African American caregiver burden: Stress factors and utilization of services

Lorna Jean LeVias

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AFRICAN AMERICAN CAREGIVER BURDEN: STRESS FACTORS AND UTILIZATION OF SERVICES

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
Lorna Jean LeVias
September 2006
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ABSTRACT

As the elderly population grows it is estimated that between 2.4 and 3.1 million spouses, partners, siblings, friends and neighbors at some point will be assuming the role of caregiver to someone with Alzheimer’s disease or other debilitating illness. There is great potential for caregivers to experience stress from the weight of caregiving, which often includes emotional, physical and financial burdens. The caregiver’s mental and physical health is often impacted by the rigorous role of caregiving.

The cross-cultural/ethnic differences among caregivers have been less examined. Relieving stress of persons who provide care to ailing family members and the underutilization of services in the African American culture was the focus of this study. This study attempted to understand what factors create the highest levels of stress for African-American caregivers. Data from this study are from a questionnaire given to caregivers that attend Inland Caregiver Resource Center and take their loved ones to Davita Dialysis Center in the Riverside area.

The findings indicated that the age of the patient receiving care and the lack of attendance at any type of
support group were the two elements which markedly contributed to caregiver stress in African-Americans. As an incidental factor, it was noted that even when adequate resources are available, the majority of African-Americans fail to take advantage of those resources. This would indicate that further research is warranted regarding the reasons these services are not utilized.
I want to first thank God for giving me the strength and wisdom to succeed in this journey. Special thanks to my sisters Jevonia, Verdell, Michelle, and Valerie, the ones who were always there for me, cheered me on, supported and encouraged me when I was down and hard on myself. To my very close friends Cleveland and Marie who stuck by me through the tears and frustration. I especially want to thank the graduating class of 2006, my cohorts and now my family, for their loving support, help and kindness. I owe part of my success to my bright, intelligent, and beautiful daughter who has inspired me since her birth. It is largely because of her I wanted to be someone that she would be proud of. I owe so much to my advisor, Dr. Tom Davis, who stuck by me and told me I could do it. He was there for me when I wanted to give up. Special thanks to Dr. Rosemary McCaslin for her patience. I also thank the office staff, Joann and Paul, for their courteous assistance and patience.
# TABLE OF CONTENTS

ABSTRACT .......................................................... iii

ACKNOWLEDGMENTS ............................................... v

LIST OF TABLES .................................................... viii

CHAPTER ONE: INTRODUCTION

Problem Statement .................................................. 1

The Purpose of the Study ........................................... 5

Significance of the Project for Social Work Practice ................. 6

CHAPTER TWO: LITERATURE REVIEW

Introduction .......................................................... 9

Care Giver Stress ................................................... 9

Gender ................................................................. 12

Service Utilization .................................................. 16

Ethnic Differences ................................................... 17

Theoretical Framework Guiding Conceptualization ....................... 19

CHAPTER THREE: METHODS

Study Design .......................................................... 21

Sampling ............................................................... 21

Data Collection and Instruments ..................................... 22

Procedures .............................................................. 23

Protection of Human Subjects ....................................... 24

Data Analysis ........................................................ 24

CHAPTER FOUR: RESULTS

Presentation of the Findings ....................................... 26
CHAPTER FIVE: DISCUSSION

Introduction ..................................................... 28
Recommendations for Social Work Practice,
Policy and Research ............................................. 30
Conclusions ....................................................... 32
APPENDIX A: QUESTIONNAIRE ............................... 35
Appendix B: INFORMED CONSENT ............................. 38
APPENDIX C: DEBRIEFING STATEMENT ...................... 40
APPENDIX D: DEMOGRAPHICS ................................. 42
LIST OF TABLES

Table 1. Stressor Correlation Results .................. 27
CHAPTER ONE

INTRODUCTION

The contents of Chapter One present an overview of the project. The problem statement and purpose of the study are discussed. Finally, the significance of the project for social work is presented.

Problem Statement

It is well documented that people caring for family members with cognitive and physical impairments are under a great amount of emotional, physical and financial burden. In fact, care giving for persons with dementia and other chronic diseases (such as stroke, Alzheimer’s Disease and Parkinson’s Disease) which impact the elder population has been recognized as a major stressor for over twenty years (Knight, et.al., 2002). It is estimated that by the year 2050, 21 percent of all Americans over 65 will be members of a minority group, with African-Americans being the largest subgroup (Ford & Hatchett, 2001). What is critical is that there are great disparities in the physical and mental health status, service availability, services access, and socioeconomic factors between elderly African-Americans and elderly Anglos. There are also multiple factors that can
contribute to the harshness of the aging experience for African-Americans.

