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DIFFERENCES IN FAMILY CAREGIVER BURDEN AND USE OF COPING STRATEGIES

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

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

by
Cathy Michelle Brown
June 2006

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ABSTRACT

This study examined the differences in caregiver level of burden and use of coping strategies by gender, ethnicity, relationship to the care-receiver, type of diagnosis and length of caregiving responsibilities. Questionnaires were sent out to 200 caregivers currently receiving services from Inland Caregiver Resource Center. Questionnaires were designed in order to elicit responses associated with experience of caregiver burden and use of coping strategies. This study identified key aspects associated with gender differences in experience of caregiver burden and pinpointed specific coping strategies utilized by this sample.

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I would like to acknowledge the caregivers associated with Inland Caregiver Resource Center and thank them for taking the time to participate in this study. As a former intern, I realize your caring responsibilities are overwhelming and time consuming and want all participants involved to know they are greatly appreciated. I would also like to acknowledge the Inland Caregiver Resource Center staff for their support and guidance, especially director David Fraser and my former supervisor Debbie Townson whom both made it possible for this research to happen.

DEDICATION

I would like to dedicate this project to my family and friends whom have supported me in my educational endeavors for the past ten years. To my beloved Johnny, I would like to express all my gratitude for the relentless support and encouragement you have given me through the years. Though sometimes it didn't seem possible, it is finally over and I realize what love is all about. To my dear daughter McKenna, your smile and understanding enabled me to get through this process and I know one day, you will follow in my footsteps. To my mother Maxine, you never gave up on me and your continual encouragement and support made this effort all the more attainable. I can not leave out all of the people from Marie Callenders who have supported me emotionally and shared in my quest for a higher education.

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CHAPTER ONE

INTRODUCTION

This chapter provides an overview of the issues facing and problems experienced by the caregiving population. This chapter also provides a definition of coping strategies, how it relates to caregiving and how it can influence caregiver burden. This chapter also discusses the purpose of this study and the implications it has for the field of social work practice.

Problem Statement

According to the Family Caregiver Alliance (2004) the term "care-giver" refers to any individual who is providing assistance to someone else who is disabled or incapacitated. Informal and family caregivers are synonymous in meaning (unpaid individuals) and include both primary and secondary care-givers. Formal care-givers are those paid service providers who care for an individual and are associated with a particular system of services (Family Caregiver Alliance, 2004).

According to Montgomery and Williams (2001) the process of caregiving involves changing demands and hardships and different individuals will be better able to cope with these factors than others. Despite the challenges that are involved with the role of caregiving, the immediate family tends to be the preferred pool of resources chosen by both the elderly and their families (Montgomery, 1984).

According to the Family Caregiver Alliance (2004) 52 million informal family caregivers provide care to someone who is disabled or ill. By the year 2007, approximately 39 million caregiving households will be involved with the care of a family member aged 50+. The oldest of the old age group (defined as 80+ years) is the fastest growing segment of the population, with women accounting for the majority of this growth (Velkoff & Lawson, 1998).

According to Knickman (2002) long-term care for the elderly will become a major public concern, considering that by the year 2030, the "baby boom" generation will be between the ages of 66 and 84 and will account for 61 million of the population. According to Tennstedt (1999), 22.9% of individuals aged 65+ are disabled and in need of long-term care in this country. These individuals need assistance with both activities of daily living (ADL'S) which include bathing, eating and dressing and instrumental activities of daily living (IADL'S) which include cooking, cleaning and transportation.

Elliot, Shewchuk, and Richards (2001) indicate that the informal caregiving role will be assumed under different circumstances, with some individuals gradually assuming the role and others will be thrust into the role because of a sudden illness or disability. Caregivers of individuals with traumatic brain injuries (TBI), a diagnosis which is often misunderstood by mainstream society, represent a large segment of the caregiving population (Chwalisz, 1996).

The role of informal caregiving is a specific and increasing problem in today's society. As the "baby boom" generation advances in age, the need for informal caregivers will be overwhelming by the year 2030. Currently there are five to seven million informal caregivers providing assistance to individuals 65 years and older (Family Caregiver Alliance, 2004). A considerable number of caregivers suffer from stress, depression, anxiety and illness and are often ill-equipped to handle and cope with their caregiving responsibilities (Elliot et al., 2001). According to Andrews (2003) depending on the care-receivers diagnosis, the caregiver may spend up to 100+ hours a week concerned with their caring responsibilities and very often ignore their own health and well-being.

Problems identified by caregivers include, but are not limited to, dealing with stress, time management, emotional and behavioral problems of the care-receiver, legal and financial issues, and feelings of guilt, depression, anxiety and inadequacy (Smith, Smith, & Toseland, 1991). Brody (1985) argues that parental care has and will become a normative stress for the family. This author points out that the needs and concerns within this population are diverse due to living arrangements, quality of the relationship and employment status of the caregiver. Rankin (1990) found several sources of stress including the care-receivers physical limitations, financial strain for spousal caregivers and competing demands outside of the caregiving paradigm for adult children caregivers.

According to Stephens, Crowther, Hobfoll, and Tennenbaum (1990) the term coping refers to an individual's cognitive and behavioral ability to manage demands and stressors. Lazarus (1966, p. 12) refers to coping as the "strategies used for dealing with threat."

When assessing a threatening situation, a primary appraisal of personal well-being is first initiated. An individual will then initiate a secondary appraisal which evaluates environmental options and resources in order to deal with the situation (Stephens et al., 1990). Lazarus and Folkman (1984, p. 142) define coping as "constantly changing cognitive and behavioral efforts to manage specific external and or internal demands that are appraised as exceeding the resources of the person." These authors' definitions are based on a process-oriented rather than trait-oriented approach, which implies a distinction between coping and automatized adaptive behavior. It defines coping to include anything that an individual thinks or does, regardless of whether it works or not (Lazarus & Folkman, 1984).

The social work profession approaches the needs of caregivers from both a micro and macro perspective. From a macro policy perspective, The Comprehensive Act for Families and Caregivers of Brain-Impaired Adults (Chapter 1658, amended by Chapter 775 in 1988) was the first landmark decision in California which established statewide services for families and individuals who care for someone with adult-onset brain impairment (www.inland caregivers.com).

Since January 2003, many bills have been introduced at the federal level and include The Social Security Caregiver Credit Act which would allow unpaid caregivers to qualify for benefits during the duration of care, The Comprehensive Long Term Care Act which would expand Medicare benefits to include education and training for caregivers and The Family and Medical Leave Enhancement Act which includes the care of an elderly family member in its parameters.

From the micro level perspective, many interventions have been created to decrease perceived level of burden and increase use of coping strategies. Such interventions include, but are not limited to psycho-educational classes, support groups, respite-based interventions, psychotherapy, workshops focusing on behavior aspects of the care-receiver and individual and group based counseling. According to Sorensen, Pinquart, and Duberstein's (2002) research, these interventions have indicated a significant improvement (decrease) in the level of burden experienced by caregivers.

