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Nia Aitaoto
University of Iowa

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PACIFIC CULTURE AND TYPE 2 DIABETES:
FORMATIVE RESEARCH TO INFORM INTERVENTIONS
TO IMPROVE GLYCEMIC CONTROL AMONG PACIFIC ISLANDERS

by

Nia Aitaoto

An Abstract

Of a thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Community and Behavioral Health (Health Communication) in the Graduate College of The University of Iowa

May 2013

Thesis Supervisor: Associate Professor Michelle L. Campo
The type 2 diabetes (T2DM) epidemic is a global health issue that is especially severe among Pacific Islanders in the United States (U.S.) and U.S. Associated Pacific Islands (USAPI) including Chuukese living in their homeland of Chuuk and the state of Hawaii. Although there are diabetes prevention and management programs in Hawaii and the Pacific, success is limited due in part to the lack of tailoring for the Pacific audience. In spite of numerous recommendations to incorporate Pacific cultural constructs into health interventions, there are no studies in Chuuk or the Pacific that examine the integration of cultural constructs into diabetes prevention and management. To address this research need, the four studies in this dissertation used Grounded Theory and Community Based Participatory Research (CBPR) processes to explore the relationships between constructs such as culture, religion, family, and diabetes prevention and control. The aims were to obtain perspectives on diabetes prevention, screening and management (Study 1) and identify socio-cultural influences that hinder or facilitate adherence to diabetes prevention and management behaviors specifically adherence to nutrition therapy (Study 2), physical activity (Study 3) and prescription medication (Study 4). Data gathered through key informant interviews (faith leaders and health care providers) and focus group discussions (individual with diabetes and caretakers).

Results from Study 1 showed that participants perceived T2DM as a major problem and the discussion followed four significant narratives: (1) the need for specific information on “how to” operationalize diabetes treatment recommendations; (2) the practice of seeking medical help only when in pain; (3) the role spirituality plays in etiology disease beliefs and its influence on help-seeking behaviors; and (4) the role emotions play in treatment compliance. Study 2 revealed barriers to nutrition therapy adherence that were similar to other minority populations in the U.S. such as cost of
healthy foods, taste preference, low availability of healthy food choices, lack of ideas for healthy meals/cooking, and lack of culturally appropriate nutrition modification options. It also elucidated: (1) food consumption and preparation practices; (2) the need for culturally tailored interventions; and (3) contextually appropriate approaches to address nutrition issues, including a plan for future research and interventions. Study 3 revealed a variety of behaviors, personal factors and environmental influences related to adherence to physical activity recommendations. Although the study was focused on physical activity, participants spent the majority of their time discussing sedentary behaviors and contextually appropriate interventions. Study 4 exposed vital factors that inclined patients’ to comply with prescribed medication. Factors associated with the healer (messenger), medicine/remedy, and focus of healing. Furthermore, this study revealed that many patients not only seek multiple healing types (western, traditional, local and new), they also rotate among the types. These findings were communicated through two narratives: healer characteristics and medication-specific features. Overall, the most salient topics in all the focus group and interview discussions were on diabetes as a major problem and the pervasiveness of hopelessness. Woven into these conversations were narratives on how to address these two issues with stewardships of the spirit, mind and body. This became the foundation of a framework to address the diabetes epidemic in Pacific.

Abstract Approved: ____________________________________________

Thesis Supervisor

__________________________________________

Title and Department

__________________________________________

Date
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TO IMPROVE GLYCEMIC CONTROL AMONG PACIFIC ISLANDERS 

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The University of Iowa 

May 2013 

Thesis Supervisor: Associate Professor Michelle L. Campo
Graduate College
The University of Iowa
Iowa City, Iowa

CERTIFICATE OF APPROVAL

PH.D THESIS

This is to certify that the Ph.D thesis of

Nia Aitaoto

has been approved by the Examining Committee
for the thesis requirement for the Doctor of Philosophy
degree in Community and Behavioral Health (Health Communication) at
the May 2013 graduation

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Edith A. Parker

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Linda Snetselaar
To Salilo-i-manatu
ACKNOWLEDGEMENTS

This community research project is reminiscent of a long journey through a peaceful but sometimes tempestuous ocean. Although this project did not launch this expedition nor will it be the last voyage, it did provide passage through unchartered territories. Thus, I would like to express my sincere gratitude to those who were brave enough to be part of this journey. First and foremost, I would like to thank God for His Love and Faithfulness. His promises and Spirit sustained me through the raging winds and roaring seas.

I would also like to thank the University of Iowa, Department of Community and Behavioral Health for providing a sturdy canoe. *Kinisow Chapwur* to Chuuk Women’s Council and my sisters Kiki Stinnett, Grace Serious and Nely Ruben for supporting the crew on Weno Island. *Mahalo Piha* to Micronesians United, Reverend Sekap & Sophie Esah, Julia Estrella and Aritae Epeluk for letting us anchor on Oahu. *Salamat po* to JoAnn Tsark and `Imi crew for supplying the escort boat. *Kommol* to my Pacific Chronic Disease Coalition family, we started this journey together and with God’s grace we will continue the course as we carry with us the dreams and hope of our people. *Si Yu’us ma’ase* to Father Ryan Jimenez and Tayna Belyu-Camacho, for when the wind dies I could always count on you both to pick up the paddles.

I also owe so much to my advisors Drs. Karen Farris, Kathy Janz, Edith Parker, Linda Snetselaar and especially my thesis supervisor, Dr. Michelle (Shelly) Campo. Words can’t express how grateful I am for your wisdom, expertise and *aloha*! Last but not least, is a word of *Fa ’afetai Tele Lava* to my *aiga* for your prayers, love and support - *malo le tapuai*!
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CHAPTER 1
TYPE 2 DIABETES AND THE PACIFIC CULTURE

Introduction

The type 2 diabetes (T2DM) epidemic is a global health issue that is especially severe in the United States Associated Pacific Islands (USAPI) including the Federated States of Micronesia’s (FSM) Chuuk State (Hosey et al., 2009). The USAPI rates ranged from 29.8% in the Republic of the Marshall Islands (RMI) to 47.3% in American Samoa (World Health Organization [WHO], 2002; 2007), which is much higher than the US rate of 7.8% (Centers for Disease Prevention and Control [CDC], 2007). Pacific Islanders living in the U.S also face a greater burden of diabetes as compared to the U.S general population as 18.3% have diabetes (Kanaya et al., 2011). Although there are diabetes prevention and management programs in Hawaii and the Pacific, success is limited due in part to the lack of tailoring for the Pacific audience (Braun et al., 2003). In spite of numerous recommendations to incorporate Pacific cultural constructs into health interventions (Davidson-Rada, 1999; Fong, Braun & Tsark, 2003; Hurst & Nader, 2006), there are no studies in the Pacific that examine the integration of cultural constructs into diabetes prevention and management.

To address this critical need for culturally appropriate programs and interventions, this formative research was conducted with one of the Pacific Island ethnic groups (Chuukese) living in their homeland (Chuuk) and migrants to the state of Hawaii. The research design was informed by the Grounded Theory and Community Based Participatory Research (CBPR) principles. In addition, Social Cognitive Theory was utilized to sensitize the research topic or used as a tentative tool to develop and organize ideas during the initial phase, one of the vital steps in the Grounded Theory methodology (Charmaz, 2006). The aims were to obtain perspectives on diabetes prevention, screening and management (Study1) and identify socio-cultural influences that hinder or
facilitate adherence to diabetes prevention and management behaviors specifically adherence to nutrition therapy (Study 2), physical activity (Study 3) and prescription medication (Study 4). These studies were also part of the Faith in Action Research Alliance’s (FARA) research project funded by the National Institutes of Health (R21 MD005975). The findings informed the development of a culturally based conceptual framework that will assist in the design of future glycemic control interventions. Given the lack of information and research on Pacific Islanders, preliminary data were collected using qualitative research methods (Table 1).

Table 1. Study Design.

<table>
<thead>
<tr>
<th>Study Design</th>
<th>Nutrition Therapy</th>
<th>Physical Activity</th>
<th>Prescription Medication</th>
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<tbody>
<tr>
<td>Faith Leader In-person Interviews</td>
<td>Chuuk</td>
<td>Chuuk</td>
<td>Chuuk</td>
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<tr>
<td>Health Care Providers In-person Interviews</td>
<td>Chuuk</td>
<td>Chuuk</td>
<td>Chuuk</td>
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<td>Community Focus Groups</td>
<td>Chuuk</td>
<td>Chuuk</td>
<td>Chuuk</td>
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<tr>
<td></td>
<td>Hawaii</td>
<td>Hawaii</td>
<td>Hawaii</td>
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</tbody>
</table>

Faith leaders and health care providers in Hawaii and Chuuk were interviewed in person (summer of 2011) to obtain their perspective, experience and actions regarding diabetes prevention, screening and management. Community focus groups were conducted in Chuuk (Fall 2011) and Hawaii (Winter 2011) for individuals with diabetes and caregivers to obtain their perspective, experience and actions (Table 1).

This research was significant for several reasons. First, it provided information to inform intervention for Chuukese in Chuuk and Hawaii, as the two sites are vastly different (Table 2). Second, it contributed to the understanding of the relationship between constructs such as culture, spirituality, religiosity and diabetes management.
Third, it informed nutrition, physical activities and drug adherence interventions to improve glycemic control for Chuukese and other Pacific Islanders. Finally, it addressed the increasing burden of diabetes among Chuukese in Chuuk and Hawaii.

Table 2. Characteristics of Pacific Islanders in Chuuk and Hawaii.

<table>
<thead>
<tr>
<th></th>
<th>Chuuk</th>
<th>Hawaii</th>
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<tbody>
<tr>
<td>Residence Status</td>
<td>Natives</td>
<td>Migrants</td>
</tr>
<tr>
<td>Ethnic group composition</td>
<td>Majority</td>
<td>Minority</td>
</tr>
<tr>
<td>Health Issue</td>
<td>Limited Health Services</td>
<td>Limited Access to Services</td>
</tr>
<tr>
<td>Provider issue</td>
<td>No Specialists (e.g., registered dietician, etc.)</td>
<td>Specialists do not speak any of the Pacific Island languages</td>
</tr>
</tbody>
</table>

This chapter includes: (1) an overview of T2DM and its burden among Pacific Islanders; (2) the vital role culture, spirituality and religiosity plays in lives of Pacific Islanders; and (3) a description of guiding theoretical principles.

**Burden of Diabetes**

T2DM is a chronic disease with multiple risk factors and complications that is disproportionately affecting Pacific Islanders including Chuukese living in their homeland of Chuuk and migrants to the State of Hawaii. Individuals with T2DM either cannot produce enough insulin or are not capable of using insulin effectively to process the glucose in the bloodstream (CDC, 2007). Millions of Americans have been diagnosed and many more are undiagnosed. In Chuuk, the prevalence rate of diabetes is 35.4%, which is four times higher than the U.S diabetes rate of 7.8% (Federated States of Micronesia, Department of Health and Social Affairs [FSM DHSA], 2012). A healthcare system assessment revealed diabetes as the leading cause of death and 40% of all deaths was attributed to diabetes and its related co-morbidities (septicemia, myocardial...
infarction, cerebrovascular disease, hypertension) in Chuuk (Ichihó, Shomour, Marar, Lippwe & Aitaoto, 2013). There is limited data on the burden of diabetes among Pacific Islanders including Chuukese living in Hawaii but anecdotal evidence suggests that there are significant problems of obesity, diabetes, and cardiovascular diseases (Kaholokula, Saito, Mau, Latimer & Seto, 2008). In the state of Hawaii, the top three reasons for Micronesian patients to visit Community Health Centers are hypertension, diabetes and pre-natal care (Pobutsky, Buenconsejo-Lum, Chow & Maskarinec, 2005).

Diabetes Risk Factors

Several risk factors have been known to increase the likelihood of developing T2DM including being over the age 45, having an impaired glucose tolerance and/or impaired fasting glucose, obesity, engaging in a minimally physically active lifestyle, having a family history of diabetes, being a member of certain racial and ethnic groups (e.g., Non-Hispanic Blacks, Hispanic/Latino Americans, Asian Americans and Pacific Islanders, and American Indians and Alaska Natives) and having low HDL cholesterol or high triglycerides, and high blood pressure. In addition, women who had gestational diabetes, or who have had a baby weighing nine pounds or more at birth are at higher risk of developing T2DM (American Diabetes Association [ADA], 2011).

In assessing behavioral and physical risk factor data for diabetes in Chuuk, the *Federated States of Micronesia (Chuuk): Non-Communicable Disease Risk Factors STEPS Report* (FSM DPHS, 2012) data showed that 63% reported low-levels of physical activity (< 600 Metabolic Equivalent of Task [MET]-minutes/week) a much higher rate than that of the U.S at 16% (Bauman et al., 2009); 77% are overweight or obese compared to 73% in the US (Ogden & Carroll, 2010); and 90% consume less than five servings of fruits and vegetables per day. In addition, the *STEPS Report* summed five important risk factors (current smokers, overweight [BMI ≥25 kg/m²], raised blood pressure [systolic blood pressure ≥140 and/or diastolic blood pressure ≥90 mmHg or currently on medication], consumed less than five combined serving of fruits and
vegetables per day, and low levels of physical activity (< 600 MET minutes per week) to indicate the overall risk for non-communicable diseases categorized as Low Risk (0 risk factors), Moderate Risk (1 or 2 risk factors) and High Risk (3 or more risk factors). As a result 62.4% of the population are at high risk, 36.6% are at moderate risk and 1.0% are low risk. More information on nutrition and physical activities are included in Chapters 4 and 5 respectively.

Diabetes Complications and Co-morbid Conditions

According to the Centers for Disease Prevention and Control (2007), numerous complications may arise from uncontrolled T2DM. Adults with diabetes have heart disease death rates about two to four times higher than adults without diabetes. Similarly, the risk for stroke is two to four times higher among people with T2DM. Data shows that T2DM is the leading cause of kidney failure, accounting for 44% of all new cases in 2008. Moreover, about 60-70% of people with diabetes have mild to severe forms of nervous system damage resulting in impaired sensation or pain in the feet or hands, slowed digestion of food in the stomach, carpal tunnel syndrome, erectile dysfunction, or other nerve problems. Almost 30% of people with diabetes aged 40 years or older have impaired sensation in the feet (i.e., at least one area that lacks feeling) and severe forms of diabetic nerve disease are a major contributing cause of lower-extremity amputations. Diabetes is also the leading cause of new cases of blindness among adults aged 20–74 years.

People with diabetes are more susceptible to many other illnesses or functional deficits and once they acquire these illnesses, they often have worse prognoses (CDC, 2007). For example, they are more likely to die with pneumonia or influenza than people who do not have diabetes. In addition, people with diabetes aged 60 years or older are two-to-three times more likely to report an inability to walk one-quarter of a mile, climb stairs, or do housework compared with people without diabetes in the same age group. People with diabetes are also twice as likely to have depression as people without
diabetes. Overall, the risk for death among people with diabetes is about twice that of people of similar age without diabetes (CDC, 2007).

In addition to the complications of T2DM, there are several co-morbid conditions that may need to be concurrently managed including atherosclerosis, hypertension, renal disease, and obesity (Handelsman et al., 2011). There are also co-morbid psychological conditions that require special care in diabetes management. T2DM is often a difficult diagnosis to accept due to its chronic nature and the lifestyle adjustment required for treatment (Rubin & Peyrot, 2001). A meta-analysis study by deGroot and colleagues (2001) showed a significant relationship between depression and diabetes-related complications. They found that as severity of depression increases, the more likely individuals develop complication, experience a greater number of complications and develop more severe complications. Sacco and colleagues (2005) suggested that depression in people with diabetes is the result of decreased feelings of self-efficacy in terms of attainment of treatment goals. Moreover, those with T2DM reported decreased levels of well-being and sense of contentment when compared to non-diabetic depressed individuals (Petersen, Iosifesco, Papakostas, Shear & Fava, 2006).

There is limited data on diabetes complications among Pacific Islanders including Chuukese. A review of the Chuuk State Hospital’s surgery logbook by Ichiho and colleagues (2013) revealed an upward trend of lower limb surgical debridement, disarticulation and amputations performed between 2004 and 2006. However, in 2007 the trend reversed and it continued to move downward (Table 3).

<table>
<thead>
<tr>
<th></th>
<th>2004</th>
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<td>Debridement</td>
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<td>9</td>
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</table>
This pattern can be explained by the implementation of the Pacific Diabetes Education Program (PDEP) that was introduced in the fall of 2006. PDEP partnered with the Chuuk Diabetes Prevention and Control Program and the Chuuk Women’s Council (CWC) in developing culturally and linguistically appropriate educational materials and training curriculum on foot care. In addition, the CWC provided outreach to communities in Chuuk including outer islands (Ichiho et al., 2013). There is no comparable data available in Hawaii as they aggregate all Pacific Island data.

There is no renal dialysis service available in Chuuk State and off island referral for dialysis service is not covered by the Chuuk State Health Plan, therefore, patients that require renal dialysis obtain these services off island and on their own expenses. Because these services are self-referred, there are no data on the number of patients who received dialysis services (Ichiho et al., 2013). There is no comparable data available in Hawaii as they aggregate all Pacific Island data.

Diabetes Treatment

The main goal of diabetes treatment is for patients to attain glycemic control. Physicians utilize a stepwise diabetes management approach to assist their patients in achieving this goal (Warren, 2004). Lifestyle modification is the first line of treatment. This includes medical nutrition therapy and increased physical activity. Although this seems like the most basic and least expensive approach to diabetes management, it is often difficult for patient to implement and maintain, as it requires a considerable amount of motivation and commitment in addition to environmental, economical and social support. If patients are not able to achieve glycemic control through lifestyle changes then physicians will prescribe an oral anti-hyperglycemic agent. If glycemic control is not achieved after the second step then physicians will prescribe a combination of therapy with multiple anti-hyperglycemic agents. If glycemic control is not achieved after the third line of treatment then physicians will prescribe insulin as a primary means or treatment or in combination with an anti-hyperglycemic agent. The American Diabetes
Association (ADA, 2011), American Association of Clinical Endocrinologists (Handelsman et al., 2011), and the International Diabetes Foundation (IDF) Clinical Guidelines Task Force (IDF, 2005) are in agreement with steps to manage diabetes and released guidelines to facilitate the implementation of the aforementioned steps.

An assessment of Chuuk’s healthcare system found numerous gaps in the infrastructure and coordination of services (Ichiho et al., 2013). Screening services are provided upon request by patients who meet the following criteria: family history of diabetes, symptoms of diabetes, and over eighteen years of age. These screening services are provided in a variety of settings including public health clinics, worksites, community centers and churches. Patients who are screened positive are referred to the public health diabetes clinic for a follow-up fasting blood sugar and diagnostics. The 2001 Guidelines for the Prevention and Management of Diabetes in the Federated States of Micronesia provide the criteria for the diagnosis of diabetes (Ichiho et al., 2013).

The Chuuk State Hospital Outpatient Clinic and the Public Health Diabetes Clinic, provided treatment and management services for patients with diabetes. There was no common set of policies and procedures or standards to provide the guidance to assure that the services that the patients are receiving are consistent, comprehensive, and high quality. There were also major issues in the system of clinical services in that screening, diagnosis, treatment and management services are not coordinated among the multiple sites that provide these services – the Public Health Diabetes Clinic, the Chuuk State Hospital outpatient department, and the private providers in the community (Ichiho et al., 2013).

**Pacific Context**

Pacific Islanders find the Western medical model approach to health incomplete as it is limited to physical health (Aitaoto, Braun, Dang & Soa, 2007; Capsick, Norris, Sopoaga & Tobata, 2009; Hosey et al., 2009; Norris, Faalau, Vaai, Churchward & Arroll, 2009). Pacific Islander’s views are akin to the American Holistic Medicine Society’s
view that disease is a result of physical, emotional, spiritual, social and environment imbalance. To that end, it is important to consider the Pacific context in health research and interventions: The Pacific context is inclusive of (1) environment, political and economic situation; (2) historical (pre-contact, colonial and post-colonial) background; (3) cultural practices; and (4) spiritual orientation.

Environmental, Political and Economic Context

This research project was conducted in the Federated States of Micronesia’s Chuuk State and the State of Hawaii. The two sites represent two distinct communities: Pacific Islanders living in their homeland (natives) and Pacific Islanders living in the U.S fifty states (migrants). There are significant differences between the two communities (Table 2) and in order to develop interventions that are appropriate for both environments, it was necessary to conduct a study in Chuuk and the U.S.

Federated State of Micronesia: Chuuk State

The State of Chuuk is one of the four states of the Federated States of Micronesia (FSM), a sovereign island nation with a compact of free association (COFA) with the U.S. It has three geographic areas, the administrative center of the state on the island of Weno (formerly Moen), the islands of the Chuuk Lagoon, and the islands of the outlying atolls. The majority of the population (estimated at 48,651 in 2010) resides in Weno and the 15 islands of the Chuuk Lagoon. Because of the vast expanse of water between islands, travel within the State of Chuuk is difficult. Within the lagoon, travel by boat from Weno to any of the other islands will take from 1.5 hours to 2 hours. Access to the outer islands is even more difficult with travel times on a cargo ship taking up to two days (Central Intelligence Agency [CIA], 2013).

