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## Race-Related Differences in the Experiences of Family Members of Persons with Mental Illness Participating in the NAMI Family to Family Education Program

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### Abstract

Families play an important role in the lives of individuals with mental illness. Coping with the strain of shifting roles and multiple challenges of caregiving can have a huge impact. Limited information exists regarding race-related differences in families' caregiving experiences, their abilities to cope with the mental illness of a loved one, or their interactions with mental health service systems. This study examined race-related differences in the experiences of adults seeking to participate in the National Alliance on Mental Illness Family-to-Family Education Program due to mental illness of a loved one. Participants were 293 White and 107 African American family members who completed measures of problem- and emotion-focused coping, knowledge about

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mental illness, subjective illness burden, psychological distress, and family functioning. Multiple regression analyses were used to determine race-related differences. African American caregivers reported higher levels of negative caregiving experiences, less knowledge of mental illness, and higher levels of both problem-solving coping and emotion-focused coping, than White caregivers. Mental health programs serving African American families should consider targeting specific strategies to address caregiving challenges, support their use of existing coping mechanisms and support networks, and increase their knowledge of mental illness.

### Keywords

Mental illness; African American; Families; Caregiving; Coping; Burden

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### Introduction

Approximately 27 % of the U.S. population fit criteria for a mental illness in a given year (Kessler et al. 2008). Family members of such individuals often assume significant responsibility supporting their ill relative. Coping with the strain of shifting roles, subjective and objective challenges of caregiving, and stigma can stress family members (Schulze and Rössler 2005). Caregiving can exact emotional and financial burdens and disrupt overall family functioning, causing significant distress among caregiving family members, including depression, anxiety, and physical health problems (Saunders 2003). On the other hand, it can create positive and rewarding experiences including a sense of fulfillment for the caregiver, engagement with the ill family member, and closer family relationships (Chen and Greenberg 2004; Cummings and MacNeil 2008). Despite awareness of the important impact of race and ethnicity on social norms, expectations, and perceptions of mental illness (Briggs et al. 2011), limited information is available regarding race-related differences in families' experiences of caretaking, coping with mental illness in the family, or interactions with mental health service systems on behalf of an ill relative. Studying these differences might give us a better understanding of why African Americans with a mental illness may have limited contact with mental health services. Families' perceptions of and experiences with mental health services may play an important role in how care is conceived and how families' cope with addressing mental health needs among African Americans.

### A Stress and Coping Perspective

A stress and coping perspective (Lazarus and Folkman 1984) helps to explain the underlying processes of caring for a loved one diagnosed with a mental illness. This perspective frames caretaking as managing multiple stressors, including the consumer's illness and functional difficulties and resulting caregiving demands (Solomon and Draine 1995a). The objective magnitude of family member stress depends on the severity of their relative's illness, the degree to which they are involved in caregiving, and their available resources. In response to these stressors, caregivers engage in an *appraisal* process through which they come to understand the stressor and its demands, as well as their available coping resources (Szmukler et al. 1996). Appraisal may be influenced by a variety of moderating factors, such as the caregivers' sociodemographic characteristics and personality, available supports, and the nature of their relative's illness (i.e., diagnosis, level of severity)

(Szmukler et al. 1996). For example, Biegel and colleagues found that high frequency of client behavioral problems correlated with increased caregiver burden in a study of 103 low-income caregivers. Additionally, when social supports (family, mental health agency) were perceived as lower, the caregiver reported increased burden (Biegel et al. 1994). This suggests that perceived social support, for example, can influence the caregiver experience

Following appraisal, caregivers engage in coping activities, falling broadly within the categories of *problem-focused* and *emotion-focused* coping. Problem-focused coping refers to efforts to directly address problems created by the relative's illness (i.e., gaining knowledge, problem-solving), whereas emotion-focused coping refers to strategies to regulate affective responses (i.e., seeking social support, engaging in self-care) (Sideridis 2006). The adjustment and well being of caregivers are conceptualized as functions of their appraisal and coping strategies, and the interplay between these processes (Cheng and Cheung 2005).

### **Sociocultural Perspective on Stress and Coping**

A sociocultural perspective on stress and coping focuses on how sociocultural factors influence the caregiving experience of racial/ethnic minorities (Haley et al. 1996; Knight et al. 2000). Specifically, it takes into account the effects of race/ethnicity via sociocultural differences on appraisal, coping styles and strategies, and psychological distress (Knight et al. 2000). In effect, race/ethnicity becomes a proxy variable for sociocultural factors that impact stress and coping.

