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Using CBPR for Health Research in American Muslim Mosque Communities: Lessons Learned

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Abstract

Background—American Muslims are understudied in health research, and there are few studies documenting community-based participatory research (CBPR) efforts among American Muslim mosque communities.

Objectives—We highlight lessons learned from a CBPR partnership that explored the health care beliefs, behaviors, and challenges of American Muslims.

Methods—We established a collaboration between the University of Michigan and four Muslim-focused community organizations in Michigan. Our collaborative team designed and implemented a two-phase study involving interviews with community stakeholders and focus groups and surveys with mosque congregants.

Lessons Learned—Although we were successful in meeting our research goals, maintaining community partner involvement and sustaining the project partnership proved challenging.

Conclusions—CBPR initiatives within mosque communities have the potential for improving community health. Our experience suggests that successful research partnerships with American Muslims will utilize social networks and cultural insiders, culturally adapt research methods, and develop a research platform within the organizational infrastructures of the American Muslim community.

Keywords

Islam; community health research; mosques; religion; minority health

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CBPR approaches offer a facilitative strategy for collaboration among community and the academy toward mutually beneficial ends.[1,2] CBPR seeks to move from conducting research "on" communities to conducting research "with" communities, and as such represents a paradigm shift that better enables health research and health interventions with underserved populations.[3] CBPR approaches have been used to address health challenges faced by a

diverse set of communities,[4-10] including refugees and other marginalized populations.[11,12] However, there is limited documentation of CBPR experiences with American Muslims, particularly related to conducting health-related research within American Muslim mosque communities.[13]

American Muslims are a diverse, growing, and socially marginalized community whose health is generally understudied. American Muslims number between 5 and 7 million[14-17] and are expected to double in number by 2030.[18] Most Muslims in America are African American (35%), Arab American (25%-30%), or South Asian American (20%-25%),[19] and more than one-half are immigrants.[20] Although most American Muslims are Sunni (65%), a significant minority (11%) identify with the Shiite denomination.[21] Across this racial, ethnic, and denominational diversity, research studies reveal that Islam influences the health behaviors of diverse groups of Muslims in similar ways. Thus, Muslims often look to Islamic ethicolegal guidelines when deciding about the range of permissible therapeutics, and Islamic values such as modesty influence health care choices for many Muslims.[22] Furthermore, a shared religious ethos means that American Muslims collectively experience negative health effects owing to living in a post-9/11 climate, and being subject to anti-Muslim bias and discrimination.[23-25]

Despite their growing numbers, there are limited data on both the aggregate health of American Muslims and how their level of religiosity impacts their health; this is because national health care surveys and databases typically do not collect information on religious affiliation. The diversity of American Muslims in terms of race/ethnicity, socioeconomic and immigrant status, and levels of religiosity poses an additional challenge for compiling a composite national picture. Community research is also challenged in the post-9/11 climate, because many American Muslims may be distrustful of researchers owing to concerns about hate crimes, discrimination, surveillance, and being targeted by the government's policies.[21,25] Researchers working with American Muslims may experience challenges similar to working with African Americans who have expressed a distrust of the health care system and health-related research owing to a history of research abuses and disenfranchisement.[26]

Against this backdrop, we chose to adopt a CBPR-based approach to conduct research on the shared salient health care beliefs, behaviors, and perceived health care challenges of American Muslims within mosque communities. Muslim communities in the United States are often centered around the local mosque, which functions as a community center offering worship, educational, and social services, thus making it an ideal and trusted setting to interact with Muslims. Furthermore, similar to health collaborations with churches in African-American, Latino, and Asian communities,[27-29] mosque communities represent a venue through which community health may be enhanced, trust established, and health care disparities reduced.[30] Given these reasons and that nearly one-half (47%) of the American Muslim population attends a mosque regularly,[21] we conducted our research within mosque communities. Our project was based in Southeast Michigan, home to one of the longest standing and largest population of American Muslims in the United States, estimated to number around 200,000 persons[31-33] and that comprises more than 40 mosques and civic organizations. Analogous to the national demographic profile of American Muslims,

Southeast Michigan hosts large communities of African-American, Arab, and South Asian Muslims, including immigrant and native-born individuals, as well as Sunni and Shiite Muslims.

