

THE STRUCTURE AND OUTCOMES OF CAREGIVING TO ELDERLY BLACKS: A RESEARCH AGENDA

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The caregiving literature repeatedly reports that caregiving is stressful, labor intensive, time consuming and it negatively affects caregivers' physical and emotional health (Schultz, Visintainer, & Williamson, 1990; Wright, Clipp, & George, 1993). This literature also shows that the majority of caregiving research has been mostly conducted on primary caregivers, and that very few studies have included the minority elderly and their families (Dilworth-Anderson & Anderson, 1994). Ongoing research, by this author and colleagues, on the structure and outcomes of caregiving to elderly blacks, funded by the National Institute on Aging (1995-1999 R01-AG12268-02), will add to the paucity of data on caregiving to the black elderly. A community-based sample, across five counties in North Carolina, of black elderly was used to identify caregivers who provide care to the elderly. This study differs from most caregiving studies in that it focuses on multiple caregivers within a family caregiving system living in both urban and rural areas who provide care to the physically and/or cognitively impaired elderly. Additionally, unlike most caregiving studies, this study uses a longitudinal design to collect three waves of data (nine months apart) to better understand what factors are associated with the structure in which care is given to the elderly, and the effect caregiving has on the health functioning and limitations of caregivers over time.

Two aims guide our research. The first aim is to describe and analyze the structure in which black caregivers provide care to older dependent family members. The structure of caregiving is of particular concern to this study because it speaks to the number of caregivers who provide care, the size and composition of the helping network, and the social support caregivers receive from others. Some research, although with few studies including black caregivers, shows that multiple caregivers (Tennstedt, McKinlay, & Sullivan, 1989), provide a viable kin network, and an informal social support system that may buffer some of the negative effects caregiving has on caregivers' well-being (Bass, Tausig, & Noelker, 1988-89; Clipp & George, 1990). Results from our ongoing study will add to the literature by providing information on the characteristics of the structure of caregiving in black families, change in these characteristics over time, and factors that are associated with this change.

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The second aim of our research is to analyze factors within the structure of caregiving, caregivers' and care recipients' sociodemographic characteristics, and their situational factors that may be associated with physical and emotional health over time. A limited amount of information is available that shows that black caregivers as compared to their white counterparts are less emotionally affected by caregiving. Different interpretations exist regarding these findings. The ones most often used suggest that cultural factors may buffer the negative effects of caregiving on black caregivers (Lawton, Rajagopal, Brody & Kleban, 1992; Morycz, Malloy, Bozich & Martz, 1987). We believe our study will add to understanding and interpreting the emotional health effects caregiving has on black caregivers because a culturally sensitive framework is being used, and multiple caregivers across different social classes living in both rural and urban areas are included in the study. Further, caregivers caring for cognitively and/or physically impaired elderly are included in the study. Some caregivers live with the care recipients while others do not. This heterogeneity in the sample, coupled with a culturally sensitive conceptual framework will provide a wider view of what factors may impact the emotional health of black caregivers to the elderly.

Conceptual Framework

An extended family system framework coupled with ideas from systems theory provide a conceptual framework for describing and analyzing the structure of caregiving to the black elderly, and the emotional and physical health outcomes of caregivers over time. Systems theory emphasizes that parts work together to provide the basis for understanding a unit such as the family and the individuals' experiences within it.

African American Families As a System of Care

African American families offer long-standing cultural models of operating within family systems whereby the presence of multiple caregivers comprises what is often characterized as a kin-network or mutual aid system of support and care to dependent and needy family members. The ability of a kin-network and mutual aid system to exist is enhanced by permeable and flexible family boundaries that allow for the existence of close kin, distant kin, and even fictive kin being a part of the family. This kin network has a tradition of providing care to children and the elderly (Burton & Dilworth-Anderson, 1991; Tolson & Wilson, 1990). We believe that African American families represent a good "fit" for studying a caregiving system of care to the elderly. This system of care may include a structure of caregiving where several caregivers are present who are close, distant, and even fictive kin, and they most likely live in close proximity to one another. An informal social support system with the help of some formal support probably exists to provide a major foundation for those who provide care to older dependent family members (Taylor & Chatters, 1991).