Although there is limited research on the experiences of African American caregivers of individuals diagnosed with a mental illness, what exists suggests that sociocultural factors do play a role in their perceived caregiver burden, psychological distress, and coping (Guada et al. 2009; Guarnaccia and Parra 1996; Woodward 2011). Research suggests that African American families on average perceive less caregiving burden than some other groups (Guada et al. 2011; Horwitz and Reinhard 1995; Stueve et al. 1997). Sociocultural differences in the use and composition of support networks tend to contribute to this overall finding of less perceived burden among African American families (Connery and Brekke 1999; Guada et al. 2009; Guarnaccia and Parra 1996; Horwitz and Reinhard 1995). The importance of wide-kin networks such as family, extended family, and the church as sources of support has been especially salient for African American families (Mattis 2004; Young et al. 2003; Taylor et al. 2001; Hatchett et al. 1991). In addition, religion and spirituality have been documented as important for positive coping among African Americans (Utsey et al. 2007), perhaps via helping people reframe the caregiver role as part of a life-learning experience (Banks-Wallace and Parks 2004; Mattis 2002). These sociocultural differences in social support may also account for lower levels of psychological distress (i.e., depression) found in African American caregivers (Pickett et al. 1993). Additionally, socioculturally determined responses to the severity of the consumer's condition (Stueve et al. 1997) and lower stigmatization of the illness (Horwitz and Reinhard 1995) may affect the ways in which African American families perceive caregiving burden. For example, African American family caregivers may be more tolerant of the family member's symptoms, behaviors, and potential consequences of the illness in such a way that allows better

integration of the ill member into the family (Horwitz and Reinhard 1995; Stueve et al. 1997). There may be an assumption that caring for a loved one in need is an expected role of family members (Guarnaccia and Parra 1996). As such, this may change a caregiver's perception about the level of burden, as well as create potential for positive feelings about contributing to the overall well being of the family member.

Sociocultural factors, such as expectations that the mental illness will be cured and higher levels of religious involvement (Guarnaccia and Parra 1996; Stueve et al. 1997), may also shape how African American caregivers in particular engage in both problem- and emotion-focused coping. For example, an important resource for many African Americans is support received from church members (Pickard et al. 2012; Taylor and Chatters 1988). Research suggests that African Americans experiencing mental illness often rely on both informal church support and professional mental health services instead of only one or the other when addressing their mental illness (Neighbors and Jackson 1984; Snowden 1998). Recently, Woodward (2011) found that more African Americans experiencing mental illness sought indigenous helpers such as clergy (24.2 %) compared to White adults (17.2 %).

The above studies highlight help-seeking patterns involving services beyond the mental health system that may differ by race, and may help to explain important predispositions for families seeking services. There remains a gap, however, in understanding race-related differences in families' experiences of caretaking and coping with mental illness as they relate to interactions with mental health service systems for their loved one. Understanding these differences is especially important given the multiple ways in which African Americans engage in both problem- and emotion-focused coping and the potential implications this may have on the overall caregiving experience for the caregiver and ill relative.

### **The Current Study**

Best practices and treatment recommendations identify family involvement as a key component in the care of individuals diagnosed with a mental illness (Dixon et al. 2010; Guada et al. 2012). In addition to benefits for persons diagnosed with a mental illness, family-based services have also been shown to improve family relationships and decrease burden for family caregivers (Dixon et al. 2010). This study uses data from the Family-to-Family Education Program (FTF) sponsored by the National Alliance on Mental Illness (NAMI), a family education intervention designed to provide support and education to families coping with the mental illness of a loved one. In FTF, family members learn skills in self-care and communication, as well as problem-solving and advocacy strategies. Recent empirical validation supports the efficacy of FTF in enhancing coping, problem-solving and empowerment, and reducing anxiety and depression (Dixon et al. 2004, 2011; Lucksted et al. 2008, 2013; Marcus et al. 2013).

With the emerging empirical support of FTF, there remains a need to understand factors that bring families to the program and that distinguish their experiences with it. Indeed, FTF may be a window to understand race-related differences in caretaking for family members at the point of seeking help outside of the traditional mental health service system. As the sociocultural perspective suggests, familial and contextual factors must be understood as

they may play key roles in the involvement and well being of family members helping a loved one diagnosed with a mental illness. Thus, the purpose of this study was to examine race-related differences in the experiences of family members caring for persons with mental illness and seeking participation in NAMI's FTF. We examined such differences in several key areas: (1) family members' experiences in caregiving; (2) problem-focused coping; (3) emotion-focused coping; and (4) subjective burden and psychological distress. Based on current research, including on the sociocultural perspective of stress and coping, we hypothesize that, relative to White caregivers, African American caregivers will report: (1) more positive caregiving experiences; (2) less perceived burden and psychological distress; (3) higher levels of positive emotion-focused coping; and (4) higher levels of problem-focused coping.