Chuuk has been colonized by Spain (1885), Germany (1898) and Japan (1914). At the end of WWII, the U.S. military occupied Chuuk and other Micronesian islands. In 1947, the United Nations placed the islands into a strategic trust with the U.S. and established the region as the Trust Territory of the Pacific. The U.S. Department of
Interior served as administrators and assisted in the post war reconstruction and development of the islands. However, minor improvements in health and education transpired. The Trust Territory of the Pacific Islands era did initiate nuclear weapon testing in the Pacific with permanent and detrimental effects on the people and environment (Kiste & Falgout, 1998). In 1975, the Micronesian Constitutional Convention resulted in the islands of Chuuk, Kosrae, Pohnpei and Yap forming the Federated States of Micronesia (FSM). In an effort to maintain ties with the U.S. and allow for independence, the U.S. drafted the Compact of Free Association (COFA) and was approved by the FSM in 1986 (CIA, 2013).

Economically major industries are fisheries, tourism and commercial agriculture, however, they only account for a small percentage of the total FSM economy. The nation’s economy is greatly dependent on government spending funded by the COFA agreement. Although 91.5% of households in Chuuk have income from employment, the average annual household income is $6,195 and many rely on subsistence farming and fishing (Federated States of Micronesia, Office of Statistics, Budget and Economic Management [FSM, OSBEM], 2008). Through the COFA agreement, the US agreed to provide health care services and resources to the USAPI, but there is disparity in health spending. For example, the USAPI annual per capita health care expenditure in Chuuk is $140 which is in stark contrast to the annual US per capita expenditure of $5,711 (Hosey et al., 2009).

State of Hawaii

The Compact of Free Association (COFA) with the U.S. allows FSM citizens to migrate to the U.S. and join the workforce without having to obtain U.S. permanent residency or citizenship (CIA, 2013). COFA migrants may work and live in the U.S. states and territories without visa or residency restrictions. They may apply for limited number of state and federal government funded financial, health and housing services. For example, they are qualified for Temporary Assistance for Needy Families assistance,
MEDQUEST and QUEST NET but not food stamps and Supplemental Security Income (Pobutsky et al., 2005).

The intention of the COFA treaty is to establish close and mutual beneficial relationships though free and voluntary associations. The U.S. is granted rights to maintain a military presence in the islands while FSM benefits from U.S. economic aid (including health care support) and military protection. However, the U.S. aid failed to improve the quality of medical services in the FSM, and therefore, Chuukese migrate to the U.S. especially the state of Hawaii to seek medical care (Pobutsky et al., 2005). Other reasons for relocating are to seek employment opportunities and better education (Liu, Blaisdell & Aitaoto, 2008). Chuukese migrants in Hawaii face many obstacles and social problems including lack of housing, discrimination and stigmatization (Hofschnieider, 2011; Yamada & Pobutsky, 2009). Moreover many of the Pacific Islander migrants in Hawaii lack job skills and have low levels of English proficiency, education and socio-economic status (Yamada & Pobutsky, 2009).

Historical Context

Little is known about the health of Micronesians before western contact. Most of the information is inferred from prehistoric human remains and genealogies. There is evidence that shows that sustained Western contact, especially during the last two centuries, greatly impacted health conditions in both positive and negative ways. In 1970, Hezel and Berg submitted a report to the Trust Territory Committee that documents events after Western contact starting in the nineteenth century when western sailing ships reached the islands introducing diseases from abroad and resulting in dramatic depopulation. For instance, in 1854, the American whale-ship *Delta* arrived on the island of Pohnpei carrying a crew with smallpox that initiated an outbreak that claimed about 4,000 lives or 40% of the island’s population. In 1899, the Germans took over, and they introduced Western medicine, opened the first hospitals, and stationed doctors on the islands of Pohnpei and Chuuk. Their efforts slowed the population decline in all the
islands except Yap. In 1914, Japan took possession of the islands and they made further improvements in health services by expanding hospitals, assigning permanent medical staff to each major island group, and offering services to the outer atolls on regular field trip visits.

World War II ended the period of Japanese administration with astoundingly few deaths from military action. However, a health survey conducted by the US Navy after the war found intestinal parasites, skin diseases and tuberculosis, which was likely due to the numerous problems with environmental infrastructure such as contaminated water and unsanitary conditions (Institute of Medicine [IOM], 1998). The same navy survey team also noted the almost complete absence of malnutrition or obesity, an observation confirmed by the photos and sketches of islanders. Moreover, the survey found no indication of diabetes. A blood pressure study conducted on the island of Pohnpei in the late 1940’s showed almost no hypertension, and it was suspected that the same was true of other islands (IOM, 1998).

Major changes occurred in the early 1960’s during the Kennedy Administration with increased US financial assistance. In 1962, US subsidy doubled and redoubled again throughout the remainder of the decade. The number of salaried government employees increased from 3,000 in 1962 to 18,000 in 1977. The per capita income grew from $60 to $400 and this dramatic influx of money in a short period of time introduced significant changes in lifestyle. Imported foods that were once prohibitively expensive became affordable. The shift toward a high-sodium, high fat and less nutritious diet resulted in increased prevalence of obesity and chronic diseases. Physical activity decreased as well due to the widespread use of kerosene that made it unnecessary to search for and cut firewood for stoves. Moreover, the multiplication of cars and the decreased use of canoes due to the introduction of motorboats also changed lifestyle.
Cultural Context

Culture is vital in health seeking behaviors as it gives meaning to health information and shapes people’s definitions of health, illness and care processes (Neilsen-Bohlman, Panzer & Kindig, 2004). According to Zarcadoola and colleagues (2005), culture literacy is “the ability to recognize and use collective beliefs, customs, worldview and social identity in order to interpret and act on health information.” Understanding culturally-based worldviews and practices is the first step in developing research and interventions to decrease health disparities. This is in line with the views of many health practitioners who believe that the basic attitudes and skills defined as “patient-centered” are also central to clinical cultural competence (Betancourt, 2001). In 2001, the Institute of Medicine (IOM) released a report highlighting a significant gap between the quality of health care people should receive, and the quality of care they actually receive; and of all the principles in the report, patient-centeredness is perhaps the most closely linked to cultural competence (Betancourt, 2001). In addition, there is a call for respect for patients’ values, preferences, and expressed needs; trust; information, communication, and education; emotional support; and involvement of family and friends when desired (Betancourt, 2001). Studies have shown the importance of cultural awareness and sensitivity to the success of health interventions in the Pacific (Aitaoto, Tsark & Braun, 2009; Davidson-Rada, 1999; Fong et al., 2003; Hosey et al., 2009; Hurst & Nader, 2006; Kaholokula et al., 2008; Puaiana, Aga, Pouesi, & Hubble, 2008).

Health and Illnesses

The western health perspective follows the biomedical model, described as being individualistic, reductionist, physical, and secular (Balint, Buchanan & Dequeker, 2006). In contrast, the Pacific’s definition of health is broad, collective, holistic, spiritual and linked to cultural identity (Butt, 2002; Drummond & Vaai-Wells, 2004). Some distinguish between Pacific illnesses and Western illnesses. While there is no formal definition of Pacific and Western illnesses, many in these communities agree that Pacific
illnesses have supernatural causes and can be cured by traditional Pacific medicine, while Western illnesses have physical causes and can be treated by Western medicine (Hubbell, Luce & McMullin, 2005; Puaina et al., 2008). The literature on the attribution of supernatural causes to diabetes is vague and there is a need for clarification, as this could have significant implications in health outcomes (Ishida, 2001; Mishra, Luce & Hubbell, 2000; Puaina et al., 2008). Moreover, some illnesses are perceived as caused by a conflict with family members, violation of a community’s traditions and/or transgression of social, moral or religious rules (Finau, 1994; Hubbell et al., 2005; Ito, 1982; Ito, 1999; Laing & Mitaera, 1994; Leslie, 2002; Lindstrom, 1999; McPherson & McPherson, 1990; Parson, 1984; Toafa, Moataane & Guthrie, 2001).

Collectivistic Orientation

Health and wellbeing in the Pacific encompasses values and obligations centered around the family and community. Pacific Islanders’ concepts of self also reflect this collectivistic orientation as it goes beyond the western notion of the bounded, autonomous individual to incorporate extended family, community, society and the environment (Ewalt & Mokuau, 1995; Fitzgerald, 1990). Collectivism is a term used to describe moral, political, or social outlook that emphasizes the interdependence of every human in some collective group (Ratner & Lumei, 2003). Pacific Islanders follow a collectivistic culture where the groups’ rights are given priority over rights of individuals. In respect to health decisions, family members (both immediate and extended) play a crucial role in deciding where and how to seek help (traditional or western). The individual suffering from the illness might have their own belief about his/her symptoms, what it means and what to do about it but might not act on this if overruled or persuaded by other family members or friends (Norris et al., 2009).

Spirituality and Religiosity

Religion and spirituality also play a significant role in the lives of Pacific Islanders and over 90% of Pacific Islanders belong to a church (Hosey et al., 2009;
Mishra, Luce & Hubbel, 2000). According to the International Religious Freedom Report (2010), nearly 100% are Christians and an estimated 60% of Chuuk’s residents are Catholics and 40% are other Christian denominations including Baptists, Assemblies of God, Salvation Army, Seventh-day Adventists, Jehovah's Witnesses, and the Church of Jesus Christ of Latter-day Saints (Mormons). Attendance at religious services is generally high; churches are well supported by their congregations and play a significant role in civil society. Church affiliation plays an even greater role for Pacific Islanders living in the U.S where churches serve as a framework for organizing in the absence of the traditional village/clan structure found in their home islands (Hubbell et al., 2005).

Spirituality has always been central in the concept of health and wellness among Pacific Islanders but its inclusion in the western bio-medical model has been deficient. There has been a resurgence of spiritual discourse in the U.S. in the past few decades as scientific-based approaches are not fully able to address a number of health problems (Sundblom, Haikonen, Niemi-Pyntarri & Tigerstendlt, 1994); individuals are searching for peace, meaningful lives and connections (Walsh, 1999); people are seeking answers to increased societal and cultural problems such as violence (Thoresen, 1999); and patients are increasingly frustrated by the impersonal managed health care system in the US and are looking elsewhere for answers for their health concerns (Gundersen, 2000).

In the literature, the words spirituality and religion are often used interchangeably but there is a distinction between the two words. In Tanyi’s (2002) review of the usage of these words in health journals, she found that “religion involves an organized entity, such as an institution with certain rituals, values, practices, and beliefs about God or a higher power.” Moreover, religions have distinct boundaries that may provide guidelines to which members adhere (Tanyi, 2002). On the other hand, “spirituality involves an individual’s search for the meaning of life, wholeness, peace, individuality, and harmony” (Tanyi, 2002). In addition, spirituality is a biological and integral component of being human (Tanyi, 2002). Although some individuals may express their spirituality
though religious values, rituals and beliefs it is contended that belonging to a religion does not automatically mean one is spiritual (Long, 1997). Conversely, while spirituality may be related to religion for certain individuals, for others it may not be (Oldnall, 1996).

A growing number of studies have indicated that individuals who are more religious report better physical and mental health (Koenig, Pargament & Nielsen, 1999; Litwinczuk & Groh, 2007; Pargament 1997; Powell, Shahabi & Thoresen, 2003; Wink, Dillon & Prettyman, 2007). Evidence supporting this conclusion emerges from cross-sectional studies; studies based on both clinical and representative community samples, and studies examining a variety of health outcomes (George, Ellison & Larson, 2002).

**Guiding Practices and Theoretical Principles**

A history of mistrust with researchers in the Pacific necessitates the use of Community Based Participatory Research (CBPR) approaches to facilitate the regaining of trust (Finau, Wainiqolo & Cuboni, 2002; Fong et al., 2003). In addition, the scarcity of information necessitates the use of Grounded Theory to guide the process as it allows culturally specific perspectives to emerge. In addition, Social Cognitive Theory was used to sensitize concepts and formulate research questions.

**Community Based Participatory Research (CBPR)**

The aim of CBPR methodologies is to strengthen individual competence and community capacity to identify and resolve their own problems (Israel, Schulz, Parker & Becker, 1998). CBPR principles require that research is based on community-set priorities, builds on community strengths and resources, provides tangible benefits, and does no harm (Israel et al., 1998). CBPR has been successful in the Native Hawaiian and Pacific Islander communities as demonstrated by the PILI `Ohana Project (Kaholokula et al., 2008; Nacapoy et al., 2008) and the `Imi Hale Native Hawaiian Cancer Network (Braun, Tsark, Santos, Aitaoto & Chong, 2006; Aitaoto, Braun, Estrella, Epelu & Tsark, 2012). Accordingly, this study abided by the following CBPR principles: (1) collaborates with partners in all research phases; (2) builds on community strengths, resources and
relationships; (3) promotes co-learning and empowering process; and (4) addresses the concept of health from an ecological perspective.

Collaborate With Partners In All Phases

For many years, Native communities have been subjected to paternalistic and unethical research practices (Boyer, 1993; Burhansstipanov, Christopher & Schumaker, 2006). Although researchers have a responsibility to do no harm, research has been a source of anguish and distress in Indigenous communities due to inappropriate methods and practices (Cochran et al., 2008). In the past, the Native Hawaiian and other Pacific Islanders (NHPI) community criticized the cultural inappropriateness of research models and the lack of follow-up after the completion of research projects (Matsunaga, 1996). Moreover, research imposed from the outside without the community’s knowledge and buy-in creates distrust and hinders participation and cooperation (Ambler, 1997; Moran, 2001; Weaver, 1997). To improve the relationship between researchers and community members, one of the principles of CBPR recommends the involvement of community members throughout the research process, from planning to dissemination. This will help develop trust, sense of ownership and builds on the strengths to continue improvements in health after the funded project ends (Deloria, 1991; Moran, 2001; Weaver, 1997). Accordingly, community representatives and stakeholders chose this study’s topic, subjects and sites. Through community workshops and meetings conducted among Pacific communities in all six USAPI jurisdictions, they identified the following topics as important T2DM research subjects: social support, cultural attitudes and beliefs concerning prevention; control activities, mainly nutrition, physical activities and drug adherence; and effective communication of promising practices to the community. In addition they identified the following research study subjects: faith leaders, health care providers, people with diabetes and family members of people with diabetes. During the 2007 Global Public Health Conference, 2008 Pacific Health Gathering and 2009
Micronesian Pastors’ Conference, these research topics and subjects were also identified and approved as research priorities.

During the 2010 Pacific Chronic Disease Coalition (PCDC) annual meeting, members selected (1) the state of Chuuk (FSM) and the island of Oahu (Hawaii) as the two research sites; (2) Chuuk Women’s Council (Chuuk) and Micronesians United (Hawaii) as community partners; (3) University of Iowa as a scientific partner; (4) Father Ryan Jimenez as the faith leader representative; (5) Moria Shomour as the health care provider representative; and (6) Tayna Belyeu-Camacho as the public health representative. Also during this meeting, PCDC agreed to respond to a National Institute of Health’s Request for Proposal to fund the project. PCDC identified community representatives assisted in the development of the research questions, reviewed and approved the questions and protocols. The community also identified individuals to assist with data collection and analysis. At the end of the project, the final results were presented to PCDC members and community members and stakeholders in Chuuk and Hawaii. In addition, a discussion session was held in both sites to review the findings, make edits, validate the results through member checking and plan the next step for intervention and research.

**Community Strengths, Resources, and Relationships**

A great majority of research among Indigenous communities is focused on deficits and problems versus strengths and assets (Ambler, 1997). However, many Indigenous scholars believe that in order for research projects to be successful, researchers must build on community strengths and existing resources (Burhansstipanov, Bemis & Dignan, 2001). One of the strengths is the Pacific culture, including culturally-based health perspectives. The Pacific’s definition of health is broad, collective, holistic, spiritual and linked to cultural identity (Butt, 2002; Drummond & Vaai-Wells, 2004). Health and wellbeing in the Pacific encompasses values and obligations centered on family and communalism (Finau, 1994). Researchers demonstrated that health care
providers and researchers who understand these cultural factors provide better services (Beckham, Bradley, Washburn & Taumua, 2008). Pacific Islanders also recognize the relationship between spirituality and health. Spirituality is a major part of NHPI’s health discourse and an influencer of health behavior (Aitaoto et al., 2007; Butt, 2002; Kaholokula et al., 2008). Pacific Islanders’ interpretation of health is holistic and many are currently struggling under the current Western biomedical model which privileges physical health (Aitaoto et al., 2007; Capstick et al., 2009; Hosey et al., 2009; Norris et al., 2009). In accordance, the aim of this formative research project was to: (1) identify socio-cultural influences that hinder or facilitate diabetes prevention and management among Pacific Islanders; (2) identify the role spirituality plays in promoting diabetes prevention and management: and (3) determine how churches can play an effective role in designing and implementing effective diabetes interventions for Pacific Islanders. This project privileged the NHPI’s holistic approach, respected Indigenous wisdom and utilized community resources. This type of CBPR project could have only evolved from true community engagement and mutual respect.

Co-learning and Empowering

Many Indigenous and non-Indigenous researchers labeled co-learning as an important and necessary component of research among Native communities (Beardi & Donnelly 1999; Burhansstipanov et al., 2006; Davis & Reid, 1999; Moran, 2001; Weaver, 1997). They expressed the need for researchers to put themselves in the role of the learner, accept new perspectives, and relinquish their position as the singular expert in the partnership. In working with Indigenous communities it is also important for researchers to learn and respect cultural protocols and practices. In many instances, Indigenous community partners are more than willing to help provide researchers (whom they trust and respect) with an understanding and appreciation of Native ways of knowing (Weaver, 1997) and social-political dimensions of Indigenous health (Chino & DeBruyn, 2006). On the other hand, Indigenous communities are looking for
opportunities to regain control over their destinies and researchers are in a great position to make available resources and training that may be useful in developing the necessary networks and skills to conduct successful health research. Accordingly, the community chose the University of Iowa as a scientific partner for this research project and the research team from Iowa travelled to both sites to learn more about Chuukese and Pacific culture and context. In addition, community members were trained to collect and analyze research data.

**Ecological perspective**

In the literature there is a great number of Indigenous researchers who believe that in order to make true progress towards eliminating health disparities, the utilization of an approach that addresses ecological, sociological and cultural issues are necessary (Dignan et al., 1993; Wax, 1991; Wright et al., 1997). This ecological approach is in agreement with NHPI’s holistic health perspective. In addition, researchers cannot avoid the conditions of poverty and crime found in many Indigenous communities. Nor can they overlook the extent to which past and current policies reinforced acculturation, racism and discrimination (Burhanssitipanov, Hampton & Tenney, 1999; Dupuis & Ritenbaugh, 2007; Olson, 1999; Wax, 1991; Wright, Naylor, Wester, Bauer, & Sutcliffe, 1997).

Researchers who are engaging in CBPR need to work with community members to identify barriers (all barriers and not just barriers related to the researcher’s topic of interest) and empower the necessary changes to improve the health and welfare of Native communities (Moran, 2001; Olson, 1999).

In public health this approach is gaining popularity as the use of Social Ecological Model in research and interventions amplified in the past decade (Rimer & Glanz, 2005). The five levels address the 1) intrapersonal level or individual characteristics that influence behavior, such as knowledge, attitudes, beliefs, and personality traits, 2) interpersonal level or interpersonal processes and primary groups, including family, friends, and peers that provide social identity, support and role definition, 3) community
level (organization/institutional factor) or the rules, regulations, policies, and informal structures, which may constrain or promote recommended behaviors, 4) community level (community factor) or the social networks and norms, or standards, which exist as formal or informal among individuals, groups, and organizations, and lastly, 5) community level (public policy) or the local, state, and federal policies and laws that regulate or support healthy actions and practices for disease prevention, early detection, control, and management (Rimer & Glanz, 2005). Accordingly, this formative research project used the grounded theory to elicit community members’ perspective on all the levels of the Social Ecological Model.

Grounded Theory

Grounded theory focuses on theoretical constructs and relationships that are derived from rather than imposed upon the data allowing for both inductive and deductive approaches to be used. The advantage of using Grounded Theory is that it is focused on real-life experiences and people’s worldviews rather than abstract concepts. It also follows the notion that the best way to study indigenous experiences is through social processes and interactions (Abdoli, Ashtorab, Parvizi & Dunning, 2009; Strauss & Corbin, 1990). Grounded Theory developers encouraged users to use the theory strategies flexibly and in their own way. Other researchers who used Grounded Theory viewed it as a “set of principles and practices, not as prescription or packages (Charmaz, 2006 pg 9).” This study embraced these views and used Grounded Theory methods to guide the research process.

