

# Diabetes Is Devastating, and Insulin Is a Death Sentence: Provider Perspectives of Diabetes Self-Management in Arab-American Patients

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■ **IN BRIEF** The purpose of this qualitative study was to examine providers' perspectives on cultural barriers and facilitators to diabetes self-management (DSM) in Arab Americans to identify factors to enhance DSM education in the Arab-American community. The main barriers to DSM from the providers' perspective were the disease itself and patients' denial or refusal to recognize it, reflecting the stigma of the disease. Cultural aspects also included overlapping themes that both facilitated and presented barriers to DSM. These results suggest that DSM education for Arab Americans will be most effective if developed and delivered in a manner consistent with the cultural facilitators and barriers noted by providers.

**D**iabetes self-management (DSM) is an integral and multifaceted component of care for patients with diabetes (1). Providers need to understand the potential influence of cultural factors on DSM so that they can provide culturally competent DSM education in a context that promotes patient understanding and adherence (2). However, the literature is limited on the role of culture in DSM from the providers' perspective (3–6), and is even more limited with regard to Arab Americans specifically.

Diabetes is a worldwide public health problem with inadequate DSM care identified as a central factor contributing to a decline in quality of life and increased morbidity and mortality (7). The National Standards for Diabetes Self-Management Education and Support (8) define the self-management activities most significantly linked to metabolic control. Although these standards provide a sound basis for treatment planning, it is unknown how often they are implemented in practice. The failure to translate clinical standards

into everyday practice contributes to gaps in care and poor diabetes outcomes.

Fewer than one-third of Arab-American patients with diabetes achieve glycemic control targets (9). Patients must develop a wide range of skills and strategies to consistently perform a variety of demanding tasks (e.g., performing daily self-monitoring of blood glucose, following medical nutrition guidelines, and performing daily physical activity) to optimize glycemic control. Medical professionals caring for patients with diabetes frequently attribute poor glycemic control to a perceived lack of adherence (10). However, Arab-American patients may be at a particular disadvantage given the lack of culturally sensitive education programs and resources available to them, which precludes them from developing the skills necessary to engage in DSM.

Proper education is central to effective DSM, and health care providers play a primary role in providing this education (5,6,11). Providers must pay special atten-

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tion to cultural competence because different cultures view diabetes, and hence DSM, in different ways. Culture influences patients' beliefs and attitudes about the information provided during clinical encounters, their perceived ability to carry out treatment recommendations, and the ways in which they enact DSM in daily life (5). Specific to Arab Americans living in metropolitan Detroit, Mich., which has one of the three largest concentrations of Arab-American residents in the United States (12), culture and environment give rise to unique challenges for DSM. For example, recent research suggests that a lack of acculturation in Arab Americans contributes to a decreased ability to self-manage diabetes (13–15). Thus, it is imperative for providers to understand and identify influential cultural factors and to encourage the provision of culturally sensitive DSM education that addresses risk factors that contribute to poor patient outcomes. This view is supported by literature stressing the need for a specific investigation of cultural barriers and facilitators given the risk factors found in regions with large Arab concentrations throughout the world (14–18).

An investigation of providers' perspectives regarding cultural factors influencing DSM could explore providers' current practices and identify the gaps they perceive in their information regarding the effect of Arab-American culture on DSM. A conceptual model of patient involvement developed by Arnetz et al. (19) suggests that both patients' and providers' views of patient involvement in their medical care must be considered to optimize health outcomes. Accordingly, identifying providers' perceptions of DSM is a crucial step toward developing an improved and effective DSM education model that is tailored to Arab-American patients with diabetes. The purpose of this qualitative study was to examine providers' perspectives on cultural barriers and facilitators to DSM in

Arab Americans to identify factors to enhance DSM education in the Arab-American community.

## Methods

### Study Design, Setting, and Subjects

Two health care practitioner focus groups were conducted to identify barriers and facilitators to DSM in Arab-American patients with diabetes. Participants included Arab-American physicians ( $n = 5$ , mean years of clinical practice  $8.00 \pm 8.89$  SD) and pharmacists ( $n = 3$ , mean years of clinical practice  $19.00 \pm 11.00$  SD) serving Arab-American patients living in the metropolitan Detroit area. All participants were recruited on a voluntary basis and completed written informed consent using procedures approved by the institutional review board at Wayne State University.

