Explaining Diabetes, Conveying Distress:
Cambodian American Explanatory Models of Type 2 Diabetes

Lara Watkins
Bridgewater State University

Abstract: Diabetes is intensifying its global reach. Yet, people do not passively experience the world; they are active agents in the interpretation and experience of their health. Migration brings together people and cultural beliefs with the promise of health challenges as well as potential innovation in health care. The aim of this study was to elicit Cambodian American explanatory models of type 2 diabetes to better understand the ways in which diabetes is experienced and interpreted. Through semi-structured interviews, 20 Cambodian Americans in southern New England answered a series of open ended questions exploring their beliefs and experiences around diabetes. Common themes around disease meaning, causes, symptoms, and treatment emerged from qualitative thematic analysis of the interviews. While explanatory models of diabetes were explicitly sought, diabetes as idiom of distress was implicitly communicated. A diagnosis of diabetes should be harnessed as a vehicle for strengthening general health promotion.

Keywords: Cambodian Americans; chronic illness and disease; explanatory models; health communication; idioms of distress; lived experience; qualitative methods; refugees, immigrants and migrants; type 2 diabetes

[1] Correspondence concerning this article should be addressed to Lara Watkins, Department of Anthropology, Hart Hall, Room 226, Bridgewater State University. Bridgewater, MA 02325. Email at lwatkins@bridgew.edu.

EXPLAINING DIABETES, CONVEYING DISTRESS: CAMBODIAN AMERICAN EXPLANATORY MODELS OF TYPE 2 DIABETES

The worldwide prevalence of diabetes increased from 4.7% in 1980 to 8.5% in 2014 (World Health Organization, 2016); the majority of those with diabetes have type 2, previously known as non-insulin dependent diabetes. An estimated 28 million Americans have type 2 diabetes, impacting quality of life, emergency room visits, and risk for heart attack, stroke, kidney disease, eye problems, and amputations (American Diabetes Association, 2016). Moreover, there is evidence that refugees are particularly at risk for medical disease, including diabetes (Kinzie et al., 2008). For many older Cambodian Americans, diabetes is layered upon a history of trauma, starvation, migration, and deprivation (Wagner et al., 2012). While past trauma and current life stressors continue to challenge Cambodian Americans, individuals, families, and communities are finding ways to survive and thrive. Diabetes represents a serious health challenge, but may be turned into an innovative outlet for strengthening survival.

Cambodian Americans: Recognizing the Past to Understand the Present

While the cultural achievements of the Khmer are highlighted in the iconic Angkor Wat, the recent past is punctuated with the destruction of the Khmer Rouge, the violent political party that rose to power under Pol Pot (Chandler, 1999; Kiernan, 2002; Mabbett and Chandler, 1995: Shawcross, 2002). Estimates of deaths caused by the Khmer Rouge through widespread starvation, relocation, and physical violence range from one to three million or 20-40% of the population (Kiernan, 2002; Mabbett and Chandler, 1995; Mollica, Donelan, and Tor, 1993). The majority of Cambodians who migrated to the United States were resettled between 1979 and 1986 in response to the violence and upheaval of the Khmer Rouge and the subsequent civil and political unrest. Cultural tradition as well as previous trauma are inscribed in Cambodian American bodies, minds, families, and communities.

Compounding past trauma, data indicates that Cambodians experience structural disadvantage in the United States (Pais, 2014). Cambodian American adults tend to have less income, fewer financial assets, and lower educational attainment than the general population (ACS, 2010; Le, 2016; Southeast Asia Resource Action Center, 2011). From 2006-2010, the per capita income of those identifying as Cambodian was $15,614, in comparison to $27,334 for the general American population (ACS). Almost 42% of those responding to the ACS in 2010 noted that they spoke English less than "very well", in comparison to about 9% of the general population. For those forty-five and older identifying of Cambodian descent, 58% reported having less than a high school diploma, 20% reported having the equivalent of a high school diploma, and 22% reported education beyond high school, in comparison to 16%, 31%, and 53% respectively in the general population.

Early in the migration stream, many areas with relatively high concentrations of Cambodians had not only cheap housing and jobs for those without much knowledge of English, but also wider urban concerns such as gangs and underperforming schools. According to community leaders, the 2008 financial crisis hit the Cambodian American community in southern New England particularly hard due to disproportionate representation in manufacturing and unskilled labor (Watkins, 2009). Increasingly calls to address racial and ethnic disparities in diabetes include addressing social inequalities as social conditions prospectively impact the development of diabetes (Kelly and Ismail, 2015).

By two decades after the initial migration stream, the major health concerns within Cambodian American communities shifted from initial acute issues following resettlement, such as malaria and malnutrition, to chronic concerns, such as diabetes and high blood pressure (Watkins, 2009). By 2007, clinicians, community leaders, and community members reported diabetes as a major health concern impacting Cambodian American communities across the nation (National Cambodian American Health Initiative, 2007). Meanwhile, an increasing body of research is

building the case that refugees are particularly at risk for diabetes given previous and persisting mental stressors in conjunction with physical conditions (Wagner et al., 2015). While including "cultural and contextual factors into health interventions results in improvement in health and health outcomes" (Cabassa et al., 2014, p. 1126-1127), there is a lack of this needed modification for those with serious mental illness, particularly for those identifying as non-white. Decades after resettlement, Cambodian Americans continue to have high levels of mental health challenges (Marshall et al., 2005).

Theoretical Background

Culture is an evolving lens through which group members make meaning out of experiences, including health, illness, and disease. Culture provides people with skills and techniques to strengthen survival. Cultural models are the patterned understanding of a particular phenomenon (D'Andrade and Strauss, 1992). Explanatory models are a subset of cultural models. Cultural models are the wider cultural explanations and ideas that inform a particular patient's specific explanatory model of their health experience; explanatory models elicit socially reproduced, cultural conceptualizations of illness experiences, targeting ideas around etiology, symptoms, pathophysiology, course of sickness, and treatment.

