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Developing Culturally Sensitive Education in Hmong Americans with Diabetes

Fay Marcia Mitchell-Brown

A dissertation submitted to the faculty of the Medical University of South Carolina in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the College of Nursing

November, 2015

Approved by:

Lynne Nemeth, PhD, RN, FAAN, Chairman, Advisory Committee

Susan Newman, PhD, RN, CCRN

Kathleen Cartmell, PhD, MPH

Keiko Goto, PhD

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Acknowledgement

My desire to obtain a doctoral degree has been an arduous journey that I will never forget. When I enrolled in this doctoral program at the Medical University of South Carolina (MUSC), I was thirsty for personal growth and professional development. I felt that having a doctoral degree was critical to my career advancement in nursing education. Being a doctoral student was a major commitment and I have had to quickly learn how to balance work, family, and school commitments to make this a success. I would not have succeeded without the invaluable support of several people along the way.

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Abstract

Despite advances in medical care for diabetes, a diabetes health disparity exists among ethnic minorities. Diabetes is a new concept for Hmong Americans. Research has highlighted the high risk that Hmong Americans face of having this chronic disease. This dissertation is a compendium of three manuscripts related to diabetes care in the Hmong population. The first manuscript is a scoping review of the prevalence of diabetes and factors affecting diabetes care in the Hmong American population. Sustaining self-management is often difficult for people with diabetes. The second manuscript focuses on sustaining self-management behaviors using a theoretical model that describes strategies for multi-level interventions. The third manuscript is a qualitative grounded study that explores the diabetes education experience of a group of Hmong Americans living in Central California. Both an inductive and deductive method of analysis was applied to this study to identify themes in diabetes education experience. The information presented within this dissertation creates the foundation for future studies focusing on diabetes in the Hmong and implementing culturally appropriate education interventions to increase access to health care and thus, improve diabetes outcomes in Hmong Americans.

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Introduction

Diabetes is one of the most challenging chronic diseases to manage and poses a great threat to the overall health of the nation (Hu, 2011). An estimated 25.8 million people were diagnosed with diabetes in the United States (US) in 2010, which rose to 29.1 million in 2012 (Centers for Disease Control, 2014). People from ethnic minority groups have a higher prevalence of diabetes and bear a disproportionate burden of the disease (Peek, Cargill, & Huang, 2007). Asian Americans have 2-6 times higher prevalence of diabetes than non-Hispanic white Americans (McNeely & Boyko, 2005b; Whittemore, Melkus, & Grey, 2004). Hmong Americans, a subset of Asian Americans, are twenty times more likely to develop diabetes than the Hmong living in Thailand (Yang, Xiong, Vang, & Pharris, 2009a).

Diabetes is a chronic metabolic condition marked by hyperglycemia, it occurs when the pancreas fails to produce insulin (absolute or type 1) or when the pancreas secretes an inadequate amount of insulin with insulin resistance (relative or type 2) (Lewis, Dirksen, Heitkemper, Bucher, & Harding, 2014). If not adequately managed, diabetes can result in complications such as cardiomyopathy, nephropathy, neuropathy, and retinopathy, and thus, result in an increased morbidity and mortality for individuals with these disease (Lewis et al., 2014; Shrivastava, Shrivastava, & Ramasamy, 2013).

To significantly reduce the risk of developing long-term complications from diabetes, people with the disease must adhere to self-management activities such as healthy eating, medication compliance, physical activity, blood glucose monitoring, problem solving, healthy coping and appropriate screening exams for early detection of complications (American Association of Diabetic Educators, 2008). Based on evidence from large randomized trials, people who have pre-diabetes can achieve more than a 50% reduction over four years in the

incidence of type 2 diabetes by making relatively small lifestyle changes (Gillies et al., 2007; Lindstrom et al., 2013). Evidence has also shown that when practiced, self-management behaviors positively correlate with glycemic control, complication reduction, and improvement in quality of life (Kent et al., 2013; Qiu et al., 2014; Shrivastava et al., 2013). However, because diabetes self-management is multidimensional and may require considerable lifestyle changes, patients are often prone to non-adherence of self-management behaviors (Delamater, 2006). Thus, diabetes education is critical to promote self-management behaviors for all individuals with diabetes.

The American Diabetes Association (ADA) recommends that all patients with diabetes receive self-management education (Funnell et al., 2012). Because of the importance of diabetes education, the ADA and the American Association of Diabetes Educators have developed national standards for diabetes self-management education based on scientific evidence to assist in the delivery of quality diabetes education to all patients with diabetes (Funnell et al., 2009). Evidence supports that educational programs have demonstrated benefits in improving diabetes knowledge and self-management behaviors (Funnell et al., 2012; Hawthorne, Robles, Cannings-John, & Edwards, 2008; Khunti, Camosso-Stefinovic, Carey, Davies, & Stone, 2008). Despite the proven benefits of educational programs, only 56.8% of American adults aged 18 years and older with diagnosed diabetes participate in formal education, and the *Healthy People 2020* goal is to increase this proportion to 62.5% (Healthy People, 2015).

Beyond the low overall participation of individuals with diabetes in formal diabetes educational programs, existing diabetes programs are often designed for the mainstream community, thus making it more difficult to provide effective diabetes education for some subgroups of the population (Khunti et al., 2008). Ethnic minorities are less likely than others to

engage in diabetes self-management behaviors (Ricci-Cabello et al., 2014). According to the ADA (2015), Asian Americans are severely affected by diabetes and they do not receive a fair share of diabetes self-management education. When diabetes education is not provided to these patients, it can lead to complications of diabetes due to poor self-management.

The Hmong people living in the US face multiple barriers to health education, which are related to factors such as language, culture, socio-economics, and a western medical system (Cobb, 2010; Smalkoski, Herther, & Xiong, 2010). These barriers can pose significant problems in achieving effective diabetes self-management behaviors in ethnic minorities (Ricci-Cabello et al., 2014) This dissertation study is warranted because Hmong Americans encounter multiple health care and learning barriers plus there are numerous gaps in research of this population.

The first gap in the literature is the lack of representation of Hmong Americans in national studies, despite their increased risk for developing diabetes (Smalkoski et al., 2010). Thao and colleagues (2015) conducted a study to compare the prevalence of diabetes between Hmong and non-Hispanic white patients in Wisconsin. The prevalence of diabetes in Hmong adult patients was 19.1% compared to 7.8% in white adults (Thao, Arndt, Tandias, & Hanrahan, 2015). The prevalence of Hmong patients was 3.3 times higher than its non-Hispanic white counterpart. The result of this study is consistent with previous findings of significantly increased diabetes risk in the Hmong of Wisconsin (Thao et al., 2015). Another prevalence study of adult Hmong Americans, conducted by Her and Mundt (2005), reported that of the 144 participants, 41% had glucose ≥ 140 mg/dl, 42 % had a waist to hip ratio of ≥ 0.9 , 51% had body mass index (BMI) ≥ 27 , 51% of those less than 65 years of age were engaged in little or no exercise, and all participants had positive risk factors for diabetes. Wu and colleagues (2011) also found that of the four Asian groups studied that included Chinese, Filipino, Hmong and

Vietnamese, Hmong Americans had the highest BMI, were most likely to have glycemic index >126mg/dl, and were most likely to report a diagnosis of diabetes. While Hmong Americans have been a focus of several small studies carried out by individual researchers, they are not represented in large national studies.

The second gap in the literature is that no studies were identified that reported on diabetes education in Hmong Americans. A comprehensive literature search revealed a total of ten studies addressing diabetes in Hmong Americans, but none of these studies focused on diabetes education. The ADA's 2014-2015 strategic plan is to promote health equity with increased diabetes research, treatment and education in minority populations (American Diabetes Association, 2015). Given the positive correlation between diabetes education and self-management behaviors and in fulfilling the premise of the ADA's (2014-2015) strategic plan, there is a dire need for research that examines diabetes education in Hmong Americans. As Hmong Americans are a unique cultural group, it is important to consider their background, lifestyle, and cultural preferences when providing diabetes education. Thus, this research offers an opportunity to identify appropriate targets for culturally-tailored educational approaches for Hmong Americans with diabetes.

The third apparent gap in the literature is the absence of a theoretical framework for guiding prior research conducted in the Hmong with diabetes. Although theories and theoretical frameworks are not always used to guide studies, they serve a very important function. A theory provides a conceptual way of understanding events or behaviors and explaining the relationships among themes or variables (Glanz & Bishop, 2010). Theoretical frameworks provide researchers with an organized guide in which to place the findings of research within a scientific context (Glanz & Bishop, 2010). Of the ten studies of diabetes in Hmong Americans, only one study

(Yang et al, 2009) applied a theory, *Margaret Newman's Theory of Health as an Expanding Consciousness* to inform their research.

This qualitative dissertation utilized an analytic model that incorporates both an inductive and deductive approach to identify themes in Hmong Americans' explanations of diabetes as an illness and their experience with diabetes education. Grounded theory (Glasser & Strauss, 1967) is a methodological approach that was used inductively to analyze the data. Grounded theory is used to help the researcher understand the meaning of concepts from the perspective of the research participants and link the concepts together to generate a theory (Dastjerdi, Olson, & Ogilvie, 2012). In applying GT to this study, the researcher identified concepts, events, situations, and categories that emerged from the interaction of the researcher and the participants to develop a substantive grounded theory (Dastjerdi et al., 2012). The deductive approach is described in the theoretical framework that follows.

Theoretical Framework

The Framework for the Study of Access to Medical Care (Aday & Andersen, 1974) was used to deductively analyze data in this qualitative dissertation. Diabetes education in the health care system where a Hmong person obtains health care is an access to medical care issue. Health care utilization studies have frequently used the Framework for the Study of Access to Medical Care (FSAMC) developed by Andersen and Aday in 1974 (See Figure 1), which is a modification of the Behavioral Model of Health Services Use (Andersen, 1995). Using the FSAMC, the concept of access to medical care is integrated into a framework which views health policy as a means to affect the characteristics of the health care delivery system and the population at risk (Aday & Andersen, 1974). These policy related factors bring about changes in the utilization of health care services and in the satisfaction of consumers with the services.

The five interrelated variables in the FSAMC (depicted in Figure 1) are health policy, characteristics of the health care delivery system, characteristics of populations at risk, access to health services and consumer satisfaction (Aday & Andersen, 1974). In applying the FSAMC to this study, the constructs analyzed were the health care delivery system, the characteristics of the population, the type of health service utilized and consumer satisfaction.

By using a deductive analytic approach, themes were first identified that emerged from the health care experience of the Hmong. From this, the researcher determined how the collected data informed the FSAMC that addresses access to health care. Immigrants sometimes face challenges in accessing health care services and this can have significant implications for diabetes education (Dastjerdi et al., 2012).

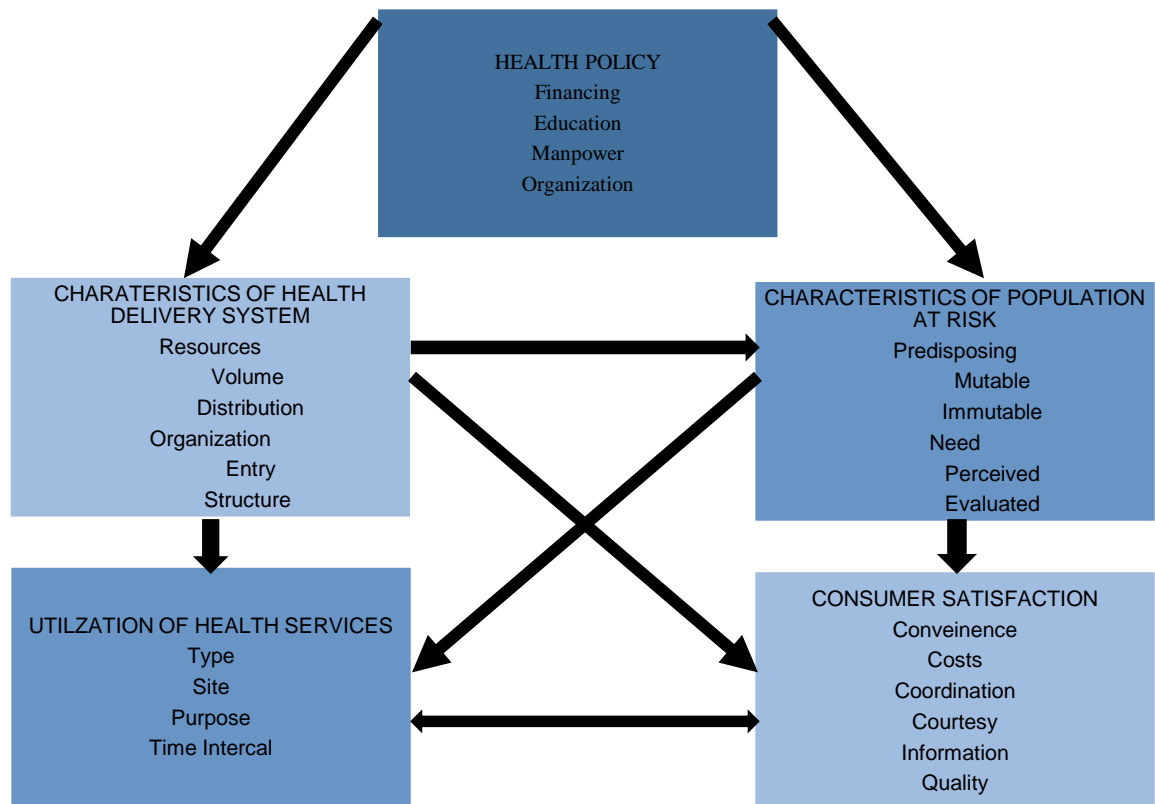


Figure 1. Framework for the study of access (Aday & Andersen, 1974)

Innovation

Living in the US, Hmong Americans encounter challenges related to language, literacy and culture (Pfeifer & Thao, 2013). These challenges can affect optimal diabetes self-management among the Hmong that presumably leads to health disparities in diabetes care. There is no research evidence that addresses diabetes education in the Hmong population. To fill the gap in evidence, this proposal offers an opportunity to gather in-depth information from an understudied, culturally unique population. Data collected in this study can support future development of culturally appropriate diabetes education for Hmong Americans.

Overview

This dissertation consists of three manuscripts, which includes: (1) a literature review of the prevalence of diabetes and factors affecting diabetes care in Hmong Americans with diabetes, (2) applying the social ecological model to present the components for sustaining self-management behaviors in people with diabetes mellitus, and (3) a qualitative study of Hmong immigrants experience with diabetes education in the United States.

Manuscript 1

Aim 1: To synthesize the findings of the prevalence and factors affecting diabetes care in Hmong Americans using the scoping literature review methodology described by Arksey and O'Malley (2005).

