

**UCSF**

**UC San Francisco Electronic Theses and Dissertations**

**Title**

Interpretive phenomenologic study of diabetes beliefs and practices among first generation Asian Indians in the US

**Permalink**

<https://escholarship.org/uc/item/7q98f6x5>

**Author**

Deol, Rupinder

**Publication Date**

2015

Peer reviewed|Thesis/dissertation

Interpretive Phenomenological Study of Diabetes Beliefs and Practices among  
First-generation Asian Indians in the US

by

Rupinder Mangat Deol

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Nursing

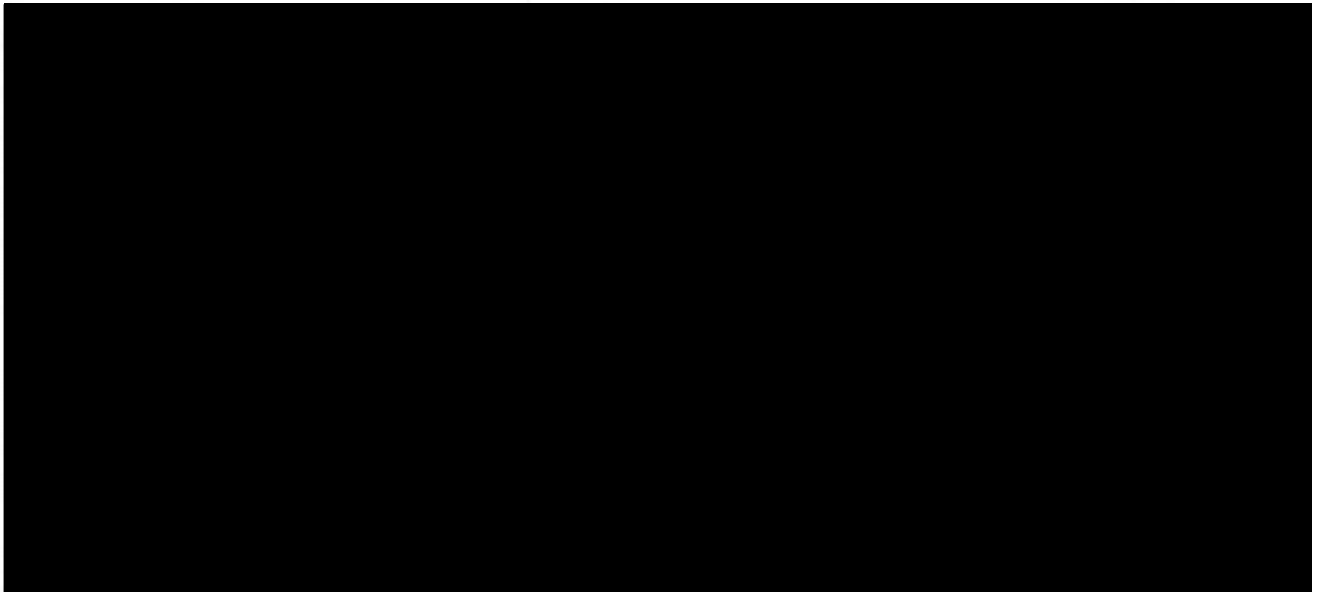


in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO



Copyright 2015  
by  
Rupinder Mangat Deol

## **Acknowledgement**

I firmly believe that no major endeavor is accomplished alone. I would like to wholeheartedly thank my children, Reina, Arjun and Bela for having faith in me and cheering me on. My husband for holding the light at the end of this tunnel also deserves my gratitude. I am thankful to my parents who always had faith and encouraged me to pursue academic excellence.

On a professional note, I would like to thank Dr. Kit Chesla for her endless advice and patience with me. I could not have done this without her support and encouragement. Also, thanks to Dr. Lisa Thompson and Dr. Kevin Chun for their support and guidance. Most of all I want to thank my participants for sharing their valuable experiences and insights with me. Finally, my many colleagues and professors that have guided me throughout my five year journey at UCSF.

## ABSTRACT

### Diabetes Beliefs and Practices among First-generation Asian Indians in the US

**Purpose:** In the United States one in six Asian Indians (AI) is diagnosed with type 2 diabetes and the prevalence of diabetes in AI (between ages 45-79) in the San Francisco Bay Area is 29%. Although culturally distinct issues have been anticipated, only a few studies have examined AI beliefs and practices regarding diabetes. The purpose of this study was to explore and understand cultural commonalities and differences in illness management in AIs. Aims of this study were to describe: 1) Beliefs about causal factors and diabetes management 2) Daily challenges and supports encountered in managing type 2 diabetes; 3) Culturally specific practices (religious, dietary and physical activity) that affected type 2 diabetes; 4) Commonalities and differences by gender differences that impacted type 2 diabetes. The overall goal was to provide an interpretive account of the daily activities, challenges and barriers faced by AI in managing their diabetes in their everyday lives.

**Approach:** Interpretive phenomenology (IP) guided the research design and analysis. In-depth narrative and explanatory data about health beliefs and practices was gathered through open-ended interviews. A convenience sample of 12 adult participants (50% female) between the ages of 40-79 who self-identified as first generation AI, diagnosed with type 2 diabetes, low income with average duration of U.S. residency of 20 years were recruited via public announcements and in person presentations at Sikh Temples. Each participant was interviewed twice in English or Punjabi to learn illness understandings including cause, culturally specific practices, supports and barriers to illness management.

**Results:** The high prevalence of diabetes in the AI community led participants to express a sense of inevitability for developing the disease. Participants uniformly suggested that social and environmental causes outweighed hereditary or biological causes for their diabetes although beliefs were gender-specific. Female participants named stressors that disrupted family harmony and overwhelming family responsibility, and a lack of quality communication with their physicians as contributing to their diabetes. Male participants suggested that employment stresses and poor diet were causal. Diabetes management was complicated by dietary, cultural and social practices. Lack of knowledge, poor access to medical care and immigration further hindered diabetes control.

**Conclusion:** Efforts in prevention and community outreach programs are needed as the AI population increases in the United States. Public health initiatives that increase early screening and awareness of diabetes may improve diabetes and its complications in the AI community. Culturally specific diabetes prevention programs for AI, assistance in managing social and environmental contributors to diabetes must be addressed alongside lifestyle (diet and exercise) changes.

## Table of Contents

Acknowledgements	iii
Abstract	iv
List of Tables	ix
Chapter 1: Literature Review	1
Background and Significance	2
Asian Indians in the United States: An Historical Overview	5
Critique of the Literature	8
Beliefs about Causation and Management of Diabetes	9
Lifestyle Factors	14
Interactions with Health Care Providers	18
Summary	20
Study Purpose and Aims	21
Chapter 2: Methodology	23
Qualitative Methods	25
Grounded Theory	27
Ethnography	29
Phenomenology	31
Philosophical Assumptions	32
Methodological Implications – Hermeneutics	35
Interpretive Phenomenology – Asian Indians with Diabetes	39

Chapter 3: Theory	50
Self-Efficacy Theory	52
Empowerment Theory	62
Health Empowerment Theory	66
Applying Self-Efficacy and Health Empowerment Theories to Asian Indians	69
Chapter 4: Results	73
Participant Characteristics	73
Beliefs about Diabetes, its Causes, and Management	74
Beliefs about Cause – Gender Differences	84
Daily Challenges and Supports	96
Social, Cultural, and Religious Practices That Affect Type 2 Diabetes	119
Exploring Gender Differences in Managing Marital and Family Roles	132
Chapter 5: Discussion	137
Implications	142
Limitations	146
Conclusion	146
References	148
Appendices	
Appendix A Flyer	167
Appendix B Consent Form	168
Appendix C Demographic sheet	171
Appendix D Interview guide	172



Glossary	175
Library Publishing Agreement	177

## **List of Tables and Figures**

### Table

1. Validity: Primary and Secondary Criteria	49
2. Participant characteristics	74
3. Self-Efficacy and Health Empowerment in AI with Diabetes	143

## Chapter 1

### LITERATURE REVIEW

Diabetes mellitus, a metabolic disease, is characterized by hyperglycemia that results from defects in insulin secretion, insulin action or both (American Diabetes Association [ADA], 2010). The three most common forms of the disease are type 1, type 2 and gestational diabetes. Type 1 diabetes results from the destruction of beta cells in the pancreas, which leads to complete insulin deficiency. Type 2 diabetes which accounts for most diagnosed cases (85%-95%) is usually characterized by insulin resistance in which target tissues do not use insulin properly. Gestational diabetes, the third type of diabetes occurs during pregnancy. Other types of diabetes are known but rare, such as those caused by drug use, genetic conditions (maturity-onset diabetes of youth), infections and other illnesses, malnutrition, infections and surgical operations. Diabetes reduces both quality of life and life expectancy and imposes a significant economic burden on individuals, their family and the health care system.

Controlling diabetes is determined by glycosylated hemoglobin (A1C) levels. Current ADA (2015) guidelines recommend that lowering A1C levels below or around 7% has been shown to reduce microvascular and neuropathic complications of diabetes. Similarly, the UK Prospective Diabetes Study Group (UKPDSG, 1998) found that maintaining A1C targets below or around 7% is associated with long term reduction of macro vascular disease. The ADA (2015) guidelines state that lowering A1C to below or around 7% has been shown to reduce the microvascular complications of diabetes, and is associated with long-term reduction in macrovascular disease.

Achieving control over diabetes is a complex process. It requires not only the management of multiple medications, but major changes in lifestyle, specifically diet and exercise. Treatment typically includes increasing one's level of physical activity, eating a healthy diet, and, in some cases, taking oral medications and, or insulin to improve or maintain glycemic control. In addition, patients are required to use glucometers at home to monitor their blood sugars several times a day. All of these interventions aid in the self-management and control of the disease. Those who do not adhere to treatment and lifestyle modification or achieve control their diabetes risk complications such as coronary heart disease, nephropathy, neuropathy, retinopathy and premature death (UKPDSG, 1998).

### **Background and Significance**

In the United Kingdom (UK), diabetes is roughly 4-6 times more common in Asian Indians than it is in Europeans (D'Costa, Samanta & Burden, 2000) and this proportional difference is similar in the United States (Mohanty, Woolhandler, Himmelstein & Bor, 2005). Asian Indians encompass individuals of Indian origin from India, Bangladesh, Pakistan, Africa and Fiji. Raleigh, Kiri and Balarajan (1997) reported that Asian Indians are more likely to develop diabetes 11 years earlier than people of European origin and to die prematurely from cardiovascular disease. They found that Asian Indians had a mortality rate 40% higher than their European counterparts. Most of the research on Asian Indians with diabetes has been conducted in the United Kingdom, but interest in this population is growing in other parts of the world. Recent studies have been published in Canada, New Zealand, and the United States (Bean, Cundy, & Petrie, 2007; Creatore et al., 2010; McNeely & Boyko, 2004; Mehrotra, Gaur, & Petrova, 2012).

Mohanty et al. (2005) reported that Asian Indians in the United States had a higher prevalence of diabetes and developed it at a younger age than non-Hispanic Whites, despite having lower body mass index (BMI). However, only a few studies have examined the incidence of chronic diseases, including diabetes in Asian Indians. In their pilot study, Kanaya et al. (2010) found that Asian Indians in the San Francisco Bay Area were at higher risk of developing diabetes than any other ethnic group in the United States; the prevalence of diabetes between 45 and 79 years of age was 29%. Venkataraman, Nanda, Baweja, Parikh, and Bhatia (2004) found the overall prevalence of diabetes mellitus in Asian Indians in Atlanta, GA to be 18.3% which is much higher than it is for Blacks (12.8%), Hispanics (8.4%) and Whites (6.6%) living in the United States (Cowie et al., 2009). Misra and colleagues (2010) reported the prevalence of prediabetes to be 33% and the prevalence of type 2 diabetes to be 17%. Studies conducted in the United Kingdom (Simmons & Williams, 1997; Unwin et al., 1998) and India (Mohan et al., 2006; Ramachandran, Mary, Yamuna, Murugesan, & Snehalatha, 2008) have reported similar findings.

Asian Indians confront several barriers in their attempt to control their diabetes. Reducing complications of diabetes and achieving control over their disease's progress are complicated processes because Asian Indians are a heterogeneous group with different languages, dialects, religions, and cultural beliefs (Farooqi, Nagra, Edgar, & Khunti, 2000). Asian Indians have less knowledge about the process of their disease, minimize the seriousness, and have a limited understanding of the relationship between achieving control and avoiding diabetic complications (Bean, et al., 2007; Macaden & Clarke, 2006). Low socio-economic status, lack of accessible health care and language barriers have also been suggested as contributing factors to poor control of diabetes in this population (Creatore, et al., 2010; Grace, Begum, Subhani, Kopelman, &

Greenhalgh, 2008; Stone, Pound, Pancholi, Farooqi, & Khunti, 2005). Migration to more industrialized nations and the resulting Westernization of diet and lifestyles have also been associated with increased incidence of diabetes in South Asians (Farooqi et al, 2000; Lawton, Ahmad, Peel & Hallowell, 2007).

Asian Indians have an increased genetic susceptibility to diabetes and excessive insulin resistance, which is enhanced by environmental triggers such as physical inactivity, excessive caloric intake and truncal obesity (Abate & Chandalia, 2001; Kanaya et al., 2010; Sinha et al., 2013). In a cross sectional study using data from the National Health Interview Survey, Mohanty et al. (2005) reported that Asian Indians had lower mean BMIs (24) than non-Hispanic Whites (26). Only 6.2% of Asian Indians were obese compared with 19.2% of non-Hispanic Whites. Despite lower BMIs, Asian Indians had greater truncal obesity and an increased waist/hip ratio (McKeigue, Shah, & Marmot, 1991), putting them at a higher risk of developing diabetes.

For Asian Indians, diabetes mellitus is a significant risk factor for cardiovascular disease and mortality. An epidemiologic study (Palaniappan, Wang, & Fortman, 2004) that examined mortality from coronary heart disease in six ethnic groups in California reported that the highest mortality rates were found in Asian Indian men and women when compared with non-Hispanic Whites, Blacks, Chinese and Japanese. Similarly, Asian Indians had the highest mortality from coronary heart disease when compared with individuals of Chinese and European descent (Sheth, Nair, Nargundkar, Anand, & Yusuf, 1999). Pre-existing diabetes was found to be more common in Asian Indians with coronary heart disease than in Whites who also had coronary heart disease (Gupta, Doobay & Singh, 2002). This finding suggests that diabetes may be contributing to Asian Indians' increased risk of death from coronary heart disease.

Currently, one in six Asian Indians in the United States has been diagnosed with type 2 diabetes (Misra et al., 2010; Venkataraman et al., 2004) which is higher than that reported for Blacks (12.8%), Hispanics (8.4%), and Whites (6.6%); (Cowie, et al., 2009). It has been projected that by 2020 more than 50% of the US population will be non-White, and Asian Indians will represent an increasing number among the immigrant population. The gaps in accessible health care for an increasing minority population will certainly worsen (Abate & Chandalia, 2001). Thus, identifying and understanding the challenges and barriers faced by Asian Indians is a public health priority.

### **Asian Indians in the United States – An Historical Overview**

In 2013, 382 million people, 8.3% of the world's adult population, was estimated to have diabetes, and the number is expected to reach 592 million by 2035 (International Diabetes Federation (IDF) 2013). The IDF has estimated that more than 65% of the world's population with diabetes will come from Asia, the world's most populous region. After China, India has the second largest number of individuals with diabetes. By 2035, it is estimated that India will roughly have 123 million people with diabetes (IDF, 2013).

Roughly 3.4 million South Asians live in the United States; the five largest community groups being Indians, Pakistanis, Bangladeshis, Sri Lankans and Nepalese (SAALT, 2010). Asian Indians comprise 16.4% of the total Asian population in the country (Greico & Cassidy, 2001). Historically, they have immigrated to the United States in four distinctive periods. The earliest immigration period has been traced to the 1890s and the 1920s when men from the Punjab region of India arrived. Most of them settled in California and worked on farms, in

lumberyards, and on steamships and railroads. The Immigration Act of 1917 and The Immigration Act of 1924 barred the immigration of South Asians into the United States.

The Immigration and Nationality Act of 1965 abolished the ban on Asian immigrants and established a preference system based on those professional skills that were needed in the United States. This second period of immigration led to an influx of South Asian immigrants who were highly educated. Most of these South Asians were professionals in engineering, medicine and science. By the 1970s and 1980s, compared with other recent immigrant groups, Asian Indians were among the highest educated, most professional and highest earning group.

The third period of Asian Indian immigration resulted from the Family Reunification Act in the 1980s. This act, which allowed well-established Asian Indian families to sponsor emigrating family members, resulted in a dramatic growth and change in Asian Indian communities across the United States. Many of these immigrants were less educated and more economically disadvantaged than their sponsors. Most of these immigrants were employed in service sector jobs, such as driving taxis and managing motels, convenience stores, and gas stations. From 1965 to 1990 1 million Asian Indians immigrated to the United States (SAALT, 2010).

During the fourth period of immigration, (1995-2000), well-educated Asian Indian immigrants came to the United States to pursue further education and employment especially in information technology. This group tended to settle in more cosmopolitan areas where high technology industries were present.

Of the 3.4 million South Asians in the United States, 1.9 million are of Indian origin. The largest populations of Asian Indian immigrants live in Chicago, Los Angeles, New



Jersey/New York, the San Francisco Bay Area, and the Washington DC Metro Area (SAALT, 2010). Asian Indians have maintained their cultural distinctiveness despite assimilation into the larger American society. This has been accomplished by the development of voluntary cultural and religious associations that have maintained a sense of community within this group (Gawlick, 1997).

In the United States, the Asian Indian population is often viewed as one of the more successful immigrant groups. On average, it is well educated and economically advantaged compared with other foreign-born groups (Misra, Patel, Davies, & Russo, 2000). Educationally, Asian Indian immigrants, on average, have acquired a bachelor's degree; economically they have median income higher than that of all other groups (Reeves & Bennett, 2004). For this, they are often referred to as a model minority. Model minority stereotype refers to a ethnic, racial, or religious minority group whose members have achieved a higher degree of success than the population average; this success is typically measured by income, education, and related factors such as low crime rate and high family stability (Vyas, Chaudhary, Ramiah, & Abbasi, 2012).

However, labeling Asian Indians as a model minority has fostered an inaccurate perception that they are uniformly successful, healthy, wealthy, and socially well assimilated. The reality is quite to the contrary. Many Asian Indians in the United States have significant disparities (SAALT, 2010). For instance, the third wave of Asian Indian immigrants was less educated, did not speak English and earned lower incomes than the previous wave of immigrants and lacked access to health care. SAALT (2010) reported that 23% of Asian Indians had limited English proficiency and 11% live in linguistically isolated homes. People from Bangladesh have the highest rates of limited English proficiency (50%) and linguistically

isolated households (32%). Thirteen percent of Asian Indians live at or below the poverty line. One in four Bangladeshis, one in five Pakistanis (SAALT, 2010) and 14% of Asian Indian children in California (Brown, 2008) live in poverty.

SAALT (2010) also reported that 21% of all the Asian Indians in the United States lack health insurance, which surpasses the national average of 18%. Health care use by Asian Indians is lower than for many other minority groups; approximately 40% of Asian Indians under the age of 65 have reported having no regular source of care (SAALT, 2010). A study of health care practices among Asian Indians reported that those who exercised regularly and abstained from alcohol and tobacco reported higher perceptions of their health status and greater satisfaction with medical care. Those who received regular medical examinations and underwent preventative screening had higher incomes and, higher levels of education than those who had negative perceptions of self-health and lower satisfaction with medical care (Gupta, Kumar, & Stewart, 2002). Kandula, Wen, Jacobs, & Lauderdale (2006) found that foreign born South Asians believed that preventive health screenings were unnecessary unless they perceived a health problem.

### **Critique of the Literature**

A comprehensive search of the Cumulative Index to Nursing and Allied Health Literature (CINAHL), the International Bibliography of the Social Sciences (IBBS) and PubMed was conducted for the period 2000-2015 using the key words: “South Asians”, “East Indians”, “Asian Indians” and “diabetes”. The search was limited to articles that related to diabetes and adult Asian Indians age 18 or older. Excluded from the search were publications that were not written in English or published only in abstract form. Most of the studies were quantitative and

discussed the pathophysiology, prevalence, and risk factors for diabetes in Asian Indians. The search terms were refined to include MeSH terms such as “psychosocial issues”, “self-management”, “perceptions”, “beliefs”, “lifestyles”, “diet”, and “physical exercise”, “metabolic syndrome” and “diabetes type 2”. However, few studies were found using a combination of these terms. Accordingly, the search was broadened to include other chronic diseases such as cancer and cardiovascular disease. As a result, 38 studies were found. Of these, 20 were conducted in the United Kingdom, 12 in the United States, 3 in Canada and India, and 1 in New Zealand. The South Asians in all the studies came from at least four countries/regions of origin (Bangladesh, East Africa, India and Pakistan) and four religious groups (Christian, Hindu, Muslim and Sikh). From this body of literature, three themes emerged that addressed the challenges and barriers faced by Asian Indians: beliefs about the causation and management of diabetes, lifestyle factors and interactions with health care providers.

### **Beliefs about Causation and Management of Diabetes.**

Although several authors have discussed Asian Indian beliefs about the causes and management of diabetes, none have found a single cohesive system of health beliefs and behaviors that span this group. Asian Indians, it must be stressed, are a diverse group with different religions and beliefs. In several studies of Asian Indians, the most commonly cited causes of diabetes were external factors that were beyond the control of study participants: hereditary factors, a divine power or the stress of migration (Macaden & Clarke, 2006; Stone, et al., 2005). Those with a family history of diabetes believed that it was inevitable that they too would develop diabetes. One participant, for example, said, “My dad had diabetes, he passed away now; my mum’s diabetic – so I knew that along the line I would end up with it” (Stone et al., 2005, p. 649).

Divine power and fatalism are often believed to cause diabetes, as reported by studies (Lawton et al, 2007; Macaden & Clarke, 2006). Some participants have said that divine power is an external cause of diabetes over which they had no control. Muslim participants have cited “*Allah’s will*” as the cause of their disease (Lawton et al, 2007). In a grounded theory study of risk perception among 20 Asian Indians with diabetes, one participant states, “Allah decided to give you the illness. He will. No matter how well you are or how healthy you are” (Macaden & Clarke, 2006, p. 179). Similarly, a Sikh participant stated “What our master wants will happen. This is how it is, we cannot do anything” (Lawton et al., 2007, p 49). Similar views on reliance on divine power and fatalism were described in a studies of Asian Indian women in Canada with breast cancer (Gurm et al., 2008) and South Asians with cardiovascular disease(Farooqi, et al., 2000).

The stress of migration, according to Asian Indians, is another presumptive cause of diabetes (Farooqi et al., 2000; Lawton et al., 2007; Macaden & Clarke, 2006). Participants in Lawton et al.’s (2007) study flatly stated that moving to the United Kingdom caused diabetes. They felt that a country so culturally and spatially different caused them to develop the disease. One participant clearly opined that moving to the United Kingdom “changed everything, the country changes, the air changes, and the water changes. That is why we get a lot of sugar” (Lawton et al., 2007, p 48). Other migration-induced stress included financial constraints and long hours at unfavorable jobs (Lawton, Ahmad, Hanna, Douglas, & Hallowell, 2006).

An association between acculturation and increasing rates of coronary artery disease, diabetes, hypertension and obesity has been identified in various ethnic groups (Hubert, Snider, & Winkleby, 2006; Kaplan, Chang, Newsom, & MacFarland, 2002). Acculturation is multidimensional and a dynamic process of cultural adjustment and adaptation arising from

sustained contact between distinct cultures and involving different degrees of cultural learning, maintenance and synthesis that are dependent on individual, group and environmental factors (Chun & Akutsu, 2008; Marin, Balls Organista, & Chun, 2003). Some authors have described it as to the extent to which immigrants adapt to elements of a host culture. (Venkatesh, Weatherspoon, Kaplowitz, & Song, 2013). Acculturation is multidimensional because cultural adjustment occurs in multiple areas of psychosocial functioning with potentially distinct adaptation outcomes. Also, acculturation is dynamic because it is a continuous and fluctuating process in which cultural adjustment demands can change across social and cultural contexts. Fundamentally, acculturation stress arises when cultural adjustment and adaptation demands, including demands to maintain valued features of one's culture of origin or learn new cultural behaviors and norms, exceed one's coping skills, abilities and resources (Chun & Hsu, 2012). Venkatesh et al. (2013) examined acculturation using the Suinn-Lew Asian Self Identity Instrument among first generation Asian Indians with diabetes (N=30) and found that the acculturation level of the overall sample was below bicultural level ranging from 1.71 to 2.8. Six out of the 15 individuals in the acculturated group reported an increased awareness of their health, increased physical activity, and perceived lack of extended family in the United States. These factors enabled them to manage their diabetes without interference (Venkatesh, et al., 2013). The participants reported that they had better control of their diabetes since moving to the United States; and had modified their cooking practices to avoid oil and fat. They also reported the increased availability of exercise facilities, absence of negative influences of social networks, good health care facilities, and access to self-monitoring devices, medical insurance and better medications. As one participant reported, "In India, there is not much of an insurance system, the medicines are too expensive, and I am not sure if they are correct. If you can't

manage in this country, then you can't manage anywhere in the world" (Venkatesh et al., 2013, p 82). Of the 15 participants who had poorer control of their diabetes, only 2 believed that it would have been easier to manage their diabetes in India because of the favorable weather and increased physical activity due to their occupation (Venkatesh et al., 2013). The researchers concluded that acculturation enables most Asian Indians to gain better control of their diabetes.

Passivity and resigned acceptance were two behaviors that were found to explain poor self-management of diabetes (Lawton et al, 2006; Macaden & Clarke, 2006). Among the older Asian Indians, the perception of aging was associated with an overpowering presence of morbidity and mortality. One participant with diabetes, for example expressed the feeling this way, "How long you're going to live, and if you have lived a fairly reasonable life, you know you don't bother. You don't take much of consideration, really" (Macaden & Clarke, 2006, p. 180). A participant in another study said "That with age you become weaker and there is not much you can do about it, and death will come when it will, it is in Allah's hands" (Lawton et al., 2006, p. 49). Resigned to their faith, some participants said that "They would leave it up to God, nobody could change their fate and it was recorded before you came into the world" (Macaden & Clarke, 2006, p. 180).

Biomedicine is a term that describes allopathic medications such as hypoglycemic agents and insulin, which require prescription authority. Asian Indians try to achieve a balance between biomedicine and food to achieve control over their diabetes. Three studies (Grace et al., 2008; Lawton et al, 2005; Pieroni, Houlihan, Ansari, Hussain, & Aslam, 2007) have reported on complementary therapies that were used in conjunction with or as a supplement to biomedicine to achieve such balance. Biomedicines are perceived as causing too many side effects. In one study (Lawton et al., 2005); Asian Indians deliberately reduced their recommended dosing of

oral hypoglycemic medications without being advised to do so. They believed that the medications were merely providing symptom relief rather than a cure, and any medication taken for a long period of time would be detrimental to their health. Some participants ate certain foods, like vegetables that were thought to be good for health and would “cure” diabetes. In their study Pieroni et al. (2007), found that, most participants believed that they needed to combine their own healing strategies with biomedicine. Women believed that the healing properties of certain plants would have a more general, preventative effect on other family members. Carrots, cassava, and radishes were thought to prevent diabetes. Angular loofah, cluster beans, drumsticks, rat tail radishes, and especially bitter melon were thought to cure diabetes. Grace et al., (2008) also reported similar findings. Pieroni et al. (2007) described an interesting humoral belief: Their South Asian participants believed that poor health occurs from a lack of equilibrium between “hot” and “cold”. Hence a cold food should be used to treat a hot illness and vice versa. Because diabetes is considered to be a cold condition, it should be treated with hot, dry foods that are bitter (Khajuria & Thomas, 1992).

In summary, most of the studies that have examined Asian Indian beliefs about health and causation of diabetes have been conducted in the United Kingdom. Participants in these studies identified hereditary factors, fatalism or a divine power, and the stress of migration as causes of their diabetes. They believed that they had no control over the development of the disease and tended to externalize its cause and accept diabetes passively. Study participants tended to manage their risks by minimizing the presence of diabetes, by weighing the consequences of actions required, or by balancing the risks of biomedicine and complementary therapies. In the one study (Venkatesh et al., 2013) conducted in the United States, participants acknowledged the positive effects of migration and acculturation on diabetes control. Differences

in study findings could be attributed to the differing participant characteristics. The participants in the U.S. study conducted were highly educated, had a higher socioeconomic status, and spoke English; participants in the United Kingdom were shift workers and did not speak English

### **Lifestyle Factors.**

Asian Indians with diabetes have found lifestyle modifications to be difficult to achieve, particularly physical activity and diet modification (Bissell, May, & Noyce, 2004; Grace, et al., 2008; Stone, et al., 2005). In several studies, participants reported lower levels of activity than the general population in the United Kingdom, especially among women and older adult participants (Fishbacher, Hunt, & Alexander, 2004; Hayes et al., 2002; McKeigue, et al., 1991). Physical activity was seen to be important for mental wellbeing and caring for one's body, and it enhanced a person's ability to control their weight (Grace, et al., 2008). In the same study, walking was considered to be a valuable exercise and, presented no challenge to modesty. Physical activity was viewed as a formal activity rather than a lifestyle. Asian Indians had been advised by their health care providers that they should be exercising regularly to control their diabetes. However, Lawson et al. (2006) found that only a few men put this advice into practice. Most participants did not exercise.

Only three studies have addressed barriers to physical activity (Farooqi et al., 2000; Grace et al., 2008; Lawton et al., 2006). Complex factors were identified as negatively affecting physical activity in Indian and Pakistani patients (Lawton et al., 2006). In a study exploring limitations to exercise among 80 Bangladeshis with diabetes, exercise among women and older adults was deemed to be inappropriate and likely to engender gossip and laughter (Grace, et al., 2008). Practical considerations such as lack of time and opportunity were often entangled with



social rules and cultural expectations (e.g., obligations to kin, gender role restrictions (women not allowed to leave home alone), and lack of socialization into sports and outdoor activities.

Lawton et al's. (2006) participants reported that working long and hours was a limiting factor for exercise. Similarly, the perception that diabetes weakened one's body and was irreversible limited participation in physical activity. Even if participants undertook physical activity, they viewed its long-term benefits with suspicion.

Diet modification was another frequently cited barrier for Asian Indians with diabetes (Farooqi, et al., 2000; Stone, et al., 2005). Yet there was some evidence that gradual changes were being made. Some participants mentioned that they were "changing, grilling instead of frying, or that teenage children won't let you cook too much" (Farooqi et al., 2000, p. 295). Dietary practices among Asian Indians vary based on religious beliefs and country of origin. However, there are commonalities. Ghee, a fat that provides a richer taste to food is frequently used for cooking in several ceremonies because of its religious symbolism. Because hospitality is greatly valued, sweets, deep fried snacks and sugared tea are often offered to guests as a welcoming gesture. Social etiquette makes it impolite to refuse such gestures. As a result, people with diabetes often find it difficult to mention their dietary restrictions to their hosts. In some studies participants with diabetes have described how their disease affects participation in social events, especially where food is served. They described limiting their social activities and depathologizing their diabetes. In a focus group interviews with 20 Asian Indians with diabetes (Macaden & Clarke, 2006) one participant stated that she had to avoid parties because she was taking insulin and had to adhere to her meal schedules. In the same study, another participant depathologized his diabetes by convincing himself that he was normal and did not have to make any lifestyle changes. Similarly, participants reported that they did not openly discuss their

disease with friends or neighbors, and that a lack of healthy food choices at Indian festivals or ceremonies were barriers to adherence to dietary recommendations (Venkatesh & Weatherspoon, 2013).

Asian Indians have displayed an awareness of what constitutes a healthy diet, and have perceived their diet to be unhealthy (Farooqi, et al., 2000). Compared with other racial and ethnic groups, some Asian Indians saw their traditional diet to be a barrier that made their diabetes control more difficult (Stone et al, 2006). A focus group study conducted with 45 Asian Indians identified several barriers to diet change: being too old, lacking knowledge and being wedded to foods that they had always eaten (Farooqi et al., 2007). Grace et al. (2008) and Simmons & Williams (1997) identified other dietary practices that were perceived to be barriers to diabetic control. In a cross-sectional survey by Simmons & Williams (1997), Asian Indian participants (N=308) were found to eat fewer meals, to eat later in the evening (2-3 hours), and to eat fewer vegetables and less brown rice than Europeans. Notwithstanding differences between specific groups, Asian Indians tended to eat more Indian sweets, fried Indian snacks and Western snacks (i.e., crisps, chips, and cake) (Simmons & Williams, 1997). In a qualitative study of Asian Indians (N=80) that used focus groups and semi-structured interviews, Grace et al. (2008) found that participants relied on fast food because it was convenient and affordable. Traditional fruits and vegetable were perceived to be too expensive, and participants were unfamiliar with cheaper, healthier Western alternatives to fast food. Venkatesh et al. (2013), whose mixed methods study examined the dietary practices of 30 Asian Indians with diabetes, found that most participants ate a Western breakfast (cold cereals, muffins, bagels oatmeal, or bread with peanut butter or margarine) rather than traditional Indian foods (idli, dosa, kichidi, roti, upma and puri).

Family dynamics also influenced dietary practices among Asian Indians because family provides behavioral, emotional, and intellectual support. Among Asian Indians with diabetes, the spouses' knowledge about preparing healthy food, their encouragement to eat healthy food and advice from family members (especially if they are physicians or affected with diabetes) were perceived to be supportive at the time of one's diagnosis (Venkatesh & Weatherspoon, 2013). In a qualitative study exploring prevention and the risks of diabetes, Asian Indians (N=80) believed that family members were policing diet control (Grace, et al., 2008). One participant describes it in this way "The family should cook the food which is advisable for him, and not to offer him any food meant for all the other members. They should not allow him to eat any food even though he asks for it" (Grace et al., 2008, p. 8). In the same study, women with diabetes said that they had to cook two separate meals, one for the entire family, and one for themselves. Not only was this time consuming, it also imposed further financial burden on the family (Bissell, et al., 2004).

Religious practices also influenced dietary practices and diabetes control (Lawton et al, 2007). In a secondary analysis of in-depth interviews with Hindu (n=4), Pakistani (n=23) and Sikh (n=5) participants with diabetes, the researchers found that fasting was common among Muslims, especially the men. Participants would fast at whatever cost; this involved adjusting their insulin or medications during fasting. For other Asian Indians groups such as Hindus and Sikhs, fasting was not a common religious practice.

Achieving control of diabetes through lifestyle modification is a complex process for Asian Indians that involves major changes in diet, cooking practices, physical activity, and religious practices. The changes, which inextricably involve family, gender roles, and social and

financial obligations, may create conflicts, within households and individuals. These factors may inhibit a person's ability to achieve control over their diabetes.

