

Barriers to Care for Cambodian Patients with Diabetes: Results from a Qualitative Study

Megan R. Renfrew, MA
Elizabeth Taing, BA
Marya J. Cohen, MD, MPH
Joseph R. Betancourt, MD, MPH
Roger Pasinski, MD
Alexander R. Green, MD, MPH

Abstract: Racial and ethnic disparities in diabetes care have been well documented. While root causes have been explored for some minority groups, less is known about smaller immigrant populations such as Cambodians. In this study, we sought to explore the potential barriers to care for Cambodian patients with diabetes. We conducted five focus groups with three study groups: health care providers, bilingual Khmer frontline staff, and Cambodian patients with diabetes. Focus groups findings revealed that certain cultural beliefs, low health literacy, and language barriers strongly affect Cambodian patients' understanding of diabetes and self-management, as well as clinicians' ability to care effectively for Cambodian patients with diabetes. Our study supports previous literature and also adds several new insights not previously described. We recommend education for health care providers on patient-centered, cross-cultural care with an emphasis on the needs of Cambodians as well as culturally appropriate diabetes education for patients.

Key words: Health care disparities, diabetes mellitus, type 2/diagnosis, culture, cultural competence, health literacy, qualitative research, focus groups, Cambodia ethnology, United States.

Type 2 diabetes is a complicated chronic disease with rapidly increasing rates of diagnosis.¹⁻³ The rates of obesity,⁴⁻⁸ which is a major risk factor for diabetes, are also rapidly increasing. According to recent estimates, 11.3% (25.6 million) of the United

MEGAN RENFREW is former Senior Project Coordinator in the Disparities Solutions Center, Mongan Institute for Health Policy at Massachusetts General Hospital. **ELIZABETH TAING** is former Research Assistant in the Disparities Solutions Center, Mongan Institute for Health Policy at Massachusetts General Hospital. **MARYA COHEN** is Physician-Researcher at the John D. Stoeckle Center for Primary Care Innovation at Massachusetts General Hospital and Instructor of Medicine at Harvard Medical School. **JOSEPH BETANCOURT** is Director of the Disparities Solutions Center and Senior Scientist, Mongan Institute for Health Policy at Massachusetts General Hospital, and Associate Professor of Medicine at Harvard Medical School. **ROGER PASINSKI** is Director of the Revere HealthCare Center, Massachusetts General Hospital, and Assistant Professor of Medicine at Harvard Medical School. **ALEXANDER GREEN** is Associate Director of the Disparities Solutions Center and Senior Scientist, Mongan Institute for Health Policy Massachusetts General Hospital, and Associate Professor of Medicine at Harvard Medical School. Inquiries about this paper should be directed to Megan R Renfrew at mrrenfrew@partners.org

States population aged 20 years or older has diabetes, and for some racial and ethnic minorities the prevalence of diabetes is even higher (7.1% of non-Hispanic Whites *versus* 8.4% of Asian Americans, 11.8% of Hispanics, and 12.6% of non-Hispanic Blacks).⁹ Some ethnic sub-populations, including Cambodian Americans, also have an elevated incidence of type 2 diabetes and are at greater risk for related complications, based on the limited data available.^{10–17} A study of the second largest Cambodian American community in the U.S. (in Lowell, Massachusetts) showed that a disproportionate share of Cambodian adult deaths were attributable to stroke and diabetes, compared with all other adults in the state.¹⁸ Further, research shows that Cambodian refugees have poor health relative to the general United States and other Asian American and Pacific Islander populations.^{19–20}

Racial and ethnic disparities in diabetes care have been well-documented. For example, African Americans and Latinos display poorer glycemic control^{21–23} and receive fewer glycohemoglobin tests^{22,24} than their White counterparts. Blacks are also less likely than Whites to have had LDL cholesterol levels checked in the preceding two years (72% *versus* 80%) and to have a dilated eye examination (50% *versus* 83%).²⁵ Racial and ethnic minorities also have significantly higher rates of diabetes-related complications.²⁶ Similar patterns are also found among uninsured patients, who are more likely to be African American or Hispanic, and less likely to report receiving annual exams (foot, eye, and glycohemoglobin tests) and to perform daily glucose monitoring, compared with patients who have private insurance.²⁷ Other socioeconomic factors such as poverty income ratio, education, and occupation have also been associated with prevalence of type 2 diabetes.²⁸

For Cambodians, little data are available on diabetes management.²⁹ However, several studies indicate that Cambodian patients with diabetes often have poor glycemic control.^{18,30–33} Reported barriers to diabetes care among Cambodians include limited English proficiency, lack of understanding of the disease, distrust of Western medical practitioners and techniques, and lack of mobility and transportation, among others.^{18–19,31,34–38} Cambodian health behaviors, which are rooted in natural, spiritual, and metaphysical beliefs about illness causality, also often dictate the course of treatment.^{10,39} For example, the use of traditional herbs and healing practices have been well documented among Cambodians.^{10,40} Since many Cambodians view Western medicine as secondary,^{37,41} these cultural practices are often used first, which may inhibit or delay care by a medical practitioner.^{40,42} Other racial and ethnic groups may experience similar barriers, but the circumstances of Cambodians are unique in that nearly all of Cambodian middle-age and older adults living in the United States have experienced an extraordinary degree of physical and/or psychological trauma.^{10,18,43–45}