The first manuscript is a comprehensive review of the literature on diabetes in the Hmong American population. The research question that guided this review is, “What is known from the existing literature about the prevalence of diabetes and factors affecting diabetes care in the Hmong American population?” Because there is an increased prevalence of diabetes in Hmong

Americans, it is important to summarize the existing diabetes research conducted with this group. A literature review was conducted using the scoping review methodology (Arksey and O'Malley, 2005) to synthesize the prevalence of diabetes and factors affecting diabetes care in Hmong Americans.

Manuscript 2

Aim 2: Describe the application of McLeroy et al., (1988) social ecological model to sustain self-management behaviors in diabetes care.

The second manuscript applied a theory-based model, the social ecological model (SEM) to promote self-management behaviors in people with diabetes (Mitchell-Brown, 2014). Given the significance of proper self-management behaviors to diabetes outcomes and the high risk for non-adherence to these behaviors, this manuscript can help to fill this gap by providing all people living with diabetes appropriate interventions that may increase compliance, thus improving their quality of life. Using the SEM, multiple levels of intervention are described that are relevant to sustaining effective behavioral change for diabetes self-management. In using the SEM, five nested levels of influence are applied to support behavior change: the intrapersonal, interpersonal, organization, community and public (McLeroy, Bibeau, Steckler, & Glanz, 1988).

Manuscript 3

Aim 3: To identify knowledge, perceptions, and practices related to diabetes among Hmong Americans through focus group interviews, in order to determine essential components for developing culturally sensitive diabetic education.

Aim 4: To explore perceived barriers and facilitators encountered with diabetes education, preferred sources, channels, and formats for diabetes education using a grounded theory qualitative study.

The third manuscript is a qualitative study (Study ID Pro00039320) which used focus group interviews to study the diabetes education experience of Hmong Americans between the ages of 18 to 70 who were residents of Fresno, California. Access into the Hmong community is very difficult for a non-Hmong researcher because of a language barrier and mistrust towards “outsiders” (Devlin, Roberts, Okaya, & Xiong, 2006). To facilitate research with this population, the principal investigator worked closely with a Hmong community partner in Fresno, CA to gain access into the Hmong community and to develop trust as an “outsider.”

To date, there is no study that was identified that examines diabetes education in Hmong Americans, and so this manuscript will help to address this gap in the scientific evidence. Factors were identified that can assist Hmong Americans to improve self-management of diabetes through culturally appropriate diabetes education and uncover unique issues that may impede effective diabetes self-management to improve diabetes outcomes in Hmong Americans.

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Manuscript 1

A Scoping review of the Hmong with Diabetes

Mitchell-Brown, F. & Newman, S. (2015). A Scoping Review of the Hmong with Diabetes. California Journal of Health Promotion. Under Review. Acceptance pending.

Abstract

BACKGROUND: Upon immigration to the United States, the Hmong people, experience a transition from an agrarian society to a more industrialized society, which places them at an increased risk for diabetes. Hmong Americans are at high risk for developing diabetes and evidence suggests that diabetes is on the rise in this population.

PURPOSE: The purpose of this paper is to conduct a scoping review of the research literature on the prevalence of diabetes and factors affecting diabetes care in the Hmong population

METHOD: The literature was systematically scoped using four databases to search for studies examining factors that influence diabetes care in the Hmong

RESULT: The empirical evidence of diabetes in the Hmong Americans is limited. A total of ten studies were retrieved. Key findings suggest that those living with diabetes have limited knowledge of the disease. Findings in this review also suggest that Hmong Americans have knowledge deficits about diabetes, there are significant cultural characteristics of the Hmong that affect diabetes care, and there are some barriers to diabetes care in this population.

CONCLUSION: The key finding from this literature review was that self-management of diabetes is inadequate among Hmong Americans. Additional research is warranted to identify and test effective strategies for diabetes education in this population.

IMPLICATION: Language, religion, and cultural beliefs are significant factors to consider in diabetes care of the Hmong.

Key words: Scoping review, scoping study, Hmong, diabetes mellitus

Introduction

In 2012, an estimated 29.1 million people in the United States (US) were living with diabetes, which represents an increase of 3.3 million people living with the disease since 2010 (American Diabetes Association, 2014, a). Of the 29.1 million, 21.0 million were diagnosed and 8.1 million were undiagnosed (American Diabetes Association, 2014, a). Asian Americans are at a particular high risk for diabetes, with 60% adjusted prevalence when compared to non-Hispanic White Americans (McNeely & Boyko, 2005a; Whittemore et al., 2004). Hmong Americans who are an Asian population are very vulnerable to developing diabetes and have little representation in empirical studies (Candib, 2008). There is no nationally representative quantitative data on the prevalence of diabetes in Hmong Americans, but anecdotal evidence suggests that diabetes is on the rise in Hmong living in the United States (US). Hmong Americans are twenty times more likely to develop diabetes than the Hmong living in Thailand (Her & Mundt, 2005).

The Hmong culture originated in China, but, because of persecution, they were forced to migrate southward (Littman, Kristal, & White, 2005). During many years of persecution in China, the Hmong language was lost, and it was not until the 1950's that Christian missionaries designed a Hmong writing system (Pao Lee & Pfeifer, 2006). Hmong Americans are a unique ethnic minority group that has suffered from war and displacement. During the Vietnam War, Hmong were recruited to help the US soldiers fight (Christian, Low Moua, & Vogeler, 2008-2009). After the war, the government in Laos sought to annihilate the Hmong. Many were killed; the remaining Hmong fled and sought refuge in Thailand where they lived in refugee camps (Culhane-Pera et al., 2003). From refugee camps, the Hmong then migrated to Western

countries, and the US received the first wave of immigration in the late 1970's (Christian et al., 2008-2009).

Approximately 260, 000 Hmong live in the US with the greatest concentrations in California, Minnesota, and Wisconsin (Pfeifer & Thao, 2013). In the US, the Hmong are vulnerable to diabetes due to high poverty rates, high rates of unemployment, low educational attainment, and a language barrier (Pfeifer & Thao, 2013). Cultural differences, linguistic isolation and economic challenges create barriers for the Hmong in accessing the complex medical systems in the US. The religion of shamanism has its traditional role in the Hmong culture (Culhane-Pera et al., 2003). In shamanism, there is the belief that illness is associated with a spiritual problem. Approximately 70% of Hmong in the US follow this traditional religion (Pao Lee & Pfeifer, 2006). In addition to shamanism, many Hmong also use herbs to treat disease. Living in the US, the Hmong do not readily seek western medical care and often do so only as last resort (Her, 2012).

To improve diabetes care for the Hmong, health care providers must recognize that Hmong have a distinct culture that brings challenges to western health care. Every effort should be made to develop and provide culturally appropriate care in Hmong Americans to improve health outcomes. Aside from good health outcomes, culturally appropriate care can increase trust, communication, and adherence to treatment regimen in people with diabetes (Caballero, 2007). The purpose of this paper is to conduct a scoping review of the research literature on diabetes in the Hmong population. Guiding this scoping review is the following research question: "What is known from the existing literature about the prevalence of diabetes and factors affecting diabetes care in the Hmong American population?"

Methods

This scoping review explored current research literature to identify the extent, range, and nature of diabetes in adult Hmong Americans. This was done by locating articles, extracting relevant data to answer the guiding question, and organizing the data in a table format. This scoping review of diabetes in the Hmong population is a stand-alone project; the main objective is to: (a) identify and summarize the nature of research findings in regards to diabetes in adult Hmong Americans. By carrying out this research, it can be used to summarize and disseminate research findings, identify the gaps in the existing literature, and inform the need for future research activity from knowledge yielded.

A scoping study is a systematic approach to reviewing literature that serves to quickly identify the extent, range, and nature of research activity on a topic, thus providing a better understanding of the current state of knowledge and clarity of the evidence (Arksey & O'Malley, 2005; Davis, Drey, & Gould, 2009). This method of review provides an efficient way to identify as much evidence rapidly and to map key concepts underlying a research area. A scoping review usually aims for greater breadth; this necessitates having a broader research aim (Chambers et al., 2013). The inclusion/exclusion criteria can be developed post hoc, and, in the initial phase of the review, assessment of quality is not a priority. Data may or may not be extracted. A scoping review also identifies gaps in the literature. Studies are summarized to identify the impact on research, practice, and policy.

This scoping review followed the method as outlined by Arksey and O'Malley (2005). Steps of this process include the following: identifying the research question, identifying pertinent articles, study selection, charting the data, and collating, summarizing, and reporting the results.

Eligibility Criteria

This literature review included studies published since 2004 because of the limited research done in Hmong Americans with diabetes. The eligibility criteria included studies addressing adult Hmong living in the US with diabetes mellitus. Additionally, studies that included Hmong as a study population and provided some level of analysis that resulted in data specific to the Hmong population were also included. Adults were defined as 18 years and older. The author decided to use the broad term, *diabetes mellitus*, because there was a suspicion that there were limited studies conducted on the Hmong with diabetes mellitus. Gestational diabetes was, however, an exclusion criterion. Only articles published in English were used.

Search Strategies and Study Selection

The search was conducted in August 2013, January 2014 and again in October 2015 by the first author to yield relevant articles about diabetes in Hmong Americans. The electronic search was conducted using four databases: CINAHL, PubMed, psycINFO, and Google Scholar. These databases included articles relevant to medical/health science, psychology and social science. The search strategy included the following key word search: *diabetes, sweet blood, ntshav qab zib/ nsthaav qab zib (Hmong translation for diabetes), chronic illness, and diabetes mellitus*. These search terms were combined with *Hmong* and *Hmong Americans*. Although the author was interested in English only articles, no articles in a foreign language were found. All studies selected were published in peer-reviewed journals.

Review

All studies that included the targeted search terms were reviewed by the first author. The abstract was initially reviewed to decide if the study met the eligibility criteria. Articles that did

not meet the inclusion criteria were removed along with duplicates that were identified. If there was uncertainty about inclusion/exclusion criteria the article was reviewed in its entirety by the first author. If the article met the inclusion criteria it went to the data extraction stage. Records identified were stored in End Note X7.

Data Extraction

The first author read each study in its entirety and extracted and organized relevant data using a table. The extracted data included the author(s) and date of publication, where the study was conducted, study purpose/research question, sample size, sample description, sample setting, study design, data collection methods, and results along with a comment column.

Result

The initial literature search yielded 3316 studies. Studies were excluded on the basis of title and keyword for review and not meeting the inclusion exclusion criteria. Duplicate articles also were removed; this reduced the total number of articles to 15. After abstract review, articles were further eliminated. A total of 10 articles appropriately met the inclusion criteria and were included for this review. Figure 1 represents the search strategy and number of articles found.

Sample and Subjects

The sample sizes of the studies ranged from 5-144 participants. Of the 10 articles, seven reported on qualitative studies and three reported on quantitative studies (See Table 1). Examination of the demographic information revealed that there were more female participants across all 10 studies. Two studies (Culhane-Pera, Her, & Her, 2007; Perez & Cha, 2007)

reported the English proficiency and education level of participants. Of 39 participants in one study, 90% had none or poor English proficiency and 56% had no form of education (Culhane-Pera et al., 2007). Perez and Cha (20) reported that of the 33 participants in their study, 76% did not understand English and only 3% has completed high school and college.

Analysis of the seven qualitative studies resulted in the generation of themes from data extracted across studies. Key themes identified in all of the qualitative studies were that Hmong Americans living with diabetes have a knowledge deficit about this chronic illness, and that cultural differences such as shamanism and the use of medicinal herbs, significantly influence their care (Culhane-Pera et al., 2007; Devlin et al., 2006; Helsel, Mochel, & Bauer, 2005; Perez & Cha, 2007; Perez & Thao, 2009; Xiong & Westberg, 2012). Additional themes identified across these studies include sense of loss, mistrust, and barriers to care. Results are organized and presented by themes in the following sections: knowledge deficits, cultural characteristics, sense of loss, mistrust, barriers to care, and risk factors for diabetes in Hmong Americans.

Knowledge Deficits

The studies revealed that the Hmong have inadequate knowledge about diabetes along with misunderstandings and misconceptions about the disease (Culhane-Pera et al., 2007; Helsel et al., 2005; Perez & Cha, 2007; Xiong & Westberg, 2012; Yang et al., 2009a). This review reveals that the majority of Hmong participants could not verbalize the meaning of diabetes, some had no knowledge of the disease (Helsel et al., 2005; Perez & Cha, 2007; Xiong & Westberg, 2012), and some participants even expressed confusion as to when to take their medications (Helsel et al., 2005). Xiong and Westberg (2012) found that participants were reluctant to adhere to medical treatment and to change their cultural diet. The study results also

revealed that the Hmong have misunderstandings about the cause of diabetes. Some participants believed that they developed diabetes due to their refugees status and living in refugee camps in Thailand (Culhane-Pera et al., 2007; Helsel et al., 2005), and others believed that fertilizers and chemicals cause their diabetes (Culhane-Pera et al., 2007; Devlin et al., 2006; Yang et al., 2009a). Although some participants acknowledged that diabetes is an illness for which that they would typically not seek spiritual medicines (Devlin et al., 2006; Helsel et al., 2005), others acknowledged the use of herbs to treat their diabetes (Perez & Cha, 2007).

Cultural Characteristics

Shamanism. Central to the Hmong culture is shamanism (Pinzon-Perez, Moua, & Perez, 2005). When confronted with an illness, the Hmong are more likely to see a shaman first before a medical doctor (Kalantari, 2012). Pinzon-Perez and colleagues (2005) reported that in a study with 115 participants, 49% saw a physician when they became ill as opposed to 54% who consulted with a shaman or traditional healer. Fifty four percent of participants were very satisfied with the services received from the shaman (Pinzon-Perez et al., 2005). Shamanism involves interaction with a spiritual healer (shaman) who undergoes various levels of consciousness to interact with the evil spirits that cause illnesses (Castillo, 2014). In shamanism, illness is not treated as it would be in the Western world; rather, the shamanic role becomes very important during this time. The shaman heals the sick by negotiation with the demons that cause illnesses. Shamanic ceremonies are private and held in the shaman's home and they can include drums, chanting, and ritual killing of animals (Castillo, 2014).

Generally, the Hmong trust shamans. Perez and Cha (2007), reported that 94% of participants identified shamanism as their religion. Helsel, Mochel and Bauer (2005) sought to

study Hmong shamans' understanding of the nature, effects, and management of a chronic illness. Of the 11 participants, six were being treated for non-insulin dependent diabetes, three for hypertension and two for hypertension and diabetes. The study reported that Hmong shamans do not have adequate understanding of chronic illnesses and the potential complications. Because of their limited understanding of factors affecting the management of diabetes, shamans did not always deliver evidence-based dietary and medical regimens.