Agencies involved with the caregiving population include the Alzheimer's Association and the Department of Aging and Adult Services. The roles of the social workers within these agencies consist of distributing community resources, home visitations and case management. A specific agency which is involved directly with the caregivers is the Caregiver Resource Center, which is a non-profit agency with eleven chapters in the state of California. Social workers within this agency are concerned with the growing difficulties and hardships that caregivers face and offer respite grants, educational classes, short-term counseling and long term case management.

Purpose of the Study

The purpose of this study was to examine the differences in caregiver burden and use of coping strategies by gender, ethnicity, relationship to the care-receiver, type of diagnosis and length of caregiving responsibilities. Because the family is the first pool of resources to be identified by a care-receiver (Rankin, 1990) the needs and difficulties encountered by this population are crucial and need to be addressed.

Gender, relationship to the care-receiver and outside employment are influential characteristics in a caregiving situation (Stephens et al, 1990). Young and Kahana (1989) propose that the characteristics of the caregiver are influential not only on the care-receiver's response to their illness, but also on the how the caregiver identifies within this role. It is important to better understand such variables and how they influence the caregiver's use of coping strategies.

This study utilized a quantitative descriptive design in which a mail survey was implemented in order to further analyze and explore the use of coping strategies. According to Grinnell and Unrau (2005) a survey is the best method to use in order to sample a population that is characterized by certain variables. According to Neuman (as cited in Grinnell & Unrau, 2005) a descriptive research study involves providing an accurate profile of a group, describes a process, mechanism or relationship, giving a numerical or verbal picture, finding new information to stimulate new explanations and documenting information that confirms or contrasts prior beliefs about a subject. This type of design is critical in capturing an accurate portrayal of caregivers' utilization of coping skills based upon specified characteristics.

Data consisted of caregivers of elderly or brain-impaired individuals who were 18 years or older and currently receiving services from Inland Caregiver Resource Center, located in Colton, California. The sample consisted of 200 stratified randomly sampled files and examined 55 caregivers. Participants were mailed the survey and were provided with a stamped return envelope addressed to the agency.

Significance of the Project for Social Work

This study is crucial to the field of social work because it identified the different variables which affect caregiver burden and use of coping strategies. Because this population often experiences a decline in health and increased levels of stress, anxiety and depression, it is important to better understand the different characteristics which are influential.

This study and its findings may lead to the future development of interventions and strategies implemented by agencies and independent practitioners and may pinpoint the need for different application of interventions in order to more accurately assist the diverse needs of the caregiving population. This study may also empower the caregiving population because their participation will direct future interventions to be modeled by their use or non-use of specific coping strategies.

This research may contribute to both the macro and micro level of social work practice. Agencies which provide services to older adults may recognize the diverse characteristics and components involved in caring for an older, frail and/or incapacitated adult and may possibly create new programs or apply for additional grants in order to alleviate some of the identified obstacles.

This study may also promote evaluation of current policies and programs within these organizations to better service this population and may impact current program development and allocation of resources and referrals. Private practitioners and licensed clinical social workers will become better acquainted with the diverse variables which are associated with the caregiving role. This study may stimulate the urgent need for models of interventions to be created or applied to these diverse characteristics.

This study incorporates information from all phases of the social work generalist intervention process. The data gathered from this study can engage both agencies and private practitioners with the overall depth involved when beginning to work with the caregiving population. This study may contribute to the assessment of caregivers by pointing both agencies and clinical social workers in a direction that will thoroughly examine the characteristics that are associated with the caregiving role.

Results from this study may elicit a plan of interventions, whether it is associated with policy or program design, or be directly related to a specific intervention model. Findings from this study may also impact the use of resources by an agency and the interventions devised by an agency and/or clinical social worker. Results from this study may allow both agencies and private practitioners to evaluate their programs and models of interventions to coincide with the identified needs of the caregiving population.

This study may also impact the termination of counseling resources directed towards burden and coping by identifying the number of sessions needed to effectively impact this population, which will be advantageous for agency allocation of program funds and practitioners use of insurance coverage.

This project examined how gender, ethnicity, diagnosis of care-receiver, relationship of caregiving dyad and length of caregiving responsibilities affects the experience of caregiving burden and use of coping strategies.

CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter discusses relevant literature pertaining to the different characteristics of caregivers and how these affect the level of caregiver burden and use of coping strategies. This section summarizes the differences, pinpointing the unique characteristics of gender, age, ethnicity, relationship to care-receiver, type of diagnosis and length of caregiving responsibilities. The literature discussing the impact of caregiving responsibilities is discussed in subsection one and the theories that substantiate these findings are discussed in subsection two. The third subsection examines the specific characteristics of gender, ethnicity, type of diagnosis, caregiving relationship and length of caregiving responsibilities as it relates to the caregiving population. Subsection four addresses literature pertaining to caregiver burden and use of coping strategies.

Impact of Caregiving Responsibilities

It is important when examining caregiver burden and use of coping strategies, to better understand the different factors that contribute to the level of burden experienced. According to Elliot et al. (2001) many more individuals will begin to assume the role of caregiver because many health care programs will continue to limit services and current research indicates an increase in the incidence of chronic disease and disability. These authors also purport caregivers of individuals with a physical disability experience greater amounts of stress than non-caregivers (Elliot et al., 2001).

Montgomery and Williams (2001) studied the impact of caregiving stressors and found that assistance with instrumental activities of daily living (IADL), personal care needs and cognitive and behavioral changes of the care-recipient influenced the experience of depression and stress. These authors propose these stressors will negatively affect the caregiver and include other aspects of the caregiver's life such as family and employment roles, self-esteem and perceived competence.

Vitaliano, Scanlan, and Zhang's (2003) meta-analysis research combined 23 studies concerned with the physical health of caregivers and compared those findings with a demographically similar group of non-caregivers. These authors note that continual exposure to the chronic ailments of the care-receiver combined with the on-going demands of care responsibilities will lead to psychological distress and health risks for the caregiver. Psychological distress included an increased level of perceived burden and experience of depression. Health risks included a decrease in health care utilization and increased experience of illness and overall ailing health.

Vitaliano et al.'s (2003) study compared six physiological health categories including level of antibodies, stress hormones and neurotransmitters, functional immunity, metabolic and cardiovascular measures and enumerative immunity. The mean age of caregiver participants was 65.6 for caregivers and 64.6 for non-caregivers. Results from this study indicated that caregivers had a 23% higher level of stress hormones and a 15% lower level of anti-body response than non-caregivers. Authors point out that these results are noteworthy because they indicate an added risk for caregivers who are experiencing illness and or other risky health ailments.

Smith et al.'s (1991) research focused on problems identified by family caregivers who were utilizing counseling services. Participants consisted of 78.5% women and 21.5% men who had a mean age of 50.2 years of age and living in the home with the care-receiver. Participants identified many problems and the authors categorized findings within seven main components: improving coping skills which included problems with time management and dealing with stress; family issues which included lack of time with spouse and problems experienced by caregivers own children; responding to care-receiver's needs; physical and safety issues and legal planning; quality of relationship with care-receiver; and eliciting informal and formal support and long term planning, which included struggles with placement.