Refugees and survivors of torture are often at heightened risk for somatic and mental health problems.^{46–52} The lives of Cambodians in the United States today are greatly influenced by years of war and strife in their homeland. From 1975 to 1979, Pol Pot and his army, the Khmer Rouge, led a bloody reign of the country. Families were torn apart and approximately 1.7 to 1.9 million people (21 to 24% of Cambodia's 1975 population) died by killing, torture, or overwork.⁵³ Approximately 152,000 Cambodian refugees came to the United States in the 1980s *via* refugee camps.^{54–55}

Trauma experienced by Cambodians can negatively affect physical, mental, and

emotional health.^{10,51,56–57} Regarding general health, in a recent study nearly 90% of Cambodian refugees in California rated their health as either fair or poor, which was approximately twice that of other Asian American and Pacific Islanders in the study and more than four times higher than the general California population; approximately 70% met screening criteria for probable disability.¹⁹ Another study links food deprivation experienced by refugees with unhealthful eating practices and obesity later in life.³³ In relation to diabetes, high rates of anxiety, post-traumatic stress and depression among Cambodians^{29,43,58–62} have been directly associated with higher rates of diabetes and poor diabetes control.^{56,63} Although Cambodians share barriers to care with other racial and ethnic populations, as refugees they have unique health care needs that must be taken into consideration for the provision of care.

In this study, we sought to explore the potential barriers to care for Cambodian patients with diabetes who receive care at a low-income, heavily immigrant, urban community health center near Boston. A preliminary assessment of adult diabetes care for Cambodians revealed that approximately 50% were in less than ideal control (HbA1c >7) (unpublished data). We were interested in the perspectives of Cambodian patients, providers, and Cambodian frontline staff. Ultimately, our goal was to use this information to create a culturally-tailored diabetes management program for Cambodian patients to improve patients' understanding and control of their diabetes, and to eliminate racial/ethnic disparities.

Methods

Study design. We conducted a qualitative study to understand better barriers to care for Cambodian patients with diabetes. The study was approved by the Partners HealthCare Institutional Review Board. Written consent was obtained from participants prior to participation in the focus groups.

Setting. In 2008, we conducted five focus groups at Massachusetts General Hospital (MGH) Revere HealthCare Center, a large, multi-specialty community-based health center that has been part of the MGH network of clinical care sites since 1981. The health center serves as the largest source of primary health care for the town of Revere, Massachusetts. Each year nearly 30,000 patients make a total of over 150,000 visits to the health center. Revere is a multiethnic community situated north of Boston. It serves as a gateway community for many immigrants to the Boston area with approximately 40% of residents speaking a language other than English at home.⁶⁴

Participants. Our study included three groups: 1) Cambodian patients with type 2 diabetes (n=15); 2) clinicians in the Adult Medicine Department (n=25); and 3) bilingual Khmer staff (n=5). The total number of participants across the three groups was 45. Patients were eligible if they were diagnosed with type 2 diabetes. The majority of Cambodian patients had poorly controlled diabetes with a mean HbA1c of 8.85 (maximum 13.5 and minimum 6.2) with a standard deviation of 2.39. More than half of the Cambodian patients were female (60%) and the mean age was 52. We excluded patients who were too physically or mentally disabled to participate. The 25 clinicians included 13 general internal medicine physicians, 11 nurses, and one dietician. The majority of clinicians were women (74%). Cambodian staff included four Cambodian

interpreters and one bilingual medical assistant, all of whom were women. We recruited participants by posting information about the study at the health center for patients and circulating email announcements to health center staff. We gave all eligible participants study factsheets, tailored to each population, upon focus group registration. Focus group moderators described the study to participants, answered any questions they had, and obtained written consent for their participation. All study materials for patients were translated into Khmer. Cambodian patients received gift cards of \$25 to a local grocery store; health center staff did not receive any remuneration.

Focus groups and discussion guide. We conducted a total of five focus groups among the three study group populations at MGH Revere HealthCare Center: two focus groups with Cambodian patients, two focus groups with clinicians, and one with Cambodian staff. Each focus group lasted approximately 1.5 hours. A Cambodian bilingual Khmer-speaking moderator facilitated the focus groups (in Khmer) with Cambodian patients and Cambodian staff. Focus groups with clinicians were conducted by staff associates. Focus groups were audio recorded, transcribed *verbatim*, and translated from Khmer to English by a professional translator when needed. We developed three similar discussion guides (one for each study population) with open-ended questions based on the available literature about barriers to care for Cambodian patients with diabetes and informal interviews with Cambodian interpreters and health care providers at MGH Revere HealthCare Center. We asked clinical and non-clinical staff about their experiences caring for Cambodian patients, or interpreting for Cambodian patients, and barriers to care for Cambodian patients with diabetes. For example, see Box 1 for the clinician discussion guide with primary questions only (detailed probes excluded). Patients were asked about their knowledge and understanding of diabetes, self-management behaviors, experiences receiving health care, and recommendations for program development. To our knowledge, patients did not receive diabetes education or nutritional counseling beyond standard medical care for diabetes. All focus group moderators had training in qualitative interviewing techniques and methods.

