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Depression and burden in African American categories of the elderly

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ABSTRACT
SOCIAL WORK

WOODS, DIONNE L.  B.S. GEORGIA SOUTHERN UNIVERSITY, 1994

DEPRESSION AND BURDEN IN AFRICAN AMERICAN CAREGIVERS OF THE ELDERLY

Advisor: Melvin Williams, Ph.D.
Thesis dated March, 1996

The purpose of this study was to compare the experience of depression and burden in African American caregivers in two different living arrangements: those coresiding with the care recipient and those living separately from the care recipient. As caregivers struggle to balance the roles they must play, burden and depression are often a result.

A purposeful sample was used to identify caregivers of a day care and a day activity center in the Atlanta area.

There was no difference in the level of depression experienced by caregivers coresiding as compared to those not coresiding with the care recipient. Also, there was no difference between those caregivers coresiding as compared to non coresiding caregivers in the experience of burden.
DEPRESSION AND BURDEN IN AFRICAN AMERICAN CAREGIVERS OF THE ELDERLY

A THESIS SUBMITTED TO THE FACULTY OF CLARK ATLANTA UNIVERSITY IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SOCIAL WORK

BY

DIONNE L. WOODS

SCHOOL OF SOCIAL WORK

ATLANTA, GEORGIA
MARCH, 1996
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ACKNOWLEDGEMENTS

The technical and emotional support of my cousin, Debora, has been never ending toward the completion of this project. My gratitude must be given to my sister for her constant encouragement. Most importantly, I would like to thank my parents whose faith has allowed me to write one line at a time. Lastly, a thank you to all of the caregivers. Your efforts do not go unnoticed.
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CHAPTER ONE

INTRODUCTION

By 2010, the early tier of the baby boomers will advance to become retirement age. By the year 2050, the Census Bureau projects the number of elderly in the United States to be doubled.¹ In addition to the aging of the baby boomers, modern technology has contributed to the increased number of people surviving disease to live longer. Despite these many advances in modern technology, many elderly require some assistance with activities of daily living. The U.S. Department of Health and Human Services report that one quarter of all elderly persons and one-half of the older old (over 85 years) have at least a mild degree of functional disability. More than four out of five persons 65 and over have at least one chronic (long-lasting or often recurring) illness, and many have multiple chronic conditions.²

The number of persons in the age group of 85 years or older (the frailest segment of the population) can be expected to be seven times as large in 2050 as it was in 1980. This population of the "oldest old" is most at risk of physical or dementing illness such as Alzheimer's Disease (AD). For example, those persons between the ages of 65 and 74 exhibit a 1 in 25 chance of having AD, and those

²Ibid., 849.
85 and older have a staggering 1 in 2 chance of developing the disorder.³

Health problems are the burden of old age. At the turn of the century, acute conditions (severe illnesses of limited duration, such as infections) were predominant. With the development of antibiotics and cures for many acute infectious diseases, chronic conditions are now the prevalent health problem for the elderly. Because people are now living to an older age, they have more years in which to suffer a chronic condition.

The leading chronic conditions of the elderly are arthritis, hypertension, hearing impairments, and heart disease. In most cases, the likelihood for disease increases with age. Older men are more likely than women to have acute illnesses that are life threatening, while older women are more likely to have chronic conditions that cause physical limitations. As these limitations increase, the elderly are often required to look for assistance.⁴

When considering the cost of this care, there has been an alarming increase in the total expenditures for nursing home care. Between 1970 and 1988 such expenditures increased from $4.7 billion to $47 billion, representing almost 11 percent of all health


care expenditures.\textsuperscript{5} Over the next several years, the cost of institutional care will only increase unless there are major changes in health care. As these changes are not the highest priority in the eyes of many governmental officials, such reforms may be unlikely in the next decade. Due to this economic burden, many of the elderly and their families wish to avoid institutionalization. As a result, many states are now offering some type of economic support for family caregivers to assist them in maintaining their family members in the home. Due to rigid guidelines enforced with the interest of "cutting costs", persons who might have remained in the hospital for long periods of time are discharged. Medicaid payment for nursing home care is not available until other resources are depleted. Families often do not have other choices but to keep their elderly members in the community as along as possible to forestall such impoverishment. Whether the reason is economic or an attempt to keep the senior in the community, the demands for caregiving will fall on families that are increasingly unable to bear such burden.\textsuperscript{6}


Statement of the Problem

The primary source of assistance to the elderly, especially in preventing and delaying institutionalization is the caregiver. Rarely mentioned is the fact that all too often these caregivers are also growing older. Nearly one-third of caregivers to older adults are currently 65 or older themselves; the average age is 57. Many of the young old (60 to 75) caring for their old-old parents (75 and up) will be experiencing their own decline in energy, finances, and health. They may be increasingly concerned about their own retirement, which may be delayed due to caring for their parent. Inflation downsizing of corporations, and other economic reversals have left many elderly more likely to need economic help and their adult children less able to provide it. \(^7\)

Forty-four percent of caregivers are spouses, and eighteen percent are daughters. The remaining approximate twenty-five percent are in different relationship or nonrelated. With divorce and families choosing to have fewer children, the pool of caregiver options is growing smaller for many elderly. When families have fewer children the elderly is not presented with many options of a caregiver. Divorce is also ever decreasing the pool of caregivers by increasing the burden on the adult children as caregivers. With

divorce, the adult child may be torn between providing care to parents who do not reside in the same household.  

Another threat to this caregiving pool is competing demands that often strain the caregivers. Every two out of three caregiving women works outside of the home. When the roles of caregiving and employment conflict women are more likely to make accommodations in their schedules to allow more time to provide care. This may be one of the contributing factors to the increased level of burden felt by caregiving women.

The choice of a caregiver is very important. There are several patterns used when selecting a caregiver these include: the hierarchical pattern, proximity pattern, and time available hypothesis.

The hierarchical pattern is often followed when choosing a caregiver. The wife (spouse) is the primary caregiver when available. The adult daughter is the next option, if no spouse if available. Other relatives would be the next to step in and assist the caregiver. When there is an elder without family, the friends and neighbors may provide.

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9 Ibid., 65.

