Qualitative Research

Attitudes towards health research participation: a qualitative study of US Arabs and Chaldeans

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Abstract

Background. The Arab Muslim and Chaldean Christian American community is unified by language but culturally diverse. Researchers are challenged to engage the Arab/Chaldean community to meet immigrant health needs. Arabs/Chaldeans are identified as white in clinical data sets making it difficult to identify health behaviours and patterns unique to the community.

Objectives. To explore the views of members of the Arab/Chaldean community, including researchers and the lay public, regarding health research participation and the role of clinicians, researchers and community leaders in the research process.

Methods. A qualitative study of Arab and Chaldean adults and researchers conducted in a US community with a large Arab/Chaldean population. Five semi-structured focus group discussions were triangulated with five in-depth semi-structured interviews with Arab or Chaldean primary care researchers. Responses were audio-recorded and transcribed verbatim. Transcripts were coded and thematically analysed, and findings confirmed with community representatives.

Results. Three themes were identified: (i) research expectations: risks and benefits; (ii) health care environment: clinicians as recruiters and (iii) research participations: risks and benefits. Themes captured concerns with social relationships, reputation or trust and the cost and benefit of research participation. In the Arab/Chaldean community, institutional and political fears and distrust are amplified. Respect for physicians, teachers and faith leaders connected with or recruiting for studies enhances likelihood of research participation.

Conclusion. Clinical researchers should address the cultural and immigration histories of Arab/Chaldean research participants. Studies that maximize trust will minimize participation bias and lay the groundwork for improved health. Institutional, sociocultural and personal factors require a pre-study phase to engage and educate participants.

Key words: Culture and disease/cross-cultural issues, health promotion, immigrant health, primary care, public health.

Introduction

Recruiting and retaining diverse participants in clinical research is important for improving generalizability of study findings (1–3). In addition, including minority, vulnerable, underserved and immigrant groups is important to identify, understand and reduce health disparities (4–6).

Arab Americans are a diverse ethnic/cultural group with heritage from 22 Arabic-speaking countries of origin (7). Arab immigration to the USA has a long history (8–10). The metropolitan area of Detroit, MI is home to a large Arab population and the largest American settlement of Chaldean Americans, who are a Christian ethnic minority

from rural Iraq. Aramaic is the traditional language of Chaldean people (9).

Today, Arabs and Chaldeans in America have higher levels of education and income than the general population (11) and may have different health risks (8,12,13) or health-promoting behaviours (14–16). Given the broad diversity in this ethnic group (reflected by country of origin, religion and its subgroups, language, diet, cultural norms, education and income), caution is needed to avoid overly broad generalizations (1,17).

The epidemiology literature reports morbidity and mortality patterns in persons of Middle Eastern descent (8,18–21). The health and social science literature includes recommended strategies and lessons learned for building trust to support culturally competent care (15,22–24) or to recruit to and retain in research (2,3,12). Yet, fewer studies have directly asked Arab/Chaldean immigrants about their attitudes towards research participation.

Here, we focus on attitudes towards research participation among Arab/Chaldean Americans residing in metropolitan Detroit. These data were collected with leadership from the MetroNet practice-based research network, as part of a larger federally funded study conducted in five locations across the USA. The parent study used a sequential, qualitative research design with an exploratory phase of key informant interviews with researchers to determine themes and practices common to their research recruiting experiences. This informed the development of a focus group interview guide to explore perspectives on research from five ethnic groups (one from each location site). Transcript analysis took an iterative analytic process to develop an initial code list, which was refined in subsequent cycles of co-coding, code comparisons and finally consensus on code definitions. Themes were identified from coding patterns across communities and confirmed through a review process at individual sites.

Findings from the larger parent study include a report on the study design and methods plus a synthesis of recommended strategies for research participation (25) and a report on the use of community engagement strategies to increase research participation of clinicians in practice-based research networks (26). Unique variations in attitudes specific to individual racial/ethnic communities were not included in the earlier publications. Therefore, the objectives for this report are to explore the views of members of the Arab/Chaldean community and researchers with expertise in that community regarding (i) strategies for engaging their community in clinical or health-related research and (ii) the role of clinicians, researchers and community leaders in the research process.

