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Overcoming Recruitment Challenges: A Pilot Study in Arab Americans

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ABSTRACT

While diabetes prevalence and cardiovascular risk factors have been increasing among Arab populations worldwide, few studies of Arab Americans have been conducted because of the difficulty in recruiting Arab American participants. Cultural sensitivity and social awareness of different immigrant groups could ensure successful recruitment and retention in clinical studies. While the primary objective of our overall research project was to determine the prevalence of metabolic syndrome in Arab Americans, the focus of this article is to describe the methodology used to overcome challenges in recruiting and enrolling Arab Americans for a community-based study. We used novel methods, including open houses, religious-based venues, and engagement of community leaders, to encourage participation in this clinical and epidemiological study. A community-based approach involving community leaders and educators was useful in recruiting and encouraging participation in this study. As a result, we were able to collect clinical and anthropometric data from 136 Arab American men and women living in the Washington, DC, area and obtain information regarding their chronic diseases, mental health, and acculturation into U.S. culture and lifestyle. Our sampling methodology may serve as a model of a successful recruitment and enrollment strategy, and may assist other researchers to ensure sufficient power in future studies. Engagement of minority participants in

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clinical studies will enable the creation of targeted clinical intervention and prevention programs for underrepresented and understudied populations.

Keywords: Arab Americans; cardiovascular risk factors; community-based research; metabolic syndrome; racial/ethnic minorities; sample recruitment.

INTRODUCTION

Research has shown that populations which are the hardest to sample in a simple randomized fashion are often the same subgroups that face more health problems. Previous studies indicate that Arab Americans may be more susceptible to metabolic, cardiovascular, and mental health conditions compared with white non-Arab Americans and other minority groups (El-Sayed, Tracy, Scarborough, Galea, 2011).

The prevalence of cardiovascular disease, diabetes, and other cardiovascular risks has been increasing at varying rates among Arab populations worldwide. In 1990, cardiovascular disease (CVD) was the third most common cause of death among Arabs, and in 2010 it was the leading cause of death (International Diabetes Federation [IDF] Diabetes Atlas, n.d). Prevalence of diabetes in the Middle East and North Africa is expected to almost double by 2035 (IDF Diabetes Atlas). In addition, six Arab countries are among the top ten worldwide in diabetes prevalence. The prevalence of other cardiovascular risks is also high in this population (Laher, 2014). Although few studies of metabolic syndrome risk factors have been conducted among Arab Americans, the few existing data are alarming. Among Arab Americans in Dearborn, MI, diabetes prevalence was 15.5% (95% confidence interval, 12.2%-18.7%) in women and 20.1% (15.0%-25.2%) in men, and in a substantial proportion (47.8% of the women and 57.2% of the men) (Jaber et al., 2003), diabetes was undiagnosed. Arab Americans also had greater CVD mortality compared with non-Hispanic whites (30.8% vs. 28.4% in men, and 29.3% vs. 26.78% in women) (El-Sayed et al., 2011). In southern Michigan, it was reported that 40% of Arab American men and 38% of Arab American women had hypercholesterolemia (Hatahet, Khosla, Fungwa, 2002), and in southern California, it was reported that 45.9% of Arab American men and 23.2% of Arab American women had hypertension (Tailakh, Mentes, Morisky, Pike, Phillips, Evangelista, 2013). The gender differential favoring better cardiovascular health among women is consistent across these studies. In contrast, in a study of 321 Arab Americans surveyed in metropolitan Washington, DC, rates of diabetes (5.9%) were lower than national rates for other ethnic groups (Centers for Disease Control, 2014). In our analysis of Arab Americans in the DC area, self-reported prevalence of hypertension and hypercholesterolemia also were lower, 16.3% and 37.6%, respectively, but may have been biased by the use of convenience sampling (Shara, Carter, Abu-Bader, Deshields, Fokar, Howard, 2010).

