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INVESTIGATING ADAPTIVE COPING MECHANISMS IN  
ELDERLY SPOUSAL CAREGIVERS

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A Project  
Presented to the  
Faculty of  
California State University,  
San Bernardino

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In Partial Fulfillment  
of the Requirements for the Degree  
Master of Social Work

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by  
Elaine Margaret Foytik  
June 2001

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ELDERLY SPOUSAL CAREGIVERS

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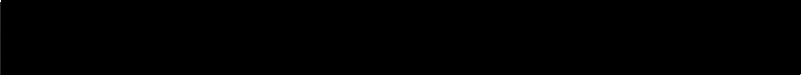
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June 2001

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## ABSTRACT

This research investigated the coping strategies that elderly caregivers use when caring for a spouse with brain impairment, categorizing their strategies into an external or internal locus of control. A qualitative and quantitative design was used to allow caregivers to describe their individual circumstances and the specific activities they used in order to continue in the caregiving role. The Locus of Desired Control survey was used to categorize the caregivers' beliefs. A t-test was used to compare scores from the study and the perceived burden felt by the caregiver. There were no significant results. However, the identified themes derived from the recorded interviews provide a wealth of information with respect to gaining a better understanding of the situation that older adult caregivers face. The information provided by caregivers will challenge professionals to continue to advocate and pursue effective measures to assist elderly caregivers as they continue to care for their partners.

#### ACKNOWLEDGMENTS

This project is the result of a collaborative effort of many. Inland Caregivers Resource Center was willing enough to provide the participants. Associated Students Incorporated, a student grant from California State University, San Bernardino, supplemented costs to make this paper possible. Thank you to all the caregivers who courageously told their stories and who make sacrifices everyday to provide loving care for their mates. Thank you Dr. Rosemary McCaslin for all your patience, expertise, and commitment to your students.

## DEDICATION

I dedicate this research to God for giving me this opportunity and His strength throughout. Special thanks goes out to my family, including my in-laws, for their words of encouragement and support throughout the last two years. Thank you to my husband and soul mate, Chad, who has always shown me patience, love, and care.

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## CHAPTER ONE

### INTRODUCTION

It is no secret that our country is aging. As technology advances, people are living longer and living with disabilities. The Census Bureau (1997) expects the population of 65 years and over to comprise 20% of the total population by 2030, compared to 13% now. According to the Census (1997), the age cohort 85 years and older is expected to double by 2025. In 1994, 52.5% of the population 65 years and older had at least one disability. In the same age group, 33.4% were diagnosed with severe disabilities (Administration on Aging (AoA), 1999). AoA (1997) reports that 4.4 million older adults have difficulty performing activities of daily living such as bathing, dressing, brushing teeth, and feeding. As the older adult population significantly grows in numbers, their needs and concerns cannot be ignored.

The aging process becomes more complex as people reflect on their lives, face their own mortality, and continue to endure daily tasks of living. This time in life can become even more complicated if the older adult becomes a caregiver for their spouse. The role of a spousal caregiver can be viewed as an extension of love and devotion to a partner or a tremendous responsibility that is resented because of unfilled expectations of less

responsibility and more leisure time in later life. The perception of the circumstances of elderly caregivers is influenced by many variables such as gender, race, religion, and prior experiences. Therefore, the possible combinations of factors influencing the caregiving situation are numerous. There is not a universal solution to the problems caregivers face. However, research conducted with a variety of specific conditions provides a diverse knowledge base from which professionals can draw in order to address individual needs.

There are many costs for family caregivers: emotions, time, energy, and physical labor. Caregivers are primarily female (75%), family members (95%) (AoA, 1999), and 36% are spouses (Stone et al., 1987 as cited in Mui, 1995). On average, caregivers spend more than six hours a day assisting an older adult (Pilisuk & Parks, 1988).

The physical strain of caregiving can be magnified by the caregiver's quality of physical health and perception of the circumstances (Mui, 1995). The strain and burden of caring for an dependent spouse can be difficult for anyone at any age. However, this can be increasingly stressful for an aging spouse who has his or her own health problems and issues to grapple with during this developmental stage.

Although later life can be just as fulfilling as the earlier years, older adults experience many losses. Not only do friends and family die, but elderly adults also experience losses in status, their roles in society, possibly financial security, and the loss of hobbies and interests due to health limitations. In addition to these losses, spousal caregivers witness daily the gradual loss of their partner, with whom they have shared their lives with for decades. It is no wonder that these caregivers suffer from depression, anxiety, somatic symptoms, and resentment. The spousal caregiver's situation is a self-sacrifice as they put aside their needs to care for their loved one and delay or prevent institutionalization, which is also of benefit to the country. Informal caregiving services save the government \$45 to \$75 billion per year (AoA, 1999). As much as these caregivers give to others, they deserve the attention and support of their community and the government.

Many community resources are available to caregivers to support them emotionally and aid in caring for their partner to allow them to continue to live in their home. Regardless of the numerous services, caregivers must learn to cope and adapt to their situation to maintain quality of life for themselves and their partner. There is a wealth of literature addressing the devastating aspects of caregiving and its psychological impact. While

it is valuable to understand the effects of caregiving on the caregiver, it is equally important to learn of the adaptive methods employed by caregivers so as to teach others who are struggling. The more that the helping professionals understand about the entire situation, the better equipped they will be to effectively serve those in need.

#### Problem Statement/Problem Focus

Simonsick's (1993) findings showed that spousal caregivers have higher levels of stress, depressive symptoms, use of psychotropic medications, and lower satisfaction in life. Elder abuse is another indicator of the amount of stress the caregiver experiences. Adult Protective Services reported a 150% increase nationwide for reported cases of elder abuse between 1986 and 1996. Ninety percent of known perpetrators were family members; two-thirds were adult children or spouses (AoA, 2000).

Depression for caregivers, especially women has been confirmed by many studies (Pruchno and Resch, 1989; Yee and Schulz, 2000; Young and Kahana, 1989). Yee and Schulz (2000) concur with Simonsick's findings of elevated depressive symptoms in caregivers. They add that female spousal caregivers showed increased levels of distress, anxiety, paranoia, and a lower satisfaction for life than male caregivers. However, at a two year follow-up, male

caregivers reported the same level of depression as the female participants (Schulz and Williamson, 1991 as cited in Yee and Schulz, 2000; Zarit et al., 1986 as cited in Pruchno and Resch, 1989). Caregivers also report suffering from anxiety, guilt, self-blame, and psychosomatic symptoms.

Research has often investigated the emotional and psychological strain of caregiving. Lovette and Gallagher (1988) as cited in Gatz, Bengston, and Blum (1990), found that 26% of caregivers in their study had, at some time, a major depressive episode. Another study found that 43% of the caregiver participants were "clinically depressed" (Haley, Brow, Berry, and Hughes, 1987 as cited in Gatz, Bergston, & Blum, 1990).

The effects of caring for older adults can be felt at many levels, from individual, family, and community, to the government. Family is considered the primary choice for caregiving (Pilisuk & Parks, 1988). Caregivers that provide constant assistance may not be willing to accept support due to the internalized beliefs of the family being responsible for their own members. However, the rates of depression, elder abuse, and stress reported by elderly caregivers relates to the necessity of support. Therefore, professionals need to acknowledge caregivers' needs and provide support so that they may continue to care for their loved ones at home, maintain

quality of life, and enjoy their remaining years. The purpose of this research is to understand caregivers' needs and learn about their effective coping strategies to aid in the development of effective programs to teach other caregivers who are struggling how to adopt more adaptive coping strategies.

Research has primarily focused on the burden and stress that caregiving can cause the family and the caregiver. Calderon and Tennstedt (1998) showed through a qualitative study that caregivers used words such as "frustration", "anger", "struggle", and "isolation" to describe their caregiving experience. The participants also reported somatic symptoms from the stress of caregiving, such as weight loss, sleeplessness, exhaustion, physical weakness, and ulcers. These feelings may stem from negative patient behaviors, lack of affective support, care recipient's physical status, and lack of assistance, which foster feelings of abandonment and the inability to manage their care (Crocker Houde, 1998). Therefore, formal services such as institutionalization and use of formal home care are utilized to relieve some of the burden.

Barusch (1988) found a theme throughout her study that caregivers do seek help, and the situation does overwhelm their coping strategies because the spousal caregivers reported a fear of "failure to cope" in a

variety of situations. However, the study also showed that caregivers are reluctant to seek or accept help because of their desire to care for their partner as long as possible. While this is an admirable quality, it can also hinder their decision-making processes, thereby making the situation unsafe for the caregiver and the recipient. Crocker Houde (1998) discussed that the ideal situation would be the family utilizing a combination of formal and informal services. Stress, burden, and perception of support have a great impact on the caregiver's ability to continue to provide home care.

