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Trust Building Recruitment Strategies for Researchers Conducting Studies in African American (AA) Churches: Lessons Learned

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Abstract

Background—An initial and vital important step in recruiting participants for church-based hospice and palliative care research is the establishment of trust and credibility within the church community. Mistrust of medical research is an extremely important barrier hindering recruitment in African American (AA) communities. A church-based EOL dementia education project is currently being conducted at four large urban AA churches. Church leaders voiced mistrust concerns of previous researchers who conducted investigations in their faith-based institutions. We explored strategies to ameliorate the mistrust concerns.

Specific aim—To identify trust-rebuilding elements for researchers following others who violated trust of AA church leaders.

Methods—Face-to-face, in-depth interviews were conducted from a convenient sample of four established AA church leaders. Interviews were held in the informants' churches to promote candor and comfort in revealing sensitive information about trust/mistrust. Content analysis framework was used to analyze the data. Elements identified from the analysis were then used to create themes.

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Authors' Note

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Declaration of Conflicting Interests

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Results—Multidimensional overarching themes emerged from the analysis included: Experience with researchers (positive and extremely negative), violation of trust and trust building strategies.

Conclusions—Findings suggest that researchers who wish to conduct successful studies in the AA religious institutions must implement trust rebuilding strategies that include mutual respect, collaboration and partnership building. If general moral practices continue to be violated, threat to future hospice and palliative care research within the institutions may prevail. Thus, potential benefits are thwarted for the church members, AA community, and advancement of EOL care scholarship.

Keywords

church-based research; recruitment strategies; African American; trust; community; collaboration

Background

National trends show that most African Americans (AAs) are Christian, express a high degree of spirituality, and regularly attend church services.[1] The black church is the spiritual and psychosocial staple for binding together the middle class and poor, culturally and religiously.[2,3] Church-based institutions are prime venues for health promotion trials because many promote healthy lifestyles through health-care ministries.[4,5] Such trials can reach a broad AA population and have great potential for reducing health disparities related to end-of-life (EOL) care.

However, historical and current mistrust in researchers by AAs decreases access to these faith-based institutions. For example, medical experimentation on AA slaves during the antebellum period, the Tuskegee Syphilis Study, unethical practices by researchers in the Henrietta Lacks story, and other clinical trials are historical tragedies that created mistrust.[6–10] Current mistrust is exacerbated with the murder of 9 AA church leaders by a white male in a South Carolina church and the national divisive sociopolitical atmosphere.[11,12]

Similar etiologies exemplify ethnic differences in underutilization of EOL palliative and hospice care by AAs compared to white Americans.[13]. Empirical data document the mistrust of physicians caused by historical and current medical mistreatment of AAs.[14] Poor communication between dyads is also problematic. Serious care decision regrets and conflicts decrease when AA family members engage in quality EOL communications with health-care providers prior to the death of loved ones.[15] Comfort-focused care versus life-prolonging treatments is more often chosen for EOL care under similar circumstances.[16] Another cause for underutilization is the lack of knowledge about advance care planning and serious EOL treatment options.[17,18] Additional causes are ethnic differences in family decision-making practices. African Americans are more likely to make serious EOL decisions through family consensus as opposed to white Americans who more often make similar decisions unilaterally.[19–21]

Faith-based hope describes the spiritual needs of AAs when faced with medically predicted death.[22,23] Spiritual hope is expressed through liberation for strength against a variety of

insurmountable pressures created from despair within their lives.[23] When AAs receive respect from medical teams based on the need for spiritual guidance, they are more likely to use hospice care over aggressive EOL interventions. Mutual support between religious communities and medical teams further enhances the use of comfort care by this minority group.[24]

