Caregiver Intervention Research: An Opportunity for Collaboration between Caregiving Investigators and African-American Faith Communities

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The African-American community in the United States is rapidly aging. Because friends and family who care for these elderly individuals often do so at the expense of their own physical and psychological well-being, there has been extensive interest in the development of interventions to reduce caregiver burden and morbidity. Few interventions, however, have targeted African-American caregivers. Given the importance of religion for many African-American caregivers, we believe that faith communities could be valuable allies to research investigators. The primary objectives of this paper, therefore, are to: 1) summarize the literature on religion and African-American caregivers; 2) provide a rationale for why caregiving investigators and African-American faith communities should collaborate; and 3) present directions for future research. We present evidence to support our assertion that, not only could collaboration result in interventions that improve the well-being of African-American caregivers, collaboration would also benefit both caregiving investigators and faith communities.

Key words: caregivers ■ religion ■ intervention studies ■ African Americans

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INTRODUCTION

Older Americans are increasingly living with chronic disease. Approximately 80% of individuals aged ≥65 have ≥1 chronic condition and 50% have ≥2.[1] Because chronic disease disproportionately affects the elderly, the number of people afflicted will increase as the population ages; experts predict an absolute increase of >50 million people aged ≥65 years from the years 2000–2050.[2]

The growing number of older adults places increasing demands on medical and social service providers. The responsibility for their day-to-day care, however, rests largely with friends and family. Roughly 44 million people provide unpaid care to ill or disabled family members, the great majority of whom are elderly.[3] Caregivers help their loved ones with activities of daily living (e.g., bathing, dressing, eating, etc.) and with instrumental activities of daily living (e.g., transportation, grocery shopping, housework, etc.). They also provide direct medical care.[4] The value of this care is estimated to be at least $257 billion per year, more than is spent on formal home healthcare and nursing home care combined.[5]

This tremendous service often comes at a price, however. A recent meta-analysis demonstrated that caregivers were under more stress, suffered from more depression and had worse physical health than their noncaregiving peers.[6] One study even showed a 63% higher mortality risk in caregivers who were experiencing emotional strain than in noncaregiving controls.[7] As a result, much effort has been spent developing interventions that reduce caregiver burden and morbidity.[8]

Despite the recent proliferation of caregiver intervention research, few interventions have been geared specifically toward the needs of African-American caregivers[9] More research in this area is needed. Not only are African Americans the largest ethnic minority group in the United States, making up 13% of the population, but the percentage of the elderly population who are African-American is increasing. From 2000–2050, the elderly Caucasian population is expected to double,

whereas the elderly African-American population will almost quadruple.[10] In addition, the African-American elderly rely more heavily on family caregivers for assistance than do Caucasians.[11]

We believe that African-American faith communities are an important resource that should be used for the development and testing of culturally sensitive caregiver interventions. Specifically, African-American faith communities and caregiving investigators could collaborate to help answer three important research questions:

1. Can collaboration result in an increased rate of participation of African-American caregivers in research?
2. Can collaboration increase the effectiveness of existing caregiver interventions?
3. Can collaboration result in the design of novel caregiver interventions?

We believe the answer to these questions is yes. In support of our position we will: 1) briefly summarize the literature on religion and African-American caregivers; 2) provide a rationale for why caregiving investigators and African-American faith communities should collaborate; and 3) discuss directions for future research.

Religion and African-American Caregivers

Religious beliefs about helping behavior have a strong influence on why African Americans assume the caregiving role.[12] Studies show that African-American caregivers tend to be more religious, pray more frequently and are more likely to use religious coping than their Caucasian counterparts.[13,14] In addition, African-American caregivers are more likely to receive support from ministers and consider God a member of their social support network.[15] The strength drawn from these religious resources may be one of the reasons that African-American caregivers generally report less burden and psychological morbidity, despite providing more difficult, time-consuming care.[16] Studies also show that greater religiosity is associated with African Americans' reporting more positive aspects of and greater satisfaction with caregiving.[17-19]