Theories Guiding Conceptualization

There are several theoretical perspectives that are directly relevant to the caregiving population. In regards to coping, the psychoanalytic ego psychology model of coping identifies this behavior to be "flexible thoughts and actions that solve problems and thereby reduce stress" (Lazarus & Folkman, 1984, p. 118). This model focuses on how individuals perceive stressful encounters in their environment and is concerned with the individual's ability of processing the problem. This theory is important to understand because caregivers encounter many stressful situations in their caregiving environment and it is important to know if and how they are able to process and solve such problems.

It is important to incorporate theories that are associated with late-life caregivers and also adult caregivers caring for their parents. Regarding late-life caregivers, the continuity theory proposes "in order to maintain and preserve internal and external structures, individuals in older adulthood tend to cope with daily life by applying the same strategies that were used in the past" (Kail & Cavanaugh, 2000, p. 530). This theory is important because spouses who have been caring for their loved one throughout their late adulthood may have a tendency to use coping skills that they learned at an earlier point in their relationship.

Concerning middle-aged or adult children who are providing assistance to their parents, gender-role identity is a theory that provides guidance in understanding how and if coping skills are guided by gender socialization. According to Zamarripa, Wampold, and Gregory (2003) gender roles are recognized as being shaped through socialization. These authors propose that rigid gender roles may adversely affect the mental health of men who engage in a "caring role" because they may be labeled as weak and incapable.

This theory also has implications for women who are struggling with the responsibilities of caring for their parents. Those experiencing dual roles of worker and career for both children and parents will experience a "role overload" and will be subjected to feelings of inadequacy and guilt.

Differential Characteristics of Caregiving

It is important when examining the problems caregivers' experience, to also examine the differential characteristics that are found among the population. Past research indicates these characteristics are important components of how burden is perceived and also how coping is experienced.

According to Hequembourg and Brallier (2005) individuals are socialized from an early age to use appropriate gender roles, which include tasks that are appropriate for women (household chores, meal preparation, assuming the caring role) and men (home repairs, substantial breadwinner). From this socialization it is often expected by both parents that the daughter will assume the role of primary caregiver. These authors propose that men use different care strategies than women such as trying to maintain their parent’s independence and waiting for them to ask for assistance.

According to Horowitz (1985) when the needs of a parent increase, the gender of the adult child is one of the most predictive measures of caregiving involvement. The author asserts that daughters provide hands-on services such as direct care and sons provide financial assistance and decision-making. This author also points out that as women continue to become more involved in the job market and their family responsibilities, sons will become the future pool of resources.

Horowitz's (1985) study examined how sons and daughters differ in their caregiving experience. Participants were adult children who were utilizing services offered to caregivers and were interviewed to assess their experience of caring for their parent. Sons were less negatively affected and were more likely to assert there were no problems. Results indicated daughters provided more direct daily care including meal preparation, emotional support and household chores, while sons provided more help pertaining to financial needs and house up-keep.

According to Johnson (2000) African American elders are more likely to utilize family members for their care needs. Family support is not only based on residential proximity, but also on the belief and value that care should be provided by a family member. Aranda and Knight (1997) assert that ethnicity and culture are significant determinants of the caregivers' experience of stress and coping processes and influence the risk of specific health ailments and other disabilities.

These authors reviewed literature that specifically focused on Latino Americans and assert these caregivers will care for older adults who have more specific types of complications than the general population. They note that the Latino culture is afflicted with a substantial number of individuals with non-insulin dependent diabetes. This caregiver will be challenged by the limiting aspects of this disease and will be confronted with visual impairment, high blood glucose, at-risk symptoms for vascular disease and poor ambulation. The authors also point out that acculturation factors associated with recent immigration will influence the way Latinos care for their aging loved ones.

Connell and Gibson's (1997) research examined and reviewed literature concerning the impact of ethnicity on the experience of caring for a family member with dementia. The authors examined 12 studies and found that African American caregivers were more likely to be an adult child, while Caucasian caregivers were more often spouses. This study also indicated that Caucasian caregivers experienced higher levels of burden, stress and depression than African American caregivers, and Hispanic caregivers reported experiencing twice the amount of burden that African Americans experienced. Additionally, Caucasian caregivers utilized support groups and private counseling, while African Americans relied on prayer, faith and religion.

When considering the relationship with the care-receiver, Chwalisz (1996) found that spouses, whom were healthy before their caregiving responsibilities began, developed a variety of physical and mental health problems.

Peisah, Brodaty, Lucsombe, Kruk, and Anstey's (1999) research concerning adult children caring for their parents found that the previous child-parent relationship along with the adult child's perception of it may determine how prepared for/willing they are to assuming this role and may also influence how much burden they experience.

Additionally, Daire (2002) examined the influence that childhood bonding has on the experience of distress among adult-child caregivers. This study's participants consisted of 40 caregiving sons whose mean age was 55.2 years and identified themselves as the primary caregiver for their parent who was placed in a skilled nursing facility. Results from this study indicated that those who reported less emotional bonding with their parents experienced more stress with their caregiving role, while those who experienced more emotional bonding with their parent in childhood reported less stress in their caring role.

According to Elliot et al. (2001), caregivers of individuals with a physical disability experience greater amounts of stress than non-caregivers. Caring for a parent, especially one diagnosed with dementia, may further contribute to the amount of experienced stress and anxiety (Meyer, 2000).

Light and Lebowitz (1989) have performed extensive research on Alzheimer's disease and conclude that although it shares some of the same problems elicited by other chronic illnesses, it is by far the most devastating in terms of a patient's needs, behaviors and caring responsibilities. Over the course of the disease, caregivers will experience feelings of helplessness and confusion over the bizarre symptoms and may double their efforts in trying to maintain control. These authors state that the most difficult and tragic symptom is the inability of the care-receiver to remember family members and recognize their own children and spouse. These same authors point out that the failure of the care-receiver to acknowledge or remember their loved one is most painful and crushing for the individual who is not recognized. Although Alzheimer's disease does mimic many other illnesses, individuals may linger on for many years in this state and the authors note this is even more debilitating for the caregiver (Light & Lebowitz, 1989).

According to Pakenham (2002), multiple sclerosis (MS) debilitates the central nervous system and affects sensory-tactile, motor and visual, bladder, sexual and bowel functioning. The burden and negative effects of caring for someone is exacerbated by the relatively young age at which this diagnosis is made, the absence of a cure and the neurological symptoms and deficits.

Bhatia and Gupta's (2003) research on Parkinson's disease reveals that the progressive impairment in motor and cognitive functioning, which occurs through stages of decreased functioning, proves to be most stressful for the caregiver. Increased levels of stress were noted by caregivers in the later stages of the disease, especially when the care-receiver displayed little movement and needed full-time care. These authors also found that caregivers' needs focused on obtaining information, advice and referrals during the beginning stages and when comorbidity with Alzheimer's symptoms (10%-40% of the time) were present during the later/ending stages, caregiver needs were associated with behavioral management and social support.