While it is important to understand caregivers' needs, it is equally beneficial to learn how caregivers successfully cope. Focusing on caregiver strengths and differences by gender and ethnicity provide professionals with the necessary knowledge to teach other caregivers with similar characteristics how to balance the demands of caregiving as well as maintain their quality of life. Therefore, this research project sets out to answer the question, how does the elderly caregiver's coping strategies reduce the burden when internal locus of control, external locus of control, or both are utilized for elderly spousal caregivers of a brain injured partner?

## CHAPTER TWO

### LITERATURE REVIEW

The care giving experience is very complex. Caregivers have many responsibilities. Although they may assume such a burdensome load willingly because of commitment and devotion to their spouse, they are at increased risk for negative physical and emotional well-being. Young and Kahana (1989) explain that it is common for caregivers to experience depression, mental illness symptoms, and burnout as a result of the demands of the caregiving role. Identifying the predictors that make caregivers at greatest risk for these physical and emotional complications would assist gerontologists in program and intervention development (Gallagher et al., in press as cited in Young & Kahana, 1989). It is helpful to investigate psychological and behavioral characteristics of those who seem to cope more adaptively.

#### Effects of Caregiving

Pilisuk and Parks (1988) define burden as "management of specific tasks to be preformed" (p. 436). Stress was defined as the "subjective appraisal of the strain" (p. 436). While the caregiver performs the physical tasks of cooking, cleaning, clothing,



transportation, etc. for the partner, they also assume the financial and decision-making responsibilities that can be quite overwhelming for one person. The psychological impact of caring for an ill spouse, especially with a brain impairment, seems to stem more from the sense of loss of a life partner, loss of plans for enjoying the benefits of freedom in old age together, and feeling helpless watching their loved one slowly deteriorate day after day (Pilisuk & Parks, 1988). It is easy to see how spousal caregivers report chronic fatigue, anger, depression, and frustration when considering the emotional strain as well as the physical.

The caregiving situation creates a range of emotions for the caregiver. Barusch (1988) investigated problems that caregivers faced as well as strategies they used. She found that the majority of spousal caregiver participants felt they had little time for themselves because of the responsibilities of caring for the spouse was time-consuming. The majority reported feeling lonely (55%) and depressed (67%). Resentment and guilt for the possible cause and inadequate care were other stated emotions that caregivers attempted to negotiate.

Researchers have found that it is not always the behaviors or physical demands that are burdensome to the caregiver. Zarit, Reever, and Bach-Peterson (1980) found that the level of burden was more associated with the

amount of available social supports, rather than the care recipient's behavior and constant needs. Home visits from friends and family seemed to lessen sense of burden. The study also recognized that building the natural support network by educating all family members about the disease, community resources, and encouraging other family members to help also led to decreased burden. Leading self-help groups for other care providers proved to be beneficial (Zarit, Reever, & Bach-Peterson, 1980). Approaches geared toward enhancing the caregiver's well being, rather than focusing on behavior management and interventions for the care recipient seemed to have positive results.

Motenko (1989) investigated the reasons spouses take on such a demanding role as caregiving and gratifications from the experience. The study considers the quality of the marriage prior to the illness and the appraisal of circumstances by the caregiver as having a significant impact on the stress felt by the caregiver. Wives considered their role as an extension of their love and marriage reported more gratification. Wives who provided care to their partner out of a sense of responsibility, duty, and viewed the illness as a disruption to their life and marriage reported more stress. Dementia and other diseases that affect the brain manifest themselves in odd behavior, loss of functioning, and ultimately,

loss of the person. Therefore, the disease process is one of gradual decline, which is a disruption to any marriage or life plans.

A buffer to caregiver burden was the ability for the couple to retain activities and companionship for one another. The couples that continued in their marital closeness perceived care giving as "reciprocity for past affection and care" (Motenko, 1989 p. 171). Caregivers with this attitude reported more gratification from caregiving and felt that the affection was a source of support. Therefore, the meaning attributed to the situation has a profound effect on the person's reaction and emotions associated with the circumstances. The study recommends that professionals assist caregivers in maintaining continuity in their marriage and minimizing disruption to promote caregiver well being (Motenko, 1989).

### Coping

Jivanjee (1994) explained that spousal caregivers use a variety of coping mechanisms to decrease the stress caused by caregiving. Emotional support and spirituality tended to increase caregiver's well-being. Active coping strategies included learning assertiveness, managing patient behavior, and re-prioritizing activities. Cognitive coping mechanisms involved reframing the

situation, taking it one day at a time, staying calm, and viewing caregiving as a job. These coping mechanisms allowed the caregivers to continue to be good caregivers while enhancing their wellness (Jivanjee, 1994). Barusch (1988) identified cognitive restructuring as being used by caregivers to deal with personal, psychological and interpersonal problems with the partner. Other active coping styles that tended to be effective were problem solving, logical analysis, and working toward acceptance (Williamson and Schulz, 1993).

Williamson and Schulz (1993) found differences in the use of coping strategies and their effectiveness. Active coping skills have been suggested to lead to fewer symptoms of depression. However, when using problem-solving skills with people suffering from memory deficits and degenerative diseases, this coping strategy can be exhausting. This exhaustion is due to the strategy of trying to problem-solve solutions with no answers, such as odd behavior and lack of communication as a result of the illness. Wishful thinking and stoicism, which was described as not asking for help or expressing feelings, was more related to depressive symptoms. When caring for a loved one with a deteriorating disease, it seems futile to expect positive change. Regardless, the caregivers need to learn more adaptive methods of coping. These authors suggested using coping mechanisms consistent with

the problem. Therefore, a caregiver needs to be equipped with a variety of coping strategies: relaxation, acceptance of losses of communication, and seeking social supports were related to lowered depressive symptoms (Williamson and Schulz, 1993).

Religiosity/spirituality is another identified strategy that caregivers reported as greatly contributing to their ability to cope with the demands of caregiving. Picot, Debanne, Namazi, and Wykle (1997) suggested that religiosity may contribute to the willingness to help others and recognize rewards in caregiving. Prayer and church attendance seem to increase support and decrease social isolation and anxiety. For African-Americans, religion seems to play a vital role in adapting to stressful situations as well as providing empowerment, high levels of self-efficacy, and cognitively redefining the circumstances (Picot et al., 1997).

Gender of the caregiver seems to have an impact on the perspective of the situation, the different coping styles exercised, and the definition of burden. Pruchno and Resch (1989) used the traditional gender role theory to explain the different reactions to caregiving between the genders. Females are socialized to be family-oriented and nurturing. Males are taught to focus on their external world. However in later years, women tend to be more assertive and instrumental, while men become more

nurturing and expressive. Therefore, caring for a loved one may satisfy the husband's new found perspective, which may explain lowered levels of depression in caregiving. Men were found to increase emotional involvement with the marital relationship. Women tend to resent limited social activities.

The subjective perception of caregiving plays an important role in attributing meaning to their situation. Men reported viewing the caregiving role as a repayment of the care his wife had given him. Mui (1995) elaborated that husband caregivers may perceive his care giving role as an extension of his authority, so it is viewed as a meaningful life experience. Wives tended to feel trapped at a time when they expected to be relieved of caregiving responsibilities, only to have them continue. Expectations for later life and socialized gender roles may contribute to the explanation of the differences in reported varying levels of burden (Pruchno and Resch, 1989).

On the other hand, male caregivers seem to struggle with role acquisition, referring to the transition into a caregiver role. The change in roles can be difficult because of the increased female responsibilities of cooking and cleaning that the man has assumed only because of spousal illness (Kramer & Lambert, 1999). Changes in marital quality, less opportunity to

socialize, and the lack of emotional support from a primary source, the spouse, are other changes that can be detrimental to a male caregiver's psychological and physical health. However, this study did observe that male caregivers increased participation in church activities, which was vital to social connection and support (Kramer & Lambert, 1999).

On the other hand, women reported more negative feelings, physical symptoms, higher levels of burden and worse morale than male caregivers. Women were also more likely to use avoidant coping skills rather than active coping mechanisms. The study showed that cognitive coping, such as prayer and positive self-talk, were helpful in reducing stress. Behavioral strategies of talking to friends and getting out of the house reduced the sense of burden for women (DeVries, Hamilton, Lovett, & Gallagher-Thompson, 1997). According to research, men seem to struggle most with the role reversal. Female caregivers have more difficulty with social isolation. Social support seems to be the most helpful in assisting the male and female caregiver's sense of wellness.

