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Factors associated with participation in cancer prevention and control studies among rural Appalachian women

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Abstract

Rural Appalachian women bear a disproportionate burden from many types of cancer yet often are underrepresented in cancer research. This paper uses two case studies to illustrate barriers faced and strategies used when recruiting hard-to-reach rural participants. Recruitment barriers include the population's competing demands and lack of trust of outsiders. Strategies employed include involving insider advocates, highlighting the positive experiences of early participants, spending extensive time in the community, and emphasizing potential community benefits of the study. We suggest recruitment strategies to better involve rural women and others who, by virtue of being "hard-to reach," often are overlooked.

Keywords

research subject recruitment; rural health; women's health; Appalachian Region; early detection of cancer

Background

Relative to their cancer burden, traditionally underserved populations, including minorities, rural residents, and those with lower socioeconomic status, tend to be underrepresented in cancer prevention and control research. Many researchers attempting to address this burden have found traditionally underserved populations challenging to involve in studies and seek strategies to conduct more inclusive studies. A handful of such researchers have shared lessons they have learned, mostly from ethnic minority groups. For example, Rodriguez and colleagues¹ who focused on Latino families in a rural community found that word of mouth was the single most powerful tool in recruitment in this population. Other approaches, including using fliers and same sex messengers, also were found to be effective recruitment tools among rural Latinos.

Researchers face similar and multiple challenges when attempting to recruit rural participants, ranging from simple logistical considerations to more complex issues of ensuring cultural sensitivity². Rural communities are traditionally geographically dispersed, making many of its members difficult to contact, interview, or involve in a longitudinal study, and it can be difficult to gain the trust of more isolated, underserved people³. Strategies used to successfully navigate these challenges include establishing and using local

community advisory boards^{4,5}, gaining support for the project from community stakeholders, such as health professionals or others who hold positions of trust and have knowledge of community needs^{6,7}, having community members on the research team⁸, and providing desired services to the community⁹. Researchers who do work with underrepresented populations tend to provide very brief descriptions of helpful recruitment approaches, and tend to avoid discussing strategies that were not successful in encouraging research participation. To rectify these deficiencies, this paper provides two case studies that highlight the barriers and challenges faced when recruiting rural residents into research studies and strategies used to overcome these barriers.

Case Study 1

The first case involves a doctoral dissertation project that sought to understand how older women from rural Appalachia develop knowledge and beliefs about breast cancer across the life course and how this information shapes their use of cancer screening. Recruitment and follow-up of participants for the study began in 2006 and continued through 2008. All data collection and analysis activities have been completed.

The Appalachian county selected was identified by the Appalachian Regional Commission (ARC) as “distressed” ¹⁰, with high poverty rates, low per capita income, and low education levels (for example, 41.5% not graduating from high school) ¹¹. Additionally, breast cancer mortality was twice as high in this rural county¹² compared to the state rates which suggests that women do not get screened or receive care as expeditiously as other women, and may be considered hard to reach.

Being seen as an “outsider,” and therefore “untrustworthy,” was a frequent barrier to recruitment³. We used several approaches to reduce these labels. One approach involved partnering with study advocates from the county, such as the Senior Citizen’s Center director, leaders of women’s groups, and other trusted individuals. Further, we became known faces in the community by attending community events, eating at local restaurants, and spending an extensive amount of time in the area. Establishing a presence in the community required a much larger time commitment than originally anticipated, especially prior to beginning study recruitment. Finally, we relied on previous participants who believed in and enjoyed taking part in the study to paint the project in a positive light and to facilitate future recruitment.

Participants were actively recruited from two sources in order to reach women with varied cancer screening histories, including never, rarely, and routinely screened. The local Senior Citizen’s Center director aided in the initial recruitment. With her high status in the community and her life-long residence in the county, she provided us with legitimacy and credibility. To diversify recruitment opportunities beyond the Senior Citizen’s Center, the director encouraged us to visit additional venues where older women might be present; following her recommendation, we attended Commodities Day (a food give-away program), low-income housing meetings, and other community events. By meeting potential participants in person at a community event rather than recruiting by mail or phone, we were able to explain the study to potential participants, answer their questions, and begin to establish trust in the community. Snowball sampling was employed to recruit additional women.

Although the extensive time commitment (three to four one to two hour long sessions) may have discouraged women from enrolling in the project, attrition was not a problem. All women completed the protocol. Successful strategies used to retain participants included scheduling future interviews at the end of each session, arranging follow-up meetings soon after the last meeting, and using reminder phone calls one day prior to the appointment. We

also provided attractive, though not extravagant, incentives to participants. Each woman received a homemade fruit basket at the beginning of each session, providing a personal touch that went beyond an impersonal monetary incentive to participation. In general, the women in the study reportedly enjoyed participating, felt comfortable with the researcher, and looked forward to future meetings. Many participants expressed a wish for more women in their community to have their voices heard and to paint a more accurate picture of women's health in Appalachia than what is typically portrayed. In the end, fifteen women were interviewed for approximately six hours across multiple sessions.