Concepts Sensitization and Questions Development

In accordance with Grounded Theory practices, this research began with a topic of interest, diabetes control (as identified and prioritized the community) and used the Social Cognitive Theory (SCT) to sensitize the topic. In other words, SCT was used as a starting point to formulate initial research questions. SCT describes the interrelationship between behavior (e.g., whether or not the person exercises, eats fresh fruit and
vegetables, monitors their blood sugar), environmental factors (e.g., whether or not there are health care facilities, places to exercise, policies supporting the behavior, social support, and cultural value), and personal factors (e.g., genetic risk, personal beliefs), all of which are likely to be relevant with Pacific Islanders (Bandura, 1989, 1998). Social Cognitive Theory explains how individuals acquire and maintain certain behavioral patterns, while also providing the basis for intervention strategies (Bandura, 2003). Moreover, the three factors (environment, people and behavior) are constantly influencing each other. In other words, behavior is not simply the result of the environment and the person, just as the environment is not simply the result of the person and behavior (Glanz, Rimer & Lewis, 2002).

Figure 1. Social Cognitive Theory.

http://www.emory.edu/EDUCATION/mfp/eff.html.

Researchers and health practitioners have used SCT to develop T2DM diabetes interventions (Nouwen et al., 2011); guide successful culturally appropriate T2DM management interventions for minority populations (Inouye et al., 2011; Utz et al., 2008); study the impact of a community-based diabetes program (Chapman-Novakofski & Karduck, 2005); and predict health care professionals behaviors (Godin, Belanger-Gravel, Eccles & Grimshaw, 2008).
Data Collection

An important component of Grounded Theory is choosing data collection approaches and tools that help answer the research questions with ingenuity and directness. This study collected information via key informant interviews with faith leaders (Appendix A) and health care providers (Appendix B) in addition to community focus groups with people with diabetes and family members of people with diabetes (Appendix C). Interviews and focus groups are directed conversations that allow an in-depth exploration of a topic with individuals with relevant experience (Lofland & Lofland, 1995). Their aim is to draw out participants’ interpretation of their experience (Seidman, 1998). The interviewer’s role is to listen, to observe with sensitivity and to encourage participants to respond (Charmaz, 2006).

Data Analysis

In accordance with CBPR principles, two representatives from the U.S. Pacific were part of the analysis team: Father Ryan Jimenez (Apostolic Administrator, Diocese of Chalan Kanoa) and Tayna Belyeu-Camacho (former Diabetes Prevention and Control Program Coordinator and current Chronic Disease Coordinator at the College of the Mariana Islands). Analysis of the transcripts was guided by grounded theory and was sensitive to the identification of individual, behavioral, and environmental influences consistent with Social Cognitive Theory (Bandura, 1989, 1998).

Initial Coding

In conformance with grounded theory practices, the first step was coding or naming segments of data with a label that concurrently categorizes, summarizes and accounts for each piece of data (Charmaz, 2006). This step started with independent initial coding (coding incident-to-incident). The codes stuck closely to the data, preserved events, suggested contexts, portrayed viewpoints, showed action and specified how things evolve. The aim was to move beyond accounts in the transcripts toward
analytical interpretation. Each member of the analysis team completed this step independently.

Following the independent coding step, the analytical team met face-to-face to do group coding. The team worked quickly through the transcript looking for coding incidences and paying attention to in vivo codes or words/phrases that compress meanings of widely used terms that participants assume everyone shares. Charmaz (2006) identified three kinds of in vivo codes she found useful: (1) general terms everyone ‘knows’ that flag condensed but significant meanings; (2) a participant’s innovative term that captures meanings or experience and (3) insider shorthand terms specific to a particular group that reflect their perspective. This third type is particularly important to the analysis as many of the terms are tied to the Chuukese cultural context. They provided a useful analytic point of departure and helped preserve participants intended meanings within the coding itself. Throughout this process the team made several memos to catch fleeting ideas about codes and noted items for further discussion. As the team progressed though the transcript they came upon similar types of responses so they implemented focused coding to synthesize and explain larger segments of data. Focused coding enabled the team to use earlier codes to sift through large amounts of data toward the later part of the process. This required decisions about which initial codes make the most analytic sense to categorize the data incisively and completely (Charmaz, 2006).

Axial Coding and Clustering

The above initial coding process fractured the data into separate pieces and distinct codes but the next step brought back together these pieces to form a coherent whole. The axial coding process facilitated this process by sorting the initial codes and grouping them into common themes. These common themes were then used to develop major categories with subcategories and showed the links between them. Moreover, the team reviewed our early memos to start the clustering process. This helped produce a tentative and flexible chart of our categories and sub-categories. The following
directions by Charmaz (2006) guided us through this process: start with the main idea at the center then move out from the nucleus into smaller sub-clusters (keeping all related material in the same sub-cluster) and keep branching out until we exhausted our codes/knowledge; make all the connections clear between each idea, code and/or category; and try several clusters on the same topic.

Refining Categories

It is important to note that the analysis team held two separate analysis sessions and both sessions followed the same analysis process up to this point. The first analysis was held after the provider interviews and on the last day of data analysis the team focused their attention on identifying research question that can elaborate and refine categories. The result of this activity informed probing questions for the community focus groups. This process helped find pertinent data to develop the emerging framework. The second analysis was held after the focus group sessions and the team continued the process of refining categories and developing the emergent framework.

Research Process and Timeline

As mentioned earlier, this study was also part of the Faith in Action Research Alliance (FARA) research project that was funded by the National Institutes of Health’s (NIH) National Institute of Minority Health Disparity (NIMHD). Therefore, the schedule followed the timeline that was in the NIMHD proposal (Table 4).
Table 4. Research Timeline.

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<td>Obtain IRB approval</td>
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</tbody>
</table>

The research plan and questions were developed, reviewed and approved by the FARA research team and community identified representatives including members of the Pacific Chronic Disease Coalition. Data collection started in the summer of 2011 with faith leaders and health provider interviews in Chuuk and Hawaii followed by the analysis of the interview data by the analysis team (early fall 2011). Interview results informed the revision of the community focus group questions and issues. The focus groups were conducted in the winter of 2011 in Chuuk and spring of 2012 in Hawaii. The data analysis for the focus group and overall analysis were done in the summer of 2012. At the end of the analysis, results were reported to both communities and discussion sessions were held to formalize a research and intervention agenda for Chuuk and the Pacific.

Research Team Positionality

With qualitative research, individuals who conduct the study are crucial as they are not passive observers but are active participants who make suppositions about what is real, possess knowledge, occupy social status and pursue purposes that influence their respective views and actions (Charmaz, 2006). For this study, the data analysis team included three members from the Pacific and a member from the continental U.S. Two (out of four) team members were Pacific Islanders but not ethnically Chuukese, one was
Filipino but lived and worked in the Pacific for over 15 years and the forth member was Caucasian living in the U.S. Midwest region.

The team leader’s interest in diabetes control and culture began over ten years ago when she was providing community mobilization, health education and technical assistance to all the USAPI jurisdictions including Chuuk. Her relationship with the Chuukese community in Chuuk and the Hawaii was facilitated by this working experience. This close relationship with the community can be both a strength and a weakness in this research project. For example, trust was already established and participants were very open in discussions. The lead researchers familiarity with the culture and formal knowledge of local context enable the team to verify some of the information and probe for deeper meanings. However, since the research lead was the health educator for the region, some of the answers provided may have been socially desirable as participants might want to please her.

The team’s understanding of the Pacific culture and protocols put them in the position to probe for appropriate answers and analyze the data within the Pacific context. However, there was also a chance that the team assumed the interpretation of the answer based on their knowledge of the Pacific and therefore did not probe further for the intended meaning. Moreover, although their relationship with the community helped gained the trust of the community, there was also a chance of participants holding back information because of familiarity. The research also included an outsider data analyzer so she played a vital role in making sure concepts and terms with cultural meanings were explained. In addition, the information was presented back to the two communities though member checking to verify meanings.

**Ensuing Chapters**

The following chapters will report and discuss the results of this research project. Chapter 2 will address the relationship between socio-economic status, culture, religion, spirituality and diabetes (Study 1). Chapter 3 will examine factors impacting nutrition
therapy (Study 2), Chapter 4 will look at physical activity (Study 3) and Chapter 5 will cover medication adherence (Study 4). The final chapter (Chapter 6) will discuss a culturally based framework that can be used to inform research and interventions for Chuukese and other Pacific Islanders.
CHAPTER 2
STUDY 1: DIABETES PREVENTION AND CONTROL AMONG CHUUKese IN HAWAII AND THE PACIFIC

Introduction

The prevalence of type 2 diabetes mellitus (T2DM) is high among the indigenous peoples of the US-associated Pacific Islands (USAPI). Although a U.S. Navy health survey in the 1940’s revealed no cases of T2DM (IOM, 2001), the prevalence rate of diabetes currently ranges from 29.8% in the Republic of the Marshall Islands (RMI) to 47.3% in American Samoa (WHO, 2002; 2007). Both rates are much higher than the US rate of 7.8% (CDC, 2007). Many attribute this change to modernization and globalization. Traditional Pacific Islander lifestyles were active, and diets consisted primarily of low-fat, high-fiber foods from the land and sea (Englberger, Marks & Fitzgerald, 2003). Today, most Pacific Islanders have sedentary lifestyles, and their diets are high in calories, salt, fat, and refined foods (Hezel, 2004).

In addition, some scholars believe incongruent views on health plays a role in health outcomes (Butt 2002; Drummond & Vaai-Wells, 2004). The Pacific’s definition of health is strongly linked to cultural identity (Aitaoto, Tsark & Braun, 2009). In respect to health decisions, immediate and extended family members play a crucial role (Ishida, 2001). Concepts of health and wellbeing in the Pacific encompass values and obligations centered around family and community (Mishra, Luce & Hubbell, 2000). Pacific Islanders’ concepts of self also reflect this collectivistic orientation as it goes beyond the Western notion of the bounded, autonomous individual to incorporate extended family, community, society and the environment (Finau, 1994; Ito, 1999; Toafa, Moataane & Guthrie, 2001).

Holistic health posits that all aspects of people’s psychological, physical and social needs should be taken into account and seen as a whole (Strandberg, Ovhed,
Borgquist & Wilhemsson, 2007). This view is similar to the Pacific health worldview that encompasses its geography, socio-economic conditions, political history, cultural practices and spiritual orientation.

During the 2010 Pacific Chronic Disease Council (PCDC) annual meeting, members identified the following determinants of health for the USAPI region: (1) income (e.g., high rates of unemployment and households living below the poverty level); (2) social status (e.g., chiefs determine land use—vegetable garden, play grounds and housing); (3) support networks (e.g., outer island residents relocating to urban centers for work and lack the supportive social network they had on their home island); (4) education (e.g., physical education is not taught in school); working conditions (e.g., lack of healthy workplace policies); (5) physical environment (e.g., safe walking paths and playgrounds); (6) cultural beliefs (e.g., chronic disease is caused by spirits); (7) societal attitudes (e.g., physical activities view as undignified); (8) health spending (e.g., the USAPI annual per-capita health expenditure ranges from $140 in Chuuk to $1,032 in Guam—a stark contrast to the annual U.S. per capita expenditure of $5,711); (9) disparities in diabetes funding awards (e.g., the average USAPI Diabetes CDC funding award during 2006-2008 was $82,000/jurisdiction compared to $270,000/state in the U.S.); (10) technology (e.g., outdated computers/software, unreliable telephone system and expensive Internet access); and (11) geographic distance from the U.S. (e.g., Atlanta’s Monday to Friday business hours of 9am-5pm is Sunday to Thursday 11pm-7am in Palau).

Although there are diabetes prevention and management programs in the Pacific, success is severely hampered because they are not tailored for Pacific Islanders and their cultural context and worldview (Braun et al., 2003; Aitaoto et al., 2009). Given the recent appearance of T2DM in the Pacific and its dramatic upsurge, there is a need to explore Pacific Islanders’ understanding of the illness, health beliefs and health seeking behaviors. To that end, the research team conducted formative research utilizing
grounded theory and community based participatory research (CBPR) principles to ascertain information that explain the relationship between constructs such as culture, religion, family and diabetes prevention and control. Community representatives through the Pacific Chronic Disease Coalition (PCDC) selected the target population (Chuukese), study subjects (faith leaders, healthcare providers, diabetics and caregivers) and sites (Chuuk and Hawaii). PCDC chose the Chuukese communities in Chuuk and Hawaii because they were ready to support this type of research. The subjects were selected because of the important role they play or potentially play in glycemic control. The aims of this formative research were to obtain:

1. Faith leaders and health care providers’ perspective, experience and actions regarding diabetes control;
2. Faith leaders’ level of willingness to support diabetes initiatives and in what capacity;
3. Health care providers’ level of willingness to work with faith leaders and in what capacity;
4. Patients and their family members’ perspective on their own experience and actions regarding diabetes control.

**Method**

Given the limited information on Pacific Islanders and diabetes, qualitative methods (key informant interviews and focus group) using Grounded Theory were used to gather information. In accordance with CBPR principles, the community approved these methods and identified research topics and study subjects. They identified the study of social support (e.g. family and church) and cultural attitudes and beliefs concerning diabetes prevention and control activities. Therefore, family members and faith leaders were part of this study. The PCDC and the University of Iowa Institute Review Board (IRB) approved the research tool. In agreement with CBPR practices, a partnership was formed between the research institution and two community
organizations, Chuuk Women’s Council (CWC) in Micronesia and Micronesians United (MU) in Hawaii. These organizations assisted with recruitment of study subjects and provided logistic support for data collection.

Measures

Healthcare Provider and Faith Leader Interviews

The objectives of the interviews were to: (1) obtain healthcare providers and faith leaders’ perspective on their patients/church members’ experience and actions regarding diabetes prevention, screening and management. For example, they were asked, what are some of their patients/church members’ barriers and facilitator to diabetes prevention, screening and control; (2) obtain healthcare providers and faith leaders’ own experience and actions regarding diabetes prevention, screening and management. For example, health care providers were asked what are some of the barriers and facilitators they are facing in providing diabetes care. Faith leaders were asked what role they play in preventing and controlling diabetes; and (3) determine whether (a) healthcare providers are supportive of faith-based diabetes initiatives and (b) faith leaders are supportive of diabetes initiatives. The interviews were semi-structured and addressed knowledge and burden of diabetes, spirituality and religiosity, and faith leaders’ and churches’ roles in diabetes control. Participants also completed a one-page demographic questionnaire that includes age, sex, religion/denomination, diabetes status and employment status. The interviews were tape recorded and ranged in time between 45 minutes and 90 minutes.

Community Focus Groups

The objectives of the community focus groups were to: (1) obtain community members’ perspective, experience and actions regarding diabetes prevention, screening and management; and (2) determine whether they are supportive of faith-based diabetes initiatives. For example, they were asked questions on diabetes knowledge, beliefs and attitude. They were also asked what role does spirituality, the church and faith leaders
play in diabetes management. Participants also completed a one-page demographic questionnaire that includes age, sex, religion/denomination and, diabetes status.

Procedures

Healthcare Provider and Faith Leader Interviews

Through several community meetings organized by Chuuk Women’s Council and Micronesians United, 12 health care providers and 17 faith leaders were identified. All identified potential participants were invited to participate via email and/or telephone using a script approved by the UI-IRB. All 29 individuals agreed to be interviewed and the interviews were conducted in the CWC office (for Chuuk faith leaders and health care providers), the MU office (for Hawaii faith leaders), or the interviewee/provider office (for Hawaii providers). The in-depth nature of the intensive interview drew out each participant’s viewpoint and interpretation of his or her experience. Interviews were recorded and the audiotapes were reviewed after each discussion to guide probing questions for the next interview. Interviews lasted approximately three hours in Chuuk and two hours in Hawaii.

Community Focus Groups

The recruitment of focus group participants followed a multi-phase approach. First, community partner organizations (CWC and MU) identified community meetings and gatherings for the Principal Investigator (PI) to attend and present information on the research project. Second, the PI attended identified meetings (e.g., CWC and MU meetings, church services, church meetings and community gatherings) to provide information on the research and collect names and contact information of interested participants. Through this process, 120 individuals expressed their desire to participate. Third, the PI contacted all 120 individuals through email and/or telephone using a script approved by the UI-IRB and 102 (85%) were able to participate. The Chuuk focus group sessions were held at a local hotel located in the center of town and the Hawaii focus groups were held at the MU conference room. In compliance with cultural protocols,
focus groups were segregated by sex and facilitators were of the same sex. The research team (facilitators and notetakers) followed general rules and a script detailed in the focus group guide and approved by the UI-IRB. The focus group sessions were recorded and the audiotapes were reviewed after each session in order to guide probing questions for the next session.

Participants

Healthcare Provider and Faith Leader Interviews

Chuukese community members identified 12 health care providers (6 in Hawaii and 6 in Chuuk) and 17 faith leaders (8 in Hawaii and 9 in Chuuk) (Table 5). All 29 individuals (18 males and 11 females) were interviewed in person. The overall average age was 50 years (49 years from Health Providers and 52 years for Faith Leaders).

Table 5. Interviewees Demographic Information.

<table>
<thead>
<tr>
<th></th>
<th>Health Care Providers</th>
<th>Faith Leaders</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Chuuk</td>
<td>Hawaii</td>
</tr>
<tr>
<td>Number of participants</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Number of male/females</td>
<td>3/3</td>
<td>4/2</td>
</tr>
<tr>
<td>Ethnicity Chuukese/non-Chuukese</td>
<td>6/0</td>
<td>1/5</td>
</tr>
<tr>
<td>Average Age (years)</td>
<td>45.7</td>
<td>51.7</td>
</tr>
<tr>
<td>Age Range (years)</td>
<td>37-58</td>
<td>36-67</td>
</tr>
<tr>
<td>Catholics/Protestants</td>
<td>Na</td>
<td>na</td>
</tr>
</tbody>
</table>

Health care providers included complimentary and an alternative medicine practitioner (n=1), traditional healers (n=2), nurses (n=3) and physicians (n=6). The majority of the providers (83%) practiced for at least 20 years and only one out of twelve practiced in the Micronesian community for over 10 years. Only one of the health care providers in Hawaii was Chuukese, and all practitioners in Chuuk were Chuukese (Table 6).
Table 6. Healthcare Providers Demographic Information.

<table>
<thead>
<tr>
<th>Site</th>
<th>Age</th>
<th>Sex</th>
<th>Ethnicity</th>
<th>Title</th>
<th>Yrs at Job</th>
<th>Yrs with PI pts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hawaii</td>
<td>67</td>
<td>M</td>
<td>Okinawan</td>
<td>Healer</td>
<td>39</td>
<td>10</td>
</tr>
<tr>
<td>Hawaii</td>
<td>36</td>
<td>M</td>
<td>Caucasian</td>
<td>Primary Care Physician</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Hawaii</td>
<td>48</td>
<td>M</td>
<td>Caucasian</td>
<td>Director CHC and MD</td>
<td>22</td>
<td>22</td>
</tr>
<tr>
<td>Hawaii</td>
<td>52</td>
<td>M</td>
<td>Japanese</td>
<td>Physician</td>
<td>24</td>
<td>24</td>
</tr>
<tr>
<td>Hawaii</td>
<td>42</td>
<td>M</td>
<td>Filipino</td>
<td>CDE – RD</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>Hawaii</td>
<td>64</td>
<td>M</td>
<td>Chuukese</td>
<td>Traditional Healer</td>
<td>20+</td>
<td>20+</td>
</tr>
<tr>
<td>Chuuk</td>
<td>47</td>
<td>M</td>
<td>Chuukese</td>
<td>Traditional Healer</td>
<td>20+</td>
<td>22+</td>
</tr>
<tr>
<td>Chuuk</td>
<td>38</td>
<td>M</td>
<td>Chuukese</td>
<td>Clinical Nurse</td>
<td>10+</td>
<td>10+</td>
</tr>
<tr>
<td>Chuuk</td>
<td>37</td>
<td>M</td>
<td>Chuukese</td>
<td>Nurse</td>
<td>10+</td>
<td>10+</td>
</tr>
<tr>
<td>Chuuk</td>
<td>58</td>
<td>M</td>
<td>Chuukese</td>
<td>NCD Doctor</td>
<td>20+</td>
<td>20+</td>
</tr>
<tr>
<td>Chuuk</td>
<td>46</td>
<td>M</td>
<td>Chuukese</td>
<td>Doctor</td>
<td>20+</td>
<td>20+</td>
</tr>
<tr>
<td>Chuuk</td>
<td>48</td>
<td>M</td>
<td>Chuukese</td>
<td>Doctor</td>
<td>20+</td>
<td>20+</td>
</tr>
</tbody>
</table>

Faith Leaders included pastors (7), pastor’s wives (4), and deacons (6). They were all Chuukese and served in the ministry full time. One of the major differences between faith leaders in Hawaii versus Chuuk was the degree to which pastors (and deacons and pastors’ wives) were required to work a second job. In Hawaii, 89% of the interviewees worked outside the Church, but in Chuuk only 25% had second jobs. In regards to denomination, 65% were Protestants and 35% were Catholics (Table 6).
Table 7. Faith Leaders Demographic Information.

