Barriers and Strategies for Research in Arab Americans

LINDA A. JABER, PHARMD

Conducting clinical research in minority populations is challenging. Barriers to participation in research and strategies to overcome these barriers have been described by Fujimoto and other investigators (1–4). These reports and experiences have been invaluable in the planning and execution of a community-based epidemiological study in the Arab-American community. The study to determine the prevalence of diabetes in this largely unstudied minority population had been quite successful and achieved a participation rate of 87%.

It was clear from the beginning that the study’s success was dependent on community endorsement and support. Therefore, a proactive approach to exploring and addressing obstacles to participation was undertaken. We found similarities in issues related to participation in clinical research in this community and other minority populations.

The major barrier to research among community members was the general fear, suspicion, and distrust of large institutions and governmental agencies. Field testing of the consent form and the study questionnaires revealed potential obstacles to participation. The standard disclaimer of the consent form was easily interpreted as threatening the right to withdraw at any time. In addition, distrust and lack of information about the research were common themes raised by community members. Study staff recruited for outreach activities were females and were viewed as more trustworthy. Study staff members were trained in Arabic and from the community. In addition, past participants and their acquaintances were contacted to encourage recruitment.

An important element of any epidemiological study of an ethnic minority population is to have an adequate knowledge of the sociodemographic characteristics of the target population. Arab Americans of the study area represent a close-knit community composed primarily of immigrants and large extended families. Although the Arabic language is a unifying factor, diversity in ethnic background, dialect, religious, cultural, and socioeconomic status exists. Study questionnaires were translated into Arabic and reviewed for linguistic and cultural accuracy by at least two independent community members. Study staff recruited for outreach activities were females and were representative of the ethnic diversity of the community. Extensive training using role-playing was conducted to ensure complete understanding of the study methodology and procedures. Manuals for recruitment and outreach activities were created and periodically reviewed with fieldworkers. Information regarding potential refusals and any misconceptions or conflicts were communicated in weekly debriefing sessions. Reluctant subjects were contacted directly and immediately by the principal investigator, and misconceptions were addressed and corrected. In addition, past participants with favorable comments about the research were extremely helpful advocates in fostering recruitment. The events of September 11th halted all study-related activities for at least 2 weeks, and issues of reluctance to participate resurfaced. Resumption of the study required the participation of the principal investigator in all home visits and outreach activities.

Another barrier was an inadequate knowledge of and misconceptions about research and research-related procedures. Research was viewed by most as experimentation that had no direct benefit to the individuals or the community as a whole. An extensive media campaign including local Arabic newspaper, TV, and radio programs that specifically target the Arab-American community was employed before the start of the study and periodically thereafter. These programs served to disseminate information about the scientific relevance of the study and its methods and procedures, including randomization and testing requirements. Misconceptions or concerns uncovered during the field operations, such as confidentiality issues, and overall benefits to the community were also addressed.

Concerns about potential conflict or competitiveness with primary care also represented a barrier to recruitment. Many individuals indicated their desire to discuss the decision to participate with their primary care physicians. A medical committee of three local physicians was established to ensure appropriate reporting, referral, and follow-up of medical care for participants with medical problems uncovered by the study. In addition, the major primary care physicians serving the community were directly contacted.

From the Department of Pharmacy Practice, Eugene Applebaum College of Pharmacy and Health Sciences, Wayne State University, Detroit, Michigan.

Address correspondence and reprint requests to Linda Jaber, Associate Professor, Department of Pharmacy Practice, Eugene Applebaum College of Pharmacy and Health Sciences, Wayne State University, 259 Mack Ave., Detroit, MI 48201-2417. E-mail: ljaber@wayne.edu.

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Abbreviations: ACCESS, Arab Community Center for Economic and Social Services.

A table elsewhere in this issue shows conventional and Système International (SI) units and conversion factors for many substances.
with information about the study’s purposes and procedures, and their endorsement was explicitly obtained.

Fear of uncovering a medical problem in a community where little emphasis is normally allocated to preventive measures was another barrier. Myths about the seriousness of diabetes compared with the risks of treatment modalities, such as insulin injections, were common. Live local TV and radio programs, as well as presentations targeting parents at the three major local schools, were conducted. These programs served to increase diabetes awareness (including risk factors), to correct misconceptions about the disease, and to discuss the benefits of early diagnosis and proper treatment of diabetes.

Other barriers included the inconvenience and time commitment in performing the testing required for the study. Approaches including flexible scheduling of clinic visits, including weekend appointments, and providing transportation were employed. Family members, neighbors, or friends were scheduled in groups on the same day. In addition, the clinic included a spacious room supplied with magazines, children’s books, toys, a television, and a VCR to accommodate children when necessary.

The seemingly insurmountable task in the beginning was achievable, with response rates exceeding our target despite limited resources. Lessons learned during the course of the study were invaluable in providing the groundwork for future studies. With careful strategic planning that is culturally compatible, recruitment and retention of Arab Americans in clinical research are feasible.

References
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