

Barriers and Facilitators to the Recruitment of Underrepresented Populations in Health Research: A Narrative Review

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Abstract

Aims: To identify barriers and facilitators to recruitment and retention of underrepresented populations into health research and propose evidence-based strategies to attenuate the barriers and foster the facilitators.

Background: Health promotion research is designed to identify sustainable strategies that enable people to live a healthier lifestyle. To identify strategies that are effective for a diverse group of people, research must include a diverse sample that is representative of the population. Researchers frequently struggle with recruitment and retention of underrepresented populations in healthcare research, yet without adequate representation, identification of effective health promotion strategies is lacking.

Methods: PubMed, CINAHL, and PsycINFO databases were searched to identify literature regarding recruitment and retention of underrepresented populations into health-related research.

Results: A total of 13 quantitative and qualitative articles were reviewed. The primary barriers to recruitment and retention included mistrust of researchers, lack of communication, and inadequate representation of the underrepresented population among the research team. Facilitators included development of community partnerships, benefits for self and community, and involvement in planning of the research.

Conclusions: Evidence-based strategies that address barriers and facilitators to underrepresented populations' participation in health research should be addressed to promote recruitment and retention.

Relevance to clinical practice: The findings guide the development of strategies as researchers plan health promotion and disease prevention interventions for underrepresented populations.

Keywords: underrepresented populations, recruitment, retention, health research

Introduction

Health promotion research is designed to identify sustainable strategies that enable people to live a healthier lifestyle. To identify strategies that are successful for a diverse group of people, research must include a diverse sample that is representative of the population. Researchers frequently struggle with recruitment and retention of underrepresented populations in healthcare research, yet without adequate representation, identification of effective health promotion strategies is lacking. This narrative literature review will describe recently reported effective strategies for recruitment and retention of underrepresented populations into illness prevention and health promotion research.

Data from the Agency for Healthcare Research and Quality (AHRQ) show that quality measures were worse for Blacks than Whites for 40% of the measures some of which include healthy living, effective treatment, and person-centered care. Over a 17-year period, only 4 of 56 quality measures for which a disparity between whites and blacks existed at baseline showed a narrowing disparity (AHRQ, 2019). According to the United States Department of Health and Human Services' Office of Minority Health ([OMH] 2019), the death rate for diseases that require long-term management including diabetes, heart disease, and asthma, is higher for blacks than whites.

In the United States, Blacks have poorer health outcomes and are disproportionately affected by chronic disease (OMH, 2021). For example, in 2018, black adults were 60% more likely than non-Hispanic white adults to be diagnosed with diabetes by a physician and twice as likely to die from diabetes (OMH, 2021). Approximately 12% of blacks aged 20 and older have diagnosed or undiagnosed diabetes compared to 8% of whites (American Diabetes Association, n.d.).

While Blacks are disproportionately affected by chronic disease, their enrollment in research designed to address strategies for improving management and outcomes of chronic disease is limited. In the United States, Whites account for 67% of the population and 83% of research participants while Blacks account for 13% of the population, but only 5% of clinical trial research participants (Myshko, 2018). Less than 10% of participants enrolled in clinical research trials today are minorities and while efforts have been made to address the under-

representation of minorities, the majority of participants continue to be from a non-Hispanic white population (Ma et al., 2021).

Aims

Research studies do not adequately represent diverse populations affected by chronic disease. Clinical research should include those who are most affected by the disease being studied to ensure the interventions developed translate effectively to that population (Luebbert & Perez, 2016; Yates et al., 2020). Khubchandani et al. (2016) stated that inclusion of minorities in health-related research can identify solutions for health disparities and promote development of targeted interventions for minorities. The aims of this narrative review of literature were to identify barriers and facilitators to recruitment and retention of underrepresented populations into health research and propose evidence-based strategies to attenuate the barriers and foster the facilitators.

Methods

Investigators conducted this narrative literature review using guidelines by Green, Johnson, and Adams (2006) and the Meta-Analysis of Observational Studies in Epidemiology (MOOSE) guidelines. The PubMed, CINAHL, and PsycINFO databases were searched to identify literature regarding recruitment and retention of underrepresented populations into health-related research. Because this literature review was done to assist with recruitment of underrepresented populations into a health promotion study for people living with type 2 diabetes, the search was conducted to include any health promotion studies and studies with participants who had diabetes. Search terms included “health promotion research” OR “research”; “minority” OR “underrepresented populations”; “recruitment”; “retention”; “diabetes” OR “diabetes type 2”. The search was limited to journal publications from the past ten years written in English and including an adult (18 and older) sample. A final sample of 13 articles including systematic reviews, integrative reviews, quasi-experimental, descriptive, and qualitative studies was included in the review. A synthesis of barriers and facilitators for recruitment and retention of underrepresented populations from the reviewed articles is presented.