Use of Medicinal Herbs. Common to the Hmong culture is the use of herbal medicine. Herbs and herbal experts are a common sight at Hmong festivals, such as the Hmong New Year. Hmong all over the world use modern biomedicine, medicinal herbs, and some shamanic rituals to ensure good health (Cha, 2010). In keeping cultural values, Hmong patients with diabetes might take herbal medicines for treatment. Helsel et al., (2005) reported that 9 out of 11 participants in their study were taking herbs. Perez and Cha (2007) reported that the majority of the participants (n=33) in their study used traditional herbal medicine to treat diabetes mellitus, and Culhane-Pera et al., (2007) reported that participants in their study felt that Hmong herbs is fitting for Hmong people and all participants (n=39) had tried herbal medicine.

Patriarchal Society. Another important cultural component is that the Hmong are a patriarchal group of people; men make important decisions (Cha, 2010). Sons are very vital to the family because they carry on the clan name and they are expected to take care of their elderly parents. When confronted with illness, it is natural that the Hmong might seek advice from a male family member or a male clan leader. Collectiveness and family based decision making is very common in the Hmong culture As a result, decisions are made for the good of the family and not solely the individual (Cha, 2010).

Sense of Loss

A sense of loss is defined as the deprivation of culture, traditions, language, and healthy habits experienced by immigrants living in America. The study by Devlin and colleagues (2006) included 12 focus groups, with 4 different ethnic groups: African Americans (n=20), American Indians (n=23), Hispanic/Latino (n=24) and Hmong Americans (n=13). This study explored the health related beliefs of all four groups. The Hmong participants expressed that the American lifestyle contributes to a loss of health, and a loss of the value of spirituality. The Hmong participants stated that “In Laos, we could work and sweat; we had places to be active, and we could eat anything” (Devlin et al., 2006, p. 50). A sense of loss was expressed in terms of homeland, lifestyle, and language (Culhane-Pera et al., 2007; Devlin et al., 2006; Yang et al., 2009a) With this loss, is a sense of “not fitting in,” in the US in several ways, such as food, activity, weather, and community (Culhane-Pera et al., 2007, p. 182).

Mistrust

Respondents reported a lack of confidence and dissatisfaction with health care providers and mistrust in the medical system in the US (Devlin et al., 2006). A few participants believed that there are medicines to cure diabetes but these are not made available to them (Xiong & Westberg, 2012). Some participants even believed that Western providers prescribed too many medicines (Yang et al., 2009a).

Barriers to Care

Perez and Thao (2009) used photo voice to document barriers in diabetes care of the Hmong (n=10) in Fresno, California. Some of the barriers identified by the participants were lack of opportunities for physical activity, personal choices, habits, lifestyle, unsafe

neighborhoods, unhealthy snacks, and easy access to vending machines (Perez & Thao, 2009), all factors that can contribute to an unhealthy weight. Another barrier identified was language difficulty (Culhane-Pera et al., 2007; Perez & Cha, 2007; Yang et al., 2009a).

Risk Factors for Diabetes in Hmong Americans

Thao and colleagues (2015) compared the prevalence of diabetes between Hmong and non-Hispanic white patients from the family medicine, pediatrics, and internal medicine clinics in Wisconsin. Multivariate logistic regression was used to control for the differences in age, sex, body mass index, and health insurance between the two populations (Thao et al., 2015). The total prevalence of diabetes in the Hmong patient population was 11.3% compared to 6.0% in the non-Hispanic white patient population ($P < 0.001$). The prevalence of diabetes in Hmong adult patients was 19.1% compared to 7.8% in white adult patients ($P = < 0.001$). Compared with non-Hispanic whites, the odds ratio (95% CI) for diabetes, adjusted for age, sex, BMI, and insurance was 3.3 (2.6-4.1) for Hmong patients. The adjusted relative odds of diabetes in this sample of Hmong patients is 3.3 times higher than its non-Hispanic white counterpart. The result of this study is consistent with previous findings of significantly increased diabetes risk in the Hmong of Wisconsin (Thao et al., 2015).

Using a community screening approach, Her and Mundt (2005) conducted a pilot study that sought to compute the risk of diabetes in Hmong adults living in Wisconsin. The two sampling sites were at a Hmong New Year festival (November, 2000) in Madison, WI and a community agency in Wausau, WI. The convenience sample ($n=144$) completed a survey that consisted of a demographic questionnaire along with the American Diabetes Association (ADA) risk test. Physical data included blood pressure, height, weight, waist circumference, hip

circumference and casual capillary blood glucose by reflectance meter. A positive screen was a casual capillary whole blood glucose ≥ 140 mg/dl, 41% of the sample was identified as having a positive blood glucose screen on the survey. Waist-to-hip ratio was also a strong predictor of a positive screen (Odds ratio=3.2, [CI=1.5, 6.2]) than the ADA risk test (Odds ratio=2.7, [CI=1.4, 5.1]). This study concluded that newly arrived adult Hmong in Wisconsin were at an increased risk for type 2 diabetes (Her & Mundt, 2005).

Diabetes Care Intervention

Culhane-Pera et al., (2005) conducted an experimental intervention in which Hmong (n=39) received diabetes care in the form of group visits in a community health center setting. Pre and post intervention measures included physical health, mental health and behavior (diet and exercise). Comparisons were made between the study participants and a control group. To determine if group visits improved diabetes management the groups were compared for changes in primary biological outcome (glycosylated hemoglobin A1C) and secondary biological outcomes (body mass index, blood pressure, low-density lipoprotein, and micro albumin/creatinine ratio). The control group consisted of Hmong with type 2 diabetes (T2DM) who declined to participate in the current study (n=22) and Hmong with T2DM from a local diabetes register (n=216) who were not participating in the study. To evaluate for improved outcome measures (primary and secondary biological, behavioral, and mental health outcomes) in the intervention group, a series of analyses pre and post intervention were conducted. The pre-post analysis was controlled, but there was no randomization. Thus, selection bias potentially affected the results of this study. Missing data were also identified; and this could have affected the power of some of the comparisons made. The study results showed no change in glycosylated hemoglobin A1C when computed as a categorical or continuous variable, but that mental health

status improved in the intervention group. There was decreased anxiety with an improvement in total anxiety depression scores. (Culhane-Pera et al., 2005).

Discussion

This scoping review was designed to evaluate the existing literature on the prevalence of diabetes and factors affecting diabetes care in the Hmong American population. One striking finding of this review is the lack of large national studies that include Hmong Americans, and thus, the lack of evidence regarding Hmong Americans with diabetes. The following discussion focuses on (a) reducing disparity, (b) diabetes global context, (c) culture, (d) culturally appropriate education, and, (e) lack of trust.

Reducing Disparity

Racial and ethnic minorities suffer a disproportionate burden of diabetes, with higher prevalence rates, poorer diabetes control, high rates of complications, and lower survival from chronic illness (Buckner-Brown et al., 2011; Peek et al., 2007). The prevalence of diabetes in Hmong Americans is high (Her & Mundt, 2005; Thao et al., 2015). This review confirms that there is little nationally representative data on Asians with diabetes. To reduce diabetes disparity in the Hmong population, practices and policies must be instituted that will improve the environment in which the Hmong live, work, and learn. For this reason, there is a dire need for more research focused on Hmong Americans with diabetes.

Diabetes Global Context

Risk factors for developing diabetes include being overweight. The Asian population has the fastest growing prevalence of overweight in children in the United States (Harrison et al.,

2005). The evidence suggests that Hmong refugees face an increased risk of being overweight, thus making them vulnerable to developing type 2 diabetes (Culhane-Pera et al., 2007; Harrison et al., 2005; Her & Mundt, 2005). In a more global context, economic development contributes to obesogenic environments, which are characterized by decreased opportunities for physical activity and increased access to high caloric diets. With the existence of social gradients, the disadvantaged are more likely to suffer from obesogenic environments and have worse outcomes. In the fight against diabetes, we must target education to high risk individuals, such as members of racial and ethnic minority groups like the Hmong.

Living in an obesogenic environment is a reality for many ethnic and racial minority groups. The Hmong have identified environment factors such as a lack of opportunity for physical activities, a safe environment for children to play, and easy access to fast food, that contribute to the development of diabetes (Perez & Thao, 2009). There is a need to modify and make their environment less obesogenic. This endeavor can be complex and challenging and requires a broad range of policy across multiple sectors to support this. Community planning must include active measures to decrease the risk of diabetes in the Hmong. This could be done by the promotion of an evidenced-based life style program that emphasizes dietary changes and physical activity in the Hmong population.

Culture

When the Hmong immigrated to the US, they brought with them their culture, customs, religion, rituals, and health beliefs. Health care providers should be aware that health in this ethnic group is seen as a harmonious balance of forces between the natural and super natural world; illness is an imbalance of these two forces (Cha, 2010). Some Hmong reported feeling

“out of balance” in the United States and believed that this imbalance contributes to the cause of their diabetes (Culhane-Pera et al., 2007, p. 182). In caring for Hmong patients, health care providers should understand their beliefs in the interconnectedness between the spiritual and physical world and how this affects health.

An important person in the spiritual world and the health of the Hmong is the shaman. One effective strategy might be to find ways for health care providers and shamans to work collaboratively. This can be beneficial to the community and empowering to shamans as they teach other Hmong about diabetes and how to better understand and manage this chronic illness. *Partners in Healing* is a program at Mercy Medical Center in Merced, California, where shamans are trained in the basics of Western medicine. After receiving training, they will often times refer the patient to see a medical doctor first. This makes the Hmong community more trusting of western health care (Kalantari, 2012).

In addition to receiving care from the western health care, a Hmong person with diabetes might be using a traditional method of care, which includes the use of herbal medicine for treatment of diabetes. Health care providers should promote an open dialogue about alternative treatments by telling their patients that they are aware of other methods of treating diabetes and ask what other methods of treatment the patients might be using. Our study findings indicate that it is important when treating Hmong individuals to ask about use of herbs in treating diabetes because they can be a potential hazard in combination with prescribed western medication.

Of equal importance is to educate health care providers about the significance of family to the Hmong. The Hmong might like to include the entire family or even clan leaders in their

care. Health care providers should be aware of this and attempt to accommodate the Hmong and at the same time take measures to adhere to confidentiality of information. Although health care providers must abide by privacy rules, it is important to consider the family, male figures, and the clan leader in caring for Hmong individuals. It is also customary for a Hmong individual to live with the extended family (Cha, 2010). The person affected with diabetes may not be the one preparing meals. Therefore, family members have to be involved in discussions and education to effectively manage diabetes.

Culturally Appropriate Education. Diabetes management can be enhanced by providing patients with education about the disease, but education is likely to be effective when one considers the patients' background and cultural preferences (Hawthorne et al., 2008). The education provided must be culturally appropriate, and programs must be designed to increase diabetes awareness and improve understanding, compliance, and the management of the disease (Cobb, 2010). In this review, some Hmong participants identified that they had no understanding of printed brochures about diabetes (Yang et al., 2009a). Therefore, diabetic educators have to make an assessment about the spoken language and the literacy level of the Hmong. A strategy to overcome a language barrier is to communicate with the Hmong in their own language. This is not always feasible for health care providers, but the use of medical interpreters is one strategy to consider. Diabetes educators should also consider using presenting education in a format that is preferred by the Hmong. This includes the use of bright colors with bold type, and, the use of bullet points and diagrams (Chu, Lawton, Martinson, & McNaughton, 2000). In teaching the Hmong with low literacy, a strategy to consider is the use of culturally appropriate artwork, such as the use of a Hmong story cloth or pa'ndau. Evaluation of these

types of interventions is also sorely needed to fill the gap in the evidence base for culturally tailored approaches to diabetes education for Hmong Americans.

Lack of Trust

Evidence suggests that mistrust negatively impacts breast cancer screening in Hmong participants (Thorburn, Kue, Keon, & Lo, 2012). The lack of trust can pose a barrier to providing health care to the Hmong population. Health care providers must work to build trust with the community, thus making an effort to gain trust and alleviate fears. Strategies to gain trust may include dissemination of information on diabetes through respected leaders, such as shamans and clan leaders. The use of Hmong lay advisors to speak about their experience with Western health care is also another possible intervention.

Strengths and Limitations

This scoping review contributes to the existing literature on diabetes among Hmong Americans. The strengths of this review include the comprehensive nature of the search and using a systematic approach to review the studies. The inclusion criteria were also broad, allowing for a larger assessment of research activities in the Hmong population.

Conclusion

This review suggests that there is limited data and research on the Hmong with diabetes. Of the 10 studies reviewed, seven used a qualitative methodology. In order for the research base on a topic to be strong, an array of both qualitative and quantitative research is needed. Thus, there is a need to conduct more quantitative research Hmong Americans with diabetes and to also include Hmong Americans in large national studies in order to improve baseline

knowledge about diabetes in Hmong Americans. This type of evidence is important for informing clinical care for this population.

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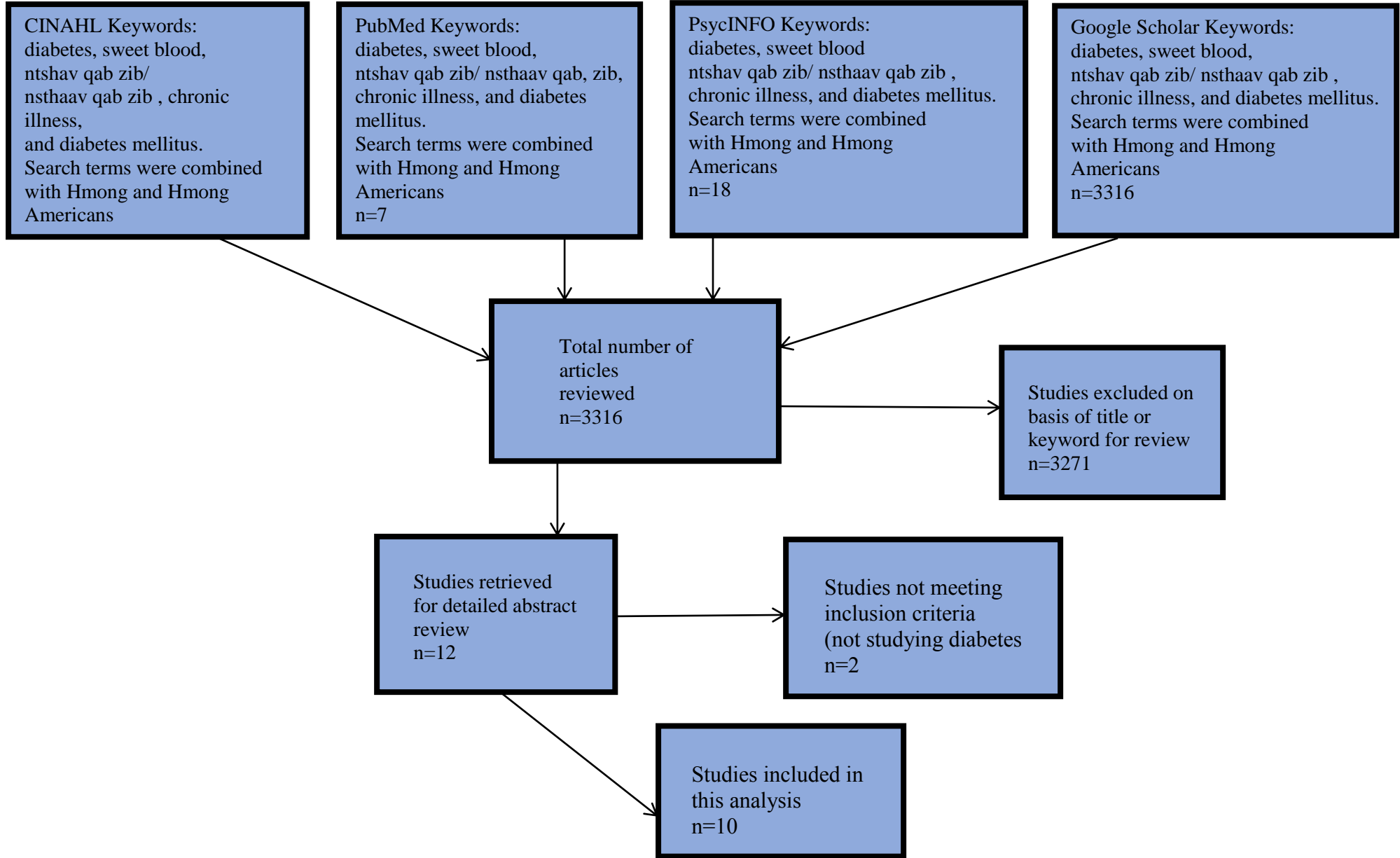


