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Perceptions and Attitudes Toward Dementia in Predominantly African American Congregants

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Abstract

The purpose of this study was to identify the perceptions and attitudes of African American congregants toward dementia before and after attending a dementia-focused workshop. Six churches in Metropolitan Atlanta, Georgia, hosted the workshops. Attendees (N = 171) participated in a free association exercise to evaluate their perceptions and attitudes toward dementia. Before and after the workshop, participants wrote words and phrases that occurred to them when they thought of dementia. Content analysis was used to identify themes. Before the workshop, participants' responses tended to include negative language (e.g., fear, memory loss, sadness). After the workshop, participants expressed more positive words (e.g., support, hopefulness, caring). These findings suggest that education can change congregants' perceptions about dementia and potentially reduce dementia-associated stigma. This change will allow families to feel comfortable both interacting with and seeking help from those in their faith communities.

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Research was approved by the Georgia State University Institutional Review Board (IRB Approval # H19562).

CONFLICT

The authors declare no conflict of interest.

Introduction

African Americans are at higher risk for dementia than other racial groups (Alzheimer's Association, 2020). Dementia is a stigmatizing disease and families of persons living with dementia are often hesitant to share a dementia-related diagnoses with individuals outside of their immediate family because of feelings of fear and shame (Birt et al., 2020; Vickrey et al., 2007). Shame can hinder families from seeking formal support which can lead to loneliness and isolation; thus, resulting in anxiety and depression (Burgener et al., 2015). African American families may be particularly susceptible to the negative effects of stigma as they hesitate in sharing dementia-related diagnoses outside of immediate family members due to fear and shame (Vickrey et al., 2007). As a whole, stigma whether actual or perceived reduces the quality of life for families (Weisman de Mamani et al., 2018). Education can counter this stigma by inducing a change in perceptions and attitudes toward dementia in the African American community (Danner et al., 2008).

Additionally, active engagement in a faith community, such as church or other religious group, can reduce dementia-related stigma (Bryden, 2016). Connection with one's faith community is important to African American families because of their reliance on the church for spiritual, emotional, social, and material support (Epps & Williams, 2020; Nguyen et al., 2019). Involvement with clergy and congregants can help persons living with dementia and their caregivers, feel more comfortable and encouraged about their diagnosis (Chatters et al., 2008; Sun et al., 2010). Despite the evidence that dementia-affected families seek and need support from religious organizations, faith leaders find themselves unable to respond to the needs of the families due to their lack of preparedness and training regarding dementia (Friedrich et al., 2020). Like the general population, some faith leaders do not view dementia as a specific illness, but rather as a normal part of aging (Hindley et al., 2016). Health education in churches has produced positive effects such as increased knowledge and readiness to change (Brewer, 2019). This study sought to identify the perceptions and attitudes of predominantly African American congregants toward dementia before and after attending a dementia-focused education workshop.

METHODS

Assessments of predominantly African American congregants' perceptions and attitudes toward dementia were conducted during six workshops held from February 2018 to February 2020. Attendees at each workshop participated in an assessment of their perceptions and attitudes toward dementia before and after the workshop. Content analysis of the responses was used to identify themes (Miles et al., 2019). This study received approval from the Georgia State University Institutional Review Board (H19562).

Recruitment

Workshop attendees were recruited by distributing flyers at the host and surrounding churches, and on social media platforms (i.e., Facebook and Twitter). Research team members also attended and spoke briefly during Sunday services at host churches to promote workshop attendance. Collectively, 227 individuals took part in the workshops, and 171 chose to participate in the assessment exercises.

