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Article

Lesson Learned in Engaging Five Culturally and Linguistically Unique, Hard-to-Reach U.S. Muslim Populations

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Abstract

Background: Engaging diverse populations including Muslims in research activities is important to support patient-centered research and improve health equity. **Objectives:** To describe the community engagement steps that informed conducting research with five distinctively diverse U.S. Muslim communities. **Methods:** Researchers engaged with leaders, advisory members, and people from five diverse communities. Strategies to support sampling, recruitment, multi-language interpretation methods, and how to support closed communities and address their concerns are discussed. **Lessons Learned:** Researchers interested in working with Muslim communities should be aware of principles of seclusion when interacting with sex-discordant participants. Including language concordant researchers demonstrated effectiveness and efficiency in the process. Researchers should be open to rejections from communities and accept stepping back to give community members the space needed to decide whether to participate in research. **Conclusions:** Flexibility and adaptability are integral in recruitment and data collection as diverse communities may respond differently to methods successfully used elsewhere.

Keywords: community-engaged research; Muslims; limited English proficiency; language interpretation; recruitment of diverse populations

Introduction

Engaging diverse, hard-to-reach populations in research in the U.S. is an understudied challenge, particularly with respect to Muslims. Diversity can include cultural, linguistic, as well as immigration status characteristics. Muslims are the most racially/ethnically diverse religious group in the U.S. [1]. About 20% of U.S. Muslims come from South Asia (Pakistan, Afghanistan), while 14% come from the Middle East and North Africa (MENA) [2]. Muslims from the same region can speak distinct languages and embrace different practices and cultures. Afghanistan's main language is Dari, while Pakistan's is Urdu [3]. Unlike Afghanistan, Pakistani's cultural traditions tend to be influenced by India [3]. The Rohingya (from Myanmar in Southeast Asia) language is primarily oral and lacks a standardized written format [4]. Muslim Arabs

are originally from the MENA region. Cultural differences and similarities are present between Arabs [5]. Half of the U.S. immigrant population have limited English proficiency (LEP) [6,7]. Language barriers significantly impact healthcare access, with over half of immigrants with LEP encountering difficulties when seeking medical services [7].

Given the size, diversity and unmet healthcare needs of the U.S. Muslim immigrants and refugees, it is important to better understand their diverse healthcare requirements and experiences navigating the healthcare system to make care more culturally responsive and equitable.

Objectives

The parent study conducted qualitative research to compare healthcare experiences and challenges of Muslim populations considering their diverse cultural, linguistic, and immigration status characteristics within a single project. The overall objective of this study is to investigate the challenges and facilitators of community-engaged research when the sample is composed of people with diverse languages and cultures. This study is unique in that earlier work sampled people from different countries of origin [8,9], but did not include non-English speaking people [9], or participants with cultural differences [10].

This paper aims to describe the community engagement steps that informed: 1) the sampling strategy; 2) multi-language interview methods responsive to cultural preferences; 3) recruitment processes; and 4) establishing legitimacy within the diverse communities ahead of recruitment. This paper reflects on learned lessons about studying distinctly different Muslim populations simultaneously. The University of Wisconsin's Institutional Review Board determined the study as exempt.

Methods

Community Engaged-Research Design Process

Community-engaged research depends on partnerships with communities [12]. Early in the study planning process, the research team leveraged existing partnerships with two Muslim community organizations serving underrepresented populations and Muslims in Milwaukee; a community health and senior center, and a locally owned community pharmacy system composed of 21 pharmacies. Their advice informed several early key study decisions and continued to guide the research through monthly meetings. During these meetings, researchers reported progress and sought advice to find strategic solutions to challenges encountered during the study. Additional community-engaged research methods included the establishment of two advisory groups—one consisting of clinicians and the other of community members. These groups provided guidance on various design decisions [13–15]. The clinician advisory group was composed of 3 racially/ethnically diverse (Arab, Asian, White) pharmacists and a physician assistant (Arab). The community advisory group members included three racially/ethnically diverse (African American, Arab, North African) people with diabetes and a case manager as a representative of the Rohingya community (i.e., a professional who assists newly arrived refugees in integrating into their new community by providing support with housing, healthcare, education, and employment). The team held a formal meeting with the group at the beginning of the project to understand the community's needs and to design the qualitative study accordingly. As the project continued, the PI met informally with each member individually to inform them of the progress of the project. Finally, ongoing interactions with community leaders and advocates offered key entry points and strategies for gaining community trust.