Despite success in recruiting some participants, such as those who had received mammography within guidelines, recruiting others, notably those out of compliance, proved to be very challenging. Rarely or never screened women were difficult to find and were less likely to be engaged in the conventional medical system. Furthermore, such women were less likely to avail themselves to the natural social network of other women; our fieldwork indicated that those who received mammograms seldom knew other women in the area who did not undergo screening. Initial recruitment through Senior Citizen's Center attendees yielded little success for such women. Expanding our efforts by recruiting from Commodities Day and other community events allowed us to reach underserved women and expand the network through snowball sampling. Surprisingly, most of the women at these community events targeting disadvantaged populations had been screened within the breast cancer screening guidelines. Perhaps these participants were already part of a system of support in the community or had the ability to travel to the event (either by driving, walking, or having family or friends transport them).

The upward mobility of recommendations when using snowball sampling was an unexpected challenge. In other words, most women recommended speaking with someone who was of a higher socioeconomic status than themselves, leading us to talk with better resourced women. Additionally, other women declined participation, feeling that cancer was something too scary to discuss. The immediate and overwhelming negative emotional response to the word cancer was most commonly experienced when the woman had a close friend or family member with a current or recent cancer experience. Unfortunately, the voices of the never screened women were not adequately captured in this study, despite using multiple recruiting strategies and actively recruiting lower income participants.

Case Study 2

Faith Moves Mountains (FMM) is a community-based participatory intervention designed to reduce the disproportionate burden of cervical cancer among Appalachian women by increasing Pap test use. Initiated in 2004, FMM has partnered with 30 churches in rural, Appalachian Kentucky through which most participants have been recruited. The four counties in which FMM operates are rural and considered economically distressed¹³. FMM involves a multi-phase process of educational programming and tailored lay health counseling. Currently, we have completed all activities aside from evaluation.

Our sample consists of approximately 430 Kentucky Appalachian women who have not received a Pap test according to standard guidelines¹⁴. One-third of the participants have not obtained a Pap test for over five years, precipitously increasing their chances of being diagnosed with invasive cervical cancer¹⁵. Given their geographic isolation, low socioeconomic status, and overall challenging life circumstances, participants are frequently labeled "hard to reach."

We found that the same issues that stymie optimal preventive care challenge participant recruitment. Such constraints include competing time demands (i.e., child care, elder care, and work schedule make it difficult to take time for interviews), mistrust and fear,

geographical distance, and lack of resources (i.e., transportation and telephone) 16. Many women seldom leave the county in which they reside and many have not been to a physician's office for decades¹⁷. Our 18 month development work suggested that recruiting through the churches, a local and trusted institution, would allow us to reach eligible women.

Our first challenge focused on recruiting churches. Through varied means (using utility listings, monitoring Easter time church listings in local newspapers, reviewing lists with clergy, etc.), we developed a comprehensive list of churches in the focal counties, and mailed invitations to randomly selected churches. Several problems emerged. First, the invitations brought little response. Most churches in the region lack the resources to have a staff member to open mail, let alone commit to an unfamiliar project. Large congregations function as a safety net and are reluctant to participate in yet another project. The few churches that did respond affirmatively likely would differ dramatically from a more typical church. Second, congregations in the region splinter, close down, consolidate, and crop up anew. Although our list was as comprehensive as possible, our sampling efforts could not adequately account for the dynamic world of rural, community churches. Finally, randomly selecting churches made little sense without understanding the geographical and social context. For example, two churches appeared on our first randomized list, one to control and one to experiment; however, we realized that these were sister churches, with joint Bible studies, a shared pastor, cooperation on special events, and overlapping membership. Our church recruitment strategy changed from a randomized design to a more feasible and internally valid quasi-experimental design using a convenience sample that closely approximated the regional distribution of religious denominations.

Forsaking passive approaches like mail recruitment, we pursued a "pavement hitting" approach. We spent extensive time knocking on doors, calling on the minister or his wife, and getting the word out about the project. In addition to attending many church services, Bible studies, and meetings, our community staff participated in volunteer efforts (food or clothing giveaways), church fundraisers, and county festivals. Participant recruitment approaches were also modified. Initially, we had anticipated that each congregation would supply us with a roster of age-eligible women, and that we would randomly select women, contact them, and, if eligible to participate, twelve women would be recruited from each congregation. Several circumstances complicated this plan, including; (1) many churches are not comfortable providing membership rosters and most are especially uncomfortable estimating women's ages; (2) many frequent attendees are actually not church members and thus not on the roster; (3) a special invitation made to only selected individuals to participate in a cancer-related project was deemed as frightening, and some churches have too few members to provide twelve participants while others have many women who are not only eligible but really wanted to be included.