Explanatory models strike at the heart of understanding a patient's view of illness. In the late 1970s, Arthur Kleinman (1988) first promoted the language of "explanatory models" of illness as a way of improving patient-health practitioner communication and, consequently, patient outcomes. The logic underlying the explanatory model implies treatment and prevention. The need to explore patients' explanatory models is key since health communication can only be effective if it is meaningful to patients. Additionally, in a community where trust has been eroded, such as those experiencing the nefarious uncertainty of the Khmer Rouge era, Frye and D'Avanzo (1994) suggest health practitioners build trust through understanding patient's explanatory models.

Schoenberg, Amey, and Coward (1998) noted that there was "a dearth of literature on lay explanatory models…of NIDDM [non-insulin dependent diabetes mellitus; type 2 diabetes]"; in addition to earlier work by Garro (1995) with an Ojibway community, now there has been published research on the explanatory model of diabetes for a variety of groups, for example, Hispanic Americans (Hatcher and Wittemore 2007), Mexicans with diabetes in Mexico (Daniulaityte, 2004; Valenzuela et al., 2003), rural white Americans without diabetes (Arcury et al., 2005), rural African Americans with diabetes (Skelly et al. 2006), individuals with diabetes from Pakistan living in the UK (Meeto and Meeto, 2005), and cross-culturally with African American, Mexican American, Great Lakes Indian, and rural white individuals with diabetes in America (Schoenberg et al., 2005). The current qualitative research adds to this research, exploring explanatory models of type 2 diabetes within a previous refugee group, Cambodian Americans.

As diabetes was noted as a major emerging concern in Cambodian American communities (National Cambodian American Health Initiative, 2007; Watkins, 2009), a series of interviews were conducted to explore the way in which diabetes was understood and integrated into the lived experiences of Cambodian Americans. Understanding the ways in which diabetes is experienced and interpreted by individuals will help to inform culturally appropriate methods to prevent and treat diabetes, while also strengthening general health and well-being in communities. Since explanatory models, may strengthen or challenge health seeking behavior and communication, the current research sought to describe Cambodian American explanatory models of diabetes with implications for the long-term health and health care of resettled refugee groups. While explanatory models of diabetes were explicitly sought in semi-structured interviews, diabetes as idiom of distress was implicitly communicated by participants.

METHODS

Study Design

The purpose of this research was to

investigate Cambodian American perspectives of a community-identified health concern – type 2 diabetes – with logistical support from a community-based organization. Initial exploratory research on health concerns and health care access within the Rhode Island Cambodian American community in 2003 documented that while acute health concerns predominated early in the migration stream, many community members expressed current concerns over chronic health issues including diabetes. Therefore, the current qualitative research was developed in response to the emerging concern over diabetes by community members. The goal of the research was to systematically explore explanatory models and experiences of diabetes by adults in Cambodian American communities of southern New England.

In 2007, 20 semi-structured interviews were conducted with the assistance of an experienced translator with specific training on the research protocol. As an exploration of views on diabetes, the perspectives of those with diabetes and caretakers of those with diabetes were actively sought; however, participants uncertain of their status or those without a diabetes diagnosis were not excluded. Rather, their perspectives were included since the intended purpose of the study was to elicit cultural perspectives on diabetes for those experiencing life in both Cambodia and the United States, not to focus purely on the perspectives of those diagnosed with diabetes. As Baer, Weller, de Alba Garcia, and Salcedo Rocha (2004) note, explanatory models are not the exclusive understanding of those with the illness or disease, but rather as cultural models, explanatory models emerge from groups with shared cultural experience. The wider interview was framed to focus on the cultural context of diabetes, high cholesterol, and hypertension; the interpretation of weight, nutrition, and personal eating habits; knowledge of family health history; and beliefs and behaviors around physical activity. Themes around explanatory models of diabetes are the focus of this article and discussed further in the results section.

Sampling

Purposive sampling was used to capture cultural variation (Bernard, 2006; Handwerker,

2001). A range of experiences and perspectives were sought. Inclusion criteria were: 1.) being at least 40 years old; 2.) living in Connecticut, Massachusetts, or Rhode Island; and 3.) self-identifying as Cambodian. Participants were recruited through informal social networks and through association with a community based partnering organization. The research team sought those more comfortable speaking about health in English and in Khmer; those diagnosed with diabetes and those without a diagnosis; earlier refugees and more recent immigrants; those with more and less education; males and females; and members of ethnic majority and minority groups from Cambodia. As noted by Guest, Bunce, and Johnson (2006), "if the goal is to describe a shared perception, belief, or behavior among a relatively homogenous group, then a sample of twelve will likely be sufficient" (76). Similar to Romney, Batchelder, and Weller (1986), Guest et al. (2006) found that in interview research entailing set questions with high participant homogeneity, the number of needed participants to achieve data saturation – the point at which no new themes are found – is relatively low when participants are highly knowledgeable about the content area. Participants converge on the same set of responses. Twenty participants, each completing one interview, was the predetermined sample size in order to financially support language interpretation, bilingual transcript review, and participant incentives. Indeed, data saturation appeared prior to completion of all twenty interviews as almost all codes appear within the first ten interviews completed.

Ethical Considerations

The study was approved by the Institutional Review Board at the University of Connecticut. The project information sheet included contact information for the principal investigator and a trusted bilingual community member knowledgeable in both the research project as well as available resources if participants had concerns or questions after interview completion. Prior to the interview, participants were informed of the study's purpose, reminded that they could skip any question and end the interview at any time, and asked if the interview could be recorded for

transcription. In addition to the project information sheet in English, a spoken Khmer version was audiotaped and played before interviews conducted in Khmer and some conducted in English, depending on participant's choice. This helped to ensure that participants provided informed consent regardless of comfort with written English. All individuals gave verbal consent to continue with the interview and allowed audiorecording for later transcription.

Data Collection and Analysis

Participants had the option of completing the interview in English with the researcher, or in Khmer or Khmer and English with an interpreter and the researcher. The interpreter was trained on the research protocol to ensure that she knew the purpose of each interview question, thereby strengthening validity. Eleven interviews were conducted in English and nine in Khmer. Interviews lasted from 45 minutes to two hours with the average running 75 minutes. Interviews were conducted in the participant's home or the home of their friend or family member. Participants were given $15 at the conclusion of the interview as a symbol of appreciation for their time.

The audiorecordings and interview notes were transcribed verbatim. A designated bilingual transcript reviewer compared the interview transcript against the audiotaped interview, thereby serving as a quality check to ensure that participant meanings were appropriately represented in the transcript. Any noted discrepancies were discussed with the researcher.

