South-South Migration

# Shaikha H. Al-Kuwari

# Arab Americans in the United States

# Immigration, Culture and Health





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# **South-South Migration**

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Shaikha H. Al-Kuwari

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Immigration, Culture and Health



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To My Brother Hamad

# Acknowledgments

This has been a long journey. This work is the result of the Ph.D. dissertation I completed in 2018 at the University of Florida under the supervision of my mentor, Dr. H. Russell Bernard. When I started forming my research ideas, I could not stop thinking about the last call I had with my diabetic father and brother, telling me about their experience fasting during Ramadan. Their emotional and physical struggles as well as their determination to ignore their doctors' recommendations of not fasting inspired me. My choice of diabetes as the focus of my research started from this call and resulted in the writing of this book.

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# **About the Author**

**Shaikha H. Al-Kuwari** is an Assistant Professor of Anthropology at Qatar University. She earned her Ph.D. in Anthropology from University of Florida, USA, in 2018. Her research focuses in studying the relation between culture and health. She is interested in building cultural models of illnesses using the latest methodological advances in social science. Her goal is to create culturally based precision medicine where the culture of people is taken in consideration in providing healthcare-related services.

# Chapter 1 Introduction



**Abstract** This chapter highlights the objectives, general themes, and theoretical drive behind this book. It discusses the relationship between culture and illness with a focus on the Kleinman explanatory model of illness and how it can be used to improve healthcare services. In addition, the chapter discusses the methodological development in studying the cultural beliefs of illnesses.

Keywords Diabetes · Explanatory model · Immigrant health

What is the hardest thing you have ever done? One answer for many Arabs in America is "leaving my country," but why did they leave? Reasons vary from fleeing war and death to poor life conditions and chasing the "American Dream"; were all their dreams of success and wealth come true.

To them, leaving their homeland means leaving behind their comfort zones, support systems, and their sense of belonging. Taking with them whatever is possible, but most important, their culture, stories, memories, and hope.

Arabs, similar to many other immigrants, are faced with the daunting task of creating their new lives after arriving in America; a life for themselves and generations to come. What makes this harder is that living the "American Dream" is not easy, being Muslim and Arab in America comes with its fair share of stereotypes and racism.

Arab Americans' past experiences, current situation, and future fears hugely affect their health, especially regarding chronic illness such as diabetes.

Ethnic groups in the United States have a high prevalence of diabetes compared to the general population. Diabetes is twice as high among Hispanics (Weller et al., 1999) and African Americans as it is among non-Hispanic whites (Flegal et al., 1991). Diabetes among Arab Americans in Michigan is estimated to be two to three times higher than in the general US population (Jaber et al., 2004). Despite this high rate of diabetes, few studies have focused on diabetes among Arab Americans.

This book shows the relationships among immigration, culture, and health. Culture guides Arab Americans in understanding their changing world in general and their health specifically. This book aims to build a cultural belief model of diabetes, a chronic illness with high prevalence among Arab Americans compared to all other ethnic groups in the United States. In doing so, questions such as "Why did I get diabetes?" "Why me?" "What is the meaning of what I feel?" and "What is the treatment for diabetes?" will be answered. In addition, the book discusses the struggles of fasting Ramadan and the role of family support in providing care. The book will touch on some identity struggles as well as the notion of not feeling 'safe, understood, or accepted' and its relation to Arab American health. The book is a result of two years of ethnographic fieldwork in Dearborn, Michigan, which is the location of the largest Arab American enclave.

#### **1.1** The Relationship Between Culture and Health

The anthropological study of illness dates back to the work of Rudolf Virchow in the 1880s (Trostle, 1986). However, medical anthropology as a named field of study began with Caudill (1953) chapter in Kroeber's monumental edited volume, Anthropology Today. Since then, anthropologists have continued to contribute to epidemiological knowledge through studying illnesses across the world.

Kleinman's (1978) early work was a turning point in studying the relationship between culture and health. In his work, he recognized the importance of the relationship between culture and health. He called for the importance of developing a theoretical model that perceived the healthcare system as a culture system (Kleinman, 1978), with emphasizing that culture system should be looked at and understood in relation with healthcare, health, and illness (Kleinman, 1978).

Kleinman (1988) presented an important framework for examining illness across cultures with his work on the explanatory model of illness from the emic perspective. The model provides an analysis of how culture influences how people understand and address illness and the healing process (Kleinman, 1978). The model dose not only view the healthcare system as a culture system but also provides a systemic understanding of how the relationship works and functions. In addition, the model provides a framework that allows a cross-culture comparison (Kleinman, 1978). Kleinman (1978) argues that without such a framework, we cannot have a comprehensive outlook of the dynamic relationship between culture and health and its effect on people.

For Kleinman, healthcare system is cultural system that contains meanings, values and behaviors, this system is similar to any other cultural systems such as kinship (Kleinman, 1978). Healthcare systems try to understand the patient's beliefs related to the causes of their illness, the way in which they understand their body, experience pain, explain symptoms, and understand and adhere to treatments (Kleinman, 1978).

Importantly, in his work, Kleinman differentiates between "disease" and "illness," where disease is the Western medical explanation related to the "malfunctioning or maladaptation of biologic and psychophysiologic processes in the individual" (Kleinman et al., 1978, p. 141). In contrast, illness represents the "personal, interpersonal, and cultural reactions to disease or discomfort" (Kleinman et al., 1978,

p. 141). For Kleinman, illness relates to the social and cultural context in which people perceive and navigate disease. This social and cultural context of illness encompasses psychological and sociological processes that effect the process of the disease's development and management from the beginning to the healing stage (Kleinman, 1978).

Usually, illness experience begins when a person notices a change in their physical status; this change might be apparent or hidden—a feeling. Following this is their social network recognizing their illness. As family and community members recognize that this person has an illness, together they start the healing process, from taking treatment recommendations to seeking different treatments options. The chosen treatment options depend on the person, their family and community explanation of its causes and how it can be treated, which might include going to the hospital (Kleinman et al., 1978).

Kleinman (1978) framework provides an understanding of why Western medicine might not be effective in providing cure. Following the same previous logic related to the differences between diseases and illnesses, doctors diagnose and treat diseases, while the patient experiences illnesses. These two factors do not always correlate; people who have the same disease might have different illness experiences than others do. In addition, people can have an illness without having a disease, and people can have diseases but not experience illness. This does not imply that diseases can be treated in hospitals by using Western medicine and illnesses can be treated by traditional healers. As Kleinman (1978) pointed out, doctors might not cure a disease if the patient is not willing to agree on the treatment and comply.

How does all of this work and function within the healthcare system? According to Kleinman, most healthcare systems contain three "social arenas," which he calls the popular arena, the professional arena, and the folk arena (Kleinman, 1978). In the popular arena, patients experience sickness within their social network, which includes family, friends, and community members. This arena plays a very important role in the patient's healing because 70% to 90% of sickness is delt with within this domain in both Western and non-Western cultures (Kleinman, 1978). From the early stages of sickness, people express what they are feeling to the people around them, looking for solutions, remedies, and recommendations. The popular arena role is not limited, and it does not stop after seeking medical treatments; people's evaluation of treatment efficiency, medicine management, and family care continue until reaching a cure. The professional arena contains the scientific Western medicine, as well as the "professionalized" traditional healing practices (Kleinman, 1978). This arena contains any interaction people have within the hospitals, clinics, or even within professionalized alternative medicine such as Chinese medicine. The folk arena contains the traditional healer and traditional healing practices that are not professionalized.

According to Kleinman (1978), in dealing with sickness, healthcare systems have the following six cultural adaptive tasks: (1) Patients learn culturally how to understand and navigate the illness. (2) Patients learn how to choose where and who will provide the care between the traditional and non-traditional medicine. (3) Patients learn how to manage the illness and express it in a way that is socially recognized. (4) Patients process the healing. (5) Patients learn the ways in which the sickness can be prevented. (6) Patients experience the way in which healing is reached and the possible treatment side effects or failure, as well as how patients navigate chronic illness and process the idea of death.

Based on the idea that healthcare systems are cultural systems that contain the three arenas, Kleinman suggested using the explanatory models of illnesses, which can be used in eliciting knowledge related to illnesses from doctors, patients, and family members. The model elicits five main domains: "etiology; onset of symptoms; pathophysiology; course of sickness (severity and type of sick role); and treatment" (Kleinman, 1978, p. 87). Kleinman emphasized that explanatory models are part of a "specific systems of knowledge and values centered in the different social sectors and subsectors of the healthcare system. Thus, they are historical and sociopolitical products" (Kleinman, 1978, p. 88).

To put the explanatory model of illness in practice, Kleinman et al. (1978) suggested working in two models: the patients' model and the doctor's model. For the patient's model, healthcare professionals should ask the following question "[1] What do you think has caused your problem? [2] Why do you think it started when it did? [3] What do you think your sickness does to you? How does it work? [4] How severe is your sickness? Will it have a short or long course? [5] What kind of treatment do you think you should receive?" (Kleinman et al., 1978, p. 147). Kleinman and colleagues also suggested additional question to enhance the understanding of the cultural and psychosocial aspect of illness, which are: "[6] What are the most important results you hope to receive from this treatment? [7] What are the chief problems your sickness has caused for you? [8] What do you fear most about your sickness?" (Kleinman et al., 1978, p. 147). Regarding the doctor's model, comparing the doctor's model with that of the patients' will be essential "in dealing with issues relating to conflicting beliefs and value systems" (Kleinman et al., 1978, p. 147).

The process does not end here, knowing the differences should move from the point of "knowledge" to a real and dynamic "practice." Kleinman emphasized that clinicians should review patients' models and compare them with doctors' models. The goal is to close the gap between both, either by educating the patient and giving them the opportunity to ask questions, or by negotiating the differences to reach a middle ground, especially regarding differences in treatments that might affect the healing process (Kleinman et al., 1978).

Kleinman et al. (1978) generated a set of hypotheses that he recommended clinicians and anthropologists test to assess the limitation of the current healthcare systems and to define the needed interventions. These hypotheses follow the fundamental assumption that doctors can treat diseases in hospitals while only folk healers can treat illness. Kleinman et al. (1978) assume that patient care satisfaction will be less if disease is treated and not the illness. Additionally, this framework assumes that healthcare professionals can be trained to treat both illness and diseases, which will result in patient satisfaction and healing processes. Their hypotheses emphasize the importance of teaching "clinical science" that accompanies both social science and biomedical science to enhance the training and understanding of health professionals to address illness. In addition, they assume that healthcare systems are mostly built based on the biomedical explanation of diseases without including the idea of illness, which creates difficulties and limitations in providing healthcare.

Kleinman et al. (1978) proposed that social science should be developed as "a clinical discipline." They suggested that every medical school and teaching hospital should have a department of clinical social science. The department should include physicians, anthropologists, and sociologists who will provide training for students. The training should be based on learning theoretical knowledge based on cases, and then applying the learned techniques on real-life clinical settings that involve patients. In addition, such a department can aid in developing the field by conducting more research related to culture and healthcare.

Kleinman (1978) laid his important work, and many tools were developed to elicit patient models of illnesses in clinical settings. Weiss (1997) developed the Explanatory Model of Illness Catalogue (EMIC). This catalogue contains a set of semi-structured interview questions to build the patient illness explanatory model by eliciting their experiences, causes, and treatment-seeking behaviors as well as general beliefs related to the illness. Lloyd et al. (1998) developed the Short Explanatory Model Interview (SEMI) to be used for patients with mental disorders. The interview contained a set of questions addressing the patient's cultural background, the symptoms, and their treatment-seeking behaviors. Broadbent et al. (2006) developed the Brief Illness Perception Questionnaire (Brief IPQ), which contained 9 items to evaluate the patient's illness perceptions.

Explanatory models' tools were developed by using both qualitative and quantitative approaches. Kleinman (1988) argues that evaluating "suffering requires more than the addition of a few questions to a self-report form or a standardized interview" (p. 28). He called for the use for ethnographic, biographic, historic, and psychotherapy methods in collecting data related to suffering from illnesses. According to Kleinman (1988), "these methods enable us to grasp, behind the simple sounds of bodily pain and psychiatric symptoms" (p. 28), which can enhance our understanding of the experience of having an illness.

Although quantitative explanatory tools can be effective in electing the patient's beliefs model, qualitative-based tools arguably "would provide richer data and a better understanding of illness representations and experiences" (Dinos et al., 2017, p. 109). In addition, it is important to consider that explanatory models based on quantitative approaches consume less time compared to qualitative-based models, which make them easier and faster in application (Dinos et al., 2017).

In addition to the models' specifications related to the method type, and in relation to the information depth and application time, Dinos et al. (2017) highlighted in their research that, "Explanatory models are not static constructs. Rather, they are fluid, and they can be influenced by a number of factors, including the type of clinician/ interviewer and the questions asked, the symptoms of the illness, and the patient's outlook/mood and migration history" (Dinos et al., 2017, p. 112). Those factors can alter and change during the course of illness. Due to this nature, Dinos et al. (2017) called for the importance of reassessing the model and altering the process throughout the healing experience.

With the development of Kleinman's explanatory model of illnesses and the methodological development of the research tools, a massive effort has been made in anthropology to study the cultural factors involved in the causes and consequences of many illnesses in many social groups. Examples include diarrhea among rural Mexicans (Ryan & Martínez, 1996), mental illness among West Africans (Edgerton, 1966), Ebola among Northern Ugandans (Hewlett & Amola, 2003), AIDS among Africans (Green & Ruark, 2011), breast cancer among Latinos (Chavez et al., 1995), hypertension among the Ojibway (Garro, 1988), hypoglycemia in the United States (Hunt et al., 1990), and diabetes among Latinos (Weller et al., 1999).

This book includes additional seven chapters. The **second chapter** will focus on discussing diabetes from a cross-cultural perspective. The **third chapter** offers a comprehensive review of the history of Muslims in America, and the **fourth chapter** will be dedicated to the research setting and methods. In the **fifth chapter**, I will discuss the results from the first stage of building the cultural belief model of diabetes. The **sixth chapter** will show the results of the consensus analysis. The **seventh chapter** discusses the possible application of the Arab American cultural belief model. **The eighth** chapter will be dedicated for the discussion and the book's conclusion.

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# **Chapter 2 Diabetes in Cross-Cultural Perspective**



**Abstract** This chapter provides a systemic comprehensive review of the causes, symptoms, treatments, and management of diabetes across cultures. The review shows some overlaps in the cultural beliefs. Diabetes can be caused by factors related to genetics, obesity, lack of physical activity, and mental illness. Most studies have found that symptoms of diabetes are thirst, vision problems, dizziness, joint problems, and headaches. In addition, studies have shown that diabetes can be treated by medication, exercise, and healthy diet.

Keywords Diabetes causes · Diabetes symptoms · Diabetes treatments

Diabetes, a chronic illness that is "characterized by elevated levels of blood glucose, accompanied by disturbed metabolism of fats and proteins. Blood glucose rises because it cannot be metabolized in the cells, due to lack of insulin production by the pancreas or the inability of the cells to effectively use the insulin that is being produced" (Roglic, 2016, p. 4). Mainly, diabetes as chronic illness is divided into two categories: (1) Type-1 diabetes, where the pancreas does not produce insulin, and (2) Type-2 diabetes, where "the body cells are resistant to the action of insulin that is being produced and over time the production of insulin progressively decreases" (Roglic, 2016, p. 4). So, what are the causes of diabetes? What are the symptoms? And who it can be treated and managed? This chapter reviews the literature to find answers to those questions from a cross-cultural perspective.

### 2.1 Causes of Diabetes Across Cultures

The question "why me?"—as Kleinman (1988) discussed—is a process in which people try to make sense of or explain why they or people they know have illnesses based on their life experiences. This process of answering "why me?" (in general) and "why has diabetes happened to me?" (specific to this research) involves multiple explanations. After reviewing the literature, three overlapping themes were extracted

across different cultures in terms of what causes diabetes from an emic point of view. The three themes are that diabetes is caused by (1) genetics; (2) behavior (diet, obesity, and lack of physical activity); and (3) mental states (susto/fright, stress, and depression).

#### 2.1.1 Genetics as a Cause of Diabetes

Neel (1962) worked on the prevalence of diabetes among indigenous populations across the world. Everett (2011) noted that Neel "has pursued the genes presumed to be associated with particular ethnic groups and their potential role in the onset of the disease" (p. 1777). Neel's (1962) thrifty genotype hypothesis "argued that diabetes mellitus involved a quick insulin trigger, which evolved in hunter-gatherer ancestors in response to periodic feast-famine conditions" (Everett, 2011, p. 1777). This hypothesis was revised later, when Neel (1999) admitted that his original hypothesis "presented an overly simplistic view of the physiological adjustments involved in the transition from the lifestyle of our ancestors to life in the high tech fast lane" (cited in (Everett, 2011, p. 1777). The knowledge that diabetes is caused not only by genetics but also by complex social and environmental factors has become well accepted in academics, but what about the emic point of view? Do people from different cultures believe that genetics can cause diabetes?

Skelly et al. (2006) worked among rural African Americans in North Carolina and showed that genes are thought to be a cause of diabetes and that, therefore, the illness cannot be prevented. A community member expressed that by saying, "It's just in the genes. It's nothing that you can prevent from happening. It's something you are born with" (Skelly et al., 2006, p. 15). This cultural knowledge of the relationship between genes and diabetes is not necessarily fully understood by people, as Skelly et al. (2006) noted. This unclear relationship was expressed by a community member who said, "I think when you... you can inherit a lot of things, that's why I think—mostly you can inherit diabetes I guess because you're from the same blood and everything—same family. I don't know. I can't really explain it" (Skelly et al., 2006, p. 15). This unclear relationship was also expressed in Baglar (2013) study in the United Arab Emirates; a community member said that diabetes has "something to do with genes" (Baglar, 2013, p. 119).

Garro (1996) found that among Canadian Anishinaabe (Ojibway), there is a similar belief that diabetes is "all in the genes" (Garro, 1996, p. 399). Diabetes is not seen as different from any other illness that might be caused by genes shared among members of a family; a community member said that diabetes "runs in the family. And that's just the same as a person with trouble with your heart. See, that runs in your family, all kinds of different diseases, you know, it runs in families" (Garro, 1996, p. 408). Through research at a public clinic in Oaxaca, Mexico, Everett (2011) also found the belief that diabetes happens because of genetic inheritance. A community member expressed this by saying, "I inherited it [diabetes] from my mother" (Everett, 2011, p. 1779). In a study of South Asians, Lawton et al. (2007) found that

community members held a concept of diabetes as a hidden gene that people inherit and that is waiting to strike at any time; one person said that diabetes has "been there in the genes just waiting to happen." Weller et al. (1999) showed that, across Latino populations, there is a consensus in the belief that heredity is a cause of diabetes, and people are thought to be born with diabetes.

Other studies showed that genes are believed to be only a minor cause of diabetes. In Choudhury et al.'s (2009) study of Bangladeshis in the UK, they found that the belief that genetics causes diabetes is not very common. Culhane-Pera et al. (2007) showed that genetics is not seen as a cause of diabetes by Hmong refugees in the United States; people from that population argued that diabetes is not caused by genetics. (Culhane-Pera et al., 2007).

Although people from different cultures mention genetics as a cause of diabetes, researchers have not examined how people think genetics can cause diabetes. How close must the genetic relationship be in order for a person to have diabetes? Can one inherit it only from immediate family, or can the source be far away in the family tree? Studies of people who say that diabetes is genetic and is just waiting to happen (Baglar, 2013; Lawton et al., 2007) do not explain what triggers diabetes. What makes the genes act up? This is a clear avenue of research.

# 2.1.2 Diet, Obesity, and Lack of Physical Activity as Causes of Diabetes

Studies among Latinos regarding cultural beliefs about diabetes show that being "chubby" (Everett, 2011) or overweight (Poss & Jezewski, 2002) are seen as causes of diabetes from the emic point of view. This belief is closely related to lack of physical activity and exercise (Jezewski & Poss, 2002). This belief is also shared by Canadian Anishinaabe (Ojibway). Garro (1996) presented a series of narratives that showed the relationship between diet, obesity, and diabetes; one community member said that people who overeat are "stuffing themselves" (p. 399) and "sometimes their faces get so round; they get so fat. I know a lot of people are going to get it [diabetes] because people are all out of shape" (p. 399).

In addition to the relationship between diet and obesity, Skelly et al. (2006) noted that among rural Africans Americans in North Carolina, there is a belief that age is closely related to lack of physical activity and obesity; one community member explained, "the older you get, the less active are your vital functions. And if you're not exercising or stuff, you have a tendency to relax more. And your chemistry makeup slows down your organs—which slows down the process of intake and outtake of nourishment to your body" (Skelly et al., 2006, p. 17).

Emically, what types of food cause diabetes? Do the quality and type of food matter, or is the quantity the main cause? Both quality and quantity seem to matter in cultural explanations of diabetes. Consuming sugar and otherwise having a poor diet are the main causes of diabetes according to people from various cultures. Latino

populations believe that poor diet (Poss & Jezewski, 2002) and "eating sugar or sweets: drinking sodas" (Weller et al., 1999, 2012) can lead to diabetes. Among African Americans, eating large quantity of sugar (Skelly et al., 2006) is seen as one of the main causes of diabetes. Sugar seems to be central in the discussion of the cause of diabetes; in fact, diabetes is known as "sugar in the blood" among Latinos (Luyas et al., 1991, p. 685) and "sweet blood" among the Hmong (Culhane-Pera et al., 2007, p. 181).

On the other hand, some African Americans are focused on eating well and maintaining body chemistry, as one community member explained: "If you're not eating right, the chemistry in the body—the body chemistry gets off. And if you're not eating right, then your sugar balance gets off. And if it gets off and stays off for a long period of time, then you're prone to get diabetes" (Skelly et al., 2006, p. 16). Among the African Americans that Skelly et al. (2006) studied, eating well means not eating food that contain sugar and salt, and food that does not contain a lot of calories, or high levels of cholesterol and oil (Skelly et al., 2006); these restrictions are much broader than only avoiding consumption of sugar.

Studies have shown that people believe that in addition to the type and quantity of food, changes in food consumption behaviors and the availability of new types of food are closely related to increased consumption of sugar and other unhealthy foods, which in turn leads to diabetes. The Canadian Anishinaabe, whom Garro (1996) interviewed, attributed their high sugar consumption to changes in diet behaviors caused by increased availability of canned food, which is possibly contaminated with chemicals (Garro, 1996, p. 399). A member of the community said that changes in food consumption behaviors resulted in people possibly developing diabetes: "People from long ago didn't have any kind of sweets or anything to get at, but when the white man came they brought all this different kind of foods, you know we start getting into it and not watching what we're eating" (Garro, 1996, p. 403).