Methods

The current study includes a secondary analysis of key informant and focus group data from the larger parent study (25), plus additional

original data collection (a confirmatory focus group of Chaldean professionals), reported here for the first time. The research team is comprised of two female clinicians and three PhD researchers, each with more than a decade of experience in community health research. Three are members of a primary care practice-based research network that serves the local Arab and Chaldean community. The Wayne State University Institutional Review Board (IRB) approved study protocols.

Data sources

Table 1 outlines the study phases with data sources, including key informant interviews, focus groups and community review. Key informant and focus group discussion questions are summarized in Supplementary Tables S1 and S2, respectively.

Key informant interviews

To elucidate strategies and recommendations for engaging and recruiting this group in health-related research, two study investigators, a licensed physician (KLS) and a PhD, medical anthropologist (KCV), conducted interviews with five key informants experienced in recruiting Arab/Chaldean participants into research studies (27–29). To ensure a breadth of perspectives on research engagement in Arab and Chaldean communities, these researchers represented academic, public health and community non-profit settings. Everyone invited agreed to participate. The interviews lasted about 1 hour with four in person and one on the telephone. Primary discussion questions addressed the following areas: (i) research recruitment and retention practices, (ii) research challenges and adaptations, (iii) participatory research methods and (iv) researcher–clinician collaboration. Interview data were professionally transcribed verbatim and coded as described above. Emergent themes were used to develop focus group questions and to triangulate with focus discussions to improve understanding.

Focus groups

Four focus groups (two Arabs and two Chaldeans) were composed along locally salient, culturally defined lines of sex, age and ethnicity. Recognizing the unique histories, religions and ethnic identities of these two immigrant groups in the Detroit area, focus group recruitment was responsive to gender, language and religious preferences. Most participants were multilingual, and the language preferred by the majority was used during discussion. Whenever participants required clarification, bilingual focus group leaders provided forward and backward translated questions and comments to ensure common understanding.

Two community organizations assisted in recruiting and hosting community members for the focus groups. One partner was a large clinical and social services centre in the Arab community (located in

Table 1. Developmental phases to identify attitudes towards health research participation (2010–12)

		Number of participants
1	Comprehensive literature review	NA
2	Key informant interviews with experienced community consultants and academic researchers	5
3	Four community focus groups:	
	Two Arab Muslims (male, female)	16
	Two Chaldean Christians (seniors, young adult)	20
4	Confirmatory community peer reviewers	4

NA, not applicable.

Dearborn, MI), and the other was a well-known Chaldean Catholic church (Oak Park, MI).

The Arab Muslim focus groups were recruited and led by a bilingual registered nurse (HH) experienced in community health, research and education, who worked at the social services centre. She contacted individuals who had participated in previous centre activities/services. The Chaldean groups were recruited and led by a PhD researcher/bilingual member of a Chaldean church (FD) who contacted individuals through the church's community network. Groups, stratified by age, were associated with immigrant status. Older Chaldean participants were Iraqi immigrants, and young adult Chaldean participants were first-generation American-born.

The focus group procedures were similar for all four groups:

- The language preference of each group was used by the bilingual moderator. Two groups were conducted in English (Arab women; Chaldean youth), one in Arabic (Arab men) and one in Chaldean Aramaic (Chaldean seniors).
- Study documents were provided in English and Arabic.
- Informed consent was secured using an IRB-approved information sheet, which was reviewed at the start of each session by a bilingual research assistant.
- Bilingual scribes were identified by group moderators, and written notes were used to confirm transcripts and to add contextual data. Demographic information sheets were completed, with assistance as needed.
- Focus group discussions lasted 70–90 minutes.
- Refreshments were provided. Participants received a \$50 gift card to recognize time and costs incurred.
- Digital recordings were transcribed by bilingual speakers (fluent in English and Arabic or Aramaic), employed by a professional translation/transcription service. Field notes were completed and typed immediately after the session. Transcripts were reviewed and confirmed by group moderators who listened to the recording while reading the transcripts.

Qualitative data coding and analytic approach

This secondary analysis focused on developing a profile of factors associated with Arab/Chaldean engagement in primary care research. The coding procedures described above are also published (25). For this report, one member of the original coding team (KCV) plus the principal investigator (AVN) conducted a secondary analysis of existing content coded data to examine culturally specific themes particular to Arab/Chaldean research participation. Data were triangulated between key informants and

community focus group participants to ensure understanding of verbal discussions. Major code categories for key informants and focus group participants are in Table 2.

