked closely with the researcher. Ms. Murdock-Elliott assisted in obtaining participants by explaining this research project to families as a family member enters the brain injury center at TRC. An informed consent form was signed if there was an interest in the study, and then the "new" participant was given the contact information for the researcher in order to schedule the interview with the primary caregiver. Ms. Cruz assisted in obtaining participants by allowing the researcher to speak with the Brain Injury Support group at their monthly meeting held at Fort Sanders Regional Medical Center. She assisted also in participant recruitment by allowing a small vignette to be placed in the monthly newsletter distributed in the Knoxville area describing the caregiving study to possible interested individuals within the community. By the end of this research project, the researcher had 10 individuals providing direct care to individuals with age-related fragility or cognitive impairment as a result of a traumatic brain injury.

Sampling Procedures

Some of the participants for this research study came from the Family Caregiving Project conducted by Dr. Priscilla Blanton. These participants were selected out of the caregiver project based on the criterion that was presented within this section of the research study. Primary caregivers providing direct care to frail elders were subject to

the same criteria as those individuals providing direct care to individuals with traumatic brain injuries. However, these participants were selected through contacts with the Tennessee Rehabilitation Center in Smyrna, Tennessee and the Fort Sanders Regional Medical Center's Brain Injury Support Group in Knoxville, Tennessee. According to Creswell (1998), participants need to be selected according to the best opportunity to learn about the phenomenon (purposive sampling), and the selection must include persons who fit both demographic and individual characteristic variables that are the focus of the phenomenon being studied (criterion sampling). The sampling criteria included the following attributes of the primary caregiving experience: (a) identified as primary caregiver to frail elder or an individual with a traumatic brain injury, (b) setting in which care is being provided, (c) socioeconomic status, and (d) participant's interest in the research study as evaluated by the researcher (potential for learning). In the process of selecting 10 participants, the goal of the selection process was to achieve the purposeful selection of primary caregivers who had experienced the phenomenon of providing direct care to an individual with age-related fragility or cognitive impairment due to a traumatic brain injury, with special attention to the extent of caregiving involvement, the care setting and environment, socioeconomic background, and the support systems available to the individual providing direct care.

Rationale for Sampling Criteria

Many constructionist and critical theorists, within qualitative research, employ theoretical or purposive sampling. These researchers seek out groups, settings and individuals where and for whom the phenomenon being studied is more likely to occur (Denzin & Lincoln, 2000). The purposeful selection of participants represents a key

decision point in a qualitative study. According to Creswell (1998), researchers designing qualitative studies need clear criteria in mind and need to provide rationales for their decisions. The logic and power of purposeful sampling lies in selecting information rich "cases" for in-depth study. Information rich "cases" are those from which one can learn a great deal about issues surrounding a certain phenomenon (Patton, 1990).

Limitations may be seen in the sampling of participants for this research study. These limitations may be seen in the following areas: (a) sampling procedures, (b) phenomenon of caregiving, and (c) in the contexts of primary caregivers who are providing direct care to individuals with either age-related fragility or cognitive impairment as a result of a traumatic brain injury.

Regarding the sample of participants that were selected for this research study, the sampling strategies ensured that the primary caregivers selected for the study were only those individuals providing direct care to individuals with age-related fragility or cognitive impairment as a result of a traumatic brain injury. This limited the number of participants that were available to share their experiences regarding this phenomenon.

The phenomenon of primary caregiving limited the sample within this study. According to Taylor (1994), "Meaning is ever changing, it is always in a process of interpretation or refinement" (p. 266). Therefore, when the researcher focuses on the primary caregiving experience and the impact of that lived experience on the caregivers themselves, the researcher must understand that the information gathered about the topic of caregiving is not going to remain the same over time. The perception of what it is to be a primary caregiver is dynamic and changing, as people constantly interpret, reinterpret and make meaningful responses to their roles as direct care providers.

Because meanings change over time and within context, the researcher should never assume that there is a single meaning to a phenomenon over time.

The sample was limited to the two contexts representing caregivers to individuals with age-related fragility and caregivers to individuals with cognitive impairment as a result of a traumatic brain injury. These groups were limited even further by demographic information and by the region of the country in which the participants were selected. Primary caregivers to individuals with age-related fragility will be selected from the Family Caregiving Project being conducted by Dr. Priscilla Blanton at the University of Tennessee. The primary caregivers to individuals with a cognitive impairment as a result of a traumatic brain injury were selected from both the Tennessee Rehabilitation Center, Smryna, Tennessee and from the Brain Injury Support Group at Fort Sanders Regional Medical Center, Knoxville, Tennessee. Both sets of participants were limited to the Middle and East regions of Tennessee.

Participants were asked to voluntarily participate in the research study. This caused a limitation in that there may be individuals who chose not to participate in the study, and the information regarding the primary caregiving experiences for those non-participants was not able to be addressed within the research study. Also, there were primary caregivers who did not know about the study, and their perceptions and interpretations of the caregiving experiences were not explored.

In spite of these sampling limitations, interpretation of the essence of the experience by the researcher was an acceptable standard of verification of this method. For Moustakas (1994), "Establishing the truth of things begins with the researcher's perceptions" (p. 57). The researcher first must reflect on the meaning of the experience;

then the researcher must turn outward to the participants being interviewed regarding their experiences and must establish intersubjective validity. "This type of validity reflects the testing out of the understanding of the phenomenon with other individuals through a social interaction" (p. 57). Accepting the authenticity of the data was based on the verbal descriptions of the phenomenon as given by the primary caregivers providing direct care. There was no single, or determinable one Truth. Instead there were multiple truths that were bound by time, the context and the individuals who believe in them (Taylor, 1994).

Informed Consent Procedures

The standards used within this research study have been outlined in the informed consent forms that have been used within Dr. Blanton's caregiver project and that were approved by the Application Review of Research involving Human Subjects Board (IRB). This form was modified to include only minor changes in the original IRB process to make the form relevant to the individual caregivers providing primary care to individuals with traumatic brain injury. These forms have been placed at the end of this study and are reflected in an Appendix B.

When the interview process began, potential participants were given the consent form to read, and if needed, to address any questions regarding the form itself. The researcher explained verbally the purpose of the research study, the procedures that were to be used in obtaining the data, and the option of withdrawing from participation in the study. The interview process proceeded and the informed consent was signed only if the participant was comfortable in sharing experiences and in continuing in the research study.

In-Depth Interview Process

All of the interviews with the primary caregivers were conducted by the researcher and ranged in length from 1 to 2 hours. These interviews were arranged at a time and place convenient for the participant, which included the options of the participant's home, place of work, or public setting such as a library. The interview environment allowed for reasonable privacy in order for the sharing of possibly sensitive information regarding the caregiving experience. The setting was appropriate to allow the researcher to observe the participant in a natural setting. All interviews were audio-taped, transcribed, checked, and rechecked for accuracy.

The format for the interview was open and flexible, allowed the participant to share their experience with the researcher. However, topical and issue questions were developed in order to assist in the interview process. This interview guide was developed based on the areas that were covered in the interview with the participant and were refined by the researcher as the interview process proceeded. In each of the interviews, the areas related to the stresses, challenges, and rewards of caregiving, as well as other areas of interest to the participant were explored.

As part of the interview process, demographic data were obtained from each participant. Due to the possible lack of time or the caregiver's desire to move directly into the interview process, these demographic data were collected at the conclusion of the interview process. The gathering of this data was included in the audio-taping of the participant when possible and on the information form taken by the researcher. Added to the original form in the Family Caregiving Project conducted by Dr. Blanton was the issue of traumatic brain injury and Social Security income.

Issues of Confidentiality

All of the in-depth interviews within this study were conduced face-to-face in a setting of the participant's choice. Participants were assured that the data from the individual primary caregiver was kept confidential and that their personal or familial identity were concealed in any written or oral presentation of the findings of the research study. Also, the participants were assured that the audio-taped interview sessions were used only for the purposes of research notes, and that the transcriptions of the tapes were managed in the appropriate manner to ensure their anonymity and confidentiality.

At the beginning of each interview, participants were asked to complete a cognitive mapping activity that involved using a target to reflect connections with family members, friends, and other community resources. The form that was used for this activity originated from the family caregiver project with Dr. Priscilla Blanton, and it was used as an ice breaking activity at the beginning of the interview. This mapping form, or target, allowed the researcher to focus on the experiences of the primary caregiver, and allowed the caregiver to reflect on their support systems and resources surrounding them in their communities.

Qualitative Analysis Strategies

The purpose of qualitative inquiry was to produce findings regarding a phenomenon and the process of data collection is not an end in itself. As stated by Patton (1990), "Data collection is the culminating activities of qualitative inquiry that involve analysis interpretation and presentation of findings" (p. 371). The challenge of qualitative analysis is to make sense of the massive amount of data collected, reduce the volume of information, identify significant patterns within the data set itself, and

construct a framework for communicating the essence of what the data revealed regarding the phenomenon. The problem is that "we have few agreed-on canons for qualitative data analysis, in the sense of shared ground rules for drawing conclusions and verifying their sturdiness" (Miles & Huberman, 1984, p. 16). There are no formulas by which qualitative researchers determine significance, and there is no way to perfectly replicate the researcher's thought processes used in the analysis of the data. However, this does not mean that there are no guidelines for assisting in the analysis of data within the research study. The guidelines and procedures for data analysis are not rules. Applying the guidelines to the research study required judgment and creativity on the part of the researcher. Due to this fact, qualitative studies are unique, and the analytical approach used was unique. "Because qualitative inquiry depends, at every stage, on the skills, training, insights and capabilities of the researcher, qualitative analysis ultimately depends on the analytical intellect and style of the analyst" (Patton, 1990, p. 373).

This chapter presented strategies, guidelines, and ideas for the analysis, interpretation and presentation of qualitative data. In actually performing the analysis, the researcher had to adapt to what is present to fit the specific phenomenon of the primary caregiving experience. The final obligation of this analysis of data was to analyze and report the true essence of the primary caregiving experience based on the verbal descriptions taken from the transcribed interviews with the primary caregivers themselves.

The Data Analysis Spiral

Data analysis is custom designed. Creswell (1998) described the contour of data analysis as a spiral image, "a data analysis spiral" (p. 142). As shown in Figure 5, to

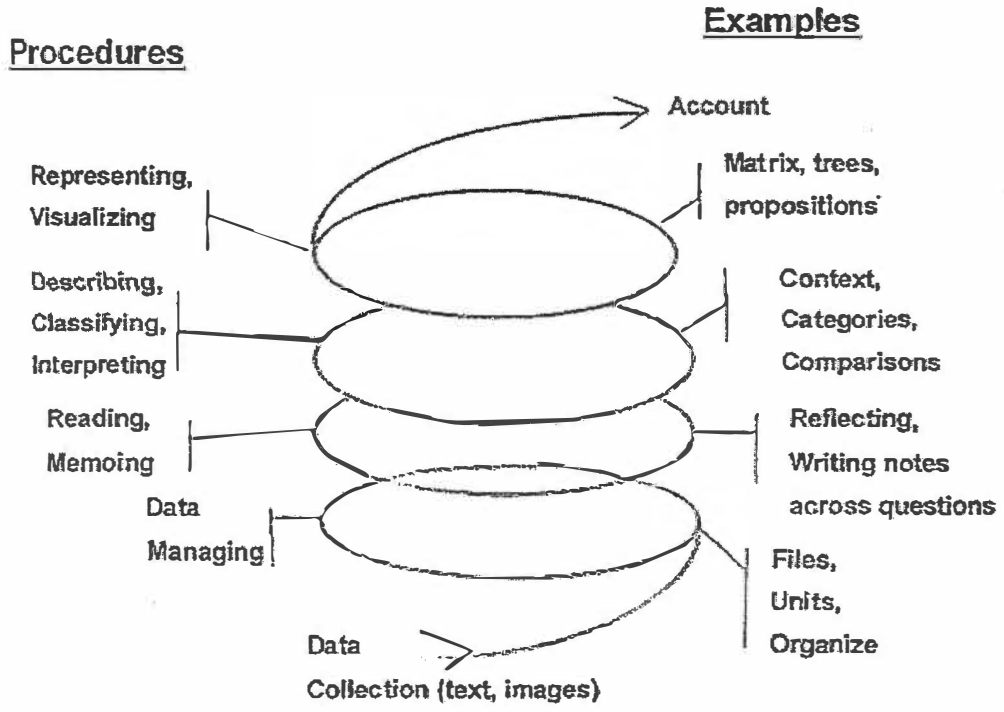


Figure 5: The Data Analysis Spiral

Source: Creswell, J.W. (1998). *Qualitative inquiry and research design: Choosing among five traditions.* Thousands Oaks, CA: Sage Publications.

analyze data, the researcher engages in the process of moving in analytic circles rather than a fixed linear approach. The researcher enters with data or images and exits with an account or a narrative. In between the beginning of the analysis process and the discovery of the essence of the experience, the researcher focuses on several aspects of analysis.

Data management is the first loop in the spiral and begins the process. At this stage in the analytical process, researchers organize their data into file folders, index cards, or computer files. Besides organizing files, the researcher must convert the files to appropriate text units (a word, a sentence, or a story) for analysis by hand. The converted transcriptions of the in-depth interviews with the participants assists in the filing process and with all analytical considerations.

Following the organization and conversion of data, the researcher continues the analysis by obtaining a sense of the whole experience. Agar (1980) has suggested that the researcher "read the transcripts in their entirely several times, immerse oneself in the details, and try to get a sense of the interview as a whole before breaking it into parts"(p. 106). Writing memos in the margins of field notes or transcripts assisted in this initial process of exploring the individual's experience. These memos were short phrases, ideas, or key concepts that occurred to the researcher while sorting through the transcriptions.

When the researcher was focusing on the data, it became necessary to analyze all of the transcriptions to identify major organizing ideas. Looking over field notes or observations, interview data, and listening to the audio-taped recordings of the interviews, the researcher had to disregard any predetermined bias regarding the phenomenon, and the researcher had to listen for what the participant was trying to share about the experience.

This process consisted of moving from the reading and memoing loop in the spiral to the describing, classifying, and interpreting loop. It was in this loop that category formation occurred. Here, the researcher describes in detail, develops themes or dimensions through some classification system, and provides an interpretation of their own view or views of the phenomenon. The researcher, as described by Creswell (1998), "employs descriptive detail, classification or interpretation or some combination of these analysis procedures" (p. 144). Detailed descriptions meant that the researcher described what is seen in the context of the setting, place, and phenomenon as described by the participant. "Classifying allows the researcher to take the text or qualitative data and

look for categories, themes or dimensions of information" (Creswell, 1998, p. 145). Classification in this research study, allowed the researcher to identify five to six major themes in order to begin the writing of the final narrative.

Interpretation of the data involved making sense of the information presented. Several forms of interpretation exist. Creswell (1998) described these interpretations as "interpretation based on hunches, insights and intuition" (p. 145). Interpretation may include also a social construct or idea or a combination of personal views with the construct or idea. It was at this point in the analysis that the researcher reflects on and forms a larger meaning of what is going on with the phenomenon (Creswell, 1998).

In the final phase of the spiral, the researcher presents the data. The data may be illustrated by presenting the conclusions within the text, presenting the conclusions in a table, or by using a figure to explain the data. First, the illustration of the data demonstrated the inductive analysis that began with the raw data consisting of multiple sources of information. Second, it demonstrated how the data was focused to include several specific themes. Finally, it demonstrated how the data has evolved to reflect the final "essence" of the experience.

Stevick-Colaizzi-Keen Data Analysis Method

Moustakas (1994) described the Stevick-Colaizzi-Keen data analysis method. This method is used frequently in phenomenological studies. The steps are as follows:

1. The researcher begins with a full description of his or her own experience of the phenomenon.
2. The researcher then finds statements (in the interviews) about how individuals share experiencing the topic, lists out these significant statements

and treats each statement as having equal worth, and works to develop a list of non-repetitive, non-overlapping statements.

3. These statements are then grouped into "meaning units", the researcher lists these units, and he or she writes the description of the "textures" of the experience-what happened-including verbatim examples.
4. The researcher next reflects on his or her own description and uses imaginative variation or structural description, seeking all possible meanings and divergent perspectives, varying frames of reference about the phenomenon, and constructing a description of how the phenomenon was experienced.
5. The researcher then constructs an overall description of the meaning and the essence of the experience.

This protocol was used in addition to the spiral procedure (Creswell, 1998) as a data analysis method to assist in exploring the experiences of primary caregiving to individuals with age-related fragility or cognitive impairment as a result of a traumatic brain injury.

Phenomenology and Standards of Verification

Creswell (1998) framed an interesting question for researchers in the area of qualitative research: "Do standards exist for assessing the quality of qualitative research, standards at either the abstract or specific level?" (p. 194). Howe and Eisenhardt (1990) suggested that there are only broad, abstract standards possible for evaluating qualitative research. Howe and Eisenhardt (1990) suggested the first standards to be applied to all qualitative research. Initially, the study is addressed in terms of whether the research

questions drive the data collection and analysis. Next, an examination of the data collection and analysis techniques are addressed to determine whether the data has been competently applied in a technical sense. Then the process questions whether the researcher's assumptions are made explicit, such as the researcher's own subjectivity. Fourth, there is a focus on whether a study has overall warrant, such as whether it is robust, uses respected theoretical explanations, and discusses disconfirmed theoretical implications. Finally, the study must have "value" both toward informing and improving practice and in protecting confidentiality, privacy, and truth telling of participants.

Multiple perspectives exist regarding the importance of verification in qualitative research, the definition of qualitative research, and the procedures for establishing this type of research. According to Lincoln and Guba (1985), to establish the trustworthiness of a study, terms should be used that "adhere to more to a naturalistic axiom" (p. 300). These authors use the terms credibility, transferability, dependability, and confirmability as the equivalents to internal validity, external validity, reliability, and objectivity (p. 300). To assist with the use and incorporation of these new terms, proposed techniques, such as prolonged engagement in the field and triangulation of the data are established to assist with credibility (Creswell, 1998). To ensure that the findings are transferable, the researcher must make sure that the phenomenon being studied is described with thick description of the experience. Rather than reliability, Lincoln and Guba (1985) suggested that "one seeks dependability that the results will be subject to change and instability" (p. 305). The naturalistic researcher looks to confirmability rather than objectivity in establishing the value of data (Creswell, 1998).

Rather than using the term validity, Eisner (1991) suggested the use of credibility of qualitative research. There is a construction of standards such as structural corroboration, consensual validation, and referential adequacy. In structural corroboration, the researcher related multiple types of data to support or contradict the interpretation. Eisner (1991) stated, "We seek a confluence of evidence that breeds credibility, that allows us to feel confident about our observations, interpretations, and conclusions (p. 110). It is with this stage that the researcher looks for recurring behaviors and actions that disconfirm evidence or are conflictual within the interpretation process. Consensual validation seeks the opinions of others. Eisner (1991) confirmed, "an agreement among competent others that the description, interpretation, evaluation and thematics of a situation are correct"(p. 112). Finally, referential adequacy refers to the adequacy and importance of criticism. Eisner (1991) describes the goals of criticism as, "illuminating the subject matter and brining about more complex and sensitive human perception and understanding" (p. 112).

Phenomenologists view verification and standards as "largely related to the researcher's interpretation" (Creswell, 1998, p. 207). Moustakas (1994), provides a focus on establishing the truth of things and begins with the researcher's perception of the interview or research experience. The individual is seen as needing to reflect, first, on the meaning of the experience for oneself; then one must turn outward, to those being interviewed to understand the true essence of the experience. The criteria used to judge the verification of this phenomenological approach is best reflected by Polkinghorne (1989), who argued that "validity refers to the notion that an idea is well grounded and well supported"(p. 57). Another tool used to judge verification of this phenomenological

approach was seen with the weekly meetings conducted with Dr. Priscilla White Blanton, and the independent analysis of the research data sets performed by Dr. Priscilla White Blanton. While conducting this research study, the researcher and Dr. Priscilla White Blanton met weekly to address emergent themes, and to address similarities and differences within the context of these themes. This lent support to the trustworthiness and the validity of this phenomenological research study.