<table>
<thead>
<tr>
<th>Site</th>
<th>Age</th>
<th>Sex</th>
<th>Denomination</th>
<th>Position</th>
<th>Work outside of ministry?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hawaii</td>
<td>62</td>
<td>M</td>
<td>Protestant</td>
<td>Pastor</td>
<td>Yes: Full-time</td>
</tr>
<tr>
<td>Hawaii</td>
<td>57</td>
<td>M</td>
<td>Protestant</td>
<td>Pastor</td>
<td>Yes: Full-time</td>
</tr>
<tr>
<td>Hawaii</td>
<td>53</td>
<td>F</td>
<td>Protestant</td>
<td>Pastor’s Wife</td>
<td>Yes: Part-time</td>
</tr>
<tr>
<td>Hawaii</td>
<td>60</td>
<td>M</td>
<td>Catholic</td>
<td>Deacon</td>
<td>No</td>
</tr>
<tr>
<td>Hawaii</td>
<td>45</td>
<td>M</td>
<td>Catholic</td>
<td>Deacon</td>
<td>Yes: Full-time</td>
</tr>
<tr>
<td>Hawaii</td>
<td>45</td>
<td>F</td>
<td>Catholic</td>
<td>Deaconess</td>
<td>Yes: Part-time</td>
</tr>
<tr>
<td>Hawaii</td>
<td>52</td>
<td>M</td>
<td>Protestant</td>
<td>Pastor</td>
<td>Yes: Part-time</td>
</tr>
<tr>
<td>Hawaii</td>
<td>43</td>
<td>M</td>
<td>Protestant</td>
<td>Pastor</td>
<td>Yes: Full-time</td>
</tr>
<tr>
<td>Hawaii</td>
<td>41</td>
<td>F</td>
<td>Protestant</td>
<td>Pastor’s Wife</td>
<td>Yes: Full-time</td>
</tr>
<tr>
<td>Chuuk</td>
<td>67</td>
<td>M</td>
<td>Protestant</td>
<td>Pastor</td>
<td>No</td>
</tr>
<tr>
<td>Chuuk</td>
<td>46</td>
<td>M</td>
<td>Protestant</td>
<td>Pastor</td>
<td>Yes: Full-time</td>
</tr>
<tr>
<td>Chuuk</td>
<td>44</td>
<td>F</td>
<td>Protestant</td>
<td>Pastor’s Wife</td>
<td>No</td>
</tr>
<tr>
<td>Chuuk</td>
<td>50</td>
<td>M</td>
<td>Protestant</td>
<td>Pastor’s Wife</td>
<td>No</td>
</tr>
<tr>
<td>Chuuk</td>
<td>50</td>
<td>F</td>
<td>Protestant</td>
<td>Pastor</td>
<td>No</td>
</tr>
<tr>
<td>Chuuk</td>
<td>43</td>
<td>M</td>
<td>Catholic</td>
<td>Deacon</td>
<td>No</td>
</tr>
<tr>
<td>Chuuk</td>
<td>47</td>
<td>F</td>
<td>Catholic</td>
<td>Deaconess</td>
<td>Yes: Full-time</td>
</tr>
<tr>
<td>Chuuk</td>
<td>59</td>
<td>M</td>
<td>Catholic</td>
<td>Deacon</td>
<td>No</td>
</tr>
</tbody>
</table>

Community Focus Groups

Eight focus groups were conducted in Chuuk (three females only, three males only, and two groups combined). A total of 43 individuals (24 females and 19 males) participated. Eight focus groups were also held in Hawaii (4 female only groups and 4 male only groups). A total of 59 individuals (32 females and 27 males) participated (Table 8). Overall, the average age of participants was 46 years (43 years in Chuuk and 47 years in Hawaii). There were a total of 43 Catholics and 59 Protestants. Fifty-four participants have diabetes, 82 were caregivers/family members, and four reported that they did not know their diabetes status. The four that did not know their diabetes status were participants from Chuuk. Every participant from Chuuk reported that they have access to health care through the Chuuk Hospital, and 49 of the 59 participants from
Hawaii claimed that they have access.

Table 8. Focus Group Participants Demographic Information.

<table>
<thead>
<tr>
<th></th>
<th>Chuuk</th>
<th>Hawaii</th>
<th>Total/All</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Focus groups</td>
<td>8</td>
<td>8</td>
<td>15</td>
</tr>
<tr>
<td>Number of Participants</td>
<td>43</td>
<td>59</td>
<td>102</td>
</tr>
<tr>
<td>Female Participants</td>
<td>24</td>
<td>32</td>
<td>56</td>
</tr>
<tr>
<td>Male Participants</td>
<td>19</td>
<td>27</td>
<td>46</td>
</tr>
<tr>
<td>Average Age (years)</td>
<td>43</td>
<td>47</td>
<td>46</td>
</tr>
<tr>
<td>Age Range (years)</td>
<td>19-64</td>
<td>19-78</td>
<td>19-78</td>
</tr>
<tr>
<td>Catholics/Protestants</td>
<td>17/26</td>
<td>26/33</td>
<td>43/59</td>
</tr>
<tr>
<td>Do you have T2DM?: Y/N/Unknown</td>
<td>25/14/4</td>
<td>29/30/0</td>
<td>54/44/4</td>
</tr>
<tr>
<td>Do you have a Health Care Provider?: Y/N</td>
<td>43/0</td>
<td>49/10</td>
<td>92/10</td>
</tr>
</tbody>
</table>

Data Analysis

In accordance with CBPR principles, two representatives from the U.S. Pacific were part of the four person analysis team. Analysis of the transcripts was guided by grounded theory and was sensitive to the need to identify individual, behavioral, and environmental influences consistent with Social Cognitive Theory (Bandura, 1989;1998). The first step was coding or naming segments of data with a label that concurrently categorizes, summarizes and accounts for each piece of data. These codes stuck closely to the data, preserved events, suggested contexts, portrayed viewpoints, showed action and specified how things evolved. The analysis team also paid attention to words/phrases that compress meanings and widely used terms that participants assume everyone shares. Charmaz (2006) described these words/phrases as: (1) general terms everyone ‘knows’ that flag condensed but significant meanings; (2) a participant’s innovative term that captures meanings or experience and (3) insider shorthand terms specific to a particular group that reflect their perspective. This third type is particularly important to our analysis as many of the terms are tied to the Chuukese cultural context. They provided a
useful analytic point of departure and helped preserve participants intended meanings within the coding itself. Throughout this process several memos were made to catch ideas about codes and noted items that needed to be discussed later. The next step brought back together these pieces to form a coherent whole by sorting the initial codes, grouping codes into common themes, and using groups to develop major categories and subcategories with the links between them.

Results

The most salient narrative among all three study groups (health care providers, faith leaders and community members) was around T2DM as major problem among Chuukese and other Pacific Islanders. Other narratives were around participants’ perspective, experience and actions regarding diabetes control. As mentioned earlier, the research probing questions were sensitized around the Social Cognitive Theory and participants narrated behaviors, personal factors and environmental influences associated with T2DM control. Therefore, the report of study results will begin with the diabetes problem narratives and the remaining narratives will be grouped according to the three Social Cognitive Theory categories of behaviors, personal factors and environmental influences.

Diabetes Problem Narratives

All the discussions usually began with participants declaring diabetes as the “sugar disease” that is common among Chuukese, new to the Pacific, spreading rapidly and killing a lot of people. Participants discussed the problem of diabetes from their own perspective as health care providers, faith leaders and community members (individuals with diabetes and/or caregivers). They also described the problem in terms of its scope and high prevalence; duration and chronic nature; current circumstances concerning prevention, detection and management; and burden of complication (Table 9).
### Table 9. Identified Diabetes Issues by Three Study Subject Groups

<table>
<thead>
<tr>
<th>Problem</th>
<th>Health Care Providers</th>
<th>Faith leaders</th>
<th>Community Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scope/Prevalence</td>
<td>High prevalence among Pacific Islanders including Chuukese and it is overwhelming the health care system.</td>
<td>Lots of family and church members have diabetes. There are more now than before.</td>
<td>Fast spreading problem (personal and community) that is killing a lot of family members and friends.</td>
</tr>
<tr>
<td>Duration</td>
<td>Difficult to treat/manage due to its long-term nature.</td>
<td>Problem for a lifetime – “it’s easy to get motivated and sacrifice for a short period of time but to do it for the rest of your life is hard.”</td>
<td>Patients and family need to live with it every day.</td>
</tr>
<tr>
<td>Prevention</td>
<td>Patients know what they need to do to prevent T2DM but no action.</td>
<td>Aware that lifestyle behaviors such as eating healthy and engaging in physical activity can prevent T2DM but they lack of “how-to” knowledge, resources, social support, motivation and hope.</td>
<td>It can be prevented with healthy behaviors but that is very difficult so in reality it can’t be prevented.</td>
</tr>
<tr>
<td>Detection</td>
<td>Patients came in with late stage complications (amputation)</td>
<td>Health care system is not using churches for detection activities. Churches are willing to assist and partner.</td>
<td>People know the signs and symptoms but don’t do anything until it gets worst and the pain is unbearable.</td>
</tr>
</tbody>
</table>
| Manage-ment/Control | • Action: patients are non-compliance  
• Health Care System: lack resources  
• Attitude/Emotion: Distrust of doctors/doctors’ advice, and “Laid back” attitude. | Non-compliance is due to the lack of “how-to” knowledge, resources, motivation and hope. Patients are not getting spiritual support (compared to cancer and other diseases). | T2DM can be controlled with healthy behaviors but that is very difficult so in reality it can’t be controlled. Lack of support from family members and church. |
| Complications   | • Attitude/Emotions: Patients feel shame, denial and indifferent.  
• Physical: Increase amputation, dialysis, and sores | Attitude/Emotions: pain, sadness and shame. Physical: amputation, dialysis, blindness and death. Cultural: losing a lot of elders and they are taking our cultural knowledge with them. | Attitude/Emotions: Fear, worry and depression  
Physical: early death, amputation, blindness and kidney failure  
Socio-economic: job loss, time off from work to care for relatives with diabetes, and cost of food, medicine and supplies. |

### Behaviors

Participants reported behaviors related to the different stages of diabetes from prevention and diagnosis to control and management. The bulk of the information on behaviors came from community members as expected given that participants were
diabetics and/or caregivers. In addition, health care providers and faith leaders provided their observations and perspectives on these behaviors.

**Diabetes Prevention**

Although the majority of community focus group participants said and agreed that diabetes can be prevented with behaviors such as healthy eating and physical activity, many reported numerous difficulties in engaging in those behaviors and some even called it impossible and not realistic in their current situation and unreachable.” As one participant from Chuuk candidly articulated,

Those things are hard, I know diabetes can be prevented but we can’t do those things for so many reasons, so the practical answer is no it can’t prevented.

Another participant added,

It’s easy to say eat right and exercise but doing them is a whole different story. We are at the point where we know that those things are important but making it a reality is so hard that I can’t even imagine what that life of eating right and exercise looks like.

Participants were probed on actions they are taking to prevent diabetes, many replied “none” or “trying but it’s hard” and a few “tried” in the past but were not successful.” At the end, many of the participants acknowledged they are not motivated to engage in preventative activities because they are feeling good and there is no pain. As one of the participants put it,

There are so many other urgent needs in my life that needs attention that if I’m not in pain then I’m not going to do anything. Don’t get me wrong, I would love to do something about it but like many of us around here we have housing issues, children getting in trouble with the law and not sure where we’re getting our next meal.

**Diabetes Diagnosis**

The majority of the participants knew the signs and symptoms of diabetes and cited the following: losing weight for no reason, craving for sweets, drinking lot of water, frequent urination, wounds hard to heal (turn black), blurry vision, lose teeth and not
feeling well (in general). Nevertheless, many reported that they or their family members do not seek medical help when these symptoms are presented. As a community participant from Hawaii remarked,

> I knew the signs but I did nothing until things got really bad and I can’t take the pain anymore so I went to the emergency room.

Another participant added,

> We usually start with traditional or local medicine, now there are other stuff like the water and oil and if that doesn’t help the pain then we go to the doctor and they are good at giving us medicine to take away the pain.

Health care providers also claimed that their Chuukese and Pacific Islander patients are being diagnosed at the clinic/hospital or the emergency room when they go in for diabetes related complications and other health concerns.

**Diabetes Management and Control**

The discussion around diabetes control was similar to that of prevention as the majority said it can be controlled by eating less fat, doing more physical activity, getting enough sleep and taking medication. However, they added that the actions that lead to control are too hard. A faith leader from Hawaii summarized these narratives by saying,

> From the biological, medical and physical point of view diabetes can be controlled but from our point of view as people from a different culture and social-economic conditions it is impossible and diabetes can’t be controlled.

Another participant added,

> In order for us to move the needle forward we need to look at culture and social-economic barriers and catalysts.

Participants also talked about what “control” means and for people with diabetes control means feeling good in general (physical), not tired/active, not sweating, and not nauseous. They also mentioned emotional benefits of control such as not being irritated, felling happy and not getting mad all the time. A participant from Chuuk testified,
If I feel good and there’s no pain, then it is controlled and I stay home and don’t see the doctor but if I feel pain or not feeling well to the point where I can’t do my church work then I go see the doctor.

These narratives confirmed health care providers claim that Chuukese patients mostly seek help when complications are at their worst.

Their search for relief led them to western, traditional, local and new/fad healing. Details on these four healing practices are in Chapter 5 (Medication Adherence). These healing practices provided medication to control pain, symptoms and complications of diabetes, however, only western and new/fad medicines dealt with diabetes control. It is also important to note that the pain and discomfort narrative did not differentiate the different sources of pain and discomfort. For example, they considered the negative consequences of medications (such as diarrhea, fatigue, headaches, bloating and stomach pain) as complications of diabetes and not side effects of diabetes medication; as a result, they rendered western diabetes medications ineffective. Furthermore, patients did not distinguish between medication that controls diabetes and medication that manages pain/discomfort. On the other side of the spectrum, there were patients who considered western medication as a cure or only solution for diabetes. For that reason, patients disregarded other diabetes management recommendations such as physical activity and proper nutrition.

Personal Factors

Several factors related to the prevention and management of T2DM were discussed by participants including beliefs on the cause of diabetes, knowledge of the disease, emotional/psychological factors and spirituality.

Disease Beliefs

Participants shared their beliefs on the cause of diabetes and it followed five types of etiology narratives. The most common narrative was around unhealthy lifestyle and behavior such as not eating the right type of food, being sedentary and living a stressful
life. The second most mentioned and discussed narrative was on the belief that diabetes is caused by God’s will and therefore behaviors do not matter. The third narrative also dismissed behavior and declared genetics as the cause. The fourth narrative combined God’s will and behavior as dual causes of diabetes. Participants stated that God is in control of everything and has a “perfect will” for their lives (good health is part of this of this perfect will). However, God also gives individuals a “free will” to choose the way they want to live. Finally, there were several groups that discussed black magic/supernatural power. They stated that someone (human) is using black magic, humans angered a spirit (e.g., land issues and relational issues), and some don’t know the cause but it is “dark spirit” and NOT “of this world.”

**Diabetes Knowledge**

As mentioned earlier the majority of the participants reported that diabetes can be controlled by healthy eating, engaging in physical activity and adhering to treatment regimens. However, participants reported that they need more detailed and “how to” information. For example, they need information on how to prepare healthy palatable meals and appropriate intensity of physical activity and tips to make it easier to take their medicine on time. Furthermore, the majority of the participants knew the signs and symptoms of diabetes and cited the following: losing weight for no reason, craving for sweets, drinking lot of water, frequent urination, wounds hard to heal (turn black), blurry vision, lose teeth and not feeling well (in general).

**Emotional and Psychological Factors**

Participants in all the focus groups engaged in lengthy discussion on emotions and psychological factors related to diabetes. The most mentioned was hopelessness, followed by a tie between fear and worry, and then shame and frustration. The feeling of hopelessness was discussed in all the focus groups and interview sessions. As mentioned earlier, participants are aware of behaviors that control T2DM but their inability to act
coupled with high prevalence of diabetes lead to numerous reports of hopelessness. A pastor from Chuuk reported,

People are giving up and we need to address the feeling of hopelessness, without hope we have no ground to stand on with our health messages.

Participants also reported being fearful of death at a younger age, amputation, blindness, kidney failure (dialysis), going to the bathroom at night and waking up tired, wounds that hard to heal. They worried about economic and social complications such as job loss, extra care for diabetes patient (hard and takes time away from other family concerns), breaks up family, can’t eat same food so can’t be part of the collective during meals and the cost of food, medicine and supplies. Shame was also a common response among the participants and as one participant puts it,

There are a lot of young people who are getting diabetes and there is a lot of shame in that because diabetes is a disease for old people.

Another participant admitted,

I have diabetes and it was hard from me to deal with the fact that some of it is my own doing and that is shameful.

Finally, participants also reported frustration with themselves for “not having the guts to take control” and with family members who are not supportive. A participant reported,

It is very hard to eat my vegetables while I’m at the dinner table with people who are eating all the food that I want to eat but cannot eat.

Another participant added,

I’m thankful that they are cooking a special meal for me but emotionally I get very depressed being the odd man out.

**Spirituality and Faith**

Spirituality was central in all the community discussions and faith leader interviewees explained some of the Christian beliefs, idioms and expressions. Participants defined spirituality as having faith or total trust in a higher power (referring to the Christian God). A participant from Hawaii pointed out that the scriptures defined faith as,
The substance of things hoped for, the evidence of things not seen which is found in the first verse of Hebrews.

Community members discussed its many benefits such as wisdom (seeing things clearly, putting struggles of life into perspective and getting directions), motivation, physical strength and healing, emotional support (release emotional stress), comfort, remove/decrease fear, hope and joy. A participant with diabetes affirmed,

Our spiritual beliefs give us hope that things will get better. This gives us strength to do things that are difficult and unpleasant. It also lift our spirit and that goes a long way.

Another participant added,

Prayer gives us comfort, our faith motivates and encourages us and it gives us the courage and strength to do the right even when we don’t feel like doing it.

Participants reported that Chuukese and Pacific Islanders trust God and turn to God for their needs. Pacific Islanders also believe in “God’s will”, as one pastor explained,

God has a perfect will for us. People get sick because there is evil in this world – we are living in a fallen world so that is one reason. Some people get sick because of their own doing and making the wrong decisions. Sometime we get sick because of what is going on in our environment. Many times we don’t know as the bible says His ways are not our ways.

He went further and explained the benefits of having a strong faith,

Ultimate the scripture teaches us to have hope and not fear, for God hath not given us the spirit of fear but of power and of love and of sound mind.

Environmental Factors

Environmental factors also influenced T2DM management and participants cited issues related to church support, social support (family members and pastors), health care providers, church, health care system and others (e.g., poverty, living in dangerous neighborhoods and discrimination). Specific and detailed information on environmental factors related to nutrition, physical activity and drug adherence are detailed in Chapters 3, 4 and 5, respectively.
Social Support

Given the collectivistic nature of the Chuukese culture, social support was also crucial to the success of controlling diabetes. Participants mentioned the need for family members, community and church leaders to provide physical, social and emotional support. Healthcare providers who were part of the interviews also emphasized the need for support. As one of the health providers from Chuuk conveyed,

Patients need to mentally, emotionally and physically willing to make lifestyle changes. This is a constant struggle and they need support from their family, church and village.

Family support in the form of encouragement, using resources to facilitate diabetes management (e.g., taxi fare so patients can make it to their appointments and purchasing/acquiring healthy foods) and incorporating diabetes control facilitators in their family activities (e.g., healthy family meals and family walks). One of the health care providers from Chuuk commented,

If families are not willing to prepare the type of food necessary for diabetes control then the person will give up and not just eating healthy, they give up on all other control measures.

Participants who were caregivers gave their perspective on providing support and they reported feeling physically tired all the time as there was no time to rest, disconnected from society as they do not have time for social activities, and have to make financial and personal sacrifices (e.g., students quit school to provide care, women quit jobs they enjoy).

Faith leaders also see themselves as vital players in diabetes control as they are well respected in the community and they can serve as messengers (health sermons), role models, counselors (biblical base) and motivators. One of the pastors said,

We can provide counseling, encouragement and hope. We can also provide health information and be advocate for support programs such as a community physical activity program. Moreover, they are experts in communication and the Pacific oratory culture. In order for this to occur pastors need to be educated in health issues, need a meeting “iron sharpens iron” to keep message current.
Health care providers were also supportive of including faith leaders as part of their diabetes team as they are well respected in the community. They stated that faith leaders have the potential of being great health educators, role models and health champions (policy and community support). They can also provide emotional and spiritual support, something that is need by the patients and health care provider cannot provide. As one of the health providers observed,

Patients come in with heavy hearts and they are not ready to hear anything until we settle emotional and spiritual struggles. And it does not end there we need to continue to encourage and motivate them for a lifetime.

He continued by saying,

We (health care providers) cannot handle all the emotional and spiritual issues of our patients and that is not our role – that is the role of the faith leaders. Faith leaders are also doing home visits to patients as part of their role in the community so they can provide diabetes education in the homes.

Healthcare Providers’ Support

For focus group participants who encountered healthcare providers, about half reported negative experiences. Patients reported that providers are impatient, disrespectful and out of touch with their socio-economic reality. Further probing revealed providers’ actions and situations that lead to these perceptions. Furthermore, health care providers and faith leaders interviewees commented and addressed these same issues and behaviors.

