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Engaging the African American Church to Improve Communication About Palliative Care and Hospice: Lessons From a Multilevel Approach

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Abstract

Background: As the spiritual family for many African Americans, the church presents an opportunity to improve communication about palliative care and hospice (PCH). However, sustainable change in church-based, practices related to PCH requires a compreshensive, multilevel approach. **Objectives:** Our primary goal was to encourage churches to embrace palliative care and hospice as acceptable alternatives for end-of-life care by creating venues to improve communications about PCH. This paper compares our experience in 5 churches, revealing lessons learned and the challenges of engaging, implementing, and maintaining a multilevel approach in the churches, and our strategies in response to those challenges. **Design:** Descriptive study Settings/ Subjects: We partnered with 5 African American Churches in the Philadelphia Region. We targeted pastors, other church leaders, and congregants. **Methods:** We created 1) a leadership-education program, 2) an intensive training program for church-based lay companions (health visitors), and 3) messages and materials to increase knowledge and influence attitudes about PCH. **Results:** We impacted church structures and policies as shown by: integration of the project activities into existing church structures, new church-based programs dedicated to training lay companions and church leaders, new roles for church members (church liaisons) dedicated to this project, and new materials and messages focusing on PCH for the general congregation. **Conclusions:** We demonstrated the feasibility of engaging the African American church in a comprehensive, multilevel process designed to improve communication about palliative care and hospice (PCH). Our success demonstrates the potential of the African American church as a community resource for lay education about PCH.

Keywords

African American, church, communication, palliative care, hospice

Background

Although African Americans (AAs) who receive hospice care give it high-quality ratings, AAs often underuse palliative care and hospice (PCH) services in favor of life-prolonging measures, thus contributing to inequities in care at the end of life (EOL).[1-7] In response to this longstanding inequity, an interdisciplinary group of AA scholars and professionals established the "Initiative to Improve Palliative and End-of-life care in the AA Community" and called for "new culturally appropriate models of care and education for health professionals and lay persons who care for AAs at the EOL."[8] As the spiritual family for many AAs, churches present an opportunity to respond to this call.[9-12]

Few church-based collaborations have focused on EOL care, EOL decision-making, or PCH in AAs and these have been limited in scope.[13-15] Investigators have partnered with AA churches to recruit AAs for studies to assess beliefs and attitudes about advance care planning and advance directives, to assess attitudes about PCH, and to deliver education interventions about advance directives.[12,16-19] In one study, AAs recruited through churches served as solo health visitors or as members of support teams for persons with "serious illnesses."[20] Another study employed volunteers from 5 church teams as part of a regional initiative to improve EOL care for safety-net populations.[21] Two studies have targeted ministers

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to collect interview or focus group data or to receive an educational intervention.[18,22] However, none of these projects aimed to incorporate activities and programs into the organizational fabric and culture of the churches consistent with a socioecological model.[13]

Sustainable change in AA church-based, health practices related to EOL decision-making and care requires a comprehensive, multilevel approach: (1) organizational (targeting pastors and other leaders and creating new policies and programs), (2) intrapersonal (targeting individuals as recipients of education and training), (3) interpersonal (targeting social interactions among church members), and (4) environmental (creating partnerships of the churches with external agencies—whether academic, government, or other).[13] However, the multilevel approach presents challenges. Pastors and other church leaders (eg, assistant ministers, deacons, elders and leaders of church ministries) have little training about EOL decision-making and many AA congregants dismiss PCH as a choice because of distrust of health-care systems, historical and social reasons, or faith beliefs.[12,18,22,23] Last, an effective engagement process can be time-consuming and labor intensive for both church and academic partners.[24]

We used a multilevel approach to alter the structure, policies, and processes relevant to PCH in partnership with AA Churches in the Philadelphia region using each participating church as a distinct organizational and cultural entity. Our primary goal was to encourage churches to embrace PCH as acceptable alternatives for EOL care by creating venues to improve communications about PCH among church members. We created (1) a leadership-education program for pastors, deacons, deaconesses, elders, ministry leaders, and other church leaders; (2) an intensive training program for church-based lay companions; and (3) messages and materials about PCH-related topics to disseminate to church members. We implemented the project based on the principles of community-based particpatory research (CBPR) and church-based health promotion.[13,15,25] Community-based participatory research requires community involvement (in this case the Church) in the full spectrum of the research process and the most effective church-based health promotion projects embrace and encompass the fundamental traditions, structures, and policies of the church.[15] This article compares our experience in 5 churches, revealing lessons learned, the challenges of engaging, implementing, and maintaining a multilevel framework in the churches, and our strategies in response to those challenges.