Data analysis. We used Strauss and Corbin's three step approach to coding and analysis (open coding, axial coding, and selective coding).⁶⁵ During open coding, three of the co-authors reviewed transcripts line-by-line, identified core concepts, developed a preliminary coding scheme, and tested it on a subset of the data. After coding for larger themes, detailed coding (axial and selective) was performed to identify sub-themes and relationships between codes. The final codebook consisted of 17 codes with detailed inclusion and exclusion criteria. To address issues of inter-rater reliability, the analysis team performed double-coding on a subset of transcripts to monitor coding agreement. We resolved disagreements in coding through discussion until the group achieved mutual consensus. This process maintained the integrity of the data, and ensured the codes were being applied correctly and uniformly across transcripts. We used Atlas.ti software for data analysis.⁶⁶

Results

Summary. Focus groups findings revealed that differences in cultural beliefs and barriers to literacy and language drastically affect Cambodian patients' understanding of diabetes and self-management, as well as clinicians' ability to care effectively for

Box 1.**FOCUS GUIDE FOR CLINICIANS:
PRIMARY QUESTIONS**

1. Can you tell me in general about the Cambodian patients that you treat at the Health Center?
2. What specific factors (if any) do you take into account when treating Cambodian patients?
3. How would you describe Cambodian patients' understanding of diabetes?
4. What are your experiences treating Cambodian patients with diabetes?
5. Have you experienced any difficulties in providing care to Cambodian patients with diabetes? If yes, what types of difficulties did you experience?
6. Can you describe specific challenges (if any) in providing routine testing, annual screenings, and/or other nutritional/lifestyle advice as recommended by ADA guidelines?
7. What are your experiences prescribing medication or in medication management for Cambodian patients with diabetes?
8. What barriers (if any) *do you think Cambodians in general experience* when seeking health care? How does _____ act as a potential barrier?
9. What factors (if any) *impact Cambodian patients' ability to manage their diabetes*? How does _____ impact patient management of diabetes?
10. What factors (such as cultural factors or other factors), if any, help Cambodian patients to successfully manage their diabetes?
11. What resources or services are currently available at the hospital for Cambodian patients with diabetes?
12. What recommendations do you have for improving diabetes care for Cambodian patients?
13. What resources would help you provide better care to Cambodian patients?

Cambodian patients with diabetes. Six primary themes emerged: 1) views of chronic disease, 2) diabetes etiology and explanatory models, 3) diabetes management, 4) communication, 5) psycho-social factors, and 6) fears and challenges interacting with the health care system. Each of these themes encompassed two to six sub-themes. The two most frequently discussed topics were diabetes management and chronic disease. See Box 2 for a summary of quotations for select key barriers described below.

Theme 1: Views of chronic disease. We found that many patients do not understand the concept of chronic disease.^{10,37} The on-going treatment and testing required for diabetes was difficult for patients to understand, particularly when symptoms are not present. (See Box 2). The lack of familiarity with and understanding of Western models of medicine can be particularly problematic in the case of glucose and hemoglobin A1c testing. A clinician's questions illustrate how this lack of familiarity with chronic disease management leads to confusion for patients, which affects medication utilization and adherence: "Why is it important? Why would you do it if you had no sense of why it is important? . . . What is it doing to your body, and what is it telling you? . . . So how do you enable that person to make behavioral decisions or actions, and actually go and do it . . . ?"

Cambodian patients and staff also described expectations that Western medicine would diagnose and treat conditions instantly. (This notion of an instant cure also has been described elsewhere.¹⁰) For example, a Cambodian interpreter said, "The patients want something to cure diabetes . . . they want the cure . . . they don't understand about diabetes that it's to control it, not to cure it . . . in their mind there is a quick fix for everything."

Theme 2: Diabetes etiology and explanatory models. As has been reported elsewhere,^{18,42} patients reported minimal knowledge of diabetes etiology and related disease conditions, which is common for low-literacy populations.⁶⁷⁻⁶⁹

Patients believed that diabetes is food-related (e.g., eating specific types of food and quantities of food causes diabetes), but they could not further articulate the specific connection between diet and diabetes. They were able to identify basic signs and symptoms (e.g., blurry vision, bloated arms and legs, and cracked feet), but few could provide a clear description of more comprehensive disease processes or long-term complications. Further, patients in the focus groups had limited understanding of the correlation between diet and blood sugar.

Cultural factors also influence understanding of diabetes. Many patients reported that diabetes is caused by consuming too much "sweet." According to several focus group participants, in Cambodian culture diabetes is often called "sweet pee," which is a term used to describe urine to which ants are attracted (supported in the literature).⁴² Another patient called diabetes a "disease for the rich," perhaps suggesting that markers of class (access and food consumption) and other cultural factors shape perceptions of who gets diabetes. Similarly, a patient described how in the United States, "We have lots of food and eat without thinking," unlike experiences of living in Cambodia or in the refugee camps.*

Many clinicians feel patients' and clinicians' views of diabetes differ. For example,

*The patient focus groups were conducted in Khmer, so the quotations in the text are translations into English of what participants said.

Box 2.