Baglar (2013) conducted a study in the United Arab Emirates on how changes in lifestyle and an economic boom led to changes not only in food habits but also in physical activity that led, according to informants, to diabetes. Reflecting on changes in her diet since the 1960s, one informant said that in the past, her diet depended on "home reared goat and chicken, fish and rice, vegetables and fruit, according to the season" (p. 113) and very "few boiled sweets" (p. 113). She also said that she and others "all ate together at the same time each day and there was no food between meals. Nobody bought the quantity they do now" (p. 113). Another female community member discussed how it was difficult to avoid being fat and to control eating habits while living a luxurious lifestyle: "They're [people she knows] all so big, they never used to be like that" (p. 112); she explained that the people she knows got to this stage because "they don't do anything, they just eat and sleep, they have maids to do everything" (p. 112).

Lawton et al. (2007) studied diabetes among Bangladeshi immigrants in the UK and discussed the process of migration from South Asia to the UK; this migration resulted in consuming more of what these immigrants consider bad food, which in turn caused them to have diabetes. A Hindu informant who was a vegetarian before

moving to the UK said that he "blamed his diabetes on a high-sugar diet, which, for him, was necessitated by moving to a non-Hindu, meat-oriented culture" (Lawton et al., 2007, p. 896).

Culhane-Pera et al. (2007) studied diabetes among Hmong refugees in the United States and discussed how changes in diet and in physical activities are closely related to migrating from their countries of origin to the United States. The Hmong thought that the type of food available in the United States was not doing them any good; they believed that the food contains a lot of sugar, salt, fat, pesticides, and fertilizers, which have a negative effect of their health. A community member summed up their lives before migrating to the United States by saying how their day used to start with, as they worked all day long on rice fields, chopping trees, and climbing hills, which in his opinion helped in getting all the toxins out of their body compared to their lives in the United States, where their physical activates dramatically decreased, which led to the toxins staying in their body and therefore they become more likely to have diabetes (Culhane-Pera et al., 2007).

## 2.1.3 Susto/Fright, Stress, and Depression as Causes of Diabetes

Susto, or fright, is a widely recognized folk illness among Latinos. It was extensively examined by Rubel et al. (1984) in what is now a classic in medical Anthropology, Susto A Folk Illness. Since that book's publication, the relationship between susto and diabetes among Latinos has been widely examined in two ways: susto as a perceived cause of diabetes (Everett, 2011; Mendenhall et al., 2010, 2012; Poss & Jezewski, 2002; Weller et al., 1999, 2012) and susto as a risk factor for diabetes (Baer et al., 2012).

Latinos, and particularly Mexicans and Mexican Americans, tend to consistently attribute their diabetes to susto, which is the result of a very stressful or emotional life event, such as being robbed (Everett, 2011; Mendenhall et al., 2010), having a bad car accident (Jezewski & Poss, 2002), or watching a child drown (Jezewski & Poss, 2002). In Oaxaca, Mexico, Everett (2011) found that susto, stress, and other emotions that were thought to cause diabetes were not necessarily linked to a single event. He found that "women in Atzompa were likely to attribute diabetes to a chronic excess of emotions (e.g. 'soy muy enojona') because they associate their failing bodies with the contradictions and disappointments of their lives" (Everett, 2011, p. 1781).

Nervios, another common ailment among Latino populations, like susto, is also an "expression of psychological distress" (Weller et al., 2008). Baer et al. (2012) designed an experiment to measure the relationship between susto, nervios, and diabetes among Mexican Americans. In this study, Baer et al. (2012) recruited two groups of people who had recently been diagnosed with diabetes and a control group of people who were not diagnosed with diabetes. The main goal of Baer et al. (2012) experiment was to empirically explore the folk belief—which was found in the abovementioned studies—that susto can cause diabetes. Baer et al. (2012) found that "the prevalence of susto among those with a recent diagnosis of diabetes (63%) was not higher than that among controls without a diagnosis of diabetes (69%)" (Baer et al., 2012, p. 344). Regarding nervios, the researchers did not find "a higher prevalence among those with recently diagnosed diabetes (52%) than among those without a diagnosis of diabetes (65%)" (Baer et al., 2012, p. 344).

Migration is a stressful life event and is believed to lead to susto/fright and thus to diabetes in some groups. Among Mexican American diabetes patients in Chicago, for example, Mendenhall et al. (2010) found that stress was highly related to susto. According to this population, high stress is caused by bad living conditions, crime, and social inequality. In addition, Mendenhall et al. (2010) showed that having stressful and traumatic experiences due to migration adds to stress levels. For example, one participant in the study said, "when one lives here illegally and one doesn't have any documentation, immigration catches you, right and so after the first time that immigration catches you, you are traumatized. The trauma affects the diabetes a lot because you find yourself scared. One has the need to work to take care of the family" (Mendenhall et al., 2010, p. 228).

The perceived relationship between stress and diabetes is not limited to Latino populations. Choi and Reed (2013) studied Korean immigrants' rates of depression and diabetes and found that people who had high levels of stress were more likely to suffer worse diabetes outcomes, have less family support, and have worse health in general.

Lawton et al. (2007) studied Bangladeshi immigrants in the UK; many participants in the study talked about having high stress due to migration and how this caused them to have diabetes. A community member expressed this by saying he had diabetes "because of stress... I had a lot of stress due to the family, like, if I was leaving them behind, how was I to move them forward. And when I did move forward [by migrating] then I thought of how to bring the family I had left behind forward... to the same place as I was. Because in our culture, even if you're married you still have to think of your sister and their children, you have to think of your mother and father—I mean there's no old people's home in Pakistan, we have to do everything ourselves... So I thought like this a lot, so I think the mistake was made here" (Lawton et al., 2007, p. 899).

Culhane-Pera et al. (2007) studied the Hmong community in the United States and discussed how not fitting in and losing their homeland contributed to diabetes in this group. Culhane-Pera et al. (2007) discussed how the community felt out of balance emotionally, struggling with depression, stress, and anxiety. The researchers found that the community suffered from "difficulties of adjusting to this new country, including not knowing the language, not being able to support themselves, and raising children in a country with different cultural values" (Culhane-Pera et al., 2007, p. 183).

In addition to migration, other lifestyle changes are linked to stress and diabetes. Baglar (2013) studied diabetes in the United Arab Emirates and discussed the relationship between stress and diabetes there. Baglar (2013) showed that high stress levels among women in the community could be a result of changes in women's roles because women now take on more responsibilities and participate in the economy by working outside of the home.

## 2.2 Symptoms of Diabetes Across Cultures

Symptoms of diabetes differ across cultures and are described as physical rather than emotional symptoms. While making sense of diabetes often includes a description of emotions and feelings, none of the studies reviewed in this chapter mentioned any emotional symptoms of the disease.

Weller et al. (1999) described the symptoms of diabetes, from the community's point of view, among a representative sample of 131 respondents in the United States, Mexico, and Guatemala. The list contained 16 symptoms of diabetes: excessive thirst, lack of animation, changes in kidney function, frequent urination, burning sensation during urination, sugar in the blood, cravings for sweet things, dizziness, headaches, irritability, problems with blood circulation, elevated blood pressure, eye problems/ vision loss, high susceptibility to other illnesses, slow wound healing, and no need to stay in bed. Another study, by Jezewski and Poss (2002), was less extensive but still listed eight symptoms of diabetes: "weight loss, visual problems, fatigue, weakness, headache, thirst, increased urination, dry mouth and skin" (Jezewski & Poss, 2002, p. 847).

Skelly et al. (2006) studied diabetes among rural African Americans in North Carolina, and the resulting list of symptoms shared many items with the lists from the studies by Weller et al. (1999) and Jezewski and Poss (2002). The participants in Skelly et al.'s (2006) study reported that the symptoms of diabetes are "increased thirst, dry mouth, weight loss, slow healing, and problems with vision" (p. 17), as well as "feeling weak, being easily tired, and having to decrease activities or symptoms of complications—fainting, shock, or coma, seizures, or swelling of the limbs" (p. 17). Masoudi Alavi et al. (2012) studied Iranian beliefs about diabetes and listed three symptoms: "fatigue, polyuria and mouth dryness" (p. 102). Culhane-Pera et al. (2007) studied the Hmong community in the United States, resulting in a list of four symptoms: "tired, weak, thirsty, with a dry mouth and frequent urination" (p. 184).

From the overall shared symptoms across the studies reviewed above, only nine symptoms were shared from among the 25 symptoms found: slow wound healing, eye/vision problems, thirst, fatigue, frequent urination, headaches, weight loss, weakness, and dry mouth.

In addition, very few participants in all cultures said that diabetes has no symptoms. Culhane-Pera et al. (2007) stated in his study of Hmong refugees in the United States that only one out of 44 male participants in his study said that diabetes has no symptoms. Skelly et al. (2006), in their study of African Americans in North Carolina, noted that people do not necessarily associate certain symptoms with diabetes until they are diagnosed by a doctor.

#### 2.3 Treatment of Diabetes Across Cultures

Studies have shown that some populations do have the knowledge that diabetes is a chronic illness that cannot be cured but that needs to be treated (Weller et al., 1999, 2012). Treatment of diabetes varies across cultures and can include diet and exercise, traditional medicine, and prayer. These treatments are often combined.

Weller et al. (1999) found 18 treatments for diabetes in Latino populations in the United States, Mexico, and Guatemala. In general, Latinos in their study believed that diabetes has no cure and that it should be treated by doctors and not by pharmacists. The treatment process requires checking blood sugar on a regular basis, having a balanced diet, losing weight, taking pills that help "to process sugar," not consuming sweets, not drinking alcohol, and not drinking lemon tea or the herbal drink known as yerba buena (Weller et al., 1999). In addition to these treatment options, Latinos recognize the danger of leaving diabetes untreated; kidney and heart problems, coma, and death are thought to result from lack of treatment (Weller et al., 1999).

Jezewski and Poss (2002) studied Mexican Americans with diabetes and listed four different treatments, which overlap with the list created by Weller et al. (1999): diet regulation, herbal remedies, prescribed medication, and regular exercise. In addition to the treatment list, this study indicated that people are afraid of having to take insulin in the future; a diabetic patient in the community said, "right now I am taking the medicine and checking the level of sugar, and I am doing more or less okay. I am doing this because, as I told you, I do not want to start taking insulin injections" (Jezewski & Poss, 2002, p. 851). Patients who are afraid of taking insulin believe that it can cause blindness, that it is addictive, or that it means they are in a very advanced stage of diabetes (Jezewski & Poss, 2002). In addition, the researchers listed several herbal treatments that are believed to treat diabetes, such as bricklebush, trumpet tree, tree of life, yellow bells, prickly pear, cactus, and creosote (Jezewski & Poss, 2002). Poss et al. (2003) studied home remedies used by Mexican Americans in El Paso, Texas, to treat diabetes and found that home remedies or herbal treatments are often used along with Western medication. Many diabetic participants in the study did not see any problems with combining the two types of treatments, but others noticed that taking some of the herbal medications could lower their blood sugar; one participant in the study said, "When I started taking Glucotrol, I stopped drinking the herbal tea. I used to drink it, but I don't anymore because I am afraid that my blood sugar may go down too much" (Poss et al., 2003, p. 315).

Skelly et al. (2006) studied diabetes among rural African Americans in North Carolina; this community showed an interesting variation in diabetes knowledge based on age and gender. Younger participants believed that diabetes has no cure, on the other hand, older participants mentioned that diabetes can be treated and cured. In addition, the study found that both young and old males were not sure if diabetes can be cured compared to females (Skelly et al., 2006). In addition, the participants in the study showed very little knowledge of diabetes treatments; one of the participants mentioned "needles" without being able to recall the treatment name (Skelly et al., 2006).

Culhane-Pera et al. (2007) studied the Hmong community in the United States and found that the Hmong believe that treatments for diabetes are strictly related to diet and exercise. People in this community believe that in order to treat diabetes, they should limit consumption of salt, sugar, soda, alcohol, fruits, short-grained rice, sticky rice, spices, and fried foods (Culhane-Pera et al., 2007). When participating in exercise and physical activities, Hmong diabetics reported feeling "lighter, looser, and less tight" (Culhane-Pera et al., 2007, p. 185) and having better sleep. Although diabetics in the Hmong community recognize the importance of exercising, they reported barriers, such as fatigue, pain, and bad weather, which prevented them from exercising (Culhane-Pera et al., 2007). In addition to diet and exercise, the Hmong respondents added that feeling happy is important for getting better: "people have many ways to make themselves feel happier, and healthier. They travel to Southeast Asia or to other states, work in their garden, create harmony at home, get out of the house, visit family and friends, see a psychologist, and come to the group visits" (Culhane-Pera et al., 2007, p. 186), and "a few people described spiritual treatments for diabetes, both intercession through Christian prayer and assistance from shaman[s] and shamanic helping Spirits" (Culhane-Pera et al., 2007, p. 186). Hmong diabetics did not necessarily think that doctors should be the first treatment source; one participant in the study said, "I manage myself like I am my own personal doctor... because I know which medicines or things will make me feel better and which ones do not. So I treat myself all the time. Only when I cannot help myself, then I come in and let the doctors help me" (Culhane-Pera et al., 2007, p. 186).

#### 2.4 Diabetes Management Across Cultures

Management of chronic illness, including diabetes, is a complex task that includes many players, parts, and situations. In order for diabetics to manage their illness well, there is a "wide range of life-long activities which must be carried out on a daily basis in different situations" (Masoudi Alavi et al., 2012, p. 101). Those daily tasks involve not only diabetic patients but also everyone with whom they live.

Accepting the illness is the first step in coping with and managing diabetes. In a study of 300 Turkish diabetes patients, Besen and Esen (2012) found that 46% had a low level of acceptance. A low level of acceptance of diabetes is associated with low levels of education, low income, having other chronic illnesses, a negative outlook on life, and less social support.

Masoudi Alavi et al. (2012) found that diabetic patients in Iran who received family support were more likely to cope with their new illness and accept it. For example, a 19-year-old participant in the study said, "I accepted my new situation very well, because of my mother, she helped me a lot and even now after 15 years, she comes to see whether I am all right at night" (p. 104).

Jezewski and Poss (2002) study of diabetes among Latinos showed a similar importance of one's family in diabetes management. Participants in the study said that most of their lifestyle and care decisions were made with the help of their family

members, such as help "from a spouse, parents, and/or children" (p. 852). In addition, the study showed that diabetic patients in this population had "changed their diets since the time of diagnosis, and most of them subsequently convinced their family members to join with them in following the new diet" (p. 852).

Baglar (2013) study of diabetes among Emiratis demonstrated the role of family when a patient with diabetes refused treatment. One man said that he initially refused to seek Western medicine and relied on traditional medicine, but because of the pressure his wife put on him, he started to go to the hospital. According to him, "I only go to keep her happy" (p. 118).

Henderson's (2010) study of American Indian elders presented the narrative of a diabetic family. A member of the family said, "we all diabetic, now, me and my brothers and sisters, and we all eat. My mom (also a diabetic), they feed her whatever she wants...makes her happy. One thing that's hard to do is change in life. I guess I just Indian (laughs)" (p. 309). In addition, Henderson (2010) study showed that for elder Indians, "Non-adherence to medical recommendations was perceived as being socially desirable, because adherence placed the elder outside their peer group" (p. 303).

Edelstein and Linn (1985) found that patient family management and environment were associated with diabetes control for diabetic men in the United Kingdom; patients who lived in a family that was "low in conflict and organization and oriented toward achievement" (p. 541) were more likely to have better control over their illness. In addition, the study suggested that diabetes as a chronic illness was not any different from any other chronic illness when it came to the family's role in management. Thus, a patient with hypertension who lives with a family with the above characteristics would also have better management of his or her illness.

Pinelli et al. (2011) studied family support and its association with success in losing weight among Arab American diabetic patients enrolled in a lifestyle intervention program. The goal of the program was to achieve 7% weight loss for each participant. This goal was accomplished by 44% of the participants in the program, and participants who achieved the goal were more likely to have a high level of family support, a high level of session attendance, and longer duration of physical activities. In addition, the amount of calories consumed by the participant was not significant in weight loss; this association was more significant among women than men. A similar result of women benefitting from intervention programs more than men was found by Chesla et al. (2014) in their study of first-generation Chinese Americans. Before enrolling in a behavioral intervention treatment program, women had a higher level of depression than men. After the program, women showed greater improvement than men. The study suggested that women are more likely to benefit from behavioral intervention treatment programs to managing diabetes.

Many studies have focused on couples' relationships and diabetes management. Houston-Barrett and Wilson's (2014) study of diabetes management across various ethnic and racial groups (18 whites, 17 Hispanics, 6 blacks, and 2 Pacific Islanders) showed that couples who had positive behaviors and attitudes had the best management of diabetes, while couples who had accepted their diabetes but did not have a positive attitude had less successful management. Finally, the couples who had negative behaviors toward accepting their diabetes were likely to have the worst management outcomes.

In Iida et al.'s (2013) study in northeastern Ohio, diabetes symptoms were associated with lower levels of enjoyment and more tension between couples. Distress was not highly associated with a high level of tension between couples with non-diabetic spouses.

Seidel et al. (2012) studied spouses' involvement in their diabetic partners' disease management in the United States. Through 139 interviews conducted with participants above the age of 50, the researchers found that "Among male patients, when both partners shared an expectation for spouse involvement, greater diet-related spouse control was associated with better diet adherence of patients" (p. 698). On the other hand, when "expectations for spouse involvement were not shared, greater spouse control by wives was associated with poorer diet adherence" (p. 698).

Other factors, such as acculturation level, seem to have an effect on diabetes management among immigrants. In a study of 211 Chinese Americans with diabetes, Xu et al. (2011) found that those who were born outside the United States and those who were older had lower levels of acculturation, whereas people with a socioe-conomic status and who had in the United States for longer had higher levels of acculturation. Moreover, those who were more acculturated were more likely to have better self-management of their diabetes than people who had lower levels of acculturation.

In addition, Weller et al. (2013) suggested a relationship between different illness models and diabetes management. In their study, the authors tested "whether differences between patient and provider explanatory models of diabetes affect self-management and glucose control in diabetes patients" (p. 1498) in Guadalajara, Mexico. The researchers found that different models of diabetes held between the patient and the provider may lead to negative diabetes outcomes and management behaviors. The study also suggested that the patient's level of education might lead to problems in understanding the provider's model of diabetes.

Other social and religious practices suggest interesting management challenges for diabetic Muslim patients. Salti et al. (2004) focused on measuring the effect of fasting during Ramadan among 1070 Muslims from 13 different countries. The researchers reported that people who have diabetes "fasted for at least 15 days" (Salti et al., 2004, p. 2306) out of the 28–31 fasting days. They also reported that only half of the participants with diabetes reported changes in their diabetes medication intake. Severe hypoglycemic episodes were reported to increase during fasting for participants with diabetes, especially among those who changed their diabetes medication dosage or physical activity patterns.

Pinelli and Jaber (2011) studied the practices of Arab Americans with diabetes during Ramadan. The authors interviewed 27 patients and found that most of the participants reported performing less exercise and physical activity during Ramadan. In addition, the researchers found that the majority of the participants in the study did not have knowledge of the risk of fasting while taking diabetes medication, when to break their fast, special diets that may be required, or how to exercise

during Ramadan. Also, half of the patients reported changes in their insulin-taking patterns. Additionally, the respondents reported struggling with thirst the most. Only one participant reported breaking the fast during Ramadan. The study included no reports of participants going to the hospital.

Bravis et al. (2010) conducted a study among Muslims in the United Kingdom to "determine the impact of Ramadan-focused education on weight and hypoglycemia episodes during Ramadan in a diabetic Muslim population taking oral glucose-lowering agents" (Bravis et al., 2010, p. 327). When designing the study, Bravis et al. (2010) divided the participants into two groups: The first group attended educational programs about "physical activity, meal planning, glucose monitoring, hypoglycemia, dosage and timing of medications," while the second group did not attend any such programs. The researchers found that, on average, the first group lost 0.7 kg after Ramadan, while the second group reported a weight gain of 0.6 kg. The researchers also found that there was a significant decrease in the number of hypoglycemic events in the first group compared to the second group. The researchers suggested that providing educational programs about fasting during Ramadan "minimizes the risk of hypoglycemic events and prevents weight gain during this festive period for Muslims, which potentially benefits metabolic control" (Bravis et al., 2010, p. 327).

Phumipamorn et al. (2008), in their study among diabetic Muslims in Thailand, tested "whether an extended pharmacy service would improve glycaemic control and cardiovascular risks in diabetic Muslims" (p. 31). To do so, they created two study groups: The first group (n = 63) received a diabetes education brochure and "met a pharmacist who educated and discussed with each patient regarding medication uses and diabetic treatment" (p. 31). The second group received regular pharmacist service. Average blood glucose levels, lipid parameters, medication adherence (number of pills taken), and diabetes knowledge score were collected from both groups. The researchers found that the first and second groups had similar average blood glucose levels, but the first group had lower levels of cholesterol and showed an increase in medication adherence and knowledge about diabetes. This means that pharmacy service similar to what the first group received has no effect on diabetes management but does have an effect on cardiovascular risks by lowering the levels of cholesterol among Muslim diabetes patients in Thailand.

Cultural models of diabetes across the world show some differences and some commonalities. The high prevalence of diabetes among ethnic groups in Western nations (the United States, the UK, Australia, and Germany) has led to a great amount of research focused on cultural models of diabetes. Building explanatory cultural models of diabetes has mainly followed the tradition suggested by Kleinman (1988) discussed in Chap. 1.

Causes of diabetes cross-culturally combine both physical causes—such as inherited genes and diet—and emotional causes, such as anger, susto, and depression. Symptoms of diabetes, on the other hand, mainly include physical symptoms such as thirst and fatigue. Those symptoms do not necessarily lead to one's realization of having diabetes but rather generally act as a push to visit the doctor. The treatment of diabetes often combines traditional medicine, such as herbal treatment; Western medicine, such as visiting the doctor; spiritual treatment, such as praying; emotional treatment, such as joining support groups; and diet and physical activities that are practiced under doctors' recommendations. Additionally, there are some cultural beliefs about what food or diet is good or bad in terms of causing or managing diabetes.

The behaviors for managing diabetes are complex; they require not only the selfeffort of patients but also that of family members and spouses. The greater the family and spousal support are, the greater the management and control of diabetes will be. In addition to family and spousal support of the patient, intervention programs, such as managing emotional factors related to having diabetes and losing weight, combined with family support seem to have a positive impact on diabetes management. Other factors that contribute to the successful management of diabetes include the level of acculturation, diet, physical activity, and lifestyle strategies for diabetic people in various daily routines.

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# Chapter 3 History and Culture of Muslims in America



Abstract This chapter offers a comprehensive review of the history of Muslims in America. The chapter will be divided into three sections. The first section reviews the history of Muslims in America, including African American Muslims, Arab American Muslims, and South Asian American Muslims, and their immigration history, as well as Islamic movements and the groups' relationships. The second section of the chapter will discuss the significance of mosques in the lives of American Muslim immigrants. This section will include ethnographic observations related to the experience of visiting mosques and the dynamic political and religious roles of mosques in Dearborn, MI. The third section of the chapter addresses the culture and identity of American Muslim immigrants as they relate to family and marriage, gender roles, and identity formation.