When examining length of caregiving responsibilities, the literature focused on the first two years in the caring role. Grant, Weaver, Elliot, Bartolucci, and Giger (2004) found that caregivers of stroke survivors who reported their problem-solving skills were poor prior to the discharge of their loved one from the hospital, were more at risk for experiencing anxiety and a decline in health over the first year of caregiving. Elliot et al.'s (2001) research focused on the relationship between problem solving abilities and caregiver adjustment during the first year of responsibilities. These authors measured depressive behavior, anxiety and physical health and found that caregivers with a greater propensity for perceiving negative attitudes towards problem solving strategies, experienced higher levels of stress during these first years.

Caregiver Burden and Coping

Zarit, Todd, and Zarit's (1986) research focused on the level of burden experienced by husbands and wives of Alzheimer's patients. They state that within this field of research, it is frequently assumed that caregiver burden is strongly related to type of diagnosis and severity of disabilities. How the caregiver copes with and responds to these disabilities, coupled with the amount of social support they have, is a predictive factor in how much burden will be experienced.

Stephens et al. (1990) maintain that burden research has been a main focus in caregiving research. These authors define burden as "the load borne by caregivers, their appraisals of the care recipient's behavior, their appraisal of the tasks performed and their evaluation of the consequences of caregiving upon different aspects of their lives" (p. 250). The authors offer a framework for conceptualizing burden and identify the caregiver's appraisal as an important aspect of whether caregiving is perceived as a burden.

For example, caregivers will draw upon various resources in order to meet the demands they face. For example, in order to provide care, caregivers use time --

viewed as a resource -- that may otherwise be used for other activities. Not being able to engage in the original activity will become burdensome for the caregiver if they appraise it to be (Stephens et al., 1990, p. 253).

Barusch and Spaid's (1989) research on caregiver burden focused on the higher levels of burden experienced by women. These authors give several reasons including greater "role overload," male care-receivers being harder to care for and male caregivers receiving and using more social support. Their study consisted of 131 caregiving participants and measured their use of formal and informal support, patient's functional status and caregiver burden. Women caregivers reported higher levels of burden and indicated the number of problems associated with the care-receivers memory and behavior as the greatest contributing source to their experience of burden.

Coping is defined as "constantly changing cognitive and behavioral efforts which manage specific external and/or internal demands that are appraised as exceeding the resources of the individual" (Lazarus & Folkman, 1984, p. 141). According to Pakenham (2002) a central component in the process of adjustment to the caregiving role is the ability to cope. Lazarus (1966) conceptualizes two concepts involved with coping: primary appraisal is concerned with the impending harm and secondary appraisal is concerned with the consequences of any coping action. This concept is based on the degree of threat or stressful circumstance that is experienced in an individual's environment.

Gottlieb and Rooney (2004) contend that individuals who believe their coping strategies manage and maintain stressful situations, will continue to use such strategies and will modify and or terminate those which have not derived benefit. These authors measured ways of coping within a pool of 141 Alzheimer's caregivers and specifically examined coping in relation to specific behavioral patterns and caregivers judgment of coping effectiveness on mental health. Results indicate that memory and behavioral problems are related to poorer mental health and exposure to excessive behavioral symptoms combined with caregivers' weak beliefs in coping skills were consistent with negative affect. Other results indicate that those with a high belief in coping skills were not negatively affected by any level of behavioral symptoms or demands.

The research of Felton and Revenson (1987) focused on age differences in a sample of 151 middle-aged and older participants who were diagnosed with a chronic illness including hypertension, rheumatoid arthritis, diabetes, and cancer. Their coping strategies included information seeking, cognitive restructuring, emotional expression, wish-fulfilling fantasy, threat minimization and self blame. Results indicate that two specific coping strategies were employed more often by these individuals: information seeking and emotional expression.

Folkman, Lazarus, Pimley, and Novacek (1987) examined age differences in perceived stressful events and coping processes in a cohort of both young and older individuals. These authors note that age related changes in coping involve two interpretations. Developmental interpretation proposes there are inherent changes in the way people cope as they age; contextual interpretation purports differences in what people have to cope with as they age. Participants were interviewed in their home once a month, for six consecutive months. Coping was measured by the revised Ways of Coping Questionnaire devised by Lazarus and Folkman (1984), which lists varied cognitive and behavioral coping strategies. Results indicate that younger participants utilized more problem-focused coping skills, while older adults used emotion-focused forms of coping. These authors question if these results were indicative of what each cohort perceived to be stressful in their lives or the developmental stage they were experiencing.

Summary

From the review of the literature, it is evident the caregiving role is associated with many stressful encounters, differs by ethnicity, and represented predominantly by women. The literature also indicates that type of diagnosis, relationship with the care-receiver and length of caring responsibilities can affect the caregiver and have implications for the experience of burden and use of coping strategies. This study provides clarity for both social workers and other professionals working with this population by defining the differences in caregiver burden and use of coping strategies by these factors.

CHAPTER THREE

METHODS

Introduction

This section provides an overview of the study design, sampling methodology and procedures. The processes involved in the data collection and data analysis are also discussed in this section. The steps involved in the protection of the human participants are also discussed in detail.

Study Design

The present study describes the differences in family caregiving level of burden and use of coping strategies by examining the variables of gender, ethnicity, type of diagnosis, relationship with the care-receiver and length of caregiving responsibilities. This study utilized a descriptive research survey design, which assist's in better understanding if the variables being examined have an affect on level of burden and use of coping strategies. This method was also chosen because descriptive research studies provide accurate information pertaining to specific groups by confirming and or contrasting prior information.

This method of assessment was accomplished by randomly obtaining participants through the case files at Inland Caregiver Resource Center. The two survey instruments utilized in this study are standardized and one of the instruments is currently used by Inland Caregiver Resource Center when assessing clients. The surveys were administered one time and required a limited amount of time to complete, which provided the least amount of inconvenience to the participants involved. This methodology is of critical importance as caregivers do not have an extended amount of time to devote to tasks other than their caregiving responsibilities.

One limitation of this study, which must be addressed, is the reliability of the survey responses of the participants. This is a concern of any survey and is a problem which is unavoidable when eliciting self-reported information. In many instances, participants may be wary due to their concerns associated with evaluation and possible stigmas attached to reports of certain feelings or behaviors. Other participants may not answer honestly because the timing of the implemented survey may coincide with a life altering event or other perceived hardship.

Another limitation of this study is the sample size. When assessing multiple variables, it is critical to obtain a large enough sample to be able to generalize to the stipulated population. In particular, the variable of gender may be problematic as the majority of caregivers are women.

Since this study is eliciting information from one particular agency, this may be another limitation. The agency is involved with distributing services to allocated counties and does not account for other caregivers who reside in different environments and come into contact with different resources. The participants involved with this study are currently receiving resources and the study does not account for those who are not.

This study examined the differences in caregiver burden and coping strategies by gender, ethnicity, relationship to the care-receiver, type of diagnosis and length of caregiving responsibilities.