Reflexivity is referred to as "personal reactions" (Gay, 1996, p.225) and is often seen in field notes. These notes include interpretations and other subjective thoughts and feelings, but they are differentiated from more objective, strictly descriptive, field notes; typically special codes will be used. In these notes, the researcher is seen as being free to share or express any thoughts regarding how the interview process may be going, where things are going in the process, and what might be concluded upon completion of the process (Gay, 1996). Reflexive notes might include statements that the researcher deems important to the interview process. This type of insight and reflexive activity adds a significant dimension to the observations and therefore will contribute to producing a rich description of the experience.

Qualitative Research Considerations

Inductive methods and data analysis strategies are the most effective approaches to use for addressing the human experience like individual primary caregivers to individuals with age-related fragility or cognitive impairment as a result of a traumatic brain injury. Charon (1998) suggests that using qualitative methods to study primary caregivers is grounded in the theoretical perspectives of family systems theory, stress theory and symbolic interactionism, for the basis of how primary caregivers experience

their roles as direct care providers. Family systems theory lends itself well in support of qualitative methodologies. This theory helps to address the needs that individuals, within the family unit will have as they take on the role as a primary caregiver providing direct care to a frail elder or an individual with traumatic brain injury (Briggs, 1998; Burr & Klein, 1994; Stephens, Crowther, Hobfoll, & Tennenbaum, 1990). Stress theory is a second perspective that lends support to the use of a qualitative paradigm. Stress theory focuses on the stress level of the family as being qualitatively different from the sum of the individual stress levels of the family members (Boss, 1998; Billing & Moo, 1984). A final theory that lends support to the use of a qualitative paradigm is symbolic interactionism. This theory reflects on the need to address meaning, and the interpretation of meaning, in order to understand how individuals interpret their lived experiences as primary caregivers (Charon, 1998; McCubbin, Sussman, & Patterson, 1983).

Qualitative researchers must be willing to take the time to "hear" the experiences of others. According to phenomenological approaches to research some of the basic assumptions that drive the methods behind this qualitative process are (1) seeing the world as made up of active individuals, (2) understanding that the center for human behavior is the concept of meaning, and (3) the knowledge that there is no one determinable "Truth" only multiple "truths". Each of these assumptions will assist the researcher in understanding the lived experiences of primary caregivers providing direct care to individuals with age related fragility or cognitive impairment as a result of a traumatic brain injury.

People as Active Individuals

"Qualitative researchers see the world as being made up of active, interpreting individuals forgoing purposeful lines of action to accomplish everyday life" (Morrison, 2002, p. 18). Individuals take note of the events going on in the world around them, and they process or assign meaning to these things. According to these active processes, individuals then plan courses of action. Because meaning arises from within the individual, the behavior of the person cannot be understood without focusing on the inner being. "Human beings are not seen as simply responding to stimuli" (Charon, 1998, p. 139). Instead, individuals are constantly trying to interpret the world around them and place meaning on an object or event. Ultimately the qualitative researcher understands that human behavior will be based on the meaningful interpretation of the event according to the specific individual (Charon, 1998).

The methodological implications of this assumption are reflected in the specific strategies that were explored to understand primary caregivers, how they explore their worlds, and how they place meaning on objects within their worlds. These strategies included the use of field observations or field notes (Taylor, 1994) and in-depth interviewing (McCraken, 1988) in trying to understand the essence of the primary caregiving experience for these participants. These two strategies are consistent with the phenomenological approach in that they try to approach the participant, within their natural setting, in order to minimize disturbance of their natural world. Also, these two strategies preserve the phenomenon and the experience of the phenomenon within the family unit.

Meaning and Interpretation in Qualitative Research

At the center of the explanation of human behavior is the meaning that the behavior holds for the individual. If the researcher can understand "meaning," then the researcher may begin to understand the direct behaviors surrounding a certain type of experience. Meaning is seen as being shared among individuals. Qualitative researchers seek to understand the shared meanings between individuals experiencing a certain phenomenon. Meaning is not seen as static, but rather changing over time and place, within context, and with people (Morrison, 1998).

For qualitative researchers, meaning is the central concept in understanding the ways in which human beings interpret the world around them. Researchers believe that in order to understand human experiences, one must be able to uncover meaningful objects in the individual's world and understand what those objects mean to the individual (Rock, 1979). All relationships, objects, and events have meaning for individuals. By focusing on the meaning as coming from inside the individual, researchers deny that meaning will come from outside the human experience. "Experiences in the life of the individual have no meaning except that meaning which is placed on them by the individual himself"(Rock, 1979, p. 125). The methodological implication, when focusing on meaning, is that the perspective of the individual will be conveyed through their verbal expression. This expression is essential in understanding the phenomenon of the primary caregiving experience.

Multiple "truths" in Qualitative Research

In the area of qualitative research there is no single Truth. Instead there are many truths to be found in the human experience. "These 'truths' are bound by time, the

context and by the individuals who believe them" (Taylor, 1994, p. 19). What constitutes truth is the shared beliefs and shared realties of individuals.

The external world does not allow for unlimited interpretation of the shared experiences between individuals. There are limitations to these interpretations, and these limitations are often defined by the culture of the individual. Experiences are not limited to a single interpretation, rather by multiple interpretations made by the individual to understand their experiences and the world around them. "Meaning changes with context" (Morrison, 2002, p. 21).

The methodological implications of this assumption include the need for the researcher to provide attention to the participants' experiences, and how these experiences impact on the participants' definition of truth within their world. By allowing the individuals to explain their realities, and the truth or truths surrounding their realities, researchers begin to gain valuable insight into the worlds of the participants. This research study sought to understand of the multiple truths that are interwoven into the lives of primary caregivers, and it sought truths in explaining the impact of the lived experiences of primary caregivers within the context of the family.

CHAPTER 4

RESULTS

Frail Elder Caregivers

The participants for this study included 10 caregivers dealing with various issues surrounding their primary caregiving experiences. The names of the primary caregivers have been changed to protect the participants' identities and to respect the privacy of the family. Table 1 below includes a brief description of the caregiving situation for caregivers involved in direct care provision to frail elders. Demographic characteristics such as condition of the care recipient, gender of the primary caregiver, gender of the care recipient, the care setting, and socioeconomic status (SES) have been identified.

Table 1

Primary Caregiving Participants: Frail Elders

Characteristic	Participant 1 (Jim)	Participant 2 (Peg)	Participant 3 (Jill)	Participant 4 (Bob)	Participant 5 (Joe)
Condition of Care Recipient	Diabetes	Emphysema	Alzheimer's	Vision loss Lung Disease	Diabetes
Gender of Care Recipient	Male	Female	Female	Female	Female
Primary Caregiver	Son	Daughter	Daughter	Brother	Son
Gender of Caregiver	Male	Female	Female	Male	Male
Care Setting	Own home/ Father's home	Own home	Nursing home	Own home	Own home/ Mother's home
SES	Working	Working	Professional	Retired Professional	Professional

The first primary caregiver, Jim, was providing direct care to his father, who was experiencing extensive medical problems compounded by his diabetic condition. Jim had decided to provide direct care to his father and he wanted to assist his father in remaining in his own home. Therefore, direct care was provided at Jim's home and at the home of his father.

The second primary caregiver, Peg, was providing direct care to her mother, who had emphysema. Peg had decided that her mother needed assistance with medical care, and that this care could not be provided in her mother's home. Therefore, primary caregiving was provided in Peg's home.

The third primary caregiver, Jill, was providing direct care to her mother who was in the middle to late stages of Alzheimer's disease. Jill was the only primary caregiver in the study who had elected to have community assistance with direct care, and had placed her mother in a nursing home care facility.

The fourth primary caregiver, Bob, was providing direct care to his sister, who had peripheral vision loss and who needed oxygen due to lung disease. Bob was providing direct care to his 85-year-old sister with assistance from his wife in their home. Bob was the only participant in the study in the frail elder group providing direct care to a sibling. Bob was the only participant in the study who was in the later stages of adulthood (81 years of age).

The final primary caregiver providing direct care for a frail elder, Joe, was providing direct care for his mother, who was experiencing problems directly related to diabetes. His mother desired to remain in her home during the day and at Joe's home in

the evening. Therefore, direct care was provided both at Joe's home and at the home of his mother.

This range of medical conditions and care settings permitted a view of the primary caregiving experiences with frail elders in several different contexts. Among these five participants, all of whom where providing direct care to frail elders, there were three males and two females. Two of the males involved in primary care to frail elders were sons and one was a male sibling. Both of the females were daughters of frail elders.

In terms of socioeconomic backgrounds, two primary caregivers were identified as working class, two as professional or middle class, and one as a retired professional, based on the self-reported demographic data regarding education, income, and occupation obtained during the interview process. It is important to note that each of these primary caregivers' identities were protected by the use of pseudonyms throughout this study, and the use of references to the demographic information of each primary caregiver was used only to explain decisions regarding their selection for the caregiving study. Care was taken to disguise attributes of the primary caregiver and to ensure that exposure or embarrassment of the caregivers would be avoided.

Emergent Themes: Caregiving to Frail Elders

Four themes emerged from the analysis of the interviews with this group of primary caregivers. The first theme focused on decisions about the setting in which care was provided. The second theme focused on the need for an acceptance of the primary caregiver role and of the responsibility to care for another individual regardless of severity of fragility. Along with acceptance of the role as a primary caregiver was the third theme which focused on the need of the caregiver to be able to access support

networks and support systems within the family unit and in the community. Participants placed emphasis on the need to access these valuable resources in order to manage the primary caregiving experience effectively. The final theme focused on the participants as they described their needs for personal time while providing care to a frail elder. The participants stressed the need to take care of themselves while taking care of others. Without the ability to take care of themselves first, the participants reflected on their inability to provide the best care possible for the frail elder.

A Desire to Provide Primary Care at Home

For primary caregivers, the desire to provide care at home is a crucial issue in the decision-making process. Individuals who desired to care for frail elders within the home often described a belief that direct care should come from individuals within the home and not from care facilities in the community. This personal belief is best illustrated by the following statements

> *When the time comes that she needs assisted living, then she is certainly going to live with us. And that's not an issue. My wife is very open about that and that's cool. So we find ourselves starting to think those thoughts: planning for the future. (Joe)*

> *I chose not to put my mom somewhere like that because I frankly didn't believe that she would last. She's a big family-oriented person. That's how we were raised and I thought putting her in a facility, putting her in a nursing home, she wouldn't last. (Peg)*

One primary caregiver had placed her mother in a nursing care facility in the community. This caregiver struggled with the fact that she could no longer provide direct care for her mother effectively, and she described her feelings of guilt due to her mother's request to

be taken back home. She explained her personal belief of caregiving within the home by the following statement.

> *Because I know sometimes she wants to be at home. She puts me in a...she sends me on a guilt trip. She said, "Well you could take me home if you want to." She says, "I took care of my mother. Why can't you take care of me?" (Jill)*

Such conflicts are an increasing challenge for many individuals who desire to provide direct care in the home but for various reasons are unable to continue doing so. Merrill (1997) has suggested that this theme is one that is extremely challenging to the adult care provider. "Caring for frail elders in the home is an ongoing process, and this process will change over time" (p. 118). This theme has been accepted in this research study by three of the participants providing care to frail elders. They were willing to provide any type of care, and as long as the care was needed, in order to ensure that the individual was cared for in the home. However, one primary caregiver (Jill) could not provide this extensive care and chose to gain assistance by placing her mother in a local nursing care facility. This posed a great challenge for her. In Jill's interview, she spoke about her feelings of guilt and remorse for having to gain assistance with the direct care for her mother. Merrill (1997) reflected on feelings of guilt and remorse by the caregiver. These feelings are best seen in terms of the caregiving process as "losing control of the caregiving process" (p. 119). This loss of control is what invokes these conflicted feelings within the individual. It is with this loss of control that the primary caregiver begins to feel as though the frail elder "will no longer receive the best care, and that care can be best provided in the home" (p. 119).

Acceptance of the Primary Caregiving Role

Participants reflected on their need to accept the role of primary caregiver within the family system. Briggs (1998) stated that this acceptance of the role of primary caregiver may be due to "the sense of familial responsibility due to reverence, belief in debt of gratitude, or an expression of friendship and love" (p. 31). All of the participants at some point during the interview process expressed their feelings of being able to accept the role as a primary caregiver. For two of the primary caregivers, acceptance of this primary caregiving role was a decision that was made easily.

> *It's just part of it. I don't, interestingly enough I've heard other people actually complain about having to do this or that for their elderly parents and it gets on their nerves and it's interesting, I just don't share those types of experiences. I might be in the minority and that is okay. It's just part of me. We've accepted it as a part of it, and I've never been aggravated about it. (Joe)*

> *I took family medical leave, took time off. I stayed with her for 6 weeks to get her settled. Actually I had fun doing that because I got to spend time with her. So it worked out really well. I never really minded it and never I mean I just knew that it had to be done (Peg).*

However, for the remaining three primary caregivers providing direct care to a frail elder was not a role that was easily accepted by the individual. Their attitudes toward their roles as primary caregivers are reflected in their feelings of ambivalence and guilt. These feelings are best illustrated by the following statements.

> *Well, when it comes to my dad, it's more what he relies on me for. It's more of me working a schedule around his needs so...he may call in a day or two in advance or for the most part at the last minute and give me a "I need." And then if I'm available to do it even if I'm not available, he puts demands on me--which puts pressure and creates situations between my wife and myself. These needs conflict, and they may conflict with what's going on in my personal life. That's just hard to accept. (Jim)*

> *Okay. Now maybe let me talk and then I'll, but it took me a long time to accept, I guess, that mother was in a nursing home. And I guess that's where the family*

council helps me now because I can go to the family when other people come in who just have guilt, you know that I have. (Jill)

I said that sometimes she just makes me feel like...ooooooooohhh. I don't know. You get frustrated a little bit. She gets tough with aging. I just do what I can do, and then I have to go. (Bob).

Role acceptance was influenced by the pathways taken by the participants in becoming direct care providers through making the decision of who would take on the role as direct care provider within the family unit. Merrill (1997) focused on these pathway factors. These factors include "who (if anyone) is selected or volunteered, particular circumstances in which the caregiver decision is made, and how the decision is arrived upon when no one came forth to volunteer" (p. 35). In this research study, three of the participants were only children. These participants did not see as acceptable the alternative of the use of nursing home care facilities in their communities. Therefore, acceptance of their role as primary caregiver was assumed due to feelings of having no other options at the time in which direct care was needed. The remaining two caregivers took on the role as primary caregiver due to the evolution of their roles as direct care providers to frail elders. These two caregivers initially began by providing minimal care to their aging parents. Eventually, due to their parents' failing health, both participants took on primary caregiving roles, which evolved out of the previous experiences that each had as direct care providers in the past. Both of these participants were described volunteering for the "job" as primary caregivers.

Support Systems and Support Networks

In order for primary caregivers to be able to manage effectively the demands of caregiving to frail elders, the participants emphasized that caregivers must have support

within their homes and in their communities. For these participants, support systems were one key element in their ability to cope and to manage the issues that arose in their day-to-day lives. Support was described not only in context of the relationships with family and friends, but also in the context of organizations within the community. One primary caregiver explained his personal and community support systems. He reflected on the importance of having a support system while in the primary caregiving role.

> *Oh with these folks, I could pick up the phone or say, "Do you have time to do lunch today and got something that I want to bounce off of you or run by you" and "I have this concern,", and that kind of thing. All of them are that way. They'll feel more comfortable in sharing their own story and their own issue, something that's come up recently and kind of help each other through it. That helps reduce the stress, absolutely. Also, Father has met with my mother on a couple of occasions when my, both my boys did First Communion and that kind of thing and my mother would come. My mother is not Catholic. But they both have been individuals that I have chatted with on occasions, and they have been helpful in that respect. (Joe)*

There is considerable documentation that shows a need for support systems to be in place in order for individuals to achieve success within their roles as primary caregivers to frail elders (Kane & Kane, 1987; Merrill, 1997; Mui, Choi, & Monk, 1998). Several of the primary caregivers in this study reflected on the lack of support within their families and community settings. This lack of and need for support and alternatives for respite care are reflected in the statements of the following participants.

> *Where with me, it's all me. You know, I'm it. There's nobody to come in and relieve me. You just need a lot of support. (Jill)*

> *There's no one that gives me direct help other than emotional support. My wife. She's the only emotional support as far as someone that I can share what is going on with as far as my caregiving process. (Jim)*

> *As far as going somewhere even overnight, that's out of the question. We don't leave her alone during the daytime, you know, totally--a couple of hours at the most. The girls have offered to stay if you want to get away for the weekend, and*

then they are busy with everything. We just don't feel like asking anybody, and that's fine. We'd spend the weekend over there--Pigeon Forge--and we'd eat at Trotters. We can't do that no more. We're handcuffed, I reckon. We're jailed for some reason. (Bob)

According to Hobbs et al. (1984), interdependent, supportive communities are the primary and principal contexts for enhancing and promoting human development in general and strengthening family functioning in particular. "A sense of community, in turn, promotes the exchange of resources and supports that constitute the range of aid and assistance that are necessary for enhancing and maintaining individuals, families, and community well-being"(p. 121). Social support is seen as the resources or useful information that is provided to individuals and families in response to a need for aid and/or assistance. Social support networks are valuable resources for those focusing on the needs of the primary caregivers who provide direct care to frail elders. According to one of the participants, to have or to develop a social network is necessary for a healthy and productive relationship with the frail elder.

It is tough. It is tough, but it can be overwhelming at times, but if you just take it one day at a time and always be prepared...and just communicate with whoever you can because that is your support group; always speak out for support. Just a lot of support. (Jill)

However, there were two participants within this study who had very little interaction with others and lacked a strong social network. This lack of a supportive network was one area about which the participants shared their frustrations and concerns regarding the caregiver role.

And you have no outlet, and you don't know where to turn. My advice would be to find an outlet to where you have different avenues and support that you can take. (Jim)

I'm her major caregiver, I mean doctor appointments, making sure she eats right, taking her medicine correctly...I mean I have help but it's up to me to arrange for the help to come in. So, I am her major caregiver...No one else and no one to assist me. (Peg)

"Without a strong support network, or strong support system, the stress buffering and health promoting influences of the support system will increase the likelihood of emotional and physical distress related to the primary caregiving role" (Singer & Irvin, 1989, p. 124).

Personal Time

Each of the participants shared attitudes toward their caregiving responsibilities, and their need for personal time to relieve some of the pressures of their roles as direct care providers. Personal time allowed each of these caregivers time away from the everyday pressures of primary caregiving to frail elders. Each participant identified the need to have some time away from the caregiving situation within the family unit. This need for personal time is reflected in the following statements.

If I don't take care of me, I'm not going to be able to care for Mom. That's what the Chaplain told me. ...You need to go home and do the things that you normally do, and take care of yourself first. (Jill)

It was like my time was here at work. My hour break at work for lunch was my I guess salvation because it was when I would sit and read my books for solid hour and no one could bother me because it was my time. (Peg)

One of the most significant statements made concerning the need for personal time was in this participant's discussion of his frustration regarding the lack of having personal self-care time.

I mean a lot of times he really does frustrate me with his demands on my caregiving. Its gets to the point where I tell him sometimes maybe he needs to call someone else. ...It can be frustrating. I have it coming from all directions. ...This is just not right. I have numerous things to take care of and I have many

places to go. I have my own personal life. ... I need to be able to have some time to take care of myself. (Jim)

Because women remain the main providers of care, the increasing number of women working outside the home has meant that caregiving has become another arena in which family and work demands must be balanced. Personal time often is seen as something that can be sacrificed in order to address these demands. Not surprisingly, employment outside the home often has been cited as one of the inhibitors of caregiving, as well as being negatively affected by the caregiver role (Merrill, 1997). However, personal time for the caregiver was described as a key factor in determining the impact that the primary caregiving role has on the individual. Participants reflected on the need to maintain personal time while in the role as primary caregiver. Each participant reflected on the need to have quiet time to relax, a time to take the focus away from providing direct care to the frail elder, and a time to focus on personal well-being and needs. This time was seen as a "safe haven" or a time to gather strength for the day. One participant described it as an "outlet" for venting frustrations and for allowing oneself to relax. All of the participants reflected on the growing loss of personal time as the frail elders' health deteriorated. "With higher expectations of the caregiving role, more restrictions are placed on the caregiver" (Merrill, 1997, p. 104). However, all of the participants described providing direct care for the benefit of the parent and not the benefit of themselves. In focusing on the experiences of these caregivers, each wanted to avoid any regrets concerning missed opportunities in the future. Therefore, the constraints on personal time were offset by the fact that each caregiver desired to provide

the best care possible and to not look back on the time shared together and wish they had done more for the frail elder.