Proximity along with relationship may also be a deciding factor in who will provide care.¹¹ This is more of a team approach then the hierarchical approach. Every member has a role to play based on their proximity to the care recipient. The neighbor provides assistance in an emergency, as they are the closest in proximity. If the care recipient becomes confused in the neighborhood or they notice an unusual amount of mail piling up in the mailbox, they would be the person to notify the relative of the problem. The friends, however, provide assistance that is slightly longer in duration. The friends usually provide assistance by coming by and visiting with the care recipient. They may also provide limited amounts of transportation, as well. They often serve as the eyes and ears of the caregiver, because they are in a better position to contact them, if they detect changes in the condition of the care recipient. The spouse, in this case, would again be the most obvious option for a caregiver. He/she is the person who already shares a household with the care recipient and posses the commitment level required when long term care is needed. Adult children fill this role when there is no spouse present or able. They usually have a commitment to long term care, but only to a certain point. There are limits to their commitment because adult children

often have other competing role that may conflict with the caregiving role.\textsuperscript{12}

Stoller, Forster, Duniho suggest that when choosing a caregiver from more than one adult child, the time-available hypothesis may be applicable. It states that "adult children with the fewest competing demands on their time provide the most help to their older parent."\textsuperscript{13} These competing roles may include: parenting, employment, or a spouse. This includes the fact that marriage, or employment pulls from the available time the adult child can spend completing caregiving roles, therefore responsibilities fall disproportionately upon those children with the least amount of pulls on their time. Employment also limits the amount of hours available to act as caregiver. An additional constraint on time includes the geographical proximity of the adult child to the care recipient. If it takes a great deal of time to reach the care recipient, the sibling that is in close proximity will more than likely bear the greater amount of task.\textsuperscript{14}

Research has consistently shown that although caregiving can have many positive effects on the caregiver, providing care to an

\textsuperscript{12} Miller, Baila, and Lynda Cafasso,"Gender Differences in Caregiving: Fact or Artifact?," \textit{The Gerontologist} 32 1992: 499.


\textsuperscript{14} Ibid., 31.
elderly family member is often highly stressful. This can be especially stressful to the caregiver who must provide for two different households: their own and that of the care recipient resulting in strain in the roles of the caregiver. Living arrangement or coresidence is rarely a major factor considered in the research. As there is such limited amount of research on caregivers living arrangements, even fewer of have included discoveries of the experience of the African American Caregiver in the various living arrangements. When discovering caregiving living arrangements there are several situations to be considered. Spousal caregiving usually the spouse and care recipient sharing a household- the spouse acting as the primary caregiver. The adult child caregiver corseting residing with the care recipient- the adult child as the primary caregiver. The last caregiver situation is that of the adult child as the primary caregiver not sharing a household with the care recipient. Considering the number of roles that the adult child caregiver may be playing, it is important to think that not all of these dyads will live within one household. It is quite difficult to establish that the importance of living arrangements is correlated to perceived burden because the great majority of the research presented does not consider this correlation as important variable to be measured. Many elderly people are physically able to live in their own households with limited assistance. It is most important not to overlook this group.
Of the few studies conducted in this area, researchers have concluded very differently about the importance of living arrangements. Deimling, Bass, Townsend, and Noelker concluded that the adult child caregiver not living with the care recipient experiences the greatest strain. Those researchers have concluded that care recipients who reside with the caregivers, especially the spousal caregivers, experience the greatest amount of care provided. The other studies compared living arrangements and the amount of assistance provided where it was concluded that coresidence increase the amount of care provided. Neither of these studies consider ethnicity. There is ample evidence to indicate that the caregiving role can have harmful emotional, physical, and financial consequences for the caregiver and can lead to feelings of depression, anxiety, and burden in those individuals who take the responsibility for the care of a spouse or other loved one.


strain could result in conflict of roles which in a chain reaction could lead to an increase in burden or depression.

Burden has been a central concept in family caregiving research since the beginning of the research on aging. Nonetheless, recent reviews of article have pointed to the fuzziness of the concept. The term has covered everything from the abilities of the care recipient and the feelings of the caregiver to the effects that caregiving has on the family from either a subject of objective perspective.\textsuperscript{18} In the early 80's the research focused on caregiver, stress and later burden. During the 90's the research focused on burden dividing the concept into 2 categories: objective and subjective burden.\textsuperscript{19} Also, researchers explored the use of a measurement of well-being to determine burden.\textsuperscript{20} The result is very misleading not to mention inconclusive about the definition of burden in the experience of caregivers.

In addition to burden, caregivers may experience depression that may be a result of their caregiver duties. According to


Poulshock, all caregivers experience depression to some extent.\textsuperscript{21} Gallagher, Rose, Rivera, Lovett, and Thompson measured depression in helping caregivers, while the conclusions imply that by the time caregivers seek help they are often depressed.\textsuperscript{22} This may quite different in the African American Community because African American caregivers do not usually actively seek assistance from formal sources. They may not have been included in his study, as they are not mentioned.

Depression with even the slightest presence can be a difficult disease with which to cope. A stressor can be a major factor in the presence and even the severity of depression. According to the DSM-IV, a stressor can be the precursor to a major depressive episode.\textsuperscript{23} The burden of caregiving can act as a stressor.


Significance of the Study

In 1990, there were 31.6 million elderly people in the United States of these 12.3 percent were African American. The proportion of older African American and other minorities is growing at a faster rate than their white counterparts. These older minorities are faced with issues of economic hardships, as well as, limited access to health care. In 1987, 19.1% of the 2 million African American elderly would need assistance with at least one activity of daily living. Even though African American elderly are often most in need of assistance, the institutionalization rate for African American elderly is lower than that of their counterparts. This places a possible greater burden upon the family to provide care for the elder.

There have been several studies to consider the experience of caregivers yet, few have considered African American caregivers. Previous studies have examined the effect of living arrangement on the amount of care related stress experienced by the caregiver or the importance of the relationship between the caregiver and care


When considering living arrangements, the only variables considered were the impact of the care recipient's impairment or the amount of care provided. Living arrangement and its impact upon the experience of the caregiver has rarely been considered. Even fewer have considered the impact of living arrangement on the experience of African American caregivers.

Generally, the research about the experience of African American caregivers has generally been compared to that of other ethnic groups. These comparisons of the African American caregiver to other ethnic groups have been done without regard to the cultural differences which would inherently make their experiences difficult to compare. When these comparisons are made it gives the impression that the amount of burden or depression experienced by the African American caregiver is insignificant because it is compared to the higher rate experienced by the white caregiver. The continuation of this type of comparison may not lead to a discovery of the characteristics that are specific to African American caregivers. This may more appropriately be done by using a sample consisting completely of African American caregivers.