### Data Collection and Analysis

The skilled moderator, a Syrian-trained physician fluent in Arabic and with extensive diabetes care experience, conducted the focus groups. Focus groups were conducted in English because all of the Arab-American health care practitioners were fluent in both Arabic and English. The sessions were both video and audio recorded. Session debriefings were conducted immediately after participants' departure per the study protocol.

Qualitative content analysis using a data-driven inductive approach was implemented (20) in an effort to establish codes and common themes derived from the data (21). Two researchers independently read both transcripts and assigned codes for commonly occurring themes. With repeated readings, similar codes were grouped into main themes. Researchers then met to discuss their findings, which revealed a consensus level of 80%. Discordant codes were discussed, and the coding was further refined until complete agreement was reached. A third researcher who

was not involved in the coding then reviewed and confirmed the final themes and sub-themes.

## Results

Four distinct overall themes emerged from the discussions of providers' perceptions of DSM among diabetes patients: 1) the meaning of DSM, 2) facilitators of DSM, 3) barriers to DSM, and 4) cultural factors. An overview of the themes and sub-themes and their respective definitions is provided in Table 1. Following is a description of the themes and sub-themes, with illustrative quotes for each.

### Theme 1: Meaning of DSM

The meaning of DSM theme reflected the providers' perceptions of what DSM means to their Arab-American patients with diabetes, and it encompassed two sub-themes: patients' understanding and patients' actions. Patients' understanding concerned patients' ability to comprehend the severity of the disease, its progression, and the risks of possible complications.

*DSM for our patients means good understanding for diabetes, the disease process, the complications and how to take care of it . . . like DSM at home, take your medication, and also, know how to follow up with the physician when it is needed . . . also, knowing when they develop complications of diabetes. (Pharmacist)*

The patients' actions sub-theme reflected a belief in the importance of patients taking active responsibility for keeping the illness under control. This sub-theme encompassed actions for managing illness by taking prescribed medications, controlling the diet, and exercising.

*Keep it under control as much as possible . . . letting them know that the burden of treating this disease is not on the physician, it's on them. (Physician)*

TABLE 1. Overview of Main Themes and Sub-Themes

| Main Themes      | Sub-Themes                           | Definitions  |
|------------------|--------------------------------------|--|
| Meaning of DSM   |                                      | Providers' perceptions of what DSM is  |
|                  | Patients' understanding              | Understanding the severity of the disease and risks of diabetes complications                    |
|                  | Patients' actions                    | Patients' active responsibility for taking care of their diabetes                                |
| Facilitators     |                                      | Factors that promote patients' DSM   |
|                  | Education                            | Providers' efforts to help patients understand diabetes  |
|                  | Health care providers                | Need for Arabic-speaking dietitians and diabetes educators and a multidisciplinary team approach |
|                  | Motivational strategies              | Providers' methods for increasing patients' motivation for DSM                                   |
|                  | Family support/involvement           | Role of family members in helping patients manage their diabetes                                 |
|                  |                                      |  |
| Barriers         |                                      | Factors that hinder patients' DSM  |
|                  | Diabetes disease itself              | Characteristics of diabetes itself; frequently no symptoms                                       |
|                  | Fear                                 | Patients' fears of diabetes medications and treatments   |
|                  | Denial                               | Patients' refusal to recognize the facts of diabetes and its management                          |
|                  | Misconceptions/lack of understanding | Patients' lack of understanding of diabetes treatment and complications                          |
|                  | Health care system                   | Characteristics of health care providers and the health care system                              |
|                  |                                      |  |
| Cultural factors |                                      | Aspects of the Arab culture that influence DSM   |
|                  | Disease as weakness                  | General view of disease as stigma  |
|                  | Family is central                    | Family as provider of support that is crucial to DSM   |
|                  | Food                                 | Food as central to the Arabic culture, affecting patients' behavior                              |
|                  | View of physicians                   | Positive and negative views that affect patients' behavior                                       |

### Theme 2: Facilitators of DSM

The facilitators theme identified factors that participants perceived as fostering DSM adoption by their Arab-American patients with diabetes and included four sub-themes: education, health care providers, motivational strategies, and family support/involvement. The education sub-theme encompassed methods and strategies used by providers to help patients understand their diabetes. All providers agreed that education was crucial to DSM. However, information about diabetes has to be simplified as much as possible and repeated many times, until patients “come around,” gradually understanding and accepting their illness. Some providers believed in the importance of offering classes with groups of patients, although resources did not always allow this.