## Methods

### Procedures and Participants

This study included two participant groups. The first consisted of individuals who participated in a randomized controlled trial (RCT) examining the efficacy of FTF on family member outcomes (Dixon et al. 2011). The second group consisted of individuals who declined participation in the RCT but who were planning to take the class and who consented to be a part of an observational sample. Both cohorts were recruited from five Maryland NAMI affiliates: Baltimore Metropolitan region and Howard, Frederick, Montgomery, and Prince George's Counties. Anyone contacting the NAMI-Maryland office or participating affiliates and expressing an interest in FTF received basic information and was referred to NAMI-Maryland's FTF state coordinator. The coordinator spoke with each person to determine whether he/she was appropriate for participation in the FTF program. If appropriate, she then described the RCT, answered any questions, conducted a preliminary screen for eligibility, and determined the candidate's willingness to participate in the RCT. Research assistants contacted eligible and willing family members and obtained informed consent via a telephone protocol approved by the University of Maryland Institutional Review Board. To address concerns regarding the consent rate, a subgroup of refusers were offered participation in the observational study (See Marcus et al. 2013). Consenting participants in both samples were assessed at baseline (before FTF started) with a structured telephone interview that lasted approximately 60 min. Study participants were recruited between March 15, 2006, and September 23, 2009 (see Dixon et al. 2011).

**Participants**—Individuals were eligible for participation in the study if they were 21 years old or older, desired enrollment in the next FTF class as a family member or significant other, and spoke English. Out of the 1,532 individuals who contacted one of the five NAMI-Maryland affiliates, expressed interest in the FTF program, and were screened for the study, 1,168 were determined to be eligible for participation. Of those eligible for participation in the RCT, 339 (29 %) considered participating in the RCT. The possibility of being waitlisted for FTF classes was the most common reason for declining study participation (Dixon et al. 2011). Of those who consented and were randomized, 84 African American participants and 206 White participants completed the baseline interview. From those in the observational sample ( $n = 124$ ), 23 were African American and 87 were White.

(See Dixon et al. (2011) and Marcus et al. (2013) for a more detailed description of the recruitment process, randomized sample and observational sample.) Thus, the current study (n = 400) includes 107 African American and 293 White individuals who participated in the randomized and nonrandomized portions of the study.

### Assessments and Variables

Baseline assessments focused on caregiver involvement with their ill relative, subjective illness burden, caregiver experiences, problem-focused coping and level of knowledge about mental illness, emotion-focused coping, family functioning, and psychological distress.

**Caregiver Involvement**—We obtained information about caregiver involvement using the Family Experiences Interview Schedule (FEIS) (Tessler and Gamache 1993). The FEIS elicits information regarding demographics and level of involvement with the participant's ill relative, the ill relative's demographics and mental health history, the extent of contact between the participant and the ill relative, and the extent to which family members provide assistance in daily living activities and supervision for their ill relative. The FEIS demonstrated strong inter-rater reliability and has been tested on African American samples (Tessler and Gamache 1993).

**Subjective Illness Burden**—Subjective illness burden was evaluated with the FEIS worry and displeasure scales (Tessler and Gamache 1993). The seven-item worry subscale asks respondents to rate their level of concern about various aspects of their ill relative's life. The eight-item displeasure subscale measures the participant's emotional distress concerning the ill relative's situation. The worry and displeasure subscales have been found to be internally consistent, with Cronbach's alphas of .89 and .85, respectively (Tessler and Gamache 1993).

**Caregiving Experience**—The Experience of Caregiving Inventory (ECI), a brief self-report measure, was used to assess caregivers' experience of caring for a relative diagnosed with a mental illness. The 66-item instrument has 10 subscales (See Table 3). The positive personal experiences and good aspects of relationship subscales are summed to form an overall positive experience subscale. The remaining eight subscales are summed to form an overall negative experience scale. The ECI has been validated with a sample of 626 relatives of individuals with severe mental illness, in which all ten subscales were found to be internally consistent, with Cronbach's alphas of 0.74–0.91 (Szmukler et al. 1996). To the authors' knowledge the ECI has not been validated with African Americans, however all subscales were found to be internally consistent for the African American sample in this study, with Cronbach's alphas of .67–.94.