In describing provider behaviors described as “impatient”, the majority of the patients talked about being rushed through their visit and their doctors not giving them time to talk or respond to questions. On the other hand, healthcare providers reported frustration over Chuukese and other Pacific Islander patients’ silence during their visit. As a physician from Hawaii reported,

I tried to engage them and I asked them question but they don’t say anything, they just give that look, we call it the blank stare, so I ended up doing all the talking.
Faith leaders commented on this same issue and one explained,

In our culture there is this long gap between a question and an answer. Even in conversations there are these silences between one statement and another statement. These gaps are somewhat long for other people but not for us – that is the way we talk. I find that doctors don’t like that gap so they ask their questions and then answer it to fill that gap. At the end I don’t get a word in.

Discourses regarding disrespectful behaviors focused on communication, mannerisms and messages that were considered impolite by the participants. In regards to communication, patients felt that their providers’ tone of voice was harsh, unsympathetic, demanding, indifferent and cold. They also commented on the loud and fearsome volume of their providers’ voices. Mannerism and practices were also discussed and patients mentioned,

Physicians talking with their back facing us - mostly working on the computer and not taking the time to sit and explain things, rather they do busy work and not once sit in front of me and to me.

Patients felt that some of the words the providers use are disrespectful. For example one of the patients gave an account of her recent visit to the doctor,

I was wearing my magnetic bracelet and the doctor said that he heard from one of the outreach workers that we believe the bracelet will heal diabetes and then went on and on about how I shouldn’t trust in the bracelet and the people that gave it to me. I was hurt because my sister gave me the bracelet.

Another patient added,

They also say things like ‘you people don’t listen’ or ‘I know you people like to eat fatty foods’ - I really don’t like when they say things like that.

Health care providers did recognize that their patient load limits the time they spend with patients. They expressed the desire to spend more time with each patient as one provider commented,

We are always in a rush and don’t have time to consider the background of each patient. As you know, we see patients from multiple cultures and it is hard to keep track. I do want to improve and learn a better way to communicate with patients.
Church Support

Church is the center of the Chuukese culture and plays a major role in the lives of the Chuukese people. Community focus group participants reported that they are highly involved with their church activities and many are spending over five days engaging in various church-related activities. Currently there is not a lot of support from the church in regards to diabetes management and participants expressed the need for churches to get more involved in activities that support diabetes management. They also gave the following examples of how churches can implement diabetes initiatives that promote diabetes education (e.g., sponsoring diabetes awareness month activities), physical activity (e.g., church cleaning, walking to church and standing during services) and nutrition (e.g., cooking classes, policy on feasting) and medication adherence (e.g., reminder and motivation). Faith leaders recognized the important role churches plays in the community and the need for churches to support health programs. A pastor from Chuuk acknowledged,

Churches are natural gathering places for Chuukese in Chuuk and Hawaii.

Another pastor added,

Churches are well organized; we have the facility and can facilitate diabetes control activities.

Healthcare System Support

Patients and providers discussed several issues related to the healthcare system including lack of allotted time, the clinic culture/processes and limited resources. The most saturated issue in regards to health care was lack of allotted time for providers to care for patients. Patients felt that they are being rushed and at the end they don’t get a lot of information, encouragement and satisfaction out the visit. In addition patients mentioned that the clinic culture and processes leave them feeling powerless and as one patient explained,

I have absolute no power in the doctor’s office, they tell me when to show up, where to sit, when to stand, where to go and what to do. They also know
everything about me, like my name and all my personal information, and I know nothing about them. I know that there is a reason why they know all my information but that does not take away the feeling that it is an unbalanced relationship.

Patients from both sites also mentioned the limited resources that lead to lack of language (translation) services (in Hawaii), lack of specialists (Chuuk), long waiting hours, and inconvenient clinic hours. Patients also mentioned the high turn-around of physicians in the health centers saying,

They always change doctor so they need to start the relationship building all over again.

Health practitioners also shared these views as they expressed the need to minimize the language and cultural gap, and health providers in Chuuk emphasized the need for resources. All sites expressed the need to build better relationships, improve communication, and respect for healing of the mind body and spirit. They also expressed the need for further research on the relationship between diabetes control and culture.

One of the health providers said,

What we are doing right now is not working, we need to do something different and I firmly believe that culture and spirituality needs to play a major role. We do not know a lot about the Pacific culture and how we can incorporate it into our treatments so research is a great start.

Economic and other Environmental Support

Participants from both sites communicated economic and environmental barriers to glycemic control that are related to poverty. For those living in Hawaii, discrimination was also an issue. Patients with diabetes and their caregivers were feeling overwhelmed with what they called “diabetes plus” or juggling the numerous actions that one needs to prevent and control diabetes plus dealing with all other struggles in life. A participant from Hawaii articulated this point by saying,

We are facing a lot of problems – everyday. We are living in a foreign land and we are poor. I can control my diabetes if my living condition was different and not poor. Our children are getting into drugs and crime, so we worry about those things. We live in dangerous neighborhoods so we worry about that. Some of us are homeless and we worry about that. At the end of the day, we don’t have time to think about not eating enough vegetables. This is where we are at so how can we get out of that?
For participants from Chuuk, they reported lack of resources (e.g., medications, glucometers and healthy foods) and infrastructures (e.g., safe roads/sidewalks and facilities to exercise). In addition to economic related issues, patients from Hawaii also reported discrimination as one of the major barriers as one participant summarized,

I go to one of the clinics where some of us go because it is near our house. I see them treat local people different; they treat them better and see them first. I can also hear the staff talk about us behind the wall, bad stuff, like they are coming here and taking too much time. That hurts and I know many of us here have that experience. You read the newspapers and you see stories like mine.

**Discussion**

This was the first study to investigate the scope and depth of the burden of the T2DM epidemic among Chuukese from the perspectives of community members (people with diabetes and caregivers), faith leaders and health care providers. Participants reported T2DM as a major problem. In response to questions based on constructs in the Social Cognitive Theory, participants revealed facilitators and barriers that were aligned with the Social Cognitive Theory. For example, the results showed personal factors (e.g., lack of specific/specialized knowledge, disease beliefs, emotional/psychological factors and faith) and environmental influences (e.g. family, church, economic and health care system support) that were similar to other population in the U.S. Furthermore, the discussions revealed socio-cultural aspects and nuances of behaviors, personal factors and environmental influences that will contribute to the literature and inform research and health programs to reduce chronic disease health disparities among Pacific Islanders including Chuukese.

During the discussions two significant narratives surfaced: the (1) pain narrative or the practice of seeking medical help only when in pain and (2) spiritual/religious narrative or spirituality’s role in diabetes control and its influence on help-seeking behaviors. These narratives will be discussed below within the context of developing interventions to improve glycemic control among Chuukese and other Pacific Islanders.
Pain Narratives

In all the conversations, pain and discomfort caused by diabetes and diabetes medication was prominent in terms of the number of individuals participating in the discussion, the amount of time it was brought up and the length of time spent of the topic. Patients cited the lack of pain as one of the reasons for not engaging in diabetes preventive and screening activities. Moreover, the presence of “unbearable pain” was the motivation to seek medical help. According to the Turner and colleagues (1998), diabetes is usually painless in its early stage and pain usually emerges at a later stage when diabetes complications are at their worst. At this point, not much can be done versus identifying the problem early so complications can be minimized or prevented (Inzucchi, 2012). Research revealed that patients use symptoms as a primary part of their assessments of their personal health and diabetes control (Lange and Piette, 2005).

Given the benefits of engaging in glycemic prevention and control activities, it is critical to address and reverse this current practice of waiting for the pain to appear to take action. This population could benefit from an intervention that aspires to increase awareness of the benefits and importance of seeking help early (before the pain) and provide a supportive environment (e.g., access to services and community encouragement) that make it conducive to seek help early. Future research is needed to determine: (1) the most effective way to communicate the “seek help before the pain” message; (2) the types of support patients need to facilitate early help-seeking behaviors; and (3) the effectiveness of these approaches in increasing prevention, screening and control activities.

There is a paucity of information on this topic for Chuukese and other Pacific Islanders. Other public health practitioners in geographic isolated areas found success in tailoring their cancer message to include no symptoms required for health screening or healthy people should be screened (e.g., Campo, Askelson, Routsong, Graaf, Losch &
They also underscored the necessity to tailor health messages to the local context.

Prior to tailoring health messages for this population, it is important to deal with the fundamental issue of disease-etioloogy beliefs because this influences where individuals go to for help. For example, those who seek help from healthcare providers believe it is God’s global will plus unhealthy behaviors, those who seek help from traditional healers believe it caused by spirits and those who do not seek help believe it is God’s will only. Spirituality is at the core of these beliefs so it is important for health practitioners to partner with spiritual leaders to help develop and deliver these messages. This study showed that healthcare providers and faith leaders are willing to work together to improve the lives of their patients/parishioner. A faith leader in Chuuk relayed the following message,

As a pastor, I want what is best for the people and I know that health is very important. Many of our people are sick so it is critical that we do something right now. I’m not a health professional and I can’t do much by myself. I’m willing to sit down and talk to the folks at the hospital and public health. I can support many of their activities but I need to know what they are and they need to let me know what I can do to help.

A health provider in Chuuk also expressed his willingness to work with churches and church leaders,

Chuukese love their churches and respect their church leaders. I know they can help us with a lot of our community outreaches and programs. I would like to work closely with the churches, and I know many of my colleagues would like the same thing.

Spiritual and Religious Narratives

The findings highlighted the centrality of spirituality and religiosity in health and health seeking behaviors. All three groups (faith leaders, health care providers and community members) agreed that most diabetes patients are not eating healthy, not engaging in physical activity and not taking their medication as directed. Health care providers reported their patients know the necessary behaviors to control their diabetes and the benefits of these actions however they are not in compliance because they are
either indifferent, in denial or stubborn. Community participants and faith leaders agreed with this assessment and further discussed three religiosity/spirituality-related reasons for these attitudes and non-compliance: God’s will (external locus of control); lack of spiritually derived guidance and emotional support; and lack of support from the church (religiosity-related).

Previous studies have examined the role of churches and spirituality in health promotion and care. Lewis and Ogedegbe (2008) developed a conceptual model of spiritual and medication adherence for African American with hypertension that includes spiritual guidance/support and church support (resources for overcoming barriers). Polzer and Miles (2007), developed a theoretical model that explains how spirituality affects self-management of diabetes in African Americans that focus on the relationship with God (God is in background, God is in the forefront and God is Healer). Baig and colleagues (2012) developed a framework for the design of church-based diabetes intervention for Mexican-American Catholics that includes information, skills, social interaction and cultural tailoring.

There is a gap in the literatures in regards to the relationship between the three spirituality related factors (God’s will, spiritual guidance/support and church support) and environmental context, emotional reaction and T2DM treatment compliance. Participants in this study described pathway-like scenarios that began with etiology of disease statement that references God’s will or lack of God’s will in the context of environmental influences (including church-based support) that led to emotional reactions and compliance to treatment (Figure 2).

The first and most mentioned narrative began with the belief that diabetes is caused by behaviors (e.g., unhealthy diet, sedentary lifestyle and not adhering to medical treatments). In spite of this awareness, they reported that their environment did not have the necessary support (spiritual, emotional and environment) to adhere to T2DM control recommendations. A Chuuk focus group participant declared,
I have diabetes and I feel sick sometimes because of the unhealthy food that I eat and I don’t follow what the doctor told me. I know that many people know that we need to eat healthy and move around but that is hard to do. There is not a lot of support and compassion for us with diabetes. I don’t get to choose the kind of food I eat because when I go to meetings I eat whatever is served and I don’t want to be rude and say this is not good for my diabetes. I get sad sometimes especially when I’m sick but I don’t say it to people because they think it is my fault that I have diabetes.

It is important to note that this was the only narrative that did not include God’s will or other spirits in the etiology statement. In other words, God didn’t cause it to happen and He didn’t give support to those who have diabetes. This context led to shame, denial and hopelessness and these feelings or emotions lead non-compliance to diabetes control activities. Participants also discussed an alternative to this scenario where patients believe that diabetes is caused by behavior but instead of non-compliance they act in accordance with a diabetes management plan. However, participants reported that this was impossible due to the lack of critical and necessary spiritual, social and environmental support.

The second most common narrative began with the belief that diabetes and everything that happens in life is “God’s will” and context remains the same. This view lead to passiveness as the locus of control was outside of themselves and this lead no action/non-compliance. The context in this scenario was the same as the first scenario however, the locus of control (both health and context) was outside, and therefore, there was no mention of shame or denial. Instead, the feeling of hopelessness surfaced during the discussion.

The third narrative was similar to the previous scenario as participants believed in God’s will. However, they also believe that it is also due to genetics or “runs in the family. The locus of control was outside and this led to passiveness and no action/non-compliance.

In the fourth narrative, participants believed that diabetes is caused by unhealthy behaviors with the acknowledgement of God’s sovereign and perfect will. Unlike the previous scenario where the locus of control is totally outside of patient’s control, this
group believed that God gave men “free will” to choose how to live their lives. Furthermore, choosing to engage in unhealthy behavior is an act of rebellion towards God. This understanding led to repentance and with God’s help (spiritual support) and with the necessary support and resources (context). Although the cultural, social and economic context in this case is the same as the previous two, participants have faith that God can provide the wisdom, resources and strength to improve their situation. To that end, patients complied with diabetes treatments (traditional, local, fad or western medicine). Discussion on these various treatments is in Chapter 5. What made this scenario’s discussion different was the mention of faith and hope that urged patients to improve their health and context. Although participants reported that not many individuals are following this scenario, they believe that it is the most positive and effective way to approach the treatment non-adherence issue.

The final narrative, patients believe that diabetes is a Pacific illness caused by spirits and not behavior, family and community members are supportive of this viewpoint and like second scenario this viewpoint does not require major environmental support. This belief lead to fear of spiritual powers and individuals therefore seek the help of traditional healers. According to study participants, this was a popular belief a generation ago but very few patients still held on this belief are seeking help from traditional healers.
These narratives highlight the importance of spirituality on the personal level as it influenced etiology of diabetes beliefs and provided emotional/mental support to patients. It also showed benefits of religiosity on the environmental level as pastors and churches can provide physical support (e.g., healthy feasting environment and safe place to exercise) and emotional/mental support. In order to improve compliance in this population, a partnership between health providers and faith leaders needs to develop to provide continuous spiritual support to patients with diabetes. There is also a need to improve environmental support for people with diabetes. Faith leaders are influential and can also play an important role in improving environment and social support through the churches.
Since this is the first study that revealed the relationship between these constructs in a pathway-like manner, future study is needed (1) to look at each of the constructs and their components; (2) determine the type of spiritual support and/or interventions patients need to comply to T2DM management recommendations’ and (3) the effectiveness of these approaches in improving health outcomes.

**Conclusion**

Diabetes is a relatively new illness in the Pacific; therefore it is necessary to understand the socio-ecological influences including cultural context and local belief system surrounding glycemic control. In other cultural groups, the understanding and utilization of an entho-medical model of diabetes has been critical in developing culturally appropriate interventions (Gittelsohn et al., 1995; Shintani, Beckman, O’Conner, Hughes & Sato, 1994; Zimmet, McCarty & deCourten, 1997). An earlier study by Cortes and colleagues (2001) stated that gaps in the current body of knowledge are Pacific Islanders perceptions of diabetes, its perceived causes, symptoms, progression, and treatment-seeking behaviors associated with these perceptions (Cortes, Gittelsohn, Alfred & Palafox, 2001). This study provided much needed information to address these gaps. The achievement of success in diabetes self-management will only commence after gaps are better understood and interventions are tailored to meet Pacific Islanders socio-cultural paradigms.

This study has several limitations. The findings have limited generalizability because the participants are from one ethnic group (Chuukese), in two geographic locations (Chuuk and Hawaii) and one religion (Christianity). The focus group sessions included English speakers, and the views of non-English speakers may be different. Moreover, respondents may have given socially desirable answers. However, participants repeated the same or similar narratives across interviews and focus groups which reassure that common responses were captured and represented a wide range of beliefs.
CHAPTER 3
STUDY 2: MEDICAL NUTRITION THERAPY

Introduction

Type 2 diabetes (T2DM) is a chronic degenerative disease with the greatest negative effects on economically productive adults. Chronic hyperglycemia is the main cause of long-term complications that ultimately result in damage of key organs, decreased years of healthy life and premature deaths (American Diabetes Association [ADA], 2005). The type 2 diabetes epidemic is a global health issue, and it is especially severe in the Pacific (Hosey et al., 2009). Although a post-World War II US Navy survey of the Pacific Islands found no cases of diabetes, subsequent population surveys have shown a dramatic increase in diabetes (Institute of Medicine [IOM], 1998). In 2007, the estimated prevalence of diabetes for the US population (adults aged 20 years or older, diagnosed and undiagnosed) was 10.7% (Centers for Disease Control and Prevention [CDC], 2007). In the U.S Pacific diabetes rates range from 24.4% in the Federated States of Micronesia to 47.3% in American Samoa (FSM DHSA, 2008; WHO, 2007).

Nutrition plays a critical role in the therapeutic strategy to keep patients with T2DM in good glycemic control and prevent complications (Franz et al., 1995). Nutrition therapy incorporated in diabetes management education has been proven to be successful and cost-effective in improving blood pressure, serum lipids and glycemic control (Johnson & Valera 1995; Miller, Edwards, Kissling & Sanville, 2002; Sheils, Rubin & Stapleton, 1999). However, many individuals with diabetes do not adhere to nutrition recommendations (Rivelles et al., 2008). Due to the high prevalence of diabetes among Pacific Islanders and the significant role nutrition plays in diabetes management it is critical for health researchers and practitioners to investigate the current state of nutrition therapy among people with diabetes in this populations and to seek ways
to improve adherence to nutrition recommendations. Moreover, community partners in the Pacific identified (1) diabetes management and specifically nutrition as a research focus; (2) healthcare providers, faith leaders, individuals with diabetes and caregivers as study subjects; and (3) Chuukese in Chuuk and Hawaii as the target ethnic group and research sites. Accordingly, the primary aim of this study is to identify socio-cultural influences that hinder or facilitate adherence to nutrition therapy among Pacific Islanders.

Several scientific societies involved in the treatment of T2DM, such as the American Diabetes Association, issued dietary recommendations. Many practitioners are utilizing the glycemic index as a tool for patients. The glycemic index categorizes food by effect on glucose levels (Jenkins et al., 1981). High glycemic index foods cause blood glucose levels to rise and fall quickly making glycemic control more difficult to attain. On the other hand, foods with low glycemic index cause glucose levels to rise at a slower steadier rate (Ludwig, 2002). Researchers found that individuals with T2DM who follow a low glycemic diet significantly decrease their HbA1c levels and their body mass index (BMI) (Burani & Longo, 2006). In addition to monitoring carbohydrate intake, it is recommended that fat intake be limited to approximately 25 to 35% of the daily calories consumed and protein should contribute to no more than 20% of the daily calories consumed (ADA, 2011). Patients with T2DM are encouraged to consult a nutritionist or dietary counselor prior to making dietary changes. In addition to offering additional level of support, nutrition consultations allow individuals to learn what foods are appropriate for them to eat as well as how often they should eat and what is an appropriate portion size.

The significance and the scientific basis of these recommendations are well documented. However, their translation into daily routine is very difficult and studies have shown poor adherence (Rivellese et al., 2008). Researchers have identified numerous factors that influence food consumption and barriers to adherence. The most ubiquitous barriers are cost of healthy foods and taste preferences (Glanz, Basil,
Other concerns are forgetfulness or reverting back to old habits, low availability of healthy choices (food environments) and lack of ideas for healthy meals/cooking (Brekke, Sunesson, Axelsen & Lenner, 2004). A recent study in a low-income neighborhood in the U.S. with high rates of T2DM showed that access to healthy foods is geographically, culturally and economically restricted (Chaufan, Constantino & Davis & , 2012).

Researchers also found facilitators such as family support (Lloyd et al., 1995; Brekke et al., 2004) and medical nutrition therapy provided by a dietitian (Al-Shoorki, Khor, Chan, Loke & Al-Maskari, 2012). Despite evidence that supports the benefits of diabetes self-management education with a nutrition therapy focus, limited information is available on the efficacy of these efforts in minority populations. Minority populations have the highest burden of diabetes (Carter, Pugh & Monterrosa, 1996), limited access to diabetes self-management resources and support (Rothman et al., 2004), and poorer glycemic control (Koro, Bowlin, Bourgeois & Fedder, 2004). Traditional interventions for minority populations have met with limited success due to low participation and retention rates (Bruce, Davis, Cull & Davis, 2003). Possible explanations for these low rates include low levels of English literacy, lack of culturally appropriate nutrition modification options and income constraints (Gohdes, 1988). Minority groups whose primary language is not English may also experience language discordance with their English-speaking care providers. Language discordance can lead to a decrease in patient comprehension, compliance and consequently poor clinical outcomes (Perez-Stable, Napoles-Springer & Miraontes, 1999). Scholars and practitioners recommend the consideration of culture in diabetes interventions to assist minority populations in their management of T2DM as this will reduce language and culture barriers, and to increase the appeal of diabetes self-management education (Gucciardi, DeMelo, Lee & Grace, 2007).
In the past few years, researchers found success in modifying mainstream programs. For instance, (Tomioka, Braun, Compton & Tanoue, 2012) and colleagues modified the Stanford’s Chronic Disease Self-Management Program for Asian and Pacific Islanders in the state of Hawaii. Other researchers developed culturally competent diabetes education programs. Gucciardi and colleagues (2007) examined the impact of two culturally competent diabetes education methods for residents of Hawaii and found a significant improvement in attitudes, subjective norms, perceived behavior control, intention towards nutrition adherence, self-reported nutrition adherence and glycemic control. Moreover, individual counseling with group education showed greater improvement in adherence. In China, Browning and colleagues (2011) found success in an intervention that uses health coaches trained in behavioral change and motivational interviewing techniques to assist with the management of T2DM.