Simonsick (1993) focused her research on the impact of a husband's health status on the wife's mental health. A spouse's failing health was considered a threat to marital intimacy, interaction, and quality to married women, which contributed to increased depressive symptoms

and low morale. According to this study's findings, relief from caregiver responsibilities didn't reduce negative effects of spouse's illness. However, enjoyable activities with peers, especially the spouse, positively contributed to the wife's mental health. The female spousal caregivers explained that having more than friend helped them cope better than having relief from caregiving responsibilities (Simonsick, 1993). Increasing support is more important to female caregivers than relieving responsibilities.

Although the aging process happens to everyone, it must be especially difficult for the aging caregiver as they watch their spouse, often of many years, deteriorate before their eyes. Managing embarrassing behaviors related to dementia and treating them like children as their minds regress is a loss of support, marital relationship, and intimacy, which women in particular treasure (Simonsick, 1993). Therefore, it seems women have more at stake while caring for spouses with dementia.

Support from friends and family seems to be a common coping strategy for caregivers, which has shown to be a predictor of well being for the caregiver (Rook, 1990 as cited in Levesque and Cossette, 1998). However, it is important to consider the quality of the family environment. Smerglia and Deimling (1997) investigated



caregiver well being in the context of the family's involvement in contributing to making care-related decisions and support. While support from family is welcome from caregivers, it can also be a hindrance. The research reports that a family environment that is conflictual or lacks cohesion may add to the caregiver's strain rather than provide support. Making decisions for an ill loved one can be a complex process, especially if too many family members are involved and in conflict. Smerglia and Deimling (1997) discussed that a family environment is best when it is flexible, lacks conflict, and the size seems manageable to the caregiver. Family support has the potential to be a mediator of stress for the caregiver if the support is perceived as helpful (Goodman, Zarit, and Steiner, 1997).

Several studies reinforce the value of social support for caregivers. African Americans rely heavily on family and friends to provide informal care to their elders. As a result, African Americans report less sense of burden, less depression, and higher levels of life satisfaction than white caregivers (Haley et al., 1995; Hinrichsen and Ramirez, 1992; Picot et al., 1997; Calderon and Tennstedt, 1998; Mui, 1995). Picot et al. (1997) also report that African Americans are taught to depend on religiosity during difficult times. However, Whites value relying on individual problem-solving skills

to overcome tough situations. By relying on religion, African Americans utilize other church members, as well as a Higher Being, for support, comfort and guidance.

Gender, spirituality, ethnicity, and coping strategies give professionals some idea about the burdens of caregiving as well as methods to teach caregivers and families how to cope. However, there are still pieces of the puzzle to be solved. The older adult population is the most diverse age group with specific needs. The aging process is so individual that professionals are still trying to understand what universal factors influence the quality of aging, if they exist. The fact that the aged have needs is not the problem, but the multitude of problems, such as loss of family and friends, health, society's lack of appreciation and value, and loss of activities/self that the aged face, seem enormous. However, some live through it, some become physically ill, some seem steady through crisis. Although, researchers have some insight on how to age well through religion, values, culture, genetics, etc., there is still much to be learned about how people endure such loss successfully. Understanding the aging process can shed light on what the spousal caregiver is experiencing and the added demands of caregiving. Thereby, exploring methods to combat the negative side effects of caregiving would be beneficial to all.

## Theoretical Perspectives

There are some theories that help understanding and guide instruction to caregivers on how to cope more effectively. Existentialism is a philosophical perspective that finds meaning in life and situations. This line of thinking focuses on the positives and provides meaning to stressful situations which may increase motivation, decrease sense of burden, and increase quality of life. Farran, Keane-Hagerty, Salloway, Kupferer, and Wilken (1991) explain that existentialism also emphasizes the freedom of choice, which many caregivers feel they do not have. In addition, responsibility and consequences of action are other assumptions of this theory. The most valuable elements of this perspective relating to caregivers are that the perception of the situation is actually a result of social conditioning, which gives the caregiver choices to assume the role of caregiving or not. In addition, creativity and attitudes toward the situation significantly influence the amount of utilization of effective coping strategies. Most importantly, existentialism recognizes that the process of finding meaning to their situation through choices and attitudes is an individual experience that is not guided by gender,

race, or relation to care recipient (Farran et. al, 1991).

Stress/adaptation theory is based on the assumption of stressors and resources having a causal relationship. General assumptions of this theory include personal control, knowledge, social exchange, and motivation. This theory would benefit professionals by establishing programs or interventions that decrease stressors to increase resources specific to the caregiver's needs. (Farran, 1997).

Role theory is another perspective that is used to understand the changing of established roles during caring for an ill relative, yet maintaining the family system (Kramer & Lambert, 1999). Men seem to struggle with the change in roles if the wife becomes ill later in life. According to Kramer and Lambert (1999), men have a more difficult time adjusting to not having the same level of emotional support from their wives as in the past. Men also transition into household duties that they were not responsible for in the past. Role theory provides insight on the changes that male caregiver experiences while caring for their wives. Interestingly, the literature does not acknowledge the tension that the wife experiences as she assumes the husband's responsibilities when he can no longer do them.

Another theory used in this field is social exchange theory. Social exchange theory is used to grasp the caregiver's perspective of costs and benefits of being a caregiver (Picot et al., 1997). Understanding the perception of costs and benefits by the caregiver can direct the kind of services used to aid effective coping. Ill loved ones are less capable of giving back to their caregivers who give so much. Therefore, over time the costs may outweigh the benefits in caring for an ill spouse. This can create such problems as abuse and neglect. In 1996, 551,011 persons 60 years and over reported abuse, defined as physical, neglect or self-neglect (AoA, 2000). This figure is considered an underestimation of the problem with four times as many cases not being reported. The perpetrators tended to be family members, two-thirds being adult children or spouses (AoA, 2000).

#### Professional Interventions

Caregiving is an expensive responsibility to families and spouses. There are programs and agencies in the community that provide valuable resources for the caregiver. California's Caregiver Resource Center is one agency that provides relief and support services for caregivers of brain-injured persons, usually from dementia, stroke, Parkinson's disease, or traumatic brain

injury. Their comprehensive services include providing finances for respite care, support groups, counseling, legal and financial consultation, and many more useful services that provide support and a relief for caregivers (Feinberg & Whitlatch, 1998).

Several studies discuss the importance of the caregiver having a close friend to enhance well-being and gain emotional support to aid in coping with the situation (Jivanjee, 1994; Simonsick, 1993). Pruchno and Resch (1989) found that female caregivers were more likely to have a confidant. Senior Companions is an agency that provides senior peers to visit with older adults in their home to provide counseling, companionship, and social interaction (Riddick, 1997). This program can provide supervision of the care recipient to give the spouse a break or be a companion to the caregiver or be a friend to the caregiver.

Freed, Elder, Lauderdale, and Carter (1999) report that a weekly support group was beneficial for the caregiver and care recipient. The weekly support groups seemed to decrease depression, health deterioration, and social isolation. The groups also seemed to increase effective coping strategies. In addition, to gaining emotional support, making social connections, and learning community resources, the groups provided information on the illness from which family member was

suffering. For dementia clients, education regarding the disease process, how to manage behaviors, find support services, and obtain a diagnosis led to better care and delayed institutionalization (Freed et al., 1999).

However, weekly meetings can be difficult for caregivers to attend due to finding someone to care for their loved one while they are away.

Zarit, Anthony, and Boutselis (1987) compared an individual and family-counseling group to a support group. Although their findings showed lower reports of burden and psychiatric symptoms, they were not significantly different from the control group. McCallion and Toseland (1994) report moderate effectiveness with group interventions. Having the group peer-led (Zarit, Anthony, and Boutselis, 1987) and developing more specific purposes for the groups (McCallion and Toseland, 1994) were a few suggestions to improve effectiveness for caregiver groups.

The literature that has investigated the effectiveness of individual and family counseling has reported positive results. Individual counseling has been shown to have a greater impact on caregivers than groups (Biegel et al. 1991, as cited in McCallion and Toseland, 1994). More specific interventions can be used in individual counseling such as teaching relaxation techniques, problem-solving, and cognitive therapy.

Family counseling has been reported favorably by caregivers with lower levels of perceived burden and increased psychological health (McCallion and Toseland, 1994). The combination of these interventions have the potential to be highly valuable and to allow the caregiver to express feelings, build informal supports, and learn to cope better. Other interventions that are considered useful are respite care and adult day care programs in reducing stress of the caregiver (McCallion and Toseland, 1994; Zarit, Anothony, and Boutselis, 1987).