Figure1 Scoping Review Search Results

Table 1
Research Studies of Hmong Americans with Diabetes

Study	Design/Method	Sample Size	Theory Used	Study Location	Authors
A Hmong cultural model of diabetes	Qualitative study Group Visits and group discussion	n=39	None	Minnesota	(Culhane-Pera, Her, & Her, 2007)
Group visits for Hmong with diabetes: A pre-post analysis	Quantitative study Pre-Post Analysis	n=39	None	Minnesota	(Culhane-Pera et al., 2005)
Focus groups of 4 ethnic groups with Diabetes	Qualitative study-phenomenology Focus group interviews	n=80	None	Minnesota	(Devlin, Roberts, Okaya, & Xiong, 2006)
Chronic illness among Hmong Shaman	Qualitative study Home Interviews	n=11	None	California	(Helsel, Mochel, & Bauer, 2005)
Risk prevalence for type 2 diabetes	Quantitative study Cross-sectional prevalence survey	n=144	None	Wisconsin	(Her & Mundt, 2005)
Diabetes knowledge, beliefs and treatments	Qualitative study Focus group interviews	n=33	None	California	(Perez & Cha, 2007)
Understanding barriers to prevention of <i>ntshav qab zib/ nsthaav qab zib</i>	Qualitative study Photo voice	n=10	None	California	(Perez & Thao, 2009)
The prevalence of type 2 diabetes Mellitus in a Wisconsin Hmong patient population	Quantitative study-risk prevalence	n=504,799	None	Wisconsin	(Thao, Arndt, Tandias, & Hanrahan, 2015)
Perspective from the Hmong population on type 2 diabetes	Qualitative study-phenomenology design Focus group interviews	n=9	None	Minnesota	(Xiong & Westberg, 2012)
Hmong American women living with diabetes	Qualitative study Home interviews	n=9	Margaret Newman's Theory of Health as an Expanding Consciousness	North Carolina	(Yang, Xiong, Vang, & Pharris, 2009)

Manuscript 2

Sustaining Self-Management in Diabetes Mellitus

Mitchell-Brown, F. (201). Sustaining Self-Management in Diabetes Mellitus. *Creative Nursing* 20(4), 234-41 <http://dx.doi.org/10.1891/1078-4535.20.4.234>

Abstract

BACKGROUND: Self-management of diabetes is believed to play a significant role in achieving positive outcomes for patients. It is well supported in the literature that adherence to self-management behaviors leads to better care that reduces and delays disease complications. Adherence to self-management behaviors also result in an improved quality of life for people with diabetes.

PURPOSE: The purpose of this paper is to apply the social ecological model as a conceptual framework for sustaining self-management behaviors in people with diabetes.

METHOD: The social ecological model was applied to diabetes self-management behaviors in people with diabetes. This theory-based model was used to demonstrate how the five nested levels of influence: the intrapersonal, interpersonal, organization, community and public are used to promote diabetes self-management behaviors.

DISCUSSION: It is hoped that the application of this ecological model will enable health care providers to reduce inappropriate care and optimize clinical outcomes in patients with diabetes.

CONCLUSION: Because self-management is so important to diabetes management and involves a lifelong commitment for patients, health care providers should actively promote ways to maintain and sustain behavior change that supports adherence to self-management.

IMPLICATION: Diabetes is a complex life long illness. Proper self-management is crucial to achieving positive health outcomes. One cannot expect to change self-management behavior using a single intervention, but rather multiple interventions to promote and sustain a behavior change.

Introduction

Diabetes mellitus (DM) is a chronic disorder of glucose metabolism due to absolute (type 1 DM) or relative (type 2 DM) insulin deficiency (Lewis, Derksen, Heitkemper, Burcher, & Camera, 2011; Shrivastava et al., 2013). The complications of diabetes affect virtually every system and can lead to chronic mortalities and morbidities (Lewis et al., 2011; Shrivastava et al., 2013). In the United States, an estimated 25.8 million people are diagnosed with diabetes and another 79 million people with pre-diabetes (American Diabetes Association, 2011). The global epidemic of diabetes can be a health care burden to individuals and society. In 2012, the total costs of diabetes care in the United States was \$245 billion, \$176 billion for direct medical cost and \$69 billion in reduced productivity (ADA, 2013). Without sustainable effective interventions to change health behavior, it is likely that the number of people with diabetes will increase (Shrivastava et al., 2013). Self-management behaviors are important to optimize outcomes in people with diabetes and in those at high risk for the disease.

Because self-management is so important in improving outcomes in patients with diabetes, national standards for diabetes self-management education has been established by the American Association of Diabetes Educators and the American Diabetes Association (Funnell et al., 2009). These standards are a way to encourage high quality diabetes care and help educators provide evidenced-based education in a variety of settings. These standards are reviewed and revised every five years by key organizations and federal agencies (Funnell et al., 2009).

Self-management behaviors (SMBs) are activities performed by people with diabetes or at risk for diabetes in order to successfully manage their own disease (Shrivastava et al., 2013). It is an ongoing process that fosters the development of knowledge, ability that promotes learning to survive with the complex nature of diabetes. People with DM are always faced with

the continuous need to adjust their diet, medication and lifestyle in order to better manage the disease. They must integrate SMBs into their lifestyle in order to achieve optimal glycemic control (Wilkinson, Whitehead, & Ritchie, 2014). The American Association of Diabetic Educators (2013) recommends that people with diabetes adhere to seven SMBs: healthy eating, medication compliance, physical activity, blood glucose monitoring, problem solving, healthy coping and appropriate screening exams for early detection of complications. Adherence to SMBs result not only in good glycemic control, but also an improved quality of life and a delay or reduction of disease complications (Anderson & Christison-Lagay, 2008; Shrivastava et al., 2013). Thus, the interrelationships of these behaviors are crucial to the successful management of a chronic disease such as diabetes.

Because diabetes is such a chronic and complex disease, all personnel should work together and apply the SEM approach to help individuals with diabetes change and sustain behaviors. In order to sustain self-management behaviors in people with diabetes, interventions must include multiple levels of problem solving including a theory based approach to translate research findings into practice and to sustain behavioral change (McLeroy et al., 1988). Well applied theories also can enable practitioners to reduce inappropriate care and optimize clinical outcomes. Depending on the relevancy, different theories are used for different disease management (Glanz, Rimer, & Viswanath, 2008).

Due to the complexity of diabetes, sustainable behavior is most likely to be successful if a framework is used, rather than one that focuses solely on the patient. To sustain behavior change in diabetes one must use a theory that provides an in-depth comprehensive framework incorporating multiple and interacting factors that determine health behavior (Glanz et al., 2008; McLeroy et al., 1988). The purpose of this paper is to apply the social ecological model that was

developed by McLeroy et al., (1988) to sustain self-management behaviors in people with diabetes.

The Ecological Model

The ecological approach to diabetes self-management includes individual responsibility in controlling behavior with an emphasis on access to resources (Fisher et al., 2005). There is an integration of individual's skills coupled with the support they receive from, (1) the social environment of family, friends, churches, organizations, and culture and, (2) the physical environment of neighborhoods, communities and the government. The ecological perspective emphasizes the access to resources including services from health care providers (HCPs) that support initiation and maintenance of health behaviors. Health behaviors are influenced by a range of factors not only from an individual standpoint, but also by social, economic, community, organization and government policy-related factors (Fisher et al., 2005).

McLeroy et al., (1988) social ecological model (SEM) employs the application of multiple level interventions in disease management, thus, making it an appropriate model for promoting and sustaining SMBs in people with diabetes. The SEM consists of five nested levels of influence: the intrapersonal, interpersonal, organization, community and public (McLeroy et al., 1988). The intrapersonal are characteristic that an individual possesses such as knowledge, attitudes, and behaviors. The interpersonal include both formal and informal social networks and social support systems that include the family, work group, and friends. The organization includes social institutions and the community level focuses on mediating structures and relationships among organizations. The public policy level addresses local and global laws that impact the health of individuals (Shumaker, Ockene, & Riekert, 2009).

Application of the Social Ecological Model

Individual

In promoting SMBs in people with diabetes mellitus, one should recognize that behaviors are influenced by skills, beliefs, attitudes and self-confidence (Norris, Lau, Smith, Schmit, & MM., 2002). Evidence suggests that incorporating individual components with medical knowledge is effective in diabetes management (Glasgow, McKay, Piette, & Reynolds, 2001). An individualized assessment by a HCP is essential to provide appropriate education. HCPs can assist patients by developing and refining problem solving skills; providing encouragement especially in challenging situations; and teaching patients how to respond to problems that may arise in someone with a chronic disease. The HCP should also assess how culture impacts self-management behaviors, and health beliefs, i.e. how patients understand their illness. Support can be provided by follow up phone calls, and self-management plans tailored to individual's needs must be reviewed on a regular basis (Trento et al., 2004). HCPs can be instrumental in delivering culturally appropriate care and can function in the role of liaison, case manager, educator, advocate and facilitator to behavior change in people with diabetes (Ferguson, Lemay, Hargraves, Gorodetsky, & Calista, 2012; Hunt, Grant, & Appel, 2011). See Figure 2.

Interpersonal

HCPs should ensure that patients have adequate social support in sustaining SMBs. Evidence suggests there is a positive relationship between social support and diabetes self-management (Gallant, 2003; Rosland et al., 2008; Schiøtz, Bøgelund, Almdal, Jensen, & Willaing, 2012). HCPs should encourage frequent contacts with friends and family and spiritual leaders. Evidence also indicates that social contact is positively related to fewer psychosocial

problems and promotes self-management behaviors such as frequent exercise (Schjøtz et al., 2012).

Peer support can be encouraged through participation in a support group for people with diabetes; this can be potent in providing and receiving support (Heisler, 2010). Peer support from a support group can be crucial as peers with diabetes have direct knowledge of DM because they have experienced the disease and they share similar characteristics with other diabetes patients in the community (Dennis, 2003). People with a chronic illness all have something in common; they may share their knowledge and experience with each other in ways that health care providers may not understand but nonetheless value (Heisler, 2010). Peer support interventions can improve diabetes self-management behaviors such as medication adherence, diet, exercise and blood glucose monitoring (Keyserling et al., 2000).

The HCP can also explore social and cultural norms that contribute to barriers that individuals face (Fisher et al., 2005). In promoting self-management behaviors every effort should be made to accommodate the family. For example, the Hmong people have an eastern communal culture, where, the health of any individual is dependent on the entire family. In promoting self-management behaviors in the Hmong population, every effort must be made to accommodate the family.

Organization

In supporting self-management behaviors, HCPs should encourage patients to verbalize long term and short term goals and this should be documented in the patients' health records. Each goal should be tracked and reviewed with patients regularly. Every effort should also be made to provide information in the patients' native language. On a broader level, HCPs should

reach out to workplaces and churches in promoting SMBs. Employers should be encouraged to adopt work site policies that support SMBs. For people with diabetes, education programs that focus on physical activity, weight control, nutrition and health screening would be beneficial. When the workplace is used in the context of supporting health behavior, it promotes social acceptability and social support (Whittemore et al., 2004) for better self-management of diabetes.

For patients who are religious, people from the place of worship can be very instrumental in helping to change health behaviors. HCPs can work with the church to promote programs that encourage increasing physical activities and improving dietary behaviors (Baruth & Wilcox, 2013). Evidence suggests that African American church members have changed up to two health behaviors with the influence of church programs (Baruth & Wilcox, 2013; Resnicow et al., 2005).

Community

Health behavior can be influenced by having access to healthy food in the community (Glanz, Sallis, Saelens, & Frank, 2005) and resources for physical activity (Humpel, Owen, & Leslie, 2002). Public health authorities and community based organizations should evaluate the accessibility of healthy food in the community, as well the extent to which physical activity is promoted. Ethnic minorities such as Hmong Americans with low income are prone to deprivation of community resources (Perez & Thao, 2009). One way to increase community resources is to by encourage people with diabetes to participate on community boards and voice their concerns and needs.

Local organizations and HCPs should be encouraged to collaborate with national organizations that promote diabetes treatment, prevention and outcomes. Collaboration with one

such organization could be the National Diabetes Education Program (NDEP) which is a federally sponsored program (National Diabetes Education Program 2013). Organizations at the community level should be encouraged to partner with NDEP in promoting the self-management of diabetes by participating in prevention campaigns and using their educational resources at the community level. The Division of Diabetes Translation (DDT) at the Centers for Disease Control and Prevention is a sponsor of NDEP. The DDT's aim is to translate the science of diabetes into practice and to provide additional information to professionals on diabetes prevention and care (CDC, 2013).

Public

When public policies are written, they should address the health of people with chronic diseases. HCPs can contribute to this process by educating policy makers about diabetes and the importance of passing legislation to support such health behaviors. The public should be educated on what to demand from law makers, in particular, what will make their community physically conducive to healthy life styles, e.g., trails, bike paths, parks, and easy access to healthy foods. The public should also be educated about the higher prevalence of diabetes, especially in racial and ethnic minorities who face a greater burden from this chronic disease (Chow, Foster, Gonzalez, & McIver, 2012).

Implications

To sustain long term behavioral change in diabetes, it is necessary to actively assist patients in maintaining SMBs because adhering to these behaviors can have positive outcomes in diabetes management and can greatly improve quality of lives for people with chronic diseases. Individual responsibility is very important in self-management of diabetes but the environmental

factors that influence health behavior should not be ignored. Individuals will more likely maximize and sustain behavior change when the environment is congruent and supports SMBs (Glanz et al., 2008). If the environment does not support healthy choices, people will be hesitant to change their health behavior and efforts to promote self-management of DM will not be sustained (Glanz et al., 2008). Lastly, health care providers need to measure and understand the impact of actions and interventions that can improve the self-management of people living with diabetes mellitus.