**Problem-Focused Coping**—Indicators of problem-focused coping were evaluated with empowerment and knowledge scales. The Family Empowerment Scale (FES) measures the level of empowerment using three subscales: family, community, and service system empowerment. The FES is a comprehensive measure of problem-focused coping as it taps into problem-solving attitudes, knowledge and behaviors related to empowerment, and advocacy. Sample questions include: "When I need help with problems in my family, I am



able to ask for help from others,” and “I know the steps to take when I am concerned (he/she) is receiving poor services” (Koren et al. 1992). The FES has been validated with a sample of parents of children with emotional, behavioral or mental disorders, in which the three subscales were found to be internally consistent, with Cronbach’s alphas of .87–.88 (Koren et al. 1992). To the authors’ knowledge, the FES has not been validated with African American samples, however subscales were found to be internally consistent for the African American sample in this study, with Cronbach’s alphas of .87–.89. We assessed knowledge about mental illness using a 20-item true–false test of factual information covering material drawn from the FTF curriculum that tapped general knowledge about mental illnesses (scale available from authors).

**Emotion-Focused Coping**—Emotion-focused coping was measured with five subscales of the Coping Orientation to Problems Experienced (COPE) Inventory: emotional social support, positive reinterpretation and growth, acceptance, religiosity, and denial (Carver et al. 1989). The COPE has good reliability and validity, has been adapted for relatives of individuals with a severe mental illness (Solomon and Draine 1995b) and has been validated for use with African Americans in its original and a culturally-modified version (Greer 2007).

**Family Functioning**—We assessed family functioning with the Family Assessment Device (FAD) and the Family Problem-Solving Communication (FPSC) scales. The FAD evaluates family functioning and family relations (Epstein et al. 1983) and is widely used in studies of family response to medical/physical illness, with well-established reliability and validity (Sawin et al. 1995). We used its general functioning and problem-solving subscales. To the authors’ knowledge, the FAD has not been validated with African American samples, however both subscales were found to be internally consistent for the current African American sample, with Cronbach’s alphas of .83 and .92. The tenitem FPSC scale measures positive and negative aspects of communication on two subscales (McCubbin et al. 1996). The Cronbach’s alphas for the subscales for the full sample and African American sample were .76–.82 and .76–.83, respectively.

**Psychological Distress**—We assessed distress with the Brief Symptom Inventory (BSI-18) and the Center for Epidemiological Studies Depression Scale (CES-D). The BSI-18 is a well-established reliable and valid measure of psychological distress designed for use primarily in nonclinical, community populations (Derogatis 2001). It measures level of somatization, anxiety, and depression and generates a total score of the respondent’s overall level of psychological distress (General Severity Index). The raw scores for the BSI-18 symptom dimensions were converted to area T scores based on norm tables for community males and community females. The modified version of the CES-D is a reliable and valid 14-item scale designed to measure depressive symptoms in the general population (Radloff 1977; Radloff and Lock 1986). The BSI-18 and CES-D have been validated for use with African Americans (Hoe and Brekke 2008; Nguyen et al. 2004; Rozario and Menon 2010).

## Data Analysis Plan

In order to determine covariates for the regression analyses, we first used *t* tests and Chi square tests to assess the difference between African American and White caregiver participants on demographics (age, gender, education, income, work status, marital status, size of household, site, relationship to consumer), mental health background (mental health diagnosis, homelessness, living status) and mental health service use of the relative diagnosed with a mental illness (mental health-related hospitalization and age first received mental health help).

Hypotheses were then tested with linear regression models (SAS, version 9.2, PROC MIXED procedure) to examine the relationship between race and baseline scores on study variables (caregiver experiences, problem-focused coping, level of knowledge on mental illness, emotion-focused coping, subjective illness burden, and psychological distress) adjusting for demographics. To control for type I error, we used the sequential Bonferroni-type procedure for dependent hypothesis tests. This test allowed us to control for the false discovery rate [the expected (or on average) proportion of falsely rejected hypotheses] at 5 % (Benjamini and Yekutieli 2001).

## Results

### Comparison of Baseline Demographics by Race

Table 1 describes the demographic characteristics of the sample, including significant differences by race. Compared to White participants, African American participants were younger (49.8 vs 53.6 years), and less likely to be male (11 vs 29 %), have an income above \$50,000 (47 vs 79 %) or be married (35 vs 74 %). Additionally, African American participants were less likely to be the parent of the ill family member (58 vs 64 %) and more likely to live in an urban or mostly urban setting (71 vs 27 %) compared to White participants. There were no significant differences by race in the proportion of family members working full time or the number of people in the household.

