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Developing a Culturally Competent Faith-Based Framework to Promote Breast Cancer Screening among Afghan Immigrant Women

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Displaced Afghans represent one of the largest refugee populations in the world. Driven by decades of conflict, the humanitarian crisis in Afghanistan has caused a sharp increase in the number of Afghan immigrants in the United States (Poureslami, MacLean, Spiegel, & Yassi, 2004). According to recent estimates, there are more than 60,000 Afghans now living in the US (UNHCR, 2004). The San Francisco Bay Area is home to the largest US Afghan community, estimated to be above 30,000; two-thirds of this population is female, a significant percent being widowed (Lipson, Hosseini, Kabir, & Edmonston, 1996). Existing studies suggest these women are among those at the highest risk for health problems due to lack of access to health services, lack of education, language barriers, social isolation, cultural and religious barriers, and men's gatekeeping (Poureslami et al., 2004). These women, the majority of them Sunni Muslims, have received limited health care and have little, or no, prior experience with the concepts of early detection and western medicine (UNHCR, 2004; Lipson, 1996; Khan, et al., 1997; Lipson, 1997). The available literature suggests that Afghan women may have a younger average age for the development of breast cancer, but they are diagnosed at a later stage when treatment options are more limited and outcomes poorer. The few existing studies of this population indicate that the late stage of presentation may be due to inadequate knowledge among the Afghan immigrant community about breast cancer and the need for breast health care (UNHCR, 2004; Lipson, 1996). In seeking health care, Afghan immigrant women face major barriers of which the rest of the population, particularly health care providers, often are unaware (Anderson, et al., 2006).

Islamic Perspectives on Health

Islam is the second largest religion in the world (Kettani, 2010). According to a 2010 demographic study, about 1.6 billion people worldwide are Muslim, representing more than 23 % of the global population (Pew Forum, 2011). Religion among Muslims is not merely a

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set of spiritual beliefs; it affects many dimensions of life and directs their cultural, socioeconomic, and even political perspectives (Gunes Murat & Azadarmaki, 2008).

Islamic frameworks may lead Muslims to attribute the causes of illness, directly or indirectly, to God's will. For example, a study of African American, Arab American, and South Asian American Muslims found that participants believed both health and illness to be decreed by God; human agents were thought to play a secondary but complementary role (Padela, Gunter, Killawi, & Heisler, 2012). In another study of South Asian Muslim women, breast cancer was often seen as a "disease of fate" ordained by God (Johnson, et al., 1999). Among Somalis in Minnesota, Deshaw also observed a fatalistic belief that disease expresses the will of God, and the authors inferred that this notion may pose a barrier to seeking preventive care (DeShaw, 2006). In a study of Arab American immigrants in New York, respondents commented that cancer was a punishment from God for their religious failings (Shah, et al., 2008). To the extent that individuals see a particular illness as a result of God's will or from their own spiritual failings, they may decide that that the illness is not to be treated. On the other hand, religious beliefs may also provide positive resources in the face of illness, as when faith in God provides psychological strength to a cancer patient undergoing chemotherapy (Powe & Finnie, 2003).

In a positively-focused, Islamic-centered framework, however, Muslims might turn to Islam itself as a source of healing (Alrawi, et al., 2011). Thus, if Muslims believe that health is constituted by, and results from, observance of the teachings and practices of Islam, they may turn to worship practices in order to restore their health. A study of Afghani elders in California found that they believed an individual's health depended upon whether the individual adhered to Islamic guidelines and performed religious rituals, and the elders engaged in worship practices for the purpose of healing (Morioka-Douglas, Sacks, & Yeo, 2004). Other studies have found that that Muslim patients experience physical and mental benefits from religious practices such as prayer, fasting, and recitation of the Qur'an (Carroll, et al., 2007). Indeed, many Islamic observances, like sexual monogamy, ritual cleansing, dietary strictures, and avoidance of alcohol and drugs, probably do promote health.

Muslims might also turn to traditional healing practices that are described in the Qur'an and the *hadith*. These may include the use of black seed, herbs, and special foods like honey. Other practices, such as cupping, are prescribed or conducted by specialized healers (Alrawi, et al., 2011). Importantly, individuals may use Islamic healing practices in addition to, or in lieu of, the treatments offered by the professional medical domain. In the latter case, by turning to Islamic healing practices, some Muslims delay or altogether avoid seeking medical attention from which they would benefit. There are few empirical studies to account for how these decisions are made or to document how often such decisions occur.