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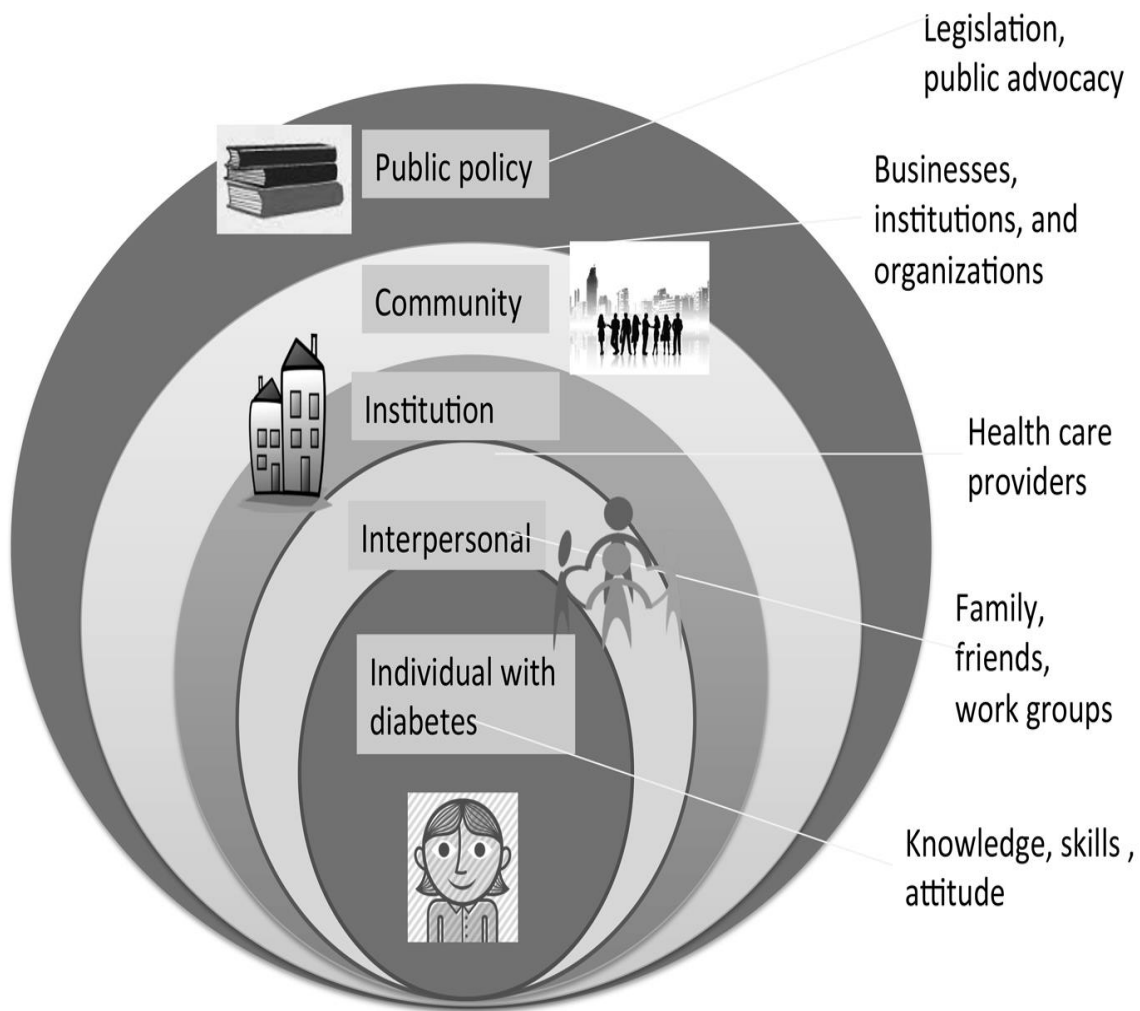


Figure 1 McLeroy et al., (1988) Social Ecological Model.

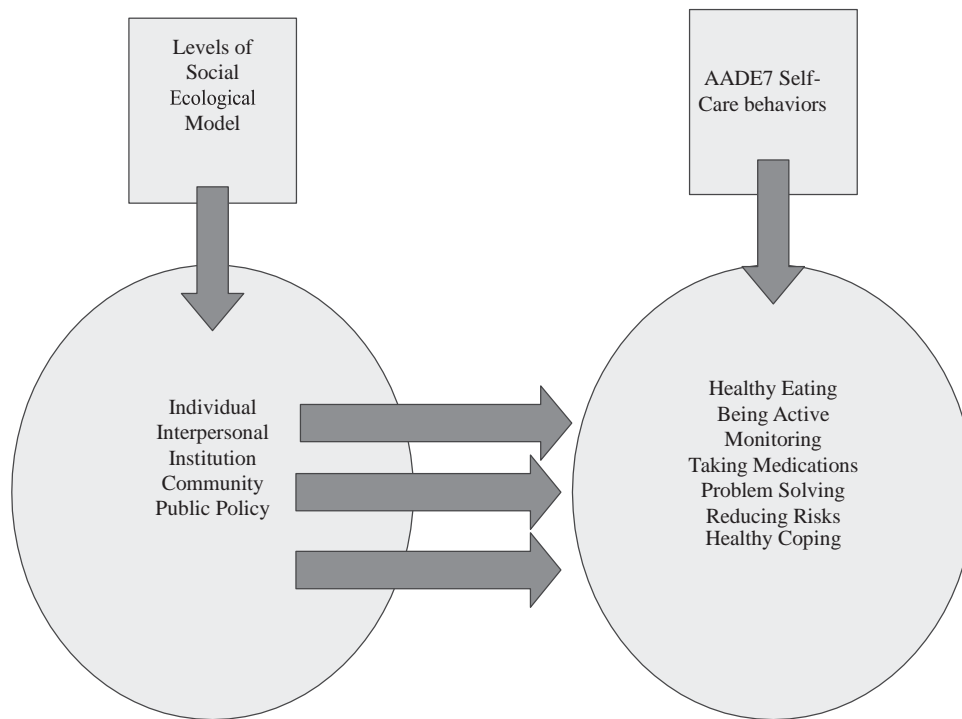


Figure 2 Application of the social ecological model to the AADE7 Self-Care Behaviors.

Manuscript 3

A Study of Hmong Immigrants' Experience with Diabetes Education: A Community-Engaged Qualitative Study

Abstract

BACKGROUND: The prevalence of diabetes is increasing in Hmong Americans and there is no research addressing their experience with diabetes education.

PURPOSE: To identify barriers and facilitators related to the diabetes education experience of Hmong Americans with type 2 diabetes, living in central California.

METHOD: This qualitative study employed a hybrid design (inductive and deductive approaches) to identify barriers and facilitators to diabetes education. Two focus group interviews were conducted among 16 Hmong American participants. The transcripts were translated into English, reviewed and coded by two investigators.

RESULT: The inductive approach identified three barriers to diabetes education: language barrier, self-management barriers, stressors and two facilitators: focused culturally specific education and peer support group. The deductive approach affirmed the relevance of a priori elements of the Access Framework within the Hmong population.

CONCLUSION: There is a need for diabetes education in Hmong Americans. Health care access and education should incorporate culturally appropriate strategies, such as oral strategies and videos that can lead to improved health outcomes for this group.

IMPLICATION: Health education and services that are culturally appropriate for Hmong persons with diabetes should address resources for healthcare access and provide culturally relevant diabetes education to assist these individuals in making behavioral changes that can improve their health and well-being.

Keywords: diabetes mellitus, grounded theory, qualitative research, diabetes education, Hmong Americans.

Introduction

Diabetes is a rapidly growing health problem that affects 387 million people worldwide and is predicted to affect 592 million people by the year 2035. In 2012, 29.1 million people in the United States (US) had diabetes (American Diabetes Association, 2014, a). The total economic cost of diagnosed diabetes in the US in 2012 was \$245 billion, with \$176 billion in direct medical costs and \$69 billion in reduced productivity (American Diabetes Association, 2013,b).

A significant diabetes disparity exists among racial and ethnic minorities (Peek et al., 2007). Asian Americans in the US are 20% more likely to be diagnosed with and die from diabetes associated complications than non-Hispanic whites (Office of Minority Health, 2014). A prevalence study of adult Hmong living in Wisconsin reported that of the 144 participants, 41% had glucose ≥ 140 mg/dl, 42 % had a waist to hip ratio of ≥ 0.9 , 51% had BMI ≥ 27 , and 51% of those less than 65 years of age were engaged in little or no exercise (Her & Mundt, 2005). Wu and colleagues (2011) also studied disease risk factors in four Asian groups, Chinese, Filipino, Hmong and Vietnamese. Of the four groups, Hmong Americans had the highest body mass index, were most likely to have glycemic levels >126 mg/dl, and were most likely to report a diagnosis of diabetes.

Most of the Hmong living in the US came from Laos. During the Vietnam War the Hmong people were recruited by the Central Intelligence Agency to help fight the war (Goodkind, 2005). After the war, the Hmong people faced persecution for their anti-communist involvement in the war. As a result most of them fled to refugee camps in Thailand. In 1976, the first wave of Hmong immigrants arrived in the US (Goodkind, 2005). The majority of Hmong people live in Minnesota, California, and Wisconsin (Pfeifer & Thao, 2013).

People from ethnic minority groups have a higher prevalence of diabetes and bear a disproportionate burden of the disease in the US (Peek et al., 2007). The problem of increased diabetes prevalence in ethnic minority groups is intensified due to migrant status, deprivation, low socio-economic standing, language, cultural and communication barriers (Hawthorne et al., 2008). This migration phenomenon has been described as the “collision of hunter gatherer genes with our modern twentieth century life styles” (Her & Mundt, 2005, p. 13). Other reasons for the increased diabetes risk in ethnic minorities are lack of knowledge of the host country, lack of knowledge of available services and lack of access to preventative services which results in deprivation in comparison to the majority (Hawthorne et al., 2008). Not being able to read and understand English can also result in difficulty accessing health information (Hawthorne et al., 2008).

When the Hmong arrived in the US in the 1970’s, they brought with them a unique cultural heritage that most health care providers do not understand (Pinzon-Perez et al., 2005). A major cultural identity for most Hmong is the practice of shamanism with the exception of those who are Christians. A shaman is a spiritual healer, and a Hmong person will often seek the help of a shaman when afflicted with an illness. The shaman uses spiritual power to cure physical illnesses (Pinzon-Perez et al., 2005). Herbal medicines are often used by the Hmong to cure illnesses (Cha, 2010). Of note here, is that the Hmong culture is patriarchal and when an individual is ill, they often seek advice from a male family member or a clan leader (Cha, 2010). Aside from these cultural aspects, there are also barriers that can influence the health experience of the Hmong in the US.

These barriers include language, lack of culturally appropriate education, socio-economics, and a western medical system (Attridge, Creamer, Ramsden, Cannings-John, & Hawthorne, 2014; Cobb, 2010; Smalkoski et al., 2010). To remove barriers to health education, research is needed to provide culturally sensitive and relevant solutions for the Hmong people who are experiencing disparities. There is no research documenting the diabetes education experience among Hmong Americans with diabetes. We addressed this gap by conducting a qualitative study to explore the perceptions and needs for relevant diabetes education of Hmong Americans. The aims of our study were: (1) To identify knowledge, perceptions, and practices related to diabetes among Hmong Americans through focus group interviews, facilitated by the collaboration between community and academic partners, (2) To explore perceived barriers and facilitators encountered with diabetes education, preferred sources, channels, and formats for diabetes education. A facilitator was operationally defined as any factor identified by the participants that promoted learning about diabetes and a barrier was any factor identified by the participants as an obstacle or difficulty learning about diabetes. Thus, this research provides an opportunity to determine appropriate targets for developing culturally sensitive diabetic education.

Literature Review

Although diabetes self-management education has proven benefits for people with diabetes (Duncan et al., 2009; Healy, Black, Harris, Lorenz, & Dungan, 2013), only 56.8% of American adults aged 18 years and older with diagnosed diabetes participate in formal education (Healthy People, 2015). Much emphasis of diabetes education should focus on self-management activities because of the chronic nature of the disease. Self-management is a process through which knowledge is developed and applied to care on a daily basis in order to sustain behaviors

to successfully manage the disease (Powers et al., 2015). Diabetes self-management (DSM) education has been shown to decrease hospital readmissions (Healy et al., 2013), improve hemoglobin A1C levels by as much as 1% in people with type 2 diabetes (Duncan et al., 2009; Steinsbekk, Rygg, Lisulo, Rise, & Fretheim, 2012), improve quality of life (Cochran & Conn, 2008; Cooke et al., 2013) and increase healthy coping skills (Thorpe et al., 2013). These benefits clearly affirm the importance of diabetes education for everyone with the disease.

Systematic reviews of ethnic minority groups with type 2 diabetes found that culturally appropriate education is more effective than mainstream diabetes education in improving glycosylated hemoglobin, diabetes knowledge, self-management behaviors, and healthier lifestyles (Attridge et al., 2014; Hawthorne, Robles, Cannings-John, & Edwards, 2010; Ricci-Cabello et al., 2014). When education provided to minority groups is not specific to their learning needs and are aimed at the mainstream community, it is difficult to accomplish meaningful behavioral change in culturally unique populations (Khunti et al., 2008). Moreover, culturally appropriate education is a foundation to reduce health disparities in ethnic minority populations and should be a priority for the health care delivery system (Agency for Healthcare Research and Quality, 2014).

Methods

Design

This study used a hybrid qualitative design (Bradley, Curry, & Devers, 2007) that included both inductive and deductive approaches to identify themes in the diabetes education experience of Hmong individuals. The relevance of the hybrid approach is that it seeks to develop taxonomy, themes and theory (Bradley et al., 2007). Ethical approval to carry out this

study was received from the Institutional Review Board at the Medical University of South Carolina.

Population and Setting

A Hmong community partner was used to assist in recruitment of the participants because difficulty in recruitment of participants was anticipated. This community partner was used because of the community trust that she has developed and her previous experience in conducting research in the Hmong community. There is still some level of mistrust of health care providers in Hmong Americans, plus the fact that they have little exposure to research (Devlin et al., 2006; Kue, Thorburn, & Keon, 2014). The principal investigator (PI), along with an interpreter screened individuals for interest in study participation and study eligibility. A convenience sample of Hmong persons with diabetes from the community in Fresno, California was recruited to participate in the study.

The inclusion criteria for this study were to: (1) identify self as first generation resettled Hmong American between the age of 18-70 years, (2) self-report as having type 2 diabetes mellitus for duration of more than 6 months, (3) not have debilitating co-morbidities that prevent participants from being able to attend and sit for a 60 minute group interview, (4) have the ability to understand English or Hmong, and, (5) agree to an interview for 60 minutes. To promote anonymity, de-identified demographic information was collected and participants were asked not to state their names while being recorded during the interviews. Participants were compensated with a \$30 gift card.