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Much of what we know about extended African American families is documented in historical and ethnographic studies of African American family life (Jarrett, 1990; Martin & Martin, 1978; Stack, 1974; Scott, 1991). This family, defined by blood and non-blood kin, places similar importance on relationships regardless of whether the person is a close blood kin, distant kin, or fictive kin. Fictive kin can, therefore, be as important in African American kin networks as those related by blood. Aschenbrenner (1975), Stack, (1974), and Taylor and Chatters (1986) proposed that these extended kin networks make available a large and diverse pool of support providers who serve in the extended kin mutual aid system.

The mutual aid system in extended African American families is rooted within a larger cultural context that evolved from the "brother" and "sister" concept in African communities (Frazier, 1932). This legacy of the mutual aid system that is prevalent in traditional African families is evident in many contemporary African American families where children, for example, and dependent others in the family are absorbed by the extended kin system of care and support (Dilworth-Anderson, 1994). In these traditional extended kin families, children are often disciplined and cared for by the different mothers, especially grandmothers (Burton, 1992). Children are not socialized nor afforded the opportunity to "make it" on their own; thus, individuation is not necessarily viewed as an adaptive developmental task (Dilworth-Anderson & Rhoden, in press; Watson & Proskiny, 1988). Instead, the goals of socialization are to encourage family enmeshment which fosters a sense of intergenerational reciprocity, responsibility and the maintenance of the kin network. Although the extended family is not unique to the African American community, especially in regard to the social support it provides (Silverstein & Waite, 1993), its existence has been described as a core feature in the African American culture (Wilson, 1989). The work of Lawton et al. (1992), suggests that intergenerational responsibility and maintenance of the kin network operate in black families. They found that almost five times as many black caregivers as compared to whites were neither spouse nor adult child. According to Cantor's (1979), hierarchical nature of caregiver selection, this may have suggested a problem regarding the quality of care the elderly received. Lawton et al. (1992) found that the quality of care to the elderly in black families did not vary by relationship to the caregiver.

The Structure of Caregiving

Structure of caregiving in our research includes: 1) the size of the caregiving network (multiple caregivers and the mechanisms families use to replace and substitute individual caregivers are being examined); 2) the composition of caregivers' helping network, and 3) the social support system of caregivers, and their level of satisfaction with the support they receive.

Given the historical existence of the extended kin network in many African American families and the cultural legacy of black families absorbing needy and dependent members, it is not surprising that we are finding that the structure of caregiving to the black elderly includes multiple caregivers. These caregivers comprise a network of caregiving individuals who live in close proximity to one another. Research suggests that a variety of types of caregivers to the elderly exist in the caregiving arrangement in black families. They generally provide support to dependent members within an extended family system where multiple helpers are available (Dilworth-Anderson, 1992; Taylor & Chatters, 1991; Yee, 1990). Barer and Johnson (1990) pointed out that the dynamics, subjective rewards, and objective rewards which occur in caregiving networks cannot be understood without information on those caregivers who are not primary caregivers. Further, Stone and Kemper (1989) suggested that researchers can gather information from multiple caregivers within the family because the vast majority of spouses and children who provide care to the elderly have immediate family networks that are potentially available to share in caregiving responsibilities.

Data are being gathered in our study on primary, secondary, and attenuated caregivers in black families. While much is known about primary caregivers to the elderly (Biegel, Sales, & Schulz, 1991; Zarit, 1989), and limited information is available on secondary caregivers (Barer & Johnson, 1990; Birkel & Jones, 1989; Chenoweth & Spencer, 1986; Hooyman & Lustbader, 1986; Miller & McFall, 1991; Tennstedt, McKinlay, & Sullivan, 1989), little is known about what we describe as attenuated caregivers. The concept of attenuated caregivers in our research derived its meaning from the conceptual and theoretical discussions by Billingsley (1968), Wilson (1986), and Johnson (1983). These authors, particularly Billingsley, differentiated nuclear and extended families from families which had less family embeddedness and fewer family members. We extend this concept by using the term, attenuated caregivers, for family members who are not a part of the day-to-day caregiving arrangement, but who exist in the caregiving situation as peripheral members. These caregivers may support the primary and secondary caregivers by performing specialized tasks.

