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Promoting dementia awareness in African-American faith communities

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Abstract

Introduction: Alzheimer's disease and other dementia-related disorders are affecting the African-American community at alarming rates. African-American churches have traditionally been places of refuge where families go for support. However, many churches lack programs or resources to support families affected by dementia. In response, a nurse-led interdisciplinary collaborative partnered with churches to promote dementia awareness through education.

Purpose: The purpose of this analysis was to (a) describe the demographics of those seeking dementia education in African-American faith communities; (b) identify prior knowledge of dementia community resources; and (c) determine the preliminary usefulness of the education provided.

Methods: Over the course of 16 months, 202 individuals attended nine educational sessions hosted by five churches across metropolitan Atlanta. Quantitative surveys were used to collect demographics and evaluate the educational sessions.

Results: The majority of attendees were African-American adults (91%), women (75%), and unaware of dementia resources (66%). Several attendees identified themselves as church leaders, community/church members, caregivers, and/or healthcare professionals. Attendees expressed the educational content was applicable to themselves or their families.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

Conclusion: Results help identify ways to alter and/or strengthen the educational content and serve as a guide for developing culturally relevant, faith-based community programs.

Keywords

Alzheimer's disease; caregiving; community awareness; dementia; patient education; religion

1 | INTRODUCTION

Approximately 5.8 million Americans live with Alzheimer's disease and related dementias (ADRD; Alzheimer's Association, 2020), making it the 6th overall leading cause of death in the country and the 5th leading cause of death among adults 65 years of age or older (Heron, 2018). It is projected that nearly 14 million Americans will have ADRD by 2050 (Alzheimer's Association, 2020). Due to the high rates and growing statistics of adults living with ADRD, it is considered a public health crisis in the United States (Olivari, French, & McGuire, 2020). Older African-American adults are particularly vulnerable to developing ADRD. They are said to be twice as likely than older White adults to have ADRD (Alzheimer's Association, 2020; Matthews et al., 2019) and are more likely than other populations to age with ADRD in the community (Schulz et al., 2010).

Although there is no cure for ADRD, a number of nonmedical, lifestyle practices are recommended for possible prevention, as a healthy disease management, and for general age-related well-being (Family Caregiver Alliance & National Center on Caregiving, 2018). There have been efforts by various organizations to bring awareness about ADRD and connect affected families to resources (Olivari et al., 2020). One such organization is the Alzheimer's Association, a leading voluntary health organization in Alzheimer's care, support, and research, with local chapters across the United States (Alzheimer's Association, 2020; Fuller, Johnson-Turbes, Hall, & Osuji, 2012; Hall, Johnson-Turbes, Fuller, Niles, & Cantey-McDonald, 2016). The Centers for Disease Control and Prevention (CDC) also developed an Alzheimer's and Healthy Aging Program, which applies principles and strategies to promote public health actions related to cognitive health, cognitive impairment, and caregiving (Centers for Disease Control & Prevention, 2019a). The CDC's work is guided by the Healthy Brain Initiative, which encompasses state and local public health partnerships to address ADRD.

Alzheimer's disease or a related dementia is substantially underreported in the African-American population (Alzheimer's Association, 2020). African-Americans often believe historical misconceptions, such as dementia is a normal part of aging (Connell, Scott Roberts, McLaughlin, & Akinleye, 2009). Therefore, they do not seek immediate medical care when they observe or experience signs of memory impairment. This lag usually results in delayed diagnosis or inadequate treatment for ADRD (Alzheimer's Association, 2020; Chin, Negash, & Hamilton, 2011; Froehlich, Froehlich, Bogardus, & Inouye, 2001). A recent survey by the Alzheimer's Foundation of America found African-Americans were concerned about the stigma associated with having ADRD (Alzheimer's Foundation of America, 2019). Misconceptions and stigmatization often result in a lack of utilization of support and resources for families living with ADRD (Aaron, Levine, & Burstin, 2003).

Therefore, health inequities related to ADRD and the African-American community are socially and traditionally constructed (Arcaya, Arcaya, & Subramanian, 2015).