SELECTED QUOTATIONS FOR KEY THEMES

	Cambodian Patients	Health Center Staff
Views of Chronic Disease	<p>"We never got tested [for diabetes] while we were in Cambodia. But we hear a lot about diabetes in this country . . . they test for diabetes on a regular basis, so therefore they know whether or not they have it. For us, we don't know."</p>	<p>" . . . as soon as they feel better, they make the assumption that they're cured, and then it becomes 10 times more difficult to increase medications and get them to a point where they're not just feeling better but staying healthy."</p>
Diabetes Etiology and Explanatory Models	<p>" . . . it's the nutrition and what we eat, I don't know how I have diabetes, but I think it is from food"</p> <p>" . . . there is something wrong inside your body. Something is dead . . . and cannot receive sugar. Then we always fill it with rice and it melts and makes it through your urine. Your body cannot melt all the food that you've eaten. You cannot receive those foods otherwise you'll have diabetes."</p>	<p>"Their understanding of diabetes is very basic . . . sugars and blood . . . a connection maybe to food that they've picked up from the community . . . but beyond that it's very basic."</p> <p>"It would be really interesting to see what the patients' perspective is, what they think of the disease. And, do they call it a disease? Or do they call it something else? Or is it a curse? I really don't know."</p>
Diabetes Management-Medication	<p>"I have a problem. I am not sure after I eat when I inject insulin."</p> <p>"When I injected myself, it does not matter how many times; it did not do anything to help me. When I measure sugar, it [is] always the same. Then I started to use Cambodian herbal medicines."</p>	<p>"They go along and they'll start doing good and they figure, 'Oh, I don't need this anymore.'"</p> <p>" . . . they [patients] just don't get it. I mean, they don't even get how to take their meds, even when we put [them] in med boxes. You know? So, I mean, we're missing something."</p>

(Continued on p. 640)

Box 2. (continued)

	Cambodian Patients	Health Center Staff
Diabetes Management-Nutrition	“ . . . according to my experience, to manage diabetes you must eat bitter and tart food. The more bitter or tart would work effectively.”	“They think it’s more of a blood disorder than a pancreatic disorder . . . all they know is that there’s too much sugar in their blood and they don’t know what to do.”
Communication Language and Literacy	N/A	“I think the biggest barrier is that we just don’t understand them, and they don’t understand us.” “A lot of times you’ll write down, make a chart of how to take medicines, and they sort of get that? But if you were to write out instructions, like, “Increase your insulin by this and this and that,” they can’t do that. So then you’re relying on their children or their grandchildren, or other family members.”
Psycho-social factors	N/A	“You know you are in trouble when you’re taking a family history and when you ask about illnesses in the family and there are none, because everybody was killed . . . gunshots. . . .” “My patients are more willing to take antidepressants from me than they are to go to a mental health practitioner and get them.”

a clinician wondered whether patients perceived diabetes as a disease or a curse and what language they use to describe the disease. (See Box 2.) Focus groups revealed the need to bridge understandings of diabetes across cultures. A clinician stated, “What would be helpful for me would be actually to talk to the interpreters and say . . . how are you actually explaining these terms to the patients?”⁴²

Theme 3: diabetes management. This theme includes an array of diabetes management components including views of diet, exercise, medication, use of complementary and alternative medicine, and diabetes education. Overall, patients reported minimal knowledge of diabetes management activities and difficulties with medication adherence. Remedies traditional in Cambodian culture are widely used (e.g., herbs), sometimes in place of medications due to fears of medication use. Clinicians also reported challenges with patient education on nutrition, medication use, and management, and difficulties with language barriers and time for patient education.

Medication. Cambodian patients reported confusion about diabetes medications and difficulties with adherence, including the use of remedies traditional in Cambodian culture either in place of medication or alongside medication. In general, patients understand that insulin corrects blood sugar, but they have more difficulty with specifics like when it should be used. For example, a patient said: “I have a problem. I am not sure after I eat when I inject insulin.” Even culturally specific beliefs about whether food is considered sweet, salty, bitter, or sour play a role in medication⁷⁰ as evidenced by a patient who said, “. . . Those medicines, they have no bitter in it.” Interestingly, there are some foods, such as *Momordica charantia* more commonly known as bitter melon, used in Cambodian cooking with biochemical properties have been shown to have anti-diabetic or hypoglycemic properties.⁷¹⁻⁷²

Many patients do not understand that insulin is a long-term medication to be taken even when symptoms are not present. A clinician said, “They go along and they’ll start doing good and they figure, ‘Oh, I don’t need this anymore.’” This belief and a lack of understanding of diabetes leads to a cycle of adherence and non-adherence, which is a major challenge for diabetes management. Some patients were reluctant to use medication and escalate care and/or focus on using their own therapies (e.g., herbs) to bring about change in disease control. (See Box 2.) A patient said, “. . . If you take the herbals you must put the medicines aside. If you take the medicines, you must leave the herbals aside.” However, another patient described taking medicine and herbs at different times of day. Several patients also reported fears associated with taking insulin and medications for diabetes in general. According to interpreters, although patients return to the clinic for glucometer teaching, many are “scared” to start insulin.

Clinicians further confirmed patients’ confusion about the use of diabetes medications, particularly with respect to taking medications (e.g., timing and purpose) and discussed how language and low literacy levels complicate medication management. Clinicians also discussed limited appointment times and busy schedules as a barrier to diabetes education, especially when interpreters are used for patients with limited-English proficiency.