Pilot Study on Afghan Women's Breast Health Behaviors

In 2007, with funding from University of California's Breast Cancer Research Program, the authors conducted a pilot study known as "Breast Health Behaviors of Afghan Immigrant Women in Northern California." This study provided a preliminary understanding of how

Afghan women in Northern California view their breast health. The specific aims of the study were: (1) to identify what Afghan community members believe to be their greatest concerns and barriers to breast health care, including both cultural and religious attitudes that may facilitate or hinder their seeking care; and (2) to identify the women's knowledge about and attitudes toward breast health care (Shirazi, Bloom, Shirazi, & Popal, 2012). Using Community Based Participatory Research (CBPR), the researchers worked collaboratively with Afghan community members to frame the inquiry and distill the information gathered.

The pilot study conducted in-depth, semi-structured interviews with 53 non-English speaking, first generation immigrant, Muslim Afghan women, 40 years and older, with no history of breast cancer. Study results indicated a very low level of knowledge about breast cancer in this group, low screening rates, and a lack of awareness of symptoms, risk factors, and screening procedures. Major barriers to screening included: an absence of culturally and linguistically appropriate breast health education information and programs, language difficulties, lack of transportation, low health literacy, embarrassment and modesty (Shirazi, et al., 2012).

In-depth interviews also highlighted the centrality of spiritual and Islamic beliefs in the lives of Afghan women. These women frequently mentioned the notion of faith; they believed health to be a blessing from God (Allah) and understood their bodies to be gifts from God. They considered themselves responsible to do everything in their power to survive or overcome health problems and to seek medical treatment as necessary. The women commented that, in their religious faith, life is sacred and must be respected and protected with care. Another religious matter was the women's perspective of the status of women according to Islam. Contrary to common Western stereotypes, many believed that Islam regards women as independent members of society who are equal to men in basic human rights and the pursuit of education and knowledge. Many expressed interest in reinforcing appropriate Islamic teachings as a way not only to empower women to acquire knowledge about breast health care, but also to improve men's understanding of the issues (Shirazi, et al., 2012).

The pilot study's results produced the following recommendations: (1) Training of "grass roots" bilingual members of the community in all aspects of the program including planning, design, implementation, and evaluation; (2) incorporation of male-specific educational sessions led by male health advisors; (3) use of narrative communication consistent with the Afghan oral culture where storytelling is used to relate information and cultural/religious values; and (4) inclusion of Islamic faith components that are inspirational and relevant to the lives of the women and their male gatekeepers (e.g. husbands, brothers) and that will influence these men to understand the women's needs and support them.

Developing a Culturally Competent Framework Using CBPR

The inclusion of community-based Islamic and cultural concepts fits well with the Afghan culture of collective identity and with Islamic views on health and well-being. It also provides valuable guidelines for ensuring that any intervention is culturally specific by

placing cultural practices and religious values at the center of the planning process. Adopting Community Based Participatory Research (CBPR) principles, a Community Advisory Board (CAB) was formed, composed of community leaders, healthcare providers, academic research partners, a cultural consultant, community navigators, and women from the community. The main goal of the CAB is to ensure the development of culturally appropriate cancer intervention programs (Israel, Eng, & Schuiz, 2005). Meetings of the CAB are structured to help develop a partnership where there is equality of control and participation by the community and research partners.

To ensure a shared understanding of both research and the CBPR approach, training sessions were conducted by research scientists. These scientists trained community leaders on various aspects of research, and the community leaders provided feedback and cultural and religious input emphasizing the key elements of conducting research in the community. Community leaders and CAB members were actively involved, and their views on cultural issues were incorporated into our framework.

In designing a faith-based breast health education framework, we considered the women's preferences for formats and how messages and information should be presented. Most immigrant Afghan women are linguistically isolated in their homes. The women we interviewed were enthusiastic about meeting in small groups, where information could be shared and passed on to other women through word of mouth. Family relationships in the Afghan culture and Muslim religion, however, were understood to be fundamental. In addition, men's gatekeeping roles, together with the traditional understanding and expectation of men as the heads of the household and caretakers of the family, often controlled women's decisions about their healthcare needs. Many women commented that these factors not only created communication barriers with healthcare providers, but also decreased the women's ability to make appropriate healthcare decisions. Therefore, the CAB recommended providing an education program using cultural/religious values to reach male family members. Because of the sensitive nature of the educational information about women's bodies, and out of respect for conservative Afghan cultural practices, members of the CAB suggested that the educational sessions be conducted in gender-specific groups led by Health Advisors (HAs) of the same gender.