All five primary caregivers brought with them different experiences of primary caregiving to a frail elder. However, when focusing on the essential nature of their experiences and in describing their experiences as caregivers, there was much similarity across interviewees. There were aspects of their experiences that were unique, but there was more similarity than was expected. They shared the common goal of wanting to provide the best care possible to the frail elder, and wanting to provide this care in the home as long as possible. These caregivers shared common stressors of a lack of personal time, and at times a lack of support networks to assist them in the challenges of the everyday tasks of the caregiving process. Finally, they shared common rewards found in being able to accept their roles as a caregiver. Participants gave of themselves willingly to take on the role of providing the best care possible to the frail elder.

Summary: Frail Elder

The meaning of the significant statements of the five primary caregivers interviewed were integrated into a description of the essential structure (essence) of the primary caregiving experience. In re-reading the transcribed interviews, the researcher concluded that there are both stressors and rewards experienced in the process of caregiving to a frail elder. Two primary caregivers seemed to describe a relatively open style of caregiving and placed emphasis on the importance of their support systems. Both of these caregivers had support from a family member or friend in times of need, although respite care options were one type of support that was not readily available. These two caregivers shared large support systems that included many individuals in their family

units and in their communities. Neither caregiver worried about the future or about what would happen at a later time. However, one primary caregiver, reflecting on her aloneness said she had feelings that she did not have someone who could come into the role of caregiver to give her some type of personal time or relief. Her role as caregiver began at an early age and has lasted for over 45 years. Her feelings about caregiving are ones that she still struggles with in the context of her caregiving experience.

The exhaustive description of the phenomenon of the primary caregiver experience was developed by focusing on all five primary caregivers' descriptions of their experiences of providing direct care to frail elders, and by integrating these experiences into a final description. The following description of these primary caregivers' experiences is expressed in Figure 6 as statement of the essential structure or essence of caregiving.

Primary Caregiving: Description of the Primary Caregiving Experience-Frail Elder

In a primary caregiving role, the caregiver does more than just care for the physical needs of the frail elder. The primary caregiver is involved in every aspect of the caregiving experience. In accepting this role, as a primary caregiver, individuals place their personal needs aside in order to share in a caring relationship with the frail elder. In this relationship, personal time is limited. Caregivers must use their support systems, or support networks, to ensure that personal time is spent on enjoying outside activities or on time away from the everyday stresses of the experience of direct care to the frail elder. This primary caregiving experience involves not only an understanding of the demands of the primary caregiving role, but it involves also an acceptance of the personal adjustments that must be made in order to adapt to this life-changing event. Caregiving to a frail elder is not easy and will never be free from stress.

Figure 6: Description of Frail Elder Experiences
Source: Author

This component of the study sought to understand the primary caregiver's experience in the role as primary caregiver to a frail elder. The essential structure of this experience demonstrated more similarities than differences in these primary caregivers' experiences. The fundamental caregiving experience "spoke" through the direct transcriptions of the interviews with the five primary caregivers providing direct care to frail elders.

Traumatic Brain Injury and Caregivers

The following section provides a brief description of the caregiving situation for caregivers involved in direct care provision to individuals with traumatic brain injury. Table 2 includes a brief description of the caregiving situation for caregivers involved in direct care provision to individuals with traumatic brain injuries. Demographic characteristics such as condition, gender of the primary caregiver, gender of the care recipient, the care setting, and socioeconomic status (SES) have been included.

The first primary caregiver to a family member with a TBI, Rose, was providing direct care to her daughter, who had sustained a traumatic brain injury in infancy. Rose had decided to provide direct care to her daughter through utilizing both personal services and support services in the community. Therefore, direct care was provided at Rose's home.

The second primary caregiver, Patti, was providing direct care to her son who had sustained a traumatic brain injury during a car accident while in his teens. Patti had decided that her son needed assistance with outpatient therapy and medical care. Therefore, Patti was traveling one hour, from her home outside of Knoxville, three times per week to Fort Sanders Medical Center to obtain outpatient medical care for her son.

Table 2

Primary Caregiving Participants: Traumatic Brain Injury

Characteristic	Participant 6 (Rose)	Participant 7 (Patti)	Participant 8 (Ann)	Participant 9 (Kim)	Participant 10 (Becky)
Condition of Care Recipient	Traumatic Brain Injury	Traumatic Brain Injury	Traumatic Brain Injury	Traumatic Brain Injury	Traumatic Brain Injury
Gender of Care Recipient	Female	Male	Male	Male	Female
Primary Caregiver	Mother	Mother	Mother	Sister	Mother
Gender of Caregiver	Female	Female	Female	Female	Female
Care Setting	Own home	Own home	Own Home/ Son's Home	Own home	Own home
SES	Working	Not Working	Professional	Not Working	Not Working

The third primary caregiver, Ann, was providing direct care to her son who had sustained a traumatic brain injury in a car accident while in college. Ann was the only primary caregiver to an individual with a traumatic brain injury, in the study, who had made the decision to have her son live outside the family's home while providing direct care. However, she addressed the struggles she had with whether this decision was correct, and she addressed concerns as to whether she should provide care for her son in her own home.

The fourth primary caregiver, Kim, was providing direct care for her daughter, who had sustained a brain injury in an automobile accident while in her teens. Kim was struggling with trying to assist her daughter to understand her limitations due to the injury, and she was providing direct care to her daughter in her own home.

The final primary caregiver providing direct care for an individual with a traumatic brain injury, Becky, was providing direct care to her brother who has sustained a traumatic brain injury during an automobile accident while in his twenties. Becky was providing direct care to her brother, with assistance from her husband and home health services in their own home. Becky was one of two participants in the study providing direct care to a sibling.

This information concerning the medical conditions and the primary care settings permitted a view of the primary caregiving experience in different contexts (please refer to Table 2). Among these five participants, all were female, and each participant was providing direct care to an individual with traumatic brain injury. Four of these females involved in primary care to brain injured individuals were mothers and one was a female sibling. All of the females had other children outside of the primary caregiving experience that impacted on direct care provision.

In terms of socioeconomic backgrounds, one of the primary caregivers was identified as working class, one as professional or middle class, and three as not working, based on the self-reported demographic data regarding education, income, and occupation obtained during the interview process. It is important to note that each of these primary caregivers' identities were protected by the use of pseudonyms throughout this section, and the use of references to the demographic information of each primary caregiver was used only to explain decisions regarding their selection for this aspect of the caregiving study. Care was taken to disguise attributes of the primary caregiver and to ensure that exposure or embarrassment of the caregivers would be avoided.

Emergent Themes: Traumatic Brain Injury

Four themes emerged from the analysis of the interviews with this group of primary caregivers to a family member with a traumatic brain injury. The first theme focused on the longing for the caregivers to have the person return that "was" before the traumatic brain injury occurred. Caregivers expressed a need to have that person back and returned to the family as once they were. The second theme focused on the need for the primary caregivers to have personal time and some extent of self-care. The third theme focused on how the participants had experienced changes in their family dynamics as a result of providing primary care to an individual with a traumatic brain injury. Along with the need to understand family dynamics, a final theme emerged which focused on the rewards and hopes that were found within the caregiving experience. The participants stressed the need to understand that there was no aspect of their lives that was left unchanged as a result of their having to take on roles as direct care providers.

Loss of Personhood

For primary caregivers, the loss of the person that was in existence before the traumatic brain injury framed many aspects of the primary caregiving experience. Caregivers who desired to share relationships, interactions and bonds with care recipients often described a belief that they no longer shared the same day-to-day experiences with this "new" person within their family unit. This personal experience is best illustrated by the following statements.

> *She was brilliant. She was a genius. While we were in Virginia she was certified a genius, and all of a sudden it's gone. That's the hard part it's all gone. It's frustrating and she's unhappy, and she's not going to have a normal life. She's not going to go to college. It's a waste. (Rose)*

There were nights when I just wanted to go out and scream. You know you get those times. He'll say something and you'll laugh. He'll do something that is just like totally what he used to be and you think well we're going to get there. He would have just a little sparkle about him like he used to be and I would think that he would come back. (Patti)

Her personality change was just unreal. She use to be such a sweet, outgoing person, and now she is outgoing, but she is not near as outgoing as she was, and she can turn on you in a heart beat where she never use to do that. She can have a good day and be just bubbly sweet and something goes wrong. Well, it's like Dr. Jekyll and Mr. Hyde. (Becky)

One primary caregiver addressed the difficulty in trying to accept the new person that had emerged from the man that is her brother. She explained her experience by the following statement.

The hardest part for me has been I miss Robert, and if I have anything to do with it he will be back. But, I'm not sure how long it's going to take. I don't know, there are times when I just want to run from here and not look back, and then he'll do something and I'm encouraged and I am ready to fight again. (Kim)

Such losses are an increasing challenge for primary caregivers who desire to provide direct care to individuals with traumatic brain injury. Perry and O'Connor (2002) have suggested that this theme is one that is extremely challenging to the care provider. "When there is a shift to a relational perspective, the importance of the other in maintaining the personhood of the individual becomes immediately obvious" (p. 81). This theme emerged from interviews with four participants providing care to individuals with traumatic brain injuries. Each of these caregivers addressed a longing for the past and the person that was, with the understanding that the person, once so much a part of these primary caregivers' lives, was not going to return to them. However, one primary caregiver (Kim) could not accept that her brother was not ever going to be the same as he was before his traumatic brain injury. This posed a great challenge for this participant.

In Kim's interview, she suggested feelings of accepting that her brother was gone, but she addressed the need to go to any length to get the brother that she once knew back into her life. Perry and O'Connor (2002) reflected on the need of the caregiver to maintain as much as possible the status of the individual and not to allow the roles in their relationships to change. Personhood is a term that "associated with self-esteem, the place of the individual in a social group, the performance of given roles, and the integrity, continuity and stability of the sense of self" (Perry & O'Connor, 2002, p. 81). This loss of personhood invoked conflicted feelings within the primary caregiver. The primary caregiver is no longer bound by, "standing or status that is bestowed upon one human being by others, in the context of relationship and social being (Perry & O'Connor, 2002, p. 81). This is best reflected in the following statement.

> *You try to remember what it was like before. You know, it kind of slips away from me now. It's been 8 years. It's like it's always been like this. It's just a level of tension that you live with that is just kind of there all the time. There aren't any kind of normal relationships. That's all there is. (Ann).*

Personal Time

All five of the participants shared statements reflecting their attitudes toward caregiving responsibilities, and their needs for personal time to relieve some of the pressures of the primary caregiving experience. Personal time allowed the caregivers time away from the continuous stresses of providing care to individuals with traumatic brain injuries. Each participant identified the need to have some type of personal or self-care strategies in place if they were going to be effective in direct care provision. This need for personal time is reflected in the following statements.

> *But as a caregiver you know you get burned out, and I don't care how much you love them it gets frustrating and its slow and everything they do its just wonderful.*

But then there is so much more. I never even have time to get a bath, I mean really. I love him, Lord knows I love him, but still you're frustrated you're aggravated. You know it's guilt really, just guilt because you let your relationships slide, and it's isolating. (Kim)

I really have not had the personal time, you know you hear so may times that the woman is the rock of the family, well in this case I am, because my husband even though he is a very strong man, I've had to deal with it all, I really have. I need to take time out to have my nervous breakdown. I haven't had time to do that yet, and I don't want to, but I don't know, I have pretty big shoulders. (Becky)

One of the most significant statements made concerning the need for personal time within the caregiving process was in this participant's discussion of her need of personal privacy.

As a caregiver you have to give care to the one that is hurt, but you also have to take care of yourself, and you sometimes have to fight to take care or yourself. Fight for that 15 minutes in the bathroom. I have an open door policy, wherever I am with the kids. I've had to because mothers don't get privacy anywhere. But sometimes I lock the door, and just have some quite time for me, and just me, and it lets me be myself. (Rose)

Although significant numbers of parents and spouses become caregivers, and provide extensive care to individuals with traumatic brain injury, they do so often at a great sacrifice. Knight, Devereux, and Godfrey (1998) reflected on the need for primary caregivers to have communication strategies and flexibility in order to be effective in their roles as direct care providers. "The process of expressing anger can be helpful, and reassurance that others feel this same way can relieve the sense of guilt that these feelings may evoke. However, one common source of stress was the lack of respite care and the opportunity for the caregiver to be alone" (p. 479). Personal time for the caregiver was described as a key factor in determining the impact that the primary caregiving role will have on the individual over time. Participants addressed their needs to maintain personal time while in their roles as direct care providers. Participants reflected on the need to

have flexibility in their roles as primary caregivers and on their need to allow themselves the ability to move in and out of the caregiving relationship. This flexibility was seen as "encouraging the caregiver to address personal issues of balance, flexibility and participation in their roles as a direct care providers" (Rolland, 1994, p. 226). This personal care time was seen as time to gather both physical and mental strength that was needed throughout the caregiving day.

Changes in Family Dynamics

The struggle by primary caregivers to achieve adaptive roles involves an ongoing process of dealing with the many issues that result from living with an individual with a traumatic brain injury. "These problems include the possible social isolation of family members, the constant demand to carry out the prescribed treatment regimen, managing the family member's own grief, dealing with unpredictable behavior, and assuming the burden of caregiving responsibilities" (Dell Orto & Power, 2000, p. 87). Primary caregivers not only had to deal with their personal role changes, but they had to deal with the changes in family dynamics within their family unit. Each participant identified the changes that occurred once the individual that had sustained the traumatic brain injury was placed back into the context of the family. This change in family dynamics is reflected in the following statements.

> *I just keep hoping that he will be Robert, and it's, you can't have the same relationship just brother and sister. You have to be mommy and caregiver and authority figure. (Kim)*

> *You know if she had been born with it, it would be different. But she wasn't. She wasn't and it's not easy. Normal has changed from being able to, you know, have the freedom that, you know, that she would have or I would have, anybody or even Michael would have. It changed my life forever, and it changed her life, it changed by son's life. We didn't ask for it. (Rose)*

> *All of us, the whole family, we were at the point of breaking, and it was probably the most difficult thing that anybody can go through. But like, from the beginning, Jeff and I have talked about how we are just getting the chance to raise Jake again. Because he is like an infant, from the time of his accident until now, he had to learn to walk, he had to learn to use the bathroom, he had to learn to hold a cup, you know he was like a baby. (Patti)*

One of the most significant statements made concerning the changes in family dynamics was in this participant's discussion of the changes within her family unit.

> *It's very difficult, it's very difficult, and it's been difficult for us. This kind of parenting has not been easy at all. Instead of retiring or you know buying a nicer home, or you know whatever, we are supporting a child and reorganizing all of our finances with that in mind. Now that you have someone who is never going to make a living on his own, and so how do you, how do you do that? It changes, it changes the whole family dynamics. It just changes everything. It changes the present because every family gathering has a potential for conflict and the potential for getting out of hand. It changes the relationships with your other children. It changes the whole family dynamics. He loses a brother and in a sense he has lost the brother that might have, you know done things with him, and now has a brother instead who is very dependent and childlike, you know just not the same relationship. It's a caregiving relationship for him too, and rather than a brother. It's always there, and it always for me there is always a sadness. He is never going to be able to do this and he is never going to be able to do that and I constantly want to well, I just, it kills you. We live such a comfortable life you know it's not like we are rich, but we are comfortable, and to think that you have a child who may be at this level, its just kind of sad. (Ann)*

With the primary caregiver's slow acknowledgment that the effects of the brain injury will be permanent, individual family members gradually begin to adjust their lives to meet caregiving demands, changes in family roles, and perhaps financial burdens of the primary caregiving experience. "As the family engages in their adaptive tasks, and in their understanding that both anger and depression are parts of the grieving process, the physical, personal, social, familial, vocational and economic ramifications of the disability become apparent" (Dell Orto & Power, 2000, p. 62). Some caregivers may perceive that the changes brought about by the injury are catastrophic, while others may

accept these changes and perceive living with the individual with the traumatic brain injury as a means for a renewed family togetherness. This renewed family togetherness is best seen with the following statement.

> *I'm okay, it's like I said, it's like we are raising Jake again and it's like having a child, you know, like back when you were, when I was raising him. I was just Mom. I am kind of back to that view. I wasn't there. Jake had moved out and Jake was living on his own when his accident happened. We, me and my husband, of course we had had Jake since we were first together, so--hum-- it was our first time just being husband and wife, and its and we are back to being mom and dad again, but it's okay. Don't get me wrong, I am just thankful that I was able to take care of him. We are a family again. (Patti)*

Adaptation to the brain injury event is ongoing, and the primary caregivers' long-term adjustment to the changes in family dynamics may become more positive as their perceptions of and time spent with the individual with a traumatic brain injury continues. However, it is important to understand that the changes in family dynamics are permanent and the family structure that was once in existence has been changed forever.

> *I would give it all back in a flash. I guess that I am just stuck. Nothing too much positive to say. We've met some wonderful people, some very caring people. I am always looking at other people to see how are you coping. How are you coping, but it just seems like everybody's experiences are different, you know. Sometimes I think that if I had more time that I could do more for my son, but sometimes I think no, if I spend more time then I would just worry more, you know. Its hard for me to see, to imagine that I can get anything good out of this whole thing. Like I said before, it changes the whole family dynamics. It changes your life. (Ann)*

Rewards and Hopes

Each of the participants shared statements reflecting the changes in their lives as a result of their experiences as primary caregivers to individuals with traumatic brain injury. Within each caregiver's story a theme emerged of reward and hope for the future. Participants sought to explain how important and rewarding their experiences had been in

sharing another person's life. This reward and hope is reflected in the following statements.

> *You grow. You become more mature whether you like it or not. You learn to respect your new life. Focus, things become more important to you or things become less important to you, and you mature a whole lot, um, some of the frivolous stuff you get over, you know? It doesn't count anymore because things are not frivolous anymore. They are serious. (Rose)*

> *I'm just so thankful that I was able to take care of him and to be able to do everything that we do. I am so thankful because what would my life be if he hadn't made it, you know? (Patti)*

> *It's hard, and lonely, and frustrating and isolating and joyous you know when you wait forever and they finally learn something you know you want to have a party, though nobody else cares. Sometimes I wonder why I thought that I had the stuff it took to do this, to bring him here, to take care of him, but then sometimes I think, well, I'm all he's got, you know? (Kim)*

One of the most significant statements made concerning the rewards and hopes within the primary caregiving experience was in this participant's discussion of her thoughts within the future. This primary caregiver begins by expressing her negative feelings surrounding a family situation and then transforms those feelings into hope for the future.

> *It was so bad enough this time that David and I, my husband and I, have been kicking around for a long time saying well we need to go to counseling, we need to go. So we didn't ever go because what are they going to tell us. Nobody can make decisions for us, you know, so but this last time was bad enough that we were like, okay, okay we don't want to do this again. So maybe some, I'm hopeful that out of this last bad episode that maybe we'll be able to look forward to something good coming out of it. I am hopeful about that. You do keeping hoping. You keep hoping that eventually you'll somehow get resolution one way or another. You won't always be alone. (Ann).*

There is sometimes a hidden element within the primary caregiving experience, and that element is the conversion of hardship into hope. This element is "a mysterious element in the hearts of caregivers, an element that permits one person's caregiving to be

a kind of alchemy, transforming a base metal into gold, while another, faced with a similar challenge, comes away embittered and exhausted" (Goldman, 2002, p. vii). Caregiving experiences are unique. Perhaps there are important lessons to be learned from caregiving, "lessons about vulnerability, about shared dependence on the kindness of strangers, about giving up illusions of control and autonomy" (Goldman, 2002, p. viii). Both the primary caregiver and the care recipient face a challenge. However, "forgiveness, compassion, acceptance, and love grow through empathy for and understanding of the experiences of others" (Goldman, 2002, p. 4). Caregiving is about the rewards and hopes for the future. These rewards and hopes for the future emerged as a theme because the primary caregivers expressed their personal thoughts of knowing their best had been given in serving the individual whom they loved.