Results

Barriers

Prejudice and mistreatment of minorities in healthcare is a well-documented phenomenon that may serve as a barrier in recruitment (Luebbert & Perez, 2016). A qualitative study examining recruitment strategies for Alzheimer's research identified lack of information regarding research, fear of research, and past history of unethical research as barriers (Hughes et al., 2017). While more than 80% of the participants in this study believed that research was done for a good cause, almost 70% also believed there was a danger that clinical research study findings could be misused. Seemingly ominous precautions like informed consent documents may be perceived as a way for researchers to avoid legal action in the event that they mistreat participants (George et al., 2014). Smith et al. (2018) also reported that African American participants may see the informed consent process as a means to legally protect researchers rather than protect participants.

A qualitative study that included primarily African American participants was conducted to identify health and research priorities for underrepresented populations, concerns related to participation in research, and strategies that can be implemented to engage underrepresented populations in research (Erves et al., 2017). Listening sessions with participants identified three major barriers including uncertainties regarding research participation, ineffective communication, and lack of cultural competence and humility for researchers. Uncertainty centered on lack of trust that information would be communicated openly and honestly leading to a second concern for their own safety if participating in research. Ineffective communication was discussed as underrepresented populations stated that opportunities to participate in research were not well communicated in the community or it was communicated, but not well understood by community members (Erves et al., 2017). No prior involvement in research correlated with mistrust of new studies (Stevens et al., 2016). Smith et al. (2018) noted that women recruited for a breast cancer research study stated they were less likely to participate in research studies because they had not been asked to participate. Participants indicated that experiences with researchers who demonstrated biases tainted initial impressions and discouraged future participation in research (Erves et al., 2017). Similarly, a study that included African

American males noted that researchers who are not part of the community of interest may not know what is in the best interest of the community and they may not prioritize the community's interest over their own interests (Graham et al., 2018).

Participants fear that data collected during research studies may be used without their permission, negatively affecting their ability to qualify for services like health insurance (George et al., 2014). Finally, African Americans identified time commitment, expenses (i.e., transportation, travel distance, day care), and general inconveniences as additional barriers to research participation (Smith et al., 2018).

Facilitators

Partnering with significant figures, events, and programs in the community may serve as a facilitator in recruiting and retaining participants in a study (Smith et al., 2018). Graham et al. (2018) found this when studying outreach strategies to recruit within a community; men who regularly volunteered their time and efforts to those around them were valuable assets in recruiting and retaining participants. Enlisting past research participants to become mentors can initiate a snowball effect and expand the reach of social networks, trust, and movement building. Familiarity builds trust in the research and reassures potential participants that their well-being will be prioritized. Suarez et al. (2019) noted that recruitment was increased by having an experienced staff who had gained the trust of potential participants through previous interactions. Smith et al. (2018) found that development of partnerships with prominent breast cancer advocates in the community led to increased recruitment and retention of African Americans in their study. Lastly, these figures/programs can better speak to the needs of the communities they serve, so they can be assets in planning studies to meet the needs of participants (Randolph et al., 2018). One study found that partnering with churches led to increased enrollment of African American participants and when the church pastor was included as a participant, that led to higher numbers of church participants (Owens et al., 2017). Luebbert & Perez (2016) recommended that researchers integrate African American community leaders in the planning and implementation of clinical research projects to improve trust issues, increase the level of comfort of the participants, and promote participation in research.

Minorities are more likely to recruit for and participate in research yielding results that will directly benefit them or their community (George et al., 2014). Participants have expressed they joined a research study because the research will help future generations, or they had a family member affected by the condition being researched and that motivated them to participate. Additionally, participants learn more about the disease being researched and make a difference in their communities by being involved in research studies (Smith et al., 2018). Focus groups identified personal benefits including gaining knowledge and resources; giving back and helping others; and compensation as facilitators of research participation (Hughes et al., 2017).

A major theme in a qualitative study with primarily African American participants was that they wanted to have a voice in identifying research priorities that affect them (Erves et al., 2017). When these participants were asked about their priorities for research, a need for research aimed at preventing disease, including diabetes was identified. They also discussed the desire to be included in research to improve outcomes for underrepresented populations and to give voice to their needs and preferences for health care and to improve patient-provider communication. A study that aimed to recruit African American males for health promotion programs and research found that being part of a larger social movement was more motivational than participating in health promotion activities just to see personal improvements (Graham et al., 2018).

Complete transparency and clear details on the structure of the study is a facilitator in recruiting participants (Erves et al., 2017). Larger studies with more participants could complicate communication but assigning participation advocates and providing them with intimate contact information like personal cell phone numbers builds trust (Sullivan-Marx et al., 2011). Being accessible throughout the entire study to answer questions and address concerns keeps participants from feeling like guinea pigs (Hughes et al., 2017).

