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The Arab American Experience with Diabetes: Perceptions, Myths and Implications for Culturally-Specific Interventions

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Abstract

Aims—Culturally-specific lifestyle diabetes prevention programs require an assessment of population disease perceptions and cultural influences on health beliefs and behaviors. The primary objectives were to assess Arab Americans' knowledge and perceptions of diabetes and their preferences for a lifestyle intervention.

Methods—Sixty-nine self-identified Arab or Arab Americans ≥ 30 years of age and without diabetes participated in 8 focus groups.

Results—Emerging themes from the data included myths about diabetes etiology, folk remedies, and social stigma. The main barrier to healthcare was lack of health insurance and/or cost of care. Intervention preferences included gender-specific exercise, group-delivered education featuring religious ideology, inclusion of the family, and utilization of community facilities.

Conclusion—Lifestyle interventions for Arab Americans need to address cultural preferences, diabetes myths, and folk remedies. Interventions should incorporate Arabic cultural content and gender-specific group education and exercise. Utilization of family support and religious centers will enable culturally-acceptable and cost-effective interventions.

Keywords

diabetes mellitus; Arabs; focus groups; health beliefs

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Introduction

Lifestyle interventions are effective in preventing or delaying diabetes in various populations[1- 7]. The landmark Diabetes Prevention Program (DPP) demonstrated that modest lifestyle modifications effectively reduced the incidence of diabetes in high-risk racially diverse individuals [1]. However, translation of these effective interventions into real-world settings for vulnerable communities with limited resources remains a challenge[8-11].

Diabetes is an emerging problem in the rapidly growing and underserved Arab American (AA) community[12-14]. In a cross-sectional, population-based study of AAs aged 20-75 years, the age- and sex-standardized prevalence rates of diabetes and prediabetes were 18% and 23%, respectively and were associated with obesity, physical inactivity, and lack of acculturation[14, 15]. Given these rates, it is expected that the burden of diabetes and its cardiovascular sequelae will substantially increase as the population ages, imposing an enormous public health burden.

The relationship of culture to health beliefs and behaviors is important in any diabetes prevention or treatment strategy that involves changing patterns of eating, physical activity, and other culturally-embedded behaviors[16]. Such knowledge informs the tailoring of interventions to the individual's culture and environment. The AA population is politically and religiously diverse, however, individuals share a common language, history, and culture[17]. Little is known about the impact of culture on health of AAs. Accurate assessment of AA health beliefs, knowledge, perception, and practices relevant to diabetes will enable successful translation of culturally- specific and sustainable interventions targeting diabetes prevention and management in this community [18]. The primary objectives of the current study were to assess AA knowledge, perceptions, and practices relevant to diabetes and their preferences for a lifestyle intervention.

Methods

Participants

Individuals were randomly selected from different stages of a larger study that was assessing the effectiveness of a culturally-specific lifestyle intervention in AAs. Participants in this larger study were randomly selected from a constructed list of 542 individuals and from the general public in Dearborn, MI. We conducted focus groups with 69 self-identified Arabs or AAs ≥ 30 years of age and without diabetes. A total of eight focus group sessions were completed, including three pilot focus groups (male-only, female-only, or mixed-gender). The Wayne State University Institutional Review Board approved study procedures.

Data Collection

We followed the principles specified by Morgan[19] for the format and conduct of focus groups. A sociologist (SJS) and an AA who is fluent in Arabic (LAJ) developed the focus group protocols. The same, trained, Arabic-speaking moderator conducted all sessions in Dearborn, MI between November 2007 and April 2009. A range of 6-14 individuals

participated in focus group sessions lasting from 90 to 115 minutes. The moderator ensured that the topic outline was covered systematically and completely.

Measures

The moderator presented each group with the same guiding questions regarding the definition, symptomatology, etiology, prevalence and perception of personal risk of diabetes. The moderator also posed questions regarding diabetes prevention and barriers to healthcare. A brief survey was completed at the conclusion of each session to collect demographic information.

Analysis

Investigators digitally recorded all sessions. A bilingual transcriptionist transcribed the sessions verbatim and a professional translator translated transcripts into English. The Principal Investigator (LAJ) reviewed transcripts for accuracy prior to analysis. A co-investigator (SJS) performed content analysis with MAXQDA2, version 2 (VERBI Software, Consult, Sozialforschung, Germany) using a grounded theory approach[20].

A co-investigator (SJS) abstracted categories and subcategories and generated narrative reports summarizing the comments of participants in each category. The authors analyzed survey responses with SPSS version 17.0 (SPSS Inc, Chicago, Illinois).

