African American Families Who Care for Adults with Developmental Disabilities or Mental Illness: A Call for Research

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Introduction

Informal caregiving of family members has increased rapidly, and the prevalence of family caregiving is higher among families of color (NAP/AARP, 1997). While most caregiving research has been associated with caring for dependent elderly populations, caregiving of children with mental, emotional or neurological illnesses across the lifespan is an emerging area of study (Greenberg, Seltzer, & Greenley, 1993; Lefley, 1987; Seltzer & Krauss, 1989). Caring for an adult with a mental disability can be challenging for any family, as it often limits caregivers' social, recreational, and work activities; increases the work load and responsibilities of the caregiver; and exposes family members to stressful interactions when the person with the disability exhibits maladaptive behaviors as a result of their disorder. In this emerging body of research, very little is known about families from populations of color who care for adult children with mental, emotional or neurological illnesses. Caregivers of color are more likely than White caregivers to care for their children with mental disabilities in the home through adulthood, which means greater exposure to the caregiving role (Heller & Factor, 1988; Heller, Markwardt, Rowitz, & Farber, 1994; Stueve, Vine, & Struening, 1997). Therefore, knowledge is needed on how this experience may impact different racial and ethnic groups differentially. This paper reviews published empirical studies that have been conducted on African American families who care for an adult with developmental disabilities and/or mental illness.

Included in this review are a total of 15 studies (6 qualitative and 9 quantitative) in which African American families of adults with mental illness or developmental disabilities were the focus. There are four topic areas that these studies have investigated: 1) caregiver well-being, 2) religion and its role in coping with disability, 3) conceptions of mental disabilities from an African American perspective, and 4) services and future planning.

Caregiver Well-being

About half of the studies included in this review focused on caregiver well-being, and all of these compared African American to White caregivers (Horwitz & Reinhard, 1995; Miltiades & Pruchno, 2002; Picket, Vraniak, Cook, & Cohler, 1993; Pruchno, Hicks Patrick, & Burant, 1997; Song, Biegel, & Milligan, 1997, Struening et al., 1995; Stueve et al., 1997; Valentine, McDerrmott, & Anderson, 1998). Two of the studies focus on caring for a family member with developmental disabilities (Miltiades & Pruchno, 2002; Valentine et al., 1998), four of them focus on a family member with mental illness (Horwitz & Reinhard, 1995; Picket et al., 1993; Song et al., 1997, Struening et al., 1995; Stueve et al., 1997), and one study examined families caring for a person with either a developmental disability or mental illness (Pruchno et al., 1997).

One research question in common in all of these studies is, "How do African American caregivers differ from White caregivers in emotional well-being?" Constructs of emotional well-being include: caregiving burden, caregiving satisfaction, depression, grief, coping mastery, self-esteem, intimacy and conflict. Several of these studies report that African American caregivers have more positive outcomes than White caregivers (Horwitz & Reinhard, 1995; Picket et al., 1993; Struening et al., 1995; Stueve et al., 1997; Valentine et al., 1998). Picket and colleagues (1993) compared 24 African American parents (both mothers and fathers) to 185 White parents of adults with serious mental illness and found that African American parents had higher levels of coping mastery and self-esteem and lower levels of depression. A major limitation is that the analysis was limited to bivariate comparisons, so important variables such as SES, physical health and characteristics of the son or daughter were not controlled for. In addition, the authors note that when comparing only mothers there was no significant difference between African American and White caregivers on depression.

In a similar study, Valentine and associates (1998) compared 28 African American mothers to 43 White mothers of adults with developmental disabilities using bivariate analyses. These researchers found that African American mothers experienced greater caregiver gratification and greater intimacy with their son or daughter than White mothers, but the two groups did not differ in caregiver burden (Valentine et al., 1998).

Horwitz and Reinhard (1995) conducted a study that compared 27 African American parents and 22 siblings to 51 White parents and 48 siblings of adults with serious mental illness. Controlling for variables such as income, gender, age of caregiver, and son or daughter characteristics, these researchers found that African American parents and siblings were less burdened than White parents and siblings, and African American siblings reported more caregiving duties than White siblings. The authors

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suggest that differences may be partially explained by the fact that White families are less likely to provide long-term care in the home and thus have fewer examples to draw upon of how best to provide that care (Horwitz & Reinhard, 1995).

