Recruitment and retention of African American and Hispanic girls and women in research

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Abstract:

Recruiting women and girls into research studies, especially minority women, continues to be a major challenge that impacts health policy and delivery systems. This article discusses various strategies to recruit and retain African American and Hispanic girls and women in studies. Strategies for successful recruitment focus on trust, familiarity and visibility, racial and ethnic similarities, environmental context, and convenience. Retention strategies include issues of transportation, language, literacy, cultural appropriateness, safety, flexibility, incentives, communication, and veracity. All strategies assist in meeting the challenge of engaging minority women in research to decrease health disparities.

Article:

Many African American (AA) and Hispanic women in the United States are marginalized by limited education and income, poor housing, and non-traditional family constellations. Women often lack political power, financial resources, and access to health care services (del Bene, 2010) and they experience multiple health disparities (Agency for Healthcare Research and Quality [AHRQ], 2011). African Americans have high rates of infant deaths, cancer, diabetes and heart disease, and Hispanics have high rates of hypertension and diabetes. African American and Hispanic women are less likely to have early detection and receive proper treatment for HIV (AHRQ, 2011), cancers, heart disease, and other chronic diseases (AHRQ, 2011). Thus, health researchers must implement strategies to ensure the inclusion of these women in research to reduce disparities. This article discusses strategies for recruitment and retention of African American and Hispanic adolescents and women for intervention and clinical trials research.

Conducting sound clinical trials is dependent on representative samples that provide generalizability. Historically, White men were research participants, which resulted in such a lack of knowledge about women and minorities. In 1994 and 2001, the National Institutes of Health implemented new guidelines for inclusion of women and minorities in research. The numbers of women and minorities participating in research have increased through various means, such as the Women's Health Initiative and the use of university and state registries, yet frequency of participation and retention rates remain suboptimal (Bertram, Chung, Yu, Salovey, & Irwin, 2011; Institute of Medicine [IOM], 2010, 2012). For NIH-funded research, female participants increased from 3 million (51.7%) in 1997 to 13 million (56%) in 2010 (US DHHS, 2011). Minorities increased in number sixfold, but proportions remained constant. However, this is a small fraction of the 190 million women in the United States. Recruiting and retaining female minorities in research studies continues to be a challenge, especially for non-reproductive health issues.

The lack of participation by African Americans in health care research has been attributed to mistrust, lack of information or misinformation, lack of understanding informed consent and other procedures associated with research, inadequate efforts to recruit participants, potential stigma associated with particular topics, fear, financial/logistical reasons, and racism (Brooks, Paschal, Sly, & Hsaio, 2009; Huang & Coker, 2010). Studies such as the Tuskegee syphilis trials dominate the perceptions of research for many African Americans, especially in the South. For Latinos, reasons for nonparticipation include immigration status, stigma associated with research topics such as HIV, lack of cultural sensitivity in study designs, and language barriers (Ahrens, Isas, & Viveros, 2011; Zayas, Hausmann-Stabile, & Pilat, 2009). Recent political and law enforcement actions have made contact with persons outside of the Hispanic community seem threatening for potential Hispanic participants. Language differences, stereotypes and prejudices, failure of minority leaders to understand the importance of research and identification of races and ethnicities by concrete and exclusive categories (Knerr, Wayman, & Bonham, 2011) results in difficulty recruiting minorities and women. Thus, increasing research participation among African American and Hispanic women and girls must be considered in the context of all of these factors.