Results

Demographic characteristics are presented in Table 1. The mean age was approximately 44 years and most participants (62%) were females. Majority of participants were immigrants originating from multiple Arab countries, although most patients were from Lebanon, followed by Iraq and Yemen.

Emerging categories from data analysis included myths about diabetes etiology and treatment and barriers to healthcare. Culturally-specific themes included gender norms and religiosity. Example participant quotes are reported in Table II.

Definition of Diabetes and Symptomatology

Most participants recognized that diabetes was related to difficulty in regulating blood glucose levels. Some participants accurately identified that diabetes is specifically related to defects in insulin secretion. Similarly, many participants were accurate in reporting the symptoms of diabetes and related their understanding to personal experiences with someone who has diabetes.

Diabetes Etiology

Diabetes myths were most evident when participants discussed diabetes etiology. Some participants linked diabetes to the use of anti-hypertensive or lipid-lowering medications, eating at bedtime, or consumption of sugar substitutes. There was a common belief that being upset, anxious, worried, under stress, or suddenly shocked could cause diabetes.

Some participants correctly identified that there is a genetic predisposition to diabetes. Many related the difficulty in regulating blood glucose levels to food intake and metabolic processes.

Participants also recognized that diabetes is associated with lifestyle. Lifestyle differences between their home country and the US were seen to contribute to the high rate of diabetes among AAs. The majority of participants believed acculturative stress was a risk factor for the development of diabetes. For example, one participant described that economic difficulties and changes in occupation necessitated a longer working day and increased stress.

Perceived Disease Prevalence in Arab Americans

Participants perceived a high disease frequency; most respondents estimated prevalence from 60% to 70% and many believed every family was affected. Participants attributed this increased prevalence with changes in diet and believed their increased risk was due to their weight, high blood pressure, heredity, lack of a healthy diet, or lack of exercise.

Diabetes Prevention and Treatment

Participants were well-versed in ways to prevent diabetes including modifying diet and exercise patterns, receiving support and/or information, and reducing stress. They discussed regular walking and exercise, a healthy diet (including reduction of fried foods, portion control, reduction in sweets and carbohydrates, and fewer “junk foods”), regular checkups, stress reduction, and self-education.

Participants recognized that age and genetic factors are non-modifiable barriers to diabetes prevention. They understood that prevention was possible, but reported that their major barriers to lifestyle modification were laziness, lack of time, and/or willpower.

The use of naturopathic or herbal alternatives also emerged from discussion as effective remedies for diabetes. Khat, a stimulant drug common in Africa and the Middle East[21], was discussed as a way to lower blood glucose levels.

Barriers to Healthcare

The most commonly reported barriers to healthcare included language barriers, negligence, lack of awareness, dislike of physicians and/or medications, and transportation issues. The main barrier identified was lack of health insurance which causes many to delay care until it is absolutely necessary. A male participant noted that this problem is especially acute among recent, unemployed immigrants.

About half of the participants expressed a preference for co-ethnic caregivers. Language issues, while a concern, were not seen as a true barrier to care due to the large number of local AA providers. Another barrier to care within the AA community is stigma for those with diabetes.

Relevant Cultural Characteristics in Diabetes Prevention and Management

Study findings illustrate that AA culture contrasts significantly with European American norms, necessitating innovations in healthcare delivery practices. Gender norms and religiosity emerged as significant factors that must be considered when translating a best-practice diabetes lifestyle intervention in this community.

Gender Norms

The strictly delineated gender roles in the Arab culture were illustrated when groups discussed the preferred target audience for health education. The majority recommended developing a program that primarily targets women. The roles of the wife and mother as means to disseminate knowledge regarding diabetes prevention to their families and as lay educators to the community were considered crucial. Women were viewed as responsible for routine medical care and for promoting healthy lifestyle choices in the family.

For example, part of the intervention program included consultation and courses on healthy food preparations. There was a general consensus that cooking was the “women’s realm” and that many men “would not be interested” in attending a course on healthy food preparation.

There was also a clear preference for gender-specific exercise programs. Most felt that separate exercise classes should be offered. The only exception was in walking groups where there was agreement that mixed groups were socially acceptable. However, “physical activities that require bending or movements,” were considered to be best practiced separately.

Furthermore, about a quarter of the participants expressed a desire for gender-specific educational groups and recommended a separation of the sexes for informational sessions. All remaining participants seemed to agree that mixed-gender groups were acceptable.

