AFRICAN AMERICAN GRANDMOTHER CAREGIVERS: RELATIONSHIPS AMONG INFORMATION NEED, PERCEIVED BURDEN, PERCEIVED HEALTH, SERVICE NEED, AND SERVICE USE

by

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DEDICATION

To the grandmother caregivers who participated in this study, I am grateful.

To All of my family. If I can do this, so can you. Nothing I do is for me. But rather, it is for all of you to witness the love and faithfulness of God and what God will do when He is given control of your life.

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ABSTRACT

AFRICAN AMERICAN GRANDMOTHER CAREGIVERS: RELATIONSHIPS AMONG INFORMATION NEED, PERCEIVED BURDEN, PERCEIVED HEALTH, AND SERVICE NEED AND USE

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African American (AA) grandmothers who parent their grandchildren may experience burden related to these responsibilities. Little is known about perceived caregiver burden and its influence on AA grandmother health and service needs. The purpose of this descriptive, correlational research study was to investigate relationships among personal characteristics, information need, perceived burden, perceived health, service need, and service use in AA grandmothers who are the primary caregivers for one or more of their biological grandchildren. Recruited through churches and community centers, 93 AA

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grandmothers, ages 36 to 78, participated in this study. These grandmothers were primary caregivers for 211 grandchildren.

The proposed relationships among the variables were analyzed using hierarchical multiple regression, controlling for demographic characteristics. Grandmother age and number of grandchildren were significantly predicted information need. Likewise, information need uniquely predicted perceived burden, service need, and service use. In addition, perceived burden and perceived health did not significantly predict service need and service use. An unexpected finding was the positive relationship between perceived burden and perceived health.

While this study has provided useful findings about grandparent caregiver issues, more research is needed to capture the essence of AA grandmother caregivers' experiences, to understand AA the impact of caregiving upon grandmother caregivers' health, burden, and their need and use of information and services.

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CHAPTER 1

INTRODUCTION

Grandparents in the United States are increasingly likely to be the primary caregivers for their grandchildren. The 2000 Census reported that 2.4 million grandparents provided care for grandchildren. Of these grandparents, grandmothers (62%) were the largest providers of caregiving. African American grandmothers comprised the greatest percentage of grandmother caregivers (51.7%). Studies have reported that grandparents often assume this role of caregiving without receiving additional financial support, thus causing financial strain (Burton, 1992; Dowdell, 1993; Kelley, Whitley, Sipe, & Yorker, 2000; Minkler, Roe, & Price, 1992). A contributor to this financial strain is the inability of grandparent caregivers to access sufficient resources, which may place grandparents at increased risk for other problems including health alterations and stress. The combination of compounded health alterations and stress in being a grandparent caregiver has led to feelings of burden by some grandparent caregivers (Dowdell, 2004).

Because of the financial problems, physical stress and strain, and additional demands grandparents face in providing care for their grandchildren, services for these grandparents must be accessible and acceptable so that grandparents can care for their grandchildren with minimal impact on their own health. Many grandparents, however,

have failed to use services provided by various public and private entities (Brownell, Berman, Nelson, & Fofana, 2003; Force, Botsford, Pisano, & Holbert, 2000).

Although African American grandmother caregivers often experience the most stress, yet they have the fewest resources (Musil & Ahmad, 2002; Musil, 2005; Ross, 2006). The purpose of this chapter is to describe some dilemmas among African American (AA) grandmothers raising their grandchildren. This introduction presents the background and significance of grandparent caregiving. The framework, purpose, research questions, and essential assumptions for this study are also described.

Background and Significance of the Study

Grandparent caregiving has increased dramatically over the years. At the time of the 2000 United States Census, 5,771,671 grandparents over the age of 30 lived in the same house as their grandchildren. Of these, around 2.5 million (42%) were the primary caregivers for their grandchildren who were less than 18 years (Simmons & Dye, 2003). Among this 2.5 million, 19% were living in poverty. Comparatively, in Tennessee in 2000, 119,968 grandparents over the age of 30 years lived in the same house as their grandchildren. Of these, over 61,000 (51.1%) were the primary caregivers for their grandchildren who were less than 18 years (Simmons & Dye). Among these 61,000 grandparents parenting grandchildren, 20% were living in poverty.

Although the struggles of being a grandparent caregiver are many, grandparents continue to assume the role of primary caregiver for their grandchildren. This caregiver role is assumed because of conditions such as parent incarceration, drug abuse, and grandchild abandonment and abuse (Bullock, 2004; Burton, 1992; Butler & Zakari, 2005; Minkler, Roe, & Price, 1992; Winston, 2003). Many grandparents prefer to be primary

caregivers for their grandchildren, especially when the alternative would be to place their grandchildren in governmental or foster care. Grandparents also report a sense of obligation to care for their grandchildren since their own children failed in the parenting role (Burden, 1992; Bullock, 2004).

Because grandparents often assume care responsibilities for their grandchildren abruptly, substantial problems ensue. These problems include altered health, financial limitations, caregiver stress, role assumption conflicts, damaged family relationships, and limited social and family support (Burton, 1992; Dowdell, 2004; Minkler & Fuller-Thomson, 1999; Minkler, Roe, & Price, 1992; Roe, Minkler, & Barnwell, 1994; Roe, Minkler, & Saunders, 1995; Whitley, Kelley, & Sipe, 2001). Grandparents have reported needing services such as childcare, stress relief, legal counsel, medical services, medical insurance, dental care, grandchild healthcare, and information about how to raise teens (King, Hayslip, & Kaminiski, 2006). Although many of these services are available to grandparent caregivers, they are underused. Grandparents cannot use services if they do not know the services are available. Even when aware of these services, grandparents may not think these services were specific to their concerns and needs. As a result, grandmothers may be unwilling to use available services. Therefore, understanding which services meet grandparent needs is important.

If grandparents knew about services available to them and felt that these services could help them, negative effects of grandparent caregiving such as altered health and caregiver stress could possibly be minimized. Grandparents with positive views of their grandparenting role experience less stress and report better health and well-being (Hayslip, Shore, & Emick, 2006). Providing individualized support for grandparents in

their caregiver role is a way to improve their perception of this role. In order to provide this type of support, information about grandparents' knowledge of services is needed to specifically address issues that are associated with stress development in grandparent caregivers.

Since care responsibilities are often assumed by grandparents without additional financial support (Burton, 1992; Dowdell, 1993; Dowdell, 2004; Kelley, Whitley, Sipe, & Yorker, 2000; Minkler et al., 1992), they face increased financial strain. This financial strain may result from insufficient income and result in the inability to meet family members' needs, including their own health needs. Because assuming the role of grandparent caregiver is stressful, research is needed into ways to decrease this stress and prevent the resulting health problems. Since grandmothers, particularly AA grandmothers are the greatest providers of caregiving for their grandchildren, providing services and information about services to AA grandmother caregivers is, therefore, critical to the psychological and physical health of these women.

Although a significant amount of research has been completed about the effects of grandparenting upon grandparents, knowledge gaps in research focusing on AA grandmother caregivers are many. Studies have shown that role transition from grandparent to parent impacts grandparent health (Bullock, 2004; Roe et al., 1994) and that grandchild concerns have been related to stress in grandparents (Burton, 1992; Gibson, 2004; Linsk & Mason, 2004). Grandparent caregiving is known to adversely affect the health of grandparents and health outcomes are reported worse in AA grandmothers than other grandparent caregivers (Bullock, 2004; Burton, 1992; Ciliandro & Hughes, 1998; Gibson. 2002; Linsk & Mason, 2004; Roe et al., 1994). In addition, AA

grandmother caregivers report increased stress related to the daily duties of being a grandmother caregiver, and that these grandmothers have the most limited services, finances, and family support. There are limited data, however, that explicitly reveal how to prevent the decline in health outcomes or the increase in stress associated with being a grandmother caregiver.

Studies are needed to explore how the use of information and services among AA grandmother caregivers influence their health status and stress levels. Moreover, research is needed to investigate views of the AA grandmother population regarding services that will help them improve their health by assisting them in their role transitions and informing them about how to more effectively deal with the stress of raising grandchildren. Since AA grandmothers report high levels of stress and are most likely to have the least resources, studies are needed to describe AA grandmother caregiver characteristics and better understand the associations between perceived health, perceived burden, and use and need of information and services available to grandparent caregivers. *Framework*

The framework for this study was adapted from the cognitive theory of stress and coping (Lazarus & Folkman, 1984). This theory was chosen over theories of burden and caregiving because they do not include coping as a response to the appraisal of stress.

Lazarus and Folkman's theory of stress and coping postulates stress as resulting from individual appraisals of personal environmental uncertainty or change and the influence of these evaluations upon well-being. Stress is defined as an individual's interactions with his or her environment (Lazarus & Folkman, 1984). This environment includes individual personal characteristics and persons and/or situations that surround the individual. For the

purpose of this study, the AA grandmother caregiver's environment was conceptualized as grandmother characteristics of age, education, income, time as a grandmother caregiver, and the number of grandchildren for whom care was provided.

Stress occurs when the environment demands are greater than the available resources. The way one deals with stress is based on cognitive evaluations. Lazarus and Folkman, (1984; 1988) assert that the cognitive component of stress is the "process of categorizing an encounter, and its various facets, with respect to its significance for wellbeing" (Lazarus & Folkman, 1984, p.31); and such categorizing includes two appraisals, primary and secondary. Primary appraisals consist of making an evaluation of the environment to decide whether this environment is harmful or poses a threat. Secondary appraisals consist of deciding what to do or how to seek out available resources that will assist with issues identified in the primary appraisal. Somewhere in the appraisal process, information is needed to assist individuals with learning to identify what they need and to seek out services that are available to meet those needs. When this knowledge is insufficient, stress ensues because the threat evaluated during the appraisals is higher than the information and resources available, which then places the individual at risk for alterations in well-being. The perception of stress was referred to as perceived burden in this study.

Stress often begins or increases when the AA grandmother caregiver takes on the responsibility of providing care for grandchildren. Many demands accompany assuming care for grandchildren, which together alter these grandmothers' environments. When the responsibilities of being a grandmother caregiver exceed the information and resources available to these women, their perceived burden increases and their health often

deteriorates. Other researchers have labeled caregiver's perceptions of stress to caregiving as perceived burden (Dowdell, 2004; Given et al., 1992). One of these studies included participants who were caregivers of patients with Alzheimer's disease (Given, et al., 1992) and, in the other study; participants were grandmothers who were primary caregivers for their grandchildren (Dowdell, 2004). Participants in both studies reported poor health and increased perceived burden.

The framework used for this study is depicted in Figure 1. This framework includes the concepts of grandmother characteristics, information need, perceived burden, perceived health, service need, and service use.

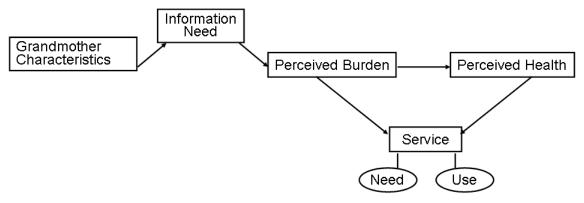


Figure 1. Conceptual Framework

Five propositions were derived from the Lazarus and Folkman (1984) theory and the review of the literature. Grandmother personal characteristics influence information need. Information need directly influences perceived burden. Perceived burden has a relationship with perceived health. Information need indirectly influences perceived health. Service need and service use are influenced by perceived burden and perceived health. These relational statements provided the basis for the research questions.

Purpose of the Study

The purpose of this study was to explore and describe need for information, the influence of information need upon perceived burden, the influence of perceived burden upon perceived health, the influence of perceived burden and perceived health upon service need and service use in AA grandmother caregivers, controlling for grandmother characteristics of age, income, education, time as a caregiver, and number of grandchildren.

Research Questions

The research questions were developed to explore the theorized relationships of the framework

- 1. What is the relationship between AA grandmother demographic characteristics and information need?
- 2. What is the relationship between AA grandmother information need and perceived burden?
- 3. What is the relationship between AA grandmother perceived burden and service need?
- 4. What is the relationship between AA grandmother perceived burden and service use?
- 5. What is the relationship between AA grandmother perceived burden and perceived health (total)?
- 6. What is the relationship between AA grandmother perceived health (total) and service need?
- 7. What is the relationship between AA grandmother perceived health (total) and

service use?

Conceptual and operational definitions.

Grandmother characteristics were defined as age, education, income, time as a grandmother caregiver, and the number of grandchildren. The operational definitions of these characteristics were the participants' responses to the related questions on the Demographic Data Questionnaire.

Perceived burden, synonymous with perceived stress in this study, was conceptualized as caregivers' reactions to caregiving. These reactions are perceptions of the caregiving experience that indicated the degree to which burden is experienced. The instrument for the perceived burden, the Caregiver Reactions Assessment by Givens et al., (1992), has five areas of assessment to determine the level of perceived burden (health, finances, family support, self-esteem, and interrupted schedules). The health items provide information about the impact of caregiving on grandmother health such as worsened overall health and physical strength. Items on finances indicate the degree of financial strain that grandmother caregivers often experience. Family support items represent the caregivers' perception of their family's assistance with providing care for their grandchildren. Self-esteem items assess caregivers' perception of whether the caregiving experience allows grandmothers time to take care of themselves (i.e., attend social activities). Interrupted schedule items assess the degree to which caregiving changes activities for daily living for the grandmothers.

Perceived health consisted of grandmother caregivers' view about their physical and mental health. This health perspective was assessed retrospectively for a four week period. Perceived health was measured using the Short Form-12v2TM Health Survey.

Information need was defined as items such as written or audio-visual literature that enhance knowledge in areas of need as identified by grandmothers and professionals. Information need was quantified by using items adapted from studies investigating grandparents' need and use of information and service (Binette & Cicero, 2003; King et al., 2006). These items were rated on a Likert scale from five (strongly agree) to one (strongly disagree) indicating grandmother level of need for information such as daycare access, child support, counseling, tutoring for grandchildren, legal assistance, and transportation.

Service was defined as opportunities for assistance such as childcare, counseling, and legal advice from personal, public, and private associations. Like information need, service need and service use were assessed by adapting items from studies examining grandparent's need and use of information and service (Binette & Cicero, 2003; King et al., 2006). Items for service need were also rated on a Likert scale from five (strongly agree) to one (strongly disagree) indicating grandmother level of need for some of the aforementioned services. In addition, need of services reflected appraisal of information by grandmother caregivers and was relative to service use. In other words, service need served as a moderator between information appraisal and service use. Service use was measured using the same items as service need. These items, however, were rated on a Likert scale from five (always) to one (never) indicating the frequency in which grandmother caregivers use available services.

Assumptions

Theoretical assumptions for this study were:

1. AA grandmothers experience stress or burden after becoming primary

- providers for their grandchildren.
- 2. The cognitive appraisal of the stress or burden experienced by AA grandmother caregivers may be conscious or unconscious.
- 3. AA grandmother caregivers' appraisal of stress, whether conscious or unconscious, affect perceived burden.

In conclusion, the study was developed to describe the characteristics of AA grandmother's caregiving for grandchildren and their information needs, perceived burden, perceived health, service need, and service use. From the cognitive stress and coping theory of Lazarus and Folkman (1984), a framework was adapted as the underpinning to suggest relationships between concepts in this study. Research questions were posed to explore these concepts and relationships.

CHAPTER 2

REVIEW OF THE LITERATURE

Grandparent caregivers have been studied for over a decade. Research studies have revealed many issues concerning grandparents who provide care for their grandchildren, including role conflicts, altered health, financial problems, social support, and family support (Burton, 1992; Minkler & Fuller-Thomson, 1999; Minkler, Roe, & Price, 1992; Roe, Minkler, & Barnwell, 1994; Roe, Minkler, & Saunders, 1995; Whitley, Kelley, & Sipe, 2001). Conditions such as parent incarceration, abandonment, and drug abuse often force grandparents to accept the role of primary caregiver for their grandchildren to prevent the placement of the grandchildren into governmental or foster care (Bullock, 2004; Burton, 1992; Butler & Zakari, 2005; Minkler, Roe, & Price, 1992; Winston, 2003). Grandparents also feel a sense of obligation to care for their grandchildren because their children failed in the parenting role.

Grandparents frequently assume the care of grandchildren without receiving additional financial support and thus experience financial strain (Burton, 1992; Dowdell, 1993; Kelley, Whitley, Sipe, & Yorker, 2000; Minkler, Roe, & Price, 1992). This financial strain may lead to resources being unavailable, which may place grandparents at increased risk for many problems including health alterations. In addition, many grandparents have failed to use services provided by various public and private entities

(Brownell, Berman, Nelson, & Fofana, 2003; Force, Botsford, Pisano, & Holbert, 2000). Because of the monetary problems, added stress, and social inequalities grandparents face in providing care for their grandchildren, services must be easy to access and satisfactory when used so that grandparents can provide for their grandchildren with minimal impact on their own health.

This study explored and described need for information, the influence of information need upon perceived burden, the influence of perceived burden upon perceived health, the influence of perceived burden and perceived health upon service need and use in AA grandmother caregivers, controlling for demographic factors of age, income, education, time as caregiver, and number of grandchildren.

The purpose of this chapter is to present an integrated literature review of grandparent caregiver studies to examine what is known and not known about grandparents providing care for their grandchildren. This three-section chapter discusses research studies investigating grandparent caregivers. The first section presents the methods for literature retrieval and selection. Sections two and three provide the relevant literature and summary of the literature, respectively.

Methods

To perform an integrated review of the literature of research studies examining grandparent caregivers, the following databases were searched: Academic Search Premier, Pre-CINAL, CINAL, MEDLINE, MasterFile Premier, Health Source: Nursing/Academic Edition, Health Source-Consumer Edition, Psychology and Behavioral Sciences Collection, PsycArticles, PsycINFO, Religion and Philosophy Collection, and Sociological Collection. The internet was also searched using

http://www.google.com and http://www.questia.com to identify other studies not included in the previous sources. Key words used to generate literature were African American (AA), black, caregiver, grandparent, grandmother, grandparent caregivers, qualitative, quantitative, women, marginalized, vulnerable, oppressed, health, service, and service use. Thousands of articles were generated; however, 40 were deemed useful and included in this literature review. The only inclusion criterion was that the research studies investigated grandparent caregivers. Otherwise, there were no limitations to inclusion in this review. The studies in this literature review have been categorized according to the framework for this study (Figure 1). Concepts used to organize this literature review are grandparent characteristics, burden, health, and information and service need, and service use.

Relevant Literature

Grandparent characteristics.

Nurturing, comforting, and even spoiling grandchildren have been traditional roles of grandparents in some cultures. With the evolution of grandparents providing care for grandchildren, however, traditional grandparent roles have been changed somewhat to parent-focused roles that encompass issues such as educating and disciplining grandchildren rather than soothing them. Determining the number of grandmothers who are parenting grandchildren is difficult. Casper and Bryson (1998) reported that, based on the March 1997 Current Population Survey, the majority of grandparents maintaining a home for their grandchildren (3.7 million grandparents) were grandmothers (2.3 million). It is unlikely that all of these grandmothers were the primary caregiver since the data included households in which a parent was present. Of these households maintained by

the grandparent, a grandmother headed 14% with no parent present and 29% with some parents present. This did not include the households in which a grandmother shared the responsibilities with a grandfather. Ages for grandparent caregivers ranged from 30 years to greater than 80 years. Grandparents aged 40-59 years comprised the greatest percentages of those providing care to grandchildren (ages 40-49 years, 29.2%; and ages 50-59 years, 35.1%). Sixty-two percent of the women provided care for their grandchildren, of which, AA grandmothers represented the largest percentage (51.7%).

The reasons for and process of grandparents assuming the caregiver role may contribute to role transition conflicts. Roe et al. (1994) conducted a qualitative study, using face-to-face interviews to obtain data from 71 AA grandmother caregivers who assumed care for a grandchild less than five years of age. These grandparents assumed the caregiver role because their grandchildren's parents were addicted to crack cocaine. The grandparents described three patterns of role assumption (sudden, negotiated, and inevitable). Sudden assumption of caregiving occurred when there was emergency need. For example, one grandparent received a call from the hospital to pick up the grandchild after birth because the parent left the hospital without the child. The second pattern, negotiated assumption of care of grandchildren, was less time urgent; some grandmothers for instance, accepted the caregiving role to permit the parent to undergo substance abuse treatment to become drug free. The third pattern, inevitable assumption of care, was reported when parents' drug habits led to child neglect.