Recruitment

Trust. A suspicion of research often exists among minority groups, thus building trust in a targeted community is essential and may be the most important consideration for enrolling low income and minority women (Kneipp, Lutz, & Means, 2009). One strategy for building trust is that of identifying key stakeholders and leaders, who are trusted by potential research participants. Historically, African American church leaders have served as a starting point for those efforts, and ministers and church boards are often an effective avenue for recruitment at African American churches (Kennedy et al., 2011; King et al., 2010; Thompson, 2010). Church leaders are important stakeholders for Hispanic women and girls as well (Baumann, Domenech-Rodriguez, & Parra-Cardona, 2011). School leaders and personnel are another group, who can assist in building trust and entre′ to minority women and girls for research. Bartlett and Shelton (2010), for example, involved school counselors, principals, and school pregnancy prevention staff to assist in recruiting minority girls and mothers for an HIV prevention intervention. Women's relationships to medical providers and clinic staff are helpful in decisions to participate

in research, including cancer research (Dignan et al., 2011), gestational diabetes prevention (Chasan-Taber, Fortner, Hastings, & Markenson, 2009), and early detection of breast cancer (Kelley, 2011). Another strategy for building trust is to ensure community engagement pre-study and long-term. Finally, including a community leader on the team is key to building trust in the planning stages of a study.

Familiarity and visibility. A key strategy for recruitment and retention of women and girls is familiarity—being involved and visible in the local community. Providing general health education or health screenings are methods to show visibility, develop trust, and become familiar to and with the community (Hu, Amirehsani, Wallace, & Letvak, 2012). Attending church services and Mass provides similar visibility. Personal announcements, newspaper articles, and flyers to advertise a study in the community prior to recruitment are useful (Falcon et al., 2011; King et al., 2010). Recruiting in churches, health clinics, and other gathering places is appropriate with African Americans (Huang & Coker, 2010) and with Hispanic women (Lopez-Cordova, Figueroa-Cosme, & Capriles, 2010). The presence of team members during recruitment activities adds to potential participants' familiarity and eagerness to participate in the study, and contributes to retention (Whitebird et al., 2011).

Racial and ethnic similarities. Racial and ethnic concordance between research team members and study participants (Falcon et al., 2011; Polanco et al., 2011) promotes trust, enhances communication, and promotes greater satisfaction with the study by participants, and conveys cultural understanding. Ahrens et al. (2011), whose study focused on sexual assault on Latinas, a highly sensitive topic, used face-to-face recruitment by either the study director (who happened not to be Latina), or by Latina study staff. Hu et al. (2012) engaged Hispanic lay workers, and Bartlett and Shelton (2010) and Thompson (2010) engaged African American nurses, group leaders, recruiters, and data collectors in HIV and physical activity studies with African American teens. These studies had greater than 80% retention.

Environmental context. Understanding the current dynamics of the community is imperative for successful recruitment and retention efforts (Byrd et al., 2012; Kelley, 2011). For example, if recent research studies have been conducted, does the community have research fatigue or distrust? Is the community ready for a new study? Knowing whether there have been recent upheavals in the community due to political, legal or cultural strife is important. If recent school issues focused on teen girls, then recruiting teen girls for a study might be extremely difficult. If recent reports show increased sexual activity, STDs, and higher pregnancy rates, then parents may welcome participation. When recruiting Hispanic participants, it is important for team members to be aware of the concerns and realities of immigration status and recent law enforcement actions (Hernandez, 2012). Immigration raids and checkpoints have made it difficult to recruit adult women (Shedlin, Decena, Mangadu, & Martinez, 2011). Federal law mandates that all children have access to public education in the US regardless of immigration status; thus partnering with schools can afford researchers some measure of trust among persons in Hispanic communities. Researchers may choose to not ask or document status (Baumann et al., 2011). Assessing the socioeconomic status of targeted women and girls is useful. Participants from lower educational and socioeconomic level may require more assistance with data responses; middle class and college educated women and girls may wish to self-administer data tools.

Convenience. Recruitment sessions or meetings at times and locations convenient to the daily lives of women and girls show respect and assist in enrollment and retention. Jones and Reiner (2010) propose that holding information sessions for potential participants, followed by a break when uninterested persons can leave anonymously, may be a useful strategy. Importantly, avoiding perceived coercion or entrapment by the school, church or clinic setting or personnel may communicate trust and confidentiality, increase enrollment, and add to study validity.