Methods

Church and Academic Partners

Four Baptist churches and 1 consortium of 3 African Methodist Episcopal (AME) churches represented the church partners. We refer to the AME consortium as one church entity as the AME church's structure and leadership has a centralized decision-making process, which governed our interactions and relationship with the AME churches. The 4 Baptist churches had active memberships of 500 to 900 persons, and the consortium of AME churches combined had an active membership of 300. In all churches, the majority of the members were over age 60. All of the churches were located in urban areas and had members from the 5 County Philadelphia metropolitan, statistical area (MSA) and from southern New Jersey and northern Delaware.

The project academic team was based in the Perelman School of Medicine, University of Pennsylvania and consisted of a geriatric-trained physician; a public health, education, and training expert (project manager); a pastoral-trained chaplain; a communications expert trained in psychology; and an evaluation specialist trained in quantitative methods. Representatives of the academic team and each church provided project leadership. The Institutional Review Board of the Perelman School of Medicine, University of Pennsylvania approved this project (approval number 820859) and participants submitted written informed consent.

Church Selection and Start-Up Process

The impetus for the project grew out of annual, church-initiated presentations by a geriatrician physician about the care of persons with advanced dementia, during which the caregivers expressed concern and distress about EOL decision-making and care. These presentations to members of multiple churches fostered a relationship between members of the academic team and the AA church community. An invited presentation to members of the Black Clergy of Philadelphia and Vicinity, a regional, interdenominational organization of AA churches with over 400 pastors, resulted in widespread interest of members in education sessions about EOL care. However, the endorsement of the organization and follow-up meetings with its education committee did not result in action. Consequently, members of the academic team requested and received invitations to present the project to the head pastors of 5 churches that had worked with members of the academic team on other health education projects.

To initiate the project in the Baptist churches, the project director and project manager met with the head pastor and other church leaders to discuss the purpose and significance of the project; subsequent meetings focused on planning and delivery. To initiate the project in the AME church, the academic team leaders met with a pastor of one of the AME churches with which we had previously worked on health education programs. This pastor presented the project for approval to 3 presiding elders (AME minister with supervising authority over several churches) serving the Philadelphia SMSA and southern New Jersey. The approval of the presiding elders paved the way for subsequent planning discussions with the head pastors of 3 AME churches, selected by the elders. Two of the Baptist churches participated in a focus group study about PCH and subsequently, the 5 churches endorsed all components of the project.[23] These 5 churches established the project as a priority, endorsed the research format of the project, promoted the project among their congregants, assigned staff, and engaged in a series of planning meetings. In all churches, the pastor was asked to identify a church liaison (CL) to serve as the key

Table 1. Project Components by Level of Engagement.

Organizational (Leadership Roles, Programs, and Policies)	Intrapersonal (Education of Individuals)	Interpersonal (Interactions among members of the church social network)
• Head pastor's initial endorsement of all elements of the program • Head pastor's sustained participation (access and advocacy) • Support of other church leadership • Church liaison participation • Leadership Training Program • Lay companion classroom education and training program • Lay companion visit program	• Congregant education • Leadership education • Lay companion education and training	• Head pastor and leadership advocacy • Lay companion visits with persons with life-limiting illnesses and their families • Lay companion monthly support group meetings

interface and to provide oversight for the project within the church for all components of the partnership; 1 CL served the AME consortium. A new church engagement was started every 4 to 6 months until all 5 churches were active.

Components of the Project

We targeted pastors and other church leaders, congregants with life-limiting illnesses (LLIs) and their significant others, and general congregants as shown in Table 1, which presents the components of the project by level of engagement. We created (1) a leadership-education program, (2) an intensive education and training program for church-based lay companions, and (3) messages and materials targeting the general congregation. Details of the leadership and lay-companion programs are the subject of another paper. This article focuses on the rationale for the education and training and the processes necessary to implement them.