Purpose of the study

The purpose of this study was to compare the experience of depression and burden in African American caregivers in two different caregiving situations: those coresiding with the care recipient and those living separately from the caregiver.
CHAPTER TWO

REVIEW OF THE LITERATURE

Burden

Zarit, Reever, and Back-Peterson looked at several factors in their research surrounding burden. This research considered how caregiver burden is affected by the impairment of the care recipient. The variables they considered included the extent of cognitive impairment, memory and behavior problems, functional abilities, duration of illness, and the frequency of the family visits. Of these only the frequency of the family visits had the greatest effect upon the degree of burden experienced by the caregiver. Unable to determine what about these visits were the determining factor; the researcher did note that the sheer number of visits seem to be of most importance. These networks within families may provide a means of coping with the often distressing behaviors of the care recipient. It is suggested that practitioners concentrate on the informal and natural support system of caregivers in helping to reduce the amount of burden felt. Most importantly Zarit, Reever, and Back-Peterson concluded that there is no connection between the burden of the caregiver and the behavior problems or cognitive

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impairment of the care recipient.\textsuperscript{2}

Pearson, Verma, and Nellett raised the question of the correlation between patient status and caregiver burden. The patient status included the functional status of the patient, a contributing factor to the burden of the caregiver. Specifically the disruptive behavior having more of an effect than that of the cognitive incapacity of the care recipient. Patient functional-status, patient disruptive discrepancies between patient abilities and behaviors were found to be important contributions to the perceptions of burden of caregivers of elderly psychiatric patients.\textsuperscript{3}

Montgomery, Gonyea, and Hooyman argued that burden should not be measured as a global variable only. It should be divided into objective burden and subjective burden. Where subjective burden includes feelings and objective burden included activities. The authors concluded that there is a difference but, no answer to the question of whether one is appropriate to measure without the other or instead of the other.\textsuperscript{4}

\textsuperscript{2}Zarit, Steven, Karen Reever, and Julie Back-Peterson, "Relatives of Impaired Elderly Correlates of Feelings of Burden," \textit{The Gerontologist} 20 1980: 650.


Stull, Kosloski, and Kercher support the trend of using the measurements of well-being as opposed to burden; when researching within the population of caregivers. The argument of using the measurement of well-being is that this measurement contained measures for many of the same variables as that of the burden measurements. This study used a well-being measurement in comparing caregivers to non caregivers. The results showed that one is unable to determine definitely that the measurements of generic well-being should replace that of measurements of burden.

Stull, Kosloski, Kercher found that both had a place in further research of caregiving of the elderly.5

Kosberg and Cairl raised the question of a possible correlation between burden and the competency level of caregiver. The initial idea is that as the competency level of the caregiver decreased the level of the burden would increase. The results did not support this hypothesis. Because the researchers found various combinations of the two, the conclusions were that those caregivers who are burdened may still provide competent assistance to the care recipient. Therefore, the level of competency of the caregiver was

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not a predictor for the amount of burden experienced.  

Young and Kahana questioned why women tested to be more burdened than men when caregivers. They found four possible explanations for this: caregiver age, difficulty caring for the patient, formal and informal support, and coping responses. The only proposition that positively explains the difference of experience is that of coping responses. Men have a greater ability to cope than the women participant.

The research has made no conclusion of a clear definition of burden. In every study the concept of burden has been defined differently. As the concept has been defined differently, no researcher has determined what variables should be included in a definition of burden therefore, no measurement of burden has been used consistently to determine is usefulness in measuring burden. As the variable that should be included in a definition of burden have not been determined the factors that contribute to burden as also vague. Researchers should continue to explore to discover as reliable definition of the concept burden.

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Living Arrangement

Deimling, Bass, Townsend, Noelker studied the effects of caregiving in three different situations: 1) husband or wife assisting an impaired spouse in their own home, 2) an adult child caring for an elderly parent living with and assisting an impaired parent, 3) an adult child caring for an elderly parent who lives alone in a nearby community. The results from this study were that the relationship to the care recipient does not effect the care related stress.

In shared household, the spouse and adult children as caregivers both experience health decline, strain, and "activity restriction." This is true even when the elderly person's impairment is taken into consideration. They found that elderly impairment to be of limited importance when considering stress. They also found that when considering living arrangements the adult child not currently residing with the care recipient experiences less decline. Deimling, Bass, Townsend, Noelker suggest that previous studies have overestimated stress in separated household. They concluded that those caregivers who did not share a household with the care recipient did experience a significant amount of strain.8

Tennstedet, Crawford, McKinlay hypothesized that the living arrangement is more important than relationships of the caregiver

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in determining the pattern of caregiving. The authors stated that sharing a household has been linked throughout research to greater amount of care.

In addition to providing more care the caregivers in shared household experience increased amounts of health decline. Researchers fail to recognize the importance of the experience of all caregivers and the effects of living arrangements.

Depression

When attempting to determine if caregiving can be a stressor resulting in depression, Gallagher, Rose, Rivera, Lovett, and Thompson determined that caregivers were often more distressed than "normal" populations. This was determined by testing caregivers of dementia patients with the same number of controls. In addition to their higher distress, the caregivers rated their overall health lower than the control group.

In addition to comparing caregivers to noncaregivers, Gallagher, Rose, Rivera, Lovett, and Thompson compared help-seekers to non-help-seekers. They determined that help-seekers were more depressed than the non-help-seekers. This is understandable


because helpseekers may have reached that point at which their coping mechanism may be lower and need the assistance of others. The authors found that the presence of depression was not determined by the age, income, length of providing care, relationship to care recipient, and whether or not the recipient was cognitively impaired. The conclusion was that by the time caregivers actively sought appropriate help for their stresses and burdens, they are likely (about half of the time) to be experiencing a full-blown clinical depression.11

According to Gallo, caregiving spouses reported more health problems including depression when compared to adult children. Caregivers coresiding with the elder reported more stress, health problems and used more psychoactive medications, when compared to a group of noncaregivers. The author notes that the specific situation and resources to the caregiver were more important than the impairment of the care recipient.12

The research suggest that the relationship to the caregiver has a greater indicator to depression than the impairment of the care recipient. The spousal caregivers experienced greater depression


when compared to adult children caregivers. Helpseekers also experience greater depression when compared to non-helpseekers.

Conceptual Framework

There are several theories that may be considered in application to this study. Role Theory is most applicable. According to Stephan and Stephan, "roles consist of the expectations for behavior characteristic of a recognized set of persons in a specific social position or status." Imbedded in role theory lies the concepts of role strain, role demand overload, role conflict, and role engulfment. These concepts are especially applicable to daughter and daughters-in-law adult children who provide care. Many who are employed or have families of their own often find themselves in the mist of conflict between the many hats or roles that they must play. The roles of social obligations, marriage, and vocation often collide prompting some difficulty. Thus caregivers often experience role strain which is defined as "felt difficulty in the fulfillment of caregiving role obligations." Role strain can lead to role overload which is when a caregiver experiences difficulty in fulfilling their responsibilities due to a lack of sufficient time, energy, or personal


resources. This occurs when the caregiver attempts to juggle all of the roles one plays. Role conflict can be another contributor to role strain, often as a result of expectations. Role conflict occurs when "roles are incompatible with the role expectations." There may be conflict if the expectations of the performance in a role are to high and unattainable. Lastly, those caregivers who coreside with the care recipient may experience the threat of role engulfment. Skaff and Pearlin examined role engulfment. They determined that those caregivers, especially women, where the care recipient is more dependent on the caregiver for daily routine is exposed to more opportunity for the caregiver to become engulfed. The caregiver identifies more with the role of caregiver than any other role.