Historically, churches have been a refuge for African-American families, and have played a vital role in provisions of health promotion and as a source of social support for African-American communities. African-Americans often turn to their church for support when in distress, which underscores the need to strengthen formal supportive services provided by churches for African-American families (Aaron et al., 2003). The institution of the African-American church has been regarded as a key public health partner in the dissemination of public health information and medical services (Corbie-Smith et al., 2010; Levin & Hein, 2012; Peterson, Atwood, & Yates, 2002). Churches have the opportunity to respond to health needs of people living with ADRD by providing education, a safe environment, and social support (Giger, Appel, Davidhizar, & Davis, 2008; Wink & Dillon, 2003). Giger et al. (2008) suggested the future role of the church should include a reciprocal collaboration among community members, universities, and government agencies who all view churches (faith-based organizations) as institutions that should be included in the dialogue and subsequent partnership to promote healthy lifestyles. When such partnerships are established, the basic tenets or models of these partnerships should be cooperation, communication, commitment, trust, understanding, and care (Giger et al., 2008; Olivari et al., 2020).

1.1 | Faith village connections

In order to address the gap in the access to resources and awareness related to ADRD in both the African-American community and faith-based organizations (Aaron et al., 2003), the primary author (F.E.) organized Faith Village Connections (FVC), a nurse-led interdisciplinary collaborative. FVC collaborators included public health and nursing professionals along with other professionals from nonprofit agencies located in Georgia (i.e., SageNavigator, Inc., AARP Georgia, Alzheimer's Association-Georgia Chapter). FVC designed culturally sensitive education that specifically aimed to: (a) enhance awareness about African-Americans living with ADRD and their caregivers; (b) stress the importance of early detection for ADRD; (c) equip church leaders with knowledge and skills to support their congregants' lives beyond the diagnosis of ADRD; and (d) equip congregants, caregivers, and community members with tools to effectively communicate with persons living with ADRD using appropriate actions and words.

The education consisted of two community forums: (a) *Understanding Dementia in the African-American Community Forum: Part 1*, and (b) *Understanding Dementia in the African-American Community Forum: Part 2*. These forums were 2 hr in length and covered topics ranging from understanding the pathophysiology of ADRD to developing an action plan after diagnosis. Additionally, an educational session specifically for church leaders was created, *The Dementia-Friendly Workshop for Church Leaders*. This workshop was 4 hr in length and was open to everyone. However, workshop objectives were geared toward equipping church leaders with the necessary skills and information to support their congregants to live more fully beyond diagnosis of ADRD. Table 1 further describes the curriculum presented for each educational session. Curriculum content included the latest

research and was guided by resources from the Alzheimer's Association and AARP. The Eden Alternative® Principles (2016) also supported content for the workshop sessions. All educational sessions included lectures, guest speakers, role playing activities, personal testimonies from attendees, and curriculum-related giveaways. At the conclusion of the sessions, attendees had the opportunity to participate in confidential memory screenings, engage in simulated dementia experiences, and visit with various community agencies to gain knowledge of local resources.

1.2 | Purpose

The purpose of this analysis is to (a) describe the demographics of those seeking dementia-related education in African-American faith communities; (b) identify prior knowledge of dementia-specific community resources; and (c) determine the preliminary usefulness of the education provided by FVC.

2 | METHODS

Faith Village Connections offered nine educational sessions from February 2018 to May 2019, which included four sessions of *Understanding Dementia in the African-American Community Forum: Part 1*, two sessions of *Understanding Dementia in the African-American Community Forum: Part 2*, and three sessions of *Dementia-Friendly Workshops for Church Leaders*. Quantitative survey methods were used to collect demographics, assess prior knowledge of resources, and evaluate preliminary usefulness of dementia-specific education delivered through community forums and workshops.

2.1 | Setting

The educational sessions were held at several predominantly African-American churches across the Atlanta metropolitan area in Georgia. FVC identified potential churches through their networks and met with senior leadership at the churches to determine their interest in hosting dementia-related educational sessions. The five hosting churches varied in Christian denominations, which included Apostolic ($n = 1$), Baptist ($n = 1$), Catholic ($n = 1$), and nondenominational ($n = 2$) congregations. Hosting churches expressed a need for dementia education and provided space for the sessions at no cost. One of the nondenominational churches hosted four of the educational sessions.

2.2 | Recruitment

Flyers advertising the educational sessions were posted on social media platforms including Facebook and Twitter. Advertisements were also purchased and boosted on Facebook. Additionally, advertisements were created and distributed on an event management platform and listed in the FVC monthly newsletter. Printed flyers were advertised at various churches and local senior-service agencies in the Atlanta metropolitan area to reach community members that are not technologically literate or without internet access. Members of FVC also appeared on radio and television broadcasts and attended worship services at host churches to promote the educational sessions.