*So, simplifying things is very important . . . for a person who never attended college . . . That's what we have in our community, we have a lot of people who never attended college . . . So, I think by simplifying things and trying to talk to them at their level and explaining to them, I think that really will help a lot. (Physician)*

The health care providers sub-theme reflected the need for Arabic-speaking health care providers to help patients maintain the best possible health. Participants believed in a multidisciplinary approach, with teams of providers that included Arabic-speaking physicians, pharmacists, dietitians, and diabetes educators.

*How many dietitians do our diabetic patients go to that speak*

*Arab fluently? We don't have enough resources in the community to effectively educate our patients . . . The physicians don't have 30 minutes . . . It can't be done in 30 minutes. It can't even be done in an hour to sit and take a newly diagnosed diabetic patient and go through the steps. There is so much . . . They need the dietitian; they need to have time with the pharmacist . . . it's a multidisciplinary team. They might even need a social worker for some of the issues like psych issues that are associated, which is also a stigma in our community. (Pharmacist)*

The motivational strategies sub-theme included methods used by providers to promote DSM skills among their diabetes patients.

Helping patients to set goals and keep records to “follow their numbers” are strategies employed to help patients gain ownership of their diabetes. Several providers stressed the necessity of employing scare tactics, explaining in graphic terms such risks as loss of vision, amputations, and kidney failure to patients who do not keep their diabetes under control.

*And maybe setting goals, saying, “In 3 months or 6 months, let’s sit back and see what have you accomplished.” I encourage them to record so we can look at the fluctuations . . . so that way it will help us maybe modify some of the diets.”* (Physician)

*Complications of diabetes, we see it all the time: kidney failure, hemodialysis, heart attacks, blindness, amputations. So, when they know that, they get scared . . . When you scare them, then they get motivated more.* (Physician)

The fourth sub-theme under the facilitators theme was family support/involvement. All participants recognized the active support of family members as a crucial aspect of DSM in Arab-American patients with diabetes. Support could be as a “watchful eye,” helping a patient maintain a good diet and avoid sweets and overeating; even children and grandchildren could be supportive by encouraging older patients with diabetes to exercise.

*Everybody should be involved in this as a family. You know, the good thing about Arabs is that the family ties are pretty good. So, by educating the family members to help us do the job that’s needed . . . at least good control, if somebody is always watching what they do, telling them, “Oh, watch out. Fruit at night is a bad idea.”* (Physician)

### Theme 3: Barriers to DSM

The barriers theme encompassed factors that the participants perceived to hinder DSM in their Arab-American patients, with five sub-themes: diabetes disease itself, fear, denial, misconceptions, and health care system. Within the diabetes disease itself sub-theme, providers characterized diabetes as a “silent killer,” with patients frequently experiencing no symptoms of illness. Several providers saw this as the main reason for lack of adherence with medications and dietary restrictions; patients simply do not feel sick.

*Some people are basically non-compliant with taking their meds . . . You might give them the prescription, and they come back in a month or so and say it’s still on the shelf because they did not believe that they have diabetes. Diabetes is a silent killer.* (Physician)

The second barrier sub-theme centered on patients’ fears of diabetes medications and treatments. Providers’ perceptions were that Arab-American patients with diabetes are fearful of needles in general, and of the necessity of injecting insulin in particular. Insulin was described as a “death sentence,” with providers saying their patients frequently describe being on insulin as the worst thing that could happen to them.