Role engulfment, conflict, strain, and demand overload are useful in their explanation of the experience of African American caregivers they perform so many roles in the course of a day. Those caregivers who coreside with the care recipient may be a greater risk for exposure to role engulfment and demand overload because of the overwhelming role of caring for someone on a full time basis. Those caregivers who do not reside with the care recipient may be


often wear. The combination of these roles may cause strain and conflict which may result in health problems for the caregivers.

As caregivers struggle to balance the many jobs they must fulfill, stress, burden and depression are often a result. The concepts of role strain, role demand overload, role conflict, and role engulfment are concepts that within role theory may be used to explain the experiences of stress, burden, and depression in caregivers of various living arrangements.

Definition of Terms

Elderly is defined as a person age 65 or older who requires some assistance.

Caregiver is defined as a person who provides assistance to an elderly person.

Coreside is the term used to describe the living arrangement of caregivers who share a household with the care recipient.

Noncoreside is the term used to describe the living arrangement of caregiver who do not share a household with the care recipient.

QUESTIONS

This research raised the following questions: 1) Do the coresiding and noncoresiding caregivers experience depression equally? 2)Do the coresiding and noncoresiding caregivers experience burden equally?
CHAPTER THREE

METHODOLOGY

Research Design

A descriptive study design was used in this study. The descriptive design was used to explain the observed relationship between the dependent variables and the independent variables rather than develop hypothesis for testing. The descriptive design is used in explaining what is observed when certain variables are present.

Setting

Because of the difficult nature of obtaining information from this population a purposeful sample was used. The caregivers were identified through contacts with a day care and a day activity center in the Atlanta area. The day care center provides rehabilitation and therapeutic activities for the seniors. These elders are most likely to reside with a caregivers. The day activities center serves as more of a "senior center" for social and recreational activities. The elders participate in arts and crafts classes, eat lunch, or just sit around and socialize with the other participants. The elderly persons participating in the day activity center are more independent and were more likely not to reside with the caregiver.

Measurement

Burden was measured by the burden interview designed by Steven and Judy Zarit. The burden interview was designed to assess the experience of family caregivers. Caregivers were asked to
respond to a series of 22 questions about the impact of caregiving on their lives. For each item, caregivers were to indicate how they felt providing care that way: never, rarely, sometimes, quite frequently, or nearly always. The more the respondent indicated

4) Nearly Always the greater the amount of burden experienced. The internal reliability for the burden interview is estimated using Cronbach's alpha at .88. Validity is estimated at .71. Two subscales have been derived from the burden interview using confirmatory factor analysis. The scales represent the dimension of personal and role strain. Personal strain and role strain are derived from the specific questions concerning each topic. The questions of the burden interview are divided into two different groups. The sum of the responses to questions of each group are calculated and the higher the score the greater the strain experienced. The internal reliability has for the personal and role strain respectively is .88 and .91.¹

The depression was measured by using the Hudson's Generalized Contentment Scale (GCS); a 25 item scale designed by Hudson and his co-workers. The respondents were instructed to indicate how often they experienced the feelings of depression asked in each question. The responses are based on a 7-point scale ranging from; none of the time to all of the time. The higher the

score the more the depression is experienced. The scores can range from 0 to 100. The internal consistency reliability is .90.²

Procedure

The director of a day care center in the Atlanta metropolitan area was contacted to assist with the distribution of the questionnaires. The questionnaires were distributed in the morning when the caregivers dropped off their loved one. If there was time they completed the questionnaire prior to leaving, otherwise they completed the questionnaire in the afternoon when picking up their loved one. Others chose to take the questionnaire and return it when picked up their loved one. The staff of the day care center gave daily reminders to the caregivers to request the return of the questionnaires. The director of the day care center collected all returned questionnaires. The identification of noncoresiding caregivers entailed a different procedure. The participants of the day activity center were asked to name a person that provided assistance to them for activities they could not complete themselves. Once these persons were identified questionnaires were mailed to them. They were instructed to complete the questionnaires and return them as soon as possible. Those participants that did not return the questionnaires were telephoned with a reminder to return the questionnaire. The day activity center also had an open

house/health fair involving caregivers and care recipients. Many caregivers completed questionnaires during this time.
CHAPTER FOUR
PRESENTATION OF RESULTS
Demographic Data

This section summarizes the information collected concerning the African American caregivers and care recipients their living arrangements of the care recipient.

Table 1 presents the distribution of demographic variables of those coresiding and noncoresiding caregivers. The mean age of the coresiding care recipients was 86.2 and were more often a female. The caregiver was most often a female (44.4%) who had been providing care for 1 to 3 years (33.3%) with a mean age of 55.9. Most of the caregivers were either married (33.3%) or single (33.3%), employed (66.7%) with children (83.3%). The noncoresiding care recipients had a mean age of 54.3 and were female (82.6%). The caregiver was most likely the daughter (56.6%) who had been providing care for 6 or more years (34.8%). These caregivers were most likely a married (69.6%) female (73.9%) who is employed (82.6%). Only 13.9% of the noncoresiding caregivers do not have children.

Table 2 describes the assistance required by the care recipient. The respondents were asked to indicate all of the tasks in which they assist the care recipient. The tasks included: bathing, toileting, getting out of a bed or chair, transportation, phone usage, shopping, money management, taking medication, eating, dressing,
### TABLE 1