Keywords American Muslims · Mosques in America · Immigrant identity

A comprehensive understanding of Arab Americans can't be done without, an understanding of their historical and social position as Muslims in America. Statistics relating to Muslims in America "are difficult to obtain" (Leonard, 2003, p. 149). The American Muslims' "total population is thought to be between 3 and 8 million" individuals (Leonard, 2003, p. 149). They include three major groups: Arab Americans (33%), African Americans (about 30%), and South Asians (29%) of the total population of American Muslims (Leonard, 2003).

In studying Muslims in America, the literature has divided American Muslims into two groups: (1) African American Muslims, labeled as the "native Muslims," and (2) the immigrant American Muslims, mostly referring to Arab and South Asian Muslim immigrants. Although the population of African American Muslims is "thought to be" the biggest in United States, very little attention has been given to studying this population. Literature on African American Muslims mostly has dealt with the history of African Muslim slaves in America, their arrival, their religious movements, their establishment of mosques, and their relationship with other American Muslim immigrants. African American Muslim population culture(s) was not examined in the literature included in this Chapter. Conversely, Arab and South Asian American Muslims' history and cultures were thoroughly examined.

The arrival, a significant event every immigrant goes through. The arrival to the land where they will build their new lives and settle. In History, Muslims in America arrived in two different waves: The "native" African American Muslims coming from Africa and the Arabs and south Asian Muslim immigrants coming from Asia. Each population arrived carrying their native cultures, religions, and ideologies. For an outsider, Muslims are viewed as a one cohesive group, this simplistic way of viewing Muslims is not accurate. Muslims in America, as all Muslims in the world, live with the hope of having Islamic Unity beside their cultural and ideological differences.

#### 3.1 African American Muslim History

Curtis (2009) book on the history of Muslims in America presented evidence that the existence of Islam in America may go back as far as 1492 when Columbus's first expedition arrived in the American lands, carrying Muslim slaves mostly from West Africa. Historical documents have consistently provided evidence that African Muslim populations have been growing year after year. In the 1530s, the "legendary African explorer Estevanico is said to have explored Arizona and New Mexico in search of gold and treasure" (Curtis, 2009, pp. 4–5). By "the late 1500s, common Muslim-sounding names such as Hassan, Osman, Amar, Ali, and Ramadan appeared in Spanish language colonial documents" (Curtis, 2009, p. 5).

History has provided stories about African slaves practicing Islam after their arrival in the America. A highly educated West African slave, Ayuba Suleiman Diallo—later named Job—from the Fulani ethnic group, who spoke both English and Arabic, arrived in Maryland, where he was sold to a tobacco farmer (Curtis, 2009). Job was allowed to practice his religion by his owner and "maintain[ed] his daily prayer schedule, and he would often walk into the woods to pray" (Curtis, 2009, p. 1). After he was freed, Job kept his Islamic practices and "butchered his own meat according to the rule outlined in the Sharia, or Islamic law and ethics; and avoided all pork" (Curtis, 2009, p. 2). Yet the number of practicing Muslims in this period of time can be estimated between the ranges of "thousands to more than a million" (Curtis, 2009, p. 4). This leaves very "little doubt that Muslims have been part of the continent's history for hundreds of years" (Curtis, 2009, p. 4).

In addition, some historical accounts have showed that "African American Muslim slaves, like slaves more generally, used whatever means were at their disposal to improve their lives and gain their freedom" (Curtis, 2009, p. 11). This meant "publicly converting to Christianity or perhaps pretending to convert to Christianity" (Curtis, 2009, p. 11). For them, this did not mean leaving Islam or not practicing it. "They claimed that Christianity and Islam were two expressions of the same religious idea. God, they say is Allah, and Jesus Christ is Mohammed—the religion is the same, but different countries have different names" (Curtis, 2009, p. 19).

After the end of slavery, African American Muslims started to form more strict positions. Leonard (2003) discussed how African American Muslims were "driven by a history of slavery and oppression in the US, chose Islam as an alternative to Christianity and to white America" (p. 150). By the early twentieth century, African American Muslims formed many movements in an attempt to reform African American Muslims. The World's Columbian Exposition in Chicago in 1893 was one of the first movements that African American Muslims participated in. They worked on "featuring mosques and practicing Muslims and including the Parliament of Religions which introduced Hindu, Buddhist and Islamic teachings and missionaries to the American religious scene" (Leonard, 2003, p. 150). In 1920, the Ahmadiyya movement targeted issues related to African American segregation and discrimination with the goal of uniting American Muslims (Curtis, 2009). In 1931, the Moorish movement in the face of white oppression under a loose rubric of what were claimed to be Islamic oriented beliefs and practices" (Haddad & Smith, 1994, p. xix).

In addition, one of the movements that created a big impact and controversy across the United States was the Nation of Islam movement. In 1930, W. D. Fard established the movement mainly to fight discrimination and racism against African Americans (Sahib, 1995). Fard, who was Muslim, started as a door-to-door seller of silk to African Americans claiming that his silk came from their country of origin and had been made by their own people (Sahib, 1995). As Fard's stories gained popularity, attracting many African American listeners, he began the preaching of Islam. According to Sahib (1995) early in Fard's career, his preaching text of choice was the Bible, but as his audience grew, "he assumed the role of prophet and began to attack teachings of the Bible and the white race." (p. 54). To help him carry out and extend the movement, Fard hired ministers, such as Elijah Muhammad and Malcolm X. As the movement grew, Fard established the University of Islam in Chicago and encouraged Muslim families who joined the movement to enroll their children in it rather than in public schools. The University of Islam children were taught about their religion and African culture rather than the "civilization of the Caucasian devils" (Sahib, 1995, p. 57). They also took courses in "higher mathematics, astronomy, general knowledge, and ending of the spook civilization" (Sahib, 1995, p. 57). Nation of Islam as a movement went as far as establishing its own military group called "the fruit of Islam" to fight the police and stand up to the government and to discrimination (Sahib, 1995).

## 3.2 Arab American and South Asian American Muslim History

Arab American Muslim immigrants arrived in the United States at the end of the 1800s (Haddad & Smith, 1994). Most of them were young men, who came with the goal of working to earn money, and go back to their countries of origin to provide
better life for themselves and their families (Haddad & Smith, 1994). After arriving in America, they mainly had two options in terms of occupation: the first option was to work as laborers, peddlers, or traders (Haddad & Smith, 1994) and settle in places like Ross, North Dakota, which has one of the earliest Muslim settlements in the United States (Haddad & Smith, 1994). The second option was to serve "as a cheap labor on work gangs, such as those in the Seattle area who were employed on the railroads" (Haddad & Smith, 1994, p. xvii). After Muslims in America settled for a while in different parts of the country, they started to establish businesses such as grocery stores, coffee shops, and restaurants, while continuing to work in factories and plants such as the Ford Motor Company in Dearborn, Michigan and Quincy, Massachusetts (Haddad & Smith, 1994). Their dream of returning home faded after a while, but the dream of earning a fortune in the United States and living the American dream was still so real.

Between the 1950s and 1960s, a second wave of Arab American Muslim immigrants arrived in the United States. This time they came with a different orientation than the past immigrants; as they came with secular orientation (Haddad & Smith, 1994). This led them to avoid formatting their new identity based on religion as a starting point and helped them focus on the Arab culture and their political engagement in America (Haddad & Smith, 1994). During this time, America started to receive South Asian Muslim immigrants who were highly educated and qualified (Haddad & Smith, 1994).

In the mid-1960s, Arab American and South Asian Muslim students arrived in the United States. The students came with strong Islamic ideologies that did not necessarily excite the migrants (Haddad & Smith, 1994). The student had significant ideas on the 'Islamization' of Muslim communities (Haddad & Smith, 1994). Students coming from Egypt carried the "Brotherhood of Egypt group" ideology, while the students from Pakistan called for the "Jamaati Islami of the Indo-Pakistani group ideology." Both groups had a different outlook on how a Muslims community in American should look like, compared to the existent Muslims community they found when they arrived (Haddad & Smith, 1994). To some extent, both groups were shocked about "the modernization (liberalization, secularization, westernization) of the Muslims society" (Haddad & Smith, 1994, p. xxi) in America. So both groups went into "forming idealistic communities, at times attempting to impose their response to western influence in Islamic countries on Muslims in America" (Haddad & Smith, 1994, p. xxi).

Both Arab and South Asian Muslim communities in America that arrived prior to the arrival of the students had different reactions to what the groups had to offer and suggest. In general, at the beginning, Muslim immigrant were excited to learn from the students about the Islamic teachings. Later on, Arab and South Asian Muslims found that those Islamic teachings were too extreme or unnecessary or unrealistic and would not work in their "new" life as immigrants in America (Haddad & Smith, 1994). This created tensions between the group of students carrying the more conservative ideas of Islam and the Arab and South Asian Muslim immigrants who had lived in America for a longer time and who became more acculturated to the American life style (Haddad & Smith, 1994).

# 3.3 "Native" African American Muslims Versus Immigrant American Muslims

Arab and South Asian American Muslim immigrants did not like the idea that African Americans had presented Islam in America prior to their arrival. They "dismissed African American knowledge of America as irrelevant. They then cast Islam as unknowable for those who had been Muslims for decades. Arabic was cast as an extremely difficult language and thus, indigenous Muslims [African Americans] could have only limited access to Islam and thus, only limited authority" (McCloud, 2006, p. 132).

Refusing to recognize African Americans as Muslims was not only discussed on the level of what Muslim immigrants believed. Haddad and Smith (1994) argued that African American Muslims claimed to be Muslims, as they were "motivated primarily by the reasons of the economics (many groups that claimed some kind of Muslim identity maintained platforms of economic advancement of blacks); of justice (reacting to continuing racism in America they ground the egalitarian teaching of Islam particularly attractive); of identity and rootedness in a history, culture, and people from which they had been severed by the experience of slavery; and of rejection of Christianity, which they believed not only had provided the ideological justification for their enslavement but centered on the worship of Jesus depicted as a blue-eyed, fair-haired Caucasian man" (p. xix).

Haddad and Smith (1994) also added that the relation between African American Muslims and American Muslim immigrants did not exist only because American Muslim immigrant consider African American Muslims to be not 'real Muslims', but also because both groups come from different life experiences, struggles, and have different goals as Americans. American Muslim immigrants are struggling with their identity as 'new' Americans, and African American Muslims experience life in America as multigenerational Muslims (Haddad & Smith, 1994).

Although the relation between the African American Muslims in America and the American Muslim immigrants did not exist in many levels for a long time, African American Muslims challenged immigrants by calling on the important of being more strict, especially when it comes to following Islamic laws related to not consuming pork and alcohol, and following the guidance related to racial equality (Haddad & Smith, 1994). But whether American Muslim immigrants have reacted to this was not indicated by Haddad and Smith (1994).

The hope for unity among Muslims in America seems to be far from becoming reality, since unity between groups has it strains, as the above discussion showed (Haddad & Smith, 1994). For many Muslim communities in the United States, the goal of having a one unity no longer exist; the goal become more realistic as they aimed to have a unity with keeping a room for ethnic and culture variation (Haddad & Smith, 1994). Although this outlook seems to be more realistic, having Islamic unity while keeping cultural diversity is still far from being understood.

# 3.4 The Significance of Mosques in American Muslims' Lives

When and where were the first mosques in America established, and by whom? This is a question that is still debatable since it is closely related to the discussion of who the first Muslims in America were (Kahera, 2013). The Ross mosque was established in North Dakota in the 1920s by Arab American Muslims and is thought to be the oldest mosque in the country (Kahera, 2013). In Kahera's (2013) review of the history of mosques in America, historical accounts presented evidence mosques were being established in America long before the 1920s, all the way to the slavery era, when African slaves were first brought to American lands. Since then, neighborhood mosques have been built across the United States. African Americans later established mosques such as those in Buffalo, New York, in 1933; Pittsburgh, Pennsylvania, in 1934; Brooklyn, New York, in 1955; and Abiquiu, New Mexico, in 1980 (Kahera, 2013). Arab Americans established many small mosques across the Unites States and then later established larger mosques and Islamic centers such as the Islamic Cultural Center in Washington, DC, in 1975 and the Islamic Center of New York in Manhattan in 1991 (Kahera, 2013).

Why are mosques important in American Muslims' lives? Mosques in Muslim countries, like those in the Middle East, are considered to be a "home of God" that is mostly designated for praying (Haddad & Smith, 1994); in America, the purpose and function of mosques is different. For American Muslims, establishing mosques is "a necessary adaptation to the world in which they [have] found themselves. It [is] an act of cultural survival" (Abraham, 2000, p. 301). A mosque in America is a place that immigrants can go to not only to practice their religion but also to socialize and gather (Haddad & Smith, 1994). It is a place that people go to with the goal of celebrating religious and cultural events, getting to know people, learning, and speaking their native languages, discussing politics, and receiving Islamic opinions and teachings on issues they face in their daily life in America.

How do people choose what mosque to attend, especially in areas that have more than one mosque? Mosques in America differ in theological beliefs, the ethnic culture of the people who attend the mosque, the native language the attendants speak in general, and the language used in the prayers in specific. These differences work as filtering mechanisms for how Muslim immigrants choose which mosque to attend. Haddad and Smith (1994) identify the process by which American Muslims make the decision to attend a specific mosque and the factors that play into the discussion. The factors are: (1) geographic location: what mosque is closer to where they live? (2) the theological beliefs they follow—for example, do they agree that women can take the role of mosque executive? (3) language: which language(s) do they prefer to speak and use in their prayers? (4) generation: what mosque do the older generations in their family go to? Are children more likely to attend the same mosque their parents chose to attend? (Haddad & Smith, 1994).

Although Haddad and Smith (1994) succeeded in their discussion of the process by which American Muslims choose which mosque to attend, they did not report on which factors are likely to be compromised over others. For example, are people more likely to compromise their theological beliefs over their language preference in choosing which mosque to attend?

In summer 2016, after a few days of arriving, I drove around the city with the goal of finding places where I could meet and socialize with people. While I was driving down Ford Road, I noticed a large mosque (probably one of the biggest mosques I have seen in America) called the Islamic Center of America and thought that it would make a perfect location to meet people, especially on Friday since most people go to the mosque for the communal Friday afternoon prayer.

Thus, on Friday afternoon I dressed up and went to the mosque one hour before the afternoon prayer. It was almost empty, so I chose a spot and sat waiting. Women sat at the back of the room, men in the front, as in most American mosques I had visited before. As the prayer time came closer, more people started to enter the mosque, and horizontal lines of people started to form. By then, I started to notice that everyone next to me had placed a small stone in front of them. This was when it hit me that everyone in the mosque was Shia Muslims and not Sunni, which is the Islamic branch I follow (Shia and Sunni Muslims have some major differences in Islamic beliefs and in political orientation). As I realized this, I was in panic mode; I really had not thought about this since in my native country, almost everyone is Sunni, and we mostly have Sunni mosques. I was mainly concerned with three things: (1) I didn't have a stone to place in front of me, and, more importantly, did I really want to place one if I don't believe in this practice? (2) I didn't know if the way I pray is similar to the way in which they pray, so should I pray with them or just leave? (3) What would happen if they noticed that I was not Shia? Would they kick me out in front of at least 200 community members? My fear became reality when the women next to me noticed that I didn't have a stone placed in front of me and they started whispering. I was unable to make the decision, so I started to pray. With every motion and movement, I slowed down to see what they were doing. As the prayer progressed, I started to feel comfortable because the movement almost matched what I was used to. After the prayer ended, it was time for the imam/shaikh (the religious man who leads the prayer) to preach for about 15 min. The subject was Shia and Sunni relations in the context of the wars in Syria and Iraq, which, by sheer luck, could not have been a more perfect subject. Everyone next to me made sure to gaze at me for the duration of the imam's sermon. Although my experience ended well as I meet new people who asked me if I am Sunni and welcomed me, I knew that being Muslim in a new place need more navigations and considerations. Having lived this experience made me think that it's more likely that American Muslims would not compromise choosing a mosque that follows the same Islamic branch (Sunni or Shia) they follow over any other factors.

After a year of field research in Dearborn, this experience became an opening for discussion, while I was chatting with a group of Iraqi women over Iraqi tea. I told them my story about my first visit to the mosque in Dearborn. They listened to my story very carefully and two of them who are Shia told me that although they are Shia, they would have a similar experience as me. As they explained, feeling that you "belong" to a mosque is beyond the matter of being Sunni or Shia, ethnicity and having the

same country of origin as people who attend the mosque is important. After that, I made a point of asking people every chance I got about which mosque they attend, this made me confirm that in Dearborn, choosing a mosque is more complicated than whether you are Shia or Sunni but is also influenced by your country of origin and your ethnicity.

In the nearly quarter century since Haddad and Smith (1994) work, and especially after 9/11 (September 9, 2001) there have been many political changes related to Islam and mosques in America. Some mosques have come under attack, and some are under surveillance by the government. Based on this, the role of mosques, as places where American Muslims pray, socialize, talk politics, and celebrate their holidays, may not be seen as safe anymore. In an article, entitled "From Imam to Cyber-Mufti: Consuming Identity in Muslim America," Zaman (2008) argued that September 11, 2001 caused mosques to lose some of their importance when it comes to providing Islamic teachings for American Muslims. Zaman (2008) argues that American Muslims thereafter started to use other resources, such as online scholars and religious websites to seek religious teaching.

Semaan and Mishra's (2010) study of Islam in cyberspace among South Asian Muslims in America involved 25 in-depth interviews on the use of the Internet for religious purposes. The study showed that South Asian participants used the Internet to "listen to religious lectures, look up information about prayer times, holidays, halal food, rules regarding the recitation of the Qur'an, and correct pronunciation of Arabic words" (Semaan & Mishra, 2010, p. 87). Also, the study showed that second-generation participants were more likely to use the religious information found online to make lifestyle changes like becoming an organ donor or wearing a hijab (head covering or veil). Semaan and Mishra (2010) argued that although there were some patterns of lifestyle changes examined in this study, it is "difficult to definitively conclude whether access to competing interpretations of Islam necessarily led to moderate or extreme lifestyle choices" (Semaan & Mishra, 2010, p. 87).

Future research on the significance of mosques in America is needed as more war and political refuges arrive in America. Questions like "If mosques are not safe places anymore—especially as a result of people coming from war zones, where mosques are targeted on a daily basis—then where are Muslims going to gather, socialize, and celebrate their holidays?" will be interesting to answer.

# 3.5 Muslim Americans' Culture and Identity

Culture and identity of Muslims Americans are complex. Although Muslims in American come from different country of origins, and ideologies, they still share many core beliefs related to family, gender roles, and marriage practices. In addition, they share the daily challenges and struggles they face as they carry and display their Islamic identity.

#### 3.5.1 American Muslims' Family and Marriage

Immigration to the United States "is typically a 'family affair'" (Britto & Amer, 2007, p. 138). Muslim immigrants arrived in the United States as families or as individuals who later brought their families along. The maintenance of families' growth, religion, and ethnic identify gives marriage huge weight, and creates strict regulations on it—mostly practiced and enforced by the first generation of immigrants.

In a critical review of the existing literature on family and marriage among American Muslims, Hammer (2015) found that American Muslims are "concerned about communal cohesion and wanted their children to marry other Muslims, preferably of a similar cultural background" (Hammer, 2015, p. 37). Therefore, Muslim families tightly control the decision of who to marry and who not to. American Muslims frequently practice arranged marriages. They start with choosing a spouse, usually by using "communal structure, social and political activities, online sites, as well as traditional forms of marriage arrangement through mediators and family networks" (Hammer, 2015, p. 37). Arranged marriages among Muslim communities in America usually have high success because families play a huge role in providing support and mediating any dispute later in life (Hammer, 2015).

In addition to the cultural power families have on marriage, Islam limits marriage options, especially for women; most Muslims follow the Islamic law that states that Muslims women can only marry Muslims men, while Muslim men have the option to marry Muslims, Christian, and Jewish women (Hammer, 2015). Hammer (2015) notes that this is not the case for all Muslims: the studies reviewed in his article indicated "shifts in the interpretation of this doctrine have occurred, and there are a number of examples of Muslim women marrying non-Muslim men. Some men nominally convert to Islam while other couples openly challenge the basis of the aforementioned rule" (Hammer, 2015, p. 38).

In addition to the regulations American Muslim families and Islam have over choosing a spouse, both Islam and ethnic cultures help determine the age of marriage. Early marriage is always preferred for both Muslim men and women. This preference "stems from concerns about sexual propriety and the perceived dangers of a society that appears to be celebrating sexual self-exploration and promiscuity" (Hammer, 2015, p. 38). Although both men and women are pressured to marry early, Muslim women face more pressure regards getting married in young age (Hammer, 2015). Hammer (2015) explains that women are more restricted on premarital sexual relations than men and that Muslim women's virginity is closely related to family honor and reputation. The "fear of losing one's reputation in 'the community' is a significant danger for women and can potentially affect other members of her family as well. A system in which the family is made responsible for a woman's sexual conduct can produce regimes of pressure and surveillance while providing few outlets for women" (Hammer, 2015, p. 38).

Hammer (2015) laid out the essential aspects of family and marriage among American Muslim populations in general, but a few critical points are important here. First, he presented American Muslims as a cohesive population that shares the same cultural beliefs, a generalization that does not hold up in deeper level of analysis. Dealing with American Muslims as one population diminishes important cultural dimensions in understanding family and marriage, since each subculture has its own practices and regulations. Hammer (2015) also discussed most aspects of family and marriage from traditional and religious points of view, when acculturation may effect on those traditional practices strongly.

McCloud (2006)Transnational Muslims in American Society makes a similar point. McCloud (2006) starts from the premise that Muslims in America come from different cultures and need to be studied as such. McCloud (2006) paid careful attention, for example, to practices and family marriage among South Asian-American and Arab American Muslim populations. Both mostly live in enclave communities, which creates great pressure on families to maintain their cultural practices and to seek the community approval (McCloud, 2006).

McCloud's (2006) discussion of family and marriage among South Asian American Muslims showed how marriage requires a high level of family engagement. South Asian Muslims American parents start the searching process early, they consider many factors in their search such as class, type of profession, and the social class. This process can be done by using their personal networks or by meeting families in marriage forums and ethnic conventions (McCloud, 2006). McCloud (2006) found marriage for both men and women was always preferred among South Asian Muslim Americans for reasons similar to those discussed in Hammer (2015). That is, South Asian American Muslim women before or immediately after finishing collage (McCloud, 2006) and the idea of getting advanced education is usually delayed until after marriage, as they don't want to be considered "too educated" which can prevent them from getting married (McCloud, 2006). South Asian Muslim families chose for their daughters' men who have stable life and income, and who can provide and take care of their daughters as same as the parents did (McCloud, 2006).