In the discussion of the findings from the interviews, our CAB decided that the small group educational sessions should be interactive, with question-and-answer sessions and storytelling in which breast cancer survivors might share their personal narratives with hopeful messages and perspectives. The literacy rate, even in their native Farsi/Dari or Pashto, is very low—40% had no formal education—so participants expressed a strong desire for educational resources, tools and formats with visual and oral components, these being perceived as most effective for learning about breast health. Videos or programs shown on Afghan TV and websites could also be incorporated into educational material.

The CAB felt that, given the many comments from interviewees expressing the centrality of religion, religious ideas including quotes from the Quran and Prophet Mohammed about the importance of preserving one's health should be incorporated in educational curricula for both women and their male family members. Reinforcing Islamic teachings would not only

empower the women but also influence their male relatives to understand the women's needs and support them.

Incorporating Islamic Concepts

We identified several Islamic concepts that can facilitate the framing of determinants for health and encourage positive healthcare behaviors among Afghan community members. The element of ***Imaan***, which means belief or faith, is the foundation on which the Islamic lifestyle is built. It highlights the importance of fellowship and community involvement and fosters an environment for social support by encouraging social organization. ***Da'waa*** literally means "invitation," inviting or calling people to know and learn about practices in real life that are beneficial for their own and their community's well-being. It applies to every Muslim's own family, relatives and friends. The main objective is to invite people to know about and participate in the provision of basic needs for their community—such as food, shelter, education and health care—through advocating for social justice, solidarity, a peaceful and safe environment, and healthy behavior. ***Taleem va Ta'alom,*** or the promotion of learning and teaching, is highly valued in Islamic culture because Islam considers education to be a sacred duty for both men and women. ***Shura,*** or collaboration, is a basic Islamic principle that ensure that the views of the community are taken into consideration in all affairs and calls for transparency and accountability. The concept of *Shura* is also used to emphasize gender justice and equality in a variety of situations, such as interpersonal relationships within the family and the community.

These concepts provide a framework for family members and kin, who occupy the center of the Islamic lifestyle. The incorporation of these four Islamic constructs in breast health education can help the majority of community members toward a collaborative understanding of the purpose of community health programs and the roles and responsibilities of both men and women in supporting the well-being of their families and community.

Conclusions

Based on the results of the pilot study, we received strong support from the Afghan community to address barriers to breast cancer screening. Guided by CBPR principles, a multi-component intervention program has been developed by a team of academic and community partners to address unmet needs of the Muslim Afghan community. The Afghan Women's Breast Health Project (AWBHP), a culturally appropriate, faith-based intervention program for Afghan immigrant women, has been awarded a 5-year grant from the National Institute of Health. To the best of our knowledge, the AWBHP is the first study that has used a faith-based CBPR approach to enhance breast cancer knowledge and screening among immigrant Afghan women. This research represents a formative area of study with respect to (1) better understanding of role of community partners and (2) experience in faith-based health promotion research, which has received limited attention in the literature of public health. Specific emphases on cultural competency, community ownership, interdependence, and capacity building will be keys to success (Israel, et al., 2001; Israel, et al., 1998).

It is important to note that the development and planning of the AWBHP involves much more than just a Farsi/Dari translation of materials and messages. Rather, it consists of collective strategies, culturally tailored for appropriateness and competency. The program recognizes the importance of faith and spirituality in this community and, by incorporating Islamic components that are important and inspirational to the lives of participants, it reframes Islam as a facilitator of women's health. Crucially, the AWBHP is geared towards defining and delivering key Islamic messages that will promote breast health care among Muslim Afghan women.

American Muslims are one minority group for whom a shared religious identity may have important health impacts that are independent of race, ethnicity, and socioeconomic status. Numbering between 5 and 7 million in the US, Muslims represent a growing minority population that is racially, ethnically, and socioeconomically diverse (Allied Media Corp., 2000). A large proportion are immigrants from Islamic countries. Therefore, the framework we propose may provide a template for reaching a wide range of Islamic communities in the US by treating religious beliefs and their influence on health and healthcare-seeking behavior as facilitators, and not merely as "cultural barriers." At the conclusion of the five-year intervention, the AWBHP will be evaluated and best practices and recommendations for a faith based program to address breast cancer screening will be adopted. We anticipate that if the program is successful, we will have a model for religious and culturally tailored evidenced-based education and breast cancer awareness programs for Muslim immigrant women, whether they speak Farsi/Dari (Afghan and Persian women) or other dialects/languages. The knowledge gained and the guidelines developed will have an impact that reaches far beyond the Afghan community in Northern California.

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Biography

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