Nutrition. Although Cambodian patients report a very basic understanding of the need to reduce sugar or “sweet” in their diet, it is unclear if they understand how particular foods contribute to sugar intake and affect overall diabetes management. This

is partly due to cultural differences in perceptions of nutrition and the language used to describe properties of food. (See Box 2.) In the United States, Western models of nutrition describe food in terms of the amount of carbohydrates, cholesterol, or sugar. However, Cambodians in our study described different qualities of food. For example, in our study, Cambodian patients overwhelmingly described foods as either *sweet*, *salty*, *sour*, or *bitter*. Such terms are commonly used in Southeast Asian cultures to describe the properties of food.⁷³ Clinicians confirmed this: “. . . They focus more on sweet stuff, not the carbohydrate thing.” Although some patients were able to heed doctors’ advice regarding carbohydrate portion control, and substituting vegetables for rice, many expressed confusion about which foods contribute to diabetes. For example, one patient asked, “Does salty and sweet mix together?” However, many patients did have basic knowledge that rice was “sweet” and intake needed to be reduced. Despite confusion about the specific connection between diet and diabetes, the majority believed that balancing sweet and salty foods is the key to diabetes management.

Exercise. Like other low-income and low-literacy populations, the Cambodian patients viewed common daily activities (walking around house, stairs, caring for children) as exercise and reported that they often do not seek out physical activity outside the home (e.g. running or going to a gym). Other common barriers to exercise described by Cambodian patients include financial challenges and work responsibilities.

Use of remedies traditional in Khmer culture. Cambodian patients discussed several different cultural remedies used to treat symptoms associated with diabetes. Several patients stated they did not use cultural remedies. The most commonly discussed remedies include Cambodian or Chinese herbs, wine marinated fruit (Nhor) and several other Cambodian fruits boiled in water, garlic pills, and a mushroom boiled in water or soaked in alcohol.⁴⁰ The majority of patients stated they do not discuss the use of herbal or other culturally-based remedies openly with their doctors. Clinicians confirmed this by describing patients as being “private” about their use of cultural remedies. The clinicians were more aware of cultural traditions such as cupping (placing small heated cup on the skin that creates negative pressure) and coining (stroking the skin firmly with the edge of the coin using a lubricating oil) mostly because they are visible on the skin rather than the use of herbs or other ingested remedies.⁴⁰ Although clinicians expressed awareness of these traditions, they did not know how, when, or why these remedies were used. Interpreters stated that clinicians occasionally will ask them to explain coining or other cultural remedies, but more typically they talk to each other to get information.

Theme 4: Communication. *Language and literacy.* According to clinicians, low literacy levels and language barriers are major challenges to diabetes treatment and management for Cambodian patients. The majority of clinicians view communication challenges as the primary obstacle to diabetes management. The increased time required for interpretation is another challenge for daily routine visits. Some clinicians felt using an interpreter made them feel “more distant,” particularly when simple yes/no questions led to a lengthy discussion between the patient and interpreter. Despite these challenges, some clinicians discussed how critical interpreters are, both in utility and experience, in facilitating care and acting as a bridge between doctor and patient. The interpreters viewed their roles as critical in initiating a trusting relationship with

the patient and the health center. According to interpreters, the Cambodian community recognizes and trusts interpreters' discretion in medical matters and most patients feel comfortable speaking freely with them, "just like family."

According to clinicians, without basic math skills it can be difficult to manage glucose levels and insulin dosing, and using pictures is often complicated by limited availability of educational resources in Khmer.³¹ A clinician said, "I think 90% or greater were rice farmers, very agrarian in their country, before they came here. So average education level is around 4th grade, so basic math skills, forget it." Clinicians also found it difficult to convey medication significance and schedules, even when using interpreters, and to assess patients' understanding of treatment plans. "You can kind of sense that maybe they [the patients] don't know, and you'll say to the interpreter, 'Do they understand?' And even the interpreter . . . will say that they're not sure . . . so that's scary because then you don't know what they're really comprehending, you know?" These literacy challenges put increased stress on family members to participate in care by interpreting instructions and other critical health information.⁷⁴

Deference to physicians. According to clinicians, Cambodian patients' desire to "please" and not "disappoint" them is a major barrier to care. For example, a clinician said, "they [patients] think they're disappointing me by having to increase the dose all the time . . . and you can see that they're disappointed that I have to keep increasing it and they're failing, and, so that's amazing to me." Clinicians perceive this "desire to please" as a barrier that limits the exchange of information and can have negative implications for treatment. Patients describe this phenomenon slightly differently and emphasize the importance of listening to physicians, since "they have more experience and expertise." A patient said, ". . . We should listen to them and should not decide on our own ideas. We don't know." Patients respect doctors' experience, and although they do not admit to not wanting to let them down, their comments do suggest deference to authority, which could lead to misinformation (or lack of shared information) during the clinical encounter.