Data for many earlier studies came from program evaluations and were constrained by limited resources and the necessity of focusing a particular program. An extensive study conducted by the New York City Office for Aging broke ground for multivariate assessments for usage patterns (Cantor, 1976, Cantor and Mayer, 1975). In that sample of 1,552 inner city elderly, turning to agencies for various forms of assistance was related to (in order of importance) prior use of public services, poor health, low income, acceptance of the concept of "welfare," experience of criminal victimization, being Latino or Black, low sense of well-being, living alone, and lack of informal support.

As mentioned earlier, caregiver burden has been studied for at least 20 years, however to a much lesser extent has it "focused attention on the role of cultural values in influencing the stress and coping process of care providers (Knight et al., 2002)." The potential for important information to be learned from cross cultural differences can be seen in studies that show that African-American caregivers find the role less burdensome than white care providers (Knight et al., 2002).
The care giving experience can also be rewarding and satisfying; however, there is no doubt that it is paved with emotional as well as physical challenges and difficulties. According to Schultz, (1999) as functional status deteriorates, the care receiver’s ability to provide for his or her own needs will regress. The caregiver must compensate for the care recipient’s deficiencies by providing for that person’s physical care needs. For example, when the care receiver lacks ability to transfer from the bed or a chair, the caregiver must physically enable the transfer. Other areas where the care receiver may need physical help include activities of daily living of bathing, grooming, dressing and toileting. The personal nature of these tasks, as well as the physical impact required to carry them out, put tremendous strain on the care provider. This study attempted to determine which factors contributed to higher levels of stress for the caregiver.

Alzheimer’s Disease and other dementias have gained public attention over the last 20 years and are recognized as a major public health problem affecting millions of Americans and their families. The medical community as well as policy makers, the social work practitioners, and the government have studied caregiver stress and burden.
Caring for people with Alzheimer's and other impairments has a number of negative consequences. Financially, people who are providing the care have a fiscal burden that directly falls on them (Morano, 2003).

The population with Alzheimer's and other dementias is growing and the need for caregivers' support will expand. Over the next 30 years the population of elderly, those who are at most risk of needing care giving assistance, is estimated to reach 25% of the American population, increasing the need for research, policy, and advocacy to identify the special needs of this population (Riggs, 2001). People are living longer, increasing the likelihood of needing care providers longer. The need for specialized senior services and support will be determined by market factors and insurance policy, making it difficult for care recipients to have other options besides informal family or friend caregivers (Riggs, 2001).

According to one study (Riggs, 2001), "Alzheimer's Disease costs the United States $70 billion each year. Medicare spends 70% more on people with Alzheimer's and other dementias than on the average Medicare recipient. American business is losing $3 billion each year primarily due to caregivers taking time off work to care for their
elderly family member or friend as they take on the dual role of worker and care provider."

The Purpose of the Study

The research consisted of 35 interviews of African-American caregiver relatives to better understand their experiences as relative caregivers and those factors which they believe contributed to greater stress levels in themselves. The study used a testing instrument that measures caregivers’ burden entitled, "Caregiver Burden Scale" (Montgomery, Borgatta, & Borgatta, 2000). The purpose was to measure which specific factors involved in the caregiving burden created the highest levels of stress in the caregiver. The independent variables were the specific factors creating stress, and the dependent variable was the level of caregiver stress. The research explored a variety of elements believed to contribute to high levels of stress in those primarily responsible for the care of the disabled relative. Given the literature, this author hypothesized that the most critical factor creating high stress among caregivers is a significant sense of isolation in their caregiving responsibilities, with simple lack of awareness of what services are
available as being the most significant reason for that isolation.

The best data source for this research was African-American caregivers. Subjects were chosen randomly from participants involved with the Inland Caregiver Resource Center and Davita Dialysis.

Significance of the Project for Social Work Practice

It was hoped that this study would enhance social workers' understanding of the African-American caregiving community and provide essential and critical skills that would promote cultural competency and efficiency, particularly when providing resources for caregivers. Findings may suggest that a variety of approaches to working with African-American caregivers may be appropriate, depending on which factors in this study rate as the highest stressors. Such information may affect the types of services social work agencies offer to various groups. Other findings may show that a more culturally competent form of formal social support may be appropriate, depending on which stress factors do indeed rate as higher in significance, and whether those factors affect the willingness of these populations to access support in a formal setting.
The findings obtained from this study can also help social work practitioners approach and relate to the care of all elders, will ultimately benefit caregivers, and build a more culturally competent practice. According to Kirst-Ashman and Hull understanding the cultural expectations, economic conditions, and social realities of the various ethnically and culturally diverse groups with whom generalist social work practitioners work is a necessity (2002, p. 349). “An aspect to the client dimension is the development of expanded services to "secondary" consumers, most commonly parents, family members, or significant others. These services may be directly supportive or may incorporate educational and advocacy activities designed to enhance the case management knowledge and skills of the client’s caregivers. Legitimating a secondary constituency reflects new policy awareness of limited program resources and greater respect for lay individuals as gatekeepers, sustainers and partners in case management” (Raiff & Shore, 1993).