Selection of Sample

Our community health center partner identified the six largest groups in their health system to capture the diversity of the U.S. Muslim community. These groups were chosen based on the language spoken at home to ensure the inclusion of hard-to-reach, non-English-speaking people

whose voices are rarely heard in U.S. research. Home languages included Arabic (people from the Middle East), Dari (Afghan refugees), English (African American and White people), Rohingya (refugees from Myanmar), Somali (people from the African country Somalia), Urdu (people from Pakistan and India).

We planned to recruit 30 people, 5 participants from each of the spoken languages: sample size was based on information power [16]. Although there are cultural differences between these groups, the Islamic religion connects all of them as one Ummah (i.e., community). Basic Islamic ethical and interaction manners (e.g., justice, respect, compassion, humility, dignity, and integrity) were important in phrasing the research purpose, sampling and communicating with this diverse group of people [17].

Multi-Language Interview Methods

Interview Guide

A semi-structured interview guide with probes was developed to inquire about different domains of interest guided by diabetes self-management activities (e.g., access to medication, diabetes management related behaviors including dieting, exercising, checking blood sugar levels, and medication use) [18]. Questions were revised by experts in qualitative research and by the members of both advisory groups. The advisory group reviewed the questions to reflect their communities' priorities [19] and the experiences of the heterogeneous communities. For instance, the refugee case manager highlighted access to care challenges faced by the Rohingya refugees.

Interview Duration

Initially interviews were planned for 60 minutes. However, some interviews took up to 90 minutes because of technical difficulties. Interviews took place between July 27, 2022, and January 18, 2023.

Interpreter Modality

Three forms of interpretation took place throughout this study: phone interpretation from a vendor, in-person interpretation from the Rohingya community, and an in-person interview by a bilingual researcher. By-phone interpretation was provided by a vendor contractor with the University of Wisconsin-Madison for all the Dari- and Urdu- speaking participants and for two of the Rohingya participants. Three out of the five Rohingya interviews were facilitated by an in-person interpreter who is a community member and assisted in participant recruitment. A.A. is bilingual and conducted all interviews with Arabic-speaking participants in Arabic.

To ensure that interpreters were not paraphrasing the information provided by the participants, the interviewer briefed interpreters about research objectives, expectations, and the importance of interpreting what participants say without paraphrasing. Although the interviewer was not familiar with the languages, she was alert for cues of misinterpretation and would ask the interpreter for clarification if it appeared that paraphrasing had occurred.

Results

Recruitment Processes

Building on partnering organizations' advice and referrals, the goal was to recruit individuals from hard-to-reach populations while being culturally responsive and sensitive. A.A. (A Middle Eastern Muslim, a second-generation Palestinian refugee, and a first-generation U.S. immigrant), had a pivotal role. The most successful recruitment strategies stemmed from trust-based relationships, drawing on this approach the team was able to recruit and interview participants from 5 of the 6 target communities. Twenty two interviews were conducted. To accomplish this, the research team pursued the following strategies to build trust and recruit eligible participants.

Finding Where People from Each Community Are Located and Understanding Their Characteristics

Identifying each community's individual needs, resources and rituals helped determine the best locations and outreach strategies to find interviewees. For instance, some communities were mainly refugees and had established roots having been in the US for a longer period than others. The Rohingya community had an established mosque that specifically caters to the Rohingya people in their own language. On the other hand, the Afghan community does not have an established mosque as the majority have been recently resettled in WI. For this community, the team identified what organizations focus on supporting their unique needs of creating a sense of community and providing English learning programs for the youth and their mothers.