Previous research has documented the presence of a large informal support system in black families (Johnson & Barer, 1990; Taylor & Chatters, 1986; Wood & Parham, 1990) which increases the availability of multiple caregivers to the elderly. For example, Gibson (1982) found that black families tended to substitute one helper for another and to use multiple family members and friends for assistance, especially as blacks become older. Gibson noted that the benefits of a broad support system include less stress on the individual helper, greater potential for support, and greater flexibility and variety of support (Gibson, 1982). White-Means and Thornton (1990), studying ethnicity and aging, found that the availability of caregiving substitutes and the size of the caregiving network were important in time allocation decisions. The availability of caregiving substitutes had a greater impact on the limitation of leisure

time for the caregiver than size of the caregiving network for each of the ethnic groups studied: English-American, German-American, Irish-American, and African-Americans. Taylor and Chatters (1991) found that frequency of interaction between the elderly and their children was an indicator of the availability of family members to assist the elderly and help them during illness or emergency situations.

Size and Composition of the Kin Helping Network

Although limited information is available that provides insight into the relationships of caregivers to the black elderly, we expect the relationships of subjects in this study will be similar to white family caregivers. They may differ however, in regard to non-blood kin and friends also serving as caregivers. Similar to white families, black caregivers are principally spouses, adult children, and in-laws (Anthony-Bergstone, Zarit, & Gatz, 1988; George & Gwyther, 1986; Lawton, Brody, & Saperstein, 1991; Morycz, 1985; Pratt, Schmall, Wright, & Cleland, 1985; Winogron, Fisk, Kirsling, & Keyes, 1987; Cox & Monk, 1990; Hinrichsen & Ramirez, 1992; Lawton et al., 1992; Segall & Wykle, 1988-89). Gibson's (1982) findings show that unlike in white families who tended to use only family members as caregivers, black families tended to use friends and a combination of family members as caregivers to the elderly. Lawton et al. (1992) report findings similar to those reported by Gibson previously. Black elderly, as compared to white elderly, were more likely to have caregivers such as siblings, other relatives or friends instead of only their spouses or adult children. In our current study, we are collecting data on the hierarchical nature of caregiver selection by studying how and why certain individuals in the family serve as caregivers to those in the older generation and what their relationship is to the elderly. It is possible given the extended kin-network in which black families care for dependent members, that close kin as well as distant and even fictive kin may serve in a caregiving role. To better understand this issue of closeness of kin and caregiving in black families, caregivers in our study are administered a "culturally" sensitive instrument on reasons for caregiving that addresses issues of relationships and cultural norms and expectations.

Social Support

The extent to which any system or structure of caregiving to the elderly can exist and maintain itself is influenced by the type, duration, and level of satisfaction with both formal and informal support (Clipp & George, 1990). Social support may influence the type, size, and composition of the network. Numerous researchers have found that extended black families provide informal social support to dependent relatives in the form of emotional and instrumental care. This informal support is particularly given to children (Pearson, Hunter, Ensminger & Kellam, 1990) and older people (Mutran, 1985; Taylor & Chatters, 1991).

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In our study, we examine perceived support and the actual support caregivers receive from the extended family. Caregivers also report on the level of satisfaction with the support they receive. Because evidence shows (Taylor 1993; Walls & Zarit, 1991) that the church provides informal support to black families, we are examining the salience of church support to caregiving black families. Further, formal support which is often needed and used by caregivers is being examined to identify formal services that may augment or replace those provided by the informal support-systems black families utilize.