Providing care for grandchildren was viewed as a natural, expected role in one sample of Filipino Americans (Kataoka-Yahiro et al., 2004). In a qualitative research study using grounded theory, the researchers conducted focus group interviews with six

Filipino Americans. These grandparents resided in three-generational homes and thus, provided care for grandchildren for 30 to 80 hours weekly. Themes found in these expected roles were unity (family support for each other), reciprocity (giving back to the family), and respect for elders. In another study, Goodfellow (2003) conducted a qualitative research study using the grounded theory method in a sample of 15 grandparents (demographic characteristics were not disclosed) who provided child care for grandchildren at least 5 hours weekly. Data were gathered during face-to-face interviews. Findings suggested grandparents perceived their role in assisting with childcare to help their children become more financially stable. These grandparents also reported that they provided childcare services for their grandchildren because they wanted their grandchildren to have stable and consistent childcare.

Other themes have been identified as potential influencers of role transitions in grandparent caregivers. In a study to explore experiences in role transition from grandparent to grandparent caregiver among 26 grandparents raising grandchildren, Landry-Meyer and Newman (2004) found three themes related to role theory. The sample was comprised of White (65%), AA (31%), and Asian (4%) grandparents. One theme, role timing, was the unanticipated disruption in plans for this time in life such as interruption of retirement. Another theme, role ambiguity, was experienced as being stressful, and grandparents stated they looked to the legal system to solidify their roles with grandchildren through custody. Custody provided delineation of grandparent parental rights and boundaries. The third theme, role conflict, occurred because the grandparent wanted to be a grandparent and instead was in the role of being the parent.

Similar to the findings of the study conducted by Landry-Meyer and Newman (2004), Ciliandro and Hughes (1998) found four role themes among a sample of ten grandmothers providing care for grandchildren affected with HIV (Latino, *n*=4; AA, *n*=6). Data were gathered using the phenomenology method and unstructured interviews to obtain the life experiences of the grandmothers as caregivers. A major theme was identified as the priority of and maintenance of the family. These grandmothers viewed themselves as continuing to be a grandmother instead of a mother when assuming parental role. Another theme was feelings of being strong and mature. The grandmothers described being strong and mature as making difficult decisions for grandchildren. Evidence of this strength included grandmothers desiring to speak out against HIV/AIDS.

A third theme, coping with a restricted environment, involved having very limited living space shared with more people and decreased contact with friends. The fourth theme was living for today and having a normal life. Having a normal life included the grandchildren maintaining school attendance and running and playing like other children. Grandmothers spoke of maintaining normalcy as a coping mechanism for dealing with the child's inevitable death. These grandmothers, for example, reported holding in their emotions and experiencing fatigue. The themes of maintaining the family, being strong and mature, coping with the environment, and having a normal life were possible ways that these grandmother caregivers emotionally dealt with being responsible for their grandchildren.

In another study of grandparents affected by AIDS, Winston (2003) sought to understand grandparents' grieving process when they were raising grandchildren whose parents died from AIDS (n = 10). These grandmothers stated they were glad to raise their

grandchildren. They voiced satisfaction that they were able to prevent their grandchildren from being placed in foster homes. Although loss and grief were discussed, coping mechanisms for loss and grief were the themes of the reported results. Among the five themes was family support. These grandmothers saw parenting their grandchild as supporting the family. Another theme was spirituality. Grandparents attributed strength in coping with the death of a child and providing care for grandchildren to the grandparents' relationship with God. A third theme, holding on to memories of a deceased child, was a way to continue bonds. One grandmother stated that each year around the anniversary of her child's death she prepared favorite foods of the deceased child and the grandchild (Winston, 2003). These grandparents saw their roles in caring for their grandchildren as consistent, stable provision of whatever the grandchild needed in ambiguous situations.

In studies of the effects of assuming the caregiving for grandchildren upon grandparent roles and transitioning into the role of grandparent caregiver, various research methods were used (Bullock, 2004; Goodfellow, 2003; Kataoka-Yahiro et al., 2004; Landry-Meyer & Newman, 2004; Roe et al., 1994; Winston, 2003). Three of these studies used participant audiotaped interviews as a qualitative data collection method (Landry-Meyer & Newman, 2004; Roe et al., 1994; Winston, 2003). In contrast, Goodfellow (2003) used a narrative inquiry approach where information was gathered through grandparent/grandchild playgroups, and Kataoka-Yahiro et al. (2004) used a focus group interview. Both quantitative (a mailed survey that elicited information about grandparent health, finances, and well-being) and qualitative methods (face-to-face interviews) were used by Bullock (2004). While two studies performed interviews at two time periods (Roe et al. 1994; Winston, 2003), only one of them specified that the second

interview was to validate analyses of the first interview's transcription (Winston, 2003). Primary ethnicity of participants varied. AA grandmothers were the primary participants in three of these studies (Bullock, 2004; Roe et al. 1994; Winston, 2003), while Caucasian grandmothers were studied by Landry-Meyer & Newman (2004), and Filipino American grandmothers were studied by Kataoka-Yahiro et al. (2004).

Burden.

Stress is a concept that has been quantified as burden (Dowdell, 2004; Given et al., 1992) and has been found to be associated with physical and mental health alterations, financial worries, and social problems in caregiver populations (Burton, 1992; Butler & Zakari, 2005; Musil, 1998; Musil & Standing, 2005). Seven studies examined the stressors of being a grandparent caregiver (Burton, 1992; Butler & Zakari, 2005; Dowdell, 2004; Gibson, 2002b; Linsk, & Mason, 2004; Morrow-Kondos, Weber, Cooper, & Hesser, 1997; Williamson, Softas-Nall, & Miller, 2003). These grandparent stressors resulted when parenting grandchildren added responsibility to a grandparent's daily activities, thus creating busy, stressful life styles. Data collection methods in one study consisted of community ethnography, focus groups, and interviews (Burton, 1992), while the other studies in this section used questionnaires and tape-recorded interviews (Butler & Zakari, 2005; Gibson, 2002b; Linsk, & Mason, 2004; Morrow-Kondos et al., 1997; Williamson et al., 2003) and face-to-face interviews (Dowdell, 2004).

Stressors in grandmother caregivers have been described as occurring in three categories: contextual, family, and individual issues (Burton, 1992; Morrow-Kondos et al., 1997). First, contextual issues were housing and neighborhood problems such as grandparent-grandchild housing, drug abuse, and crime infested environments. Burton

(1992) found, among 60 AA grandparent caregivers (grandmothers, *n*=39; great-grandmothers, *n*=11; grandfathers, *n*=10) ages 43 years to 82 years, that raising grandchildren caused stressors such as cramped living environments, financial limitations, and social isolation. For example, these grandparents remained in the same housing environment after assuming care of their grandchild.

Family issues, the second category, included grandparents' responsibility to care for spouses or other kin in addition to keeping up with children's activities, e.g., assisting grandchildren with homework. One study reported that grandparents felt strained in relationships with their adult children (Burton, 1992) and stressed by legal problems and the transition to parent role (Morrow-Kondos et al., 1997). Some strain and stress was due to the grandparents' feelings of guilt. They blamed themselves for their adult children's behaviors. For example, one grandparent experienced difficulty in accepting that her child was not a good parent, and another grandparent experienced relationship conflicts with her adult child.

Family issues were also indicated in two other studies that found grandparent stressors related to grandchild concerns (Gibson, 2002b; Linsk & Mason, 2004). Linsk and Mason (2004) conducted a qualitative, exploratory study using interviews to elicit day-to-day experiences from 28 grandparent caregivers. Women comprised 96.4% of the sample; 86% of the women were AA. Most (n=17) of the grandparents had grandchildren affected with HIV. Grandchild concerns were the primary family stressors among this group of grandparents. One group of grandchild stressors was due to emotional and behavioral problems of the grandchildren such as threats of suicide, sexual abuse, lying, stealing, disobedience, and overeating. Other grandchild stressors involved problems with

adolescent independence and school performance such as poor grades. Exacerbations of the grandchild's illness and medical care posed unique stressors in this sample of grandparents. The last type of family stress was caregiver specific. One grandparent needed surgery but was worried about who would care for the grandchild while she was in hospital (Linsk & Mason, 2004).

Like Linsk & Mason (2004), Gibson (2002b) identified family stressors related to grandchild concerns among 12 AA grandmothers providing care for their grandchildren. This grounded theory, exploratory/descriptive study revealed three emerging themes including "new awareness of problems, adjustments to behaviors, and concerns about conditions" (¶ 17). Each theme builds on the previous theme. New awareness of problems consisted of grandmothers becoming aware of grandchild problems such as low self-esteem, developmental delays, and hyperactivity. These grandmothers were unprepared to intervene in these problems because their own children had not experienced such problems as young children. This new awareness gave these grandmothers insight to their lack in skills to guide their grandchildren appropriately during problem situations. However, as an adjustment to their grandchildren's problems and their lack of knowledge related to these problems, grandmothers learned about their grandchildren's problems and thus learned to deal with them. Once grandmothers became aware of their grandchildren's problems, they became concerned about their grandchildren's conditions and well-being as they acknowledged grandchildren's problems.

The third category, individual issues, consisted of sacrifices grandparents made in their personal lives. Some grandparents took time away from their jobs to care for grandchildren, and others reported self-neglect which led to health problems. Personal sacrifices may lead to grandparent caregiver emotional stress. Williamson et al. (2004) found emotional stressors among a sample of seven grandmothers (Caucasian, *n*=4; Hispanic, *n*=3) in a qualitative study that sought to understand grandmother caregivers' experiences and emotions. These findings suggest individuals (e.g., grandchildren's parents, grandchildren, and the grandmothers' spouses) and circumstances (e.g., grandchild issues with school and disciplining, adult child interference, and money problems) influenced grandmothers' emotional stress. Grandparents stated they felt hopeless about their money problems and disciplining grandchildren. Grandparents also said they felt overwhelmed with trying to maintain a home for grandchildren.

Stress has been associated with grandparent perception of poor health (Butler & Zakari, 2005; Dowdell, 2004). In a research study using mixed methods with 17 grandmothers (AA, *n*=15; White, *n*=2), data were collected to describe the health and levels of stress in grandmother caregivers (Butler & Zakari, 2005). Health, demographic, and stress data were obtained through the Functional Assessment Inventory (FAI) and the Parental Strain Index (PSI). Qualitative data were gathered through an audiotaped face-to-face interview. This interview consisted of 15 questions that ascertained information about grandparent role assumption, quality of life, family relationships, and access to services.

While only one grandmother reported being severely impaired mentally, 50% indicated some level of anxiety (Butler & Zakari, 2005). The PSI scores, a measurement of perceived stress, were increased in 47% of these grandmothers. Sources of stress reported by these grandmothers were childrening conflicts with the grandchildren's

parents, not having time to spend with spouses or other family members, mistreatment from parent teacher organization members, and finances. These grandmothers (18%) reported chronic disease exacerbations such as hypertension, arthritis, and diabetes. In addition, 35% of these grandmothers reported worse health than before they assumed the grandmother caregiver role.

A descriptive correlational study was conducted among 104 grandmothers (AA, 58%; Caucasian, 38%) to examine grandmother perceived physical health and caregiver burden or stress (Dowdell, 2004). A mixed method approach was used to collect qualitative data using face-to-face interviews to explore physical health, and the Caregiver Reaction Assessment tool was used to quantitatively measure caregiver burden (Dowdell, 2004). During the interviews, grandparents reported worsened health problems. Furthermore, these grandparents stated that they placed their grandchild's' well-being before their own, and as a result, neglected their own health needs.

The Caregiver Reactions Assessment (CRA) was used to measure grandmother health and burden. Some reported burdens or stressors (Dowdell, 2004) were sick grandchild doctor visits and grandchildren school problems. These grandmothers had a higher response to perceived poorer health. Increased stress levels, therefore, are associated with poorer health perceptions in grandmother caregivers.

Health.

Physical and mental health alterations have been found to be associated with providing care for grandchildren (Bullock, 2004; Burton, 1992; Ciliandro & Hughes, 1998; Dowdell, 2004; Gibson, 2002b; Kataoka-Yahiro et al., 2004; Linsk & Mason, 2004; Roe et al., 1997).

Several studies examined grandparent self-reported health problems (Kelley, Yorker, Whitley, & Sipe, 2001; Minkler & Fuller-Thompson, 1999; Musil & Ahmud 2002; Roe et al., 1996). Studies revealed caregiving grandparents reported more ill health than grandparents who do not provide care for their grandchildren (Musil & Ahmud 2002; Solomon & Marx, 1999). Research also revealed that some grandparents neglected their own health while attending to the needs of their grandchildren (Dowdell, 2004; Haglund, 2000; Minkler et al. 1992; & Poe, 1992). Additionally, exacerbation of chronic illness while caring for grandchildren has been reported (Burton 1992; Butler & Zakari, 2005; Haglund 2000; Strawbridge et al., 1997; & Roe et al., 1996). For example, one grandmother delayed hip surgery because she did not have anyone to care for her grandchildren while she was in the hospital (Haglund, 2000). In these studies, participants were primarily AA grandmothers who indicated some level of stress from parenting grandchildren.

Although research outcomes revealed altered physical health, other studies have yielded no change in health status (Ehrle & Day, 1994; Musil, 1998). In one study, grandparents reported feeling a sense of joy and fulfillment along with increased physical activity since assuming the role of grandparent caregiver (Ehrle & Day, 1994). This study, however, was conducted among a group of 15 Caucasian grandmothers. Overall, researchers have demonstrated that providing care to grandchildren has a negative effect on grandparent health.

While grandparenting research has revealed associations of providing care for grandchildren to health problems, only a few studies investigated and/or reported specific diseases in grandparents as a primary focus (Kelley et al., 2000; Lee et al., 2003; Minkler

et al. 1997; Musil, 2000; Whitley et al., 2001). These studies revealed grandparent health problems such as mental, coronary artery disease, hypertension, chronic pain in back and joints (Kelley et al., 2000; Lee et al., 2003; Minkler et al. 1997; Musil, 2000; Whitley et al., 2001). All of these studies used quantitative research methods. A prospective study investigated the incidence of coronary heart disease (CHD) in women ages 46-71 years who provided care to children and grandchildren. Findings suggested that there was an increased incidence of CHD in grandmother caregivers who provided care for grandchildren at least nine hours weekly (Lee et al., 2003).

Health issues and stress have been associated with depression in grandparent caregivers. Seventy-four grandmother caregivers ages 39-72 years (AA, *n*=54; White, *n*=20) completed the Self-Assessed Health, Center for Epidemiological Studies-Depression (CES-D), and Parenting Stress Index (PSI) short form scales to measure physical and mental health and stress (Musil, 2000). An association was found between depression scores and increased parenting stress. In addition, less stress was associated with better self-reported health. In a study among AA grandmothers ages 38-78 years, measures completed were the Brief Symptom Interview (assesses mental health subjective symptomology), Family Resource, Family Support, and Short Form-36 (SF-36) General Health Survey (Kelley et al., 2001). Grandmothers with better support systems rated their health better and reported less psychological distress. Younger grandmother caregivers, however, reported more anxiety.

In a study of 100 AA grandmother caregivers, health was measured using the SF-36 and the Healthier People Health Risk Appraisal (Whitley et al., 2001). Blood pressure, weight, cholesterol, and blood glucose levels were taken by registered nurses. Health

problems that these participants had were high blood pressure (54%), weight greater than 20% over ideal body weight (80%), high cholesterol levels (22%), and diabetes (23%). These health problem statistics indicated that grandmother caregivers had health problems that may have been detrimental to individual quality of life and, therefore, should be addressed.

Common threads in these studies were the findings of health problems and their associations with the stress of caregiving. Possible solutions to grandmother health problems and increased stress after becoming a grandmother caregiver are to provide these grandmothers with information such as neighborhood safety tips and drug prevention strategies as well as services such as childcare and tutoring for grandchildren. Since grandmothers have identified these information and service areas of need, accommodating these identified needs may prove helpful in improving their health and decreasing their perceived burden.

Information need and information use.

Studies to foster community participation among grandparent caregivers have attempted to empower them to increase self-care and self-efficacy in their caregiving role, to enhance caregiver coping skills, and to assess knowledge, sense of control, decision-making, and provision of care (Brown, Jemmott, Outlaw, Wilson, Howard, & Curtis, 2000; Cox, 2002). During the first phase of a 3-phased qualitative study of 35 AA grandmother caregivers ages 44 to 83 years, grandparent concerns were identified (Brown et al., 2000). These concerns included grandchild sexual behavior, drug abuse, and violence, as well as disagreements with their adult children's behaviors. The second phase of the study was a 4-day intervention to provide education related to the identified

concerns. For instance, grandmothers wanted safety information to prevent grandchildren from becoming victims or perpetrators of violence, so these grandmothers were provided violence education. This education empowered these grandmothers with knowledge and skills, which built their confidence in their ability to decrease grandchildren risk.

Like Brown et al. (2000), Cox (2002) conducted an intervention study to empower a group of AA grandmother caregivers (*n*=14). Ages of these caregivers were 50 to 75 years. The intervention consisted of 12 education classes with a curriculum designed by study participants and researchers. Classes offered information grandparents needed to assist them with parenting their grandchildren. The grandmothers reported enhanced self-advocacy and coping skills that led to the grandmothers becoming active as community advocates. Both Brown et al. (2000) and Cox (2002) used education to enhance their study participants' empowerment.

Some information about grandparent caregiver information and service needs has been provided by the American Association of Retired Persons (AARP). This organization conducted a cross-sectional quantitative study among its Tennessee (TN) members to explore grandparent perceptions about healthcare for their grandchildren, access to childcare, and information and resource types preferred by grandparent caregivers (2003). Surveys were mailed to active AARP members to assess grandparent health, health maintenance, and preferred methods of receiving information. Participants were 89% White and 8% Black, with 50% being female and 47% male. The grandparents wanted information about grandchild healthcare and insurance coverage (49%), financial services (48%), legal issues (47%), talking with grandchildren (42%), and affordable childcare and community activities (41%). Preferred methods of receiving information

included newsletters (30%), magazines (29%), books (17%), workshops (15%), email (11%), and the World Wide Web (11%). In addition, many grandparents reported they did not know what services were available. The AARP suggested that some grandparents did not know about services because of a lack of coordination in regional and state service programs.

These findings are important to the whole population of grandparent caregivers.

AARP grandparent participant characteristics, however, are likely to be different in ethnicity, education, and income from grandparents in Memphis who seek assistance.

Therefore, application of findings from the Tennessee AARP study to AA grandmother caregiver populations in Memphis may not be appropriate. Furthermore, the US Census Bureau (2003) reported that among the 62% of grandmothers who provided care to their grandchildren, AA grandmother caregivers comprised the greatest percentage (51.7%). In addition, AA grandmother caregivers received 90% of relative caregiver assistance provided by a program in Memphis (P. Beckly, personal communication, September 13, 2006).

Service need and service use.

Frequently grandparent caregivers must seek help for themselves and their grandchildren because of problems encountered during the grandparent-grandchild relationship. This help may be found through private and public service providers and family and friends. Many research studies have examined grandparent and grandchild needs and use of services (Brownell et al., 2003; Burnette, 1999; Force et al., 2000; Gibson, 2002a; Janicki, McCallion, Grant-Griffin, & Kolomer, 2000; McCallion, Janicki, Grant-Griffin, & Kolomer, 2000).

One study sought to determine grandparents' use of formal (governmental agencies) and informal (family and friends) services (Janicki et al., 2000). Participants were 164 grandparent caregivers ages 40 to 82 years. Although females (96%) and AA (80%) were the primary participants, some males and other ethnic groups (European, Hispanic, Native American, and other) participated. These grandparents completed surveys about their use of services such as respite, day programs, and transportation. Grandparents reported "difficulty accessing services because of ambiguous guardianship and legal situations" (p. 50). In addition, service appointments were viewed by these grandparents as time-consuming with unnecessary red tape. Some grandparents also felt that they were not free to disclose true depictions of their grandparenting experiences because service providers would seek ways to remove their grandchildren from the homes.

While Janicki et al. (2000) examined only the grandparents' perspectives about services, McCallion et al. (2000) explored service representative perspectives regarding grandparents' use of services and the problems these representatives encountered while providing services for grandparent clients. These clients included 120 grandparent caregivers ages 42 to 80 years who provided care for a child who was developmentally delayed or disabled. While females (94%) and AA (79%) were the primary participants, males (6%) and other ethnic groups such as European (6%), Hispanic (12%), and Native American (2%) also participated.