Sampling

The participants involved in this study were obtained from the Inland Caregiver Resource Center located in Colton, California. The participants were the caregivers of brain impaired or elderly and frail adults who are currently receiving services. This agency services the counties of San Bernardino, Riverside, Inyo and Mono. This study consisted of caregivers whose cases are currently active. From these active cases, a stratified random sampling of client files was utilized which yielded a total possible sample of 200 caregivers. This sampling method was chosen in order to more efficiently draw from the stipulated variables of ethnicity and gender.

Data Collection and Instruments

The data was collected through a self-administered questionnaire containing two standardized scales (dependent variables), one of which was comprised of eight subscales. The dependent variables measured were caregiver burden and the type(s) of coping strategies used by caregivers. The independent variables were gender, ethnicity, type of diagnosis, relationship with care-receiver and length of caregiving responsibilities.

The variable of caregiver burden was measured by the Zarit Burden Interview (ZBI) which is specifically designed to measure the stressors experienced by caregivers of dementia patients (Zarit, 1980) (See Appendix A). This instrument is currently used by Inland Caregiver Resource Center and participants were asked to complete the interview again. This scale consists of 22 questions measured on a four point Likert scale. Caregivers are asked to indicate how often they experience various feelings using corresponding responses ranging from "never" (0) to "nearly always" (4), with a possible point total of 88. Severe burden is denoted as scores between 61 and 88, moderate to severe between 41 and 60, mild to moderate between 21 and 40, and little or no burden below 21. According to Gaugler, Kane, and Langlois (2002), the internal reliability coefficients for this scale is 0.88. The ZBI has consistently shown good internal consistency with a Cronbach's alpha range between .85 and .93.

Coping strategies were measured by the Ways of Coping Checklist (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Green, 1986) (see Appendix B). This survey can be self-administered and identifies eight coping strategies: confrontive, distancing, self-controlling, seeking social support, accepting responsibility, escape/avoidance, planful problem solving and positive reappraisal. This scale consists of 66 questions on a four point Likert scale ranging from "not used" (0) to "used a great deal" (3). In terms of measuring confrontive coping it has a Chronbach alpha level of .70 and for seeking social support it has an alpha level of .76 (Folkman et al., 1987).

The demographic portion of the survey (See Appendix C) consisted of questions regarding gender, ethnicity, relationship to the care-receiver, type of diagnosis and length of caregiving responsibilities. All of these variables were measured nominally, except for length of caring, which will be assessed using a continuous, scale level of measurement.

Procedures

Permission was obtained to conduct this study at Inland Caregiver Resource Center in Colton, California. Participants for this study consisted of caregivers currently receiving services and were obtained from active case files. Participants were solicited through the mail and were asked to complete the questionnaire at their next earliest convenience. Self-addressed stamped envelopes were supplied with the questionnaires and caregivers were asked to mail directly back to Inland Caregiver Resource Center. The survey return envelopes were addressed to the agency and questionnaires were mailed out by the researcher and received back by ICRC designated staff member, who was under the guidance of this researcher. Permission was obtained through a letter of approval from the director of Inland Caregiver Resource Center and the questionnaire was administered from January of 2006 to March of 2006. IRB approval was elicited in December of 2005 and confirmed in January 2006.

Participants for this study were provided with an informed consent letter (see Appendix D) which was provided along with the questionnaire. Participants indicated their consent to participate in this study by marking an "X" in the allocated box. In order to ensure client confidentiality, names were not elicited from the questionnaire and all participants were provided with a debriefing statement upon completion. The debriefing statement (see Appendix E) informed participants about the purpose of the study and also provided them with information concerning how to obtain results. The debriefing statement stipulated the name of a worker to contact from the agency for those participants who have further questions regarding the study or become distressed from participation.

Protection of Human Subjects

Several measures were taken in order to protect the confidentiality of the participants involved with this study. All participants involved with this study were voluntary and the questionnaire did not identify the participants by name. All questionnaires were mailed directly to the participants from the agency. The information elicited in the demographic portion was limited to gender, ethnicity, relationship with care-receiver, length of caring and type of diagnosis.

An informed consent letter accompanied the questionnaire which asked permission to participate in the study. Furthermore, the informed consent explained anonymity and confidentiality. The anonymity of the participants was also maintained through the mailing process. Return envelopes stipulated the address of the agency and the clerical staff individual in charge of handling in-coming mail placed the returned envelopes in a brief case provided by the research. This brief case was locked and was routinely picked up by the researcher. Once evaluation and input have been completed, questionnaires will be shredded and recycled.

Participants involved with this study were informed via the consent letter that if they encountered a question they perceived as too personal or that elicited feelings of distress, they had the right to not answer the question. Participants were advised that survey participation was voluntary and they may stop filling out the questionnaire at any time. Participants were also informed that their responses were confidential and would only be evaluated for the purpose of this study. A debriefing statement was provided to participants with information regarding the study and how to obtain results. An ICRC agency contact name and number was provided to the participants if they wished to discuss feelings pertaining to the survey.

Data Analysis

The data from this study were analyzed using descriptive statistics including frequency distributions and measures of central tendency and dispersion. The dependent variables of burden and use of coping strategies were measured using a scale level of measurement, while the independent variables of gender, ethnicity, type of diagnosis, relationship to care-receiver were evaluated using a nominal level of measurement. Length of caregiving was measured using a continuous scale level of measurement.

An independent sample t-test was employed in order to compare the means of the dependent variables of caregiver burden and eight sub-scales of coping by the independent variable of gender.

One-way Anova was employed in order to compare the means of the nine dependent variables by ethnicity, type of diagnosis, and relationship to care-receiver. In order to identify between group differences, a Tukey post-hoc test was implemented.

A Pearson correlation was utilized in order to study the relationship between the nine dependent variables and length of caregiving responsibilities.

Summary

This study explored the differences in family caregiver level of burden and use of coping strategies by examining the variables of gender, ethnicity, relationship to the care-receiver, type of diagnosis and length of caregiving responsibilities. This section provided information regarding the study design and the recruitment of sample population, has described the data which will be collected and measuring scales which were employed. This section has also evaluated the scale's validity and reliability and has described the specific procedures involved with this study. The description of how the protection of human subjects was implemented and how the data was analyzed has also been discussed.

CHAPTER FOUR

RESULTS

Introduction

This section provides an overview of the results generated from this study. Demographic findings will first be discussed including descriptive statistics of the sample and all relevant findings associated with caregiver burden and use of coping strategies. Statistically significant bivariate and inferential results will also be discussed.

Presentation of the Findings

Before discussing the findings of this study, this author would like to note that shortly after mailing out the surveys, this researcher had expected to provide the agency with a briefcase in order to hold all returned surveys. Due to the unexpected high rate of returned surveys (within 4-7 days from mailing), surveys were instead placed in a desk drawer by the designated ICRC staff employee, and only that employee. All envelopes remained sealed, bundled, and stored out of sight in the desk drawer, and, again, no identifying data were collected from study participants, so there was no risk for breach of confidentiality despite this slight deviation in the data storage plan.