The 4-hour leadership-education component targeted head pastors, assistant ministers, deacons and deaconesses, elders, and leaders of church ministries. To create the greatest influence on church culture, ministry leaders were not restricted to health-related groups (eg, bereavement or comfort ministries). The church leaders were important for 3 reasons: (1) they represented the traditional organizational structure and authority of the churches, (2) their advocacy and endorsement was influential in garnering acceptance by the general congregants, and (3) they represented the church members who traditionally visited persons with LLIs. The leadership education consisted of presentations and interactive discussions about 4 topics: (1) the relation of faith beliefs to death and dying decisions, (2) the concept and criteria of a LLI, (3) a discussion about the difference between goals of care and values versus pathways to care (eg, treatment options), and (4) the meaning and benefits of advance care planning, PCH. In the Baptist churches, leaders volunteered after appeals by their head pastors. In the AME church, leaders were selected by the church elders.

The intensive, lay-companion program prepared members selected by the churches to serve as visitors to church members with LLIs. While AA church visitors to congregants with LLIs have been comfortable providing spiritual support and assisting with manual tasks such as assistance with chores and errands, they have expressed a lack of knowledge and preparedness to communicate with other church members about palliative care.[18,20,22,23] Therefore, we conceived the lay companions as church-based, lay experts who could fill a gap in communicating about EOL care and decision-making. The lay-companion program consisted of 3 parts: (1) a 30-hour, modular, interactive classroom, education and training component, guided by a curriculum and workbook, and delivered over weeks; (2) visits of the lay companions to church members with LLIs; and (3) monthly support group meetings within each church attended by the lay companions, the geriatrician and the project manager. Modest monetary support was offered to lay companions who attended the training.

The general congregant engagement consisted of presentations about messages about the overall project, presentations during church services about the purpose and benefits of the lay-companion program, and messages in church bulletins and brochures about general aspects of PCH and the lay-companion program, and small group presentations and discussions about various aspects of PCH at either preexisting church meetings or meetings organized to present aspects of this project.

Results

Although all 5 churches initially expressed support for all levels of the project, success was variable. We judged success by capacity to create and maintain all levels of the program as summarized in Table 1. The 2 most successful churches maintained all elements of the project for 4 years. At the opposite end of the spectrum, 1 church could not identify a CL and consequently could not initiate the lay companion training. The other 2 churches had intermediate levels of success. In the following section, we describe the engagement process on organizational, intrapersonal, and interpersonal levels.

Organizational Level (Church Personnel, Structure, and Policies)

The 5 head pastors were critical for project startup and implementation. They provided input on the church culture, the

structure and role of existing health-related ministries (eg, bereavement), and selected the CL. The 2 most active head pastors presented the program to their congregants during church services, introduced the academic-staff members to key church-based decision makers, scheduled presentations by academic team members to the congregants during church services, authorized messaging in announcements and church bulletins, encouraged volunteers for the lay companion training, and participated in problem solving. In 3 of the churches, the head pastor attended the leadership-education program and in 1 church, the head pastor encouraged all deacons and deaconesses of his church to participate in leadership education. In the 3 churches in which the head pastors were least involved, the lay-companion program never started or stalled after the classroom sessions.

Assistant pastors, deacons, deaconesses, and other ministry leaders had key roles as advocates for the partnership in general and for its components. In 3 of the 5 churches, members of the academic team were invited to present to deacons, deaconesses, and ministry leaders at a variety of forums such as the monthly deacon or deaconess meetings, ministry breakfast meetings, and other special programs.

A CL was critical to all levels of church engagement. The CL functioned as an ambassador, coordinator, and planner and was the key interface between team members from academia and the church leadership and members. The CL scheduled lay-companion meetings, communicated eligibility criteria for receiving lay companion visits to the congregation, helped to develop the process for requesting lay companion visits, and communicated frequently with the academic project staff. The CL attended the lay-companion training to attain familiarity with the program, but did not function as a lay companion. Church liaisons were given a small stipend. One church could not identify an effective and active CL. Three of the Baptist churches created new ministries to encompass the work of the project.