*And then when you tell them they’re on insulin, it’s like a death sentence: “Oh my God, insulin!”* (Pharmacist)

*Sometimes I get a patient who needs to be on insulin, and you tell them about the injection, they’ll freak out: “This is the end of the world. Am I going to die? You’re giving me insulin injections? I’m gonna die.”* (Physician)

Denial, the third barrier sub-theme, reflected providers’ view that Arab-American patients often do not take their diabetes seriously. This was expressed as patients’ belief that

pills cannot control blood glucose or rationalizing that eating a little sugar is okay because “It won’t kill me.” Providers described patients who refuse to take responsibility for their diabetes and shift the blame, saying that they were “forced” to eat pizza or sweets, simply because these foods were provided by someone else.

*Maybe they are just turning a blind eye to the fact of the dangers of diabetes or the fact that they can’t eat whatever they want to eat, whenever they want to eat it.* (Physician)

Providers also saw generational differences among their patients. One provider described a “war mentality” among the older generation of patients that makes them feel obligated to eat whatever food is available, since they do not know if more will be forthcoming.

*There is this aspect of the older generation that comes from war mentality: “OK, I have this much food, I’m gonna eat this much food.” And it’s not something that they can control. It’s just something that they’ve [had] . . . pounded into them.* (Physician)

The fourth sub-theme under barriers was misconceptions/lack of understanding. Providers said that patients’ misconceptions regarding diabetes include viewing medication as a cure that protects you and removes the need for self-responsibility; simply taking medication is all one needs to do to manage diabetes. This attitude leads to a false feeling of security, with patients believing that they can eat what they please, as long as they are on diabetes medication.

*I had a patient . . . he’s on insulin . . . the day he came to see us in the office, the day before was his birthday, and he knew he was going to eat cake on his birthday, so he doubled up on his insulin on his own and thought that was*

*a great idea. So, in the morning, he doubled his insulin, and at night he had a huge slice of cake, and when he came in, I think his blood sugar was like 450, It was insanely high . . .* (Physician)

Several providers noted that some Arab-American patients see herbal or other alternative preparations such as cinnamon as viable alternatives to medications. Underlying these misconceptions is a lack of understanding of the seriousness of the disease and the risk of complications.

*You have a lot of them where they don't want to take the medication. They heard about this herb or these concoctions from the Middle East, and they give it to each other, and they tell each other about it.* (Physician)

The health care system sub-theme primarily concerned insurance issues and differences among health care providers, particularly physicians. Participants perceived limited insurance or a lack of insurance as a major barrier to some of their Arab-American patients, especially with regard to medications. The process of authorizing medications is frequently long and complex and is an additional barrier, even for insured patients.

*Some of it is straight insurance issues. Quite a few people don't have insurance, or have limited insurance that will cover only certain medicines and doesn't cover others. So, the problem is getting an insurance that can sustain their needs as far as getting the medications.* (Physician)

Providers also described “old-school” and “new-school” physicians, with old-school physicians taking a much more holistic approach to patient care. The old-school physicians take time with their patients and discuss all health matters with them, whereas new-school physicians

transfer responsibility to specialists, in this case endocrinologists. A younger physician in one of the focus groups clearly saw the benefits of the old-school approach, but explained that time limitations and financial constraints simply do not allow for the old-school type of provider-patient encounter.

*See, there's a huge difference in old school and new school. The old-school physicians, they take time with their patients. They sit, they talk to the patients. They really, truly, and genuinely care about the entire spectrum, anything from a common cold to diabetes. You have new school that's not necessarily lazy; it's a transfer of responsibility. So, somebody is diabetic, they just pawn him off to an endocrinologist. So, they don't really take the time to sit and deal with a diabetic patient.* (Physician)

#### **Theme 4: Cultural Factors**

Cultural factors, the fourth theme, encompassed aspects of the Arab culture that participants perceived influenced DSM in their Arab-American patients. This theme had four sub-themes: disease as weakness, family is central, food, and view of physicians. In general, providers described Arab Americans as having a general view of illness as a weakness. Patients with diabetes do not dare to tell others about their disease, due to this stigma.

*To them, first, when they initially find out about it, it's like disaster, first of all.* (Pharmacist)

One provider stated that there are many phobias in the Arab-American culture, explaining that cancer, for example, is often called by another name, just to avoid using the term. This reluctance to admit to having diabetes was considered a primary cultural barrier to DSM. Reluctance to accept the diagnosis is also reflected in resistance among many

newly diagnosed patients to start prescribed medications.