Rationale for Collaboration for Caregiver Intervention Research

Despite the importance of religion to African-American caregivers and the recent flurry of interest in developing interventions for caregivers of dependent adults, investigators have not involved faith communities in caregiver intervention research. There are several reasons to believe that increased collaboration could be beneficial. First, investigators could benefit from the existing infrastructure and resources provided by faith communities. There are >350,000 religious congregations in the United States.[20] At least 13% primarily serve the African-American community.[21] Second, collaboration would allow investigators to build on the established health and service efforts currently being used in faith communities. For example, approximately 40% of Americans with mental health concerns seek the help of clergy, making clergy among the most frequently sought sources of help for general psychological distress.[22] Given that psychological distress can result from caregiving, clergy likely play an important role in the counseling of caregivers. Investigators, however, have not included clergy in intervention research. Third, establishing partnerships with faith communities enhances the ability of investigators to reach caregivers who may feel marginalized by societal institutions.[23] For instance, in a study involving two urban Catholic churches, health-related activities connected with the Church were perceived as more accessible and user friendly than those associated with secular institutions.[24] Fourth, churches are the foremost source of volunteers, far outnumbering other civic organizations.[25] Volunteers could, for example, be recruited to participate in research studies that evaluate the impact of outreach assistance on caregivers (e.g., assistance with caregiving related chores, telephone counseling, etc.).[26-28] Data from the health promotion literature demonstrate that church volunteers can be effective in these roles.[29] Finally, by working with faith communities, investigators can learn more about the intersection of religion and the physical, social and cultural aspects of caregiving. The religious dimension of caregiving has typically been ignored, despite work demonstrating that it may make an independent contribution to caregivers' well-being.[17]

Faith communities also stand to benefit from increased collaboration. For example, there have been calls for faith communities to improve the services they provide to the elderly and their caregivers.[30] Collaboration with caregiving investigators could increase the scope of these programs. Because expanded health ministries and community outreach allow congregations to become more visible and accessible to nonmembers, new members may be drawn to the congregations.[31] People may also be attracted to congregations by the opportunity to provide volunteer assistance to the elderly and their caregivers.[32] Collaboration would also benefit clergy directly. Data from the Epidemiologic Catchment Area (ECA) Study, the largest study of the use of services by the mentally ill in the United States, showed that clergy do not differ from mental health practitioners in terms of the type or severity of psychiatric disorders they treat.[33] Many clergy, however, feel ill prepared to recognize mental illness, inadequately trained in counseling skills and lacking in knowledge of the services offered by mental health agencies. As a result, many want more training in these areas.[22] Collaborating with investigators who have expertise in mental health would

allow clergy to improve these skills. Table 1 provides a summary of the benefits that collaboration may provide to caregiving investigators and faith communities.

Directions for Future Research

We believe that collaboration would help answer the following three research questions:

- Could collaboration result in an increased rate of participation of African-American caregivers in research?

Caregiving investigators have reported that the recruitment and retention of African Americans for clinical studies is often difficult.[34] A primary reason for this difficulty is that African Americans are less likely to trust the motives of clinical investigators than are Caucasians.[35] Partnering with faith communities could help investigators overcome this barrier; the church is central to the African-American community and is typically perceived as a trusted, healing resource that offers a sense of belonging and support.[36] The long and successful history of partnerships between academic investigators and African-American faith communities for health promotion research is testimony to this fact and should serve as a model for caregiving investigators.[29,37]

- Could collaboration increase the effectiveness of existing caregiver interventions?

Interventions for caregivers can be broadly categorized into two groups, those aimed at reducing the amount of care provided by caregivers (e.g., respite) or those aimed at providing information and improving caregivers' coping skills (e.g., support groups and counseling). We describe below how collaboration could increase the effectiveness of existing interventions (respite and support groups) and result in the design of novel caregiver interventions (religious/spiritually oriented counseling).

Respite. Despite the frequency with which respite care is advocated, providing respite care to caregivers has not been shown conclusively to improve their well-being.[38] A primary reason is that caregivers frequently do not feel comfortable leaving their loved one in the care of strangers.[39] This may be a particular issue for African-American caregivers.[40] The use of faith communities to provide respite volunteers may help overcome this problem; caregivers are more likely to trust congregation members than to trust strangers. In addition, caregivers derive a greater sense of comfort from their cocongregationalists than from others, as cocongregationalists share a world view that helps provide meaning to life experiences.[41] This enhanced level of trust and shared world view may make respite care more palatable to African-American caregivers.