### **Interactions with Health Care Providers**

Health care providers play a significant role in managing the care of patients with diabetes. Eight studies were found that discussed the interaction of health care providers with Asian Indian patients. In a qualitative study examining barriers to health care, Asian Indians (N=21) perceived that somebody else (i.e., mainly their physician) other themselves should be in charge of their diabetes. Accordingly, they transfer the responsibility of disease management to the healthcare professional. Physicians, they rationalize have the knowledge, expertise and authority to guide them about their disease (Bissell, et al., 2004). The same researchers found that the idea of a collaborative relationship between the provider and the patient was unfamiliar. As one participant explained he would "rather leave it up to those with more information" (Stone et al., 2005, p. 651). A participant in another study (Macaden & Clarke, 2006) missed a follow-up appointment because the health care worker who reminded her and took her to the appointment fell sick. Vyas et al. (2003) found that Asian Indians were apt to miss scheduled appointments with their health care providers and that providing specialty care for this group did not improve their diabetes knowledge or self-management. Similarly, one interpretive study examining empowerment in diabetes self-management found that, although the Asian Indian participants (N=15) had high regard for education, and a positive attitude towards empowerment, they had low motivation to become partners in their diabetes management (Stone, et al., 2005).

Asian Indians also expected their physician to provide support and education about diabetes and self-management behaviors. Patients expected their physician to provide them with

open communication, individualized care, an understanding of Asian Indian food, and advice on physical activity and diabetic resources (Venkatesh & Weatherspoon, 2013). They also found that participants, especially those in the medical field expected their physician to provide knowledge, support, further refinement of treatment, and more in-depth information.

Farooqi et al. (2000) found that language and gender barriers affect patient-provider relationships. Reliance on children to translate during medical appointments created barriers. As one participant stated, “Even my children sometimes get annoyed, and don’t explain thing properly to the doctors. So yes, language is a problem” (Farooqi et al., 2000). Similarly, the language barrier extended to Asian Indian providers who did not speak Hindi or Punjabi (Farooqi et al., 2000). Gender preferences, especially for women were important, “Female patients want female doctors” (Farooqi et al, 2000).

Although most of the studies reviewed how Asian Indians patients perceived their providers, only two studies discussed how health care providers perceived Asian Indian patients. (Bandesha & Litva, 2005; Grace, et al., 2008). In Bandesha and Litva’s (2005) qualitative study, the health care providers (N=13) reported language barriers, the unwillingness to change traditional ways, financial constraints and the unwillingness of the Asian Indians to be actively involved in their care. Grace et al.’s (2008) qualitative study of 25 health care providers, mainly physicians, found that they believed that Bangladeshis associated obesity with fertility and health. As a result, they significantly underestimated their patients’ willingness to lose weight. The health care professionals also expressed a lack of confidence in their ability to provide culturally relevant advice.

All of the studies described above identified, several barriers and challenges in interactions between Asian Indian and their health care providers. Perceptions of these patients, their lack of motivation, missed health care appointments, language barriers, gender preferences, and a lack of understanding of cultural differences hindered control of diabetes among Asian Indians.

### **Summary**

Several gaps were identified in the recognition and understanding of barriers and challenges faced by Asian Indians with diabetes. First of all, research in the United States has been limited. Because majority of the research on this population has been conducted in the United Kingdom, little information has been available on the barriers to care for the Asian Indians residing in the United States. The characteristics of these individuals may be quite different from those in other parts of the world, in terms of country of origin, religion, socioeconomic status, education, and employment. As the population of Asian Indians in the United States increases and the diabetes epidemic continues to grow, the gap in minority health will certainly worsen in this country. Accelerated research on Asian Indians would not only strengthen health care providers' understanding and insight into their beliefs and challenges, but also provide opportunities to develop new interventions, and, screening and treatment guidelines for them.

Another evident gap is that most of the studies were limited to first generation South Asians of lower socioeconomic status and limited education. Most of those participants were aged 50 and older and not fluent in English. Further, in the UK studies, the middle class, younger individuals, second generation Asian Indians and or educated Asian Indians are not

represented. The few studies that have been conducted in the United States have involved Asian Indians who are college educated, of higher socioeconomic status and generally fluent in English. Describing and understanding the experiences of lower and middle class Asian Indians in the United States, is equally important if health care providers are to develop interventions and implement them at an early stage to reduce the risk of diabetes and its complications.

Asian Indians are a diverse group with distinct cultural and religious beliefs. Studies in the United Kingdom were compromised by including predominantly Muslim participants. Because Hindus and Sikhs represent a significant portion of the Asian Indian diasporic population (Ballard, 1994); research on these groups is needed. This research should focus on how these populations integrate their beliefs with modern medical information on diabetes and how they self-manage their disease.

### **Purpose and Aims**

The South Asian Association for Regional Corporation (SAARC) has reported that the rate of diabetes among Asian Indians is higher than for other expatriated ethnic group worldwide (Srivasta, 2002; UKPDSG, 1998;). Although much research has been conducted in the United Kingdom, little investigation has been done on the barriers and challenges faced by Asian Indians with diabetes in the United States.

Diabetes and its complications among Asian Indians are attributable to cultural, behavioral, social and economic influences. Current studies have provided limited insight into the barriers and challenges of immigrant Asian Indians in the United States, although these may parallel those found in the predominantly UK based studies. Because the prevalence of diabetes

in this country is similar to the United Kingdom and the genetic predisposition of developing diabetes and complications occur earlier in Asian Indians, further examination of barriers and supports to diabetes care in Asian Indians in a US health care system and environment is warranted.

After reviewing the research several aims are posed for this research:

1. Understand and describe the health care beliefs about cause and diabetes management among Asian Indians.
2. Describe daily challenges and supports that Asian Indians encounter in managing their type 2 diabetes.
3. Articulate culturally specific practices (dietary, physical, and religious) that affect how Asian Indians manage their type 2 diabetes on a daily basis.
4. Identify commonalities and differences by gender among Asian Indians in managing type 2 diabetes.

Asian Indians worldwide have a high prevalence of diabetes, which occurs at an earlier age and is associated with premature morbidity and high mortality. Researchers and health care providers must understand the health care beliefs, practices and challenges this group encounters. Ideally, this information could be used to develop culturally specific education; and to improve screening and management of the disease. It would raise awareness among health care professionals and the Asian Indian population and ultimately, improve diabetes control and reduce complications in this population.



## Chapter 2

### Methodology

Diabetes mellitus has been growing at a pandemic rate and has been associated with an increase in serious medical complications. Diabetes related complications and comorbidities include micro vascular diseases (retinopathy, blindness, nephropathy, and kidney failure) and macro vascular diseases (coronary heart disease, stroke, peripheral vascular disease, and lower extremity amputations) (ADA 2010). The IDF (2013) has predicted that the number of individuals with diabetes will increase from 382 million in 2013 to 592 million in 2035; more than 60% of the world's population with diabetes will come from Asia, the world's most populous region. Currently, India has the second largest number of individuals with diabetes. By 2035, it is projected that India will lead the world with approximately 123 million people with diabetes.

In the United States, there are 3.4 million South Asians and Asian Indians are the one of the fastest growing immigrant groups in the country (SAALT, 2010). Studies have reported that Asian Indians have higher prevalence rates of diabetes (Mohanty et al., 2005) than Blacks (12.8%), Hispanics(8.4%) and Whites (6.6%) in the United States(Cowie et al., 2009). Researchers found that Asian Indians in the San Francisco Bay Area found that Asian Indians between the ages of 45 and 79 had a diabetes prevalence of 29%, and were at higher risk of developing diabetes than any other ethnic group in the United States (Kanaya et al., 2010). Venkataraman et al (2004) found an overall prevalence of diabetes mellitus of 18.3% among Asian Indians in Atlanta, GA. Similar high prevalence rates have been reported in the United Kingdom (Unwin et al., 1998) and India (Mohan et al., 2006; Ramachandaran, et al, 2008)

Asian Indians experience more morbidity and mortality than other groups. Diabetes is roughly 4 times more common in Asian Indians than in Europeans (D'Costa et al., 2000). They are more likely to develop diabetes 11 years earlier than people of European origin and also to die prematurely from cardiovascular disease (Raleigh et al., 1997). Asian Indians had a higher mortality rate (40%) than their European counterparts. Studies of Asian Indians in the United Kingdom (Bissell et al., 2004; Farooqi et al., 2000; Lawton et al., 2006) and the United States (Grewal, Stewart, & Grace, 2010; Mohanty, et al., 2005) have found that reducing diabetic complications and achieving control over diabetes is a complicated process for Asian Indians because they are a heterogeneous group with different languages, dialects, religions and cultural beliefs. Several barriers to achieving control have been identified, including increased genetic susceptibility (Abate & Chandalia, 2001), less knowledge about the disease process (Vyas et al., 2003) less regard for the seriousness of their disease (Macaden & Clarke, 2006), and less understanding of the relationship between achieving control and decreasing diabetic complications (Bean et al., 2007). Some studies have also attributed poor diabetic control to low socio economic status, lack of access to health care, and language barriers (Lawton et al., 2007; Macaden & Clarke, 2006; Vyas et al., 2003). Migration to more developed regions and increased Westernization are other possible factors that increase the risk of developing diabetes (Abate & Chandalia, 2001; Farooqi et al., 2000; Lawton et al., 2007)

By the year 2020, more than 50% of the US population is projected to be non- White. As the numbers of people of South Asian descent continues to grow, including new immigrants, the gaps in the health of this minority population will certainly worsen (Abate & Chandalia, 2001). Thus, addressing the challenges and barriers faced by this ethnic minority has become a public health priority. The purpose of this study was to identify and understand the challenges

and barriers faced by Asian Indians in the United States in achieving control of their diabetes. The aim of the study was to provide an interpretive account of the challenges and barriers they faced in their everyday lives.

### **Qualitative Methods**

Qualitative research was the most appropriate option to study my phenomenon of interest for several reasons. It has its roots in sociology and anthropology and has been increasingly valuable in contributing to nursing knowledge. Further, traditional quantitative approaches simply cannot explain several phenomena and human experiences. Unlike quantitative approaches, qualitative research which explores human experiences, perceptions, motivations, and behavior provides a detailed understanding of feelings, thought processes, and emotions that are often essential in understanding human behavior. Qualitative research allows investigators to study the nuances and complexities of human experiences, and bring meaning to those experiences.

Qualitative research offers a diverse collection of approaches that generate knowledge which is actually grounded in human experience (Long & Johnson, 2000). Qualitative researchers study participants in their natural settings and attempt to make sense of and interpret their phenomena; in terms of the meaning that people give to their experiences (Denzin & Lincoln, 2005). Qualitative research is inductive and is shaped by the experiences of the researchers and the participants experiences. Because research on the experience of Asian Indians with diabetes is limited and my goal was to understand the lived experience of Asian Indians with diabetes, particularly the challenges and barriers faced by this group, a qualitative approach was deemed best. Furthermore, my epistemological stance view was that an objective

perspective is not optimal when it comes to studying human experience or behavior. A qualitative approach adds inter-subjectivity to an objective world and addresses multiple realities. In other words, there is not one truth, but several truths in how humans experience the world. Sustained contact with Asian Indians in their environment would provide the rich, descriptive data that was essential to understand their experiences with diabetes.

Carter and Little (2007) proposed that methodology and method are guided by the researcher's epistemology. Epistemology, methodology and methods are fundamental in establishing internal consistency and rigor in qualitative research. Carter and Little describe epistemology as tacit and inescapable. A researcher's epistemology guides the choice of methodology for his or her research. It is impossible to create knowledge creation without at least tacit assumptions about what knowledge is and how it is constructed (Carter & Little, 2007). Accordingly, I considered several qualitative methods (e.g., grounded theory, ethnography and phenomenology). What follows is a brief description of the similarities and differences between methods, the methods I considered, and why interpretive phenomenology was best suited for my study.

Qualitative research methods have several similarities. They all aim to explore social actions, human behavior and human experiences. Participants are selected for their ability to inform the questions posed. Data sources include interviews, observations, field notes and textual representations. Data management includes recording, transcribing and analysis using computer- assisted software. All of these methods require a researcher to collect and meaningfully interpret the data.

Although qualitative methods have similarities; the differences set them apart. These differences are based on what a researcher wants to accomplish, and how data are analyzed and presented. These differences will be discussed in more detail when I describe methodologies. Despite the commonalities and flexibility that may be tolerated across methods, a coherent study must be firmly based in an appropriate method (Holloway & Todres, 2003). Initially, I considered two alternative methodologies for this study: grounded theory and ethnography.

### **Grounded Theory**

Grounded theory was a logical consideration because I was familiar with the methodology in my undergraduate work. Its origins can be traced back to symbolic interaction which was developed by George Herbert Mead (1894-1931) and Herbert Blumer. Symbolic interactionism emphasizes meanings and interactions as the key to understanding human behavior (Pawluch & Neiterman, 2010). Grounded theory was introduced by sociologists at a propitious time, when qualitative research was losing favor to quantitative research.

Barney Glaser and Anselm Strauss (1967) introduced grounded theory in their seminal work, *The Discovery of Grounded Theory*. They believed that the theories used in research were often inappropriate for the participants being studied. They defined grounded theory as one that arose directly out of the social world and was grounded in the experience of social actors (Pawluch & Neiterman, 2010). It, they believed, would close the gap between empirical research and theory and legitimize qualitative research. Since the 1960s, grounded theory has been successful when other theories have been inadequate for situations demanding social or cultural specificity. It has been defined as a qualitative methodology in which the inquirer generates a general explanation of a process, action, or interaction shaped by the view of a large number of

participants (Strauss, 1998). It is an iterative process. Data are collected on the topic of interest, which is grounded or embedded in the experiences and views of several participants. It is an inductive process, in that the development of theory is based on participants' experiences and views of the participants. In the analysis of data, open coding and axial coding are used to conceptualize theoretical codes. Relationships and interactions between the theoretical codes are then examined to develop theory. The task of grounded theory researchers is to discover new meanings and conceptualize the complex interactional processes of participants.

With the growing interest in postmodernism, grounded theory was further modified into constructive grounded theory by Charmaz (2003, 2006). She posited that all knowledge is situated knowledge. Just as social actors interpret and make sense of what is "real", so do researchers who study them (Pawluch & Neiterman, 2010). Realities and meaning are constructed by individuals as they assign meaning to the world around them (Appleton & King, 2002). In constructive grounded theory, Charmaz proposed that a researcher interprets and presents how participants construct their realities and multiple perspectives. Adele Clark, a constructivist, shifted the focus of grounded theory from a social process to situational analysis. Clarke (2005) defines situational analysis as focusing on the situation-centered, social worlds or arenas framework. The situation that a researcher is interested in studying becomes the unit of analysis. Clarke proposed a research process that lays out situational maps that include human and non-human elements and positional maps that lay out the positions taken or not taken, differences, and controversies. Situational analysis allows a researcher to go beyond the social processes to a fuller understanding of the world in which the social processes are embedded. Situational analysis uses various types of maps to provide access points into a person's data and linkages between various conceptualized sites. In situational analysis, there is an explicit

political agenda (Pawluch & Neiterman, 2010). These modified versions of grounded theory have gained popularity within several disciplines such as nursing, education, sociology, and psychology.

Grounded theory was not well-suited for my phenomenon of interest because I did not have a political agenda; nor was theory development my intention. The intention of my proposed study was to understand the lived experience of Asian Indians with diabetes.

Grounded theory also uses highly complex systematic procedures in analyzing data. These procedures limit flexibility in interpretation and seemed a more a positivist approach and time consuming.

### **Ethnography**

Ethnography was the second methodology that I considered because I was studying Asian Indians - a minority population in the United States. Ethnography is the oldest qualitative method. The term, which is derived from the Greek, means a description of the people, a “writing of culture” (Holloway & Wheeler, 2010). Ethnography enables a researcher to describe and interpret the shared and learned patterns of values, behaviors, beliefs, and language of a culture-sharing group (Harris, 1976). It has its origins in British social anthropology, American cultural anthropology and the qualitative sociology of the Chicago School of Professional Psychology (Phinney & Chesla, 2003). Bronislaw Malinowski (1932), the founder of ethnography, systematically laid out its philosophy and methods of ethnography in his study of the Trobriand Islanders, who live off the southeast coast of Papua New Guinea. The underlying assumption of ethnography is that every human group evolves in a culture that guides its members in their view of the world and the meanings they attribute to their experiences (Bailey,

1997). Ethnography provides an opportunity for people to describe their experiences in their own terms (Sorrell & Redmond, 1995). Ethnographers explore the unspoken features that influence the attitudes and behaviors of entire cultural groups, societies and institutions. It values the idea that to know other human beings, one has to do as others do, live with others, eat, work, and experience the same daily patterns as others (Madden, 2010). In other words, a researcher must immerse himself or herself in the day-to-day lives of their participants, collecting data from participant observations, interviews and secondary sources.

Ethnography involves an extensive amount of time gathering information in the field. Gatekeepers, or key informants, provide a researcher with access to his or her participants. A fundamental characteristic of ethnography is that the researcher is physically situated in the environment and surroundings of the group under study (Broussard, 2006). Careful attention is paid to the structure of society and the social positioning of persons of interest. Ethnography is a useful method if a researcher is interested in describing how cultural groups function and to explore beliefs, language, behavior and issues such as power, resistance, and dominance (Creswell, 2007). Although early ethnographic researchers studied primitive cultures, ethnography has gradually broadened its scope to modern societies, examining the social structures of institutions such as corporations and hospitals. Ethnographers will, on occasion, produce theories about cultures or institutions that can be tested and applied to other situations (Holloway & Todres, 2003).

Ethnography was unsuitable for my study for several reasons. It was practically impossible to locate a community that comprised of only Asian Indians with diabetes in California. Because my goal was to study individual perspectives, commonalities, and experiences, ethnography did not offer the best approach to understanding the experiences of



Asian Indians with diabetes. Observing participants and their interactions with others was not needed. In my judgement, the most efficacious way to understand individual experiences was to interview participants and building a rapport and trust with them. Repeated interviews helped me understand my participants' daily practices, clarify meanings, and discover the commonalities in their nuanced daily activities. In conclusion, the methodology that best suited my phenomena of interest was phenomenology.

### **Phenomenology – Historical and Philosophical Origins**

Phenomenology is a philosophy with both epistemological and ontological roots (Mackey, 2005). Its epistemological roots were developed by Edmund Husserl in the last half of the nineteenth century in Germany (Lavery, 2003). Husserl saw the limitations of the positivist approach of applying scientific methods to human experience. He understood that human beings are more complex than animals and do not follow the same, strict stimulus response behavior demonstrated by Pavlov's dogs (Lavery, 2003; Mackey, 2005). Husserl argued that human beings do not react automatically to external stimuli. Rather they respond to their own perceptions of what these stimuli mean. He introduced the study of consciousness into the process understanding human actions and responses. Husserl viewed consciousness as a dialogue between a person and his world (Valle, King, & Halling, 1989), where the mind and body work together seamlessly. He posited that human beings are engaged in dialogue of what stimuli mean in their world; and that minds and objects both occur within experience, eliminating therefore the mind-body dualism that had been the foundation of many empirical, rationalist approaches to science (Benner, 1994).

Martin Heidegger (1889-1976) is credited with creating a shift in the ontological underpinnings of phenomenology. He began his career in theology and later turned to phenomenology while working with Husserl at Freiberg University in Germany (Lavery, 2003). After Heidegger assumed Husserl's professorship, he disassociated himself from Husserl's work and proceeded to develop hermeneutic phenomenology to uncover the meaning of "*being*" of human beings (Plager, 1994). Hermeneutic phenomenology is also known as interpretive phenomenology, especially when used as a methodology (Benner, 1994). Heidegger believed that the epistemological focus of traditional science or Cartesian science inhibits our understanding of what it is to be human in the world. His philosophical stance suggests that persons are actively engaged beings in the world. Hence, he shifted the conversation from problems of epistemology to ontology – that is, of what it is to be human beings? (Leonard, 1994). Interpretive or hermeneutic phenomenology is concerned with the life world or human experience as it is lived. Heidegger posited that phenomenology should focus on *dasein*, that is, what it means to a person to exist in the world. To use interpretive phenomenology as a methodology, one has to understand its philosophical assumptions.

### **Philosophical Assumptions**

From a phenomenological point of view, the first philosophical assumption is that an essential facet of a person centers on his or her relationship to the world (Leonard, 1994). Every person has a "world" which is preexisting and into which one is born. This world, according to Heidegger is apriori and human beings are thrown and socialized into a preexisting world of everyday activities and involvements (Lavery, 2003). This Heidegger refers to as "*thrownness*." In interpretive phenomenology, the preexisting world is described as a set of meaningful relationships, practices, and languages that we develop by being born into a culture

(Leonard, 1994). Our language and cultural traditions create the possibilities of how we feel and interpret “our world.” Self-interpretation is influenced by our linguistic and cultural traditions and makes sense only against a background of significance. We adapt to these skills and practices without paying much attention to them, and yet these skills and practices make our world intelligible, creates possibilities, and guides our action. Nothing can be encountered independent of our background understanding (Leonard, 1994). The self is thrown into a world with preexisting culture, history, and linguistic practices. How we develop skills and, interpret and understand our world is influenced by that world. In other words, the world is constitutive; the self is raised and shaped by the world one is thrown into. We accept the preexisting cultural practices, language, and traditions without much thought or reflection and pursue possibilities of our existence within our given world. The world situates us and offers possibilities of what we can become. Heidegger describes this as persons being *situated beings*; our freedom is also situated by our world. Freedom, in Heidegger’s view, is situated freedom (Taylor, 1991). Human existence entails working out the possibilities that exist for us by virtue of our being thrown into a particular culture, historical, or familial world (Leonard, 1994). As Benner (1994) explains, a person is not a radically free arbiter of meaning. Our world with its cultural practices, languages, and traditions creates and limits our *dasein*.

The second philosophical assumption underlying interpretive phenomenology is that human beings are caring beings. From the phenomenological perspective, persons have concerns to that matter to them. Certain practices have significance and value. These concerns shape our life worlds, influencing what is seen, what is spoken and what actions we take (Dreyfus, 1991). It is “basic characteristic of *dasein* that things show up as mattering – as threatening, or attractive, or stubborn, or useful, and so forth” (Dreyfuss, 1987, pg 264). Things and concerns

that matter are qualitatively different based on one's culture, language and situations. Hence, in interpretive phenomenology, a researcher has to understand a person's behavior or expressions in context in order to understand what matters or concerns the person. Human beings are inextricably linked to their world, and one has to study people in context, for it is only there that what they value and hold significantly is visible (Leonard, 1994).

The third assumption is temporality or beings in time. Heidegger had a perception of time that differs from our traditional view of linear time. In his view, the past, present and future are all interrelated. He referred to this as temporality. Phenomenology holds that all human experience is grounded in time, and the experience of time is fundamental to understanding of being, and the ways of being (Mackey, 2005). The person is always in "a time." A person is always aware of his past, which affects his or her present experiences and future expectations. Temporality, in interpretive phenomenology is directional, relational, and applies to being in the world. Temporality allows the past, present and future to be experienced in unity (Mackey, 2005).

The fourth philosophical assumption is being embodied. Human beings are always engaged, or embodied, in their world. Being embodied is a central feature of existence and makes possible all modes of engagement in meaningful relationships and practical activities (Plager, 1994). Heidegger described three modes of engagement: ready-to-hand, unready-to-hand, and present-to-hand. Human beings are primarily involved in the world in the ready-to-hand mode. In this mode of engagement, equipment and practical activities function smoothly and transparently (Plager, 1994). The mind and body work together seamlessly in daily activities, and the mode requires no critical thinking. A person is embodied, and thought and action cannot be separated from each other (Leonard, 1994). In the unready-to-hand mode, the

smooth functioning of equipment or activities breaks down. Taken-for-granted activities and relationships become disrupted and noticed. During an illness, for example, one notices symptoms that may disrupt normal daily activity. The breakdown of the ready-to-hand mode has made phenomenology an ideal method of discovering the experiences of various pathologies (Phinney & Chesla, 2003). Finally, in the present-to-hand mode, a person reflects on the equipment or activities. In this disengaged and reflective mode, activities such as theoretical reflection, observations and experimentation occur (Plager, 1994). This mode of being most closely parallels the view of human epistemology, because it provides an outside looking in perspective.

### **Methodological Implications - Hermeneutics**

Hermeneutics assumes the philosophical tenets of interpretive phenomenology. These tenets guide the role of a researcher, data collection and analysis; and the validity of a study. In interpretive phenomenology, writing and reporting are part of the analytic process, in that the researcher's thinking and interpretation generally develops during the writing process. A researcher is "a tool" for interpretation and is continually interacting with the data. He or she has to be fully present throughout interviews and data analysis. To develop a rich understanding of a person's life, a researcher must enter and observe it from the inside.

A researcher is involved in interpreting and understanding human practices that are self-interpreted by a study's participants. A researcher's background understanding is essential in developing and conducting a study. In interpretive phenomenology, a study is designed, guided, and approached by a researcher's preliminary background or understanding of the phenomenon. This pre-understanding, or background understanding, is known as the *fore-structure of meaning*,

which has three aspects: the *fore-having, foresight and fore-conception*. Fore-having is the taken-for-granted meaning of what interests a researcher. Foresight is the point of view from which a researcher approaches his or her phenomenon. Researchers view a research question, through an interpretive “lens” that orients them to the phenomenon of their study in a particular and important way (Leonard, 1994). This lens allows the researcher to establish a certain perspective, interpretation and enter the hermeneutical circle. Entering the hermeneutical circle involves going back and forth between the parts and the whole, between the fore-structure and what the data reveal. A researcher is always in the hermeneutic circle, trying to understand and interpret participant interaction, gain new perspectives and uncover meanings of taken-for-granted practices. Finally, the fore-conception, is a preliminary sense of what constitutes a question and what would count as an answer (Leonard, 1994). Fore-conception is more distant from the engaged perspective; and is sometimes termed the *theoretical stance of a problem*. In summary, a researcher’s pre-understanding, or the fore-structure of meaning, influences his or her questions and interpretation of the phenomenon.

In a phenomenological research project, data collection typically involves open-ended questions, reflexive questions, and in-depth narrative interviews to illuminate the complex world of the individual’s lived experience (Schwandt, 1994). It also involves multiple interviews, accurate transcription, observations if needed, and data interpretation between interviews.

In interpretive phenomenology, multiple interviews allow an interviewer to listen to interviews again; or, if they are transcribed, to read them for gaps or blind spots (Benner, 1994). Repeat interviews are essential because they provide a deeper understanding of a person’s life and further clarification as data are analyzed.

Interpretive phenomenology draws on participants' narratives and stories to describe their concerns and practices. Narrative interviews reveal the participants' lived world, their concerns and possibilities. A researcher queries participants about their direct, concrete, and recent experiences which include both positive, negative and everyday stories (Chesla, 2011). It is through these stories and narratives, acquired during data collection, that human beings understand and express their world.

A phenomenological approach to narrative analysis sees the stories that people construct as revealing what matters and its meanings in their lives (Benner, 1994). Narrative analysis involves examining stories and actions, context, concerns, emotions, coping, resources, and resolution. The art of story-telling is essential in interpretive phenomenology. Narratives allow speakers to give more detail to the concerns that shape their experience and perception of events. They give a researcher access to the participants' worlds. Reflexive questions allow participants to generate narratives which a researcher should listen to without interruption. Furthermore, seeking clarification of stories leads to better narratives and thick descriptions of significant concerns.

Data analysis begins with the researcher fully immersed in an interview and continues as interviews are transcribed. Transcribing is a fundamental step of analysis. Its goal is to convert oral speech into the printed word accurately (Sandelowski, 1994). Data analysis involves a process of reflecting, clarifying, and making explicit the participants' lived experiences. Interviews are initially read to get a global understanding of the story. Later, the story is deconstructed for deeper understanding. A researcher move systematically from the parts to the whole; and back again to better understand and clarify interviews. The goal is to produce text as complete as possible, identifying puzzles, incongruities, and mysteries (Benner, 1994).

Benner (1994) described three narrative strategies that provide the basis for entering practical worlds and understanding socially embedded knowledge: paradigm cases, thematic analysis, and exemplars. A paradigm case is a discovery stage, an entry point into the text. An interview is read for global understanding of the narrative, after which it is broken into parts to further understand concerns, differences, or practices. A paradigm case usually identifies strongly with a participant's life world. It is a strong instance or example of being in the world (Benner, 1994). This paradigm case is used to examine other cases, comparing similarities and differences across cases. The practical world of one paradigm case creates a basis of comparing similarities and differences with other paradigm cases (Benner, 1994). Paradigm cases provide an initial holistic understanding of the participants' life world.

The second strategy of narrative analysis is thematic analysis. Meaningful patterns, stances, or concerns are considered rather than more elemental units such as words or phrases (Chesla, 1994). These themes capture the practical reality of a lived experience of the phenomenon studied. To capture the practical reality of the phenomenon and create themes, a researcher moves back and forth between portions of the text and portions of the analysis, from themes and situations, and from thematic analyses to paradigm cases (Benner, 1994). Texts are read multiple times in a hermeneutic circle, with consideration to how the whole illuminates the parts, and how the parts in turn offer a more full and comprehensive understanding of the whole.

The third strategy of narrative analysis is exemplars. After a researcher has identified a pattern of meaning, common situations, or embodied experience, exemplars may be extracted from the text to demonstrate similarities or contrasts (Benner, 1994). Exemplars are short narratives or vignettes that capture the meaning of situations in such a way that the meaning can be recognized to explain paradigm cases and themes.



## **Interpretive Phenomenology – Asian Indians with Diabetes**

As a methodology, interpretive phenomenology illuminates details and aspects of experiences that may be taken for granted; its goal is to create meaning and achieve a sense of understanding (Wilson & Hutchinson, 1991). It aims to unfold and give new meaning to the experiences of everyday life by explaining patterns of meaning in life events, relationships, and practices for people in similar contextual experiences (Chesla, 1994). For these reasons, interpretive phenomenology was well suited to study the lived experience and to understand the daily practices of Asian Indians with diabetes. Because the aims of my study were to explain the particular and distinct patterns of meaning and actions of Asian Indians with diabetes, and to understand their everyday practices, challenges and concerns, interpretive phenomenology could provide a deeper understanding of their everyday (taken-for-granted) world and provide knowledge and insight into the practices within their lived world.

### **Study Design**

The design of this study relied on Benner's (1994) research practices in conducting an interpretive phenomenology study. These included participant observations and interviews for data collection, narrative accounts of particular experiences to identify paradigm cases, and exemplars, and thematic analysis to describe the lived experience of the phenomenon. A pilot study was conducted to understand the method and to modify the questions on the interview guide. Approval to conduct this study was received from the Committee on Human Research, Institutional Review Board at the University of California, San Francisco.

### **Data Management**

The interviews were transcribed in English (Punjabi and Hindi interviews were transcribed into English) and reviewed. Confidentiality of participants' all written records and audio transcriptions were coded using pseudonyms. Audio recordings and transcriptions were encrypted and maintained on a password protected computer and backed up on a hard drive, which were kept in a locked filing cabinet. Audio recordings were erased after transcription had been reviewed for accuracy and data analysis completed.

### **Participants**

In an interpretive study a researcher's aim is to select participants who have lived the experience that is the focus of the study, who are willing to talk about their experiences and who are diverse enough from one another to enhance the possibility of rich and unique stories (Polkinghorne, 1988). Approved flyers (Appendix A) with a brief description of the study and my contact information were placed in Hindu and Sikh temples in Roseville, CA. To be included in the study, individuals had to be of Asian Indian origin, diagnosed with diabetes for at least 6 months, over the age of 18, a legal or permanent U.S. resident, and to have had no hospital admissions for the past 6 months. Asian Indians were defined as being of Indian origin or from India, Africa, or Fiji. Twelve adult participants (50% women) between the ages of 40 and 75 years who met the inclusion criteria were recruited. The average length of residency in the United States was 18 years (range 1-43 years), and the average time of being diagnosed with diabetes was 11 years (range 1-25 years). .

### **Data collection and procedures**

Data sources for the proposed study included a consent form (Appendix B), demographic sheet (Appendix C) and a non-standardized interview guide (Appendix D). The consent form

was reviewed and signed by the participants before the demographic sheet was filled out. The demographic sheet included pseudonyms, age, gender, medications, and recent, self-reported hemoglobin A1C. A general interview guide which had been tested in a pilot study was used to conduct private interviews with the participants in either English or Punjabi. These interviews lasted between 40 and 90 minutes and were audio taped. Field notes during and after the interviews were used to clarify subsequent interviews and data analysis.

### **Data analysis**

Data analysis involved a process of reflecting, clarifying, and making explicit the lived experience of the participants. The goal was to make the invisible, visible. The purpose of phenomenological reflection is to grasp the essential meaning of something ( Van Manen, 1990). To accomplish this, one has to be reflective, insightful, sensitive to language, and open to various experiences. Each participant was interviewed twice in English or Punjabi to learn his or her understanding of diabetes, the subjects touched upon its cause, culturally specific practices, supports, and barriers to illness management. The interviews were tape-recorded, translated into English, and transcribed verbatim as soon as they were completed. The goal of transcription is to convert speech into a printed copy, accurately, capturing the participants' exact words (Sandelowski, 1994). For a qualitative researcher, transcribing is a fundamental step of data analysis because it allows the voices and emotions of participants to be heard. This intimacy cannot be experienced by just reading a text.

Each interview was read and listened to multiple times to create a "*gestalt*" of the participants or the phenomenon. Narrative texts were highlighted using ATLAS, ti (Version 7), a widely recognized qualitative data analysis program, and analyzed using narrative

interpretation analysis, as described by Chesla (2011). In this process, central questions were asked of the narratives: Where is the situation and what is the background of the situation? How did the situation unfold? What is the narrator's emotional tone and expression throughout the narrative? What concerns are apparent, what happened, how did the person cope? What are the outcomes of the narrative? This process has been described as revealing what participants really experience from the inside out (Geertz, 1973.); it allows a researcher to understand how they live, interact with their world and what matters most to them. Attention focuses on the situated process of developing rich and interpreted accounts or stories and the capacity of these stories to facilitate change (Stige, Malterud, & Midtgarden, 2009).

Transcribing, rereading and re-listening to interviews allows entrée to the hermeneutic circle, to focus on the participant as a unit of analysis, to immerse oneself in the data and to enter the participants' life world and begin interpretation. Narratives were analyzed to develop them into paradigm cases and exemplars.

Self-reflection which is embedded and essential to the interpretive process (Laverly, 2003) is an ongoing process not only in data analysis, but throughout interpretive phenomenology. Considerable thought was given to my personal experience and how it related to the issues under study. Re-reading, re-listening, transcribing, self-reflecting and writing memos allowed entry into the participants' world and a preliminary understanding of their lived experience. For this study, I wrote my feelings and thoughts in a reflective journal as each text was read and listened to. Self-reflection is an integral part of the fore structure of interpretation. Interpretive phenomenology emphasizes that there is no detached or privileged standpoint from which one objectively records "reality" (Addison, 1989). I revisited my self-reflective journal several times to clarify thoughts that I had during the interviews and data analysis.