Retention

Transportation. A major concern for participant retention is transportation (Falcon et al., 2011). In urban areas, service may be unavailable, unsafe, unreliable or cost prohibitive, especially for persons living in minority and low-income neighborhoods. Public transit is rarely available in rural areas. Careful consideration of the requirements for group or individual intervention and data collection times, and the transportation needs of potential participants must be planned. Community centers, churches, grocery stores, health departments, and clinics provide useful recruitment and study sites (Byrd et al., 2012; Hu et al., 2012; Kelley, 2011). If individual sessions are required, confidentiality, safety, bias, and respect must be considered. For example, many persons may not want strangers in their homes, and may be embarrassed to have formal visitors, or the home may not provide adequate privacy for collecting data.

A strategy used by many studies is to provide vouchers, gas cards or cash for transportation to research sites. For example, Bartlett and Shelton (2010) provided $5 per trip to mothers, who transported daughters to and from intervention activities. Sessions can be held in central community settings such as public libraries, community or health centers (Hu et al., 2012) and churches (Thompson, 2010). Collaborations with taxicab services, social service vans, and mass transit may enable prepaid and scheduled access (Hernandez, Zule, Karg, Browne, & Wechsberg, 2012), especially for clinical trials requiring medical treatment and diagnostic testing at a hospital or medical center. Another strategy is to schedule appointments and diagnostic tests on the same day as the research protocol. This requires additional effort on the part of the research team, but may be an invaluable retention tool, especially if persons have long trips or require a family or friend to transport them to sessions. However, long days with multiple activities may cause high burden and fatigue for participants, resulting in dropout.

Language. African Americans and Hispanics, like those in all other cultures, have dialects and colloquial phraseology that give cultural meaning to words. African American women living in New York or Texas use different terms from those of persons living in the South Carolina low country. Teens use cohort language and terms that differ from language of older African American and Hispanic women. Lay health workers, who understand the terms and language of potential participants are an excellent resource to assist with planning, recruitment, and implementation (Byrd et al., 2012). In addition, enrollment and retention of Hispanic women and girls requires translation of forms (consent and others) into Spanish. Proper translation and back translation must be assured (AHRQ, 2011). Appropriate language is critical so that participants can speak and identify with a team member for consistent implementation of an intervention and accurate data collection and responses (Bartlett, Williams, & Lucas, 2011).

Literacy. For African American and Hispanic women and girls, no assumptions should be made about persons' reading abilities or health literacy; lay terminology should be used as much as possible (Bouris et al., 2010). One way to avoid reading difficulty and embarrassment is to administer intervention content and data collection verbally or graphically. Including a community member in planning studies will assist the team in knowing which literacy issues may occur (Byrd et al., 2012). Readability levels for study materials in English and Spanish should be no higher than the sixth grade. This is a reasonable understanding level in terms of avoiding "big", multi-syllable words and long sentences. Use of common words, visual analogue scales, smiley face or other cards with tool response sets has been effective. Participants' understanding of what is asked of them and the way they respond to intervention methods and activities are influenced by reading and health literacy (Evans, Lewis, & Hudson, 2012). It is important in a diabetic intervention to clarify what participants are responsible for keeping (daily logs, trying self-management activities) and why the activity keeps participants healthy or helps them meet their life priorities, such as working or caring for the family. To illustrate, there may be a cultural stigma to having dialysis and being "hooked" to a machine. Discussing the short-term and long-term effects that blood sugar has on a woman's eyes and kidneys may have meaning for her and enable her live a life to prevent dialysis.

Cultural appropriateness. Ahrens et al. (2011) and Byrd et al. (2012) recommend the formation of a research team whose members include Latinas, and training for research staff that reflects the research focus. *Machismo* and *marianismo* affect health behaviors and decisions to participate in research (Hernandez, 2012; Hernandez et al., 2012). Women and girls may not feel they can decide about study participation for themselves or their daughters without input from the husband/father or grandparents. Inviting family members to recruitment sessions is one strategy. Family issues should be considered in study planning, implementation, and evaluation, especially among minorities (Baumann et al., 2011).