The empirical research findings from our project are reported elsewhere[34-38]; this paper focuses on documenting our CPBR experience. We draw on meeting minutes, recruitment reports, and debriefing of members of the collaborative team to highlight the challenges faced and lessons learned from our experience. We describe our collaborative procedures with community partners and report on our tailored research methods to provide insight for researchers hoping to work with American Muslim mosque communities.

Methods and Results

Project Partnership

To become familiar with the key stakeholders and specific cultural mores of the Southeast Michigan Muslim community, the principal investigator (PI; A.I.P.), a native-born American Muslim physician of Pakistani descent who had relocated to Michigan only months before the beginning of this project, spent the large part of a year (2008-2009) visiting mosques, participating in cultural events, and meeting with imams and Muslim community leaders to learn about ongoing health-related projects. Through these initial conversations, he identified four organizations as potential community partners, all of whom had deep networks among mosque leadership and were actively involved in advocating for municipal and regional political structures to meet the needs of the local Muslim community: ACCESS (Arab Community Center for Economic & Social Services) an Arab community health and social services organization, ISPU (Institute for Social Policy & Understanding) a social policy institute focused on American Muslims, and ISCOM (Islamic Shura Council of Michigan) and CIOM (Council of Islamic Organizations of Michigan) two umbrella Islamic organizations that represent more than 25 mosques in Southeast Michigan. None of these organizations had previously collaborated on a health research project focused on mosque communities, and none (except for ACCESS) were familiar with CBPR approaches. A collaborative team was formed and included academic advisors, representatives from each of these community organizations, and local community leaders who served as liaisons with participating mosques.

Over a period of 6 months (January 2009 through July 2009) and several phone, face-to-face, and individual and group meetings, the collaborative team discussed community health needs, available research on American Muslim health, and CBPR methods. Collectively, the group decided on a mixed-method, two-phase research design aimed at describing the salient health care beliefs, behaviors, and perceived health care challenges of the American Muslim community. Phase 1 of the study involved in-depth, semistructured interviews with community stakeholders designed to categorize the influences of Islam on health behaviors of Muslims and to provide foundational themes for exploration within community focus.[36,38] Phase 2 involved focus groups and surveys with mosque congregants designed to provide greater context to and clarify themes brought up during the individual interviews. All participants received a $20 remuneration for participation. The University of Michigan Institutional Review Board approved the project, and shortly thereafter, an observant

Muslim social worker (A.K.) who was active in the Southeast Michigan Muslim community and had previously worked with two of the partner organizations, was referred to the PI by one of the community partners for hire as the project manager.

Given the relative inexperience of our community partners with CBPR, a flexible approach to CBPR methods was employed. We mutually agreed that community partners would be involved in all phases of the project to the fullest extent possible; however, at a minimum they would facilitate data collection through their relationships with mosque leaders and attend bimonthly team meetings where interval project updates and data analyses would be presented. Additionally, each community partner identified a particular dissemination product that they would concentrate their organizational resources toward. These outputs included a community luncheon, press releases, a policy report, and academic publications. Although funding constraints precluded fiscal incentives for the community partners, funds were allocated toward covering the cost of their travel to local and national meetings of the Robert Wood Johnson Foundation Clinical Scholars program. We also expected that this pilot would lead to future joint grant applications.