In addition, McCloud (2006) discussed very interesting changes in family and marriage that South Asian American Muslim communities go through after arriving in America and the process of acculturating to their new lives. Those changes are not necessarily fully the "American way of doing things," but an interesting mix of culture in the South Asian countries of origin and in the United States. As noted previously, class is a very important factor in choosing a spouse; the South Asian class concept is based on the Hindu caste system carried to America by first-generation immigrants, and maintained in the South Asian Muslims' communities generation after generation (McCloud, 2006). Color is closely related to class and lighter is always better (McCloud, 2006). Although South Asian American Muslims strongly emphasize marrying from the same culture, the importance of having light-skinned children seems to diminish this emphasis in some cases. McCloud (2006) showed that while South Asian American Muslim women buy and use skin lighting creams, South Asian American Muslim men and their families see the opportunity of marrying lighter skin women from outside the community (McCloud, 2006). A participant mentioned in McCloud (2006) that families "are very excited to marry their sons to women from cultures where they're light skinned. Not necessarily that they are

non-Muslims but, you know, that they take pride in lighter colored children, here even, folks say, 'I saw the cutest baby, he was so fair'" (McCloud, 2006, p. 64).

McCloud (2006) discussion of marriage among Arab American Muslim communities in the United States showed that some marriage practices were similar to those of the South Asian American Muslims as well as some differences. Arab American Muslims' first concern is that "children get married and that they preferably marry Arabs from their country, then perhaps Arab Muslims from other countries, European Americans (Muslims or not), and then perhaps other Muslims. No matter who a young adult marries, there is a general understanding that the family needs to approve" (McCloud, 2006, p. 83). Arab American Muslim communities highly prefer arranged marriage (McCloud, 2006). The male family head usually takes the role of choosing a spouse. They either bring wives for their sons from the family country of origin "back home" or choose them from their community in America (McCloud, 2006). In some cases, couple meet each other while they are in schools or collages in the United States or in other countries (McCloud, 2006). Arab American Muslim men are the head of families, have the power of making decisions, and are expected to have stable work (McCloud, 2006). Arab American Muslim women are the head of the household, are expected to take care and manage their homes, and raise their children to have traditional Arab values (McCloud, 2006).

Other studies show acculturation has contributed to changes in family and marriage. Kulczycki and Lobo (2002) used the marriage data on Arab Americans in the US 1990 census data to examine the effect of acculturation on intermarriage. They found that 79% of Arab men and 73% of Arab women born in the United States had a non-Arab spouse. They also found that people with high levels of acculturation who speak English fluently and have higher education are more likely to marry non-Arabs. The study also found that "one major consequence of the high rates of intermarriage is that fewer children are reported as Arab" (Kulczycki & Lobo, 2002, p. 208). Although this study did not measure the effect of religion of the intermarriage patterns found, Kulczycki and Lobo (2002) suggested that Arab American Muslims are less likely to have intermarriage than Arab American Christians.

Britto and Amer (2007) conducted an internet study to examined cultural identity within sociodemographic and family contexts among 150 Arab American Muslims age between 18 and 25. The participants of the study "fell into three cultural identity groups: High Bicultural, Moderate Bicultural, and High Arab Cultural" (Britto & Amer, 2007, p. 137). What is interesting is that the study found links between these three cultures' identity groups, getting married, and receiving family support. Moderate Bicultural people were "more likely to be single and with higher academic achievement compared to the High Bicultural and High Arab cultural identity groups. On the other hand they also experienced greater acculturative stress and less family support compared to the other two groups" (Britto & Amer, 2007, p. 145).

Al-Johar (2005) interviewed 27 Muslim Americans from different ethnic groups (Arab and South Asian) groups in Houston, Texas to examine "how strongly Muslims born or raised in the United States identify with the cultural heritage of their immigrant parents affects the choices they make with respect to marriage" (Al-Johar, 2005, p. 557). Al-Johar (2005) found that American Muslims who practice arranged

marriage (which requires the family to become very involved in choosing a spouse and a huge preference for marrying from the same ethnic group) are more likely to identify themselves as being from a specific ethnic group first. The study also showed that people who self-identify as being Muslims are more likely to practice self-initiated marriages, where participants recognize "the importance of preserving religious viability rather than, and sometimes at the expense of, cultural viability" (Al-Johar, 2005, p. 566). Putting religion first is common among second-generation American Muslims, since second generation "has become more orthodox overseas (both in the U.K. and the U.S.) and is more attracted to Muslim organizations" (Al-Johar, 2005, p. 567). In addition, Al-Johar (2005) found that American Muslims who self-identify as American first are more likely to practice self-achieved marriages, where they "place greater importance on choosing their own spouses and fulfilling their own personal desires than on prerequisites such as religiosity or language ability" (Al-Johar, 2005, p. 571). In this type of selecting a spouse, American Muslims minimize the role of family by making "the decision to marry without consulting family and relatives" (Al-Johar, 2005, p. 571).

# 3.5.2 Living Everyday Life as American Muslim Women, and Men

There is no doubt that living in America as a Muslim woman or man from different ethnic cultures can be challenging. The challenges they face come from their ethnic cultural obligations and practices, from acculturation to life in America, and stereotypes and discrimination. Those challenges become more obvious when it's come to American Muslim women and men roles outside the family: what is expected from them, their experiences with stereotypes and discrimination in public, and the challenges they face from the way they look and dress and from the way they chose to identify themselves to others.

Meeting family expectations and performing what is expected from them as a man and women coming from ethnic culture who live in the United States are highly important. McCloud (2006) discussed how in South Asian American Muslim communities, both men and women are hold to high standards by family and community. Both men and women "are reared to excel, be mindful of their parents' desires, and to struggle for the best at every level. When this does not happen, the shame on the family is made even more intense by the south Asian community as gossip begins" (McCloud, 2006, p. 62). South Asian American Muslim men usually are put under huge pressure to meet their family expectations (McCloud, 2006). Those expectations requires them to have advance profession, acquire a lot of wealth and provide for their family (McCloud, 2006). Men in South Asian Muslim communities in America are pushed to seek high degrees in medicine and natural sciences; if not, community members practice shaming as they think less of any other families who have male who is not specialized in medicine or natural sciences (McCloud, 2006). Women in South Asian communities are "looked at pretty much to serve men" (McCloud, 2006, p. 63), learning from young age how to be good daughters, sisters, wives, and moms, and how to take care of a home. (McCloud, 2006). In addition, South Asian women are expected to go to the best school, excel in education, with keeping in mind that their main goal is to get married to a man with a certain profession (McCloud, 2006).

Although women's education seems to be important among American Muslims, work can be a secondary goal. Read and Oselin (2008) conducted a study among 38 Arab American Muslims and Christians in Houston, Texas to examine the relation between education and employment. They found that education is weakly related to employment; women receiving advanced degrees does not guarantee their involvement in the workforce. Arab Americans support female education "as a resource, not for economic mobility, but to ensure the proper socialization of children, solidarity of the family, and ultimately the maintenance of ethnic and religious identity" (Read & Oselin, 2008, p. 296).

Kumar et al. (2014) conducted a study among Arab American Muslim male and female adolescents from seven schools from the American Midwest. They found that gender roles among the participants are salient to Arab culture. The participants discussed how brothers would not allow their sisters to communicate with other boys in school (Kumar et al., 2014). Participants saw themselves as being able to protect themselves and providing needed protection to females; this belief is driven by the gender role of men in Arab culture, as the men are seen as the head of the household, and the ones responsible for protecting and providing for the family (Kumar et al., 2014).

Following those ethnic traditional gender roles and expectations seems to create acculturation difficulties among American Muslims, especially among first-generation American Muslims. Volk (2009) conducted a study among Muslim Yemeni immigrant women in San Francisco attending ESL classes. The goal of the study was to examine their experience as women living in San Francisco. The women were all married, had lived in the United States at least five years, and were aged 22–36. One of the challenges they had was learning English. The participants in the study had in common that performing their traditional role of being mothers has burdened their English language learning process. The women who participated in the study felt it was their responsibility to make sure their children spoke Arabic and therefore practiced the rule of only speaking Arabic with their children (Volk, 2009).

Women's transition from their country of origin to the United States might not give them an easier life. Sayigh (2012) noted that American Muslim immigrant women have huge responsibilities, as on one hand, they are "often face the contradictory expectations of maintaining their family's ethnic identity and cultural continuity based on practices and beliefs of their country of origin, while at the same time helping family members be successful in their host country" (p. 409) and on the other hand, they struggle as individuals to live in America. This has disturbed the picture painted of the United States as the "land of the free," especially when it comes to Muslim women, for whom the land of free "has brought pain, frustration, and insecurity rather than liberation" (Sayigh, 2012, p. 109).

Do women always choose to maintain their cultural and religious traditions or do they choose to alter some of their beliefs and cultural practice to cope with their lives in America? Volk (2009) discussed how maintaining Islamic dress in America became one of the struggles that American Yemeni Muslim immigrant women have. The women in the study felt the need to respect their religion and culture but were concerned about how other people will perceive them. Volk (2009) participants did not share beliefs about which Islamic dress code is acceptable. Some women only wear hijabs, covering their hair, while others wear niqabs, covering their face except for their eyes. The participants in the study were mainly divided into two groups, some who felt they needed to modify the way they dressed since they were no longer in Yemen and others who insisted on keeping their dress as it is. One participant said that "she had ignored encouragements from her husband to take off the face veil to make herself less conspicuous in public. She proudly maintained it was her choice to wear the niqab, which she considered the proper dress for a Muslim woman. But she also admitted that, as a result, she rarely left the home alone" (Volk, 2009, p. 403). As a reaction to this story, other women in the group felt that a woman should not keep her nigab because she is in a new environment and taking it off would "make it easier on herself" (Volk, 2009, p. 404). Some participants also suggested wearing a colorful veil insisted of a black veil. But all Yemeni women in this study "felt strongly about wearing their veils, be it in traditional or 'advanced' styles, because they felt women should dress modestly, even if it meant that they were scrutinized in public." (Volk, 2009, p. 404).

Read's (2003) study on the impact of religion on gender roles among Arab Christian and Muslim American women showed that the stereotypes of Arab American women as "veiled and secluded" were not necessarily true. Still, in an email survey of a sample of Arab American Christian and Muslim women Read found that Muslim women are "more gender traditional than Christian respondents, even when considering differences in educational attainment, presence of children, and age" (Read, 2003, p. 207). In addition, he found that American Muslim women born outside the United States, who had Arab spouses, and who lived in Arab communities were "significantly more traditional in their gender role attitudes than those respondents without these ethnic affiliations" (Read, 2003, p. 216). Read (2003) explained that this result of his study should not be seen as the effect of religion on gender, because factors such as marrying Arabs and living in Arab communities also contributed to keeping their traditional gender roles.

It is a truism in Anthropology that beliefs, whether they come from ethnic cultures or religion, go through modifications, and alterations. This does not always happen at the community level or family level, but mostly on the individual's level—and sometimes in shocking and challenging ways to American Muslims communities. Haddad and Sharify-funk (2012) studied the controversy of female imams (leaders of prayer, a role always taken by men according to interpretations of Islamic texts mostly made by men). They presented one of the first, Amina Wadud (followed later by a few other Muslim women in America), who led Friday prayer as an imam in a public prayer of a mixed gender group. Wadud was an Islamic Studies professor at Virginia Commonwealth University. The goal behind the idea of women becoming imams was to challenge the classic interpretations of Islamic texts. The main question was, "Can Islamic texts and communities of interpreters accommodate female religious authorities?" (Haddad & Sharify-funk, 2012, p. 102). This action has created controversy between Muslims and non-Muslims, not only in America, but around the world, concerning how much freedom women have when it comes to religious authority, and religion practices.

In addition to challenging female gender roles by changing classical interpretations of Islamic texts, other studies have examined different approaches to challenge gender roles, and ethnic cultural traditional practices. Naber's (2005) study of "Muslim first, Arab second" is based on 35 interviews of young, second-generation Arab American activists in the San Francisco Bay area who self-identify as Muslims first and Arab second. According to Naber (2005), the participants made that choice because it "provide[d] a broad ideological framework for confronting and reconfiguring family relationships, in particular, their immigrant parents' constructions of masculinity, femininity, and marriage" (p. 479). In other words, the group of participants felt the need to extend their accepted behavior options, marriage options, and gender roles, mostly imposed by their Arab parents. For instance, Arab parents only allow their daughters to marry Arab Muslims based on Arab traditions, whereas as a matter of doctrine, a Muslim can marry any Muslim, by birth of conversion. What is interesting is that the participants in the study expressed how their parents had not separated those two identities in their upbringing: as one said, "The religion was the culture and the culture was the religion'... The distinction between the things that are 'Arab' and the things that are 'Muslim' were blurred throughout the childhood and adolescent years for most of my research participants" (Naber, 2005, p. 483). One of the most significant points in the study is how the identity participants presented altered their views on traditional roles of men and women in marriage. For a women to be considered good, "she has to come from a good background, know how to cook, and seem like she can be fertile and have lots of kids and be good to her in-laws," while a man "has to come from a good family and has to have a good financial background" (Naber, 2005, pp. 483-484).

McCloud (2006) showed how being "Muslim first" was also common among young South Asian American Muslim generations, but not necessary for the same reasons Naber (2005) discussed. To him, Muslim reject being identify as American Muslims, because they never felt that they belong to their homeland (McCloud, 2006).

Self-identification of being Muslim first seems to be driven with the feeling of a need for more freedom (more room of acceptable behaviors) or coming from the feeling of not belonging to the countries of origin cultures. Other reasons of self-identification as Muslim in the United States were strongly related to political awareness, experiences with discrimination, and religious differences within American Muslim communities. Kumar et al. (2014) studied Arab American Muslim male and female adolescents from seven schools in the American Midwest. They found finding that understanding the formation of identity among Arab American adolescents is complicated, as the early stage of their lives were effected by 9/11 and what it caused of anger, and discrimination against Muslims in America (Kumar et al., 2014). Arab American Muslim adolescents report events "where they felt unfairly

judged and unwelcome in this country, expressing anger, frustration, and anxiety at being misunderstood and misjudged" (Kumar et al., 2014, p. 33). The participants of the study reported not feeling safe, and facing violent from the public, especially outside of their communities. (Kumar et al., 2014); the feeling of rejection was very clear as one study participants expressed that in America they don't like Arab American (Kumar et al., 2014). The participants also reported problems based on the way they dressed and looked. One participant described the airport: "like you wear a scarf, or a beard and they'll like search you and stuff... after 9/11 they started like picking on us... I don't care what they say; I just ignore them, just pretend like I didn't hear. Like there's some nice people, they treat you the same as like everybody" (Kumar et al., 2014, p. 34). In conversation between the participants, the effects of these experiences of discrimination could not be clearer or stronger:

Omar: No. Well we're Arab-American.

Wasim: I mean we're all Americans.

Ahmad: No. I'm not... don't even put American next to my name... it makes me 100 percent Arab. (Kumar et al., 2014, p. 36)

Some participants felt that self-identifying as American could diminish or even minimize the chance of receiving discrimination in public and feeling more acceptance (Kumar et al., 2014). On the other hand, at least in Kumar et al.'s study, choosing to be Arab and not American possibly shows strong resistance and feeling unwelcome to be an American.

Kumar et al. (2014) also discussed how the two main Islamic branches (Sunni and Shia) affected the way in which American Muslims choose to self-identify. A Muslim participant in Kumar et al.'s (2014) study said "We [he and his family] go to the Mosque every weekend... we pray every single day five times... Most Arab families are like that... Like in our religion, we look at each other as brothers and sisters, all of the Muslim community" (Kumar et al., 2014, p. 29). Although the participant emphasized Muslim community, other participants did not necessarily agree on the idea of one cohesive Arab Muslim community. A part of conversation between four participants who were Sunni and Shia was as follows:

Ahmad: Yea, I'm a Shia, we're all Shia.

Omar: Yea, we're Shia.

Omar: Yea, he's a Sunni.

Ahmad: You're Sunni?

Wasim: I don't, I don't find that a difference between people. I don't... It doesn't matter if you are Sunni or Shia.

Ahmad: Yea it does.

Sara: No it doesn't. (Kumar et al., 2014, p. 29)

American Muslims are diverse; they come from different ethnic backgrounds, political orientations, and Islamic ideologies and they go through different life experiences and acculturation processes. Mosques play a major role in American Muslims' lives and can be considered one way in which American Muslims maintain their ethnic cultures. Mosques are places where American Muslims practice their religion, socialize with other people, talk politics, practice their native languages, and celebrate their cultural and religious holidays (Haddad & Smith, 1994). They also are places where native cultures survive and thrive in America (Abraham, 2000). This importance has continued generation after generation, but it seems to be threatened by recent political events.

When it comes to understanding the culture of American Muslims—including their marriage practices, family practices, gender roles, and identity—not only religion must be examined, but also the role of ethnic cultures in regulating and navigating its individual members through what are accepted behaviors and what are not. Examining the formation of American Muslims' identity shows that there were no single or common identity-formation patters. Some American Muslims preferred to keep self-identifying as Arabs only (Kumar et al., 2014), and others chose to be Muslims first (McCloud, 2006).

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# Chapter 4 Research Setting and Design



Abstract This chapter is dedicated to the research setting, which is Dearborn, MI. It explains why Dearborn is an ideal place to build the Arab American cultural model of diabetes. This chapter will take the reader on a journey that will make them experience life in Dearborn and how it looks from the people there to its streets and houses. This chapter argues that Dearborn is not like any other place in the Middle East; it is a unique city, where a combination of Middle Eastern countries is represented in the same place. In addition, this chapter discusses the data collection process and how the Arab American cultural beliefs model of diabetes was built. It includes two stages of data collection, where the data were collected in the first stage using participant observations as well as semi-structured and structured interviews and a cultural consensus survey was used in the second stage. The chapter also includes details related to the sampling techniques and data analysis tools.

Keywords Cultural consensus · Dearborn michigan

The main goal of this research was to build a cultural beliefs model of diabetes among first- and second-generation Arab American Muslims in Dearborn, Michigan, and the practices associated with those beliefs. Variations in beliefs were examined based on sex, age, generation, education level, and country of origin.

The research included two stages of data collection that combined different types of data collection approaches and analysis. This chapter answers the question, "Why Dearborn, Michigan?" and describe the research design and methods in details.

## 4.1 Research Setting

Detroit is "the home to the largest, most highly concentrated population of Arabs in North America" (Abraham & Shryock, 2000, p. 18). The population of Arab Americans in Detroit was estimated to be around two hundred thousand people in 2000 (Abdulrahim & Baker, 2009), but other sources place the number at over three

hundred thousand (Americans, 2018). Immigration of Arab Americans to Detroit began in the 1880s, and thousands of Arabs kept arriving to Detroit every year, mostly from war zones such as Lebanon, Iraq, Palestine, Yemen, and Syria (Abdulrahim & Baker, 2009).

Dearborn, a suburb of Detroit, is the largest Arab American enclave in the United States. As soon as you enter the city, it is obvious that Arabs live there; there are shop signs written in Arabic, Arabic restaurants, coffee shops, barber shops, and groceries all run by Arabs. West Warren Ave is the main street in the city, with most of the Arab-owned shops in a segment just five or six blocks long. There are many dentists, chiropractors, and other clinics, small and large, lined up next to each other, all with Arab doctors' names.

The women and men walking in the streets are wearing a vast combination of clothes; Yemenis mostly wear traditional clothes—women with the black "Abaya" and men wearing "thobs" (long white dresses). Lebanese and Syrian women wear jeans, tops, and head covers, and the men wear mostly jeans and shirts or t-shirts; Iraqi men and women wear something in between what the Yemini and Lebanese people wear.

Some people might say that being in Dearborn is just like being in the Middle East, but that is far from the truth. Dearborn is a combination of different Middle Eastern countries all represented in the same city. Little glimpses of Lebanon, Iraq, Yemen, Palestine, and Syria make the city of Dearborn a very special city with an interesting dynamic to live and study in.

In addition to the interesting composition of the city, the prevalence of diabetes among Arab Americans in Michigan is estimated to be two to three times higher than in the general US population (Jaber et al., 2004). Several studies have focused on this disease among Arab Americans, including studies on the effect of acculturation (Al-Dahir et al., 2013), diabetics' access to healthcare services (Berlie et al., 2008), the presence of comorbidities such as hypertension (Dallo & Borrell, 2006), the reporting of diabetes (Jamil et al., 2008), self-management practices during Ramadan (Pinelli & Jaber, 2011), and family support (Pinelli et al., 2011). No study has yet derived an overall cultural model of diabetes among Arab Americans. The following sections describe the research design and methods, that were followed to achieve the goal of building a cultural beliefs model of diabetes and the practices associated with those beliefs.

#### 4.2 Research Design and Methods

The two main objectives of this study are:

O1: To build a cultural model(s) of the belief's diabetes among first- and second-generation Arab American Muslims in Dearborn, Michigan.

O2: To test variations in beliefs about diabetes in this population based on variables such as age, generation, sex, education level, and country of origin.

To achieve these objectives, data were collected in Dearborn for two years between 2016 and 2018. The data collection comprised two stages. The first stage was to answer the question: What are the cultural beliefs about the causes and symptoms of and treatments for diabetes among Arab Americans in Dearborn? In the second stage, I focused on measuring consensus in knowledge about those causes, symptoms, and treatments and discerning whether there was any variation in that knowledge based on sex, generation, education level, and country of origin. This research was approved by University of Florida Behavioral/Nonmedical Institutional Review Board.

# 4.2.1 Stage One of Data Collection

#### 4.2.1.1 Participant Observation

Participant observation (DeWalt & DeWalt, 2011) was carried throughout the full period of data collection. The main goal for conducting the participant observation was to understand and experience the simple, everyday life tasks of Arab Americans—things like going to the grocery store, praying in the mosque, going to the pharmacy, and visiting a doctor, as well as the more complicated everyday life issues, like being Muslim in America.

During the participant observation, experiences, observations, and interactions with people on a daily basis were recorded in field notes (Bernard, 2017). Writing the field notes helped in approach people for interviews and guided the process in how to ask the questions, what to focus on, and what to avoid. The cultural patterns that became apparent while writing the field notes helped in mapping the participants in the city and select informants to interview. For example, if I was looking for male participants in their 60s from Yemen, then the coffee and doughnuts place was clearly the place to go, since most of the customers there were older men dressed in traditional Yemeni clothing.

#### 4.2.1.2 Semi-structured/Structured Interviews

The goal for each interview was to cover a fixed set of topics while allowing the participant to speak freely and to share their opinions, experiences, and stories. The interview guide contained 15 questions, three of which involve the free-listing tasks that will be discussed in the next section. The other 12 questions covered topics that were derived from a pilot study conducted in summer 2015, as well as questions adapted from Kleinman et al. (1978) discussed in Chap. 1. This included questions about what diabetes does to the body, how severe diabetes is, the length of the illness, what people fear about diabetes, and the severity of diabetes. Each question was followed by probes to maximize the depth of the answers. The interviews were available in both English (Appendix A) and Arabic. All participants were given the chance to choose the language in which they would take the interview, and two

participants chose to take the interview in Arabic. In addition, all participants choose whether to have their interview audio recorded or not and signed informed consent forms. The interviews were transcribed and coded by using MAXQDA. The data were coded by using 14 structured codes (based on the themes of the questions in the interview guide) and 6 data-driven codes/thematic codes (Bernard et al., 2016).