Data collection

Focus groups interviews (FGIs) were used for data collection. The FGIs were semi-structured, they were audio recorded and lasted for approximately 60 minutes. Two Hmong interpreters were used to facilitate the focus group procedures. A *Statement of Research* describing study procedures, potential risks and benefits, and voluntariness of participation, was read in Hmong to all participants prior to the study and verbal consent was received from all participants prior to their study participation. Demographic information was collected prior to the beginning of the interviews. The primary interpreter started the FGIs by asking the scripted questions in Hmong (See Table 1). The PI wrote reflexive field notes during and immediately after the interviews. Field notes are notes written during and after observation of a phenomenon and included reflection by the PI (Hesse-Biber & Leavy, 2011).

The second interpreter translated the focus group discussion for the PI and validated the Hmong interpretation by the primary interpreter. The two interpreters were bilingual, bicultural Hmong Americans who were both paid for interpretation services. The PI trained the interpreters and reviewed the study protocol with them in detail. The *National Standards for Interpreters in Health Care* was also reviewed with the interpreters with the expectation of upholding these standards during the research study (National Council on Interpreting in Health Care, 2005).

Data Analysis

Both FGIs were translated and transcribed verbatim from Hmong directly into English by two different interpreters. The transcribed interview files were uploaded into NVivo 10 (QSR International, Pty. Doncaster, Victoria, Australia) software. The PI and a senior qualitative mentor (LSN) reviewed the data to validate and refine themes. Data saturation was reached during the second FGI. The PI met with five participants in the community to report the study

findings, to seek verification of the study findings and to obtain more information to aid in interpreting the study results. Member checking is a process in which individuals who participated in qualitative research are asked to review findings as a strategy to increase the validity of findings (Lincoln & Guba, 1985).

Data Analysis Method. *Inductive Approach.* Grounded theory (GT) is a systematic inductive, approach used to construct theories and to identify conceptual categories. The GT approach was used to formulate constructions of knowledge from the experiences and meanings attached to diabetes education by the research participants. The research question framed the approach to identify themes in the participants' responses that emerged from descriptions of their diabetes education experience. During analysis, important features of grounded theory were applied, which included (1) simultaneous data collection and analysis, (2) constant comparative analysis (CCA), (3) writing up of theoretical ideas in memo format as ideas emerged, and (4) theoretical sampling.

The first step in analyzing the data was coding, which is a process of sorting or categorizing the data (Bryant & Charmaz, 2007). Data analysis started with open coding, transcripts were read, and labels were assigned to sections related to the participant's perspectives. The initial open codes were created using the participant's words. After the iterative coding process, the data was grouped together into categories of diabetes education experience using CCA. Based on similarities and differences, the data were grouped conceptually. This allowed for more focused coding of larger segments of the data. Using CCA, focused codes were refined, which led to the final themes and a conceptual framework (Bryant & Charmaz, 2007; Glasser & Strauss, 1967).

Deductive Approach. The *Framework for the Study of Access to Medical Care* (Aday & Andersen, 1974) was used in the deductive approach. This framework (FSAMC) proposes that health policy determines the characteristics of the health care delivery system to the population at risk, which then influence utilization of health care services and satisfaction of consumers (Aday & Andersen, 1974). Selected FSAMC constructs applied to this study were health policy, characteristics of the health delivery system, characteristics of the population at risk, utilization of health services and consumer satisfaction. These constructs were utilized to operationalize access to health care among Hmong Americans with diabetes. Specifically, the coding categories included consumer satisfaction (sub-constructs: cost and quality) and health care delivery system (sub-constructs: resource and organization).

The FSAMC was used to verify if themes that emerged from diabetes education experience of Hmong Americans were congruent with the theoretical constructs of this model. The a priori constructs extracted from the access framework guided the initial coding. In coding the statements by the participants, the researcher had to identify whether the content was represented within the dimensions of the access framework (Aday & Andersen, 1974). After preparing several iterations of the participants' statements, where the content was reviewed against the a priori constructs of the FSAMC framework, the themes were reduced to those reported here. This framework was appropriate to use, as access to health care is a challenge that immigrants face (Dastjerdi et al., 2012). Immigrant populations are more likely to access health care if organization provide culturally competent care, which can be measured by providing services with appropriate language proficiency, quality, cost, and satisfaction.

Results

Population

Table 2 summarizes participant characteristics. The 16 participants were all born in Laos, self-reported Hmong ethnicity, and reported Hmong as the primary language spoken at home. Eleven participants had providers who were of Hmong ethnicity and were fluent in Hmong. The remaining five had providers who were not Hmong and did not speak the language.

Conceptual Framework

The results of this study are conceptualized into a framework (Figure 1) that identifies three major points in the diabetes education experience of a population of Hmong Americans with diabetes: health care access, health care experience, and output. These points in the model are important because (1) the *health care access* category is the input into the system from two a priori constructs of the FSAMC framework, consumer satisfaction (sub constructs are cost and quality) and the health care delivery system (sub constructs are resources and organization), and (2) the *health care experience* category describes the diabetes education experience of the Hmong and is divided into three perceived barriers (language barrier, self-management barrier, stressors) and two perceived facilitators (focused culturally specific education and peer support group). The intervention target in this model addressed the perceived barriers and facilitators which leads to (3) the *output* category that reflects the end products of the health care experience and health policy regarding access to care.

Health Care Access

Consumer Satisfaction. Consumer satisfaction refers to “the attitudes toward the medical system by those who have experienced a contact with it” (Aday & Andersen, 1974, p.

215). Cost plays an important role in consumer satisfaction. In this study we found that the cost of health insurance created stress for participants. *“For all my visits and prescription, I pay from my own pocket. This is what makes me upset.”* Utilization of health care services can be influenced by the quality of care that individuals receive when they access the system. In this study the participants described quality of care with the satisfaction of their health care provider. There were divergent views on how satisfied the participants were with their health care provider, but the majority of the participants reported that they were satisfied. *“My doctor is Hmong in the clinic. She is very good. When I explain my symptoms like coughing, she is willing to take me for an x-ray because she is worried my lungs might have problems. She is very good and cares for me.”* *“My doctor is Hmong and she helps me a lot, she does accordingly to what I want and I feel good with her.”* *“I would like her (provider) to prescribe me stronger medication or change the medication that my uncle told me about. But she only prescribes me medication that helps me stay "comfortable" and does not have any affect to my health. Well, they don't even work for me.”*

Health Care Delivery System. The delivery system includes how care is rendered to the consumers and has two components, resources and organization. Resources describe health personnel and structures in which health care and education are provided; organization describes what the system does with its resources (Aday & Andersen, 1974). Based on our study data, this construct was exemplified in terms of communication, provider mistrust and translation. All participants in this study reported that they receive health care in primary care clinics in Fresno, CA. Five participants had non-Hmong providers who did not speak the Hmong language. Participants expressed that communicating with a non-Hmong provider created difficulty in communication. *“I only go to a Vietnamese doctor, so for me, when I go visit my doctor, I take*

my child with me to translate for me. She is 11 years old. And sometimes she has to miss school". "Sometimes you see some of the Hmong workers but not much Hmong workers there, but mostly just Vietnamese." Eleven participants had Hmong providers who were fluent in Hmong, and the majority of participants reported that communication was enhanced when the provider spoke Hmong. *"It is satisfying to go to a Hmong doctor. It is easier to explain and express your need."* Although participants expressed that their providers were willing to help them, they also articulated major mistrust in their providers. *"Yes, if they wanted us to get better, then maybe they would have provided us some education about diabetes. Because they don't, we always go in for visits to get medications. It's a way for them to get money from us."* There was no difference expressed in this sentiment for Hmong versus non Hmong providers. A common theme throughout both FGIs was inadequate translation and the nonexistence of a formal translation service when participants see their provider for health care. Participants reported that the bilingual Hmong staff in the clinic were used for translation, namely the nursing aid, the Hmong nurses and the receptionist. *"There is.... people that work there, the nursing aid, the Hmong nurses help to translate."* *"The receptionists are the ones that translate the information in Hmong to you"* One participant said, *"They (staff) know how to explain it, but their translation is a bit "shaky."* *"Yes, there is translation at the clinic, the Hmong workers there help translate. Sometimes they are busy checking people in or doing something else but I wait."*

Health Care Experience

Diabetes Understanding. Diabetes is a new concept for the Hmong people. There is no term for diabetes in the Hmong language, and it is translated as "sweet blood. To develop an understanding of what is known about diabetes in the sample of Hmong Americans, questions were asked that addressed their diabetes knowledge and their responses indicated that they did

not understand the cause of diabetes. They were asked directly to explain what they understood to be the cause of diabetes. Some examples of their responses include: *“I do wonder why is it that when we lived in Laos, our elders never had this disease, but when we moved here to America, how is it that we are getting it now?”* *“They say that those who are overweight have it (diabetes), but how come some who are overweight don’t have it. I’m skinny and I still have it. I have no idea how it came about.”* *For me, I think that diabetes is a bad disease and I don’t know why I have it.”* There were different thoughts expressed about diet and the influences of diabetes risk as reflected in these statements, *“When you do over-eat, the vitamins in the foods cause diabetes and raise your blood sugar level.”* *“My doctor mentioned to me that we, Hmong, eat too much sticky rice and white rice. Once it gets digested, then it becomes some sort of liquid, I forgot what it’s called, but that causes sweet blood to happen.”* The participants also expressed their understanding of physical aspects of diabetes. *“There are two kinds. First kind is Type I, they say it’s Type B or Type A. If you have Type A, you have to filter the blood (dialysis). Type B, they will only give you medicine. Their medication is only for Type A.”* *“I’m guessing that if diabetes appears, then it might be because our liver, heart and kidneys are not working well to absorb the proper nutrients for our system, so it gets mixed into our blood.”*

All participants believed that diabetes education is important to their care. When participants were asked if they received diabetes education in the health care setting, the answers ranged from no education to minimal education and some even reported inadequate follow-up on scheduling diabetes education sessions that had been planned. *Participants stated: “No, we have not received any,” “I have learned about it but I forgot.”* Participants expressed a desire to learn about diabetes. *“I would love to learn about it. They tell me that they will schedule an*

appointment, but it never happens". All participants affirmed that they felt like more diabetes education was needed.

Perceived Barriers to Diabetes Education. *Language Barrier.* Of the sixteen participants, seven reported that they can read and write Hmong, and one could read and write English. *"If a lot of English is spoken at one time, then it's hard to understand, but when a few easy words are used then I understand a little bit.* All participants except one agreed to this statement: *"Yes, I just know the easy words to get by."* Other statements made about diabetes education are, *"Yes, for me, my doctor has given me a pamphlet in English about diabetes. But I cannot read it, I have it at home in a paper bag."* *"I ask about education, they told me that at the location where they teach about it does not have Hmong translation. So, it's got to be that I must know English, but I don't know English, so I need to find someone that will help me translate, but I can't find one."* *"Not a lot of us can read in English, we need the information in Hmong too. If we get the information in Hmong, we read it in Hmong, then maybe we will understand it better. If it's given in English, we will just take it home and not even read it. Our children will read it but they can't explain it for us."*

Self-Management Barriers. A very consistent theme in this study that the participants reported is that they did not adhere to self-management behaviors (SMBs). Participants reported a range of feelings for not adhering to SMBs, including inadequate self-control, and memory failure. *"We elderly have to eat rice. If we just eat vegetables, then we won't be comfortable working."* *"In one day, they tell you to take it (medications) three times. But, it's not just one kind, there are about three kinds that you have to take, so there's just too much at hand to take."* Participants in this study also expected that the medication would totally eliminate the problems of high blood sugar. As this is not the case, the participants poorly complied with their

medication regimen. *“They (providers) tell you to take many pills, then you'll see your blood sugar rise and it will rise. I don't believe the pills help my sweet blood, and that is why I don't follow the instruction accordingly.”* *“The reason I do not take medications prescribed by the doctor is because some does help you and some may just attack your system and causes other health concerns like kidney failure and blurred vision.”* *“I don't take the medication my doctor prescribed for me much. Maybe just two in one day just to help relieve the symptoms.”* When asked what would happen if she did not take care of herself, the participant responded, *“For me, I don't know how to answer that.”* Seven other participants nodded in agreement.

Stressors. Participants reported that living with diabetes is stressful. They reported having difficulty in managing the disease versus curing the disease. They expressed difficulty in living with the disease that has no cure. *“But, when you have high blood sugar, then you will have to live with it until the day you die, it is a very sad thought...”* *“There won't be a medication that can help you heal from it, so those medicines are what you will have to take for the rest of your life.”* *“If they can't find anything to help cure diabetes, then for sure, our lives would be "poor.”*

Perceived Facilitators to Diabetes Education. Focused Culturally Specific Education. Participants' statements indicated that focused culturally specific education was needed and is a critical component to their diabetes education. Participants were asked what would be the best way for them to learn about diabetes. All participants agreed that diabetes education should be taught with the consideration of their literacy level and culture. Two participants' comments below exemplify how they would like to receive diabetes education: *“There should be a program focused on diabetes education and offered in Hmong too, so that we can understand it better. “I would like you (researcher) to take pictures of fruits, grains, or any*

foods, that way I see it, because I cannot read it. This is better than a paper in English that I cannot read.” When the Hmong language was taken away by their oppressors, the Hmong people developed pa’ndau for communication (Vang, 2014). Pa’ndau is a is an elaborate story cloth embroidery, which Hmong women learn to make at an early age (Vang, 2014). *”For “pa’ndau,” the best way to go is, number one, it represents our Hmong culture. If it was used to create a way for us to understand foods and health conditions, and it will help, Hmong remember our culture.* Although they felt that pa’ndau depicts their culture, the majority of the participants agreed that that watching a movie would best facilitate diabetes education because of their inability to read and write English and Hmong. *“Putting it in a movie setting will definitely help me learn. “So, for anything that involves reading will not help, but movie is definitely a better choice.”*

Peer Support Group. Participants also viewed peer support group in the community a facilitator to diabetes education. Participants described support groups as a way to share information and gain knowledge. In addition support groups offer an assistance to help them cope with diabetes. *“We need to meet in a group with the same health condition that comes together to help encourage each other and to give advice about what they have done to help themselves fight diabetes. It's like learning from each other and using each other's ideas.” “Like I said, the group helped me maintain normal blood sugar. They taught me to check my blood sugar and eat good foods.”*

Discussion

To the best of our knowledge, this study is the first to examine perceptions about diabetes education and health care access from the perspective of Hmong Americans. These findings can be used to inform appropriate education for this understudied population. Hmong Americans

encountered several barriers in access to care for their diabetes, such as cost, quality, communication, mistrust and lack of translation services. Improving access to health care in this population will likely be improved by addressing these barriers to care.

