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Two Case Examples of Reaching the Hard-to-Reach: Low Income Minority and LGBT Individuals

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ABSTRACT

‘Hard-to-reach’ is a term primarily used by researchers to describe groups of people who have been historically difficult to find or contact. It is important for the public interest to include hard-to-reach groups in research because excluding certain sub-populations diminishes the ability to identify groups that potentially have the highest burden of illness and to develop an understanding of why group differences exist. Thus, the purposes of this paper are to: 1) describe the challenges in recruiting hard-to-reach population in two separate research studies; 2) discuss the strategies that were used to overcome those challenges; and 3) provide recommendations for researchers. This paper followed a case study research strategy, with the authors using two of their own research studies involving hard-to-reach populations as case studies. The research studies used in these case studies involved two different hard-to-reach groups—low-income ethnic minorities who were un- or under-insured and lesbian or bisexual women and transgender men. Two overarching themes were identified as barriers to reaching the population of interest: (1) *gaining interest* and (2) *building trust*. These themes add to the literature regarding the multi-prong approach that is needed to recruit members of hard-to-reach populations. Despite the authors having buy-in from stakeholders and a multi-prong recruiting approach, barriers to gaining the interest of potential participants included language in recruitment flyers, competing demands for time, and transportation to the data collection site. Building trust with interested study participants was also a large issue noted between both studies, especially concerning sensitive questions or cultural barriers regardless of the reliability and validity of the tools used in the study.

INTRODUCTION

‘Hard-to-reach’ is a term primarily used by researchers to describe groups of people who have been historically difficult to find or contact due to geographical location, social and economic situations, concealment of identity due to fear, social pressure, stigma, or social invisibility, among other reasons (Faugier & Sargeant, 1997; Shaghghi, Bhopal, & Sheikh,

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2011). Although there is not just one definition of the term, hard-to-reach typically refers to populations that are underserved, hidden (people who do not wish to be found or contacted), or belonging to a minority group (Brackertz, 2007). For the purposes of this paper, hard-to-reach will refer to populations that have been traditionally difficult for researchers to access and include in studies (Sydor, 2013).

People who belong to a hard-to-reach population are likely underrepresented in research studies (Bonevski et al., 2014; Egleston, Dunbrack, & Hall, 2010; Fisher & Kalbaugh, 2011). It is important for public interest to include hard-to-reach groups in research because not including certain subpopulations in research diminishes the ability to develop an understanding of why group differences exist. Moreover, not including hard-to-reach groups poses threats to the external validity and generalizability of research findings (Bonevski et al., 2014). People who belong to a hard-to-reach population tend to be the most socially and economically disadvantaged and could arguably benefit from being included in research. Moreover, gaining a deeper understanding of them through research is imperative to developing effective health and medical programs and interventions.

The term hard-to-reach implies that the only barrier to recruiting the population is reaching or accessing them. Researchers know that is not the case though. After reaching the hard-to-reach, researchers often encounter challenges in recruiting and retaining participants (Shaghghi et al., 2011). In a systematic review of research including hard-to-reach populations, Bonevski and colleagues (2014) identified numerous barriers to recruiting and gaining consent of participants, including mistrust, perceiving that the research presented no benefit to them or their community, fear of being publicly exposed, cultural beliefs prohibiting participation, and low literacy levels. Other research (Wendler et al., 2006) suggests that minority populations are equally inclined to participate in research but characteristics of the individual research study affect the willingness of the participants. Regardless of the reasons, recruiting and retaining members of a hard-to-reach population is clearly more challenging than just accessing a group. This paper will focus on describing the challenges of successfully recruiting participants after accessing a hard-to-reach group.

Successful recruitment is dependent on the research context and design but is usually defined as a study achieving a sample size and obtaining data that is sufficient to yield statistical power so that inferences can be made about the study population. However, when researchers fail to achieve the projected sample size or have missing data points, the data has not lost all meaning and is usually still useful. There are still ways to meaningfully interpret and report the findings from an underpowered study (Maxwell, Kelley, & Rausch, 2008). The two research case studies used in this paper did not obtain the original estimated sample sizes; however, both had enough subjects and data to conduct statistical analyses and to make important contributions to the scientific literature.