At the agency level, the findings of this research will enhance current knowledge and provide a foundation that could possibly structure programs for this population which would encourage a broader spectrum of services.
specifically designed to alleviate the highest stress factors and therefore lessen the burden of care giving. Additionally, it is possible that African-American caregivers can share with the general public positive approaches to the experience of caring for others and others may learn from this group how they cope with the stressful demands of the role of caregiving. It was important to undertake this study so that the stress of caregiving is recognized and supported for current and future caregivers.
CHAPTER TWO
LITERATURE REVIEW

Introduction

A substantial amount of research has been completed regarding caregiver burden. This chapter divides previous research into the following subsections: caregiver stress, gender differences, service utilization and ethnic differences.

Care Giver Stress

Family caregivers face an endless array of novel problems generated by aspects of in-home care, including physical care of the patients, the care receiver’s behavior, and the caregiver’s emotional responses to providing care. Some of these problems or challenges are tangible such as those related to providing physical care (Wakerbath, 1999), while others are of an emotional nature, such as making the decision to place a loved one in out-of-home-care (Wakerbath, 1999).

Family caregivers tend to experience strain or burden when they care for their older relative (Cohen, Swanwick, O’Boyle, & Coakely, 1997. Caregiver strain is defined as “a weight that is dragging down the quality of life of the caregiver and negatively influencing his or her physical
or mental health” (Atchley, 1997, p. 218). What makes caregiving a difficult task and why is it that many caregivers experience strain? Studies show that levels of caregiver strain are affected by “the care recipient’s characteristics, caregiver’s characteristics, and their living arrangements (Kosberg, Cairl, & Keller, 1990).” Due to experiences with racism, discrimination, and personal histories of encountering injustices from formal support systems of care, older African-Americans have relied on a “helper network” (Chatters, Taylor, & Jackson, 1986) that includes spouses, children, grandchildren, siblings, friends, neighbors, and quasi-formal institutions such as community churches. Additionally, the support network is characterized by reciprocity that arises out of the African-Americans’ senses of community and the African-American helping tradition. In spite of the fact that many of the caregivers are themselves likely to be in poverty or near poverty levels, the African-American sense of community persists as the cultural foundation for providing informal care to African-American older adults, and thus increasing stress levels in an already overburdened relational system.

This concept impacts caregivers in our society. The reluctance to access services is a problem that needs
further research. The baby boomers are growing old, becoming caregivers, and will also need care and resources themselves in the future. There is a need to educate prospective caregivers and provide them with comfort to access resources.

Some research argues that informal or relative caregivers are the backbone of the service provided to surviving stroke patients but of course this is not without consequences to the care provider (Bugge, et al., 1999). Time and time again studies show that caregivers complain of stress and burden due to the many complex problems with which this role comes.

Most caregivers experience stress (also known as “burden” or “strain”) in becoming a fulltime caregiver of an ailing family member (Burack-Weiss, 1995). There have been studies of the relationship between caregiving and stress (McCallion et al., 2004). Differentials such as gender, age, ethnicity, illness, and relationships, contribute to the stress of caregiving. The role of full time caregiver is overwhelming in the event the caregiver does not have sufficient resources to care for both the care receiver and caregiver. The caregiving experience is complex and multifaceted. Providing care to a physically or mentally dependent loved one presents a variety of
challenges for the caregiver. "The caregiver will need to solve daily problems that affect the well-being of the caregiver, but also make a variety of long-term decisions affecting the care receiver (Wakerbarth, 1999)."

Gender

Family members, many of whom are adult daughters, provide care in their home for approximately 75% of Alzheimer's disease patients in the US (Donaldson & Burns, 1999; Atienza, Henderson, Wilcox, & King, 2001). However, giving care to family members at home can lead to stress, exhaustion, and subsequently premature long-term care institutionalization for the impaired older adult (Buono et al., 1999; Nagatomo, Akasaki, Uchida, Tominga, Hashiguchi, & Takigawa, 1999). Despite an abundant number of studies that examine the extent to which the cognitive and non-cognitive features of the impaired older adult influence the burden of family caregivers, Donaldson and Burns (1999) acknowledged that "gender and kinship of the family caregiver warrant considerably more research attention."

It is important to understand the effects of the caregiver role on all family members both in terms of caregiver psychological morbidity and caregivers as
patients themselves (Gonzalez-Salvador, Arango, Lyketos, & Barba, 1999). Recent research has demonstrated the differential effects of this increased burden on caregivers' physical health status and psychological morbidity. For instance, Atienza et al. (2001) found that female caregivers of persons with dementia experienced greater blood pressure reactivity to caregiving-related stress than did male caregivers. Donaldson et al. (1999) also found, in another study, that among 100 family caregivers living in the UK, being female was a significant risk factor for psychological morbidity. In a systematic review of 53 studies of caregiver burden published between 1980 and 1997, Bedard, Malloy, Pedlar, Levar, and Stones (1997) revealed that “30% controlled for gender. Among those that controlled for gender, female family caregivers usually experience more burden than their male counterparts.”