Another key element to interpretive data analysis is linguistic, semantic or language use. The accuracy of the English translations was verified by re-interviewing the participants and further clarification was sought from peers that were fluent in both Punjabi and English. In this study, particular attention was paid to the participants' language and words. For example, they described having a relationship with diabetes. They used words as "diabetes is my friend", using phrases like, "knowing diabetes well." These terms were later used to develop or discuss more conceptual meanings. In this interpretive phenomenological study, was a multidimensional process that encompassed flexible thinking, reduction, expansion, revision, creativity and innovation.

### **Validity and Rigor**

Several perspectives and tensions exist when attempting to establish the validity of qualitative research. Researchers have compared rigor in qualitative research to validity and reliability in quantitative research in multiple ways. Rigor and validity in scientific research establish trust and confidence in a study. Establishing validity in qualitative research is challenging because it incorporates not only rigor and subjectivity but also creativity into the scientific process (Johnson, 1999). The validity criteria for quantitative research are inappropriate because qualitative research has a different ontology, epistemology and methodology. The type of knowledge collected is also different from quantitative research. Qualitative research seeks depth over breadth and attempts to uncover the subtle nuances of life experiences as opposed to aggregate evidence (Ambert, Adler, Adler, & Detzner, 1995). Qualitative research is also contextual and subjective rather than generalizable and objective (Whittemore, Chase, & Mandle, 2001). Qualitative studies cannot be replicated due to purposeful sampling and the social context in which they are conducted.

The validity of qualitative research, which is a critical factor of qualitative research, indicates thoroughness and competence. However, qualitative researchers continue to debate whether validity can be fully achieved and by what means it can be achieved. No universal consensus has been reached. In quantitative research, there are practical procedures and routines to follow that lead to generalizability and the prediction of future events. By contrast, in qualitative research, the goal is not to find generalizable results, but to explore and understand human experiences. Qualitative researchers collect a lot of information on one topic or phenomenon, or experience to enrich their desired understanding (Thomas & Magilvy, 2011).

Validity in qualitative research is further challenged by multiple research approaches, such as grounded theory, ethnography and phenomenology, and by the type of data collected. Because qualitative researchers use interviews and observations instead of questionnaires and numerical measures, issues of truth and reality cannot be addressed in a neatly designed manner as in quantitative research (Cho & Trent, 2006). Carter and Little (2007) suggested that the explanation of how qualitative researcher's epistemology informs methodology and, in turn methods, can provide internal consistency and demonstrate rigor. Whittemore, Chase and Mandle (2001) refer to rigor as the diligent adherence to the chosen methodology, techniques, and philosophy during the course of the study. Rigor in qualitative research is demonstrated by describing how data are collected, analyzed and interpreted.

Strict adherence to rigor has been posited to threaten creativity, artfulness and sensitivity to meaning, all of which are essential in the development of qualitative research (Sandelowski, 1993). Qualitative researchers need the freedom to immerse themselves in the research process, and to thoughtfully and creatively consider all possible meanings of the data (Atkinson, Heath, &

Chenail, 1991), while not compromising the quality of the science. Creativity and the art of qualitative research must be preserved, but rigor should be maintained.

To preserve the creativity, art and rigor of qualitative research, its methodologies and research designs require flexibility in validity criteria. Several criteria have been proposed in establishing such validity. Lincoln and Guba's (1985), whose translated criteria remain the gold standard, proposed the concepts of credibility and authenticity as bench marks for validity criteria. They ask "How can an inquirer persuade his or her audiences (including self) that the findings of an inquiry are worth paying attention to, worth taking account of?" (Lincoln & Guba, 1985, p 290). Their proposed model addresses the four components of validity: truth-value (credibility); applicability (transferability); consistency (dependability); and neutrality (confirmability). This model has been criticized for being theoretical and impractical. Maxwell (1996) suggested that validity is both a regulative and a relative ideal, meaning that it has to be evaluated in relationship to the purposes and circumstances of the research. Whittemore et al. (2001) posited that qualitative investigators rely on the theoretical assurance of validity at the expense of practical application. Hence, they proposed that further synthesis of validity criteria for qualitative research is fundamental. These authors proposed primary and secondary criteria. Credibility, authenticity, criticality and integrity are considered primary criteria and are necessary for qualitative research. Explicitness, vividness, creativity, thoroughness, congruence and sensitivity are considered secondary criteria (Whittemore, et al., 2001). Although both primary and secondary criteria are essential in qualitative research, they do not assure validity.

The primary criteria of credibility and authenticity establish whether a study is believable and reflects its participants' accurate meanings and experiences. Guba and Lincoln (1989) suggested the term *credibility* to describe the degree to which the researcher's conclusions

accurately reflect the phenomenon under investigation (Long & Johnson, 2000). The strategies used to establish credibility and authenticity are reflexivity, member checking, and peer debriefing (Thomas & Magilvy, 2011). Reflexivity incorporates the subjective value of a researcher's feelings, experiences and attitudes. In interpretive phenomenology, reflexivity is affected by an interviewer's fore-structure while interpreting the text. This dialogical process requires openness, sensitivity, and scrutiny so that the world disclosed in the interpretation provides an accurate understanding of the lived experiences. The fore-structure is integral to interpretation and influences the interpretation of text and affects credibility. In interpretive phenomenology, the concepts of situatedness, embodiment, and temporality which relate to the interpretation of the lived experience should be explained to demonstrate credibility. In this study, accurate interpretation was maintained by writing and rewriting interpretations of the text; and consistently using the procedures outlined in the data analysis of each case or interview. Interviews and narrative texts were read several times; exploratory notes, descriptive and reflective comments, and memos were written; and interpretations of themes were discussed with peers and professors (triangulation).

Data collection, analysis, and interpretation demonstrate this study's credibility and authenticity. The hermeneutic circle demonstrated rigor between epistemology and methods. The hermeneutic circle is an iterative process during which a researcher moves from the parts to the whole and back again to develop an understanding of the lived experience. The hermeneutic circle was used for each interview to understand the lived experience of Asian Indians with diabetes. Credibility was also achieved by conducting multiple interviews to clarify participants' comments. Reengagement (second interviews) in interpretive phenomenology checks the authenticity of a researcher's emerging insight and verifies the participants' intended meanings



(Cutcliffe, 2000). Member checking and peer debriefing involved returning to the participants and peers to ensure that interpretations were accurate representations of the participants' experiences (Thomas & Magilvy, 2011). A qualitative study is considered credible if it presents an accurate description or interpretation of the human experience or phenomenon that it intends to describe, explain, or theorize (Krefting, 1991; Long & Johnson, 2000). Criticality and integrity are also demonstrated through recursive checks of interpretations with participants and peers to ensure that all interpretation was grounded in the data. Using thick descriptions of narratives and remaining close to the text were also attempts to maintain the accuracy and dependability of interpretation. Redundancy in repeated interviews, and emergence of patterns and themes in interviews provided more confidence in interpretations.

Secondary criteria include explicitness, vividness, creativity, congruence, thoroughness, and sensitivity. Explicitness which has been referred to as audibility is analogous to transparency. It demands intellectual honesty and openness. In this study, explicitness was maintained by writing down and discussing decision trails with peers to trace interpretations or findings. Vividness was illustrated by providing thick descriptions and detailed descriptions of salient themes. The creativity of a study is grounded in the methodology used. Congruency is described as methodological congruency and theoretical connectedness. A logical connection should be maintained between the research question, the method and the findings; between data collection and analysis; between the current study and previous studies; and between findings and practice (Whittemore et al., 2001). The thoroughness of this study was demonstrated by the comprehensiveness of its sampling, data collection, and data analysis, to maintain a connection between themes and full development of ideas (Whittemore, et al., 2001). Sensitivity, the last secondary criteria, embraces ethical considerations and the sensitivity of a researcher to the

human, cultural and social context of a study. The research participants should benefit in some way and concern for human dignity and respect should be demonstrated (Lincoln, 1995). Sensitivity was maintained by interviewing participants privately, addressing all of their concerns and questions during and after interviews. In addition, they were given a monetary gift and a thank you card after the completion of each interview.

Describing this study's purpose, discussing inclusion and exclusion criteria, following the methodology and philosophical underpinnings of the study, discussing interpretations and findings, and presenting validity criteria were essential in achieving the validity of this study's findings. After all, it is the researcher's integrity that will determine if validity was achieved. Paying attention to validity from the conceptualization of this research study, leaving an audit of the decision trail, self-descriptions, reflexivity, respondent validation, prolonged involvement, persistent observations and peer debriefing were also essential. These criteria provided an opportunity for critique and further development of the science.

Because research on Asian Indians with diabetes in the US is limited, interpretive phenomenology was a methodology well-suited for my phenomenon of interest which was to identify and understand the challenges and barriers faced by the Asian Indians in this country in achieving control of their diabetes. Interpretive phenomenology allow to suddenly "see" something that enriches the understanding of everyday life experience (Van Manen, 1997). An interpretive account of the lived experience of Asian Indians with diabetes provides an understanding of what being an Asian Indian with diabetes means. The main purpose of this interpretive phenomenology study was to better understand the daily practices and experiences of Asian Indians within their "life world." Interpretive phenomenology uncovered some of the deep challenges and concerns Asian Indians with diabetes face every day.

Table 1

## Validity: Primary and Secondary Criteria

Primary Criteria	Description	Current Study
Credibility and Authenticity	Conclusions accurately describe the human experience	Multiple interviews Hermeneutic circle
	Criticality and Integrity of the study	Writing and rewriting interpretations Remaining close to the text Exploratory notes Reflective memos Member checking and peer debriefing Redundancy, emerging of patterns and themes
Secondary Criteria	Description	Current Study
Explicitness	Transparency	Writing down and discussing decision trails with peers
Vividness	Describe and present distinct findings	Thick and detailed descriptions of salient themes
Thoroughness	Maintaining a logical connection between research questions, methodology, findings and previous studies	Comprehensive data sampling, data collection and analysis to develop full themes and ideas
Sensitivity	Ethical considerations, concerns for human dignity and respect, benefit in some way	Private interviewing, addressing all concerns, monetary gift for their time

## Chapter 3

### Theory

In 2013, 382 million (8.3%) of the world's adult population was estimated to have diabetes. By 2035, the number is expected to reach 592 million (IDF, 2013). The IDF (2013) has estimated that more than 65% of the world's population with diabetes will come from Asia, the world's most populous region. After China, India has the second largest number of individuals with diabetes. By 2035, it is estimated that India will have approximately 123 million people with diabetes (IDF 2013). In the United States there are roughly 3.4 million South Asians, the five largest communities of which are Indians, Pakistanis, Bangladeshis, Sri Lankans and Nepalese ([SAALT], 2010). Asian Indians comprise 16.4% of the total Asian population in the United States (Greico & Cassidy, 2001). They have a higher prevalence of diabetes and develop it at a younger age than non-Hispanic Whites (Mohanty et al, 2005). In the San Francisco Bay Area, Asian Indians were found to be at higher risk of developing diabetes than any other ethnic group in the United States with a prevalence of 29% for people between the ages of 45 and 79 (Kanaya et al., 2010). Venkataraman and colleagues (2004) also found an overall prevalence of diabetes mellitus of 18.3% in Asian Indians in Atlanta, GA, which is much higher than Blacks (12.8%), Hispanics (8.4%), and Whites (6.6%; Cowie et al, 2009) One in six Asian Indians in the United States has been diagnosed with type 2 diabetes (Misra et al, 2010; Venkataraman, et al, 2004).

Achieving control over diabetes is a complex process. Not only does it include medications, but also major lifestyle changes that include diet and exercise. Treatment typically includes increasing levels of physical activity, eating a healthy diet; and, in some cases taking oral medication, or insulin to improve, or maintain, control. In addition, patients are often

expected to monitor their blood sugars at home using glucometers. All of these interventions, aid in the self-management and control of the disease. Those who do not adhere or achieve control are at risk of developing complications such as coronary heart disease, nephropathy, retinopathy, neuropathy and premature death (UKPDS, 1998). Studies have suggested that reducing the complications of diabetes and achieving control over it is a complex process for Asian Indians because they are a heterogeneous group with different languages, dialects, religions and cultural beliefs. Several barriers to achieving control have been identified: Asian Indians have relatively less knowledge about their disease, they understate the seriousness of the disease, and they have poor understanding of the relationship between glucose regulation and complications (Bean, Cundy, & Petrie, 2007; Macaden & Clarke, 2006). Some studies have also found associations between low socioeconomic status, inaccessibility of health care, language barriers and poor control of diabetes in this group (Farooqi, Nagra, Edgar, & Khunti, 2000; Lawton, Ahmad, Peel, & Hallowell, 2007) .

Diabetes is a life-long condition that affects all aspects of a person's life. Because it is a chronic condition, it can have a significant effect on a person's quality of life as well as their family. Nonetheless, people with diabetes can understand and manage their disease. But they need to make life-style, behavioral and dietary changes to achieve control over their disease. Additionally, they need to understand that they have to make important health decisions that may conflict with cultural practices (Anderson & Funnell, 2005). Managing diabetes involves the interplay between personal, behavioral and environmental factors. To manage diabetes successfully people with diabetes must set goals, learn new skills, and make daily decisions that lead to effective management their disease. Several approaches and theories to managing diabetes have been purposed. For the purpose this dissertation I propose to discuss three middle

range theories (i.e., self-efficacy theory, empowerment and health empowerment theory) to explain this interplay of personal, behavioral and environmental factors and daily self-management of diabetes in Asian Indians.

Theories guide nursing practice and research and aid in identifying and expressing key concepts. Through the application of theory, phenomena may be explored in terms of general or more delimited descriptions and explanations of person, health and environment, and nursing (Walker & Avant, 2004). There are two classes of theory, grand theory and middle range theory. Both have been widely used in nursing research. Compared with grand theories, middle range theories are more specific, use fewer concepts and address more limited aspects of the real world (McEwan & Wills, 2002). Their concepts are easily operationalized, and provide easier interpretation of behavior, situations, and events. Middle range theories can elucidate the connections between diagnoses and outcomes, and between interventions and outcomes (Fawcett, 1999). Hence, self-efficacy theory, empowerment theory and the health empowerment theory can be easily adapted to guide nursing practice.

### **Self-Efficacy Theory**

Self-efficacy is a term that is often used in nursing and has been acknowledged to be a significant predictor of successful self-management of chronic disease. As found in the Merriam-Webster Online Dictionary (2011), efficacy is “the power to produce an effect”. Self-efficacy theory evolved from grand theories, namely social learning theory and social cognitive theory. Dissatisfied with the principle of behaviorism and psychoanalysis, Bandura presented the social cognitive theory in 1986. He believed that behavior principles and psychoanalysis ignored the role of cognition in motivation and the role of situations. In social cognitive theory,

it is assumed that individuals do not simply respond to environmental influences but actively seek and interpret information. They contribute to their own motivation, behavior and development within a network of reciprocally interacting influences (Bandura, 1977). Human behavior is explained in terms of the triadic, dynamic, and reciprocal interplay of personal, behavioral and environmental influences (McAllister, Perry, & Parcel, 2008).

Self-efficacy, which is a major construct in social cognitive theory, is based on the assumption that exposure to certain conditions and environments results in behavioral changes by altering an individual's level and strength of self-efficacy. Because managing diabetes involves interplay between personal, behavioral and environmental factors, self-efficacy is applicable in improving the self- management of diabetes. Bandura (1977) defined self-efficacy as person's judgment of his or her capabilities to organize and execute a course of action required to attain designated type of performance. Self-efficacy beliefs are theorized to affect behavior initiation and cessation, effort and persistence, motivation, thought patterns, and emotional reactions (Bandura, 1997). Ideally, self-efficacy should increase the confidence of a person with diabetes to manage their disease.

The theory of self-efficacy conceptualizes person-behavior-environment interaction as a triadic reciprocity, the foundation for reciprocal determinism (Bandura, 1986). Bandura describes *reciprocal* as an interrelationship between person, behavior, and environment; *determinism* is the belief that behavior, cognitive factors, personal factors, and environmental influences all operate interactively as determinants of each other (Resnick, 2004). How people interpret the consequences of their behavior informs and alters their environment and their personal factors (cognitive, affective and biological events), which in turn, informs and alters subsequent behavior (Allen, 2004). Given appropriate skills and adequate incentives, efficacy

determines how much effort or time people spend on an activity. This theory makes the assumption that people exercise influence over what they do. People decide how to behave and have the ability to produce a desired or intended effect (Liu, 2012).

According to Bandura (1997), cognitive thought does not exist in a vacuum. Social cognitive theory suggests that acquisition of new skills in the face of personal, social, and environmental barriers requires a strong sense of self-efficacy expectations and outcome expectations (Iannotti et al., 2006). Bandura further divides self-efficacy expectations into efficacy expectations and outcome expectations. Efficacy expectations are judgments about one's ability to accomplish a given task. Bandura believes that one can execute a certain behavior in a specific situation to produce an outcome. Efficacy expectations are a major determinant of one's choice of activities; and how much effort, or time, is spent on them. Self-efficacy expectations are important factor for both short and long term changes in health behaviors (Holden, 1991). The effect of information on efficacy expectations also depends on how information is processed and transformed. Cognitive appraisal of information is affected by several contextual factors including the social, situational, and temporal circumstances under which events occur. In other words, a social situation, its location, and the time in which the event occurs affect how a person processes the situation. For example, Asian Indians with diabetes who believe that they can monitor and control their blood glucose levels during cultural and religious events should be better able to persevere and succeed in the face of other situational barriers than an Asian Indians who believe that they have no control over blood sugar levels.

Efficacy expectations vary on several different dimensions: magnitude, generality, and strength. The magnitude of a task is expressed when a task is ordered by different levels of difficulty. The efficacy expectations of individuals may limit them to a simpler task, or extend



into a more difficult task. For example, Asian Indians who are technically savvy may easily adapt to a new insulin pump, while Asian Indians who are not as savvy may find it easier managing diabetes with insulin injections or oral medications. Efficacy expectations also differ in generality. Some experiences create circumscribed mastery while other experiences create a sense of efficacy that extends beyond the specific treatment situation. Asian Indians with diabetes may learn to control their diabetes with carbohydrate insulin correction factors of common foods taught to them during their basic diabetic education class. They can then apply this mastery of carbohydrate counting to the carbohydrate insulin correction ratios with foods that are culturally appropriate.

Efficacy expectancy varies in strength. The strength of people's conviction in their own effectiveness is likely to affect whether they will even try to cope with given situations (Bandura, 1977). The stronger the perceived efficacy, the greater the effort to cope and accomplish a task; the weaker the perceived efficacy, the weaker the effort to accomplish the task. Depending on the success of previous experiences, an Asian Indian with diabetes may have more confidence and be more willing to expend more effort in achieving diabetes control. Individuals who possess strong expectations of mastery will persevere in their coping efforts despite disconfirming experiences. If, however, there has been failure in previous experiences, achieving control may be more difficult. For example, if initial dietary and lifestyle changes are not followed by improvements in glycosylated hemoglobin (H<sub>g</sub>A<sub>1c</sub>) levels, Asian Indians with diabetes may conclude that they have no control over their blood sugars. However, weaker expectations are easily extinguishable by disconfirming experiences. In this case, one would encourage a person with diabetes to make changes that had positive outcomes, with the intention of increasing confidence which is essential in achieving control of diabetes.

In Bandura's (1977, 1986) view individuals use four principal sources of information to achieve self-efficacy - enactive attainment, vicarious experience, verbal persuasion, and physiological state. Enactive attainment occurs when one actually performs a task; it strengthens or may require readjusting one's self-efficacy. It is grounded in past experience and is the most influential source of efficacy. Positive and negative experiences can influence a person's ability to perform a given task. If one performed a previous task well, he or she is more likely to perform a similar task well (Bandura, 1977). Individual self-efficacy will be high if a person has had previous positive experiences; he or she is more likely to try harder to complete tasks at hand with much better results. However the opposite is equally true. Self-efficacy may be reduced if a person has experienced failure previously. However, if these failures are overcome at a later time, self-motivation increases and the task is viewed as an achievable challenge (Bandura, 1977).

Several modes of therapy have been used in enactive attainment: participant modeling, performance desensitization, performance exposure, and self-instructed performance. These modes have been used in designing diabetes education programs. For example, in teaching Asian Indians with diabetes how to use a glucometer, an educator may review the procedure, and allow patients to test their blood sugar using the educator's verbal guidance. This strategy exemplifies participant modeling, performance desensitization, performance exposure, and self-instructed performance. The patient observes the diabetes educator use the glucometer (participant modeling and exposure) and then uses it in her presence (performance desensitization and exposure). Thereafter, patients can practice, or self-instruct the use of the glucometer. These modes of therapy improve behavioral functioning and increase coping skills in similar situations. For example, self-efficacy gained by overcoming needle phobia may

increase coping efforts in other situations, such as testing blood sugar; or inserting an insulin pump catheter.

Vicarious experience refers to the observation of another person successfully performing similar behaviors (Liu, 2012). This has greater effect if the behavior is new. People can persuade themselves that, if others can do it, they too should be able to achieve some improvement in their performance (Bandura, 1977). People can develop high or low self-efficacy by observing other people's performances. They can watch others perform successfully and then compare their competence with the others' competence (Bandura, 1977). Mentoring programs are a good example where Asian Indians are paired with individuals who have successfully achieved control of their diabetes. The vicarious exposure could strengthen one's beliefs in diabetes self-efficacy. Of course, the opposite outcomes are possible when Asian Indians with diabetes witness others who have developed complications of diabetes. Lower self-efficacy may result, this may create a concern that Asian Indians cannot achieve diabetes control because of their diet or cultural health beliefs. Modeled behavior with clear outcomes conveys more efficacy information than if outcomes are ambiguous. If a person sees someone similar to them succeed at a task, their self-efficacy may increase. For example, a patient with diabetes may benefit by observing healthy eating practices or successful insulin administration. Observation may reduce anxiety or distress and promote perseverance especially if the outcomes are clearly defined. On the other hand, if a person observes someone similar to them fail his or her self-efficacy may decrease. Although Bandura (1977) believes that vicarious experience relies on inferences from social comparisons, it is a less dependable source of information about one's capabilities than direct evidence of personal accomplishments.

Self-efficacy, as it pertains to a person's ability to perform a task, is also influenced by verbal encouragement or discouragement. Verbal persuasion, which can convince people of their capabilities to achieve and master a task (Liu, 2012), is widely used because it is so easy to practice. Positive verbal persuasion can motivate a person to expend more effort and succeed, while negative or discouraging verbal persuasion reduces the person's ability to succeed. Verbal persuasion is also affected by credibility. The more credible the source of verbal persuasion, the greater the influence. People who are socially persuaded that they possess the capabilities to master difficult situations are likely to mobilize greater effort (Bandura, 1977). For example, a culturally sensitive diabetes educator may be considered more credible than a family member in initiating an appropriate diet for an Asian Indian with diabetes.

The final and least influential source of information for self-efficacy is the physiological state. People experience bodily sensations and how they perceive these emotional arousals influences their beliefs of self-efficacy (Bandura, 1977). Physiological feedback occurs when one uses information about their physiological state to judge their ability. High or low arousal states can either enhance or debilitate a person's performance. For example when people are diagnosed with diabetes and given information on medications, they may be highly aroused and accept all the information or, they may "shut down" and refuse it. Low level arousal states may also produce similar behaviors. High and low arousal states may have positive or negative effects on self-efficacy. Modeling, biofeedback, and desensitization are strategies to reduce high arousal states or improve low arousal states.

Outcome expectations are defined as judgments on what will happen if a task is completed. They are concerned with the possible consequences of a specific behavior. An outcome expectation is a personal estimate that a given behavior will produce a certain

outcomes (Bandura, 1977). Outcome expectations may be influenced by self-efficacy judgments. A person's belief on how well he or she can perform a task, affects outcome expectations. Self-efficacy influences the efforts people make and determines persistence in the face of obstacles and failures (Bandura, 1986b). Outcome expectations may have beneficial or detrimental effects, favorable or adverse social reactions, and positive or negative self-evaluative reactions (Bandura, 1997). For example, when Asian Indians with diabetes believe that they can control their blood sugar and achieve acceptable HgA1c levels by limiting carbohydrate intake, self-efficacy is reinforced. Achieved outcome expectations enhance perceived self-efficacy and the efforts one uses to master the challenge. On the other hand, Asian Indians with diabetes may not meet their outcome expectations. The outcome expectation may be to achieve blood sugar control, but modification of their diet and life-style does not improve glycemic control. This may lower self-efficacy and lead to poor long term control of diabetes.

Self-efficacy in the absence of high outcome-expectations and outcome expectations can be disassociated from self-efficacy expectations. This usually happens when outcomes are not affected by performance or ability. For example, people with diabetes that have tried all of the oral hypoglycemic agents and insulin, without success, may feel that they have no control over their disease. They may feel that no matter what they do, they will have persistently high blood sugars. This may engender a feeling of helplessness. Similarly, if they do not believe in outcome expectations, they may not perform expected behaviors. For example, if persons with diabetes do not believe that controlling their blood sugar will reduce their risks of heart disease, they may not exercise, or adjust their lifestyle. Efficacy expectations and outcome expectations play a critical role in promoting self-management of diabetes control.

Self-efficacy also plays an important role in the self-management of chronic disease because it determines whether individuals will initiate behavioral changes (Holman & Lorig, 1992). The theory of self-efficacy has been used world-wide, to describe the clinical aspects of care, education, and nursing competency and professionalism (Resnick, 2004). Most research studies have focused on the education of nurses and caregivers and, behavioral changes in the management of chronic diseases, exercise and health promotion. Self-efficacy has also been used in diabetes prevention and control programs, including physical activity, weight loss and dietary modification. It offers a basis for improving the effectiveness of diabetes education because it focuses on behavioral change (van der Bijl & Shortridge-Baggett, 2001). A positive relationship has been reported in several studies between the level of self-efficacy and diabetes self-management behavior. Efficacy expectations and outcome expectations have been related to healthy eating. The theory of self-efficacy holds that having more diabetes knowledge improves self-efficacy (Sousa & Zauszniewski, 2010).

Self-efficacy has been used to understand patient behavior for many of the components diabetes self-management, for example, metabolic control, health related quality of life, coping, problem solving, self-care adherence, diet adherence, insulin therapy, blood glucose testing and exercise adherence (Anderson et al., 2005; Kavanagh, Gooley & Wilson 1993; Ludlow & Glein, 1995; Rubin, Peyrot & Saudek, 1989). In recent years, several interventions to improve diabetes self-efficacy have been developed and tested. These have shown that patients achieved better control of their diabetes (Heisler, Smith, Hayward, Krein, & Kerr, 2003; Strut & Hearnshaw, 2002) with increased self-efficacy. Having confidence to perform diabetes related self-care is essential to control the disease. Finally, the theory of self-efficacy has also been studied in multiple ethnic and cultural groups with diabetes around the world: China, India, Singapore, and

Taiwan (Su-Fang et al., 2007; Venkataraman et al., 2012). All of these studies have found that self-efficacy is essential in achieving control of diabetes.

### **Strengths and Limitations**

Self-efficacy has been extensively tested and well supported in many aspects of nursing and chronic disease management. Research supports the conclusion that self-efficacy affects how people perceive themselves and how they achieve their goals. People with high self-efficacy have greater motivation and commitment in accomplishing personal goals. Learning and mastering specific tasks are transferable to other situations and challenges. Although self-efficacy has been extensively reviewed and used, only a few studies that have examined self-efficacy and outcome expectations together or their potential effects. Furthermore, outcome expectancies have not been researched as frequently as efficacy expectations because they cannot be discretely separated from the former. In addition, there are fewer established measurements of outcome expectations because they vary from person to person.

In summary, self-efficacy theory integrates the cognitive, social and skills capabilities that a person must perform during a course of action. It plays an important role in the self-management of diabetes because it determines whether individuals will initiate certain behavioral change (Holman & Lorig, 1992) to achieve control over their diabetes. It is also an important determinant of how much effort and time a person will spend in managing their diabetes. Self-efficacy can instill the confidence and power people with diabetes need to make changes in their diabetes management.

## Empowerment Theory

Empowerment, derived from the Latin verb for power, *potere*, means “to be able”. Its prefix “em” means “cause to be” or “provide with” (Abdoli, 2008). Hence, its current definition is “to provide with power”. Researchers have posited three levels of empowerment: personal, small group and community. At the personal level, empowerment is the experience of gaining increasing control and influence over daily life and community participation (Keiffer, 1989). At the small group level, empowerment involves the shared experience, analysis and influence of groups on their own efforts (Presby, Wandersman, Florin, Rich, & Chavis, 1990). At the community level, empowerment revolves around the utilization of resources and strategies to enhance community control (Labonte, 1989b). The three levels are highly interactive and difficult to separate. Understanding empowerment at the personal level not only influences group and community level empowerment, but also leads to policy changes that are essential in chronic disease management. Thus research on Asian Indians with diabetes must begin with an understanding of personal empowerment.

In the past, most diseases were managed by the medical model, which was designed to treat acute health care problems. In that model, health professionals were the authorities who were responsible for diagnosis, treatment and patient outcomes. Educational programs were prescriptive and developed to promote compliance and adherence to motivate patients to change and gain control of their disease. As chronic illness became more prominent, the medical model was re-examined (Anderson & Funnell, 2000; Funell & Anderson, 2000; Glasgow & Anderson, 1999). This led to a paradigm shift where patient involvement and control were now essential in the self-management of chronic disease. Empowerment entered into the self-management of chronic disease.



Empowerment, which has its origins in education, was popularized in the 1960s by a Brazilian educator, Paulo Freire. He posited that empowerment entailed a process in which the teachers and students learned from one another. Empowerment increased the awareness of students to think critically and increased their autonomy in decision making. The role of teachers was to learn from students and construct knowledge in ways that were meaningful. Funnell and Anderson (1991) adopted the term empowerment in diabetes education and proposed that it is first and foremost about helping patients get what they need and want (Anderson & Funnell, 2010). Health professionals may be clinically expert in diabetes, but they may not know what is best suited for patients.

Empowerment has been defined as a process in which patients gain the knowledge, skills, attitudes and self-awareness necessary to influence their own behavior and that of others to improve quality of life (Shearer, 2009). Patients have full responsibility for managing their diabetes. Empowerment focuses on person's strengths, rights and capabilities (Abdoli, 2008) and has been further defined as a dynamic process that emphasizes "purposefully participating in the process of changing oneself and one's environment, recognizing patterns and engaging inner resources for one's well-being (Shearer & Reed, 2004, p. 257). It conveys the notion that individuals have the power and control to achieve their well-being in a meaningful way. The theoretical view of empowerment is based on four assumptions: (1) empowerment is a power that is inherent in the individual and is ongoing (Labonte, 1989a); (2) empowerment is a relational process, expressive of the mutuality between person and environment; (3) empowerment is an ongoing process of change that is continuously innovative; and (4) empowerment is expressive of a human health pattern of well-being. From the empowerment perspective well-being is the ultimate health outcome (Shearer, 2009).

Empowerment has been extensively used in diabetes education and self-management. It focuses on three fundamental aspects: choices, control and consequences (Funnell & Anderson, 2004). The theory posits that the choices individuals make about their diabetes self-management have a greater effect on their self-management, than the choices of their health care provider. Patients are in charge of determining which decisions they wish to make for themselves. They have the right and responsibility to manage their diabetes in a way that is best suited to them within their context and cultural beliefs (Funnell & Anderson, 2004). The most important choices that affect the well-being of patients are made by patients not by health care providers. Patients take control of their diabetes self-management. Finally, individuals with diabetes are responsible for the consequences of their self-management. Empowerment shifts the responsibility of diabetes control and self-management to patients instead of health care providers.

Funnell and Anderson (2004) proposed that empowerment is neither a technique nor a strategy, but rather a vision that guides each encounter with patients and requires that both professionals and patients adopt new roles. Health care providers must give up the notion that they are responsible for their patients; and acknowledge that patients are always and everywhere in charge. The hypothesis is that providers must shift their positionality about patient responsibility, and patients must become more actively involved in achieving control of their diabetes. Funnell and Anderson conceptualize empowerment as both an outcome and a process. As an outcome, it results in patients' enhanced ability and confidence to make autonomous decisions about their diabetes. The role of health care providers is to help these patients, through education and care recommendations, to make informed decisions on how to achieve their goals and overcome barriers. Empowerment is collaboration between patients and health care

professionals. Professionals bring knowledge and expertise about diabetes and its treatment, and patients bring expertise on their life and what will work for them (Funnell & Anderson, 2004).

Empowerment has also been understood as a process of change. For patients to become empowered, they must gain information about themselves and, their environment and be willing to identify and work with others for change (McClelland, 1975). Empowerment should increase patients' capacity to think critically and make autonomous, informed decisions. System-specific strategies can be implemented to promote patient-empowerment and self-management. Studies have shown that creating patient-centered practices that provide support for on-going active self-management led to improved diabetes control. Diabetes empowerment was associated with increased medication adherence; increased knowledge; and effective self-care behaviors (including diet, physical activity, blood sugar testing and foot care) (Hernandez-Tejada et al., 2012). Patients improved their self-efficacy and saw greater reduction in HgA1C, blood pressure and cholesterol levels (Castillo, Giachello, Bates, Concha, Ramirez, C, et al., 2010). A recent study evaluating the efficacy of an empowerment-based self- management consultant intervention found that empowerment improved quality of life in patients with diabetes (Anderson et al., 2009).

### **Strengths and Limitations**

Empowerment has been well- studied in the management of diabetes and diabetes education. Studies have shown that empowerment-based interventions are effective in achieving control of the disease. Empowerment places patients, rather than health care providers, at the center of responsibility and control in health care decisions. It allows individuals to set personal goals and, increases autonomy and satisfaction. However, empowerment has limitations: It does

not provide an alternative for patients who are not willing to make choices. It focuses only on the relationship between providers and patients with diabetes who are willing to make choices. McClelland (1975) has suggested that for people to take power, they must gain information about themselves and their environment and be willing to identify and work with others for change. Awareness of personal and socio-contextual resources plays an important role in promoting well-being in chronic diseases. To further understand empowerment beyond the personal level and to promote fullest health potential for a person with diabetes, the health empowerment theory will be discussed next.

### **Health Empowerment Theory**

The theory of health empowerment is based on Martha E. Rogers's Science of Unitary Human Beings. Her principle of *integrality of human beings* suggests that humans are enmeshed in their physical and social environment as they conduct their daily lives and experience their health (Shearer Crawford, 2009). Health empowerment is a social action process that promotes the participation of people and communities in achieving individual and community goals and improving quality of life. The assumptions underlying the theory of health empowerment are that (1) individuals are assumed to understand their own needs better than anyone else and therefore should have the power to define and act upon them (2) all people possess strengths that they can build on (3) empowerment is a life-long process, and (4) personal knowledge and experience are valid and useful in coping effectively (Whitmore, 1988).