In a study that compared 43 African American, 44 Hispanic, and 93 White caregivers of persons with severe mental illness, researchers found that African American caregivers reported lower levels of burden (Stueve et al., 1997) and lower levels of grief than the other two groups, but found no differences in level of depressive symptoms (Struening et al., 1995). These researchers controlled for level of education, income, gender, age, caregiving-related stressors, social support, and other important variables (Struening et al., 1995; Stueve et al., 1997). The authors were cautious in their conclusions, noting the differential findings between different outcome measures (e.g. depression and burden) and pointing out that because of the constraints of voluntary participation in studies, African Americans who are more burdened may be electing not to participate (Struening et al., 1995; Stueve et al., 1997).

Other studies conducted similar comparisons and found mixed and more complicated results with respect to racial differences (Miltiades & Pruchno, 2002; Pruchno et al., 1997; Song et al., 1997). Song and colleagues (1997) compared 55 White and 48 African American low income caregivers of persons with chronic mental illness and found that, on a bivariate level, Whites exhibited higher depressive symptoms. However, this difference disappeared when researchers controlled for maladaptive behaviors of the person with mental illness, living status, gender and social support. A strength of this study is that both racial groups were of low socioeconomic status, removing the confound between race and SES.

Pruchno and colleagues (1997) attempted to disentangle the relationship between race and psychological well-being by using a structural equation model when comparing 100 African American mothers of adults with schizophrenia or developmental disabilities to 741 White mothers. Their bivariate comparisons indicated that the African American mothers had lower income and education and poorer health than the White mothers, yet reported higher caregiver satisfaction and lower burden, consistent with previously reported studies. When controlling for SES, maternal age and health, and maladaptive behaviors of the son or daughter, researchers found that race was not predictive of caregiver satisfaction but maintained a small effect with burden in a linear relationship. However, in the structural equation model they did not find direct or indirect effects of race on burden or caregiving satisfaction (Pruchno et al., 1997). The authors believed their path model partially explained why African Americans report higher caregiving satisfaction: caregivers with lower incomes are more likely to live with their family, allowing for more opportunity for caregiving satisfaction (Pruchno et al., 1997). However, the burden finding was more puzzling given that poor health is often highly related to more

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burden, yet the African American mothers were significantly less burdened while in much poorer health (Pruchno et al., 1997).

Pruchno and associates investigated these issues further by utilizing a structural equation model to examine racial differences in religious coping and caregiving satisfaction and burden (Miltiades & Pruchno, 2002). Their sample consisted of 71 African American and 71 White mothers of adults with developmental disabilities, matched on age, education, marital status, employment status and income. On a bivariate level, there were no differences between racial groups on caregiving satisfaction and burden; however, in the structural equation model there was an indirect relationship between African American caregivers and higher burden, due to the relationship between poor health and African American caregivers. Miltiades and Pruchno (2002) concluded by pointing out that while African Americans draw upon cultural resources such as religion which strengthen their satisfaction with caregiving, they also suffer negative outcomes such as poor health and burden.

Religion and its Role in Coping with Disability

While there is much written about the importance of religion for African Americans, very few empirical studies have been conducted to investigate its importance with families who have children with mental illness or developmental disabilities. In a conceptual paper on the relationship of religion and disability to African American families, Rogers-Dulan and Blacher (1995) discuss ways in which religion may influence different aspects of caring for a child with a disability. The authors identified two themes that may be influenced by religion and are important in adaptation of families who have a child with a disability: interpretation of the disability and coping resources. Rogers-Dulan and Blacher (1995) assert that the structure of religious beliefs is similar between African American and Anglo American Christians; however, African Americans emphasize religious views relating to oppression, slavery, and equality. Within this context, the idea that we are all God's children, and that all children are important, is often embraced by African Americans and may foster an interpretation of disability that results in positive acceptance of the child with a disability. On the other hand, having a child with a disability may be interpreted as a punishment from God or a loss to the family. With respect to coping resources, Rogers-Dulan and Blacher (1995) identify ways in which religious connectedness may enhance social, material and psychological resources: The church and its members may provide social and material assistance, while a person's religious beliefs may provide psychological resources. Research on the ways in which religion may contribute to coping resources will be discussed below, along with the ways in which religion plays a role in interpretation of mental illness in the section on conceptions of mental illness.