All five primary caregivers brought with them different experiences of primary caregiving to an individual with a traumatic brain injury. However, when focusing on the essential nature of their experiences and in describing their experiences as caregivers, there was much similarity across interviewees. There were aspects of their experiences that were unique, but there was more similarity within the contexts of their caregiving situations than expected. They shared the common goal of the longing for the person that used to be a part of their lives before the traumatic brain injury occurred. These participants shared the experiences of multiple changes in their personal lives and changes in their family dynamics as a result of providing primary care to an individual with a traumatic brain injury. Finally, they shared common rewards and hopes that were found within the caregiving experience. These participants not only became caregivers as a result of unforeseen circumstances and unplanned events, but they emerged out of

the primary caregiving experience with valuable insight into the rewards that were received throughout this experience and the ability to achieve hope for the future.

Summary: Traumatic Brain Injury

The meaning of the significant statements of the five primary caregivers interviewed were integrated into a description of the essential structure (essence) of the primary caregiving experience. In re-reading the transcribed interviews, the researcher concluded that there are both stressors and rewards experienced in the process of caregiving to an individual with a traumatic brain injury. Three primary caregivers seemed to describe a relatively open style of caregiving, and placed emphasis on the importance of their support systems. Each of these caregivers had support from family members or friends in times of need. These three caregivers shared large support systems that included many individuals in their family units and in their communities. However, two primary caregivers reflected on their needs to have individuals to come into the home and to provide some type of personal time or relief for the primary caregiver. These two individuals had limited resources within the community and had lost several contacts with friends and other family members throughout their experiences as primary caregivers.

The exhaustive description of the phenomenon of the primary caregiver experience was developed by focusing on all five primary caregivers' descriptions of their experiences of providing direct care to individuals with traumatic brain injuries and by integrating these experiences into a final description. The following description of these primary caregivers' experiences is expressed in Figure 7 as a statement of caregiving's essential structure or essence.

Primary Caregiving: Description of the Primary Caregiving Experience-TBI

In a primary caregiving role, the caregiver does more than just care for the physical needs of the individual with a traumatic brain injury. The primary caregiver is involved in every aspect of the caregiving experience. By accepting this role as a direct care provider the primary caregiver's life is changed forever. Providing direct care to a person who is not known as they were before the occurrence of a brain injury causes the primary caregiving experience to be overshadowed by a need to have the person back and returned to the family as they once where. This will never occur and the primary caregiver is led into a new and ever-changing life experience. There is no longer personal time for the primary caregiver, and there is no longer a time when the caregiver will not be needed. There is chaos, anger, grief, and resentment. However, in the midst of all of the unknown circumstances, there emerge some rewards and hopes for the future. Life has been forever changed, yet in the midst of the primary caregiving relationship there is a gift in disguise. This gift is the experience that moves the caregiver toward a more meaningful connection within the self and within their caregiving relationships to others.

Figure 7: Description of Traumatic Brain Injury Experiences
Source: Author

This study sought to understand the primary caregiver's experience in the role as primary caregiver to an individual with traumatic brain injury. The essential structure of this experience demonstrated more similarities than differences in these primary caregivers' experiences. The fundamental caregiving experience "spoke" through the direct transcriptions of the interviews with the five primary caregivers providing direct care to individuals with traumatic brain injury.

Comparison of Primary Caregiving Experiences

Similarities in the Caregiving Experience Between Groups

A comparison of the two primary caregiving groups revealed three similarities between the two groups of primary caregivers. The first similarity focused on the changes in employment for women while in their role as primary caregiver. Caregivers in the "sandwich generation" addressed concerns regarding their ever-changing roles as

direct care providers. A second similarity focused on the need of each of the primary caregivers to have personal time and/or respite services. This personal time and/or respite services allowed the caregivers time away from the caregiving experience, and allowed them to be able to focus on their personal mental and physical well-being. A final similarity between these two groups of caregivers focused on the ways in which the primary caregiving experience alters the life of the caregiver. All of the participants addressed the need for the researcher to understand that there was no aspect of their lives that was left untouched as a result of their caregiving experience. Each of their lives had been changed by their primary caregiving experiences forever.

Employment and the Sandwich Generation

Typically, women who are employed must continue to provide direct care to individuals with age related fragility or individuals with a traumatic brain injury. Therefore, obtaining and keeping employment brings new problems to individuals who are providing direct care in primary caregiving roles. "The problem of balancing paid work and family work continues to be seen as an issue, and women do most of the adjusting" (Cancian & Oliker, 2000, p. 63). Caring for the ill and disabled is another kind of caregiving that falls mostly to women. "With the aging of the U.S. population, disability, and the shortening of hospital stays, the need for care is growing" (Cancian & Oliker, 2000, p. 65). Although caregiving is a full-time occupation for many, other caregivers work outside the home. Time spent at work is time away from caregiving, which may be detrimental or beneficial for the caregiver. However, no matter what the employment structure, the economic and psychological burdens of having to provide

these types of intensive care are substantial, and there is little or no assistance available from resources within the community.

Although employment was not an emergent primary theme within the context of the individual caregiving groups, this theme emerged when providing a comparison of contexts of both groups of caregivers. Both groups of primary caregivers were impacted by reduction of hours with employment, hardship, and/or loss of work as a result of the primary caregiving experience. The caregivers reflected their thoughts in the following statements.

> *I just work part-time on Tuesdays, Wednesdays, and Thursdays, and that's one good thing about where I work too is that I can work as much as I want or as little as I want. I have all that stuff at home to do, and then taking care of mother, you know, it's just hard for me. (Jill)*

> *I took a family medical leave and took time off. I happened to have some money saved up so it was no problem. I took some time off and stayed with her for six weeks. Like I say, you make it. You don't have the car paid for, and there are days that you think that it's never going to end. A sandwich generation I think that they are calling it now. But, it keeps me going. (Peg)*

> *I had a job and lost it. I had worked stupid jobs for years, and I was finally in a job that I really liked, and you know whenever Jake had his accident, I was, it kind of fell on me. I lost my job. I lost what I loved doing. It is just going to be my goal to get back to work. (Patti)*

One of the most significant statements made concerning the impact of the changes in the work environment and the impact of the "sandwich generation" on the primary caregiving experience was in this participant's discussion of her thoughts concerning her past employment and her brother's injury.

> *I immediately had to quit. It just became obvious when I brought him home that I could not work anymore and take care of him. I had no choice really, and I am not sorry that I made it, but I am a little amazed that we have made it this far, you know. We certainly weren't ready, we just weren't ready. You know Tim, my son,*

was 13 when this happened, and we gave up his entire junior high and high school. (Kim)

There are positive and negative aspects concerning the area of work when focusing on the primary caregiving experience. Both groups of primary caregivers reflected on positive and negative implications within the context of the working environment. The positive potential of employment for caregivers allows for benefits that individuals may accrue from working outside the home in contrast to exclusively taking care of the individuals who have age related fragility or who have disabilities. "Work provides an escape from the immediate care situation, while often entails unpleasant, repetitive, and boring tasks that are not highly esteemed" (Aneshensel et al., 1995, p. 87). However, employment entails labor. With this labor comes more tasks to be perform, more hours to be active, and more demands to be placed on the individual. "In addition to sheer work overload, work and caregiving may come into direct conflict. While at work, caregivers worry about the well-being of their relatives; conversely, work-related pressures sometimes interfere with the provision of care at home" (p. 87). The balance between the costs and benefits of employment will vary across caregiving situations. It is important to understand that employment is not positive or negative for caregivers. Instead, it is the intersection of the working environment and the caregiving environment that will direct the primary caregiver into their experience within the context of the working environment. Therefore, it is important not only to consider whether the primary caregiver is employed, but also to consider the, "extent to which work and caregiving complement or collide with one another" (Aneshensel et al., 1995, p. 87).

Personal Time/Respite Care Services

Caregivers are seen as needing care too. Often, individuals fail to recognize that caregivers have the right to have positive or negative feelings regarding their caregiving duties. "Caregivers need to give themselves permission to care for themselves by taking some time for activities that give them a life outside of the loved one" (Papalia, Camp, & Feldman, 1996, p. 393).

Counseling, social support, and self-help groups enable caregivers to share problems, gain information about the community's resources, and improve their caregiving skills. In this research study, those caregivers who had adequate community and social support reported less stress, more personal involvement, and greater reward within the context of the caregiving experience. Those caregivers who lacked support voiced their needs for services and support within their communities. However, these unsupported caregivers still maintained a focus on their needs, not only for personal time, but for respite services as well.

> *If I didn't have any support I couldn't have done it. You need to have strong family support, but also know that the family gets really tired and aggravated cause its no way and no how a bed of roses. Tom's in it as deep as I am. There's three of us, my son, my husband and me. We have no other family. Tom's family has pretty much helped out, but as far as respite care, I have none. (Kim)*

> *You have to have respite time. Time for you. You have to take time when you can sit in the bathtub and a bubble bath and just read for hours, and someone else can be in charge. You have to take time to get away on weekends. Just you, or who ever you want to go with you, but just get away, just get away from the problem. (Rose)*

> *As far as us going overnight that is out of the question. We don't leave her alone during the daytime you know. We used to sneak over to Pigeon Forge. Oh, it's different. We can't do that anymore. We're handcuffed, I reckon, we're jailed for some reason. (Bob)*

I really and truly don't know as far as the support thing. I have just basically had to do it myself. (Becky)

There were three caregivers who accepted the changes in their personal time as a result of their primary caregiving situations. These caregivers reflected on the need to look beyond the present caregiving situation and to look toward an acceptance of the primary caregiving experience.

Interestingly enough, I've heard other people actually complain about having to do this or do that for their elderly parents, and its gets on their nerves. I just don't share those types of experiences. It's just a part of me. We've accepted it as a part of it and I've never been aggravated about it. (Joe)

It's pretty fun. It's busy, but it's fun. I don't sweat the small stuff. I just don't. Sometimes I am tired, you get tired. But it's wonderful, it's wonderful that we are all together. (Peg)

I am just thankful that I was able to take care of him, and to be able to do everything that we do. (Patti)

There is an urgent need for more community support to reduce the strains of caregiving and to assist in preventing caregiver burnout. "Expanded support programs for caregivers could reduce or postpone the need for institutilization. Such support services may include free or low-cost daytime activity programs; transportation and escort services; in-home services; and most important, respite care-letting caregivers get away for a day, a weekend, or a week" (Papalia, Camp, & Feldman, 1996, p. 393). For without these types of support services, caregivers cannot cope with their roles as primary caregiver effectively, and they cannot emerge from the primary caregiving experience with success.

Changes within the Primary Caregiver's Life

In coping with stressful events, caregivers tend to draw not only on their own resources but on the resources of those closest to them. The financial, emotional, and physical well-being of those around the caregiver may be utilized in order to assist the individual with adaptive coping throughout the caregiving experience. When these types of resources become depleted, as they often do in providing care to frail elders and individuals with traumatic brain injury, one outcome is that the primary caregiver will experience a loss of resources. Due to this loss of valued support and resources, the burden of the chronic illness or disability will have widespread effects on the lives of primary caregivers.

"When a family member must be cared for, other family members face chronic, severe stress in multiple areas of their lives" (Stephens, Crowther, Hobfoll, & Tennenbaum, 1990, p. 222). Furthermore, the care recipient's compromised functioning often creates a restriction of social activity for the primary caregiver. This decrease in social activity may lead to social isolation. "Social isolation is an important factor in the development of depression and may in itself make coping more difficult for caregivers" (p. 223).

Within this research study, both groups of primary caregivers addressed their concerns about the changes within their lives. Each caregiver addressed changes that evolved as a result of their primary caregiving experience. Frustration, economic strain, isolation, and burnout were prevalent themes of some of the caregivers' experiences.

> *It changes your life forever. It's very difficult, it's very difficult for us, because this is just a huge, huge setback. Instead of retiring or, you know, buying a nicer*

house, or you know whatever, we are supporting a child and reorganizing all of our finances with that in mind. (Ann)

He doesn't have any friends and I have very few left, just to be honest with you. Very few people have stuck with us. You know when you can't get out and go and there is a whole big world out there, you kind of get left behind real quick, and a lot of people don't, can't be interested. They are afraid, and they don't see that. (Kim)

I have to try to take care of my dad, but he has no idea what I have to go through and what I go through to help take care of him. Just to get through the day-by-day and getting myself through the days. ...I do more for him all the time, and I'm frustrated by it. (Jim)

Like I said, she gets a little nerve wracking sometimes. Yeah, I might say I get all fluffed out once in a while, but not too bad. But I have been known to lose my patience. (Bob)

However, there were four caregivers within the research study that emphasized more positive life changes that evolved as a result of their primary caregiving experience. Hope for the future and the rewards of the caregiving relationship were prevalent themes throughout these caregivers' experiences.

I have to get over it. I have to go on. I have to cope. I have to raise her. I have to teach her whatever I can and to make sure she doesn't get hurt however I can. I don't have any other options, cause I am not going to give into negatives, and just dwindle down and cry about it. You know, I 'm just going to do it. The most important thing is you have to be positive. You have to learn to be positive and just be positive. (Rose)

I think we've done a good job. I feel pretty good about it. ...I would like to tell other people that you'll get through it, even with issues, you will get through it. It's hard. It's not easy. Don't ever tell anybody that it's easy. Don't ever let anybody say that, but it's worth it. (Patti)

It's tough. It is tough, but it can be overwhelming at times, but if you take it one day at a time and always be prepared because you never know what's going to happen, and just communicate with whoever you can. ...And then I complain sometimes and think, well, no you don't have nothing to complain about. I know that this won't be forever. (Jill)

Some days you go, "Okay am I doing the right thing and everything?" But you know I have no regrets. Absolutely no regrets. I wouldn't change it. (Peg)

Individuals frequently become caregivers through unforeseen circumstances. "A father falls suddenly ill, a mother becomes increasingly forgetful, a spouse is diagnosed with a terminal illness, a grandmother is too frail to care for herself, an elderly friend is without a family or resources, a child is born with a severe physical or mental limitation. With little or no warning, we become caregivers" (Goldman, 2002, p. 5). In that moment of time, an individual's life is changed forever. "Often we don't know what we're getting into, but we make the leap anyway, take on the responsibility, and hope for the best" (Goldman, 2002, p. 5). Caregiving often includes dealing with frustration, stress, and exhaustion. However, these are only some of the aspects of the caregiving experience. The caregivers within this study bring to the forefront a need to address the rewards that are now a part of their changed lives. There is a need to look toward the future with hope. "Through the caregiving experience we can expand our vision, touch new depths of compassion and gratitude, and reassess our priorities. Caregiving is about knowing we've done our best and served someone we love" (Goldman, 2002, p. 5).

Differences in the Caregiving Experience Between Groups

A comparison of the two primary caregiving groups revealed three differences between the individual primary caregivers. The first difference focused on the developmental appropriateness of the primary caregiving experience. Primary caregivers addressed concerns surrounding the duration of care and the length of time associated with having to provide such intensive levels of care. A second difference focused on who was providing direct care to these two groups of care recipients. Direct care for

individuals with age related fragility was typically provided an adult child, while direct care for an individual with a traumatic brain injury was seen as being provided by a parent. A final difference between these two groups of caregivers focused on the intensity of the level of care within the primary caregiving experience. Each of the participants addressed the need for the researcher to understand the intensity and demand of providing direct care to the elderly and/or the disabled.

Length and Duration of Care

Unlike caregiving for children, who become more independent with age, caregiving for the severely impaired requires more effort throughout the progression of time. Coping skills and management strategies become stretched to the limit. Clearly, providing care for a frail parent or individual with a disability might promote compassion and personal growth or it might become overwhelming with a negative outcome for both the caregiving child and the parent (Hillier & Barrow, 1999). "Care involves constant tension between attachment and loss, pleasing and caring, seeking to preserve a person's dignity and exerting unaccustomed authority, overcoming resistance to care and fulfilling extravagant demands, reviving a relationship and transforming it" (Hillier & Barrow, 1999, p. 272).

Families providing care for older family members have needs, stresses, resources, and experiences that are different from those families caring for a member with a traumatic brain injury. Later life families have unique characteristics that either may enable them to or inhibit them from dealing with the changes associated with the aging of a frail elder. These families have a lengthy family history as they enter into the primary caregiving experience. "Husbands, wives, children, siblings, and other relatives have

been part of the family network for many years. The frequency and content of interactions and the ethos that guides interactions may vary" (Stephen, Crowther, Hobfoll, & Tennenbaum, 1990, p. 30). These interactions may have been disrupted in years past, and neither the parents nor the children turn to each other to deal with the changes that occur in later life and within the context of the caregiving experience. Families with children that have sustained traumatic brain injuries do not have the same option to regulate interaction. "If a mother fails to interact with her child, she can be adjudicated for neglect" (p. 30).

Within this research study, both groups of primary caregivers addressed their concerns regarding the developmental contexts of their primary caregiving experience. Each group of caregivers addressed changes that evolved as a result of their primary caregiving experience. They reflected on the differences in their feelings surrounding their primary caregiving experiences. For the participants providing care to frail elders the caregiving experience was accepted and was seen as a developmental part of life that ends with the death of the care recipient. This is best illustrated by the following.

> *I've seen it before for forty something years and know how it can, you know, it eventually takes its toll on you. I guess I kind of resent the fact that I have to, there's resentment there, which I can understand. But I know that some days that it'll be okay. It'll be okay. I ain't going to be able to see tomorrow. ...I know that this won't be forever. (Jill)*

> *I can only imagine how it makes him feel to have to depend on his son. Like, I'm dad. You know. I don't see any other adults my age dealing with their parent's issues. ...They would say I know my business, you're not my mom and dad--you're my child. It's a different connection. I will never try to sever any ties. (Jim)*

> *Well sometimes I have it rough. Really, I do try to help her. I just do what I can do. ...She just, she just has to be handled like a baby. I take care of her. ...I just need to be here. You can't tell what might happen. So my only problem, my*

biggest problem is this: I've got it in my head sometime I may come in there to wake her up and she'd be dead. I'd hate to do that, you know? But it is a, it could be anytime, you know. I reckon some day I will have to face it. (Bob).

For the primary caregivers to individuals with traumatic brain injury, the primary caregiving experience was described as developmentally inappropriate, stressful, and life-long.

You know if she had been born with it, it would be different. But she wasn't, and it's not easy. Normal has changed. It's tough, the what could have beens, is tough. It's hard to watch a waste. A lot of life being wasted. It's really hard. ... Hum, you see how fortunate we are, in comparison, but still, she's not like her brother, she's not what I started off with. ...I have to get over it, I have to go on. You know, I'm just going to do it. ...My caregiving ends when I die. (Rose)

Again this is a 13 year old training period here, the day after that she may be 8, the next day she could be 17. I mean you never know because of her and whatever situation she's in that day. ...I would like to be able to live to see her happy. I see caregiving as not ending. The only way that I see it ending is when I die. (Becky)

Any way so he walks, he talks, and he chews gum, and it's been very difficult and it's been complicated. So he is better off as long as we can stay separate. I think it is better for both of us. Definitely easier than having him in our home. It's been very difficult, it's very difficult, and it's been difficult for us. This type of parenting has not been easy at all. ...I don't see in terms of long-term. I think there is always going to be a component of it (caregiving). I mean not that I spend a lot of time thinking about that, but I can't even solve the future, not the present, and let alone the future, but it is a thought, and then I keep in mind that if I make it to be 70 or 80 I may have a son that is very dependent, you know. (Ann)

"Traumas are multifaceted, and long-term stressors and coping occur in multiple contexts" (Stephen, Crowther, Hobfoll, & Tennenbaum, 1990, p. 102). Therefore, it is useful when focusing on the experiences of primary caregivers to focus on how stress, coping, and the developmental time-line impact on the primary caregiving experience. The stages of the developmental time-line may be biologically, psychologically, or culturally determined. However, there may be crucial times for accomplishing certain

tasks within the developmental context. Trauma and caregiving effects depend, in part, on the developmental stage at which the responsibility is assumed in becoming a primary caregiver to a frail elder or individual with a traumatic brain injury. Coping with caregiving involves reorganizing maps that were ruptured by catastrophe.

> Caregivers are now expected to assimilate their caregiving duties, find personal meaning and regain a view of the world as meaningful. Traumatization causes severe stress and unique changes in the realm of caregiving. There appears to be a contrast between required emotional demands in middle age, that were structured in the traumatic period, and those of old age (Stephen, Crowther, Hobfoll, & Tennenbaum, 1990, p. 109).