2.3 | Measures

Attendees were asked to complete an 11-item survey. Basic demographic questions included race, age, gender, and description of their professional, church, and individual role affiliation. More specifically, attendees identifying as caregivers were requested to provide the chronic disease and illness of those they were caring for. Attendees were also queried about their learning preferences. Eight options were available for participants to select from, to include: videoconferences, support groups, face-to-face seminars, videos/webinars, blogs, podcasts, reading materials/flyers, and other. Attendees were also asked if they had prior knowledge of dementia-specific resources and to provide examples. The attendees' applicability and appropriateness of the content and length of the workshop and forums were also assessed using a series of Likert scales.

2.4 | Data collection and analysis

This project received approval from Georgia State University Institutional Review Board (H19562). All educational sessions were delivered on Saturdays. The community forums were held from 10:00 a.m. to 12:00 p.m. and the workshops were held from 10:00 a.m. to 2:00 p.m. At the conclusion of each educational session, attendees were asked to complete surveys that were located in their informational packets and turn them into one of the FVC team members. Verbal consent was obtained from participants before completing evaluation surveys. FVC team members were available to aid attendees that needed assistance with completing surveys.

Team members collected all surveys and inputted them into Excel databases for analysis. Survey responses were analyzed using descriptive statistics (i.e., frequencies, means, and percentages). Completed surveys were summarized after each event and shared with senior leadership of the hosting church.

3 | RESULTS

There were 202 individuals who attended nine educational sessions over the course of 16 months, of which 164 attendees completed surveys (81% completion rate). Out of the analytic sample of 164 respondents, the majority of respondents were women (75%, $n = 124$), African-American (91%, $n = 149$), and 50 years of age and older (86%, $n = 141$). Over half of participants were between the ages of 50 and 69 (56%, $n = 92$). Eighty-four percent ($n = 138$) of the female respondents acknowledged they were caregivers/care partners for someone with a chronic disease such as hypertension, diabetes, or heart disease. Several of the respondents identified themselves as having one or more roles: 46% ($n = 75$) of respondents identified as a church and/or community member, 26% ($n = 43$) identified as a church leader (e.g., pastor, minister, lay leader), 35% ($n = 57$) served as a caregiver/care partner to an individual living with dementia, 29% ($n = 48$) identified as a family member and/or friend of someone living with dementia, and 3% ($n = 5$) identified as a person living with dementia. The distribution of demographic characteristics of the respondents is shown in Table 2.

Respondents chose face-to-face seminars (48%, $n = 79$), reading materials/flyers (46%, $n = 59$), and videos/webinars (21%, $n = 34$) as the most favorable options for how they prefer to receive information on dementia. Six percent ($n = 10$) of respondents cited “other” with some specifically indicating emails as their preferences for receiving information. Table 3 lists all options respondents chose related to their preferred method of receiving educational information.

Close to two-thirds of the respondents were not aware of dementia-specific resources prior to attending the community forums and workshops (66%, $n = 108$). Respondents who indicated they were aware of prior resources listed specific examples such as the Alzheimer’s Association, AARP, Alzheimer’s Foundation of America, and Area Agencies on Aging. Respondents also shared they had received information on dementia from their healthcare provider and through internet searches.

The majority of the participants for all events also expressed they would recommend the educational session to others (98%, $n = 160$). When examining the educational offerings separately, many of the respondents who attended the workshop for church leaders (92%, $n = 67$), Part 1 community forum (96%, $n = 66$), and Part 2 community forum (95%, $n = 21$) strongly agreed the material presented was applicable to them and/or their family. Respondents overwhelmingly agreed the length of the community forums was appropriate (93%, $n = 85$). Ninety-three percent ($n = 68$) of the respondents felt the length of the workshops was sufficient for the topics covered. Table 3 displays specific results related to the usefulness of the community forums and workshops.

4 | DISCUSSION

For many older adults, particularly in the African-American community, the church is their safe haven. However, church can be a lonely place if church leaders and other congregants do not understand the specific chronic condition with which a person may be living with ADRD (Jewell, Cole, Rolph, & Rolph, 2016; Lee & Sharpe, 2008). The education offered to faith communities by FVC was designed to educate the community on the pathophysiology of and risk factors for ADRD, raise awareness about how the African-American community is affected by ADRD, and equip church leaders with the proper tools and skills to effectively accommodate congregants affected by ADRD. Since the FVC team is in the early stages of partnering with churches to provide dementia-specific education, it is pertinent to understand who is attending the sessions, their knowledge of dementia resources, and the usefulness of the community forums and workshops.