Our revised recruitment protocol was more consistent with cultural norms of inclusivity, politeness, and food sharing. We invited anyone interested in learning more about cancer to join us at an educational luncheon. The minister, his wife, the leader of the women's groups or health ministry (if they existed) introduced our project staff from the pulpit and advocated for this educational luncheon. Our staff members generally connected with a church "cheerleader." The luncheon was deemed a non-threatening, social, enjoyable meeting with friends and neighbors rather than stigmatizing. We assessed eligibility and undertook our informed consent and baseline interview procedures prior to the educational activities, and the educational luncheon was open to all—men, women, young, and old. As is fairly typical in rural communities, the word of mouth about our friendly staff, good programming, and great food encouraged churches and eligible women to join us.

We soon learned, however, that although church involvement is fairly common in Kentucky Appalachia¹⁸, we were overlooking key sectors by limiting our work to the four walls of established churches. Indeed, some of the hardest to reach women felt stigmatized by churches or otherwise were uncomfortable in formal church settings. We recruited these women through church outreach efforts, like Bible studies at the housing project, church food giveaways, and church-sponsored facilities, including day cares and nursing homes where employees might fall behind on Pap tests.

We also gained access to hard to reach women by confronting our incorrect assumptions. For example, although lower income women are more likely to lack current Pap tests, since nearly one-third of eligible women age 50 + in the region are out of compliance¹⁹, even women from affluent congregations were eligible to participate in our project. Additionally, although we anticipated that religiously conservative congregations would be reluctant to participate in a project involving discussion of sexual organs, many of these denominations felt particularly passionate about their involvement since their members tend to be close knit and disproportionately affected by cervical cancer.

Another important element to our success in accessing hard to reach rural women involved heavily investing in local residents. Having our logo designed by a local graphic artist, using the local print shop for our tee-shirts and letterhead, employing county residents for IT, transcription, catering, and most other goods and services helped to infuse the community with our project. Additionally, careful selection of our project leadership was a key element in recruitment and retention efforts. Rather than selecting our project manager on irrelevant but standard employment criteria (e.g., having a college degree), our selection was based on the recommendations of trusted local colleagues, her social standing in the community, and other characteristics that must be assessed subjectively (trustworthiness, judgment, persistence).

At 7%, attrition rates for FMM have been low. We speculate that the same factors that encourage a high enrollment rate account for the high retention rate. These factors include flexibility with all the recruitment process, modification of existing protocols to account for local circumstances, inclusivity with initial recruitment, extensive face to face contact by local residents, liberal use of local talent, and careful selection of key project leadership.

Discussion

Two key challenges in health research are to identify those groups at elevated risk, generally referred to as the “hard to reach” populations, and to devise culturally appropriate strategies to recruit and retain rural participants in research studies². The two case studies presented in this paper demonstrate certain overlapping as well as specific distinctive strategies that can be used to deal with barriers to recruitment and retention of rural participants in research studies. Both case studies found that partnering with trusted community insiders and researcher(s), and becoming known in the community play essential roles in overcoming the trust barrier. While partnering with community insiders is not new, the combination of investing in local talents, researcher involvement in volunteer activities in the community, and hiring a project manager based on subjective attributes was novel and helpful. In addition, both case studies highlight the importance of personal attention to recruitment rather than more passive strategies, such as mailed invitations or handing out fliers. One of the most successful strategies in both cases was “hitting the pavement” or visiting potential participants, whether churches or individuals, and explaining the study in person. Abandoning the more traditional way of recruitment and introducing these studies in this novel way allowed both studies to gain critical early entry into the insiders circle in these communities.

Recommendations

Traditionally, a larger time commitment will be needed when working with hard to reach populations. The first case study demonstrates the need to take time to establish a presence in the community, especially on the front end of the project, in order for the project to be successful. Not all recruitment will be successful as originally planned and barriers will commonly arise. There is a need to be flexible and creative in the recruitment and retention processes, especially when working with hard to reach populations. However, it is essential to work with the sponsor/research funder before any changes in protocol occur.

These case studies also highlight the utility of partnerships among community members, public health and social service professionals, and researchers. As the first case study demonstrates, without the advocacy of a well respected member of the community who also served in a position of visibility and power as the Senior Citizen's Center director, the researcher, a young graduate student from outside the region, would have lacked the credibility needed to recruit participants. At the same time, the graduate student's presentation of an information session on breast cancer proved to be advantageous to the Senior Citizen's Center director, as these centers are mandated to conduct educational sessions. Enrollment of women rarely screened for cervical cancer was enhanced by partnering with the Kentucky Homeplace Project, a medical case management program. At the same time, community members consistently described their participation in the program as very positive. Additionally, Faith Moves Mountains was beneficial to public health providers by increasing referrals of women seeking a Pap test. Indeed, the local health departments saw an upsurge in the use of the CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP). Since federal guidelines for inclusion in this program requires participants to be uninsured or underinsured, with incomes at or below 250% of the federal poverty level, such an upsurge occurred among traditionally hard to reach women. Among other approaches, flexibility, mutually beneficial programming, and the passion to pursue those at greatest risk get us closer to involving those who most warrant research attention.

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