Embedded in the sociological tradition of using text as a proxy for experience, inductive thematic analysis was used to identify themes within the data, giving voice to the research participants (Braun and Clarke, 2006; Guest, MacQueen, and Namey, 2012). Similar to grounded theory, inductive thematic analysis is a systematic, but flexible methodology for generating codes from qualitative data, whereby the codes are firmly "grounded" in the data. These codes can then be used to build theoretical models or find solutions to real world problems (Guest et al., 2012, 17). Inductive coding of themes based on repetition and similarity ensured that the findings were firmly rooted within the data of the interview transcripts. Atlas.ti was used to code and manage the transcripts and themes. Coded data varied in length from a sentence fragment to a paragraph. A codebook was generated to summarize and organize the data. Codes were refined over time with initial codes subsequently reviewed and revised to standardize across interviews and to organize the increasingly in-depth codes developed as thematic analysis proceeded, thereby strengthening reliability. Themes were discussed by the author with a senior researcher overseeing the research project. While explanatory models of diabetes were the foci of the interviews and, consequentially the presumed rough organizational scheme for themes, inductive coding of the transcripts, in addition to participant observation, led to the emergence of the theme of "diabetes as idiom of distress". This could have been overlooked if a more constrained approach to analysis had been taken.

FINDINGS

The findings are broken down to sample characteristics (Table 1), general health, and then an exploration of the meaning, causes, symptoms, and treatments for diabetes. The findings conclude with discussion of diabetes as idiom of distress. Quotes are maintained in their original form. Due to providing verbatim quotes and particularly verbatim quotes of non-native English speakers, […] is used to denote text deleted for brevity and clarity of meaning.

Table 1. Participant Demographics (n=20)

% identifying as female/male	55%/45%

Age
40-49	25%
50-59	55%
60-69	15%
70+	5%

Year of arrival in US
1975-1979	15%
1980-1989	70%
1990-1999	5%
2000-2007	10%

Years. of formal education
None	30%
Less than high school	15%
High school	10%
Some college or vocational	45%

Employment
Employed	30%
Retired	10%
Not employed	60%

Self-reported health status
Excellent	0
Good	15%
Fair	55%
Poor	30%

Diabetes status
Diagnosed	40%
Participant unsure	10%
Caretaker of diabetic	15%

Hypertension	50%
High cholesterol	55%

Sample Characteristics

Fifty-five percent of the sample identified as female. The mean participant age was 55.6 years old with a range of 43 to 74 years. The majority (75%) of participants spoke a language other than English (predominately Khmer) at home. The majority (60%) of participants were not employed, while 30% were employed and 10% identified as retired. Ninety-five percent of respondents were Buddhist.

On average, participants completed 8.1 years of education; however, the number of years of education varied dramatically from no formal education (30%) to some post-secondary training/education (45%). This sample demonstrates the range of educational experiences within the Cambodian American community. It also includes voices from a range

of migration experiences including three early wave refugees, who left in 1975 during civil war, but before the full brutality of the Khmer Rouge, and two more recent immigrants, who arrived in the United States in the 1990s and 2000s. All participants were born in 1964 or earlier and had lived through the traumatic experiences of the 1970s and 80s in Cambodia, either firsthand or through the uncertainty and psychological trauma of family, friends, and compatriots. On average participants arrived in the US in their 30s, but the age at arrival ranged from 13 to 64 years of age.

General Health

In terms of health status, 40% of the sample was diabetic, while 10% did not know their diabetes status. Two individuals (10%) without a diagnosis of diabetes identified themselves as a "caretaker" for a family member with diabetes. Fifty percent of participants reported high cholesterol and 40% reported high blood pressure. Twenty percent reported smoking at least "some days". Eighty-five percent of the sample had at least one of the following: diabetes, high blood pressure, or high cholesterol. On a scale of poor, fair, good, or excellent health, most (55%) of the participants rated themselves as being in fair health with a high percentage (30%) being in poor health (negative extreme). No one self-identified as being in excellent health.

Of those responding to a series of questions on knowledge of family health history, 100% felt that they knew "a little" or nothing about their grandparents' health, 64% knew "a little" or nothing about their parents' health, and 50% knew "a little" or nothing about their siblings' health. Explanations offered by participants for not knowing about the health of family members included separation, not talking about reasons for ill health, and only knowing the immediate cause of death. Some individuals reported not knowing about the health of their family because of death and physical separation due to the Khmer Rouge period. During this time, children were forcibly separated from their parents; however, some parents chose to separate family members in order to increase their chances of survival. Three of the 20 participants did not know about their family's

health since they were taken care of by hired help or attended boarding school. In contrast to the majority of Cambodians arriving in the United States in the late 20th century, these three participants came to the US in 1975 when the Khmer Rouge took over Cambodia. Two of these individuals were adopted by families in the United States.

Diabetes Course and Meaning - "Diabetes is a difficult time"

In Khmer, diabetes is referred to as ទឹកនោមផ្អែម or "teuk noam pha-em", which literally translates to "sweet urine". Some community members recall knowing that someone had diabetes in Cambodia because ants were attracted to their urine. Prior to the Pol Pot time, diabetes was considered a disease of the rich; only those who could afford a surplus of food were thought be at risk for diabetes. These individuals tended to live in cities and were more educated. Regardless of their perception of diabetes in the past in Cambodia, all participants either had diabetes or knew someone diagnosed with diabetes. A 47-year-old female with diabetes mentioned: "Every time we get together among Cambodians, we always talk about diabetes because they see a lot of people have it; people die." A 57-year-old male with diabetes said "[Diabetes] is scary." Within discussions of diabetes, there are anecdotes of diabetic symptoms, how to manage it, and horror stories of complications.

Participants with diabetes tended to emphasize that after the initial shock, they were nervous about the diagnosis. Yet, they compared themselves to those who were worse. They knew that they could take precautions to care for themselves, but scary stories of others experiences perpetuated worry. On being diagnosed with diabetes one 53-year-old female mentioned, "you feel bad because you never want to be like that. It's a little shock, but that's ok; we are still alive." Another stated, "You feel like 'why me?'[…] My friend that is working with me, she became blind!" Some participants offered that diabetes is difficult because it is a lifelong disease with no cure. These individuals recognized the ongoing struggle to manage and maintain their health.