**FREQUENCY DISTRIBUTION OF DEMOGRAPHIC VARIABLES OF CAREGIVERS**

<table>
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<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>2</td>
<td>11.1</td>
<td>1</td>
<td>4.3</td>
</tr>
<tr>
<td>Daughter</td>
<td>8</td>
<td>44.4</td>
<td>13</td>
<td>56.6</td>
</tr>
<tr>
<td>Son</td>
<td>2</td>
<td>11.1</td>
<td>2</td>
<td>8.7</td>
</tr>
<tr>
<td>Sister</td>
<td>2</td>
<td>11.1</td>
<td>2</td>
<td>8.7</td>
</tr>
<tr>
<td>Daughter in law</td>
<td>2</td>
<td>11.1</td>
<td>1</td>
<td>4.3</td>
</tr>
<tr>
<td>Great-niece</td>
<td>2</td>
<td>11.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Niece</td>
<td></td>
<td></td>
<td>1</td>
<td>4.3</td>
</tr>
<tr>
<td>Aunt</td>
<td></td>
<td></td>
<td>1</td>
<td>4.3</td>
</tr>
<tr>
<td>Cousin</td>
<td></td>
<td></td>
<td>1</td>
<td>4.3</td>
</tr>
<tr>
<td>Granddaughter</td>
<td></td>
<td></td>
<td>1</td>
<td>4.3</td>
</tr>
<tr>
<td><strong>How long have you provided care?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 months or less</td>
<td>2</td>
<td>11.1</td>
<td>5</td>
<td>21.7</td>
</tr>
<tr>
<td>6 to 11 months</td>
<td>2</td>
<td>11.1</td>
<td>1</td>
<td>4.3</td>
</tr>
<tr>
<td>1 year to 3 years</td>
<td>6</td>
<td>33.3</td>
<td>3</td>
<td>13.0</td>
</tr>
<tr>
<td>4 to 6 years</td>
<td>1</td>
<td>5.6</td>
<td>6</td>
<td>26.1</td>
</tr>
<tr>
<td>6 or more years</td>
<td>7</td>
<td>38.9</td>
<td>8</td>
<td>34.8</td>
</tr>
<tr>
<td><strong>Caregiver Marital Status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>6</td>
<td>33.3</td>
<td>16</td>
<td>69.6</td>
</tr>
<tr>
<td>Single/Never Married</td>
<td>6</td>
<td>33.3</td>
<td>4</td>
<td>17.4</td>
</tr>
<tr>
<td>Divorced</td>
<td>5</td>
<td>27.8</td>
<td>3</td>
<td>13.0</td>
</tr>
<tr>
<td>Widow</td>
<td>1</td>
<td>5.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Caregiver gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3</td>
<td>16.7</td>
<td>1</td>
<td>4.3</td>
</tr>
<tr>
<td>Female</td>
<td>15</td>
<td>83.3</td>
<td>17</td>
<td>73.9</td>
</tr>
<tr>
<td><strong>Caregiver Employment</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working</td>
<td>12</td>
<td>66.7</td>
<td>19</td>
<td>82.6</td>
</tr>
<tr>
<td>Not working to care for care recipient</td>
<td>6</td>
<td>33.3</td>
<td>1</td>
<td>4.3</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>33.3</td>
<td>3</td>
<td>13.0</td>
</tr>
<tr>
<td><strong>Does caregiver have children</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>15</td>
<td>83.3</td>
<td>17</td>
<td>13.9</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
<td>11.1</td>
<td>5</td>
<td>21.7</td>
</tr>
<tr>
<td>Assistance required by Care recipient</td>
<td>Coresiding N</td>
<td>%</td>
<td>Noncoresiding N</td>
<td>%</td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>--------------</td>
<td>---</td>
<td>----------------</td>
<td>---</td>
</tr>
<tr>
<td>Bathing</td>
<td>14</td>
<td>77.8</td>
<td>13</td>
<td>56.5</td>
</tr>
<tr>
<td>Tolletting</td>
<td>10</td>
<td>55.6</td>
<td>7</td>
<td>30.4</td>
</tr>
<tr>
<td>Getting out of bed or chair</td>
<td>12</td>
<td>66.7</td>
<td>17</td>
<td>73.9</td>
</tr>
<tr>
<td>Transportation</td>
<td>16</td>
<td>88.9</td>
<td>18</td>
<td>78.3</td>
</tr>
<tr>
<td>Phone usage</td>
<td>15</td>
<td>83.3</td>
<td>17</td>
<td>73.9</td>
</tr>
<tr>
<td>Shopping</td>
<td>17</td>
<td>94.4</td>
<td>17</td>
<td>73.9</td>
</tr>
<tr>
<td>Money management</td>
<td>17</td>
<td>94.4</td>
<td>12</td>
<td>52.2</td>
</tr>
<tr>
<td>Taking medication</td>
<td>16</td>
<td>88.9</td>
<td>14</td>
<td>60.9</td>
</tr>
<tr>
<td>Eating</td>
<td>12</td>
<td>66.7</td>
<td>13</td>
<td>56.5</td>
</tr>
<tr>
<td>Dressing</td>
<td>13</td>
<td>72.2</td>
<td>10</td>
<td>43.5</td>
</tr>
<tr>
<td>Emotional support</td>
<td>15</td>
<td>83.3</td>
<td>17</td>
<td>73.9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Care Recipient Receive financial assistance</th>
<th>Coresiding N</th>
<th>%</th>
<th>Noncoresiding N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>13</td>
<td>72.2</td>
<td>9</td>
<td>39.1</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
<td>27.8</td>
<td>14</td>
<td>60.9</td>
</tr>
</tbody>
</table>
and emotional support. Some tasks were more demanding because they required some physical assistance such as bathing, toileting, getting out of bed or chair, dressing, and eating. These may indicate that the care recipient is more physically limited. Other tasks do not require such physical assistance such as: shopping, money management, transportation, phone usage. Assistance with these task may indicate the elder is more mentally limited as opposed to physically limited. The top four tasks requiring assistance of coresiding caregivers included shopping(94.4%), money management(94.4%), taking medication(88.9%), and transportation(88.9%). The top four responses for the noncoresiding care recipient included: transportation(78.3%), phone usage(78.3%), shopping(73.9%), and getting out of bed or chair (73.9%). Caregivers were also asked if the care recipient received any financial assistance to help with the cost of providing care. Only 72.2% of the coresiding care recipients receive assistance, while only 39.1% of the noncoresiding care recipient do no receive assistance.

Table 3 summarizes the assistance received by the caregiver. Caregivers were asked if they received help with providing assistance for the care recipient. Seventy-two percent of the coresiding caregivers stated they did received assistance while, 60.9% of the noncoresiding caregivers received assistance. The respondents were asked what type of caregiving assistance did they
### TABLE 3
**FREQUENCY DISTRIBUTION OF ASSISTANCE RECEIVED BY CAREGIVER**