#### 4.2.1.3 Free List

To determine the causes and symptoms of and treatments for diabetes, free lists were collected (Weller & Romney, 1988). Each participant was given a pen and paper and asked to first list all the causes of diabetes they could think of and then the symptoms of and treatments for diabetes. Thus, each participant produced three free lists. The participants were encouraged to talk, explain, and tell stories about each item they listed (Weller & Romney, 1988). In addition, elicitation probes (Brewer, 2002) were used to help people think of items they might add to the lists. In particular, the items they listed were read back to them one at a time and they were asked if they could think of additional, similar items to add to each list (Brewer, 2002).

#### 4.2.2 First Stage Sampling

As mentioned previously, the interview guide included free list tasks and interview questions; both were collected from the same participants. The data were collected from 31 participants (22 women and 9 men). Both first- and second-generation Arab Americans, both men and women, from different countries were included as much as possible. A total of 31 interviews was an appropriate number, since previous studies have shown that 20 is often a sufficient sample size for in depth interviews (Handwerker & Wozniak, 1997). Also, when it comes to free lists, a sample of 20 to 30 informants is adequate to reach saturation for most cultural domains (Weller & Romney, 1988).

## 4.2.3 Stage Two of Data Collection

#### 4.2.3.1 Cultural Consensus Survey

Building a cultural consensus survey is not an easy task. There is an art to this, as there is in making any culturally sensitive survey. Cultural consensus surveys can be designed using information from previous stages of data collection, from the literature on particular cultures, or from any other types of scientific publications (Weller, 2007). To build the cultural consensus survey, the following data were used: (1) The core items in the causes, symptoms, and treatments free lists—that is, items

mentioned by at least by 10% of the participants; (2) the information collected in the interviews; (3) the field notes; and (4) information obtained with the Cornell Medical Index (Brodman et al., 1949) related to diabetes and cardiovascular disease—in particular, information not obtained from the interviews or the free lists. By using these four sources of data, 52 true–false statements about diabetes were developed, with 29 true statements and 23 false statements. The cultural consensus survey was available both in English (Appendix B) and Arabic (Appendix C). In conducting the survey, participants were allowed to read and answer each statement, and to ask questions if they had any.

#### 4.2.4 Second Stage Sampling

For the second stage of data collection, a quota sample was used to select 78 participants: 19 first-generation women, 20 s-generation women, 20 first-generation men, and 19 s-generation men. The goal for the quota sample was to have approximately 20 participants for each generation and sex category (Weller & Romney, 1988). The sample included participants from Yemen, Lebanon, Syria, Palestine, Iraq, Jordan, and Egypt between the ages of 18 and 53.

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# Chapter 5 Arab Americans' Cultural Beliefs of Diabetes



**Abstract** This chapter discusses the results from the participant observation and semi-structured and structured interviews. It outlines the first stage of building the cultural beliefs model of diabetes. This chapter answers the following questions from the Arab American point of view: (a) What are the causes of diabetes; (b) what are the symptoms of diabetes; and (c) what are the treatments of diabetes? In addition, this chapter will include issues related to who is susceptible to diabetes? the fear of having diabetes, the severity of diabetes, the experience of fasting in Ramadan with diabetes, the role of family in providing care, diabetes health-seeking behaviors, and diabetes healthcare access.

Keywords Diabetes causes · Diabetes symptoms · Diabetes treatments

The first step in understanding the cultural beliefs of diabetes is to build an emic cultural beliefs model. Studies on the cultural beliefs of diabetes have been carried out across many cultures using different approaches (Adejoh, 2012; Arcury et al., 2004; Caballero, 2005; Luyas et al., 1991; Weller et al., 1999). Following the steps of Weller et al.'s (1999) study of diabetes among American Latinos, first, I collected free lists of the causes, symptoms, and treatments of diabetes for Arab American Muslims using the methods detailed in Chap. 4.

This study advances the work of Jaber et al. on diabetes among Arab Americans in Dearborn (Jaber, Brown, Hammad, Nowak, et al., 2003a, 2003b; Jaber, Brown, Hammad, Zhu, et al., 2003a, 2003b; Pinelli & Jaber, 2011) and develops a cultural model of diabetes. Being an Arab American Muslim with diabetes presents unique challenges that are not present in other US ethnic groups. For example, observant Muslims fast for a month each year for Ramadan and have many dietary restrictions, including the avoidance of alcohol and pork. In addition, Arab American Muslims in Dearborn, Michigan, have immigrated from war zones such as Syria, Lebanon, Yemen, and Iraq, which adds a layer of complexity to their health; this will become apparent in the data.

This chapter answers the following questions: What are the cultural beliefs about diabetes among Arab Americans in Dearborn, Michigan? Specifically, what do Arab

Americans in Dearborn understand to be the causes, symptoms, and treatments of diabetes? How do people with diabetes manage fasting during Ramadan?

#### 5.1 Causes, Symptoms, and Treatments of Diabetes

The process of creating a cultural model begins by specifying a semantic cultural domain for diabetes. A cultural domain is "simply the subject matter of interest, a set of related items" (Weller & Romney, 1988, p. 9). In this research case, the cultural domain includes the causes, symptoms, and treatments of diabetes among Arab American Muslims. Chapter 4 details the methods and techniques used in the collection and analysis of the causes, symptoms, and treatments of diabetes.

#### 5.1.1 Causes of Diabetes

The participants in this study (N = 31) listed a total of 34 items for the causes of diabetes. Table 5.1 shows the free list of statistics calculated using ANTHROPAC (Borgatti, 1996). In analyzing the free list, two things must be explained: (1) the frequency (i.e., how many times an item was listed; shown in the second column in Table 5.1). and (2) the salience (i.e., how early an item was mentioned in a list; shown in the fourth column of Table 5.1). The salience was calculated using Smith's salience index (Smith, 1993). The more important and most shared items were mentioned earlier in the list.

As shown in Table 5.1, the causes of diabetes list has at least 12 core items, where core means that the items were listed by at least three participants or 10% of the respondents (Bernard, 2017). Those 12 items include the following: runs in the family, unhealthy diet, lack of exercise, obesity, eating sugary food, eating too much sugar, stress, high level of blood sugar, high blood pressure, pregnancy, alcohol, and eating fast food.

As mentioned in Chap. 4, as each participant listed the items, they were encouraged to explain what they meant exactly and were told that they could discuss each item listed if they had specific stories to share. Of the 31 participants, 12 said that at least one person in their family had diabetes; thus, many stories were told about the item "runs in the family." Table 5.2 shows responses for the question, do you know someone with diabetes? One participant claimed to know at least five diabetics family members or friends, two knew four, and the others knew 1–2. Regarding their relationship with the known diabetic, they listed the following: mother, father, brother, grandparent, uncle, aunt, cousin, niece, and friend.

The second most frequently listed cause of diabetes was "unhealthy diet." Each time a respondent listed unhealthy diet or any type of food that can cause diabetes in their list, they were asked what they considered to be unhealthy and to provide examples of foods that people with diabetes should not eat.

#	Items	Frequency	Average rank	Smith's S
1	RUNS IN THE FAMILY	21	2.429	0.429
2	UNHEALTHY DIET	17	3	0.329
3	LACK OF EXERCISE	12	3.167	0.202
4	OBESITY	11	3.182	0.208
5	EATING SUGARY FOOD	9	2.333	0.214
6	EATING TOO MUCH SUGAR	7	2.286	0.158
7	STRESS	6	3.333	0.117
8	HIGH LEVEL OF BLOOD SUGAR	6	1.667	0.164
9	HIGH BLOOD PRESSURE	4	1.5	0.116
10	PREGNANCY	4	3	0.075
11	ALCOHOL	3	5.333	0.019
12	EATING FAST FOOD	3	2.667	0.065
13	SMOKING	2	5	0.022
14	GREASY FOOD	2	1	0.065
15	EATING SALTY FOOD	2	4	0.035
16	SUGARY DRINKS AND SODA	2	2	0.052
17	DEPRESSION	1	5	0.006
18	LACK IF EXERCISE	1	5	0.011
19	ILLEGAL DRUGS	1	3	0.016
20	PANCREAS	1	7	0.008
21	COFFEE	1	3	0.022
22	ICE CREAM	1	3	0.016
23	LACK OF EXERCISING	1	4	0.02
24	UNHEALTHY ENVIORNMENT	1	6	0.012
25	VIRUS	1	7	0.008
26	UNHEALTHY ENVIRONMENT	1	3	0.016
27	NOT DRINKING A LOT OF WATER	1	3	0.016
28	SITTING AROUND	1	4	0.008
29	UNHEALTHY	1	2	0.024
30	EATING TOO MUCH	1	1	0.032
31	NOT ENOUGH SLEEP	1	2	0.022
32	OVER WORKING	1	3	0.011
33	IT RUNS IN MY FAMILY	1	2	0.016
34	EATING TO MUCH SUGAR	1	1	0.032

**Table 5.1** Free list descriptive statistics for causes of diabetes (N = 31)

	Participant code	The relation to the participant	Number of people they know with diabetes
1	F1Y191	Mother, mother's father, mother's sister, fathers' father	4
2	F1Y188	Uncle	1
3	F1Y244	Father, aunt, niece, uncle, brother	5
4	F2I205	Cousin	1
5	F2Y186	Father, father's father	2
6	F2Y203	Mother's father	1
7	F2Y215	Aunt	1
8	F2Y241	A friend	1
9	M2Y204	Mother's mother	1
10	M2Y231	A friend, aunt	2
11	F1L192	Father	1
12	F2Y197	Grandparent both sides	4

**Table 5.2** People they know who have diabetes (n = 12)

A participant from Yemen (F1Y188) said, "People who have diabetes should be on a special diet. Eating food that has a lot of sugar can cause diabetes." I asked the participant for her opinion regarding two famous Yemeni dishes (staples in every Yemeni home) that are made up of flour, oil, salt, and plenty of honey; other participants listed this as an example of unhealthy Yemeni food. She said,

"It's heavy on the stomach, but maybe good, not sure." In addition, people listed other examples of unhealthy foods such as chocolate, cake, sweets, pizza, fries, burgers, and packaged foods.

It is important to highlight here that honey has a significant cultural relevance, especially among Yemenis, and many participants mentioned that elderly members in their family start their day with a glass of water mixed with honey, even if they are diabetic. Instead, other participants mentioned that they stopped eating it after realizing that US honey is not pure and has added sugar, unlike Yemen honey; thus, honey in the United States "can't be trusted."

On the other hand, the city of Dearborn has no shortage of food options. West Warren Avenue is one of the city's main streets where one can find all types of restaurants, coffee shops, grocery stores, and bakeries run by Arab Americans from Lebanon, Iraq, Syria, and Yemen. One of the busiest and most famous bakeries in the area is located on West Warren Avenue, and it has become a regular, if not daily, gathering place for Arab Americans. Fresh Lebanese traditional sweets, fruit juices topped with custard, nuts, honey, locally made ice cream, cake, chocolate, and pastries are on offer. When asked about diabetes, Participant M1L269 explained his struggle with having daily access to this type of food:

If you don't want diabetes, work at an Arabic bakery ... you know how I don't have diabetes? I don't eat anything from my work ... while I am there working. When you see the same

#### 5.1 Causes, Symptoms, and Treatments of Diabetes

food every day, you don't want it anymore. People always ask me in the bakery how I stay fit. I say, "just don't eat it"... yeah, if you don't want to get fat and have diabetes, then don't go to the bakery with all the sweets and cakes ... it's impossible!

So, what should people with diabetes eat? Participant F1Y191 said, "People who have diabetes should eat a healthy diet, like eating chicken, green tea, salad, Samak [fish in Arabic], and hummus." Another participant, F2Y186, said, "My dad does not eat sweets, he only eats bananas." When asked about the type of food people with diabetes should eat, participant M2L183 responded, "They should eat salad, lettuce, carrots, fish, and chicken breast." Participant F2Y197 suggested replacing sugar in coffee or tea with honey.

Six people mentioned "high levels of stress" as a cause of diabetes. When I asked them about the causes of stress, the reasons included the following: financial difficulties, missing home, immigration status, fleeing war, and losing family members. Participant F1Y191 said,

My mom got diabetes because my family was going through a very bad time. We had debt, and we were financially struggling to pay it. Also, at the same time, my brother got shot [in Dearborn], and my mom was really stressed at the time. He is fine now.

This story was not different from or unique to the other stories, where participants listed stress as a cause of diabetes. Arab Americans in Dearborn are mostly made up of people coming from war zones, leaving their countries of origin with almost nothing. The data show that Fleeing war has a tremendous effect on the mental health of Arab Americans and, therefore, a large consequence on their physical health. As F1L376 said,

People that are coming from war-torn areas—their bodies are very stressed. We see hypertension in 14- and 15-year-olds; this is not what we see among the general population. So, if we compare Arab Americans to regular Americans, Caucasians, that's not going to work. That's never going to work; the numbers are too skewed.

One of the other themes accrued during the interview was related to the relationship between stress and faith. Based on the data, Arab Americans have religious and cultural beliefs that affect the way in which they perceive illness or even think about the possibility of having an illness such as diabetes. During the interviews, most participants recited "in God well" and "in Allah's hands." Based on the data, in most cases, having a strong faith helps tremendously in dealing with the stress related to having diabetes, but in a few cases, it seems that faith can be used as a reason for refusing to receive treatment, thus trusting in God's power to treat them.

In addition, people listed a lack of exercise and obesity as causes of diabetes. When it comes to obesity, it cannot be understood without linking unhealthy diet (covered above) and physical activity. Many participants described a decrease in physical activity after immigrating to the United States, saying, "we don't feel safe walking to places," "the weather is so cold," and "we leave the house to visit who? I don't know anyone here."

#### 5.1.2 Symptoms of Diabetes

The participants (N = 31) listed 45 symptoms of diabetes. As shown in Table 5.3, 15 items were mentioned at least three times. These included the following: dizziness; headache; fatigue; weight loss; dehydration related; fainting; feeling tired; sweating; weight gain; high blood pressure; shaking; dry mouth; weakness; foot, hand, and joint pain; and vision problems.

Participants listed 15 items when talking about symptoms of diabetes, but "fainting" was one of the symptoms that prompted the most stories. Participant F1Y191 said, "We found out that my mom had diabetes after she fainted after feeling very tired, and we took her to the doctor; her sugar levels were not balanced." Participant F2Y197 told a story about her grandmother's symptoms of diabetes, saying, "One time, we were at a park, and the weather was so hot. She got sweaty and dizzy, and we immediately gave her pop; her blood sugar was really low."

Participants also shared stories about "eye problems" or "vision problems." Participant F2Y215 said, "My aunt had two surgeries, including one in her eyes because she had water in her eyes; also, her kidney used to hurt a lot, all because of diabetes." In addition, Participant 2F1I313 said, "My grandmother lost her vision; she can't see anymore. For a long time, she has had diabetes, the doctor said, but we didn't know. She hates going to the hospital."

Participants mentioned that another symptom of diabetes was tiredness. As some explained, the feeling includes the inability to finish daily tasks without taking a break to lay down, napping, and watching TV instead of doing anything else. According to the participants, this can cause worse diabetes complications because it results in decreased physical activity and weight gain.

# 5.1.3 Treatments of Diabetes

The participants (N = 31) listed 20 treatments for diabetes. Out of the 20 treatments listed, six were mentioned at least three times: taking medication, maintaining a healthy diet, exercising, getting tested, eating less sugar, and eating sugar (Table 5.4).

When analyzing the narratives based on the free lists for the treatment of diabetes, two points stood out. First, when people listed "medication" in their lists, they were asked if they had specific stories about diabetics taking their medication. Participant F1Y191 said,

My grandmother takes insulin shots. She does not take care of her insulin shots; she throws it in a sunny room all day, and she uses the same needle more than one time instead of using it one time only, which she must do. Also, my grandmother injects herself with different insulin quantities without thinking of how much she needs.

While visiting one of the Arabic pharmacies in Dearborn, I chatted with an Arabic pharmacist who told me about her experiences with diabetics and her struggles getting people to take their medication:

	Item	Frequency	Resp pct	Avg rank	Smith's S
1	FEELING DIZZY	16	52	2.25	0.384
2	HEADACHE	9	29	2.667	0.172
3	FATIGUE	6	19	2.833	0.128
4	LOSING WEIGHT	5	16	2.6	0.113
5	DEHYDRATION RELATED	5	16	2.8	0.114
6	FAINTING	5	16	3.4	0.063
7	FEELING TIRED	5	16	3.2	0.091
8	SWEATING	5	16	3.6	0.084
9	GAINING WEIGHT	5	16	2	0.116
10	HIGH BLOOD PRESSURE	4	13	1.75	0.108
11	SHAKING	4	13	1.75	0.098
12	DRY MOUTH	3	10	2.333	0.066
13	WEAK	3	10	3	0.047
14	FOOT HANDS AND JOINTS PAIN	3	10	3	0.059
15	VISION PROBLEMS	3	10	5.333	0.023
16	NOT FEELING WELL	2	6	3	0.024
17	GET TESTED	2	6	3.5	0.041
18	LONGER HEALING TIME	2	6	2.5	0.04
19	KIDNEY PROBLEMS	2	6	4.5	0.025
20	FEELING LAZY	2	6	2.5	0.043
21	LOSSING WEIGHT	1	3	1	0.032
22	BRUISED EASILY	1	3	3	0.019
23	NUMB FEET	1	3	2	0.016
24	LOWER BLOOD SUGARS	1	3	2	0.024
25	XANAX	1	3	3	0.011
26	HARD FEET	1	3	2	0.026
27	GETTING HUNGRY	1	3	2	0.026
28	SLEEPY	1	3	4	0.018
29	INSOMNIA	1	3	4	0.013
30	EXHAUSTED	1	3	4	0.016
31	FAST HEARTBEAT	1	3	5	0.011
32	SLOW HEARTBEAT	1	3	6	0.005
33	SAD	1	3	2	0.024
34	SWOLLEN LEGS	1	3	2	0.024
35	INACTIVE	1	3	4	0.008
36	LOW BLOOD PRESSURE	1	3	1	0.032
37	ANGER	1	3	1	0.032

**Table 5.3** Free list descriptive statistics for symptoms of diabetes (N = 31)

(continued)

	Item	Frequency	Resp pct	Avg rank	Smith's S
38	BEING SKINNY	1	3	2	0.016
39	URINATING TOO OFTEN	1	3	1	0.032
40	TINGLING IN THE FEET AND HANDS	1	3	3	0.019
41	FEELING DIZZT	1	3	2	0.022
42	NAUSEA	1	3	1	0.032
43	OBESE	1	3	1	0.032
44	NO EXERCISE	1	3	2	0.024
45	THROWING UP	1	3	3	0.016

Table 5.3 (continued)

**Table 5.4** Free list descriptive statistics for treatments of diabetes (N = 31)

#	Item	Frequency	Average rank	Smith's S
1	MEDICATION	28	1.821	0.709
2	HEALTHY DIET	24	1.833	0.582
3	EXERCISE	23	2.87	0.37
4	GET TESTED	6	3	0.089
5	EAT LESS SUGAR	4	1.75	0.102
6	EAT SUGAR	3	2	0.073
7	EATING LESS	2	2	0.043
8	DO NOT SMOKE	2	3.5	0.027
9	DO NOT EAT SUGAR	2	2	0.054
10	TAKE CARE OF YOURSELF	1	3	0.016
11	WEIGHT LOSS	1	2	0.016
12	CHECKING UP WITH BLOOD PRESSURE	1	3	0.016
13	RELAXING	1	5	0.006
14	ALNEEM PLANT	1	4	0.008
15	GREEN TEA	1	5	0.006
16	PREGNANCY COURSES	1	3	0.011
17	LESS STRESS	1	3	0.019
18	DRINK WATER	1	4	0.013
19	AMPUTATING	1	6	0.005
20	DIALYSIS	1	3	0.011

Non-complaints, drives me nuts! They don't take their medication. They say things like "My sugar was not that bad, I didn't eat anything sweet. I've been watching my diet. God will protect me, and it's in God's hands." Nonsense . . . nonsense, but this is how it works. They ask questions like, "Do I have to take it every day?" There are some . . . I don't want to say they are stupid. "Can I give this to my neighbor? Can I use my neighbor's insulin when I run out? If I stopped sugar, can I reduce the number of shots?" I had a patient who took 60 units

#### 5.2 Who is at Risk of Diabetes?

every night; he stopped sugar on his own, so he lowered his unit to 13. It's amazing that he did not have a stroke.

The second major theme that emerged in the narratives was people not knowing they had diabetes until they went for their regular checkups or visited their doctor for a reason other than diabetes. The item "getting tested" was listed as one of the steps to treat diabetes. When I asked people to tell me more about that, Participant F1Y191 said,

My mom had diabetes before coming to America. She was in Yemen, living in a small village. She got pregnant and lost two children. She lost the first baby because she got internal bleeding one day . . . she was bleeding so badly, I remember seeing the blood; it was awful and scary. We thought she was going to die. We took her to a doctor; she lost the baby, and the doctor told her she has type-2 diabetes. This is when she first learned about her diabetes. She was only 32 years old. Also, she lost the second child after she gave birth; the baby was too sick and died.

Participant F2I205 told me that her cousin did not know she was diabetic until she got tested after discovering she was pregnant. Her cousin gave birth to a healthy child but now has diabetes for life. In addition, the participant listed "getting tested" as a treatment for diabetes and said, "When my aunt got older, she got diabetes. She went for a regular checkup and found that she got it, so now she is watching her diet and taking medication."

In addition to the lists of the causes, symptoms, and treatments of diabetes, participants were asked questions related to who can have diabetes who is susceptible to diabetes, the fear of having diabetes, the severity of diabetes, experience of fasting in Ramadan while having diabetes, diabetes family care, diabetes health-seeking behaviors, and diabetes healthcare access. The questions were driven by the theoretical framework of Kleinman (1988) discussed in Chap. 1. The following sections of this chapter will cover each subject in detail.

#### 5.2 Who is at Risk of Diabetes?

Following the interview guide, all 31 participants were asked the following: who is at risk of diabetes? Are some people at a higher risk of having diabetes than others? Why? I used probes such as age, weight, and sex to elicit more comparison.

Out of the 31 participants, 28 thought that age had an influence, as people are more likely to get diabetes as they age. Participant F2I205 said, "The older the person is, the body weakens so that they have more chance of getting diabetes." Only three people did not think that older people have a greater risk of getting diabetes. Participant F1L192 said,

I mean, you have people that are in their 90s and healthier than people in their 20s, so it all goes back to taking care of yourself and being as healthy as possible. So, if I don't take care of myself, I can be in my 90s; heck, I can be in my 60s and dying. For someone taking care of themselves, they can last until their 90s, and they are healthier than me. So, it goes back to, when you were young, how you took care of yourself.

Most people agreed that obesity can increase the risk of having diabetes. Participant M2Y204 said, "People with heavy weight have more sugar stored in their body and therefore have more chances of getting diabetes." Participant F1Y244 shared her fear of her sister's obesity and the possibility of having diabetes:

My sister is 10 years old now; she is fat . . . the only thing she does all summer long is eat and watch TV; she does not move or do anything. I always tell her, "Please move, you will have diabetes," but she does not listen. A few days ago, we took her to the hospital for a test; we don't know yet if she has diabetes or not. I am really worried about her.