The majority of the caregivers, 86.7 percent (n = 39), were female and 27.3 percent (n = 15) were male. Among the caregivers, 58.2 percent (n = 32) were Caucasian, 20.0 percent (n = 11) were Hispanic, 9.1 percent (n = 5) were African American, 9.1 percent (n = 5) were Asian and 1.8 percent (n = 1) indicated "other."

Care-receiver diagnosis results indicated that 47.3 percent (n = 26) had Alzheimer's, 16.4 percent (n = 9) had dementia, 9.1 percent (n = 5) were diagnosed with Parkinson's, 25.5 percent (n = 14) indicated "other" and was substantiated by "stroke," and 1.8 percent (n = 1) had Multiple Sclerosis.

Caregiver's relationship to care-receiver consisted of 32.7 percent (n = 18) wives, 27.3 percent (n = 15) husbands, 21.8 percent (n = 12) daughters, 14.5 percent (n = 8) indicated "other," and 1.8 percent (n = 1) as the son. Length of caregiving responsibilities ranged from 1 to 34 years with a mean length of 6.65 years.

The results of caregiver burden ranged from 9.0 to 79.0, with a mean score of 41.90 (SD 16.36). A mean score of 46.40 (SD 15.63) was indicated for female caregiver burden, while a mean score of 30.43 (SD 12.75) was indicated for male caregiver. The Ways of Coping survey mean scores and standard deviations were: confrontive coping = 5.12 (SD 3.21); distancing coping = 6.32 (SD 3.33); self-controlling coping = 9.56 (SD 3.86); seeking social support = 9.43 (SD 4.25); accepting responsibility = 4.12 (SD 2.54); escape avoidance = 6.27 (SD 4.96); planful problem solving = 9.06 (SD 3.26) and positive reappraisal = 12.21 (SD 4.61) (See Table 1).

An independent sample T-test was employed to identify differences between the dependent variables of caregiver burden and eight sub-scales of coping by gender. A statistically significant difference between the experience of burden between the two genders was found ($t(45) = -3.370$, $p < .01$). The mean of females was significantly higher (m = 46.39, sd = 15.63) than the mean of males (m = 30.43, sd = 12.75).

Table 1. Demographics

		Frequency	Percent
gender			
Valid	male	15	27.3
	female	39	70.9
ethnicity			
Valid	African-American	5	9.1
	Caucasian	32	58.2
	Hispanic	11	20.0
	Asian	5	9.1
	other	1	1.8
	Total	54	98.2
diagnosis			
Valid	Alzheimer's	26	47.3
	Parkinson's	5	9.1
	Dementia	9	16.4
	Multiple sclerosis	1	1.8
	other	14	25.5
relationship			
Valid	wife	18	32.7
	husband	15	27.3
	daughter	12	21.8
	son	1	1.8
	mother	1	1.8
	other	8	14.5
length			
Valid	1	4	7.3
	2	8	14.5
	3	6	10.9
	4	7	12.7
	5	7	12.7
	6	3	5.5
	7	4	7.3
	8	3	5.5
	9	3	5.5
	10	1	1.8
	12	1	1.8
	14	1	1.8
	15	3	5.5
	16	1	1.8
	17	1	1.8
	20	1	1.8
	34	1	1.8

Results also revealed gender differences in the use of certain coping strategies, including a significantly higher percent of females using self-controlling ($t(47) = -2.360$, $p < .05$) and planful problem solving ($t(45) = -2.263$, $p < .05$) coping strategies than males (See Table 2).

Pearson correlations between the nine dependent variables and length of caregiving were performed. Results indicated no significant difference in caregiver burden or use of coping strategies based on length of caregiving.

A one-way Anova was run between the dependent variables and relationship with the care-receiver, type of diagnosis, and ethnicity. Results indicated a statistically significant difference in caregiver burden ($F(3,42) = 7.02$, $p > .001$) by the type of relationship with care-receiver. In order to identify where the statistically significant differences were found in the types of relationship with care-receiver, a Tukey post hoc test was employed and results revealed significant differences between role of wife and role of husband ($m = 20.324$, $p > .001$), and role of wife and daughter ($m = 20.067$, $p > .001$). There were no other statistically significant differences in the use of the eight coping strategies by type of relationship with the care-receiver. Results also indicated no significant differences in caregiver burden and use of coping strategies by type of diagnosis or ethnicity.

Table 2. Differences by Gender

Dependent Variables	Sample Mean (SD)	Female Mean (SD)	Male Mean (SD)
Positive reappraisal	12.21 (4.61)	12.25 (4.96)	12.00 (4.09)
Self-controlling	9.56 (3.86)*	10.20 (3.57)	7.50 (3.74)
Seeking social support	9.43 (4.25)	10.12 (3.92)	7.62 (4.84)
Planful problem solving	9.06 (3.26)*	9.70 (2.91)	7.43 (3.65)
Distancing coping	6.32 (3.33)	6.71 (3.02)	5.40 (4.00)
Escape/avoidance	6.27 (4.96)	6.47 (4.97)	5.36 (4.96)
Confrontive coping	5.12 (3.21)	5.59 (3.42)	4.00 (2.51)
Accepting responsibility	4.12 (2.54)	4.24 (2.22)	3.53 (2.97)

Differences by Gender: $*p < 0.05$

Summary

This chapter provided an overview of the significant results elicited from this study. Statistically significant results revealed differences by genders in the use of certain coping strategies and level of caregiver burden. Results also showed significant differences in caregiver burden by the type of relationship with care-receiver.

CHAPTER FIVE

DISCUSSION

Introduction

This section will discuss the implications that this study has for caregivers of individuals with brain impairment. Experience of and differences in caregiver burden among participants will be discussed. Differences in caregiver use and non-use of coping strategies will also be discussed. Limitations of this study will also be examined as well as recommendations for future social work practice, policy and research.

Discussion

The findings of this study suggest that family caregivers face a significant amount of caregiver burden as they care for family members and loved ones. The mean score of caregiver burden (m = 41.90) indicates caregivers who participated in this study suffer from moderate to severe burden and a significantly higher level of burden was experienced by female caregivers. These results are consistent with the findings of the Gallicchio, Siddiqi, Langenberg and Baumgarten (2002) study where 27.2% of female caregivers, compared to 14.5%

of male caregivers experienced high levels of burden, and the Grafstrom, Fratiglioni, and Winblad (1994) study where the mean score of subjective burden among females was significantly higher than males.

Findings from this study also confirm that spousal caregivers, especially wives, experience a higher level of burden. This is consistent with the findings of the Zarit et al. (1986) study of husbands' and wives' experience of caregiver burden. This longitudinal study looked at wives caring for their husbands and husbands caring for their wives. Results from this study found caregiving wives' burden to be higher than that of caregiving husbands. Zarit et al. (1986) participants were solely caring for spouses with dementia and propose that high levels of burden are associated with the care-receivers physical disabilities. This theory cannot be generalized to participants involved with the present study as no significant results were obtained from examining caregiver burden and type of diagnosis.