In contrast, it is currently estimated that almost 30 percent of in-home, pre-placement caregivers are men, the predominant subset being elderly spousal caregivers (FG & Applegate, 1994; Kramer, 2002; Olson, 1994). Male caregivers, however, have only occasionally been mentioned in the body of care giving literature that has appeared in the past two decades. Their experiences continue to be
neglected and marginalized (Kramer, 2002) or used as a contrast in comparison to women caregivers (cf. DeVries, Hamilton, Lovett, & Gallagher-Thompson, 1997; Horowitz, 1985; Miller, 1987; Zarit, Todd, & Zarit, 1986). In a review of existing literature, Carpenter and Miller (2002) found only 18 small studies on men as caregivers between 1988 and 1999, in spite of increasing involvement of men in care giving.

Some studies (cf. Stone, Cafferata, & Sangl, 1987; Kosloski, Montgomery, & Kramer, 1999) found that husband caregivers are more likely to seek respite and receive outside support than wife caregivers, yet other studies found husbands less likely to seek assistance (Miller, 1990, Montenki, 1998). Coe and Neufeld (1999) argue that they did so only as a “last resort,” describing outside supports as a sign of dishonor and a violation of their own sense of pride and their family’s privacy.

In the absence of support networks, many men felt that their work was unappreciated (Archer & MacLean, 1993).

When social support networks, formal and informal, are established, the impact on men’s psychological well-being has been found to be both negative and positive (Carpenter & Miller, 2002). Men were able to shelter
themselves effectively from caregiver stress, depression, and burnout according to many studies (cf., Braithwaite, 1996).

In general, there is a growing body of scholarship that supports the contention that men adapt to care giving with less burden or adverse impact on physical and mental health than do women. Additional scholarship (Braithwaite, 1996) maintains that “men adopt a care giving model that combines management skills from the workplace, such as social networking, with modes of affective and nurturing care.” Further, men appear to experience less difficulty with taking respite time for themselves (Motenko, 1998; Perkinson, 1995) and avoid role engulfment by maintaining outside interests as well as social contacts (Archer & MacLean, 1993).

It has been reported that female caregivers are more vulnerable to strain compared to male caregivers (e.g., Horowitz, 1985; Kosberg et al., 1990. This may be because female caregivers spend more time caring for an older relative and are responsible for a larger number of care giving tasks than male caregivers (Dwyer & Coward, 1991); his study attempted to answer these questions and presents the results of a brief exploratory and descriptive survey of African-American family caregivers. Who are these
family members caring for elders? A consistent finding in previous studies is that the majority of family caregivers are women (e.g., Cohen-Mansfield, Besansky, Watson, & Bernhard, 1994; Montgomery & Borgatta, 1989; Mui, 1995). At the same time, however, as elderly parents receive assistance from their adult children, the adult children are themselves aging.

Service Utilization

There often is reluctance by the caregiver to seek resources in the community to lessen the strain. African-American caregivers tend not to utilize respite, caregiver support groups, or other community resources. The most frequently mentioned reason for caregivers not using community services had to do with the broad category of care receiver resistance. Subcategories of caregiver resistance included the care receiver would not accept assistance, was fearful, or embarrassed, and refused or resisted help from service providers (Winslow, 1997).

Minorities have a disproportionately larger number of older adults (Tirrito et al., 1996). Ethnic older adults are often looked at as victims two-fold; they are old and nonwhite (Dwyer & Miller, 1990). Differentials between the caregiver and the service provider in cultural background,
economic status and communication styles seem to add to their frustrations (Tirrito et al., 1996). Ethnic older adults are often looked at as victims two-fold; they are old and nonwhite (Dwyer & Miller, 1990). Another major problem associated with underutilization of services is a lack of transportation and the ability to access services such as adult day care. Some adult day care centers provide transportation, but if they do not, it is the caregiver’s responsibility to drop off and pick up recipient at the adult day care center (Hegeman, 1993; Mace & Rabins, 1999).

Ethnic Differences

Some studies suggest that there are ethnic differences in care giving. Cox’s (1995) research compared experiences of black and white caregivers of dementia patients. The findings suggested that lack of informal supports and a sense of incompetence increased stress among the black caregivers but had no effect on white caregivers. The main issue of the white caregiver was the illness of the patient. Cox (1995) stated, “Because culture can play a major role in influencing responses and behaviors, it may also affect the nature of the care giving process.” “To develop sensitive and appropriate
interventions, it is essential to examine how caregiving may vary among ethnic groups." (p.344).