Intrapersonal Level (Education and Training of Individuals)

We targeted all members of the church as learners with the goal of increasing knowledge and changing attitudes about PCH using variable approaches depending upon the role of the church members and the project component. The leadership education was successful in all churches. In the 4 Baptist churches, the head pastors, most of the other ministers, over 90% of the deacons and deaconesses, and 30% to 50% of the other ministry leaders attended the training (total N = 131) and all the attendees completed it. In the AME church, 9 members (2 ministers, 2 elders, and 5 other group leaders) attended and completed the leadership education. The lay-companion training was attended by 35 members from 3 Baptist churches and 10 members from the AME church. All attendees completed the training. Four churches completed the classroom component of the lay companion training. The most active and successful lay-companion training program was in a church in which the head pastor attended the leadership education and some of the lay-companion training sessions. The church that failed to identify a CL was unable to establish the lay-companion program. The 2 churches most successful in enlisting congregants to use the lay companion service were those with the most active pastors and CLs. In the 2 churches in which the head pastors were least involved, the lay-companion program stalled after the classroom sessions. We encountered significant difficulties arranging education sessions with the general congregants of all churches because of multiple reasons: reluctance to discuss death and dying, scheduling difficulties, and competing church activities. Consequently, the interactions with the general congregation were typically limited to 10 to 30 minutes during church services or during meetings that were scheduled for other purposes.

Interpersonal Level (Church-Based Group or Interpersonal Interactions)

Interpersonal influences were most evident during the monthly, lay companion, support-group meetings, which were attended regularly by the lay companions and 2 members of the academic team. During these meetings, the lay companions shared visit experiences, and received feedback and support from other attendees. Interactions between the lay companions and congregants with LLIs provided another forum for learning and attitudinal change, but the impact of these interactions was limited by the small number of persons with LLIs who accepted visits from the lay companions. In Table 2, we summarize significant or key lessons learned and challenges from this type of engagement and our suggested responses.

Conclusions

Our article is the first to demonstrate the feasibility of engaging the AA church in a comprehensive, multilevel process designed to change attitudes about EOL care and EOL decision-making. We impacted church structure and policies as shown by: integration of the project activities in existing church structures, new church-based programs dedicated to training lay companions and church leaders, new roles for church members (CLs) dedicated to this program, and new materials and messages focusing on PCH for the general congregation. We found that the head pastor's endorsement was necessary but insufficient to sustain all levels of our project; other church leaders such as deacons are necessary to fully engage the church.

The degree of engagement varied by level of engagement. The leadership education was the most successful example of the intrapersonal level of engagement, perhaps because it targeted a limited number of persons in each church for a relatively short (4-5 hours) training program. On the other hand, the lay-companion training was the most challenging intrapersonal component because of the significant time commitment required of the lay-companion training and role and the need to establish an effective process for identifying persons with LLIs. We found that the lay-companion training program cannot

Table 2. Engagement Lessons and Responses.

Lesson or Challenge	Response
Endorsement of the head pastor is necessary for start-up but insufficient for full implementation.	Devote significant time explaining all steps of the program and eliciting pastors' input and preferences.
Endorsement and engagement of other church leaders (deacons, ministry leaders, assistant pastors) is necessary.	Discuss the project activities as new assets, rather than as substitutes for pre-existing church activities.
Implementation of the lay-companion training program is the most challenging component of the program.	Devote significant time to discussing the purpose of the companion training, the commitment required of the companions, and the support they will receive (inclusive of small monetary support to the church).
One or 2 church members, serving as church liaisons (CLs) are critical.	Ask the church to identify a person who is respected by the church members, who understands and endorses the goals and activities of the program, who is capable of communicating those goals and activities, and who can initially devote 4-6 h/wk and subsequently 1-2 h/wk to the project.
Church members at all levels may be reluctant to discuss death and dying.	Encourage the head pastor to discuss palliative care, hospice, and death and dying in multiple venues.
Decision-making about death and dying are linked to faith beliefs for many persons in the church.	Include a faith perspective in discussions about PCH, revealing how PCH is consistent with faith beliefs.
Persons with life-limiting illnesses (LLIs) may be receptive to visits by their traditional church visitors (eg, deacons); but the sensitivities of congregants about death and dying make them reluctant to accept visits from lay companions whose focus is on death and dying issues.	Encourage deacons and other traditional visitors to undertake the companion training; for those who do not, encourage them to undertake the leadership training program.
Persons with LLIs and their families are concerned about the stigma of illness and the potential loss of privacy.	Devote significant time to discussions with church members about privacy of all information
Direct access to congregants can be achieved by established, preexisting church events.	Use multiple, alternative formats to target the general congregation.
The research steps of the project may not be priorities for Church members and may add additional time to program components.	Plan for the time necessary to discuss the significance of informed consent, evaluation, and data collection.

succeed without a dedicated CL and that members of the general congregations are difficult to engage because of competing church-based events, privacy concerns, and sensitivity about discussing death and dying. At the interpersonal level, the interactions of lay companions during the monthly meetings provided positive peer-based, reinforcement and peer-directed learning. These successes demonstrate the potential of the AA church as a community resource in lay education about PCH.