The Effect of Caregiving on Caregivers

A major finding of caregiving research is that caregiving impacts the well-being of caregivers (Schultz, Visintainer, & Williamson, 1990). Caregivers' emotional and physical health have been found to be negatively impacted by providing care to the elderly. However, Wright, Clipp, and George (1993) suggest that despite the fact that a caregiving role can last for almost twenty years, limited information is available on the cumulative health consequences of caregiving. Regardless of whether we know about the health consequences of caregiving from cross-sectional or longitudinal data, studies that have addressed this issue have failed to include black caregivers. As a result, little is known about how black caregivers' emotional and physical well-being are impacted by their caregiving roles.

Specific Physical Outcomes of Caregiving

Besides the need to gather information on the health outcomes of black caregiving, health outcomes are important to our research because the health of blacks in the age groups that most likely serve as caregivers is problematic. Both black males and females between the ages of 45 and 64 years of age experience significant health problems (Gibson, 1986; Horton & Smith, 1990). Additionally, findings suggest that caregivers to the elderly in black families may be vulnerable to poor physical health outcomes because black families generally take upon themselves the care of elderly and other dependent members (Yee, 1990, Taylor & Chatters, 1986 & 1991; White-Means & Thornton, 1990); they under-utilize formal support services to assist them when caring for dependent members (Segall & Wykle, 1988-89), and blacks have higher morbidity and mortality rates as compared to whites in the same age group typically providing care the elderly (US Dept. of Health & Human Services, 1991).

Further, when older black spouses and peers are caregivers, the issue of frailty among caregivers is important due to age and declining health. Ferraro (1987) found that older blacks were, in general, more negative than whites in evaluating their own health and manifested more physical disabilities than white elders. However, while no difference was found in the likelihood of having a chronic condition or serious illness,

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these conditions were more functionally debilitating to older blacks than to older whites. Research also has shown that spousal caregivers have more health problems associated with the caregiving experience than do other relatives who are caregivers (George & Gwyther, 1986). Consequently, the effects of caregiving could be potentially debilitating to black spouses and other age peers in the extended caregiving network who may already exhibit functional debilitation.

Specific Emotional Outcomes of Caregiving

Emotional outcomes including increased feelings of stress, anger, and depression have been found to be associated with caregiving (Cantor, 1983; Cicirelli, 1988; Fitting, Rabins, Lucas, & Eastham, 1986; George & Gwyther, 1986; Motenko, 1989). Among the few studies that have included blacks in their samples, findings suggest that black caregivers experience less depression, burden, and stress in their caregiving roles (Hinrichsen & Ramirez, 1992; Lawton et al., 1992; Morycz et al., 1987). It has been suggested that these findings might be associated with black families utilizing a larger helping network that is flexible (Gibson, 1982) and which uses the principle of substitution of helpers in the network, when needed. Lawton et al. (1992) point out that social norms in black families may lessen negative emotional reactions to caregiving. The idea of social norms and beliefs regarding caregiving in black families serving as a stress buffer is being explored through open-ended questions in this study.

Summary

Without actual data to report on at this time, wave one data collection will be completed in September 1996, tracking of certain responses to questions during interviewing provide a few insights. We expect findings to show that caregiving to elderly blacks is provided within a system of care. This system is comprised of multiple caregivers: primary, secondary, and attenuated caregivers. We expect that they will substitute for one another thereby creating interchangeable roles as caregivers. Caregivers most likely live in close proximity (within 30 minutes) to the care recipient and one another. They also probably receive support from others in the kin network and from formal services to assist in their caregiving roles.

As with most families caring for dependent older members, we expect caregivers to experience both emotional and physical effects. The effects, however, will be fully examined to better understand what sociodemographic characteristics of the caregivers and care recipients are involved. The effects of the care recipient's health status, and level of caregiver's competing demands, and the social support caregivers receive from others will also be fully examined. Although we believe that caregivers' emotional and physical health will be affected by caregiving, it is expected that they will experience more physical as opposed to emotional problems.

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