Nutrition data for Pacific Islanders including Chuukese is scarce. Surveillance data collection has just begun in the past ten years with the first round of STEPwise survey conducted by the World Health Organization. According to the *Federated States of Micronesia (Chuuk): Non-communicable disease risk factors STEPS Report* (FSM DPHS, 2012), 90% of the population consume less than five servings of fruits and vegetables per day. U.S surveillance systems currently aggregate Asian American and Pacific Islander data. Available data show that Pacific Islanders in general have poor diet that is high in fat and low in fruits and vegetables (Jackson, 1997; Lako & Nguyen, 1991). A recent study exploring social determinants of proper nutrition in a low-income minority population in the US similar to our target population found cost of food, transportation, language, stigma, immigration status, work conditions and competing basic needs or constraints of poverty as barriers to healthy eating (Chaufan, Constantino & Davis, 2012). For immigrants/migrants, individual and interpersonal factors also play a significant role in eating practices as many continued to consume ethnic food despite their perceived concerns that these foods may not be good for their health. Respondents
described such foods as strength giving and highlighted a cultural expectation to participate in acts of commensality with family/community members (Lawton et al., 2008). These factors are also likely to be contributing to nutrition adherence among Chuukese in both Hawaii and Chuuk, which are explored in this research study. Due to the lack of information on nutrition therapy adherence, this formative study explored issues around nutrition therapy adherence from four perspectives: health care providers, faith-leaders, diabetes patients and diabetes patients’ family members/caregivers.

Method

Community representatives selected the research topic, subjects and sites through various community meetings and consultation with the Pacific Chronic Disease Coalition. They also selected the University of Iowa as their scientific partner and the use of Community Based Participatory Research (CBPR) principles as guidelines. CBPR principles calls for research that is based on community-set priorities, builds on community strengths and resources, provides tangible benefits, and does no harm (Israel et al., 1998). This method of research has been successful in the Native Hawaiian and Pacific Islander communities as demonstrated by the PILI `Ohana Project (Kaholokula et al., 2008; Nacapoy et al., 2008) and the `Imi Hale Native Hawaiian Cancer Network (Braun, Tsark, Santos, Aitaoto & Chong, 2006; Aitaoto, Braun, Estrella, Epelulk & Tsark, 2012). To that end, research tools were developed with the approval of community representatives (members of the Pacific Chronic Disease Coalition) and the University of Iowa Institute Review Board (IRB). Partnerships with two community organizations, Chuuk Women’s Council (CWC) and Micronesians United (MU) were formed to assist with study participants recruitment and data collection logistic support. This study was part of a larger qualitative inquiry that included overall diabetes inquiry.

The scarcity of information on nutrition therapy adherence for Chuukese and other Pacific Islanders necessitates the use of Grounded Theory and qualitative methods (key informant interviews and focus group) to gather information. Grounded Theory
highlights theoretical constructs and relationships that are derived from rather than imposed upon the data allowing for both inductive and deductive approaches to be used (Charmaz, 2006). Other indigenous researchers used it because it also follows the notion that the best way to study indigenous experiences is through social processes and interactions (Abdoli, Ashtorab, Parvizi & Dunning, 2009; Strauss & Corbin, 1990). In addition to the Grounded Theory and in accordance with Grounded Theory practices, the Social Cognitive Theory (SCT) was used to sensitize the topic. SCT was used as a starting point and formulate initial research questions. SCT describes the interrelationship between behavior, environmental factors, and personal factors (Bandura, 1989, 1998).

Measures

Data were obtained from four perspectives: faith leaders, health care providers, individuals with diabetes and caregivers. The first set of data from faith leaders and health providers were acquired through one-on-one interviews. The objectives of the these interviews were to (1) obtain their perspective regarding nutrition and nutrition therapy for diabetes prevention and control; (2) obtain their experience and actions regarding nutrition therapy adherence; and (3) determine whether they are supportive of faith-based nutrition interventions (see Appendices A and B, for full interview protocols). Participants also completed a questionnaire on demographic information such as age, sex, religion/denomination, diabetes status and employment status. The second sets of data were obtained from individuals with diabetes and caregivers through focus group discussions. The objectives of the focus groups were to (1) obtain their perspective, experience and actions regarding nutrition therapy; and (2) determine whether they are supportive of faith-based nutrition initiatives. Participants also completed a questionnaire on demographic information such as age, sex, religion and diabetes status.
Procedures

Healthcare Provider and Faith Leader Interviews

In accordance with CBPR principles two community partners, Chuuk Women’s Council (CWC) and Micronesians United (MU), organized community meetings to identify faith and health care providers for the interviews. A total of 12 health care providers and 17 faith leaders were identified and all 29 were invited to participate via email and telephone using a script approved by the UI-IRB. All 29 individuals agreed to be interviewed. Interviews were conducted in the CWC office (Chuuk faith leaders and health care providers), MU’s office (Hawaii faith leaders) and interviewee/provider office (Hawaii providers). Interviews were recorded with the permission of the interviewees and were reviewed after each discussion to guide probing questions for the next interview session. Interviews lasted approximately three hours in Chuuk and two hours in Hawaii. The difference in time was due to communication styles and cultural knowledge. The Chuuk participants were all Chuukese and they explained numerous cultural practices in details and on the other hand Hawaii participants were mostly non-Chuukese. The in-depth nature of these intensive interviews was ideal for this study as it extracted each participant’s viewpoint and interpretation of his or her experience.

Community Focus Groups

Focus groups are small groups of individuals replying to a set of open-ended questions that provide a means of gaining a broad understanding of values, meanings, and perceptions of phenomena (Morgan & Krueger 1998). The recruitment of focus group participants began with presentations during CWC and MU meetings, church services, church meetings and community gatherings. Those who were interested in participating were formally invited via email and telephone using a script approved by the UI-IRB. A total 120 individuals were contacted and 102 (85%) participated. The Chuuk focus groups were held at a local hotel because it was the most accessible site for participants.
The Hawaii focus groups were held at community non-profit organizations’ conference rooms.

CBPR practice necessitates the transference of skills to community members; hence two community leaders were trained to facilitate and record focus group sessions. Per cultural protocols, a female staff facilitated the female focus groups and a male facilitated the male focus groups. Focus group sessions were recorded and the audiotapes were reviewed after each session to guide probing questions for the next session. A focus group guide that included general rules and a script (Appendix C) was provided to the facilitators and note takers. Focus group conversations were audio taped with permission and key ideas were recorded on paper posted on the wall for all to review, and participants were free to offer corrections to this record.

Participants

A total of 12 health care providers (6 in Hawaii and 6 in Chuuk) and 17 faith leaders (8 in Hawaii and 9 in Chuuk) participated in key informant interviews (Table 10). The average ages were 50 years for health care providers and 52 years for the faith leaders. A total of 102 individuals (people with diabetes and caregivers) participated in a focus group sessions held in Hawaii and Chuuk (Table 11).

Healthcare Providers and Faith Leaders Interviews

The category health care providers included three alternative medicine practitioners, three nurses and six physicians. The majority (83%) practiced for at least 20 years, 58% were Chuukese, and all five non-Chuukese providers practiced in Hawaii. The category of faith leaders included seven pastors, four deacons, four pastor’s wife and two deaconesses. They were all Chuukese and served in the ministry full time. In Hawaii, 89% of the interviewees worked outside of their church in addition to full time ministry as compared to 25% in Chuuk.
Table 10. Interviewees Demographic Information.

<table>
<thead>
<tr>
<th></th>
<th>Chuuk Health Providers</th>
<th>Chuuk Faith Leaders</th>
<th>Hawaii Health Providers</th>
<th>Hawaii Faith Leaders</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Participants</td>
<td>6</td>
<td>8</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Number of male/females</td>
<td>3/3</td>
<td>5/3</td>
<td>4/2</td>
<td>6/3</td>
</tr>
<tr>
<td>Ethnicity Chuukesenate/non-Chuukese</td>
<td>6/0</td>
<td>8/0</td>
<td>1/5</td>
<td>9/0</td>
</tr>
<tr>
<td>Average Age (years)</td>
<td>45.7</td>
<td>52.2</td>
<td>51.7</td>
<td>50.8</td>
</tr>
<tr>
<td>Age Range (years)</td>
<td>37-58</td>
<td>44-59</td>
<td>36-67</td>
<td>41-62</td>
</tr>
<tr>
<td>Catholics/Protestants</td>
<td>na</td>
<td>3/5</td>
<td>na</td>
<td>3/6</td>
</tr>
</tbody>
</table>

Community Focus Groups

A total of 102 individuals participated in a total of 16 focus groups. Eight focus groups were conducted in Chuuk (three females only, three males only and two combined males and females) and a total of 43 individuals (24 females and 19 males) participated. Eight focus groups were conducted in Hawaii (4 females only and 4 males only) and a total of 59 individuals (32 females and 27 males) participated (Table 11). Overall, the average age of participants was 46 years (43 years in Chuuk and 47 in Hawaii).

Table 11: Focus Group Demographic Information

<table>
<thead>
<tr>
<th></th>
<th>Chuuk</th>
<th>Hawaii</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Focus groups</td>
<td>8</td>
<td>8</td>
<td>15</td>
</tr>
<tr>
<td>Number of Participants</td>
<td>43</td>
<td>59</td>
<td>102</td>
</tr>
<tr>
<td>Female Participants</td>
<td>24</td>
<td>32</td>
<td>56</td>
</tr>
<tr>
<td>Male Participants</td>
<td>19</td>
<td>27</td>
<td>46</td>
</tr>
<tr>
<td>Average Age (years)</td>
<td>43</td>
<td>47</td>
<td>46</td>
</tr>
<tr>
<td>Age Range (years)</td>
<td>19-64</td>
<td>19-78</td>
<td>19-78</td>
</tr>
<tr>
<td>Catholics/Protestants</td>
<td>17/26</td>
<td>26/33</td>
<td>43/59</td>
</tr>
<tr>
<td>T2DM status: Y/N/Unknown</td>
<td>25/14/4</td>
<td>29/30/0</td>
<td>54/44/4</td>
</tr>
<tr>
<td>Health Care Provider: Y/N</td>
<td>43/0</td>
<td>49/10</td>
<td>92/10</td>
</tr>
</tbody>
</table>
Data Analysis

In line with CBPR principles, the two representatives from the U.S. Pacific that were part of the data collection team also participated in data analysis. Grounded theory principles guided the analysis of the interview and focus group transcripts with sensitivity to individual, behavioral, and environmental influences consistent with Social Cognitive Theory (Bandura, 1989, 1998). The team started the process with the analysis of the faith leaders and health care providers data in the fall of 2011. The first step was applying labels to portions of data with a code that concurrently categorizes, summarizes and accounts for each piece of data (Charmaz, 2006). The data analysis team did this independently and met face-to-face a two weeks later to do group coding. The team worked quickly through the transcript identifying coding incidences and paying attention to In Vivo codes or words/phrases that compress meanings that consist of widely used terms that participants assume everyone shares. The team also made notes of fleeting ideas about codes and noted items for later discussions. As the team progressed though the transcript they came upon similar types of responses so they implemented focused coding to synthesize and explain larger segments of data. Focus coding allowed the team to use previous codes to sift through large amounts of data and required decisions about which initial codes make the most analytic sense to categorize our data incisively and completely (Charmaz, 2006).

The initial coding process breaks the data into separate pieces and codes but the axial coding process reunited these pieces to form a coherent whole. This process sorted the initial codes, grouped them into common themes, used groupings to develop major categories with subcategories, and showed the links between them. The group also reviewed early memos to start the clustering process. This process produced a tentative and flexible chart of our categories and sub-categories. This process directed the team to a tentative theory that needs further examination and refinement. Finally, the team
identified future research questions that can elaborate and refine categories in our theory. The analysis of focus group results followed the same protocol.

**Results**

Key interview and focus group participants communicated various aspects of nutrition therapy adherence. As mentioned earlier, the research questions were sensitized around the Social Cognitive Theory. Therefore, the results are organized below by behaviors, personal factors and environmental influences. Moreover, participants gave suggestions on culturally and contextually appropriate interventions for their community and they are included below as intervention ideas.

**Behaviors**

Focus group discussions around nutrition therapy behaviors began within comments on overall diabetes self-management adherence, as many were not following their doctor’s advice including nutrition recommendations. For those who sought medical assistance for diabetes did so to manage pain or other complications. A Chuukese faith leader who is also a diabetic stated,

> We go to the doctor to make us numb to the pain. We only go in because something was wrong and wanted our doctor to give us medicine to make the pain go away but we have no desire to follow all the other advice like eating right and exercise.

Participants in all 16 focus group sessions also reported low intake of fruits and vegetables, high intake of unhealthy foods (foods with high salt, sugar and fat contents) and widespread unhealthy cooking practices (e.g., deep-frying and marinating in salty sauces). As one of the participants from Hawaii described,

> We eat a lot canned food because it’s cheap and we are used to it. It is also easy to cook. I usually put it on the frying pan and fry it. During the war time it was the only kind of food that was available and my mother grew up eating that way so she raised me that way and now my children are used to eating canned food. We usually eat it with rice because it’s cheaper and easy to cook. My kids also like to eat rice with lots of shoyu.
Results from faith leaders and healthcare provider interviews also agreed with these statements. A healthcare provider in Hawaii who works with Micronesians in Hawaii reported,

A typical meal contains starch and protein. For a starch, they usually eat white rice because it’s easy to get. Sometimes they eat taro, tapioca or breadfruit but very rare because they are more expensive and it takes extra time to prepare. For protein, they eat mostly canned or processed meat but sometimes they eat chicken. If they include vegetable, it usually because it was incorporated in the protein dish, like a stir-fry with beef or chicken. They also tend to add a lot of salt in their foods.

Personal Factors

Conversations in all 16 focus groups included discussions on nutrition knowledge or what participants considered healthy and unhealthy foods. In regards to healthy foods, participants were very general in their description of what was considered healthy foods. Most cited fruits, vegetables and foods with less fat, less sugar and less salt. In regards to unhealthy foods, participants were also very general in their descriptions, citing sugary, salty, fatty foods and fried foods, however, they also gave specific examples like corned beef, sausages, turkey tails, donuts, cookies, candies and sodas. Furthermore, all 16 focus group discussions suggested that Chuukese recognized the importance of good nutrition in the prevention and control of diabetes as demonstrated by this comment made by the one of the caregivers,

I know that the kind of food my family eats is important as it can help put off illnesses that are harming our people, like diabetes, heart attack and stroke. However, a great majority of participants reported negative emotions and attitudes toward healthy foods and positive emotions and attitudes towards unhealthy food. They stated that unhealthy foods are palatable and make them emotionally satisfied. The majority of participants mentioned emotions and its relationship to food. As one male focus group participant from Hawaii summarized:

Eating tasty food is the only pleasure we have in life. There is not much going for us, if you look around, life is not that great so eating these foods makes us happy and lifts our spirit.
Another participant added,

Even if we know that it will make us sick later, it is that moment of happiness that matters.

On the other hand, participants reported that healthy foods were not palatable and did not have any emotional connections. A participant from Chuuk summed this up by saying,

I did not grow up eating these types of food, especially vegetables so I’m not used to the strange flavor and it doesn’t make feel good - emotionally.

Another participant added,

Healthy foods have no flavor, they don’t taste good and I feel angry and depressed after I eat them. We are so used to eating salty foods so switching to bland foods like vegetables is a hard.

Healthcare providers also took notice of these emotions and attitudes towards foods. A Chuukese healthcare provider stated,

Patients have the hardest time changing their diet. It’s both physical and emotion. On the physical side, some of my patients said they lost their taste buds so they eat very salty food to get some kind of taste from the food. On the emotional side, these unhealthy foods are also their comfort food.

In addition to emotional and attitude issues, satisfaction from healthy foods was also a major concern. Healthy foods did make them full or it does not satisfy. A diabetic from Chuuk said,

Eating vegetables is a waste of time because at the end I’m still hungry and that is why I like eating meat and starch because it makes me full, and I feel full for a long time.

Another issue that was mentioned by the majority of the focus group participants and all key informant interviewees (faith leaders and health providers) was the lack of motivation or willingness to change. A pastor from Chuuk reported,

Many people have not made up their mind to follow a healthy diet. They just want to continue to live the life of eating, drinking, smoking, sitting, doing what feels good.

Although many expressed similar sentiments, there were a few who were motivated and started following the recommendations but discontinued because they were faced with numerous environmental barriers.
Environmental Factors

As mentioned earlier, environmental factors do influence compliance to nutrition therapy. Participants cited access to healthy foods (including issues related to poverty), deeply engrained cultural practices and lack of support from health care providers, faith leaders, church and community.

Access issues

The discussions around access began with poverty and their inability to purchase healthy foods as many participants are living below the poverty level. Hawaii participants reported that the cost of healthy food, especially traditional healthy foods was unaffordable. This theme was repeated in all the Hawaii focus group discussions. In fact several participants spoke up regarding this topic, with one participant explaining,

We are poor; some of us are homeless and we can’t afford to pick the type of food we eat because money is tight and it is much cheaper for us to buy unhealthy food, like a hotdog, chips and soda at the food truck.

Other Hawaii participants mentioned availability of fruits and vegetables in their neighborhood. A caregiver from Hawaii conveyed her personal experience with purchasing foods,

I live in the housing and the stores that I can walk to doesn’t sell fruits and vegetables, I don’t have a car so I have to catch the bus to the nearest supermarket, when I get to the market I don’t want to buy fruits and vegetables because they are bulky and heavy so I buy lighter foods like ramen and small canned meat.

For participants living in Chuuk, their access issues included costs beyond economics as they considered the amount of work it takes to grow, harvest and prepare healthy local foods as costs. As one caregiver explained,

I know doctors promote eating local food - our vegetable, fish and other seafood - but it takes a lot of work to catch and prepare and it is much easier to drive to the store, buy canned tuna and I don’t even have to cook it. For local fruits and vegetable I have to grow them, pick them, cook them – a lot of work. I would rather buy a bag of rice. The reality is, people now have full time jobs and don’t have the time to go fishing and prepare local foods.
Another participant added cost as it was related to safety,

Fishing in the open ocean is very dangerous. Every year lives fishermen are lost out there in the ocean and that is a great cost to us and our community. Farming is also dangerous as many have to go up to the mountains to plant and gather food.

Many other participants agreed with this sentiment and they said that more people are moving away from these traditional practices and are buying canned and processed food from the stores.

Cultural Practices

Another environmental factor that all sixteen focus groups discussed was cultural practices that influence nutrition therapy adherence. Chuukese and other Pacific Islanders follow a collectivistic culture and engage in activities together including dining. The majority of the participants from the focus group and faith leaders sessions partook in group dining and reported the popularity of this practice in their community. A faith leader from Hawaii stated,

We eat a lot of meals together as a church because it is part of our culture. We are not living in our homeland so breaking bread together helps us remember that we are part of a whole and there is comfort in that because I know I am not alone here in this foreign place. If I need help there are others who will come to my rescue. This also shows our children who are growing up outside of our home island that they are Chuukese and that means you are part of a bigger family.

A person with diabetes in Chuuk also expressed a similar view,

Here in Chuuk, being part of a group is very important because we live on small islands, and we cannot survive by ourselves we need people around so eating together is a way we form a stronger bond. It is more than just a meal we do a lot of church business meeting during these meals.

One of the participants described the type of food served during these church and community meals,

We have five types of meat dishes (mostly fried), potato salads, rice, traditional starches (like banana, cassava and yams), desserts and sweet drinks.
Another participant added,

Everybody around me are eating those things so if I am eating something different then I will feel odd, and I don’t like that, I want to fit in, and I don’t want to stand out.

This collectivistic theme also plays an important role within families, as people with diabetes do not want to consume a meal that is different from the rest of family. Focus group and interview discussions continued with emotional aspects of food and dining within a collectivistic culture, specifically the feeling of comfort and belonging. One of the participants from Chuuk affirmed,

Food is more than nourishment our physical body, eating a meal with family and friends is fellowshipping, and it makes have that feeling of belonging and that is comforting.

Another participant added,

If I eat something different than other people, they will feel sorry for me, and I will feel shame so I eat what everybody else is eating.

Faith leaders and health care providers also mentioned the strong influence culture has on what people eat. They are convinced that in order to change eating behaviors for Pacific Islanders these cultural issues need to be addressed.