The wide range of prevalence estimates for metabolic syndrome risk factors reported to date may reflect the diversity of the Arab American population. Arab people originate from 22 countries in North Africa and western Asia and are genetically and culturally diverse. This diversity may confer variable susceptibility for the development of diabetes, hypertension, and hyperlipidemia. In the United States, factors such as acculturation play a role in risk factor modification. Studies that have explored the effect of acculturation and sociological stress on Arab Americans have shown a non-uniform risk modification. In one study, acculturated participants with hypertension were more adherent to medications and physical activity and had better blood pressure control (Tailakh et al., 2014) than those who were less acculturated. However, in another study, more acculturated immigrants drank more alcohol than less

acculturated immigrants, suggesting that interactions with other factors may modify specific health behaviors (Jadalla & Lee, 2012).

The high prevalence of CVD risk factors among Arab Americans studied to date may have a substantial public health impact in the United States, especially because the Arab American population is increasing. According to the 2010 U.S. census, almost 1.7 million Arab Americans were living in the United States, up from 1.2 million in 2000 and 860,000 in 1990. A third of Arab Americans live in California, Michigan, and New York, with 94% living in large cities. Much of the data on Arab-American health comes from Michigan, which has the second largest population of Arab Americans, representing four distinct Arab groups: Lebanese, Iraqi/Chaldean, Palestinian/Jordanian, and Yemeni Americans (Jadalla & Lee, 2012). It is not clear whether the data from the Michigan population can be generalized to Arab Americans in other areas of the United States. Therefore, it is important to conduct research among diverse groups of Arab Americans and disaggregate data to accurately reflect risk and risk behavior. To this end, it is essential to engage diverse Arab communities in research, to consider unique barriers and challenges to conducting research, and to tailor research approaches accordingly.

Barriers to Recruitment

A number of sociological characteristics unique to Arab Americans make recruitment for research and addressing their health problems difficult. First, Arab Americans are a heterogeneous group which has not been represented adequately in research studies. Second, Arab Americans are considered “white” by the U.S. Census and many other national surveys (such as NHANES); therefore, data from population-level epidemiological studies do not provide information on Arab Americans and random nationwide phonebook sampling methods (Amer, 2014) cannot identify Arab Americans.

Recent study designs have used internet- and email-facilitated sampling methods, which have the benefit of recruiting participants from different geographical locations, but are prone to bias toward younger and technologically capable, and therefore, richer and more educated participants (Clay, 2011). Lastly, much like a number of other hard-to-sample populations, Arab Americans may have a tendency to distrust government entities or researchers (Ejiogu et al., 2011; Jaber, 2003). Specific to the Arab population is the negative post 9/11 socio-political effect that has led to reluctance to participating in studies (Amer & Hovey 2005; Clay, 2011; Jaber, 2003). Studies have shown that the 9/11 effect is related to negative health effects as well, so without carefully addressing this problem, a sample of health outcomes may be biased (El-Sayed & Galea, 2009). As such, extra effort is usually needed to stimulate recruitment and participation in this population. Convenience sampling is frequently used to maximize engagement at a community level. Effective convenience sampling involves building trust and connection through community leaders and figures and focusing on visibility and accessibility of the study in locations frequented by the population of interest. When appropriately calibrated to the subpopulation one is interested in capturing, convenience sampling is beneficial, as recruitment and retention can be improved compared with a lackluster ability to recruit and retain these populations using more random and systematic sampling methods.

Numerous articles have been written about recruitment in clinical studies, each offering the “best” approach (Beach et al., 2006; Brown et al., 2015; Brown, Lee, Schoffman, King, Crawley, Kiernan, 2012; Duda et al., 2011; Hussain-Gambles, Leese, Atkin, Brown, Mason, Tovey, 2004; Keyzer et al., 2005). In this study, we aimed for the highest level of

cultural sensitivity and used the “cycle-of-trust framework,” suggested by Getrich et al. (2013). The cycle of trust suggests using culturally sensitive methods during four stages to enhance recruitment and retention: 1) before initiation of the study, 2) during recruitment, 3) throughout the study, and 4) after study completion. The main drawback of convenience sampling is the risk of substantial homogeneity in the sample drawn. The sample will be sensitive to the demographic characteristics of the people who frequent the sampling locations and who are most connected to the investigative team or the community partners. The risk of excessive homogeneity can be avoided by selecting more varied sampling locations, although remedial measures must often be tailored to the specific population, location, and problem (Ejiogu et al., 2011). The other weakness of convenience sampling is the function between cost and statistical robustness. Representative and extensive convenience samples can be achieved but often require tremendous time and monetary resources to attain. Studies that have thoroughly engaged the community and were keyed into the cultural sensitivity of the population have had good recruitment and retention (Ejiogu et al., 2011; Jaber et al., 2004). Without such success in recruitment and retention, the sample may be biased.