Results from this study revealed that females more often take on the role of caregiver. This finding is consistent with several surveys including the National Alliance for Caregiving/AARP (1997) (as cited in

Tennstedt, 1999) which reported that 72.5% of caregivers from their national sample were female and the Family Caregiver Alliance (2004) who found that 3/4 of all caregivers are women.

Results from this study also indicate that caregivers predominately use four types of coping strategies: positive reappraisal, self controlling, seeking social support and planful problem solving. Caregiver use of the planful problem solving strategy directly involves altering the problem associated with their caregiving environment (Folkman & Lazarus, as cited in Monat & Lazarus, 1991, p. 212). Caregivers who utilized this coping strategy indicated on the survey they were able to "concentrate on what I had to do next," "drew on past experience; "I was in a similar experience before," "changed something so things would turn out all right," "made a plan of action and followed it" and "came up with a couple of different solutions to the problem."

Use of positive reappraisal, self-controlling and seeking social support involves the caregiver directing their attention at managing stress (Folkman & Lazarus, as cited in Monat & Lazarus, 1991, p. 212). Caregivers using positive reappraisal indicated on the survey they were able to be "inspired to do something creative," "came out of the experience better than when I went in" and "changed something about myself." Utilizing self controlling entailed "keeping my feelings to myself," "tried not to act to hastily or follow my first hunch," "tried to keep my feelings from interfering with other things too much" and "tried to see things from the other person's point of view.' Those caregivers who were able to employ seeking social support strategies were able to "talk to someone to find out more about the situation," "accept sympathy and understanding from someone," "got professional help" and "asked a relative or friend for advice."

It is interesting to note that Lazarus and Folkman (as cited in Monat & Lazarus, 1991, p. 215) propose that coping by avoidance "is one of the most common ways people deal with stress." These strategies involve jogging, relaxation, going on vacation and involvement with hobbies and may increase physical and emotional well-being. Although this coping strategy may be beneficial, individuals caring for loved ones are often unable to find respite time away from their caring situation. Results from this study confirm that participants did not use this type of strategy.

Findings from this study also revealed that caregiving females used self-controlling and planful problem solving coping strategies more than male caregivers. This indicates that women from this sample were able to direct their attention to the problem they experienced by either trying to prevent it from happening in the future (planful) or altering the feelings elicited from the experience (self-controlling). Folkman and Lazarus (as cited in Monat & Lazarus, 1991) warn that too much vigilance may increase the intensity of emotions and may cause more distress in a situation where nothing else can be accomplished to prevent the problem from occurring again (p. 216). In some caregiving situations, all possible resources may have been exhausted and those caregivers who use these strategies may encounter more burden.

This author found it surprising that caregiver's ethnicity and care-receivers type of diagnosis were not influential on the experience of caregiver burden. According to Montgomery and Williams (2001) ethnic and cultural norms, values and traditions associated with kinship care are determinants of caregiver role assumption and experience of burden. Current literature also suggests that Caucasian caregivers of family members diagnosed with Alzheimer's disease experience a higher level of burden than African American caregivers (Aranda & Knight, 1997).

Limitations

One of the limitations of this research is the small sample size. Although 200 surveys were mailed out, only 25% (55) surveys were returned. The findings from this study, although consistent with previous literature, thus cannot be generalized to the caregiving population.

Another limitation associated with this study is that participant's were recruited from one particular agency. This population may not accurately represent caregivers in the general public as they have sought out and are receiving services. Other caregivers who have not reached out for informal support may experience and utilize coping strategies differently and may experience different levels of caregiver burn-out.

Another limitation associated with this research is that results are based on caregiver self-report, which can be skewed due to timing of the survey and overwhelming caring responsibilities.

Recommendations for Social Work Practice, Policy and Research

Results elicited from this research pinpoint the need for agencies associated with this population to begin to develop education classes and workshops which are based upon the different coping strategies utilized by the participants of this study. By developing such, caregivers will be able to better understand what coping strategies they use and perhaps even learn new coping strategies that provide more relief than those currently being used. Caregiver support groups particularly can be an effective tool to this end.

Current literature has consistently pointed to the overwhelming responsibilities of caregivers as well as the growing needs of the "baby boom" population. It is imperative for social work practice to become more involved with addressing this challenging period of life for older adults and their families, which includes decline in both emotional and physical health, multiple losses, retirement and caregiver stress and coping. Agencies offering counseling to these clients need to embrace a strengths based perspective and focus on the older adult's capabilities and assets rather than deficiencies often associated with this population.

Social work policy will also need to address the issue of caregiving and include programs which will better sustain older individuals living in their own homes and provide additional compensation to those individuals who assume the caregiving role both formally and informally.

Future social work research should begin to address the growing needs of caregivers who experience burden and develop integrative instruments pinpointing not only their experience of burden, but also promote their physical health and psychological well-being. Future research should also focus on interventions such as support groups and mentoring relationships which will allow caregivers to engage in the roles of leadership and empowerment.

Conclusion

Results from this study suggest that individuals caring for loved ones, especially those with brain impairments, do experience feelings of burden associated with this role. Though specific coping strategies were identified to be used more frequently than others, it is important that caregivers recognize what type of strategies they are using and understand how these strategies will help decrease their experience of burden.

APPENDIX A

QUESTIONNAIRE (BURDEN INTERVIEW)

BURDEN INTERVIEW

Instructions:

The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently or nearly always. There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he or she needs?
   0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

2. Do you feel that because of the time you spend with your relative, you don't have enough time for yourself?
   0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

3. Do you feel stressed between caring for your relative and trying to meet other responsibilities?
   0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

4. Do you feel embarrassed about your relative's behavior?
   0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

5. Do you feel angry when you are around your relative?
   0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

6. Do you feel that your relative currently affects your relationship with other family members?
   0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

7. Are you afraid about what the future holds for your relative?
   0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

8. Do you feel that your relative is dependent upon you?
   0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

9. Do you feel strained when you are around your relative?
   0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

10. Do you feel that your health has suffered because of your involvement with your relative?
    0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

11. Do you feel that you don't have as much privacy as you would like because of your relative?
    0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

12. Do you feel that your social life has suffered because of your caring responsibilities?
0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

13. Do you feel uncomfortable having your friends over because of your relative?
0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

14. Do you feel that your relative seems to expect you to take care of him or her, as if you were the only one to do so?
0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?
0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

16. Do you feel that you will be unable to take care of your relative much longer?
0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

17. Do you feel you have lost control of your life since your relative's illness?
0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

18. Do you wish that you could just leave the care of your relative to someone else?
0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

19. Do you feel uncertain about what to do about your relative?
0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

20. Do you feel you should be doing more for your relative?
0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

21. Do you feel that you could do a better job in caring for your relative?
0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

22. 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

APPENDIX B

QUESTIONNAIRE (WAYS OF COPING)

WAYS OF COPING

Please think of a specific caregiving situation which you feel was stressful. Then, please read each item below and indicate, by using the following rating scale, to what extent you used <u>it in the situation you have just thought about.</u>