Table 2 reflects the mental health background and mental health service use history of the relatives diagnosed with a mental illness (consumers) as reported by family caregivers. Compared to White consumers, African Americans consumers were more likely to have a diagnosis of schizophrenia (29 vs 13 %) and less likely to have a diagnosis of bipolar disorder (35 vs 54 %). African Americans were also more likely to report their family member had been homeless in the last year (16 vs 9 %) than Whites. No other significant differences by race were found.

### Baseline Analyses by Race, Adjusting For Demographics

As reflected in Table 3, our linear regression model examined baseline assessments with race as a predictor controlling for age, gender, relationship to the ill relative (parent versus other family member), education, income, and marital status of program participants.

**Experiences with Caregiving**—Although no significant differences were found on the overall positive experiences or negative experiences scales, African Americans experienced



higher caregiving problems than Whites on a number of individual dimensions. These included higher levels of mental health service delivery challenges ( $\beta(SE) = .30(.11)$ ,  $df = 380$ ,  $p < .05$ ), and greater concern about the family member's level of dependency on them ( $\beta(SE) = .27(.10)$ ,  $df = 380$ ,  $p < .05$ ).

**Problem-Focused Coping and Knowledge About Mental Illness**—In relation to problem-focused coping, African Americans reported greater levels of service system empowerment ( $\beta(SE) = .26(.11)$ ,  $df = 380$ ,  $p = .05$ ) and community involvement and advocacy ( $\beta(SE) = .27(.10)$ ,  $df = 380$ ,  $p < .05$ ) than Whites. On the other hand African Americans scored significantly lower than Whites ( $\beta(SE) = -8.55(2.14)$ ,  $df = 380$ ,  $p < .01$ ) on knowledge about mental illness.

**Emotion-Focused Coping**—African Americans reported greater use of a positive reframing coping style ( $\beta(SE) = .93(37)$ ,  $df = 378$ ,  $p = .05$ ), greater use of denial as a way of coping ( $\beta(SE) = .70(22)$ ,  $df = 379$ ,  $p < .05$ ), and greater use of religion ( $\beta(SE) = 2.65(53)$ ,  $df = 379$ ,  $p < .001$ ), as a way of coping.

**Subjective Burden and Psychological Distress**—In regards to both subjective burden and psychological distress, no significant race-related differences were found.

## Discussion

The present study examined race-related differences in the experiences of African American and White family caregivers, of individuals diagnosed with a mental illness, who sought family support from the NAMI Family-to-Family Program (FTF). Our hypotheses were partially supported. As hypothesized, African American caregivers reported more problem-solving and positive emotion-focused coping than White caregivers in two main dimensions: community involvement/advocacy and religious coping. Contrary to our hypothesis, African American caregivers reported more negative emotion-focused coping (denial). African American caregivers also reported more negative caregiving experiences than Whites, including difficulty with mental health services, and less knowledge about mental illness. All results held while controlling for theoretically important demographic factors. Collectively, results suggest that caring for a loved one diagnosed with a mental illness creates a challenging experience for which African Americans seek to cope in a variety of ways.

### Challenging Caregiving Experiences and Problem-Focused Coping

There were several areas in which African American family members reported challenging caregiving experiences. Relative to White caregivers, African American caregivers experienced more service delivery challenges (i.e., dealing with mental health professionals, whether these professionals would take them seriously, how best to navigate the mental health system) and expressed more worry about the ill family member's dependency on the family. These results are consistent with research documenting racial disparities in mental health service access and utilization for African Americans, which may be related to limited availability of service and insurance coverage, and to greater mistrust of mental health services due to historical medical mistreatment of African Americans (Briggs et al. 2011).

As a response to such challenges, African American families who seek FTF may become more proactive regarding their loved one's mental illness. Furthermore, service system challenges may stress caregiving family members, eliciting feelings of worry and spark problem-solving activation. As hypothesized, African Americans reported more problem-focused coping than Whites, including involvement and advocacy in the mental health community. Thus, it is plausible that their higher levels of involvement and advocacy were in reaction to challenging experiences with the mental health service system. Alternatively, it is possible that those with greater levels of involvement and advocacy were more able to seek help from programs such as FTF to cope with caregiver burdens. Consistent with recent research (Gerson et al. 2009), African American caregivers were also found to have less knowledge about mental illness than White caregivers.