Workers from three service agencies were trained to provide grandparent clients with services specific to their needs (McCallion et al., 2000). For instance, some topics covered in the training included "Grandparent Carer Issues" and "Kinship Foster Care-

Issues and Services." This training prepared service workers for facilitating support groups and case management specifically for grandparent caregivers. Trained agency workers administered surveys to grandparent participants during support group meetings. Grandparents were skeptical about services offered by the agencies and feared that these agencies were helping them because they ultimately desired to take the child out of the grandparents' homes. This type of thinking by grandparents, therefore, may lead to their failure to use services provided. Agency workers also reported that some grandparents fell "through the cracks" because grandparents did not fit into the traditional family model, which was the basis for the development of eligibility criteria for these services. For example, one grandparent caregiver was denied service because she waited too long after she assumed care of her grandchild to seek assistance.

A sample of 74 Latino grandparent caregivers 50-78 years old and primarily female (93.2%) participated in another study to explore their use of services and identify their unmet needs (Burnette, 1999). While these grandparent caregivers used available services, they continued to have unmet needs, including information about available services, respite, parent and grandparent education, children's camps and enrichment services, and rehabilitation for their adult children. Participants reported the primary reason for their unmet needs was that they were unaware of such services being offered.

In a study to understand grandmother perceptions of service systems and their representatives, Gibson (2002a) held "in-depth interviews" with 12 grandmother caregivers ages 42 to 71 (AA, n=10; White, n=2). Many of these grandmothers received services from governmental agencies (n=8), while more than 50% provided care for their grandchildren informally (without legal arrangements). Findings suggested three

categories for these grandmothers' experiences: service access barriers, discoveries about services systems, and shared thoughts with grandmother caregiver peers about service experiences. Reported barriers were grandmothers feeling shame because they needed help and fear that service representatives might think that they were inadequate in the ability to care for their grandchild and, therefore, seek to remove the grandchild from the grandmother's home.

In addition, these grandmothers felt that service agency representatives displayed unfavorable attitudes toward them (Gibson, 2002a). Through experience, these grandmothers discovered how these systems worked and gained insight about how their approach in seeking help from service agencies influenced the process. Grandmothers reported that education about the service systems and perseverance was helpful when seeking help from the agencies. Lastly, grandmothers shared with peers how to influence these systems to get maximum results during interactions with service representatives. For instance, grandmothers instructed those seeking assistance to maintain eye contact and speak with confidence and knowledge of the services being sought.

In a study with a different focus for grandparent services, Brownell et al. (2003) investigated the occurrence of grandparent abuse by grandchildren, available services for these grandparents, and unavailable services that might help these grandparents.

Participants consisted of six groups. Two groups were comprised of AA and African-Caribbean, one group of Hispanic grandparent caregivers 61 to 80 years of age, and three groups of child welfare service workers. Each group consisted of up to 12 members who completed audiotaped focus group interviews facilitated by the service workers. Reported abuse included verbal, financial, and physical such as cursing, taking money, and hitting

grandparents. Services deemed useful to these grandparents were counseling, church, support groups, family, friends, and police. Like participants in Burnette's (1999) study, these grandparents reported service needs such as respite for grandparents and camps for the grandchildren. In addition, public recognition was reported as a service that would motivate and encourage grandparents.

Since 2001, a program, in Memphis, Tennessee, has assisted 827 relatives who provide care to children in their extended families with various caregiver needs (P. Beckly, personal communication, September 13, 2006). Ages of these caregivers ranged from 25 years to 82 years. Most caregivers who received help were grandparents (67%); of these, 90% were AA grandmothers. Services offered to these grandparent caregivers were childcare, recreation (a group of the grandchildren attended a movie chaperoned by adults and a group of grandparents were taken fishing), and transportation to planned events such as educational workshops. While some grandparent caregivers in Memphis received help, many did not.

Summary of the Literature

In conclusion, although many researchers have conducted studies and disseminated findings about the effects of grandparenting upon grandparents, significant knowledge gaps in research among AA grandparent caregivers still exist. We know that grandparenting adversely affects the health of grandparents and that AA grandmothers report worse health outcomes. Studies have shown that role transition from grandparent to parent impacts grandparent health (Kataoka-Yahiro et al. 2004; Roe et al. 1997) and that grandchild concerns have been related to stress among grandparents (Burton, 1992; Gibson, 2004; Linsk & Mason, 2004). We do not know, however, how to improve such

health outcomes. Investigations are needed to improve or significantly decrease the impact of providing care for grandchildren upon the health of AA grandmother caregivers.

Studies are also needed to explore AA grandmother caregiver perceptions of what will help them in their role transitions and how to deal more effectively with the stressors of raising grandchildren. Grandparents have indicated that the provision of respite services for them and their grandchildren such as overnighters and camps might help them to cope with being grandparents. Additional research is needed to examine the impact of grandparent caregiving upon families, specifically looking at how these families function as a group. Studies are also needed to examine AA grandmother caregiving families as a unit and to explore this population's perceptions of how family functioning (roles) influences their lives and to identify skills that may help meet their needs. Furthermore, studies are needed to identify and test remediation strategies among the grandparent caregiver population. More research studies using qualitative methods are needed to understand how individuals and groups (families) internalize their grandparent caregiver experiences and to describe the day-to day life of a grandparent caregiver.

A subgroup about which even less is known is younger grandparent caregivers, especially AA. Investigations of AA grandparents' use of existing services and the efficacy of these services in AA grandmothers ages 35 to 50 years are needed. This research may assist in understanding associations between perceived burden (stress), perceived health, and information and service need and use in AA grandmothers. Finally, further exploration of service need and use may assist with understanding how this need

and use may be influenced by AA grandmother caregivers' perceived health and perceived burden. This study addressed this latter gap in knowledge. AA grandmother caregivers participated by providing data pertaining to their characteristics, perceived burden, perceived health, information need, and service need and use.

CHAPTER 3

METHODS AND PROCEDURES

The number of grandparents serving as primary caregivers for their grandchildren has been on the rise for over a decade. Grandparents become providers for their grandchildren without additional monies, a circumstance which often leads to financial tension (Burton, 1992; Dowdell, 1993; Kelley, Whitley, Sipe, & Yorker, 2000; Minkler, Roe, & Price, 1992). As a result, grandparent caregivers experience inability to access sufficient resources, which may be associated with problems including health alterations. The purpose of this chapter is to present the methods and procedures used to describe the relationships between AA grandmother information need, perceived burden, perceived health, and service need and use. This eight-section chapter discusses the research design and sample selection in sections one and two. Presented in section three is the research setting. Sections four and five provide the measurement methods and procedures.

Discussed in section six are the human subject's protection and ethical considerations.

Sections seven and eight describe the data analyses and delimitations.

Research Design

This study had a descriptive, correlational research design. The study examined the relationships between AA grandmother caregiver demographics, information need, perceived burden, perceived health, service need, and service use. Strengths of this

correlational design were the ability to examine many variables and the opportunity to explore relationships among the variables of grandmother characteristics, information need, perceived burden, perceived health, service need, and service use. Another strength of this study was its ability to provide information about the degree to which relationships between variables exist. A weakness of this design was that the cause and effect nature of relationships cannot be ascertained.

Sample

The sampling method was a non-random selection of women who considered themselves AA and grandmothers. Initially, recruitment to the study consisted of church bulletin announcements and flyers. Announcements were placed in the church bulletins for three consecutive weeks prior to the data collection date. Flyers were also placed in areas designated by church leaders during this time. Additional AA grandmother caregivers were recruited through a religious affiliated outreach center and recreational community centers. Similarly, announcements and flyers with meeting dates and times were placed in designated areas of the centers. All AA grandmother caregivers who came to the meetings, met the inclusion criteria, and agreed to complete the surveys were included in the study.

Inclusion criteria for grandmother participants in this study were: (a) women who considered themselves AA and grandmothers, (b) AA grandmothers who had custody or were the primary caregiver for one or more of their biological grandchildren ages 18 years or less, (c) AA grandmother caregivers who lived with their biological grandchildren, and (d) AA grandmothers who resided in Memphis, Tennessee.

Grandmothers who did not meet the inclusion criteria were excluded from this study.

Those who volunteered but did not meet inclusion criteria were thanked for their willingness to participate. AA grandmothers who agreed to participate were provided an information sheet (Appendix A), which described the study and provided principal investigator and Institutional Review Board (IRB) contact numbers.

Prior to data collection, sample size was calculated by using an effect size, which is an indication of the strength of the relationships between variables. The effect size may also provide information about a research study's statistical significance, which was set at .05 for this study. A medium effect size was chosen to estimate the sample size. According to Cohen (1988) using a medium effect (d = .50) with a significance level of .05 and an estimated sample size of 100 would yield a 97% rate of correctly rejecting the null hypothesis. A sample size of 100 was identified as being appropriate to yield significant relationships between variables. Preliminary analyses with 75 participants revealed significant relationships between variables. Data collection, therefore, was closed after completing previously scheduled sessions, which totaled 93 participants. *Setting*

Participants were recruited from predominately AA churches, daycare centers, community centers, and neighborhood outreach centers in a large metropolitan southern city. Although numerous recruitment attempts for grandmother caregiver participants were made to AA churches, day care centers, recreational community centers, Memphis City Schools, and neighborhood outreach centers, many chose not to participate or recruitment efforts did not produce participants. Sites in which participants completed research surveys included nine churches and one neighborhood outreach center. These particular affiliations were sought to recruit participants because they were crucial social

organizations located in communities with large percentages of grandparent caregiver residents, based on the Census 2000 tracts within Memphis. Permission to conduct data collection at selected sites was granted (Appendix B). Announcements and invitations to participate in this study were placed in church bulletins (Appendix C) and recruitment flyers were posted in each site (Appendix D).

Measurement Methods

Data collection consisted of all participants completing surveys about grandmother information need, perceived burden, perceived health, and service need and use. Surveys were completed at the sites during times announced in the church bulletins and flyers. Participants completed surveys by self-administration. The primary investigator (PI) remained present while the participants completed the surveys to answer participant questions or concerns.

Prior to the participants completing the surveys, the PI described the study and asked participants to read the information sheet stating the research purposes, data collection procedure, benefits and risks to participation in the study. The PI allowed time for reading of the information sheet and questions from the participants. A telephone number was provided for participants if they may have wanted to call to ask questions or voice complaints. Participants were informed that completing the survey was considered consent for taking part in this study. Time was allowed for participant questions and answer responses by the PI, again before beginning survey completions. Some participants informed the PI that they could not "see" the surveys. The PI read surveys to these participants and assisted them with marking their responses. Each participant completed the Caregiver Reaction Assessment (CRA [Appendix E]), The Short Form-

12v2[™] (SF-12v2[™]) Health Survey (Appendix F), and a Demographic Data Form (DDF [Appendix G]).

Caregiver reaction assessment.

The CRA measured the reactions of family caregivers (Given et al., 1992). The CRA was developed and validated over a series of three studies to measure physical and mental reactions to caregiving. The original study was conducted with 377 family caregivers of patients with Alzheimer's disease. The second study confirmed the original study by adding family caregivers of patients with cancer. The third study was a longitudinal comparison with a subset of 185 caregivers from the original study and the caregivers in the second study. The CRA evolved from continued refinement and a factor analysis, which resulted in the final 24 items with five sub-scales. These 24 items assesses aspects of the caregiver's life that are synonymous with burden.

There are sub-scales that measures five domains of caregiver reactions. The first domain, health, has four items and measured the impact of caregiving on grandmother health. This domain assessed alterations in health status including physical problems. Questions in this domain include whether grandmother was more tired or had worse health since caring for their grandchildren. Finances, the second domain, have three items that measure the financial strain that caregivers experienced. Questions in the finance domain consist of grandmother perspectives on whether their finances were adequate and if they experienced financial strain. The family support subscale with five items measures the caregivers' perception of their family's help in providing care for the grandchild. Questions in the family support domain included whether grandmothers easily received help from their families and whether they felt abandoned by their families. Domain four,

self-esteem (7-items), measures caregivers' perception of how the caregiving experience impacts their lives. This domain assesses how grandmother caregivers felt about being primary caregivers for their grandchildren. The fifth domain, interrupted schedule (5-items), measures the degree to which caregiving interrupts daily living. Questions in this domain include whether grandmother activities are centered around the care of the grandchildren and whether grandmothers visit their friends and family to the same degree as before assuming the role of caregiver. Participants respond to the five subscales of caregiver reactions on a 5-point Likert scale, rating the 24 items from strongly disagree to strongly agree with five items (3, 7, 13, 15, and 19) being reversed scored.

Scoring of items consisted of simply adding respondent selections after the reversed scored items were coded. To compare subscales of different lengths, item scores for each subscale were totaled and divided by the number if items in each subscale to determine the item mean for the subscale. Higher scores reflect higher perceived burden. Alpha coefficients in previous studies have ranged from .81 to .90 for all measured components demonstrating internal consistency. Although developed for family caregivers of individuals with Alzheimer's disease or cancer, the CRA has been used in studies with grandparent caregivers (Dowdell, 2004; Dowdell 1993). The expectted length of time to complete this survey was 15 to 30 minutes.

The Short Form-12v2TM health survey.

The SF-12v2TM (Ware, Kosinski, & Keller, 1995; Ware, Kosinski, & Keller, 1996; Ware, Kosinski, & Keller, 2002) is a health survey, developed from the original SF-36. The SF-12v2TM produces two summary measures of self-perceived health, physical and mental component summaries, which are equivalent with those component

summaries of the SF-36. The subset of items in the SF-12v2TM was determined over time, and studies have shown that the alpha coefficients of the SF-36 and the SF-12v2TM are consistent across data sets (Ware et al., 1995; Ware et al., 1996; Ware, Kosinski, Turner-Bowker, & Gandek, 2002). The SF-12v2TM has 12 items grouped into eight categories (Table 1). Four of the categories have one item and the other four categories contain two items. Ten items are scored on a 5-point Likert-type scale, and two items are scored on a 3-point Likert-type scale (higher total scores suggest better health status). Scores were calculated in three steps using the scoring manual for the SF-12v2TM (Ware et al., 2002). Step one included recoding items for general health (item 1), bodily pain (item 5), mental health (item 6a), and vitality (item 6b). These four items were recoded to be consistent

Table 1 SF-12v2TM Categories

Variable	Instrument	Score
Perceived Health (Total)	SF12	Sum of items 1, 2a, 2b, 3a, 3b, & 5
General Health	SF12	Item 1
Physical Functioning	SF12	Sum of items 2a & 2b
Role Physical	SF12	Sum of items 3a & 3b
Bodily Pain	SF12	Item 5
Physical Health (Total)	SF12	Sum of items 4a, 4b, 6a, 6b, 6c, & 7
Social Functioning	SF12	Item 7
Role Emotional	SF12	Sum of items 4a & 4b
Vitality	SF12	Item 6b
Mental Health	SF12	Sum of items 6a & 6c

with the rest of the scale. In their original state, higher scores indicate poorer perceived health, which is the reverse interpretation of the final transformed scores. Items in the same subscales were added to compute raw scale scores in the second step. Finally, raw scale scores were transformed to a 100 point scale to represent total perceived health scores, which ranged from 0 to 100. Higher transformed scores represented better perceived health.

The physical health components include four health attributes a) physical functioning (i.e., mobility and ability to perform activities of daily living); b) bodily pain (whether individuals experience pain and to what degree this pain interferes in the routines of their lives); c) role limitations resulting from physical health problems (i.e., does physical health limit ability to complete role tasks?); and d) general health perceptions (i.e., disease exacerbations or worsened health). The mental health components (4) are general mental health (presence of anxiety and depression), role limitations due to emotional problems, social functioning (participation in social events), vitality (energy and fatigue levels). In this study, SF-12 total transformed scores were used in the data analyses.

Reliability evaluations of the SF-12v2TM have been presented in studies of the general population (Ford, Havstad, Hill, & Kart, 2000; Resnick & Nahm, 2001). Alpha coefficients range from .70 to .87 providing support for internal consistency for the SF-12v2TM as a measure of perceived health status. The SF-12v2TM may be completed in a brief time period, and is recommended for health status monitoring and evaluating health changes over time. The anticipated length of time to complete the SF-12v2TM is five to ten minutes.

The demographic data form.

The demographic data form (DDF) was adapted with permission (Appendix H) from a research study conducted with Tennessee AARP members who were grandparents (Binette & Cicero, 2003; King et al., 2006). This form elicits personal and situational information about grandmother caregivers. The personal information includes data such as age, education, income, and health insurance. The situational information obtains data about the number of grandchildren being cared for by the grandmother, the length of time grandchildren have lived with grandmother, and the grandchildren's frequency of contact with their biological parents. Several items in the original surveys were categorical and dichotomous measurements (Binette & Cicero, 2003; King et al., 2006). Items such as education and income were changed for this study to continuous variables to elicit more usable information for regression analyses.

Information need, service need, and service use.

Data about grandmother caregiver information need, service need, and service use were obtained through 21 parallel items regarding topics such as access to daycare for grandchildren, child support, grandchild and grandmother counseling, grandchild and grandparent activities, school tutoring for grandchildren, legal assistance, and transportation resources. These parallel items indicate the degree to which the grandmother caregivers need the listed information and services. The 21-items for information need and service need are rated on a 5-point Likert scale, ranging from 1 (strongly agree) to 5 (strongly disagree). For these two subscales, lower scores indicated greater information need and service need. Using identical topics to those in the information and service need, the third subscale service use, measures the extent to which

grandmothers used services. Similarly, these items are rated on a 5-point Likert scale; however, the range varied from 5 (always) to 1 (never). Higher scores demonstrated greater use of services. Reliability was established for each measure (information need, service need, and service use) using the data collected in this study (see the following paragraph). The length of time required to complete this survey was 30 to 40 minutes. To assess the readability level of the CRA, SF-12v2TM, and the demographic data form, they were temporarily merged into one Microsoft Word document. The Microsoft Word Tools Assistant yielded a 7.2 readability level.

To answer this study's research questions about information need and service need and use and to decrease statistical problems that arise by analyzing each item separately (Type I error), new central scores were created for each variable (information need, service need, and service use) by summing responses of items in each subscale and calculating the subscale mean by dividing the number of items into the sum of responses. These mean scale scores assisted in ascertaining an overall observation of grandmother information need, service need, and service use. The possible range of scores for information need and service need were 1 (strongly agree) to 5 (strongly disagree) with 3 being neutral. Lower scores for information need or service need indicated greater need for information or services, while higher scores indicated participants disagreeing that they need information or services. Questions related to service use ranged between 5 (always), 3 (sometimes), and 1 (never), indicating how much services were used. All scales demonstrated internal consistency (.94-.97, respectively).

Procedures

The PI used a data collection script to ensure consistency in the explanation of this study to participants (Appendix I). Procedures for questionnaire completions were planned as follows:

- Participants were informed of the study purpose and asked to read the Research
 Information Sheet; then participants were instructed on the steps for completing
 the questionnaires and informed how these data were managed.
- 2. Participants were encouraged to ask questions about the study and interject any concerns.
- 3. Participants completed three questionnaires. Time for completion of the questionnaires was 20 minutes to 1.5 hours.
- 4. Compensation for participant's time occurred once all participants completed the questionnaires. All participants were given meal coupons from a fast food chain. In addition, when participants entered the data collection room, each was given two tickets with the same number. The participant kept one ticket and placed the other in a basket for a gift card drawing. A grandmother participant drew a ticket from the basket. A gift card was given at each participating site.

After data collection was completed, data were stored and kept confidential. Data management consisted of securely storing raw data including the data entered into the statistical computer software. There were two sets of raw data, an original and a xeroxed copy. Data were saved in the form of hard copies and USB memory sticks. Each participant survey was coded and stored in a locked cabinet to which the PI maintained the only key. Since signed document of informed consent was waived, no names or

private data were collected.

Human Subject Protection and Ethical Considerations

Human subject protection is essential in conducting an ethically sound research study. Ethical rigor necessitates appropriate informed consent and protection of human subjects (Burns & Grove, 2001). The Institutional Review Board (IRB) endorsed this study before it began (Appendix J). Two IRB applications were required for completion of this study: one for The University of Texas, Arlington, and one for The University of Memphis. Every aspect and detail of the study was delineated in the IRB applications. These detailed applications were comprehensive including consent forms, study sites, participants, risks and benefits to participants. A modification was requested from both university IRBs to expand data collection sites to places other than churches when participant recruitment was low. This modification was granted (Appendix K). Furthermore, a waiver of documenting written consent eliminated the use and recording of participant names and thus, enhanced participant confidentiality and minimized risks for participant disclosure. There is always a possibility for untoward participant risks in research studies. Risks for AA grandmother participants included emotional and social effects. Participants in this study were involved in face-to-face completion of survey questionnaires in the same room with other grandmother caregivers. These grandmothers often talked among themselves and openly, sharing personal information and rehashing experiences. The PI was available to support participants during emotional and embarrassing moments. There were, however, no emotional outbreaks during this time of sharing among grandmother participants. Participants may have chosen to remove themselves from the study at any time or declined to answer questions without any

consequences; this information was included in the research information sheet along with a telephone number for the PI and the IRB for complaints. Grandmothers who came to the data collection sessions remained throughout the duration of the sessions.