Religion

The Arab community is devoutly religious; the name of *Allah* was invoked repeatedly throughout the sessions. Participants recognized the importance of mosques as community centers and suggested holding information sessions at these venues to reach a broader audience. The role of Islam is inseparable from the fabric of the Arab culture with daily prayers, dietary considerations, periods of fasting, etc. One participant noted that a lifestyle intervention program should reflect the history, diversity, and religiosity of the Arab community.

Discussion

Study findings provide a rare window into the knowledge and views of diabetes among AAs. This immigrant population has adopted several misunderstandings regarding the etiology and treatment of diabetes. Participants believed that medications used for hypertension or hyperlipidemia, late-night eating, and use of sugar substitutes were causative factors. Many participants also believed that emotional stress caused diabetes. Natural remedies were generally considered as effective and appropriate medical therapy for diabetes.

Despite misunderstandings regarding diabetes etiology and treatment, almost all of the participants appropriately perceived a high prevalence of diabetes in the AA population and believed that they were personally at increased risk for developing diabetes. Participants believed that acculturative stress, especially related to socioeconomic changes post-immigration, contributed to the increased perceived risk. We have previously shown that lack of acculturation is a risk factor for the development of diabetes in AAs in Dearborn, MI[15]. In contrast, a study of AAs in southeast Louisiana did not find a positive correlation between low acculturation and diabetes risk[22]. Differences in socioeconomic factors and the host society (such as history of racial segregation or public health implications of Hurricane Katrina) between Metropolitan Detroit and southeast Louisiana potentially contribute to this discrepancy[22].

Participants were also well aware that healthy lifestyle behaviors are crucial to prevent and manage diabetes but identified multiple barriers to the adoption of these activities such as inadequate time or personal willpower. Concordantly, in the Michigan Behavioral Risk Factor Survey 2013, AAs reported significantly less leisure time physical activity or adequate exercise (as recommended per national guidelines) than non-Hispanic whites[23]. Other impediments to healthy behaviors noted in the current study were barriers related to seeking and utilization of healthcare such as lack of medical insurance and the cultural stigma associated with the disease.

Findings reported here build on our previous study that explored AA perceptions of barriers and facilitators to diabetes self-management [24]. A common thread between studies includes the influence of religious beliefs on health behaviors and preferences. The preference for incorporation of religious imagery into educational programs identified here alludes to the significant effect of religion on diabetes beliefs and behaviors. Indeed, in our previous study we found that some participants fasted during Ramadan against physician recommendations and despite manifestations of dysglycemia [24]. Another previous finding that is corroborated here is a preference for gender-separated physical activity due to cultural and religious expectations of female modesty [24].

Our findings compare and contrast with perceptions of diabetes previously described in European Americans. Concerns common to both populations include financial barriers to healthcare access and the importance of social support[25, 26]. In contrast, a study by Tessaro et al. demonstrated that Appalachian Caucasians lacked adequate knowledge about diabetes and perceived a low personal risk[26]. Whether the difference in perceived risk for diabetes is related to the fact that diabetes is more prevalent in AAs[14] or is the result of socio-environmental factors such as greater emphasis on social interaction and interpersonal information sharing in AAs is not clear. Increased perceived risk noted in our study might, in theory, prompt AAs to make healthy lifestyle changes sooner than their European American counterparts and can be leveraged to reach more AAs through public health initiatives. Additionally, both our study and Tessaro’s reported a stigma to diabetes but for differing reasons: AAs believe the disease reflects poorly on the family reputation (due to the genetic component of diabetes etiology) and European Americans report feeling guilty because they believe diabetes is self-induced (due to the environmental component of diabetes etiology).

This difference may reflect the collectivist nature of AA culture compared to the individualism emphasized in American culture.

Arab immigrant populations in Western countries likely share similar perceptions of diabetes and health beliefs. A literature search revealed one study by Sulaiman et al. that assessed diabetes and healthy lifestyle knowledge and perceptions in Turkish and Arabic-speaking immigrants in Australia with low socioeconomic status [27]. Despite some patent demographic differences (such as inclusion of Turkish individuals and differing gender proportions), several similarities to our study are noted. Most striking is the commonality of perception in regards to diabetes etiology. Participants in both studies cited stress as a causative factor for diabetes. Participants in the Sulaiman study perceived an association between leaving their home countries and the development of diabetes, believing that the inevitable changes in lifestyles due to immigration resulted in unhealthy habits and subsequently caused disease. Participants in our study clearly linked the American lifestyle and acculturative stress with diabetes. Additionally, participants in both studies expressed a clear preference for walking as an exercise form, being inexpensive (as noted by the Sulaiman study) and can be done in mixed-gender groups (as noted in our study). Participants in the Sulaiman study also discussed cultural gender roles and expectations, especially the role of women in caring for their family. Whereas the participants in our study focused on the potentially beneficial role of women as healthy lifestyle educators and promoters, participants in the Sulaiman study perceived women to be constrained by their family roles and responsibilities.