Theme 5: Psycho-social factors. Although we did not ask explicitly about the impact of the Khmer Rouge on health beliefs and experiences, it was mentioned repeatedly in various contexts by all study groups as playing a significant role in self-management and the provision of care. For example, a clinician described how taking a basic social history, particularly gathering information about illnesses in the family, can be difficult given the atrocities that many Cambodians experienced under the Khmer Rouge. (See Box 2.) Secondly, caring for survivors of the Khmer Rouge and their families is particularly complicated in the case of diabetes, since many survived mass starvation. A clinician said, "Starvation was a big thing for their culture, and so they come here and the pan of rice is always on the stove. Food is huge. They couldn't get access to it." The food and diet management necessary for proper diabetes care is a major challenge. "Limiting one's food is culturally hard . . .," a provider said. Further, issues of stigma in the Cambodian community and cultural beliefs make treating mental health conditions particularly difficult.⁷⁵ For example, a clinician described how patients would rather be treated by a primary care physician than go to a mental health clinician. It been noted elsewhere that refugees from Southeast Asia might avoid referrals to mental health clinics, psychotherapists, or psychiatrists.⁷⁶ Finally, familial care-taking patterns

were another commonly discussed psycho-social factor affecting diabetes management. According to clinicians, the elders in the family are typically the primary caregivers for their grandchildren rather than the parents, and this can be particularly challenging when several generations are living in one household. This has implications for both getting to the health center for visits and adherence to treatment plans.

Theme 6: Fears and challenges interacting with the healthcare system. According to clinicians, many Cambodian patients have difficulty navigating pharmacy-related services, particularly for refills and medication pick-up, which is partly due to language and literacy barriers discussed earlier. “I’ll look and they’re taking three of the same cholesterol pill and they don’t realize it because they’ve gotten a refill from a different pharmacy . . . and it looks different, so now they’re taking triple dose of a cholesterol medication and none of the diabetes medications,” said one clinician. Clinicians also felt there was “a good amount of distrust” among Cambodian patients in relation to health care practitioners and the system more broadly. Although patients do not describe specific experiences of mistrusting practitioners or the health care system, the Cambodian interpreters described how many Cambodian patients are scared of tests and procedures, including mammograms, getting blood drawn, and x-rays. For example, a Cambodian interpreter said, “Some say . . . maybe x-ray, it eat my bones . . . and make shorter life” and, in regard to getting blood drawn, “Too much . . . draw the blood too much.” These fears are often amplified by elderly patients as they are likely less familiar with Western health care traditions. As for diabetes, both Cambodian interpreters and patients described how fear of needles leads to a hesitancy to check blood sugar. However, patients did not specifically describe other fears associated with navigating the healthcare system more broadly.

Discussion

Our study supports previous findings regarding Cambodians’ perspectives on chronic disease and diabetes disease processes. For example, we found that the concept of chronic disease is foreign to many Cambodian patients,^{10,31,35,42} and that many Cambodian patients are unfamiliar with common Western medical practices.^{37,42,77} For diabetes in particular, we confirmed findings that many Cambodian patients have limited understanding of the disease and related care-processes^{10,31,42,77} and report varying degrees of use of cultural and traditional remedies.^{10,40,42,78} However, the majority of patients in our study discussed using these either alongside or in place of prescription medicine. The notion of an “instant cure” for medical conditions was raised often and is typical of other groups with limited health literacy and education,⁷⁹ but not described, elsewhere, to our knowledge, in relation to Cambodian culture specifically.

We offer new insights into these issues by providing the perspectives of patients, providers and bilingual Khmer staff. Our findings highlight a mismatch between Cambodian patients’ and their health care providers’ views of diabetes, which presents serious obstacles to self-care and disease management. Although this lack of conceptual matching is not particular to Cambodians (as many patients see diabetes or other chronic illnesses differently from how Western medicine sees them⁸⁰⁻⁸⁴) our findings indicate that Cambodians in the United States, as a refugee population with a particularly

traumatic history, have unique health care needs.^{34,85} The physical and psychological trauma that occurred during the Khmer Rouge period has been well described as a critical component to consider in the provision of care to Cambodian patients.^{38,85–86} In our study, providers discussed the ways in which this can complicate otherwise simple tasks such as taking a family history and diet management for diabetes. These factors must be addressed to ensure high quality and culturally appropriate care.^{57,87}

Our study reveals the interest and need for education for both providers and patients. Providers and patients are interested in learning more about the topics discussed. Patients requested more information on diabetes, the purpose and use of medication, potential complications, and other care management tools. Providers requested more knowledge about Cambodian cultural beliefs and practices relating to diabetes and Western medicine, which they felt could help improve the quality of care provided to their Cambodian patients.

Our findings suggest that cultural competency training for providers, and diabetes education for patients that is flexible and responsive to their unique perspectives, would be extremely helpful in correcting the mismatch between Cambodian patients' beliefs and practices and those of the Western biomedical system.^{30,34,87,88} If providers understood patients' views of diabetes better it might help open the dialogue with patients and allow for increased trust-building. Creating a shared vocabulary entails provider education on common cultural perceptions of diabetes, including Khmer words to describe diabetes (and their meanings and connotations) as well as common foods consumed. Interpreters could play an important role in helping train providers on common dietary practices as well as cultural beliefs associated with food. For example, an interpreter might provide a brief presentation at a general medicine meeting with providers and care team members.^{89–91} It is also critical for providers to understand that the concept of chronic disease is foreign to many Cambodian patients. This can help provide insight into the cycle of medication adherence and non-adherence, which is a particularly difficult challenge to care management. If providers are aware of this conceptual mismatch, they can target education efforts to directly address Cambodian patients' beliefs around a disease "cure"¹⁰ and to build knowledge around ongoing testing, medication use, and daily self-management that is required for chronic diseases like diabetes.