Causes of Diabetes

Many interview participants initially mentioned that they did not know the causes of diabetes. Shortly thereafter most offered causal opinions; however, three of the older women (ages 64, 67, and 74) interviewed in Khmer did not offer any causal opinion.

General nutrition was the most frequently cited cause of diabetes. A 49-year-old male demonstrated the breadth of this theme: "…[I]t goes back to the daily diet […] people are working and they just don't really pay attention…" A substantial minority of participants reported that eating too much sugar was a cause of diabetes. A 49-year-old male explained in English,

> I think back in Cambodia, we seldom heard about this term. We think that it is only […] wealthy people […] because we always think […] about diabetes in our language [the literal translation is] 'sweet urine', so […] people eat too much sugar and [that] is what caused diabetes. But now, as we come to the United States, we understand that it is not because you eat too much sugar, it is because our body cannot digest it.

Ideas circulating in Cambodian American communities connect eating too much sugar and developing diabetes. While the origin of this connection remains unknown, the connection may stem from the literal translation of the term "diabetes" into Khmer and the previous connection to those with more money; it could also be an interpretation of medical advice. On the other hand, while some participants noted an association with sugar, participants did not focus on obesity. It was only offered as a cause of diabetes by two participants and one participant specifically mentioned the inverse, that obesity is NOT a cause for Cambodians.

Only one quarter of the sample offered family history or genetics as the cause of diabetes. Additionally, genetics was never offered as the only cause of diabetes. Any participant that mentioned the importance of genetics recognized that other experiences (from exercise and diet, to imbalance and "thinking too much") impacted the development of diabetes. A forty-seven-year-old female identifying as pre-diabetic noted,

> …[S]ometimes I think that it is because of the family […] because my mother had diabetes, and, knock on wood, I don't have it yet, but I know my brother has [it] and my sister has [it] right now […] and also maybe something to do with your depression. You don't eat right and you don't take care of your body.

This perspective represents a broader understanding of the causes of diabetes. The participant notes that health is realized in a wider environment. Mental health and taking care of oneself impact the actualization of genetic predisposition.

Impaired mental health was mentioned as a cause of diabetes by three participants and all three strongly emphasized its role in the development of diabetes. A 57-year-old male with diabetes offered "I think that it is from the family, but if you don't have stress, maybe diabetes will not come up too, not fast like that." Another participant, a 47-year-old female with diabetes, mentioned, "Probably some people get [it] from the genes […], you know, the family […] plus all the stress […] because it builds up in the whole body system." This suggests that Cambodian Americans, on a personal level, were recognizing a trend noted in the anthropological literature with other cultural groups. Stress has a complex relationship with diabetes.

Symptoms of Diabetes

Irrespective of diabetes status, 25% of participants stated that diabetes may be present without any symptoms. General malaise, fatigue, dizziness, polyuria or frequent urination, and polydipsia or thirst were cited by a substantial minority of the sample. Participants noted their need (or the need of those they knew with diabetes) to urinate frequently and have increased thirst. They grounded their statements

in their lived reality and not through knowledge of a "list of diabetes symptoms".

Irritability or anger was a symptom reported by a quarter of the sample. Three people mentioned that those with diabetes tend to become angry quicker. A 57-year-old male diabetic noted, "I can see in myself. I can get angry very fast, faster…like mood swing very badly." Irritability is a noteworthy reported symptom since it extends beyond the individual, impacting interpersonal interactions. In addition, shaking (n=7), swelling (n=4), vision impairment (n=4), weight loss (n=3), hunger (n=3), numbness (n=3), difficulty breathing/tightness in chest (n=2), and neck pain, sweating, and difficulty sleeping were mentioned as symptoms of diabetes. The symptoms of diabetes – in both the analysis of the interviews as well as in clinical manifestation – are difficult to differentiate from complications of diabetes, as complications may appear as symptoms for those with undiagnosed diabetes.

Participants blended physical and emotional symptoms of diabetes. The presumed symptoms of diabetes are challenging in that they could be caused by a variety of health and sociocultural factors. For example, one 59-year-old female with diabetes explained, "I think too much! At 5:00 [AM], still I am not sleeping. [I am] angry all the time at everybody. [My] mind is here, there, all over, [thinking about my family in Cambodia]." Clearly, the experience of diabetes is intimately woven with current mental health. Diabetes may contribute to feelings of depression and, at the same time, the symptoms may interact with existing stress and depression. Feelings of anger may be exacerbated by current life stressors as well as a traumatic past. Yet, the most widely recognized symptoms of diabetes by this sample include the major symptoms acknowledged within biomedicine, demonstrating that overall the participants were knowledgeable about the widely understood symptoms of diabetes within medicine.

Treatment for Diabetes

The majority of participants recognized that diabetes is well managed under the supervision of a medical professional with nutritional and general lifestyle changes. Some participants mentioned the need to exercise, manage stress, and self-test. Amidst these "standard" diabetes management recommendations was also the understanding that traditional medicine outside the formal health care sector *may* be effective at treating diabetes. The use of traditional medicine implies a broad understanding of health that incorporates diabetes within a healthy lifestyle.

Upon follow-up questioning, 90% of participants recognized some form of traditional diabetes medicine outside formal health care. Some frankly stated they did not believe in herbal treatment. Some participants recognized traditional vegetables, fruits and herbs as effective for diabetes, while others recognized these items as being good for general health. Some participants were hesitant to recognize that traditional medicine may be effective in treating diabetes. One participant noted, "I don't know if it works for diabetes. I don't know, but maybe some of it, because it works for everything else, must be healthy for that too!" Community members with diabetes may use traditional medicine for general health with secondary benefits for diabetes.