Mui (1995) confirmed that caregivers are a very heterogeneous group. Therefore, a multidimensional approach is a necessity to be effective. The use of a multidimensional strategy individualizes the combination of interventions to best suit that caregiver and their specific needs.

Designing programs and policy to fit individual needs seems unrealistic. However, the more professionals understand about the situation, the better they can plan community resources to benefit the majority. During Knight, Lutzky, and Macofsky-Urban's (1993) study of interventions, they discussed that the course of caregiver's distress over time is not understood. They also found that some caregiver's in their control group improved without intervention. The use of longitudinal



studies would be best to investigate this phenomenon. Jivanjee (1994) suggests longitudinal studies are also necessary to gain a better understanding of effective caregiving by learning how to reduce stress, minimize depression, enhance well-being, and improve coping skills.

Raveis, Siegel, and Sudit (1990) identify many areas that require further investigation to better understand caregivers. There is a need to study a variety of subgroups such as male and different ethnic caregivers. Much of the research has focused on females and whites. Caregivers caring for older adults of different illnesses are another area in need of exploration. Hinrichsen and Ramirez (1992) point out that most research studies contain small samples of ethnic groups. With such a diverse population, it would be best to include larger sample sizes of a variety of ethnicities in research. Finally, a comprehensive multidimensional instrument to assess the distinct dimensions of the psychological impact of caregiving needs to be developed. Labeling and defining the specific characteristics of burden and stress directly related to caregiving could provide an instrument that can be used across a variety of situations and populations (Raveis, Siegel, and Sudit, 1990).

## Prevention

Caregivers play a vital role in our society by caring for older adults. How can we relieve some of the burden so that the caregiver and recipient have a positive experience? Eliminating caregiver burden is not realistic. Every caregiver, care recipient, and situation is unique, so burden and crisis in later life are inevitable. However, Jivanjee (1994) suggests social workers intervening during the beginning of the caregiving process by providing support, and education can reduce abuse and enhance well-being. Early awareness of support also gives the caregiver knowledge of community resources available to help meet his/her needs as well as the loved one's needs before the situation becomes overwhelming.

Mittelman, Ferris, Shulman, Steinberg, and Levin (1996) strongly suggest a multi-faceted approach to assisting caregivers. Their study utilized individual and family counseling, weekly support groups, and continuous availability of counselors to caregivers and family members. Other considerations that need to be addressed are the amount and duration of services. Caregivers need different levels of support and respite care. Finding the correct dose of counseling, respite care and housekeeping services for specific caregivers and situations can turn

a burdensome situation into a manageable or positive experience (Knight, Lutzky, and Macofsky-Urban, 1993). Treatment plans or combination of services need to be flexible to meet the changing demands of the care recipient.

Caregiving is a broad topic whose characteristics remain a mystery to some degree. The research cited is merely an introduction to the reasons caregiving is an issue in later life, what interventions are available, which areas need further investigation, and challenges of prevention. While the government has begun to take notice of the elderly population, the idea of caring for older adults by the public is relatively new. Caring for family has been considered a private matter. However, we are finally realizing that caregiving requires much assistance from formal and informal resources. Therefore, existing programs need refining due to current findings in research, and new policies are desired to fill in the gaps to enhance quality of life for the caregiver and care recipient.

#### Locus of Control

Appraisal of a situation and belief in one's ability to manage the problem has a profound effect on the outcome of the situation. Haley, Levine, Brown and Bartolucci (1987) found that the caregiver's subjective

appraisal of the circumstances and belief in ability to manage the care recipient's behaviors were stronger predictions of depression than objective rating of severity of behaviors. Active coping such as logical analysis, information seeking and problem solving were related to higher self-reported health. This indicates that the participants had a more positive sense of well-being when they were able to actively pursue resources.

This study sets out to better define the caregiving experience through identifying use of locus of control by the caregiver. Locus of control is defined as

the extent to which a person sees his outcomes (events he experiences and reinforcements he receives) as being contingent upon his own efforts or abilities (internal) or as being determined by chance, fate, and powerful others (external) (Reid, Haas, & Hawkings, 1977 p. 441).

This concept directly relates to how a person perceives the world and adapts to situations based on their perspective. Those who employ internal locus of control tend to use more direct coping skills such as problem solving, whereas, those labeled externals used more avoidant coping strategies (Ruth and Coleman, 1996). Labouvie-Vief et al. (1987), as cited in Ruth and Coleman (1996), explains that older adults reframe negative situations into positive circumstances more easily due to an "inner mastery." Although this notion is somewhat contradictory to the previously reported accounts of

burden and frustration from caregivers, understanding and developing ways to teach such mastery may be one underlying objective to training caregivers. The position of locus of control is mostly attributed to a personality trait, which may make it more difficult to teach. However, understanding the point of reference, internal or external, can direct specific interventions to detour thinking toward empowerment and personal control.

Lefcourt (1983) has extensively researched locus of control in a variety of situations. His findings showed that cardiac patients with external locus of control had a worse prognosis than the internals. He hypothesized that the difference was due to the internals' being more cooperative and not having depression symptoms, which the externals exhibited. Perception of control of an event or resolution seems to have negative physical consequences.

Other differences between internals and externals are that externals tend to exercise more emotion-directed coping strategies such as withdrawal and hostility, as opposed to problem solving strategies used by internals.

Personal orientation is defined by Goodman, Zarit, and Steiner (1997) as "an individual self-evaluation or self-perception in a social context" (p. 149). They explain that self-evaluation and perception are influenced by internalized social and cultural expectations. These appraisals are based on feelings of

competence, obligation, guilt and reciprocity rather than the actual event to evaluation level of stress. If the caregiver feels competent in their role and is providing care out of affection and reciprocity, then they are more likely to report positive perceptions. Those who view their role out of obligation and guilt are more likely to report added stress and burden. Feeling competent in their caregiving role is another available buffer to stress (Goodman, Zarit, and Steiner, 1997; Perlin, Mullan, Semple, Skaff, 1990). The lack of feeling competent comes from the caregiver's perspective of not fulfilling society's expectations of the spouse caring for the ill partner and doing it well. Therefore, this research challenges professionals not only to intervene effectively with the individual caregiver, but to educate the public of the truth of the caregiver and what they need to rectify societal misconceptions.

Perception of control is also influenced by position in society and race. African Americans consistently demonstrate an external locus of control orientation more than their white counterparts (Lefcourt, 1976). Lower-class children express more externality than the middle-class children. Higher socioeconomic status is closely related to internality, which is explained by greater access to opportunity (Lefcourt, 1976). These findings can be applied to older adult caregivers in the same

situations, which sheds more light on the differences between caregivers.

Assessing locus of control of caregivers is only a small piece of the puzzle to understanding the psychological dynamics of the situation. Zarit et al. (1985) as cited by Haley, Levine, Brown and Bartolucci (1987) explained that it is best to comprehensively assess caregivers for problem solving, social support, and feelings of self-efficacy to better determine the uniqueness of the situation and individualize intervention strategies. The caregiving situation is different for each couple, caregiver, and family. Therefore, it is vital that research continue to strive to understand all the dynamics, positive and negative, about caregiving and the caregiver to be equipped to provide and develop effective interventions and programs.

## CHAPTER THREE

### METHODOLOGY

The purpose of this study was to explore coping strategies that elderly spousal caregivers utilize when caring for a partner suffering from a brain injury. Therefore, a survey research design was used. The participants were asked three open-ended questions in a face-to-face interview and then given a short questionnaire for locus of control and demographics. Since the participants were selected to obtain a particular population, they were not randomly chosen. Therefore, generalizability of the findings is restricted to a specific population.

To achieve a rich and in-depth look at caregiver's coping mechanisms, a qualitative design seemed appropriate. The Inland Caregivers Resource Center (ICRC) consented to use their clients in the study. The participants were chosen based on certain criteria based on information from the agency's intake information. The criteria consisted of the caregiver being a spouse, being over 55 years old, and had been receiving services from ICRC for at least six months. Interviews consisted of a few open-ended questions, one page of demographic information, and the locus of control questionnaire. The content of the interview was transcribed and then sorted



and organized to identify themes of coping. The reported coping strategies were then sorted by internal and external locus of control.

Although the interviews provide good information, there are limitations. The limitation of performing face-to-face interviews is social desirability. Another foreseeable obstacle of conducting interviews in the caregiver's home is the caregiver being distracted with the needs of the care recipient during the interview. Thereby, the interviewer may be unable to obtain true information from the caregiver or have their undivided attention to be able to thoroughly answer the questions. Therefore, when setting up appointments the participants were asked to make arrangements so that the interview was private.