METHODS

Design

In the current study, we adopted ways to use cultural sensitivity throughout the “cycle-of-trust” stages to maximize recruitment.

Before initiation of the study. In the metropolitan DC Arab American community, we learned that trust is best gained through the community leaders and educators. We engaged key stake-holders in determining ways to make the study feasible. Data were collected through a convenience sampling with the snowballing technique (Watters & Biernacki, 1989).

In preparation for the study visits, the research staff at Georgetown University searched the literature for culturally appropriate methods for conducting studies with Arab populations (Ahmad, 2004). In addition, one of the Arab American researchers trained the research staff in culturally appropriate approaches in this population, specifically issues related to Muslim women and their preference for being seen by a female study member and for being seen privately rather than in front of others.

During recruitment. To improve accessibility, community leaders and educators were asked to hold all-day clinics in their homes, church, mosque, and/or Arabic school. Clinical facilities were established in three private houses, owned by community members who volunteered to host clinics; one school, which agreed to have its employees participate in the study; and one church. Walk-in participants also were encouraged. The community leaders, educators, and clinic hosts invited guests to attend the clinics, and they encouraged guests to invite additional guests via email and bulletin board postings in their school, church, or mosque. In addition, walk-in clinic hours at MedStar Georgetown University Hospital, MedStar Union Memorial Hospital, MedStar Health Research Institute, and Howard University Hospital were available for participants. Participants also referred additional participants from their extended families and friends, thus forming the snowball recruitment strategy for this study (Handcock & Gile, 2011).

Throughout the study. At all study sites, we conducted the study in a culturally sensitive manner, ensuring privacy and language and gender concordance between participants and research personnel. Separate space was set up for women during anthropometric measurements and blood sampling. Female staff members conducted the visits with the women and in most cases offered a private area for the women to participate.

Translators were available to help participants when obtaining informed consent and to assist with questionnaires.

At the completion of the study. Participants were given a letter with the results of their blood work. When cardiovascular risks such as high blood pressure were identified during the visit, the reading was recorded and the participant was counseled regarding appropriate follow up. This procedure ensured that the community understood that their test results mattered and that the information obtained benefitted them. This study was approved by the institutional review board. Data used for the analyses were de-identified.

Measures

Survey, laboratory, clinical, and anthropometric data were collected from the participants. To determine the efficacy of the sampling, sociodemographic information including income, education, country of origin, and religion was recorded. Frequencies and proportions were calculated using R 3.1 (R Core Team, 2014). Data collected for the subsequent health analysis included information about physical activity and sedentary behaviors, food and nutrition choices, disease prevention, smoking history, alcohol use, health locus of control (Wallston, Wallston, Kaplan, Maides, 1976), depression (Radloff, 1977), stress, medical history, and access to health care. Sociodemographic information, health behaviors, and access to health care were all self-reported, while medical history was self-reported and participants were asked if they had ever been diagnosed with a cardiovascular or metabolic condition. Health locus of control was captured using the Multi-Dimensional Health Locus of Control (MHLC), an 18-question inventory used to assess participants' degree of belief in control of their own health, which has been applied to numerous studies of Arabs with good reliability (Afifi, 2007; Clay, 2011; Cohen & Azaiza, 2007; Zawawi & Hamaideh, 2009). Depression was measured using the Center of Epidemiological Studies-Depression (CES-D) scale, a 20-question survey used to assess clinical depression that has proven reliability for Arab American respondents (Amer, Awad, Hovey, 2012). The physical exam included measures of height, weight, waist circumference, and blood pressure. A fasting blood sample was collected to measure glucose and lipids, and urine was collected to measure albumin and creatinine.