The authors of this paper each conducted a research study with a hard-to-reach group, including low-income ethnic minorities who were un- or under-insured and lesbian or bisexual women and transgender men. Each author was able to access their respective population but encountered numerous challenges in recruiting participants and in collecting all of the necessary data necessary. Thus, the purposes of this paper are to: 1) describe the challenges in recruiting

hard-to-each population in two separate research studies; 2) discuss the strategies that were used to overcome those challenges; and 3) provide recommendations for researchers.

METHODS

This paper used case study as a research strategy. The authors used two of their own research studies involving hard-to-reach populations as case studies for this paper (Gatlin, 2016; Johnson, Mueller, Eliason, Stuart, & Nemeth, 2016). Using a case study strategy was appropriate because of the complex nature of recruiting hard-to-reach populations. To accomplish this case study paper, the two authors conceptualized the project, discussed and wrote out the specifics of each study, identified the barriers and successful strategies for recruitment of each study, and then triangulated the findings to develop overarching themes and sub-themes.

The first research case study (Gatlin, 2016) was a cross-sectional work examining the relationship among severity of type 2 diabetes, working memory, executive function, and diabetes self-care in middle- and older-age adults at a Federally Qualified Healthcare Center (FQHC). The FQHC primarily served under- or un-insured ethnic minorities in a major metropolitan area. Study subjects reported to the FQHC clinic to test their blood glucose level and to complete a variety of questionnaires. The second research case study (Johnson et al., 2016) was mixed-methods and aimed to determine factors that influenced participation in cervical cancer screening behaviors of lesbian and bisexual women and transgender men (hereon referred to as LGBT people). Quantitative data were collected via an anonymous internet survey and qualitative data were collected via in-depth semi-structured telephone interviews.

Accessing and Recruitment for Case #1

The principal investigator (PI) gained access to a busy FQHC in a metropolitan area to recruit participants (goal sample size $N = 100$). A recruitment flyer was posted around the clinic, in each exam room, and at the check-out reception desk. Additionally, the clinic healthcare providers agreed to inform their patients about the research study. The PI went to the clinic once a week for eight hours to talk to interested patients. Participants were compensated with a \$20 gift card for their time. The recruitment flyer included information about the study's purpose and procedures, inclusion criteria, time requirements, incentive for participating, and the PI's contact information.

By month 12 of the study, recruitment efforts yielded 25 participants. To increase enrollment in the study, IRB approved changes included mailing out the recruitment flyer to over 500 clients in the clinic's database and distributing them at health fairs. Additionally, the PI increased clinic time to two eight-hour days every week. These additional recruitment strategies had only yielded 10 additional subjects, and thus the PI and clinic modified the approach again at the 20-month and 22-month marks. At the 20-month mark, the PI started calling potential participants to set up appointments to talk to them before or after their next clinic appointment (enrollment increased from 36 to 49 during month 20 and 21). At the 22-month mark until the end of the study, the PI went to the clinic every day during the week (increase in enrollment from 50 to 72). The PI finished collecting data at month 26 of the study and had a sample size of 72, which is 72% of the original sample size.

Accessing and Recruitment for Case #2

Accessing and recruiting LGBT people involved an extensive three-pronged approach, including internet-based, community-based, and snowball approaches. The community-based approach involved the PI attending LGBT pride events in the southwest United States and distributing flyers. The internet-based approach involved the PI identifying and contacting over 300 LGBT groups and centers and numerous LGBT internet publications across the United States. The groups consisted of university student groups, online social groups (i.e., Facebook.com and Meetup.com), and LGBT email groups (i.e., listservs). The centers consisted mostly of LGBT community centers. The PI emailed the gatekeeper(s) for all of the groups and centers and requested that they disseminate a recruitment flyer to its LGBT members. A majority of the gatekeepers reported disseminating the recruitment flyer to its members. However, these approaches yielded only about 180 respondents, which was only 50% of target sample; therefore, the PI supplemented the recruitment strategy by purchasing advertising space on a few popular LGBT dating and social websites. The advertisements on the dating and social websites resulted in 80 more respondents, bringing the final sample to 260. However, the sample size for analysis was 226. The difference between the actual and analysis sample sizes was due to large amounts of missing data. To be included in the study, the respondent had to have less than 10% of missing data.