Encouragement and Accountability

Focus group participants consisting of people with diabetes and caregivers reported lack of encouragement and accountability from health care providers. People with diabetes recalled their diabetes doctor or nurse telling them to “eat healthy” and some provided nutrition education. The majority of the patients tuned out the “eat healthy” advice as they felt that providers are required to say that for all other conditions not just diabetes and providers are saying it so many times they don’t pay attention to it. They also felt that there was no sense of urgency or importance in the doctors and nurses’ voice or action as providers wait until the end of the appointment to mention it and the tone is the same as the farewell statement. Moreover, there was also no encouragement,
motivation or accountability which was very important to in their culture. One diabetes patient from Hawaii recalled his last visit to the doctor,

I was only in there less than 10 minutes. He went over my test results, spent most of the time explaining my medication and at the end he told me to watch what I eat, exercise and take care.

Other focus group participants relayed similar experiences and health care provider interviewees do agree that they don’t have the time to spend with their patients. For Hawaii providers, language was a major problem; they spend a lot of their time explaining the vital information like medication safety. Providers did recognize that in order to make any stride, in nutrition adherence, physicians need to make significant changes in the way they communicate the importance of nutrition therapy to patients and provide comprehensive support especially referring patients to a nutrition specialist.

Some of the patients from Hawaii were referred to a nutrition specialist but few followed through because they felt it was not important and there was no accountability from the doctor (the doctor or nurse did not ask the patient whether or not they attended a nutrition education session during follow-up sessions). Chuuk does not have a nutrition specialist so none of the Chuukese participants were referred to a nutrition specialist. However, the diabetes program nurse is providing education, but she is also responsible for all diabetes education and does not have the time give the proper attention to nutrition therapy education. For the few who attended nutrition therapy session, they did not recommend it to the others. It is important to note that the primary reason others did not attend was because they heard from family members and friends that the sessions were not helpful. In their evaluation, the session or sessions (the number of sessions varied from one to five) lacked (1) motivation and encouragement; (2) skill trainings especially on how to eat healthy given the social context of poverty; (3) cultural competency including language, food preference and group dining. Health care providers who participated in the interviews recognized these issues and expressed the need for interventions that are tailored to the need of this population.
Intervention for Program and Research Ideas

Although there were not many participants who followed nutrition therapy recommendations, they did give recommendations on how to improve compliance to nutrition therapy. Recommendations were specific to improving access, health provider communication, nutrition education and faith based support.

**Healthy Foods Access**

To improve access to healthy foods, the majority of the discussion started with a discourse around poverty and the need for a serious conversation and action to improve the economic situation among Chuukese in Hawaii and Chuuk. The participants suggested: (1) legislative policies such as tax incentive to make fruits, vegetables and other healthy foods affordable especially for business around the low income housing area (Hawaii); (2) a program similar to the Women, Infants and Children (WIC) program that give voucher specifically for food with high nutritional values since many of the Chuukese rely on government funded programs for support including food; and (3) having healthy foods, especially fruits and vegetables available at the local food banks.

**Motivational Support**

The second most salient suggestion was to provide motivational support in addition to education. Participants cited numerous types of motivational support including collective prayers; words of encouragement from family, friends and pastors; and most importantly family and church members eating the same types of foods. The centrality of the motivation in nutrition therapy intervention was mentioned by all faith leaders interviewees and ten of the twelve health care providers and all 16 focus groups, as summarized by a male participant,

> It will take a lot of work to motivate people to cook and eat right but it will be worth it because it will last forever. For us, you have to change the group and if you can motivate the group the families and individuals will follow.
Another participant added,

Motivation needs to come first. I know there are other issues like the cost of food but if we are motivated to eat healthy food we as a group can do something to overcome those issues we can fight that type of social injustice but we need to be motivated first. On the other hand, we can have all the healthy foods available us but we will not cook or eat them because we are not motivated to do so. Motivation needs to come first.

Participants expressed the need for multi-prong tailored interventions for churches, families and individuals. They want providers to implement group educational and motivational activities that include the entire family to participate not just individuals with diabetes. Accountability also came up as participants recognized this as one of the most important factors in motivating people in the Chuukese community. In a collectivistic Chuukese and other Pacific culture, group behavior is important in the maintaining cohesive and identity. As one participant put it,

I know I need to eat healthy but if no one is doing it then I won’t do it but if everyone else around me is doing it and checking up on my eating then of course I will do it.

Nutrition Education

The third most popular topic of discussion was on how to improve nutrition therapy education. Participants suggested a program that provides: (1) specific recommendations (e.g., name of foods, portions and preparation) within context (e.g., cost, access, and taste preference); (2) skills training for caretakers to address economic affordability of food concerns (e.g., how to shop for healthy foods on a limited budget and making the most of community resources including food from the food bank); (3) food preparation classes and tasting sessions with new recipes as many did not grow up preparing or eating foods that were recommended by health care providers; and (4) local foods and pot-luck time nutrition recommendations and preparation. This female caretaker’s request summed up nutritional educational needs of the participants,

It would be useful to have a skill building class on how to buy healthy food on the limited money that we have, how to prepare healthy food that are also tasteful and how to motivate your family, diabetics and non-diabetics, to be on board.
Faith Leaders and Organizations Engagement

Finally, participants expressed the need to involve faith leaders and churches. People with diabetes and their caregivers wanted to hear motivational healthy eating messages from the pulpit. A diabetes patient said “we respect and listen to our pastors a lot more than doctors and we go to church and listen to sermons a lot more often.” Another participant added,

Eating healthy is a lifetime thing, we need motivation for all the time for a lifetime so where do we go all the time for a lifetime? The answer is church so getting churches involved makes sense to me.

Faith leaders also agreed with these types of statements and believed they have the time and capacity to provide continuous motivation. They were also willing to provide nutrition counseling and motivation. A faith leader from Hawaii commented on how this can be accomplished,

There are many ways we can support and motivate our people, I can focus my sermon of healthy eating and there are many scriptures in the bible that can support those types of sermons. I also do bible studies during the week and we can do a whole series on eating right. I talk to people on a daily basis and I can include words of encouragements. I also lead collective prayers and I can include prayers for resources and strength to live healthy.

Faith leaders also requested technical assistance in learning more about nutrition therapy so they can include them in their teachings and counseling. In addition to these sessions, people with diabetes want the church environment to be supportive by implementing healthy food policies for church gathering and providing group nutrition education sessions. A caregiver said,

We spend a lot of time at church for various reasons, we are at church four to six days a week and we eat a lot meals there as all our life celebration from birth to death involves the church so it would be nice to have nutrition policies and classes in churches.

Many of the focus group participants and faith leaders expressed similar views. In addition, getting church members involved can also help with encouragement, motivation and accountability needs of people with diabetes and their family members. Given the
high rates of diabetes in this population it is important to consider church support as a resource.

**Discussion**

This was the first study that investigated socio-cultural influences that hinder or facilitate adherence to nutrition therapy among Chuukese in Chuuk and Hawaii. This study used Grounded Theory to explore this topic. In following with Grounded Theory practices, the Social Cognitive Theory was used to sensitize the topic and the results showed behavioral, personal and environmental factors related to nutrition. The results showed barriers that were similar to other minority populations in the U.S. such as cost of healthy foods, taste preference, low availability of healthy food choices, lack of ideas for healthy meals/cooking, and lack of culturally appropriate nutrition modification options. It also elucidates nutrition practices, barriers, facilitators and needs that are specific to this population. Moreover, the results of this study were presented back to community stakeholders and they formulated a plan for future intervention. Accordingly, this discussion is divided up into two sections: (1) the discussion on current practices and needs and (2) the discussion on a future intervention plan developed by community stakeholders.

**Current Practices and Needs**

This study elucidates nutrition related practices of Chuukese and the need for culturally tailored interventions, especially an intervention that addresses motivation. The (1) food consumption and preparation practices segment narrates current practices; (2) culturally and contextually tailored intervention segment explains the community’s need for appropriate intervention to address the food consumption and practices concerns; and (3) motivation intervention segment discusses a critical intervention that was identified by the community as appropriate and critical.
Food Consumption and Preparation Practices

Participants’ narratives of low consumption of fruits and vegetables was not surprising because according to surveillance data, Chuukese living in Chuuk on average consume 1.0 serving of fruit 2.6 days a week and 1.1 servings of vegetables 3.1 days a week (FSM DHSA, 2012). Moreover, 90.4% consume less than five servings of fruits and/or vegetables on average per day (FSM DHSA, 2012). Surveillance data also support participants’ report of consuming great amounts of canned food as Chuukese on average consumed tinned fish 5.2 days per week. It is important to note that this is for canned fish only and there is a strong possibility that amount of overall canned meat would be higher if other tinned meats were included in the survey. Moreover, despite the fact that fiscal cost of fresh fish is very low since there is considerable access and availability of fish in local ocean, costs were still perceived as high since they factored in time, safety, physical exertion, etc. as part of cost. As for food preparation, 89.6% use vegetable oils to prepare their meals (FSM DHSA, 2012).

Culturally Tailored Interventions

Given the high rates of diabetes in the Chuuk and the Pacific, the need for interventions to address the aforementioned nutrition needs of Chuukese is critical. The need for interventions that are tailored to the local culture and context (historical, social and economic) was prominent in all the focus group and interview discussions. Pacific Islanders including Chuukese hold holistic views on health. It was no surprise that participants discussed the value of holistic nutrition interventions that address the needs of the mind (e.g., nutrition education and skills training), body (e.g., care for the physical body, family, community and environment) and spirit (e.g., faith, encouragement, motivation and accountability).

In developing these interventions, participants emphasized the necessity to employ a multi-prong approach that engages caretakers (primary decision maker on the type of food people of diabetes eat), individual with diabetes, family members, faith-
leaders and healthcare providers. Participants were very clear on their definition of engagement, as they want to be engaged as recipients, implementers, planners and evaluators of nutrition intervention. These needs are in-line with their desire to be engaged in research and program that affect them directly. Moreover, they specifically insisted on involving faith leaders to provide spiritual and motivational support; conducting group interventions in churches as many consume meals during church meetings and functions; and incorporating the Chuukese language and foods in the interventions.

Motivational Interventions

In moving the nutrition therapy adherence agenda forward with the community’s prioritized focus on motivation, researchers need to be mindful of the aforementioned context and desires. These community requests also have some backing from the literature as according to research, lasting lifestyle changes take time and that health care support must be adapted to the individual in light of their social setting (Hansen, Landsgtad, Hellzen & Svebak, 2011). The focus on motivation (spiritual and emotional support) is also supported by the literature as health consequences of emotional problems include poorer metabolic outcomes, morbidity, mortality and poorer quality of life (Lustman et al., 2000; Rosenthal, Fajardo, Gilmore, Morley & Naliboff, 1998).

Motivation is an important conceptual variable in diabetes regimen adherence including nutrition therapy and one method that is used to improve nutrition adherence is motivational interviewing (VanWormer & Boucher, 2004). Moreover, the focus on emotion in the motivational process is also gaining momentum in practice and research as scholars are beginning to look at the role of emotions in motivational interviewing (Wagner & Ingersoll, 2008). Individuals with diabetes reported overall emotions and attitudes such as shame, fear, denial, hopelessness, passiveness and sadness (Figure 2). Moreover, participants shared strong emotional connections and attitudes (both positive and negative toward food). Therefore, the next step is to explore the adoption of
Motivational Interviewing principles to develop a motivational intervention for Chuukese. Motivational Interviewing is a method that follows a directive, client-centered style of counseling that help clients to explore and resolve their ambivalence about changing (Rollnick & Miller, 1995). Principles include understanding the client’s view accurately, avoiding or de-escalating resistance and increasing clients’ self-efficacy and their perceived discrepancy between their actual and ideal behavior (Miller & Rollnick, 1991).

Community Identified Intervention Plan

In compliance with community based participatory principles, the overall findings of this study were presented to community members and they drafted the following plan for future interventions (Table 12). This community participatory planning process addresses the need for community to use research data to plan their own activities versus researchers and public health administrators planning activities without the input of community members and stakeholders. It also gives community members the opportunity to share their ideas that integrate cultural practices and local context.
Table 12. Nutrition Therapy Plan by Target Population.

<table>
<thead>
<tr>
<th>Target Population</th>
<th>Lead Implementers</th>
<th>Activities</th>
</tr>
</thead>
</table>
| Caretakers        | Nutrition Specialists | 1. Nutrition classes: type of foods, portions, etc.  
|                   |                   | 2. Skill trainings: budgeting, food shopping, food preparation, etc.  
|                   |                   | 3. Motivation and encouragement sessions: testimonies, sharing circle, etc.  |
| Patients & Family Members | Nutrition Specialists | 1. Nutrition classes: type of foods, portions, etc.  
|                   |                   | 2. Motivation and encouragement sessions: testimonies, sharing circle, etc.  |
| Faith Leaders     | Nutrition Specialists & Theological Technical Advisor | 1. Train-the-trainer session: nutrition classes  
|                   |                   | 2. Training Session: developing healthy church policies  
|                   |                   | 3. Technical Support: developing sermons and church bulletins that incorporate the scripture and nutrition.  |
| Church            | Faith Leaders     | 1. Healthy Sermons  
|                   |                   | 2. Healthy messages in a bulletin  
|                   |                   | 3. Healthy nutrition policies (church policies)  
|                   |                   | 4. Healthy food policies (legislative)  |
| Physicians and Nurses | Health Administrators | 1. Patient Communication Training: Nutrition Therapy Recommendations and Referrals  
|                   |                   | 2. Systems Change: Nutrition Therapy Referral and Follow-up  |

**Conclusion**

This study revealed the need to modify several nutrition related behaviors and practices. Participants advocated for a multi-prong approach that involves numerous community stakeholders and addresses spiritual and emotional support. This study had similar limitations to other qualitative studies, as it was limited by its small size and purposeful sampling. Participants were likely to be different than those who did not. For example, we asked community members who wanted to share their experience in diabetes care as individuals with diabetes and caretakers so our participants likely reflected the ‘talkative’ rather than the ‘shy’ members. Moreover, the interviews and focus group were also conducted in English so those who were not fluent in English might have different experience and perspectives. However, with the focus on the Chuukese perspective and the use of the CBPR approach and the research team felt
confident that our findings can be used to develop culturally appropriate diabetes control intervention in the state of Hawaii and Chuuk. The team believed that programs and research based on the Pacific values, beliefs and traditions would also appeal to other Pacific communities. Finally, they felt that their participatory process using grounded theory principles can serve as a model for other researchers working with minority groups to reduce health disparities.
CHAPTER 4
STUDY 3: SEDENTARY BEHAVIORS AND PHYSICAL ACTIVITY

Introduction

The type 2 diabetes (T2DM) epidemic is a global health issue and it is especially severe in the Pacific (Hosey et al., 2009). Although a post-World War II US Navy survey of the Pacific Islands found no cases of diabetes, subsequent population surveys have shown a dramatic increase in diabetes (Institute of Medicine [IOM], 1998). This indicates that diabetes is a relatively new and growing people in the Pacific. In 2007, the estimated prevalence of diabetes for the US population (adults aged 20 years or older, diagnosed and undiagnosed) was 10.7% (CDC, 2007). In the U.S Pacific diabetes rates range from 24.4% in the Federated States of Micronesia to 47.3% in American Samoa (FSM DHSA, 2002; WHO, 2007).

Physical Activity (PA) is a significant contributor to health (Booth et al., 2004; Bull, Bauman, Brown & Bellew, 2004) and is proven to have benefits in improving mental, metabolic, and skeletal health and providing protection from T2DM (Aarnio, Kujala & Kaprio, 1997; Pate, Heath, Dowda, et al., 1997). A meta-analysis study found that T2DM individuals who engage in regular physical activity significantly decrease their HbA1c level and this in turn led to significant decreases in the risk of developing diabetes related complications (Boule, Haddad, Kenny, Wells, & Sigal, 2001). However, like medical nutrition therapy, many people with diabetes do not engage in regular physical activity. Due to the high prevalence of diabetes among Pacific Islanders and the significant role physical activity plays in the management of diabetes it is critical for health researchers and practitioners to investigate the current state of physical activity among people with diabetes in this populations. Furthermore, community partners in the Pacific through various community engagement activities identified (1) diabetes management, including physical activity as a research focus; (2) healthcare providers,
faith leaders, individuals with diabetes and caregivers as study subjects; and (3) Chuukese in Chuuk and Hawaii as the target ethnic group and research sites. Accordingly, the primary aim of this study is to identify socio-cultural influences that hinder or facilitate physical activity adherence among Chuukese in Chuuk and Hawaii.

Physical activity encompasses any bodily movement produced by the skeletal muscles that results in a substantial increase over resting energy expenditure (Bouchard, Blair & Haskell, 2007). It includes leisure-time physical activity, exercise, sport, transportation, occupational work and chores (Bouchard et al., 2007). Last year, Pettee-Gabriel and colleagues (2012) proposed a physical activity conceptual framework with the goal to standardize definitions, guide design and development of self-report measures and provide consistency during instrument selection. Based on this framework, the authors acknowledged physical activity as a complex and multidimensional behavior and defined physical activity as “the behavior that involves human movement, resulting in physiological attributes including increased energy expenditure and improved physical fitness (pg. S15).”

National, international, and professional organization recommendations for the amount of physical activity are fairly consistent across various guidelines with the general sentiment being that individuals begin slowly and gradually increase the duration and frequency of exercise to approximately 30 to 45 minutes of moderate to vigorous physical on the majority of days a week. Moreover, for persons with T2DM, it is also recommended to incorporate flexibility and strength training exercises (Handelsman et al., 2011). The American Heart Association released their Statement on Exercise: Benefits and Recommendations for Physical Activity Programs for All Americans where they declared that a sedentary lifestyle is a major and independent risk factor for premature development of atherosclerotic cardiovascular disease (Fletcher et al., 1996). Frequent reported reasons for non-active lifestyle include lack of time, laziness, uncertainty about how to begin, existing illness or injury, concerns about the risks of
exercise, lack of access to convenient or safe areas to exercise, and confusion about the
difference between being busy and being physically active (Haskell, Blair & Bouchard,
2007).

There are few studies that focus on the Pacific islands and physical activity. One
of the earliest physical activity studies was conducted in New Zealand to enhance PA
assessments among the New Zealand population. This study objectively measured
metabolic equivalents (METs) intensities of culturally-specific PA performed by Pacific
Islanders. The result of this study showed that the New Zealand-derived METS were
slightly higher compared to the U.S. but overall they showed strong correlations
($R^2=0.62$). Some interesting disparity in METs levels (New Zealand METs versus U.S.
METs) included: Kitchen activity (3.4 versus 2.0), Emotion/Stress/Sport spectator (3.4
versus 1.5), Socializing/Eating (3.4 versus 1.5), Religious/church activity (3.4 versus
1.5). This study also provided the opportunity to create a New Zealand-specific
compendium of PAs that included age-gender- and culturally-specific MET including
several traditional activities performed by the Pacific Islander population (Moy, Scragg,
McLean & Carr, 2006).

Surveillance data collection in the Pacific is very recent, and the U.S. surveillance
systems currently aggregate Asian American and Pacific Islander data so the best
available population data are comparable data (Table 13).

Table 13. Physical Activity Levels.

<table>
<thead>
<tr>
<th>Levels</th>
<th>U.S.</th>
<th>Pacific Islanders in the US</th>
<th>Chuukese in Chuuk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>16%</td>
<td>80%</td>
<td>63%</td>
</tr>
<tr>
<td>Moderate</td>
<td>22%</td>
<td>18%</td>
<td>11%</td>
</tr>
<tr>
<td>High</td>
<td>65%</td>
<td>2%</td>
<td>26%</td>
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</tbody>
</table>
In 2009, the proportions of U.S. adults classified into low (less than 600 MET minutes per week), moderate (600-1500 MET minutes per week) and high (greater than 1500 MET minutes per week) PA categories were 16%, 22%, and 65%, respectively (Bauman et al., 2009). During the same year comparable data using the same measure of physical activity reported Pacific Islanders physical activity at 80% low, 18% moderate and 2% high (Moy, Sallis & David, 2009). In 2012, the Federated States of Micronesia, Department of Health and Social Affairs (FSM, DHSA) released physical activity data for Chuuk collected in 2009, and physical activity levels were at 63% low, 18% moderate and 26% high (FSM DHSA, 2012).

The great majority of the literature on Pacific Islanders and physical activity is on social determinants research. The latest study by Nelson and colleagues (2010) underscores the importance of social connections (both distal and proximal connections) in influencing Indigenous people to engage in physical activity. Indigenous communities have been utilized as sites for sport and physical activity initiatives (Brisbane City Council, 2008; Cairnduff, 2001). Sport and leisure physical activity, have been seen by many Indigenous people as an important part of social life and PAs mean more than engagement in ‘exercise’ for an individual’s physical health benefits as they also provide opportunities for social connections (Atkinson, 1991; Beneforti & Cunningham, 2002; Grimley, 1996; Thompson, Gifford & Thorpe, 2000). In some communities, organized sport events has become a site of social engagement in which participation occurs through both the sport itself and the ancillary tasks such as organizing competition and providing food (Australian Bureau of Statistics, 2005). Research with urban adults found that PA is embedded in a complex web of meanings that tie people to their family and community with the decision to be physically active significantly impacted upon by connections with family and community (Thomson et al., 2000; Thompson & Gifford, 2000). For example, some viewed individual health and fitness activities as a disconnecting and shameful experience because it focused on them as an individual rather
than on social relationships (Abbot et al., 2008). Other research has cited a lack of family oriented sustainable activities as a barrier to their engagement in PA (Hunt, 2005).