Analysis

The purpose of this article is to explore and discuss the barriers and strategies to recruiting hard-to-sample populations, such as Arab Americans. In light of the general barriers as outlined by previous research, we will explain the barriers we confronted in our data collection; the methods we implemented to avoid them; and the benefits, shortfalls, and costs of these remedial measures. Participant demographic data were observed and tabulated for the purposes of evaluating the statistical merits and shortfalls of the sampling method.

RESULTS

Demographic and personal characteristics of the sample

We were able to recruit 136 participants (Table 1) in 18 months via walk-ins to our clinical research facilities and at five community clinics (three held in private homes, one held in a school clinic, and one in a church). We found that the clinics held in private homes attracted the most participants, as the potential participants were reassured by the fact that they knew the hosting member of the clinic and had the option of observing before they chose to participate.

Fliers and announcements used to disseminate information about the study were detailed, so all participants who arrived knew what the study would entail. All participants who

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arrived at a site chose to enroll. At the first open house, 38 participants enrolled. At the second open house, 30 participants enrolled, and at the last one, 20 participants enrolled. At the school clinic, 15 participants enrolled. At the church venue, no patients were enrolled but information was relayed and prospective participants were directed to attend an open house or go to a clinical research facility. Ten patients enrolled at MedStar Union Memorial Hospital, 20 at MedStar Georgetown University Hospital, and three at Howard University Hospital.

Table 1: Demographics of the Participants

Variable	Number of Responses	Percentage
Age (Missing = 1)		
18-29	27	20.0
30-39	29	21.5
40-49	42	31.1
50-59	25	18.5
60 +	12	8.9
BMI (Missing = 9)		
< 16 (Very Underweight)	0	0.0
16-18.5 (Underweight)	1	0.8
18.5-25 (Normal)	31	24.4
25-30 (Overweight)	53	41.7
30-35 (Obese I)	30	23.6
35-40 (Obese II)	10	7.9
40 + (Obese III)	2	1.6
Gender (Missing = 1)		
Male	53	39.3
Female	82	60.7
Religion (Missing = 31)		
Muslim	95	89.6
Christian	8	7.5
Other	2	1.9
Marital Status (Missing = 30)		
Married or Living with Partner	85	80.2
Never Married	11	10.4
Widowed/Separated/Divorced	10	9.4
Education		
≤ 3 years of college	27	25.7
Undergraduate Degree	36	34.3
Graduate Degree	42	40.0
Born in the United States (Missing = 30)		
Yes	9	8.5
No	97	91.5
Employment (Missing = 31)		
Yes	75	71.4
No (Students)	30	28.6
Annual Income (Missing = 39)		
< \$15,000	11	11.3
\$15,000-\$30,000	4	4.1
\$30,000-\$50,000	14	14.4
\$50,000-\$75,000	14	14.4

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\$75,000-\$100,000	11	11.3
\$100,000-\$150,000	22	22.6
\$150,000 +	21	21.6

Participants were self-identified Arab American adults living in the DC metropolitan area during January 2010 to August 2011. Most respondents were women ($n = 82$, 89.6%), and the average age was 42.2 years ($SD = 13.0$). Ninety-seven respondents (91.7%) were not born in the United States. Respondents were asked from which country they came: about one-third of the participants self-identified as being from the Palestinian territories (33%). Others self-identified as being from Syria (17%), Egypt (12%), Lebanon (11%), and Iraq (9%). The rest were from Morocco, Jordan, Libya, Sudan, Algeria, and Yemen. A large proportion of the sample was Muslim (89.62%, $n = 95$), married (80.19%, $n = 85$), had either undergraduate (34.29%, $n = 36$) or postgraduate (40%, $n = 42$) degrees, and had a stable job (71.43, $n = 75$). Of the sample, 69.9% reported making more than \$50,000, and 55.5% were by definition considered middle class in the DC metropolitan area (Chou, 2012).