Two people did not think that weight gain necessarily leads to diabetes. Participant F1Y191 said, "Weight does not necessarily contribute to diabetes; it more likely depends on health... if someone has diabetes in the family, a high level of stress, and a bad diet." Participant F2Y203 shared this opinion: "It's not necessary; you can be skinny and have diabetes or overweight and have diabetes."

Do women or men have a greater risk of having diabetes? All participants, except for one, agreed that it does not matter: both men and women are equally vulnerable to diabetes. The one who disagreed, Participant M2Y204, said, "Men have more chances of getting diabetes than women. Men do whatever they want to do; they don't listen, and women are more likely to take care of themselves."

#### 5.3 Fear of Having Diabetes

What do people fear most when it comes to having diabetes? During the first stage of the interviews (N = 31), each participant was asked to discuss what the people around them feared most about having diabetes and what they would fear most if they personally had diabetes.

Out of the 24 participants who answered the question, 12 people mentioned that they and the people around them are most worried about the inability to eat whatever they want. Participant M1L269 said,

What people are most afraid of, in my opinion, is not being able to eat freely and control what they eat. People don't want to be told what to eat. You know, us Arabs, all we do in the house is eat, so you want the person who has diabetes not to eat like everyone in the house! It's hard. They want to eat just like everyone else; for them, it must be like fasting all the time . . . not being able to eat whatever they want.

Participant M2Y204 expressed his fear about diabetes and food by saying, "I fear not being able to eat as much sugar as I want." In addition to sugar, other participants mentioned the fear of having to stop eating fast food or junk food and drinking coffee in the morning. Furthermore, Participant M2Y231's response to the question suggests an additional diet management difficulty for older people who have or might have diabetes:

The worst thing people fear about having diabetes is not being able to eat what they want. Older people—maybe overseas more than here—can feel neglected. Older people—especially overseas but also here—find it harder to stick to a diet. They just don't want to give

#### 5.3 Fear of Having Diabetes

up, like in Yemen, where older people eat assal baladi [honey in English] every single day . . . so they don't listen when they are told not to do so.

In addition to diet, four people feared that diabetes could lead to death; five mentioned fears about having to exercise more and increase their physical activity; two mentioned the fear of having to take medication on a daily basis; two mentioned the fear of losing their vision; and one feared the possibility of passing diabetes on to her children in the future. Regarding loss of vision, Participant F1Y244 said, "I fear losing my vision; losing my vision means staying home and not doing anything." When discussing the fear of other diabetes complications, Participant F1Y191 said,

My uncle does not want to have diabetes; when my mother is checking her blood at the house, he asks her to check for him, too. He thinks that because he is the oldest brother in the family, he will probably get it. He does not want to have an illness and has problems like my mother: fainting and going to the emergency room.

Only Participant F1L192 did not have any fears; she said, "I know a lot of people might be saying, 'Oh my God, I have diabetes,' and get stressed about it. I think people are ignorant, and they fear what they don't know."

I also asked the participants the following questions: What does diabetes do to the body? What does diabetes do to the body of the person who has it? How does diabetes work? Will it have a long or a short course? When I asked these questions, 21 participants responded. For the first and second questions, 10 said they did not know exactly how diabetes worked in the body, and two said that diabetes can cause health complications. Participant F2Y197 said that "their body does not produce more insulin. People start to have health complications... diabetes affects their kidney and pancreas. My grandfather's feet got swollen. He went and saw a doctor; now he wears special socks." Participant F1Y188 said that "when people have diabetes, the body becomes weaker; they can't do certain stuff like physical activities." Participant F2I205 said that when it comes to the effect diabetes has on the body, it causes people to have high levels of sugar in their blood. Participant F1Y244 added that "diabetes makes you fat; my dad goes to the gym. It does not help; he is still fat because of the insulin he takes. My aunt is fat, too."

In response to the question about diabetes' effect on the body, Participant F2Y186 said that it increases the level of sugar in the body. In addition, she stated that people with diabetes "get very tired when they do too much work." Many of the participants did not have a clear understanding of diabetes' effect on the body.

When asked if people can cure themselves of diabetes, out of the 21 participants who answered the question, 11 did not know, two thought that diabetes can be cured, and eight thought that it cannot be cured. Based on this, it is clear that people understand diabetes in the context of its symptoms and complications more than its effect on the body. Furthermore, knowledge about the possibility of a cure seems to be limited among the participants.

#### 5.4 Severity of Diabetes

Twelve people answered the following questions: How severe is diabetes? Can diabetes cause death? Out of the 12, nine people thought that diabetes can be severe and can cause death if people do not take care of themselves. Participant F2Y203 said, "It can be severe; people can make it severe by doing all of the things that cause it and not eating right." Other participants mentioned that refusing to take medication can result in increased severity of diabetes. Participant F2Y215 said that diabetes can increase in severity and even cause death for the following reasons: "people not watching their health as they used to, now always on their phones, not moving much, and using elevators." Participant M2Y204 stated, "I don't think that diabetes is severe; it's not like AIDS, but eating so much candy can lead to death."

Only one participant did not think that diabetes can cause death, and Participant F1L192 thought that death can be caused by anything. She said, "Anything can be severe; it's just luck with some things, you know? I think anything can cause someone to die."

Overall, participants thought that the severity level of diabetes depends on how well diabetics comply with their medication regimen and take care of themselves, which includes eating a healthy diet and increasing their physical activity. Furthermore, participants seemed to understand that the increased health complications caused by diabetes can lead to death.

#### 5.5 Fasting in Ramadan

In Dearborn, the month of fasting, Ramadan, is unlike any other. The city sees dynamic changes. During the day, the streets are empty, and businesses are closed. The streets come alive at night, as restaurants and coffee shops open late to accommodate those attending Iftar (the meal eaten after sunset to break the fast). Long lines of people wait for their turns at the buffet in restaurants, and passers by can smell and see busy outdoor hookah lounges with loud Arabic music and smoke.

Ramadan is known for its feasts. Breaking fast begins with water and dates, followed by all types of traditional foods. People then snack for hours on sweets, tea, and Arabic coffee. One day in Ramadan 2017, I ate at an Iftar buffet in one of the Lebanese restaurants in Dearborn. I arrived 15 min before sunset, chose a table, and sat down. The restaurant was already packed. I saw at least 25 tables filled with families and even some with at least three generations sitting together. The tables had dates and water on them, and all I could hear were people talking about what they were going to eat.

A group of Arab American men in their 60s and 70s was sitting next to my table. They discussed how they were going to get their food from the buffet. One of them said, "Let's line up from now so we get our food first." The second said, "I will get a big plate of rice and lamb to share before anyone, and you guys get the rest." They argued about what to get in addition to the rice and lamb and even stopped the waiter to ask him what dishes were available in the buffet. As I continued to observe, these men were not the only ones with this plan. Lines started to form in front of the buffet, even though it was still too early to break the fast. Everyone was ready with a plan.

When it came time to break the fast, the tables were filled with food, but no one ate immediately. Everyone was looking around, making sure that it was indeed time to break the fast and they were not the first ones to eat. This awkward situation happens for several reasons. In the Middle East, breaking the fast happens immediately after the sun goes down and the sunset prayer call goes out from the mosques on their loud speakers. In Dearborn, you cannot hear the prayer calling, so you are limited to Islamic websites that publish the time for breaking the fast. The time for this announcement changes by a few minutes each day, according to the actual time of the sunset in each location and is difficult to keep up with. Therefore, if you are in a restaurant and do not have access to the Internet, the best option is to wait for someone near you to eat first so that you can save yourself the embarrassment of eating before the appointed time. After a few awkward looks, everyone began eating. The men next to me ate about 20% of what they got from the buffet, and leftover food was noticeable on everyone's table. One of the men said that he needed to take his medication and that he was feeling tired and sleepy. The other men suggested going to smoke hookah for the rest of the night.

After the Iftar, I left the restaurant and went to the Arabic bakery on West Warren Avenue. As I arrived in the parking lot, street parking was almost full. People were lining up to buy sweets, children were running around playing, and families were sitting and chatting at full tables. I saw many of the same families from the restaurant I had just eaten at. We looked at each other and smiled, sharing an unspoken understanding: "Great minds think alike: Iftar is best followed by sweets."

Thirty-one participants were asked the following questions: How do people with diabetes survive Ramadan? What are their struggles? Do people think that it is possible to fast? How do families accommodate a person with diabetes when having Iftar?

People with diabetes who want to fast during Ramadan must consider whether their medication needs to be taken during the hours of fasting or not. If they need to take their medication in the daytime, they cannot fast during Ramadan. Many of the stories my participants shared demonstrated diabetics' fasting struggles during Ramadan.

Limiting physical activity and resting are a couple ways diabetics cope with fasting for long hours. Participant F2Y186 said, "My dad does fast; he sometimes gets really dizzy, so he does not do a lot; he prays, sits all day, and takes naps." Participant F2Y197 said, "Although the doctor told my grandmother that she should not fast, sometimes she fasts. She wants to keep her pride, you know. So, she sleeps or lays down the whole time." Fasting in this case is a sign of strength and ability, not of weakness and inability.

Participant M2Y231 shared an experience he had with his friend:

My friend was working in the kitchen on Ramadan, and then he was dizzy and fell down, fainted. We tried to put water on his face, but he did not wake up. So, we called 911. He was taken to the emergency room, and doctors told him not to fast again. This is after fasting for 2-3 days. So, he did not fast after that.

In addition to the struggle of fasting during Ramadan, evidence from the narratives suggests that families do contribute to the diet management of diabetic family members eating meals with them. Participant F1Y191 shared how her mom copes with Ramadan and the food choices she makes:

My mom can fast in Ramadan, but the first two or three days, she gets very tired. Also, when she makes sweets, she does not use a lot of sugar. For example, in Mahalabia [pudding], she does not use sugar at all. Our whole family is now used to eating Mahalabia without sugar.

What do people do if they cannot fast during Ramadan, especially because fasting is one of the five pillars of Islam? Participant F1Y191 provided this insight on community practice: "When my mom or dad can't fast, they give zakah [amount of money] to the local mosque or they send it back home and tell someone back home to give it to people in need." This practice of giving alms is one of the most important obligations in Islam and is known among Muslims across the world, though it is not necessarily practiced by all. Participant M2Y231 has a friend who cannot fast during Ramadan because of his diabetes. I asked if the friend was doing anything to make up for the days he was not fasting. The participant answered, "No he does not pay zakah or anything like that, I just don't think he thought about it that deep, you know."

"Let's make it simple and easy," Participant M2Y204 said, "Everyone is tired in Ramadan," implying that anyone with diabetes can simply do what they want. Still, ethnographic data show that one of the main struggles for people with diabetes during Ramadan is managing their diets when they have limited physical activity all day and are confronted with feasts after Iftar. Giving alms to charity as a penance for not fasting indicates an added layer of stress for those in this position.

#### 5.6 Family Role in Diabetes Care

As noted earlier in this chapter, the roles of the family in providing care for diabetic members are not limited to food management. Out of the 31 participants in the first stage of data collection, 29 agreed that diabetes not only affects the person who has it but also everyone around them. Participant F1Y191 said, "I feel bad for my mom [who has diabetes]. When she is tired, I try to help her with housework." Participant F1Y244 stated that her responsibilities toward her father increased when he was diagnosed with diabetes: "I need to take care of my father, listen to him when he is complaining, call the doctors, drive him to the doctor, and all that." She added, "Feelings affect everyone; physically, only the person who has diabetes is affected." Participant F2Y203 emphasized a similar point: diabetes "is not a virus," so it is not

contagious, but the responsibility of taking care of a person with diabetes is a task for everyone around them.

Participant F2Y197 noted that as the diabetic ages, their care becomes more challenging. She said, "Diabetes affects people around the sick person, especially when they are old; my grandparents don't know when it's time for insulin, so we keep reminding them." Participant F1Y188 said, "If they [people who have diabetes] are old, the family needs to remind them to take their medication."

In addition to the care that families provide to diabetic members, diabetes can bring financial stress to the rest of the family. Participant M2L183 said that "diabetes affects people around them, like the payment of medical bills."

Only two participants in my sample (N = 31) did not think that family effort is required. Participant M2Y204 stated, "Diabetes only affects the person who has it," and then told me to make sure to write, "Take care of yourself." He explained that he does not think that anyone should care for other people in the family; every member should be able to take care of themselves.

Some patterns in the type of care provided are worth noticing here; female participants' support for diabetic family members involves in-home care, such as preparing food, medication management, scheduling appointments, and accompanying them during doctor visits. For male participants, support was mostly related to the financial backing required to pay for medication. This reflects the classic role of women and men in Arab culture, which I elaborate on in Chap. 3.

# 5.7 Diabetes Health-Seeking Behaviors: When is It Way Too Much?

As shown above, some of the data suggest that diabetes was not discovered until visiting the doctor for a casual checkup; in other cases, the data also suggest there is a tendency among Arab immigrants, especially recent immigrants, to go to the hospital "way too much" or more frequently than they used to in their country of origin. But would this not be beneficial? Is it better to be "safe than sorry" and go to the doctors as much as possible? Why would some immigrants go to the hospital and others refuse or prefer not to go?

The data suggest that Arab Americans' behavior of seeking medical treatments falls within two main categories. The first category includes people who tend to see doctors way too much. Participant F1L376 explained the reasons driving this behavior in her own opinion:

There is, for some reason or the other, a lot of people who come with the old-school mentality of war, and so they come from war-torn areas. People are coming from the Middle East, specifically Syria, Iraq, and Yemen—all these areas—because they made it out of war, I think they panic . . . they start to panic, saying, "I made it out of war; let's make sure my health is okay," so they overdo it.
Going to the hospital is positive in the sense of being safe, but it may have other negative outcomes. First, during the interviews, many participants shared the struggles they experience with their family members during their hospital visits, such as difficulties driving them to their appointments, especially during work and school hours. In addition, going to the hospital too much requires more appointments and visiting medical facilities with more frequency. This can put pressure on the medical system, especially when it comes to doctors who speak Arabic in Dearborn. This is because most recent immigrants, or even first-generation immigrants, prefer an Arab doctor because of the language barrier and the shared culture.

The second category in health-seeking behaviors is related to people who refuse to seek medical help. During the interviews, many participants outlined why someone with diabetes, or any other chronic illness would not go to the hospital, and it all came down to two main reasons: (1) they view a chronic illness to be a sign of weakness; and (2) they have limited understanding of the illness. First, chronic illness as a sign of weakness is an outlook that is more apparent among Arab men. The Arabic culture places Arab men in a position where they should be "strong" and "unbroken," which is jeopardized by the prospect of an illness; therefore, they tend to avoid the hospital or delay visits as much as possible. Second, regarding the lack of understanding of the illness, during the interviews, many participants expressed their struggles when it comes to monitoring their diabetes and receiving medication for the rest of their life. One of the participants, a pharmacist, described this gap in knowledge as such:

Patient knowledge is what is missing; a lot of doctors depend on the pharmacy: "You have diabetes, I am going to give you insulin, and this is how you take it," and bam! So, when they get here, they say, "Oh, I have diabetes" . . . "Do you know what that means? Do you know the details? Do you know the steps going forward?" None of them know.

#### 5.8 Diabetes Healthcare Access: Arab American Doctors' Availability

Finding an appointment with an Arab doctor is not an easy task. One of participants said, "We have Arab doctors here. The problem is that they are so overwhelmed; they are not even taking new patients now." The question here is, why do Arab Americans prefer to visit Arab doctors over non-Arab ones. The data provide two main reasons: First, first-generation Arab Americans have difficulty communicating due to language differences. Having an Arab doctor eases these challenges and ensures mutual understanding between doctors and patients. The second reason that they prefer to see an Arabic doctor is related to the fact that the doctors are familiar with the patients' cultural beliefs and behaviors.

Having a shared culture is important with regard to choosing a doctor, as it might affect the healing and diagnosis processes. One of the participants shared a story about her sister who had a non-Arab doctor when she was being treated for cancer. She said that her doctor did not know that her sister was taking traditional medicine, which negatively affected her health. She said that Arab doctors ask if their patients use traditional medicine before anything else because it is a common practice among Arabs.

An Arab pharmacist described an additional motive, other than cultural beliefs, to see an Arab doctor. She said,

We are sending the overflowed to other cultures that do not have an accurate understanding of this, especially people coming from Syria, Iraq, Yemen, and Libya. All these places have conflict issues, so they're coming with a lot of PTSD, a lot of mental issues, so there is no ground to understand... because, for example, if you have a doctor from India, I know they have their own conflicts, but it's not the same as with people coming here, you know... or a Chinese doctor is not going to fully understand or even encompass with someone who is coming from the Middle East.

This shows that shared cultural beliefs and an understanding of the political and social struggles of the Middle East are important in choosing doctors to Arab Americans.

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# Chapter 6 Diabetes and Cultural Consensus



**Abstract** This chapter will show the results of the cultural consensus analysis and discuss the complete Arab American cultural beliefs model of diabetes. In addition, the chapter will discuss the variation in the model "beyond agreement," based on sex, generation (first or second), education, age, country of origin, and the language of the survey. The results in this chapter show that Arab American Muslims in Dearborn, MI, share an overall cultural model of diabetes that does not contradict the medical knowledge.

Keywords Cultural consensus · Diabetes beliefs · Diabetes

Cultural consensus analysis refers to "a collection of analytical techniques and models that can be used to estimate cultural beliefs and the degree to which individuals know or report those beliefs" (Romney et al., 1987, p. 339). The model "estimates each individual's level of cultural competency (the degree to which each individual shares the group or normative values) and the answer to each question" (Weller et al., 1999, p. 723). In other words, the model estimates individual differences in cultural knowledge about a particular domain (such as diabetes) and allows for testing variation across respondents based on variables associated with subgroups of respondents (Romney et al., 1987).

The cultural consensus model is based on three main assumptions: (1) each participant answers questions about a cultural domain independently from other participants, (2) the questions asked of respondents belong to one specific cultural domain, and (3) that there is only one answer for each question. (Romney et al., 1987; Weller et al., 1999). This model has been used in many studies to understand people's knowledge about diabetes among US Latinos (Weller et al., 1999), the classification of disease among Mestizo and indigenous Guatemalans (Romney et al., 1986), postpartum hemorrhage among mothers and midwives in Bangladesh (Hruschka et al., 2008), and the causes, symptoms, and treatments of AIDS, diabetes, the common cold, empacho, and mal de ojo in Guatemala, Puerto Rico, and Mexico (Weller & Baer, 2001). In this chapter, I report the results of applying the consensus model to answer two questions: (1) Do Arab Americans have homogeneous beliefs about the causes, symptoms, and treatments for diabetes? (2) If not, then are their discernible differences in their knowledge of diabetes based on sex, age, generation, education level, country of origin, and language in which the survey is taken. To answer these questions, I followed the methods detailed in Chap. 4 to build a cultural consensus survey and collect data from 78 Arab American Muslim respondents in Dearborn, Michigan.

#### 6.1 Cultural Consensus Results

The consensus analysis routine in UCINET (Borgatti et al., 2002) produces four outputs of data: (1) a participant-by-participant agreement matrix (the percentage of times each participant agrees with every other participant in his or her answers to the questions on the knowledge and beliefs about diabetes test); (2) the first and second eigenvalues from the factor analysis of the agreement matrix, the number of negative factor scores (competencies), and the ratio of the first to the second eigenvalue; (3) a competence score for each respondent; and (4) the answer key found for the cultural consensus survey, calculated from the responses of the survey participants. If there is one cultural belief regarding diabetes among Arab Americans in Dearborn, MI, then we expect the first eigenvalue to be much larger than the second, and we also expect to have no negative individual competence scores (Romney et al., 1986, 1987; Weller, 2007).

Table 6.1 shows the first- and second-factor eigenvalues and the number of negative competencies (that is, negative values on the first factor) found in the data (N = 78). The ratio of the first eigenvalue (22.220) to the second (2.939) is 7.561, and, as shown in Table 6.2, there are no negative individual competence scores. This indicates that the data fit the consensus model, and that Arab Americans in Dearborn share an overall cultural model of diabetes. Their shared answer key is shown in Table 6.3. The shared answer key represents the overall shared model of diabetes among Arab American Muslims in Dearborn, Michigan. In general, the beliefs presented in the model, dose not contradict with the Western medical knowledge. One issue related to fasting in Ramadan can be noticed in the model. Arab American Muslims share the beliefs that people who have diabetes should fast in Ramadan (even if they are old and have health complications) and maintain their usual year-round diet while fasting.

Although there is a single cultural model of diabetes among these Arab Americans in Dearborn, the 2nd-factor eigenvalue of 2.9 shows that there is possible variation in the model. To check whether there was enough variation to be tested in the model, I followed the recommendation of Romney et al. (1987) and checked the standard deviation for the respondents' competence scores. The standard deviation for the average score is 0.21, which is above the 0.18 cutoff suggested by Romney et al. (1987), indicating sufficient variation to be tested in the model.

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Table 6.1First and second factors' eigenvalue, ratio, and number of negativeMeasurementScoreNo. of negative competencies0			
number of negative No. of negative competencies 0	<b>Table 6.1</b> First and second factors' eigenvalue, ratio, and number of negative competences	Measurement	Score
		No. of negative competencies	0
competences Largest eigenvalue 22.220		Largest eigenvalue	22.220
Second largest eigenvalue 2.939		Second largest eigenvalue	2.939
Ratio of largest to next 7.561		Ratio of largest to next	7.561

#### 6.2 Testing Variation Using 2nd-Factor Loading

Using the loadings on the 2nd factor to look for substantive variation in a consensus model was suggested by Boster (1986), who posited the presence of systematic deviations from consensus "by pairs of informants who agree with each other more than would be expected on the basis of their approach to the general consensus" (Boster, 1986, p. 431). Boster (1986) referred to "agreement beyond the overall cultural consensus" as "residual agreement" (Dressler et al., 2015, p. 24). In their work comparing novice and professional fishermen, Boster and Johnson (1989) presented a method for examining residual agreements in a consensus model, and Dressler et al. (2015) describe the method for what they call "finding culture change in the second factor."

To look for possible subgroups in the 2nd-factor loadings shown in Table 6.4, I correlated the 2nd-factor loading with the following variables: sex, generation (first or second generation), education, age, country of origin, and the language the survey was taken in (For statistical tests, SPSS software was used).

Eta coefficient was used to examine the correlation of the categorical variables with the 2nd-factor loadings. The Eta coefficient ranges from 0 to 1, with a score of 0.3 or greater considered sufficient to establish a significant correlation (Garson, 2008). As shown in Table 6.5, only one of the variables examined (generation; eta = 0.369) was significantly correlated with the 2nd-factor loading. We conclude, then, that there may be significant differences in cultural beliefs about diabetes between first- and second-generation Arab Americans. The correlation between the 2nd-factor loading and age was 0.52 (Table 6.6), indicating possible differences in cultural beliefs about diabetes based on age.