Previous research has shown African-American older adults and women are groups most likely to participate in church activities (Pew Research Center, 2014). Similarly, the majority of the attendees seeking dementia awareness in their faith communities, at the educational sessions described in this paper, were African-American older adults and women. Additionally, over half of the women in attendance were current or former caregivers/care partners to a person living with a chronic disease (e.g., hypertension, diabetes, heart disease). Data revealed that despite their role, older adults and women in African-American

faith communities were still seeking education on a chronic disease that disproportionately affects their demographics.

Historically, African-American women have not only found emotional support in the church, particularly in times of illness, they have also found a place to gain and exercise their leadership skills (Peterson, 1997). Exercising such leadership skills may include leading efforts to strengthen various church programs, health promotion ministries, and resources. In the United States, 60% of informal caregivers to persons with ADRD are women (Alzheimer's Association, 2020); therefore, having a greater number of women present during these educational sessions may indicate their motivation to learn about the disease and about ways to support their loved one living with the disease. A high attendance rate of female, African-American caregivers supports the reasoning that educational sessions such as the "*Understanding Dementia in the African-American Community Forums: Part 1 and 2*" and "*Dementia-Friendly Workshop for Church Leaders*" are necessary and important.

Over half of the participants were older adults and had no prior knowledge of dementia-related community resources. The general belief in the African-American community that dementia is a normal part of aging leads to symptoms often going unacknowledged or unaddressed until elders are unable to fulfill their family/social roles (Alzheimer's Association, 2020; Chin et al., 2011; Connell et al., 2009; Froehlich et al., 2001). The stigma associated with dementia, particularly in the African-American church and community, results in many individuals not seeking services. Consequently, these individuals are not aware of the resources that exist to aid families affected by this disorder. ADRD is considered a "silent" epidemic in the African-American community due to the lack of awareness of the scope of the problem and other risk factors related to the nation's historical health inequities impacting African-Americans (Sörensen & Conwell, 2011). The lack of awareness correlates with the health disparities experienced by African-American families and sheds light on the fact that many African-American families affected by ADRD may not have the resources and tools they need to successfully support themselves. With the church serving as a place of refuge, it would be useful to provide culturally tailored dementia-friendly programs, education, and resources to point families in the right direction of obtaining similar help on a routine basis. The community forums and workshops offered by FVC will lead to creating a safer, more welcoming space for those living with dementia and their families to practice their faith (Epps et al., 2020).

The majority of participants from all sessions indicated they felt the material presented was applicable to them and/or their families. These results support the preliminary notion that these educational sessions positively affect participants and are useful community resources. Over half of the participants selected face-to-face seminars as their preference for receiving information on ADRD, followed by reading materials, and videos or webinars. This knowledge is beneficial for future collaborators and programs to understand how stakeholders want to receive information on this topic and to utilize this information to produce resources and information that fall within these preferences. Therefore, FVC should continue offering the community forums and workshops and consider creating newsletters and video vignettes for faith communities to use as resources for their congregation.

4.1 | Limitations and recommendations

There are a few limitations of this analysis. The educational sessions were offered in the metropolitan area of Atlanta, Georgia and the results are not generalizable to the greater population. Research has shown an increased awareness of ADRD risk factors are significant to motivating behavior change in African-American adults (Glover, CoCroft, James, & Barnes, 2019). Thus, survey questions could have been worded more clearly to better assess knowledge and impact of the education on participants' attitudes and perceptions toward ADRD and associated risk factors. Additionally, a pre- and posttest survey (e.g., Basic Knowledge of Alzheimer's Disease Survey; Wiese, Williams, Tappen, & Newman, 2019) would have been useful to better evaluate whether there were changes in the participants' knowledge.

For developing a built-in evaluation plan to use in the future, it may be helpful to use a logic model to clearly develop and refine evaluation questions (Centers for Disease Control & Prevention, 2019b). Future evaluations should include open-ended questions allowing participants to report what they liked and disliked about the educational sessions and provide suggestions of topics for future educational offerings. In the future, we also recommend that activities and survey questions be designed to evaluate attitudes and beliefs toward dementia. This assessment would aid in debunking myths that contribute to individuals' negative attitudes toward persons living with dementia.