Benefits outweighed the risks in this study. Being in the presence of other grandmother caregivers created a sense of comradery and allowed grandmothers to know that they were not alone in their experiences. Moreover, these AA grandmother caregivers were sources of support for each other. This study assisted with identifying services and resources that AA grandmothers felt were helpful as they sought care for their grandchildren and themselves. Grandmother participants received a list of currently available services and service providers for grandparent caregivers in their residential areas. Finally, as compensation for participants' time in this study, participants were given a fast food coupon and had the opportunity to win a gift card.

Data Analyses

The data analysis process involved several methods. Frequency distributions and measures of central tendency and dispersions were used to describe the sample and participant responses on the instruments. In addition, bivariate correlations were determined by using a Pearson product moment correlation, which identified relationships between AA grandmother caregiver demographics, perceived burden, and perceived health. Once correlations were determined, hierarchical regression analyses were computed, using age, number of grandchildren being cared for, time as grandmother caregiver, education (in years), and income as demographic variables. Table 2 represents the variables that were used in the multiple regression analyses.

These analyses were useful in predicting information need, service need, and service use with an emphasis on the influence of grandmother information need, perceived

Table 2 Variables Used in Multiple Regression Analyses

Variable	Instrument	Score
Perceived Health	Short Form 12v2 TM	Sum of to all items after
(Total)		recoding items 1, 5, 6a, &
		6b; Higher score reflects
		better perceived health
Perceived Burden	Caregiver Reaction	Sum of responses to all items
	Assessment	all items after items 3, 7, 13,
		15, 19 are reverse scored;
		Higher score reflects higher
		burden
Information Need	Demographic Data	Item 14 comprised of 21
	Form (DDF)	sub-items
		Mean of responses from 1-5;
		Higher score reflects
		strongly disagree with need
		for information
Service Need	DDF	Item 15 comprised of 21
		sub-items
		Mean of responses from 1-5;
		Higher score reflects
		strongly disagree with need
		for services
Service Use	DDF	Item 17 comprised of 21
		sub-items
		Mean of responses from 1-
		5; Higher score reflects
		greater use of services

burden and perceived health as independent variables.

Data from completed surveys were hand entered into an Excel spreadsheet and exported into the Statistical Package for the Social Sciences (SPSS) software database. Data were verified by a trained assistant and twice by the principal investigator to enhance accuracy and integrity of the hand entered and exported data. The assistant was taught specific information regarding the items in the questionnaires.

Missing data may be adjusted by excluding the particular missed items or the entire case from the analyses (Burns & Grove, 2005). This study performed pair-wise case deletions from analyses for missing data. Reliability was established for each survey used in this study. Cronbach's alphas were calculated as estimates of internal consistency reliability.

Delimitations

The delimitations of this study were:

- 1. This study was limited to AA grandmother caregivers who attend the one-time planned meeting scheduled at one of the chosen data collection sites and to those who decided to complete the questionnaires.
- 2. This study was limited to AA grandmother caregivers who were recruited from the chosen sites.

Not all of a given population is accessible to sample for any research, which affects the external validity or the generalizability of the study (Burns & Grove, 2005). Settings were selected with large percentages of AA grandparent caregiver residents. This sample is only representative of those who participated and results of this study, therefore, may only be applicable to the participants in the study.

In summary, using the methods and procedures in this chapter, a rigorous, ethically sound research study was conducted, with a goal to make a contribution to the understanding of AA grandmother caregiving.

CHAPTER 4

FINDINGS

Grandparents, over the years, have increasingly assumed the role of primary caregiver for their grandchildren. In assuming this role, grandparents often lack financial resources (Burton, 1992; Dowdell, 1993; Kelley, Whitley, Sipe, & Yorker, 2000; Minkler, Roe, & Price, 1992), which may contribute to the inability of grandparent caregivers to access adequate resources. Without adequate resources, grandparents are at increased risk for other problems including health alterations and stress.

In light of the financial troubles, additional hassles, and social bias grandparents face in providing care for their grandchildren, services for these grandparents must be available and efficacious so that grandparents can care for their grandchildren with nominal impact to their own health. A great number of grandparents, however, have not used services provided by different public and private entities (Brownell, Berman, Nelson, & Fofana, 2003; Force, Botsford, Pisano, & Holbert, 2000). African American (AA) grandmother caregivers often have the most stress, yet they have the least resources (Musil & Ahmad, 2002; Musil, 2005; Ross, 2006).

The purpose of this two-section chapter is to present and discuss the findings of a research project conducted with AA grandmothers raising their grandchildren. The first section contains descriptive statistics to ascertain characteristics of the sample and

participants' responses on the study instruments. The first section also concludes with the statistical results related to each research question. Hierarchical multiple regression analyses were used to determine relationships between variables while controlling for grandmother demographics (age, income, education, time as a caregiver, and number of grandchildren). The second section of the chapter provides a discussion of the results.

Results

Sample characteristics.

Data were collected from 93 AA grandmothers who were primary caregivers for their grandchildren. Grandmother ages ranged from 36 years to 78 years (M = 54.59, SD = 8.07). Twenty-one percent of grandmothers were over age 60 years. The typical grandmother in the sample had a high school education and 29 grandmothers (31%) had completed at least some college. In contrast, seven (7.5%), had completed less than 8 years of formal education. Grandmother's yearly income ranged from \$0 to \$102,000 (M = \$26,679, SD = \$23,595. Thirty percent of the grandmothers had annual incomes of \$10,000 or less (n = 26) while 16 (18%) had income of \$50,000 or more (Table 3).

These grandmothers were primary caregivers for 211 grandchildren (M = 2.27,

Table 3 Description of AA Grandmothers Caring for their Grandchildren (N = 93)

Characteristic	Range	M (SD)	Median
Age	36 – 78 years	54.59 (8.07)	
Education	4 – 18 years	12.11 (2.58)	12.00
Income	\$0 - \$102,000	\$26,678 (\$23,595)	\$20,700

SD = 1.9). Most of the grandmothers (69.9%) were caring for one or two grandchildren (Table 4). Their time as caregivers ranged from 0 years (1 month) to 25 years (M = 7.45 years, SD = 5.84). Many grandmothers had either no formal custody (51.6%) or had legal guardianship (46.2%) of their grandchildren (Table 5). For most grandmothers, this caregiving was done without the support of a husband or partner. Only 24% were married or living with a partner (Table 6).

Table 4 Description of Number of Children AA Grandmothers Raised (N = 93)

# of Grandchildren	Frequency (%)	
1	38 (40.9)	
2	27 (29.0)	
3	14 (15.1)	
4	7 (7.5)	
5	4 (4.3)	
6	1 (1.1)	
8	1 (1.1)	
15	1 (1.1)	

Table 5 Description of AA Grandmothers Custody Status of Grandchildren (N = 92)

Custody Status	Frequency (%)
Legal Guardianship	43 (46.2)
Adopted	1 (1.1)
No Formal Custody	48 (51.6)

Table 6 Description of AA Grandmothers Marital Status (N = 92)

Marital Status	Frequency	Percent	
Married	23	24.7	
Widowed	8	8.6	
Divorced	28	30.1	
Separated	17	18.3	
Live with Partner	1	1.1	

Information need, service need, and service use.

Grandmothers (N = 93) completed demographic data questionnaires, which elicited data about grandmother information need, service need, and service use. The frequencies for the grandmother responses to the information need, service need, and service use items are included in Appendices L, M, and N, correspondingly. Table 7 provides the central scores and Cronbach alphas for each subscale.

Table 7 New Scale Scores for Information Need, Service Need, and Service Use with Cronbach's Alpha (N = 93)

Scales	Number of Items	Mean (SD)	α
Information Need	21	2.39 (.977)	.94
Service Need	21	2.42 (1.001)	.95
Service Use	21	3.499 (1.335)	.97

Information need scores revealed a mean of 2.39 (SD = .977) designating that these grandmothers agree that they need information to assist them with raising their grandchildren. The highest combined percentages of strongly agree and agree for information needs reported were financial resources (78.5%, M = 1.86, SD = 1.194), community resources for children activities (78.5%, M = 1.92, SD = 1.337), educating grandchildren (74.2%, M = 2.01, SD = 1.354), support groups for people raising grandchildren (70%, M = 2.13, SD = 1.400), and community resources for grandparent activities (70%, M = 2.31, SD = 1.337). On the other hand, the lowest information needs reported were legal help for getting custody of grandchildren (31.2%, M = 3.32, SD = 1.460) and coping with sick grandchildren (49.5%, M = 2.88, SD = 1.473).

Similarly, grandmothers agree that they need services (M = 2.42, SD = 1.001). The greatest combined percentages of strongly agree and agree for service needs identified were financial resources for people raising grandchildren (79.6% M = 1.75, SD = 1.112), community resources for children activities (77.5%, M = 1.96, SD = 1.275), educating grandchildren (75.3%, M = 1.95, SD = 1.285), support groups for people raising grandchildren (73.2%, M = 2.09, SD = 1.316), and homework tutoring for grandchildren (73.1, M = 2.10, SD = 1.311) while the lowest reported service need were legal help for getting custody of grandchildren (15.8%, M = 3.42, SD = 1.391) and counseling for grandchildren (40%, M = 2.25, SD = 1.373).

The mean score for service use was 3.49 (SD = 1.335), demonstrating that grandmothers used services sometimes. The services which the most grandmothers indicated always or sometimes using were healthcare coverage for grandchildren (65.6%, M = 2.70, SD = 1.703), medication expenses for grandchildren (63.5%, M = 2.81, SD = 1.703)

1.719), and educating grandchildren. The services used the least was counseling for grandmother caregivers (34.5%, M = 3.88, SD = 1.551), support groups for teenage grandchildren (37.7%, M = 3.80, SD = 1.602), support groups for people raising grandchildren (38.7%, M = 3.74, SD = 1.679), and legal help for getting child support from the grandchildren's parents (38.7%, M = 3.67, SD = 1.656).

Perceived burden.

Eighty-five grandmothers completed the 24-item questionnaire that elicits information about grandmother perceived burden. Burden scores ranged from 24 to 90 (M = 63.70, SD = .56), suggesting that these grandmothers reported, on average, increased perceived burden. Forty-three (51%) of grandmothers, however, perceived their burden to be higher than this mean while only 11.8% rated their burden less than 50. Table 8 presents computed perceived burden scores. Grandmothers reported the least

Table 8 Perceived Burden Sub-scales: Measures of Central Tendency and Internal Consistency (n = 92)

Subscales	Observed (Subscale Range)	Mean (SD)	Cronbach's α
Caregiver Esteem	6-23 (7-35)	11.93 (3.765)	.66
Impact on Finances	3-15 (3-15)	8.565 (3.188)	.56
Lack of Family Support	5-25 (5-25)	16.946 (4.960)	.78
Impact on Schedule	6-24 (5-25)	13.370 (4.941)	.79
Impact on Health	4-20 (4-20)	14.120 (3.860)	.79
Total Burden Score	24-90 (5-120)	63.70 (.56)	.84

amount of burden in the area of their own esteem (M = 1.71, SD = .534). Greater burden levels were reported for impact on finances (M = 8.565, SD = 4.941), lack of family

support (M = 16.946, SD = 4.960), impact on schedule (M = 13.370, SD = .986), and impact on health (M = 14.120, SD = 3.860). Scores on the Caregiver Burden Scale indicated that grandmother health was the greatest source of distress. Cronbach's alpha for each sub-scale demonstrated low to acceptable internal consistency and were lower than those in other studies (Dowdell, 2004; Dowdell, 1993; Givens et al. 1992).

Perceived health.

The 12-item SF12 questionnaire was used to measure perceived health. This questionnaire has eight subscales (Table 9) and obtains data about overall health perceptions and Cronbach's α . Cronbach alphas for some subscales were not calculated because the subscale consisted of one item. Participant responses were transformed on a 0

Table 9 Perceived Health Descriptive Statistics (Possible range 0-100)

Subscale	N	M (SD)	Cronbach's α
Physical Functioning	92	61.14 (38.40)	.880
Role Physical	91	56.6 (29.95)	.923
Bodily Pain	91	35.44 (31.64)	UTC (1 item)
General Health	91	53.3 (22.43)	UTC (1 item)
Vitality	93	44.35 (24.21)	UTC (1 item)
Social Functioning	93	63.44 (29.15)	UTC (1 item)
Role Emotional	91	66.21 (26.91)	.883
Mental Health	93	53.76 (14.95)	.616
Perceived Health Total	93	54.25 (10.56)	.562

Note: UTC = Unable to calculate

to 100 point scale, using the instructions provided in the SF-12 Scoring Handbook (Ware

et al., 2002).

Ninety-three grandmothers rated their overall health between good and fair (range 26.56 to 73.44, M = 54.25, SD = 10.56). Perceptions of bodily pain was rated lowest (overall score = 35.4) while role emotion was rated highest (overall score = 66.2). Bodily pain measured the extent to which pain interfered with normal work inside and outside of the home whereas role emotion measured the extent to which emotional problems interfered with daily activities.

Physical health scores were calculated from the subscale scores of physical functioning, role physical, bodily pain, and general health while mental health scores were a grouping of the vitality, social functioning, role emotional, and general mental health subscales scores. Physical health scores ranged from 38.5 to 84.6 and mental health scores were from 33.3 to 93.3. Both physical health and mental health perceptions were reported good (M = 63.6, SD = 10.05; M = 66.9, SD = 12.00, respectively).

Hierarchical regression analysis.

Hierarchical regression analysis predicts or explains the influence of sets of independent variables (IVs) upon a dependent variable (Cohen & Cohen, 1983; Pedhazur, 1997). This analysis helps to explain the amount of variance (change) in the dependent variable (DV) that occurs with each independent variable set. Table 10 presents the process used for entering IVs and DVs into the hierarchical regression equation for each research question. An independent variable set was entered simultaneously to each research question. An independent variable set was entered simultaneously to determine R^2 (Block 1). Then, additional IVs were entered into the hierarchy individually (Block 2); and upon each IV entrance, R^2 change was monitored to assess the portion of the variance

explained by this entrance. The beta scores reflected the strength and significance of the relationship between the independent variables and the DV.

The research questions were developed to explore relationships of variables in the framework (Figure 2). For each research question in this study, the first set of IVs entered analyses. An intercorrelation matrix with IVs and all of the dependent variables is depicted in Table 11.

Table 10 Block Entrance of IVs and DVs in Hierarchical Regression Equation

Research Question	IVs	DVs
1	Block 1 GMD	IN
2	Block 1 GMD Block 2 IN	РВ
3	Block 1 GMD Block 2 IN Block 3 PB	SN
4	Block 1 GMD Block 2 IN Block 3 PB	SU
5	Block 1 GMD Block 2 IN Block 3 PB	РН
6	Block 1 GMD Block 2 IN Block 3 PH	SN
7	Block 1 GMD Block 2 IN Block 3 PH	SU

Note. GMD= Grandmother Demographics, IN=Information Need, PB=Perceived Burden, SN=Service Need, SU=Service Use

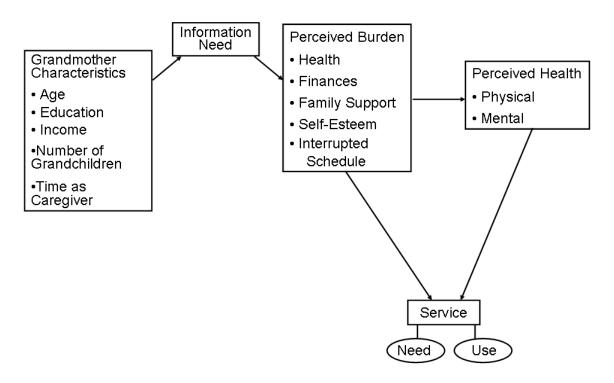


Figure 2. Framework with Subscale Detail

Grandmother demographics and information need.

What is the relationship between AA grandmother caregiver demographics and information need? Demographics were entered as a block to assess the impact of the demographic variables (IVs) on information need (DV) scores. The mean information need subscale item score was used for analyses in blocks with information need. The resulting multiple regression equation predicting information need by demographics was significant, F(5, 81) = 3.519, p = .006, $R^2 = .178$, adjusted $R^2 = .128$. The variables grandmother age (B = .298, p = .009) and number of grandchildren (B = -.270, p = .010)

Table 11 Intercorrelation Matrix of Hierarchical Regression Analyses (N = 93)

	Age	Age N GC	Y CG	Ed	Income	PB	ЬН	Z	SN	Ω S
Pearson Age	1.000	1.000 .125	.415**	085	080.	.205*			.240*	.051
N GC		1.000	.132	.016	060	184*	025	224*	222*	171
A CG			1.000	113	920.	620.	.147	.123	.073	067
Ed				1.000	.304 *	.186*	* 802.	.151	.212* .179*	.179*
Income					1.000	.200*	.214*	.119	.133**	.259*
PB						1.000	.430 **	** 60S.	.489**	.316*
ЫН							1000	.368 **	.354**	.289*
IN									.936**	.409**

Note. N GC = number of grandchildren; Y CG = years caregiving; Ed = education; PB = perceived burden; PH = perceived health; IN = information need; SN = service need; SU = service use; * p < .05; **p < .01.

were significant predictors of information need (Table 12). This analysis indicates that as grandmother age increases the need for information increases.

Table 12 Summary of Hierarchical Regression Analysis for Predicting Information Need by Demographics (N = 93)

Variable	В	SE B	β	
Step 1				
Age	.036	.013	.298**	
Number of Grandchildren	139	.053	270**	
Years Caregiving	.009	.019	.054	
Education	.069	.041	.181	
Income	.000	.000	.020	

Note. $R^2 = .178 (p = .006), **p \le .01$.

Information need and perceived burden.

What is the relationship between AA grandmother information need and perceived burden? To assess the impact of the subscale information need (IV) on perceived burden (DV) scores, information need was entered as the second block. The concluding multiple regression equation was significant in predicting perceived burden by demographics and information need, F(6, 74) = 5.230, p = <.001, $R^2 = .298$, adjusted $R^2 = .241$. Information need uniquely predicted perceived burden, $\beta = .434$, p = <.001 and explained 15.5% of the variance of perceived burden (Table 13).

Table 13 Summary of Hierarchical Regression Analysis for Predicting Perceived Burden by Demographics and Information Need (N = 93)

	Variable	В	SE B	β
Step 1				
	Age	.334	.174	.227
	Number of Grandchildren	-1.322	.680	211
	Years Caregiving	.049	.241	.024
	Education	.816	.524	.177
	Income	.000	.000	.113
Step 2	2			
	Age	.144	.165	.098
	Number of Grandchildren	588	.646	094
	Years Caregiving	.001	.220	.001
	Education	.455	.486	.099
	Income	.000	.000	.105
	Information Need	5.268	1.305	.434**

Note. $R^2 = .143$ for Step 1: $\Delta R^2 = .155$ for Step 2 (p = <.001), **p < .01.

Perceived burden and service need.

What is the relationship between AA grandmother perceived burden and service need?

To assess the impact of information need and perceived burden on service need scores, information need was entered as the second block, and perceived burden was entered as the third block. The mean service need subscale item score was used for analyses in blocks with service

need.

The concluding multiple regression equation was significant in predicting service need by demographics, information need, and perceived burden, F(7, 73) = 77.928, p = <.001, $R^2 = .882$, adjusted $R^2 = .871$. Information need was a significant predictor of service need, $\beta = .922$, p = <.001 (Table 14). Perceived burden was not a unique predictor for service need ($\beta = .005$, p = <.915).

Perceived burden and service use.

What is the relationship between AA grandmother perceived burden and service use? To assess the impact of the subscales information need and perceived burden on service use (DV) scores, information need (IV) was entered as block 2, and perceived burden (IV) was entered as block 3. The mean service use subscale item score was used for analyses in blocks with service use. The multiple regression equation predicting service use by demographics, information need, and perceived burden was significant, F(7, 73) = 3.254, p = .005, $R^2 = .238$, adjusted $R^2 = .165$. Information need was the sole predictor of service use, B = .408, p = .001 (Table 15). Perceived burden, however, did not uniquely predict service use ($\beta = .063$, p = .599).

Perceived burden and perceived health.