Interpretive themes were cross-validated across interviews and focus groups. For confirmatory purposes, a convenience sample of four immigrant Chaldean professionals (three Iraqi-trained physicians and one social services professional) reviewed the results. Three of these individuals were employed as university research assistants, and a fourth was a recent physician immigrant.

Results

The five key informants included three researchers, a study recruiter and a clinician consultant. Table 3 shows characteristics and professional experience of the five key informants. Key informants averaged 20 years of experience in health program evaluation and/or research in the Arab/Chaldean communities and were associated with recognized academic, clinical and non-profit organizations. All key informants approached for the study agreed to participate.

Thirty-six adults participated in the four focus groups: eight in each Arab Muslim focus group, ten in each Chaldean Christian group. Table 4 summarizes the demographic characteristics of focus group participants. The majority of participants reported no direct experience with research. Participants primarily identified themselves by their home country and the number of years living in the USA. Two focus groups were composed entirely of immigrants, Arab men (median age 48 years) and Chaldean adults (median age 66 years). The Arab women group (median age 34 years) included two who were born in the USA. The Chaldean youth group (median age 25 years) had six participants who were first generation in the USA; most identified themselves as college students during introductions.

In response to discussion question about the value of research and attitudes towards research participation (Supplementary Tables S1 and S2), findings are organized by three themes—research expectations: risks and benefits, health care environments: clinicians as recruiters and research participation: risks and benefits.

Research expectations: risks and benefits

We detected a basic understanding that research is valuable and involves asking questions, collecting information and drawing conclusions. Yet, most participants lacked any previous exposure to health research and believed that most immigrants would have no idea what it entailed. However, after discussion, participants concluded that research was important to define the health needs and interests of their heterogeneous community. It was also an opportunity for the rest of the world to learn about Arab and Chaldean communities.

- Many people that come from their home, they don't know what research is... There is not a culture of research in that country. (Arab woman)
- ... the rest of the world doesn't know us. So I think it is very important for us to partake in research. Not many people know what Chaldean is. (Young adult Chaldean)

When discussing expectations, focus group participants and key informants expressed concerns with issues of trust. Participants referred to both positive and negative aspects of community cohesion, in terms of maintaining privacy and fear of stigma. The importance of social exchange was a key emphasis for developing

Table 2. Key codes used in qualitative data coding from Arab and Chaldean focus groups

Key informants	Focus group participants
Role of trust	Attitudes towards research
Caring interpersonal relations	Group cultural beliefs
Control empowerment	Perspectives on health care
Cultural group issues	
Group attitudes on involvement in research	
Setting the stage awareness	Setting the stage expectations
Recruiting enrollment	Motivations for participation
Study activities	Participation expectations
Study retention	
Study wrap-up	
Participatory strategies	

Table 3. Characteristics of key informants providing perspectives on conducting research with Arab participants (2010)

	KI				
	KI #1	KI #2	KI #3	KI #4	KI #5
Expertise	Consultant Arab health	Research recruiter	Clinical research	Community research	Community research
Role	Community advocate	Community collaborator	Academic	Academic	Academic
Years of experience	20+	10	20+	20+	20+
Ethnicity	Arab	Arab Christian	Arab	Arab	Non-Arab

KI, key informants.

Table 4. Characteristics of focus group participants on participating in research (2010)

	Arab Muslim participants		Iraqi Chaldean participants	
	Group 1 (<i>n</i> = 8)	Group 2 (<i>n</i> = 8)	Group 3 (<i>n</i> = 10)	Group 4 (<i>n</i> = 10)
Age				
Median	48	34	66	25
Mean	43	35	66	24
Gender				
Men	8/8		5/10	5/10
Women		8/8	5/10	5/10
Language (focus group)	Arabic	English	Chaldean Aramaic	English
Years in USA (omitting native-born US citizens)				
Median	9	8 ^a	18	17 ^b
Mean	11	9 ^a	20	13 ^b
Country of birth				
Egypt	1/8	0		
Iraq	1/8	2/8	10/10	4/10
Lebanon	2/8	2/8		
Syria	1/8	0		
Yemen	3/8	2/8		
USA	0/8	2/8		6/10
Previous research participation	0	0	4/10	0

^a*n* = 6 because two participants were born in the USA.

^b*n* = 4 because six participants were born in the USA.

and maintaining interpersonal relationships as a prelude to clinical research or collaboration. Outsiders may be viewed with suspicion, and relationships are facilitated if there is a 'trusted broker' for introductions. Several recounted historic fears of personal data used to harm or threaten citizens in home countries. Discriminating clinical research from these memories was difficult for some participants.