Huang and Coker (2010) and Kelley (2011) recommend projects that are ethnically sensitive and the use of culturally tailored interventions to the African American experience to enhance success. Recruitment and intervention could include matriarchal roles and family constellations in health and decision making. Another part of the African American experience is victimization of slavery and the unethical conduct of the Tuskegee research study. Even in 2012, African Americans voice concern about being 'guinea pigs' when asked to participate in research studies (Evans et al., 2012). Designing recruitment and intervention activities with key stakeholder and community involvement for cultural specificity and transparency is paramount. The use of focus groups may be useful to gain this information.

The dress and appearance of recruiters and research staff may convey a sense of qualification and trust, or authority and mistrust. In most rural areas and with many lower socioeconomic groups, teams should avoid "putting off" participants by not wearing formal business dress and flashy jewelry, opting for casual business. With some groups, jeans and tennis shoes may be perceived as disrespectful and a lack of the professional demeanor expected of a professional or health care provider, unless the study is conducted for physical activity or in a gymnasium or club setting. In large medical centers, the choice of wearing a white lab coat, colored scrubs, or business casual clothes may be dictated by the setting, the role of the researcher on the team, and

the institution. Teams must consider how dress impacts perception for the group, location, gender, and age in the cultural context of the study.

Safety. Attention to the perceptions, needs and fears of minority women and girls who enroll in an intervention trial is critical to retention. For safety, public places such as fast food restaurants or the public library, or homes may be preferred. Planning sessions with girls and women in trusted and safe places like schools, community centers, churches, or public libraries may be comforting to mothers and girls, as well as their husbands, fathers, and grandparents. Women and girls may find that using public places avoids conflict with families about participating since women and girls go to these places for day-to-day activities and meetings with friends. Retention can be affected by setting and time of day. Thus, providing a choice of settings for intervention delivery and data collection times greatly enhances retention (Falcon et al., 2011; Kennedy et al., 2011).

Flexibility. Maximal flexibility in scheduling activities with participants is critical for recruitment and retention. Many women have child care and other family responsibilities, as well as work and social commitments. Scheduling at the end of the school day, in the evenings, at lunchtime or midmorning, or on weekends may be convenient to participants, even if it is not convenient to the research team. Sundays after Mass may be an excellent time for Latinas, but after church may not be a good time for African Americans. In one study, intervention sessions were held at 6:00 p.m. after the workday (Hu et al., 2012), and in a study with middle school minority girls, intervention and data collection sessions were held immediately after school (Bartlett & Shelton, 2010.) Scheduling sessions for girls in close proximity to and immediately after school makes it easier for girls to remember to attend and may avoid transportation issues. Key stakeholders and community members can provide scheduling possibilities and preferences when planning the study.

Incentives. Providing incentives presents unique opportunities and challenges when working with marginalized groups. Balancing the amount of a financial incentive against the time and effort being asked of participants and the potential for coercion is often difficult. The major consideration is whether incentives may change a decision to participate (or not) or alter the findings of the study. One method to evaluate incentives with women and girls is a post study focus group or to ask selected questions about the conduct of the study and perceptions of the incentive timing, amount, and importance. Key stakeholders can be included in this decision in the planning stages of the study. Also, Institutional Review Board (IRB) members can share the common type of incentives and amounts used.

Level of incentive may differ depending on the amount considered coercive. IRBs often require the same level and type of incentive for each woman or girl in a study, regardless of socioeconomic status. However, avoiding coercion with one group may deter participation by another group. Researchers must decide whether each family member is provided the same incentive with different involvement, whether experimental and control participants receive the same incentives, and if cash or small gifts or medications are selected.

When working with mothers and girls from minority populations, an additional consideration for retention is who should receive the incentive and whether a financial incentive can result in harm

due to local theft or patriarchal decision making. Gift cards and cash are often used as incentives for intervention studies. Gift cards provide a simple incentive and can be targeted to locals using cards from grocery or big box stores. Cash is useful for short-term or episodic studies, or when use of gift cards to big box stores would mean additional transportation costs for participants. Requiring signatures on participant receipts can be disincentives for persons who have literacy issues or unclear legal status (Ahrens et al., 2011).