When a disabling or life-threatening disorder occurs earlier, it is out of phase in both chronological and developmental time. Therefore, developmental stage processes influence the experiences of primary caregivers. It is the primary caregiver that must be flexible enough to absorb change and emerge out of the primary caregiving experience with new understanding and reward.

Provision of Care and Gender

"Caring for ill and disabled family members is another kind of caregiving that falls mostly to women. Contrary to the myth that Americans are increasingly abandoning older people to institutional care, families continue to provide most care for frail and disabled elders" (Cancian & Oliker, 2000, p. 65). The amount of care that families provide for frail elders and individuals with disabilities is growing due to increased life expectancy. Caring for family members who have acute or chronic illnesses is another area that is growing in society today. Typically the burden of the primary caregiving role falls to a single person. Most often that person is a wife or daughter. While husbands do provide care, they generally do not assume the primary caregiver role, unless a daughter

or daughter-in-law is unavailable. Men are seen as taking on the tasks of indirect care such as financial and legal matters (Briggs, 1998).

Within this research study, there were seven women providing direct care to frail elders or individuals with traumatic brain injury. For the participants providing care to frail elders the caregiving experience was overshadowed by a sense of filial responsibility. "This sense of filial responsibility may be the result of parental reverence, belief in a debt of gratitude, or an expression of friendship and love" (Briggs, 1998, p. 31). This is best illustrated by the following statements.

> *But we do it because she's our mom and that's fine. I just get up and go do it because she's my mom. ... I mean if my mother would rather stay with us, she will stay with us first. (Joe)*

> *I've basically been a caregiver for my mother ever since I was four years old. Because that's when she had her first stroke. ...So I mean I've been doing this for about 45 years. You know you give up things for her. But maybe my mother's care is better because of this. (Jill)*

> *Everyday, some days you go, "Okay am I doing the right thing and everything?" But you know I have no regrets. Absolutely no regrets, and I never really minded it and never I mean I just knew that it had to be done. ...I mean, she's my mom but I would imagine that there's people out here that don't really care for their parents like I care for mine and maybe it's the way I was raised or maybe it's just the person that I am. (Peg)*

For the participants providing direct care to individuals with traumatic brain injury, the primary caregiving experience was overshadowed with a need to express their concerns and "heart-break" surrounding the injury to the care recipient.

> *There were days like when we were coming up here, he would literally try to thrown himself out of the car or there were times that were just pretty bad. All of us, the whole family, we were at the point of breaking, and it was probably the most difficult thing that anybody can go through. ...And I said I'm just his mother I wasn't trained to deal with this. I'm just a good old country girl. (Patti)*

She won't be any better. She can learn more skills, but she won't be any smarter. That's tough, that's tough to cope with. You do your best to make her life or whichever child's life as normal as possible. But, it will never be normal. (Rose)

You try to remember what it was like before. You know, it kind of slips away from me now, it's been 8 years. ...You really lose, you really lose what was, and you are left with something quite different. ...My experience for me is still I just can't transform it into a hopeful experience. The struggle with yourself, you go why can't I just change my attitude. The glass has to be half full others say. Everyday I struggle for him, you know, and it's bad for me, I can't imagine what it must be like for him. (Ann)

There are no rules for who must assume the primary caregiving role within the context of the family. Each family must work this out for themselves. "Sometimes this is consciously done; more often the roles simply evolve" (Briggs, 1998, p. 31). It has been suggested that individual families focus on the strengths of the individual members. However, the gender differences in caregiving clearly demonstrate the woman's more frequent and intensive involvement in the care of family members. However, men and women approached caregiving tasks differently. "Men were found to use a task-oriented approach, carrying out duties in a linear fashion, typical of the approach used in the workplace" (Briggs, 1998, p. 33). Their focus was on the completion of the caregiving activities or task in the most efficient manner, which involved the delegation of responsibilities for everyday tasks to others.

In contrast to female primary caregivers, within this research study there were three men providing direct care to frail elders and individuals with traumatic brain injury. For all of these male caregivers, there was a sense of filial responsibility and a need to complete the caregiving task in an efficient and effective manner. This is best illustrated by the following statements.

I get her up. She gets up. My wife's done gone to work and so there's nobody here but me and her, and I go into the other room to see that she gets up, and I fill her oxygen tank up. I fill it up and stand there until she gets ready to take it. She gets up, and I bring her downstairs. She stays downstairs all day. ...Well, somebody has to do it. I'm the closest kin, so I guess it's my duty. We try to look after one another. (Bob)

It's been heavy involvement. Transportation mainly. We usually meet her transportation and financial needs. (Talking about his brother's contribution to caregiving) *His contribution is right now continues to be financial. He works up and works for Massachusetts. He emails and keeps up with what's going on. But, generally he will send me money to give to her. ...That's right, that's what I tell him, send money. (Joe)*

So he needs support from me. It's more of me working a schedule around his needs. ...And if I'm not available to do it, even if I'm not available, he puts demands on me. ...It's like if he could have a business--personal secretary--however you would say it, a personal assistant, that he could leash around and tag along with him, that's me. (Jim)

Regardless of gender, the caregiving experience is difficult under any circumstances. With little or no encouragement, praise or thanks from the care recipient, primary caregiving becomes overwhelming. These feelings impact every aspect of the primary caregiver's life. However, the primary caregiving experience can provide an opportunity for expressing love. The experience of providing care can be a time for discovery and strength. Also, it may disclose strengths in caregivers and enable their caregiving experiences to be of real contribution.

Intensity and Level of Care

The level of demand presented by the caregiving situation impacts caregivers' lives and attitudes. To determine the intensity of caregiving, The National Alliance on Caregiving developed "a Level of Care Index which classifies caregivers into different levels of care according to the kinds and numbers of assistive activities that they perform and the number of hours per week they devote to caring for their principal care recipient"

(National Alliance for Caregiving, 1997, retrieved Oct. 17, 2002 from http://www. caregiving.org, p. 6). The individual caregiver is classified into one of five levels, with level one being the lowest in caregiving demand and level five being the highest in caregiving demand. Within each level of care there is a range of different activities and a number of hours of direct care that is provided during the week. Each successive level involves a greater degree of caregiving responsibility and demand (National Alliance for Caregiving, 1997, retrieved Oct. 17, 2002 from http://www. caregiving.org).

Regarding the primary caregiving experience, the level of caregiving demand was a prevalent theme throughout both groups of primary caregivers. For the caregivers to frail elders, levels of strain seemed to be greater for women who were responsible for the home care of frail elders. The demands of their multiple roles and responsibilities were at times stressful. "This stress is mediated by the history of the relationship with the parent, by the extent of social support the caregiver has, by her coping skills, and by her self-image" (Hillier & Barrow, 1999, p. 271). Sometimes adult caregivers have long histories of conflict with the parent for whom now they are responsible. These histories shape the caregiving experience for both the caregiver and the care recipient. Adult children most commonly begin the caregiving experience by offering help at levels one and two of care. "Adult children caregivers most commonly offer help with the following activities: getting out of bed and going to the bathroom, shopping for food, traveling, doing laundry, preparing meals, and providing personal, supportive communication" (Hillier & Barrow, 1999, p. 272). However, the progression of the fragility in the elder produces further cognitive, physical, and emotional deficits within the care recipient and impacts on the caregiving experience. The level of care begins to increase due to the intensity of care,

and primary caregivers are seen as providing constant and continuous care to frail elders. Perhaps, most devastating for caregivers is the knowledge that the caregiving experience will end with the death of the care recipient. However, there is reward in knowing that the caregiving experience is temporary and will not be life-long.

> *It's different because every day changes. ...They have just helped me to accept, you know, the condition and what I have to deal with because I know mother is never ever going home again. It's tough. It's tough to do, but each day gets better because I know that it's not forever. It's not going to be forever, and that's really not a good thing to say, but that's just inevitable. (Jill)*

> *I never have time off because I am always using it. You know, it's like we never have big amounts of time saved up like I used to before Mom got sick. ...There are days when you think that it's never going to end. It's really stressful sometimes. You get angry and things because it's a lot of time. ...She's my mom, and it's not forever. (Peg)*

The intensity and level of care was greatest, however, for the primary caregivers providing direct care to individuals with traumatic brain injuries. Unlike caregiving to frail elders who become more dependent with age, caregiving for individuals with traumatic brain injuries requires intense, long-term care with longer duration of caregiving responsibilities (Hillier & Barrow, 1999). Severely ill or disabled individuals often need a great deal of care over a longer period of time. This impacts the transitions for both the care recipient and the primary caregiver. "The developmental transitions involve beginnings and endings, as in births, launching young adults, retirement, divorce, and death" (Rolland, 1994, p. 187). The presence of a brain injury alters the developmental transitions within the family. Transitions may be more vulnerable to the emotional imbalance generated by the sustained brain injury. Most primary caregivers "provide assistance seven days a week and devoted an average of four hours a day to caring work"(Cancian & Oliker, 2000, p. 66). While information and support services

may ease the transition for primary caregivers, the complex, long-term nature of a severe brain injury will impact on the primary caregiving experience.

> *It's very difficult. This type of parenting is not easy at all. ...If we can't move him any further along, then we really need to readjust our own lives because this is just a huge, huge setback. ...You keep trying to switch over to, well, we could be thankful for this, we could be thankful for that. But it changes your life. ...But they walk and talk. I don't see in terms of long-term, I think there is always going to be some component of it* (referring to caregiving). *...I keep in mind that I may be 70 or 80, I may have a son that is very dependent. (Ann)*
>
> *She won't be any better. She can learn skills, but she won't be any smarter. That's tough, that's tough to cope with. ...He knows that when I am dead that he will be in charge of her* (referring to her son). *She will live in the same town that he lives in, wherever he lives. And that's not fair, that's not fair to him. ...I've had to learn too much that I didn't want to learn and that I didn't expect to learn. That's for doctors and nurses, not for moms and dads. ...You learn to respect your new life. ...Caregiving will end when I die. (Rose)*
>
> *It's irritating because I want him to do and he can't. ...Everything is affected by him, and life doesn't stop because you do. ...Oh Lord, I never see it ending* (referring to caregiving). *I don't think that he will ever be able to take care of himself. ...Nobody prepares you for this either. (Kim)*

"The onset of serious illness is expected in later adulthood, when the quest for meaning, integration and acceptance of one's own personal and family life, and anticipation of death are normative, universal tasks" (Rolland, 1994, p. 187). When a disability occurs earlier in the developmental life cycle, it can cause the intensity and level of care to immediately predominate the relationship. When such events are untimely or catastrophic, caregivers may lack the psychological preparation necessary to transition into caregiver roles with relative success. The intensity and level of care impacts on the interpretation by the primary caregiver concerning their caregiving experience. Age-related fragility breaks through the denial of death and confronts the fact of temporary, intense caregiving with eventual loss of the care recipient to death.

However, for the caregiver providing direct care to an individual with traumatic brain injury, there can be no promise of a normal life, and there is no aspect of life that is left untouched. The primary caregiver's experience will be severely altered by life-long, intensive caregiving with eventual loss of the primary caregiver to death.

Summary: Frail Elder and Traumatic Brain Injury

The meaning contained within the significant statements of the 10 primary caregivers interviewed were integrated into a description of the essential structure (essence) of the primary caregiving experience. In re-reading the transcribed interviews, the researcher concluded that there are both similarities and differences experienced in the process of caregiving. The similarities focused on the changes in employment for women while in the role as primary caregiver, the need of each of the primary caregivers to have personal time and/or respite services, and a focus on the ways in which the primary caregiving experience alters the life of the caregiver. Both groups of caregivers reflected on the need to look beyond the present caregiving situation and to look toward an acceptance of the primary caregiving experience.

Families that consist of older members have needs, stresses, resources, and experiences that are different from those families consisting of members with traumatic brain injuries. Therefore, these two distinct groups of caregivers, also, shared differences within the caregiving experience. These differences were seen in the areas of the developmental appropriateness of the primary caregiving experience, in who was providing direct care to these two distinct groups of care recipients, and in the intensity of the level of care within the primary caregiving experience. All 10 primary caregivers brought with them different experiences of primary caregiving. However, when focusing

on the essential nature of their experiences and in describing their experiences as caregivers, there was more similarity than difference across interviewees. There were aspects of their experiences that were different and unique, but there was more similarity than was expected.

The exhaustive description of the phenomenon of the primary caregiver experience was developed by focusing on all 10 primary caregivers' descriptions of their experiences of providing direct care to frail elders and individuals with traumatic brain injury and by integrating these experiences into a final exhaustive description. The following description of these primary caregivers' experiences is expressed in Figure 8 as a statement regarding caregiving's essential structure or essence.

Primary Caregiving: Description of the Primary Caregiving Experience
Frail Elder and Traumatic Brain Injury

In a primary caregiving role, the caregiver does more than just care for the emotional and physical needs of the care recipient. Primary caregivers are involved in caring for themselves as well as their care recipients. The individual's life is changed forever. Along with the awareness that a cure will not be possible, there is an acceptance of what cannot be controlled or changed. Caregiving involves adjusting from what was, to now what is, and to what will be. This adjustment has been devastating to some, but has been a gift in disguise for others. The primary caregiving experience involves not only an understanding of the demands of the primary caregiving role, but it involves a meaningful connection with others. Through the caregiving experience, individuals learn that, by having forgiveness, compassion, and acceptance, there can be growth.

Figure 8: Description of Overall Caregiving Experiences
Source: Author

CHAPTER 5

DISCUSSION

The discussion of the results was generated by the inductive processes of the phenomenological approach to research and addresses the inquiry process utilized in forming the frame of study. The discussion of the results addresses comparisons between results of the present research study and earlier scholarly work. Also, this section focuses on the implications of the results in the areas of theory, methods, practice, and policy. Finally, this section offers suggestions for future research and considers the strengths and limitations of the present study.

Discussion of Results

This phenomenological study focused on describing the meaning of the "lived experiences" for primary caregivers. This type of study explores the human experience and searches for the underlying meaning of that experience. Therefore, these conclusions are presented as a reflection of the experiences shared by primary caregivers themselves. Conclusions from the present study were drawn from the thick, deep, and rich descriptions of the experiences of the primary caregivers, and they must be understood in the context of caregiving processes to frail elders and individuals with traumatic brain injuries.

Caregiving Across Groups

Families provide most of the primary care for the ill individuals and persons with disabilities. Results from the present study provided a basis for several conclusions that reflected the experiences of primary caregiving across caregiving groups. The first

conclusion focuses on the relationship between employment and caregiving experiences. Primary caregivers described a reduction of hours or loss of employment due to their roles as primary care providers. A second conclusion focused on the strong desire for primary caregivers to provide direct care in the context of their own homes when at all possible. The primary caregivers expressed a strong commitment to providing care within the context of their own homes which they felt enhanced the quality of life for care recipients. A third conclusion that was drawn was reflected not only in the issues surrounding caregiver burden, but also in the rewards of the caregiving process. Caregivers reflected on the altered dynamics of the interactions within the context of the family due to caregiver roles and responsibilities. Caregivers described not only the challenges of the caregiving process but also the rewards of the caregiving experience. A final conclusion, drawn across caregiver groups, was that caregivers' lives were described as having been changed extensively by caregiving processes, although the pervasiveness of the changes varied. Each of the primary caregivers described the need for personal time and respite care services.

Because women are so prominent as providers of primary care, their increased involvement in the labor force prompts concerns about how these competing concerns surrounding care can be met (Connidis, 2001). Nine of these primary caregivers' experiences were impacted by reduction of hours and/or loss of employment as a result of assuming the caregiver role. This "caregiver picture" becomes even more complicated when the impact of both hours at work and hours providing care was considered. Earlier research supported the conclusion that among those who worked up to 18 hours per week, hours of care increased with hours of work (Connidis, 2001; Doty et al., 1998).

These caregivers reflected on the real impact that the reduction of hours and/or loss of employment had on personal income and financial needs. All of the primary caregivers who reduced their working hours or left employment were women. In contrast to primary caregiving women in the workforce, there were two men providing direct care in this research study who were working professionals. These men continued to work outside of the home and maintained their employment due to the use of paid care resources. A third male caregiver in this study was retired. However, he did reflect a loss of odd jobs that he could have been performing as part-time work had he not had to provide direct care to his female sibling. More than half of the employed caregivers reported that they were required to leave work early, arrive late, or take additional time off as a result of their caregiving roles. Regardless of the positive or negative reports by primary caregivers concerning the response of their work settings, it was clear that there was a need for the workplace to accommodate the schedules and the demands of these caregivers.

Regardless of the demands of the primary caregiving experience on the lives of the primary caregivers, the participants in this study desired to provide direct care in their own homes and communities if at all possible. To meet the challenges of providing direct care to frail elders and individuals with traumatic brain injuries, caregivers stressed their needs to have access to resources within their communities and to be able to secure assistance through a range of services. Earlier research found similar results. Services accessed included respite services, day programs, assisted living, and commitment to full participation of elders and those with disabilities in community life (Pinkston & Linsk, 1984). It was only through the availability of such resources that caregivers felt they

were able to cope with demands of as primary caregiving to both frail elders and individuals with disabilities.

Family caregivers described sometimes feeling burdened, overwhelmed, and stressed. Most often, individuals had become primary caregivers through unanticipated circumstances. Like caregivers described in earlier scholarly work, individuals took on their roles as primary caregivers because all too often there were no other acceptable alternatives (Goldman, 2002). All of the caregivers in the present study described aspects of caregiver burden, but they also described rewards and hopes as part of the primary caregiving experience. As described in earlier research citations, primary caregivers reflected on the everyday challenges faced in providing direct care to frail elders or to individuals with traumatic brain injuries. Some of these challenges included time away from spouses and other children, lack of close friendships with individuals outside the context of the family, and a lack of personal time due to the caregiver role. Each participant reflected on the need to have quiet time to relax, a time to take the focus away from providing direct care to the frail elder and a time to focus on personal well-being and needs. This time was seen as a time to gather strength for the day. These caregivers described their challenges, yet within their descriptions they spoke clearly of some of their rewards in meeting their challenges. Caregivers described how their lives had been changed due to their caregiving experiences. Each of the caregivers reflected on the tremendous impact that the caregiving experience had on their lives and on how thankful they had become for the relationships that were being shared with the care recipient. Caregivers addressed how non-important the small, trivial things had become to them in their lives, and they described the importance of never giving up hope that the future

would be bright and that life again would be normal. Caregiving was about their hopes for the future. These primary caregivers expressed their personal thoughts of knowing their efforts had been given in serving the individual that they loved. "Forgiveness, compassion, acceptance, and love grow through empathy for and understanding of the experiences of others" (Goldman, 2002, p. 4).

A final conclusion that may be drawn regarding caregiving across groups was seen in caregivers' lives being changed extensively by caregiving processes. These participants shared the experiences of multiple changes in their personal lives and changes in their family dynamics as a result of providing primary care to a frail elder or individual with a traumatic brain injury. Every caregiver described changes that evolved as a result of their primary caregiving experience. Frustration, economic strain, isolation, and burnout were prevalent themes from six of these primary caregivers' experiences. As described both in previous research and in the present study, caregivers have needs for personal care time and more respite services to assist them in the challenges of direct care provision (Hillier & Barrow, 1999; Singer & Irvin, 1989). Primary caregivers who addressed the greatest challenges in providing direct care reflected on the intensity, extensiveness, and duration of care. Many of these caregivers had been providing direct care for long periods of time and in intensive care relationships. The level of strain described seemed to be greater for caregivers who were responsible for the care of the elderly and disabled in their own homes. Research also reflected on the demands of the multiple roles of care given to the elderly and the disabled as well as caregiving to other family members, and the impact of expanded responsibilities in the context of the family were at times profoundly stressful (Knight et al., 1998; Moen et al., 2000; Moules &

Chandler, 1999; Wallace et al., 1998). However, four primary caregivers emphasized more positive life changes that evolved as a result of their primary caregiving experience. These caregivers described more in-depth and personal relationships, renewed kinship ties, and deeper emotional attachment to the care recipient that had evolved out of the caregiving relationship. Each of these caregivers described feelings of the importance of connections with the care recipient and the importance of knowing that the best possible care was being provided in the caregiving relationship. Each of these caregivers shared familial ties, kinship ties, and friendship ties in their communities. These outside relationships sustained the caregivers in times of great need, in times of great joy, and supported them throughout the caregiving experience (Thomas, 2000; Anderson & Sabatelli, 1995). All of the caregivers within this study brought to the forefront the need to address not only the challenges within the caregiving process but the rewards that are now a part of their changed lives. "Through the caregiving experience we can expand our vision, touch new depths of compassion and gratitude, and reassess our priorities. Caregiving is about knowing we've done our best and served someone we love" (Goldman, 2002, p. 5).