Approaching Communities

Multiple steps were taken to ensure that the community's spaces and preferences were respected. First, leaders and advocates for the community were identified. In some instances, building trust required several connection attempts, attending various events to reach out and establish a trusting genuine relation. It was important to establish clear communication channels with leaders and advocates and identify their preferred methods of communication (e.g., phone calls, messages, emails, etc.). In engaging with community advisory members, phone calls emerged as the preferred method of communication. This preference was due to some individuals relying on their children to access emails or not regularly checking their personal email accounts. It was critical to learn about community norms, be humble, assume that we knew nothing about the communities, ask for clarifications when needed and include justifications for our questions. For instance, our community partners informed us that the Rohingya language is exclusively spoken, which was new information for us. Consequently, during our advisory meeting, community members suggested creating a video for advertising purposes instead of using flyers for the Rohingya community. It was important while asking questions, to be prepared to be asked questions and share about ourselves as humans and not only as academics. A key element was discussing how the research project benefits their communities to create a transparent message about what we brought as much as what we were asking for. We always asked for permission, giving plenty of time and space to approve our study whether as is or with their own terms and conditions. Empowering communities with a leadership role through shared decision-making was an important part of this process: 1) partnering organizations were engaged early in the process to help formulate the research focus and define the characteristics of the study sample; 2) the advisory group members shaped the research questions and informed the advertisement process; 3) the research team worked around the community organizations' schedules and preferences, and followed their guidance around the logistics that worked best for them. When in their community, it was important to continue to respect their norms and preferences and apologize for any misunderstandings. For instance, when the team was in a community's mosque, the plan was for the leader to announce about the study after the Friday sermon, then community members could approach us to learn more. However, people started leaving the main room and approaching our team before the leader's announcement was over. We apologized to the leadership team for our inability to manage the timing of community interactions until the leader's announcement was completed. When leaving the community, it was equally important to speak positively and respectfully of them, keeping their secrets, continuing to connect with them regularly, and bringing back the research results to share. The team engaged with a community health center that serves the refugee population to present preliminary findings from the parent study. This consultation helped the health center to gain insights into the challenges faced by community members and facilitated a collaborative brainstorming session to develop strategies for improving healthcare accessibility for this population.

Example

In connecting with the Rohingya leaders, researchers leveraged relationships through the CEOs of the partnering community organizations. One person connected the team with a refugee case manager and the Rohingya mosque leader. The other CEO connected the team with a bilingual Rohingya interpreter who is the niece of the mosque leader. The refugee case manager had integral roles in the advisory group discussions and in further connecting the team with the mosque leader. The research lead, A.A., contacted the mosque leader, introduced herself, explained the mission of the research, and outlined her role. This allowed A.A. to learn about the community, its norms, activities, and the mosque's structure. This provided an opportunity to gauge their interest in the research and whether involving community members would be beneficial. The leader approved of the team to approach the community after the Friday prayer sermon, scheduled for a designated room within the mosque. The leader explained that this event is mainly attended by male individuals. Therefore, in respect to the community's mosque structure and religious preferences, it worked well to involve the leader's niece in the recruitment activity as a trusted community member and an interpreter. On a regular basis A.A. wore a Hijab as a Muslim, and she was aware that a respectful practice of attending a mosque is to wear Abaya (long modest dress with full sleeves).

Leveraging Personal Connections for a Direct-to-Participant Recruitment Process

After the initial contacts, ongoing personal connections within the community were a valuable resource for recruitment. A.A. leveraged personal connections with a physician who previously supported the Michigan Muslim community and a pharmacy owner in Milwaukee to inform specific community members about the research and encourage them to participate if interested. Leveraging existing connections to establish a trustworthy relationship was one of the most successful recruitment strategies; more than five people were recruited through these two connections.

Engaging with Communities

The research team engaged with communities by participating in community events and volunteering in activities. For example, A.A. helped with women's activities at a program tailored for Afghan refugees and expressed interest in continuing to help with these events. Community members were able to connect with the researcher and build a genuine human relationship that supported people's interest in participating in this research, when previously the same people did not show interest in response to an earlier advertisement on the community's WhatsApp chat group. To be in this space, A.A. used the same strategy described earlier in approaching communities.