The recruitment flyers contained images and words that were culturally sensitive to LGBT people. The flyer directed people to visit the study's website, which was also designed to be culturally sensitive. The website included details about the study, information about the PI, including his reasons for conducting the study, a direct link to the online survey, and a contact form for those people interested in participating in a qualitative telephone interview. The website also encouraged people to share this study with other LGBT people in their networks. Those participants who completed the online survey could enter their name into a raffle to win a \$100 gift card, and those who completed an in-depth telephone interview were compensated with a \$20 online retail gift card for their time.

RESULTS

Through open discussions between the two authors regarding the challenges of reaching their hard-to-reach populations, two overarching themes were identified—*gaining interest* and *building trust*. These themes represent the multi-prong approach that is needed to recruit members of hard-to-reach populations. The remainder of the results section will elaborate on these two themes.

Gaining Interest

After receiving approval and support of stakeholders to recruit participants, one of the first major challenges that a researcher will presumably encounter is garnering interest for the study. The authors identified four interrelated barriers, or sub-themes, to gaining the interest of potential study participants, including passive recruitment flyers, difficulty conveying value, lack of transportation, and time constraints. While lack of transportation and time constraints could be considered logistical issues, these barriers affected interest and participation in the studies.

Researchers routinely use flyers or similar advertisements to garner the interest of potential participants. This approach tends to be the most common because it is well accepted by Institutional Review Boards (IRB) and is inexpensive. However, the authors found that flyers

were largely ineffective at recruiting their hard-to-reach populations. Despite the high visibility of the flyer in the FQHC clinic study and despite a sizeable number of group stakeholders disseminating the flyer to their members in the LGBT study, enrollment numbers remained low. The authors posit that the low enrollment yield was due to the passive recruitment flyers, which were ineffective at capturing the attention of the hard-to-reach members. Designing a recruitment flyer that is eye-catching and suitably informative yet succinct can be challenging.

Conveying the value of a study to potential participants is crucial to recruitment, yet this aspect of gaining interest is difficult to accomplish. This theme overlaps with the last one because the value of a study is first communicated through the recruitment flyer. However, it is distinct because the value of a research study can also be conveyed through personal or electronic communication. Both of the authors sensed that they were not effectively conveying the value of their studies on recruitment flyers. Although both authors did notice an improvement in enrollment after they started using personal and electronic communication, they both encountered people that still did not find value in the study.

Time constraints proved to be another challenge in gaining the interest of potential participants. Researchers have the task of trying to garner the interest of potential participants and persuading them to allocate time in their day to volunteer for a research study. This challenge was a challenge for both the FQHC and LGBT studies. The FQHC study required participants to be on-site at the clinic for two hours. The LGBT study had a qualitative component that required participants to devote at least 30 minutes for the telephone interview. Each of the PIs encountered potential participants who were unwilling to enroll in the study because of perceived time constraints.

Lastly, many participants lacked transportation, which posed serious challenges with recruiting participants for the FQHC study that required face-to-face participation. Although lack of transportation could be considered a logistical issue, it was also clearly a barrier to gaining the interest of potential participants. The PI tried to identify solutions, such as public transportation; however, the potential subjects were still reluctant to volunteer.

Building Trust

After research teams successfully garner the interest of potential participants from hard-to-reach populations, they need to build trust to strengthen the likelihood that the potential participants will enroll in and complete the study. This area is presumably one of the most challenging parts of effectively recruiting members from hard-to-reach populations. The authors identified three major challenges, or sub-themes, to recruiting participants in their own studies, including cultural sensitivity, cultural appropriate instruments, and collection of necessary data.

Researchers who conduct studies with hard-to-reach populations presumably design them with the intention of being culturally sensitive. The authors of this paper referred to literature and consulted with other experts about culturally sensitive recruitment strategies, yet they still encountered problems that jeopardized the trust of some potential and enrolled participants. For example, the research team for the LGBT study mistakenly used a word on the recruitment flyer that confused transgender people about their ability to participate. The research team did not become aware of the mistake until months later when a transgender person called to inquire about the study and told the PI that some of the wording on the recruitment flyer was confusing and potentially insensitive to some people.

Selecting reliable, valid, and widely accepted instruments is integral for many study designs, yet researchers may overlook the fit between the instrument and the target population. For example, the research team for the FQHC study utilized the reliable, valid, and widely used Center for Epidemiologic Studies Depression Scale (CESD), but quickly realized that some of their participants did not understand certain items on the instrument. This was especially true for participants who did not speak English as a first language. For example, one of the items on the instrument used the word “blue” to mean sad or depressed; participants who were not familiar with the cultural context of the word “blue” in the English language thought the word was referring to the color.