Caregiving Between Groups

There were several conclusions that could be drawn from the results that reflected differences between caregiving groups. By focusing on these differences within caregiving groups, the impact of the differing contexts of age-related fragility and traumatic brain injury had on the "lived experiences" of primary caregivers in caregiving relationships could be considered. The first conclusion focused on the need to address the caregivers' acceptance of their caregiving roles and the impact that gender had on

enacting the roles of the primary caregiver. Both men and women were providing care to frail elders, but all of the caregivers in the traumatic brain injury groups were women. There were differences in the ways in which men and women approached and carried out caregiving processes. A second conclusion addressed differences between the groups in terms of a developmental perspective for caregiving. Each of these groups were impacted by the developmental context of the family and of the caregiving experience. A final conclusion focused on the need to understand the concepts of loss and grief as experienced by both groups of caregivers. The caregivers in these two groups described the impact that these processes had on shaping their overall "lived experiences" as primary care providers.

In general, family caregiving fulfills traditional family functions. These family functions include economic, domestic/health care, recreation, socialization, self-identity, affection, educational, and vocational care (Merrill, 1997; Singer & Irvin, 1989). In the present research study, caregivers' acceptance of roles and the impact of gender were seen as influencing the roles of men and women in caregiving processes with its effects being more influential for caregiving to individuals with traumatic brain injuries as seen in previous research (Robinson & Howard-Hamilton, 2000). When focusing on these groups of care providers, a reason that the impact of gender was more prominent with traumatic brain injury was due to individual caregiver roles within the context of the family. More often than not, much of the responsibility for supporting the brain-injured person during the years that follow trauma are assumed by informal caregivers, usually mothers and as was true in the present study (Dell Orto & Power, 2000; Knight, Devereux, & Godfrey, 1998; Wallace et. al., 1998). In contrast, when focusing on

primary caregivers to frail elders, adult daughters are seen to provide more assistance than adult sons and to help with more, hands-on, intensive, and emotional support tasks (Cancian & Oliker, 2000; Connidis, 2001; Schaie & Willis, 2002). These differences also were found in the present study. Therefore, gender made an impact on the primary caregiving experience not only because of the gender of the primary care provider but also because of the relationship between both the care provider and the care recipient. In the present study, the process of primary caregiving differed for men and women. As with earlier research, it was suggested that individual families focus on the strengths of the individual members. Both men and women provide contributions to the process of caregiving. However, there were biases found in the literature reflecting on gender differences in caregiving. These biases were clearly demonstrated in the more frequent and intensive involvement of women in the care of family members (Ceserta, Lund, Wright & Redburn, 1987; Robinson & Howard-Hamilton, 2000). Men and women approach caregiving tasks differently. Men were found to use a task-oriented approach, carrying out duties in a linear fashion, typical of the approach used in the workplace, whereas women approached caregiving tasks not only to care for the physical needs of the care recipient but the emotional needs as well (Briggs, 1998). As reflected in both literature and the present study, the focus by men has been on the completion of the caregiving activities or tasks in the most efficient manner, which involved the delegation of responsibilities for everyday tasks to others. Also, there have been biases in previous literature toward the de-valuing contributions of men in roles as primary care providers. There is a need for research to focus not only on the contributions of women in the caregiving process, but to focus also on the contributions that men bring to the context of

the caregiving experience (Carter & McGoldrick, 1999; Mace, Whitehouse & Smith, 1993; Merrill, 1997).

Results of this study suggested that most families transmitted values about care by means of expectations, religious beliefs, family rules, or interactions of these components when making decisions regarding caregiver roles and responsibilities. Similar to other studies, when focusing on primary caregiving to frail elders, caregivers took on caregiving roles often times out of a sense of familial responsibility or because there was a lack of another person to provide this type of extensive care. Also, caregiving roles may be taken on due to the strength of the attachment between the caregiver and the care recipient (Mace, Whitehouse & Smith, 1993; Marks, Lambert, & Choi, 2002). In this study, there were both men and women providing direct care to frail elders. Women involved in direct care provision most often provided care out of a sense of familial responsibility. Adult daughters provided direct care out of reverence, a belief in debt of gratitude, or an expression of friendship and love. These women described having strong emotional ties to frail elders, and they provided not only physical care, but emotional support as well. In contrast, the two adult sons were involved with direct care provision primarily because there were no available females within the context of the family that could take on these primary caregiving responsibilities. One of the male caregivers in the study was providing direct care to his female sibling, as he was the only person left in his family to provide such care. The reason that he was the primary caregiver was due to his sister never having been married or never having had children.

In contrast to caregiving to frail elders, caregivers to individuals with traumatic brain injuries had greater on-going responsibility to provide care to their children or, in

one case, care was provided to an older sibling. Similar to previous research, the experiences of these caregivers were impacted by the sudden onset of a drastically altered caregiver role due to a catastrophic event. Primary caregivers in these care relationships not only had to deal with their personal role changes, but they had to deal with the changes in family dynamics within their family unit (Barber & Pasley, 1995; Mui, Choi, & Monk, 1998; Rolland, 1994). All of these caregivers were women. Mothers in primary caregiving roles reflected upon their sense of an ongoing and long-term adjustment to the changes in both their roles and family dynamics. When focusing on family dynamics, these women were impacted not only by the catastrophic event of the disability but also by the direct care provision to other children in the context of the family unit (Connidis, 2001; Doty, et al., 1998; Robison & Howard-Hamilton, 2000). These women were providing direct care to other children in the context of the family, and they addressed concerns about having the time to provide the best care possible for both the individual with the disability as well as their other children. These mothers accepted their roles as primary caregivers more readily than the one sibling in the study providing direct care to her older brother. For the caregiver providing direct care to her brother, acceptance of the caregiving role was due to the lack of other family members to assist with primary caregiving responsibilities. There were no other siblings in this family to assist with caregiving responsibilities, and the care recipient's parents were both deceased. This caregiver addressed her challenges and frustrations at having to take on this direct caregiving role. Also, she described having a teenaged child that she was providing care to in her own home. She addressed, directly, the impact that the caregiving role had on his development. She voiced her concerns about having to

sacrifice the time she spent with her own child in order to provide direct care to her brother, and she spoke of how these changes in roles and relationships had impacted and changed her life forever.

Families have a lengthy history as they enter into the primary caregiving experience to frail elders. "Husbands, wives, children, siblings, and other relatives have been part of the family network for many years. The frequency and content of interactions and the ethos that guides interactions may vary" (Stephen, Crowther, Hobfoll, & Tennenbaum, 1990, p. 30). In contrast, families with children who have sustained traumatic brain injuries do not have the same history and options for regulating interaction. Therefore, it was useful when focusing on the experiences of these primary caregivers to focus on how stress, coping, and developmental processes impacted the primary caregiving experience. Stages of developmental processes are influenced by biological, psychological, or social changes. Caregiving to a young adult occurs in a time of high demands for families developmentally. Caregiving demands are more extensive and must be managed in a developmental context where other demands require coping resources as well (Aneshensel, Pearlin, Mullan, Zarit, & Whitlach, 1995; Brody, 1990; Merrill, 1997).

Clearly, providing care for a frail parent or individual with a disability might promote compassion and personal growth and/or it might become overwhelming with a negative outcome within the caregiving relationship (Hillier & Barrow, 1999). Therefore, a second conclusion addresses the need to focus on these groups in the context of a developmental perspective to further understand perceptions of and experiences within the challenges and rewards of the caregiving process. Both groups of primary

caregivers described their sense of the developmental appropriateness of primary caregiving. For the participants providing care to frail elders, the caregiving experience was to some extent anticipated, occurred gradually, and was seen as an appropriate developmental part of life that would end with the death of the care recipient. These caregivers described caregiving as a process that was temporary. In contrast, for the primary caregivers to individuals with traumatic brain injuries, the primary caregiving experience was described as unanticipated and sudden, developmentally inappropriate, and extensive. Similar to previous research (Figley, 1983; Mui, Choi & Monk, 1998; Schaie & Willis, 2002), these caregivers described their caregiving relationships as life-long, and ending only for them with their deaths. An issue of concern for these caregivers was who would provide care after their deaths or who would provide care if they became unable to do so.

A final conclusion was drawn regarding differences between caregiving groups focuses on the need to understand the concepts of loss and grief processes. Developmental transitions are involved in beginnings and endings, as seen in births, launching young adults, retirement, divorce, and death with all of these transitions impacting on the primary caregiving experience (Rolland, 1994; Hillier & Barrow, 1999; Cancian & Oliker, 2000). Loss was a very real part of the caregiving experience for both groups and each of these groups dealt with the ambiguity of losses related to changes occurring with fragility and disability. However, caregivers to those with traumatic brain injuries also grieved for the loss of the future they had anticipated both for themselves and for these young adults. The grief process experienced in response to losses for the two groups of primary caregivers was distinctly different. Caregivers providing care to

frail elders experience grief for what is to come in the shorter-term future. These caregivers were grieving for losses associated with aging and the death of the care recipient. However, they were sustained by the memories shared with the frail elder over a lifetime and the sense that frail elders had lived a long life. In contrast, primary caregivers to individuals with traumatic brain injuries grieved in a context of a more ambiguous loss (Boss, 1999; 2002). These caregivers longed to recapture the person that existed before the traumatic brain injury, and they experienced sorrow about the person that now was lost as a result of that trauma. Caregivers addressed having to "recreate a life" with an individual that was unknown to them in the context of the family. This loss of personhood was described in previous research by Piercy and Chapman. Piercy and Chapman (2001) reflected on the need to preserve personhood for the individual in the context of the family. They addressed the complexities derived out of the context of the family as a result of loss of personhood and as a result of now having to create a life with someone who is unknown in the context of the family. Also, these primary caregivers shared feelings of chronic sorrow over the person who previously existed. There was no aspect of their personal thoughts that were not at times focused on what could have been or what should have been for the individual with the traumatic brain injury. These caregivers could not be sustained by shared memories because they longed for the person that had been and for the future that had tragically been altered. Each of them tried to move forward to embrace a new life with this new member of the family, yet in their thoughts they carried with them a sorrow that never could be completely accepted. However, these caregivers did not become immobilized by their chronic sorrow, for in

the midst of adapting to grief and loss, some caregivers experienced redefined hopes for the future, but always with a sadness for what might have been.

Conclusions from the Phenomenological Analysis

The emergent themes within this research study illustrated and supported several of the concepts within the theoretical perspectives of family systems theory, symbolic interactionism, and family stress theory. In addition, the results lent support to the importance of understanding the impact of patterns of relationships as described by Thomas (2000) in the context of family systems theory. Further, the results also supported the importance of the influence of meaning and symbolic interactions as described by Charon (1998) in understanding the challenges and rewards of the caregiving experience. Finally, the present study lent support to Boss's (1988, 2002) notion of boundary ambiguity and how this family stress theory applies to the lived experiences of primary caregivers.

Theoretical Implications

Patterns of Relationships/Family Systems Theory

Thomas (2000) suggested that the emphasis on the pattern of relationships among family members and on how these patterns were affected by changing conditions was important in capturing the experiences of primary caregivers. Such ripple effects of caregiving were apparent in both the primary caregivers' lives as well as their descriptions of patterns of relationships with significant others besides the care recipient. The financial, emotional, and physical well-being of those around the caregiver were described in this research study in the context of others offering to assist the caregiver with adapting and coping throughout the caregiving experience. When caregivers

described these types of resources as becoming depleted, as they often do in providing care to frail elders and individuals with traumatic brain injury, the outcome was that the primary caregiver experienced a loss of resources. Due to this loss of valued support and resources, the burden of the chronic illness or disability had widespread effects on the lives of primary caregivers. Furthermore, the care recipient's compromised functioning often created a restriction of social activity for the primary caregiver and caused a decrease in social activities, which led to social isolation. Thomas (2000) also addressed the need to focus on the family system as either a relatively open or closed system. Whether the caregiver described a relatively more open family system or a more closed family system greatly influenced their caregiving experiences. Three of the caregivers (Jill, Kim, and Ann) described a more closed family system, which impacted on both the availability of resources inside and outside of the family. These families relied on support only found in the context of the family system, and they relied only on those resources that could be accessed through the family itself. Also, this decreased the availability for physical and mental restoration for the individual primary caregiver, forcing these families to describe a greater incidence of caregiver burden. In contrast, five of the primary caregivers (Joe, Peg, Jim, Bob, and Patti) described a relatively open family system. Such family systems allowed these caregivers to experience changes in a more positive manner. Within this open system, family members can access useful resources from inside and outside of the context of the family system. Support for these family members was described not only in context of the relationships with family and friends but also in the context of organizations within the community.

Anderson and Sabatelli (1995) discussed poorly differentiated family systems and some of the difficulties such families are likely to experience. These types of systems demonstrate a tendency for families to fuse under stress, establish dysfunctional exchanges, and establish cross-generational coalitions and triangles that impede effective family functioning. Two of the caregivers (Rose and Becky) described less differentiated family systems. These two caregivers focused on creating family ties that involved rigid triangles that contributed to poorly managed conflicts. Both of these caregivers were involved in triangles with other people in the family, and these triangles led to escalations of conflict in dealing with issues surrounding caregiving responsibilities and the familial needs of other children and spouses. Also, these caregivers continued to use denial of some of the realities of the physical and emotional impairment of the care recipient, and thus were unable to take direct actions to cope effectively with the challenges before them. These caregivers could not accept the fragility and disability in their care recipients and they could not accept that the person that once existed in their families was now gone to them forever. Therefore, they used denial of the realities of the impairment to assist them in coping with caregiving demands.

Influence of Meaning/Symbolic Interactionism

Charon (1998) suggested that symbolic interactionism is a perspective that is relevant in understanding the experiences of primary caregivers. The element of symbolic interactionism that makes it so useful is the focus on meaning as a central element in the caregiving process. The caregivers in this research study shared the meanings that their caregiving experiences had for them as individuals as well as members of a family. For six of the primary caregivers (Jill, Bob, Ann, Rose, Kim, and

Becky), the caregiving experience often included dealing with challenges, frustration, stress, and exhaustion. Their interpretations of their caregiving experiences were shaped by their greater emphasis on their challenges as primary care providers. These caregivers described their needs for personal time to allow them release of frustrations surrounding the caregiving relationship. Each participant reflected on the need to have quiet time to relax, a time to take the focus away from providing direct care to the frail elder, and a time to focus on personal well-being and needs. Personal time for the caregiver was described as a key factor in determining the negative impact that the primary caregiving role had on the individual caregiver over time. Also, these caregivers addressed the challenges that were faced in dealing with social isolation and the loss of ties outside the context of the family. However, for the remaining four primary caregivers (Joe, Peg, Jim, and Patti), the meanings of their caregiving experiences emphasized more of their hopes and rewards. They described their primary caregiving experiences with expressions of greater understanding of and closeness with the care recipient, as well as a better understanding of who they were as individuals. Greater respect and connectedness between the primary caregiver and the care recipient was noted throughout the present study. Meaningful interactions became an enjoyable collaborative endeavor for the caregiver and for the individual with either age-related fragility or cognitive impairment as a result of traumatic brain injury. These interactions of belonging, and understanding of self-significance that emerged through the primary caregiving process.

Boundary Ambiguity/Family Stress Theory

Family stress theory conceptualizes the stress level of the family as being qualitatively different from the sum of the individual stress levels of family members

(Boss, 1988; Boss, 2002). This research study supported the notion of family stress as described by Boss (1988, 2002). Family crisis is seen as being brought about by such severe stress that the family for some period of time is immobilized. For the five caregivers providing direct care to frail elders, there was a sense of family stress but not family crisis. These caregivers reflected on the day-to-day challenges of their roles as direct care providers, and they addressed how they coped with these challenges throughout the caregiving day. However, family crisis was seen in all five of the experiences of the primary caregivers to individuals with traumatic brain injuries. Each of these caregivers, within the context of the family, became temporarily immobilized and felt that second order changes in their families were required due to the extent and impact of the injury on a family member. Three of these caregivers described having reached a turning point in their experiences, and they had begun moving toward acceptance. However, there was one of these caregivers who had not yet reached such redefinition. One caregiver (Ann) was unable to come to terms with her caregiving experience, and she had not found anything in her experience as a primary caregiver that was positive. She described her feelings of bitterness, resentment, and aloneness in her role as a primary caregiver.

Also this research study supported the notion of boundary ambiguity in the context of family stress theory as described by Boss (1988, 2002). One type of high boundary ambiguity that was supported by this research study was seen when there was a physical presence experienced with psychological absence. It is in this situation that the family is intact, but there is one member that remains emotionally unavailable to the family system. Boss (2002) described this situation as leaving without saying good-bye.

This type of ambiguity is seen as a barrier to effective management of the stressor event, and it is the perception of the event or situation that is a crucial element in determining the degree of boundary ambiguity. Traumatic brain injury was seen as the most acute level of boundary ambiguity. This was the most acute level because it is with this type of high boundary ambiguity that physical presence is experienced along with psychological absence. This concept was described by the primary caregivers in the present study, and was the hardest component of the caregiving process. There was an acceptance within the context of the family that these care recipients were physically present, but psychologically absent in the ways their family experienced them before cognitive impairment. Primary caregivers described being left with someone that now they did not know, and wanting a person that once they knew.

The primary caregivers' experiences were impacted greatly by their perceptions and meanings of their caregiving situations. Feelings of guilt, blame, and anger emerged out of the ambiguity felt by the primary caregivers in this study. There were primary caregivers, however, who managed to accept their changed roles and relationships. It was with this acceptance that these caregivers learn to effectively manage their high boundary ambiguity.

Implications for Research

Research attention should be given to the issues of gender and caregiving. Embedded in our social institutions, patterns of gendered caregiving continue to influence primary caregiving experiences. Caregiving is seen as being socially valued in some ways, but because women are primarily caregivers, they pay a considerable price in terms of social power, privilege, and prestige (Cancian & Oliker, 2000). Questions need to be

explored as to how women who are primary caregivers and in professional environments can balance a career pattern that requires successful workers to work full-time or without interruptions from family caregiving. Because the focus of caring has been on the abilities of women, the skills and the knowledge required for good caregiving generally remain specified. This brings to the forefront a question regarding how caregiving knowledge and skills are attained. This question not only needs to address how females develop primary caregiving knowledge and skills but also needs to address how men develop such skills. The involvement of men in caregiving relationships is important because currently, there are more men involved in direct care provision than at any other time in history (Cancian & Oliker, 2000). However, literature has only addressed how men are seen as providing direct care out of a sense of filial responsibility. Men are seen within earlier research as demonstrating a need to complete the caregiving task in an efficient and effective manner with less attention to expressive aspects of care (Carter & McGoldrick, 1999; Merrill, 1997; Mace, Whitehouse & Smith, 1993). Men have been described as lacking emotional attachment to their care recipients. Therefore, a second question that needs to be addressed within research is how the emotional ties of men and women to care recipients are similar and different and how these emotional ties influence the caregiving experience. Men and women experience caregiving differently. Therefore, research must address caregiving differences that are impacted not only by attachment to the care recipient, but also by traditional gendered roles within society. By exploring these questions, experiences of men as well as of women may be more fully understood in the context of the impact of gender on the caregiving situation.

A third question that needs to be explored when focusing on gender is how does caregiving impact on specific caregiving groups? Do all caregiving groups experience the impact of caregiving in the same manner, or are there distinct differences in the expectations of gendered caregiving roles, and therefore differences in the caregiving experience? By addressing culturally diverse caregiving groups researchers may begin to explore and understand the impact that gendered caregiving has not only on the individual but also on the individual in the context of their culture and cultural norms. Also, gender and the influence of cultural norms and expectations must be explored in order to more fully understand how gender roles and responsibilities impact on who will become primary care providers in the context of the family.