Health empowerment, which emerges from a synthesis of personal and social-contextual resources, enhances the possibilities for people to control their own lives. Crawford Shearer (2007) describes health empowerment as consisting of: resources (personal and social

contextual) and purposeful participation. Crawford Shearer (2007) defines personal resources as self-capacity which is the inherent strength and unique capability that individuals have to make change. Crawford Shearer (2009) theorizes that self-capacity includes promoting change and growth by acknowledging personal strengths and advocating for self. People understand their own needs better than anyone else and should have the power to define and act upon them. Self-capacity enhances problem solving and autonomy in making meaningful changes. Self-capacity is vital in achieving and expanding personal empowerment.

Social contextual resources include social networks and social services (Shearer Crawford, 2009). Support from social networks includes practical and moral support that provides needed reinforcement, assistance and motivation. Practical support is the tangible support that other people provide, and includes information that enhances a person's ability to make decisions. Practical support includes transportation, access to educational programs and medical care. Access to social services and social networks provide access to valued resources (Lord & Hutchinson, 1993). Good working relationships with health care providers can mean quick access to professional help when needed (Thorne, 2006). Moral support provides people with an opportunity to confirm their own intuitions, increase their belief in themselves, and recognize their own strengths and capabilities. It includes informal sources such as strong relationships with family and friends that occurs in the daily management of diabetes. When informal sources acknowledge the strengths and capabilities of persons with diabetes, it is hypothesized to increase their self-perceptions of strength. Moral support is hypothesized to influence overall well-being, and improve outcomes and control of diabetes.

Purposeful participation in health and health care decisions is also a core component of the health empowerment process. Purposeful participation in goal attainment is a theoretical

mediator between the health empowerment relational process and the health outcome of well-being (Crawford Shearer, 2009). It is manifested through self-motivation, awareness, choices, freedom to act intentionally, and involvement in making change. It involves the active participation of persons and their inherent capabilities.

In summary, the health empowerment theory is a relational process that emerges when individuals recognize that they possess the personal and social contextual resources to achieve well-being (Crawford Shearer, 2007, 2009). According to the theory, interdependence between personal and social contextual support and purposeful participation is essential for Asian Indians to develop control of diabetes.

### **Strengths and Limitations**

The health empowerment theory has several strengths. It shifts control of health and well-being from the health care providers to the patients. The theory allows individuals to set goals, and mobilize their unique personal and social contextual resources. It provides a holistic view of people with diabetes, suggesting the importance of allowing them to gain necessary information about their disease and environment. Beliefs in personal capabilities and unique characteristics foster confidence in the ability to take initiative in changing one's life. Secondly, and perhaps most important for the purpose of this dissertation, the health empowerment theory considers the socio-contextual and socio-cultural context of the people with chronic disease.

Health empowerment theory can be adapted to Asian Indians with diabetes since it allows for setting unique personal goals. Incorporating empowerment approaches that are based on culturally adapted diabetes education has been found to reduce hemoglobin A1c, blood pressure and cholesterol (Castillo, Giachello, Bates, Concha, Ramirez, C, et al., 2010). Finally, the health

empowerment theory can be used to eliminate the barriers that Asian Indians in the United States face when managing their diabetes. By building on patients' strengths and capacities, the health empowerment theory can improve a sense of well-being and control over diabetes among the Asian Indians.

However, the health empowerment theory does have its limitation: It does not provide an alternative to unfavorable outcomes. Emphasis is placed on identifying and strengthening those factors that promote well-being. The theory does not sufficiently conceptualize factors or processes that may deter patients from self-reliance or their resources to engage in purposeful participation.

### **Applying Self-Efficacy and Health Empowerment Theory to Asian Indians**

Understanding diabetes in the Asian Indians is complex and multifaceted. A synthesis of the self-efficacy and the health empowerment theories is an apt theoretical approach to understanding diabetes in this population. Self-efficacy has been described as “the power to produce the effect”, and empowerment is “to provide the power”. The concepts of self-efficacy and health empowerment are well defined and can be easily operationalized in Asian Indians. A conceptual model of the synthesis of self-efficacy and health empowerment will be presented to improve diabetes management among Asian Indians.

Health empowerment and self-efficacy have been identified as predictors of successful self-management of chronic disease. Both involve interplay between personal, behavioral and environmental influences. Self-efficacy and health empowerment enable patients to gain autonomy and the ability to understand and achieve control of their disease. Health empowerment theory defines personal resources as self- capacity, which is inherent in people.

The theory allows Asian Indians with diabetes to identify personal resources based on their unique cultural and religious background. Self-capacity is also influenced by self-efficacy expectations. Bandura (1977) described self-efficacy as judgments or beliefs that one has in their ability to accomplish a given task. These beliefs are shaped by cognitive, situational and temporal circumstances under which events occur. Self-capacity in Asian Indians is strongly influenced by their cultural philosophy and religious beliefs. Setting personal goals within their cultural context increases the chances for success. Self-capacity and self-efficacy expectations take into account the unique perspective and characteristics of each person, and the time, place and meaning of the presenting situation. If Asian Indians with diabetes have culturally constituted goals and have mastered the skills to manage their diabetes, self-capacity and efficacy expectations will be enhanced, ultimately, improving outcomes of their diabetes.

Social contextual resources are essential in achieving control over diabetes. Studies have found that Asian Indians tend to have smaller social networks and use social service less frequently because they are distant from extended family, may be immigrants to this country or may not have access to diabetes information in their language (Grewal, Stewart, & Grace, 2010). Other studies have identified two types of social supports in Asian Indians (Stone, Pound, Pancholi, Farooqi, & Khunti, 2005): shared experience and knowledge. The former is an important source of emotional support which is achieved through peers, family members and friends. Asian Indians with diabetes should be encouraged to identify social networks, including supportive persons, and to develop strategies for increasing awareness of and access to resources within their communities to improve diabetes control.

Because Asian Indians confront several barriers to achieving control over diabetes and promoting well-being, important personal, contextual and cultural decisions should be made



about life styles (Anderson et al., 1995). Asian Indians may need to develop a range of competencies to take greater responsibility for and control over their condition. These competencies include: personal resources like, self-capacity (Crawford Shearer, 2007), self-efficacy and social contextual resources. Social networks (Davis, Vander Meer, Yarborough, & Roth, 1999) and social service utilization (Crawford Shearer, 2006) have been identified as being essential in achieving well-being in Asian Indians.

Using self-efficacy and health empowerment theory will facilitate self-directed behavioral change in Asian Indians with diabetes. Bolstering beliefs in their capabilities and personal characteristics could foster confidence in their ability to make change and improve self-management of their diabetes. The synthesis of self-efficacy and health empowerment will increase their confidence and self-esteem and increase their ability to take control of their future. Self-efficacy and health empowerment work interdependently increase patient autonomy. Health empowerment can be viewed as an outcome enhanced by self-efficacy (Anderson et al, 1995). Using self-efficacy and health empowerment together should help Asian Indians build skills and knowledge to increase their self-management of diabetes and improve their quality of life.

### **Conclusion**

Self-efficacy theory and the health empowerment theory can be used to understand diabetes in Asian Indians. Both theories posit positive outcomes and well-being as final outcomes. Individuals are constantly undergoing change, and adapting to unique situations. Self-efficacy theory in conjunction with the health empowerment theory provides a framework to understanding well-being and health outcomes in Asian Indians with diabetes. Framed in the self-efficacy model, health empowerment fosters an active role for individuals, helping them

build partnerships while taking on the responsibility of their outcomes. Ideally, this would improve self-esteem, confidence, personal responsibility, independence, and autonomy, which would ultimately improve control of their diabetes.

## **Chapter 4**

### **Results**

Following the principles of the hermeneutic tradition, this research study was designed to explore and understand the lived experiences of Asian Indians with diabetes. Its overall goal was to provide an interpretive account of the daily activities, challenges, and barriers faced by this population. The study aimed: 1) to describe Asian Indian beliefs about type 2 diabetes and its management, 2) to describe the daily challenges and supports that Asian Indians encounter in managing their type 2 diabetes, 3) to describe culturally specific practices (i.e., religious, dietary, and physical activity) in Asian Indians with type 2 diabetes, and 4) to explore gender differences in managing the marital and family roles of Asian Indians with type 2 diabetes. Managing diabetes for Asian Indians is a complex process that is influenced by distinct personal experiences, health, social, religious and cultural practices.

#### **Participant Characteristics**

For this interpretive study 12 adult participants (50% female) between 40 and 75 years of age who self-identified as first generation Asian Indian were recruited from Sikh temples. The average length of residency in the United States was 18 years (range 1-43 years) and the time from diagnosis of diabetes was 11 years (range 1-25 years). All the female participants worked as part time caregivers. Male participants had various occupations, such as owning small businesses and managerial positions. Some males were unemployed. Each participant was interviewed twice, either in English or Punjabi, to learn (a) what the participants understood of their illness, including its cause; (b) their culturally specific practices; and (c) supports and

barriers to illness management. The interviews were audio recorded, translated into English, and transcribed verbatim for interpretative phenomenological analysis using ATLAS ti (Version 7).

Table 2

## Participants Characteristics

Gender	Age	US residency in years	Language	Medications	A1c Self-reported	Diabetes in years
1 Female	60	23	Punjabi	Oral	Unknown	12
2 Male	65	19	English	Oral	7.5	10
3 Male	56	20	English	Oral	6.4	16
4 Female	73	15	Punjabi	Oral	8.0	12
5 Female	63	15	Punjabi	Oral	7.0	3
6 Male	57	43	English	Oral	7.5	2
7 Male	45	1	Punjabi	Oral	Unknown	1
8 Female	42	22	Punjabi	Insulin	13.3	11
9 Male	65	19	English	Oral	7.0	25
10 Female	50	12	Punjabi	Oral	Unknown	12
11 Female	57	30	English	Oral	7.0	10
12 Male	49	12	English	Oral	6.8	10

**Aim 1: Beliefs about Diabetes, its Causes and Management.**

Previous studies of Asian Indians have cited hereditary factors, the presence of a divine power, and the stress of migration as common external causes of diabetes (Farooqi et al., 2000; Lawton et al., 2007; Macaden & Clarke, 2006). In this study beliefs, about the causes of diabetes and its management were influenced by the participants' personal experiences while caring for family members who had diabetes, the participants' own lack of knowledge of the disease, and gender roles. These factors led to an early awareness and familiarity with the disease, which affected the Asian Indians' beliefs about its causes and management.

## Uncertainty and Family History

Although both male and female participants alluded to their strong family history of diabetes as a cause of their diabetes, some participants were uncertain. This uncertainty stemmed from a lack of knowledge about the disease, and it facilitated a passive acceptance by male and female participants alike. A 57 year old female participant acknowledged she was uncertain of the causes of her diabetes. On reflection, she felt that her family history, her childhood diet, and her body's physiological functions were all possible causes. She lacked accurate information and was unable to identify the actual cause of her illness. This led to a passive acceptance of the disease.

I: What do you think caused your diabetes?

P111F: I have no idea, because since I was a small girl like her (referring to her granddaughter who is 6 years old) I ate very little sweets or sweet things. I was more into salt things but not in sweet things. Maybe, I don't know, I have no idea. So when I ask my physician he says maybe it is in my genes.

I: So you don't know what caused your diabetes?

P111F: Yes, I have no idea. Sometimes I think when I was small, I used to eat ice cream, eating gums – my mind says that. I should not have taken that. So now I think I shouldn't have eaten that. I should not have eaten ice cream, or ice blocks, and all that. Then I should not have had diabetes. I am thinking also that if our parents had given us brown rice, brown atta from when we were small. But I don't know... they say never mind so even if you eat sweets, if your insulin does not build then you are going to get diabetes. So when I take all that in my mind, that insulin does not build then I think I am okay, okay, it is not my parents it is my body (laughs).

Hmmm... Yes, sometimes I think that I... I think about my parents if they had no diabetes then I would have not been diabetic. I think that – I blame my mom and dad (laughs). It is because of our genes.

For many participants in this study, diabetes was a common part of everyday life and they believed that it was only a matter of time before they were diagnosed. Some participants casually accepted the diagnosis of diabetes, especially if they already had family members who had diabetes. Believing that there was no chance of escaping the disease, they took no measures to

prevent it. A 63 year old female participant who had seen her father and brother develop diabetes acknowledged that it was inevitable that she too would develop the disease. Family history had sealed her fate, and there was nothing she could do or could have done to avoid the disease.

P105F: No, I don't think I could have changed anything; it is because I have known all along what diabetes is – if it was something that I did not know then I would have thought of things I could have changed. I knew that I would get it because my dad had it, and now my brother has it too and he is younger than me – so now I know it is in the family. My younger brother had it before me.

Similarly, a male participant said that he had a greater chance of developing diabetes because of his family history. Yet, he took no measures to prevent it. Like several other men, he anticipated his diagnosis by having his blood drawn frequently blood and was relieved to find out that he had diabetes. For him, finding out was reason to change his lifestyle.

P107M: Look, in the beginning I never had this problem – because my father has it and every 3 months I would get my blood work done in India, fasting and non-fasting, It never came to me – it would be 96, 97. One day they came to check it here and it was 180.

I: Do you think you got diabetes because you came here or did you have it when you were in India?

P107M: No, I can't really tell whether I got it here, the disease that is going to happen – you know sometimes it is a circle like when you get your sugar checked and mostly you have an 80% chance that it will come back as having diabetes. If you don't get it checked then you will never know, it will be inside of you and it will keep going inside of you this disease. But you need to cover it quickly. I think it is good that I found out I have diabetes.

### **Familiarity—a Relationship with Diabetes**

Several studies have reported a high prevalence of diabetes in Asian Indians (D'Costa et al., 2000; SAALT, 2010)) and a likelihood of developing the disease 11 years earlier than their European counterparts (Raleigh, et al, 1997). A key finding in this study was that participants reported that they were born into a “world of diabetes.” As one woman (P104F) stated,

“I know, I know – it is since I was born I have been aware of diabetes-I know it very well”.

Being born into a “world of diabetes” led participants to characterize the disease as a simple and accepted part of their everyday lives. Looking after family members with diabetes led to an early awareness and familiarity the disease that how they anticipated or accepted their diagnosis. It also influenced how they understood and managed their diabetes. A 73 year old female participant described how she developed an awareness of diabetes as a young adolescent. Because she looked after her grandmother who had diabetes, she was familiar with the self-care and practices that were required by the disease. Her grandmother relied on her to check her blood sugar, administer her insulin and prepare her tea.

P104F: My grandmother (paternal) had diabetes when I was 15-16 years old. My grandmother had it and in those days I used to test her sugar and give her shots. .... I would always check my grandmother’s sugar and give her medications. I would give her tablets, her tea and everything she needed.

Dietary changes that family members made also influenced how participants chose to manage their diabetes. Participant 104F explained that how she helped her grandmother manage her diabetes influenced how she managed her own. She believed that she could manage her diabetes by making the same dietary changes that she had seen her grandmother made. After the participant was diagnosed, she started drinking bland tea like her grandmother did and avoided sweets, which helped control her blood sugar temporarily.

P104F: I like bland tea, with no sugar – hmm, I like bland tea now. Initially, my grandmother used to drink tea without sugar – in those days when I was 15-16 years old. I would make her bland tea, and I would have a sip or two with her. I have never really eaten much sweet.... I was not taking any medications; I wanted to stop eating sweets. I felt that it was no problem that my diabetes would control itself. I did not want to take medication, I would control everything – I told my physician in Ganganagar that I do not want to take any medication. I told him if I would stop eating sweet things then I could

control my blood sugar and would not get diabetes (laughs). But with that, I was able to bring down my sugar readings by 60-80 points.

Later, she conceded that she was not surprised that she could not control her diabetes with dietary modifications alone. She accepted her physician's advice that she would have to take medications. Dietary and medical management of her diabetes was likely influenced by the awareness and familiarity she had with diabetes earlier in her life.

P104F: Then it came back again, it used to be 320, and then it came down to 200s. The physician told me with such high sugar you cannot stop diabetes, you will have to take medications definitely. He then started me on one tablet, like they do in India; with that in mind he started me on one tablet. We then stayed in India for a short while after that, and with that one tablet my sugar stayed well-controlled at 105, sometimes 100. I would never go higher than that. After I had eaten it would go up to 150-160. It was very controlled.

Another participant whose father-in-law had diabetes recounted that she had no fear of being diagnosed. Having seen her father-in-law manage his own diabetes, made it easier for her to accept her diagnosis.

P101F: No, I was not scared; there is no reason to be scared. My father in law had diabetes and I told the physician that it is in the family and it is in his family, but his son does not have it. The physician told me it can happen even without a family history. So I said okay, then it can happen.

Some participants perceived positive aspects to having a strong family history of diabetes. They realized the immutability of the diagnosis - It was not going away nor was it curable. By watching and learning how her father and father-in-law managed their diabetes, this participant learned positive, if simple, approaches to controlling hers. There was no sophisticated story about how diabetes works or about limiting her carbohydrates, or spreading them throughout the day. Rather she was quite satisfied that her blood glucose levels were controlled by simple dietary changes that limited her extraneous sugar intake. Although she



wished that she could be cured by making these simple changes, she knew logically that this was not possible. Even though she knew that the disease could not be cured, she still hoped for a cure. She also expressed gratefulness to God that her caregiving experiences taught her how to successfully manage her own diabetes.

P105F: Yes, because they say it runs in the family, so I would get it. That's what happens, my brother is in India and he has it. I was not worried about it, not much. I thought that it is not going to go away – I had seen it with my father in law and father. I knew that diabetes does not go away. With the help of God I have had better control of it, my sugar have gone down. But like I told you now I don't eat anything sweet. I eat only one roti in the evening and I eat cookies that are sugar free – like the rusks. I know there is some sugar in them, but they are not as sweet. Otherwise, in the past, I used to eat regular cookies all the time. I think it is taking control of sugar that has helped, I think that is all there is to it – avoid sugar. My mind keeps telling me that my sugar can go high again, so don't say that you have been cured.

Another positive aspect of being surrounded by people with diabetes was the fact that one's own diagnosis carried less emotional shock. A 60 year old female participant acknowledged that her care giving experience with her father-in-law who had diabetes prepared her for her own diagnosis. She accepted that diagnosis without feeling emotionally overwhelmed.

P101F: I did not get a shock or anything like that when I was diagnosed with diabetes. If I had not had experienced or seen anyone with diabetes then I would feel shocked – like oh what has happened to me now? But if you have seen some one at home with diabetes then the shock is less. That is how I felt.

Familiarity with the symptoms of diabetes led some participants to anticipate its onset in their own life. Several male participants monitored their symptoms, acknowledged that their lifestyle could cause diabetes, and sought medical care in anticipation of the disease. Participants compared their symptoms with those of their family members. Two male

participants described how their feet started burning like their family members who had diabetes.

Recognizing the symptoms led them to seek medical advice.

P106M: She is diabetic, so I was checking blood sugar and I had little burning in my feet. I knew there was something wrong and she said, “check your blood sugar”. It was high. And then I went to see the physician and he put me on the medicine.

P102M: Symptom that one and I had what you call it ..... the leg cramps, my feet get like a burning you know, those 2 symptoms, and the other thing was I was scared was that my mom was diabetic. So they said - I read in the paper it runs in the family. So I might as well check.

Anticipation also led some participants to get frequent screenings for diabetes. For one male participant, family history increased his awareness of the disease. In anticipation of diabetes, he had frequent screening bloodwork. He believed that it was only a matter of time before he would develop diabetes. Finding out that he had diabetes was a relief because he then had reason to make the lifestyle changes that were necessary. It seemed that Asian Indians changed their diet and lifestyle only after they were diagnosed. Despite anticipating their diagnosis, they took no preventative steps.

P107M: Look, in the beginning I never had this problem – because my father has it and every 3 months I would get my blood work done in India, fasting and non-fasting, It never came to me – it would be 96, 97. One day they came to check it here and it was 180.

I: Do you think you got diabetes because you came here or did you have it when you were in India?

P107M: No, I can't really tell whether I got it here, the disease that is going to happen – you know sometimes it is a circle like when you get your sugar checked and mostly you have an 80% chance that it will come back as having diabetes. If you don't get it checked then you will never know, it will be inside of you and it will keep going inside of you this disease. But you need to cover it quickly. I think it is good that I found out I have diabetes.

Living in a community where diabetes was common certainly heightened the participants' anxiety that they too would get the disease. However, they lacked an awareness of personal risk factors and the motivation to prevent diabetes. A 57 year old male participant

acknowledged that his life style was a precursor of diabetes. Even though he was familiar with its symptoms and causes, he took no preventative action.

P106M: Well, it was a shock, I knew it was coming, I could already tell it was coming. You know because you see fellow people you know people that are diabetic, you know who got it, why they got it, and you know it is coming – so you go to do something about it. A lot of time you don't do it until it hits you.

### **Diabetes as a Sickness**

For several participants, diabetes is a sickness that affects all aspects of their life, their activities, and their diet. Daily management of the disease required more discipline and routine. Checking blood sugar routinely, monitoring diet, and taking medications were associated with being sick.

P111F: If you have any sickness the mind will always tell you that you are sick, I do feel sick, I think I am sick.

P108F: It is a sickness. Yes it is a sickness. I feel that all the time I am sick

Female participants, in particular, emphasized that diabetes took over their life. For those, who followed the recommendations for managing their diabetes, the routine was considered rigorous and overwhelming. A female participant (P111F) said this,

“I don't think so. I don't think there is anything easy about being diabetic. If you are a diabetic it is not easy”.

Women also found that diabetes challenged their ability to attend their children's events and household routines. They felt strongly that managing diabetes on insulin raised particular dilemmas. For example, they could not eat on time or have the right foods available while on the go. Frequent monitoring of blood sugar and administering insulin were frequent reminders that they were sick. Thus, for women, diabetes was intrusive, especially when it interfered with their household duties and busy schedules.

P108F: Like, I gained weight after that, and became very lazy, very tired, very fatigued – you know. So it effects my –my like activities, you know and it is tough, very tough.

I: What is tough?

P108F: Like every day I get up in the morning, I check – I poke myself, check how much it is, then I have to take my insulin, sliding scale. Then I don't like it – you know – I don't like it, it is hard, then again at lunch time and at supper time. Sometimes I am not checking it – my sugar – you know. I just give insulin by myself, you know. And you know because I have to take my son to the game and stuff, then I have to pack all the food with me – it makes it so hard sometimes. Sometimes I can't eat on time, and when the kids eat in the evening. I eat like 9 o'clock – 10 o'clock. It is hard to, like to do my diet, so hard. It is hard to control and I think it is – I don't know I think maybe I can't learn how to live with diabetes. And it is hard.

The life transforming demands of diabetes, also affected some of the men. For example, making lifestyle changes to manage his diabetes made one male participant feel sick. Watching what he ate and taking medications were associated with being sick. He described how his father ate and walked consistently to control his diabetes and believed that he would have to do the same to control his.

P106M: Yes, I am sick– I have to watch myself; I have to watch what I eat. My dad died of old age, but he had type 2 diabetes. He controlled it, he died when he was 83, he controlled it – he ate – like every time he came here, he came from Fresno, he lived with my younger brother, he will walk over to Bel Air (a grocery store), we lived close to it. He would walk over there and he would get a melon, not a water melon, a cantaloupe. He would not ask anybody, he would walk over there buy it and an apple. He ate an apple every day, every day. He ate an apple every day.

I: Do you think because you have diabetes you are sick?

P106M: Yes that is a disease. I mean you got a disease that means you're sick you know.

For some participants, diabetes was a sickness and difficult to live with; for others, diabetes was a fearful disease, particularly its complications. Participants recounted how their parents developed these complications early in their lives, and how this experience made them fear similar outcomes.

P105F: I think that in the long run diabetes is going to ruin my kidneys. I am going to die like my father in law, (laughs). That is what I think – most diabetics get bad kidneys

in the end. I know the heart gets weak also, as time goes by. Heart disease is there too and it is because of this thought I have stopped eating sugar.

I: You are scared of this?

P105F: Yes, I am.

One of the most visible sequela of long term uncontrolled diabetes is the need for kidney dialysis. Several participants expressed fear of dialysis for themselves or judged the disease to be a negative influence in their lives because of end stage organ damage.

P102M: Because my mom was on dialysis because her kidneys failed, it all comes from diabetes, because she had diabetes... It is because my mom had like the kidneys gone, you have to go for kidney transplant, very hard or you go to dialysis which is very hard process, which is not easy for you go three times a week, like you know, three times a week. And you stay over there for 2-3 hours, I think and I used to stay with my mom 2-3 hours sometimes and then after that I used to drop her in the morning 5 o'clock and then go pick up at 10 o'clock. So that put me on my nerve that diabetes is BAD.

The fear of complications, especially kidney disease, led some participants to seek prompt medical care. Several were fearful of kidney disease because they had seen their parents undergo dialysis. Having a physician reassure them that they had not developed this comorbidity was a great comfort. One female participant admitted that her fear of developing kidney failure led her to seek medical attention for any flank pain. In this instance, past family experience was sufficiently negative to prompt this response.

P111F: I am scared of dialysis.

I: Why?

P111F: I am diabetic, and I know diabetes hurts the kidney much, that is why I am so scared. Whenever I have pain over here (pointing to her lower back), I think it is my kidneys. I go and bug my physician (laughs..) I just go bug and ask him to check my kidney. I tell him my family had the kidney problem and my dad had the kidney problem, take my blood please check my kidneys. Please check my blood just to make sure.

Familiarity with the complications of diabetes led many to seek expert medical consultations.

Female participant P112 sought medical advice for her kidneys and her eyes because her father had kidney failure and her mother had retinopathy.

I: Do you worry about your heart, your eyes, stroke, etc...

P111F: Oh yeah, I do. The main is the kidney – I have seen my dad. I'm also scared of my eyes because my mom had to have laser treatment to her eyes - It is called retinopathy from diabetes. My mom was not under that much control over her diabetes. She was not under control. That is why I keep bugging the physician to check my kidneys and my eyes. He keeps saying it is because of allergies my eyes are watering. Now give me the letter for the eye physician, I want to be checked for my diabetes. So he said next month I have my appointment.

Most of the study's participants were diligent about keeping their medical appointments so that they could manage their diabetes and avoid complications. One participant, who helped his mother during her dialysis treatment, kept his routine medical appointments so that he could avoid any kidney or liver damage.

P102M: It really bothers me when I think about diabetes; I hope it does not affect my kidneys, what will happen to me when my sugar gets too high? But I go to the physician every month, on regular basis and every 3 months I do the blood work you know and that keeps me updated on how my kidneys are, how my liver is and how the functions are. But it gets on my nerve that it is dangerous if you do not control it.

I: Why do you think it is dangerous?

P102M: Dangerous, because diabetes if it is not under control but the first thing it will do is it will start to affect your kidneys. So kidneys are the main organs.

### **Beliefs about Cause - Gender Differences**

Although the participants' beliefs about the causes of diabetes revealed several similarities, there were gender differences, which were likely influenced by the distinct cultural roles of Asian Indian men and women. In Asian Indian culture, women are traditionally considered to be more passive than men; they manage the home by keeping family and social issues in order. Men are typically the bread winners and the primary contacts outside of the

home. Female participants described personal stress, family stressors, and a lack of medical advice as causes of their disease, male participants described sedentary life style, lack of knowledge, and dietary practices as causes of their diabetes.

***Female participants.*** Even though several female participants had a family history of diabetes, they described stress and worry as major contributors to their disease.

P105F: Not very long – my dad had diabetes so that is why they say someone in the family can get it. And also with stress and tension you can get it.

I: Stress and tension?

P105F: I am talking with you quite openly; I usually do not talk much.

I: Sometimes it is good to talk.

P105F: Yes, yes it is good to talk. Yes, stress is a major cause of diabetes in our females

Similarly a female participant who had helped her grandmother manage her diabetes was surprised to find out that she too had diabetes. She also blamed stress as the cause of her diabetes.

P104F: Yes, I sometimes don't know – I never thought I would get diabetes, even when I went for my blood tests. I was so surprised and concerned when I found out I was diabetic. The physician told me.

I: Why do you think you got diabetes?

P104F: I feel that I think that I got it because of tension. Worries caused me diabetes.

Stress as a cause of diabetes was a strong belief in this study's female participants. So much so that one woman was convinced that her son developed diabetes because he was worried about her health. Several female participants expressed the conviction that stress, not family history, was a cause of diabetes.

P110F: I think, it is because of all the worries and concerns that I had. Usually when that is the case one develops diabetes. ....My oldest son has developed it too. When I was sick he cried so much and did not take care of his health, and he got so stressed out that he developed diabetes. He lives in Delhi. My two younger sons came with me to the US. We got the older one married before we came here. That is when I got sick after I came back from his wedding.

I: So it was after his marriage?

P110F: Yes, I got sick after he got married. He was far away so he worried more and got diabetes.

**Migration – family stressors.** The stress of migration to the Western world and adapting to life in a new country has been reported to be a major cause of diabetes in the Asian Indian population (Farooqi et al, 2000). Several female participants reported that worrying about their children who did not migrate with them was a key stressor that led to their diabetes. One woman provided a vivid example. Although, she had migrated to the United States about 3 years earlier, she commuted to India several times a year to look after her ailing son. This compounded the stress of acculturation in her new country. But, she felt responsible to provide financial and emotional support for her son. Financially, she had to return to the United States to earn enough money for her son’s care in India. Her son’s suffering, the frequent travel, and the emotional stress of providing care were considered insurmountable stressors which led her to develop diabetes.

P105F: So when he got married, and after that we came here. While we were here, my son and his wife went for a vacation and he fell off the motor cycle. He hurt this area of his knee (pointing to her knee), and it moved. He did not go to the hospital right away, and did not do anything about it. He self-treated it for 3 years. He would adjust his dislocated knee and continued to work on the farm. He then told me that “Mummy my knee continues to hurt.” He then went and had surgery. And with the surgery he got an infection. So for one whole year he was bed ridden in Amritsar. So I had to go every 2-3 months for 2-3 months. It was hard here too; we did not have work to do. And you know how it is there, you can have a lot of money there, but still people need help from what you earn here. So we helped him financially. I would come here earn some money, and then go back.

Finally, his foot started to turn in and then they told him that they have to amputate his leg. He has his leg amputated from here, (pointing to her knee.) They told us that if he did not get the amputation then he would have an infection into his kidneys. If that happens then we cannot guarantee that he will live. So he had to have his leg amputated. He does have prosthesis now, but you know how it is in India, it is not like it is here. The prosthesis is so heavy and when he walks even a little bit his legs starts to hurt. This how my story goes, and we have gone through a lot of hardships. But now it is okay, that’s



okay. But it is because of this hardship I have gotten diabetes. Thinking and worrying about this, running around because of this – I still remember that time and I go crazy thinking about it. Since, then I have had diabetes.

Culturally, Asian Indian women are expected to maintain their family unit. It is not uncommon for Asian Indian parents to be separated from their adult children when immigrating to the United States. Separation from adult children was described by one female participant as a major cause of her diabetes. The tension, the lack of sleep and worrying about her adult children's immigration status caused her to have diabetes.

P104F: ...coming here I don't know what happened. I came here in good health and when I started living here – it was maybe due to my son's immigration paperwork – there was always a problem. It was very stressful for us for a while. He was illegal, and that was always causing some type of tension, there was always tension. And when I found out I was diabetic I was surprised, and concerned that how did this happen to me, why did I get diabetes? I feel that I think that I got it because of tension. Worries caused me diabetes.

I: Worries?

P104F: Yes, one was that my son was all alone here. He came here and nothing would work for him. He could not get his paperwork done, he could not come visit us because if he left the US he would not be able to come back – he was illegal. We were left there, in India all alone. Then slowly, slowly we got our immigration to the US and then you know. And then we had a younger daughter R\*\*\* we got her papers first, and then we could not leave her there in India alone either. There was a lot of tension in those days when I got diagnosed with diabetes. I could not sleep at night, thinking I hope this works out this way and this works out that way. I could not sleep at night.

Another female participant described being left alone in India with her children while her husband migrated to United States. Worrying about her family caused her diabetes.

I: Where you alone in India when you developed diabetes?

P110F: Yes, my husband was here and I was in India. That was a stress and then I had my children to worry about – all this stress thinking about your family, let to me developing diabetes.

Even though female participants had a family history of diabetes, they interpreted family stressors to be major causes of their diabetes. As documented here, family separations were

singled out as major stressors. Being separated from their families during migration caused emotional and financial stressors, which in turn led to diabetes.

***Family responsibilities.*** Maintaining social harmony within the family is considered a woman's responsibility in Asian Indian culture. Household responsibilities are often overwhelming for Asian Indian women who are expected to cook, work outside the home, and maintain the family unit. One female participant described her overwhelming responsibilities, lack of personal time, and busy daily routine as causes of her diabetes. Consumed by her responsibilities, she said that she no time to learn about prevention. These factors created a sense of powerlessness which led to poor glycemic control.

P108F: ... you know so much stress, the Asian woman working hard – they don't care about their health or themselves. They just watch out for their responsibilities, all the time busy, busy, and busy. And they need more awareness and what is diabetes – they need to attend sessions, stuff like that. Because now you know for many their diabetes going on, and they have to watch their diet and they have to give time themselves, and give some time to relax at least at the end of the day, you know, or in the morning. They need less responsibility.

Pause

South Asian women just care about the family and responsibilities. They don't care about their problems. They don't know the disease, or they don't understand. But it is going to be like that until it is too late. Then they can't go back.

***Lack of medical advice.*** Asian Indians hold physicians and health care providers in high regard and highly respect their advice. They expect health care professionals to monitor their patients' disease progression and management. One female participant blamed her physician for not giving her enough information about her thyroid condition and ignoring her pre diabetes symptoms. She felt that the physician ignored her weight gain and fatigue. If this woman had

received medical guidance and knowledge about thyroid disease, she felt that she would not have developed diabetes.

P108F: I think-you know-when I came here from India, I was not working, I was at home, like a housewife, and I have kids after I came here after 2 years. I got my daughter first, then after a year I got my son, then I am just sitting at home, and you know. But then after my second son, when he was born after that I got problem like thyroid, and I don't know what is thyroid. So at that time 20, 19-18 years ago, you know, not even in my family nobody is like in the medical field, and my physician she does not explain to me what is thyroid. And she never told me that I have to take these pills every day. It is very important, you know and this may affect or create other problems. And I sometimes took my pill in the morning or sometimes not. I did not care about the thyroid. I gained weight after that – like 70lb almost. Then like I become very tired – I tell my physician, so many times. She did not do any blood test or anything, even though there was no awareness at that time. So that is why. I never cared about my thyroid and I gained weight. I think after that it creates the diabetes.

I: So if you think she would have told you – it would have changed?

P108F: Yeah, I think if she – it is because of her I have this problem. It is because of my physician I have this problem.