Mosque Engagement and Participant Recruitment

Our mosque engagement and participant recruitment strategy was based on leveraging the respective social networks of the PI, project manager, and community partners. Additionally, we tailored our data collection strategies to be sensitive to the cultural norms within mosque communities and to be attuned to the infrastructural capacities and organizational norms within mosques. For Phase 1, community partners identified potential interviewees as key stakeholders on account of their knowledge of the local Muslim community's health challenges and behaviors. A sampling frame was generated from this list of individuals to obtain diversity in race, ethnicity, gender, and specific role in community. Ultimately, 12 individuals were interviewed; the results of Phase 1 are reported elsewhere.[36,38]

To engage mosque leadership before carrying out the Phase 2 focus groups, members of the team (A.I.P., A.K.) presented project ideas to mosque leaders during several organizational meetings facilitated by our community partners and under the CIOM and ISCOM banner. Subsequently, research staff visited mosques whose leaders expressed support for the study to discuss data collection logistics, obtain approval for participant recruitment methods, and to establish lines of communication between mosque leaders and the research team. We utilized purposive sampling of area mosques to ensure representation of the racial and ethnic diversity of the American Muslim community. Each mosque maintained autonomy over the choice of recruitment methods and, therefore, we utilized all of the following: flyer distribution at worship services, emails on mosque listservs, notices on mosque and organizational websites, announcements made by mosque leaders during worship services and community events, and staffed tables at the mosque, particularly during the Friday prayer service. After potential participants signed up for the study, research staff confirmed their eligibility and the time/venue of the focus groups via phone calls, letters, and/or emails. Given the large number of Arabic-speaking mosque congregants in Southeast

Michigan,[31-33] recruitment materials were translated into Arabic, and one focus group was held in Arabic at the request of participants at that respective mosque.

A total of 392 community members signed up for Phase 2 of the study. Of these 392, however, we were able to confirm only 166 persons for the focus groups. All 166 individuals received focus group date and venue reminders by phone, email, and/or mailed letters. Despite these varied efforts, 64 (39%) of the 166 community members that had communicated their intention to attend did not show. Attendance at each mosque varied and ranged from 4 to 12 individuals. Participants shared that the most effective recruitment strategy was announcements made during prayer services and community events (42%); flyers (8%) and emails (5%) were the least effective methods of publicizing the study.

Dissemination Efforts

Dissemination outputs from our collaboration were identified at the outset of our partnerships and involved a community luncheon, press releases, a policy report, and academic publications. We were successful in creating all of the outputs with the involvement of our community partners. Project findings were cycled back to research participants and community stakeholders at a community luncheon attended by approximately 50 individuals. At the luncheon, we discussed study findings, and then a spontaneous discussion ensued about the importance of community-partnered research with American Muslims. Video from the event was broadcast on YouTube, and many attendees expressed enthusiasm for our novel project and wished to see more mosque community-based research. With the support of ISPU staff, a policy report detailing the health care needs of American Muslims[37] was published online, circulated nationally to health policy groups, and shared broadly via press releases, briefs on listservs, and presentations at community events. Furthermore, the project resulted in multiple media reports in local and national newspapers as well as several publications and presentations, both within the American Muslim and the larger public communities.[34-42]

Lessons Learned

To our knowledge, this is the first study to utilize a CBPR approach for health research within American Muslim mosque communities. Our partnership demonstrated that CBPR approaches hold promise for capturing American Muslim experiences and for studying the health behaviors of this population. We were successful in collecting and disseminating data about the health beliefs, practices, and health care challenges of American Muslims. We also learned the value of utilizing social networks and cultural insiders to engage mosque communities and recruit participants, as well as the importance of culturally adapting research methods to the religious needs and sociocultural reality of this community. However, during the course of the project, we faced significant challenges in maintaining the involvement of community partners and sustaining the community partnership. Although some of these challenges were expected as part of the nascent capacity-building process, we further reflect on our experiences below to provide insight to others hoping to carry out research in the context of mosque communities.