Addressing Community Concerns and Respecting Their Decisions

Particular communities were harder to open up to the research team. For instance, people from the Somali community were hesitant to share their personal information and had concerns about privacy. To address this, the research team made multiple contacts with people from this community, consulted with researchers who work with Somalis in Minnesota to learn their recommendations for working with them. Despite all these efforts to involve the Somali community, the team had to take a step back and respect the community's decisions about participating in research.

Lessons Learned Across Different Muslim Populations

Cultural Preferences During Interview Procedures

Seclusion or Khalwah refers to a situation where a man and a woman, who are not closely related (non-mahram), are alone together in a private space [20]. This is prohibited in Islam to prevent any allegations or occurrences of illicit relations [20]. During this research, the team followed their rules across all the communities to prevent seclusion and to offer a comfortable setting. For example, during A.A.'s visit to the Rohingya community in the mosque, another female with a close

relationship (mahram) to the community's leader (his niece) was present in the mosque while communicating with male participants. The pre-arrangement with the mosque leader was important to provide a private meeting room for the research team to stay in. This allowed the team to be away from mass traffic and only interested participants were able to enter the room to communicate their questions or interests with the team. Second, during the in-person one-on-one interviews with male participants, the interviewer (female) conducted interviews in a clinic's private room either with the presence of one other female from the research team or by leaving the room's door slightly open to prevent seclusion [21]. Consistent with previous research, it was important to ensure gender concordance between research participants and the interviewer [22]. Understanding the religious concept behind it supported researchers in appreciating these preferences by community members.

How Well Did the Different Interpretation Methods Work?

A.A. felt distinct differences in the dynamics of interpreter-assisted interviews compared to those where interpretation was not needed. Interviews that were conducted with Arabic-speaking and English-speaking participants flowed in a smoother manner, took less time, and were less exhausting for both the interviewer and the interviewee. There are multiple challenges to using interpretation services over having a bilingual researcher conducting the interviews. Challenges include interpreting information accurately, the time and effort needed, and securing resources and funding for interpretation costs. Researchers are recommended to check for certifications and other indicators of qualification when using an interpreter from the community. In addition to staying alert for cues that may indicate inaccurate interpretation. By-phone interpretation offers a cheaper hourly rate, however, concerns about qualifications and providing accurate interpretation still apply. Technical challenges, such as call disruptions and unexpected disconnections, are expected to arise. The structure of these services, based on interpreter availability, complicates the process of securing a specific interpreter or reconnecting with a previously engaged one after a call drop. Call dropping required the interviewer to call back, wait to be directed to a new interpreter, then to brief the interpreter about of the interpretation expectations and goals.

Overall, having a language-concordant researcher conduct interviews was the most effective approach. Advantages of having a multi-lingual researcher(s) outweigh the cost-cutting benefits. Working with an in-person interpreter, especially from the community, can provide additional benefits such as leveraging trust-based connections to facilitate recruitment and understanding the culture. By-phone interpretation offers an affordable option; however, researchers need to brief the interpreter about the study and expectations, understand that interpreters are not able to see visual cues, and that technical challenges are anticipated [23].

How to Support Closed Communities in Addressing Their Concerns

Previous research discusses recruitment from the Somali community including the experienced challenges [22,26]. Researchers contacted community members multiple times, who expressed the need to include other community members to feel more comfortable participating in the study [26]. In future research, researchers are recommended to engage early and often with each community and continuously work to build trust-based relationships with community members and leaders. Also, multi-institution collaborations are encouraged, especially to focus on areas where specific populations tend to cluster, such as Minnesota for the Somali community. This type of research will require more funding to support these collaborations.

Conclusions

This research highlighted the feasibility and importance of community-engaged research to help researchers collaborate with diverse communities in a single study. Within each community, researchers worked hard to build trust with community leaders and organizations, leverage personal connections, adapt to community norms and needs when collecting data and addressing community

concerns. This study underscores the need for flexibility and adaptability in recruitment and data collection as different communities may respond differently to methods successfully used elsewhere. Nevertheless, their shared Muslim foundation facilitated the adoption of several similar recruitment and data collection strategies honoring their beliefs.

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