#### 6.3 Cultural Consensus Analysis Based on Generation and Age

In sum, there are two variables that can be used to check for possible subgroups in the cultural beliefs about diabetes among Arab Americans in Dearborn, MI: generation and education. Therefore, I first divided the sample based on generation into two subgroups, first generation (n = 40) and second generation (n = 38), and I ran the cultural consensus for each subgroup separately, again using UCINET. Table 6.7

#	Participant code	Individual scores
1	2F1I201	0.333
2	2F1Y207	0.701
3	2F1Y196	0.489
4	2F2Y182	0.625
5	2F1Y195	0.300
6	2F1Y204	0.086
7	2F1Y193	0.494
8	2F1Y218	0.734
9	2F2S182	0.189
10	2M2L196	0.412
11	2M1S461	0.634
12	2M1L189	0.472
13	2M2L185	0.312
14	2F2L180	0.512
15	2F1Y184	0.507
16	2F1L211	0.497
17	2F1I298	0.621
18	2F1L223	0.243
19	2M1I537	0.573
20	2F1L212	0.437
21	2F1I429	0.687
22	2M1Y256	0.483
23	2M2L203	0.685
24	2F1Y233	0.066
25	2F2L181	0.345
26	2F2P198	0.259
27	2F2L244	0.729
28	2F1Y209	0.576
29	2M2Y224	0.139
30	2F1L218	0.084
31	2F1P227	0.319
32	2F2L226	0.596
33	2F2Y245	0.645
34	2F2L190	0.660
35	2F2L189	0.577
36	2F2I180	0.651
37	2F2P181	0.635
38	2M2E183	0.780

 Table 6.2
 Individual competency scores

(continued)

#	Participant code	Individual scores
39	2M1P194	0.441
40	2M2L205	0.629
41	2F2P196	0.672
42	2F2I187	0.704
43	2M1Y220	0.454
44	2M2Y291	0.367
45	2M1Y219	0.569
46	2M2Y228	0.389
47	2M2L193	0.482
48	2M2Y222	0.097
49	2F2L194	0.537
50	2F2L235	0.676
51	2M2L184	0.693
52	2M2L186	0.120
53	2M2L187	0.670
54	2F1L210	0.426
55	2F2P202	0.228
56	2M1L219	0.014
57	2M1L221	0.283
58	2M1L200	0.032
59	2F1Y252	0.569
60	2F1I313	0.457
61	2M1Y205	0.497
62	2M1J387	0.733
63	2M1Y374	0.666
64	2M1Y286	0.707
65	2M1P501	0.782
66	2M1P442	0.694
67	2F2Y220	0.546
68	2M1I298	0.253
69	2F2Y309	0.479
70	2F2L263	0.846
71	2M2L214	0.301
72	2M2I245	0.444
73	2M1P2046	0.650
74	2M1S467	0.634
75	2M1Y378	0.666
76	2M2I249	0.444

 Table 6.2 (continued)

(continued)

#	Participant code	Individual scores
77	2M2L200	0.629
78	2M2L252	0.843

Table 6.2 (continued)

shows the results. Both first- and second-generation cultural consensus results show that the 1st factor is much larger than the 2nd factor, and that there are no negative individual competence scores. This indicates that the data fit the consensus model, and that first- and second-generation Arab Americans in Dearborn, MI share a cultural model of diabetes.

To further examine the differences between the first- and second-generation knowledge, I compared the answers keys for each group. Two differences were found between the answer keys for first-and second-generation subgroups: (1) For first-generation respondents, the consensus answer to the statement "People who have diabetes have the same risk of having depression as people who don't have diabetes" was true, while for the second generation it was false. (2) For first-generation respondents, the consensus answer to the statement "People who have diabetes should be prevented from eating sugar at all" was true, while for the second generation it was false. These differences may be explained by the level of education-those born in the United States (the second generation) having higher levels of education, on average, than those of the first generation. It is also very important to think about the culture that drives those differences especially when it comes to mental illness in general and depression in specific. During my daily interactions with the community members, I noticed that first-generation Arab Americans tend to dismiss the idea of having mental illnesses, as they see it as a sign of "not having faith." When chatting with one of the second-generation participants, she mentioned that the word "depression" is banned in their house by her parents (first generation). As she explained further that her parents believe that not praying and not staying close to God is the reason for feeling depressed.

To test for possible differences by age, the data were divided into two age subgroups: 18-24 (n = 57) and 25-53 (n = 21) and ran the consensus analysis separately on each subgroup. Table 6.8 shows the results. For both age groups, the 1st factor is much larger than the 2nd, and there are no negative individual competence scores in either group. This indicates that the data for both age subgroups separately fit the consensus model.

Next, I compared the answer key for the age group 18–24 with the answer key for age group 25–53. Four differences were found: (1) Younger respondents (18–24) answered the statement "lack of exercise can cause diabetes" as true, while older respondents (25–53) answered it as false. (2) Age subgroup 18–24 answered the statement "people who have diabetes have the same risk of having depression as people who don't have diabetes" as true, while those 25–53 answered it as false. (3) Age subgroup 18–24 answered the statement "people who dan't have diabetes" as true, while those 25–53 answered it as false. (4) Age subgroup

Question	Answer
Some people have diabetes because it runs in their family	True
An unhealthy diet can lead to having diabetes	True
Lack of exercise can cause diabetes	True
Having a dry mouth is not a sign of having diabetes	False
Feeling dizzy is a sign of having diabetes	True
People with diabetes may have frequent headaches	True
Young people who have diabetes don't have to control their blood sugar	False
It does not matter how old you are, old and young people have the same chance of getting diabetes	True
When a person faints, it's possible that they have diabetes	True
People who have diabetes usually sweat more than people who don't have it	True
People who have diabetes tend to feel tired more than people who don't have it	True
People who have diabetes feel thirsty a lot	True
People who have diabetes have the same risk of having depression as people who don't have diabetes	True
Having a high level of stress does not put people at higher risk of having diabetes	False
Only old people who have diabetes are at risk of getting cardiovascular disease	False
People who have diabetes have shaky hands and\ or feet	True
There's nothing you can do to prevent complications from diabetes	False
People who have diabetes should monitor their blood pressure on a regular basis	True
People can get diabetes when other people envy them and give them the envy eye/ evil eye	False
Eating too much sugar can cause diabetes	True
Regular exercise makes diabetes worse	False
Numbed feet is something that people who have diabetes suffer from	True
People who have diabetes can fast in Ramadan	True
Type-2 diabetes doesn't affect your emotions	False
People of all ages have the same chance of having type-2 diabetes	True
People who have diabetes do not need to take medication on a regular basis	False
Diabetes can cause the kidney to stop function	True
Only old people get health complications when they have diabetes	False
Foot pain is one symptoms of diabetes	True
People who have diabetes should eat less sugar	True
Vision problems are not something people who have diabetes suffer from	False
Losing weight is a good way to manage diabetes	True
It is common that people who have diabetes have high blood pressure	True
(0	continued)

 Table 6.3 Diabetes overall knowledge answer key

Question	Answer
People who have type-2 diabetes actually feel stronger than people who don't have it	False
Being obese increases the risk of having diabetes	True
Diabetes can be cured	False
Getting tested is the first step to treat diabetes	True
People who have diabetes drink a lot of water	True
Drinking alcohol heavily is not related to having diabetes	False
People who have complications from diabetes can still fast during Ramadan	True
People have diabetes because their body is not producing enough insulin	True
If diabetes is not treated and managed well it can cause death	True
People who have diabetes usually have high blood sugar	True
Eating fast food does not cause people to have type-2 diabetes	False
When you have type-2 diabetes, you have a lot of energy and are rarely fatigued	False
Only older people who have diabetes can stop fasting during Ramadan	False
Obese people with diabetes have higher risk of cardiovascular disease	True
When women have type-2 diabetes while pregnant they increase the chance of having type-2 diabetes after they give birth	True
When people who have type-2 diabetes faint, you can help them by giving them a sugary drink or piece of candy	True
During Ramadan, people who have diabetes can maintain their usual, year-round diet	True
People who have type-2 diabetes should be prevented from eating sugar at all	False

#### Table 6.3 (continued)

18–24 answered the statement "people who have complications from diabetes can still fast during Ramadan" as true, while the age subgroup 25–53 answered it as false.

Regarding the differences in answers to the first statement, people with higher education levels (ages 18–24) are more likely to have higher awareness of the importance of exercise on health. For statements 2, 3, and 4, it's possible that people in age subgroup 25–53 have more health complications, making them aware of health and depression as well as the possibility of not fasting during Ramadan.n

Participant code	Second-factor loading
2F1I201	-0.163917288
2F1Y207	-0.216271028
2F1Y196	-0.097178146
2F2Y182	0.254946321
2F1Y195	-0.157138973
2F1Y204	-0.174898103
2F1Y193	-0.210947663
2F1Y218	-0.368477643
2F2S182	0.082135536
2M2L196	0.154919192
2M1S461	0.036346730
2M1L189	0.010340351
2M2L185	-0.213338464
2F2L180	0.191108108
2F1Y184	-0.322737992
2F1L211	-0.081286214
2F1I298	0.032066520
2F1L223	-0.279170185
2M1I537	-0.074116737
2F1L212	-0.157446384
2F1I429	0.019017415
2M1Y256	0.021156108
2M2L203	-0.102682978
2F1Y233	0.307276666
2F2L181	-0.134767309
2F2P198	0.383328855
2F2L244	-0.105208613
2F1Y209	-0.105615042
2M2Y224	0.089898400
2F1L218	-0.078527302
2F1P227	-0.014347324
2F2L226	0.173565045
2F2Y245	0.136900187

**Table 6.4** Second-factor loading (N = 78)

(continued)

Participant code	Second-factor loading
2F2L190	0.157431722
2F2L189	0.058450744
2F2I180	0.025687920
2F2P181	-0.135200426
2M2E183	0.172143430
2M1P194	-0.220902532
2M2L205	-0.173415765
2F2P196	-0.135766447
2F2I187	0.101377338
2M1Y220	-0.203592241
2M2Y291	-0.417179972
2M1Y219	-0.403850555
2M2Y228	0.369503558
2M2L193	0.287198633
2M2Y222	0.020090846
2F2L194	0.004578135
2F2L235	0.263548255
2M2L184	-0.099751629
2M2L186	0.197850421
2M2L187	0.372515738
2F1L210	-0.123623103
2F2P202	-0.113608077
2M1L219	-0.167182207
2M1L221	0.193702087
2M1L200	-0.082845286
2F1Y252	0.135545030
2F1I313	-0.164705709
2M1Y205	-0.052338395
2M1J387	-0.055316411
2M1Y374	0.048752293
2M1Y286	0.075582325
2M1P501	0.133372054
2M1P442	-0.040458091
2F2Y220	-0.110532105
2M1I298	-0.029120525
2F2Y309	0.022676686
2F2L263	-0.088911004

 Table 6.4 (continued)

(continued)

Participant code	Second-factor loading
2M2L214	-0.046673223
2M2I245	0.525705576
2M1P2046	0.112064645
2M1S467	0.036346730
2M1Y378	0.048752293
2M2I249	0.525705576
2M2L200	-0.173415765
2M2L252	0.150698766

#### Table 6.4 (continued)

**Table 6.5** Eta results for the categorical variables (N = 78)

Variable	Eta coefficient score
Generation	0.369
Education	0.089
Country of origin	0.243
Sex	0.146
Language of the survey	0.011

**Table 6.6** Pearson's correlation for age and second-factor loading (N = 78)

		CCA 2nd-factor loading	Age
CCA 2nd-factor loading	Pearson correlation	1	0.0750
	Sig. (2-tailed)		0.0515
	Ν	78	78
Age	Pearson correlation	0.075	1
	Sig. (2-tailed)	0.515	
	N	78	78

<b>Table 6.7</b> Results of cultureconsensus for first $(N = 40)$				
	Generation	Measurement	Score	
and second generation ( $N =$	First generation	No. of negative competencies	0	
38)		Largest eigenvalue	10.930	
		Second largest eigenvalue	1.777	
		Ratio of largest to next	6.152	
	Second generation	No. of negative competencies	0	
		Largest eigenvalue	11.865	
		Second largest eigenvalue	1.915	
		Ratio of largest to next	6.197	

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Table 6.8 Consensus analysis results for both ages group 18–24 (N = 57), and age 25–53 (N = 21)	Age subgroup	Measurement	Score
	18–24	No. of negative competencies	0
		Largest eigenvalue	14.195
		Second largest eigenvalue	2.673
		Ratio of largest to next	5.309
	25–53	No. of negative competencies	0
		Largest eigenvalue	8.382
		Second largest eigenvalue	1.340
		Ratio of largest to next	6.253

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# Chapter 7 What is Next?



Abstract The chapter discusses the possible real application of the Arab American cultural beliefs model of diabetes and how medical professionals can use it to gain a better understanding of patients' cultural knowledge. This chapter argues that the current culturally competent healthcare services provided in hospitals—if any—have missing links. Using cultural beliefs models of illness built using cultural consensus models as part of cultural competence techniques can enhance medical professionals' understanding of their patients' cultures.

Keywords Cultural beliefs · Cultural competence

This book aimed to build the cultural belief model of diabetes among Arab American Muslims in Dearborn, Michigan. Results showed that Arab American Muslims share an overall cultural model of diabetes that does not contradict with the biomedical knowledge. Although they share an overall model of diabetes, the data also showed some variation in the level of knowledge based on age, education level, and generation.

In addition, this research presented data related to different aspects of Arab American Muslims and diabetes, such the role of family in providing care, fasting in Ramadan, and diabetes healthcare access. This research presents evidence that although Arab Americans Muslims established a long-lasting community in Dearborn, MI, they still face major difficulties related to receiving healthcare especially for chronic illnesses such as diabetes. So, what can be done next?

Statistics are not available regarding how many Arabic-speaking doctors are available in Dearborn, MI, but by just walking down the city's streets, it is impossible to deny the number of hospitals and clinics that Arab Americans operate. Although hospitals and clinics have an apparent number of doctors and medical staff who are Arabs (they have the same or similar culture as their patients and they speak Arabic to some extent), it is still apparent, as shown in Chaps. 4 and 5, there are difficulties in obtaining access. This happens mainly due to the large number of Arabs in Dearborn, or due to the unavailability of some of the doctors' specializations. Additionally, the data shown in Chap. 4 evidence a lack of information provided to patients during the

doctor visits. In addition, in some cases, the data also suggested the care provided to Arab American Muslims was challenged by patients' cultural beliefs that minimized the importance of receiving mental health services.

Is Dearborn unique? Do the issues found among Arab American Muslims not exist among other immigrant populations? The answer is no. As shown in Chap. 1, many immigrant populations in the Unites States and in other parts of the world share similar difficulties and suffer from high prevalence of different illnesses compared to the general populations. So, how can this be fixed?

For such a complex issue, the solution is not easy. One of the core solutions is to provide an effective culturally competent healthcare services to immigrants. In this chapter, I review the main principles of providing culturally competent healthcare services and I challenge the missing links on different elements used in those strategies, showing how this study can help fill the gaps.

#### 7.1 Culturally Competent Healthcare System

Cultural competency is defined as, "a set of congruent behaviors, attitudes, and policies that come together in a system, agency or amongst professionals and enables that system, agency or those professionals to work effectively in cross-cultural situations" (Brach & Fraser, 2002; Brach & Fraserirector, 2000; Cross, 1989, p. 182). For some, cultural competency can be seen as being "culturally sensitive" or being "culturally aware," but it is more than that. Cultural competency "includes not only possession of cultural knowledge and respect for different cultural perspectives but also having skills and being able to use them effectively in cross-cultural situations" (Brach & Fraserirector, 2000, p. 183).

Having culturally competent healthcare system is not an option, it is a must at this point; estimates in the United States show that by the year of 2050, 47% of the population will be minorities (Brach & Fraserirector, 2000). This trend is not any different cross the globe; the United Nations stated that "the world is on the move, and the number of international migrants today is higher than ever before." (Handtke et al., 2019, p. 2).

Previous efforts in providing culturally competent healthcare mainly focused on providing language interpretation services. White et al. (2019) conducted a study in Australia, where the population is very diverse and consists of people who migrated from 190 countries and have up to 300 different ancestries, that focused on studying the effect of using interpreters in doctor–patient communication for people who have limited English proficiency. The study results showed that using interpreter reliance on family members to do the translations.

Pocock et al.'s (2020) study focused on the difficulties migrants and refugees face in accessing health services in Thailand and Malaysia from the stakeholders' perspective. The study focused on the lack of using interpreters for the immigrants and refugees in the hospitals to make the health services accessible to them. The

study showed the health stakeholders in Malaysia had a lack of understanding on the need and benefit of using interpreters in medical settings; for these stakeholders, "Malay was perceived to be an easy language that migrants could learn quickly" (Pocock et al., 2020, p. 1). The study showed that "Health workers in Malaysia used strategies including Google Translate and hand gestures to communicate, while migrant patients were encouraged to bring friends to act as informal interpreters during consultations" (Pocock et al., 2020, pp. 1–2). In Thailand, the situation was different, "formal interpreters, known as Migrant Health Workers (MHW), could be hired in public facilities, as well as Migrant Health Volunteers (MHV) who provide basic health education in communities." (Pocock et al., 2020, p. 1).

Brach and Fraser (2002) study in the United States showed that in every five Americans, one has difficulties in communication with their healthcare provider. The study also showed that 27% of Asian Americans and 33% of Hispanics have issues related to communication. The study suggested that people who have language proficiency issues are more likely to have "fewer physician visits and receive fewer preventive services, even after controlling for such factors as literacy, health status, health insurance, regular source of care, and economic indicators" (2002, p. 16). The study emphasized that reducing disparities would require "surmounting not only these linguistic barriers but broader cultural ones as well" (Brach & Fraser, 2002, p. 16).

#### 7.2 Cultural Competence Techniques in Healthcare System

Providing culturally competent healthcare services goes beyond providing language interrupters. Efforts had been made in developing cultural competence techniques that can be used to provide better healthcare services across cultures by decreasing disparities in healthcare. Brach and Fraserirector (2000) study composed a set of culturally competent techniques that have been discussed in the literature, including the following techniques: using interpreter services, recruiting staff who have a similar culture and language to the different cultures represented in the population, cultural competency training for staff to increase cultural knowledge and awareness, collaborating with a traditional healer to increase patient adherence, hiring community health workers, involving the patient's family, creating culturally competent health promotional programs, and additional accommodations such as related to the clinic's location and the working hours. Other studies have also shown similar strategies (Anderson et al., 2003; Kagawa-Singer & Chung, 1994; Weech-Maldonado et al., 2012).

In addition, Campinha-Bacote's (2002) model of cultural competence was developed to encompass many important aspects to navigate patients from different cultural backgrounds. The model sees "cultural competence as the ongoing process in which the healthcare provider continuously strives to achieve the ability to effectively work within the cultural context of the client" (Campinha-Bacote, 2002, p. 181). This dynamic model "requires healthcare providers to see themselves as becoming culturally competent rather than already being culturally competent" (Campinha-Bacote, 2002, p. 181). Having cultural competence in the Campinha-Bacote's model means becoming involved in the "integration of cultural awareness, cultural knowledge, cultural skill, cultural encounters, and cultural desire" (Campinha-Bacote, 2002, p. 181). Cultural awareness means accepting the idea that people from different backgrounds will have different thoughts and behaviors as well as not have an ethnocentric position regarding others. Furthermore, cultural knowledge means having educated knowledge about people's cultural beliefs; this education "must focus on the integration of three specific issues: health-related beliefs and cultural values, disease incidence and prevalence, and treatment efficacy" (Campinha-Bacote, 2002, p. 182). Cultural skill is "the ability to collect relevant cultural data" (Campinha-Bacote, 2002, p. 182). Health professionals should conduct a cultural assessment where they obtain information from their patients regarding their beliefs, values, and cultural practices to provide them with the best medical interventions. Additionally, cultural encounters entail putting healthcare professionals in direct contact with people from different cultural backgrounds. In this model, such interactions would help in minimize wrong assumption and stereotypes and it would promote a better understanding of other people's cultures. Lastly, cultural desire focuses on building the "motivation of the healthcare provider to want to, rather than have to, engage in the process of becoming culturally aware, culturally knowledgeable, culturally skillful, and familiar with cultural encounters" (Campinha-Bacote, 2002, p. 182).

Why would providing culturally competent healthcare services make a difference? Studies have shown that people who receive care that is more customized toward understanding their language, cultural knowledge, and behaviors will more likely to have successful diagnoses, treatments, and adherence to treatment plans (Kagawa-Singer & Chung, 1994). In addition, studies have found that "differences between patients and providers will lead to diagnostic errors; missed opportunities for screening; failure to take into account differing responses to medication" (Brach & Fraser, 2002, p. 16). Furthermore, studies have shown that culturally competent healthcare services provide healthcare professionals the opportunity of having a better understanding of people from across cultures, and to manage their behavior inside and outside of the hospital setting. Culturally competent service can go as far as understanding the traditional medicine patients take and the possible harm it could cause, as well as helping to direct patients to traditional healers that the medical provider trusts to aid in the healing processes (Brach & Fraserirector, 2000).

Having a culturally competent healthcare system is not an easy task. Studies have shown that there are many barriers that prevent applying such techniques. The first barrier is related to a lack of resources regarding providing training to the staff and martials to the patients (White et al., 2019); studies have proposed different training programs that can extend between 3 and 6 months to establish the necessary cultural knowledge (Kagawa-Singer & Chung, 1994). These programs have shown to be difficult to accomplish mainly due to financial capacities. Furthermore, the second and most important barrier is the actual realization of the importance and benefits of cultural competency (Weech-Maldonado et al., 2012).

#### 7.3 How Can This Study Help?

Cultural knowledge is one of the core aspects of all cultural competence techniques and models used in healthcare discussed in this chapter. It is impossible to create a culturally competent healthcare system without knowing the culture of the people who are seeking healthcare. Having the cultural knowledge in small countries where few ethnic groups exist is possible, but in countries such as the United States, it is almost impossible to follow the cultural competence techniques as detailed in this chapter. Conducting a cultural assessment per Campinha-Bacote's model of cultural competence—in each patient level—is more likely to hinder the process and will return the system to the limitations and challenges discussed above.

This study suggests utilizing the studies on cultural beliefs of illness conducted by using cultural consensus models to fill the cultural knowledge gaps in the cultural competency strategies. The model has been used across cultures and tested to be effective in creating cultural models of different illnesses. The data collected to create the cultural beliefs model of illnesses produced two main beneficial outputs that can be utilized in cultural competency strategies in healthcare: (1) a set of questions that elicited the cultural beliefs related to the illness and (2) people's overall cultural beliefs answer key to those question, which represent their cultural belief related to each item. To explain the ways in which those outputs can be used, I will use the Arab American cultural belief model of diabetes collected in this research.

First, as shown in Chap. 6, the Arab American diabetes culture belief model contains 52 true/false statements. The statement measures the knowledge related to the cause of diabetes, symptoms of diabetes, treatments of diabetes, fasting in Ramadan, fears of having diabetes, the belief of the evil eye and its effect on diabetes, depression and diabetes, and many others. Those statements have been tested and shown to elicit the cultural beliefs of diabetes among the study population. This means that those statements are appropriate ones to ask patients to answer in a hospital setting, where the questions will aid healthcare professionals to build a clear understanding of the patient's cultural knowledge at each level and provide better healthcare services.