The perceptions reported here can be applied to inform future diabetes prevention interventions in the AA community. Lack of medical insurance is identified here as a major barrier to healthcare in AAs, thus improving accessibility/utilization of care requires that interventions be cost-effective. Optimization of already available resources in the community will help to defray cost. The emphasis on the central role of family in AA culture suggests that family engagement might promote intervention effectiveness. In fact, many individuals believed that their purpose for being involved in the lifestyle intervention was to work within their own families and to disseminate what they had learned to the broader community. The gender norms delineated in our data further illuminate the importance of each individual’s specific role in the family: the male as the leader and the female as the nurturer. Women were viewed as leaders and educators in promoting health behaviors and education for their family and the community. It was clearly evident that a family-centered lifestyle intervention with a focus on women will have a higher probability of success. Indeed, we later demonstrated that family support predicted achievement of the prescribed weight loss goal[28]. A potential application of family support and the nurturing role of women is to incorporate educational sessions and activities that specifically target women who care for family members with diabetes. This can help initiate and sustain healthy behaviors for the individual with diabetes and further extend the benefits of the intervention to the whole family. Our suggestion is further supported by Sulaiman et al. who also recommend leveraging the role of women in intervention efforts[27]. In addition, the importance of religion for many participants suggests that religious centers are strategic outreach locations for intervention recruitment and implementation. Facilities are readily available, familiar, and are often located conveniently within the community. Additionally,

the stigma associated with diabetes may be offset by the positive connotation associated with a place of worship.

Findings from this study informed the development of a DPP-modeled, culturally-modified lifestyle intervention aimed at diabetes prevention in AAs[29]. The intervention offered gender- specific educational and exercise sessions to address cultural preferences and gender norms. It also targeted women and solicited family involvement to promote family buy-in of healthy food preparation. The educational curriculum included cultural anecdotes, proverbs, and religious ideology to represent the influence of religion on the community. Consequently, the resultant intervention had been shown to be effective and feasible with 86% of participants completing the entire study[29].

While the findings here are invaluable to developing culturally-specific interventions for this community, there are some limitations. This study was conducted in Dearborn, MI and the majority of participants were of Lebanese descent, thus generalizability is limited. However, several other nationalities were also represented, including Iraqis, Yemenis, Palestinians, and Syrians. These different nationalities share similar cultural norms, beliefs, and language. Female silencing and lack of self-disclosure due to the patriarchal nature of AA culture may have affected findings obtained from mixed-gender focus groups. However, the inclusion of two gender-specific focus groups avoids this phenomenon. Additionally, the degree of impact of the perceptions identified here on health behaviors and outcomes in AAs is unclear. For example, a recent cross-sectional survey of health risk behaviors in Michigan AAs found that a numerically higher percentage of AAs than non-Hispanic whites with hypertension used antihypertensives[23]. Thus the perception reported by our sample that antihypertensives cause diabetes does not necessarily indicate that AAs avoid these medications. Quantitative data from comprehensive, population-based surveys can be triangulated with the data identified here to establish the validity, scope, and public health impact of these findings.

Summary and Conclusions

To our knowledge, this is the first study to evaluate perceptions and knowledge of diabetes and the cultural influences on intervention preferences in the at-risk AA population. The findings reported here have important implications for the development and implementation of culturally relevant strategies for diabetes prevention and management. Program developers need to actively address myths and misconceptions about diabetes, especially disease etiology and alternative treatment options. Interventions need to be culturally acceptable and financially accessible, which can be aided by use of available resources, e.g. family support and religious/community centers as well as the incorporation of AA gender norms and religious beliefs.