The research question of this study was, how does the elderly caregiver's coping strategy reduce burden when internal locus of control, external locus of control or both are utilized for elderly spousal caregivers of brain injured partners? The independent variable was the locus of control, which was defined by the terms of the questionnaire. The dependent variable was the self-reported perceived burden of caregiving.

## Sampling

Participants that met the selection criteria of being 55 years or older, caring for a spouse, and had been an active client at ICRC for six months or more were recruited by sending a letter from the director (see APPENDIX A) and an informed consent (see APPENDIX B) to solicit voluntary participation. Those who returned their informed consent were contacted to schedule an interview. Therefore, non-probability, purposive sampling would best describe the type of sample obtained for this study.

## Data Collection and Instruments

Data were collected by administering a 20 to 60 minute tape-recorded interview in the participant's home consisting of a few open-ended questions, one page of demographic information (see APPENDIX D) and a questionnaire (see APPENDIX E). The open-ended questions were: 1) In your own words, describe your caregiving experience; 2) what are some things you do for yourself to stay in this role; 3) what are some lessons you have learned from others about caregiving that have helped you? 4) Is there anything else you would like to add, that I didn't ask? (see APPENDIX C). The author of the study asked the questions, transcribed and sorted through the narrative to identify themes and patterns.

The primary independent variables were internal locus of control, external locus of control or both utilized by each participant. The level of measurement for locus of control was interval because the range of summed scores from the survey described the level of internal locus of control, high to low. The dependent variable was the self-report perception of burden on the demographic page. The level of measurement for burden was ordinal.

The scale that was used is the Locus of Desired Control instrument developed by Reid, Haas, and Hawkings (1977). The 14-item instrument assesses locus of control and expectancies. The first seven questions relate to the individual's desirability of control of specific situations by using a 4-point Likert scale. The second set of corresponding questions addressed the individual's perceived ability to exert control using the same type scale. For the purposes of this research, some modifications were required. The original questionnaire asked "How important is it for you to be able to place your possessions where you want to place them?" (Reid, Haas, and Hawkings, 1977 p.444). During the pre-test, participants were confused by the question because it did not apply to their living situation. Therefore, that question and corresponding question, "I am able to place

my possessions where I want to place them'' (p.444) were omitted.

The reliability index was reported to be .64 in one study of 60 residents of an institution. In the second study of 147 participants, 78 were residents in an institution and 65 were independently living, the reliability was reported at .66 (Reid, Haas, and Hawkings, 1977). Ziegler and Reid (1979) used a very similar test that showed a reliability index of .91. For this research, the Cronbach's alpha showed a reliability of .69. Validity measures are not reported or available in other resources.

Mullins (1982) used the Locus of Desired Control scale in his study. He explained that the mean of the study defined the separation of high or low internal locus of control. Therefore, scores below the mean of this study (45) are considered to have a lower internal locus of control compared to those who scored higher than the mean.

#### Procedures

The author sent 99 informed consents (see APPENDIX B) with a letter (see APPENDIX A) requesting voluntary participation from the director to the consumers of Inland Caregiver Resource Center that met the selection criteria. Those who returned their informed consent were

contacted by phone to set up an appointment for an interview at the participant's home. The interviewer explained that the session would be recorded, so requested privacy.

Before the interview, the author of the study reminded the participant that their identity would be kept confidential, if they felt uncomfortable answering any of the questions, they did not have to answer. If the participant wished to turn off the tape recorder at any time, the interviewer would do so. They were given the opportunity to ask any questions before the interview started. Then the interviewer continued by asking the open-ended questions. After the open ended questions, the open page of demographic questions and the survey was given to the participant to fill out while the interviewer waited for the participant to complete it. The participant was thanked for their time and given a debriefing statement (see APPENDIX F) at the end of the interview. Through the mail, the interviewer sent a thank you letter for their participation. All information was kept confidential.

#### Data Analysis

The purpose of the study was to explore the coping mechanisms that elderly caregivers use to manage the caregiving experience. The underlying hypothesis was that

the caregivers who employ internal locus of control coping strategies would report less burden. Univariate statistics such as frequency distribution, measures of central tendency and dispersion were used to describe the findings. Mean, standard deviation, range, and median of age, income, and reported burden were used to depict the population of the study.

The bivariate statistic of a t-test was employed to determine if a relationship existed between the locus of control and self-reported burden question. Pearson r was used to find any relationship between the reported hours of caring for the spouse and perceived burden.

The qualitative design required that the contents of the interview be transcribed. Then the contents were reviewed to assess any themes or patterns for each participant and group. Categories were created based on the themes and patterns identified in the transcriptions. Then the transcriptions were coded by the assigned categories. The codes were counted and summarized for each category and participant.

## CHAPTER FOUR

### FINDINGS AND RESULTS

#### Demographics

Of the 42 caregivers who returned informed consents, 32 were interviewed. Ten interviews did not take place for a variety of reasons, such as spouse's death, illness, or lack of time. Twenty-two females (68.8%) and 10 males (31.3%) comprised the sample studied. The range for age was 58 to 89 years and the mean was about 71 years (70.91, SD= 8.11). Of these participants, the majority was White (90.6%). African Americans, Asian Pacific Islander, and those of Hispanic decent each made up 3.1% of the population. The mean income of the households was between \$20,000 and \$29,999 (range= \$12,000-\$15,999 to \$40,000 or above). Twenty seven (84.4%) of the care recipients were cared for at home. The other five (15.6%) had been placed in long-term care facilities. The participants were primarily white females with a middle class status.

A variety of diseases that cause brain impairment were represented in the sample. About a third (31.3%) were stroke victims. The second most diagnosed disease in the sample was Alzheimer's (21.9%). Lewy Body Disease, which is a combination of Alzheimer's and Parkinson's, affected four participants (12.5%). About 15% of the

population reported having Parkinson's. The other causes of brain impairment in the partners were alcohol-related dementia, dementia, multiple sclerosis, lateral sclerosis, traumatic brain injury, and anoxia.

Duration of caregiving responsibilities was considered. The length of time for caring for the partner ranged from 1 year to 20 years ( $M= 6.73$ ,  $SD= 4.72$ ). The amount of time the caregiver provided assistance was evaluated. Hours of care provided per week ranged from 8 to 168 hours ( $M= 100.38$ ,  $SD= 43.35$ ). Perceived burden was rated on a 5-point Likert scale ranging from 0 (not at all) to 4 (extremely burdened). Quite a bit burdened (3.81) was the mean describing perceived burden of caregiving responsibilities.

The scores of the Locus of Desired Control survey were created by multiplying each desirability item with the corresponding expectancy item and summing the results (Reid, Haas, and Hawkings, 1977). The possible range for the final score was 6 to 96. The actual scores for this samples ranged from 22 to 80. The mean was 45.1, so fifteen participants scored below the mean and 16 scored above the mean with a value indicating a high internal locus of control. Of the 32 participants, 13 females and 3 males scored with a high internal locus of control. Out of these 16 that scored above the mean, 11 females and



one male provided care for their partner on average for eight hours or more a day.

### Qualitative

Responses to the first open-ended question, "in your own words, describe your caregiving experience," concurred with Calderon and Tennstedt (1998) study that reported caregivers describing their experience as frustrating and isolating. Feelings of guilt, resentment, and loneliness were other adjectives that caregivers reported that are consistent with the literature.

Many studies discussed depression as being a prevalent psychological problem with caregivers. In this study, five people reported depression (4 females, 1 male) and two females were taking prescribed antidepressants. Assuming all responsibilities of the household seemed to overwhelm the caregivers (8 females, 2 males). One 69 year old female, had respite care for her husband, but explains ". . . there are still all these other responsibilities of having to do all the things we used to do together that I have to do now." As a result, many described caregiving as consuming. A 73-year-old female summarized it as "I had no other activities than taking care of him, which I wanted to do, but after awhile it wears you down."

Participants also explained that caregiving required them to make many sacrifices (8 females, 7 males), whether it be their interests and hobbies, or relinquishing of their retirement plans with their spouse. Five males and seven females reported that their partner's illness changed their activities or lifestyle. A 78-year-old Hispanic male describes how caregiving had changed his life, "Our plans are completely different than what we're doing now. You just don't plan for things like that. How many people know what they're going to get when they're 60 years old?"

Others found it difficult to watch their spouse decline in health and ability (5 females, 2 males). An 80-year-old female describes after 62 years of marriage, "the hardest thing perhaps, with your mate having Alzheimer's, is that they become different people than they have been through the years."