Workshop

Six predominantly African American churches in metropolitan Atlanta, Georgia hosted four-hour education workshops comprised of lectures and role-playing activities. The churches varied in Christian denomination and included United Methodist (n = 1), Pan African Orthodox Christian (n = 1), African Methodist Episcopal (n = 1), Catholic (n = 1), and non-denominational (n = 2) congregations. The workshops were facilitated by Faith Village Connections (FVC), an interdisciplinary collaborative developed by the primary author and comprised of predominantly African American women, to address gaps in the lack of resources and awareness about dementia in African American faith communities (Epps et al., 2020a). Current research and resources from aging support organizations (i.e. Alzheimer's Association, AARP, The Eden Alternative, and Sage Navigator) guided the curriculum content. The following topics were presented: (a) basics and warning signs of dementia; (b) dementia-friendly communication; (c) re-engaging dementia families; (d) role of the church; and (e) research opportunities. The workshop content targeted church leaders; however, the general congregation and community members were invited to attend.

Assessment—To assess attendees' thoughts and feelings about dementia, free association assessment exercises took place before and after workshops. Free association is a widely accepted tool to assess attitudes in various contexts (Wiers et al., 2010). At the beginning of the workshop, participants wrote their first thoughts, either a word or phrase, upon hearing that a friend or family member was diagnosed with dementia. Afterward, the participants reviewed and discussed the terms and phrases written. The same activity was performed after the workshop. Field notes were maintained throughout the exercises by two members of the research team.

Data Collection

At the beginning of each workshop, all attendees were given an information sheet and verbally informed of the study and consenting process. Attendees were told their participation in the evaluation activities (i.e., assessment exercise, evaluation survey) implied agreement to participate in the study. At the beginning and end of each workshop, we collected data on perceptions and attitudes toward dementia from attendees who agreed to participate in the free association exercise described earlier. Participants expressed their thoughts in open group exercises at each workshop, providing a variety of words and phrases. After each workshop, demographic information (age, gender, race, and role affiliation) was collected using surveys.

Data Analysis

The quantitative data were analyzed using descriptive statistics (i.e., frequencies, percentages, and means). Qualitative data were analyzed using NVivo 12 (QSR International). For all workshops, we conducted content analysis on responses from the pre- and post-workshop free association exercises (Miles et al., 2019). The primary author, who trained in nursing and qualitative analysis, worked with two team members from nursing and public health to independently review data and create codes via de novo assembly of responses. These codes were grouped based on similar concepts to identify thematic

categories. Disagreements were discussed and consensus gained before identifying emerging themes.

RESULTS

Two hundred and twenty-seven individuals attended the workshops. Overall, 171 attendees participated in the assessment exercises. Of those attendees, 146 (64%) participated in the pre-workshop and 138 (61%) participated in the post-workshop assessment exercise. The majority of participants were women (82%), African American (93%), and 50 years of age or older (91%). Thirty-five percent of the participants were 70 years of age or older. Approximately 45% of the participants identified as congregants and 24% as church leaders (i.e., pastor, minister, lay leader, etc.). Participant demographics are displayed in Table 1.

Themes

The exercises yielded various insights and feelings toward dementia. Figures 1 and 2 provide simple visualizations related to the frequency of pre- and post- workshop responses using word clouds. An analysis of responses led to the identification of thematic categories pre- and post- workshops.

Seven thematic categories emerged from the responses collected before the workshop: Anger, Despair, Cognitive Impairment, Distress, Powerless, Terminal, and Elderly. The responses trended mostly negative and included words and phrases such as *my God, crazy, fear, damn, childhood behaviors, death, old age, challenging, sadness, and senile*. The most frequently used words were associated with memory loss ($n = 36$) and pleading for help ($n = 21$). The discussion of these responses led to emotional reactions from several of the participants. Some participants openly cried, which reflected the anger, despair, and distress felt by many. These participants were comforted by other attendees and the FVC team. Some participants also provided inspirational and encouraging responses related to prayer and support.