Similar to selecting a culturally sensitive instrument, researchers may not recognize that collecting certain data could potentially threaten the trust of study participants. Participants who belong to a stigmatized or marginalized group might be wary of disclosing certain information. For example, the research team for the FQHC study asked participants about their annual income. Many of the participants, who were presumably low-income since they were using an FQHC clinic, were reluctant to provide information about their income. Upon further investigation, the researcher discovered that some participants were afraid of losing benefits from the clinic if they shared their income. Similarly, the research team for the LGBT study found a trend in the incomplete surveys; nearly all of the incomplete surveys stopped at a question that asked about the number of lifetime sexual partners. One possible reason the participants could have chosen not to answer the questions is that it may have been too intrusive. In both studies, the PIs recognized afterward that these questions were not essential to the specific aims of the research studies.

DISCUSSION

Many researchers assume that underserved or vulnerable populations are hard-to-reach; however, are they hard to reach because they are unwilling or because researchers do not know how to reach them? Reaching a population of interest requires researchers to consider the opportunity to participate; gaining interest and building trust is essential. Recruiting in environments known to have high numbers of participants with the characteristics of interest can still yield low sample sizes if the researcher does not consider how to effectively garner the interest and build trust. The remainder of this section will offer recommendations to other researchers on how to gain interest and build trust with hard-to-reach populations.

Gaining Interest

Although posting study flyers is presumably one of the oldest and simplest methods for recruiting participants, it is not always effective or efficient. As compared to proactive recruitment strategies (e.g., physical presence of a staff member at the recruitment site), flyers can be up to 10 times more expensive in terms of staff time and materials because they yield the fewest subjects (Graham, Lopez-Class, Mueller, Mota, & Mandelblatt, 2011). Researchers should consider more proactive face-to-face or creative recruitment approaches, such as social networks, research portals, or snowball sampling (Graham et al., 2011; Nolte, Shauver, & Chung, 2015). Additionally, since public and social events are convenient ways to reach vulnerable populations, researchers could ask potential participants to provide contact information and then follow-up with them.

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If researchers decide to create print or electronic recruitment advertisements, they should include non-offensive images that are germane to the population (King, O'Rourke, & DeLongis, 2014). Although not always feasible, creating personalized and targeted letters may be more effective at recruiting participants than generic flyers (Yancey, Ortega, & Kumanyika, 2006). Moreover, researchers attempting to gain trust of hard to reach populations must actively seek and be receptive to feedback from the community members and research participants as to how to best create a safe and welcoming study environment.

Although the recruitment approach and study advertisements/flyers are important to conveying interest to potential participants, researchers could also use cultural brokers. Cultural brokers, which have existed in health care research for a few decades (Jezewski, 1995), can be used when there are language or other cultural barriers between the researcher and the target research population. The cultural broker may be an effective link between the researcher and potential participants.

Although neither author of this paper used a cultural broker in their study, they can be an effective recruitment strategy. The cultural broker should be a person who is in the community where researchers hope to recruit participants. The person should ideally be someone who regularly engages with the community (Lawson et al., 2015). Since researchers usually have a limited amount of time that they can spend in the community, cultural brokers can maintain a presence in the community and quickly disseminate information and answer questions. The cultural broker should be identified during the research development phase and should be part of the research team (Lawson et al., 2015; National Center for Cultural Competence, 2004). Cultural brokers can be anyone who mediates a relationship between the researchers and the community. For example, Cadzow and colleagues (2013) trained 13 people in their study to be diabetes cultural health brokers who were then able to reach and have conversations with over 700 community members over three months.

Lack of transportation to the data collection site can be a barrier to recruiting participants, especially for those individuals with limited financial resources. Researchers should consider the cost and ease of transportation and parking conditions. Odierna and colleagues (2014) found that participants were more willing to participate in a research study if the data collection site was nearby their residence, convenient to access, and had affordable and easy parking. They also found that public transportation or personal access to a vehicle was most helpful.