A church-based dementia education randomized controlled trial (RCT) is currently being conducted in 4 mega urban AA churches. The purpose is to determine the efficacy of a culturally tailored education intervention developed to improve the quality of advance care planning and informed EOL treatment decisions made by AA family caregivers of patients without decisional capacity. Cardiopulmonary resuscitation, mechanical ventilation, and tube feeding are the EOL treatments of interest. The investigation embraces community-based participatory research (CBPR) concepts and culturally appropriate and spiritually sensitive methods throughout the study. The sample (n ¼ 304 planned) is being recruited from the 4 churches: 2 intervention (n ¼ 152) and 2 control (n ¼ 152) sites. A leader from each church serves as a liaison to the RCT and is a collaborative member of the research team to enhance recruitment strategies and other related initiatives associated with the investigation. During the initial phase of the study, church leaders voiced mistrust concerns of researchers who conduct investigations in the faith-based institutions. As part of the start-up work to initiate the trial, the investigators launched several in-depth interviews with the church leaders to explore strategies to ameliorate trust for the successful implementation of the study that is now underway. Specifically, as a collaborative team building process, interview sessions were held to identify trust rebuilding elements for the research team that was following others who violated trust of the church leaders.

Methods

Design

Individual, face-to-face, in-depth, debriefing discussions were held with the 4 church leaders. One interview was held with each informant that lasted approximately 1.5 hours and was tape-recorded and transcribed. All sessions were held at the churches to promote candor and comfort in revealing sensitive information about trust/mistrust. Discussion guides led to the highly interactive format. The RCT, with its collaborative implementation process with the church leaders as research team members, was approved by the institutional review board at the University of Illinois at Chicago.

Sample and Setting

The sample (n ¼ 4) consisted of 2 ministers and 2 deacons each re their respective church. The 2 ministers presenting were men and church pastors. The deacons were women, administrative assistants to the pastors, and directors of very active health-care ministries. Church denominations were the Church of God in Christ (1), nondenominational (1) and Pentecostal (2). They are among the largest religious institutions in the metropolitan area with attendance that ranged from 2000 to 7000 congregants with a median age of 45 years (see Table 1).

Measures

Demographic characteristics of the informants included age, gender, education, employment status, and years served in the ministry. The 6-item discussion guide included open-ended questions about prior personal experiences with researchers.

- Tell me about your experiences with researchers?
- Do you know any other pastors or church leaders who have had experiences with researchers?
- Tell me about those experiences?
- What did the researchers do that fostered your trust?
- What did the researchers do that violated your trust?
- What did they do to rebuild the trust?

Procedures

The informants were solicited to receive detailed information about the RCT and discuss strategies for the recruitment of study individuals. Mistrust concerns of researchers were initiated and described by 2 informants during the meetings. The researcher expressed dismay and a need to explore the possibility of similar concerns felt by the other informants. A second face-to-face meeting was requested and subsequently held with each informant to ask permission for an interview to address possible experiences with previous researchers that generated mistrust. Details of the discussion guide were described including in-depth open-ended dialogue and audiotaping of the sessions. Respect was stressed including confidentiality, privacy, and anonymity of information shared by the informants to the researcher. Permission was granted and interviews were later held at respective church sites.

Data Analysis

The audio-recorded discussions were transcribed verbatim. A content analysis framework was used to analyze the data.[25] Comparative thematic processes were applied for data encoding.[26] Information from each informant was compared and contrasted until the researcher was satisfied that no new issues emerged. Transcriptions were combined with interview notes recorded by the researcher and discussed in detail among the analysis group. Elements identified were then used to create themes. The themes represented a pattern of responses that shaped the content of the underlying data described by the 4 informants. Trust worthiness of the analysis process was assured with credibility of findings through representativeness of details described across informants, verbatim descriptions of mistrust experiences, and triangulation techniques, comparing consistencies of information provided against related empirical data.[27]

Results

Demographics

The pastors were older than 43 years with doctorates in divinity from the established well-known theological institutions. They served in the ministry over 20 years and pastored over

mega-churches from 10 to 34 years. Directors of health ministry leaders were deacons, older than 55 years, and church members for more than 18 years. Both had a Bachelor of Science degree and 1 also had a Master of Science degree in nursing.

Content Analyses

Three categories emerged during analysis: experience with researchers, violation of trust, and trust building strategies. Within each of these 3 categories, themes also emerged.