This study's female participants felt strongly that adapting to life in the United States and maintaining family harmony were stressors that led to diabetes. Cultural expectations compelled them to maintain family harmony, and they went out their way to perform care-giving, even though it negatively affected their health and well-being. Migrating to the United States, compounded with other stressors that affected family harmony, led to emotional, financial, and personal stressors that contributed to their diabetes. Female participants also believed that a lack of personal time due to household responsibilities, care giving, and family obligations led to their diabetes. One participant attributed lack of quality communication with physicians was a cause of her diabetes. She felt that the physician was inattentive to her symptoms and did not take the time to explain the importance of her thyroid medication. If she had known that not taking her thyroid medication would have caused her weight gain, she would have been more compliant in

taking her medications as prescribed. She blamed her physician's lack of guidance as a cause of her disease.

***Male participants.*** All male participants reported a family history of diabetes, but several attributed their diabetes to external factors, for example, a lack of knowledge or migrating to the United States. They also described lack of exercise, sedentary employment, and overabundance of food in the United States as causal.

I: What do you think caused your diabetes?

P106M: Lack of exercise, and I don't know eating wrong foods – I guess.

I: What kind of food?

P106M: Dahl, roti, lots of pakoras (laughs). Barfi (laughs).

***Lack of knowledge.*** Some male participants thought that a lack of knowledge in the prevention of diabetes, especially while growing up, led to their disease. Unaware that diabetes can be hereditary; one participant believed that he could have prevented it if he only had some knowledge about it and its complications as a younger adult. He would have changed his diet and exercised.

P102M: I think if I could have controlled my habit a little bit in the past I could have maybe avoided it – but if it runs in the family, like my mom and her parents had it, you know. So I don't know if it is from some reason coming from the family. You can only do so much alone. But I think if I would have stopped to watch what the diabetes is I think I could have – you have no knowledge in India what diabetes is. It is over here like before 2004, I started diabetes. If I knew early, then I would have changed a little bit about my lifestyle.

I: What would you have changed, or liked to have known?

P102M: Like what diabetes is, how it affects your body, you know? And why it is so dangerous, and how I could have controlled it at an early age. That are something's I wish I had known.

I: What would you have done?

P102M: I could have – I never controlled my diet, I could have controlled my diet. I could have done some exercises. Yeah that is what I could have done.

***Sedentary lifestyle and long working hours.*** Migrating to the Western world, working odd jobs, and working long hours to make ends meet have been reported as causes of diabetes in Asian Indians (Lawton, et al, 2006). Similarly, this study's male participants described adapting to a new work environment, sedentary employment, long hours and a lack of exercise as causes of their diabetes. One gentleman stated emphatically that working long hours in his store caused his diabetes, even though he acknowledged that it can be hereditary. He tells his sons that they can get diabetes because he has it, but he does not believe that hereditary factors caused *his* diabetes.

P109M: Actually, when my sons came here they got handed over more responsibility. My older son realized that his father was working very hard, and he started working with me at the liquor store. So we both worked, while my younger son and daughter went to school. He would go to drop them off school. I would get up every day at 6 am, and then go to work till mid night. He saw that and he started working too. I have told them not to eat sweet stuff because they can get diabetes because I have it. But it is due to my circumstances that I got diabetes. It is not hereditary, and that is why I think they will not get diabetes. I don't think they have diabetes.

Another participant explained that his job required him to "sit down" for long hours.

Lack of control of his work environment was a precursor for his diabetes.

P106M: If I had my way, if I had a different kind of environment. Different kind of job, maybe one you walk around a little bit and that would probably help. My job is sitting down.

I: So you don't get much time to walk around?

P106M: No, we are on the train for a certain amount of hours. Then we go there, and by the time you get there you're tired.

I: So you ride the train from Sacramento to Shasta.

P106M: Yes. I am a locomotive engineer on the Union Pacific.

I: So you don't drive up?

P106M: No I ride in the train. I'm a locomotive engineer. We work for 24 hours on the train.

Migrating to the United States led several male participants to change their profession.

This is not uncommon for Asian Indians. One participant who was a teacher in Fiji was now working in a bank. In Fiji, he was physically active during the day, routinely walked 6-10 miles.

Since he migrated to the United States, his daily physical activity decreased considerably due to the change in his work environment. He believed that his sedentary bank job caused him to have diabetes. Changes of work environment, overabundance of food and weight gain were precursors to the disease.

P112M: But what caused this thing is if I was living in my country- I come from a big family, like 14 people, and I am number 9 down. My older sister lives here only about 10 minutes away from here. And no one is diabetic in my family except my mother. It's because of my lifestyle changes. I am positive about it and the major reason is when I say that is the type of work I did over there, was kind of like I was physically active. Now I came over here my clothes were loose, my normal clothes were loose. I had to change a set of clothes here since I gained weight. Also the type of work I do here is not physically active. Over there my job was physically active. Not only that I used play around, like games and all.

I: What did you play?

P112M: Soccer. I played with my kids everywhere; it was part of my life.

I: Probably a lot of walking?

P112M: Oh yeah probably over there where I worked at the school I probably walked 6-10 miles a day. Just at work only.

I: And here?

P112M: Yeah sit and work. Yes, sit and eat donuts.

***Migration-Missing social interaction.*** Migrating to the United States also affected daily social practices, which are essential to Asian Indians. During the interviews, male participants in particular recounted how they missed daily social interaction with their friends in India. In India, especially in the villages, it is not uncommon for people to visit with each other every day after work. For one participant, these visits were considered to be exercise and therapeutic after a long day of work. Visiting with his friends as he walked home from work was exercise and it helped him deal with his daily stressors. In the United States, his life was mundane and dull, driving to work and home again with no social interaction. This, he believed, caused his diabetes.

P106M: I think I would have been better off in India with my diabetes because I would be working in the farm. Here there is only one job, you do that job and then sleep and then you go back to work the next day.

There are also other activities there, here you work and then you eat and then sit at home. I go to the store and then I come home. There – this is the stress here. There I did not have that type of stress. After work, I would walk home, visit with friends – my wife will say to me, “How come after working so hard you still have time to visit your friends?” I told her that it is a type of activity also, it is relaxing to talk to people also. It is not that one needs to lie down to relax. If you see a friend on your way home, you could socialize with him and you feel relaxed.

***Dietary causes—over indulgence.*** Indulgence in food, so readily available in the United States, was cited by male participants as a cause of their diabetes. One individual whose parents had diabetes reported that when he moved to this country, he overate candy, sugar, and chocolate, even though he knew it was not healthy. He continued to eat Indian food, but indulged in “rubbish” food which eventually led to his diabetes. It is not uncommon for Asian Indians to describe Western sweets and candies as rubbish.

P103M: Why I got it? You know I was eating too much rubbish, candies, sugar, - (laughs) - chocolate, you know – and all of that and on top of it Indian food also.

I: How about Indian sweets?

P103M: Some, yeah some, sometimes. Mainly chocolate and candy.

For another male participant, food in the United States was a novelty and readily available. He described it as being delicious, especially the cakes and donuts, which he ate without considering the consequences. He gained a considerable amount of weight, which led to his diabetes.

P112M: .....It’s because of my lifestyle changes.....Now I came over here my clothes were loose, my normal clothes were loose. I had to change a set of clothes here since I gained weight. And there is a lot of different types of or more food variety here in abundance, like cakes, donuts and those things. And honestly I loved eating those, we did not have them over there, you know. We did not have those things there. It was so tasty and cheap too and you know I just made good use of what was available, without taking into consideration of what impact it would or could have on me.

Wife: Honestly we never knew about diabetes over there. We never ate donuts over there either.

All participants in this study ate at least one Indian meal a day. Male participants, in particular attributed the amount of food they ate as the cause of their diabetes. A common breakfast food “paratha” was singled out by one participant as the cause of his diabetes. Paratha is a flatbread stuffed with potatoes or cauliflower and fried in oil or butter. The same participant, a resident of the United States for 50 years conceded that overeating Indian food was the cause of his diabetes. He still ate the delicious and hard to resist “parathas” several times a week.

P106M: Well I don't think so. We overdid a lot of the things. We should not have, we need to watch it. Watch food and how much sugar we eat, and carbs is what is causing it. They taste good, it is fatty food and it tastes good, and carbs taste good.

P106M: Roti have a lot of carbs, paratha, my wife is good at making them. That's what did it – the parathas did it. I was eating two, two big parathas a day. She makes those big ones, as big as a plate. I told her no more paratha's. I haven't eaten a paratha in 3 months. I ate two parathas the other day, but I said no more. Eating paratha used to be a regular thing. Like 3-4 times a week. I gained about 25 pounds. Parathas, are killers- I don't know if pakoras are killers too? They are fried and have potatoes. If you eat a little bit you know it is ok

I: Is it hard to eat a little bit?

P106M: Yes because it tastes good you want more.

Overuse of antibiotics was also cited as a cause of his diabetes. A male participant who developed a severe infection after a surgical operation blamed overuse of antibiotics as the cause of his diabetes. Because his parents did not have diabetes, he determined that the antibiotics he received led to his diabetes. He failed to recognize make that his poorly controlled diabetes could have led to his long recovery from the infection.

109M: It is because of the Sporidex shots I have developed diabetes, because my parents do not have it. It is because of overmedication I have developed diabetes. Nobody has told me this – I personally think that is why. It is because of overmedication I have developed diabetes – it is my own discovery. I had very good health, I had no problems, and I never ate too much. I was very active, never sat down for even a minute, and even if I ate a lot I never sat down. I would never take a nap, there was no time to nap in the daytime. From the time I got up early in the morning, 6am to midnight I was very active.



## Summary

Asian Indians have several common beliefs about diabetes. All of the participants believed that diabetes is hereditary and that it was inevitable that they too would develop the disease. Both male and female participants developed an early relationship and awareness of diabetes. A family history of diabetes and care giving for family members who had diabetes influenced beliefs that caused the disease. Participants witnessed daily management routines, comorbidities and complications in their family members which influenced how they accepted and managed their own diabetes.

How Asian Indians viewed the disease varied. Some participants felt that eventually they would get diabetes. They anticipated the diagnosis and, prepared to make lifestyle changes after it happened. They had no fear and were not emotional about being diagnosed. For several participants, familiarity with diabetes led to a casual acceptance of their diagnosis, for others it fueled a fear of developing the complications, especially renal impairment and dialysis. .

Despite familiarity and awareness of diabetes, participants did not discuss or pay attention to prevention of the disease. Believing that diabetes was inevitable led some participants to get frequent screenings. In some families, diabetes was such a “given” that the possibilities of preventing it or delaying its onset did not occur to the participants. Additionally, there seemed to be little energy in preventing its onset in family members who were disease free. Participants were more likely to change their behavior after they were diagnosed. Once diagnosed, participants described diabetes as a sickness that interfered with their normal routines. They attributed the rigorous routines, dietary changes, and medication management as difficult and constant reminders of their sickness.

Beliefs about the causes of diabetes were influenced by gender roles which were culturally specific. Traditionally, Asian Indian women preserve family and social harmony. In this study, female participants believed that family and personal stressors caused their diabetes. The stressors that disrupted family harmony were many: ailing adult children, separation from their adult children and husbands during immigration to the United States, overwhelming family responsibility, and lack of communication with their physicians. They perceived these factors to be external and beyond their control. The worrying, stress and the lack of control over these external factors led to their diabetes.

The male participants' beliefs about the cause of diabetes were influenced by the traditional Asian Indian expectation that man is the family's principle breadwinner. Male participants explained how they changed professions to make ends meet in the United States. Sedentary employment, long working hours, and a change in employment as caused their diabetes. The male participants also believed that dietary factors caused their diabetes. For this immigrant group, the novelty of abundant food in the United States led to indulgence and weight gain, which eventually led to diabetes.

### **Aim 2: Daily Challenges and Supports that Asian Indians Encountered in Managing their Diabetes**

Daily management of diabetes was a complicated process for participants in this study and was influenced by several factors. Although participants identified several commonalties, they also managed their diabetes on a daily basis in unique ways. Gender roles which were cultural specific also influenced daily diabetes management. Female participants described diabetes as intrusive and used DESI medications to manage their diabetes. Male participants, on

the other hand, made drastic dietary changes such as not eating roti, abstaining from alcohol and meat and exercising.

### **Managing diabetes gradually**

Male and female participants made gradual changes to adapt to their diabetes. But, it seemed that there was a lack of urgency in controlling their disease or its complications. For example, female participant P104F described that how, over time, her blood sugar started to rise and she started to take more medications,

“After that we came here and then it slowly, slowly started to .....now I even take a blood pressure medication, cholesterol medication, - just a small dose.”

Making dietary changes was also a gradual process for several participants. Having been around family with diabetes, participant P101F was aware that diabetes management required making changes to her diet. Making and maintaining these changes that were so engrained in her was a struggle. Rather than make drastic changes, she decided to make gradual changes in her sugar and sweet consumption. This gave her a great sense of accomplishment.

P101F: So I said to myself if my father in law can drink tea without sugar than so can I. But I can't drink it, I can't bring myself to drink it. Then slowly, slowly I started to drink tea without sugar..... It is like this when I did not know much about diabetes I would eat more and now I know then you slowly, slowly cut back on how much you ate. I still eat but I have cut back. I used to make pinea a lot but now I don't. I used to make a lot of sweets. And now I drink tea with no sugar.....But I have stayed in this way or circle of life – I have had to change some, like I will not eat anything sweet.

Even though making gradual dietary changes was a struggle, it was a strategy that several participants found acceptable. This participant below stopped making Indian sweets at home after her husband died. And, she limited the number of times or amount of parathas she made. Making changes gradually helped her achieve glycemic control.

P101F: It is like this when I did not know much about diabetes I would eat more and now I know then you slowly, slowly cut back on how much you ate. I still eat but I have

cut back. I used to make pinea a lot but now I don't. I used to make a lot of sweets, my husband used to like to eat them. He would tell me make this, make gulab jamuns, and now I don't make it and have forgotten how to make it. Even if I made it I would have to eat it. So I don't make it anymore.

I used to make parathas every weekend, potato ones, whenever I felt like it. But now I make them once a month. Or if I feel like it I will make them with less potato for me and the others I will put more potatoes.

In contrast, a male participant made drastic changes to his diet based on information from physicians who came to his work place. Because he valued their information, he subsequently made substantial dietary changes.

P112M: Yes, I changed the way, for a couple of months, or the first 2-3 months I was not eating the way we used to eat. I changed the whole pattern of how I used to eat. Then at my workplace I get physicians every once in a while. I tell them I have diabetes. I have this one physician who comes once in a while. She tells me what to do. She says your diet is very important. Take 10 different types of fruits and vegetables every day in very small portion, so that everything is there. She convinced me there is a way out of diabetes, but it is not easy.

Even though this participant made drastic changes to his diet, learning portion sizes and nutritional values took several years. He said it was a long, complicated process which was time-consuming due to the lack of culturally specific dietary information.

P112M: The books told me how many calories each food had. Like one tortilla, fries, half cup of grapes..... so you get used to that. So you have to learn it for a couple of times – it is not easy and is difficult to do. And I think one can do it. So my food for the first couple of years was totally different.

### **What to Eat and What Not to Eat?**

Participants were concerned about what to eat and what not to eat. Rice and roti are staple foods that are served with main dishes at Indian meals. Limiting or avoiding these foods were difficult for several participants. Instead of avoiding these foods, one female participant replaced her white rice and roti with brown rice, brown roti and vegetables. She felt that giving up meat would be easier than her rice and roti.

P111F: Main thing was my eating (laughs) – Like all the stuff I could not eat, what I could and couldn't eat. You cannot eat starch stuff. For example, we used to eat white rice and now we cannot eat white rice. Main thing on my mind was eating. I mostly eat brown roti, brown rice, and more vegetables -no white. I don't even want to eat meat. I want to quit it. I don't feel like eating it at all. Yes, it is a vegetable we cook all the time. It is better to eat the vegetable. I have to eat roti and rice with vegetables, I can't live without roti or rice – I always take in portion one cup of rice and vegetables. We Indians like our carbs, even the older folks like to eat roti, that's the first thing they ask for when they get up in the morning. Why can't they eat brown bread or something with less carbs – it is because we are Indians we like our roti. It is our lifestyle. You could make a thin roti.

Moderation and limiting what to eat were other practices that emerged as participants struggled to establish control. On her physician's advice, one female participant limited the number of times she would eat rice or roti. She also tried to control her blood sugar by eating fruit that was bitter and avoided soda.

P101F: Eat half a banana, and even a mango you could eat half a mango. I was told by D.... physician, he has now gone to the county hospital, and he told me that I could eat everything. Like he said you will say I don't want to eat rice, but you don't have to do that. It is not that you are going to eat rice all the time, maybe once a month, or every 2 weeks eat one or two spoonfuls. Now, like makki di roti, sometimes you feel like eating. He said, "You can have half a roti, but I have notice if I eat makki di roti, my sugar jumps up. It jumps up. I sometimes feel like eating it especially when I make saag, and I will eat it then. But now I am trying my best to eat wheat roti, even when I make saag.

I: It is sometimes hard.

P101F: Even an apple, he told me to eat the bitter ones, if not a whole one, a half one is okay to eat. Eat bitter stuff he told me. Sweet apples you only have one piece and no more. I don't drink soda. Can you believe it 7 up, no not 7 up but Pepsi and coke - I have not drunk them for over 15-16 years, maybe more.

Like several participants she also gave up soda after she was diagnosed with diabetes. She did purchase it if she was expecting company. She only drank water, tea, or juice and refrained from soda at all cost.

P101F: When we had our store I drank all types of soda, in fact I drank all the sodas you can imagine. But now I only drink 7 up or Sprite. If I make pizza or order it then I will have 7 up with it. Or if I go to a store and they don't have water or I don't like the taste

of the water then I will buy Sprite or 7 up. I will drink only a little bit and leave the rest in the glass that they give you. But 7 up and Sprite are the only sodas I drink. I don't drink any others. I drink them rarely; I don't even bring them for home. Even if I have guests I don't offer them soda, I tell them have tea or water.

You know if the kids are coming over and you know they drink soda, then I will buy some, otherwise I never have soda at home. I don't drink it if I go visiting either. If I really feel like having soda then I will have half a glass only and that is it. A small glass. Juice, – I drink pomegranate, celery - I must have some here – not every day.

For some participants, avoiding certain foods was not difficult. One woman asserted that she did not bring any Indian sweets home. For snacks, she opted to eat to dry fruits and low sugar Indian cookies, which are readily available at the Indian store.

P105F: It is not hard to stop eating something, especially if it raising my blood sugar readings. I say to myself, “ It is better I don't eat this stuff, and, if I do, I need to eat very little. Like a small piece. I don't even bring any Indian sweets home. If I brought them home I would not be able to resist them. Then you feel like eating it and you console yourself that it is okay to eat. I have started dry fruits now, like almonds, walnuts and cashew nuts. I will eat 3-4 of each nut with my tea in the morning or 2 rusks. They say nuts are good to eat. I get my rusks from the Indian store. They have sugar in them, but less than the other cookies. Cookies have more.

The amount and the type of sugar that was consumed was another struggle for several participants. The same female participant told her friends that the only way to control blood sugar was to limit the amount of sugar they ate and take their prescribed medications.

P101F: I tell my friends and anyone who has diabetes to eat less, eat less sugar and they need to take their medications. They don't have to give up everything, eat less, don't eat it every day, and eat it once a month or once in a while. If you want to have a gulab jamun, eating it once a month is not going to harm you. If you want to eat it every day or every third day, and then continue to take you medications – then it is not going to work. Eat what you like, but it less, eat it sometimes. Like when you go to a wedding, I tell the host that I would like to eat salty semia, and not the sweet ones. Laughs

## Lack of Knowledge

Lack of knowledge, lack of access to knowledge, and lack of reliable knowledge influenced diabetes self-management. Participants confessed that lack of knowledge was a challenge to daily diabetes management. One female participant stated that, because she did not know much about diabetes, she was unable to give much advice to any of her family members. She told them to make simple dietary and lifestyle changes; she told her children to avoid negative thoughts that created unwanted stressors. Based on her life experiences, unnecessary stress had caused her diabetes. Limiting stress would prevent diabetes.

P110F: I don't really give them much advice, because there is not much that I know about diabetes. I tell them to eat sensibly that is limit the amount you eat, don't take on stress, and don't talk bad or think badly about anyone.

I: What do you mean eat sensibly?

P110F: I tell them to eat chana atta roti, mix it with wheat, and avoid Coke. Drink unsweetened tea or coffee.

Similarly a male participant felt that he had insufficient knowledge in diabetes management.

Even though he yearned for more information he did not know how to access it.

P103M: Roti, eat more salad and more – actually I don't know much else to eat.

I: Do you find that you don't know what to eat?

P103M: No, I don't have enough information, maybe only 10-15%. I don't know much about – like I don't go to any classes. If they have some class or seminar, I can attend then I can know more.

Not knowing what to eat, especially carbohydrate counting and calories, created further challenges for several participants. One participant described how he controlled his diet by watching his carbohydrate intake, yet when asked how many carbohydrates he consumed he described the amount of calories he ate. He also limited the number of times he ate roti daily and ate mainly vegetables.

P102M: The food I changed is mostly vegetables, before I used to eat too many of those rotis, you know? Right now I eat roti only one time, only one time I eat roti. Before I eat

anything, I used to, I mean I watch the nutrition, how much carbohydrate there is in there, sugar or fat are in there. Before I never used to watch, I just used to eat.

I: So you are counting your carbs?

P102M: Yeah, yeah.

I: So how many carbs are you eating?

P102M: What I think is I try to eat less than 2,000 calories, at least. For my health like my physician said 1,400 -1,500, like I try to eat mine under 2,000 calories

Participants implemented dietary changes based on unreliable sources such as social networks.

They used this information to achieve glycemic control. One participant described hearing from an unknown source that eating only two meals a day was recommended for adequate glycemic control. Like several other participants in the study, he limited his food portions and switched to whole wheat flour. This was a major accomplishment for him.

P112M: Yes, because the thing is it is the amount of calories you burnt, and say you had a lot of physical activities during the day, and you need to take an extra piece of bread to cover for that. Another major problem is don't take too heavy meals, like portion control, like not to eat anything for at least 2 hours after a meal. A recent study in England said two meals a day for diabetes is good. I don't know if you have heard about it or not? But I just heard it 2-3 weeks ago and they said that two meals and that is where I am. I eat only two meals a day. Like afternoon meals is more like a snack, or probably no meal. No meals meaning you just take something which is non-caloric. For breakfast I will have a brown tortilla, roti. Homemade roti – pure brown and not half brown. Not mixed white and brown, some people do that.

### **Ayurveda, lifestyle and Western Medication- A Balancing Act**

Although participants lacked knowledge and access to knowledge in managing their diabetes, they sought balance and harmony between herbal, lifestyle, and pharmacological practices. Seeking balance and harmony in illness management is a common practice in Asian Indians that originates from *Ayurveda*. *Ayurveda*, an Indian system of medicine, means “knowledge of life” and is engrained in cultural practice. It is a holistic approach in which herbal remedies are the principal means of preventing and curing illness. Both male and female participants considered herbs and dietary practices safe and effective with no adverse side effects. They reported achieving control of their daily blood sugar when using *Ayurveda*.



**Ayurveda-DESI medications:** Female participants controlled their diabetes by blending herbal, dietary and Western medicine. They typically preferred familiar herbs that were readily available in Indian stores to control their diabetes, even though they did not know how the herbs lowered their blood sugar. They often referred to the herbs as “DESI” medications and described the different combinations they used. Most of their information about “DESI” medications came from informal sources such as Indian TV, radio shows, and their social networks.

P101F: Sometimes I take DESI medications too. Some people tell me to take fenugreek leaves, or something else. I heard it on the radio about 15 days ago, and they recommend getting saro, grinding it and eating it three times a day, half a teaspoon each. You know rye, take it also, and it controls your sugar too. I will go buy it and try it. I went to the store yesterday and forgot to get the packet.

Female participants were familiar with the recommended herbs because they are essential ingredients that are frequently used in Indian cuisine. Common herbs like fenugreek, methi, rye, saro and sauf were thought to improve glycemic control.

P101F: Yes, I have tried some – methi, olives and sweet sauf. You need to grind these three ingredients equally and then take one teaspoon in the morning. It made a big difference to my sugar, it improved them.

P105F: There are some things that I take at home – like the DESI things – like Kerala powder. I mix it with yogurt every morning and eat it. Then I will take olive powder, sauf powder, methi – I keep all these ingredients at home and I will eat them a lot. I like to do this and it is because of them my diabetes is under control. That is why my sugars are under control.

No unique formula of herbs was used by participants. Each described the various herbal preparations that they took to achieve glycemic control. For example, one woman described how she alternated herbal mixtures, believing each had a positive effect on her blood sugar.

I: You also use desi things?

P105F: I take those too, but I don't mix them all up. I take one powder at a time, for example for the first few weeks I will eat methi, olive and sauf powder. I usually will mix

it all up and put it in a bottle and when that finishes then I start my Kerala powder. I don't keep taking one type of powder I mix it up. I feel that I should finish the powder that I made first, before I make another powder. I don't want to have all these bottles lying around that I never used. I also use flax seed. I will grind it and put it in my milk sometimes, or in my cereal. I keep doing these types of things because I think they help with my diabetes.

These herbs were considered safe because they had no adverse effects and were used in every day meals. One participant opined that they were natural remedies that were beneficial for the body.

P110F: I will buy it and make a powder of it, you know saro. We call it rye. They say to eat it 3 times a day; half a teaspoon and sugar should stay normal. These types of remedies are also good for the body. They have no negative effects to the body, because they are what we eat. For example if you make bitter melon, pan fry the rye in it for the tharka, and you can use rye in anything, it does not cause any damage.

Along with herbal blending, female participants experimented with various blends of flour to make roti. Roti is Indian flat bread, which is made from stoneground whole wheat flour, traditionally known as atta, and is an Indian staple. The women avoided using whole wheat flour, which they thought contributed to high blood sugar. Instead they used various other blends of flour and herbs to make missi roti. Missi roti comprised of mixing herbs with soy flour, bajra, chick pea and lentil flour. Women reported that eating missi roti daily brought their blood sugar down.

P101F: With that my sugar came down when I used soy flour, bajra and hmmm, black chick peas and green lentil flour – mix this flour and I would make enough for one or two rotis and eat it as soon as I cooked it. I will eat missi roti – it is the best to keep your sugar under control. I will sometimes put methi, thania, onions, garlic, salt, chili, and mix my flours – wheat, chana atta.

Blended flours which are easily available at Indian stores, made it easier for one participant to make her missi roti. The flour was marketed for people with diabetes.

P105F: It has soy bean, chick pea flour and wheat in it. You get it at the Indian store, and it says it is for diabetes. It has very little wheat flour in it.

I: Is it like regular flour

P105F: Yes, you can get it in bags. They used to get big bags, now they have it in smaller bags, and I usually buy two smaller bags now. The shop keeper told me to take two bags. I only eat that now, the rotis are really good with that flour. It is at the Indian stores. Even the Sujatha flour, one is regular and one is for diabetes.

**Bitter melon – a commonality:** Both males and female participants ate kerala or bitter melon to control their blood sugar and for its hypoglycemic effects. Often referred to as bitter melon, this fruit like the herbs and flour, it is easily available at Indian stores. One participant, who lacked health insurance due to his immigration status, ate bitter melon every day when he had no medications left to control his blood sugar.

“What do you do if you don’t have access to medications? I still had some medications from India – they finished and then I would eat bitter melons every day”. (P109M)

He described kerala as being as effective as insulin in lowering blood sugar. Each part of the fruit (peel, seeds and juice) was described as therapeutic.

P109M: Bitter melons are stuffed with insulin, even the peels. We should not throw that stuff away. How we make them by taking off the peels and the seeds instead we should eat them. We should eat the peels of the bitter melon that is what has insulin. You should tell our people with diabetes to eat bitter melon. In fact you should try it yourself. You should check it yourself first before you tell people. You should not tell people that because I told you or she told you, you should try it yourself first. Just try it once before you tell anyone, because people tend to sue you here. Check how much insulin there is in a bitter melon, and then let me know.

Like the herbal mixes and the roti, bitter melon was prepared in several different ways to control blood sugar. For example, one participant squeezed and drank a teaspoon of bitter melon juice to help him lower his blood sugar.

P109M: So then I ate my bitter melons and with the bitter melon my sugar came down. A lot of people are surprised when I tell them that I eat bitter melon, I eat them raw. Bitter melon, you know, bitter melon, you take the peel off, take a fistful and squeeze out the juice, you usually will get 1 teaspoon, maybe two – you will definitely get 1 teaspoon.

One teaspoon of that is equivalent to two vials of insulin – it has so much insulin in it. There are at least two vials of insulin in one teaspoon of bitter melon juice.

A female participant, who put small slices of bitter melon in her water overnight and drank it in the morning reported positive effects on her blood sugar.

P111F: I take my pills the one the physician gave me and sometimes I will take herbals too, like...sometimes bitter melon.

I: How do you take that?

P111F: I cut it in pieces and put it in the fridge. And then in the night time I put it in a bowl of water and then drink the water in the morning.

I: So you don't cook it?

P111F: No, I don't cook it. I just drink the water, I don't even squeeze it or peel. When you put it in the water at night, it already too much bitter and it controls your sugar too. I wash it and slice it into very thin pieces in the water.

I: Does the bitter melon help lower blood sugar?

P111F: Yes

I: So you take it in the morning?

P111F: Yes, I take it in morning and it controls my blood sugar for the whole day.

Bitter melon had severe hypoglycemic effects. A male participant recounted an incident when he developed severe hypoglycemia after drinking half a cup of bitter melon juice, considerably more than the usual one teaspoon.

P109M: I did not know what diabetes was at that time, so I bought bitter melons in Amritsar and went home to my village, which was on the outskirts. I started peeling the bitter melon and filled half a cup with the juice. I drank all of it not knowing what it would do to my sugar. I then went to my farm water pump and when I got there my sugar went too high. I think that saved me because I started to sweat, and I did not know that because I drank the bitter melon juice that my sugar was dropping so low. Half hour later I felt better, my body recovered by itself from the hypoglycemic episode. I then spoke with the same guy at the pharmacy, and I told him that, they used to call him Ustad. I said to him that "Ustad this is what happened to me yesterday", and he told me I was lucky; because I had high blood sugar. Had I started off with low blood sugar and drank the juice I would be dead. There was no one there to help me either had I passed out. What I am trying to say is that there is so much insulin in the bitter melon.

### **Lifestyle changes**

**Diet.** The male participants were more influenced by beliefs in causal factors than the women, Attributing overeating as the cause of their diabetes, several modified their diet.

Instead of taking his prescribed medications, one participant stopped eating roti, an Indian staple, as soon as he was diagnosed. He believed that roti was the cause of his high blood sugar; by avoiding it he could gain better control of his disease.

P106M: After that I said this is no good (laughs). I did not take the medicine, so I gave up lot of the food I was eating, I know what causes it, so I quit eating rotis that is the first thing I did. I have not eaten roti for 2 months you know – no roti.

I: You have not eaten roti for 2 months?

P106M: I did not for that time, for 2 months, but now I will eat once in a while. Like I will eat it once in a while, but I don't eat roti everyday still.

Although several male participants emphasized that they could control their diabetes with their dietary changes, they seemed to lack an understanding of what foods to eat. This led to drastic dietary changes. For example, one male participant gave up all of his “junk food” (sweets and candy), fried foods, spicy foods and meat to achieve glycemic control. He only ate vegetables and pasta.

P103M: It worried me. I have changed; now I have changed.

I: How have you changed?

P103M: I changed – like I don't eat like a spicy, fried , even like a I am not eating like a non-veg,

I: Non-veg?

P103M: I only eat like vegetables and like pasta.

I: Any other changes you have made?

P103M: Biggest change is like my diet.

I: Your diet? You are not eating like.....

P103M: Not eating much like I used to eat.

I: What did you used to eat?

P103M: I used to eat meat, like beef, and you know chicken and mutton and fish and egg. Now I don't eat it anymore. I used to eat a lot of IN-N-Out burgers. And then I would go to a steak house and eat and after that

Several male participants became vegetarians after they were diagnosed with diabetes. Eating meat was considered to have a negative effect on blood sugar. One male participant related how he stopped eating meat and cut back on his roti to manage his diabetes. He ate only salads, and

limited the amount of food he ate. He decided that a low calorie, vegetarian diet was necessary to achieve glycemic control.

I: Do you think you have a good handle of your diabetes?

P103M: Yeah, yeah, a good handle.

I: So what do you do to get a good handle of your diabetes?

P103M: Yeah, I know what to do what to eat

I: For example.

P103M: No, I take medicine, but I also watch my diet, I don't over eat. I take a light breakfast, light lunch and light dinner.

I: Like what do you mean by light?

P103M: Better to eat like a salad, more salad. I think like the wheat has a lot of sugar, then it is better to stay away from wheat and meat.

***Exercise.*** Male participants also seemed to think that exercising combined with diet control was essential in managing their diabetes. One man explained it this way:

P107M: Look I think you should avoid junk food. Actually I eat it too – but I think you should avoid it. It is the biggest culprit and causes the most problems. You should pay attention to what you eat. You need to go to the gym.

***Alcohol control.*** Male participants also reported avoiding or abstaining from alcohol to control their diabetes. For example, one man felt said that if he could control his alcohol use he could control his diabetes better.

P109M: That is my negative point, everything else I do pretty well, that is my negative point. I will have my one glass of alcohol, eat my dinner and go straight to bed.

**Western Medications.** Both male and female participants used Western medications as an adjunct to their herbal and dietary practices. However, several participants preferred to manage their diabetes with Ayurveda and dietary practices first before resorting to Western medications. One female participant described how she adjusted the amount of diabetes medication she took after she had eaten her herbal supplement and her missi roti.

P101F: I can take my medications the one I told you about the methe and the sauf, the one I told you about earlier, if I have it in the am and take missi roti in the morning my sugar comes way down and I am able to control it better, it gets really low then, I like to – keep it at 100-130. Then I will take my western medication, instead of two tabs I will take one tab.

Participants placed great importance on managing their diabetes with Ayurveda, lifestyle changes and dietary practices. They had their own set of beliefs and practices and seemed to place great importance on staying healthy. They tried to achieve control of their diabetes by balancing herbal mixtures, flour blends, and Western medicine. Although all three modalities were considered essential in achieving and maintaining control of their diabetes, the participants, when questioned did not understand how these practices worked. Rather they followed patterns that were familiar or were recommended by family members or community members. If none of the modalities affected glycemic control, they blamed their fate.

P101F: Yes I did, sometimes I felt better. I take regular medication and DESI medication and they work. If you stop one or the other for some time then it gets worse. If neither of them worked then it was your “kismet” or fate that it was not meant to work. I don’t know whether homeopathic medications are better or not, it is your body, you don’t know how it is going to react. I take both. It is your kismet what works, sometimes the DESI medication works better for you and sometimes Western medications work, sometime neither of them work.