### **Emotion-Focusing Coping Responses to Challenges of Caregiving**

African American family members responded to the challenges of caring with both positive and negative aspects of emotion-focused coping revealing the complexity of responses to caring for a loved one with a mental illness. African American family members reported greater use of denial as a means of coping compared to White family members. This type of avoidance coping mechanism may be related to the stigma and shame that family members may feel as a result of having a relative with a mental illness (Corrigan and Miller 2004). Stigmatization of mental illness is related to variety of problematic coping mechanisms including withdrawal from/avoidance of others and secrecy surrounding mental illness (Link et al. 1991). Furthermore, stigma has been cited as factor in the secrecy surrounding mental illness, specifically for African Americans (Briggs et al. 2011; Alvidrez et al. 2008). The findings from this study suggest that stigma may be an important factor influencing how African American family members cope with mental illness, including denial of mental health problems. Despite reporting greater levels of denial, African American caregivers still sought help from FTF, a nontraditional mental health program. It may be that African American caregivers saw FTF as a safe space to discuss their experiences with a loved one with mental illness given that FTF is peer-taught and caregivers are surrounded by families with similar needs. As such, use of denial as a coping mechanism may be bound to situations outside of FTF where caregivers feel stigmatized by their loved one's mental illness.

In contrast, African American family members reported more positive reframing as indicated by items on the COPE positive subscale such as, "I try to grow as a person as a result of the experience; I try to see it in a different light, to make it seem more positive; I look for something good in what is happening; I learn something from the experience." African American caregivers were able to reframe the caregiving experience in a positive light. This illustrates an ability on the part of the caregiver to reappraise a stressful caregiving situation, tapping into the positive aspects of the caregiving experience. The research on positive aspects of caregiving is not as prevalent as the research on caregiver burden (Cummings and MacNeil 2008). However, a few studies on predominantly White caregivers have shown that family members do report positive aspects of the caregiving experience (Chen and Greenberg 2004; Cummings and MacNeil 2008). The present study

adds to the racial/ethnic diversity in a growing body of research on positive caregiving experiences by exploring the experiences of White and African American families.

In addition to higher levels of positive reframing, African American family members in the present study reported more religious coping, on COPE religious subscale items such as, “I put my trust in God; I try to find comfort in my religion; I pray more than usual.” As suggested by Knight et al.’s (2000) sociocultural model of stress and coping, a positive appraisal of or less stressful perspective on the caregiving experience may be related to sociocultural factors such as the use of religious and spiritual coping as described above. Research has shown that many African Americans utilize religion and spirituality as an important source of coping with adverse life events (Utsey et al. 2007; Banks-Wallace and Parks 2004; Mattis 2002). African American women have reported that spiritual beliefs in a “larger life plan” aided in reappraising challenges and negative life events as opportunities for individual and familial growth (Mattis 2002). Utsey et al. (2007) found that for African American men and women, spirituality was a factor in improving quality of life by impacting their ability to cope with adversity. For African Americans in the present study, positive reframing and religious/spiritual coping may be related and reinforce a less stressful perspective on the caregiving experience.

A less stressful perspective on the challenging demands of the caregiving experience may also be related to expectations of the availability of and reliance on social support from family and the community. In general, reliance on extended family, fictive kin, friends, community, and religious supports has been especially important in creating the potential for larger social networks and sources of support for African Americans (Taylor and Chatters 1988; Taylor et al. 2001, 2003) and more specifically for African American families coping with severe mental illness (Guada et al. 2009; Guarnaccia and Parra 1996; Horwitz and Reinhard 1995). Future research should examine the relationship among the demands of caregiving, social support and coping styles for African American caregivers of relatives diagnosed with a severe mental illness.

## Limitations

This study has several limitations. Participants were recruited from urban and suburban communities in a Middle Atlantic state and it is therefore unclear whether the sample generalizes to other communities. Additionally, African American families tended to live in urban neighborhoods as compared to White families, which could potentially affect access to mental health services. However, the current sample was drawn from current members of NAMI who were active help-seekers of these services. Through NAMI, participants in the study had access to information about mental health treatment and providers in their respective communities.

Due to the cross sectional nature of the present study, we were unable to determine how caregiver perceptions and experiences may change over time. However a previous study of the Family To Family Education Program found that knowledge of mental illness was the only variable that differed between Whites and nonwhites after participating in FTF such that nonwhites did not significantly improve over time (Dixon et al. 2004).

Additionally, longitudinal analysis with the same sample used in the present study indicated that knowledge of mental illness increased more for Whites than nonwhites after participating in FTF (D. Medoff, personal communication, December 9, 2013). Future research should continue to examine caregiver experiences over time and the effects of programs in decreasing or eliminating race-related differences in caregiver burden for African Americans. Although the present study contained a limited number of African American men, this is consistent with other studies on caregiver burden that found that women tend to be caregivers of family members with severe mental illness (Awad and Voruganti 2008). This study also included a help-seeking sample of African American families with a relative diagnosed with a mental illness. The perceptions and experiences of African American families that are not participating in self-help programs are therefore absent from our analyses.

