Lessons Learned Recruiting Minority Participants for Research in Urban Community Health Centers

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Conflict of Interest Statement: None of the authors have any financial, personal, or other associations that might pose a conflict of interest in connection with the submitted article.

Financial disclosure: The authors report no conflicts of interest or financial relationships associated with this article.

Acknowledgments: Funding: This research was supported by the National Cancer Institute of the National Institutes of Health under Award Number R21CA165939 (JMF). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. The National Cancer Institute had no involvement in the study design; collection, analysis and interpretation of data; writing of the report; nor the decision to submit the article for publication.Special thanks are extended to the New Jersey Primary Care Research Network and the following individuals for their assistance in recruiting patients and conducting the research: Jennifer Bayly, Gabrielle Davis, Richa Dhawan, Shaniqua McGraw, Connie Pascal, Mary Nell Quest, Usha Rao, KelliAnn Seaman, Mariya Shalukmova, and Samantha Tate.

Abstract: To help understand and mitigate health disparities, it is important to conduct research with underserved and underrepresented minority populations under real world settings. There is a gap in the literature detailing real-time research staff experience, particularly in their own words, while conducting in-person patient recruitment in urban community health centers. This paper describes challenges faced at the clinic, staff, and patient levels, our lessons learned, and strategies implemented by research staff while recruiting predominantly low-income African-American women for an interviewer-administered survey study in four urban Federally Qualified Health Centers in New Jersey. Using a series of immersion-crystallization cycles, fieldnotes and research reflections written by recruiters, along with notes from team meetings during the study, were qualitatively analyzed. Clinic level barriers included: physical layout of clinic, very low or high patient census, limited private space, and long wait times for patients. Staff level barriers included: unengaged staff, overburdened staff, and provider and staff turnover. Patient level barriers included: disinterested patients, patient mistrust and concerns over confidentiality, no-shows or lack of patient time, and language barrier. We describe strategies used to overcome these barriers and provide recommendations for in-person recruitment of underserved populations into research studies. To help mitigate health disparities, disseminating recruiters' experiences, challenges, and effective strategies used will allow other researchers to build upon these experience in order to increase recruitment success of underserved and underrepresented minority populations into research studies.

Keywords: Recruitment ■ Health disparities ■ Underserved populations ■ Minorities

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http://dx.doi.org/10.1016/j.jnma.2017.06.011

INTRODUCTION

Underserved minority populations are disproportionately affected by higher rates of chronic diseases and worse health outcomes. Examples include the increased prevalence of obesity and diabetes in African-American and Hispanic adults,[1,2] the higher rates of hypertension and deaths from heart disease and stroke among African-Americans,[3] and the highest rates of late stage cancer and mortality for several cancers among African-Americans.[4] It is unclear if these racial disparities reflect unequal access to health care, including prevention, screening, diagnosis, and treatment of disease, or other factors.[5] To help understand and mitigate health disparities, it is important to conduct research with underserved and underrepresented minority populations under real world settings.

Federally Qualified Health Centers (FQHCs) are community health centers and programs that provide primary care and other medical services in low-income underserved urban and rural communities.[6–9] While there is an abundance of studies being conducted in FQHCs,[6–12] few publications detail the actual process of recruiting patients, particularly for interviewer-administered surveys. Previous papers have described recruitment of patients in rural community health centers (CHCs),[13–15] and recruitment of CHC patients remotely by mail or phone[16–18]; or, they focused on Latino populations,[17,18] or one aspect of recruitment, such as the informed consent process.[19] Furthermore, prior literature describes recruitment of patients into clinical trials,[13–18,20] which may be more difficult due to greater requirements and need for retention compared with observational survey studies. There is a gap in the literature detailing real-time research staff experience, particularly in their own words, while conducting in-person patient recruitment in urban community health centers.

This paper describes challenges faced, lessons learned, and strategies implemented by research staff while recruiting predominantly low-income African-American

women for an interviewer-administered survey at four urban FQHCs in New Jersey. Our experiences from this study provide practical strategies to aid other researchers recruiting underserved minorities for research studies.