Utilizing Social Networks and Cultural Insiders

A key element in CBPR is to build on the strengths and resources within a community[1]; thus, we collaborated with mosques and well-known community-based organizations in the Southeast Michigan Muslim community, utilizing social networks to engage mosques and recruit participants. We were often referred to various contacts within mosque leadership before reaching an authority who could endorse the study and grant permission for recruitment and use of mosque facilities for the focus groups. This lack of initial clarity occurs because infrastructural support in mosques is often limited. Mosques generally have an executive board and a presiding imam who provides religious and educational services. Although some mosques may employ directors, administrative assistants, and youth workers, most mosque staff tends to be volunteers. Therefore, there are often multiple points of contact at each mosque, as well as high turnover rates and limited accountability in mosque governance. To better work with existing human capital deficits in the mosque infrastructure, community partners identified gatekeepers in each mosque community to serve as contacts for mosque engagement and participant recruitment. Access to the gatekeepers was also facilitated by the fact that the PI and main project staff were Muslims, thereby religious and cultural insiders to the mosque communities. This concordance allowed us to bridge the gap between the academy and the mosque community, analogous to how some researchers carry out work in communities of color.[43] Our reliance on the social networks of our community partners helped to establish trust and facilitate the mosque engagement and participant recruitment processes. Overall, we found that mosque leaders and community members were generally receptive to the project, willing to help generate support and recruit participants, and grateful for an initiative attempting to understand their health care needs as a faith community. Researchers working with American Muslims may be well-served in employing religious and cultural insiders to facilitate trust and community engagement.

Cultural Adaptation of Research Methods

Our recruitment success may have been as a result of using a variety of culturally tailored, community-based approaches. Indeed, a review of the public health literature has found that such approaches facilitate the recruitment of racial/ethnic minority participants in health research.[44,45] We highlight a few of our methods below.

Establishing Trust

Similar to the distrust of research by African Americans owing to past abuses,[26] American Muslims also tend to be guarded and mistrustful of public institutions and researchers outside of the community, particularly after 9/11.[21,25] To address this phenomenon, early in the project we distributed to community leaders an introductory letter that provided an overview of the study and welcomed a follow-up conversation with the PI (A.I.P.). The flyer framed collaboration in terms of helping to create the evidence basis upon which Muslims can advocate for their culturally tailoring of health care delivery. In this way, the research project was intricately connected to community interest and positioned for success. To alleviate distrust of potential participants, we employed imams and community leaders to make announcements during prayer services and community events at the mosques. As

evidenced earlier, focus group participants felt that this was a particularly apt strategy for recruitment. To further assist with trust building, we held the focus groups at local mosques, thereby signaling the buy-in of mosque leadership while also validating the project's importance and the credibility of the research staff. Before the beginning of each focus group discussion, we allotted extra time to providing participants with an overview of the project, emphasizing confidentiality of responses, and answering their questions regarding the study. Although this strategy is routine in research, it may have been a critical step in facilitating active participation within this community. Finally, as mentioned, utilizing religious and cultural insiders helped to establish legitimacy and increase trust. Researchers conducting studies with American Muslims may seek to utilize any of these strategies to establish trust with a community that is particularly sensitive to surveillance and prone to distrust of outside agencies in a politically charged environment.

Respecting Religious Norms

We adapted our research methods culturally by scheduling the interviews and focus group sessions at a time that did not conflict with worship services or the five daily prayer times. We also crafted the interview guides so that the questions would be relevant to both Sunni and Shiite Muslims, for example, ensuring participants from both denominations shared a specific textual narration. Additionally, we were cognizant of gender interaction norms in the Muslim community. Islamic teachings about modesty often result in gender segregation in worship and social settings. These teachings also carry over into health care encounters.[46] Thus, before conducting the Phase 1 interviews, we inquired about and accommodated participant preferences for a gender-concordant interviewer. We also segmented the focus groups at the mosques by gender and used a gender-concordant facilitator. We found that doing so demonstrated respect for religious values, helped to establish safety for participants, and resulted in greater comfort in sharing about their experiences. To avoid breaching religious mores about cross-gender interaction, researchers may choose to employ our strategy. Although our consideration of gender concordance was based on religious sensibilities, CBPR projects in other minority communities have utilized gender concordance to promote participant comfort and engagement.[47,48]

