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An intensely sympathetic awareness: Experiential similarity and cultural norms as means for gaining older African Americans' trust of scientific research

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ABSTRACT

Well-known trust-building methods are routinely used to recruit and retain older African Americans into scientific research studies, yet the quandary over how to overcome this group's hesitance to participate in research remains. We present two innovative and testable methods for resolving the dilemma around increasing older African Americans' participation in scientific research studies. Certain specific and meaningful experiential similarities between the primary researcher and the participants, as well as clear recognition of the elders' worth and dignity, improved older African Americans' willingness to adhere to a rigorous research design. Steps taken in an intervention study produced a potentially replicable strategy for achieving strong results in recruitment, retention and engagement of this population over three waves of assessment. Sixty-two (n = 62) older African Americans were randomized to treatment and control conditions of a reminiscence intervention. Sensitivity to an African American cultural form of respect for elders (recognition of worth and dignity), and intersections between the lived experience of the researcher and participants helped dispel this population's well-documented distrust of scientific research. Results suggest that intentional efforts to honor the worth and dignity of elders through high level hospitality and highlighting meaningful experiential similarities between the researcher and the participants can improve recruitment and retention results. Experiential similarities, in particular, may prove more useful to recruitment and retention than structural similarities such as age, race, or gender, which may not in themselves result in the trust experiential similarities elicit.

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Introduction

It has been difficult to convince older African Americans to participate in scientific research studies despite health disparities across most health indicators when compared to other older adults in the US (Rooks & Whitfield, 2004; Pinn, 2000; Belgrave & Allison, 2009). The issue of trust is central to this difficulty and has long pervaded the literature on recruiting and retaining older African Americans (Braunstein

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et al., 2008; Byrd et al., 2011; Curry & Jackson, 2003; Dennis & Neese, 2000; Dilworth-Anderson, 2011; Freimuth et al., 2001; Gonzalez et al., 2007; Levkoff & Sanchez, 2003; McHenry et al., 2012; Sinclair et al., 2000; Yancey et al., 2006). Among other factors, the distrust of scientific research is influenced by memory of the Tuskegee Experiment. In a study of 179 adults in Detroit (91 of whom where African American), Shavers et al. (2000) found that 81% of the African Americans had knowledge of the Tuskegee Experiment and that knowledge of the experiment resulted in distrust of scientific research. Forty-six percent (46%) of the African Americans indicated that this knowledge directly influences their willingness to participate in scientific research (see also Freimuth et al., 2001; Shavers, Lynch, & Burmeister, 2002).





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The strength of the distrust is compounded by current suspicion of similar mistreatment (Corbie-Smith et al., 1999). In a study of 1440 randomly selected patients from 13 Maryland medical clinics, African American participants were significantly more likely than white participants to report that doctors would use them as guinea pigs without their consent; prescribe medications as a way of experimenting on people without their knowledge; ask them to participate in research even if it would harm them; and that doctors had previously experimented on them without their consent (Braunstein et al., 2008), even after controlling for age, socio-economic status, sex, and health risk status.

The National Institutes of Health (NIH) has mandated the inclusion of women and ethnic minorities in all NIH-funded research projects involving human participants (Arean et al., 2003; Curry & Jackson, 2003; Dennis & Neese, 2000; Reed et al., 2003). The US Department of Health and Human Services and the Resource Centers for Minority Aging Research also enjoin researchers to improve the science of including older African Americans in scientific research studies (Chadiha et al., 2011; Sood & Stahl, 2011), thus researchers must identify strategies that settle this issue of trust if they are to consistently attract and engage older African American participants. Research has shown that trust of people in general as well as trust toward specific individuals increases among the aged of all ethnic groups worldwide (Li & Fung, 2013), so this group is likely to be inherently responsive to good-faith efforts.