With respect to coping resources influenced by religion, King (1998) interviewed five African American women with disabilities (three of whom had developmental disabilities) about how they are received in their churches and found that the women did not perceive much support. Themes that emerged from the interviews were feelings of devaluation, lack of acceptance, over-protectiveness, and themes of ambivalence on the part of the church towards persons with disabilities through "spotlighting" and "correction." Spotlighting involved turning the disability into an inspirational symbol for the congregation, and correction referred to healing, implying the need to fix what was wrong. The author argues that despite its positive influence in the struggle for justice on behalf of African Americans, the Black church often contributes to the marginalization of its own members with disabilities (King, 1998).

Other studies that examined religious coping and caregivers reported more positive outcomes. Some studies have reported that compared to White caregivers, African American caregivers rate the importance of religion in their lives higher (Heller & Factor, 1988; Stueve et al., 1997) or report using religious coping more frequently (Miltiades & Pruchno, 2002). The study by Miltiades and Pruchno (2002) specifically examined the effect of religious coping on caring for adults with developmental disabilities, comparing 71 African American caregivers to a matched sample of 71 White caregivers. They found not only that African American caregivers use more religious coping but that religious coping was positively related to better caregiving satisfaction.

Conceptions of Mental Illness from an African American Perspective

A qualitative study conducted by Morrison and Thornton (1999) focused on the relationship of religion and perceptions of mental illness among African Americans in the South. This study included interviews with five African American leaders, primarily ministers and academic faculty. Through their interviews and further review of the literature, the authors identified three southern religious traditions for African Americans: Voodoo, slave religion, and evangelical Protestantism. The former two are combinations of African pagan traditions with either Catholicism (Voodoo) or the protestant form of Christianity (slave religion). While there are differences among the three, all of these traditions view mental illness as oppression by spirits, sometimes by demon spirits, and, within Christianity, mental illness can be seen as punishment by God (Morrison & Thornton, 1999). A case study was provided in which a well-educated African American woman was hospitalized with a diagnosis of bipolar disorder with paranoid features. Both the woman and her mother who brought her to the hospital expressed the belief that the woman had been taken over by the spirit of a deceased relative. The authors noted that hospital staff dismissed these beliefs as part of the illness rather than trying to understand the cultural/religious issues involved (Morrision & Thornton, 1999).

A study conducted by Guarnaccia and colleagues (Guarnaccia & Parra, 1996; Milstein, Guarnaccia, & Midlarsky, 1995) interviewed 29 African American, 45 Hispanic, and 16 White caregivers of adults with serious mental illness. The majority of caregivers were parents, but some were siblings and other family members. These researchers found that African Americans were similar to Whites in their view of mental illness as being either a medical problem or the result of negative personality characteristics. However, African American caregivers were more likely than White caregivers to disagree with labels given to their relatives by professionals. African American and Hispanic families were more likely than Whites to believe there would be a cure for their relatives' mental illness. Consistent with the discussion of religious beliefs, some of the African American families believed that demonic possession was a cause of mental illness and viewed religion as a subsequent cure (Milstein et al., 1995).

Hines-Martin (1998) conducted an ethnographic study of 16 African American caregivers of persons with severe mental illness to explore the experience and perceptions of caregiving among this group and to understand the environmental context. The caregivers were mothers, wives or ex-wives, girlfriends, sisters, or daughters. The author also observed participants in many settings and had interactions with people in the African American community about mental illness during these observations. She noted that there was a general lack of knowledge about mental illness and discomfort towards it among African American clergy and the African American community. The caregivers reported experiencing discrimination towards themselves and their family member with mental illness and reported there was stigma attached to mental illness in their communities (Hines-Martin, 1998).

Services and Future Planning

An important issue in the mental health field with respect to service utilization and satisfaction is that of pathways to care, or patterns of help-seeking. In a separate analysis of the qualitative study described earlier (Guarnaccia & Parra, 1996; Milstein et al., 1995), Guarnaccia (1998) reported that African American caregivers were more likely to use a pathway in which there was more family involvement, culturally based resource use, community leader consultation, and reluctance in accepting psychiatric referral for their family member with mental illness. In contrast, White caregivers were more likely to seek help from mental health professionals early on. Additionally, African American caregivers were more likely than White caregivers to seek help initially through legal and social agency involvement (Guarnaccia, 1998). Consistent with the latter finding, Hines-Martin (1998) found that many of the caregivers of persons with mental illness in her study reported using law enforcement for assistance in crisis situations with their family members.

