"I Don't Want to be a Guinea Pig"

Recruiting Older African Americans

Recruitment efforts for clinical trials within the African American community, especially those targeting older African American adults, has traditionally been difficult. Ford et al. (2013) found that minority group members welcomed the opportunity to participate in intervention research. The African American participants in their focus groups revealed that barriers to recruitment included costs, lack of diversity on the recruitment team, and general mistrust of medical research. In this editorial, we would like to describe our experience in recruitment to expand on the last concern: mistrust.

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The research study for which we were recruiting involved no cost and included a diverse research team. The intervention was nonmedical; members of the team provided oral hygiene to the participants, who had a diagnosis of dementia and were identified by the staff as resistant to mouth care. We even provided all mouth care supplies. To improve our ability to recruit minority participants, we targeted nursing homes in the area that had significant (≥40%) minority representation. The first author was born and raised in the area and is also an African American woman. In her words, "When I walked into the facility I felt welcomed up until I said the word, 'research.' At which point, the suspicion began." When we discussed this reaction, Ms. Jones observed that the suspicion regarding the term *research* was age-dependent. That is, African American participants and family members older than 50 were unlikely to participate or provide consent. These individuals, as opposed to those younger than 50, exhibited more caution when considering the trial, were less likely to respond or return calls after initial conversations, and were more outspoken about past research misdeeds within the Black community. Given that there were no costs and the research team was diverse, mistrust seemed to be the underlying factor. Both of us were initially puzzled by the difference between the two groups. We quickly realized that the age-dependent mistrust in our study may have also been exacerbated by Birmingham's history of discrimination. At the time of our recruitment, the 50-year anniversary of civil rights demonstrations was being memorialized. To those who lived through the harsh treatment of the 1960s and may have had loved ones directly affected by the Tuskegee Syphilis experiment (Brandt, 1978), our research team was a vivid reminder of unethical decisions. We often heard, "I don't want to be a guinea pig."

After realizing that the older adults who needed to give consent had a great deal of initial mistrust and suspicion about the research process itself, Ms. Jones initiated a more open conversation and gently asked questions when they were experiencing hesitation. This change of approach led the consent process to become more of a dialogue where Ms. Jones gave people a chance to share what specifically was making them uncomfortable about participating. Although memories of Tuskegee seemed to form the underlying tone, the wording in the consent forms proved to be pivotal in whether

individuals gave consent. For example, a resident's wife decided to withdraw consent from participation in the trial. Although the wife had originally signed the consent form, she later consulted with other family members and showed them the document. Ms. Jones learned about the family's suspicion that our research team would use the resident's medical information for more than just the mouth care study. Providing reassurance to the family that our team would only document what was necessary was not enough. This was not the only case where language in the consent form sparked questions and feedback from the participants; several times subsequent refusal was based on the wording of the consent form.

Colloquial expressions also provided insight. For example, we had been using the term *dementia* when discussing study eligibility. During a conversation, one of the potential participants stated, "Yeah, I've had the 'forgets' for years." The "forgets"? That was a new one for both of us. Ms. Jones immediately began using the term *forgets* interchangeably with dementia, and the response to study participation improved.

Although we aimed to make the consent form as easy as possible to understand, many older individuals found the document intimidating. We were required by our Institutional Review Board (IRB) and by the Health Insurance Portability and Accountability Act to include specific verbiage. For example, we were required to include a mandatory paragraph indemnifying the University if any harm occurred that would require medical treatment. This wording was translated to potential participants and family members as: "If anything happens to my mother, then the University will not pay for it." This perception overshadowed the positive benefits of the study and the low risk of injury inherent in the design. Ms. Jones tried to counteract fears by explaining that the study did not involve medical procedures, experimental medications, or experimental devices. Her explanations, however, were not enough to dissipate their fears. We will have to discuss the need for mandatory language in future consent forms with the IRB, especially for studies with a high benefit/low risk ratio.

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We learned much from this experience. First, the word *research* triggered immediate negativity. The word *study* was better received by the individuals providing consent. By incorporating colloquial expressions, such as the "forgets," we also improved our communication with potential participants and their family members. Another way we reduced mistrust was to allot more time to the consenting process. There is a fine line between following up and pressuring. For example, many family members would respond to the initial contact by saying, "Let me keep the information and call me next week." Ms. Jones would follow up as initially requested. She limited follow-up contacts to two attempts, spaced 3 days apart, to avoid the appearance of badgering. Additionally, Ms. Jones remained on-site in the nursing homes (especially during visiting times) to interact with the residents, staff, and family on a daily basis. Ensuring a presence at the facility made us appear as less of an "outsider," and that we were genuinely concerned and not just there to gather data.

We, as researchers, have a responsibility to continuously modify our approaches to recruitment and share successful strategies. These strategies have to go beyond the superficial practice of merely having a minority recruiter. "Looking the part" is insufficient. The take-home message is that we learned that we needed to be sensitive to and aware of a community's terminology; to respond to their level of understanding of the research process; and to address perceived stigmas associated with research participation. Recruitment of minority participants involves continuous cultural awareness and responsiveness to feedback from participants. Otherwise, we perpetuate the cycle of minority groups equating research participation with "being a guinea pig."

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