In response to this pressing need, this article details an innovative method for enhancing trust among respondents in a community-research partnership. It describes the application of known trust-building recruitment and retention strategies, and poses the question whether clear recognition of African American elders' worth and dignity and specific and meaningful experiential similarities between the researcher and the participants enhanced participants' trust in the research project. Process evaluation activities indicated that high-touch hospitality (fitting and prompt responses to needs relevant to the research) and certain experiential similarities may have improved older African Americans' buy-in to a rigorous research design, and revealed key elements in a replicable strategy for achieving excellent results in recruitment, retention and engagement of this population over at least three waves of assessment.

Methods

The recruitment and retention insights described in this article emerged from the Harlem Life Review & Health in Later Life Study (HLRHLL) conducted in 2005. Participants were older adults receiving services at a senior center that is part of the Central Harlem Senior Center Coalition (CHSCC). CHSCC was established in 1973 by a concerned citizens committee composed of local neighborhood residents of Harlem, New York City (NYC). Colleagues at Weill Cornell Medical College and at the Cornell Institute for Translational Research on Aging (CITRA) who were already engaged in community-based research at CHSCC and had long-term relationships with NYC center directors facilitated the initial introduction. The CHSCC Directors and Advisory Committee approved the study after a detailed review and discussion of the intervention protocol. The Cornell University Institutional Review Board also approved the study. Eligible participants were 60 years of age or older and English speaking with no significant symptoms of cognitive, hearing, or visual impairment. Screening was conducted by the Center Program Director and the Center social worker, both of whom knew each center member well.

The mean age of participants was 72 years (SD = 8). Ninety percent (90%) of the participants were female. All the participants were of African heritage (N = 2 Caribbean American). Forty-three percent (43%) of the participants were widowed; 39% were single; 10% were married. Twenty-five percent (25%) of the participants completed high school or earned a GED. Thirty-nine percent (39%) completed some college or obtained an associate or vocational degree. Sixteen percent (16%) earned a bachelor's degree, and 11% earned a master's degree.

Following randomization to treatment and waitlist control conditions, participants completed a pre-test and then met for eight (8) consecutive weekly two-hour sessions of deeply engaging oral reminiscence work. Each received a weekly \$10 stipend and healthy refreshments each session. With participants' consent, the sessions were audio-recorded and transcribed. A structured reminiscence protocol was used, and questions posed were open-ended. Participants took turns responding orally to the questions, followed by open-ended and fluid discussion. (Detailed information on the intervention is available from the first author.) Participants completed post-tests immediately following the intervention and six months later.

Applying known trust-building strategies

There is a growing inventory of strategies and recommendations for recruiting and retaining older African Americans in research trials, and the successful strategies address the trust issue, whether explicitly or implicitly (Dilworth-Anderson, 2011). These approaches include sanctioning or gaining the support of formal or informal leaders (Dennis & Neese, 2000); clarifying and emphasizing the benefits of participation; clarifying and addressing cultural barriers to participation; providing feedback to the community following the completion of a study (Arean et al., 2003; Arean & Gallagher-Thompson, 1996); increasing face-to-face interaction (Dennis & Neese, 2000; Gilliss et al., 2001); retaining the same interviewer across all assessments (Thompson & Gallagher, 1984); providing incentives (small stipends and honorariums); making participation as convenient as possible (Arean & Gallagher-Thompson, 1996); using age-sensitive recruitment and study materials (Lefler, 2009); and race-matching, which seems particularly intuitive for trust-building in this instance, and is detected in most studies of recruitment and retention of older African Americans. We applied these standard strategies and recommendations in the present study as follows.

Following a CHSCC advisory board meeting where board members discussed the protocol in great detail, the Center Executive Director invited the primary researcher (PR) to present information about the study at a monthly birthday celebration. Printed invitations to participate were handed out as Center members entered, providing an opportunity to make *eye contact* with each member individually and to increase their interest in the PR's presentation. Immediate response capacity was made possible by including a detachable slip of paper on the back of each printed invitation. On Download English Version:

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