What is the relationship between AA grandmother perceived burden and perceived health? To assess the impact of the subscale perceived burden (IV) on perceived health (DV) scores, perceived burden was entered as the second block. The final multiple regression equation predicting perceived health by demographics, information need, and perceived burden was significant, F(7, 73) = 3.590, p = .002, $R^2 = .256$, adjusted $R^2 = .185$. Perceived burden

Table 14 Summary of Hierarchical Regression Analysis for Predicting Service Need by Demographics, Information Need, and Perceived Burden (N = 93)

	Variable	В	SE B	β
Step 1				
	Age	.345	.920	.285
	Number of Grandchildren	.035	.014	262
	Years Caregiving	139	.056	.014
	Education	.091	.020	.235
	Income	.000	.000	.022
Step 2				
	Age	.001	.006	.009
	Number of Grandchildren	006	.023	012
	Years Caregiving	006	.008	036
	Education	.026	.017	.067
	Income	.000	.000	.003
	Information Need	.944	.050	.922**
	Perceived Burden	<.001	.004	.005

Note. $R^2 = .181$ for Step 1: $\Delta R^2 = .701$ for Step 2 (p = <.001), **p < .01.

Table 15 Summary of Hierarchical Regression Analysis for Predicting Service Use by Demographics, Information Need and Perceived Burden (N = 93)

	Variable	В	SE B	β
Step 1	Age	.017	.020	.102
	Number of Grandchildren	113	.078	161
	Years Caregiving	021	.028	092
	Education	.060	.060	.115
	Income	.000	.000	.213
Step 2	Age	002	.019	012
	Number of Grandchildren	041	.076	058
	Years Caregiving	026	.026	112
	Education	.024	.057	.046
	Income	.000	.000	.206
	Information Need	.522	.153	.382
Step 3	Age	003	.020	017
	Number of Grandchildren	043	.076	061
	Years Caregiving	025	.026	107
	Education	.024	.057	.046
	Income	.000	.000	.220
	Information Need	.557	.168	.408**
	Perceived Burden	148	.281	063

Note. $R^2 = .115$ for Step 1: $\Delta R^2 = .120$ for Step 2: $\Delta R^2 = .003$ for Step 3 (p = .599), **p = < .01.

Table 16 Summary of Hierarchical Regression Analysis for Predicting Perceived Health by Demographics, Information Need, and Perceived Burden (N = 91)

	Variable	В	SE B	β
Step 1	Age	.112	.180	.075
	Number of Grandchildren	295	.706	047
	Years Caregiving	.274	.251	.133
	Education	.878	.543	.188
	Income	.000	.000	.138
Step 2	Age	037	.179	025
	Number of Grandchildren	.280	.702	.044
	Years Caregiving	.236	.239	.115
	Education	.595	.527	.128
	Income	.000	.000	.131
	Information Need	4.125	1.417	.336
Step 3	Age	081	.174	055
	Number of Grandchildren	.461	.681	.073
	Years Caregiving	.236	.231	.115
	Education	.455	.512	.098
	Income	.000	.000	.100
	Information Need	2.504	1.511	.204
	Perceived Burden	.308	.122	.304*

Note. $R^2 = .099$ for Step 1: $\Delta R^2 = .093$ for Step 2: $\Delta R^2 = .065$ for Step 3 (p = .014), *p < .05.

distinctively predicted perceived health, β = .304, p = .014 (Table 16). The direction of the relationship, however, was unexpected. As perceived burden increased in these grandmothers, their perceived health was better.

Perceived health and service need.

What is the relationship between AA grandmother perceived health and service need? To assess the impact of the subscale perceived health on service need (DV), information need and perceived burden (IVs) were entered as block 2 and perceived health

(IV) was entered as block 3.

Significant predictors for service need by demographics, information need, perceived burden, and perceived health were yielded using the multiple regression equation, F(8, 72) = 67.256, p = <.001, $R^2 = .882$, adjusted $R^2 = .869$. Information need ($\beta = .921$, p = <.001) exclusively predicted service need (Table 17). Perceived health, did not uniquely predict service need ($\beta = .002$, p = .963).

Perceived health and service use.

What is the relationship between AA grandmother perceived health and service use? To assess the impact of the subscale perceived health on service use (DV) scores, information need and perceived burden (IVs) were entered as the second block while perceived health (IV) was entered as the third block.

The data yielded a significant overall regression equation predicting service use by demographics, information need, perceived burden, and perceived health F (8, 72) = 3.050, p = .005, R^2 = .253, adjusted R^2 = .170. Information need individually predicted service use, β = .313, p = .016 (Table 18). Perceived health, conversely, did not predict service use (β = .120, p =

Table 17 Summary of Hierarchical Regression Analysis for Predicting Service Need by Demographics, Information Need, Perceived Burden, and Perceived Health (N = 93)

	Variable	В	SE B	β
Step 2	Age	.001	.006	.009
	Number of Grandchildren	006	.023	012
	Years Caregiving	006	.008	036
	Education	.026	.017	.067
	Income	.000	.000	.003
	Information Need	.944	.050	.922
	Perceived Burden	.000	.004	.005
Step 3	Age	.001	.006	.009
	Number of Grandchildren	006	.023	012
	Years Caregiving	006	.008	036
	Education	.026	.017	.067
	Income	.000	.000	.003
	Information Need	.944	.051	.921**
	Perceived Burden	.000	.004	.004
	Perceived Health	.000	.004	.002

Note. $R^2 = .181$ for Step 1: $\Delta R^2 = .701$ for Step 2; $\Delta R^2 = <.001$ for Step 3 (p = .963), **p < .01.

Table 18 Summary of Hierarchical Regression Analysis for Predicting Service Use by Demographics, Information Need, Perceived Burden, and Perceived Health (N = 93)

	Variable	В	SE B	β
Step 2	Age	004	.020	022
	Number of Grandchildren	034	.077	048
	Years Caregiving	026	.026	112
	Education	.019	.058	.036
	Income	.000	.000	.195
	Information Need	.461	.170	.337
	Perceived Burden	.012	.014	.103
Step 3	Age	002	.020	015
	Number of Grandchildren	040	.077	157
	Years Caregiving	029	.026	126
	Education	.012	.058	.024
	Income	.000	.000	.183
	Information Need	.428	.173	.313*
	Perceived Burden	.007	.014	.066
	Perceived Health	.013	.013	.120

Note. $R^2 = .115$ for Step 1: $\Delta R^2 = .127$ for Step 2; $\Delta R^2 = .011$ for Step 3 (p = .312), *p < .05.

.312).

Figure 3 provides a summary of findings in the study about the relationships between the variables. The figure shows the standardized betas between the variables of the framework. In

the discussion, a revised framework will be proposed based on the findings.

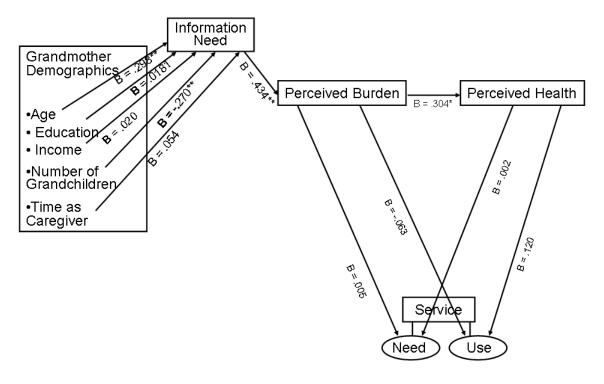


Figure 3. Framework with Standardized Betas Note. *p<05, **P<01

Discussion

The need for increased knowledge about the relationships between AA grandmother demographics, information need, perceived burden, perceived health, and service need and use was the impetus for this study. Discussion of the findings for this research study is presented in this section. In addition, methodological limitations, implications for the framework, implications for nursing, future recommendations, and conclusions are offered.

Sample characteristics.

Grandmother demographics in this study were generally consistent with those in other studies (Binette & Cicero, 2003; Bull, 1990; Burton, 1992; Casper and Bryson, 1998; Dowdell, 2004, Hayslip et al., 2006; King et al., 2006). A large number of grandmother caregivers in this

study were younger than 50 years of age. A much smaller number of these grandmothers were older than 65 years. Again, like other grandparent caregiver studies, grandmothers cared for, on average, two grandchildren. One grandmother provided care for 15 grandchildren. The majority of these grandmothers had been caring for their grandchildren for three years. Some, however, have been providing care for 10 years or more. Most grandmothers had at least a high school education with incomes at or below the poverty level. Only one-forth of all grandmothers in the study reported being married whereas the remaining grandmothers had no spousal or significant other support. These characteristics provide insight into why AA grandmothers may not have sufficient resources to care for their grandchildren. While all grandmothers in the study were AA, the sample was diverse in age, education, and income. The demographics indicate that AA grandmothers have experienced burden when caring for their grandchildren irrespective of age, education, and income.

Information Need, Service Need, and Service Use.

Based on the individual item means, the information needs reported by the most grandmothers were financial resources, community resources for children activities, educating grandchildren, support groups for people raising grandchildren, and community resources for grandparent activities. Conversely, five topics for information needed by the fewest grandmothers were obtaining legal help for getting custody of grandchildren, coping with sick grandchildren, seeking legal help for getting child support from grandchildren's parents, needing access to daycare, and disciplining grandchildren. Although these information needs were selected less frequently, at least 30% of the subjects reported needing the information. The findings highlight the need for information being offered about activities and services available

in the community for grandmothers and their grandchildren. Furthermore, these findings may offer an understanding of which information needs may be more important to grandmother caregivers and thus possibly provide a way to prioritize information offered to grandmothers.

Correspondingly, the services needs identified by the largest numbers of grandmothers were financial resources for people raising grandchildren, community resources for children activities, educating grandchildren, support groups for people raising grandchildren, and homework tutoring for grandchildren. The service needs reported by fewer grandmothers were legal help for getting custody of grandchildren and counseling for grandchildren. Similar service needs among grandparent caregivers have been reported (Binette & Cicero, 2003; King et al., 2006).

Service use comprised assistance in healthcare coverage for grandchildren, medication expenses for grandchildren, and educating grandchildren. The services least used were counseling for grandmother caregivers, support groups for teenage grandchildren, support groups for people raising grandchildren, and legal help for getting child support from the grandchildren's parents. Similar to findings in other studies (Dowdell, 2004; Haglund, 2000; Hayslip & Shore, 2000; Minkler et al. 1992), these grandmothers placed themselves secondary to their grandchildren and therefore, information need and service need and service use were more directed to the needs of their grandchildren. Grandmothers who cared for larger numbers of grandchildren reported higher information need (Table 11). One study found that grandparents needed information about raising teens and available services (King et al., 2006). A limitation in examining information need, service need, and service use in this study was that the ages of grandchildren were not collected, assuming that grandchildren of different ages would pose

different needs for information and services.

Perceived burden.

Perceived burden is a complex concept. Grandmothers do not see caring for grandchildren as burdensome (based on anecdotal conversations with some participants); however, these grandmother caregivers reported increased burden. Many grandmothers (54%), in this study, reported that they resented having to be the primary caregiver for their grandchildren (CRA item 7). In contrast, an even greater number of grandmothers (66%) reported feeling privileged to care for their grandchildren (CRA item 1). These contradictory findings may indicate ambivalence on the part of the grandmother.

The components of perceived burden included impact of caregiving on self esteem, schedules, and personal health as well the amount of family support available, Grandmothers reported the least impact of caregiving on their self esteem. As a group, these grandmothers felt good about themselves as caregivers. Lack of family support and impact on schedule accounted for a considerable amount of the perceived burden. Caregiving had had the greatest impact on the grandmothers' personal health and contributed to their perceived burden. Three-fourths of the grandmothers reported that they were not healthy enough to care for their grandchildren (CRA item 19). This was surprising since their responses on the SF-12 (perceived health) indicated that these grandmothers perceived their health as good.

Perceived health.

Health problems, depression, and stress have been found to coexist in grandparents raising grandchildren (Kelley et al., 2000; Lee et al., 2003; Minkler et al. 1997; Musil, 2000; Whitley et al., 2001). Most grandmothers in this study perceived their overall health as good or

better. Although the majority rated their overall health as good or very good, they reported that their physical health prevented them from accomplishing regular daily activities such as work (Appendix P). Furthermore, most grandmothers reported being depressed or anxious at varying degrees. Almost 75% grandmothers reported that they experience pain that interferes with their normal work. In addition, grandmothers reported that emotional and physical health problems decreased their desire and ability to visit others and participate in social events.

Grandmother demographics and information need.

Grandmother age and the number of grandchildren cared for by grandmothers were significant predictors of information need in this sample of grandmother caregivers. The statistically significant relationship between age and information need suggests that older grandmother caregivers reported higher levels of information need. One may presume that older caregivers were further removed from when they parented their own children and may be less aware of what was available in the community. Counter to expectations, as the number of grandchildren cared for increased, information need decreased. Perhaps, grandmothers are afforded more opportunities to deal with their needs and learn from their experiences as they care for larger numbers of grandchildren. Because the demographic variables as a block explained only 17% of the variance in information need, personal characteristics of grandmothers not assessed in this study may affect information need.

Information need and perceived burden.

Information need was a significant predictor for perceived burden. According to the framework in this study, the association between information need and perceived burden was expected. One would anticipate higher burden to co-exist with greater information need. Studies

are needed to specifically investigate information need in the context of burden among grandparent caregivers. Providing information may be a way that health care professionals can decrease the burden experienced by AA grandmothers.

Perceived burden and service need.

Based on this study's framework, a relationship between perceived burden and service need was expected. The findings did not support perceived burden as a unique predictor of service need when demographic variables and information need were controlled by entering them first into the regression. Service needs have been examined as instrumental, formal, or informal social support (Hayslip & Shore, 2000; King et al., 2006). Use of such social support has mitigated stressors in grandmothers in other studies. Possibly as burden increases, individuals may not have the insight that they need services nor which services may be helpful.

Perceived burden and service use.

An unexpected finding was that perceived burden did not significantly predict service use. Neither grandmother demographics nor perceived burden accounted for a significant portion of the variance. Perceived burden had no significant influence on service use. Perceived burden, therefore, did not promote service use independent of grandmother demographics and information need. The emotional states of depression and down hearted (92% of this sample) may interfere with the use of services. Perhaps not enough grandmothers in this sample used services to adequately determine the relationship between perceived burden and service use. This is disturbing because grandmothers in this study indicated that they needed services, yet, these grandmothers reported under utilization of services. The busy schedules and lack of family support reported by these grandmothers may have contributed to this use of services.

Significant barriers to service use in other studies included a lack of time related to demanding schedules (King et al., 2006), lack of family support (Dowdell, 2004; Given et al., 1992; King et al., 2006) and grandparents not being aware of services offered (Burnette, 1999). Grandmothers in this study reported a lack of family support, which may have contributed to the busy schedules of these grandmothers to the extent that the grandmothers were too busy to use available services. In addition, bodily pain was reported by grandmothers. This indicated interference with grandmother work inside and outside of the home. This may impede these grandmothers seeking services that they need as pain is possibly a deterrent to acquiring assistance outside of the home. A director at one data collection site informed the PI that one grandmother had body pain and was too sick to participate. Another director provided transportation to the data collection site for one grandmother because the grandmother expressed a desire to participate in this study but did not have means to get to the site.

Perceived burden and perceived health.

Perceived burden can predict perceived health indicating interactions among the physical and mental woes of providing care to grandchildren. While the regression analysis was significant, perceived burden explained only a small portion (16.6%) of the variance in health. This study validated the relationship between perceived burden and perceived health. Research studies (Burton, 1992; Butler & Zakari, 2005; Dowdell, 2004; Given et al., 1992; Hayslip et al., 2006) are congruent with grandparent health as a designate of increased stress (burden). They found, however, that burden and health had an inverse relationship. Conversely, perceived burden and perceived health had a positive relationship in this study. This finding was unexpected and is not clearly understood. Most of the grandmothers were recruited from faith-

based organizations (churches). Faith or other spiritual resources may have mediated the effects of burden and promoted positive perceived health in this grandmother caregiver sample.

Perceived health and service need.

In contrast to the theoretical prediction of the model, perceived health was not a significant predictor of service need. Service needs reported by grandparents include mentors or support groups, psychological counseling for themselves and their grandchildren, and legal and parenting counsel (King et al., 2006). Grandmothers, in this study, reported service needs for grandmother support groups and community resources for grandchildren activities. One study found that grandmothers who had stable support systems reported better health and less psychological tension (Kelley et al., 2001).

Perceived health and service use.

Perceived health was not a unique predictor of service use. Information need was the only significant predictor of service use. One explanation for this finding may be the use of the parallel items to ascertain information need, service need, and service use and the use of item averages for the regression analyses. These items may not have captured the essence of these grandmother caregivers' information need, service need, and service use. Information need may have been such a strong predictor of service need and use because the stem of these survey items were identical. This may account for the strong relationships between information need and service need and information need and service use. Finally, there were no items that specifically queried grandmothers about service need or service use in the context of their own health.

Limitations

A correlational, cross-sectional research design guided the exploration of the

relationships among AA grandmother caregiver demographics, information need, perceived burden, perceived health, service need, and service use. Strengths and weaknesses of this design were evident. Because this study was not an experimental or longitudinal by design, causal relationships were not established and would be inappropriate to suggest. Moreover, specific items such as medical records to examine perceived health in the context of service need and service use were not used. Clear understandings of these relationships, therefore, could not be established. In addition, this study has limited generalizability because the sample consisted of AA grandmother caregivers who attended a one-time scheduled meeting at sites in communities with primarily AA residents. While there were 93 AA grandmother caregiver participants in this study, this sample was only representative of those who participated. Results of this study, therefore, may only be applicable to the participants in the study.

The researcher adapted the instrument to assess the information need, service need, and service use from the questionnaire used by AARP to assess these factors among grandparents in Tennessee. Participants responded to the individual items of each scale on an ordinal scale. To use the data from the information need, service need, and service use subscales in the regression analyses, a measure of central tendency (mean) was calculated to convert the ordinal-level data into a single representative score for the subscale. This conversion may have attenuated these variables and inadequately measured these concepts.

Despite those weaknesses, the findings in this study have contributed to a conceptual understanding of the relationships among the variables examined. Figure 3 offers a depiction of how these data modify the framework of this study. Implications of this modified framework assert that the grandmother demographics of age and number of grandchildren influence

information need. In addition, information need influences service need, service use, and perceived burden while perceived burden influences perceived health.

Implications for Nursing

Nurses must provide nonjudgmental and sensitive care to grandmothers raising grandchildren because AA grandmothers are a diverse group representing a wide range of ages, incomes, educational levels, and life experiences. Nurses cannot assume what the needs of AA grandmothers caring for their grandchildren are. Nurses should be aware of the services available for grandmother caregivers within their own communities. Women caring for grandchildren are heavily tied to the responsibilities of raising them rather than focusing on their own health or achievements. Often times, the responsibilities of raising grandchildren lend toward stress or burden, which has been shown to be a source for developing illness (Lee et al., 2003). Nurses should, therefore, be intentional about

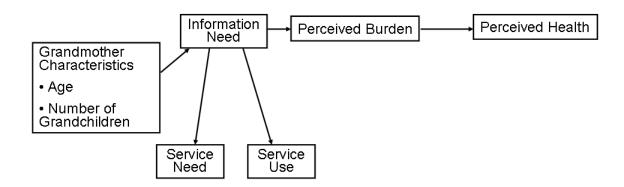


Figure 4. Modified Framework Based on Study Findings

assessing for burden and altered health in grandmother caregivers and provide essential information as well as make necessary referrals to prevent or minimize this burden and altered

health.

Nurses must also assist grandmother caregivers with identifying and establishing support systems, referring at risk grandmothers to appropriate service agencies for assistance.

Grandmothers have reported that knowledge about services provided and how to persevere until service needs are met was useful when services were sought (Gibson, 2002a). Consequently, nurses should provide as much information about service providers along with explicit information about the services to which grandmother caregivers are referred and the processes for receiving such services. In addition, nurses should follow-up with the grandmother caregiver to assess for issues that may accompany visits to a service provider. One study found that grandparents are exposed to negative attitudes from the service providers (Gibson, 2002a). This may be a deterrent for some grandmother caregivers. Therefore, nurses should ask the grandmother if her needs were met when she received the services or determine whether she went to the service provider (she may not have gone).