<table>
<thead>
<tr>
<th>Self Rating of Physical Health (Caregiver)</th>
<th>Coresiding</th>
<th>Noncoresiding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Good</td>
<td>9</td>
<td>17</td>
</tr>
<tr>
<td>Fair</td>
<td>6</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Caregiver receive assistance</th>
<th>Coresiding</th>
<th>Noncoresiding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>13</td>
<td>14</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
<td>9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Type of assistance received</th>
<th>Coresiding</th>
<th>Noncoresiding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informal (non-paid)</td>
<td>12</td>
<td>16</td>
</tr>
<tr>
<td>Formal assistance</td>
<td>13</td>
<td>9</td>
</tr>
<tr>
<td>Formal (non paid)</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Frequency of Formal Assistance</th>
<th>Coresiding</th>
<th>Noncoresiding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does not receive help</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Occasional</td>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td>1 to 4 hours per week</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>5 to 9 hours per week</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>10 to 15 hours per week</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>more than 15 hours per week</td>
<td>8</td>
<td>8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Frequency of Informal assistance</th>
<th>Coresiding</th>
<th>Noncoresiding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does not receive help</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Occasional</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>1 to 4 hours per week</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>5 to 9 hours per week</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>10 to 15 hours per week</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>more than 15 hours per week</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Do you receive support from you job?</th>
<th>Coresiding</th>
<th>Noncoresiding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>9</td>
<td>19</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>As a result of Care provided have you had to...</th>
<th>Coresiding</th>
<th>Noncoresiding</th>
</tr>
</thead>
<tbody>
<tr>
<td>reduce the number of hours worked</td>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>rearrange work schedule</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>take time off without pay</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>leave a job</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>
receive, informal, formal (non-paid), or formal (paid) assistance. Informal assistance included the help given by friends or family; free of charge. Formal assistance was help requested from an agency or formal organization there is a attached fee to the service. For example, meals-on-wheels which brings meals to the care recipient on a daily basis for a small fee. The last type of assistance included that of formal non-paid assistance. This service is given by a formal organization with no fee attached such as a church group organized to act as sitting companions for senior members of the congregation. The type of assistance received by the majority of the coresiding caregivers was formal assistance and noncoresiding caregivers received more informal assistance (69.6%). Caregivers were asked the frequency of each type of service received. Forty-four percent of the coresiding caregivers received more the 15 hours per week of formal assistance, while 52.2% of the noncoresiding caregivers received this assistance only occasionally. The majority of the coresiding caregiver received 5 to 9 hours per week of informal assistance. Of those noncoresiding caregivers receiving informal assistance, 1 to 4 hours per week was all they received (30.4%). Those caregivers who were employed were asked to indicated if they received support from their employer. Time off for illness of the care recipient or time away for emergencies are examples of the type of support given by employers. Of the coresiding caregivers, half indicated that support was received from their job. Eighty-two percent of the noncoresiding caregivers also indicated they received
support from their employers. When providing care one must often make schedule changes to allow more time to provide this care. Caregivers were asked to indicate if they have made changes in their work schedule to accommodate their caregiving duties. Forty-four percent of the coresiding caregivers had rearranged their work schedule to provide care. Fifty-two percent of the noncoresiding caregivers had reduced the number of hours worked to accommodate the duties of caregiving.

Table 4 presents the mean and standard deviation of depression. When comparing the means, the coresiding caregivers experienced a greater amount of depression than those noncoresiding caregivers. A t-test was performed on this data which revealed that there is no difference in the level of depression experienced by the caregivers coresiding (t=2.0, df=16, p<.05).

| Table 4 | MEAN AND STANDARD DEVIATION OF DEPRESSION, CORESIDING AND NONCORESIDING CAREGIVERS |
|---------|---------------------------------|-----------------|
|         | **N** | **Mean** | **Standard Deviation** |
| Coresiding caregivers | 18   | 36.4   | 12.0       |
| Noncoresiding caregivers | 23   | 24.6   | 10.0       |

Table 5 presents the mean and standard deviation of burden. The mean experience of burden of noncoresiding caregivers is
greater than that of the coresiding caregivers. The results of a t-test indicate that there is no difference between those caregivers coresiding ($t=2.8, df=16, p<.05$) as compared to non coresiding with the care recipient.

**TABLE 5**

**MEAN AND STANDARD DEVIATION OF BURDEN, CORESIDING AND NONCORESIDING CAREGIVERS**

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coresiding Caregivers</td>
<td>18</td>
<td>26.0</td>
<td>12.4</td>
</tr>
<tr>
<td>Non Coresiding Caregivers</td>
<td>23</td>
<td>37.2</td>
<td>12.1</td>
</tr>
</tbody>
</table>

Table 6 presents the mean and standard deviation of role strain. Noncoresiding caregivers experience a greater amount of role strain, as described by a comparison of the means. The results indicated that there was no difference in the experience of personal strain of caregivers who coreside with the care recipient ($t=1.0, df=16, p<.05$) as compared to those who do not share a household with the care recipient.
Table 6
MEAN AND STANDARD DEVIATION OF ROLE STRAIN, CORESIDING AND NONCORESIDING CAREGIVERS

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coresiding Caregivers</td>
<td>18</td>
<td>11.3</td>
<td>4.2</td>
</tr>
<tr>
<td>Noncoresiding Caregivers</td>
<td>23</td>
<td>7.2</td>
<td>4.2</td>
</tr>
</tbody>
</table>

Table 7 describes the mean and standard deviation of personal strain. When comparing the means, the coresiding caregivers experienced a greater amount of personal strain. The t-test indicated that there was not difference in the experience of role strain in coresiding caregivers ($t=2.1, df=16, p<.05$) as compared to noncoresiding caregivers.

Table 7
MEAN AND STANDARD DEVIATION OF PERSONAL STRAIN, CORESIDING AND NONCORESIDING

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coresiding Caregivers</td>
<td>18</td>
<td>25.8</td>
<td>9.2</td>
</tr>
<tr>
<td>Noncoresiding Caregivers</td>
<td>23</td>
<td>19.0</td>
<td>9.5</td>
</tr>
</tbody>
</table>
CHAPTER 5
SUMMARY AND CONCLUSION

There was no real difference in the mean age or gender of the caregiver or care recipient in either group. Both groups provided assistance with activities that did not require a great deal of physical exertion. The tasks in which assistance was provided may indicate more cognitive assistance required for the care recipient. Both caregiver groups received assistance yet, this assistance was given in different forms with difference frequencies. The coresiding caregivers received 15 or more hours of formal assistance with only occasional informal assistance. The noncoresiding caregivers received only 1 to 4 hours of informal assistance with only occasional formal assistance. Despite of these differences in type and frequency of assistance received, there was no significant difference in the experience of depression and burden in African American caregivers.

Role and personal strain were added subscales to the burden measure. There was no significant difference in the experience of the role strain or personal strain in either group of caregivers. Yet, the means indicate that there was a greater experience of burden in noncoresiding caregivers while coresiding caregivers experienced greater role and personal strain. As role and personal strain are subscales of the measurement of burden, it is interesting to note that the group of caregivers that measured greater burden did not measure increased levels of role and personal strain.
These findings suggest that despite these low levels of reported burden and depression by African American caregivers in previous studies, the experience of depression and burden by these caregivers is important for further study.