There is a need for further research addressing different contexts of primary caregivers. Research has predominantly addressed caregiving experiences in the context of caregiving to elders and children (Kane & Kane, 1987; Mc Call, 1999; Merrill, 1997; Mui, Choi, & Monk, 1998; Perry & O'Connor, 2002; Piercy & Chapman, 2001; Singer & Irvin, 1989). In order for researchers to more fully understand the "lived experiences" of caregivers they must begin to focus on non-traditional and diverse caregiving contexts such as caregiving to individuals with terminal illness, to individuals who have recently sustained life altering disabilities, to individuals who are in institutional care facilities, and to other ethnically and culturally diverse caregiving groups.

Previous research has utilized primarily the quantitative research paradigm in studying primary caregivers. Much of the previous research used valid and reliable scales and questionnaires (e.g. Likert-type scales, Care Burden Scale, and Social Support Index) when measuring stressors, support systems, and burden of care. Fewer prior

research studies utilized qualitative methods for understanding the caregiving experience. Pyke and Bengtson (1996) reflected on the increasing need for qualitative research focusing on family caregiving. These researchers suggested that an increase in the use of the qualitative paradigm would allow the experiences of the participants to be more fully understood, and the participants would have a greater chance to voice personal thoughts and feelings surrounding their experiences. A final suggestion regarding the use of research paradigms would be to focus on using both quantitative and qualitative paradigms within research studies. This multi-method approach to research would allow the researcher the ability to generalize regarding certain aspects of the data, and it would allow the researcher to have a rich, deep description of the individualized salient features of the phenomenon. By using both paradigms for exploration, caregiving experiences may be examined through different methodologies. Multi-method studies could address a greater variety of research questions and would provide the results with both breadth and depth.

Implications for Policy

According to the Wacker, Roberto, and Piper (1998), persons aged 65 and older constitute 8.1% of the population in 1950. By the year 2050, that percentage will increase to 22.9% (Wacker et al., 1998, p. 4). The percentage of older adults and individuals with disabilities in each age group will increase as well. Because of the increased life expectancy, demographic projections call for a substantial increase in the percentage of older and disabled adults ages 85 and older. "Moreover, persons 85 years of age and older represent the fastest-growing part of the adult population" (Wacker et al., 1998, p. 5).

The social implications for such an increase in the older and disabled adult populations are many. Kingston (1996) pointed out that the increase in the number of adults (older and with disability) in the next century does not mean that society will be overwhelmed with caring for these populations, but it does suggest that individuals need to begin to prepare for the needs of these adult populations. "Shifts in the composition of the labor force, as well as other social, economic, and technological trends, have led to increased interest in family-responsive policies, benefits, and services in the workplace" (Neal et al., 1993, p. 191). Bowen (1988) has referred to these types of policies and programs as corporate supports for the family lives of employees. Several possibilities for organizing frameworks exist for considering the range of employer responses to employee familial responsibilities. These include considering informal and formal policies and the nature of employee benefits.

Informal and Formal Policies

"Policies can be thought of as the formal or informal ways in which employees work and leave schedules are handled. Policies provide parameters for dealing with certain situations" (Neal et al., 1993, p. 192). Employer options for enhancing work flexibility include reduction of the numbers of hours worked, change in demands of the workplace, and initiating flexibility regarding how work is scheduled over time. "Training managers to increase their sensitivity to the needs of employees who have dependent-care responsibilities and to educate them about formal family-responsive policies that are in place is another important element for enhancing work flexibility" (Neal et al., 1993, p. 192). Options that result in a reduced number of hours worked also include leave policies. This type of leave may be paid or unpaid. "Family leave options

involve voluntary leaves of absence, paid or unpaid, for the birth or adoption of a child or for the care of an ill or disabled family member. Such leave options protect the job of the employee while she or he is away for a specified amount of time" (p. 196).

Benefits

Benefits comprise a second type of support that employers may provide for their employees. Typically, employee benefit plans have several features. First, benefits provide "protection against the loss of earnings when regular earnings are lost as a result of death, injury, illness, disability, retirement, or loss of job" (p.204). Second, benefits typically cover payment of the medical expenses associated with illness, injury, or other health care needs. Third, these benefit plans cover paid release time for vacations, holidays, and personal needs. Finally, employee benefits cover certain non-medical services (legal, educational, or mental health), or they may be provided as benefits directly to employees (Neal et al., 1993). Although benefits packages will vary, such plans recognize that needs vary depending on the situation, circumstance, and need of the individual. Being able to tailor benefits most useful to their situations would offer greater support to employees.

There have been several responses to employee familial responsibilities in the forms of different benefits that may be selected by primary care providers. Benefits for caregivers include dependent-care assistance plans, dependent-care tax credits and long-term care insurance plans. As authorized under Section 129 of the Internal Revenue Code, "Dependent care-assistance plans (DCAPs) are a mechanism through which employers can help employees who have dependent-care responsibilities and who must purchase dependent-care or related services in order to be gainfully employed" (Neal et

al., 1993, p. 207). These plans are available only when set up by employers for employees, and are established so that the employee can continue to work and balance caregiving activities. In addition, Dependent-Care Tax Credits have been established as "a federal tax credit for employment-related expenses incurred for those individuals who have dependent-care responsibilities for children, adults with disabilities, or elders" (Neal et al., 1993, p. 210). Even though employers have no direct intervention or implementation of these tax credits, employers may publicize the availability of these credits to those individuals who are providing direct care to these populations. This type of tax credit assists primary caregivers because it decreases or reduces the amount of income tax the individual owes by a percentage of the expenses incurred as a result of the responsibilities for direct care provision. A final benefit for the primary caregiver is seen with long-term care insurance. This type of insurance is offered as an addition to the standard employee benefits package. Such is important when focusing on primary caregiving because it provides for "a set of health, personal care, and social services delivered over a sustained period of time to persons who have lost or never acquired some degree of functional capacity" (Neal et al., 1993, p. 213). Therefore, this type of benefit is beneficial for caregivers who are providing direct care for individuals who have physical and mental limitations.

Policies and types of employee benefits plans have been addressed as options that may be of assistance to caregivers who have family-care responsibilities. It is important when focusing on primary caregivers to understand the impact that these types of policies and benefits have on the primary caregiving experience. Although it is crucial to be aware of the range of policies and benefits available to primary caregivers in the

workforce, researchers must take under consideration the extent to which such initiatives are actually implemented and determine possible obstacles to the implementation process for both policy and practice. "Family caregiving presents a unique challenge to policymakers because it is a group issue in a society that emphasizes individuals in its legal and financial systems" (Aneshensel et al., 1995, p. 329). There are few precedents for policies that must consider both persons with disabilities, elderly and their families. This situation may be complicated by the fact that the needs of the care recipient and those of the primary caregiver diverge at key points of the caregiving experience. Also, the interests of each may differ from the interests of the society at large. No matter what the caregiving situation may be, policies and benefits will have a crucial impact on the primary caregiving experience.

Implications for the Family

Caregiving Families

Illness, disability and death are universal experiences that confront families with one of life's greatest challenges. "The impact of the diagnosis of Alzheimer's disease, or daily living with a serious disability reverberates throughout the family system leaving no one untouched" (Rolland, 1994, p. 1). This study brings to the forefront the idea that for some families, the quality of life will deteriorate, while others find strength and become resilient and thrive. Illness and disability may strike any family, but what is significant is at what point in life, in what form, with what intensity they occur, and how long they persist (Rolland, 1994). Perhaps the most important of all is seen in how the experience affects cherished family relationships. "With major advances in medical technology and improved standards of living for many segments of society, people are living much

longer and better with conditions that used to be fatal" (Rolland, 1994, p. 1). This extension of life has heightened the strain on spouses, parents, and adult children who must contend with the competing interests of caring for aging parents, child-rearing, and other societal pressures placed on the family. This reflects ever-growing numbers of families who are coping with chronic disorders over increasingly greater parts of their lives (Rolland, 1994).

In acute health crises that are resolved within days, weeks, or months, a focus on good medical care takes priority over any other issues within the context of the family. This medical care priority is best seen in the context of adult children providing care to individuals with age-related fragility. At this time, psychosocial demands may be intense, but they are time-limited. In contrast, chronic conditions such as traumatic brain injury creates uncertainties and ambiguities that often extend into the distant future, frequently with the expectation that the individual will continue to be dependent on the primary care provider. "Families enter the world of illness and disability without a psychosocial map. Often they desperately need a psychosocial guide that can provide support and reassurance that they are handling their experiences effectively in the context of the family" (Rolland, 1994, p. 2). This raises a fundamental question: What is normative coping and adaptation for families living with illness and disability? A basic problem arises with the seeking of a single, universal definition of the healthy family, as distinct from a dysfunctional family, in terms of coping with serious health conditions. Research documents a broad range of diverse, multicultural family forms and styles of functioning that are compatible with normal, healthy family development (Carter & McGoldrick, 1999; Connidis, 2001; Rolland, 1994). This suggest that there are a variety

of ways that families may adapt successfully to illness and disability, and this provides a way to rethink rigid models of the ideal family. However, in the existing literature there is no model that combines illness and disability in a schema that covers the past, the present, and the future when focusing on the direct issues related to the family. Therefore, the functioning of the any family must be considered in terms of how effective it organizes its structures and available resources to master the challenges throughout the caregiving experience.

Implications for Practice

When focusing on implications for consultation and practice with caregiving families, it is important to evaluate the components and organizational patterns of the family to determine family functioning. "Family functioning encompasses concepts of organization, adaptability, cohesion, and communication styles. These concepts assume that families face three kinds of life tasks--basic, developmental, and hazardous" (Rolland, 1994, p. 64). Each of these concepts and tasks allow the family the ability to adapt and change within the context of changing circumstances or life developmental tasks. This is important when focusing on consultation and practice because practitioners must be aware of family functioning patterns.

Family Adaptability

Family adaptability is one of the requisites for well-functioning family systems. Stability and flexibility are also two requisites that assist families in ever-changing family contexts. "Family flexibility may vary on a continuum from the dysfunctional extremes of very rigid to the chaotic" (Rolland, 1994, p. 66). As illustrated in this research study, families at extremes of adaptability will have more problems with certain types of

conditions. Because rigid families have a particular difficulty with change, practitioners will have difficulty with consultation regarding issues of rapid change, shifting roles, and adherence to change in the family regimen. Therefore, practitioners must have patience and continue to work not only with the family, but also with the individual members of the family, to ensure that over time changes may occur that will assist the family in moving toward positive growth and adaptation.

Family Cohesion

Along with family adaptability, family cohesion has been shown in this research study to be a major predictor of family coping with illness and disability. Families are seen to have a need to balance closeness and connectedness with a respect for separation and individual differences (Rolland, 1994). This balance and shift allows the family to move normally through the life cycle. However, an illness or disability may intensify or prolong normal transitions and will provide shifts in family cohesion. Practitioners must be aware of varying norms in cohesion. In some cultures and within some familial contexts, highly cohesive family styles are a normal process, and this process should not be seen as dysfunctional (Rolland, 1994). Therefore, it is important for practitioners to understand the impact that cohesion will make on family transitions. Also, practitioners must understand the impact that these transitions have on the experiences of individual caregivers within the context of the family.

Family Communication

"Effective communication is absolutely vital to family mastery of illness and disability" (Rolland, 1994, p. 72). Communication in this study was seen as the verbal or nonverbal responses made to caregiving situations that arose both on an individual and/or

familial level. All verbal and nonverbal behaviors conveyed interpersonal messages, and in every communication each participant sought to define the nature of their interactions with the care recipient as well as other members of the family. In families facing major, long-term, health problems, communication was regularly left unclear or unresolved without problems being noted within family relationships. Family units, as ongoing relationships, are seen to stabilize the process of defining caregiving roles through mutual agreements or family rules (Rolland, 1994). Therefore, practitioners need to be aware of how families interpret or define roles in the context of the family, and they need to be aware of familial rules in order to further understand family dynamics. In a family evaluation, a practitioner must assess family members' abilities to communicate both pragmatic and emotional issues related to the relevant illness or disability. Clarity and directness of the communication is important in both areas. Also, specific patterns of communication regarding emotional issues must be regarded as sensitive and should be explored empathetically. Often times, it is best to meet with family members individually to understand individual as well as group feelings surrounding caregiving experiences. In this way practitioners are allowed to view an overall picture of the caregiving experience, and the practitioner will be able to work on specific issues as they directly relate to each individual family member.

Limitations and Strengths of the Research Study

Limitations of the Study

Several factors related to sampling issues limit the extent to which results in the present study would hold standard to other caregivers. Volunteer bias may have influenced the types of caregivers interviewed. Sampling was limited even further by

demographics and by regional characteristics of the caregivers interviewed. There were more female primary caregivers than male primary caregivers in this research study which limited the exploration of the influences of gender on caregiving. However, though this was a limitation, it does reflect the demographic characteristics of the primary caregiving population in terms of gender. A final limitation factor was that only 10 primary caregivers were selected and interviewed for this research study. The phenomenological focus on these 10 caregivers and their caregiving experiences was useful. However, focusing on larger and more varied samples of caregivers would enhance the trustworthiness of qualitative data.

Strengths of the Study

The comparison of two groups of caregivers providing care in different contexts was a strength. By comparing these contexts, issues surrounding developmental appropriateness of care, the impact of roles and relationships in the context of the family, and the length and duration of care primary caregiving experiences were more fully understood. Also, this study brought into focus the need to address caregiving in varying contexts. It is only by addressing caregiving experiences in multiple settings, multiple types of care recipients, and under different caregiving situations that the "lived experiences" of primary caregivers may be more fully understood. Another strength of the study was seen in the rich descriptions of the rewards and hopes described as a part of the caregiving experience. Opportunities for self-fulfillment and enrichment of the lives of caregivers were abundant in this study. This is important because it is a finding that is typically not emphasized in scholarly work. Piercy and Chapman (2001) noted that a stress theory perspective has predominated in caregiving research. However, primary

caregiving experiences transcended what was typically thought of as a challenging, stressful, and in some cases burdensome relationships. Each of the participants shared statements reflecting the changes in their lives as a result of their experiences. There was a hidden element within the primary caregiving experience, and that element was the conversion of hardship into hope. Caregiving experiences are unique, and both the primary caregiver and the care recipient face challenges in the caregiving process. However, "forgiveness, compassion, acceptance, and love grow through empathy for and understanding of the experiences of others" (Goldman, 2002, p. 4).

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APPENDICES

APPENDIX A

BRACKETING ACTIVITIES

MY CAREGIVING EXPERIENCES

As a primary caregiver to two frail elders, I understand first hand the impact that the primary caregiving experiences have on a person. I assisted my mother in providing care to both her mother and father. As only children, my mother and I relied on one another in both the good and bad times we shared throughout our caregiving experiences.

My caregiving duties began with the care provided to my grandmother, Jessie Mitchell Cox. My grandmother was very much a part of my life as a young child and later on as I grew into adulthood. Every Sunday my mother and I would go into my grandmother's house to assist with her personal care. My grandmother had osteoporosis and was shut-in from the world. My mother and I would go and get her groceries every Sunday and that was the day that we always spent time with her. She was always so glad to see us when we came in and always had a great Sunday lunch prepared. As a young child my grandmother was always a part of my life. In times when she was the most sick, she would come and stay with our family at home. She would be waiting for me as I came home on the school bus and she would always have some type of snack waiting. As I got older there was always a struggle within myself and between my mother and I regarding caregiving. Sunday grocery shopping began to be more of a hassle and I struggled with my frustrations of wanting to spend time with my mother and not having to take care of Grandmother Jessie. Looking back on my experience I was so self-centered. However, once I got to her house, she always had her arms open and welcomed me with warm words. I began to understand that she always looked forward to seeing us, and I felt guilty at times for not wanting to go. My grandmother had been so sick off and on in the course of my life that I never knew her any other way. My mother used to tell me how fun she was and about the wonderful times that they shared together when she was younger. However, my grandmother always tried to make everything as wonderful as she could, and she was always so glad to see me. She shared so much a part of my life.

My grandmother always worked in her yard. She was so frail and fragile looking, but her flowers and her yard were her life. Her yard kept her going and she loved it so much. One afternoon she had been working in the yard. She came in and everything was fine, until the next morning. My grandmother called my mom that morning and asked her if she could stop by as Mom went to work to check on her hand. My grandmother's hand was really sore, and my mom, being a nurse, might could tell what was wrong. Mom told me that night that she thought that Grandmother Jessie might have cellulitis in her hand and that she was going to have it checked by the doctor. At this point in my life, Mom always took Grandmother Jessie to her doctors appointments so I thought

Figure A-1. My Family Caregiving Experiences

nothing of it at all. I really don't know exactly what happened in the doctor's office, but they admitted my grandmother into the hospital for some tests. They ran an EGD scope test on her. This test allowed the doctor to see down into my grandmother's stomach. When they inserted the tube, they tore her esophagus. Everything changed in our family after that. My grandmother was admitted into intensive care at the hospital, and the doctors told my mother that the likelihood of her living was slim to none. They did not know if her esophagus would ever heal after that. However, even then she was strong. The first place that she was transferred to was a nursing home facility. There she could have one-on-one care until my mom could finish out her academic school year, and we could care for her all summer. Upon leaving the nursing home, she came home to live with us. We did everything we could to take care of her. We took care of her personal care needs and tried to nurse her back to a full recovery. She was so strong, and she did so well. I remember vividly one experience while she was at home with Mom and I. I had my senior prom coming up and I had to make all these Mardi Gras masks for the prom. The masks were made, but we needed the straws glued on to make the handles. Grandmother Jessie and I sat together in my living room and glued until she got really tired and returned to bed for a nap. It was so much fun and she was doing so much better. Life was getting better for all of us. Time passed and she returned into her own home with a caregiver with her fulltime. The caretaker assisted with her physical care needs during my mother's work hours. She took great care of her while she was there. She kept getting better and it was so amazing to me because she was fighting so hard just to heal. She did heal. She healed fully from all of that. It was amazing. However, we did not know that the next chapter in our lives would be so intense, and that we would not be so lucky the next time.

My grandmother became ill for the last time. My mother went in to check on her and she was having problems. She had begun to have problems with eating and spitting up with some types of food. She also began to have coffee ground looking stuff that came out of her when she coughed. Mom took her to the doctor to have this checked and they admitted her. They wanted to run the EGD scope again to determine what if anything her stomach had to do with it. My mom and I talked and we both agreed that we could not allow that since it could have hurt her again. After talking, it was decided that we would run whatever tests we could to determine what was going on, but that scope was not an option. My grandmother stayed in the hospital and I guess I really never even considered that this would be how everything ended. I was getting ready to begin college and life was looking so great with a new world out there for me to conquer and explore. However, the first day of that exploration, I lost one of my greatest treasures. My grandmother died. At first, I was shocked, as it seems I always am with death. However, my mother was with her when she died and I could see that Mom drew comfort from knowing that my grandmother no longer suffered.

Figure A-1. continued

Looking back on this experience now, and bracketing my feelings, I think it is the first time that I have actually felt that it was important for me to mourn her loss. I wanted to be strong for my mother and I was so concerned with my own interests and what I thought were my needs, that I never realized the impact that her loss had on me personally. My grandmother had always been a part of my life. I can honestly say that my grandmother helped to shape the person that I am today. It has taken so long for me to realize the impact that she had on my life, and to understand how fortunate I was to have her in my life. Now that she is gone I realize how greatly she is missed.

My caregiving experiences continued on into my young adult life. After the death of my grandmother, my time with my grandfather seemed to increase. My grandfather, Richard M. Cox, had always been a wonderful part of my life and had been a part of my life as long as I could remember. My grandparents were separated from the time of my birth. However, they did not divorce. My grandfather's separate life included his companion, so my relationship with providing care to him was different than with my grandmother. My relationship with my grandfather was very different than my grandmother in several ways. My grandfather had wonderful health when he was younger, and this continued as he aged. He was very mobile and could get out and do as he pleased, so there was little care that was done with him until he broke his hip. My childhood with him was spent going to the Shriner's circus and always having him come to see me on every Saturday that he could come. He always brought a present for me and was always interested in what I was doing. I feel that he came to spend so much time with me because he and my mother, in the past, had not had a very good relationship. He wanted to share his experiences with me and not miss out on sharing love.