Future Recommendations

Grandmothers in this study reported increased perceived burden with increased perceived health, which is contrary to other studies. Studies, therefore, are needed to further examine these phenomena when they coexist. Use of actual medical information and physical exams may supplement the SF-12. In addition, qualitative research methods may prove beneficial in obtaining information about grandmother caregiver experiences of burden. Perhaps the appropriate questions were not asked to ascertain true perceptions of burden and health in these women. Studies, therefore, using phenomenology to ascertain grandmothers' lived experiences of information need, perceived burden, perceived health, service need, and service use are

needed. This research approach may provide rich data, which could explain the relationships between these concepts.

Furthermore, studies indicated barriers to service use include busy lifestyles and lack of family support (Dowdell, 2004; Given et al., 1992; King et al., 2006). Grandmothers in this study reported busy schedules and lack of family support as components of perceived burden. Perhaps grandmothers in this study did not have time to attend or seek services that they needed. Thus, research exploring ways to reduce these and other barriers to service use in grandparent caregivers may be useful in improving service use and therefore may improve health outcomes of grandmother caregivers.

While grandmothers reported a need for services in this study, they did not optimize their use of services. These grandmothers reported that they used available services sometimes.

Perhaps, the items to extract service use data from these grandmothers were not appropriate. For instance, grandmothers were not asked specifically why services were or were not used. Studies are needed to examine grandmother caregiver's definition of service use, their perceptions of service use, and efficacious service providers.

Finally, information need was a strong predictor of service need and service use. Studies are needed to develop and test interventions to address information needs that potentially influence service need and service use outcomes. In addition, explorations of how these interventions influence other grandmother caregiver problems such as perceived burden, perceived health, parental skills, and family relationships are needed.

Conclusions

Recently, there has been a great deal of research examining the grandparent raising grandchildren phenomenon. Yet, many aspects of the phenomenon have not been explored. This study explored relationships between AA grandmother characteristics (age, number of grandchildren, time as caregiver, education, and income), information need, perceived burden, perceived health, service need, and service use.

Findings in this study supported some components of the adapted conceptual framework.

Information need was a significant predictor of perceived burden while perceived burden predicted perceived health. Neither service need nor service use were predicted by perceived burden or perceived health.

Results also showed that (a) perceived burden was not a significant predictor for service need or service use nor did burden predict significant amounts of the variance for service use and (b) perceived health was not found to be a significant predictor for service need or service use, and perceived health did not predict significant quantities of the variance for service use when grandmother demographics and information need were extracted.

In summary, women providing care for their grandchildren are vulnerable to decreased health and increased burden, thereby, necessitating need for services. There are no simple answers to ameliorate grandparent caregiver's issues, however, learning about the effects of grandparent caregiving is not only crucial for the individual, it is vital for the family. This knowledge will affect us globally, but most importantly and most immediately families and communities are impacted. Local communities are extensions of families, which eventually affect the larger world community. The hope is to care for children through caring for their

grandmother caregivers by investigating ways of limiting grandmother information need, burden, health alterations, service need and service use. In addition, gaining insight to what these grandmothers need to enhance their health, decrease their burden, meet their service needs, and improve their service use will enhance quality of life for them as well as their grandchildren.

APPENDIX A

RESEARCH INFORMATION SHEET

Research Information Sheet

PRINCIPAL INVESTIGATOR: Gloria F. Carr

TITLE OF PROJECT: African American Grandmother Caregivers: Relationships Among Information Need, Perceived Burden, Perceived Health, and Service Need and Use.

PURPOSE:

The purpose of this study is to explore and describe AA grandmother caregivers' perceptions about their health, the influence of perceived health upon perceived burden, the influence of perceived burden and perceived health upon information and service need and use in AA grandmother caregivers.

DURATION

The anticipated time for participants to complete the procedures for this study is 1.5 hours. There are seven church sites that have given permission for this study to be completed in their facility with their members. I anticipate at least 50 participants at each church location.

PROCEDURES

Procedures for questionnaire completions are planned as follows (I will be present during this process):

- 1. I will inform participants of the study's purpose and ask them to read the Research Information Sheet; then I will instruct them on the steps for completing the questionnaires and tell them how this data will be managed.
- 2. Participants will be encouraged to ask questions about the study and interject any concerns. The projected time for completion of 1 and 2 is 15 to 30 minutes.
- 3. Participants will complete three questionnaires.
- 4. Compensation for participant's time will occur once all participants have completed the questionnaires. All participants will be given meal coupons from a fast food chain. Participants who decide not to complete the surveys or leave before completing the surveys will be given a food coupon as they leave. In addition, when participants enter, each will be given two tickets with the same number. The participant will keep one ticket and place the other in a basket for a gift card drawing. There will be a separate drawing at each participating church. A grandmother participant will draw a ticket from the basket.
- 5. General information from the study's results will be shared with each participating church congregation.

POSSIBLE RISKS/DISCOMFORTS

I understand there are no known physical, psychological, social, or economic risks for my being in this research study. Although there are no known risks to participate in this study, I realize the questions may stir old memories or painful feelings as I think about questions while completing the surveys. The facilitator will be available to support me during any emotional moments. I may also choose to remove myself from the study at any time during the study.

POSSIBLE BENEFITS

I understand that I may not benefit from this research study, but this study may help healthcare providers and other professionals learn more about ways they can help grandmothers who take care of their grandchildren stay healthy. Being in a group with other grandmothers and answering questions may be interesting to me, and I may learn more about my health and ways to stay healthy.

ALTERNATIVE PROCEDURES / TREATMENTS

I understand that the alternative to taking part in this research study is to not to take part in it.

<u>CONFIDENTIALITY</u> I understand that all the information I give to the researcher is confidential and will be locked in a secure place. My name will not be used on the research records. Results from the research study will be grouped and reported on by group. The information will be available to the research staff, University of Texas, Arlington Institutional Review Board (IRB), and University of Memphis IRB. The IRB is protecting my rights for taking part in this research study.

Every attempt will be made to see that the study results are kept confidential. A copy of the records from this study will be stored in a locked file cabinet for at least three (3) years after the end of this research. The results of this study may be published and/or presented at meetings without naming me as a participant. Although my rights and privacy will be maintained, the Secretary of the Department of Health and Human Services, the UTA IRB, the FDA (if applicable), and personnel particular to this research (individual or department) have access to the study records. The data will be kept completely confidential according to current legal requirements. They will not be revealed unless required by law, or as noted above.

COMPENSATION FOR MEDICAL TREATMENT:

I understand that I am not waiving any legal rights or releasing the University of Memphis and the University of Texas, Arlington or their agents from liability or negligence. I understand that, in the event of physical injury resulting from this research

study, the University of Memphis and the University of Texas, Arlington does not have funds budgeted for compensation either for lost wages or for medical treatment.

Therefore, these Universities do not provide for treatment or reimbursement for such injuries.

If injury should occur, efforts will be made to locate resources in the community to provide needed medical treatment. No compensation for injury or health care will be available through the sponsor of this research study.

FINANCIAL COSTS

I understand there will be no costs to me for being in this research study. If I identify unmet health needs during the group discussion, I will be referred to a professional for health care. The cost of further evaluation and treatment will be my responsibility or the responsibility of my insurance company.

CONTACT FOR QUESTIONS

If you have any questions, problems or research-related medical problems at any time, you may call Gloria Carr at 901-678-3080, or Jennifer Gray at 817-272-5295. You may also call the Chairman of the University of Texas, Arlington Institutional Review Board at 817-272-1235 or the University of Memphis Institutional Review Board at 901-678-3424 for any questions you may have about your rights as a research participant.

VOLUNTARY PARTICIPATION

<u>Participation in this research study is voluntary.</u> You may refuse to participate or quit at any time. If you quit or refuse to participate, the benefits (or treatment) to which you are otherwise entitled will not be affected. You may quit by discontinuing the completion of the questionnaires and informing the facilitator, Gloria Carr.

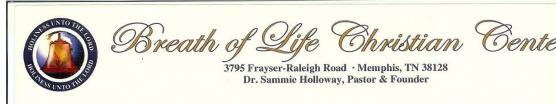
By completing the questionnaires, I confirm that I have read or had this document read to me. Completing the questionnaires I also confirm that I agree to participate in this study. I may keep this document for your records. I have been and will continue to be given the chance to ask questions and to discuss my participation with the investigator.

I freely and voluntarily choose to be in this research project.

APPENDIX B

AGENCY PERMISSION LETTERS

Agency Permission Letters



November 8, 2006

University of Memphis ATTN: Institutional Review Board 3890 Central Avenue Memphis, TN 38111

To Whom It May Concern:

Breath of Life Christian Center is pleased to grant permission to Gloria Carr, PhD student, to conduct her study, title, "African American Grandmother Caregivers: Health Status, Methods for receiving information and Service use and needs" at BOLCC. Gloria Carr will distribute invitations for caregiver participation via our church bulletin, contact the prospective participants, and collect data from these individuals in a room at our facility using the appropriate protocols as approved by the University of Texas, Arlington and University of Memphis Institutional Review Boards.

Please feel free to contact my office if you need further information or assistance.

Sincerely,

Rhonda Pegues Director of Operations

PO BOX 281394 · Memphis, TN 38168 · Phone: 901.373.7219 · Fax: 901.373.9404 · www.bolcc.org



Breath of Life Christian Center

3795 Frayser-Raleigh Road · Memphis, TN 38128 Dr. Sammie Holloway, Pastor & Founder

November 8, 2006

University of Texas, Arlington ATTN: Institutional Review Board P. O. Box 19497 Arlington, TX 76019-0497

To Whom It May Concern:

Breath of Life Christian Center is pleased to grant permission to Gloria Carr, PhD student, to conduct her study, title, "African American Grandmother Caregivers: Health Status, Methods for receiving information and Service use and needs" at BOLCC. Gloria Carr will distribute invitations for caregiver participation via our church bulletin, contact the prospective participants, and collect data from these individuals in a room at our facility using the appropriate protocols as approved by the University of Texas, Arlington and University of Memphis Institutional Review Boards.

Please feel free to contact my office if you need further information or assistance.

Sincerely,

Rhonda Pegues Director of Operations

PO BOX 281394 · Memphis, TN 38168 · Phone: 901.373.7219 · Fax: 901.373.9404 · www.bolcc.org

Coleman Avenue Church of Christ

3380 Coleman Avenue • Memphis, Tennessee 38122 • 901-324-8831 E-mail address: colemanavechurchofchrist.org

John J. Deberry, Jr., Minister Samuel P. Thompson, Sr., Associate Minister Elders: John Chatman John J. Deberry, Jr. Deacons: James Fields
Keith House
Richard Hutchison
Lamont Matthews

The Coleman Avenue Church of Christ (CACOC) 3380 Coleman Avenue Memphis, TN 38122

To Whom It May Concern:

The Coleman Avenue Church of Christ (CACOC) is pleased to grant permission to Gloria Carr, PhD Student to conduct her study, titled, "AFRICAN AMERICAN GRANDMOTHER CAREGIVERS: HEALTH STATUS, METHODS FOR RECEIVING INFORMATION AND SERVICE USE AND NEEDS" at CACOC. It is assumed that Gloria Carr will distribute invitations for caregiver participation via our church bulletin, contact the prospective participants, and collect data from these individuals in a room at our facility using the appropriate protocols, as approved by the University of Texas, Arlington and University of Memphis Institutional Review Boards.

Please feel free to contact my office if you need further information or assistance.

Sincerely,

minister

"A Church Where the SON Shines In"



Cummings Street Missionary Baptist Church 250 East Raines Road Memphis, TN 38109

Telephone (901) 332-5492 Fax number (901) 396-0439

January 16, 2007

GARY FAULKNER SENIOR PASTOR

BRO, CALVIN RALLINGS CHAIRMAN OF DEACON

BRO. MILTON MONTGOMERY CHAIRMAN OF FINANCE COMMITTEE

ADMINISTRATIVE STAFF:

REV WILLIAM WATSON MINISTER OF PASTORAL CARE

REV. DR. DWIGHT GUINN MINISTER OF CHRISTIAN EDUCATION

To Whom It May Concern:

BRO, MICHAEL INGRAM PROJECT MANAGER

Cummings Street Missionary Baptist Church (CSMBC) is pleased to grant permission to Gloria Carr, Ph.D. Student to conduct her study, titled, "AFRICAN AMERICAN GRANDMOTHER CAREGIVERS; HEALTH STATUS, METHODS FOR RECEIVING INFORMATION AND SERVICE USE AND NEEDS" at CSMBC. It is assumed that Gloria Carr will distribute invitations for caregiver participation via our church bulletin, schedule a meeting for grandmother caregivers who decide to come, and complete questionnaires with these grandmothers in a room at our facility using the appropriate protocols, as approved by the University of Texas, Arlington and University of Memphis Institutional Review Boards.

Please feel free to contact my office if you need further information or assistance

Sincerely,

Gary Faulkner, Sr.

Pastor /



EMMANUEL EPISCOPAL CENTER

Proclaiming Jesus Christ in Word and Deed

The Rt. Rev. James M. Coleman, Bishop The Rev. Colenzo Hubbard, Executive Director

May 8, 2007

The University of Memphis Loewenberg School of Nursing Newport Hall, Room 306 610 Goodman Street Memphis, TN. 38152

To Whom It May Concern:

The Emmanuel Episcopal Center is pleased to grant permission to Gloria Carr, PhD Student to solicit and meet participants for her study titled "African American Grandmother Caregivers: Relationships Among Information Need, Perceived Burden, Perceived Health, and Service Need and Use" at our facility.

Please feel free to contact my office if you need further information or assistance.

Sincerely,

John mous

Zola Morris

Women on the Move Coordinator

An Outreach Ministry of the Diocese of West Tennessee

604 St. Paul Avenue - Memphis, Tennessee 38126 - 901/523-2617

Friendship Baptist Church 1355 Vollintine Ave. Memphis, TN 38107 (901) 274-5990 Phone (901) 274-0889 Fax

Walter J. Green, Senior Pastor Lonnie D. Wilson, Chair of Deacons Carolyn S. Watkins, Chair of Trustee

Tuesday, December 05, 2006

RE: Gloria Carrs' Grandparent Caregiver Project

To Whom It May Concern:

The Friendship Baptist Church has been a member of the Klondike-North Memphis Community for over the past 102 years. We are committed to providing the best spiritual, social, economical, and personal care possible for our congregants, and the community at large. As a church we seek to partner with agencies, civic and social groups that seek to empower and improve the quality of life for the members of our church community, and the larger Klondike community.

We are pleased to provide any assistance to Mrs. Gloria Carrs for her project with Grandparents. We entrust that all research protocols will be followed in regards to those associated with our church, and the north Memphis community. All liabilities in regards to this project will be the obligation of the researchers.

Again we are pleased to assist in this important venture, and hope that its impact will empower and encourage the participants.

His servant,

Walter J. Green Walter J. Green, Senior Pastor



Luke 4: 18-19, 21

1542 Jackson Avenue Memphis, TN 38107 (901) 272-7337 Office (901) 272-7338 Fax Reverend Andre E. Johnson Senior Pastor

August 12, 2007

Sincerely,

Pastor Andre Johnson The Gift of Life Ministries 1548 Jackson Ave Memphis, TN 38107

To Whom It May Concern:

The Gift of Life Ministries is pleased to grant permission to Gloria Carr, PhD Student to conduct her study, titled, "AFRICAN AMERICAN GRANDMOTHER CAREGIVERS: RELATIONSHIPS AMONG INFORMATION NEED, PERCEIVED HEALTH STATUS, PERCEIVED BURDEN, AND SERVICE USE AND NEEDS" at The Gift of Life Ministries. It is assumed that Gloria Carr will distribute invitations for caregiver participation via our church bulletin, schedule a meeting for grandmother caregivers who decide to come, and complete questionnaires with these grandmothers in a room at our facility using the appropriate protocols, as approved by the University of Texas, Arlington and University of Memphis Institutional Review Boards.

Please feel free to contact my office if you need further information or assistance.



Mississippi Boulevard Christian Church

70 North Bellevue Boulevard • Memphis, TN 38104 (901) 729-6222 • FAX: (901) 726-5418 Web Site: mbccmemphis.org

Dr. Frank A. Thomas Senior Pastor

November 1, 2006

Mississippi Boulevard Christian Church 70 North Bellevue Memphis, TN 38104

To Whom It May Concern:

Mississippi Boulevard Christian Church is pleased to grant permission to Gloria Carr, PhD student, to conduct her study, titled, "African American Grandmother Caregivers: Health Status, Caregiver Reactions, Service Use and Needs, and Methods for Receiving Information" at MBCC.

It is assumed that Gloria Carr will distribute invitations for caregiver participation via our church bulletin, contact the prospective participants, and collect data from these individuals in a room at our facility using the appropriate protocols as approved by the University of Texas, Arlington and University of Memphis Institutional Review Boards.

Please feel free to contact my office if you need further information or assistance.

Sincerely.

Denise Bell Rev. Denise Bell

Senior Associate Pastor

Mississippi Boulevard Christian Church



Mt. Vernon Baptist Church

WESTWOOD, INC.

"There's A Sweet, Sweet Spirit in This Place" Dr. James L. Netters, Senior Pastor

Rev. Melvin Watkins Assistant Pastor

Rev. Hattie M. Thompson

Quincy Hathorn Deacon Board

Clyde Brassell
Deacon Board
Vice-Chairman

Albert Renfrod Trustee Board Chairman

Charles Porter Deacon Board Scoretary

Laverne Joyne Trustee Board Secretary November 22, 2006

TO WHOM IT MAY CONCERN:

The Mount Vernon Baptist Church (MVBC) is pleased to grant permission to Gloria Carr, PhD Student to conduct a meeting in a room at our facility with gandmother caregivers who decide to come. Ms. Carr also has permission to place literature about this meeting at the information booth at the church.

Please feel free to contact my office if you need further information or assistance.

Sincerely,

NS

New Sardis Baptist Church

Organized in 1874 Dr. L. LaSimba M. Gray, Jr. Senior Minister

7739 E. Holmes Rd. Memphis, TN 38125 (901) 754-3979 Phone (901) 759-1911 Fax

September 2, 2007

Dr. L. LaSimba Gray The New Sardis Baptist Church (NSBC) 7739 E. Holmes Rd. Memphis, TN 38125

To Whom It May Concern:

The New Sardis Baptist Church (NSBC) is pleased to grant permission to Gloria Carr, PhD Student to conduct her study, titled, "AFRICAN AMERICAN GRANDMOTHER CAREGIVERS: HEALTH STATUS, METHODS FOR RECEIVING INFORMATION AND SERVICE USE AND NEEDS" at NSBC. It is assumed that Gloria Carr will distribute invitations for caregiver participation via our church bulletin, schedule a meeting for grandmother caregivers who decide to come, and complete questionnaires with these grandmothers in a room at our facility using the appropriate protocols, as approved by the University of Texas, Arlington and University of Memphis Institutional Review Boards.

Please feel free to contact my office if you need further information or assistance.

Sincerely,

Dr.'L. LaSimba Gray

"A Church on the Move with a Mission and a Message"

APPENDIX C

CHURCH BULLETIN ANNOUNCEMENTS

Are You A Grandmother Raising Your Grandchildren?

- What information or services do you need to help you raise your grandchildren?
- How is your health?
- Do you feel stressed?
- Do you feel burdened?
- What methods of receiving information are best for you?

yourself and what you need to help you raise your grandchildren. You may Come join other grandmother caregivers. You will complete surveys about bring other grandmother caregivers with you.

Your assistance is needed and appreciated...Thank you in advance!

Meeting Date:

Place:

Refreshments will be served.

Time:

Please call Gloria Carr at 901-678-3080 for more information.

APPENDIX D CHURCH FLYERS

Are You A Grandmother Raising Your Grandchildren?

What information or services do you need to help you raise your grandchildren?

How is your health?

Do you feel stressed?

Do you feel burdened?

What methods of receiving information are best for you?

yourself and what you need to help you raise your grandchildren. You may Come join other grandmother caregivers. You will complete surveys about bring other grandmother caregivers with you.

Your assistance is needed and appreciated...Thank you in advance!

Meeting Date:

Place:

Refreshments will be served.

Time:

Please call Gloria Carr at 901-678-3080 for more information.