A big obstacle in providing care to the Hmong is the language barrier (Cobb, 2010). This was reinforced in this study and was also corroborated by Yang et al., (2009). Having a complex disease like diabetes requires a high level of patient understanding and engagement for successful management. Researchers compared rates of blood sugar control among Latino patients and found no difference in blood sugar control between English-speaking Latinos and non-English speaking Latinos if they had access to a doctor who spoke their language (Fernandez et al., 2011). This research highlights the potential positive influence of having Hmong health care providers who directly communicate to participants about diabetes education. Language assistance also facilitates timely access to health care and services.

The majority of the participants in this study expressed mistrust of health care providers and questioned if medications to cure diabetes were being withheld from them. Devlin and colleagues (2006) also found Hmong participants reported suspicions that a cure for diabetes is being withheld from them. Mistrust of providers can lead to a less engaged patient who might not follow the treatment plan provided by their provider. When patients trust their physicians, this can lead to improved shared decision-making and positive patient self-management behaviors (Peek et al., 2013). Mistrust of physicians among patients with diabetes can be addressed through provider training in cultural competence and interpersonal and communication skills.

In this study, we found that the clinic staff provided translation services in addition to their usual roles, which is not the ideal method for communication. Health care providers over the years have frequently used bilingual staff and family members to translate for non-English patients (Wielawski, 2009). Not providing a formal translator can result in inaccurate translation, and compromise the information given to the patients (M. Thao, Leite, & Atella, 2010). Hmong language is uncommon and there are many dialects of the language (Cobb, 2010). The majority of Hmong Americans speak white or green Hmong, and some medical terms do not exist in the Hmong language increasing the difficulty in translation (Cobb, 2010). It is therefore, important to have a formal translation service with trained medical interpreters where clients access health care. *The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (CLAS)* is a guide to help individuals and health care organizations implement culturally and linguistically appropriate services to consumers (Office of Minority health, 2013). A recommendation of the CLAS Standards is that individuals providing language assistance should be trained to ensure competence (Office of Minority health, 2013).

Very evident in our findings was the lack of education that is provided for Hmong Americans with diabetes. Evidence supports that educational programs have demonstrated benefits in improving diabetes knowledge and self-management behaviors (Funnell et al., 2012; Hawthorne et al., 2008; Khunti et al., 2008). Although there is evidence that diabetes education works, gaps still remain in referring patients to diabetic educators. This can be changed by encouraging providers to make these referrals, providing them with a resource for diabetic educators, and emphasizing the value of education for their Hmong patients living with diabetes (American Diabetes Association, 2015, c). Receipt of a referral from a healthcare provider can

also influence clients' behavior. When providers refer patients to a diabetes education program, there is a greater likelihood for participation than without those referrals (American Diabetes Association, 2015, c), thus making diabetes education referrals critical to managing diabetes.

Participants in our study recognized that they needed more diabetes education. In providing diabetes education, an underlying principle is a patient-centered approach that is responsive to clients' needs (Inzucchi et al., 2012). Culturally appropriate diabetes education supports patient empowerment and proper self-management of the disease (Delamater, 2006; Hawthorne et al., 2010). The CLAS Standards encourage patient-provider relationships at the organizational level to change policies, practices and procedures and develop a strategic plan to integrate cultural competence (Office of Minority health, 2013). Changes in the system, as well as provider knowledge, attitudes and skills are necessary to provide culturally competent care.

Multiple barriers to diabetes self-management behavior were evident in this study, and this is consistent with findings from prior studies (Helsel et al., 2005; Perez & Cha, 2007; Xiong & Westberg, 2012; Yang, Xiong, Vang, & Pharris, 2009b). There are seven essential domains to diabetes self-management which include healthy eating, being active, monitoring blood sugar, taking medication, problem solving, reducing the risks for developing health problems and healthy coping (American Association of Diabetic Educators, 2015). Personalized diabetes education with clear communication and a team that includes a provider, an educator and the person with diabetes is necessary for effective self-management (Powers et al., 2015). These elements are critical to ensure that goals are clear, progress toward goals is achieved and appropriate interventions are taking place. The participants in this study highly rated the use of movies or videos in providing them with culturally appropriate education. Lor and Bowers (2014) evaluated three techniques together, which included: video, pictograph and hands on

activities to teach 150 Hmong participants about cancer screening. In using these three techniques, nearly all the participants perceived an increased understanding, reported greater acceptance of cancer screening and increased willingness to screen (Lor & Bowers, 2014) following the use of these combined educational techniques. For a long time the Hmong people did not have a written language and education occurred through oral tradition. Older Hmong people are unfamiliar with written communication, and so the use of video with cultural and linguistic sensitivity is worth exploring for future diabetes education interventions.

The participants in our study also expressed a need to have support groups to help them to cope with the disease. In another study Hmong participants endorsed the idea of having support groups in the community (Devlin et al., 2006). Peer support can be helpful, as the people in the group may have knowledge of the disease, similar experiences, and similar characteristics as others in the group. People with a chronic illness all have something in common; they may share personal knowledge and experience with each other in a way that health care providers do not understand. Peer support groups should be encouraged for the Hmong with diabetes because they are an eastern communal culture, where, the health of any individual is dependent on the entire family or clan.

Limitations

In our study, the majority of the participants could not read or speak English fluently. There is the possibility that some meaning got lost in the translation process because translation is an “interpretive act” (Van Nes, Abma, Jonsson, & Deeg, 2010, p. 313). Two other limitations worth noting are that the Hmong language does not contain many medical terms. Some concepts in English may be understood differently in Hmong or there might not be a word to describe a phrase or concept.

Although the conceptual model developed from this study should be applicable to Hmong Americans with diabetes, the participants in this study were older, had little to no formal education and may not represent the experience of all Hmong people. Further research is also needed to expand the conceptual model we evaluated to form a theory. Despite these limitations, our study contributes to the literature about the diabetes educational experiences and needs of Hmong Americans.

Conclusions

Diabetes education was reported to be inadequate among the Hmong Americans in our sample. Hmong Americans recognized that they need culturally appropriate and accessible diabetes education. In promoting positive health outcomes for Hmong Americans with diabetes, the barriers and facilitators of diabetes education must be used to build health policies that will improve access to care. When barriers and facilitators to diabetes education are addressed, it is hoped that clients will have better health outcomes, increase in self-management skills, decreased complications, better disease management, and improved receipt of preventative services.

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Table 1 Focus Group Interview Questions

Interview Questions
What do you understand about diabetes? What is diabetes? What does diabetes mean to you? What would happen if you don't take care of your diabetes? What do you think causes diabetes? How comfortable are you in speaking and understanding English? How do you communicate with health care providers What do you want to know about diabetes from your provider? What kind of about diabetes have you received? What did you find helpful about the diabetes education? What was not so helpful? If yes, from whom? Has it helped you in any way to manage your life differently to maintain your health? If yes, what language was the diabetes education provided in? Do you find that diabetes education helps you to understand the illness more? How would you like to receive diabetes education? Do you think using pa'ndau would help you understand diabetes?

Table 2. Demographics of Participants

Demographics of Study Participants, n=16										
Participants	Age in years	Sex	Birthplace	Marital Status	Language Spoken	Level of Education	Read and write Hmong	Read and write English	Length of diabetes diagnosis (in years)	Length of time lived in US (in years)
P1	51	F	Laos	M	Hmong	None	Read only	No	16	21
P2	60	M	Laos	M	Hmong	None	Yes	No	1	20+
P3	60	F	Laos	M	Hmong	None	No	No	U	20+
P4	52	M	Laos	M	Hmong	None	Yes	No	2	21
P5	60	M	Laos	M	Hmong	None	No	No	2+	>30
P6	57	F	Laos	M	Hmong	None	No	No	4+	30+
P7	48	M	Laos	S	English & Hmong	None	Read only	No	3	27
P8	47	F	Laos	S	English & Hmong	High school only	Yes	Yes	13	35
P9	55	F	Laos	M	Hmong	None	No	No	5	21
P10	40	F	Laos	M	Hmong	None	Yes	No	U	20
P11	66	M	Laos	M	Hmong	None	Yes	No	10	29
P12	56	M	Laos	M	Hmong	None	No	No	8	24
P13	69	F	Laos	W	Hmong	None	No	No	7	22
P14	50	M	Laos	M	Hmong	None	Yes	No	U	22
P15	56	F	Laos	M	Hmong	None	No	No	12	29
P16	55	F	Laos	M	Hmong	None	Yes	No	U	20+

P=Participant=Female, M=Male=widow, M=Married, S=Single, U=Unknown

Table 3 Result of the Inductive and Deductive Analyses

Themes from the Inductive Analysis	A priori Constructs from the Deductive Analysis
<p>Perceived Barriers</p> <ul style="list-style-type: none"> • Language Barrier • Barriers to Self-Management • Stressors 	<p>A priori Constructs:</p> <p>1. Consumer Satisfaction</p> <p>Sub-constructs: Cost Quality</p>
<p>Perceived Facilitator</p> <ul style="list-style-type: none"> • Focused Culturally Specific Education • Peer Support Group 	<p>2. Health Care Delivery</p> <p>Sub-constructs: Resource Organization</p>

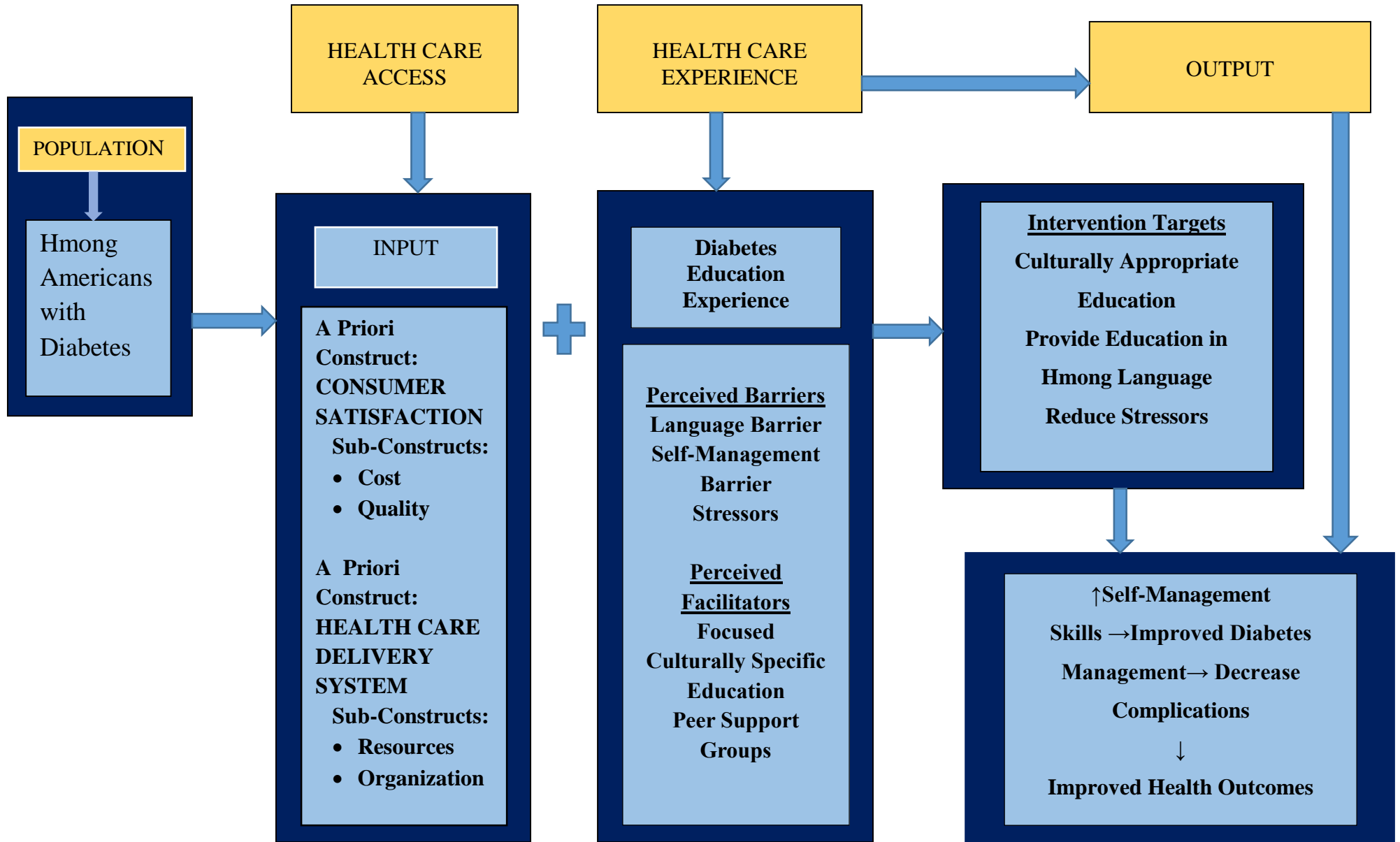


Figure 1 Conceptual Framework explaining the diabetic education experience of Hmong Americans with diabetes

Summary and Conclusion

This dissertation consists of three manuscripts; (1) a literature review of the prevalence of diabetes and factors affecting diabetes care in the Hmong with diabetes, (2) the application of the social ecological model (SEM) to sustain self-management behaviors in people with diabetes mellitus, and (3) a qualitative study to examine the diabetes education experience of Hmong immigrants in the United States. The information presented within this dissertation creates the foundation for future research studies to identify appropriate interventions to educate Hmong Americans about diabetes to increase adherence to treatment regimen, and thus, improve health and quality of life outcomes.

The first manuscript is a scoping literature review of diabetes in the Hmong population. This type of literature review was conducted because the methodology covers a greater depth and a broader research aim. A total of ten articles were extracted from this literature review, seven were qualitative studies, and three were quantitative studies. Findings from this review suggested that Hmong Americans have misunderstandings and misconceptions about diabetes, there are significant cultural characteristics (such as the practice of shamanism, use of medicinal herbs), mistrust of health care providers is common, and a language barrier, all of which can affect diabetes care. Key to this review is that there was inadequate self-management of the disease by Hmong Americans and that there was limited empirical evidence about diabetes education in this population. The next two manuscripts in this dissertation addressed these two findings.

In addressing poor self-management of diabetes in the Hmong population, the subsequent manuscript focused on the application of the social ecological model to identify factors that promote and sustain self-management behaviors in people with diabetes. Because self-

management is so important to diabetes management, health care providers should actively promote ways to maintain and sustain behavior change that supports adherence to prescribed self-management routines. McLeroy et al., (1988) social ecological model is used to address the importance of interventions directed at changing interpersonal, organizational, community and public policy, factors which support and maintain self-management behaviors and help to optimize clinical outcomes in individuals with diabetes.