Challenges in Maintaining Partner Involvement and Partnership Sustainability

A key element of CBPR is the equitable and sustained participation of community stakeholders.[49] This is particularly challenging for CBPR projects with faith-based organizations, because the lack of time[50,51] and frequent changes among staff and leadership[50] can pose significant barriers to participation. Over the course of our 18-month project, the involvement of the community partners waned. A few months into the project, one of the most vocal and highly visible community partners left his post within his organization, and his replacement did not share the same enthusiasm for the project. Despite several attempts to persuade the new community partner of the tangible benefits of an ongoing collaboration, he rarely attended project meetings; subsequently, the organization he represented came to be nominally involved. Months later, we experienced another challenge when a community partner abruptly withdrew from the project after data

collection, citing the need for direct monetary compensation and ghost authorship on papers for his continued participation. Additionally, a challenge to sustainability arose from the merger of two of the community partners (ISCOM and CIOM) in the 2 years after data collection ended. Given that these two organizations were undergoing radical restructuring, identifying individuals to contribute toward dissemination activities became exceedingly difficult. In general, the community partners were more likely to be involved during the initial phases of the project, such as the development of study materials and recruitment of participants, as opposed to the later stages of data analysis and dissemination, although paradoxically they had identified select dissemination outputs as the most enticing aspects of the project proposal.

Based on the debriefing with the community partners after the completion of the study, we identified a few factors that contributed to the decline in partner participation and challenge in sustaining the partnership. First, our community partners had limited time and competing priorities. Most were volunteers at their respective community organizations; only one person was a part-time employee. Thus, scheduling conflicts and lack of financial incentives may have prevented our partners from full engagement in the research process. Given that community partners involved in research often face financial costs and time taken away from other job responsibilities,[52,53] monetary compensation and involving individuals with fewer responsibilities may have been more conducive to partnership success. Second, we relied heavily on phone meetings for convenience sake, and this may have adversely impacted the cohesiveness of the collaborative group. As noted, the extent to which CBPR partnerships pay attention to group dynamics impacts the group's ability to achieve its goals[54]; therefore, we recommend incorporating into the partnership process opportunities for community partners and researchers to interact on a personal level and cultivate their relationships. Third, the relative lack of familiarity with CBPR often times led some community partners to view their input as inconsequential, even while academic members of the project solicited their input. However, for other community partners, it lead to inappropriate expectations about the levels of participation warranting attribution and authorship within dissemination products, consequently raising ethical issues for members of the team. Researchers and academic institutions should provide learning opportunities about CBPR and the research process to assist with the long-term development and capacity building of community partnerships.

Finally, and most important, sustainability of CBPR efforts can be challenging within Muslim communities because many organizations are young and underresourced and lack the appropriate infrastructure to sustain a collaborative research effort. With the exception of one organization (ACCESS), all of the partner organizations on our project had been established less than 10 years ago and employed no more than five full-time staff. Sustainability of research collaborations can be especially challenging for mosque institutions owing to dependence on a wholly volunteer workforce, as well as the primary focus of mosque leadership on "higher priority" activities such as providing weekly worship and spiritual services to congregants, as well as responding to the sociopolitical happenings involving American Muslim communities. Additional efforts are needed to develop a research platform within the organizational infrastructures of the American Muslim community. Despite the challenges faced in maintaining our community–academic

partnership, we recognize that CBPR is characterized by a broad range of approaches[55] and that our collaboration was still informed by key CBPR principles, including treating the community as a unit of identity, building on community resources, facilitating collaborative community partnerships in all phases of research, and disseminating findings and knowledge gained to all partners.[1] Given the organizational capacities of American Muslim organizations and their relative unfamiliarity with CBPR, researchers conducting CBPR with the American Muslim community will have to calibrate the application of these principles over time to meet the changing needs of their community partners. For more successful collaborations, researchers would do well to evaluate the progress of the CBPR partnership using interviews and surveys early on in the process and continuing for the duration of the partnership.[56] Table 1 summarizes strategies for researchers conducting CBPR within American Muslim mosque communities.