About 25% of participants suggested that there is a connection between bitter flavor and effective traditional diabetes treatments. One participant said, "A lot of herbs that are sold […] in the Chinese community or [other community], they said can treat diabetes or health. Most of them are from bitter plants, like bitter melon, the leaves…and guava leaves…and pomegranate skins." There is recognition that sometimes individuals will buy "traditional medicine" because it says that it is "for diabetes". The purchaser might not know what it is, but it is often cheaper than other medicine. At least half of the participants knew of an herbal tea used as diabetes medication; sometimes herbs were fermented in liquor. Some participants expressed concern that sellers prey on those who cannot afford prescription medication. There was a spectrum of beliefs in the effectiveness of traditional remedies for diabetes. Some did not think that traditional medicines help at all, some believed that they should be used in conjunction with lifestyle

changes, and some strongly believed in their effectiveness.

Diabetes as Idiom of Distress

In addition to explanatory models of diabetes, participants offered a view of diabetes as "idiom of distress". One female participant with diabetes rapidly spoke in Khmer, "Diabetes is difficult because…" She continued to describe her current concerns and life stresses. Her daughter had not been "quite right" since she had suffered an injury during the Pol Pot era. Her daughter had been able to hold various factory jobs, but recently had been laid off and was having trouble finding another position. Her daughter did not have any health insurance and, in a community screening the previous year, she had been informed that she had diabetes. The participant, a diabetic herself, was greatly concerned about the health and well-being of her daughter. Unsolicited by the research team, she used the interview and her diabetes to convey her wider distressing family situation. The interviewee's health as well as that of her daughter was still being impacted by the persistent pernicious effects of previous trauma. This example illustrates how diabetes may be used as a vehicle through which a more complex life situation may be expressed. Another female participant with diabetes believed that her diabetes onset occurred through the build-up of stressors including her emotional divorce. Diabetes was used as a vehicle for talking about current and past life stressors.

DISCUSSION

Sample Description

A few general trends noted in this sample warrant further discussion. First, intracultural variation is clearly demonstrated. Thirty percent of the sample reported no formal education at all. On the other hand, 55% of the sample completed at least high school. These extremes represent a key area of cultural variation within this study and the wider Cambodian American population. Additionally, there is also variation around the experiences of those at the beginning, middle, and later in a migration stream. The variation in migration history of this sample is a strength. While the sample is small in order to accommodate the intensive nature of qualitative research, the

sample is varied in background, suggesting that the overall emergent themes are less likely to be skewed toward specific subpopulations. Health promotion needs to recognize the individual and cultural variation within ethnic communities and not equate ethnicity with cultural homogeneity (Kleinman and Benson, 2006). Second, the high level of poor self-reported health documented in this sample is note-worthy because as Rock (2003, p. 133) reports "distress and duress may contribute directly to the sweetening of blood [i.e., development of diabetes] and concomitant complications". Poor subjective health at a group level may be indicative of increased risk for diabetes and/or its complications. There is a well-established bidirectional link between mental health and diabetes (Balhara, 2011; Ducat, Philipson, and Anderson, 2014). The meaning of diabetes may be different for groups experiencing different life stresses and experiences. For this population, diabetes is embedded in the unique embodiment of previous trauma and current life stressors.

Additionally, this sample was not confident about their knowledge of relatives' health. Therefore, health practitioners might find conversations around the knowledge of health history a gateway for exploring previous trauma and ongoing mental health. Minimal knowledge of the health of relatives may lead to a noticeable gap in health history; while the gap indicates the absence of information, it also indicates the presence of an entryway to explore wider life experiences. This finding should be applicable to health promotion of other refugee groups experiencing multiple relocations amidst broader civil unrest.

Bidirectional Relationships: Mental Health and Diabetes

While three participants noted the role of genetics in the development of diabetes, none of them proposed it as the only cause of diabetes. There was a clear theme that compromised mental health was a contributing factor in the development of diabetes. Schoenberg et al. (2005) list anthropological studies in which participants of varying ethnicities link diabetes onset with wider emotional life circumstances (i.e. Garro 1995; Hunt et al., 1998; Poss and Jezewski, 2002; Weller et al., 1999). Mercado-Martinez and

Ramos-Herrera, (2002, 797) also found that those with diabetes often attribute the onset of the disease to anger, rage, or emotional upset. In the current study, stress was not seen as a singular cause of diabetes, but it was noted as a contributor. Similar to the findings of Schoenberg et al. (2005), diabetes was integrated into the wider social situation whereby blood glucose and diabetes serve as measures of stress, and stress level serves as a measure of diabetes management. Alba Garcia and colleagues also found that emotional problems were associated with poorly controlled diabetes in a Mexican sample, while fewer economic problems were reported among those with well controlled diabetes, suggesting the variety of interacting factors that need to be considered when developing, implementing, and evaluating diabetes management interventions (Alba Garcia et al., 2007). As emphasized by Ducat, Philipson, and Anderson (2014), roughly one-third of patients with diabetes and mental health comorbidity receive treatment, therefore, health professionals must recognize and address the bidirectional nature of mental health and diabetes, particularly for those with limited resources, education, and social supports. As social isolation is a predictor of increased morbidity and mortality (Grant, Hamer, and Steptoe, 2009; Nicholson, 2012; Norman et al., 2013), older refugees with current life stressors – including the isolation of aging and the generational chasm with younger relatives embedded in American culture (Watkins 2009) – coupled with past trauma are particularly in need of assessment and referral.

While irritability is cited in the biomedical literature, anger is a symptom that diabetes interventions do not tend to explicitly address. The fact that the current sample recognized this symptom hints at its significance in their daily lives and the need for a holistic understanding of the experience of diabetes. This is in alignment with Rock's (2003, p. 149) finding that "classic symptoms of diabetes…overlap with the symptoms of …psychiatric disorders", demanding a holistic approach to managing health for Cambodian Americans with diabetes. Health practitioners may find the alleviation of symptoms through

addressing patients' particular stressors (Kleinman and Benson, 2006).