Two other areas where additional training is needed for providers are the use of Cambodian cultural traditions and remedies⁴⁰ and how to effectively work with refugees and survivors of torture.⁵⁷ Any patient-centered and culturally sensitive approach should include queries into patients' use of complementary or alternative medicines.^{88,92} This is particularly important for working with Cambodian patients who may be using these remedies either alongside or in place of their prescription medicines. If providers familiarize themselves with the general types of cultural remedies or traditions this also might help facilitate dialogue and insight into problems with medication management. Finally, providers need training on how to care effectively for refugee populations. For example, the topic of reducing food intake, particularly rice, is complicated for many Cambodian patients given the starvation and torture commonly endured during the Khmer Rouge Period. Typically, Cambodian patients will eat white rice, which has spiritual as well as nutritional value, multiple times throughout the day. Box 3, which

Box 3.

**CAMBODIAN PATIENT WITH DIABETES:
PATIENT PROFILE**

- 60 year old female diagnosed with Type 2 Diabetes Mellitus in 2005
- Well controlled on Metformin until 2007
- HbA1C ranging from 6.7% to 9.6%
- Current HbA1C 8.10%

Social Background

- Immigrated to the United States in 1982 with her husband and daughter
- Survived the concentration camps where she lost 2 children, a 1 year old daughter to starvation and a stillbirth at 8 months gestation from working in the rice fields
- Her sister and a close friend died from complications of diabetes, they were poor and were unable to get healthcare

What factors contribute to effective diabetes control?

- Transition to American life and culture
- Depression and PTSD
- Fear of Western Medicine
- Fear of early death
- Feelings of hopelessness

“Why did I survive the starvation, torture, and loss of my children to come to the land where everything is available for you, only to have to suffer with *diabetes*?”

highlights a patient’s experience at MGH Revere HealthCare Center, further shows how experiences of trauma impact can affect health, specifically in the context of diabetes. This underscores the importance of understanding patients’ cultural and experiences as they shape perceptions of health and health behaviors.

Further, Cambodian survivors of the Khmer Rouge have also been shown to have increased rates of post-traumatic stress disorder (PTSD)^{43,45,49,51,93} making treating depression and mental health conditions of particular concern among survivors with diabetes.^{51,94–95} According to Dr. Richard Mollica, Director of the Harvard Program in Refugee Trauma (HPRT) of Massachusetts General Hospital and Harvard Medical School, it is critical that providers feel sufficiently comfortable discussing forms of torture with refugee populations, which will make it easier to treat the psychological sequelae of such trauma.⁵⁷ Providers’ ability to perform a basic and culturally appropriate mental health assessment is critical and will often require questions regarding trauma experiences.

Bridging this gap in communication is not solely dependent on cultural competency training for providers; the goal is to bridge these diverse cultural perspectives, not to