Support groups. African-American caregivers are less likely to participate in traditional support groups than their Caucasian counterparts. In large part, this reflects the trust issue described above and the fact that traditional groups ignore the ethnic and cultural aspects of caregiving.[42] For example, in one study, caregivers of patients with dementia were frustrated with the absence of culturally sensitive support services and local support groups. As a result, most caregivers sought support from the Church and thought that support groups should be conducted on church grounds.[43] Faith communities are an ideal partner for testing the effect of culturally sensitive support groups on caregiver well-being because the key features of a successful support group—providing role models, promoting a sense of community, teaching effective coping strategies and providing a network of

Table 1. Potential benefits of collaboration between investigators and African-American faith communities for the design of caregiving interventions

Benefits to Investigators
Faith communities share common values regarding health promotion.
Faith communities are prevalent, accessible and stable institutions.
Faith communities are already involved in health activities and counseling.
Faith communities are trusted institutions that can reach underrepresented populations.
Faith communities have a cadre of volunteers.
Faith communities could educate health professionals regarding the religious/spiritual aspects of aging and caregiving.
Benefit to Faith Communities
Collaboration with health professionals can confer "legitimacy" to health programs and interventions.
Collaboration with health professionals allows faith communities to expand their health ministry.
An expanded health ministry has the potential to attract new members to the congregations.
Collaboration with health professionals provides opportunities for the education of the congregations regarding issues of health and caregiving.
Collaboration with health professionals provides opportunities for the education of clergy regarding the recognition of mental illness, counseling and referrals.

social relationships—characterize African-American faith communities.[44-46] Preliminary research suggests that support groups based in African-American churches can improve caregiver outcomes.[47]

- Could collaboration result in the design of novel caregiver interventions?

Counseling. Although faith communities have often been used as a vehicle for health promotion, religious beliefs and practices have themselves rarely been used as a vehicle to promote health.[48] One promising area of research is the incorporation of religious themes into counseling interventions. The basis of these interventions is the fact that religion is often used by caregivers to cope with the demands of caregiving.[3] For those for whom religion is salient, the appraisals offered by religion can provide meaning and purpose for stressful life events.[49] These appraisals, in turn, can improve caregiver well-being by providing meaning for their or their loved one's suffering.[50]

Although a small body of research suggests that religious/spiritually oriented counseling is at least as effective as secular treatment, these interventions have not been tested in African-American caregivers.[51] There are several reasons to believe that the incorporation of religious themes in counseling could benefit African-American caregivers in particular. First, as discussed previously, African-American caregivers tend to be more religious, pray more frequently and are more likely to use religious coping. Second, the majority of African Americans conceptualize personal distress within a religious framework.[52] For example, a national survey of African Americans' attitudes toward depression found that 63% conceptualized depression as a personal weakness; only 31% felt depression was a health problem; 60% believed that prayer and faith were the most successful methods for treating depression; and 36% said that they would recommend that a friend seek help from a minister for depression.[53] As such, African Americans are more likely than Caucasians to want religion and spirituality incorporated as part of the treatment for mental health distress.[54] Third, African Americans are more likely to seek clergy for help than are Caucasians.[55,56] African-American pastors, in turn, are more likely to include spiritual dimensions when counseling and place a greater emphasis on using religious practices (e.g., church attendance) as a method for treating emotional problems.[57] Recent data suggest that these practices are associated with improved well-being in caregivers (Hebert RS, Dang Q, Schulz R. *American Journal of Geriatric Psychiatry*, under review).

Finally, two points deserve mention. First, our discussion is based on data from Judeo-Christian samples. Future research should include work with other groups—in particular, Muslim congregations. Muslims are one of the most rapidly growing minority groups, and approximately 30% of mosques are predominantly African-American.[58] Second, although we focus on African Americans, the caveat should be made that African Americans are a diverse group. For example, an African-American congregation in the Bible Belt south may endorse different religious beliefs and practices than one based in the urban northeast. In addition, not all blacks are African Americans. Blacks also include individuals from Africa, the Caribbean and multiracial individuals.[59]

CONCLUSION

The United States is facing the daunting task of providing care to an increasingly older population. Care provided by friends and family is integral to the care of older adults, although often at the expense of the caregivers' health. Given the salience of religion for many African-American caregivers, health professionals who understand the religious experience could use this information to develop effective interventions. Although it is not possible for faith communities to be the primary resource to meet all the needs of African-American caregivers, mutually beneficial partnerships between the health professions and faith communities can play a role in improving their well-being.

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