A facilitator to recruiting and retaining a diverse sample of participants is to accommodate individual physical, socioeconomic, and cultural needs. Examples of this include providing interpreters or materials in languages other than English and addressing cultural or historical events that may have shaped potential participants' perceptions of research (Frierson et al., 2019). Providing reliable transporta-

tion to study locations may make a study more accessible to members of the community who cannot transport themselves or cannot afford to pay for public transportation (Frierson et al., 2019; George et al., 2014). Offering financial incentives for participants has also been shown to increase participation (Perez et al., 2013).

Discussion

The most critical factor to address in recruitment and retention of underrepresented populations into healthcare research is the pervasive lack of trust created by past unethical research methods. Researchers must understand the race and culture of the population being recruited (Erves et al., 2017). Ideally, the research team will include members of the population being recruited so potential participants can trust that their ideas and perspectives will be honored (Randolph et al., 2018). Communication with potential and actual participants is essential (Randolph et al., 2018; Smith et al., 2018). Providing educational and question-answer sessions prior to study enrollment and presenting informed consent in terms that are easily understood can build trust (Khubchandani et al., 2016; Smith et al., 2018). Including trusted liaisons from the community in planning and implementation of the study is important for both researchers and community members (Graham et al., 2018; Owens et al., 2017; Randolph et al., 2018). A community liaison can provide information about the community including its needs and resources and can ensure researchers are addressing what is important to potential participants in a culturally appropriate way (Khubchandani et al., 2016; Randolph et al., 2018).

Because many potential research participants from underrepresented populations seek benefit for themselves or others through research, these benefits should be clearly conveyed in the study explanation and informed consent process (Smith et al., 2018). Researchers should discuss personal goals with participants to ensure the study will assist them in meeting those goals. Participants should understand that they are contributing to the development of interventions that may improve their own health as well as the health of their community (Randolph et al., 2018).

Finally, researchers must ensure that participation is as convenient as possible. Participation is a time commitment so compensation for their time may promote participation (Smith et al., 2018). Partici-

pants may have childcare needs so childcare could be offered during study activities (Randolph et al., 2018). As much as possible, data collection and study implementation should be done at locations convenient to the participant (Khubchandani et al., 2016).

The following recommendations for recruitment and retention of underrepresented populations are made based on the review of literature:

- Provide cultural competence training for researchers.
- Include researchers on the team who mirror the population of interest.
- Educate potential research participants on the various aspects of research, including types of research studies, benefits of participation, what research studies involve, opportunities for participation, and safeguards in place to ensure research is conducted in an ethical manner.
- Maintain transparency and frequent, open, and honest communication from recruitment through study conclusion.
- Develop community partnerships.
- Outline benefits to self, community, and greater population from research participation.
- Accommodate time, childcare, and other physical needs as much as possible.

Limitations

Narrative literature reviews present a broad perspective on a topic and, for this review, was beneficial to inform recruitment methods for a study promoting physical activity among people living with diabetes. Limitations exist and include the potential for bias due to the lack of a systematic process used to search the literature. Additionally, articles representing a range of evidence level including systematic reviews, integrative reviews, quasi-experimental, descriptive, and qualitative were included, but the number of articles was small at 13.

Conclusion

This review of literature identified ongoing concerns about the lack of diversity in health promotion research. Inclusion of underrepresented populations in research is essential for addressing health disparities. Mistrust of research and researchers continues to be a primary challenge to recruitment. Literature indicates clear communication and community partnerships can lead to trust and support of the strategies to improve health among underrepresented populations.

Relevance to Clinical Practice

Because multiple barriers and facilitators to recruitment and retention exist, researchers should assess and connect with the under-represented population of interest to identify their specific needs and gain buy-in to ensure effective health promotion and disease prevention interventions.

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Appendix

Author & Title	Study Design	Participants	Study Purpose	Major Study Findings
Erves et al (2017). Needs, Priorities, and Recommendations for Engaging Underrepresented Populations in Clinical Research: A Community Perspective	Qualitative study	117 Participants from racial/ethnic minority groups, economically disadvantaged groups, and hearing-impaired communities	To present the health and research priorities of diverse groups of underrepresented populations in biomedical research, their concerns for participating in research, and strategies to engage them in their healthcare and research studies.	<ul style="list-style-type: none"> - Providing literature with frequently asked questions to participants prior to enrollment may decrease their concerns - Maintain open lines of communication between participants and researchers at all phases to promote involvement - Intentional questions about expectations and goals can help prioritize the health concerns of participants
Frierson et al. (2019) Bridging the Gap: Racial Concordance as a Strategy to Increase African American Participation in Breast Cancer Research	Qualitative study	57 African American women	To identify research perceptions and motivating factors needed to increase racial/ethnic minority participation in breast cancer research	<ul style="list-style-type: none"> - Motivating factors included community activities to learn about research, race-matched researchers, importance of breast cancer awareness, and community knowledge of the researcher and expected study outcomes. - Barriers included physical (lack/cost of transportation and childcare), language and literacy levels, fear due to historical events, and concern that randomization may not be equitable