Despite these limitations, the present study contributes to the growing body of literature examining race-related differences in caregiving experiences of family members with a loved one diagnosed with a mental illness. Several factors contributed to an engaging yet challenging caregiving experience for African American families including different coping styles and challenges in the mental health help-seeking process.

## Implications

African American family members' concerns and problems with mental health services indicate the need for interventions to address challenges faced by African Americans when interacting with mental health services. Mental health programs, as well as self-help organizations, may consider specific strategies for African Americans that address caregiving challenges, support the use of existing positive coping mechanisms and support networks and increase knowledge about mental illness. Furthermore, mental health services and self-help organization may also consider education and training programs for service providers aimed at increasing knowledge of sociocultural issues relevant to African Americans, and improving interactions and reducing bias when interacting with African American caregivers. Future research should examine the help-seeking patterns of African American families and the challenges they encounter in the mental health system to help programs better serve African American families with a relative diagnosed with a mental illness. Future research should also examine how sociocultural factors influence the caregiving experience for African Americans families coping with mental illness.

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**Table 1**

FTF family member demographics by race

Demographics	Full sample (N = 400)		White (N = 293)		African American (N = 107)		Comparison		
	n/M ± SD	%	n/M ± SD	%	n/M ± SD	%	Test	df	p
Age (years)	52.6 ± 10.6		53.6 ± 10.7		49.8 ± 9.9		-3.23 <sup>b</sup>	397	.001
% Male	96	24	84	29	12	11	13.09 <sup>a</sup>	1	<.001
Education									
Less than HS (8–11)	7	2	5	2	2	2	.00 <sup>c</sup>		.001
High school graduate (12)	53	13	34	12	19	18			
Some college (13–15)	96	24	58	20	38	36			
College graduate (16)	105	26	81	28	24	22			
Post graduate (17)	139	35	115	39	24	22			
% Family income >\$50000	274	70	226	79	48	47	38.22 <sup>a</sup>	1	<.001
% Work full time	231	58	169	58	62	58	.00 <sup>a</sup>	1	.962
% Married or living as if married	253	63	216	74	37	35	51.66 <sup>a</sup>	1	<.001
Total people in household	3.0 ± 1.6		2.9 ± 1.4		3.3 ± 2.1		1.45 <sup>b</sup>	143	.150
Site of collection									
Baltimore Metro/Prince George's County	155	39	79	27	76	71	70.09 <sup>a</sup>	3	<.001
Montgomery County	126	32	112	38	14	13			
Frederick County	54	14	52	18	2	2			
Howard County	65	16	50	17	15	14			
Family relationship to consumer									
Parent	250	63	188	64	62	58	.00 <sup>c</sup>		.009
Child	23	6	13	4	10	9			
Sibling	46	12	31	11	15	14			
Spouse/partner	45	11	40	14	5	5			
Other Kin	31	8	18	6	13	12			
Nonkin/friend	5	1	3	1	2	2			
Who provides most support									

Demographics	Full sample (N = 400)		White (N = 293)		African American (N = 107)		Comparison Test	df	p
	n/M ± SD	%	n/M ± SD	%	n/M ± SD	%			
No one	4	1	4	1	0	0	.00 <sup>c</sup>		<.001
Parents	270	71	202	73	68	67			
Spouse	48	13	43	16	5	5			
Sibling	22	6	13	5	9	9			
Children	19	5	10	4	9	9			
Other kind	13	3	4	1	9	9			
More than one sources	1	0	0	0	1	1			
Nonkin Friend	1	0	0	0	1	1			

<sup>a</sup> Chi square test

<sup>b</sup> t Test

<sup>c</sup> Fisher exact

**Table 2**

FTF consumer mental health background by race as reported by family members

	Full sample (N = 400)		White (N = 293)		African American (N = 107)		Comparison	
	n/M ± SD	%	n/M ± SD	%	n/M ± SD	%	Test	df
Consumer diagnosis								
Schizophrenia	69	17	38	13	31	29	.00 <sup>c</sup>	.002
Bipolar disorder	194	49	157	54	37	35		
Depression	58	15	44	15	14	13		
Anxiety	23	6	16	5	7	7		
Obsessive-compulsive disorder	40	10	27	9	13	12		
Substance abuse	3	1	3	1	0	0		
Other	1	0	1	0	0	0		
Unknown	12	3	7	2	5	5		
% of consumers who had a mental health hospitalization in the past 6 months	147	37	103	35	44	42	1.30 <sup>a</sup>	1 .255
% of consumer who were homeless in the past 6 months	42	11	25	9	17	16	4.60 <sup>a</sup>	1 .032
% of consumers living independently	117	29	92	31	25	24	2.35 <sup>a</sup>	1 .125
Age at which consumer first received mental health help	20.6 ± 12.5		20.2 ± 12.1		21.7 ± 13.5		1.04 <sup>b</sup>	380 .299