This study puts attention on cultural values in finding how this would influence the stress and coping process of people caring for elders with dementia. African-American caregivers scored relatively low on reporting feeling depressed or anxious and the study supports other research that suggests that African-American caregivers score relatively low on caregiver burden (Knight, et al., 2002).

African-American caregivers regularly report less burden than their White counterparts, and African-American caregivers provide more hours of care to their elders, mostly due to higher levels of functionally disability among ethnic minority elders. A qualitative study was undertaken to detect differences in the way caregivers in three ethnic groups (African-American, Puerto Rican and White) describe their experiences with and reactions to caregiving. Caregivers were selected from the larger sample of the Springfield Elder Project, a study of a population-based sample of older adults and their caregivers. Ethnic and gender differences were detected both in how caregivers in the three groups describe the caregiving experience and how they cope with it. White and
African-American females, and Puerto Rican males expressed feelings of frustration and anger during difficult times in their caregiving situations. Puerto Rican female caregivers described their caregiving situation as one which fostered social isolation. Resignation, denial, respect and faith in religion were ways these caregivers these caregivers dealt with the burden of their caregiving responsibilities. These findings suggest that African-American and Puerto Rican caregivers are experiencing burden, but expressing it in different ways than White caregivers and that available measures of caregiver burden do not adequately measure the impact of caregiving on minority caregivers (Cox, 1998).

Theoretical Framework Guiding Conceptualization

The impact of history and oppression on African-American families is a useful framework for assessing and explaining the dynamics involved in their experience with caregiving. Understanding the cultural expectations, economic conditions, and social realities of the various ethnically and culturally diverse groups whom generalist social work practitioners work with is a necessity. The conceptual framework that is based on systems theory was used as a guide in this study.
Lloyd and Bryce stress that social workers "must understand the family's culture and values if they are to be effective helpers. Insensitivity to cultural values can result in unintended and unrealized attacks on any area of the family's life - language, appearance, relationship patterns, aspirations" (1984, p.25).

Devore and Schlesinger emphasize that "social work's major obligation is to attend to current issues, with full awareness that the distribution and incidence of problems is often related to the ethnic reality" (1999, p.143).
CHAPTER THREE

METHODS

Study Design

A quantitative approach was used as the research method. The Caregiver’s Burden Scale (CBS), a 5-point Likert-scale instrument, consisting of questions regarding the effects of various elements of stress, was administered to 35 participants, all of whom where acting as primary caregivers to someone with whom they had a significant social relationship. (In other words, these were not paid providers, but rather friends and/or family of the patient.) The CBS is a 27-item scale designed to measure feelings of burden experience by caregivers and provides a systematic assessment of caregivers’ perceptions of these burdens.

Sampling

The data was obtained from a sample of caregivers varying between the ages of 55 and 70 who were caring for their parents, spouses, siblings and others. Over half were biologically related to the care receiver. There were no restrictions on length of time for the care that was given, however they must have held and exercised primary responsibility for the day-to-day care of the recipient.
This sample was chosen to expand on previous research that did not fully explore from a cultural perspective the various reasons certain factors create higher stress overall than other factors. Furthermore, this sample was chosen to yield data from African-Americans and view from their perspective the level of stress and how it affects their personal lives and relationships.

Data Collection and Instruments

Quantitative data were gathered from a self-administered questionnaire designed specifically for use with caregivers of patients receiving long-term care outside of a formal institution. (See Appendix A.) Participants were asked to complete The Caregiver Burden Scale (CBS) (Zarit, Reever, & Perterson, 1980) and additional questions including age of caregiver, age of care receiver, how long the care receiver has been dependent on caregiver, whether the caregiver has knowledge of resources in the community, and if so, what type of services/resources the caregiver has utilized. Additionally, if no services were utilized, what were the reasons for that?

The items for the CBS were selected based on clinical experience and prior research, and covered those areas
most frequently mentioned by caregivers as problems. Because of the increasing aging of the population and the emphasis in the gerontological literature on finding alternatives to institutionalization for the elderly, there is a need to be aware of the potential burden on family members of caring for older relatives, especially those with dementia.

Procedures

Data were collected between January and March 2006. Of 35 caregivers available, 22 surveys were actually completed. The individual time involved in completing the survey was approximately 15 minutes. The questionnaire (see Appendix A) utilized in each interview was provided to the participants as they arrived at the dialysis center. Some filled out surveys before leaving the site, while others took the surveys home to be completed. Additional surveys were distributed at a local Family Caregiver support group and were completed and returned during the meeting itself. All surveys returned to the Social Services Department for scoring and analysis within 5 days of the original distribution.
Protection of Human Subjects

For the protection of each participant, informed consents (see Appendix C) were obtained from each person surveyed. Participants were also informed and assured that involvement in the study would be confidential and the response of the individual participants would not be reported or disclosed at any time. The questionnaires were locked in a file cabinet and shredded upon completion of the project (See Appendix B). In addition, the researcher provided a debriefing statement (see Appendix D) with a contact phone number to call in the event of any questions or problems arising as a result of this study. The contact listed was Dr. Rosemary McCaslin, Ph.D., the University advisor for this project. The author informed participants of the completion date for this project and the availability of the final report at the agency after this date.