Nutrition and Alternative Therapies

The use of alternative therapies and the interpretation of medicinal efficacy warrant patient-practitioner elaboration. Some studies report the beneficial effects of alternative therapies in managing diabetes. In a small scale animal study, Noni juice given in conjunction with insulin improved fasting glucose levels better than either alone (Horsfall et al., 2008). Noni tea is one of the remedies marketed as "for diabetics" within Asian markets. Interestingly, the National Cambodian American Diabetes Project noted that increasing energy was a perceived mechanism of traditional remedies (National Cambodian American Diabetes Project, 2006). Shimada and colleagues (1995) found that the perceived effect of medication on energy or internal strength led to noncompliance among Cambodian patients. Health practitioners should consider that since a symptom of diabetes is fatigue, perceptions of a treatment's impact on energy may alter usage. Yet, challenges that health professionals face in understanding perspectives on traditional medicine outside the formal health care sector include: 1.) that it may be used for general health (versus as a specific treatment to lower blood glucose) so patients do not consider it relevant in discussions of diabetes, 2.) perceptions of traditional medicine as stigmatizing or provincial, 3.) and also lack of trust between patient and health practitioner. However, the knowledge of and use of traditional medicine and biomedicine speak to persisting ways of seeking health.

Similar to any cultural domain, the themes presented here do not have universal acceptance by Cambodian Americans. Individual beliefs vary, but there are some shared themes in Cambodian American explanatory models of diabetes. Ninety percent of the sample has been in the US for over 20 years. Beliefs and experiences from the United States have melded with those in Cambodia. The explanatory models of diabetes conveyed by this sample suggest some variations on the general biomedical model of diabetes. Embedded throughout the narratives is the

complex interaction of diabetes and stress. Diabetes may be caused by stress, challenging to manage because of stress, and also used to convey stress.

Diabetes as Idiom of Distress

In contrast to the findings of Pitaloka and Hsieh (2015, p. 1157) among Javanese women with diabetes, those interviewed for this study clearly drew on diabetes as a cause of their ill health. As one 47-year-old female with diabetes explained, "Some days I just get so tired, exhausted and all the time…I feel sleepy and I don't want to get up [and] do anything." Diabetes was the lens through which other social problems and experiences were framed.

Findings from this study provide insight into the life and health experiences of an underrepresented population in both the medical and social science literature. This study provides another perspective on the lived experience of diabetes, elucidating the ways in which diabetes impacts and is impacted by the wider sociocultural environment. It also demonstrates the complexity of addressing diabetes within not only this population specifically, but also in the general population. Building on the cross-cultural work of Schoenberg et al. (2005), this study adds another group to support that stress and diabetes warrant joint consideration in health care. This study also demonstrates the need for a wider understanding of diabetes embedded in living with inequality. The complexity of diabetes and inequality was raised about 30 years ago by Scheder (1988), but has still not been fully explored (personal communication, January 9, 2009). In alignment with the work of Rock (2003), this study calls for an understanding of the ways in which distress and diabetes are intimately intertwined.

White and Marsella (1982) suggest that a particular diagnosis or illness may be utilized as a venue for expressing general suffering. Chung and Singer (1995) emphasize that Southeast Asians tend to report distress in a less direct, more socially acceptable manner, combining somatic and psychological distress. Building on the finding of Chung and Singer (1995), some interview participants in the current study clearly used diabetes to express distressing life situations.

While explanatory models of diabetes were explicitly sought in interviews, diabetes as idiom of distress was implicitly communicated by participants. Findings from this study suggest that diabetes may serve as one way of expressing distress for Cambodian Americans. Although diabetes is a physiologically real, metabolic disorder, it can be co-opted as an "idiom of distress". Previous discussions of this manner of communicating angst intertwined with health tend to focus on psychosomatic symptoms as a means of expressing ethnopsychiatric concerns (Nichter, 1981). Somatic idioms of distress "refer to the ways in which visceral responses to distress communicate angst to significant others" (Nichter, 2008, 166). This method of communication integrates health problems with additional individual and social problems (Kirmayer and Sartorius, 2007). "Idioms of distress are socially and culturally resonant means of experiencing and expressing distress in local worlds" (Nichter, 2010). To some degree, the concept of "idioms of distress" has focused on the expression of stress or trauma-related phenomena, avoiding medicalization. Diabetes is a concern that many Cambodian Americans experience as they age. However, some take the experience of diabetes and use it as a vehicle to obtain health care and to express broader suffering. Some Cambodians use diabetes as an idiom of distress. In this context, it is meant that Cambodians take a biomedically salient disease – in comparison to a "culturally" salient syndrome such as ataque de nervios (Schechter, 2015) – and use it as a means through which to express distress with the larger social environment and life experiences. In this way, diabetes is used as a way to bridge cultural divides.

The co-opting of diabetes as a biomedically appropriate idiom of distress serves multiple purposes. First, diabetes serves as a vehicle for obtaining more consistent health care. Many Cambodians do not go to the doctor without a specific health concern and, without a specific health concern, they may not be able to actually obtain medical assistance. Without diabetes, their concerns may be of lesser priority to overworked community based workers who serve as interpreters or would be overlooked in

the American health care system with no specific category for diagnosis or reimbursement. Second, diabetes serves as a vehicle for expressing other symptoms and receiving relief from them. Overlapping symptoms may be couched in a way that is treatable by the American health care system. Next, diabetes serves as a vehicle for expressing the effects of past trauma, which might be under-recognized by the health care system. Additionally, diabetes also serves as a means of garnering social support and expressing current life stresses. Cambodian Americans may co-opt diabetes as an idiom of distress, explaining their larger life experiences and suffering in a language they hope others will understand; few can truly relate to the horrors of the Khmer Rouge era or the layered stresses of refugee camps, immigration, and resettlement. The use of a biomedical disease as an idiom of distress is one way in which a resilient population may seek to promote health and survival.

Limitations and Areas for Future Research

There are limitations to the research. First, while explanatory models are embedded in the minds of those participating in a particular culture, future research targeting those diagnosed with diabetes with follow-up questions around what they see as the cause of their diabetes in particular, their personal diabetes care, and the use of the American health care system could help to provide additional pragmatic recommendations for ways in which to strengthen health and health care interactions (Mercado-Martinez and Ramos-Herrera, 2002). Follow-up quantitative research could help to hone in on the shared cultural patterns of beliefs and practices around diabetes, teasing out idiosyncratic perspectives. Furthermore, future research should also consider measures of social isolation as those who are more socially isolated might not be aware of their diabetes status or may have specific challenges to diabetes management (Gomersall, Madill, and Summers, 2011). Research specifically targeting the conditions under which diabetes is used as an idiom of distress is also warranted for promoting the health and well-being of those with diabetes. With civil unrest scattered throughout the world

and particularly in light of the immigration crisis in Europe, knowledge of how to strengthen the long-term health of refugees is perennially relevant. While the specific stressors may change, the experiences of Cambodian Americans can serve as a harbinger of future challenges for those facing past trauma and current structural disadvantage.