Limitations of the Study

The limitations of the study include, 1) a very small sample, 2) limited generalizability, 3) nonrandom sample, Suggested Research

Further research should include a larger sample size. In addition to a larger sample size, a randomly selected sample would also increase the generalizability of the study to more populations. Further research should include more samples of African American caregivers to determine specific variables effecting the African American caregivers.
CHAPTER SIX
IMPLICATIONS FOR SOCIAL WORK PRACTICE

To realize the benefits of family care, to forestall the institutionalization of elderly person while preventing the negative impact of such care on family caregivers, two approaches should be taken simultaneously by social work practitioners in the future. First, social workers should direct their intervention toward preventing the premature dependence of elderly family members on their potential caregivers for as long as possible. This approach will help to ensure that the family and other resources necessary to support the dependent family members will be there when required. Secondly, when such dependence is necessary, practice efforts should be directed at lessening the negative impact of caregiving on physical and mental health but may further prevent the necessity of the older adult's placement into a nursing home. Although it is advantageous to the elderly, their family, and society to prevent unnecessary institutionalization, the caregivers and their families must not be sacrificed.

On the policy level, social workers should also become effective advocates for clients in the health care debate. In the future, older adults will require access to costly long-term care through a federally supported insurance system that does not require their depleting every dollar earned over their lifetime. Just as importantly, they will also need the financial and technological supports required to remain in their homes. An array of services
from telephone check-ins to daily chore, homemaker, and home health services would serve to prevent the premature use of family caregivers. Funding should be provided for the renovation of existing residences to make them useable by those with emerging physical and sensory disabilities. Money should be directed toward these services that are more cost-effective, consistent with our values of family responsibility and autonomy, and more feasible than constructing institutions.

Of particular concern in the future must be the growing number of elderly who have neither children nor spouses to support them. Useful ideas must be borrowed from other age groups and earlier times to prevent the isolation that often results in institutionalization. For example, workers must promote older adults; having roommates, taking in borders, renting out rooms in their forms, and utilizing dating service. Elders should be offered such options as boarding houses and cooperative houses. Just as such co-ops on college campuses are organized around interest (such as foreign languages), elderly co-ops could also be organized around such interests as hobbies, prior careers, or travel. Even more basically, they may be organized around skills and abilities, with some of the elderly preparing meals while other attend to maintenance and cleaning responsibilities. Such arrangements would compensate for the individual's deficits, further extending his or her independence.
When these supports are no longer successful in maintaining the older adult in an independent residence without significant amounts of family support, the focus of social work intervention must shift to assisting the caregiver. By focusing on the caregiver, not only can the debilitating physical and emotional problems that they may experience be prevented, but the financial step toward long-term care of the loved one may also be forestalled.

It is also critically important that we develop additional support systems for the caregivers. Family and individual therapy, support groups, psychoeducational groups, and skills training must all be readily available to the growing number of family caregivers. We must recognize, however, that the empirical support for the effectiveness of most such programs is subject to many interpretations. We must, therefore, be creative in the development and evaluation of additional programs.

Family caregivers will also need material support to effectively provide the care to their family member at nominal cost to their physical and emotional health. As to hinder dependence, public funds must be provided to support the family in maintaining the older adult in the community. As more and more families are dependent on two wage earners, family members will be unable to interrupt their careers for substantial periods of time without financial support. Family members must be compensated for what that effort means not only to their loved one but to society as whole.
Support should also be increasingly available for routine in-home support and respite care, as well as for adult day care and drop-in centers. The caregivers not only must have regular assistance with the care of their loved one but must be able to leave their responsibilities for a few hours or a few weeks. Relief in the form of respite care and drop-in centers needs to be available not only for the errands and chores or the planned vacation but as a way to escape the daily hassles and frustrations of providing care. Such a break from caregiving duties can have a tremendous impact on the caregiver's ability to regain perspective, to refresh and renew. It has been shown that feeling tied down and unable to control time is very stressful for caregivers. It must be recognized that caregiving does not follow a predictable course, and the demands of caregiving vary on a day-to-day basis, as do the emotional and physical resources of the caregiver. As a result, caregivers may need relief unexpectedly and quickly. Red tape should be kept to a minimum; service caps should be minimal; and justification should not be required.

When maintaining the older adult in the community, even with the support of the family, is no longer feasible, social workers must be prepared to help families to place their loved one in institutional care with minimal guilt and regret. This is more likely if the kind of assistance outlined above has been provided to both the older adults and the family. Social workers must also recognize that placement of the family member in a nursing home does not
eliminate the family's need for support. The burden of care does not automatically stop at the nursing home door. Adult children are often raced by guilt and remorse; they continue to grieve for their parent and for their own childhood; they continue to demand of themselves that they supervise and monitor their loved one's care. Nursing homes of the future must acknowledge the need for this ongoing involvement of the family and provide them with more than an opportunity to visit or to receive answers to specific questions. Support services, grief groups, and multigenerational family counseling must all be available for the families of nursing home residents.

As a society, we will become increasingly dependent on the labor of family caregivers, due to both the number of elders and our intolerance of creating another system to "warehouse" a dependent population. Currently, we receive much of this care at no cost. However, as more families are dependent on two wage earners, this may not continue in the future. If suddenly there were no informal, unpaid caregivers, the needs of the elderly simply could not be met, either now or in the future. Despite the family's expected continuing commitment to care for its own, this is unrealistic in light of the prolonged period of dependency that my result from the increasing life expectancy and the limitations of all forms of family resources.

As Social workers, we must take all measures possible to delay premature dependency and assist families and their elder members in making the best use of time to prepare for the future. When dependency becomes unavoidable, we must support the family to limit the victims of the aging process.
APPENDIX A

February 16, 1996

Dear Caregiver:

My name is Dionne Woods and I am a Masters Degree Candidate in the School of Social Work at Clark Atlanta University in Atlanta, Georgia. As part of my educational program, I am required to complete a research project. I am interested in information from those who care for the African American elderly. Their spouse may provide care, as well as, others. This may include the adult children, grandchildren, nieces, nephews, or friends. I am interested in seeking information about the experience of those who care for the elderly. Please assist me by completing the attached questionnaire. Your participation is completely voluntary.

Please answer each question carefully and as completely as possible. The responses to this questionnaire will be kept completely confidential.

I hope that this research will contribute to further the understanding of the experience of caregivers. This better understanding could give rise to knowledge to help determine the type of assistance needed by caregivers. The results may also give agencies the opportunity to implement program and increase funding for programs that will more effectively assist the informal caregiver of the elderly.

I hope you will be willing to help in this project. I wish to stress that your participation in this survey is strictly voluntary. If you have any questions you may contact me at Clark Atlanta University School of Social Work (404) 880-8555.

Sincerely,

Dionne Woods

I have read and understand the purpose of this research study. I voluntarily agree to participate in this study.

Participant ___________________________ Date ___________________________
QUESTIONNAIRE

1. Please complete the following information to the best of your knowledge. When completing the questionnaire make sure to place an (X) next to your response OR write your response on the given line.

Terms:
Caregiver - The primary person providing assistance to an elderly or ill person
Care recipient - elderly person who receives assistance.