Data Analysis

This study used a quantitative research design, including the self-administered Caregiver Burden Scale, which measures burden in two domains, personal and relationship consequences. The scoring ranges from “never” to “nearly always.” There are a total of 27 items on this
instrument which are added to create an interval scale ranging from 0-135. CBS scores were compared for groups in this sample using Pearson’s correlations.

Of a possible 35 participants available, only 22 (63%) actually took part in answering the questionnaire. Of those 22, 6 participants did not complete all questions, thus invalidating their scores and leaving a total of 16 actual sets of scores to work with (45% of our original sample.) Of a possible score of 135, with n=16 the maximum score noted was 65, the minimum, 33, for a Mean of 49.88% (Standard Deviation of 9.844) of caregivers feeling some significant burden of stress.
CHAPTER FOUR
RESULTS

Presentation of the Findings

A Pearson Correlation Coefficient, was calculated for factors that might affect stress levels, including gender of caregiver, age of caregiver, age of recipient, types of stress felt, and intensity of stressors. Those stress factors with significant correlation were advanced age of care receiver (.758), those who never attended any type of support group (.642), those who did attend a support group but still felt significant isolation (.575), caregiver never taking advantage of respite care (.572), and those whose own health has suffered as a result of the caregiving burden (.961). These correlations were all significant, indicating that all of the above factors play a role in high stress levels. The single-most contributory factor is that of the caregiver’s own health being compromised over time as a result of the caregiving burden. When Pearson’s correlations between CBS scores and caregiver characteristics of age, support group participation, feelings of isolation, not making use of respite care, and decline in personal health of caregiver, were examined for significant associations, the
relationship approached significance \((r = .528, .077)\). A positive correlation was shown between advancing age of caregiver and higher stress levels.

The original hypothesis was that the most critical factor creating high stress among caregivers is a significant sense of isolation in the course of their caregiving responsibilities. However, the findings do not entirely support this hypothesis. Instead they appear to indicate that while a sense of isolation does indeed contribute significantly to stress among caregivers, the single most significant stress factor is when the caregivers' own health becomes compromised as a result of the burden of care.

Table 1. Stressor Correlation Results

<table>
<thead>
<tr>
<th>FACTORS</th>
<th>CORRELATION</th>
<th>“p”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Those whose own health has suffered as a result of the caregiving burden.</td>
<td>(.961)</td>
<td>0.01</td>
</tr>
<tr>
<td>Advance age of care receiver.</td>
<td>(.758)</td>
<td>0.01</td>
</tr>
<tr>
<td>Those who never attended any type of support group.</td>
<td>(.642)</td>
<td>0.01</td>
</tr>
<tr>
<td>Those who did attend a support group but still felt significant isolation.</td>
<td>(.575)</td>
<td>0.01</td>
</tr>
<tr>
<td>Caregiver never taking advantage of respite care.</td>
<td>(.572)</td>
<td>0.01</td>
</tr>
</tbody>
</table>
CHAPTER FIVE

DISCUSSION

Introduction

The present study examined which factors were the main contributors to stress in African-American caregivers, and whether utilization of services lessened the burden of caregiving. Prior studies had concluded that caregivers' knowledge of resources did not necessarily lead to higher utilization of services. Certain barriers to formal service use have been identified in the caregiving literature. Research indicates that African Americans may experience barriers such as physical access, affordability, and availability of services (Yeatts, Crow, Folts, 1992). Therefore, informal networks are of particular importance in addressing the needs of caregivers.

The results of this study indicate that the majority of the participants found that stress was most prevalent when their own health suffered as a result of their caregiving activities, when they did not attend any type of group support, when they felt isolated despite attendance at group support, and that stress increased with the increasing age of the care receiver.
Findings seem to further indicate that those who did take advantage of available support groups often felt that their attendance did not make any appreciable difference in their perception of felt stress or in their sense of isolation. It would seem that group support alone is not sufficient to alleviate caregiver burden, but may be very useful when combined with other community services available, such as respite, adult day care, and in-home support or hospice care. For instance, attendance at support groups may provide not only information regarding additional services available, but also a network of supportive friends whose presence could make participation in the new experience of joining in other services less intimidating.

One factor which could not be accounted for in the statistical calculations was the number of participants who expressed a lack of knowledge of community services available to them. (It was stated on at least five of the questionnaires, written in the margin, that the participant was completely unaware of the availability of a particular service.) Therefore, it is the opinion of this author that caregiver’s lack of knowledge of services is a critical factor in their under-utilization. This
would seem to indicate a need for better advertisement regarding community resources, not improved services.