**Navigating care in India and the United States.** Accessing health care in the United States was challenging for several participants. SAALT (2010) has reported that 21% of all South Asians living in the United States lack health insurance, surpassing the national average of -18%. The rate of health care utilization by South Asians is lower than many other minority groups, roughly 40% of South Asians reporting no regular source of care as compared with non- Hispanic Whites (SAALT, 2010).

In this study, several participants lacked health insurance due to their immigration or employment status. One male participant stated that he had no health insurance for 8 years because he could not find a job with health benefits.

P109M; I developed diabetes in 1991 and I came here in 1996. Then I came here and I have no health insurance. I went back to India in 2004, the first time after I became legal in the US. When I got there I got a thorough medical exam and that is when they changed my medications. They gave me this medication... Then I came here and I was able to get health insurance, actually I got it before I went back to India. From 1996 – 2004, I was working at a store and the owners were my friends, and they told me they wanted to get me insurance. They got me insurance before I went back to India.

Participants recounted how they coped with the lack health care and the cost of health care in the United States. Transnational health care is a theme that emerged as participants coordinated their routine health care in India while living in the United States. Lack of health insurance and high health care costs led participants to coordinate routine laboratory work and their medication refills during visits to India. One participant who had lived in the United States for 15 years explained that she had never had her blood work done in the United States and this was going to be the first time since she had qualified for health care benefits.

P105F:... but I have not done any blood work here yet, and this if this first time I am going to do it.

I: Did you have bloodwork done before you got insurance?

P105F: No, I never got my blood work done here, I got it all done in India. Even now I just got back from India 3 months ago, and I got my bloodwork done there. I got everything done there and they also told me that I had a little bit of diabetes and everything else was fine.

Accessing health care in India was described as easier and more affordable for several participants. One woman, who had lived in the United States for 12 years, commented that in India how she was not charged for laboratory work or consult with a physician.

I: Have you done any blood work here?

P110F: No, all my preventative and screening blood work was done in India.

I: And medications?

P110F: He wrote it for me for free. Otherwise it would have cost me 200 rupees.



Access to medical care was further challenged because participants lacked health insurance due to fluctuation in employment status. This often led to a lack of continuity of care. One woman participant complained that she kept changing physicians due to changes in her employment and health benefits.

P101F: I took his medications for a while and then I started working, and at work I started to see a physician at Kaiser, Dr. D..... In 2000 I got my medications from him and then I lost my Kaiser insurance. Then I saw Dr. C..... on El Camino, he gave me medications then. Then after that, after I lost my job, I could not see him, I had no insurance then.

To maintain continuity of care, she paid cash to access a health care provider who prescribed her routine medications. Without any health insurance coverage, her appointments were expensive effectively limiting visits with the provider.

P101F: Then I went to Dr C..... still, gave him money to see me once or twice and then he would give me 3 refills. Then I told him without insurance I could not afford to visit him. Then my daughter got me on her plan with Kaiser.

Thus, although most participants managed their health using transnational connections, fluctuating employment status and paying out of pocket for health care access was deemed a milestone. Most of them would get a “full check-up” once they secured health care benefits.

P110F: I now have a health card – Obama care, no, not that I have a card that old people have now too.

I: Medicare?

P110F: Yes, I do have that one now. It just started, and I have an appointment in June. Let's see what happens.

I: Where is your appointment?

P110F: I will have to go to somewhere, I will ask my friends where I can go. The card just got activated so let's see what they tell me.

Similarly a participant, who had just turned 65, was excited about being able to access hospital and prescription coverage.

P109M: Now I am 65 and am qualified for Medicare Part A and p Part B, so now I will. Now I have hospital coverage too. I am applying for my prescription drugs. There is a program called extra help program and that may help with the cost of my drugs.

One woman happily announced that she had just received her Obama care 2 weeks ago and was now able to get a thorough evaluation.

P105F: Yes, but I have not done any blood work here yet, and this if this first time I am going to do it.

I just got my medical insurance 2 weeks ago. The people I work for they, actually the guy he referred to me – you know where there are students, he sent me there – they checked me and told me which medications to take. Then he would order the medications they recommended for me. I work for them in the morning. It is just in the last 2 weeks that I got some medical insurance, Obama care, and now I have been able to check everything out.

Qualifying for Medicare, MediCal or Obama care was an enormous relief because now they could receive medical care in the United States.

P101F: But now I have the other insurance, the county one, and now I have Obama care. I got Obama care now. Now I can go to the Kaiser physician. These are medicines I take now – pointing to them.

P109M: Yes, but I have not done any blood work here yet, and this if this first time I am going to do it.

**Relationships with physicians.** Managing one's diabetes was influenced by the participants' relationships with their physicians. Understandably, participants preferred to have Asian Indian physicians; they felt that they could communicate and relate to them better. Asian Indian physicians could better understand their health care practices, especially when participants sought care in India. One female participant, whose physician refilled her medications for a minimal fee, indicated that she would continue to see him now that she had insurance.

P110F: He is an Indian physician in YC. As soon as I got my card I contacted him. He has been seeing me for free whenever I needed medications. I always went to him, he is very nice physician.

I: He sees you free?

P110F: No, he does not see me free; he will charge 40 dollars, but now since we have the cards, he did not charge us.

I: Does he let you know how your diabetes is doing?

P110F: Yes, he does and he does check me, he is a good doctor.

Most participants were comfortable discussing alternative medications with their physician, especially if they were of Asian Indian origin. One participant told his physician of an encounter with a person who tried to convince him to take herbal medication to cure his diabetes.

P112M: .... he is an Indian guy just like me and he said, "I am going to get rid of your diabetes. I asked him what he was going to do? And he said, "I make bottles of medication". I said to me "Come on dude." I was pissed, that is not right. Come on, that is not right, you are in America and you are selling those stuff. I am not saying it is illegal, it is herbal medication, you can keep it for yourself, and sell it to other people. And my physician fortunately is also from Pakistan, I told her and she said to me, "Don't listen to these uneducated people", she was quite straight forward with me. So I said to her, "No, no, I am not going to listen to him. I am telling you because he is from your country – these guys do this every time."

Although one participant had been in the United States for 30 years and could speak English, she still preferred an Asian Indian physician. She felt she could communicate with him better.

I: What physician do you go to?

P111F: I was in Kaiser but now I changed to – he is in West. He is in West Sacramento. It is a small hospital type ..... I go to a county clinic in West Sacramento. They are pretty good there, I have an Indian physician from India- he is very good.

I: Do you prefer to have an Indian physician?

P111F: It is more good, especially if you don't know English very well. It is better to explain to him your concerns in Hindi. Because we don't regularly talk in English, I can understand English well but I cannot speak it as well. It is hard to speak. Because in Fiji, we do not talk English at home. We speak English in school.

Overall, participants valued their relationship with their physicians; they felt they had easy access to them.

P102M: I am , I shouldn't say I am proud of myself but I am confident of myself that I am managing pretty good. And when it goes a little high my physician, gives me the warning that you either you start exercising or .....when he sees my report he can discuss whatever the pick mark – then he called me like what if it goes over 6.5, then he calls me.

I: So you have a good relationship with your physician?

P102M: Yes, I do have good relationship.

Participants valued when physicians complimented them, especially when it came to lifestyle changes. One elderly participant took great pride in how her, Asian Indian physician used her as an example of a patient who looked after herself.

P104F: I stay well if I walk. Yes, the physician would ask me every time if I walked, and I would tell her yes. Now she knows so she does not ask me anymore because she knows I walk every day. She knows I really look after myself. She says she tells about me to her other customers. She gives me as an example of a person who really looks after herself. She says there is a lady who is elderly and she really looks after herself. She states that when she sees some patients who do not look after themselves, she would like me to be present then and there so I can tell the patients how to look after themselves like I do (laughs)

Being able to communicate with their physician was important to the study's participants. Not all exchanges went well, however. One woman complained that her physician was rude and would not listen to her concerns. Another participant switched physicians because she desired someone who would listen to her and encourage her to manage her diabetes.

P108F: But now I have another endocrinologist. She is very young doctor and she is encouraging me. It has gone better since 3-4 months, yeah. And before that my physician, my endocrinologist, he is very rude. I am already upset and he told me you have to do this and you have to do that, and you know you are not watching your diet, blah, blah, blah. And you know – it is easy to say but hard to do then I changed my physician.

Developing a relationship and trust with physicians was important. A participant, who had been screened at a health care camp offered by her temple, consulted with an Asian Indian physician with whom she worked. He told her to go to the community clinic to be screened since she had no health care insurance and he helped coordinate her care. As an aside, Asian Indians often refer to elderly women as *aunty*, out of respect.

P105F: For one, I used to get a lot of post nasal drip in the early morning hours, at 4am. Like at 4 am I used to cough a lot and would get watery eyes. Then my legs started hurting just a little bit, and then there was a camp at the temple and I got my blood sugar checked and found out I have diabetes. I did not believe them at the camp, I thought it was because I had just eaten that's why my sugar was high. Then I talked to the

physician I work for and they told me, “Aunty, please go to this free community health screening clinic, and they will test you properly and you will find out for sure if you have diabetes or not”. I went to the community clinic and they told me that I will have to take diabetes medications, and they wanted to know who my family physician was? I gave them the physician’s number and the poor thing called in the medications for me. I started taking my medications; I had never been to a physician before all of this. The physician I work for is Dr..... and he works for Sutter. I take his kids to school in the morning and pick them up in the evening.

Managing diabetes was considered to be a patient’s responsibility by some participants.

Participants had full faith in their physicians whom they trusted to safe guard them from harm.

Patients are to blame if their diabetes gets out of control.

P112M: The physicians are doing their job. It is the patients, who are not listening. The physicians are doing perfect – there is nothing wrong with what the physicians are doing. A physician will never tell a patient, especially in America or anywhere in the world something wrong – the blame should be on the patient.

Even though they had good relationships with their physicians, participants sought more knowledge about diabetes.

P102M: I have always had good experiences. The physicians – I mean – they are researching for the medications, but I think it will be better if somebody gives us the knowledge what diabetes is, you know. There are still many uneducated people in America too. You know if no tells them what diabetes is they will not control it.

Overall, all of this study’s participants preferred to have Asian Indian physicians. They believed that Asian Indian physicians understood their health care needs better, and they felt more at ease in communicating with them. Often these physicians were part of the community. They accommodated participants who did not have health care and those who sought care in India. Being able to discuss alternative medical practices with their physician was an important factor for participants. Several valued their relationship with their physicians because they had easy access to them, the physicians addressed them in a socially appropriate manner, and they were encouraging. Ultimately, participants were responsible for managing their diabetes. How successful they were was influenced by their relationship with their physicians.

**Health Care systems.** Participants who had access to health care reported that health care in the United States was better than it was in India. They could access their physicians and get routine blood work done.

“I think it is better to control in the United States than India right now. Nobody goes there for the blood test regularly. At least over here you can go to the physician” (P102M).

One participant described how easily she can access emergency health care here as compared with India. She did not have to rely on anyone.

P101F: Please come with me, take me there – that is what you have to do in India. Here you can call the ambulance whenever you need to; a third person could call it for you too, if necessary. Over there which ambulance are you going to call, nobody is going to help you. If someone falls or hurt, nobody will help. That is life there.

U.S. health care facilities were described as being clean and accessible and their personnel attentive. One participant credited her survival to the treatment she received in this country. Had she been in India, she would have died. In other words, living in the United States was like “living in heaven”.

P110F: In India, I think I would have died. It is because I was here I got saved. It is so clean here, and all the care I got here and would not have gotten that in India. There are patients there too whose lives are saved, but you know it is because we live here now that we think in India I would not have survived. It is because it so clean here. Every 5 minutes there was a physician or someone who would come to check on you. That is why I am saved. People live in India too, and they survive and poor things have to get treated too. But here it is good. It is like we are living in heaven as compared to India. There are no flies or mosquitoes, everything is clean here

**Diabetes Education.** Diabetes education is critical to the success of managing diabetes. In the view of one participant, language barriers and lack of culturally appropriate dietary information dissuaded many attending diabetes education classes.

P101F: There is one thing that I think would really help me with my diabetes and that is getting information on the types of food I eat and how it affects my sugar. My physician

told me to go to the diabetes classes and I told her I don't want to. I did not tell her the reason though – I will tell you the reason. I am not a fan of classes and really I don't understand English that well – so what is the point of going. I will be wasting my time and I don't eat the food they eat. I eat mainly Indian food.

By contrast, a male participant asserted that diabetes classes taught him portion control and other preventative behaviors that improved his glycemic control.

I: How do you know how many portions you eat?

P111F: Yes, I took classes. Diabetes classes. I learned that in those classes. They were helpful.

I: Anything you else you changed?

P111F: Yes, all the time you just have to be careful of whatever you eat. Plus you have to take care of yourself all the time, like when you are walking you don't hurt your leg.

I: So you are more careful with what your diet, walking and you're taking care of yourself.

P111F: Yes, I check my feet all the time, before I go to bed.

Overall, the study's participants preferred to get their health care in the United States for the reasons above. However, several participants had no access to health care due to their immigration status or lack of employment. Some participants would coordinate their routine care (i.e., blood work and medication refills) with visits to India. However, after they qualified for Medicare, MediCal, or Obama care, they preferred to receive their care in the United States. This was an important mile stone for them.

Notwithstanding their general comments on physicians, all participants acknowledged that Asian Indian physicians understood their health care needs better than others. Participants could discuss alternative medicine practices with them and appreciated the respect and encouragement they received from them. Participants felt that they had a good relationship with their physicians because they were members of their community who spoke their language and had easy access to them.

Diabetes education was discussed by only two participants in this study. One described language barriers and lack of culturally appropriate information as reasons for not attending diabetes education. The other asserted that he received useful information from diabetes education (e.g., portion control and preventative behaviors).

### **Summary**

Daily diabetes management posed several challenges for the Asian Indian participants. Although they feared complications of the disease, they lacked a sense of urgency in controlling it. They chose to make gradual changes that were familiar and had the least side effects. Western medications were thought to have side effects and were often used as a last resort. Ayurveda was commonly used to achieve control of their diabetes. It was readily available in Indian stores and was frequently used especially for participants who lacked health benefits due to their immigration status. Female participants in particular believed that daily herbal and flour blends had beneficial effects. Bitter melon was used by both male and female participants for its hypoglycemic effects. Male participants also chose to make lifestyle changes that they felt led to their diabetes. Some made drastic changes to their diet such as avoiding roti, meat, and alcohol. However, these changes were hard to maintain because family members, especially children, were not receptive.

Asian Indians lacked knowledge of culturally specific information that further hindered their glycemic management. Most of their information was gathered from social networks and familiar cultural practices that. Although they made dietary changes, such as limiting portion sizes, avoiding carbohydrates, and sugar, they lacked access to reliable information. For example, avoiding sugar was a struggle for several participants, but none considered using sugar substitutes. Daily diabetes management is a complicated process for Asian Indians. It takes into



account their beliefs, personal experiences, and cultural practices. A lack of culturally specific knowledge and language barriers further hindered daily diabetes management.

Lack of health care insurance led Asian Indians to seek health care and medications in India. They valued their relationships with Asian Indian physicians in the United States because these physicians felt understood their health seeking behaviors and could accommodate them, especially if they lacked health insurance. Study participants preferred to receive health care in the United States and qualifying for health care benefits was a major milestone.

### **Aim 3: Social, Cultural and Religious Practices That Affect Type 2 Diabetes.**

#### **Tea? Sugar or No Sugar?**

Traditionally, drinking tea, a preferred beverage for Asian Indians is an engrained social and cultural practice. Participants acknowledged that drinking Asian Indian tea is essential in maintaining their Asian Indian identity. As one woman (P101F) explained,

“I have to make tea – without tea things are not the same – we Indians love our tea.”

Although drinking sweet Asian Indian tea affected their glycemic control, participants found it difficult to give up. Several themes emerged as participants tried to stop drinking sweet Asian Indian tea, avoiding it, drinking it without adding sugar or by supplementing it with *jaggery* (raw cane sugar).

Typically, tea is prepared by boiling tea leaves in water, milk and sugar. Sometimes cardamom, fennel seed, and cloves are added to the tea for extra flavor. Giving up sugar in Asian Indian tea was the hardest dietary change for several participants. One woman took great pride in sharing that she now drank both sweetened and unsweetened tea.

I: What is the hardest thing that you have had to do since you had diabetes?

P105F: Is stop using sugar in my tea.

I: How about anything else?

P105F: Nothing with the roti. We have been using that atta for a long time now. But I thought in the beginning that people where just saying that by adding sugar to your tea, it affects your blood sugar, I did not believe them. Now, I have left sugar and I don't miss it and it has helped my sugars. I can drink both sweet and unsweetened tea now.

Some participants were not able to give up sweet tea, those who did compensated by eating Indian sweets.

P101F: Even my family members tell me, they will say, "Give her tea without sugar and give her some gulab jamun or something else to eat?"

Laughs.

Even my daughter says, "My mother won't stop eating her gulab jamuns and she also can't drink tea without sugar."

Abstaining from sweet Asian tea was challenging for participants. One participant described it to be more difficult than accepting her diagnosis of diabetes. It took great effort and time for her to reduce her sugar intake. She had to learn how to drink unsweetened tea "slowly, slowly" like her father-in-law.

P101F: So I said to myself, "If my father-in-law can drink tea without sugar, then so can I." But I can't drink it, I can't bring myself to drink it. Then slowly, slowly I started to drink tea without sugar.

Other participants substituted brown sugar for white refined sugar thinking it had a lesser impact on their blood sugar. For example, one woman characterized white sugar as "poison".

"Yes, sugar is damaging, and brown sugar is better to take. You can use brown sugar in your tea. I don't like white sugar; it is poison to your diabetes." (P110F).

Foregoing sugar in their tea led many participants to seek an alternative sweetener, jaggery. Jaggery, a raw form of sugar is made from sugar cane and is commonly used by Asian Indians. Although, no studies that have examined its effects on diabetes, it is a common belief that jaggery has no adverse effects on glycemic control. Participants felt safe using jaggery since they were familiar with it and had used it while growing up in India.

P101F: Our people eat sugar and not that they would eat brown sugar and jaggery. Only the folks in the cities would eat sugar, we used only jaggery and brown sugar. Whenever we had a guest we would say, “Give him brown sugar and ghee, it is tasty.” They would love to eat it. We never made tea with sugar, it was very rare. We made tea with jaggery in the village always.

Participants were unaccustomed to drinking unsweetened tea. To improve the taste of her tea, one woman added only, “a little bit” of jaggery. It proved to be a suitable alternative.

P101F: Really, sometimes I like to drink tea with jaggery in it, - it is so tasty, tea made with jaggery. You don’t have to put too much jaggery in it, add very little. If I feel like having tea I will add brown sugar or jaggery into it. I use them sparingly. If I don’t want to have unsweetened tea I will add one teaspoon of brown sugar or jaggery. It just makes the tea taste different just a little bit, not too much difference just a little bit. If you put one teaspoon of sugar in two cups of tea, and it divides it up.

Adding sugar to tea is so engrained in Asian Indian practices that one participant weighed the advantages/disadvantages of adding sugar before or after the tea was boiled. She did not understand that sugar affects her blood sugar regardless of how tea is made. Although she knew that sugar or jaggery affected her blood sugar, she resisted changing her habit. Sweet tea for her was so much a part of being an Asian Indian.

P101F: Can you tell me one thing? When you make tea and boil it with milk, and once you put sugar in after you have boiled it, then the sugar is not harmful to you? Is that true?

I: It is still sugar, I don’t think it makes a difference.

P101F: My friends told me if you boil sugar in water then it is bad, but not when you add it after you have boiled the milk. I have told that I did not believe that was true. We can eat sugar but we have to limit it.

For Asian Indians, offering and drinking tea are expressions of hospitality. It is customary for Asian Indians to drink sweetened tea when visiting friends or attending social events. Participants did so as well, but this created a sense of frustration. Often they drank the sweet tea to avoid offending their host. The following comments exemplify the dilemma, one

male participant experienced. He felt obligated to drink sweetened tea while visiting a friend in Fiji and in United States.

P112M: Sometimes I feel when I go back to my country they would force you to drink a cup of tea with large amounts of sugar in it. You can't put it in your mouth, because I have not taken sugar in my tea for a long time now. So if you don't take the tea it's an insult to them, which is not right. So at times you have to take it and you know what I am just going to drink it because I came to this person's house probably after 4-5 years.

I: Does that happen here?

P112M: Whoever I sit with they know or if I go to a new friends house I tell them that I'm diabetic so they don't force me. Let me eat and drink what I want because I know what is right for me.

I: Are people tolerant of that?

P112M: Some are, others are like one cup of tea won't hurt. I think that is what you call ignorance, and I don't know how they feel about that. It does not make me feel good when people do that. It is more frustrating for me. You don't drink that stuff at home but yet when you go to someone's house they want you to drink it? That does not sound right, when they are forcing something down your throat. It does not make sense.

I: So then what do you do?

P112M: Well, if I will eat it just to satisfy them.

Drinking Asian Indian sweet tea is a common daily social practice that was essential to all participants in this study. Tea is being Asian Indian and is commonly served during social events. Participants felt obligated, pressured even, to drink it. The social practice of drinking tea posed several challenges to their glycemic control. Participants struggled between drinking sweetened and unsweetened tea. Participants tried various strategies to avoid sugar: reducing the amount they used, adding it to tea at different times and substituting jaggery for sugar.

### **Social Events and Weddings**

Attending social events and weddings maintain social networks and preserves traditional cultural practices. The Asian Indian participants acknowledged the negative effects of social events had on their blood sugar, but they devised several strategies to balance their diabetes and social life: disclosing their diabetes to friends and family, limiting portions of food and drink, and avoiding certain foods. Attending weddings was particularly challenging for participants.

They described lacking control over their diet, and felt burdened by cultural obligations to eat and drink what is customary at weddings. Several participants succumbed to the pressure.

Eating and drinking at social events, especially weddings, are essential. At these events, large elaborate meals are prepared and sweets are served as an expression of hospitality and goodwill.

Asians Indians are expected to eat what is offered by their host. Not eating or eating small amounts is viewed as being disrespectful. Maintaining glycemic control in these circumstances was especially taxing. One male participant recounted his blood sugar went out of control at social events.

P112M: Hard for me, so like when you stay at home as a normal person then there is a good control for you. It is easy for you to manage it, but when once you go out of the house especially for parties it is very hard then things get out of control.

Eating is also considered to be one of the most enjoyable aspects of social events. Not being able to eat what is offered is viewed as lacking a life or joy. Not being able to enjoy a party because she could not eat the foods offered, a female participant felt that she would be isolated from her social network. This would eventually have a negative effect on her social life. For her, the whole purpose of attending a party was to eat. Not being able to do so would affect her quality of life. She felt that her friends and family would not invite her if she did not eat what was offered.

P111F: Yes, it did. When we would go to parties, everyone would be eating cakes and stuff, and I could not eat them. Everyone is going to feel bad. I felt I was missing out.

I: So you felt like you were missing out?

P111F: Yes. It looks like I had no life not being able to eat.

Asian Indians consider attending social events to be essential in preserving culture and traditional values. Participants described how they tried to maintain a balance between their

social lives and the need to take care of their diabetes. Disclosing their diabetes to family and friends was an obvious first step. And it was more socially acceptable than managing their disease in isolation. Participants continued to attend social events but developed varying types of disclosure. For some participants, the familiarity and prevalence of diabetes in the Asian Indian community made disclosure easier. One male participant chose to disclose his diabetes only to family and close friends. He used them for support at social events. Limiting his social network and relying on his family during social events helped him balance his social life with his diabetes.

I: Has it affected you socially?

P103M: No, it has not affected me socially.

I: So you think that it has not affected you socially? Do your friends know you are diabetic?

P103M: Not much, I don't have many friends. I have only a few friends - I don't trust to many people. We have, you know, I know a lot of people, but you know I don't many friends, close friends, hang out with them. I stay with my family. Yes, when somebody invites me they have marriage party. I will go but I don't much have to go sit out and talk and this and that. I just try to focus on my diabetes.

Some male participants had to constantly remind their friends that they had diabetes.

One individual disclosed his diabetes to all his friends. Being frank helped him achieve better control of his diabetes because his friends stopped urging him to eat. It was important that his friends respect his diabetes and not coerce him to eat during social events. By being open about his disease, this man could maintain his social life and achieve glycemic control.

I: Has diabetes affected your social life?

P106M: No, not really

I: Do most of your friends around you know you're diabetic? Like when you go out people say, "Eat it, eat it."

P106M: Yes I tell them. I tell them like I'm border line diabetic. I don't want to eat that.

I: So then they don't force you?

P106M: No, they stop forcing you.

Diabetes did not seem to limit the number of social events participants attended. One woman confirmed that she still went to all of her social events. She told everyone that she had diabetes because she was convinced that everyone would eventually know anyway.

I: Do you tell your friends you have diabetes.

P111F: Yes. I never hide. I do not like to hide because somehow or the other it is going to come in front of you. Someday it is going to be more and people are going to know I have diabetes. So I don't hide, so I tell everyone I am diabetic.

Another female participant practiced what she preached. She attended all of her social events but avoided eating sweets, and took her medications as advised. In doing so, she believed she could control her diabetes. Eating sweets at social events is symbolic of goodwill, and it is customary for everyone to eat sweets at weddings. To deal with this cultural expectation and be socially appropriate, she limited her sweet snacks, telling the host that she preferred salty snacks. This maintained her glycemic control.

101BK: No, no I go everywhere. I go to parties, weddings and to other people's homes. I have not really changed my social life. I tell my friends and anyone who has diabetes to eat less, eat less sugar and they need to take their medications. They don't have to give up everything, eat less, don't eat it every day, and eat it once a month or once in a while. If you want to have a gulab jamun, eating it once a month is not going to harm you. If you want to eat it every day or every third day, and then continue to take you medications – then it is not going to work. Eat what you like, but less, eat it sometimes. Like when you go to a wedding, I tell the host that I would like to eat salty semia, and not the sweet ones (laughs).

In order to attend social events one female participant limited her portions and made healthier choices. If she concluded that the food was unsuitable, she ate just a bit at the event and home later. She went to great lengths not to inconvenience to her host.

I: What about parties?

P112M: Well, if it's a party, I won't eat cake.

I: What do you eat then?

P112M: Something a little healthier. But you know once in a while, see the basic thing is diabetes doesn't stop someone from eating everything – like cake. You just have to eat it in smaller portions and you need to be aware of your calorie counts, and then stay away from something else so you don't overdo it on the calories.

I: Does it affect what you eat or what people make for you when you go to their house?

P111F: When I go to anybody's house and there is not food right for me or diabetes, I just take a little bit. Then I come home, and then eat.

I: Do they tell you why aren't you eating?

P111F: Yes, they do. They ask me, "Why are you eating this little? Eat some more, eat some more." I sometimes will tell them I ate at home before I came over. I feel bad telling them don't make this for me because I am diabetic. I don't want them to make anything special for me – like salads, or little bit fries, or anything else. So if there is salad I will take a little bit of salad, little bit rice and that's it.

Avoiding social events was described by only one woman, but she did so because ambulation was difficult, not because of her diabetes. She avoided attending events because of her limited ability to walk and not because she had diabetes. At social events, she limited her food choices and did not indulge in the elaborate meals that were offered.

I: How about when you go to weddings and social events?

P110F: I don't really go – (laughs). I don't really go because I can't walk much and if I do go I eat only one roti. I don't eat much or do anything special. I listen to what my body says. I have to look after it. If I stay on this plan, then I don't have to worry about what is going to happen. Another thing is that I don't drink any juice.

Asian Indian weddings are elaborate events that entail several rituals and practices that can last several days. It is customary to consume traditional sweets and snacks during such auspicious occasions. As one female participant (P101F) conceded,

“You have to eat something at a wedding.”

Asian Indian weddings last for several days and are considered very important in maintaining social and family networks. Certain foods, which are symbolic of good will and prosperity, are served and one is expected to partake. Several participants reported that attendance at weddings to India had a negative effect on their blood sugar. One female participant explained that her blood sugar started to fluctuate while flying to India. Unable to resist the food that was offered



at the wedding also negatively affected her blood sugar, she had to increase her medications when she returned to the United States.

P104F: But this time the physician increased my medication a little bit – you know how when we go in an airplane and it jerks you – your blood sugar goes up or down. I went to India, and it went up, and then coming back I was at a wedding. In India, there was also a wedding and even there my blood sugar was up and down. You get to eat these things even though you do not want to eat them at weddings. Then when we came to England there was another wedding, and then as soon as I came back I had a physician’s appointment. I had made it so I could see him as soon as I got back. I made it before I went to India. He then increased my medication.

It is a cultural norm that Asian Indians eat what is offered to them at weddings. Refusing to do so is considered socially inappropriate. Female participant P104F felt obligated to eat what was offered to her, even though her blood sugar fluctuated. The adverse effect food can have on glycemic control was also down played by Asian Indians at weddings. Reluctantly, this woman “caved” under the host’s pressure and ate the “forbidden” food.

P104F: At weddings (laughs) that is why it has gone up. Everyone knows I am diabetic, but then they say you can eat a little bit more – it is not going to affect you that much. Look so and so has it and nothing’s happening to them. Take at least a little bit of food – it is because of that it goes up. Then I think, so what I am going to take medication and that is what other people say the medication is going to control your diabetes (laughs) – at weddings my sugar goes up.

Attending weddings in India were characterized as carefree but stressful. One participant described how she had no control over her diet and was unable to control her blood sugar during a visit to her brother in India. Although she could not control her diet, she felt carefree because she was enjoying the wedding in India. Fulfilling familial obligations and cultural expectations at the wedding were more important than her diabetes. At the wedding, she was expected to eat sweets. This customary practice of “sweetening your taste buds”, symbolizes good will and prosperity. Despite feeling carefree and exercising during her stay in India, this woman experienced considerable stress in not being able to control her diabetes.

I: Does that mean you eat less sugar?

P101F: No, I eat sweets. Like I went to India recently – there I don't care what I eat. It is hard to follow any diet there. We went to a wedding there, my brother has diabetes and we are twins. He has had it for a few years now, about 7 years. He would encourage me to eat, he told me one day eat the ladoos, I just got them delivered this morning. Taste them and let me know if they are good. I told him first you tell me not to eat and then you tell me to eat them. He told me you are at a wedding and that is what you do at a wedding, eat (laughs). And we ate half a laddoo each. When I go to India it is that we get more exercise, over there we keep walking in the house, here where do you walk the houses are so small. There are also fewer cars there and if you want to go to the bazaar you walk, you don't need a car. Also there is more tension in India, and yes it does make a difference in your diabetes. When you come here, you go eat at the temple but not at home.

Serving alcohol at weddings is also an important expression of hospitality and happiness.

For several male participants attending wedding parties meant drinking alcohol. One male participant, who selectively disclosed his diabetes to his family and a few friends, said that he felt more pressure to drink alcohol than to eat at weddings. To avoid the stigma of being seen as a diabetic he drank alcohol that was offered to him.

I: How about food? Like at a wedding?

P103M: Wedding. I take only a little bit.

I: Do you feel people force you to eat?

P103M: Oh nobody force to eat – only force to drink.

I: Yes, so how do you handle that?

P103M: No like you know Punjabi, like always you know – they bring the drink for you – you know. Give it to you in your hand, you know. They force for drink and not eat (laughs), this is true. Really.

P103M: It is like Punjabi, wherever you go, they have treated you well if they have offered you a drink. You are not drinking, are you sick? You are sick then you know you have to cover it. Even if you are sick you take it, drink it, don't feel like you are weak, or sick. You know how the Indian people are, they talk afterwards.

Even though socializing had a negative effect on their glycemic control, socializing was considered essential for nearly all the study participants. Socializing in the Asian Indian community enhances social networks and preserves cultural and traditional values. Participants tried to maintain some control of their blood sugar during social events by using several

strategies: disclosing their diabetes, limiting their social networks, controlling food portions, and avoiding social events. To avoid offending hosts and acceding to the customary wedding rituals and celebrations, participants often gave into the pressures of eating food and drinking alcohol.

For this study's participants, attending weddings, especially of relatives, was reported to be stressful. Participants indicated that the attendant familial and social obligations adversely affected their blood sugar. Long distance travel to India, lack of control over diet and blood sugar once there and difficulty resisting food at weddings were commonly identified as key factors. In addition, the effect of eating on blood sugar was down played at weddings. The lack of control and the feeling of being care free while visiting India caused considerable stress. Visiting in India had detrimental effects on their diabetes, and there was nothing they could do about it.

### **Religious Practices**

Most participants in this study were Sikh and attending the temple for worship on Sundays was a common practice. The temple, a community center, was also associated with maintaining and creating social networks. As one male participant (P106M) noted,

“Sikh temple is pretty much a community center. You get to go over there to talk to people.”

Attending the temple meant eating at the temple, always a challenge for diabetes management. Eating at the temple is a Sikh tenet, and entails that the congregation prepare and eat food together (langar). It is a way of expressing equality and that everyone is the same in the eyes of God. The institution of the Sikh langar, or free kitchen, was started by the first Sikh guru, Guru Nanak, and was designed to uphold the principle of equality of all people regardless of religion, caste, color, creed, age, gender or social status. This was a revolutionary concept in the caste-ordered society of sixteenth century India where Sikhism began. The tradition of

langar also expresses the ethics of sharing, community, inclusiveness, and oneness of all humankind. Usually breakfast, lunch, and dinner are served at the temple and consist of traditional Indian vegetarian meals and snacks. The meals usually consist of lentils, vegetables, yogurt, rice and roti; common snacks include “pakoras” and traditional Indian sweets. Study participants could anticipate what would be offered at the temple. As one man (106M) observed,

“Lot of us go the Sikh temple to have pakoras.”

Temple fare challenged participants in achieving glycemic control. They pre planned their meals and refrained from and resisted the traditional foods that were offered. For example, one woman explained how she ate before going to the temple so that she would not eat too much once she was there. However, once at the temple, she found it difficult to resist the delicious food.

P101F: I sometimes miss some Sundays, I eat before I go to the temple, but then I drink tea at the temple. I try to eat less there, but sometimes I will eat a piece of bean, but my favorite is gulab jamuns. I don't eat them though, I don't eat gulab jamuns, I will take a piece of besan and sometimes I won't. I then will take some pakoras. At the temple besan is really tasty.

Participants allowed themselves to eat at the temple because they did not eat snacks or sweets at home. One woman changed her diet at home, but not at the temple.

P101F: And sometimes I go to the temple eat their langar and then have one or two jalebis. There are many changes I have made, maybe at home – like fruit, I used to eat a banana every day and someone told me if I wanted to eat it I should eat it raw, not ripe. This is what I need to know, especially as far as fruit is concerned?

Although participants knew that eating at the temple would negatively affect their blood sugar, they were satisfying a craving, and it was acceptable to eat at the temple once a week.