My grandfather had fallen and broken his hip while getting out of a car. After this event, his life changed forever. My grandfather had to have his hip looked at, and it seemed as though his hip would not heal. His companion at this time was taking care of him. However, she had cancer in the past and was having a hard time taking care of my grandfather. My grandfather's companion was not able to pull on him and move him around as he needed for his physical care. My mother intervened and spoke with his companion about getting nursing home assistance until he was stronger. Both of them agreed that they needed help and he was placed into a nursing home facility in Maryville. My grandfather's companion spent a lot of time with him in the nursing home and my mom went everyday. I went when I could, but now that I was married did not go as I should have. During this time my grandfather lost a lot of weight. He was essentially getting to look like a skeleton. The weight loss became of concern when my grandfather started having pains in this stomach area. Once checked out by the doctor, these pains turned out to be pancreatic cancer. My contact with my grandfather began to increase as he was moved to the residential hospice. There he had a private room and was heavily sedated so that he could rest. I went often and spent time with him. His eyes would light up when I entered the room. It seemed as he began to slip away that he would only talk when I came to see him.

Figure A-1. continued

He lost so much weight in such a short time and he was wasting away. Finally, I got a phone call one night from my mom. She told me that he was not doing as well as before and that I might want to go and see him the next morning as he was not going to live long. I told Mom that I would go by the next morning and see him just to check in and try to make him feel better. However, this was not to be. I received a call from Mom at 6:00 a.m. the next morning. My grandfather had died in the early morning and I would not be going to see him that day. I think of that phone call often and I wonder what would have changed if I had gone that day. Would I have known he would be gone? What would I have said to him as he slipped away? I am comforted in knowing that my mom was there with him as he died, but I feel that I should have been there for her that night. My grandfather taught me to live my life as if there were no tomorrow. To cherish the times that we have today, as you may not have tomorrow to share them. He also showed me the value of friendships and loved ones. My grandfather lived his life for himself, and was always a strong and proud man. However, it was through failed health and the connections he had with my mother and I that he finally demonstrated vulnerability. Finally, we could have a glimpse at the man we could have known, and a glimpse at the man that once my grandmother knew intimately.

Figure A-1. continued

MY EXPERIENCES AS A PARTICIPANT IN QUALITATIVE RESEARCH

From my experiences as a participant in a qualitative research project, I learned first hand, how it felt to be vulnerable regarding my personal feelings, especially when the subject of the research study was personal in nature. At the beginning of the interview process, which involved about 1 hour to 1 ½ hours of interviewing with Brooke Matchen, I found it easy to talk with Brooke regarding intimate details of my life due to the manner in which she established rapport with me in the very beginning. Brooke seemed to establish a sense of trust and seemed to care about my feelings throughout the interview process. I felt that she respected me as a person and that we had the chance to establish connection and openness with one another.

I learned from this experience the need to always be aware of others feelings regarding the phenomenon or topic of discussion. During the times when I got very emotional Brooke allowed me time to take a breath, and sometimes she waited on me as I had to gather my composure and talk on about my experiences. I learned from this interview the need to allow time for reflection of ideas. This experience involved my reflection on my personal experiences in articulating these to Brooke, and it allowed me to further understand the powerful effect that the voicing of these experiences had on my perceptions of my experience. I shared my experiences and as I voiced my story I learned more about the experience, and how I truly felt about my experiences. I had never thought about my feelings in such a meaningful and power way. As I spoke to Brooke, it took me back to those crucial events in my life and I found that my experiences were powerful and meaningful to me. I was truly surprised that I learned more about myself and what my experiences meant to me by talking with Brooke. I had no idea that would be the case as I thought I had taken the experiences, internalized them, and moved on in my life. In fact, talking with Brooke became almost therapeutic in expressing my raw experiences and emotions.

I felt that my experiences were of value when participating as an interviewee, and I enjoyed the close, personal contact that developed between the interviewer and myself. Each time that I approach a new participant in the study, I want to remember my interview with Brooke. I want to remember how vulnerable it was to talk with her about my most personal thoughts and moments in my life, and I want to try to proceed with my participants in a kind, caring manner always remembering their vulnerability.

Figure A-2. My Experiences as a Participant in Qualitative Research

MY FEELINGS AND EXPOSURE TO PRIMARY CAREGIVING

I feel that it is of real importance that I bracket my thoughts on caregiving. As a primary caregiver to two frail elders I have seen a lot over time regarding caregiving situations. My feelings on caregiving is that we as direct care providers need to have support services that include both personal and community resources. In my past I have done a lot of volunteer work with nursing home facilities and I have spent a great deal of time in a hospice type setting. Both of these institutional care settings are reflected in some literature as places that people go to die and to live out the end of their lives alone and lonely. I feel that before I can truly interview my participants, I need to address my views on this subject. Everyone will care for their loved ones in a different manner. I provided care to both of mine by accessing these nursing type facilities. Yes, there are those people who decide that nursing care is were you take people, and leave them there to die. However, there are those people who truly need help and nursing care facilities allow people the aid to continue their lives. In my experience, nursing homes and hospice did contain a lot of death. Especially in hospice care settings because people truly died there everyday. However, both facilities also had a lot of life. People shared with each other, and they built relationships with those people down the hall or those people who were next to their room. Yes, there is cognitive impairment and physical impairment, but these facilities allowed several people to not be alone. They provided care, hope and sense of family for those who had no family left.

I guess, as a bracketing activity this taught me that my experiences with caregiving were not all negative and to always try to understand that death is a part of life. Caregiving is not always something that everyone can provide to their loved one. Some people are just not willing or able to give something that they don't have. They give all they can and then that is all they can give. Therefore, I have learned that experiences for caregivers are not always negative and that they are not always positive. Every person must be looked at on his or her own merit and they must be understood from the context of their caregiving experiences with others.

Figure A-3. My Feelings and Exposure to Primary Caregiving

APPENDIX B

DR. PRISCILLA BLANTON'S FAMILY CAREGIVING RESEARCH PROJECT AND MODIFICATIONS TO THE FAMILY CAREGIVING RESEARCH PROJECT FOR INDIVIDUALS WITH TRAUMATIC BRAIN INJURIES

RESEARCH ON CAREGIVING

Dr. Priscilla Blanton, a professor of Child and Family Studies at The University of Tennessee, is conducting a study of caregiving to an elderly family member. Her study is being done to provide descriptions of the challenges and rewards experienced by family members in the process of caregiving. The findings of the study will hopefully identify ways in which caregiving families can be helped and supported. Participants will be interviewed for 1 ½ - 2 hours at a time at a private location of their choosing. She hopes to interview 2-3 members from each caregiving family. However, each person will be contacted individually and will agree to their own participation. If you are interested in participating in the study, please contact Dr. Blanton at her UT office 974-6270. She will give you further information about the study.

Figure B-1. Summary of Family Caregiving Research Project

RESEARCH ON CAREGIVING

Lee Ann R. Grubbs, a doctoral student in the Department of Child and Family Studies at the University of Tennessee, is conducting a study of caregiving to an individual with cognitive impairment as a result of a traumatic brain injury. Her study is being done to provide descriptions of the challenges, stressors, and rewards experienced by family members in the process of caregiving. The findings of her study will assist, hopefully, in identifying ways in which caregiving families can be helped and supported. Participants will be interviewed for 1-2 hours at a time, and at a private location of their choosing. Ms. Grubbs hopes to interview one member from each caregiving family. Each person will be contacted individually and will agree to their own participation in the study. If you are interested in the study, please contact Ms. Grubbs on the University of Tennessee campus at (865) 974-3502, or at (865) 689-5112. She will be glad to give you further information regarding the study.

Figure B-2. Summary of Caregiving Research Project Modification for TBI

INFORMED CONSENT

You are invited to participate in a research study. The purpose of this study is to explore the process of family caregiving through interviewing family members who are providing care to an individual with a traumatic brain injury.

Procedures: As a participant you will be interviewed at a time and private location of your choosing. Each interview will last approximately 1 ½-2 hours and will be held in a private area. The interviews will be audio taped. The audiotapes will be transcribed. If you decide to withdraw participation at any point your audiotape will be erased in your presence. Also, there will be a demographics sheet that will be completed for each participant. If you decide to withdraw participation at any point your demographic sheet will be destroyed or returned to you per your request.

Risks: There are few anticipated risks involved in your participation in this study. Participation is voluntary. It is anticipated that you might find it helpful to talk about your caregiving experience. However, if you have evidence of anxiety or other negative emotional responses to the interview process, then you will be provided with a name and telephone number of a mental health center that provides services in your area.

Benefits: The results of the study will only be used to help develop a better understanding of the impact of the roles of primary caregiving in families. Data will be used for research purposes only. Data will be prepared in manuscript format and may be published in professional journals and books. The data may, also, be presented at professional meetings to assist in the educational advancement of the field.

Confidentiality: All data will be kept confidential. After transcription and analysis, the data will be stored in a locked file in a locked office. The data will be kept for five years and then destroyed. Your identity will be kept totally confidential through the use of pseudonyms. The consent form will be stored in a separate locked file from the interview transcriptions in a locked office, at the University of Tennessee, for five years and then destroyed. The only individuals having access to this information will be Lee Ann Grubbs (researcher) and/or Dr. Priscilla Blanton (student advisor).

Compensation: This study is for research purposes only, and there will be no financial compensation or any direct medical treatment given should injury occur. The only treatment that will be given, in case of negative emotions as a result of the interview process, is the name of the mental health professional within your community.

Contacts: You may contact the following persons if you have further questions or concerns about the project or your participation in it.

Priscilla Blanton/ Lee Ann R. Grubbs
Department of Child and Family Studies
College of Education, Health and Human Sciences
The University of Tennessee, Knoxville
Knoxville, Tennessee 37996-1900
(865) 974-6270
(865) 974-3502
Email addresses: pblanton@utk.edu
lgrubbs@utk.edu

Participation: Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at anytime without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed, your data will be returned to you or destroyed. The tape of your interview will be erased in your presence if you desire.

Your signature below indicates that you have read the above information, agree to participate in this study, and have received a copy of this form.

Participant Name (print): _____

Participant Signature: _____

Date: _____

Figure B-3. Informed Consent Form

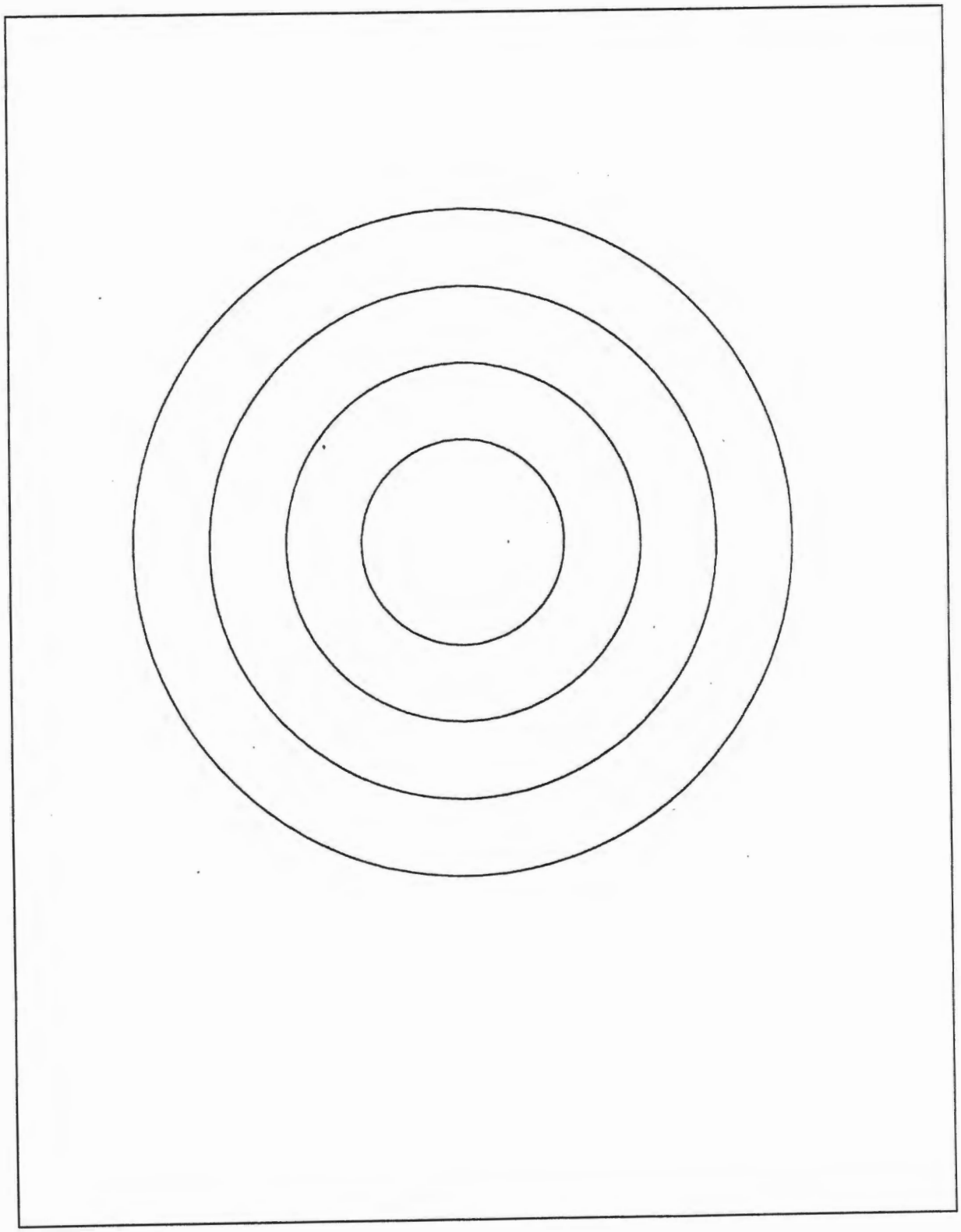


Figure B-4. Cognitive Mapping Activity

Please check or fill in the following information:

Gender: M_____ F_____
Marital Status: Married __; Divorced__; Separated___; Widowed___; Never married___

Age:_____

Educational Level (please check one):

___ some high school	___ college degree	___ doctoral degree
___ high school degree	___ some graduate work	
___ some college work	___ master's degree	

Occupation: _____

Number of hours you work on your job each week: _____

Number of Children: _____

For each child, please provide their age, gender, and residence

Gender	Age	Lives with you
M____ F_____	_____	Yes____ No___
M____ F_____	_____	Yes____ No___
M____ F_____	_____	Yes____ No___
M____ F_____	_____	Yes____ No___
M____ F_____	_____	Yes____ No___
M____ F_____	_____	Yes____ No___
M____ F_____	_____	Yes____ No___

(optional) Your personal annual income: _____
Your family annual income: _____
Annual income of individual: _____

Have you ever paid others to help with care? Yes____ No____
If yes, how often? _____

Have you ever used home health services? Yes____ No_____
If yes, how often? _____

Relationship to frail elder: _____

Is your mother living? Yes____ No_____
If yes, age: _____

Is your father living? Yes____ No_____
If yes, age: _____

Is your mother-in-law living? Yes____ No_____
If yes, age: _____

Is your father-in-law living? Yes____ No_____
If yes, age: _____

Please list gender and age of your siblings

Gender	Age
M ____ F_____	_____
M ____ F_____	_____
M ____ F_____	_____

Figure B-5. Demographic Information of Family Caregiving Project

Please check or fill in the following information:

Gender: M_____ F_____
Marital Status: Married __; Divorced__; Separated___; Widowed___; Never married____

Age:_____

Educational Level (please check one):

____ some high school
____ high school degree
____ some college work
____ college degree
____ some graduate work
____ master's degree
____ doctoral degree

Occupation: _____

Number of hours you work on your job each week: _____

Number of Children: _____

For each child, please provide their age, gender, and residence

Gender		Age	Lives with you	
M_____	F_____	_____	Yes_____	No____
M_____	F_____	_____	Yes_____	No____
M_____	F_____	_____	Yes_____	No____
M_____	F_____	_____	Yes_____	No____
M_____	F_____	_____	Yes_____	No____
M_____	F_____	_____	Yes_____	No____
M_____	F_____	_____	Yes_____	No____

(optional) Your personal annual income: _____
Your family annual income: _____
Annual income of individual (TBI): _____

Have you ever paid others to help with care? Yes____ No_____
If yes, how often? _____

Have you ever used home health services? Yes____ No_____
If yes, how often? _____

Relationship to individual with a traumatic brain injury: _____

Is your mother living? Yes____ No_____
If yes, age: _____

Is your father living? Yes____ No_____
If yes, age: _____

Is your mother-in-law living? Yes____ No_____
If yes, age: _____

Is your father-in-law living? Yes____ No_____
If yes, age: _____

Please list gender and age of your siblings

Gender		Age
M ____	F_____	_____
M ____	F_____	_____
M ____	F_____	_____

Does the individual with a traumatic brain injury have insurance other than SSI/SSDI? Yes ___ No___

Figure B-6. Demographic Information Modification for TBI

VITA

Lee Ann Russell Grubbs was born on July 23, 1976 in Knoxville, Tennessee. Lee Ann's parents were, also, from Knoxville, Tennessee. James P. Russell II and Richa Cox Russell settled in Halls Crossroads, Tennessee in 1972, and Lee Ann spent all of her life in that community. An only child, Lee Ann enjoyed spending time with her grandparents, attending and participating in athletic events, and taking piano and violin lessons in her community.

Lee Ann attended Knox County Schools, through her high school graduation in May 1994, and she proceeded to enter into The University of Tennessee at Knoxville in the summer semester of 1994. She earned a B.S. degree in Human Services in August 1997 and began graduate work immediately upon completion of her undergraduate work. That same summer of 1997, Lee Ann married Brent Kenyon Grubbs, with whom she resides in Halls Crossroads, Tennessee. Together they have no children, but they enjoy spending time together, and they enjoy time spent with both family and friends.

Lee Ann earned her Master of Science degree with a concentration in Rehabilitation Counseling from The University of Tennessee Knoxville in December 1998. Lee Ann's career took many paths throughout her experiences. While attending the university and training to become a rehabilitation counselor, Lee Ann worked as a family support coordinator for Emory Valley Center in Oak Ridge. There, she supervised twelve counties with responsibilities for budgeting and family support coordinators located within those twelve counties. Her working knowledge of different communities and her brief supervision experience led her to an employment opportunity with

Tusculum College as an Admissions Counselor in the Organizational Management program located in Knoxville. Here, Lee Ann learned to work effectively with both students and faculty on issues surrounding advising and admissions. She spent most of her time recruiting students for their academic programs. While at Tusculum College, Lee Ann began her work on her doctoral degree at The University of Tennessee, Knoxville, in the area of Child and Family Studies. Due to conflicts between late working hours and her need to attend classes Lee Ann left Tusculum College in the summer of 1999 to pursue her doctoral degree full-time. During this transition, Lee Ann was offered a position with the State of Tennessee as a vocational rehabilitation counselor for the Blind and Visually Impaired. Lee Ann took this opportunity and continued her work to fulfill her goals to attain her doctoral degree. After working two years for the State of Tennessee as a rehabilitation counselor, Lee Ann transitioned into a grant-funded position through the State of Tennessee to become a Rehabilitation Counselor/Instructor in the graduate program in Rehabilitation Counseling at The University of Tennessee. She is currently employed in that position.

As Mrs. Grubbs returned to The University of Tennessee as a full-time student in the fall of 1999 to pursue a doctoral degree in Child and Family Studies, her research focus was in the areas of family studies, disability and geriatrics. While completing her academic degree, Lee Ann took classes that would assist her in learning more about geriatrics, aging, disability, and research. Lee Ann has been able to share her research findings through various professional organizations and presentations. Lee Ann has presented at multiple conferences in her two years working with the rehabilitation counseling program. She has been a presenter at conferences such as the National

Rehabilitation Association, National Council for Rehabilitation Educators, and the Mid-South Educational Research Association Annual Conference. Also, Mrs. Grubbs has been involved with and served as an officer in professional organizations. Lee Ann is currently a member of The National Rehabilitation Association, The National Council for Rehabilitation Educators, and The National Council on Family Relations. Lee Ann has completed certifications that have strengthened her skills in her focus areas. These certifications include a Certified Rehabilitation Counselor credential (CRC) in the area of rehabilitation, and a Certified Family Life Educator credential (CFLE) in the area of child and family studies. Upon completion of her doctoral degree, Lee Ann would like to continue working in a collegiate environment. She would like to continue her academic work as both an educator and researcher.

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