Recommendations for Social Work Practice, Policy and Research

This paper has attempted to describe in some detail elements seeming to contribute to intense stress for African-American caregivers. It also has emphasized whether the utilization of services by those caregivers is perceived as helpful or not. Actual answers from the caregiver participants provided a revealing and informative picture of their frustrations, feelings of guilt, burden, and stress over the responsibilities they have assumed. It is hoped that the information herein will stimulate the dissemination of more knowledge to the caregiving community regarding those services that are waiting to be taken advantage of. While most workers in the human services field are quick to recommend the usefulness of group support, it may be that group support will be felt to be more valuable to caregivers when used in tandem with other services. For instance, use could be made of speakers promoting other available resources, anecdotal vignettes by caregivers who have already successfully navigated the task, and cinema therapy centered around subject families effectively meeting the
demands of care giving, all of which will provide encouragement and motivation.

Regarding questions of policy, it may prove worthwhile for insurance companies and regulating agencies to implement and provide coverage for the use of combined services; for example chore and personal care along with respite. Such policies could conceivably result in an increased sense of well-being by caregivers, decreased secondary illnesses of caregivers resulting from stress-related complaints, and an overall decrease in community health-care costs. One example of this would be a Social Health Management Organization such as SCAN Insurance, which provides case management to assist with accessing services such as personal care, transportation, home delivered meals, and respite under certain qualifying circumstances.

This study stimulated many additional questions for the researcher. Why services which are well-known to caregivers continue to be under-utilized remains a mystery. Historically, African-Americans have typically been left out of activities and services which others take for granted as inalienable rights. It has not been that far back in history that African-Americans were denied the right to vote, secure an education, ride a bus, or even
drink from a public water fountain. One does not have to look too far to see remnants of the legacy of those injustices in the present day. (It was only as recent as 2003 that Bryon de la Beckwith, the killer of civil rights activist Medgar Evers, was convicted - and that was after two prior mistrials.) It is no wonder that the African-American community as a whole may be hesitant to take advantage of those services that other citizens see as their entitled right. Further research is certainly warranted to determine whether there is a correlation between that sense of disenfranchisement often felt by the African American community in many social areas, and resistance to the use of available community services.

Conclusions

"Some of what we know about elder care has been well documented in the literature and is generally accepted by researchers and practitioners. For example, families, not professionals, provide 80 to 90 percent of care to older people" (Brody, 1995). Since the current generation of middle-aged caregivers and older-aged care receivers are the very ones who have pioneered this shift in American society, it is unlikely that they would have predicted this turn of events decades ago. Because of this,
relatively little is known at this time about the effect of the various stressors involved on various aspects of the care-giver's wellbeing, such as physical, emotional, and mental health, as well as the effect those same stressors have on the care-giver's own relationships and social welfare.

In addressing caregiver needs, the literature and experience indicate that caregiving of a loved one is a complex and highly personal task, and one which cannot be easily delegated to an "outsider vendor" in the same way one might approach the tasks of mowing the lawn or repairing the car. Because of the intricate, and sometimes intense, nature of our close familial relationships, and the wide variety of challenges involved in this type of caregiving, it is virtually impossible to procure "paid help" that is adequate to perform these often very personal tasks with the same degree of caring and loving interaction needed to provide optimum emotional and physical support for the care-receiver. To compound the task, often caregivers must contend with their loved one's behavioral problems, increasing demands on their time, stress and concomitant depression, as well as planning for future and end-of-life issues, all within the context of the grief and loss that accompanies having a spouse or
relative diagnosed with a debilitating or terminal illness.

Caregiving, therefore, involves a diverse range of continually evolving tasks, some of which require more emotional presence of the caregiver than can be provided by someone outside the family circle, and encompassing an increasingly wide variety of pressures (likely as diverse as the sheer numbers of the caregivers themselves) (Yeo & Gallagher-Thompson, 1996). It is not surprising that "one size fits all" interventions cannot possibly be effective in these situations (Knight et al., 1993). It is increasingly evident as well that one's ethnicity and culture will have an enormous effect on the types of interventions needed with the cared-for family member. If we are to provide the type of care which our family members are deserving of in their later years, that is care during the final phase of life by a loving family member, it is critical that we put significant efforts now into determining more effective and more readily available information regarding appropriate support for family caregivers.
APPENDIX A

QUESTIONNAIRE
CAREGIVER BURDEN SCALE

The following is a list of statements which reflect how people sometimes feel when taking care of another person and resources caregivers use. In the space below to the left of each statement, please indicate how often you feel that way and what resources you have used using the following scale:

1 = Never 2 = Rarely 3 = Sometimes
4 = Usually 5 = Nearly Always

1. I feel resentful of other relatives who could but do not do things for my loved one/other.
2. I have conflicts with family members.
3. I feel like I don’t have enough time for myself.
4. I feel stressed between trying to give to my loved one/other as well as other family members.
5. I feel anxious.
6. I feel guilty about my interactions with my loved one/other.
7. I feel that I don’t do enough for my loved one/other.
8. I feel angry about my interactions with my loved one/other.
9. I feel depressed, trapped or resentful.
10. I don’t get enough sleep.
11. I am afraid of what the future holds for my loved one.
12. I feel pleased about my interactions with my loved one/other.
13. I feel my health has suffered because of my interaction with my loved one/other.
15. I feel useful as a caregiver.
16. I feel use respite services on a weekly basis.
17. I have knowledge of resources for caregivers.

18. I don't have knowledge of resources for caregivers.

19. I use Adult Day Health Care services weekly.

20. I have never used Adult Day Health Care services.

21. I feel guilty when I want to go on vacation alone.

22. I have never used respite services.

23. I attend caregiver support groups regularly.

24. I have never attended support groups.

25. I feel less burden/stress when I take my loved one to Adult Day Health Care.

26. I don't notice a difference when I take my loved one to Adult Day Health Care.

27. I don't feel alone when I attend support groups.
APPENDIX B

INFORMED CONSENT
INFORMED CONSENT

The study in which you are being asked to participate is designed to investigate caregiver burden and formal service use. This study is being conducted by Lorna LeVias (MSW student) under the supervision of Dr. Rosemary McCaslin, Professor of Social Work. This study has been approved by the Social Work Subcommittee of the Institutional Review Board, California State University, San Bernardino.

In this study you will be asked to respond to several questions regarding services for caregivers. Some of the questions ask about your view of caregiver burden and strain. The Dialysis center will not know whether you participated and your decision will have no effect on services you receive. The Caregiver Burden Questionnaire should take about 1 to 15 minutes to complete. All of your responses will be held in the strictest confidence by the researcher. Your name will not be recorded with your response. All data will be reported in group form only. You may view the group results of this study upon completion in July 2006 at the Davita Dialysis center.

There are no foreseeable risks associated with this study and your participation in this study is totally voluntary. You are free to answer any questions and withdraw at any time during this study without penalty. When you have completed the questionnaire, you will receive a debriefing statement describing the study in more detail, and you may be eligible to enter the raffle of a gift certificate as a thank you for your participation. In order to ensure the validity of the study, we ask that you not discuss this study with other students or participants.

If you have any questions or concerns about this study, please feel free to contact Dr. Rosemary McCaslin, Professor of Social Work, at (909) 537-5707.

By placing a check mark in the box below, I acknowledge that I have been informed of, and that I understand the nature and the purpose of this study, and I freely consent to participate. I also acknowledge that I am at least 18 years of age.

Please check mark here: _____  Today's date: _______
APPENDIX C

DEBRIEFING STATEMENT
DEBRIEFING STATEMENT

The study you have just completed was designed specifically to explore social work knowledge of relevant treatment considerations and issues regarding caregiver burden. This study also set out to investigate caregiver’s perspective about use of community services and support.

Thank you for your participation and for not discussing the contents of the Caregiver Burden Questionnaire with any other caregivers. If you feel distressed in any way from participating in this study please see the attached list of resources.

Your participation in this study will add to the research about social work knowledge regarding caregiver burden and stress issues. If you have any questions about the study, please feel free to contact Dr. Rosemary McCaslin at (909) 537-5707. If you would like to obtain copy of the group results of this study, please contact the Davita Social Services Department or Inland Caregiver Resource Center.
APPENDIX D

DEMOGRAPHICS
DEMOGRAPHICS

Please check all that apply:

_____ Male _____ Female

_____ My Age _____ Age of Loved One

Relationship:

_____ Parent _____ Sibling(brother or sister) _____ Other

I have cared for my loved one for: _____ # of years
REFERENCES


48


Snider, E.L., Awareness and use of health services by the elderly: A canadian study. Medical Care, 1980, 18, 1177-1182.


This began as a two-person project where authors collaborated in the beginning phase. However, these authors agreed to part after chapter three was completed. For each of the beginning phase the authors took primary and joint responsibility. The responsibilities were assigned in the manner listed below.

1. Data Collection:
   Individual Effort: Lorna LeVias

2. Data Entry & Analysis:
   Individual Effort: Lorna LeVias

3. Writing Report and Presentation of Findings:
   a. Introduction and Literature:
      Team Effort: Lorna Levias & Yevonne Amador
   b. Method & Design:
      Individual Effort: Lorna LeVias
   c. Results:
      Individual Effort: Lorna LeVias
   d. Discussion:
      Individual Effort: Lorna LeVias