CONCLUSION

While Cambodian Americans identify many aspects of the biomedical model of diabetes, they have life experiences in Cambodia and America that impact their risk for diabetes and their ability to manage it. Diabetes may be utilized as an idiom of distress outside of Cambodian American communities for other specific populations and also by a general aging population. Mendenhall and colleagues (2010) suggest that diabetes is both a product and expression of social suffering used by Mexican Americans. It is possible that while diabetes serves as an idiom of distress, the exact content of that message may differ by cultural group, reflecting common experiences and concerns and allowing the expression of suffering in a socially acceptable form. In everyday experience, physical, social, and mental well-being are not clearly differentiated. The interconnections between life experiences challenge the medical system to treat patients within a wider social milieu where health is defined, influenced, and interpreted. This is particularly relevant for treating diabetes where so much of the onus is placed upon those with diabetes to "self-manage" their care. As proposed by Kleinman and Benson (2006), explanatory models should start rather than end conversation between patient and health practitioner.

REFERENCES

ACS – American Community Survey. (2010). "2006-2010 Selected Populations Tables." United States Census Bureau. https://factfinder.census.gov/faces/nav/jsf/pages/searchresults.xhtml?refresh=t

Alba Garcia, J., Salcedo Rocha, A.L., Lopez, I., Baer, R.D., Dressler, W., & Weller, S.C. (2007). "Diabetes is my companion": Lifestyle and self-management among

good and poor control Mexican diabetic patients. *Social Science and Medicine,* 64, 2223 – 2235.

American Diabetes Association. (2016). "Statistics about Diabetes." www.diabetes.org.

Arcury, T.A., Skelly, A.H., Gesler, W.M., & Dougherty, M.C. (2005). Diabetes beliefs among low-income, white residents of a rural North Carolina community. *The Journal of Rural Health* 21(4), 337-345.

Baer, R.D., Weller, S.C., de Alba Garcia, J.G., & Salcedo Rocha, A.L. (2004). A comparison of community and physician explanatory models of AIDS in Mexico and the United States. *Medical Anthropology Quarterly,* 18(1), 3-22.

Balhara, Y.P.S. (2011). Diabetes and psychiatric disorders. *Indian Journal of Endocrinology and Metabolism,* 15(4), 274-283.

Bernard, H.R. (2006). *Research Methods in Anthropology: Qualitative and Quantitative Approaches.* 4th edition. New York, NY: AltaMira Press.

Braun, V. & Clarke V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology,* 3(2),77-101.

Cabassa, L.J, Siantz, E., Nicasio, A., Guarnaccia, P. & Lewis-Fernandez, R. (2014). Contextual factors in the health of people with serious mental illness. *Qualitative Health Research*, 24(8), 1126-1137.

Chandler, D.P. (1999). *Brother Number One: A Political Biography of Pol Pot*, revised edition. Boulder, CO: Westview Press.

Chung, R.C., & Singer, M.S. (1995). Interpretation of symptom presentation and distress: A Southeast Asian refugee example. *Journal of Nervous and Mental Disease,* 183(10), 639 – 648.

D'Andrade, R. & Strauss, C. (Eds.). (1992). *Human Motives and Cultural Models.* New York, NY: Cambridge University Press.

Daniulaityte, R. (2004). Making sense of diabetes: Cultural models, gender and individual adjustment to type 2 diabetes in a Mexican American community.

Social Science and Medicine, 59, 1899-1912.

Ducat, L., Philipson, L.H., & Anderson, B.J. (2014). The mental health comorbidities of diabetes. *Journal of the American Medical Association*, 312(7), 691-692.

Frye, B.A. & D'Avanzo, C. (1994). Themes in managing culturally defined illness in the Cambodian refugee family. *Journal of Community Health Nursing,* 11(2), 89-98.

Garro, L.C. (1995). Individual or societal responsibility? Explanations of diabetes in an Anishinaabe (Ojibway) community. *Social Science and Medicine,* 40(1), 37-46.

Gomersall, T., Madill, A., & Summers, L. (2011) A metasynthesis of the self-management of type 2 diabetes. *Qualitative Health Research* 21(6), 853-871.

Grant, N., Hamer, M., & Steptoe, A. (2009). Social isolation and stress-related cardiovascular, lipid, and cortisol responses. *Annals of Behavioral Medicine,* 37, 29-37.

Guest, G., Bunce, A. & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods,* 18(1), 59-82.

Guest, G., MacQueen, K., & Namey, E. (2011). *Applied Thematic Analysis.* Thousand Oaks, CA: Sage Publications.

Handwerker, W.E. (2001). *Quick Ethnography.* Walnut Creek, CA: AltaMira Press.

Hatcher, E. & Whittemore, R. (2007). Hispanic adults' beliefs about type 2 diabetes: Clinical implications. *Journal of the American Academy of Nurse Practitioners,* 19, 536-545.

Horsfall, A.U., Olabiyi, O., Aiyegbusi, A., Noronha, C.C., & Okanlawon, A.O. (2008). Morinda citrifolia fruit juice augments insulin action in Sprague-Dawley rats with experimentally induced diabetes. *Nigerian Quarterly Journal of Hospital Medicine,* 18(3), 162-165.

Kelly, S.J. & Ismail, M. (2015). Stress and type 2 diabetes: A review of how stress contributes to the development of type 2

diabetes. *Annual Review of Public Health,* 36, 441-462.

Kiernan, B. (2002). *The Pol Pot Regime: Race, Power, and Genocide in Cambodia under the Khmer Rouge, 1975-79,* second edition. New Haven, CT: Yale University Press.

Kinzie, J.D., Riley, C., McFarland, B., Hayes, M., Boehnlein, J., Leung, P., & Adams, G.

 (2008). High prevalence rates of diabetes and hypertension among refugee psychiatric patients. *Journal of Nervous and Mental Disease*, 196(2), 108-112.

Kirmayer, L.J. and N. Sartorius. (2007). Cultural models and somatic syndromes. *Psychosomatic Medicine,* 69(9), 832–840.