1. What type(s) of illness(if any) is care recipient suffering that requires assistance?(ex. Alzheimer's, Dementia, Kidney Problems, Stroke, etc....)(Please specify)

2. What is their gender?
   ______ 1. Male
   ______ 2. Female

3. What is the current age of the care recipient (elderly)? __

4. What is the number of years (months) you have been providing care for this person?
   ______ 1. 6 months or less
   ______ 2. 6 to 11 months
   ______ 3. 1 to 3 years
   ______ 4. 4 to 6 years
   ______ 5. 6 or more years

5. Do you and the care recipient share a household?
   ______ 1. Yes
   ______ 2. No

6. If no, then do they live independently?
   ______ 1. Yes
   ______ 2. No

7. If no, then with whom do they live?
   ________________________________________
8. What is your relationship to the care recipient?
   
   ____ 1. Spouse
   ____ 2. Daughter
   ____ 3. Son
   ____ 4. Sister
   ____ 5. Brother
   ____ 6. Other (please specify) ________________

9. Estimate the number of hours per day you spend providing assistance to the care recipient.
   
   ____ 1. None
   ____ 2. 1-2
   ____ 3. 3-4
   ____ 4. 5 or more

10. Please place an (X) by ALL of the tasks in which you provide assistance to the care recipient.
    
    _____ Transportation
    _____ Shopping (grocery, other)
    _____ Use the phone
    _____ Money management
    _____ Taking medication
    _____ Eating
    _____ Bathing
    _____ Dressing
    _____ Toileting
    _____ Getting out of bed or chair
    _____ Emotional Support
    _____ Other (Please Specify) ______________________

11. Does the care recipient receive any financial help that would assist with his/her care.

    ____ 1. Yes
    ____ 2. No

12. Do you receive any assistance with your caregiving duties?

    ____ 1. Yes
    ____ 2. No
13. If yes, then what type of assistance do is received? (Mark ALL that apply)
   _____ 1. Informal (non-paid assistance from family or friends)
   _____ 2. Formal (paid assistance from an agency or service organization)
   _____ 3. Non Paid Formal (non-paid assistance from agency of service organization.)

14a. How often is assistance given from outside informal sources (family or friends)?
   _____ 1. Does not receive help
   _____ 2. Occasional
   _____ 3. 1 to 4 hours per week
   _____ 4. 5 to 9 hours per week
   _____ 5. 10 to 15 hours per week
   _____ 6. More than 15 hours per week
   _____ 7. Not applicable

14b. What type of assistance is provided?

15a. How often is assistance received from formal sources (Social Service Agencies, Meals on Wheels, Adult Day Care, Respite Services, Support Groups, etc.)?
   _____ 1. Does not receive help
   _____ 2. Occasional
   _____ 3. 1 to 4 hours per week
   _____ 4. 5 to 9 hours per week
   _____ 5. 10 to 15 hours per week
   _____ 6. More than 15 hours per week
   _____ 7. Not applicable

15b. If these services are received, please list all the services received.

16. What is your current age? _____

17. What is your gender?
   _____ 1. Male
   _____ 2. Female
18. What is your current marital status?
   ______ 1. Married
   ______ 2. Single
   ______ 3. Divorced/ Never Married

19. What is your employment status?
   ______ 1. working
   ______ 2. never worked
   ______ 3. not working to care
           for care recipient

20. As a result of the care provided, have you had to . . .
    (check all that apply)
   ______ 1. reduce the number of hours worked?
   ______ 2. Rearrange work schedule?
   ______ 3. Take time off without pay?
   ______ 4. Leave a job?

21. If you are employed, do you receive support from your place of
    employment? (time off for illness of the care recipient or time
    away for emergencies, etc.)
   ______ 1. Yes
   ______ 2. No

22. Do you have any children?
   ______ 1. Yes
   ______ 2. No

23. If Yes, how many under age 18? ______

24. Overall, rate your physical health at present?
   ______ 1. Excellent
   ______ 2. Good
   ______ 3. Fair
   ______ 4. Poor
II. The next part of this questionnaire surrounds what you may be feeling about the care that you provide. Please answer each question carefully. Remember the care recipient is the person who is receiving the care. Please place the number of the correct response on the line.

0 = Never  
1 = Rarely  
2 = Sometimes  
3 = Quite Frequently  
4 = Nearly Always

______ 1. Do you feel that your relative asks for more help than he/she needs?

______ 2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?

______ 3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

______ 4. Do you feel embarrassed over your relative's behavior?

______ 5. Do you feel angry when you are around your relative?

______ 6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

______ 7. Are you afraid of what the future holds for your relative?

______ 8. Do you feel your relative is dependent upon you?

______ 9. Do you feel strained when you are around your relative?

______ 10. Do you feel your health has suffered because of your involvement with your relative?
11. Do you feel that you don't have as much privacy as you would like because of your relative?

12. Do feel that your social life has suffered because you are caring for your relative?

13. Do you feel uncomfortable about having friends over, because of your relative?

14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?

15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?

16. Do you feel that you will be unable to take care of your relative much longer?

19. Do you feel you have lost control of your life since your relative's illness?

21. Do you wish you could just leave the care of your relative to someone else?

22. Do you feel uncertain about what to do about your relative?

23. Do you feel you should be doing more for your relative?

24. Do you feel you could do a better job in caring for your relative?

25. 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
III. This section of the questionnaire is designed to measure the way you feel about your life and surroundings. It is not a test, so there are no right or wrong answers. Answer each item as carefully and as accurately as you can by placing the number of your response on the line.

1= None of the time  
2= Very Rarely  
3= A little of the time  
4= Some of the time  
5= A good part of the time  
6= Most of the time  
7= All of the time

1. I feel powerless to do anything about my life.  
2. I feel blue.  
3. I think about ending my life.  
4. I have crying spells.  
5. It is easy for me to enjoy myself.  
6. I have a hard time getting started on things that I need to do.  
7. I get very depressed.  
8. I feel there is always someone I can depend on when things get tough.  
9. I feel that the future looks bright for me.  
10. I feel downhearted.  
11. I feel that I am needed.  
12. I feel that I am appreciated by others.  
13. I enjoy being active and busy.  
14. I feel that others would be better off without me.  
15. I enjoy being with other people.  
16. I feel that it is easy for me to make decisions.  
17. I feel downtrodden.  
18. I feel terribly lonely.  
19. I get upset easily.  
20. I feel that nobody really cares about me.  
21. I have a full life.  
22. I feel that people really care about me.  
23. I have a great deal of fun.  
24. I feel great in the morning.  
25. I feel that my situation is hopeless.
BIBLIOGRAPHY


Zarit, Steven H. and Judy M. Zarit, The Memory and Behavior Problems Checklist and The Burden Interview 1990, Pennsylvania State University, Pennsylvania, PA.