- So when [researchers] go to them and ask them for help, sometimes they expect that maybe [researchers] hold something against you. Maybe ... a kind of medicine would kill [your people]. (Arab woman)
- The Arab community, with all its nationalities and groups, are sensitive towards researchers who conduct studies about a specific subject... They consider these researchers to be investigative researchers who collect personal information about individuals... (Arab man)

Younger Chaldean adults felt more confident in judging the credibility of outsiders and relate this to their ease with US culture and institutions. As one participant stated, 'I think our generation is a little better with that [judging outsiders]. We know how to determine who we trust and who we don't, and it has made it a little easier for us to assimilate and to partake in studies. It will get better for the next generation.'

Health care environments: clinicians as recruiters

The key informants elaborated on the importance of social exchange in building trust. They reflected on how their credibility as researchers was the result of a community partnership and that busy clinicians or researchers may overlook the few minutes it would take to establish a relationship prior to inviting patient participation in clinical research.

- [Trust] happens not in a formal way. That's considered rude and intrusive. Especially people who've emigrated from war-torn countries, they still feel like they don't quite trust the system here... (KI #2)
- You smile, you drink tea, and you're just human. Your humanness has to come ... before your professionalism, although your professionalism needs to be there. (KI #1)

Physicians and community leaders are important sources of health information and education in Arab/Chaldean communities. Key informants emphasized that research participation is enhanced when preceded by a phase of education.

- ...most patients do not really question their physicians but it [engagement] has to be done with education. It has to be preceded by an effort to build awareness before the physician will break the mistrust thing. (KI #1)

- I think what the Arab community suffers from, especially the community I belong to, is the absence of education and communication between doctors and the community... Doctors [could] engage with the community... to maintain a line of communication between them and the community. Education is essential. (Arab man)
- Leaders, such as those from faith organizations or physicians and teachers, are respected and viewed as credible leaders, especially for the older participants. 'For me and you, we accept the word of the physicians. For my kids, they are not like me.' (Arab woman) Similarly, younger participants were less uniform in their confidence regarding clinician researchers: 'I don't think doctors should give (distribute) surveys, period. Their job is to help the person. That's it.' (Young adult Chaldean)

Research participation: risks and benefits

Participants discerned between the personal benefits of clinical research and social benefits of 'helping my people'. Interest in improving personal health is an important initial consideration followed quickly by expectation that the results achieve community benefit. For example,

- I think that it's the most important research that everyone should participate in, because it will benefit in either way. You know, benefit your kids, benefit you, adult, older, girl, boy, so it's something for your health. So I think we should look at it more seriously and do research regarding medical issues. (Arab woman)
- What's going to come out of it? ...Is it going to benefit me? Is it going to benefit my age group, my kids, or elderly, whoever it is? I just want to know is it going to benefit the community. (Young adult Chaldean)

Despite interest in helping oneself or the community, there are strong barriers to participating in clinical research. In a tightly integrated community, stigma and shame are significant barriers to participation in primary care research.

- For me a lot of those issues as far as depression, somebody being bipolar, things like that, ADD (attention deficit disorder), ADHD (attention deficit, hyperactive disorder), I look at it as a label. ...I think that all brings shame...in this community that is something that is a disgrace and a weakness. (Young adult Chaldean)
- When it comes to asking questions about diabetes or cancer, you should be very cautious. People try to conceal things like that - even amongst their family members. (Chaldean elder)

Finally, traditional beliefs about disease causality and risk arose among elders or among participants reporting about their older family members during discussions about research related to specific diseases. Traditional beliefs hold that speaking out loud about disease or death can cause the feared outcome. An elder Chaldean woman interrupted the discussion in her group to admonish her peers, and a similar sentiment was expressed among Arab women in another group.

- Please be quiet - don't talk about death. We are not in the mood to hear that. ... Death is God's power, so please think about something else. This repeated talk about diseases and the circumstances after death -God, Blessed Virgin Mary, keep us safe. (Chaldean elder)
- It's a culture thing too, especially the old ones... 'No, no, we don't get sick. Oh, no, we could take care of ourselves without anything,' You know? 'We're strong.' ... When they hear some kind of disease they get afraid. (Arab woman)

Confirmatory/community peer review

We presented the above themes and findings to four Chaldean professionals for a final confirmatory effort. The three immigrant physicians had not encountered research in their home country (Iraq) and agreed that 'research' was an unfamiliar concept with most people in Middle Eastern countries. They reinforced that personal contacts from a community member would be most successful for research recruitment. They also stressed the good reputation of the university in the Chaldean community and that this added some legitimacy for study recruitment.