Limitations

We acknowledge several limitations to our CBPR experience. Our project utilized some but not all CBPR principles. Although community members participated in the study, assisted with mosque engagement and participant recruitment, and attended the community luncheon, intermediaries to the community were involved in the decision making and ownership of project outcomes. In future CBPR initiatives, community members should be involved as more equitable participants in the research process. Limited funding prevented us from compensating our community partners and may have been a challenge to sustaining the research partnership. Our academic and main project staff included religious and cultural insiders to the Muslim community; our partnership experience and research outcome may have been different if the people “on the ground” did not identify with the Muslim faith tradition. Focusing on mosque communities and mosque-based recruitment limits the generalizability of our experience, as research partnerships among other segments of the American Muslim population may yield outcomes different than the ones we noted. Finally, given that the American Muslim community in Southeast Michigan is large and well-established with significant social capital, our project aims may have been easier to accomplish and community partners more easily identified. Researchers working with smaller and less-established Muslim communities may face different, and likely more significant, challenges.

In conclusion, our experience demonstrates how CBPR initiatives within mosque communities can lead to a productive research experience and have the potential for improving community health. Utilizing a partnership with four community organizations, we successfully engaged seven local mosques in health research, completed data collection in less than 1 year, and thereby provide a blueprint for CBPR-based health research partnerships between Muslim organizations and the academy. Although we were successful in data collection and dissemination efforts, maintaining community partner involvement and sustaining the project partnership proved challenging. Our experience suggests that successful research partnerships with American Muslims will employ cultural insiders, culturally adapt research methods, and develop a research platform within the organizational infrastructures of the American Muslim community. Additional research projects are needed

to foster a culture of research collaboration and instill ownership of and commitment to research within American Muslim mosque communities.

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Table 1

Strategies for Community-Based Participatory Research Within American Muslim Mosque Communities

Challenge	Recommendation
Establishing Trust: American Muslims can be guarded and mistrustful of researchers outside of the community, particularly after 9/11.	-Utilize religious and cultural insiders to engage mosque leadership and to recruit participants. -Conduct the interviews at the mosque to enhance participant comfort and to legitimize the research project.
Mosque Engagement: Infrastructural support in mosques is often limited, characterized by a mainly volunteer staff, high turnover rates, and limited accountability in governance.	-Utilize the social networks of community partners to facilitate mosque engagement. -Participate in the organizational meetings of community partners, frequent mosques to establish presence of research team, and meet with mosque leaders to develop rapport.
Participant Recruitment: American Muslims may be reluctant to participate in research.	-Employ a variety of recruitment methods including: flyer distribution at worship services, emails on mosque listservs, notices on mosque and organizational websites, announcements made by mosque leaders during worship services and community events, and staffed tables at the mosque, especially during the Friday prayer service. -Provide bilingual study documents and interviewers to overcome language barriers.
Religious Norms: Muslims are instructed to pray 5 times a day, and Islamic teachings about modesty often result in gender segregation in worship and social settings.	-Schedule the interviews around worship services and the five daily prayers to minimize disruption to data collection and to convey respect for religious observances. -Respect gender interaction norms by accommodating preferences for gender concordant interviewers and by segmenting interviews by gender.
Partner Involvement and Sustainability: Many American Muslim organizations are young, underresourced, and lack the appropriate infrastructure to sustain a collaborative research effort.	-Set and articulate realistic expectations for the involvement of community partners. -Create opportunities for relationship building among the community-academic team to increase rapport and group cohesiveness. -Consider providing monetary remuneration to community partners for their time on the project.