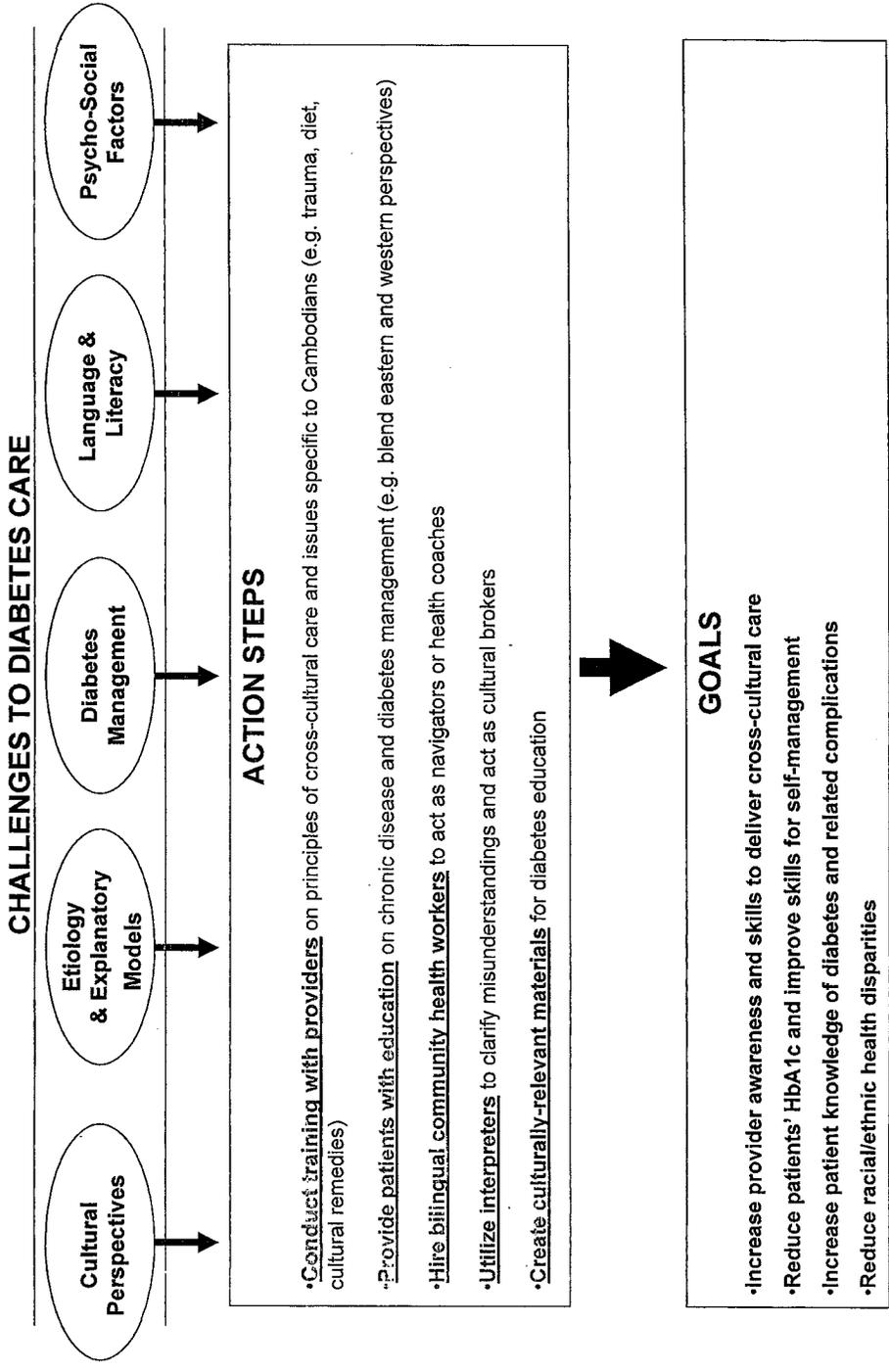


Figure 1. Recommendations for Improving Provision of Care to Cambodian Patients with Diabetes

supplant one perspective with another. Basic education for Cambodian patients about the Western medical system, chronic disease, and the anatomy of the body, as well as diabetes-specific education and management is equally important. Cambodian patients in our study, when asked about interest in further education, were eager to learn more about diabetes, including nutrition and exercise. If Cambodian patients do not truly understand the link between diet, blood sugar, and diabetes complications they will have difficulty managing their diabetes effectively. Making sure patients understand chronic diseases, and the on-going care and maintenance required, regardless of whether symptoms are present, is critical. Although this may go against cultural beliefs regarding health or illness, it is important to find creative ways to explain these concepts in a culturally appropriate way. See Figure 1 for a summary of recommendations.

For both patients and providers, language and literacy barriers greatly complicate perceived simple care management practices (such as organizing medication, getting refills from the pharmacy, tracking HbA1c levels). A Khmer-speaking community health worker, or diabetes coach, could be an effective way to address the challenges associated with language and literacy, as well as help bridge the cultural divides.^{20,34,37} These types of programs are currently being conducted and studied with vulnerable populations and may prove to be cost effective. Interpreters could also be trained to act as “cultural brokers” when needed and could assist in helping patients navigate the health system, as well as organize medications and act when miscommunication arises between the patient and provider. While interpreters have often been trained to avoid getting involved in patient care issues, there is a movement that is beginning to value their potential role as patient advocates as well.^{30,96-98} This kind of support would be directly beneficial to both patients and providers. A major challenge is having culturally appropriate education materials, as so few are available in Khmer and many health centers do not have the resources to translate materials into multiple languages. Further, with so many patients with low levels of literacy, in many cases audio files with education materials in Khmer are more effective.

Limitations. Our study had several limitations. Although we had a reasonable sample size of physicians, we don't assume that these findings are representative of all physicians providing care to Cambodian patients. Given the limited number of focus groups, we were not able to ensure that we achieved full saturation of themes. Further, given that the focus groups took place at the health center, patients may have felt hesitant to reveal personal information about their perspectives, experiences, and attitudes towards Western medicine. We tried to minimize the chance of this by involving a non-affiliated Khmer-speaking focus group moderator, but it is difficult to know how forthcoming participants felt they could be. Additionally, cultural values of respect for physicians may have affected participants' ability to share concerns about their health care or experiences at the Health Center. Further, although focus groups with patients and interpreters were conducted in Cambodian (Khmer), there is always a risk of conceptual misrepresentations across languages and cultures. We attempted to minimize these risks by reviewing findings with the moderator and other Cambodian project staff. Unlike other studies, we included the perspectives of Cambodian

interpreters and Cambodian staff that were able to either confirm patient perspectives or provide additional insight.

Conclusion. This qualitative study describes a wide range of socio-cultural barriers to diabetes care for Cambodian patients at an urban community health center. Many of our findings reflect similar challenges described in previous literature both for this population and for other disadvantaged groups. However, we also describe several new findings that provide additional insight into cultural beliefs and practices that affect diabetes care and self management for Cambodian immigrants. Our findings underscore the fact that this population has unique health care needs that must be addressed in a culturally appropriate way if we are to achieve high-quality care. We recommend education for health care providers on patient-centered cross-cultural care with an emphasis on the unique needs of Cambodians as well as culturally appropriate diabetes education for patients. Cambodian patients would benefit greatly from a Cambodian diabetes coach/community health worker that could provide education on diabetes, address social barriers, and help patients navigate the health care system. Interpreters may also play an important role in helping to bridge cultural perspectives by educating providers and identifying culturally mediated missed connections that limit communication between patients and providers.

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