The physical strain of caregiving was most reported by this population through exhaustion. The literature discussed somatic symptoms as a result from the stress of caregiving. One caregiver, a 63-year-old African American female, had a speech impediment, Botoch's, resulting from the stress of caregiving. Interestingly, she marked "not at all" burdened.

On the other hand, three participants described their experience as a time of learning about themselves

and life. One man stated, "It's been very, very much a growing experience. . . you grow in your relationship with your spouse. . . you learn about yourself. You learn a lot about your role and boundaries and what you're willing to do and why." Another man describes his situation this way, "I've learned a lot about caring for a person . . . There is an awful lot involved in taking care of a person . . .I've found out this one in taking care of her and in the giving there is a terrific reward."

Unfortunately, some experienced difficulty in finding quality respite care and endured much hardship in just trying to get help. One woman who has had several negative encounters with trying to find help explains, "That has been the worst aspect of being a caregiver, is getting help. If it wasn't for that, I think I could handle it pretty well."

Question two asked them what they did for themselves so that they could stay in their caregiving role. There were a variety of responses and combinations of activities that allowed these caregivers to provide care. Formal services such as respite care, day care, support groups and counseling were used by several of the participants. Two females hired people to care for the lawn and housecleaning, so they could focus on caregiving. Inland Caregivers Resource Center (ICRC) and

other community agencies provide support groups in which many of them participated (12 females, 4 males). Support groups seemed to be most helpful in reframing the caregiver's situation. Several caregivers (11 females, 4 males) used reframing of their situation to keep going. A 75 year old woman summed it up nicely, ``. . . there are so many people, their circumstances are worse off than mine. Sometimes it's good to know because you don't have an excuse to feel sorry for yourself if somebody has more problems.''

ICRC also conducts classes to teach caregivers how to manage their frustration, which has been beneficial to many. In this class, they learn relaxation-breathing techniques that reduce stress and how to change their attitude to stop their frustration. An 84-year-old male explains, ``These seminars have taught me to breathe deeply 5 times, 10 times, whatever it takes-stop. Leave the room if you have to . . . change your attitude. Get over your mad.''

Another prevalent recommendation from the caregivers was that taking care of themselves is just as important as caring for their spouse. However, many of them had to learn this lesson because they had forgotten about themselves. Thirteen women and two men attributed their ability to stay in their role by taking care of

themselves by exercising, eating healthy, and staying active.

Informal support played a pivotal role in the caregiver's well-being. Staying connected with family and friends by talking on the phone, visits, or going out to lunch together helped the caregivers get away from their responsibilities at home and have socialization. Two women did not have family or friends in the area, but they were able to feel supported by them through electronic mail. Attending church and being involved in church activities provides an opportunity for caregivers to see friends and receive support from fellow church members. Church is also a chance to get the care recipient out to socialize.

Short trips with the ill spouse to visit family were another activity that seemed to facilitate coping. It was also a chance to get out of the house and socialize.

"I'm not stuck right here all the time. I look forward to those couple times a year to go up there," a 59-year-old explains about going to Bishop to visit their daughter. Two females and three males discussed the luxury of doing activities with their spouse even if it was going to the mall, which they looked forward to and enjoyed. This seems to be concurrent with Barusch's (1989) study of the benefits of continuity of activities in the marriage.

Solitary activities were also considered important to the caregiver to maintain psychological well-being as well as a relief from responsibilities. Reading was the most utilized solitary activity for coping (14 females, 6 males). Other activities those caregivers enjoyed doing alone were praying, journaling, going to the movies or taking time for themselves to do whatever they wished.

Some other healthy hobbies that helped coping were activities such as crafts, building a plane, going to the salon, and shopping. Spirituality gave some comfort. A 74-year-old male explains, "I think a spiritual dimension adds to it. I think it would be tough if you didn't have some religious background to fall back on. Without that it's all kind of blank."

Caregivers sought information about their partner's illness to understand the process so that they had some idea of what to expect. Seven women and one male actively educated themselves about their partner's illness. A white, 66 year old female explains:

I knew one lady, her husband was further advanced with Parkinson's. . . . She told me about some things that may be happening down the road, which were not good things. At least she gave me a clue. This wasn't reading from a book or anything. It was a person talking to me, telling me what I might expect as time passes. When something happens it won't be such a huge surprise.

Caregivers seemed to use a combination of formal and informal supports if they were available. On a daily

basis, caregivers had activities to rely on that allowed them to continue to care for their spouse.

The third question inquired about lessons they had learned that helped them with their caregiving. The most noted lesson was learning how to take care of themselves. The next most reported skill learned was finding out that their situation was not nearly as bad as other caregivers. Therefore, reframing the situation by comparing their circumstances to others was another coping mechanism employed. Patience (9 females, 1 male) was a skill learned along the way as their partners slowed down and could no longer perform certain tasks.

Some learned practical skills about medications and medical equipment needed to assist their spouse. Another participant learned how to make a bed with her disabled husband in it and how to give a shower. Four females learned the valuable lesson of allowing their ill partner to continue to do as much for themselves as possible.

"The thing that has helped me the most was my last ICRC workshop- don't do anything for your husband that he can do for himself. . . All of a sudden, here I am, I've been doing these little things that he could have done himself. . . that is absolutely wonderful," describes a 69 year-old Asian female.

Acceptance of the situation seemed to be another method that helped the caregiver cope. Seven women and

one man reported accepting their circumstances. Some chose to see it as a positive thing, ". . . God gave him to me to take care of, so I will take care of him as long as I can. I will say we're lucky." Others had a different perspective, ". . .you just realize that things really aren't going to get much better. Life is what you make of it. You better get on with it." Both these women loved their husbands and enjoyed their company, yet still struggled with frustration. With balance they managed to accept their role.

When comparing the interview transcripts between those who scored above and below the mean on locus of control, some interesting themes emerged. Those who scored above the mean, indicating a high internal locus of control, seemed to engage in activities that allowed them to maintain their sense of self while continuing to care for their spouse. They had more activities than those with lower scores and the activities were more specific to their needs. Some enjoyed being creative with making crafts or building a plane. Others stayed active by exercising and being involved in activities with other people and volunteering for community events.

Those who maintained their hobbies before they became caregivers maintained their identity. For example, the participant who scored the highest was an 85-year-old male who was active in many hobbies, which he had prior



to his wife's illness. Shortly before the interview, he had won a snow skiing contest for his age division. He was very proud of his flying career in WWII and loved to fly planes. Unfortunately, he had to sell his plane because they didn't use it, but he was in the process of building one, was a member of flying clubs, and flew occasionally to test planes.

Another difference between the groups was the caregiver's ability to adapt to their situation. This characteristic is consistent with the idea of locus of control. If a caregiver feels that they have control over their situation, then they have the ability to manipulate their circumstances to cope according to their needs. Those with a high internal locus of control participated in a combination of solitary and active leisure pursuits. The other group mostly engaged in solitary activities such as reading.

Social support from family or friends was another factor that helped these caregivers stay in their role. Some caregivers did not have family available or were in conflict with family members, but had friends that were available and emotionally supportive. A majority of the high internal locus of control participants reported having someone they could call to vent their frustrations. Family being willing to visit or allow caregiver and recipient visit was another form of support

that the caregivers appreciated so they could have social interaction and get out of the house. Those with lower internal locus of internal control reported little or no support available to them.

All the caregivers gave of themselves and made sacrifices because of their circumstances. The groups did not differ in describing their situation. Caregivers in both groups reported "losing it", being isolated and having changes in life they did not expect. Reported perceived burden did not differ between the groups. However, the outlook they possessed separated the high and low internal locus of control participants. Those with a high locus of control seemed to continue to have a positive attitude about life and accepted their situation. One of the most uplifting interviews was with an 89-year-old male, who exuded a zest for life by expressing his continued and growing love for his wife. He made comments like, "everything has worked out" and "this is what life is all about." When talking about dying he states, "Not that you are afraid of dying, far from that. To me, that's just another great adventure."

Caregivers with a high internal locus of control also continued to do activities with their spouses such as small trips, going to church, and shopping. The caregiver's marriage seemed to be a strength in their life. In spite of their spouse not being able to

communicate, they seemed to maintain that sense of connection by continuing activities together. This was consistent with the literature from Motenko (1980) that couples sustaining activities serve to buffer burden.

The most interesting theme that emerged was that spirituality and a strong belief system was evident in 11 out of the 16 participants with high internal locus of control compared to 2 participants with low locus of internal control. Their spirituality seemed to be a source of strength, give them reassurance, and give meaning to their circumstances. Those who attended church also had a weekly opportunity to socialize, get out of the house, and continue an interest with their spouse.