Although research funding dollars are becoming scarcer, researchers should not underestimate the importance of transportation and should have several different options for reimbursement. For example, researchers could arrange for free parking at the data collection site, provide gas station gift cards, or offer passes for public buses or gift certificates for an online transportation network (e.g., Uber and Lyft). Additionally, researchers should be flexible (if possible) with the data collection day and time (Odierna & Bero, 2014). For example, if the study is being conducted at a health care facility/clinic, the researchers should try to accommodate the participants on a day he/she is there for a medical appointment.

It is important for researchers to be mindful and understanding of the time constraints faced by potential participants. To help potential participants plan their schedule, it would be helpful to specify the time requirement to complete the study on the recruitment advertisements. It is also important to remind the potential participants about the time requirements during the

informed consent process, and to verify whether the appointment time (if applicable) is still convenient. For online data collection methods, researchers should include a status bar that continuously displays how much time is remaining before completion. Additionally, including factoids on internet surveys can be useful for preserving the attention and interest of the participant (King et al., 2014).

Building Trust

Missing data has been widely discussed and debated in literature; although missing data is not unique to hard-to-reach populations, it is important to discuss this in the context of building trust among vulnerable groups. If the researchers determine that the missing data is not ignorable (intentionally skipping a question) (Allison, 2002), they should consider if the question(s) were sensitive or offensive to the population. If the researchers catch the problem with missing data early in the study, then can quickly amend the survey. Otherwise, they will need to determine the best approach to handle the missing data. If the researcher intentionally includes a sensitive question in the survey that is important to the aim of the study, they should consider either adding an alternative option (e.g., “I would rather not say”) or rewording the question.

Similarly, researchers should scrutinize each question on the survey to determine if the results of that item will be pertinent to the study. Although demographic data can help to identify how close a sample replicates the known population and allow for analysis of sub-groups, some questions may be sensitive to the respondent, such as education, employment, or salary. If certain relationships have already been established (e.g., higher education is correlated with self-management of health), the researcher should strongly consider the necessity of sensitive questions, and perhaps work with a cultural broker to develop such questions. The goal is to gain as much information from the population of interest to answer the research questions.

The reliability and validity of an instrument is another topic that has been widely discussed and debated in literature (Carmines & Zeller, 1979; DeVon et al., 2007). Although researchers are usually attentive to the psychometric properties of an instrument, they may not consider how cultural nuances and connotations can affect meaning and quality beyond obvious language issues (Centers for Disease Control and Prevention, 2014). Unfortunately, most widely used instruments have only been normed with a dominant cultural group, and thus are not always appropriate for other cultures. To revise or develop a survey for a diverse population, researchers could use cognitive interviews or a similar qualitative approach (Napoles-Springer, Santoyo-Olsson, O'Brien, & Stewart, 2006; Ramirez, Ford, Stewart, & Teresi, 2005; Ridolfo & Schoua-Glusberg, 2011; Willis, 1999).

Conducting cognitive interview studies is the preferred method for developing or adapting surveys for vulnerable and diverse populations. However, instruments likely undergo a surface structure adaptation or adaptations that match superficial characteristics of the target population. To be culturally sensitive, they should undergo a deep structural adaptation, which are those that address core cultural values or those ethnic, cultural, historical, social or environmental factors that may influence specific health behaviors (Nierkens et al., 2013). To achieve deep structure adaptations, researchers should consider using cultural brokers during the planning, development, and implementation phases of cognitive interviews.

Community-based participatory research (CBPR) has emerged in the past decades as an approach to reach vulnerable populations and reduce health disparities (Wallerstein & Duran, 2006). The CBPR approach can be an effective solution to partnering with and reaching populations who have been historically difficult to engage (Horowitz, Brenner, Lachapelle, Amara, & Arniella, 2009). Although the authors of this paper partnered with organizations and agencies in their studies and ultimately reached successful sample sizes, they did not use a CBPR approach. Given the effectiveness of CPBR in developing trust with vulnerable populations, using a CBPR approach could accelerate the development of trust between researchers and participants.

CONCLUSION

Including hard-to-reach groups in research is imperative to understanding group differences and to developing effective health programs and interventions. However, recruiting members of a hard-to-reach group is much more challenging than just acquiring access to a facility or community. Researchers need to utilize various approaches to gain the interest of and build trust with potential and enrolled participants. While designing these recruitment approaches, researchers should consider the impact that study advertisements and research team members have on potential participants. Moreover, researchers should scrutinize their own studies to ensure the recruitment and data collection approaches are culturally sensitive for the target population.

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