Experience with researchers—Positive and extremely negative themes emerged from the transcripts. Positive experience consisted of information about researchers, which was filtered to the pastors through trusted church leaders known as gate-keepers. They were deacons, elders, trustees, or ministry directors. Decisions made by gatekeepers heavily influenced the pastor's choice for confirming appointments with research team members and authorizing studies for implementation in the church. One pastor stated, "I have a pretty good experience with researchers but only because I have trusted church members to first connect with them." Another positive experience occurred when researchers took initiatives to learn about the church culture prior to requesting permission to conduct studies at the church. They obtained flyers or other public notices about health initiatives sponsored by the church and attended the events. In addition, they volunteered for service at future events. Over time, positive relationships formed among researchers and church leaders, which opened discussions for researchers to describe their studies and solicit collaborative partnerships with church leaders.

Negative experiences with researchers were attributed to vague research aims and confusion over reciprocal roles between church leaders and the research team. Some unclear aims were inconsistent with the church mission when researchers clarified study goals. A pastor reported, "We would not have let them in (conduct study in the church) if we had known the goals of the study before it started. We said no to them a second time when they wanted to return (with another study)." Relationships improved with researchers when church leaders acquired the knowledge to ask appropriate questions to make informed decisions prior to study authorization.

Violation of trust—Mistrust themes included paternalistic attitudes, failed promises, invisibility of principal investigators, and unethical study design. Paternalistic attitudes were exhibited by researchers who assumed complete authority over the project. Church leaders preferred collaborative processes. One participant stated, "They took data from us but did not involve us with interpretation of findings nor results from the study." Failed promises were experienced when researchers violated a contract in a blood drive study. Church leaders reported donated blood thought to be given to sickle cell babies were administered to others and not to the designated chronically ill infants. In another instance, researchers promised to train church members after completion of the study, but no follow-up training was provided. Invisibility of principal investigators was a common complaint as well. Participants stated, "They (researchers) would send AA staff members to meet with us. We never saw leaders of the research team or we saw study leaders only at the beginning of the project without any additional contact." Violation of trust was further described in an

unethical study design implemented to screen church parishioners for HIV. The study purpose was to identify positive cases but failed to have protocols for follow-up treatment or referrals. When church leaders discovered no follow-up treatment plans existed, they intervened and refused access for researchers to the study site until requirements for follow-up were established and implemented.

Within the mistrust themes were subcategories of anger, confusion, and disappointment expressed by informants toward researchers. One reported anger at researchers who failed to refer for follow-up the parishioners who were tested positive for HIV. A second expressed confusion with researchers who were unable to clearly define the purpose of their study but expressed a dire need to recruit individuals on behalf of service to the black community. Several described anger and disappointment at behaviors of researchers who continually referred to them and parishioners as “you people” as opposed to addressing them by their given name.

The church leaders felt violated and betrayed stating, “They kicked us to the curb.” Such negative feelings were generated from perceptions that trust was violated through negative actions exhibited by some investigators.

Trust building strategies—Informants discussed successful trust building strategies that are consistent with frameworks derived from principles of CBPR and National Culturally and Linguistically Appropriate Services (CLAS).[28,29] The themes of this category include careful attention to partnership development, efforts to understand the cultural context of the church community, and reciprocity that includes plans to ensure program sustainability. Researchers were favorably received by church leaders who conducted health promotion lectures at the church site on topics entirely different from the aims of the investigation under study. The activity enhanced trust and facilitated collaboration with the church leaders. Other researchers met periodically with church leaders giving ongoing updates on progress of the study. One principal investigator attended church services and events to enhance their own cultural understanding of the black church. Some collaborated with church leaders to write grants for seed money to fund needed church-sponsored projects. Such partnerships helped build genuine relationships. One informant stated, “They (Researchers) must understand we are not like regular community-based groups, we are faith based and our goals are driven by scripture. Therefore, project goals must be aligned and consistent with the pastor’s theological mission.”