5 | CONCLUSION

Currently, there is no cure for ADRD. While finding the cure is important, it is also crucial interventions are developed to help those diagnosed with the disease and their families to live more fully beyond diagnosis. This can be done by providing persons living with dementia, their caregivers/care partners, and their community with information, skills, and tools to help properly care for and communicate with each other. The presentations and activities included in the community forums and workshops were helpful to the participants. These educational sessions serve as good resources because they (a) provide information about the pathophysiology of ADRD; (b) identify then discuss measures to reduce risk; and (c) highlight services to support families affected by ADRD. Furthermore, culturally tailored education can also increase ADRD literacy among African-Americans (Lincoln, Chow, & Gaines, 2019). This analysis has the potential to identify ways to alter or strengthen the educational content, and serve as a guide for developing culturally relevant, faith-based community programs. In addition, these findings can help ensure future public health programs and policies adequately allocate resources to groups who desire a better understanding of ADRD, interested in learning ways to reduce exposure, and increase access to coping strategies.

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TABLE 1

Educational content

Dementia-friendly workshops for church leaders		
Length of time	4 hr	
Content	<ul style="list-style-type: none">• ADRD overview• Signs and symptoms of ADRD• Dementia-friendly communication• Reengaging families affected by ADRD• Role of the church and supporting congregations beyond ADRD• Importance and opportunities for research participation	
Understanding dementia in the African-American community forum: Part 1		
	2 hr	
	<ul style="list-style-type: none">• ADRD overview• Signs and symptoms of ADRD• Importance of early detection• Importance and opportunities for research participation	
Understanding dementia in the African-American community forum: Part 2		
	2 hr	
	<ul style="list-style-type: none">• ADRD overview• Action steps after recognizing dementia symptoms• Importance and opportunities for research participation	

Abbreviations: ADRD, Alzheimer’s disease and related dementias.

TABLE 2

Demographic characteristics of the participants

Characteristics	% (n)
Gender	
Male	18 (29)
Female	75 (124)
Missing responses	7 (11)
Race	
African-American	91 (149)
White	6 (10)
Asian	2 (3)
Other	1 (2)
Age (years)	
18–34	4 (6)
35–49	9 (15)
50–69	56 (92)
70 or older	30 (49)
Missing responses	1 (2)
What best describes you? (select all that apply)	
Living with dementia	3 (5)
Educator/research professional	13 (21)
Care partner to someone with dementia	35 (57)
Church leader (e.g., pastor, minister, etc.)	26 (43)
Family/friend to someone with dementia	29 (48)
Healthcare professional/student	6 (10)
Church/community member	46 (75)
Other (e.g., former caregiver, attorney)	6 (10)
Missing responses	7 (11)
Preference(s) on how to receive information (select all that apply)	
Videoconferences/teleconferences	17 (28)
Support group meetings	21 (34)
Seminars	48 (79)
Videos/webinars	30 (49)
Blogs	9 (15)
Podcasts	20 (33)
Reading material/flyers	46 (59)
Other (e.g., emails)	6 (10)
Missing responses	9 (15)

TABLE 3

Individual educational session results

	Dementia-friendly workshops for church leaders	Understanding dementia in the African-American community forum: Part 1	Understanding dementia in the African-American community forum: Part 2
No. of attendees	89	86	27
No. of surveys completed	82% (<i>n</i> = 73)	80% (<i>n</i> = 69)	81% (<i>n</i> = 22)
Aware of dementia-related community resources			
Yes	35% (<i>n</i> = 26)	33% (<i>n</i> = 23)	18% (<i>n</i> = 4)
No	63% (<i>n</i> = 46)	67% (<i>n</i> = 46)	73% (<i>n</i> = 16)
Missing responses	2% (<i>n</i> = 1)	0	9% (<i>n</i> = 2)
Material applicable to "me and/or my family"			
Strongly agree/agree	100% (<i>n</i> = 73)	96% (<i>n</i> = 66)	95% (<i>n</i> = 21)
Strongly disagree/disagree	0	3% (<i>n</i> = 2)	0
Missing responses	0	1% (<i>n</i> = 1)	5% (<i>n</i> = 1)
Recommend session to others			
Strongly agree/agree	100% (<i>n</i> = 73)	97% (<i>n</i> = 67)	90% (<i>n</i> = 20)
Strongly disagree/disagree	0	3% (<i>n</i> = 2)	0
Missing responses	0	0	10% (<i>n</i> = 2)
Length of session			
Too short	1% (<i>n</i> = 1)	4% (<i>n</i> = 3)	5% (<i>n</i> = 1)
Just right	93% (<i>n</i> = 68)	95% (<i>n</i> = 65)	90% (<i>n</i> = 20)
Too long	3% (<i>n</i> = 2)	1% (<i>n</i> = 1)	0
Missing responses	3% (<i>n</i> = 2)	0	5% (<i>n</i> = 1)