The 52 statements can be used as one set, or they can be used within categories for a faster assessment by healthcare professionals. Therefore, I divided the true/false statements into nine categories (Appendix D):

- 1. Diabetes and diet, including 6 statements.
- 2. Diabetes, weight, and physical activities, including 5 statements.
- 3. Diabetes and fasting in Ramadan, including 4 statements.
- 4. Diabetes and age, including 5 statements.
- 5. Diabetes and mental health, including 4 statements.
- 6. Diabetes and comorbidities, including 7 statements.
- 7. Diabetes treatment and cure, including 4 statements.
- 8. Diabetes other causes, including 4 statements.
- 9. Diabetes effect on the body, including 15 statements.

Health professionals can identify the categories they can use depending on their patient's health condition. For example, if the patient is obese, then the category "diabetes, weight, and physical activities" that contain five questions can be the section on which they focus.

Second, health professionals can use—as a guide—people's overall cultural beliefs key answers (in Chap. 6) to quickly and efficiently build their cultural knowledge related to diabetes by reading only 52 statements (in my research case and around 60 in most cultural consensus models). For example, if the cultural consensus model for the common illness in each culture group within the population is built, it will be easy and more time and cost efficient for health professionals to build their "cultural knowledge."

This solution does not dismiss the other important aspects of cultural competence techniques and models followed in healthcare systems, but it provides a different outlook that requires an interdisciplinary approach to find a solution that can increase the benefits and decrease the challenges and difficulties related to the cultural knowledge of illnesses.

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# Chapter 8 Discussion and Conclusion



**Abstract** This chapter includes the book's discussion and conclusion, highlighting the main objectives, arguments, and results. In addition, this chapter will include the study's shortcomings and a roadmap for future research.

Keywords Immigration · Diabetes beliefs · Immigrant health

The goal of this book was to build a cultural belief model of diabetes among Arab American Muslims in Dearborn, MI. In doing so, knowledge related to causes, symptoms, and treatments of diabetes was discovered. In addition, the book provided an insight into the community regarding who can have diabetes and what it does to the body. This book is the result of two years of ethnographic fieldwork in Dearborn, MI, which added depth to the discussion of diabetes and its relation to the historical, social, and political expression of Arab American Muslims in Dearborn, MI.

Regarding the causes of diabetes, there is strong evidence that first- and secondgeneration Arab American Muslims in Dearborn believe that diabetes is caused by genetics. This confirms what researchers have found in the belief systems of other cultures, including North Africans (Skelly et al., 2006), Canadian Anishinaabe (Garro, 1996), South Asians (Lawton et al., 2007), and Latino populations (Weller et al., 1999). Although studies have shown that people from various cultures believe that diabetes can be caused by genetics, the studies did not examine how close the genetic relationship must be for a person to have diabetes. As discussed in Chap. 5, for Arab Americans, the fear of having diabetes that is caused by genetics is limited to having parents or grandparents who have diabetes (the relation can be clearly tracked throughout the narratives discussed in the chapter). Statements such as "My brother has diabetes because my father has it" and "Because my grandmother has diabetes, I might have it" indicate that people think diabetes is caused by genetics and can run in their family.

The belief that being "chubby" (Everett, 2011), "fat" (Garro, 1996), or overweight is a cause of diabetes has been noted in several studies. This belief is similar among Arab American Muslims in Dearborn, many of whom believe that being "fat" and "lazy" indicate an inactive lifestyle and can cause diabetes.

Studies have shown that stress is one of the main causes of diabetes across many cultures. Stressors such as being an immigrant and going through traumatic experiences, including violence and death, were mentioned as reasons for stress across several cultures (Lawton et al., 2007; Mendenhall et al., 2010; Weller et al., 1999). Arab American Muslims in Dearborn share similar explanations for stress. Many diabetics are first-generation immigrants who came from war-torn countries such as Syria, Iraq, Yemen, and Lebanon. Most of the time, those immigrants were forced to leave their countries, leaving behind their life, homes, and extended family. Most of them, as they shared, fled with nothing and underwent a challenging journey till they reached the United States. Their arrival to the states did not mean that all difficulties diminished as they started a new life, learning English, finding permanent homes, finding jobs, and navigating the new social and political reality they lived in.

In addition, two other sources of diabetes-related stress are worth highlighting for this population. First, people who cannot fast because of illness are not required in Islam to do so during Ramadan (Dukes, 2009-2017; Navigator, 2018). Although this knowledge is common among Arab American Muslims in Dearborn, the data showed that some people who have diabetes refuse or try their best not to break their fasting during Ramadan. Many consider being unable to complete the religious duty of fasting due to diabetes a sign of weakness. This creates stress over the ability to fast, maintaining a "strong" image in front of others, and how people with diabetes should alter their daily lives to be able to fast from sunrise to the sunset for a month. Second, people who have diabetes and choose to break their fast during Ramadan or were forced to by their doctors due to health complications experience financial stress because they give to charity as compensation for not fasting during Ramadan (discussed in Chap. 5), especially people with low income.

Many studies across cultures have shown that thirst and fatigue are symptoms of diabetes (Culhane-Pera et al., 2007; Jezewski & Poss, 2002; Skelly et al., 2006; Weller et al., 1999). Arab American Muslims believe feeling thirsty and tired might be a sign of diabetes. What is worth noticing here is that all symptoms of diabetes that the participants listed were physical ones; none of the participants listed an emotion or a feeling as a symptom of diabetes.

When it comes to treatments, it is very interesting—and promising—that Arab American Muslims listed medication as the first treatment of diabetes. Although medication was listed as a well-known treatment recognized by the population, knowing did not correlate with their medication consumption behavior. Many participants expressed difficulties regarding how long they would have to take the medicine, adherence, and understanding the right dosages and ways of storing the medicine.

In addition to medicine, Arab American Muslims in Dearborn acknowledged the importance of a healthy diet as a treatment for diabetes. Many participants recommended giving up fast food, having a healthy diet, and giving up delicious Arabic sweets as a must for people who have diabetes. This awareness of the importance of a healthy diet among Arab Americans confirms the results of studies of other cultures (Garro, 1996; Lawton et al., 2007; Skelly et al., 2006; Weller & Romney, 1988).

Most Arab American Muslims' cultural beliefs related to the treatment of diabetes are similar to those of other cultures (Culhane-Pera et al., 2007; Jezewski & Poss,

2002; Weller et al., 1999), but clear differences emerge regarding whether diabetes can be cured. Most Arab American Muslims in Dearborn believe that diabetes can cause death if it is not treated or managed well.

Furthermore, the data showed participant knowledge regarding the side effects of diabetes treatment, which was not explored enough in other studies of cultural beliefs. Participants in this study noted that treatments for diabetes in general—and insulin specifically—can lead people to gain or lose weight, that is, that diabetes can make a person fat or skinny, but they did not know why the medication would have different effects on different people.

Following the same thread regarding stress stemming from the causes, symptoms, and treatments of diabetes, participants did not list any psychological treatments for diabetes. Two questions consequently arise. First, if the participants were asked, "What can a person do to prevent having diabetes?" would they include any psychological treatments to deal with stress? Second, does this mean that Arab American Muslims in Dearborn don't believe that a person who has diabetes needs to manage their stress and therefore needs psychological treatment? This study clearly shows that more attention needs to be given to understanding the relation between chronic illness and mental illness among Arab American Muslims in Dearborn, with a focus on the stigma and cultural beliefs.

In addition, diabetes management is an important aspect of treatment. Several studies have shown that the better the family involvement and help for the diabetic family member, the better the diabetes management outcome (Edelstein & Linn, 1985; Henderson, 2010; Pinelli et al., 2011). For Arab Americans in Dearborn, diet management, carrying the financial burden, dealing with their emotions, reminding them of medication, going with them to doctor's appointments, and carrying the workload with the decrease in physical activity are the types of support and care provided.

Pinelli and Jaber (2011) and Pinelli et al. (2011) found that help with diet, physical activities, and medication management are the main problems that diabetic Arab Americans deal with during Ramadan. My study confirms the findings of Pinelli et al. (2011), and with ethnographic data, it adds the viewpoint of family members regarding the care they provide during Ramadan as well as stories of people who have diabetes feeling dizzy, passing out, and going to the emergency room due to fasting.

In Chap. 6, I explored the first CCA model for Arab American Muslims' cultural beliefs about diabetes. In general, the models have shown that Arab American cultural knowledge of diabetes does not contradict the medical knowledge. The model also showed the cultural beliefs regarding fasting in Ramadan and the evil eye/envy.

In Chap. 7, I argued that the results from the CCA models for illness cross cultures and can be used to fill the gaps of "cultural knowledge" in the current healthcare systems. An effort to provide culturally competent healthcare has been made, but with many limitations (Brach & Fraser, 2002; Brach & Fraserirector, 2000; Handtke et al., 2019; Pocock et al., 2020; White et al., 2019). Many studies have shown the important of cultural knowledge and included it as an important aspect in developing cultural competence techniques and models to be used in providing healthcare services cross cultures (Anderson et al., 2003; Brach & Fraserirector, 2000; Campinha-Bacote, 2002; Kagawa-Singer & Chung, 1994; Weech-Maldonado et al., 2012).

This study focused on studying the community cultural knowledge of diabetes. The sample included people who did not have diabetes, but experienced diabetes through their diabetic family members. I was able to collect narratives and stories of experiences of people dealing with diabetes in relation to their family members in daily life including the month of Ramadan. In addition, I was also able to gain insight into the family dynamics of people who have diabetes, especially the help that family members provide to diabetics. Although the community cultural knowledge of diabetes is important, its essential to conduct future studies that focus on building cultural knowledge of people who have diabetes, which was not part of this study. In addition, one of the other shortcomings of the study is that the participants were mostly young, between the ages of 18 and 25, which did not allow for greater comparison based on age.

Researchers can eliminate this study's limitations by including people who have diabetes in the sample and comparing their cultural belief model with the cultural model found in this study. Also, it would be interesting for researchers to compare the care provided for people with diabetes from the family's point of view and that of the diabetic person who received the care. Do they see their family managing their diabetes medication and their diet as a good thing? Is it helpful? Does it cause them stress? A cross-comparison would show how effective family members' care and management practices actually are for diabetics. Most important, more efforts are needed in studying Fasting in Ramadan and diabetes among Muslims in America, as well as studying the link between mental illnesses and chronic illnesses among immigrants in general and Arab Americans specifically.

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# **Appendix A: Stage One Data Collection Interview Guide**

#### **General Participant Information**

Interview language:

□ Arabic □English

#### **Participant Category**

□ First generation

□ Second generation

Sex

□ Male □ Female

Age .....

Question 1: Personal Background—First, I'm interested in hearing a bit about

yourself. Can you tell me the story of where you were born, where you grew up, and

your family?

#### Probe

□ How long has your family been in the U.S.?

□ When did you come to the U.S.? And which state did you go to when you arrived here?

<sup>□</sup> When did your parents or grandparents come to the U.S.? And which state?

□ In which country were your parents/ grandparents born?

□ How many years have you been in the U.S.?

How many years have your parents/ grandparents... been in the U.S.?

□ Marital status □Married □ Divorced □ Widowed□ Remarried

- □ Number of children (with each spouse if they have been married before)
- □ Number of people in household
- □ Family members in the U.S.

**Question 2: Education**— Can you please tell me more about your education? For how many years did you study? Where did you study? And what is your degree/ major (if they have 13+ years education)?

**Question 3: Occupation**— Now let's talk about your occupation, what is your current occupation? How long you have been doing this? What other occupations have you had? Where?

**Question 4: Origin Visits**— (If not U.S. born): When did you last visit (country of origin)? And the time before that? How many times have you been back since you came to the U.S. (If U.S. born): How many times have you been to (country of parents or grandparents' origin)?

**Question 5: Social Network**— We have been talking about you, and your family, now I would like to ask you some question related to Arab American health and specifically about diabetes Do you know someone with diabetes? If so, how many?

#### > Probe

□ How each one is related to you? Family, friends, coworkers...etc.

How often do you communicate with them? Do they talk with you about their experience with having diabetes?

**Question 6: Causes**— What causes diabetes? Just list as many causes as you can think of.

- Probe
- □ Anything else? What other things can you think of that cause diabetes?
- □ Read the list and ask the respondent if the list is complete.
- □ You mentioned x (item from the free list), what other items that you have not mentioned are like x? (Repeat for each item mentioned in the free list).

**Question 7: Symptoms**— What are the symptoms of diabetes? how could a person know that they might have diabetes, what are the signs? Just list as many things you can think of that are symptoms of diabetes.

#### Probe

- □ What other things you can think of?
- □ Read the list and ask the respondent if the list is complete.
- □ You mentioned x (item from the free list), what other items that you have not mentioned are like x? (Repeat for each item mentioned in the free list).

**Question 8: Treatment**— What do people do to treat diabetes? Just list as many treatments as you can think of.

#### > Probe

□ What other things you can think of?

 $\Box$  Read the list and ask the respondent if the list is complete.

□You mentioned x (item from the free list), what other items that you have not mentioned are like x? (Repeat for each item mentioned in the free list).

# Question 9: who can have diabetes? Do some people have more chance of having diabetes than other people? Why?

> Probe

- □ Based on age.
- Based on wieght.
- Based on gender.

# Question 10: what dose diabetes do to the body of the person who has it? Do people have health complications from having diabetes? How dose diabetes work? Will it have a long or a short course?

#### > Probe

can you give me examples or stories you heared about the effect of diabetes on ones body?

#### Question 11: How sever is diabetes? What does make it sever?

#### > Probe

□ can diabetes cause death?

□ do you know someone who have a sever diabetes? why their case is sever? What are they expersing?

#### Question 12: What do people fear most about diabetes?

#### Probe

□ do you think having diabetes can make everyday life difficult? If yes why and how? Give me examples please.

### Question 13: Do diabetes effect the person who has it only, or dose it has effect on people around them, their family and friends? Why? How?

Probe

how they family is effected? What do they need to do to the diabetes person? Do they need to provide care in any types? What are the types of care or the things they need to do in order to help the diabatic person?

□ do people openly talk about having diabetes in family and community settings? If not, why?

#### Question 14: Can people who have diabetes fast in Ramadan?

> Probe

□ if they fast, do they have problems during fasting? Give examples.

when does fasting become hard for a person who have diabetes? are they allowed to not fast? If yes, why are they allowed? do people who have diabetes feel comfortable about taking about not fasting in Ramadan with other people?
Do other people around them feel that its ok not to fast?

□ if a person could not fast in Ramadan, what should they do? (hint, giving money for charity for everyday they did not fast- islamic practice-)

Question 15: we all know that Ramadan means having a lot of food, and the best of it, from having traditional dishes to delicious deserts. Do people with diabetes need to have special diet in general and in Ramadan in specific? What are the things they can eat and can't eat?

#### > Probe

□give examples of food they can and can't eat.

do you think people with diabetes always self monter what food they eat or do they need some help from other people around them? who help them and how?
what a perfect Ramadan meal (when braking the fast) in your family looks like? if there is diabatic person having the meal with you, do you think there are dishes that they should not eat? If yes, why? Would you recommend them not to eat it? if not, why?

# **Appendix B: Cultural Consensus Survey**

In this survey, I will ask you to read and answer 52 true false statements based on your knowledge about diabetes. Take your time to answer the survey and if you have any questions, please feel free to ask me.

- 1. Some people have diabetes because it runs in their family ().
- 2. An unhealthy diet can lead to having diabetes ().
- 3. Lack of exercise can cause diabetes ().
- 4. Having a dry mouth is not a sign of having diabetes ().
- 5. Feeling dizzy is a sign of having diabetes ().
- 6. People with diabetes may have frequent headaches ().
- 7. Young people who have diabetes don't have to control their blood sugar ().
- 8. It does not matter how old you are, old and you young people have the same chance of getting diabetes ().
- 9. When a person faints, it's possible that they have diabetes ().
- 10. People who have diabetes usually sweat more than people who don't have it ().
- 11. People who have diabetes tend to feel tired more than people who don't have it ().
- 12. People who have diabetes feel thirsty a lot ().
- 13. People who have diabetes have the same risk of having depression as people who don't have diabetes ().
- 14. Having a high level of stress does not put people at higher risk of having diabetes ().
- 15. Only old people who have diabetes are at risk of getting cardiovascular disease ().
- 16. People who have diabetes have shaky hands and\ or feet ().
- 17. There's nothing you can do to prevent complications from diabetes ().
- 18. People who have diabetes should monitor their blood pressure on a regular basis ().
- 19. People can get diabetes when other people envy them and give them the envy eye/ evil eye ().
- 20. Eating too much sugar can cause diabetes ().
- 21. Regular exercise makes diabetes worse ().
- 22. Numbed feet is something that people who have diabetes suffer from ().

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S. Al-Kuwari, *Arab Americans in the United States*, International Perspectives on Migration, https://doi.org/10.1007/978-981-99-7417-7
- 23. People who have diabetes can fast in Ramadan ().
- 24. Type-2 diabetes doesn't affect your emotions ().
- 25. People of all ages have the same chance of having type-2 diabetes ().
- 26. People who have diabetes do not need to take medication on a regular basis ().
- 27. Diabetes can cause the kidney to stop function ().
- 28. Only old people get health complications when they have diabetes ().
- 29. Foot pain is one symptoms of diabetes ().
- 30. A healthy diet is necessary to treat diabetes ().
- 31. People who have diabetes should eat less sugar ().
- 32. Vision problems are not something people who have diabetes suffer from ().
- 33. Losing weight is a good way to mange diabetes ().
- 34. It is common that people who have diabetes have high blood pressure ().
- 35. People who have type-2 diabetes actually feel stronger than people who don't have it ().
- 36. Being obese increases the risk of having diabetes ().
- 37. Diabetes can be cured ().
- 38. Getting tested is the first step to treat diabetes ().
- 39. People who have diabetes drink a lot of water ().
- 40. Drinking alcohol heavily is not related to having diabetes ().
- 41. People who have complications from diabetes can still fast during Ramadan ().
- 42. People have diabetes because their body is not producing enough insulin ().
- 43. If diabetes is not treated and managed well it can cause death ().
- 44. People who have diabetes usually have high blood sugar ().
- 45. Eating fast food does not cause people to have type-2 diabetes ().
- 46. When you have type-2 diabetes, you have a lot of energy and are rarely fatigued ().
- 47. Only older people who have diabetes can stop fasting during Ramadan ().
- 48. Obese people with diabetes have higher risk of cardiovascular disease ().
- 49. When women have type-2 diabetes while pregnant they increase the chance of having type- 2 diabetes after they give birth ().
- 50. When people who have type-2 diabetes faint, you can help them by giving them a sugary drink or piece of candy ().
- 51. During Ramadan, people who have diabetes can maintain their usual, year-round diet ().
- 52. People who have type-2 diabetes should be prevented from eating sugar at all ().

# **Appendix C: Cultural Consensus Survey** in Arabic

## **Appendix D: Diabetes Cultural Consensus Survey Categories**

#### **Diabetes and Diet**

- 1. An unhealthy diet can lead to having diabetes ().
- 2. Eating too much sugar can cause diabetes ().
- 3. A healthy diet is necessary to treat diabetes ().
- 4. People who have diabetes should eat less sugar ().
- 5. People who have type-2 diabetes should be prevented from eating sugar at all ().
- 6. When people who have type-2 diabetes faint, you can help them by giving them a sugary drink or piece of candy ().

#### **Diabetes, Weight, and Physical Activities**

- 1. Being obese increases the risk of having diabetes ().
- 2. Losing weight is a good way to manage diabetes ().
- 3. Obese people with diabetes have higher risk of cardiovascular disease ().
- 4. Lack of exercise can cause diabetes ().
- 5. Regular exercise makes diabetes worse ().

#### **Diabetes and Fasting in Ramadan**

- 1. People who have diabetes can fast in Ramadan ().
- 2. During Ramadan, people who have diabetes can maintain their usual, year-round diet ().
- 3. Only older people who have diabetes can stop fasting during Ramadan ().
- 4. People who have complications from diabetes can still fast during Ramadan ().

#### **Diabetes and Age**

- 1. It does not matter how old you are, old and you young people have the same chance of getting diabetes ().
- 2. Young people who have diabetes don't have to control their blood sugar ().
- 3. People of all ages have the same chance of having type-2 diabetes ().
- 4. Eating fast food does not cause people to have type-2 diabetes ().
- 5. Only old people get health complications when they have diabetes ().

### **Diabetes and Mental Health**

- 1. People who have diabetes have the same risk of having depression as people who don't have diabetes ().
- 2. People who have diabetes have the same risk of having depression as people who don't have diabetes ().
- 3. Having a high level of stress does not put people at higher risk of having diabetes ().
- 4. Type-2 diabetes doesn't affect your emotions ().

### **Diabetes and Comorbidities**

- 1. People who have diabetes should monitor their blood pressure on a regular basis ().
- 2. Only old people who have diabetes are at risk of getting cardiovascular disease ().
- 3. Diabetes can cause the kidney to stop function ().
- 4. There's nothing you can do to prevent complications from diabetes ().
- 5. Obese people with diabetes have higher risk of cardiovascular disease ().
- 6. Vision problems are not something people who have diabetes suffer from ().
- 7. It is common that people who have diabetes have high blood pressure ().

## **Diabetes Treatment and Cure**

- 1. If diabetes is not treated and managed well it can cause death ().
- 2. People who have diabetes do not need to take medication on a regular basis ().
- 3. Diabetes can be cured ().
- 4. Getting tested is the first step to treat diabetes ().

## **Diabetes Other Causes**

- 1. Some people have diabetes because it runs in their family ().
- 2. People can get diabetes when other people envy them and give them the envy eye/ evil eye ().
- 3. Drinking alcohol heavily is not related to having diabetes ().
- 4. When women have type-2 diabetes while pregnant they increase the chance of having type- 2 diabetes after they give birth ().

## **Diabetes Effect on the Body**

- 1. Having a dry mouth is not a sign of having diabetes ().
- 2. Feeling dizzy is a sign of having diabetes ().
- 3. People with diabetes may have frequent headaches ().
- 4. When a person faints, it's possible that they have diabetes ().
- 5. People who have diabetes usually sweat more than people who don't have it ().
- 6. People who have diabetes tend to feel tired more than people who don't have it ().
- 7. People who have diabetes feel thirsty a lot ().
- 8. People who have diabetes have shaky hands and  $\$  or feet ().

- 9. Numbed feet is something that people who have diabetes suffer from ().
- 10. Foot pain is one symptoms of diabetes ().
- 11. People who have type-2 diabetes actually feel stronger than people who don't have it ().
- 12. People who have diabetes drink a lot of water ().
- 13. People have diabetes because their body is not producing enough insulin ().
- 14. People who have diabetes usually have high blood sugar ().
- 15. When you have type-2 diabetes, you have a lot of energy and are rarely fatigued ().