*They all carry that stigma that disease would equate to weakness or breakdown, and they like to see themselves being viewed in the community as the strong person. They don't like people knowing that they're ill.* (Physician)

The second sub-theme focused on the central significance of family in the Arab culture. The family was described as being involved in every aspect of a patient's life. Thus, by necessity, providers felt that they need to include patients' family members in informational sessions regarding diabetes treatment and control.

*The family is already involved in every aspect of your life . . . the Arabic community, the culture, encompasses everything around family.* (Physician)

*Not only do you have to have buy-in from the patient in the Arab-American community, you have to have buy-in from their family, too, for them to be successful.* (Pharmacist)

Food emerged as a cultural sub-theme that was discussed repeatedly. Food and hospitality emerged as central aspects of the Arab culture, with implications for DSM. Food was described as an ever-present temptation for patients with diabetes at every family gathering, party, or social event. Invitations into someone's home always includes food as an offer of hospitality, and often sweets; refusing the offering is considered an insult.

*This is the Arab culture. For the holidays, they give sweets, and somebody is diabetic . . . and he'll say, "Oh, it's the holiday, one piece, two pieces is not going to kill you."* (Pharmacist)

Several providers also noted that the cultural importance of food is not adequately reflected in some of the educational materials available to Arab-American patients with diabetes.

*The sad thing is, I've seen pamphlets and I've seen diets—they give them at the hospital. The food on there doesn't make sense. They would never eat it in a million years. You will never find a Hajji [a Muslim who has been to Mecca] eating a turkey sandwich.* (Pharmacist)

The final sub-theme, view of physicians, described both positive and negative attitudes toward physicians. On one hand, physicians are respected, and patients will do what they can to please the doctor, such as attempting to keep blood glucose levels under control. On the other hand, patients associate physicians with illness because it is the physicians who make the diagnoses.

*They have the belief that, with doctors, all the times they go there, they make him sick . . . not by medications, but by giving a new diagnosis. You go there; now you have diabetes, and you need medications. "But I am feeling good, I have no symptoms, I am okay. I go to my physician . . . and now I am sick!"* (Physician)

## Discussion

This study explored providers' perceptions of barriers and facilitators to DSM in Arab-American patients with diabetes. Analysis revealed more culturally related barriers than facilitators. Consistent with previous research in other cultural groups, education was a key finding, and its impact on patients' ability to self-manage their diabetes was crucial (2–5,11,16–18). Health care providers have been identified in past studies as being key facilitators of successful DSM, which was also the case

in this study (3). This was especially true given the high regard that participants reported their Arab-American patients have for physicians. Providers discussed the significance of their role in management in terms of taking the extra time to go through the steps required to establish a patient's diagnosis (3–5) and noted the importance of being able to speak the same language as their patients. Providers also discussed the importance of being part of a multidisciplinary team to better address the various aspects of DSM as noted by the National Standards for Diabetes Self-Management Education and Support (8). These providers expressed the need not just for multidisciplinary teams, but also for teams that are Arabic speaking and have an adequate understanding of the Arabic culture.

Motivational strategies such as goal-setting are key factors in managing diabetes given patients' natural desire to do well and be held accountable. For example, the literature shows that both patients and providers discuss the importance of goal-setting (3,22,23); however, patients equated goal-setting for DSM to making New Year's resolutions that can be difficult to stick to in the long term. This study also exemplified the difficulty in accomplishing one or two major goals compared to smaller more achievable goals. For example, losing weight is often a goal that is set but not met, although weight loss may in fact be attainable through smaller and more realistically achievable aims. Furthermore, goal-setting is an essential component of DSM and in fact is listed as a specific practice standard (8). Finally, as has been noted in previous studies (2,3,5,8), family support and involvement emerged as the most important and potentially the most effective facilitator of DSM. In this culture, families tend to be close-knit; family takes center stage, whereas lack of family support impedes patients' ability to achieve and maintain self-care behaviors. Therefore, a family-centered approach

has the potential to deliver the most effective, practical, and sustainable DSM education and support.