<sup>a</sup>Chi square test

<sup>b</sup>t Test

<sup>c</sup>Fisher exact

Table 3

FTF linear regression analysis by race, adjusting for demographics

Race (African American vs. White) Variables	B (SE)	df	t	p
<i>FEIS—assistance in daily living module<sup>a</sup></i>				
Objective daily living assistance	.14 (.12)	380	1.18	.331
Objective supervision	.07 (.08)	380	.92	.477
<i>Family member problem-focused coping</i>				
FES Family Scale <sup>b</sup>	.12 (.08)	380	1.53	.224
FES Service Scale <sup>b</sup>	.26 (.11)	380	2.51	.050
FES Community Scale <sup>b</sup>	.27 (.10)	380	2.78	.042
Knowledge Scale	-8.55 (2.14)	380	-4.00	.001
<i>Family member emotion-focused coping<sup>c</sup></i>				
Cope Positive Scale	.93 (.37)	378	2.51	.050
Cope Denial Scale	.70 (.22)	379	3.26	.013
Cope Religious Scale	2.65 (.53)	379	5.01	<.001
Cope Emotional Scale	-.82 (.41)	378	-1.99	.116
Cope Acceptance Scale	-.07 (.31)	377	-.24	.837
<i>Family member psychological distress</i>				
CESD sum <sup>d</sup>	-1.57 (.99)	375	-1.59	.224
BSI Area 1 Score of General Severity Index <sup>e</sup>	-1.82 (1.26)	375	-1.45	.250
BSI Area 1 Score of Somatization Subscale	1.77 (1.15)	375	1.54	.224
BSI Area 1 Score of Depression Subscale	-2.95 (1.25)	375	-2.36	.063
BSI Area 1 Score of Anxiety	-1.69 (1.25)	375	-1.35	.284
<i>Family system functioning</i>				
FAD General Functioning Scale <sup>f</sup>	-.20 (.83)	370	-.25	.844
FAD Problem Solving Scale <sup>f</sup>	-.08 (.36)	367	-.21	.844
FPSC Affirming Communication <sup>g</sup>	-.21 (.37)	374	-.57	.682
FPSC Incendiary Communication	.08 (.41)	370	.20	.844
<i>ECI—experience of care giving inventory<sup>h</sup></i>				
ECI Difficult Behavior Scale	.15 (.11)	377	1.31	.289

Race (African American vs. White) Variables	B (SE)	df	t	p
ECI Negative Symptom Scale	.06 (.11)	377	.51	.699
ECI Stigma Scale	-.06 (.11)	380	-.56	.682
ECI Problem w Service Scale	.30 (.11)	380	2.72	.042
ECI Effect on Family Scale	.22 (.11)	380	2.10	.096
ECI Need of Backup Scale	.12 (.10)	380	1.21	.330
ECI Dependency Scale	.27 (.10)	380	2.67	.042
ECI Loss Scale	-.02 (.10)	380	-.26	.837
ECI Positive Personal Experience Scale	.20 (.08)	380	2.34	.063
ECI Good Aspect of Relationship Scale	.07 (.09)	380	.78	.555
ECI Positive Scale	.26 (.14)	380	1.85	.149
ECI Negative Scale	.94 (.60)	380	1.56	.224
<i>FEIS—family member subjective burden</i>				
FEIS Worry Scale	.22 (.10)	380	2.21	.080
FEIS Displeasure Scale	.03 (.11)	380	.28	.837

<sup>a</sup> *FEIS* Family Experiences Interview Schedule

<sup>b</sup> *FES* Family Empowerment Scale

<sup>c</sup> Coping Inventory (COPE) Scales

<sup>d</sup> *CES-D* Center for Epidemiological Studies Depression Scale

<sup>e</sup> *BSI* Brief Symptom Inventory

<sup>f</sup> *FAD* Family Assessment Device

<sup>g</sup> *FPSC* Family Problem-Solving Communication Scale

<sup>h</sup> *ECT* Experience of Caregiving Inventory