One woman, who stopped making and eating Indian sweets at home continued to eat them at the temple to satisfy her craving for sweets.

P101F: It is like this: When I did not know much about diabetes I would eat more and now I know then you slowly, slowly cut back on how much you ate. I still eat but I have cut back. I used to make pinea a lot but now I don't. I used to make a lot of sweets, my husband used to like to eat them. He would tell me make this, make gulab jamuns, and now I don't make it and have forgotten how to make it. Even if I made it I would have to eat it. So I don't make it anymore. The children don't eat it; my daughter does not want to eat them. Gulab jamuns she won't eat, she will eat jalebis because her father used to like them too. I like jalebis too – I still don't eat them. I only eat them at the temple, especially when I can't control myself. There is a guy who comes to the temple his name is Minder, if he is making them then I will tell him, "Brother, make me a fresh one but don't put it in the sugar syrup". Then I will eat it. If he is not there and I really want to eat a jalebi, I will take a small piece. Half of a small piece just to satisfy my desire to eat. (laughs). Then I say to myself you have eaten it, and it is because I really wanted to eat it. You know when you want to eat something you try hard to say that I don't want to eat it, you still end up eating it because you really want to eat it. You always end up eating it. A woman from my village in India she brought me some pinea from India, and I will eat a little bit of it once in a while but if I don't want to then I won't eat it.

Eating sweet Indian snacks during religious and festive events symbolizes good will and prosperity. While attending temple, it is customary to eat parsad, a blessed sweet pudding that is made out of equal parts of ghee, sugar and flour and is given to all members of the congregation. Parsad is considered sacred food and all that receive it are believed to be blessed. Participants with diabetes tried to balance "sweetening their mouth" and their diabetes in a gracious manner.

Consider the example of this female participant:

I: When you attend weddings and religious functions?

P105F: Then I eat what is offered, just a little bit. I eat what I feel like eating but a little bit. But you know I have always liked salty things versus sweets. I like pakoras, but you have to make your mouth sweet, then I will take something small, something or the other just to make my mouth sweet. At the temple, I will take parsad.

I: You have to do that at the temple?

P105F: Yes, I have noticed how when I go to the temple, I really want to eat something sweet. In the past, I never ate anything sweet, everyone would tell me that she likes only salty stuff. Now since I got diabetes, I crave sweet snacks.

Going to temple was important for all the study participants. It allowed them to maintain their religious practices, meet as a congregation, and develop social networks in their community. Going to the temple entailed receiving parsad and partaking in langar which are

important religious practices. Participants tried several strategies to balance eating at the temple and maintaining glycemic control. They preplanned their meals and tried to resist the delicious food that was offered. In most instances, their self-control was not up to the pressure, and they ended up eating the food. In this study, participants were involved in temple activities. Future studies of non-practicing Sikhs are needed to address their diabetes challenges and coping strategies.

### **Summary**

Attending social, cultural, and religious events involved the preparation and eating of lavish meals and drinking tea and alcohol. Refusing to eat or drink what was offered was considered offensive to the host. Because food at religious and social events symbolizes prosperity and blessings, it was expected that the participants accept it. They developed several strategies to achieve balance and control of their diabetes. Further, they characterized the social and cultural practices as essential to with Asian Indian identity.

### **Aim 4: Exploring Gender Differences in Managing Marital and Family Roles of Asian Indians with Type 2 Diabetes.**

Culturally specific family and gender roles affected daily diabetes management, especially for female participants. Traditionally, Asian Indian women are responsible for household chores, meal preparation, and housekeeping and are often the primary care givers of children and elderly parents. It is not uncommon for elderly Asian Indians to live with their children and grandchildren. One female participant divulged that she felt overwhelmed with family responsibilities and lacked any time to manage her diabetes because she had to cater to her mother-in-law's dietary preferences. She had no time to make her own meal because making

two separate meals would only increase her household chores. As a result, she ate the parathas and roti, even though they had negative effects on her diabetes.

P108F: I usually like breakfast, I eat toast and peanut butter and this is usually breakfast, at lunch I eat roti, parathas and because you know my mom she does not like missi roti – it is healthy but she does not want it so then I never make one for myself, I make you know – if she eats paratha then I eat paratha. It is too much work

I: It is too much work.

Because families lacked understanding and knowledge about diabetes, support for several female participants was inadequate. The same female participant described how her family's lack of understanding of her diabetes hindered her glycemic control. She felt overwhelmed and described her husband's support as superficial. Although he encouraged her to walk and care for her diabetes, he did little to help her with her chores.

P108F: But they don't know much about it. They say okay mom is okay, doing her stuff, she is working all the time, and maybe it is normal. Nobody understands what diabetes is. So it is very hard.

I: How about your husband?

P108F: He is worried too, aah – so he says no it is okay, okay – you can, he encourages me, actually praises me go for walk and, but they expect, but he is working full time – so I have to take care of my mom at home and kids, you know. And he helps me, but it makes me tired. At the end of the day, it is a lot of responsibility.

In addition to being overwhelmed with family responsibilities, being diagnosed with diabetes posed meal time challenges for this participant. She struggled between cooking meals for the family and managing her dietary needs. Her and her family's strong preference for traditional Indian food made it difficult to modify meals. Modifying meals meant cooking two meals which created more work for her.

P108F: I just like my Indian food (laughs). It is very heavy, and because at home, my mother-in-law, I have to cook for her Indian food, because she likes Indian food, and then I can't make like – everybody wants you know normal food. Nobody understands that I

am diabetic, that I have to make it like my way - but they don't like it. I have to make myself different, and my husband he wants something different, he doesn't like it. I have to make something different. So then I make for everybody, so then I eat that. I am not making anything special for myself.

Complicating meal preparation, some family members wanted vegetarian fare and others wanted meals that included meat, which created further challenges. The same participant described how she had to cook chicken for her husband and son and a vegetarian meal for herself and her mother-in-law. Catering to family meal preferences and activities left no time for female participants to make dietary changes that would benefit their diabetes. This participant relied on her mother to make her meals while she cooked meals for her husband and son.

P108F: Yes. At suppertime I usually cook – because I am vegetarian so I don't eat meat. So I have to make something vegetarian for myself and for my husband and my son like chicken,. So I make them you know meat and stuff. So then I have to cook for myself and then for my mother in law Indian food. It is very hard. Three meals almost every day.

I: How long does it take you?

P108F: Sometimes one hour, sometimes more than that, but sometimes I ask my mom she makes for myself and for herself. My mom and not my mother in law. She will cook for me dhal and stuff. So then I get some help, because I am so busy in the evening with the little one. He plays ice hockey. So then when I come back from the game, and she makes for me dhal, so that is a little help.

Maintaining glycemic control was challenging as it required frequent monitoring of blood sugar, administering insulin, and monitoring food. This participant's glycemic control was further hindered by her busy lifestyle.

I: What is tough?

P108F: Like?

I: Like every day?

P108F: Like every day I get up in the morning, I check – I poke myself, check how much it is, then I have to take my insulin, sliding scale. Then I don't like it – you know – I don't like it, it is hard, then again at lunch time and at supper time. Sometimes I am not checking it – my sugar – you know. I just give insulin by myself, you know. And you know because I have to take my son to the game and stuff, then I have to pack all the



food with me. It makes it so hard sometimes. Sometimes I can't eat on time, and when the kids eat in the evening. I eat like 9 o'clock – 10 o'clock. It is hard to, like to do my diet, so hard. It is hard to control, and I think it is – I don't know I think maybe I can't learn how to live with diabetes. And it is hard.

For some male participants, managing their diabetes was easier, especially because their spouses prepared their meals. One male said that because his wife had diabetes he was able to control his diet. She bought the food and prepared his meals.

I: As far as your family is concerned are they supportive of you being diabetic, or do you think they hinder it.

P106M: They're supportive I mean she has diabetes too.

I: So that makes it a little bit easier for you?

P106M: Yes she understands. She cooks; and buys the food I want to eat. That is another thing you have to be in the position to afford what you want to eat. You know? Some of them they can't do it. They have to eat roti every day.

I: Some of the food is pricey.

P106M: Yup

I: That is a good point.

Several male participants implemented dietary changes within their family. One male switched to whole wheat bread and whole wheat roti for the whole family.

P112M: And now I am concentrating on brown foods versus white food. Actually now my whole family has moved into brown food, actually 80% of them, instead of white. Like brown bread. No more white bread in this house. The kids got used to it. Except for rice one of my daughters eats white rice. So I said okay go ahead but be in control. From that time I did not put any sugar in my tea. Fruits too, I stay away from them – I listened to my physician and that was the most important thing. As far as diabetes is concerned, actually there was a time that after 6 months I actually lost 60 pounds. And I was on my actual weight.

Although family involvement and making dietary changes were important, the process was not easy. One male participant expressed frustration that his children did not exercise or eat healthier. He blamed not only their lack of motivation, but also the lack of a social network in the neighborhood. He recounted that as a child he spent most of his time playing with his friends in his neighborhood in Fiji; in the United States neither he nor his children knew any of their

neighbors. The change in his children's social environment and their lack of motivation to exercise and eat healthier made him feel powerless.

P112M: Yes, they have changed their eating habits, like candy. Seriously, me being diabetic has had a big impact on my family, they know what to eat. But the thing is right now the kids are home so I see these people are more relaxing and it is because it is holiday time. Every day I tell my kids, when are you going to exercise, that is my daily thing. If I am I 50 years old and exercising, and my kids are 18-19, 23 years old and they are not exercising, what is wrong with you guys, come on. When I was your age, I could play whole day in the sun. We were physically active. The problem here is we have all houses around us and neighbors they don't know each other, say if we had known all these neighbors and their kids; my kids would be playing with them somewhere. Used to be like or it probably still happens in certain parts of America, where there are more rules set up and they still do that. It is only when you live in an urban or suburban community like this, and we have to get out of this. So I tell my kids to exercise every day. Sometimes they do and sometimes they don't. The thing is I can tell them but I can't force them, that is the other thing.

### **Summary**

Gender and family roles affected daily management of diabetes. Family responsibilities and caregiving activities had a negative impact on glycemic control for female participants. They lacked personal time to manage their diabetes because they had to cater to the needs of their children, husband and elderly parents. Glycemic control was further hindered by the lack of family support. Family members lacked knowledge and took it for granted that women were the family's primary caregivers. There seemed to be no family discussion about the disease or its management, except when it affected Asian Indian men, not the women. Asian Indians men reported having better control of their diabetes because their wife prepared their meals. However, implementing dietary changes within their families was a challenge hindered by children lacking motivation, lack of social support, and exercise.

## Chapter 5

### Discussion

Managing diabetes in Asian Indians is a complex process that involves managing multiple medications, dietary and other life style factors. Deeply ingrained cultural beliefs and practices are important to understand, as they may impact patient care. Asian Indians come from India, Bangladesh, Pakistan, Africa and Fiji and their religious affiliations are as diverse as their geographic distribution including Hindus, Sikhs, Muslims and Christians. Although several studies have been conducted in the United Kingdom, most of the participants were Muslims; Hindu and Sikh participation was limited. No studies have been done to differentiate the beliefs and practices of these diverse groups despite the fact that their religious and cultural practices are quite distinct. Although Hindus and Sikhs represent a significant portion of the Asian Indian diasporic population (Ballard, 1994), research on their health care practices and beliefs about chronic diseases is extremely limited.

Studies in the United Kingdom have reported several factors that influence Asian Indian beliefs about the causes of diabetes and its management such as fatalism, hereditary factors, and the stress of migration (Macaden & Clarke, 2006; Stone et al., 2005). In this current study, Sikh and Hindu participants were recruited from temples to explore and understand their experiences with diabetes. They expressed varied beliefs about the causes of their diabetes. Because some were convinced that family history and hereditary factors would inevitably lead to diabetes, they lacked the motivation to prevent it. Some anticipated the diagnosis, which led to frequent screening, but they did not adopt preventive health behaviors. Other participants were uncertain about the causes of diabetes, but they too lacked the knowledge to take preventive measures. In

summary, hereditary factors, uncertainty as to the causes of diabetes and lack knowledge led to passive and casual acceptance of the disease.

Even though participants had a family history of diabetes, they believed that external causes superseded hereditary factors. Commonly cited external cause was migration to more industrialized nations. In the United Kingdom, first generation Asian Indians associated diabetes with the Westernization of diet and lifestyle (Farooqi et al, 2000; Lawton et al., 2007). However, a study (Venkatesh et al., 2013) conducted in the United States with participants who were highly educated, had higher socioeconomic status, and spoke English acknowledged that migration had positive effects on diabetes control.

In this study, the stressors of migration were influenced by gender roles. Traditionally, Asian Indian men are the breadwinners of the family. For the men in this study, migrating to the United States led to changes in employment. They believed that sedentary jobs and an abundance of food caused their diabetes. Post migration they abandoned physical activity, such as walking to work, that was part of their previous routine. Pre-migration routines included daily exercise that provided emotional therapy after a long day at work. The lack of physical activity was further compounded by an abundance of food that led to diabetes. Female participants described stressors that affected family harmony during migration. Being separated from their husbands and adult children, worrying about their children's illnesses and immigration status were major stressors that they believed caused diabetes. The Asian Indian women also attributed lack of communication with their physicians as a cause of their disease. Even though participants were familiar with diabetes, they lacked the knowledge of causative and preventive factors. They all attributed the cause of diabetes to external factors as a result of migration.

Managing diabetes was also influenced by life experiences such as previous care-giving experiences. Once diagnosed with diabetes, Asian Indians described it as an intrusive sickness that interfered with all aspects of their life. The rigid routine of diabetes management compelled participants to realize that they really were sick. Accordingly, they made significant dietary and lifestyle changes because they feared the complications of diabetes. This fear stemmed from caring for family members with diabetes, especially those who had developed renal disease. And this fear motivated participants to become more active in their own care and seek immediate medical attention when symptoms arose.

Daily management of diabetes required that participants make dietary and lifestyle changes. These changes were influenced by gender roles, previous care-giving experiences and knowledge obtained from informal sources, such as social media and social networks. Male participants attempted to control their diabetes by making lifestyle changes, especially in diet and physical activity. Their drastic changes involved avoiding meat, alcohol and roti and eating more pasta, vegetables, and fruit. The male participants found it easier to make dietary changes because their wives prepared their meals and made the dietary changes that were necessary to improve glycemic control. Female participants chose to make gradual and simple changes such as limiting portions sizes and avoiding certain Indian foods, which they had witnessed as hindering glycemic control when they were young. Making changes gradually was a strategy that worked well for female participants. Overall, any dietary change was a major accomplishment for both male and female participants.

Families and gender roles played significant roles in the management of diabetes. Female participants reported that overwhelming household and family responsibilities hindered glycemic control. They described a lack of family support and time to manage their diabetes or

plan their care. Implementing dietary and lifestyle changes within the family was described as challenging. Because family members were unwilling to change their dietary practices to accommodate participants with diabetes, female participants were forced to prepare separate meals. Further, children lacked the motivation to exercise or change their diet. Lack of social support in neighborhoods, where children could play with others and be physically active, was thought to hinder physical activity that is essential in preventing diabetes.

Previous studies (Bean, et al., 2007; Macaden & Clarke, 2006) reported that Asian Indians had less knowledge about the process of their disease, minimized its seriousness, and had a limited understanding of the relationship between achieving control and avoiding diabetic complications. In this study, male and female participants also reported as lack of knowledge about the causes and management of diabetes. Some believed that they could have prevented the disease had they known earlier. Most of the knowledge they had was influenced by personal and social experiences. The lack of culturally specific knowledge and language barriers hindered diabetes management and prevention. The effectiveness of diabetes education classes was limited for this reason. Participants felt that the classes were not tailored to their needs and were too complicated. Counting calories and carbohydrates was a “foreign” concept. Asian Indians preferred to control their diabetes by making gradual changes to their diet such as exercising portion control, limiting the number of daily meals, and avoiding sweets and sodas.

To achieve control of diabetes, participants used several other modalities such as: balancing Ayurveda and Western medicine and adopting new lifestyle practices. Ayurveda and dietary practices were preferred because they were familiar. Female participants blended and ate several herbs and flours that have been commonly used in Indian cuisine for generations. Readily available in local Indian markets, these herbs and flours were believed to have a positive

effect on blood sugar. Male and female participants both described bitter melon as a fruit with such positive properties. The herbs, flours, and bitter melon were also thought to have fewer side effects than Western medications.

Access to medical care and Western medication in the United States was limited due to the participants' lack of health care coverage, immigration situation and employment status. These barriers led some participants to coordinate their care with visits to India and to seek routine medical care from physicians in their community who understood their health care practices and challenges. Participants reported that they paid cash for their visits and avoided medical care in the United States until they could secure health care benefits. Achieving such benefits was a major milestone because participants believed that health care in the United States was better overall than in India. Health care facilities in the United States were considered to be clean and of high quality, offering comprehensive health care services and efficient staff.

Participants enjoyed favorable relationships with their physicians because the latter accommodated their health care challenges and practices. Most of the participants preferred Asian Indian physicians, because it was easier to communicate with them and access to them, especially if they were members of their community. Physicians were trusted to have the knowledge and expertise to guide the participants' care and understand their social and cultural practices.

Social, cultural, and religious events were essential in maintaining social networks and preserving Asian Indian cultural and traditional values. Attending these events involved eating lavish meals and drinking sweetened tea and alcohol, which had detrimental effects on glycemic control. Traditional and cultural food practices were difficult to resist and challenging. Participants tried to maintain a balance between their social lives and their diabetes by disclosing

their disease to their family and friends. In an attempt to manage their diabetes, they limited or avoided the food and alcohol that were offered. Often, however, they caved into the pressure of eating the “wrong foods” in order to conform to the traditional and cultural practices. They ate what was offered to avoid offending their host and to fulfill family obligations. Several participants admitted that glycemic control was often down played at these events.

Drinking tea, an important Asian Indian practice, symbolizes hospitality and is an important cultural practice. Tea is often served at social and cultural events. Participants found it difficult to give up sweetened Indian tea. They tried to avoid it, drink it without sugar, or use jaggery to sweeten it. Drinking sweetened tea is so much a part of being Indian that it presented symbolic and real barriers to diabetes management.

### **Implications**

This study provides insight into the beliefs, barriers and challenges of first generation Sikhs and Hindus in the United States. The findings offer a preliminary understanding of the beliefs and management of diabetes in this population. For most of the participants, diabetes was a familiar part of their world. This familiarity influenced their beliefs about its causes and management and led to a passive acceptance. Strategies to prevent and achieve control over diabetes in Asian Indians need to be developed in order to improve health outcomes for this population.

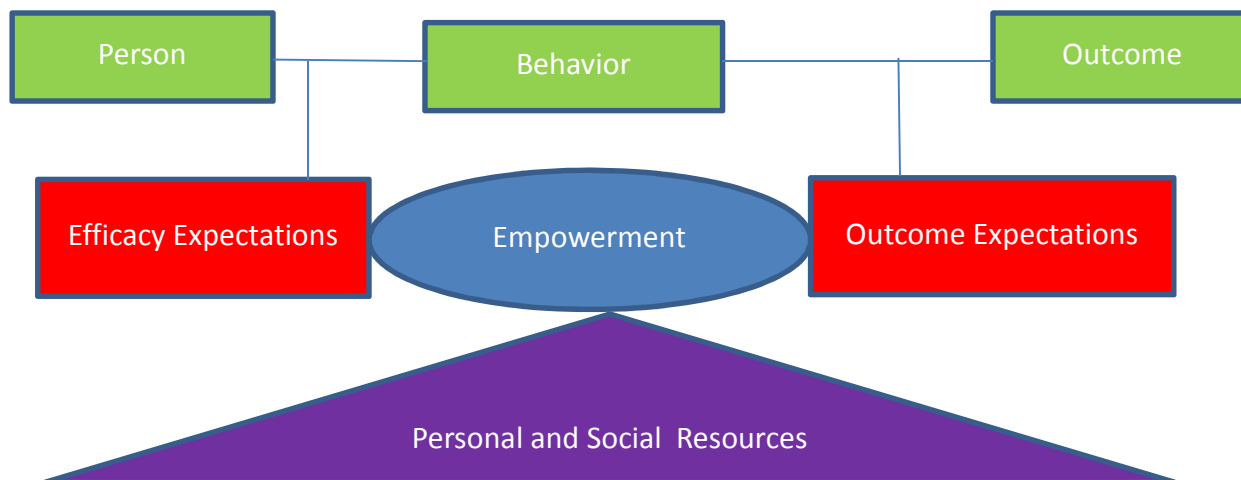
Health empowerment and self-efficacy theories have been used to successfully self-manage chronic disease. The interplay between personal, behavioral and environmental factors provides a framework within which strategies could be developed to motivate Asian Indians to engage in preventive behaviors. Because the rate of developing diabetes is so high among Asian Indians, culturally appropriate behavioral strategies should be implemented as early as possible,



especially during routine health visits. Setting goals within the cultural context, by identifying personal and social resources such as dietary practices, cultural and religious beliefs, and incorporating them into strategies to improve diabetes management would enhance self-capacity, which would lead to empowerment and improve self-efficacy in this group (Figure 3).

Public health strategies should be aimed at enhancing prevention and improving knowledge of diabetes in this population, even before they develop prediabetes. Incorporating personal resources into preventive programs that emphasize motivation and information on personal risk factors of diabetes should be implemented as early as

Figure 3: Self Efficacy and Health Empowerment Theories in Asian Indians with Diabetes



possible for this group to prevent or delay the onset of diabetes. For example, the dietary practices and behavior, such as eating a “missi roti” and skills that they have learnt from caregiving activities should be incorporated into preventive programs. Asian Indians should undergo early screening for diabetes, and health care providers should encourage them to

exercise routinely (especially daily walking) and maintain healthy, Asian specific BMIs. Risk factors and prevention should be discussed at routine visits, especially if there is a family history of diabetes.

Even though Asian Indians are familiar with diabetes and often passively accept it, they fear it and lack knowledge of the disease and its complications. Acknowledging this fear and lack of knowledge could facilitate open discussion and communication between health care providers and Asian Indians, providing an opportunity to educate this population and address their concerns. Preventive programs that couple information about risk with data on positive outcomes that can be achieved by changing health behaviors are likely to be the most efficacious (Ho, Chun & Chesla, 2012).

Understanding the importance of tea drinking in Asian Indians has several health care implications. Health care providers must understand and acknowledge that drinking tea is a culturally specific practice among Asian Indians. During screening for or treatment of diabetes, health care providers should ask Asian Indians about their tea consumption. They should encourage patients with diabetes to limit their tea drinking to two cups a day and to avoid an excessive amount of sugar and milk in their tea. The effects of sugar on glycemic control should be discussed, and alternative options should be offered. Positive reinforcement of efforts to avoid sugar and use of alternative sweeteners should be offered at routine visits.

Ayurveda and Vegetarianism are common Asian Indian practices that are thought to control diabetes, but the numbers of studies that have examined their effects have been limited. To provide culturally appropriate care for Asian Indians with diabetes, more research should be conducted on these everyday practices. Health care providers should assess the herbal and flour blends that are believed to be salutary for diabetes control in everyday practices. As additional

information is developed, these practices can be incorporated into the care and treatment of diabetes in this population. Until such scientific information is developed, patients can be encouraged to test their pre and post prandial blood sugar to see how they respond to using Ayurveda self-treatments and Vegetarianism.

Gender roles and social support also influence diabetes management among Asian Indians. Women report less support from family members than males. Strategies to provide greater support for Asian Indian women such as local support groups and dietary information sessions are needed to empower them to achieve control of their disease. More information on available resources for the care of elderly parents would be ideal and might decrease the responsibilities that female participants reported. Developing culturally specific ways to engage family members, especially spouses and children, in understanding the disease process and how to support female patients must be developed.

Addressing social resources should include discussing the challenges of living with diabetes and offering suggestions on how to handle food at social and cultural events may be beneficial for participants with diabetes. Strategies to improve dietary practices should be shared with congregation leaders at temple. Holding nutritional seminars, lifestyle seminars, and exercise programs at temple would provide valuable knowledge to Asian Indians with diabetes. Discussing portion sizes, baking versus deep frying foods, the use of low carbohydrate vegetables and the use of artificial sweeteners may further benefit this population. Ideally these sessions should be offered by physicians and health care providers who are involved in the community. Understanding Asian Indian cultural practices and implementing culturally specific strategies would help build the partnerships that are essential in improving knowledge and increasing motivation to prevent diabetes and its complications. Developing culturally sensitive

educational programs on prevention and community health would ultimately improve control of diabetes.

### **Limitations**

Because this study described the lived experiences of first generation Asian Indians (i.e., Sikhs and Hindus) who were recruited from local temples, its findings cannot be generalized to other Asian Indian groups (i.e., Muslims and Christians) or second generation Asian Indians. Further, all of the participants had type 2 diabetes; thus findings cannot be applied to persons with type 1 diabetes. Finally, most of the participants self-reported A1Cs that were within normal control, but there was no way of verifying that.

### **Conclusion**

This interpretive phenomenological study found several factors that influence the cause of diabetes and its management in Asian Indians. Participants were familiar with diabetes, but they lacked the knowledge and motivation to prevent it. This familiarity led to a passive acceptance of the disease but fueled their fear of its complications. This fear, in turn, led participants to make drastic changes in their diet and lifestyle, and seek frequent medical attention. Beliefs about the cause of diabetes and its management were significantly influenced by gender roles. Even though participants attributed their disease to hereditary causes, female participants believed that familial stressors, caused by migration to the United States, led to their diabetes. Male participants, on the other hand, attributed change in job status, sedentary lifestyle, and an abundance of food as causes of their disease. Diabetes management was complicated because Asian Indians tend to use familiar dietary practices, Ayurveda and Western

medications at the same time. Cultural, religious and social practices, lack of access to medical care, and immigration status also influenced diabetes management.

Managing diabetes in Asian Indians is a complex challenge for health care professionals. Further studies and efforts in prevention, health education, and community outreach are needed as the Asian Indian population increases in the United States. Public health initiatives that empower and increase self-efficacy in a culturally sensitive manner, and increase awareness of and screening for diabetes may improve diabetes and its complications in the Asian Indian community.

## References

- Abate, N., & Chandalia, M. (2001). Ethnicity and type 2 diabetes: Focus on Asian Indians. *Journal of Diabetes and its Complications*, 15(6), 320-327.
- Abdoli, S., Ashktorab, T., Ahmadi, F., Parvizi, S., & Dunning, T. (2008). The empowerment process in people with diabetes: An Iranian perspective. *International Nursing Review*, 55(4), 447-453. doi10.1111/j.1466-7657.2008.00664.x
- Addison, R. B. (1989). Grounded interpretive research: An investigation of physician socialization. In M. J. Packer & R. B. Addison (Eds.), *Entering the circle: Hermeneutic investigation in psychology* (pp. 39-57). New York, NY: State University of New York Press.
- Allen, N. A. (2004). Social cognitive theory in diabetes exercise research: An integrative literature review. *The Diabetes Educator*, 30(5), 805-819.
- Ambert, A. M., Adler, P. A., Adler, P., & Detzner, D. F. (1995). Understanding and evaluating qualitative research. *Journal of Marriage and Family*, 57(4), 879-893.  
doi:10.2307/353409
- American Diabetes Association. (2010). Standards of medical care in diabetes - 2010. *Diabetes Care*, 33(Suppl. 1), S11-S61. doi:10.2337/dc10-SO11
- Anderson, R. M., & Funnell, M. M. (2000). Compliance and adherence are dysfunctional concepts in diabetes care. *The Diabetes Educator*, 26(4), 597-604.
- Anderson, R. M., & Funnell, M. M. (2005). Patient empowerment: Reflections on the challenge of fostering the adoption of a new paradigm. *Patient Education and Counseling*, 57(2), 153-157. doi:10.1016/j.pec.2004.05.008
- Anderson, R. M., Funnell, M. M., Aikens, J. E., Krein, S. L., Fitzgerald, J. T., Nwankwo, R., Tannas, C.L., & Tang, T. S. (2009). Evaluating the efficacy of empowerment-based self-

- management consultant intervention: Results of a two-year randomized controlled trial. *Therapeutic Patient Education*, 1(1), 3-11.
- Anderson, R. M., Funnell, M. M., Nwankwo, R., Gillard, M. L., Oh, M., & Fitzgerald, J. T. (2005). Evaluating a problem-based empowerment program for African Americans with diabetes: Results of a randomized controlled trial. *Ethnicity & Disease*, 15(4), 671-678.
- Appleton, J. V., & King, L. (2002). Journeying from the philosophical contemplation of constructivism to the methodological pragmatics of health services research. *Journal of Advanced Nursing*, 40(6), 641-648.
- Atkinson, B., Heath, A., & Chenail, R. (1991). Qualitative research and the legitimization of knowledge. *Journal of Marital and Family Therapy*, 17(2), 161-166. doi:10.1111/j.1752-0606.1991.tb00879.x
- ATLAS.ti (Version 7) [Computer software]. Berlin, Germany: Scientific Software Development GmbH.
- Bailey, P. H. (1997). Finding your way around qualitative methods in nursing research. *Journal of Advanced Nursing*, 25(1), 18-22.
- Bandesha, G., & Litva, A. (2005). Perceptions of community participation and health gain in a community project for the South Asian population: A qualitative study. *Journal of Public Health*, 27(3), 241-245.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84(2), 191-215.
- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs, NJ: Prentice-Hall, Inc.
- Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York, NY: W. H. Freeman.

- Bean, D., Cundy, T., & Petrie, K. J. (2007). Ethnic differences in illness perceptions, self-efficacy and diabetes self-care. *Psychology and Health, 22*(7), 787-811.
- Benner, P. (1994). The tradition and skill of interpretive phenomenology in studying health, illness and caring practices. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 99-128). Thousand Oaks, CA: Sage Publications, Inc.
- Bissell, P., May, C. R., & Noyce, P. R. (2004). From compliance to concordance: Barriers to accomplishing a re-framed model of health care interactions. *Social Science and Medicine, 58*(4), 851-862.
- Broussard, L. (2006). Understanding qualitative research: A school nurse perspective. *The Journal of School Nursing, 22*(4), 212-218. doi:10.1177/10598405050220040501
- Brown, E. R. (2008). *The changing faces of American communities: "No data, no problem."* Paper presented at the University of California, Los Angeles, Los Angeles, CA.
- Carter, S. M., & Little, M. (2007). Justifying knowledge, justifying method, taking action: Epistemologies, methodologies, and methods in qualitative research. *Qualitative Health Research, 17*(10), 1316-1328.
- Castillo, A., Giachello, A., Bates, R., Concha, J., Ramirez, V., Sanchez, C., Pinsker, E., Arrom, J. (2010). Community-based diabetes education for Latinos: The diabetes empowerment education program. *The Diabetes Educator, 36*(4), 586-594.  
doi:10.1177/0145721710371524
- Charmaz, K. (2003). Grounded theory. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 81-110). London, United Kingdom: Sage Publications, Inc.



- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage Publications, Inc.
- Chesla, C. A. (1994). Parents' caring practices with schizophrenic offspring. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 167-184). Thousand Oaks, CA: Sage Publications, Inc..
- Chesla, C. A. (2011). Lecture on *interpretive phenomenology in nursing and health science*. Personal collection of C. A. Chesla, University of California, San Francisco, San Francisco, CA.
- Cho, J., & Trent, A. (2006). Validity in qualitative research revisited. *Qualitative Health Research, 6*(3), 319-340. doi:10.1177/1468794106065006
- Chun, K. M., & Akutsu, P. D. (2008). Assessing acculturation in Asian American immigrant and refugee families: Guidelines for mental health practitioners. . In N. H. Trinh, Y. Rho, K. M. Sanders, & F. Lu (Eds.), *Handbook on Asian American Health: Families, Acculturation and Resilience*. . Totowa, NJ: Human Press, Inc.
- Chun, K. M., & Hsu, J. (2012). Adjustment disorders in Asians. In E. C. Chang & E. C. Chang (Eds.), *Handbook of adult psychopathology in Asians: Theory, diagnosis, and treatment*. (pp. 328-356). New York, NY, US: Oxford University Press.
- Clarke, A. E. (2005). *Situational analysis: Grounded theory after the postmodern turn*. Thousand Oaks, CA: Sage Publications, Inc.
- Cowie, C. C., Rust, K. F., Ford, E. S., Eberhardt, M. S., Byrd-Holt, D. D., Li, C., William, D.E., Greg, E.W, Bainbridge, K.E., Saydah, S.H., & Geiss, L. S. (2009). Full accounting of diabetes and pre-diabetes in the U.S. population in 1988-1994 and 2005-2006. *Diabetes Care, 32*(2), 287-294. doi:10.2337/dc08-1296

- Crawford Shearer, N. B. (2007). Toward a nursing theory of health empowerment in homebound older women. *Journal of Gerontological Nursing*, 33(12), 38-45.
- Crawford Shearer, N. B. (2009). Health empowerment theory as a guide for practice. *Geriatric Nursing* 30(2 Suppl.), 4-10. doi:10.1016/j.gerinurse.2009.02.003
- Crawford Shearer, N. B., & Reed, P. G. (2004). Empowerment: Reformulation of a non-Rogerian concept. *Nursing Science Quarterly*, 17(3), 253-259.
- Creatore, M. I., Moineddin, R., Booth, G., Manuel, D. H., DesMeules, M., McDermott, S., & Glazier, R. H. (2010). Age- and sex-related prevalence of diabetes mellitus among immigrants to Ontario, Canada. *Canadian Medical Association Journal*, 182(8), 781-789. doi:10.1503/cmaj.091551
- Creswell, J. W. (2006). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Cutcliffe, J. R. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing*, 31(6), 1476-1484.
- Davis, E. D., Vander Meer, J. M., Yarborough, P. C., & Roth, S. B. (1999). Using solution-focused therapy strategies in empowerment based education. *The Diabetes Educator*, 25(2), 249-252, 255-257.
- D'Costa, D. F., Samanta, A., & Burden, A. C. (1991). Epidemiology of diabetes in UK Asians: A review. *Practical Diabetes International*, 8(2), 64-66. doi:10.1002/pdi.1960080208
- Denzin, N. K., & Lincoln, Y. S. (2005). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.