Kleinman, A. (1988). *Rethinking Psychiatry: From Cultural Category to Personal Experience.* New York, NY: Free Press.

Kleinman, A. & Benson, P. (2006). Anthropology in the clinic: The problem of cultural competency and how to fix it. *PLOS Medicine*, 3(10), e294.

Le, C.N. (2016). "Socioeconomic statistics & demographics." Asian-nation: The landscape of Asian America. http://www.asian-nation.org/demographics.shtml.

Mabbett, I. & Chandler, D. (1995). *The Khmers.* Cambridge, MA: Blackwell Publishers.

Marshall, G.N., Schell, T.L., Elliott, M.N., Berthold, S.M., & Chun, C. (2005). Mental health of Cambodian refugees 2 decades after resettlement in the United States. *Journal of the American Medical Association,* 294(5), 571-579.

Meetoo, D. & Meetoo, L. (2005). Explanatory models of diabetes among Asian and Caucasian participants. *British Journal of Nursing*, 14(3), 154-159.

Mendenhall, E., Seligman, R.A., Fernandez, A. & Jacobs, E.A. (2010). Speaking through diabetes: Rethinking the significance of lay discourses on diabetes. *Medical Anthropology Quarterly*, 24(2):220–239.

Mercado-Martinez, F. & Ramos-Herrera, I.M. (2002). Diabetes: The layperson's

theories of causality. *Qualitative Health Research*, 12(6), 792-806.

Mollica, R.F., Donelan, K. & Tor, S. (1993). The effect of trauma and confinement on functional health and mental health status of Cambodians living in Thailand-Cambodia border camps. *Journal of the American Medical Association*, 270(5), 581-586.

National Cambodian American Diabetes Project. (2006). Interim Progress Report. West Hartford, CT: Khmer Health Advocates.

National Cambodian American Health Initiative. (2007). Health Emergency in the Cambodian Community in the United States - Report. West Hartford, CT: Khmer Health Advocates.

Nicholson, N.R. (2012). A review of social isolation: An important but underassessed condition in older adults. *Journal of Primary Prevention,* 33, 137-152.

Nichter, M. (1981) Idioms of distress: Alternatives in the expression of psychosocial distress: A case study from South India. *Culture, Medicine, and Psychiatry,* 5(4), 379–408.

Nichter, M. (2008). Coming to our senses: Appreciating the sensorial in medical anthropology. *Transcultural Psychiatry*, 45(2), 163 – 197.

Nichter, M. (2010). Idioms of distress revisited. *Culture, Medicine, and Psychiatry* 34, 401 – 416.

Norman, G.J., Hawkley, L., Ball, A., Berntson, G.G., & Cacioppo, J.T. (2013). Perceived social isolation moderates the relationship between early childhood trauma and pulse pressure in older adults. *International Journal of Psychophysiology*, 88(3), 334-338.

Pais, J. (2014). Cumulative structural disadvantage and racial health disparities: The pathways of childhood socio-economic influence. *Demography,* 51, 1729 – 1753.

Rock, M. (2003). Sweet blood and social suffering: Rethinking cause-effect relationships in diabetes, distress, and duress. *Medical Anthropology*, 22, 131 –

174.

Romney, A., Batchelder, W., & Weller, S. (1986). Culture as consensus: A theory of culture and informant accuracy. *American Anthropologist,* 88, 313-338.

Schechter, D.S. (2015). "Ataque de nervios." *Encyclopedia of Immigrant Health*, 244-246.

Scheder, J.C. (1988). A sickly-sweet harvest: Farmworker diabetes and social inequality. *Medical Anthropology Quarterly,* 2(3), 251 – 277.

Schoenberg, N.E., Amey, C.H., & Coward, R.T. (1998). Stories of meaning: Lay perspectives on the origin and management of noninsulin dependent diabetes mellitus among older women in the United States. *Social Science and Medicine,* 47(12), 2113 – 2125.

Schoenberg, N.E., Drew, E.M., Stoller, E.P., & Kart, C.S. (2005). Situating stress: Lessons from lay discourses on diabetes. *Medical Anthropology Quarterly,* 19(2), 171 – 193.

Shawcross, W. (2002). *Sideshow: Kissinger, Nixon, and the Destruction of Cambodia*. New York, NY: Cooper Square Press.

Shimada, J., Jackson, J.C., Goldstein, E., & Buchwald, D. (1995). "Strong medicine": Cambodian views of medicine and medical compliance. *Journal of General Internal Medicine,* 10(7), 369-374.

Skelly, A.H., Dougherty, M.C., Gesler, W.M., Burns, D., & Arcury, T.A. (2006). African American beliefs about diabetes. *Western Journal of Nursing*

Research, 28(1), 9- 28.

Southeast Asia Resource Action Center. (2011). "Southeast Asian Americans at a Glance."http://www.searac.org/sites/def ault/files/STATISTICAL%20PROFILE % 202010.pdf.

Valenzuela, G.A., Mata, J.E., Mata, A.S., Gabali, C., Gaona, E., Thom, D., & LeBaron, S. (2003). Knowledge and beliefs regarding type 2 diabetes mellitus in rural Mexico. *Ethnicity and Health,* 8(4), 353-360.

Wagner, J., Berthold, S.M., Buckley, T., Kong, S., Kuoch, T., & Scully, M. (2015). Diabetes among refugee populations: What newly arriving refugees can learn from resettled Cambodians. *Current Diabetes Reports,* 15(8), 56.

Wagner, J., Burke, G., Kuoch, T., Scully, M., Armeli, S., & Rajan, T.V. (2013). Trauma, healthcare access, and health outcomes among Southeast Asian refugees in Connecticut. *Journal of Immigrant and Minority Health,* 15(6), 1065-1072.

Watkins, L. (2009). Beyond ethnicity as risk factor: Biocultural context and correlates of type 2 diabetes in a Cambodian American community. PhD dissertation, Anthropology Department, University of Connecticut.

White, G.M. & Marsella, A.J. (1982). *Cultural Conceptions of Mental Health and Therapy.* Pp.3-38. Boston, MA: D. Reidel Publishing Company.

World Health Organization. (2016). "Global Report on Diabetes." Geneva. www.who.int.