Four thematic categories emerged from the responses collected after the workshop: Understanding, Hope, Love, and Partnership. Participants expressed more positive words and phrases regarding dementia such as *support, hopefulness, caring, grace, value what remains, and education*. The most frequently used responses were associated with offering help ($n = 22$) and hope ($n = 20$). Several participants communicated their appreciation for the workshop. For example, a former caregiver expressed that the session was informative, and she felt *more equipped to combat this disease*. Other participants provided supportive statements after the workshop, such as *we're going to get through this together* and *I will partner with you, together we can make this journey*. Additionally, participants expressed the need to pray and responded by writing *God bless* and *God knows*. Figures 3 and 4 illustrate the grouping of participants' pre- and post-workshop responses into thematic categories.

DISCUSSION

The purpose of this study was to identify the perceptions and attitudes of predominantly African American congregants toward dementia before and after attending a dementia-

focused workshop. Although the workshops were open to congregants and the general community, the curriculum was designed to target ministry leaders because they may be the best conduits for promoting, facilitating, and implementing behavior change and sharing health information. The attendees of the workshops were primarily congregants who expressed their desire to openly discuss this topic and work toward better understanding dementia to support affected families.

Our findings showed that after attending the workshop, participants adopted more optimistic and accepting perspectives about dementia compared to the more stigmatizing views that they held at the start of the workshop. During the pre-workshop free association exercise, some participants got emotional and sad during the discussions. This response substantiates the difficulty that the general population has acknowledging and discussing dementia-related topics (Lishman et al., 2016). Thus, the free association exercise was an innovative strategy to use in the African American community to solicit insights and feelings toward dementia. Post-workshop, the participants appeared to be more informed and comfortable discussing dementia and its associated signs and symptoms. Further, quotes from participants suggested they were more equipped, hopeful, and willing to offer help.

Overall, the workshops appeared to be effective based on participants' pre- and post-views, which shifted from negative to positive. If churches provide education on dementia-related topics, families may feel more welcomed and supported, thus more comfortable about breaking their silence related to sharing a dementia diagnosis. Ultimately, continued education in faith communities and dementia-friendly initiatives may allow African American families affected by dementia to feel comfortable seeking help from the church, an essential resource in their community (Epps et al., 2020b).

Limitations and Recommendations

The study consisted of African American congregants from urban Christian churches. Thus, these findings may not generalize to other faith communities, racial or ethnic groups, or rural areas. The post-workshop exercise was conducted immediately after the workshop when participants' enthusiasm and affinity for the subject may have been highest. Based on the limitations of this study and the promise of its results, we suggest further research to identify the perceptions about dementia by members of other faith communities and individuals in rural areas. We also recommend assessing knowledge and exposure to dementia through pre- and post- surveys, and longitudinal follow-up. Continued follow-up with congregations, to determine whether the church community has made policy or practice changes towards dementia families, may further demonstrate the education program's effectiveness in reducing the stigma surrounding dementia. Given the immensity of the struggles faced by families living with dementia, it is crucial to continue developing interventions and programs to reduce barriers caused by a lack of education about dementia.

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Figure 1.
Pre-Workshop Visualizations

Figure 2.
Post-Workshop Visualization

Figure 3.
Pre- Workshop Responses

Figure 4.
Post-Workshop Responses

Table 1.

Demographic Characteristics

Characteristics	% (n)
Gender:	
Male	16% (28)
Female	82 % (140)
Missing Responses	2% (3)
Race:	
African-American	93% (160)
White	2% (3)
Asian	1% (1)
Other	4% (7)
Age (yrs.):	
18–34	4% (6)
35–49	5% (8)
50–69	56% (96)
70 or older	35% (61)
What Best Describes You? (select all that apply)	
Living with Dementia	1% (1)
Educator/ Research/Healthcare Professional	19% (32)
Church Leader (e.g., pastor, minister, elder, etc.)	24% (41)
Caregiver/Family/Friend to person with dementia	32% (54)
Congregant/Church Member	45% (77)
Other (e.g., caregiver for person with other chronic illness, community leader, former dementia caregiver)	10% (17)