#### Quantitative

The means of perceived burden (female=2.18, male=2.00) and the total score of the survey (female=44.14, male=47.56) did not show a significant difference when categorized by gender. There was no significant relationship found between the amount of hours caring for the partner and reported perceived burden as assessed by Pearson correlation. Although the correlation was not significant, the statistic showed an inverse relationship between hours of caring for their spouse and perceived burden. The hypothesis that those who employ an internal locus of control type of coping

would perceive less burden was not confirmed by this study.

## CHAPTER FIVE

### CONCLUSIONS AND RECOMMENDATIONS

Although this research did not confirm the research question of internal locus of control buffering caregivers' sense of burden, it provided useful information about caregivers. The number of interested participants indicates that regardless of the overwhelming amount of time it takes to care for another person, elderly caregivers are willing to make time to relate their situation to help other caregivers. The opportunity to have a visitor come to their home, when they don't have many visitors, may be another explanation for such a high return rate of the informed consents.

Another interesting note was that these caregivers were willing to explain their personal lives and troubles to a stranger. Most of the time, it seemed that the participants were eager to tell their story. While support groups are helpful, it seems that the caregivers need more socialization and support. Most of the caregivers reported being confined to their homes because of their spouse. Therefore, outreach type services seem appropriate and needed. It is always nice to have family and friends visit, but it is not always realistic. Many caregivers reported how helpful it was to vent their feelings to someone or just get out of the house to do

something with a friend, which concurred with Devires, Hamilton, Lovette and Gallagher-Thompson's (1997) findings of social support being vital to a caregiver's well-being. If friends and family are not available, a service that provides the caregiver with a person to do activities with or just call at their convenience would be beneficial.

Many of these caregivers have been married for decades. Their sense of commitment and duty to their spouse is another factor that gives them the strength to continue to provide care. The devotion felt for their partners has also led to the caregivers being protective of their partner and being reluctant to have strangers care for them. However, when respite was provided, the poor quality of care or its unavailability reinforced the caregiver's reluctance of using respite, which prevented the caregiver from getting a break. The cost of respite was another consideration that sometimes interfered with getting help. Although there are programs and services available for respite care, too many caregivers will not utilize this service because the financial aspect is beyond what a limited income can support.

This research should make professionals aware that something has to be done to uniformly help caregivers receive quality respite care at an affordable cost. A few respondents had begun to look at long-term care

facilities in case their spouse had to be placed. They were discouraged by the cost and quality of care available. The caregivers began to realize that they were the only alternative for good care for their spouse. Institutional care cannot compare to personal care from a life partner. However, that does not excuse professionals from continuing to pursue improving the quality of care in institutions.

The findings from the research were consistent with the literature. Jivanjee's (1994) article about the positive benefits of active coping skills for caregivers was confirmed by those who scored above the mean and utilized a variety of active coping methods. The aspect of spirituality being incorporated as a coping mechanism was consistent with the research by Picot, Debanne, Namazi and Wylke (1997). The amount of spirituality identified seemed to serve as a support to the caregiver, as well as a barrier against depression and helps maintain the caregiver's health. This is another reminder to professionals to acknowledge and use spirituality to engage caregivers and foster psychological welfare.

ICRC seems to be on the right track with providing a range of services that the caregiver can choose from to fit their needs. However, the waiting lists for respite can be lengthy. Therefore, more programs that offer the same type of services need to be more visible and

accessible in the community. A multidimensional approach tailored to the needs of the caregiver and the situation seems to be the most effective and logical form of intervention.

One of the limitations of this research is the lack of diverse ethnicities represented. Although there were a few different ethnicities that participated, the majority was white. Also, more male caregivers need to be included in further research.

These findings cannot be generalized because the participants were recruited based on certain criterion, which limits the results to this population. Also, this population may not accurately represent the general public because these caregivers are receiving informal support and are motivated to reach out for help, which may not be true of the entire community.

Another limitation of this study was that the results are based on self-report, which can be skewed by the participant wanting to impress the interviewer and not fully explaining their situation.

Some recommendations for researching this population would be to include the education level of the caregivers, and the use of additional scales to determine their psychological and physical well-being to understand the true nature of their situation. Some mentioned their



own physical problems and depression, while others reported more on what was going on with their loved one.

The elderly spousal caregivers in this research put their heart and soul into their partners. While they managed to adapt to their situation and constant emergencies, they continued to attempt to reconcile their own aging process. While this report may not have proven anything statistically significant, it did give these few willing participants an opportunity to tell their story and feel as though they were a part of the solution. More research and listening ears are needed to hear their needs and put findings into action.

APPENDIX A:  
SIGNED APPROVAL LETTER  
FROM INLAND CAREGIVERS  
RESOURCE CENTER



Inland Caregiver  
Resource Center

1881 COMMERCIAL EAST  
SUITE 102  
SAN BERNARDINO, CA  
92408-3317  
909-387-0440  
(800) 875-0084

November 17, 2000

To Whom It May Concern:

The Inland Caregiver Resource Center is a private, non-profit social service agency providing services and support to family caregivers of adults with brain-impairing conditions (Alzheimer's, Parkinson's, Stroke, Traumatic Brain Injury, etc.) We provide a number of services and programs to family caregivers, including Information & Referral, Family Consultation, Respite Care and Short Term Counseling.

Inland Caregiver Resource Center has been a field placement site for first year MSW students from California State University, San Bernardino for a number of years.

David Fraser, Executive Director, and I have met a number of times with Ms. Elaine Foytek, a second year MSW student from California State University, San Bernardino. She plans to carry out her Research Project on an aspect of caregiving. She has kept us abreast as she has formulated her plan for the Research Project. She has our permission to work with our clients in the completion of her research.

Ms. Foytek seems to be a bright and capable student and we look forward to being her host agency for the Research Project. Please do not hesitate to contact Mr. Fraser or me if you have any questions.

Sincerely,

Cathy Andre, M.S.W., L.C.S.W.  
Assistant Director

A NONPROFIT  
TAX-EXEMPT  
CORPORATION, PART  
OF A STATEWIDE  
SYSTEM OF REGIONAL  
RESOURCE CENTERS  
SERVING FAMILIES  
AND CAREGIVERS OF  
BRAINIMPAIRED  
ADULTS.

APPENDIX B:  
INFORMED CONSENT

SOUTHWORTH  
PARCLEMENT, DEED  
100% COTTON FIBER

The study in which you are about to participate is designed to investigate caregiver's experience. This study is being conducted by Elaine Foytik, a Master's of Social Work student, under the supervision of Dr. Rosemary McCaslin, Professor of Social Work. This study has been approved by the Department of Social Work sub-committee of the Institutional Review Board, California State University, San Bernardino. The university requires that you give your consent before participating in this study.

In this study you will be asked to respond to a few questions and fill out a short survey. The task should take at the most 60 minutes to complete. All of your responses will be held in the strictest of confidence by the researcher. Your name will not be reported with your responses. All data will be reported in group form only. You may receive the group results of this study upon completion August 1, 2001 in the California State University, San Bernardino library.

Your participation in this study is totally voluntary. Inland Caregivers Resource Center will not know who participates or not. Your decision will not affect the services you receive in any way. You are free to withdraw at any time during this study without penalty. When you complete the task, you will receive a debriefing statement describing the study in more detail. In order to ensure the validity of the study, we ask you not to discuss this study with other members of Inland Caregivers Resource Center.

If you have any questions about the study, please feel free to contact Dr. Rosemary McCaslin at (909) 880-5507. By placing a check mark in the box below, I acknowledge that I have been informed of, and that I understand, the nature and purpose of this study, and I freely consent to participate. I also acknowledge that I am at least 18 years of age.

Place a check mark here      Today's Date \_\_\_\_\_

SOUTH WORTH  
PLACEMENT DEED  
TOOK OUT ON HER

BARCLAY'S BANK  
100 COTTON STREET

APPENDIX C:  
INTERVIEW GUIDE

1. In your own words, describe your caregiving experience

If need prompting, How has caring for your spouse changed your life? Financially? Socially? Personally?

2. What are some things you do for yourself as a caregiver to stay in that role?

3. What are some lessons you have learned from others about caregiving that have helped you?

If need prompting, such as classes, seminars or other caregivers.

4. Is there anything else you would like to add, that I didn't ask?



APPENDIX D:  
DEMOGRAPHIC QUESTIONS

These questions are designed to better understand your situation and get to know you better. All of the information provided will be kept confidential.