Discussion

The objective of this study was to explore the views of Arab and Chaldean community members regarding health research participation. Themes captured concerns with social relationships, reputation or trust and the cost and benefit of research participation. Respect for physicians, teachers and faith leaders connected with, or recruiting for, studies enhances likelihood of research participation.

One important contribution of this study is its qualitative methodology. Much of the published health research on Arab/Chaldean communities is quantitative (30); therefore, the deeper underlying meanings of health may not be well understood. Our study found that concerns with social connection, trust and the perceptions of the risk and benefit of engaging with clinicians and researchers may be magnified by the traumatic conditions of migration and displacement due to conflict (31–33). Participants provided variations in interests, motivations and perceived barriers for research engagement that argues against simplistic approaches. Arab and Chaldean people represent diverse subcommunities with particular political and social histories, needs and interests. Assumptions about identity, expectations and motivations may be misleading. A phase of pre-engagement relationship building allows community beliefs, values and barriers to be identified and accommodated (34–36).

Epidemiologic research suggests areas in which the health of Arab/Chaldean communities in America differs from that of whites and other minorities (37,38). One of the challenges of understanding Arab and Chaldean Americans' health patterns is that these population groups are classified as 'white' by the US federal government (39). Therefore, any variation in their health status is masked under the white category. Engaging Arab and Chaldean Americans directly in clinical research will give voice to this less visible minority group.

Researchers seeking to include participants with Middle Eastern backgrounds should consider engaging community leaders/interpreters to promote culturally competent engagement with Arab/Chaldean communities during planning and intervention stages. These communities build relationships within a social structural context that reinforces social cohesion, respect for clinicians, teachers and religious leaders. While university faculty or other research leaders are widely respected, they also are expected to be visible and establish their reputation by participating in public events; these community activities are identified as 'enabling' influences in the literature (40).

Finally, research engagement in a diverse Arab/Chaldean immigrant community will be enhanced by collaborative strategies that build community understanding and trust. As members of the research team, traditional cultural brokers and social organizations give voice to community interests and offer support with language, cultural interpretation and educational outreach. A heterogeneous Arab/Chaldean community, though, demands that researchers ensure that 'multiple perspectives' are at the table. The activist, as well as the 'person around the corner', each has particular motivations and interests important for success. Summary recommendations for research recruiting and ongoing participation are detailed in the [Box 1](#).

Box 1. Summary Recommendations for Research Recruiting and Ongoing Participation

- *Outreach*: involve faith, educational and clinical leaders to improve cultural competence and credibility
- *Engagement*: plan pre-study educational offerings to develop the community's research readiness; develop a research team that reflects community diversity
- *Enrollment and Retention*: communicate through 'person-to-person' networks (rather than mail or telephone) to support study activities
- *Dissemination*: distribute study results to participants and organizational stakeholders

Strengths, limitations and conclusions

The study included US- and foreign-born Arab and Chaldean participants of varying duration in the USA, yielding a breadth of perspectives. Our purpose was not to provide a typology of demographic groups but rather to identify common ground for working with individuals with Middle Eastern heritage. Participants in this study may not represent the perspectives of those unable or unwilling to attend focus group discussions. Limitations also include findings derived from a single urban Detroit metropolitan area in 2010, which does not represent the perspectives of a globally dispersed diaspora of immigrants and refugees. However, Tohid *et al.* (41) recently reported similar findings in a large sample from Qatar, lending more credence to our findings. Many of the suggestions here can be taken under advisement by clinicians as well as researchers. With new refugees and immigrants, some of these issues may have heightened saliency for future research into doctor–patient communication, therapeutic decision-making and referral follow-up. Informed collaboration between clinician researchers and Arab and Chaldean immigrants/refugees/descendants should improve recruitment and retention in clinical research and ultimately culturally sensitive health care.

Supplementary material

Supplementary material is available at *Family Practice* online.

Declaration

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Ethical approval: This research study was reviewed and approved by the Wayne State University Institutional Review Board.

Conflict of interest: none.

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