APPENDIX E

PERCEIVED BURDEN

(CAREGIVER REACTION ASSESSMENT)

Perceived Burden (Caregiver Reaction Assessment)

Caregiver Reaction Assessment

Instructions: Please carefully read each of the following statements and then select the anwser that best describes your response to each of the statements. There are no right or wrong answers; just give your own

Not Like This> ⋈ ຝ	Strongly Agree	Agree	Neutral	Disagree	Strongly
1. I feel privileged to care for my grandchildren.	0	0	0	0	0
Others have dumped caring for my grandchildren onto me.	0	0	0	0	0
 My financial resources are adequate to pay for things that are required for a grandmother caregiver. 	0	0	0	0	0
My activities are centered around care for my grandchildren.	0	0	0	0	0
5. Since caring for my grandchildren, it seems like I am tired all of the time.	0	0	0	•	0
6. It is very difficult to get help from my family in taking care of my grandchildren.	0	0	0	0	0
7. I resent having to take care of my grandchildren.	0	0	0	0	0
8. I have to stop in the middle of work.	0	0	0	0	0
9. I really want to care for my grandchildren.	0	0	0	0	0
 My health has gotten worse since I have been caring for my grandchildren. 	0	0	0	0	0
I visit family and friends less since I have been caring for my grandchildren.	0	0	0	0	0
12. I will never be able to do enough caregiving to repay _	o	0	0	0	0

Page 1 of 2

03/08/2007

53180

S	Strongly Agree	Agree	Neutral	Disagree	Strongl Disagre
13. My family works together at caring for my grandchildren	. 0	0	0	0	o
14. I have eliminated things from my schedule since caring for my grandchildren.	0	0	0	0	0
15. I have enough physical strength to care for my grandchildren.	0	0	0	0	0
Since caring for my grandchildren, I feel my family has abandoned me.	0	0	0	0	0
7. Caring for my grandchildren makes me feel good.	0	0	0	0	0
18. The constant interruptions make it difficult to find time for relaxation.	0	0	0	0	0
19. I am healthy enough to care for my grandchildren.	0	0	0	0	0
20. Caring for my grandchildren is important to me.	0	0	0	0	0
21. Caring for my grandchildren has put a financial strain on the family.	0	0	0	0	0
22. My family (brothers, sisters, children) left me alone to care for my grandchildren.	0	0	0	0	0
23. I enjoy caring for my grandchildren.	0	0	0	0	0
24. It is difficult to pay for my grandchildren's health needs and services.	0	0	0	0	0

24. It is difficult to pay for and services.	r my grandchildre	n's health needs	0	0	0	0	0
Caregiver Reaction Assessment	03/08/2007	Page 2 of 2		100	1 -	110	0 0
eleform created 11/09/06 bsd						2003	531802

APPENDIX F $SF-12v2^{\intercal M} \ HEALTH \ SURVEY © 2002$

Your Health and Well-Being

Instructions: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Thank you for completing this survey!

For each of the following questions, please completely fill in the circle next to the answer that best describes your answer.

	O Excellent O Very good O Good O Fair O Poor			
2.	The following questions are about activities you might do	luring a typical da	ay. Does you	r health nov
	limit you in these activities? If so, how much?	Yes, limited a lot	Yes, limited a little	No, not limited at all
	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	0	0	0
	Climbing several flights of stairs	0	0	0

work or other regular daily activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Accomplished less than you would like	0	0	0	0	0
Were limited in the kind of work or other activities	0	0	0	0	0

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Accomplished less than you would like	0	0	0	0	0
Did work or other activities less <u>carefully than usual</u>	0	0	0	0	0

						- 1			10.00		
SF-12v2 Health Survey	THE PROPERTY OF	D 1 62	1	^		1	30	1	1		
16304	03/08/2007	Page 1 of 2	Т	U	U	Т	-	Т	1	U	0

SF-12v2TM Health Survey 1994, 2002 by QualityMetric Inc SF-12® a registered trademark of Medical Outcomes Trust. (SF12v2 Standard, US Version 2.0) 0614163045

107

		All of the time	Most of the time	Some of the time	A little of the time	None of the time				
	Have you felt calm and peaceful? Did you have a lot of energy?	0		0	0	0				
		0		0	0					
	Have you felt downhearted and depressed?	0	0	0	0	0				
7.	During the past 4 weeks, how much of interfered with your social activities (notional probl	ems				
	O All of the time									
	O Most of the time									
	O Some of the time									
	O A little of the time									
	O None of the time									
_	Thank you for	completii	ng these	e quest	ions!					

5. During the <u>past 4 weeks</u>, how much did pain interfere with your normal work (including both work outside the home and housework)?

O Not at all O A little bit O Moderately O Quite a bit O Extermely

APPENDIX G DEMOGRAPHIC DATA FORM

Demographic Data Form

The following questions are for classification confidential.	n purposes only and will be kept entirely
1. My age on my last birthday was	years.
2. I am raising grandchildren (How	many).
3. I have been raising my grandchild for	years (How long).
4. My highest level of education completed	is years.
5. My total household income in 2006 was	\$
 6. My current work status is: O Full-time O Part-time O Retired and not working O Unemployed and looking for work O Not working due to being ill or disable O Other such as homemaker 	
7. My sources of income include: (CHECK	ALL THAT APPLY)
O Salary O Child Support O AFDC O Salary O Social Security O Retirement/Pen O Other	sion
8. My insurance coverage is provided by:	
O Employer O Tenncare O Medicare O None (I do not have any) O Other (Please write in answer):	ease Print Clearly
O Other (Please write in answer):	Pase Print Clearly

9. Currently, I am:	
O Married	
O Widowed	
O Divorced	
O Separated	
O Live with Partner	
O Never married	
10. I have:	
O Legal guardianship of my grandchildren	
O Adopted my grandchildren	
O Foster parent of my grandchildren	
O No formal custody of my grandchildren	
11. The gender of my grandchildren are:	
O Male How many?	
O Female How many?	
12. My grandchildren spend amount of tir	ne with their parents each week.
(Please print answer below.)	ne with their parents each week.
Which parent? O Mother O Father O Both	7.
Describe your grandchildren's contact with their	r parents:
Describe your grandenndren's contact with their	i parents.
	9111117
	Metaployer
3. Are you primarily responsible for the basic need	ds of other kin who are living with
you? By kin we are referring both to relatives ar	nd non-relatives who you consider part
of your family.	
O Yes O No	

14. Rate how much you <u>need</u> the following <u>Information</u> to help you raise your grandchildren:

s	trongly Agree	Agree Ne	either Agre	e Disagree	Strongly Disagree
Disciplining your grandchildren	0	0	0	0	0
Coping with sick grandchildren	0	0	0	0	0
Educating your grandchildren	0	0	0	0	0
Homework tutoring for your grandchildren	0	0	0	0	0
Counseling for your grandchildren	0	0	0	0	0
Counseling for grandmother caregivers	0	0	0	0	0
Access to daycare for your grandchildren	n 0	0	0	0	0
How to speak to the parents of grandchildren you are raising about child support	0	0	0	0	0
Legal help for getting child support from the grandchildren's parents	0	0	0	0	0
Legal help for getting custody of your grandchildren	0	0	0	0	0
How to speak to grandchildren about sexual activity	0	0	0	0	0
How to speak to grandchildren about drug use	0	0	0	0	0
How to speak to grandchildren about their friends	0	0	0	0	0
Healthcare coverage for your grandchildren	0	0	0	0	0
Medication expenses for your grandchildren	0	0	0	0	0
Support groups for people raising grandchildren	0	0	0	0	0
Support groups for teenage grandchildren	0	0	0	0	0
Community resources for children activities	0	0	0	0	0
Demographics (GCarr)			100	1 - 1 :	100

03/09/2007 Page 3 of 8

Transfer to the second state of	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
Community resources for grandparent activities	0	0	0	0	0
Parenting your grandchildren	0	0	0	0	0
Financial resources for people raising grandchildren	0	0	0	0	0

15. Rate how much you need the following Services to help you raise your grandchildren:

St	trongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
Disciplining your grandchildren	0	0	0	0	0
Coping with sick grandchildren	0	0	0	0	0
Educating your grandchildren	0	0	0	0	0
Homework tutoring for your grandchildren	0	0	0	0	0
Counseling for your grandchildren	0	0	0	0	0
Counseling for grandmother caregivers	0	0	0	0	0
Access to daycare for your grandchildren	1 0	0	0	0	0
How to speak to the parents of grandchildren you are raising about child support	0	0	0	0	0
Legal help for getting child support from the grandchildren's parents	0	0	0	0	0
Legal help for getting custody of your grandchildren	0	0	0	0	0
How to speak to grandchildren about sexual activity	0	0	0	0	0
How to speak to grandchildren about drug use	0	0	0	0	0
How to speak to grandchildren about their friends	0	0	0	0	0
Healthcare coverage for your grandchildren	0	0	0	0	0
Medication expenses for your grandchildren	0	0	0	0	0

Page 4 of 8

	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
Support groups for people raising grandchildren	0	0	0	0	0
Support groups for teenage grandchildren	0	0	0	0	0
Community resources for children activities	0	0	0	0	0
Community resources for grandparent activities	0	0	0	0	0
Parenting your grandchildren	0	0	0	0	0
Financial resources for people raising grandchildren	0	0	0	0	0

16. Rate how much you have <u>used</u> the following <u>Information</u> to help you raise your grandchildren:

	Iways		Sometimes		Never
Disciplining your grandchildren	0	0	0	0	0
Coping with sick grandchildren	0	0	0	0	0
Educating your grandchildren	0	0	0	0	0
Homework tutoring for your grandchildren	0	0	0	0	0
Counseling for your grandchildren	0	0	0	0	0
Counseling for grandmother caregivers	0	0	0	0	0
Access to daycare for your grandchildren	0	0	0	0	0
How to speak to the parents of grandchildren you are raising about child support	0	0	0	0	0
Legal help for getting child support from the grandchildren's parents	0	0	0	0	0
Legal help for getting custody of your grandchildren	0	0	0	0	0
How to speak to grandchildren about sexual activity	0	0	0	0	0
How to speak to grandchildren about drug use	0	0	0	0	0

Demographics (GCarr)
62371 03/09/2007
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1 0 0 1 - 1 1 0 0
8226623717

	Always		Sometimes		Never
How to speak to grandchildren about their friends	0	0	0	0	0
Healthcare coverage for your grandchildren	0	0	0	0	0
Medication expenses for your grandchildren	0	0	0	0	0
Support groups for people raising grandchildren	0	0	0	0	0
Support groups for teenage grandchildren	0	0	0	0	0
Community resources for children activities	0	0	0	0	0
Community resources for grandparent activities	0	0	0	0	0
Parenting your grandchildren	0	0	0	0	0
Financial resources for people raising grandchildren	0	0	0	0	0

17. Rate how much you have $\underline{\sf used}$ the following $\underline{\sf Services}$ to help you raise your grandchildren:

A	lways		Sometimes	101	Never
Disciplining your grandchildren	0	0	0	0	0
Coping with sick grandchildren	0	0	0	0	0
Educating your grandchildren	0	0	0	0	0
Homework tutoring for your grandchildren	0	0	0	0	0
Counseling for your grandchildren	0	0	0	0	0
Counseling for grandmother caregivers	0	0	0	0	0
Access to daycare for your grandchildren	0	0	0	0	0
How to speak to the parents of grandchildren you are raising about child support	0	0	0	0	0
Legal help for getting child support from the grandchildren's parents	0	0	0	0	0

Demographics (GCarr)
62371 03/09/2007
Page 6 of 8

1 0 0 1 - 1 1 0 0
8345623719

	Always		Sometimes		Never
Legal help for getting custody of your grandchildren	0	0	0	0	0
How to speak to grandchildren about sexual activity	0	0	0	0	0
How to speak to grandchildren about drug use	0	0	0	0	0
How to speak to grandchildren about their friends	0	0	0	0	0
Healthcare coverage for your grandchildren	0	0	0	0	0
Medication expenses for your grandchildren	0	0	0	0	0
Support groups for people raising grandchildren	0	0	0	0	0
Support groups for teenage grandchildren	0	0	0	0	0
Community resources for children activities	0	0	0	0	0
Community resources for grandparent activities	0	0	0	0	0
Parenting your grandchildren	0	0	0	0	0
Financial resources for people raising grandchildren	0	0	0	0	0

18. Please rate which way you would <u>most</u> prefer to receive information about raising

grandchildren from the list below.	Strongly Agree	Agree	Neither Agree	Disagree	Strongly Disagree
E-mails	0	0	0	0	0
Web pages or web sites	0	0	0	0	0
Speakers or classes in your church	0	0	0	0	0
Newsletters or brochures sent in the ma	il o	0	0	0	0
Magazine or newspaper articles	0	0	0	0	0
Books	0	0	0	0	0
Videos or DVDs	0	0	0	0	0

Demographics (GCarr)
62371 03/09/2007
Page 7 of 8

	omputer at home, at work, or some other place?
O Yes O No	
IF YES:	
Do you have access to the Int	ternet or the ability to use online services?
O Yes O No O Don't know	v
For me the most difficult part	t of raising my grandchildren is:
	ne minkantin
	and the second s
For me the best part of raising	g my grandemden is:
6.2	
	Administration (Control of the Control of the Contr
	war a mining

APPENDIX H INSTRUMENT USE PERMISSION

Instrument Use Permission

Demographic Data Form

From: Binette, Joanne [mailto:JBinette@aarp.org]

Sent: Fri 1/12/2007 2:52 PM **To:** Gloria Fulton Carr (gcarr)

Cc: Guengerich, Terri

Subject: FW: AARP Tennessee Member Opinion Survey

Hi Gloria,

I'm responding for Terri. You can go ahead and feel free to use our survey as a guide for your own evaluation. I don't have any reliability evaluations for this survey.

If you have any other questions please let me know. I'll be back in the office on Tuesday.

Thanks, Joanne

Caregiver Reaction Assessment

From: Lindsay Morris [mailto:Lindsay.Morris@hc.msu.edu]

Sent: Mon 10/16/2006 6:16 AM To: Gloria Fulton Carr (gcarr) Subject: Re: Tool Use Request

We are happy to provide you with the Caregiver Reaction Assessment (CRA) from the Family Care Research Program at Michigan State University.

It is available online at: http://www.cancercare.msu.edu/tools/tooluse.htm.

From here you may view it online, or print off a hard copy.

Should you have any questions or comments, please don't hesitate to contact us.

Regards,

Lindsay Morris Family Care Studies Michigan State University B510 West Fee Hall East Lansing, MI 48824 (517) 353-0306

Short Form12v2TM Health Survey

From: Dana Kopac on behalf of Heather Looney

Sent: Wed 11/8/2006 8:37 AM To: Gloria Fulton Carr (gcarr)

Subject: Survey Forms for License #28401

Dear Gloria,

Thank you for returning the signed agreement and payment to license version 2 of the, SF-12v2TM, 4-week (standard) Health Survey(s). Please find attached Microsoft Word and Adobe Acrobat files for the language(s) you have requested to license.

NOTE: If you have licensed other languages besides US English, please print a hard copy of the Adobe Acrobat file for each translation. We would like to ask that you compare the Microsoft Word file against the Adobe Acrobat file before administering the surveys to your patients. If you do not have Adobe Acrobat Reader installed on your computer, you can download a FREE copy at http://www.adobe.com/support/downloads/main.html The reason for this verification is your computer may not have all the fonts installed to open up the Microsoft Word document correctly.

Please do not hesitate to contact me with questions.

<u>www.qualitymetric.com</u> - information about our products, consulting services and licensing our surveys

www.sf-36.org - information about our surveys

www.iqola.org - information about the validation of our surveys

Kind Regards,

Dana Kopec Administrative Assistant Phone: 401.642.9267 Fax: 401.334.8770

dkopac@qualitymetric.com

APPENDIX I DATA COLLECTION SCRIPT

Data Collection Script

1) Introductions:

Hello my name is Gloria Carr (please call me Gloria). I am the facilitator/leader of your meeting. I am a graduate student at the University of Texas and am in the process of completing my dissertation study. I am interested in learning about grandmothers raising grandchildren in Memphis and what services grandmothers need to help them raise their grandchildren.

We are here today so that you can complete surveys about yourself, your health, how grandparenting has influenced your life, and services you think would help you to raise your grandchildren. There are no right or wrong answers, so complete the survey honestly. All information that you provide will be kept confidential. Your names will not be connected to any information that you provide. Once these surveys are collected, they will be kept in a locked cabinet. I am the only person who has a key to the locked cabinet.

To compensate for your time, you will be given a meal coupon from a fast food chain in Memphis, TN once everyone has completed the surveys. In addition, each of you has two tickets with the same number. At the end of this, you will keep one ticket and place the other in a basket to draw for a family dinner.

After all of your information has been categorized, I will be back to share the information with you.

2) Obtain informed consent

There is an information sheet in front of you. Please read this form completely. We will take time for you to ask questions and me to respond after everyone has indicated that they are finished reading the sheet. You may begin reading (Wait and look for indications of completion from participants). Ask: Have all of you completely read the information sheet? If yes...Ask: Are there any questions? Respond to questions. Inform participants that they may keep the research information sheet to refer to later if needed. Also, inform participants that completing the surveys will serve as their consent to participating in this study. However, you may stop completing the surveys at any time during this process.

3) Completion of the surveys

You may begin completing the surveys. There is no right or wrong answer. Please raise your hands if you have any questions. (Wait and look for indications of completion from participants). Ask: Have all of you completed the surveys?

If yes, serve refreshments.

4) Refreshments

Let's take a 10 minute break for refreshments and mingling. Give the meal coupon. Ask participants for one of their tickets to place in the basket. Ask one of the grandmother participants to draw a ticket. Call out the winning number. Congratulations to the winner!!!

Remember to look for flyers informing you of my return date so that I can share this information with you. I look forward to seeing you all then.

Thank you. Thank you, Thank you

5) Distribute Certificates of Appreciation

APPENDIX J

INSTITUTIONAL REVIEW BOARDS INITIAL APPROVAL

Institutional Review Boards Initial Approval

The University of Memphis

THE UNIVERSITY OF MEMPHIS

Institutional Review Board

To:

Gloria Carr

Nursing

From:

Chair, Institutional Review Board

for the Protection of Human Subjects

Administration 315

Subject:

African America Grandmother Caregivers: Relationships Among Information Need, Perceived Burden, Perceived Health, and Service Need and Use (E07-202)

Approval Date: February 22, 2007

This is to notify you that the Institutional Review Board has designated the above referenced protocol as exempt from the full federal regulations. This project was reviewed in accordance with all applicable statutes and regulations as well as ethical principles.

When the project is finished or terminated, please complete the attached Notice of Completion and send to the Board in Administration 315.

Approval for this protocol does not expire. However, any change to the protocol must be reviewed and approved by the board prior to implementing the change.

Chair, Institutional Review Board The University of Memphis

Dr. J. Gray

The University of Texas at Arlington



OF TEXAS

AT ARLINGTON

Office of Research Integrity and Compliance

> Box 19188 202 E. Border Arlington, Texas 76019-0188

T 817.272.3723 F 817.272.1111 www.uta.research February 28, 2007

Gloria Carr Jennifer Gray, PhD Nursing Box 19407

TITLE: African American Grandmother Caregivers: Relationships among Information Need, Perceived Burden, Perceived Health and Service Need and Use

Re: Exempt Approval Letter

IRB No.: 07.124e

The UTA Institutional Review Board (UTA IRB) Chair (or designee) has reviewed the above-referenced study and found that it qualified as exempt from coverage under the federal guidelines for the protection of human subjects as referenced at Title 45--Part 46.101(b)(2). You are therefore authorized to begin the research as of February 15, 2007.

Please be advised that as the principal investigator, you are required to report local adverse (unanticipated) events to this office within 24 hours. In addition, pursuant to Title 45 CFR 46.103(b)(4)(iii), investigators are required to, "promptly report to the IRB any proposed changes in the research activity, and to ensure that such changes in approved research, during the period for which IRB approval has already been given, are not initiated without IRB review and approval except when necessary to eliminate apparent immediate hazards to the subject."

All investigators and key personnel identified in the protocol must have documented *CITI Training* on file with this office. The UTA Office of Research Integrity and Compliance appreciates your continuing commitment to the protection of human research subjects. Should you have questions or require further assistance, please contact this office by calling (817) 272-2775 or (817) 272-3723.

Yours sincerely,

Judy Wilson, PhD Associate Professor

UTA IRB/Clinical Vice-Chair

APPENDIX K

INSTITUTIONAL REVIEW BOARDS MODIFICATION APPROVAL

Institutional Review Boards Modification Approval

The University of Memphis

THE UNIVERSITY OF MEMPHIS

Memorandum

TO:

Gloria Carr

Nursing

FROM:

Chairperson, University Committee on the Protection of Human Research Participants

SUBJECT:

Review and Approval of Research Protocol Modification

TITLE:

African America Grandmother Caregivers: Relationships Among Information Need, Perceived Burden, Perceived

Health, and Service Need and Use (E07-202)

DATE:

June 6, 2007

Modifications:

Including survey in packets given by community agencies

and institutions

This is to confirm Committee approval of the modifications to the above referenced research protocol. These revisions were reviewed and approved 6/6/07 in accordance with all applicable statutes and regulations as well as ethical principles.