MATERIALS AND METHODS

Study design, setting and participants

The patient surveys were part of a pilot study, conducted in 2013−2015, which tested a practice-based educational intervention in improving health professionals' beliefs, attitudes, and behaviors toward individuals with obesity.[21] Four urban FQHCs were chosen for the parent study because minority and poor or less educated women have high prevalence of obesity and may experience high rates of weight bias.[22−24] All centers were typical FQHCs in New Jersey that provide primary health care services, including adult medicine, gynecology, pediatrics, dental care, podiatry, nutrition, and social services. Each center treated 12,000 or more low-income underserved patients per year, and had greater than 40,000 patient visits per year. The centers were interested in improving care of patients with obesity in their clinics, and they received $1000 for participating.

A convenience sample of women with obesity was recruited to complete an interviewer-administered survey prior to the practice-based intervention, with a different sample recruited one year after the intervention. Details of the 50-item patient survey have been described elsewhere.[21] Briefly, the goal of the exit survey was to assess the impact of the practice-based education on the women's perception of weight stigmatizing situations in the practice, ratings of their physician's empathy, and receipt of cancer screening recommendations and counseling. The survey lasted approximately 30 minutes and also included questions from the Behavioral Risk Factor Surveillance System (BRFSS) survey asking demographic information and self-ratings of their physical and mental health.[25] We focused on women in the study because stigmatization and bias from obesity affect women more profoundly than men, who are much less likely than women to report weight discrimination.[24,26] Women were eligible to participate if they were 21-70 years old, had obesity (body mass index [BMI] $>$ 30 kg/m^2), were English speaking, and were established patients in the practice for over 12 months, with at least one other appointment at the center within the last 12 months. Exclusion criteria included pregnancy or history of breast or cervical cancer. All participants signed informed consent, and they received a $25 gift card at completion of the survey. The Rutgers-Robert Wood Johnson Medical School Institutional Review Board approved this study.

Recruitment protocol

Eleven different research assistants recruited and interviewed patients during the course of the 2-year study. All received standardized training regarding protection of human subjects via the online Collaborative Institutional Training Initiative course (https://www.citiprogram.org), recruitment procedures, informed consent, study confidentiality, and the interview protocol, including asking of questions without being leading or biased. Due to turnover in staff, the longer than anticipated time required to recruit participants, and the lack of funds needed to hire additional research personnel, we enlisted and trained part-time student interns to assist with recruitment. One to two (if there was a trainee present) research assistants worked at one time in each assigned health center. Occasionally, recruiters would move to another health center after completing their assignment.

Participants were recruited on site from Adult (Family or Internal) Medicine or Women's Health at each FQHC and interviewed immediately after their physician visit. Because we were interested in participants' experience with the physician and the clinic, we elected to conduct in-person recruitment at the time of the patient visit to minimize recall bias. The original protocol included having one main contact person at each clinic who served as the liaison between clinic staff and research staff, assisting with promotion of the study to clinic members, and determining scheduled times for the research staff to be on site. The initial recruitment protocol asked the nursing staff, after weighing patients, to give English speaking women with BMI $>$30 kg/m^2 a flyer and recruitment script, and to advise them that a research assistant would approach them after their physician visit to discuss the study in more detail. The recruitment script advised patients about the purpose of the study, the eligibility criteria, the incentive, and that the survey would ask about their experiences with the office and their physician. The recruiter was to approach the women in the examination room after the physician's visit, explain the study, confirm eligibility, review and obtain informed consent, assure confidentiality, and answer all questions before administering the survey. Because we were asking patients to rate their physician's empathy, we did not involve physicians in the recruitment process in order to minimize selection bias. The principal investigator and project manager coordinated with each clinic's administration to adapt recruitment procedures and schedules that worked best for their clinic with the least amount of disruption.

For this paper, we analyzed fieldnotes and research reflections written by the research assistants (RAs), along with notes from team meetings during the study. The