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Hines-Martin (1998) also reported that the type of mental health services caregivers used for their family members were often based on economic need (e.g., rarely private psychiatrists due to costs and most frequently community mental health services). These caregivers reported dissatisfaction with aftercare services and expressed the need for more counseling, respite care, rehabilitation, vocational assistance and social services (Hines-Martin, 1998). At least half of the caregivers reported that there was a lack of services that provide support and indicated that families are often left out of services (Hines-Martin, 1998). Biegel, Johnsen and Shafran (1997) discovered a similar theme of lack of services for family in their study of barriers faced by African American families of persons with mental illness. These researchers conducted four focus groups that included 22 caregivers, 24 consumers, 19 case managers and 11 mental health board staff members. A concern expressed by all four groups was the exclusion of family members from the treatment process. This exclusion included lack of outreach and education to families about resources available, a devaluation of family involvement, and structural barriers to family involvement such as lack of transportation and child care (Biegel et al., 1997). Consumers reported that caregivers needed help in becoming more competent in their caregiving (e.g. education about the illness and treatment) (Biegel et al., 1997).

In a separate study, Biegel, Song, and Milligan (1995) compared 104 African American families caring for relatives with mental illness to different groups of White caregivers (those with similar socioeconomic status [low SES] to the African American families and those with high SES) and found that African Americans were involved in the mental health systems and had greater satisfaction with mental health service than the high SES Whites. One explanation provided by the researchers is that most of the African American families were recruited from mental health agencies within their own communities, agencies which may have had more staff members who reflected their own backgrounds (Biegel et al., 1995).

Two studies examined service issues for African American families caring for adults with developmental disabilities (Heller & Factor, 1988; McCallion, Janicki, & Grant-Griffin, 1997). Heller and Factor (1988) compared 25 African American families to 75 White families on issues of permanency planning and found that the African Americans were more likely to want to care for the person with the developmental disability in their home, less likely to have made financial plans for their relative, and more likely to make arrangements for siblings to continue care when the parents could no longer provide care. McCallion and associates (1997) conducted focus groups that included families of adults with developmental disabilities from many different racial and ethnic backgrounds (African American, Chinese, Haitian, Hispanic, Korean and Native American). Service issues raised by African American participants were the fear of having their family member taken away and put in out-

of-home placement and the importance of locating extended family members if the main caregiver became unable to provide care (McCallion et al., 1997).

Implications for Future Research

Overall, research on African American families caring for adults with mental disabilities is a slowly emerging area of study, and while some studies show strength in methods, sample sizes are generally small, limiting the generalizability of findings. With respect to understanding the experiences of African Americans as a racial and cultural group, and understanding the conceptualization of mental illness and disability from the African American perspective, more qualitative studies are needed, from different regions of the country. How religion gives meaning to disability, how mental disabilities are perceived in African American communities, and what kinds of informal supports are provided to families are all areas that need further exploration.

With respect to service utilization, more studies are needed that shed light on the reasons for certain pathways to care and whether service utilization varies if services are delivered in a culturally relevant manner. There should also be further exploration of the finding that services should be more family inclusive and address the needs of the entire family. Discrimination practices of service providers towards African American consumers and their families is an area not explored which should be addressed. How African American families plan for the future of their member with a disability is another area needing study.

To understand the impact of caring for a family member with a mental illness or developmental disability on the well-being of African American caregivers, we need to move beyond Black/White comparisons that focus exclusively on emotional well-being. African Americans and other people of color experience unique environmental contexts and ecological circumstances that may not be shared by Whites (García-Coll et al., 1996). How culture and environment influence the expression of distress for different groups is overlooked in these comparisons. Dillworth-Anderson, Williams and Gibson (2002) note that comparisons between caregiving and non-caregiving groups are needed in research with ethnic and racial groups to determine whether well-being outcomes are actually associated with the caregiving experience. Further, any examination of well-being among African American families should investigate not only emotional health, but also physical health. Comparison studies consistently show that African American caregivers are in poorer physical health than Whites. Pruchno and colleagues (Miltiades & Pruchno, 2002; Pruchno et al., 1997) have alluded to the importance of not overlooking negative impacts such as health. Research shows that African American women are significantly more likely than White women to have hypertension, diabetes, and other chronic conditions (Kington & Smith, 1997; Williams, 2002). African American caregivers may already

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be compromised in physical health independent of the caregiving role, which suggests that it is especially important to explore the relationship of chronic stress to poor physical health and chronic illnesses for these caregivers.

In conclusion, African American families who care for members with developmental disabilities and mental illnesses draw on many internal, cultural and social strengths in their caregiving role, but also face challenges that are often overlooked by research and social services. More research is needed to understand in greater depth the strengths as well as the challenges these families face.

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