- Dreyfus, H. L. (1990). *Being-in-the-world: A commentary on Heidegger's being in time, Division I*. Cambridge, MA: The MIT Press.
- Farooqi, A., Nagra, D., Edgar, T., & Khunti, K. (2000). Attitudes to lifestyle risk factors for coronary heart disease amongst South Asians in Leicester: A focus group study. *Family Practice, 17*(4), 293-297.
- Fawcett, J. (1999). *The relationship of theory and research* (3rd ed.). Philadelphia, PA: F. A. Davis Company.
- Fischbacher, C. M., Hunt, S., & Alexander, L. (2004). How physically active are South Asians in the United Kingdom? A literature review. *Journal of Public Health, 26*(3), 250-258.
- Funnell, M. M., & Anderson, R. M. (2000). The problem with compliance in diabetes. *Journal of the American Medical Association, 284*(13), 1709.
- Funnell, M. M., & Anderson, R. M. (2004). Empowerment and self-management of diabetes. *Clinical Diabetes, 22*(3), 123-127. doi:10.2337/diaclin.22.3.123
- Gawlick, M. (1997). *Adaptation strategies of second generation Asian Indians*. Paper presented at the 1997 Conference on Asian Studies on the Pacific Coast, Asilomar, CA.
- Geertz, C. (1973.). *The interpretations of culture: Selected essays*. New York, NY: Basic Books.
- Glasgow, R. E., & Anderson, R. M. (1999). In diabetes care, moving from compliance to adherence is not enough. Something entirely different is needed. *Diabetes Care, 22*(12), 2090-2092.
- Grace, C., Begum, R., Subhani, S., Kopelman, P., & Greenhalgh, T. (2008). Prevention of type 2 diabetes in British Bangladeshis: Qualitative study of community, religious, and professional perspectives. *British Medical Journal, 337*, a1931. doi:10.1136/bmj.a1931

- Greico, E. M., & Cassidy, R. C. (2001). *Overview of race and Hispanic origin: Census 2000 brief* (C2KBR/01-1). Retrieved from the U.S. Census Bureau website:  
<https://www.census.gov/prod/2001pubs/c2kbr01-1.pdf>
- Grewal, K., Stewart, D. E., & Grace, S. L. (2010). Differences in social support and illness perceptions among South Asian and Caucasian patients with coronary artery disease. *Heart and Lung, 39*(3), 180-187. doi:10.1016/j.hrtlng.2009.06.016
- Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation*. Newbury Park, CA: Sage Publications, Inc.
- Gupta, A., Kumar, A., & Stewart, D. E. (2002). Cervical cancer screening among South Asian women in Canada: The role of education and acculturation. *Health Care for Women International, 23*(2), 123-134.
- Gupta, M., Doobay, A. V., Singh, N., Anand, S. S., Raja, F., Mawji, F., Kho J., & Yusuf, S. (2002). Risk factors, hospital management and outcomes after acute myocardial infarction in South Asian Canadians and matched control subjects. *Canadian Medical Association Journal, 166*(6), 717-722.
- Gurm, B. K., Stephen, J., MacKenzie, G., Doll, R., Barroetavena, M. C., & Cadell, S. (2008). Understanding Canadian Punjabi-speaking South Asian women's experience of breast cancer: A qualitative study. *International Journal of Nursing Studies, 45*(2), 266-276.
- Harris, M. (1976). History and significance of the EMIC/ETIC distinction. *Annual Review of Anthropology, 5*, 329-350. doi:10.1146/annurev.an.05.100176.001553
- Hayes, L., White, M., Unwin, N., Bhopal, R., Fischbacher, C., Harland, J., & Alberti, K. G. (2002). Patterns of physical activity and relationship with risk markers for cardiovascular

- disease and diabetes in Indian, Pakistani, Bangladeshi and European adults in a UK population. *Journal of Public Health Medicine*, 24(3), 170-178.
- Heisler, M., Smith, D. M., Hayward, R. A., Krein, S. L., & Kerr, E. A. (2003). How well do patients' assessments of their diabetes self-management correlate with actual glycemic control and receipt of recommended diabetes services? *Diabetes Care*, 26(3), 738-743.
- Hernandez-Tejada, M. A., Campbell, J. A., Walker, R. J., Smalls, B. L., Davis, K. S., & Egede, L. E. (2012). Diabetes empowerment, medication adherence and self-care behaviors in adults with type 2 diabetes. *Diabetes Technology and Therapeutics*, 14(7), 630-634.  
doi:10.1089/dia.2011.0287
- Ho, E. Y., Chesla, C. A., & Chun, K. M. (2012). Health communication with Chinese Americans about type 2 diabetes. *The Diabetes Educator*, 38(1), 67-76.  
doi:10.1177/0145721711428774
- Holden, G. (1991). The relationship of self-efficacy appraisals to subsequent health related outcomes: A meta-analysis. *Social Work Health Care*, 16(1), 53-93.
- Holloway, I., & Todres, L. (2003). The status of method: Flexibility, consistency and coherence. *Qualitative Research*, 3(3), 345-357. doi:10.1177/1468794103033004
- Holloway, I., & Wheeler, S. (2010). *Qualitative research in nursing and healthcare* (3rd ed.). Chichester, West Sussex, United Kingdom: Wiley-Blackwell.
- Holman, H., & Lorig, K. (1992). Perceived self-efficacy in self-management of chronic disease. In R. Scharzer (Ed.), *Self-efficacy: Thought control of action* (pp. 305-323). Washington, DC: Hemisphere.

- Hubert, H. B., Snider, J., & Winkleby, M. A. (2005). Health status, health behaviors, and acculturation factors associated with overweight and obesity in Latinos from a community and agricultural labor camp survey. *Preventive Medicine, 40*(6), 642-651.
- Iannotti, R. J., Schneider, S., Nansel, T. R., Haynie, D. L., Plotnick, L. P., Clarke, L. M., Sobbel, D.O., & Simons-Morton, B. (2006). Self-efficacy, outcome expectations, and diabetes self-management in adolescents with type 1 diabetes. *Developmental and Behavioral Pediatrics, 27*(2), 98-105.
- International Diabetes Federation. (2013). *IDF diabetes atlas* (6th ed.). Brussels, Belgium: Author.
- Johnson, M. (1999). Observations on postivism and pseudoscience in qualitative nursing research. *Journal of Advanced Nursing, 30*(1), 67-73.
- Kanaya, A. M., Wassell, C. L., Mathur, D., Stewart, A., Herrington, D., Budoff, M. J., Ranpura, V & Liu, K. (2010). Prevalence and correlates of diabetes in South Asian Indians in the United States: Findings from the metabolic syndrome and atherosclerosis in South Asians living in America study and the multi-ethnic study of atherosclerosis. *Metabolic Syndrome and Related Disorders, 8*(2), 157-164. doi:10.1089/met.2009.0062
- Kandula, N. R., Wen, M., Jacobs, E. A., & Lauderdale, D. S. (2006). Low rates of colorectal, cervical, and breast cancer screening in Asian Americans compared with non-Hispanic whites: Cultural influences or access to care? *Cancer, 107*(1), 184-192.
- Kaplan, M. S., Chang, C., Newsom, J. T., & MacFarland, B. H. (2002). Acculturation status and hypertension among Asian immigrants in Canada. *Journal of Epidemiology and Community Health, 56*(6), 455-456.

- Kavanagh, D. J., Gooley, S., & Wilson, P. H. (1993). Prediction of adherence and control in diabetes. *Journal of Behavioral Medicine, 16*(5), 509-522.
- Khajuria, S., & Thomas, J. (1992). Traditional Indian beliefs about the dietary management of diabetes - An exploratory study of the implications for the management of Gujarati diabetics in Britain. *Journal of Human Nutrition and Dietetics, 5*(5), 311-321.  
doi:10.1111/j.1365-277X.1992.tb00170.x
- Kieffer, C. H. (1984). Citizen empowerment: A developmental perspective. *Prevention in Human Services, 3*(2-3), 9-36. doi:10.1300/J293vo3n02\_03
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *American Journal of Occupational Therapy, 45*(3), 214-222.
- Labonte, R. (1989a). Community and professional development. *Canadian Nurse, 85*(3), 22-28.
- Labonte, R. (1989b). Community empowerment: The need for political analysis. *Canadian Journal of Public Health, 80*(2), 87-91.
- Laverty, S. M. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods, 2*(3), 21-35.
- Lawton, J., Ahmad, N., Hallowell, N., Hanna, L., & Douglas, M. (2005). Perceptions and experiences of taking oral hypoglycaemic agents among people of Pakistani and Indian origin: A qualitative study. *British Medical Journal, 330*(7502), 1247.
- Lawton, J., Ahmad, N., Hanna, L., Douglas, M., & Hallowell, N. (2006). "I can't do any serious exercise:" Barriers to physical activity amongst people of Pakistani and Indian origin with type 2 diabetes. *Health Education Research Theory and Practice, 21*(1), 43-54.

- Lawton, J., Ahmad, N., Peel, E., & Hallowell, N. (2007). Contextualizing accounts of illness: Notions of responsibility and blame in white and South Asian respondents' accounts of diabetes causation. *Sociological Health Illness*, 29(6), 891-906.
- Leonard, V. W. (1994). A Heideggerian phenomenological perspective on the concept of person...Fundamental reason. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 43-64). Thousand Oaks, CA: Sage Publications, Inc.
- Lincoln, Y. S. (1995). Emerging criteria for quality in qualitative and interpretive research. *Qualitative Inquiry*, 1, 275-289. doi:10.1177/107780049500100301
- Liu, T. (2012). A concept analysis of self-efficacy among Chinese elderly with diabetes mellitus. *Nursing Forum*, 47(4), 226-235. doi:10.1111/j.1744-6198.2012.00282.x
- Long, T., & Johnson, M. (2000). Rigour, reliability, and validity in qualitative research. *Clinical Effectiveness in Nursing*, 4(1), 30-37. doi:http://dx.doi.org/10.1054/cein.2000.0106
- Lord, J., & Hutchison, P. (1993). The process of empowerment: Implications for theory and practice. *Canadian Journal of Community Mental Health*, 12(1), 5-22.
- Ludlow, A. P., & Gein, L. (1995). Relationships among self-care, self-efficacy and HbA1c levels in individuals with non-insulin diabetes mellitus (NIDDM). *Canadian Journal of Diabetes*, 19, 10-15.
- Macaden, L., & Clarke, C. L. (2006). Risk perception among older South Asian people in the UK with type 2 diabetes. *International Journal of Older People in Nursing*, 1(13), 177-181. doi:10.1111/j.1748-3743.2006.00026.x



- Mackey, S. (2005). Phenomenological nursing research: Methodological insights derived from Heidegger's interpretive phenomenology. *International Journal of Nursing Sciences*, 42(2), 179-186. doi:<http://dx.doi.org/10.1016/j.ijnurstu.2004.06.011>
- Madden, R. (2010). *Being ethnographic: A guide to the theory and practice of ethnography*. London, United Kingdom: Sage Publications, Inc.
- Malinowski, B. (1932). *The sexual life of savages in North-Western Melanesia: An ethnographic account of courtship, marriage and family life among the natives of the Trobriand Islands, British New Guinea* (3rd ed.). London, United Kingdom: Routledge & Kegan Paul Ltd.
- Marin, G., Balls Organista, P., & Chun, K. M. (2003). Current issues and findings in acculturation research. In G. Bernal, J. E. Trimble, F. T. L. Leong, & B. A. K. (Eds.), *Handbook of Ethnic Minority Psychology*. Thousand Oaks, CA.: Sage Publications.
- Maxwell, J. A. (1996). *Qualitative research design: An interactive approach (applied social research methods)*. Thousand Oaks, CA: Sage Publications, Inc.
- McAllister, A. L., Perry, C. L., & Parcel, G. S. (2008). How individuals, environmental, and health behaviors interact: Social cognitive theory. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health behavior and health education: Theory, research, and practice* (4th ed., pp. 169-188). San Francisco, CA: Jossey-Bass.
- McClelland, D. C. (1975). *Power: The inner experience*. New York, NY: Irvington Press.
- McEwen, M., & Wills, E. M. (2002). *Theoretical basis for nursing*. Philadelphia, PA: Lippincott, Williams & Wilkins.

- McKeigue, P. M., Shah, B., & Marmot, M. G. (1991). Relation of central obesity and insulin resistance with high diabetes prevalence and cardiovascular risk in South Asians. *The Lancet*, 337(8738), 382-386.
- McNeely, M. J., & Boyko, E. J. (2004). Type 2 diabetes prevalence in Asian Americans: Results of a national health survey. *Diabetes Care*, 27(1), 66-69.
- Mehrotra, N., Gaur, S., & Petrova, A. (2012). Health care practices of the foreign born Asian Indians in the United States. A community based survey. *Journal of Community Health*, 37(2), 328-334. doi:10.1007/s10900-011-9449-4
- Misra, R., Patel, T. G., Davies, D., & Russo, T. (2000). Health promotion behaviors of Gujuarti Asian immigrants in the United States. *Journal of Immigrant Health*, 2(4), 223-230.
- Misra, R., Patel, T. G., Kotha, P., Raji, A., Ganda, O., Banerji, M.,...Balasubramanyam, A. (2010). Prevalence of diabetes, metabolic syndrome, and cardiovascular risk factors in US Asian Indians: Results from a national study. *Journal of Diabetic Complications*, 24(3), 145-153. doi:10.1016/j.jdiacomp.2009.01.003
- Mohan, V., Deepa, M., Deepa, R., Shathirani, C. S., Farooq, S., Ganesan, A., & Datta, M. (2006). Secular trends in prevalence of diabetes and impaired glucose tolerance in urban South India - the Chennai urban rural epidemiology study. *Diabetologia*, 49(6), 1175-1178.
- Mohanty, S. A., Woolhandler, S., Himmelstein, D. U., & Bor, D. H. (2005). Diabetes and cardiovascular disease among Asian Indians in the United States. *Journal of General Internal Medicine*, 20(5), 472-478.
- Palaniappan, L., Wang, Y., & Fortmann, S. P. (2004). Coronary heart disease mortality for six ethnic groups in California, 1990-2000. *Annals of Epidemiology*, 14(7), 499-506.

- Pawluch, D., & Neiterman, E. (2010). What is grounded theory and where does it come from? In I. Bourgeault, R. Dingwall, & R. De Vries (Eds.), *The SAGE handbook of qualitative methods in health research* (pp. 174-193). London, United Kingdom: Sage Publications, Inc. doi:<http://dx.doi.org/10.4135/9781446268247.n10>
- Phinney, A., & Chesla, C. A. (2003). The lived body in dementia. *Journal of Aging Studies*, 17(3), 283-299. doi:10.1016/S0890-4065(03)00029-X
- Pieroni, A., Houlihan, L., Ansari, N., Hussain, B., & Aslam, S. (2007). Medicinal perceptions of vegetables traditionally consumed by South-Asian migrants living in Bradford, Northern England. *Journal of Ethnopharmacology*, 113(1), 100-110.
- Plager, K. A. (1994). Hermeneutic phenomenology: A methodology for family health and health promotion study in nursing. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 65-84). Thousand Oaks, CA: Sage Publications, Inc..
- Polkinghorne, D. E. (1988). *Narrative knowing and the human sciences*. Albany, NY: State University of New York Press.
- Prestby, J. E., Wandersman, A., Florin, P., Rich, R., & Chavis, D. (1990). Benefits, costs, incentive management and participation of voluntary organizations: A means to understanding and promoting empowerment. *American Journal of Community Psychology*, 18(1), 117-149.
- Raleigh, V. S., Kiri, V., & Balarajan, R. (1997). Variations in mortality from diabetes mellitus, hypertension and renal disease in England and Wales by country of birth. *Health Trends*, 28, 122-127.

- Ramachandran, A., Mary, S., Yamuna, A., Murugesan, N., & Snehalatha, C. (2008). High prevalence of diabetes and cardiovascular risk factors associated with urbanization in India. *Diabetes Care*, *31*(5), 893-898. doi:10.2337/dc07-1207
- Reeves, T. J., & Bennett, C. E. (2004). *We the people: Asians in the United States. Census 2000 special reports* (CENSR-17). Retrieved from the U.S. Census Bureau website: <http://www.census.gov/prod/2004pubs/censr-17.pdf>
- Resnick, B. (Ed.). (2004). *Self-efficacy* (2nd ed.). Philadelphia, PA: Lippincott, Williams & Wilkins.
- Rubin, R. R., Peyrot, M., & Saudek, C. D. (1989). Effect of diabetes education on self-care, metabolic control, and emotional well-being. *Diabetes Care*, *12*(10), 673-679.
- Sandelowski, M. (1993). Rigor or rigor mortis. The problem of rigor in qualitative research revisited. *Advances in Nursing Science*, *16*(2), 1-8.
- Sandelowski, M. (1994). Notes on transcription. *Research in Nursing and Health*, *17*(4), 311-314.
- Schwandt, T. A. (1994). Constructivist, interpretivist approaches to human inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 118-137). Thousand Oaks, CA: Sage Publications, Inc.
- Sheth, T., Nair, C., Nargundkar, M., Anand, S., & Yusuf, S. (1999). Cardiovascular and cancer mortality among Canadians of European, south Asian and Chinese origin from 1973-1993: An analysis of 1.2 million deaths. *Canadian Medical Association Journal*, *161*(2), 132-138.
- Simmons, D., & Williams, R. (1997). Dietary practices among Europeans and different South Asian groups in Coventry. *British Medical Journal of Nutrition*, *78*(1), 5-14.

- Sinha, S., Misra, P., Kant, S., Krishnan, A., Nongkynrih, B., & Vikram, N. K. (2013). Prevalence of metabolic syndrome and its selected determinants among urban adult women in South Delhi, India. *Postgraduate Medical Journal*, *89*(1048), 68-72. doi:10.1136/postgradmedj-2012-130851
- Sorrell, J. M., & Redmond, G. M. (1995). Interviews in qualitative nursing research: Differing approaches for ethnographic and phenomenological studies. *Journal of Advanced Nursing*, *21*(6), 1117-1122.
- Sousa, V. D., & Zauszniewski, J. A. (2005). Toward a theory of diabetes self-care management. *Journal of Theory Construction and Testing*, *9*(2), 61-67.
- South Asian Americans Leading Together. (2009). *Health care issues affecting South Asians in the United States*[Homepage]. Retrieved from <http://www.saalt.org/pages/About-the-South-Asian-Community.html>
- South Asian Americans Leading Together. (2010). *About the South Asian Community*[Homepage]. Retrieved from <http://www.saalt.org/pages/About-the-South-Asian-Community.html>
- Srivastava, R. (2002). South Asia's governments exhorted to focus on CVD. *The Lancet*, *359*(9309), 858.
- Stige, B., Malterud, K., & Midtgarden, T. (2009). Toward an agenda for evaluation of qualitative research. *Qualitative Health Research*, *19*(10), 1504-1516. doi:10.1177/1049732309348501
- Stone, M., Pound, E., Pancholi, A., Farooqi, A., & Khunti, K. (2005). Empowering patients with diabetes: A qualitative primary care study focusing on South Asians in Leicester, UK. *Family Practice*, *22*(6), 647-652.

- Strauss, A. L., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Los Angeles, CA: Sage Publications, Inc.
- Sturt, J., & Hearnshaw, H. (2002). *UK validation of the International Diabetes Self-Efficacy Scale (DSMES) and the Perceived Therapeutic Efficacy Scale (PTES)*. Coventry, United Kingdom: Centre for Primary Health Care Studies, University of Warwick.
- Taylor, C. (1991). *The ethics of authenticity*. Cambridge, MA: Harvard University Press.
- Thomas, E., & Magilvy, J. K. (2011). Qualitative rigor or research validity in qualitative research. *Journal for Specialists in Pediatric Nursing, 16*(2), 151-155.  
doi:10.1111/j.1744-6155.2011.00283.x
- Thorne, S. (2006). Patient-provider communication in chronic illness: A health promotion window of opportunity. *Family & Community Health, 29*(1, Suppl.), 4S-11S.
- UK Prospective Diabetes Study Group. (1998). Intensive blood-glucose control with sulphonylureas or insulin compared with conventional treatment and risk of complications in patients with type 2 diabetes (UKPDS 33). *The Lancet, 352*(9131), 837-853. doi:http://dx.doi.org/10.1016/S0140-6736(98)07019-6
- Unwin, N., Alberti, K. G., Bhopal, R., Harland, J., Watson, W., & White, M. (1998). Comparison of the current WHO and new ADA criteria for the diagnosis of diabetes mellitus in three ethnic groups in the UK. *Diabetic Medicine, 15*(7), 554-547.
- Valle, R. S., King, M., & Halling, S. (1989). An introduction to existential-phenomenological thought in psychology. In R. S. Valle & S. Halling (Eds.), *Existential-phenomenological perspectives in psychology: Exploring the breadth of human experience* (pp. 3-16). New York, NY: Plenum Press.

- van der Bijl, J. J., & Shortridge-Baggett, L. M. (2001). The theory and measurement of the self-efficacy construct. *Scholarly Inquiry for Nursing Practice, 15*(3), 189-207.
- van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. London, Ontario, Canada: Althouse Press.
- van Manen, M. (1997). From meaning to method. *Qualitative Health Research, 7*(3), 345-369.  
doi:10.1177/104973239700700303
- Venkataraman, K., Kannan, A. T., Kalra, O. P., Ghambir, J. K., Sharma, A. K., Sundaram, K. R., & Mohan, V. (2012). Diabetes self-efficacy strongly influences actual control of diabetes in patients attending a tertiary hospital in India. *Journal of Community Health, 37*(3), 653-662.
- Venkataraman, R., Nanda, N. C., Baweja, G., Parikh, N., & Bhatia, V. (2004). Prevalence of diabetes mellitus and related conditions in Asian Indians living in the United States. *American Journal of Cardiology, 94*(7), 977-980.
- Venkatesh, S., & Weatherspoon, L. J. (2013). Social and health care provider support in diabetes self-management. *American Journal of Health Behavior, 37*(1), 112-121.  
doi:10.5993/AJHB.37.1.13
- Venkatesh, S., Weatherspoon, L. J., Kaplowitz, S. A., & Song, W. O. (2013). Acculturation and glycemic control of Asian Indian adults with type 2 diabetes. *Journal of Community Health, 38*(1), 78-85. doi:10.1007/s10900-012-9584-6
- Vyas, A., Chaudhary, N., Ramiah, K., & Abbasi, S. (2010, May). *SAHNA 2010: A South Asian health needs assessment of the Washington, D.C. region*. Retrieved from the George Washington University, School of Public Health and Health Services website:  
<http://publichealth.gwu.edu/staticfile/SPHHS/SAHNA%202010.pdf>

- Vyas, A., Haidery, A. Z., Wiles, P. G., Gill, S., Roberts, C., & Cruikshank, J. K. (2003). A pilot randomized trial in primary care to investigate and improve knowledge, awareness and self-management among South Asians with diabetes in Manchester. *Diabetic Medicine*, *20*(12), 1022-1026.
- Walker, L. O., & Avant, K. C. (2004). *Strategies for theory construction in nursing* (4th ed.). Upper Saddle River, NJ: Pearson/Prentice Hall.
- Whitmore, E., & Kerans, P. (1988). Participation, empowerment and welfare. *Canadian Review of Social Policy*, *22*, 51-60.
- Whittemore, R., Chase, S. K., & Mandle, C. L. (2001). Validity in qualitative research. *Qualitative Health Research*, *11*(4), 522-537.
- Wilson, H. S., & Hutchinson, S. A. (1991). Triangulation of qualitative methods: Heideggerian hermeneutics and grounded theory. *Qualitative Health Research*, *1*(2), 263-276.  
doi:10.1177/104973239100100206
- Wu, S. F., Courtney, M., Edwards, H., McDowell, J., Shortridge-Baggett, L. M., & Chang, P. J. (2007). Self-efficacy, outcome expectations and self-care behaviour in people with type 2 diabetes in Taiwan. *Journal of Clinical Nursing*, *16*(11C), 250-257.



# Diabetes and Asian Indians

## University of California

Did you know that:

Asian Indians have a **higher prevalence of diabetes** as compared to any other ethnic minority in the US.

In 2030, Asian Indians will have the **highest prevalence of diabetes in the world.**

**1 in 6** Asian Indian has diabetes in the US and develop it **10 years earlier** than other groups.

Asian Indians **die younger** from cardiovascular complications.

Dr. Catherine Chesla and Rupinder Deol from UCSF are studying Asian Indians with diabetes in order to gain understanding of the challenges Asian Indians with diabetes face in achieving control.

If you are an Asian Indian over the age of 18; diagnosed with diabetes and been in the United States for at least 6 months, you may be eligible to participate in this study. Participation is strictly voluntary. If you are interested in participating in this study, please contact Ms. Deol at (916) 765-4348. Participants will be compensated with \$20 per interview.

Contact Rupinder Deol

University of California, San Francisco

## **Diabetes and the Asian Indians – A lived experience**

### **Consent to take part in a Research Study**

**Study Title:** Diabetes and the Asian Indian – a lived experience.

Dr. Catherine Chesla, PhD and Rupinder Deol, RN, GNP and a doctoral student from the Department of Family Health Care Nursing, University of California, San Francisco are studying the experiences and meanings of diabetes in Asian Indians.

#### **Participation in this study is voluntary.**

Research studies include people who choose to participate in them. You are being chosen to participate in this study due to your experience as being an Asian Indian with type 2 diabetes. You may choose to participate in this study or you may choose not to participate in this study after you have started. Please take your time to make your decision. If you have any questions you may ask Rupinder Deol.

#### **Why is this study being done?**

The purpose of this study is to better understand the meaning and experiences of Asian Indians with type 2 diabetes. The study seeks to answer the questions: What is the meaning and experience of having type 2 diabetes in the Asian Indians? This study is not being financially supported through personal funds of the PI. This study will serve as the foundation for a larger study that will study the experiences of Asian Indians with type 2 diabetes.

#### **How many people will take part in this study?**

The research will be interviewing 15-20 people.

#### **What will happen if I take part in this study?**

If you agree to take part in this study, the following will occur:

- You will be asked to fill out a sheet with some personal information.
- You will meet with Ms. Deol at a location that will provide privacy and comfort and take part in a private interview. You will be asked to describe your experiences with your diabetes and your feelings about those experiences. This interview will take no longer than 90 minutes.

- A second or third interview may be necessary to clarify information about the first interview. The second or third interview should not take longer than 90 minutes.
- All interviews will be tape recorded, and transcribed into a computer. Once the transcription has been reviewed and compared to the audio recording, all the names will be removed and recordings will be erased at the end of the study.
- Ms. Deol will also be making hand written notes to record her observations and thoughts during the study. These notes will remain confidential.
- All of these procedures will be done at a location that is **mutually** agreed upon between you and the researcher. The location will provide for privacy, comfort and safety for **you and Ms. Deol.**

### **How long will I be in the study?**

Participation in the study will take a total of about 1 – 3 hours over a period of one to three interviews.

### **Can I stop being in the study?**

Yes, you can decide to stop being in the study at any time. Just tell the study researcher right away if you no longer want to be in the study.

### **What risks can I expect from being in the study?**

The interview will require you to remember past experiences, which may be difficult to recall. Some questions may make you uncomfortable, but you are free to not answer any questions that you do not want to answer.

### **Are there any benefits to taking part in the study?**

There is no direct benefit to you from participating in the study, but results from the study may help the researchers and other health care providers to better understand the experiences of South Asians with diabetes.

### **What other choices do I have if I do not want to part in the study?**

You are free to choose not to participate in the study. There will be no penalty to you if you choose not to participate.

### **Will information about me be kept private?**

We will do our best to keep your personal information private, but total privacy cannot be guaranteed. If information of this study is presented in or published at scientific meetings, your name or personal information will not be used.

**What are the costs of taking part in the study?**

There will be no costs to you for taking part in this study.

**Will I be paid for taking part in this study?**

In return for your time, effort and travel expenses you will be paid \$20.00 per interview for taking part in the study, **the maximum payment will be \$60.00**. You will be paid in cash, immediately following the completion of each interview.

**What are my rights if I take part in this study?**

Taking part in this study is your choice. You also have the choice to leave the study at any time.

**Who can answer my questions about the study?**

You may talk to the researchers, about any questions, concerns, or complaints, you have about this study. Contact the researchers Rupinder Deol at (916) 765-4348 or Dr. Catherine Chesla at (415) 476-4439.

If for any reason you do not wish to talk with the researchers, or have further concerns, you may contact the office of the **Committee on Human Research**, UCSF's Institutional Review Board (a group of people who review research procedures to protect your rights). You can reach them at the CHR office at (415) 476-1814 (8am-5pm, Monday through Friday) or by writing to Committee on Human Research, Box 0962, University of California, San Francisco, San Francisco, CA 94143.

**CONSENT**

You have been given a copy of this consent form to keep.

**PARTICIPATION IN THIS STUDY IS VOLUNTARY.** You have the right to decline to be in this study or to withdraw from it at any point without penalty. If you wish to participate in this study, you should sign below.

---

Date

---

Date

---

Participant's Signature for consent

---

Person Obtaining Consent

University of California, San Francisco

**Diabetes in Asian Indians– A Lived Experience**

**Demographic Information Sheet**

Pseudonym: \_\_\_\_\_ Country of Origin: \_\_\_\_\_ Age: \_\_\_\_\_

Gender: Male/Female Marital Status: \_\_\_\_\_ Religion: \_\_\_\_\_

Language spoken during interview: \_\_\_\_\_ At home: \_\_\_\_\_

Number of people living at home: \_\_\_\_\_ Generational Status: \_\_\_\_\_

Years in the US: \_\_\_\_\_ Age at Immigration: \_\_\_\_\_ Formal Education: \_\_\_\_\_

Years since diagnosis of diabetes: \_\_\_\_\_

**Current Medications:**

---

---

---

---

---

---

---

---

Diet: \_\_\_\_\_ Who is the primary cook in the home: \_\_\_\_\_

Exercise: \_\_\_\_\_

Self-Reported Hemoglobin A1C: \_\_\_\_\_ Date measured: \_\_\_\_\_

Self-Reported Weight \_\_\_\_\_ Self-Reported Height: \_\_\_\_\_

Last MD appointment: \_\_\_\_\_

University of California, San Francisco

## **Diabetes in the Asian Indians – A Lived Experience**

### Interview Guide

Before we begin with the interview I would like to thank you for agreeing to participate in this study and to remind you of the purpose of this study. I am interested in understanding the experiences of having diabetes in the Asian Indians. Is there anything that you would like to ask me before we begin?

1. To start with, tell me a little bit about yourself?
  - How long have you lived in the United States?
  - What made you come to the US? (work, education, marriage)
  - Where are you from, what part of India?
  - Do you live with your family? Who is your family?
  
2. Tell me how you found out that you had diabetes?
  - Did you know that something different was going on with your physical health? What type of symptoms were you having?
  - What made you seek medical help?
  - Can you tell me how you learned of the diagnosis?
  - Why do you think you got diabetes? Or what caused it?
  - Tell me about your thoughts and feelings about being diagnosed with diabetes?
  
3. What does it mean to you to have diabetes?
  - Are you sick? How are you managing?
  - What types of foods, medication, and lifestyle changes have you made since you were diagnosed with diabetes?
  - How do you evaluate how you are doing with diabetes?
  - Do you feel you have a good handle/control on it?
  
4. What aspects of your life have changed since you were diagnosed with diabetes?
  - What are some new things that you do because of your diabetes? (Food, medications and lifestyle).
  - How has it affected your family life, social life, and interacting with your friends or family?

- Has it made a difference in religious practices, cultural events or social events?
  - Is there anything else that you have changed?
5. Please think about the things you do every day to manage your diabetes. Please tell me a story about a time or instance when caring for your diabetes that was problematic or trying?
- What led up to this situation?
  - What did you do? Were there things that you considered doing but rejected?
  - How did what you did change the situation? How did it impact others?
  - Did your action change your feelings about the situation?
  - Looking back on it now, how do you think things turned out?
  - Looking back on it now, is there anything you would do differently?
  - Is there anything else about this situation that you think I should know about, something my questions haven't covered?
6. Now think about a time when caring for your diabetes was straightforward or easy, or when something challenged you but you felt quite successful. Please tell me the story of what happened.
- What led up to this situation?
  - What did you do? Were there things that you considered doing but rejected?
  - How did what you did change the situation? How did it impact others?
  - Did your action change your feelings about the situation?
  - Looking back on it now, how do you think things turned out?
  - Looking back on it now, is there anything you would do differently?
  - Is there anything else about this situation that you think I should know about, something my questions haven't covered?
7. As you look back, is there anything that you would change about your experience? Where there certain things that might have helped you care of your diabetes better?
- Was your family supportive?

- Did immigration to the US make it difficult or easier to manage your experience?
  - What about the health care system (doctors, nurses, etc.) how did that influence your experience?
  - Would it have been different if you were in India?
8. Compared to other ethnicities how is it different being an Asian Indians with diabetes than other ethnicities? How so?
- Do you feel that you have experience discrimination in your care because you are Asian Indian?
  - Or has your care been comprised by your race?
9. After your experience, is there anything that you would tell someone who has recently been diagnosed with diabetes? Especially the future generation?
10. Before we end today, is there anything that we haven't talked about that you would like to talk about? Or bring up?
11. Is there anything you want to ask me about the interview/questions?

Thank you again for sharing your experiences with me.

(If appropriate the interviewer will set up a time for the next interview).



**GLOSSARY**

Ajwain:	Bishop weed.
Atta:	Whole wheat flour commonly used to make chapattis, parathas and puris.
Bajra:	Pearl millet, grounded into flour.
Barfi:	Dense milk based sweet Indian confectionary. The main ingredients of barfi include condensed milk and sugar.
Besan:	Gram flour, made out of dried chick peas or a sweet snack.
Chana:	Chick pea or garbanzo beans.
Dahl:	A variety of lentils or thick lentil soup.
Dosa:	Fermented crepes made out of black de-husked lentils and rice.
Gulab jamman:	Traditional milk solid dessert, served with sweet syrup.
Idli:	Savory cakes made out of black de-husked lentils and rice batter.
Jalebi:	Deep fried wheat flour pretzels which are soaked in sugar. Usually served at festive and religious events.
Jeera:	Cumin.
Ladoo	Sweet gram flour rolled into a ball. Symbolizes good will and luck.
Kichidi:	Rice and lentil mixture.
Methi:	Fenugreek.
Missi roti:	Chapatti made of a blend of flours with herbal additives such as ajwain, coriander leaves and onion.
Pakorاس:	Fried fritters, usually potatoes, peas and spinach.
Parantas:	Pan fried Indian bread, usually stuffed with potatoes.
Pinea:	Flour roasted with sugar, nuts, butter and herbs.
Puri:	Unleavened deep fried bread.
Roti:	Flat bread, made from stoneground whole wheat flour.
Saro:	Mustard leaves.
Sauf:	Fennel seed.

Semia: Noodles, served either sweet or salty.

Tharka: Base for Indian cooking, contains oil, onions, tomatoes, garlic, ginger, chili and spices.

Upma: Thick porridge made out of dry roasted semolina or rice flour.

**Publishing Agreement**

It is the policy of the University to encourage the distribution of all theses, dissertations and manuscripts. Copies of all UCSF theses, dissertations, and manuscripts will be routed to the library via the Graduate Division. The library will make all theses, dissertations and manuscripts accessible to the public and will preserve these to the best/of their abilities, in perpetuity.

I hereby grant permission to the Graduate Division of the University of California, San Francisco to release copies of my thesis, dissertation, or manuscript to the Campus Library to provide access and preservation, in whole or in part, in perpetuity.

Rupinder K. R. J.

12/15/15  
Date