In contrast to the comprehensive engagement process that we sought, other church-based collaborations relevant to PCH targeting AAs have focused on the intrapersonal (individual) level of engagement, most often recruiting individuals for research studies testing knowledge or attitudes about PCH or testing the results of education and training on knowledge or attitudes.[12,16,18,19] Pastors, but not other key church leaders, have been targeted for interviews, focus groups, and education. Six AA pastors in the Midwest, representing 4 denominations, and AA pastors of 23 churches in North Carolina lamented their lack of information about PCH and expressed a desire to learn more about PCH.[18,22] African American congregants have participated in church-sponsored, focus groups and education sessions about advance directives and advance care planning.[18,23] AA churches in North Carolina partnered with academicians to educate and train congregants to serve as solo health visitors (similar to our lay companions) or to serve as members of support teams for persons with "serious illness."[20] Unlike our lay companions, their support team members mainly focused on practical assistance such as errands and chores and their solo health visitors did not feel prepared to discuss palliative care with the persons they visited. In another study, volunteers from 5 church teams provided "practical, emotional, and spiritual support" as part of a regional initiative to improve EOL care for safety-net populations.[21] That study did not characterize the churches, or the training program for the volunteers and did not delineate the activities of the volunteers. One study found that AA patients who viewed themselves as "well supported by religious communities" accessed hospice care less and accessed aggressive medical interventions more when near death, but this study did not incorporate churches as partners in the research.[26] In contrast to the findings of that study, our findings demonstrate that the AA church can be an ally of health systems and health providers in discussions with patients and families about less aggressive care at the EOL and the acceptance of PCH as an option for EOL care.

Our study comports with the recommendations of studies that espouse approaches to CBPR in general and in partnerships with AA churches.[13,15] As with other CBPR projects, we found that CBPR requires attention to relationship-building and is time consuming and organization specific.[25,27] Consistent, with this view, we found that churches must be approached as distinct entities. Our process of engagement was congruent with

the 4 principles of church and academic partnerships to eliminate health disparities proposed in one study: (1) identify and prioritize partner churches, (2) develop trusting relationships, (3) respect institutional priorities and traditions, and (4) promote local control and power.[15] We cast a wide net for church partners but ultimately worked with those that had the commitment and capacity to actively participate. Our church partnerships were grounded in preexisting, trusted relationships, which were maintained by enlisting the views and often the leadership of church members throughout the process. The church priorities and traditions influenced and often dictated the processes employed. Last, by engaging church members in planning all components of the project, the churches had substantial control over all steps in the process.

Our project demonstrates some limitations. The staggered start time of the churches biased success in favor of the churches we engaged later in the process, although all lessons are relevant and our goal was to learn from each interaction. The challenges presented by the structures, policies, and religious precepts of various denominations may differ. We partnered with only 2 denominations, Baptist and AME. However, since the largest percentage of AAs are Baptist, our project may reflect the structures, policies, and religious precepts encountered in other church-based partnerships.[28] Irrespective of different religious precepts, our attention to the decision-making pathways of the churches and our attention to the traditions of each church make our process replicable.[15]

Improvements in EOL care in the AA community require that patients and their families consider PCH as a potential venue for improved care, rather than dismissing PCH as abandonment, neglect, or a violation of their faith beliefs; accomplishing this change requires more effective approaches to communicating about PCH. Our successful engagement with AA churches demonstrates the potential for replicability in many communities in the United States, the feasibility of a multilevel approach, and the value of targeting diverse members of the church leadership. This approach is one response to the need to reduce inequities in health-care delivery at the EOL and consistent with a recommendation of The Institute on Medicine Report "Dying in America" to tailor messages to appropriate audience segments.[15,29] Our next steps are to assess the knowledge and attitudinal changes of various church members, assess the effectiveness of the lay-companion program, and create and test new church-based approaches to interact with general congregants.

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