Dr. J. Gray

The University of Texas at Arlington



THE UNIVERSITY
OF TEXAS

AT ARLINGTON

Office of Research Integrity and Compliance

> Box 19188 202 E. Border Arlington, Texas 76019-0188

T 817.272.3723 F 817.272.1111 www.uta.research April 23, 2007

Gloria Carr Jennifer Gray, PhD Nursing Box 19407

RE: Minor Modification Approval Letter

Title: African American Grandmother Caregivers: Relationships Among

Information need, perceived Burden, Perceived Health, and Service

Need and Use

IRB No.: 07.124e

The UTA Institutional Review Board (UTA IRB) Chair (or designee) reviewed and approved the modification(s) to this protocol on **April 23, 2007** in accordance with Title 45 CFR 46. 110(b)(2). Therefore, you are authorized to conduct your research. The modification(s), indicated below, was deemed minor and appropriate for expedited review.

· Protocol modified to add additional community agency sites

Pursuant to Title 45 CFR 46.103(b)(4)(iii), investigators are required to, "promptly report to the IRB <u>any</u> proposed changes in the research activity, and ensure that such changes in approved research, during the period for which IRB approval has already been given, are not initiated without IRB review and approval except when necessary to eliminate apparent immediate hazards to the subject."

The modification approval will additionally be presented to the convened board on May 8, 2007 for full IRB acknowledgment [45 CFR 46.110(c)]. All investigators and key personnel identified in the protocol must have documented *Human Subjects Involved in Research (Tier II) Training* or other UTA approved compliance education in the responsible conduct of human subject research on file with the UTA Office of Research Integrity and Compliance (ORIC).

The UTA Office of Research Integrity and Compliance appreciates your continuing commitment to the protection of human research subjects. Should you have questions or require further assistance, please contact this office by calling (817) 272-0867.

Sincerely, Jupo, PND, RJ, CNAA, BC

Patricia Turpin, PhD, RN, CNAA, BC

Associate Clinical Professor

IRB Clinical Chair

APPENDIX L

FREQUENCY DISTRIBUTION TABLE FOR INFORMATION NEED

Frequency Distribution Table for Information Need

Item	SA	A	Z	D	SD	M(SD)
	N (%)	N (%)	N (%)	N (%)	N (%)	
Rate how much you <u>need</u> the following <u>Information</u> to help you raise your grandchildren:						
Disciplining your grandchildren	35(37.6)	20(21.5)	10(10.8)	11(11.8)	16(17.2)	2.49(1.523)
Coping with sick grandchildren	20(21.5)	26(28)	12(12.9)	15(16.1)	20(21.5)	2.88(1.473)
Educating your grandchildren	47(50.5)	22(23.7)	5(5.4)	8(8.6)	9(9.7)	2.01(1.354)
Homework tutoring for your grandchildren	41(44.1)	23(24.7)	11(11.8)	9(9.7)	9(9.7)	2.16(1.346)
Counseling for your grandchildren	37(39.8)	23(24.7)	11(11.8)	9(9.7)	11(11.8)	2.27(1.399)
Counseling for grandmother caregivers	37(39.8)	22(23.7)	11(11.8)	8(8.6)	11(11.8)	2.26(1.402)
Access to daycare for your grandchildren	23(24.7)	27(29)	8(8.6)	8(8.6)	24(25.8)	2.81(1.571)
How to speak to the parents of grandchildren you are raising about child support	30(32.3)	25(26.9)	11(11.8)	10(10.8)	17(18.3)	2.56(1.492)
Legal help for getting child support from the grandchildren's parents	34(36.6)	16(17.2)	(2.6)6	13(14)	20(21.5)	2.66(1.605)
Legal help for getting custody of your grandchildren	14(15.1)	15(16.1)	17(18.3)	16(17.2)	28(30.1)	3.32(1.460)
How to speak to grandchildren about sexual activity	31(33.3)	28(30.1)	(6.5)	13(14)	15(16.1)	2.49(1.479)
How to speak to grandchildren about drug use	40(43)	23(24.7)	3(3.2)	12(12.9) 15(16.1)	15(16.1)	2.34(1.529)

Item	SA	A	Z	D	SD	M(SD)
	N(%)	N (%)	N (%)	N (%)	N (%)	,
Rate how much you <u>need</u> the following <u>Information</u> to help you raise your grandchildren:						
How to speak to grandchildren about their friends	38(40.9)	24(25.8)	6(6.5)	12(12.9)	13(14)	2.33(1.469)
Healthcare coverage for your grandchildren	34(36.6)	25(26.9)	5(5.4)	8(8.6)	19(20.4)	2.48(1.566)
Medication expenses for your grandchildren	35(37.6)	23(24.7)	7(7.5)	9(9.7)	18(19.4)	2.48(1.551)
Support groups for people raising grandchildren	44(47.3)	21(22.6)	9(9.7)	7(7.5)	11(11.8)	2.13(1.400)
Support groups for teenage grandchildren	40(43)	15(16.1)	12(12.9)	9(9.7)	16(17.2)	2.41(1.542)
Community resources for children activities	52(55.9)	21(22.6)	4(4.3)	7(7.5)	9 (9.7)	1.92(1.337)
Community resources for grandparent activities	42(45.2)	23(24.7)	11(11.8)	8(8.6)	9(9.7)	2.31(1.337)
Parenting your grandchildren	38(40.9)	24(25.8)	8(8.6)	10(10.8)	12(12.9)	2.28(1.432)
Financial resources for people raising grandchildren	50(53.8)	23(24.7)	9(9.7)	5(5.4)	6(6.5)	1.86(1.194)

APPENDIX M

FREQUENCY DISTRIBUTION TABLE FOR SERVICE NEED

Frequency Distribution Table for Service Need

Item	SA	A	Z	D	SD	M(SD)
	N(%)	N (%)	N (%)	N (%)	N (%)	
Rate how much you <u>need</u> the following <u>Services</u> to help you raise your grandchildren:						
Disciplining your grandchildren	25(26.9)	23(24.7)	12(12.9)	14(15.1)	19(20.4)	2.77(1.505)
Coping with sick grandchildren	20(21.5)	25(26.9)	13(14)	14(15.1)	20(21.5)	2.88(1.474)
Educating your grandchildren	48(51.6)	22(23.7)	6(6.5)	8(8.6)	7(7.5)	1.95(1.285)
Homework tutoring for your grandchildren	41(44.1)	27(29)	9(9.7)	7(7.5)	9(9.7)	2.10(1.311)
Counseling for your grandchildren	36(38.7)	29(31.2)	8(8.6)	9(9.7)	11(11.8)	2.25(1.373)
Counseling for grandmother caregivers	34(36.6)	29(31.2)	8(8.6)	8(8.6)	12(12.9)	2.29(1.393)
Access to daycare for your grandchildren	19(20.4)	30(32.3)	10(10.8)	10(14)	10(14) 19(20.4)	2.81(1.460)
How to speak to the parents of grandchildren you are raising about child support	29(31.2)	26(28)	(2.6)6	11(11.8)	17(18.3)	2.58(1.499)
Legal help for getting child support from the grandchildren's parents	29(31.2)	19(20.4)	11(11.8)	14(15.1)	19(20.4)	2.73(1.549)
Legal help for getting custody of your grandchildren	12(12.9)	12(12.9)	21(22.6)	18(19.4)	28(30.1)	3.42(1.391)
How to speak to grandchildren about sexual activity	35(37.6)	20(21.5)	9(9.7)	14(15.1)	15(16.1)	2.51(1.515)
How to speak to grandchildren about drug use	40(43)	20(21.5)	5(5.4)	13(14)	13(14) 15(16.1)	2.39(1.540)

Item	SA	A	Z	D	SD	M(SD)
	N (%)	N (%)	N (%)	N (%)	N (%)	,
Rate how much you <u>need</u> the following <u>Services</u> to help you raise your grandchildren:						
How to speak to grandchildren about their friends	35(37.6)	24(25.8)	7(7.5)	13(14)	13(14)	2.40(1.468)
Healthcare coverage for your grandchildren	34(36.6)	24(25.8)	10(10.8)	7(7.5)	17(18.3)	2.45(1.507)
Medication expenses for your grandchildren	31(33.3)	24(25.8)	11(11.8)	7(7.5)	18(19.4)	2.53(1.551)
Support groups for people raising grandchildren	42(45.2)	26(28)	9(9.7)	7(7.5)	9(9.7)	2.09(1.316)
Support groups for teenage grandchildren	33(35.5)	18(19.4)	12(12.9)	9(9.7)	19(20.4)	2.59(1.563)
Community resources for children activities	46(49.5)	26(28)	6(6.5)	6(6.5)	8 (8.6)	1.96(1.275)
Community resources for grandparent activities	41(44.1)	22(23.7)	11(11.8)	8(8.6)	(2.6)6	2.14(1.346)
Parenting your grandchildren	35(37.6)	24(25.8)	7(7.5)	13(14)	13(14)	2.40(1.468)
Financial resources for people raising grandchildren	53(57)	21(22.6)	9(9.7)	3(3.2)	5(5.4) 5)	1.75(1.112)

APPENDIX N FREQUENCY DISTRIBUTION TABLE FOR SERVICE USE

Frequency Distribution Table for Service Use

Item	Always		Sometimes		Never	M(SD)
	N (%)	N (%)	N (%)	N (%)	N (%)	
Rate how much you <u>Use</u> the following <u>Services</u> to help you raise your grandchildren:						
Disciplining your grandchildren	26(28)	3(3.2)	14(15.1)	2(2.2)	44(47.3)	3.39(1.756)
Coping with sick grandchildren	20(21.5)	1(1.1)	18(19.4)	2(2.2)	47(50.5)	3.63(1.649)
Educating your grandchildren	31(33.3)	1(1.1)	20(21.5)	4(4.3)	34(36.6)	3.10(1.723)
Homework tutoring for your grandchildren	22(23.7)	3(3.2)	25(26.9)	3(3.2)	37(39.8)	3.33(1.615)
Counseling for your grandchildren	22(23.7)	4(4.3)	13(14)	0	51(54.8)	3.60(1.721)
Counseling for grandmother caregivers	14(15.1)	5(5.4)	13(14)	3(3.2)	54(58.1)	3.88(1.551)
Access to daycare for your grandchildren	18(19.4)	8(8.6)	18(19.4)	3(3.2)	42(45.2)	3.48(1.617)
How to speak to the parents of grandchildren you are raising about child support	17(18.3)	(6.5)	15(16.1)	1(1.1)	51(54.8)	3.70(1.625)
Legal help for getting child support from the grandchildren's parents	20(21.5)	3(3.2)	13(14)	5(5.4)	49(52.7)	3.67(1.656)
Legal help for getting custody of your grandchildren	15(16.1)	5(5.4)	17(18.3)	6(6.5)	48(51.6)	3.74(1.541)
How to speak to grandchildren about sexual activity	19(20.4)	5(5.4)	15(16.1)	0	52(55.9)	3.67(1.660)

Item	Always		Sometimes		Never	M(SD)
	N (%)	N (%)	N (%)	N (%)	N (%)	
Rate how much you <u>Use</u> the following <u>Services</u> to help you raise your grandchildren:						
How to speak to grandchildren about drug use	23(24.7)	4(4.3)	13(14)	1(1.1)	50(53.8)	3.56(1.727)
How to speak to grandchildren about their friends	23(24.7)	4(4.3)	18(19.4)	1(1.1)	45(48.4)	3.45(1.695)
Healthcare coverage for your grandchildren	39(41.9)	5(5.4)	17(18.3)	4(4.3)	26(28)	2.70(1.703)
Medication expenses for your grandchildren	36(38.7)	6(6.5)	17(18.3)	3(3.2)	29(31.2)	2.81(1.719)
Support groups for people raising grandchildren	20(21.5)	3(3.2)	13(14)	0	55(59.1)	3.74(1.679)
Support groups for teenage grandchildren	16(17.2)	5(5.4)	14(15.1)	1(1.1)	54(58.1)	3.80(1.602)
Community resources for children activities	19(20.4)	8(8.6)	23(24.7)	1(1.1)	40(43)	3.38(1.604)
Community resources for grandparent activities	19(20.4)	4(4.3)	16(17.2)	2(2.2)	50(53.8)	3.66(1.641)
Parenting your grandchildren	22(23.7)	4(4.3)	17(18.3)	1(1.1)	47(50.5)	3.52(1.689)
Financial resources for people raising grandchildren	20(21.5)	3(3.2)	18(19.4)	3(3.2)	47(50.5)	3.59(1.640)

APPENDIX O

FREQUENCY DISTRIBUTION TABLE FOR PERCEIVED BURDEN

Frequency Distribution Table for Perceived Burden

Item	SA	A	z	D	SD	M(SD)
	N (%)	N (%)	N (%)	N (%)	N (%)	
I feel privileged to care for my grandchildren.	61(65.6)	25(26.9)	4(4.3)	2(2.2)	0	1.42(.683)
Others have dumped caring for my grandchildren onto me.	24(25.8)	23(24.7)	10(10.8)	20(21.5)	15(16.1)	2.77(1.461)
My financial resources are adequate to pay for things that are required for a grandmother caregiver.	31(33.3)	21(22.6)	5(5.4)	20(21.5)	15(16.1)	2.64(1.531)
My activities are centered around care for my grandchildren.	41(44.1)	36 (38.7)	8(8.6)	7(7.5)	0	1.79(.896)
Since caring for my grandchildren, it seems like I am tired all of the time.	20(21.5)	19(20.4)	24(25.8)	18(19.4)	11(11.8)	2.79(1.314)
It is very difficult to get help from my family in taking care of my grandchildren.	21(22.6)	15(16.1)	12(12.9)	27(29)	16(7.2)	3.02(1.453)
I resent having to take care of my grandchildren.	50(53.8)	20(21.5)	9(9.7)	6(6.5)	7(7.5)	1.91(1.264)
I have to stop in the middle of work.	12(12.9)	23(24.7)	13(14)	17(18.3)	26(28)	3.24(1.440)
I really want to care for my grandchildren.	54(58.1)	21(22.6)	9(9.7)	5(5.4)	2(2.2)	1.68(1.010)

Item	SA	A	Z	D	SD	M(SD)
	N (%)					
My health has gotten worse since I have been caring for my grandchildren.	14(15.1)	13(14)	12(12.9)	21(22.6)	32(34.4)	3.48(1.471)
I visit family and friends less since I have been caring for my grandchildren.	20(21.4)	22(23.7)	7(7.5)	17(18.3)	26(28)	3.08(1.564)
I will never be able to do enough caregiving to repay	26(28)	28(30.1)	12(12.9)	15(16.1)	9(9.7)	2.48(1.334)
My family works together at caring for my grandchildren.	13(14)	12(12.9)	13(14)	32(34.4)	22(23.7)	3.41(1.360)
I have eliminated things from my schedule since caring for my grandchildren.	23(24.7)	39(41.9)	8(8.6)	11(11.8)	10(10.8)	2.41(1.291)
I have enough physical strength to care for my grandchildren.	3(3.2)	13(14)	12(12.9)	35(37.6)	29(31.2)	3.80(1.131)
Since caring for my grandchildren, I feel my family has abandoned me.	5(5.4)	8(8.6)	6(6.5)	33(35.3)	39(41.9)	4.02(1.164)
Caring for my grandchildren makes me feel good.	44(47.3)	37(39.8)	9(9.7)	2(2.2)	0	1.66(.745)
The constant interruptions make it difficult to find time for relaxation.	15(16.1)	31(33.3)	9(9.7)	21(22.6)	16(17.2	2.91(13.88)

Item	SA	A (20) W	N	D (90.2)	QS	M(SD)
	N (%)	(%) N	N (%)	N (%)	(%) VI	
I am healthy enough to care for my grandchildren.	1(1.1)	7(7.5)	7(7.5) 10(10.8)	43(46.2)	31(33.3)	4.04(.925)
Caring for my grandchildren is important to me.	62(66.7)	26(28)	4(4.3)	0	0	1.37(.569)
Caring for my grandchildren has put a financial strain on the family	25(26.9)	25(26.9) 15(16.1) 11(11.8)	11(11.8)	28(30.1)	13(14)	2.88(1.459)
My family (brothers, sisters, children) left me alone to care for my grandchildren.	7(7.5)	11(11.8)	7(7.5)	7(7.5) 36(38.7)	31(33.3)	3.79(1.245)
I enjoy caring for my grandchildren.	56(60.2)	28(30.1)	8(8.6)	0	0	1.48(.654)
It is difficult to pay for my grandchildren's health needs and services.	15(16.1)	15(16.1) 21(22.6) 18(19.4) 21(22.6) 17(18.3)	18(19.4)	21(22.6)	17(18.3)	3.04(1.366)

APPENDIX P

FREQUENCY DISTRIBUTION TABLE FOR PERCEIVED HEALTH

Frequency Distribution Table for Perceived Health

Item	N (%)	N (%)	N (%)	N (%)	N (%)	M(SD)
	Excellent	Very Good	Good	Fair	Poor	
General Health	5(5.4)	12(12.9)	44(47.3)	26(28)	4(4.3)	3.13(.897)
	Yes, limited	Yes, limited	No, not limited			
	a lot	a little	at all			
Physical Activities: Can you						
Push a vacuum cleaner?	21(22.6)	21(22.6)	50(53.8)			2.32(.824)
Climb stairs?	24(25.8)	32(34.4)	36(38.7)			2.13(.801)
	All of the time	Most of the time	Some of the time	A little of the	None of the time	
				time		

Problems as a result of your physical health:						
<u>Do you do all</u> you would Like?	6(6.5)	6(6.5) 23(24.7)	31(33.3)	13(14)	19(20.4)	19(20.4) 3.17(1.210)
Limited in work or other activities	6(6.5)	6(6.5) 18(19.4)	33(35.5)	7(7.5)	27(29)	3.34(1.276)
Problems as a result of emotional problems:						
Did less than you want? Were less careful than usual?	2(2.2)	2(2.2) 15(16.1)	29(31.2)	29(31.2) 17(18.3)	28(30.1)	3.59(1.154)
	3(3.2)	8(8.6)	53(55.5)	18(19.4)	30(32.3)	3./0(1.11/)
	Not at all	A little bit	Moderately	Quite a	Extremely	

Pain interference inside or outside home?	29(31.2)	21(22.6)	21(22.6)	14(15.1)	6(6.5)	2.42(1.265)
	All of the time	Most of the time	Some of the time	A little of the time	None of the time	
How much:						
Have you felt calm and peaceful?	14(15.4)	34(36.6)	35(37.6)	10(10.8)	0	2.44(.878)
	8(8.6)	26(28)	44(47.3)	9(9.7)	6(6.5)	2.77(.968)
Did you have a lot of energy?	1(1.1)	6(6.5)	34(36.6)	16(17.2)	36(38.7)	3.86(1.049)
Have you felt downhearted and depressed?						
How much has your <u>physical</u> health or emotional <u>problems</u> kept	5(5.4)	5(5.4) 11(11.8)	31(33.3)	31(33.3) 21(22.6)	25(26.9)	3.54(1.166)
you from visiting others?						

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BIOGRAPHICAL INFORMATION

As a nurse with many years experience, I have enjoyed an on-going practice in service and academia. My nursing education began with completion of a Diploma in Nursing. A Master of Science degree was completed within seven years of my initial nursing education. Recently, a PhD in Nursing education was completed.

Professional activities include efforts to increase experience in developing and disseminating scholarly projects and collaborating with experienced nurse scientists. In the past months, two peer-reviewed abstracts were presented and published. The Kyba Dissertation Fellowship supported the completion of the dissertation work for this PhD. As a National Coalition of Ethnic Minority Nurses Association (NCEMNA) Mentee, opportunities to collaborate with more experienced nurse scientists for enhancement of personal research knowledge, integrity and network building were afforded.

Future goals consist of becoming a proficient tenured professor, teaching in the baccalaureate and graduate nursing programs of a state university. As a nurse scientist, an active research program with two components will be developed. The primary research component focus is on health promotion in African American (AA) grandmother caregivers. Developing community partnerships with AA grandmothers is a priority in order to decrease their health disparities through developing and implementing efficacious interventions.

The second research component involves conducting research focused on retention, progression, and matriculation of minority nursing students. This research offers information about how to improve minority student success rates in nursing school and information that adds to the understanding of strategies needed to promote this success. The resulting increase in the number of culturally competent minority nurses will empower more minority groups to assist in the improvement of their social conditions.