Discussion

The black church remains a historical and foundational structure within the AA community, and high levels of religiosity are still documented for many AAs.[30] Based on the centrality of the church and also findings that AAs use religion and connections to pastors to cope with health, it is clear why researchers desire to partner with the church to recruit minority participants and to improve health outcomes. However, a question that researchers are now forced to answer is why the church would want to partner with them. Consequently, it is critical that researchers consider how a research partnership will benefit the church—its leaders, congregation, and the broader church community.

Researchers have found that pastors and lay leaders remain willing to engage with researchers to address health issues within their churches.[31,32] The positive experience theme that emerged from our findings and the willingness of the churches to participate in the larger study support that churches are indeed willing to participate in research studies. However, church leaders emphasize the need for researchers to be sensitive to the church environment and to take time to develop relationships.

Unfortunately, findings from this study related to negative experience with researchers support other evidence that church leaders and members still view researchers as "taking but not giving." Fortunately, findings from this study also provide guidance related to how researchers and universities can be better stewards with black churches to build and sustain partnerships. Our findings confirm that when working with churches, similar to working with many others, it is the "relationship" that has to be built and sustained.

Relationship building requires respect, consistent contact, and reciprocity. Respect, an underlying ethical principle as well as an underlying principle of CBPR and CLAS remains critical to relationship building.[28,29,33] Despite this, church leaders and community members still perceive paternalistic attitudes rather than respect from their academic partners. In addition, they state that the "faith-based" foundation of the church is not respected and considered. Throughout the process of working with churches, researchers must continually ensure that their research goals and the goals of the church are clear and mutually accepted.

In a context where researchers want to discuss advance care planning and EOL with church members, they must consider how this fits with the church's mission to help and support its members. African American communities deal with death often. Writings from scholars can help researchers understand and appreciate that the community's relationship with death that is disproportionately violent death and/or untimely death.[34] Furthermore, researchers may want to explore and identify any implicit or explicit biases toward individuals who hold religious "hope" and belief in miracles as foundational beliefs.

Contributing to the central tenet of respect for the church and its members and community is consistent face-to-face contact with principal investigators and leaders of the research study. Findings still show that church leaders want to meet and engage with the principal investigator and other leaders of the study.[35,36] The importance of this to church leaders was noted within our violation of trust category. Inconsistent contact with leaders of the research study not only can adversely affect the research relationship but can also affect recruitment efforts and have a negative effect on willingness of churches and congregation to engage in other research partnerships.

Church gatekeepers, including pastors and others, are increasingly more likely to insist that they as researchers give back to the church and/or community. Importantly, if they are to indeed create partnerships, it is critical that they collaborate from the beginning and that the partnership is beneficial for all. Specifically, noted within our mistrust theme was the desire to be involved in the interpretation of findings from studies that involved the church. Efforts to help the church with applying for other grants or leaving resources in place for the church to continue to help its congregants and communities to reduce risk and/or overcome

obstacles can be helpful.[37] Such trust building strategies contributed to sustainability of church programs. Other researchers have found that expanded opportunities for professional development, exposure, and networking also work.[38] In the language of many black churches, researchers and universities must be good stewards.

Conclusions

Church-based institutions in the AA communities are prime venues for health promotion trials because many churches have health-care ministries that promote healthy lifestyles. Although such trials can reach a broad AA population and have great potential for reducing health disparities, historical mistrust in researchers decreases access to these institutions. Trust rebuilding strategies were identified for researchers to follow, which may facilitate amelioration of relationships with AA church leaders. Utilizing principles of CBPR, CLAS, and general moral practice is required for successful trust building. If the principles are violated, threat to future hospice and palliative care research within AA church-based institutions may prevail. Thus, potential benefits are thwarted for the church members, AA community, and advancement of the EOL care scholarship.

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Table 1

Demographic Profile of the 4 Churches.

Demographics	Church 1	Church 2	Church 3	Church 4
Total members	4000	7000	4500	2000
Median household income	US$32 000	US$38 000	US$35 000	US$33 000
Location	Urban	Urban	Urban	Urban
Denomination	Pentecostal	Pentecostal	Church of God in Christ	Nondenominational