DISCUSSION

This study elucidated several issues that should be considered when conducting studies with cultural and ethnic subpopulations. Arab Americans are a heterogeneous group with both geographical and ethnic diversity. Moreover, we approached a couple of people who fit the definition of being Arabs (descended from one of the 22 countries in which Arabic is the main language spoken) who did not consider themselves Arab. They either considered themselves African because their ancestors were from African countries (e.g., Egypt, Sudan, Somalia, Morocco), or Phoenician if their ancestors were from Lebanon for example. We encouraged participants who self-identified as Arab American to participate in this study. Although this strategy helped to increase recruitment, it may have biased the sample. This sample was mainly a convenience sample recruited through a “snowball” sampling modality, which has been shown to be effective in this population (Watters & Biernacki, 1989). Additionally, we found that the population recruited represented a higher socioeconomic group, reflecting the location of the recruitment catchment areas and perhaps the community stakeholders identified.

Several obstacles to participation were brought to our attention throughout the recruitment period. Some community members were reluctant to participate, because they were leery of how their information would be used. Additionally, a few community members who were approached asked the study team if we were collecting sensitive information and for what purpose. This clinical study was a new experience for members of the community in this area and some education was necessary to raise awareness and reassure the community members that the study would help their community to make healthy lifestyle changes that would improve their lives. Two would-be participants admitted that they were not fasting and were removed from the study. Overall, the community leaders were receptive and supportive of this effort and provided suggestions for future endeavors, such as providing actual medical consultation during the study and including Arab American study members at each event to answer questions and provide translation services as needed. Finally, community leaders suggested that compensation be provided for participants in future studies.

We have demonstrated that community leaders and educators can play a major role in engaging community members in clinical research studies, assuring participants that research is beneficial and can be conducted in a culturally sensitive manner. In addition, the community leaders and educators reinforced to participants the importance of efforts to promote healthy

lifestyles and to avoid risk factors. To facilitate the success of research endeavors in underserved, understudied, and underrepresented groups, effort to engage stake holders, community members, and community leaders is critical. In addition, culturally sensitive research conduct, in our population emphasizing privacy and confidentiality, and educational activities to promote the goals and objectives of the research were key factors that led to the success of recruitment.

We also highlighted the importance of the findings to this community. The impetus behind this action was to inculcate a trust of researchers in the community and an understanding that research can be beneficial. By bringing to light issues that Arab Americans care about, such as the health issues of their families, friends, neighbors, and colleagues, and demonstrating that it was through the research method that this information was observed, drawn, and published, we advertised the utility of medical and psychosocial research in this historically difficult-to-sample population. Through the development of a culture amenable for research, members of the Arab American community will be more likely to participate in studies and surveys that use more robust randomized sampling, thereby avoiding the inherent biases of a convenience sample.

Because of the nature of the sampling method, the sample observed was biased in terms of its demographic profile. Nearly all the survey respondents had a college degree, were Muslim, and were wealthier than national estimates for Arab Americans (U.S. Department of State, 2013). The correlation between education and wealth on health outcomes is well known, so these factors may have biased the sample, showing better health outcomes than a more representative sample would have shown. Additionally, religious practices that strictly prescribe healthy behavior, such as Islam's prohibition on alcohol consumption, pork ingestion, and fornication (Pargament, 2009), may affect health outcomes. Although there was no recording of religiosity or intensity of orthopraxy, the fact that the sample was heavily Muslim may have positively biased the health results. These demographic biases may have further skewed the analyses on health outcomes. Also, there was a large degree of missing data for a number of variables, and it is reasonable to assume that the missing data were not missing at random (i.e., the missing data may have been correlated with the outcomes of interest). Therefore, the health-related outcomes may not be reliable. These issues can be addressed by promoting the merits of research participation in the Arab American community and by using a more robust sampling method in future studies. If costs and resources were not an issue, a more extensive convenience sampling could mitigate these biases as well, much like other convenience samples have done (Jaber, Zhu, Brown, Herman, Hamad, 2004).

CONCLUSION

The sharing of successful recruitment and enrollment strategies may assist other researchers in sampling sufficient numbers to power future studies in this and other minority populations, thus enabling creation of targeted clinical interventions and recommendations for understudied populations. Collaborating with community leaders and engaging influential members of the ethnic groups targeted for trials may form the cornerstone of our ability to recruit hard-to-reach populations, including the underserved, minorities and understudied groups. Future research efforts should include a hybrid of recruitment modalities to ensure proper representation of the population of interest.

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