Communication. Consents for women and assents for girls must be clear and simple explanations of what they are being asked to do, the risks, and the details and steps to maintain confidentiality and anonymity. If the intervention topic is sensitive, like those associated with sex (Bartlett & Shelton, 2010; Hernandez et al., 2012) or weight loss (Thompson, 2010) a culturally and gender sensitive approach leads to more successful recruitment and retention (Martinez, McClure, Eddy, Ruth, & Hyers, 2012). Sensitivity to adolescent participants with topics such as these can be challenging, especially to obtain parental consent and participation. Women and minorities may require a trusting relationship with the researcher before discussing personal issues (Hernandez, 2012; Hu et al., 2012). Consistency with research team members contacting and working with women and girls across recruitment, enrollment, intervention, and data collection study activities builds trust, security, and communication (Martinez et al., 2012).

Women have many responsibilities at home and work that may interfere with study participation, and school aged girls can easily forget scheduled appointments. Whitebird et al. (2011) suggest weekly or biweekly reminder calls to promote attendance at study sessions and to prompt participants to practice the skills learned. During a follow-up phase, monthly calls or text messages to promote engagement between the participants and the study staff add value to participation (Baumann et al., 2011). Another communication strategy is to follow up by phone with any participant, who misses a session (Whitebird et al., 2011). This call communicates the participant's importance to the study and allows research team members to determine if problems have arisen that need to be addressed. Authors have reported success with written communication through newsletters, post cards, and birthday cards (Falcon et al., 2011; Stockton, McClanahan, Lanctot, Klesges, & Beech, 2011).

Veracity. Although not traditionally addressed in the literature, one of the most important issues in retaining women and minorities in research studies is to follow through on what has been promised. This begins with informational recruitment sessions, full disclosure on consent forms, the risk and benefits, and involvement level (Evans et al., 2012; Shedlin et al., 2011). Consistency of actions and attitudes and maintaining schedules, activities, and personnel are essential. This may require adapting the intervention for "make up" sessions or a make-up few minutes at the beginning of sessions (Stockton et al., 2011), providing space for family members who transport participants to sessions, and implementing multiple reminder strategies to encourage and validate completion of intervention activities (Martinez et al., 2012). Researchers must consider veracity when planning the study, selecting measures, developing protocols, writing consent forms, and recruitment flyers, allocating study resources and selecting and training personnel.

The recruitment and retention of minorities and women in research is one mechanism for changing health policy, improving health, and decreasing disparities (AHRQ, 2011; IOM, 2012).

Strategies that involve varying levels of effort have been termed "best practices" (Carroll et al., 2011) and have been recommended by researchers (Hines-Martin, Speck, Stetson, & Looney, 2009; Shedlin et al., 2011; Stockton et al., 2011). These include advertising a study through the media, joining with community members, agencies and organizations in recruitment efforts, matching study staff with the ethnic group in ethnicity and language, and having appropriately trained research team members. Building trust (Baumann et al., 2011), tailoring the study to a particular gender and ethnic group's culture and context (Sadler et al., 2010), considering literacy issues (Evans et al., 2012), and focusing on the community of participants' needs (Falcon et al., 2011) can enhance recruitment and retention.

This article discusses strategies for recruiting and retaining women and minorities, including development of trust, familiarity and visibility, racial and ethnic similarity, convenience, transportation, language, literacy, cultural appropriateness, safety, flexibility, incentives, communication, and veracity. Many of these are traditional nursing concerns and practices that can be applied to research. In addition, many of the strategies are consistent with community-based participatory research. Multifaceted and innovative efforts to recruit and retain African American and Hispanic women and girls in research are essential for intervention and clinical trial findings appropriate for generalization to communities and to direct future efforts for improving health and decreasing disparities. Developing and monitoring recruitment and retention strategies in the classifications discussed and based on experience and scientific literature, as well as adapting strategies to the community, culture, developmental age, health status, and information needs of the targeted intervention group and on the observations of study staff can aid in policy, practice, and delivery system improvement.

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