The qualitative study employed a hybrid design to study the diabetes education experience of Hmong Americans. The inductive approach identified three barriers: language barrier, self-management barriers, stressors and two facilitators: focused culturally specific education and peer support groups. The findings in this study suggest that Hmong Americans have difficulty adhering to self-management behaviors and thus, demonstrated the importance of manuscript two. Findings also suggested that Hmong Americans with diabetes understand that they need more diabetes education and are asking that that diabetes education must be culturally tailored to the Hmong with diabetes. The deductive approach affirmed previous a priori constructs of The Framework for the Study of Access to Medical Care (FSAMC) Access Framework. The constructs from the FSAMC are consumer satisfaction (sub-constructs are cost and quality) and health care delivery system (sub-constructs are resource and organization).

Implication for Practice

The results of this dissertation point to several implications for clinical practice for the care of Hmong Americans with diabetes. None of the published studies retrieved during the literature search for this study reported on the diabetes education experience of Hmong Americans. This substantiates the need for this research focusing on the diabetes education experience in Hmong Americans. The use of a medical access framework, combined with a

grounded theory method identified facilitators and barriers to diabetes education for the Hmong which provides invaluable information on diabetes care and management.

The main emphasis of diabetes education is the promotion of self-management activities. When practiced SMBs positively correlate to glycemic control, reduction in complications and improved quality of live (Kent et al., 2013). Diabetes self-management education is associated with multiple benefits to managing this chronic illness and improving quality of life (Cochran & Conn, 2008; Duncan et al., 2009; Healy et al., 2013). However, diabetes education may be more effective if it is specific to the population. Applying research from the mainstream culture to Hmong Americans, it may be difficult to achieve significant behavior change because of the unique cultural heritage of Hmong Americans. Applying culturally appropriate education that is accessible should be a priority for the health care delivery system. For Hmong Americans culturally appropriate education includes the use of video, pa'ndau, medical interpreters, provider training, and diabetes education in the Hmong language.

The Agency for Healthcare Research and Quality (2014) supports the use of culturally appropriate education to reduce health disparity in ethnic minority populations and that this should be a priority for the health care delivery system. The Office of Minority Health has established national standards for culturally appropriate health services to improve health care quality and equity for the increasingly diverse communities in the US (Agency for Healthcare Research and Quality, 2014). This result of this dissertation supports the call for policies focusing on barriers and facilitators to diabetes education and health care access.

Findings from this research have implication for health policy and advocacy. Racial and ethnic minorities carry a disproportionate burden of the diabetes epidemic, which include higher prevalence rates, poorer diabetes control, and higher rates of complications. With recent

emphasis on the need to decrease health disparity in minority population, this dissertation study suggests the need for legislation that prioritizes health care access and health outcomes for this underserved population.

Future Research

Based on this research study, several areas for future research were identified. It was clear from the scoping review that Hmong Americans with diabetes have limited knowledge of the disease and as a group are understudied. The empirical evidence about diabetes in the Hmong is limited and more research is needed in this understudied population. In keeping with the ADA (2014-2015) strategic plan, there is a need for increased diabetes research and education in ethnic minority groups such as Hmong Americans to promote health equity (2009).

Barriers and facilitators to diabetes education were also identified in this dissertation study. These results can be used to inform the development of culturally appropriate interventions for Hmong Americans with diabetes. When barriers and facilitators to diabetes education are addressed, it is hoped that clients will have better health outcomes, increase in self-management skills, decreased complications, better disease management, and improved receipt of preventative services.

Summary

Hmong Americans face an increased risk of diabetes (Her & Mundt, 2005; Wu et al., 2011). The first manuscript in this dissertation provided a review of the existing body of research on the prevalence of diabetes and factors affecting diabetes care in Hmong Americans with diabetes. Sustaining diabetes self-management is difficult for people with diabetes and is supported by the findings in manuscripts one and two. The second manuscript proposed an ecological model for sustaining diabetes self-management behaviors which focuses attention on

both the individual and social environmental factors as targets for self-management interventions. The third manuscript examined the facilitators and barriers to diabetes education in a sample of Hmong Americans with type 2 diabetes. This dissertation provides preliminary evidence for the application of culturally appropriate diabetes education in future intervention research. Culturally appropriate education has proven benefits for improving health outcomes and can serve as a foundation for reducing health disparities in ethnic minority populations.

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Appendices

Appendix A

Permission to Use Article from Journal Editor

To: "mlewishunstiger@chcm.com" <mlewishunstiger@chcm.com>
 From: "Mitchell-Brown, Fay" <fmitchellbrown@csuchico.edu>
 Date: 01/04/2015 12:08AM
 Subject: Published article in Creative Nursing

Hi Marty,

I am a doctoral student and I am writing to obtain permission to use the article I recently published (in Creative Nursing) as part of my PhD compendium. Ps see below for the article I am referring to:

Mitchell-Brown, F. (2014). [Creative Nursing](#), Volume 20, Number 4, 2014, pp. 234-241(8)

Your attention to this matter would be much appreciated.

Thank you

Fay Mitchell-Brown

Fay M Mitchell-Brown, RN, MSN, CCRN
 Assistant Professor
 California State University-Chico
 Chico, CA 95929-0200
 Phone (530) 898-6368

Email: fmitchellbrown@csuchico.edu
From: mlewishunstiger@chcm.com [<mailto:mlewishunstiger@chcm.com>]
Sent: Sunday, January 04, 2015 6:49 PM
To: Jim Costello; fmitchellbrown@csuchico.edu
Subject: Fw: Published article in Creative Nursing

Hello Fay - Happy New Year! Thank you again for your fine article on diabetes self-management - it was a valuable component of our Timeless Wisdom: Community issue of *Creative Nursing*. I'm sure the use you wish to make of it is fine - I am forwarding your request to Jim Costello at Springer Publishing, who can advise you further. Best wishes, Marty L-H

Marty Lewis-Hunstiger, BSN, RN, MA

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 Creative Health Care Management
 5610 Rowland Road, Suite 100
 Minneapolis, MN 55343-8905
mlewishunstiger@chcm.com

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Managing Editor, the *Interdisciplinary Journal of Partnership Studies*
<https://sites.google.com/a/umn.edu/ijps/>

From: Jim Costello [<mailto:jcostello@springerpub.com>]

Sent: Monday, January 05, 2015 7:46 AM

To: Mitchell-Brown, Fay

Cc: mlewishunstiger@chcm.com

Subject: RE: Published article in Creative Nursing

Dear Fay:

Please consider this note to be formal permission to reproduce your article in Creative Nursing as part of your PhD compendium.

Best regards,

Jim Costello

Vice President, Journal Publishing Program
Springer Publishing Company, LLC
11 West 42nd Street, 15th Fl
New York, New York 10036
T: 212-804-6223

Appendix B



Institutional Review Board for Human Research (IRB)

Office of Research Integrity (ORI)

Medical University of South Carolina

Harborview Office Tower

19 Hagwood Ave., Suite 601, MSC857

Charleston, SC 29425-8570

Federal Wide Assurance # 1888

APPROVAL:

This is to certify that the research proposal **Pro00039320** entitled:

Facilitators and barriers to diabetes education in Hmong Americans in the United States: An exploratory Study

Submitted by: **Fay Mitchell-Brown**

Department: **Medical University of South Carolina**

For consideration has been reviewed by **IRB-I - Medical University of South Carolina** and approved with respect to the study of human subjects as adequately protecting the rights and welfare of the individuals involved, employing adequately methods of securing informed consent from these individuals and not involving undue risk in the light of potential benefits to be derived therefrom. Additionally, the Institutional Review Board for Human Research (IRB) recommends approval of the investigator's request for Waiver of Signed Consent in accordance with 45 CFR 46.117(c)(1),(2) because the only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality and/or because the research presents no more than minimal risk and involves no procedures for which written consent is normally

required outside of the research context. No IRB member who has a conflicting interest was involved in the review or approval of this study, except to provide information as requested by the IRB.

Original Approval Date: **12/12/2014**

Approval Expiration: **12/11/2015**

Type: **Expedited**

Chairman, **IRB-I - Medical University of South Carolina**

Susan Newman*

Statement of Principal Investigator:

As previously signed and certified, I understand that approval of this research involving human subjects is contingent upon my agreement:

1. To report to the Institutional Review Board for Human Research (IRB) any adverse events or research related injuries which might occur in relation to the human research. I have read and will comply with IRB reporting requirements for adverse events.
2. To submit in writing for prior IRB approval any alterations to the plan of human research.
3. To submit timely continuing review reports of this research as requested by the IRB.
4. To maintain copies of all pertinent information related to the research activities in this project, including copies of informed consent agreements obtained from all participants.
5. To notify the IRB immediately upon the termination of this project, and/or the departure of the principal investigator from this Institution and the project.

** **Electronic Signature:** This document has been electronically signed by the IRB Chairman through the HSSC eIRB Submission System authorizing IRB approval for this study as described in this letter.*

Appendix C

Recruitment Flyer

YOUR CHANCE TO PARTICIPATE IN HMONG DIABETES RESEARCH

IF YOU ARE INTERESTED IN PARTICIPATING IN A RESEARCH STUDY TO IMPROVE DIABETES CARE IN THE HMONG POPULATION, PLEASE CONTACT:

Principal Investigator:

Fay Mitchell-Brown

(530)520-0430

mitchef@musc.edu

Community Partner:

Chia Thao

Telephone: (559)260-7421

Email: chiat@csufresno.edu



IRB Number: «ID»

Date Approved ««_attribute154»»

Appendix D

Demographic Questions

1. How old are you?
2. Are you male or female?
3. Are you single or married?
4. What language do you speak?
5. What is your highest level of education
6. Can you read and write Hmong?
7. Can you read and write English?
8. How long have you had diabetes?
9. Where were you born?
10. If not the US, how long have you lived in the US?

Appendix E

Focus Interview Questions with Probes

1. How comfortable are you in speaking and understanding English?
Probe: What situations are you most comfortable in speaking and understanding English?
How well do you speak and understand English?
2. What do you understand about diabetes, what is diabetes? Probes: What does living with diabetes mean to you? What would happen if you don't take care of your diabetes?
3. What does diabetes mean to you?
Probe: What do you think causes diabetes? What do you want to know about diabetes from your provider?
4. What is your experience with health care providers? Probes: Do you attend a clinic or medical practice that has translation services? Do you feel satisfied with the communication you receive there?
5. Have you received any education on diabetes? If yes, from whom? Has it helped you in any way to manage your life differently to maintain your health? If yes, what language was the diabetes education provided in?
6. If received diabetes education, what kind of information were given to you (brochures, handout)? Probe: What would help you understand diabetes better? Probes: photos, videos, one-on-one instruction? What do you prefer?
7. What would help you understand the illness more?
8. What does pa'ndau mean to you? Do you think using pa'ndau would help you understand diabetes and how to manage your diabetes?

Appendix F

Off Campus Study Site Form



Office of Research Integrity

19 Hagwood Ave, Suite 601

(843) 792-4148

Fax (843) 792-7457

Off Campus Study Site Form

PRO/HR # 00039320

STUDY TITLE: Facilitators and barriers to diabetes education in Hmong Americans in The United States: An exploratory Study

PRINCIPAL INVESTIGATOR: Fay Mitchell-Brown

Co-Investigator: Lynne Nemeth

ADDRESS OF OFF-SITE FACILITY:

1300 E Shaw Ave Ste 117

Fresno, CA 93710

NAME OF NON-MUSC INVESTIGATOR/ INSTITUTIONAL OFFICIAL: Chia Thao

SECTION I**A. Is the off-campus site “engaged” in human subject’s research pertaining to this study?**

To make this determination you will need to consult the OHRP website to assist in determining if the off campus site’s role in this study makes the site “engaged.” In general, an institution is considered *engaged* in a particular non-exempt human subjects research project when its employees or agents for the purposes of the research project obtain: (1) data about the subjects of the research through intervention or interaction with them; (2) identifiable private information about the subjects of the research; or (3) the

informed consent of human subjects for the research. See the following link for categories and guidance:

<http://www.hhs.gov/ohrp/policy/engage08.html>

1. Check either A or B below: (Completion of A or B is required)

(A) Activities at the off-campus site are consistent with examples under Category A; the site is engaged in human subjects research

If you checked this section, please identify the specific type of activity or activities to be done at this off site campus by providing the number of the example from the OHRP website. For example: A1, A2, A3, etc.

X (B) Activities at the off-campus site are consistent with examples under category B; the site is not engaged in human subjects' research (B4-B5)

If you checked this section, please identify the specific type of activity or activities to be done at this off site campus by providing the number of the example from the OHRP website
B5

2. Does the off-campus site have a Federal Wide Assurance (FWA)?

Yes If yes, what is their FWA:

X No

3. Does the off-campus site have an Institutional Review Board for Human Research?

Yes X No

If Yes, the individual or site must contact that IRB and provide MUSC with documentation on whether IRB approval is required.

Please provide the name, address and phone number of the IRB:

If Yes, has the off-campus site's IRB approved this study?

Yes No

If the off-campus site's IRB has not approved this study, will review by that IRB be required?

Yes No

If no, please explain.

SECTION II. (Complete this section if you selected Section IA(1)(A)).

A. List all community individuals that will be engaged in the study.

Individuals are “engaged” if they will: (1) obtain data about research participants through intervention or interaction with them; or (2) obtain identifiable private information or identifiable specimens about the participants of the research – even if they do not directly interact with them or (3) the informed consent of human subjects for the research. More information pertaining to what constitutes engagement can be found in the OHRP guidance on engagement at: <http://www.hhs.gov/ohrp/policy/engage08.html>

Individual's Name <i>Use full legal name</i>	Individual's Credentials and/or Position <i>(e.g., M.D., Executive Director., recruitment specialist)</i>	Individual's Role on the study <i>(e.g., consent, deliver interventions, data analysis)</i>
Fay Mitchell-Brown	RN, MSN, Doctoral Student	Principal Investigator

To expand table, move to the end of the last row and press the tab key.

***Any community individual “engaged” in research will need to complete the CITI MIAMI training course and be listed on the eIRB personnel list.*

**** If any community individual member of a facility is considered “engaged” in research, the site is then considered “engaged in research under section I(A)(1) of this form.**

B. For each individual listed above who will be involved in the informed consent process, please complete the information below.

Name:

Current Position/Role at the Facility:

Human Subjects Education/Training:

You may copy and paste this box as many times as needed. Box expands.

***For those individuals and/or sites that do not have their own IRB, MUSC may consider taking on the role of IRB of Record. Please review the [guidance](#) provided by SCTR (pg2) on how to apply for a Federal Wide Assurance (FWA) / Institutional Authorization Agreement (IAA). Contact your MUSC IRB administrator if you have questions.

**MUSC may assume IRB responsibilities for non-affiliated institutions and investigators only under certain conditions (i.e., such as when an approved IRB Authorization Agreement exists designating the MUSC IRB to serve as the IRB of Record and the facility applies for and receives and FWA from OHRP).

**If the MUSC IRB takes on the role of IRB of Record, individuals must complete an IRB approved education program ([CITI MIAMI](#)) for the protection of human research participants prior to conducting this, or any other, research involving human participants.