Not Used	**Used Somewhat**	**Used Quite A Bit**	**Used A Great Deal**
0	**1**	**2**	**3**

____ 1. Just concentrated on what I had to do next-the next step.

____ 2. I tried to analyze the problem in order to understand it better.

____ 3. Turned to work or substitute activity to take my mind off things.

____ 4. I felt that time would make a difference-the only thing to do was to wait.

____ 5. Bargained or compromised to get something positive from the situation.

____ 6. I did something which I didn't think would work, but at least I was doing something.

____ 7. Tried to get the person responsible to change his or her mind.

____ 8. Talked to someone to find out more about the situation.

____ 9. Criticized or lectured myself.

____ 10. Tried not to burn my bridges, but leave things open somewhat.

____ 11. Hoped a miracle would happen.

____ 12. Went along with fate; sometimes I have bad luck.

____ 13. Went on as if nothing had happened.

____ 14. I tried to keep my feelings to myself.

____ 15. Looked for the silver lining, so to speak.

____ 16. Slept more than usual.

____ 17. I expressed anger to the person(s) who caused the problem.

____ 18. Accepted sympathy and understanding from someone.

____ 19. I told myself things that helped me to feel better.

Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
0	1	2	3

____ 20. I was inspired to do something creative.

____ 21. Tried to forget the whole thing.

____ 22. I got professional help.

____ 23. Changed or grew as a person in a good way.

____ 24. I waited to see what would happen before doing something.

____ 25. I apologized or did something to make up.

____ 26. I made a plan of action and followed it.

____ 27. I accepted the next best thing to what I wanted.

____ 28. I let my feelings out somehow.

____ 29. Realized I brought the problem on myself.

____ 30. I came out of the experience better than when I went in.

____ 31. Talked to someone who could do something concrete about the problem.

____ 32. Got away from it for a while; tried to rest.

____ 33. Tried to make myself feel better by eating, drinking, smoking using drugs or medications.

____ 34. Took a big chance or did something very risky.

____ 35. I tried not to act to hastily or follow my first hunch.

____ 36. Found new faith.

____ 37. Maintained my pride and kept a stiff upper lip.

____ 38. Rediscovered what is important in life.

____ 39. Changed something so things would turn out all right.

____ 40. Avoided being with people in general.

____ 41. Didn't let it get to me; refused to think much about it.

Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
0	1	2	3

____ 42. I asked a relative or friend I respected for advice.

____ 43. Kept others from knowing how bad things were.

____ 44. Made light of the situation; refused to get too serious.

____ 45. Talked to someone about how I was feeling.

____ 46. Stood my ground and fought for what I wanted.

____ 47. Took it out on other people.

____ 48. Drew on my past experience; I was in a similar situation before.

____ 49. I knew what had to be done, so I doubled my efforts to make things work.

____ 50. Refused to believe that it had happened.

____ 51. I made a promise to myself that things would be different next time.

____ 52. Came up with a couple of different solutions to the problem.

____ 53. Accepted it, since nothing could be done.

____ 54. I tried to keep my feelings from interfering with other things too much.

____ 55. Wished that I could change what happened or how I felt.

____ 56. I changed something about myself.

____ 57. I daydreamed or imagined a better time or place than the one I was in.

____ 58. Wished that the situation would go away or somehow be over with.

____ 59. Had fantasies or wishes about how things might turn out.

____ 60. I prayed

____ 61. I prepared myself for the worst.

____ 62. I went over in my mind what I would say or do.

____ 63. I thought about how a person I admire would handle this situation and used that as a model.

Not Used	**Used Somewhat**	**Used Quite A Bit**	**Used A Great Deal**
0	**1**	**2**	**3**

____64. I tried to see things from the other person's point of view.

____65. I reminded myself how much worse things could be.

____66. I jogged or exercised.

APPENDIX C

DEMOGRAPHICS

DEMOGRAPHICS

The following questions are intended to provide additional information regarding your caregiving situation.

1. Gender: (Circle one) 1) Male 2) Female

2. Ethnicity: (Circle one)
   1) African-American 2) Caucasian 3) Hispanic
   4) Asian 5) American Indian 6) Other

3. Care-receivers type of diagnosis: (Circle one)
   1) Alzheimer's 2) Parkinson's 3) Lou Gehrig's
   4) Dementia 5) Multiple Sclerosis
   6) Other (Please specify) ________________

4. Relationship to care-receiver: (Circle one)
   1) Wife 2) Husband 3) Daughter 4) Son
   5) Mother 6) Father 7) Other Family 8) Non Family

5. Length of caregiving: (Circle one)
   1) Less than one year 2) 1-2 years 3) 2-4 years
   4) 4-5 years 5) More than five years

APPENDIX D

INFORMED CONSENT

INFORMED CONSENT

The study in which you are being asked to participate is designed to examine the differences in caregiver burden and coping strategies. This study is being conducted by Catherine Brown, under the supervision of Assistant Professor Dr. Herb Shon from the Department of Social Work at California State University San Bernardino. This study has been approved by the Social Work Human Subjects Review Board Subcommittee at California State University San Bernardino.

The questionnaire was designed in order for you to indicate if you have experienced burden and what coping strategies you have used. The Caregiver Questionnaire you are about to fill out will take approximately 20-30 minutes to complete. All of your responses will remain anonymous and will only be evaluated by the researcher. You will not indicate your name on the questionnaire and will mark the specified box in order to confirm your consent to participate.

Your participation in the study is completely voluntary. As a participant, you are free to withdraw at anytime during the study. There are no foreseeable short or long term risks associated with this study. If you find a question to be too personal or distressing, you may choose not to answer it. This questionnaire is intended to provide the participant with the opportunity to better understand their own sense of burden and use of coping strategies. In order to ensure its validity, we ask you not to discuss its contents or answers with other possible participants. After completion of the study, you will be provided with a debriefing statement which will describe the study in more detail. As a caregiver, your caring responsibilities come first, so please complete this questionnaire at your next earliest convenience.

If you should have any questions regarding this research study, please contact Dr. Herb Shon at 909-537-5532.

By placing an X in the box below, I acknowledge that I have been informed and understand the nature and purpose of the following study. By marking this box, I acknowledge that I consent to participation and am at least 18 years of age.

Please mark here (   )   ______________

Today's Date

APPENDIX E

DEBRIEFING STATEMENT

DEBRIEFING STATEMENT

This study was specifically designed by Catherine Brown to examine the differences in caregiver burden and use of coping strategies by ethnicity, gender, relationship to the care-receiver, type of diagnosis and length of caregiving responsibilities.

Thank you for your participation and disclosure of caregiving experiences. If you experience feelings of distress associated with the participation in this study, please contact Debbie Townsend, LCSW from Inland Caregiver Resource Center at 800-675-6694.

Your participation in this research design will add to the current knowledge about caregivers views of burden and use of coping strategies. If you should have any further questions regarding the questionnaire, please contact either Catherine Brown or Dr. Herb Shon at 909-537-5532. Results can be obtained from the agency after September 2006.

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