Barriers were numerous and included both controllable and uncontrollable attributes of care. For example, the health care system represents an uncontrollable attribute of care in terms of a lack of insurance or ability to pay for services and medication. This is well noted throughout the literature that explores barriers to DSM from both providers' and patients' perspectives (4,5). In addition, the diagnosis of diabetes itself, language barriers, lack of family support, and inherent cultural factors are barriers that are difficult to modify. Interestingly in this study, family was viewed as both a facilitator and a barrier; family has the potential to either enhance or impede patients' ability to self-manage diabetes. This phenomenon also has been seen in specific subgroups within the Latino population, in which family support is viewed as a facilitator, whereas familial roles—specifically the significance of meals and food traditions in specific cultures—represent an inherent barrier (3). Although Arab Americans tend to have close family relationships, this closeness also leaves them vulnerable to appeasing family members given their familial roles and responsibilities. In addition to these more static barriers that affect DSM, fear, denial, and a lack of understanding are noted barriers that can be influenced with education and thus affect DSM in a positive way.

The main barriers to DSM from the providers' perspective were the disease itself and patients' denial or refusal to recognize it, reflecting the stigma of the disease. Stigma can have a profound impact on the policy and practice of diabetes, including negatively affecting patients' psychological well-being (24). From the providers' perspective, patients do not want to accept the diagnosis and its accompanying stigma. Although other cultures report negative views of diabetes (3,17,25), Arab-American

providers described dependency on insulin as being equivalent to a death sentence. In addition, food traditions, which are central to the Arabic culture, can both hinder and facilitate DSM. Food plays an integral role in the Arab-American culture, in which family matriarchs tend to be primarily responsible for feeding and nourishing the family. Food is also important in social functions and with visitors to the extent that declining an offering of food can bring great offense to the person and family making the offering. This presents additional issues within the Arab-American culture, in which most people with diabetes do not want to provide a truthful explanation to their family or friends because of the stigma.

Cultural aspects also included overlapping themes that both facilitated and presented barriers to DSM. Physicians' attitudes about a diabetes diagnosis can be detrimental to patients because providers often referred to an official diagnosis as a major weakness. In the literature, the importance of providers' disposition when providing a diagnosis has been noted (5) and can have an immediate effect on how a patient responds to the diagnosis and the need for DSM. Although many Arab Americans revere the role of physicians, there is still a gap in information and education that occurs between patients and providers with regard to DSM specifically (15).

### Implications

These results suggest that DSM education for Arab Americans will be most effective if developed and delivered in a manner consistent with the cultural facilitators and barriers noted by providers. Providers themselves reported the need to allocate time during clinical encounters with patients to provide DSM education and motivational strategies; establishing attainable patient goals after performing an appropriate assessment and developing a plan of care with

follow-up was perceived as a positive motivational method to address DSM with Arab Americans. Providers also noted their lack of time and resources and reported that patients require multidisciplinary care to ensure adequate DSM education. Including patients' family for support of DSM, while carefully acknowledging both the positive and negative effects of family given the strong culture of mealtime and familial roles within the Arab-American culture, were also important aspects to consider with DSM. In addition, providers described the crucial role of education in addressing diabetes stigma within the Arab-American culture and its effects, including diagnosis denial and subsequent lack of adherence to DSM. Furthermore, training and education for patients and families was perceived to be more effective when it occurred jointly (i.e., individually offered to patients and their family in face-to-face sessions). These perceived implications, if implemented, could potentially have a positive effect on Arab-American patients' and families' understanding of diabetes and promote the importance of DSM.

### Limitations

These findings are limited in that the study included a small sample of Arab-American physicians and pharmacists practicing in one geographical area; thus, they may not be generalizable to all health care providers caring for Arab-American patients in other contexts.

The low number of participants per group could have limited interaction among the participants. Further exploration of providers' and patients' perceptions of cultural influences on DSM should be evaluated to optimize outcomes.

The information presented here provides a necessary piece of the puzzle toward improving patient outcomes in Arab-American patients with diabetes. Future research to examine a broader sample of health care providers and Arab-American

patients with diabetes will provide a more holistic view of DSM, enabling a better understanding of the range of perceptions of cultural factors influencing the adoption and adherence to DSM skills and behaviors.

### Duality of Interest

No potential conflicts of interest relevant to this article were reported.

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