1. What is your ethnicity? (Check one)

- 1. African American
- 2. Asian Pacific Islander
- 3. Hispanic/Latino/Chicano
- 4. White
- 5. Other, specify \_\_\_\_\_

2. What is your household's annual income? (Check one)

- 1. under- \$8,000
- 2. \$8,000- \$11,999
- 3. \$12,000- \$15,999
- 4. \$16,000- \$19,999
- 5. \$20,00- \$25,999
- 6. \$26,000- \$29,999
- 7. \$30,000- \$35,999
- 8. \$36,000- \$39,999
- 9. \$40,000 or above

3. How long have you been caring for your spouse? \_\_\_\_\_

4. Overall, how burdened do you feel in caring for your relative?

- 0. Not at all
- 1. A little
- 2. Moderately
- 3. Quite a bit
- 4. Extremely

5. What services from Inland Caregiver Resource Center do you use or have used at any time? (Check all that apply)

- 1. individual counseling
- 2. family counseling
- 3. family consultation
- 4. respite care
- 5. legal consultation
- 6. Training or conferences
- 7. Caregiver's retreat
- 8. Support groups

6. How many hours a week do you provide care, assistance, supervision or companionship to your relative? (Do not include hours of sleep or respite care) \_\_\_\_\_ Hours per week

7. What is your gender  1. female

2. male

8. What is your age \_\_\_\_\_?

APPENDIX E:  
LOCUS OF DESIRED CONTROL SURVEY

100M CONTROL AREA  
EXPERIMENTAL  
SOUTH WORTH

Please circle the choice below the question that best fits your feelings about the statement.

How desirable or important is it for you . . .

to receive regular visits from your friends or relatives?

- a. Not important
- b. Somewhat important
- c. Generally important
- d. Very important

2. to be able to decide on your own what your daily activities will be?

- a. Not important
- b. Somewhat important
- c. Generally important
- d. Very important

3. to be able to place your possessions where you want to place them?

- a. Not important
- b. Somewhat important
- c. Generally important
- d. Very important

4. to receive attention or recognition from those around you?

- a. Not important
- b. Somewhat important
- c. Generally important
- d. Very important

5. that your doctor come to see you when you ask for him?

- a. Not important
- b. Somewhat important
- c. Generally important
- d. Very important

6. to be able to find privacy from others?

- a. Not important
- b. Somewhat important
- c. Generally important
- d. Very important

7. to be with your friends when you want to be?

- a. Not important
- b. Somewhat important
- c. Generally important
- d. Very important

8. To what extent can you cause friends or relatives to come and visit regularly?
  - a. Cannot cause
  - b. Can cause somewhat
  - c. Can cause quite a bit
  - d. Can cause a great deal
  
9. How often can you yourself decide what your daily activities are going to be?
  - a. Never
  - b. Sometimes
  - c. Quite often
  - d. Always
  
10. I am able to place my possessions where I want to place them.
  - a. Cannot cause
  - b. Can cause somewhat
  - c. Can cause quite a bit
  - d. Can cause a great deal
  
11. How often can you acquire attention from those around you?
  - a. Cannot cause
  - b. Can cause somewhat
  - c. Can cause quite a bit
  - d. Can cause a great deal
  
12. To what extent do you think you can cause your doctor to come and see you whenever you ask for him?
  - a. Cannot cause
  - b. Can cause somewhat
  - c. Can cause quite a bit
  - d. Can cause a great deal
  
13. How often can you give yourself privacy when you want it?
  - a. Never
  - b. Sometimes
  - c. Quite often
  - d. Always
  
14. How often can you be with your friends?
  - a. Never
  - b. Sometimes
  - c. Quite often
  - d. Always

APPENDIX F:  
DEBRIEFING STATEMENT

100% COLONIAL  
PATRIOTIC  
MEMORIAL

The study you have just completed was designed to investigate caregivers coping strategies. In this study, the coping strategies that caregivers use to handle caring for an ill spouse were assessed. The caregiver's perception of their control over the situation and specific tasks used by the caregiver were considered when evaluating how the caregiver coped with the situation. We believe that this information will be useful in developing programs and approaches to help other caregivers who are struggling with the caregiving experience.

Thank you for your participation and for not discussing the contents of the questions with other caregivers. If you have any questions about the study, please feel free to contact Dr. Rosemary McCaslin at (909) 880-5507. If you would like to obtain a copy of the group's results of this study, they will be located at California State University, San Bernardino library August 1, 2001.

APPENDIX G:  
SUMMARY OF DEMOGRAPHIC INFORMATION



		<u>Female</u> (n=22)	<u>Male</u> (n=10)
<u>Ethnicity</u>	African American	1	
	Asian Pacific Islander	1	
	Hispanic/Latino/Chicano		1
	White	20	9
<u>Annunal income</u>	\$12,000-\$15,999	1	2
	\$16,000-\$19,999	6	3
	\$20,000-\$25,999	7	1
	\$26,000-\$29,999	4	1
	\$30,000-\$35,999	3	3
	\$40,000 or above	1	
<u>Caring for spouse</u> (Years)	1-5 years	13	5
	6-10	5	2
	11-15	3	3
	20	1	
<u>Perceived burden by caregiver</u>	Not at all	2	2
	A little	3	1
	Moderately	8	4
	Quite a bit	7	1
	Extremely	2	2
<u>Hours of care provided per week</u>	1-20	2	
	21-40	1	1
	41-60	2	2
	61-80	1	
	81-100	4	
	101-120	4	3
	121-14	6	2
	141-160	1	
161-168	2	1	
<u>Age of caregiver</u>	55-60	1	1

	61-65	5	2
	66-70	8	
	71-75	5	2
	76-80	2	1
	81-85		2
	86-90		2
	<hr/>		
<u>Disease of care recipient</u>	Stroke	8	2
	Alzheimer's	4	3
	Lewy Body	4	
	Alcohol-related dementia	1	
	Dementia	1	
	Multiple sclerosis	1	
	Lateral sclerosis	1	
	parkinson's	3	2
	Traumatic brain injury	1	
	Anoxia	1	

APPENDIX H:  
SUMMARY OF RESPONSES FROM  
INTERVIEW QUESTION 2

	male	female		male	female
<u>FORMAL HELP</u>			doing activities together	3	3
respite	4	7	small trips	2	5
day care	1	6	fishing trips	1	0
classes on frustration	2	7	meeting people	0	1
support groups	4	11	visit family or friends	2	5
hired help for house	0	2	painting class	0	1
counseling	1	2	swap meets w/ family	2	0
senior center		1	<u>SOLITARY ACTIVITIES</u>		
<u>CARING FOR SELF</u>			go for a drive	1	0
walk			window shopping	0	2
swim		1	sit in restaurant	0	1
dance	1	1	meditate	0	1
golf	1		prayer	1	2
skiing	1		sew	0	1
yoga		1	crafts	1	1
gym		1	puzzles	0	1
gardening	5	4	journaling	2	1
staying active	2	1	crossword puzzles	0	2
			read	6	12
			one hour nap		1
<u>INFORMAL SUPPORT</u>			movie	2	2
talking w/ other CG	2	6	work on computer	1	1
talking to friends	3	7	scream/yell	2	2
family support	3	10	take time for self	2	4
clubs	2	3	shopping		2
e-mail friends & family	0	2	watch television	1	1
church activities	4	6	write letters	0	1
retreats	2	8	going to the salon	0	1
playing cards	0	1	caring for house	1	0
going out to w/ friends	2	7	walk away	1	1
bunko	0	1	write newsletter	0	1
bingo	0	1	go to the library	0	1
part-time work	1	1	build cars & planes	1	0
<u>OTHER</u>					
positive attitude	2	1			

devotion to partner	6	5
ability to express self	3	1
reframe situation	4	11
pamper self		1
sense of humor	1	1
nothing	1	1

NOTHING  
PAMPER SELF  
REFRAME SITUATION

APPENDIX I:  
SUMMARY OF RESPONSES FROM  
INTERVIEW QUESTION 3

SOUTH/WORTH  
PARCEMENT DEED  
100% COTTON TREE

	male	female
care for self	1	10
say no		2
ask for help		3
family involvement	1	5
family support	3	10
watched others	2	1
day by day		1
got to be strong		1
don't take things personally	0	2
you need help	1	
Acceptance of situation		
patience	1	10
sympathize w/ partner	6	5
prior experiences	2	5
trouble finding respite care	3	3
simplify life	1	1
feels good to have purpose	3	4
one day at a time		2
adapt to the situation & changes	4	6
medical equipment		2
foster partner's independence	1	4
practical skills training		1
let go	1	
acceptance of situation	1	7
preparing for future	1	4

SOUTHWORTH  
EARTHMENT DEED  
1863 - 1868



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