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Highlights

- There is a lack of data on Arab American diabetes perceptions
- Perceptions and cultural preferences will help develop culturally-specific programs
- Lifestyle interventions should address myths and folk remedies
- Interventions should incorporate cultural content and account for gender norms
- Family support and religious centers can enable cost-effective interventions

Table I

Demographic Characteristics of Arab Americans Participating in Focus Groups on Diabetes Perceptions and Intervention Preferences, November 2007-April 2009

N	69
Age, mean ± SD[a]	44.2 ± 9.9
Sex, n (%)	
Male	26 (38)
Female	43 (62)
Country of Birth, n (%)	
Lebanon	39 (57)
Iraq	7 (10)
Yemen	7 (10)
Palestine	4 (6)
Syria	4 (6)
Other Countries	8 (11)
Length of Stay in the US, n (%)	
Short Duration (≤ 5 years)	8 (12)
Mid Duration (6-9 years)	19 (27)
Long Duration (≥ 10 years)	34 (49)
Born in US/No Response	8 (12)

[a]SD = standard deviation

Table II

Arab American Participant Quotes Regarding Various Aspects of Diabetes Perceptions and Preferences for Lifestyle Intervention

Topic	Example Participant Quotes
Definition of Diabetes and Symptomatology	“My husband who is diabetic has dry mouth. He has dry skin. His skin splits. He has dry feet. He has blurred vision. During the night, no matter what he eats, he feels hungry. He wants to eat anything, mostly something sweet.”
Diabetes Etiology	“Diabetes is the result of shocks. In addition, being upset has an effect. Any person, who experiences a shock and being upset regarding a loved one, becomes diabetic. This greatly affects a person.” "…It is hereditary. This is more difficult. In case of hereditary, one has to protect oneself more from the normal person, because he has it in the family." “The first thing is the way we eat, the quality of food we eat, eating sweet products more than it is necessary. It is the lack of balance in the body between what is necessary food to eat the necessary food and the sweet products that one eats more.” “Since we came to this country [the United States], we have to live a different way of life and in consideration of the American way of life, whether moving by cars, etc. However, over there [in home country], one could walk a long distance. The closeness of life there [in home country] makes you exert an effort. The fats are secreted from the body. Here, it is not so. The Americans controlled this lifestyle. They go to the gym, for example, whether men or women. They know the equation because of lack of activity limited to the office and home. Hence, they go to the gym daily for an hour…Our problem, as Arabs in America, we did not live as Americans 100%, nor we kept our Arabic lives...” “…The reality of the American life is that I have work and have no free time. I do not work 15 hours in my home country. Here, I must work from 12 to 15 hours a day. This cumulative stressful situation causes in me sluggishness/laziness. Sluggishness will lead to cholesterol like we just said in this hour.”
Perceived Disease Prevalence in Arab Americans	“I think in every home there is one who is diabetic whether a mother, a father, a child or one of the relatives. I think everyone became aware of diabetes because they have someone in the family who is diabetic.”
Diabetes Prevention and Treatment	"One must pay attention about his lifestyle. One must not eat too much sugar. One must watch about everything, because this disease is very sensitive. The sugar level rises very fast and to lower the level is very difficult." "My mother's sugar level reached 600. They could not lower the sugar level in the old fashioned way, and the "azaqan" lowered it. Now, when my mother goes to the female doctor, if the doctor finds it [sugar level] high she tells her go and drink from it. This is something popular." "Khat, you know, Khat lowers the level of sugar in the blood…It is bitter, bitter herbs. Everything that is bitter lowers diabetes..."
Barriers to Healthcare	“When people come from the old country they do not find a job right away or find a job without health insurance; most companies are now cutting back anyway.” "…here, in our community there is shame. We have shame in our community to ask [about diabetes]."
Relevant Cultural Characteristics in Diabetes Prevention and Management: Gender Norms	“It is a part of the Arabic culture that men are not interested in cooking.” “When men attend these sessions, they will communicate with us better, listen and accept the meals we cook... I think you should invite women and their husbands.” “Walking in groups around the neighborhood is encouraging and supportive. It can be done in group with family, or friends, certainly.” “Possibly we can express ourselves more freely in women [-only educational] session.” “You should define the community you will deliver the speech to.

Topic	Example Participant Quotes
	As an example in the ICD [mosque], we have mixed gender lectures where men and women are seated separately, but in the same place, where they listen to the same lecture at the same time. However, there are separate lectures for women only on Wednesdays at 1:00 PM that deals with topics important to women, so it depends on the place and topic."
Relevant Cultural Characteristics in Diabetes Prevention and Management: Religion	"Bring wise old Arabic sayings from the Chaldean culture in the Iraqi history to the Greek and Arabic culture that was in Lebanon and all cultures. You can find subjects or stories about nutrition and medicine dealing with nutrition. All these, if we include, it will feel that this is a book automatically; a special book that includes ethnic matters."