A study with Native Hawaiians put forth a recommendation to culturally adapt PA strategies to make them relevant. Participants reacted positively to the idea of group activities that were culturally relevant, hands on, purposeful (e.g., walking children to school, the market or church, dancing hula, farming, canoeing and running on the beach), and inclusive (doable by people at many fitness levels). Participants felt that it is essential to involve and engage the support of family and friends (Van Duyn, McCrae, Wingrove, Henderson, et al. 2007). In contrast to the above findings, a study by Nelson and colleagues (2010) of urban Indigenous youth found that solitary physical activity provided an opportunity for relaxation and a reprieve from social issues. Due to the lack of information on physical activity recommendation adherence, this formative study explored issues around physical activity from four perspectives: health care providers, faith-leaders, diabetes patients and diabetes patients’ family members/caregivers.

**Method**

Given limited information on Pacific Islanders and physical activity, Grounded Theory and qualitative methods (key informant interviews and focus group) were chosen for this study. The advantage of using Grounded Theory is that it is focused on real-life experiences and individual’s worldviews rather than abstract concepts. In addition, Social Cognitive Theory was selected to organize the questions and data. Social cognitive theory explains how individuals acquire and maintain certain behavioral patterns, while also providing the basis for intervention strategies (Bandura, 2003).

CBPR principles dictate the approval of methods, research topics and study subjects by community representatives. Accordingly, through community meetings facilitated by the Pacific Diabetes Education Program, community members identified the study of social support (e.g., family and church) and cultural attitudes and beliefs concerning diabetes prevention and control activities (including physical activities).
They also identified faith leaders, healthcare providers, individuals with diabetes and family members of people with diabetes as study subjects. Moreover, the Pacific Chronic Disease Coalition chose the Chuukese community and the two sites Chuuk and Hawaii.

Following CBPR principles, two community representatives were involved in the development of the tools which were approved by the Pacific Chronic Disease Coalition and the University of Iowa Institute Review Board (IRB). In addition, a partnership with two community organizations, Chuuk Women’s Council (CWC) and Micronesians United (MU) assisted with subject recruitment and logistics support for data collection. This study was part of a larger qualitative study that was looking at all aspects of diabetes control.

Measures

The first set of data on physical activity is derived from faith leader and healthcare provider interviews. The objectives were to (1) obtain their perspective and action regarding physical activity and glycemic control; and (2) determine whether (a) healthcare providers are supportive of incorporating faith and faith initiatives to interventions or (b) church leaders support incorporating health initiatives in churches. Participants also completed a one-page demographic questionnaire that included age, sex, religion/denomination, diabetes status and employment status.

The second data set was obtained from focus group discussions with people with diabetes and their family members in Chuuk and Hawaii. The objectives were to (1) obtain the community’s perspective, experience and actions regarding physical activity and (2) determine whether the community is supportive of faith-based diabetes initiatives. Participants also completed a one-page demographic questionnaire that included age, sex, religion/denomination and, diabetes status.
Procedures

Healthcare Provider and Faith Leader Interviews

Key informants interview participants were invited through email and telephone using a script approved by the UI-IRB. They all agreed and interviews were conducted in the CWC office (Chuuk faith leaders and health care providers), Micronesians United’s office (Hawaii faith leaders) and interviewee/provider office (Hawaii providers). Intensive qualitative interviewing fits grounded theory methods exceptionally well as they are both open-ended yet directed, shaped yet emergent and paced yet unrestricted (Charmaz, 2006). The in-depth nature of an intensive interview draws out each participant’s viewpoint and interpretation of his or her experience. Interviews were recorded and the audiotapes were reviewed after each discussion to guide probing questions for the next interview. Interviews lasted approximately three hours in Chuuk and two hours in Hawaii.

Community Focus Groups

Focus group participants were invited via email and telephone using a script approved by the UI-IRB. In keeping with the CBPR practice of transferring skills, a faith leader and public health practitioner from the U.S Pacific were recruited and trained to facilitate the sessions and record and transcribe data. Focus groups are small groups of individuals responding to a set of open-ended questions, providing a means of gaining a broad understanding of values, meanings, and perceptions of phenomena (Morgan & Krueger 1998). This methodology was appropriate because the objective of this study was to understand Chuukese beliefs, attitudes and behaviors with regard to health and diabetes, while also observing the influence of cultural involvement and the church setting. Additionally, focus groups fit in with Pacific culture, which includes an oral-aural tradition, a preference for collective learning, and the importance of face-to-face meetings that allow people to gauge intent, sincerity, and trustworthiness as information is exchanged (Braun et al. 2002). The Chuuk focus group sessions were held at a local
hotel and the Hawaii focus groups was held at the CWC Palama Conference Room. Focus group sessions were recorded and the audiotapes were reviewed after each session in order to guide probing questions for the next session.

Participants

A total of 131 individual participated in this study: 12 health care providers (6 in Hawaii and 6 in Chuuk), 17 faith leaders (8 in Hawaii and 9 in Chuuk) and a total of 102 individuals (people with diabetes and caregivers).

Healthcare Providers and Faith Leaders

Health care providers included three alternative medicine practitioners, three nurses and six physicians. The majority (83%) practiced for at least 20 years, 58% were Chuukese, and all five non-Chuukese providers practiced in Hawaii. The category of faith leaders included seven pastors, four deacons, four pastor’s wife and two deaconesses. They were all Chuukese and served in the ministry full time. In Hawaii, 89% of the interviewees worked outside of their church in addition to full-time ministry as compared to 25% in Chuuk.

Community Focus Groups

A total of 102 individuals (43 in Chuuk and 59 in Hawaii) participated in 16 focus groups (8 in Chuuk and 8 in Hawaii). The average age of participants was 46 years (43 years in Chuuk and 47 in Hawaii); 55% were females, 53% had T2DM, and 90% had a healthcare provider.

Data Analysis

In accordance with CBPR principles, Pacific representatives from faith based and health care organizations were part of the analysis team. The analysis process was guided by grounded theory and was sensitive to the need to identify individual, behavioral, and environmental influences consistent with Social Cognitive Theory (Bandura, 1989, 1998). To conform with Grounded Theory practices, our first step was coding or naming segments of data with a label that concurrently categorizes,
summarizes and accounts for each piece of data (Charmaz, 2006). The analytic team then met face-to-face to do group coding. They worked quickly through the transcript looking for coding incidences and paying attention to *In Vivo codes* or words/phrases that compress meanings of consist of widely used terms that participants assume everyone shares. Charmaz (2006) identified three kinds of *in vivo* codes she found useful: (1) general terms everyone ‘knows’ that flag condensed but significant meanings; (2) a participant’s innovative term that captures meanings or experience and (3) insider shorthand terms specific to a particular group that reflect their perspective. This third type is particularly important to our analysis as many of the terms are tied to the Chuukese cultural context. They provided a useful analytic point of departure and helped preserve participants intended meanings within the coding itself. They also scripted early memos and flagged focused codes. Throughout this process they made several memos to catch ideas about codes and noted items we need to discuss later. As they progressed though the transcript they came upon similar types of responses so we implemented focused coding to synthesize and explain larger segments of data. Focus coding let the team use earlier codes to sift through large amounts of data toward the later part of our process. This required decisions about which initial codes make the most analytic sense to categorize our data incisively and completely (Charmaz, 2006).

The above initial coding process fractures the data into separate pieces and distinct codes but our next step brought back together these pieces to form a coherent whole. The team started the axial coding process by sorting the initial codes and grouping them into common themes. We then use those grouping to develop major categories with subcategories and showed the links between them. Moreover, we reviewed our early memos to start the clustering process. This helped us produce a tentative and flexible chart of our categories and sub-categories. The following directions by Charmaz (2006) guided us through this process: start with the main idea at the center then move out from the nucleus into smaller sub-clusters (keeping all related
material in the same sub-cluster) and keep branching out until we exhausted our
codes/knowledge; make all the connections clear between each idea, code and/or
category; and try several clusters on the same topic. This exercise directed us to a
tentative theory that needs further examination and refinement.

On the final day of our key informant interview analysis meeting (September 28, 2011), we focused our attention on identifying future research questions that can elaborate and refine categories in our theory. This theoretical sampling seeking process will help us find pertinent data to develop our emerging theory (Charmaz, 2006). Since we were preparing for Study 3 (focus groups with community members) we used this opportunity to review our focus group questions and make notes of any additional probing questions. The analysis of our focus group results followed the same protocol.

**Results**

Key interview and focus group participants communicated a variety of behaviors, personal factors and environmental influences related to adherence to physical activity recommendations. These were consistent with the Social Cognitive Theory and the result section is organized in this format. It is important to note that although the study was focused physical activity and questions were on physical activities, participants spent majority of their time discussing sedentary behaviors. Due to its prominence in the discussions, the focus of this chapter now includes sedentary behaviors. In addition, participants communicated ideas on culturally and contextually appropriate interventions for their community.

**Behaviors**

The discussion around physical activity began with an overall discussion of diabetes self-management adherence. Diabetics were seeking medical assistance to manage pain and other complication. However, they were not following physical activity recommendations. A Chuukese faith leader and a diabetic declared,
We go to the doctor to make us numb to the pain. We only go in because something was wrong and wanted our doctor to give us medicine to make the pain go away but we have no desire to follow all the other advice like eating right and exercise.

Participants in all 16 focus group discussions described existing sedentary and physical activity behaviors. They can be classified into four categories: sedentary with action/movement, sedentary without action/movement and behaviors, purposeful activities and recreational activities.

**Sedentary Behaviors with Action/Movement**

The participants reported that they spent the majority of their time engaging in sedentary behaviors that involve actions (energetic behaviors such weeding grass and fishing) or motions (movements such as eating and playing card games). Participants reported that sedentary behaviors with actions/movements could be purposeful (e.g., weaving baskets and working on the computer) or recreational/relaxing (e.g., playing cards and games).

**Sedentary Behaviors with No Action/Movement**

The second most common discussed behavior was sitting with no action/movement. This can be purposeful such as watching the house to prevent break-ins, talking to friends who need support, attending church and participating in meetings or recreational/relaxing like watching television, taking with a friends or people watching.

**Purposeful Physical Activity**

For those who engaged in physical activity, the great majority mentioned activities such as walking to the store, clinic or church, doing household chores, competing (e.g., dancing, volleyball, basketball) and celebrating (preparation and dancing). Although some of these activities can be consider as recreational, the group did not see it as such because they were engaged in these activities for a competition for church or church celebration. Activities were divided by age (e.g., young adults were expected to serve their elders and therefore do bulk of the work) and gender (e.g., men do
fishing, building houses and do heavy lifting while women rear children and watch the home).

Recreational or Leisure Physical Activity

Very few participants engaged in recreational activities (e.g., canoeing, volleyball and basketball), and among those that did, they were all young males. The majority of the participants felt that recreational and leisure physical activity was a waste of time as there were many other useful activities that need to be done; however, a few disagreed, and one young male participant expressed,

I apologize for disagreeing with the older guys but for me – maybe because I’m from a different age group, I go play basketball with my friends and that help me get away from the stress.

Another young male participant added,

Me too, I play volleyball with the guys and its fun and makes me happy.

Personal Factors

Conversations in all 16 focus groups mentioned personal factors such as knowledge, attitude preference, and personal barriers. Participants cited numerous activities that were considered physical activities such as sweeping the floor, vacuuming, walking, swimming and playing basketball. However, knowledge of duration and frequency of activity was very limited. They requested information on the types of activity that is beneficial to health, injury prevention, frequency and duration. In addition, they wanted activities to fit into their cultural context (e.g., gender and age specific activities) and physical capacity (e.g. activities for overweight/obese individuals and diabetics). The majority of the participants believe that physical activity was “good for your health” but some felt that physical activity was not effective because they knew people who have engaged in physical activity but still got sick and die. As one participant in Hawaii observed,
I live in the valley and there is nice track back there and I made friends with a lot of people using that area for walking, running and walking and I know many of them still get sick and some ended up dying of diabetes and heart attack at the end.

The discussions naturally progressed toward attitudes toward physical activity and sedentary behaviors. Conversation focused primarily on activity purpose and reasons behind engaging. Participants reported five different types of sedentary behaviors with different purpose and motives: The labeling and categorizations of these activities were derived from the participants narratives within their cultural contexts.

(1) *Purposeful Sitting* or sitting while engaging in activities that meet individual, family, community and church needs. Motivations behind engaging in these activities include desire to conform to cultural expectations, kindness, and fulfilling family roles (e.g., mother, caregiver and provider). Participants reported feelings of satisfaction, fulfillment and pride in engaging in these activities, which can also be a reward for continuing.

(2) *Lazy Sitting* or sitting while there are unmet individual, family, church and community needs and individuals were physically able to meet those needs. The most common reason for lazy sitting was hopelessness or the feeling that doing certain activity/activities will not change their bleak situation, which leads to discouragement from engaging in the specific activity/activities. Other reasons include indifference, sadness and emotional pain sadness due to overall bleak situation (not necessarily linked to the specific activity as mentioned in “hopelessness”). Participants reported feeling of guilt and shame when engaged in lazy sitting.

(3) *Wasting time* was described as sitting while there are family, church and community needs that needed to be met and individuals were physically able to meet those needs but lack motivation. Unlike “lazy sitting”, the reasons behind wasting time were more intentional such as expressing anger, frustration and discontentment. Sometimes individuals express their feelings of anger and frustrations by being “passive aggressive”. Moreover, individuals who were discontented with current situation do not
engage in activities as an act of rebellion. Individuals felt justified with their people and do not feel shame but the community as a whole frowned upon wasting time as mainly because it was not serving the needs of the community.

(4) Resting and Recreational reward defined as “resting” was similar to “lazy sitting” or not engaging in activities that meet the needs of the individual, family, church and community while have the ability to do so but unlike “lazy sitting” individuals were taking a break or rewarding themselves from purposeful activities. Similar to “wasting time”, this includes include non-action behaviors such as watching television, talking story and people watching as well action behaviors such as playing cards/games. But unlike “wasting time” individuals and the community considered these activities acceptable and positive.

(5) No-can move is sitting while there were needs that need to be met, which was very similar to “lazy sitting” but the difference was individuals had limited physical capacity due to illness or injuries. Depending on the illness or injury, individuals can engage in action and/or non-action activities. Individuals and the community considered these activities acceptable and positive.

In regards to physical activity, caregivers and individuals with diabetes described personal barriers such as lack of time, no energy, depression, shame (of diabetes as a disease and physical activity as breaking cultural norms), pain (caused by the illness and engaging in physical activity), and lack of motivation to start and continue. Participants from Hawaii explained some these points by saying,

When you are feeling down and emotionally distraught the last thing you want to do is to exercise, I want to sit, watch TV and sleep. Life here in Hawaii is very busy, I have to work for a living and I have church activities on top of that so I don’t have time to do physical activity. Even if I have time, I get so tired at the end of the day that I don’t have any energy left to exercise.

Participants from Chuuk added,
I feel shame walking around the streets all by myself – going nowhere. I just don’t feel like doing it, nothing in me is pushing me to go out and exercise.
Environmental Factors

Environmental factors also influenced compliance to physical activity recommendations and participants cited (1) access to facilities and culturally or contextually appropriate programs, (2) deeply engrained cultural practices and norms related to physical activity/inactivity and (3) lack of support from health care providers, faith leaders, church and community.

Access issues

The discussions around access began with poverty and living in low-income communities where streets were not safe for walking and facilities were lacking. Chuuk participants cited lack of sidewalks, no streetlights, teens throwing stones at pedestrians and stray dogs as barriers to walking (main type of purposeful physical activity). They also reported lack of physical activity facilities such as gyms, playgrounds, soccer/football fields and running tracks as barriers to recreational physical activity. Hawaii participants reported the availability of sidewalks but safety was a barrier as the rate of crime and gang activity high in their neighborhoods. Moreover, there were facilities (gyms, playgrounds and fields) near the housing areas but participants reported bullying and safety issues so they were not utilizing them.

Cultural Practices

Another environmental factor that all sixteen focus groups discussed was cultural practices and norms that influenced physical activity. Prominent topics were (1) collectivistic practices, (2) age-appropriate physical activities, and (3) gender-specific physical activities. The most mentioned cultural related topic were the collectivistic practices of engaging activities as a group and putting great value on group consensus and approvals. A faith leader explained,

We do everything in groups, it is part of our culture, we grew up doing things in groups and we like doing things in groups. If you look around, it very rare to see one person going to places by themselves.
Another pastor added,

A lot of the physical activities that we do on a regular basis are group activities like walking to church together, practice dancing for church celebrations and village cleanups.

The second most mentioned cultural practice was age appropriate physical activities. The discussion centered on the practice of the young serving elders. A caregiver from Chuuk gave this explanation,

Our culture fully respect our elders, they contributed a lot to our community and when they older they deserve to be served. You see many of the old folks sit and the younger folks fetch drinks, serve food, massage and stuff like that. This is how we show respect and we don’t do it then other people will think that we are bad people. Our culture frowned on not following these practices.

An elder woman from Chuuk added,

It is not regal for older folks to do all the running around so we normally sit and play the role of advisor.

Finally, participants discussed gender-specific cultural roles and its relationship with physical activity. Culture dictates the separation of males and females in many situations including chores and recreational activities. A focus group participant from Hawaii observed,

We moved here from Chuuk about eight years ago and I know the culture here is different men and women can do stuff together. I saw men and women doing exercise dancing in the same room but none of us joined in because it just doesn’t feel right.

Encouragement and Accountability

People with diabetes and caregivers reported lack of encouragement and accountability from health care providers. People with diabetes recalled their diabetes doctor or nurse telling them to “exercise” but they did not provide physical activity education, referral or encouragement. The majority of the patients tuned out the “exercise” advise because they heard it many times and felt that providers are required to say that for all other conditions. They also felt that there was no sense of urgency or importance in the doctors and nurses’ voice or action. One diabetes patient from Hawaii recalled his last visit to the doctor,
I was only in there less than 10 minutes, he went over my test results, spend most of the time explaining my medication and at the end he told me to watch what I eat, exercise and take care.

Health care provider interviewees did agree with these remarks and admitted that they do not have time to spend with their patients. They also recognized that in order to make major strides toward improving physical activity adherence, physicians need to make significant changes in the way they communicate the importance of physical activity and provide comprehensive support especially referring patients to physical activity specialists, encouragement and accountability.

Ideas for Interventions

Although many participants were not engaged in physical activity, they did give recommendations on how to improve compliance. Recommendations were specific to improving access, physical activity education and motivational support and faith based support.

Access to Physical Activity Facilities and Programs

To improve access to physical activity, the discussion started with issues related to poverty and the need to improve the current economic and crime situation. They also gave the following suggestions specific to physical activity: improve or construct sidewalks and exercise facilities; implement culturally appropriate physical activity programs especially group activities; and begin a sport/cleaning equipment lending library.

Physical Activity Education and Motivational Support

The second most salient suggestion was to provide physical activity classes in additional to motivational support. As mentioned earlier, purposeful activities were the most accepted form of physical activity and participants suggested that physical activity practitioners develop programs that incorporate purposeful activities. They expressed the desire to learn how to make activities such as walking to the store or church more beneficial. For example, a participant from Hawaii said,
My doctor told me to walk for 30 minutes. I’m not going to just go and walk around for no reason – people will think I’m crazy but if they see me walking with friends, heading to the store and carrying bags on our way back then that is OK. I do walk to the store with two of my neighbors, it is a 10 minutes walk and I only need to go twice a week and I don’t think that is enough. So it would be smart for the doctor to work and add more to things I’m already doing.

Other participants added similar types of suggestions that incorporate physical activity programs to daily purposeful activities.

In addition to providing physical activity lessons, participants wanted motivational support. This was mentioned by all the interviewees and discussed in all the focus group sessions. The importance of motivation in physical activity programs dominated conversations as summarized by a diabetic from Chuuk,

The doctor told us to exercise but we don’t do it and we have many reasons and excuses. In order for us to start and continue to follow doctor’s order we need motivation and God’s help. Something needs to spark within us and the fuel for that spark comes from our faith, family and friends.

Faith Leaders and Organizations Engagement

Finally, participants expressed the need to involve churches and faith leaders. Churches can provide facilities for physical activity programs and social support (encouragement and accountability). Faith leaders can provide education and motivation as people with diabetes and their caregivers wanted to hear motivational physical activity messages from the pulpit. A diabetes patient said,

We respect and listen to our pastors a lot more than doctors and we go to church and listen to sermons a lot more often.

Discussion

This was the first study that investigated socio-cultural influences that hinder or facilitate adherence to physical activity recommendations for Chuukese in Chuuk and Hawaii. This study used Grounded Theory to explore this topic. In accordance with Grounded Theory practices, the Social Cognitive Theory was used to sensitize the topic and the results showed behavioral, personal and environmental factors related to physical activity. The results showed barriers that were similar to other populations in the U.S. such as laziness, existing illness and lack of access to convenient or safe areas to
exercise. It also elucidates physical activity and sedentary behaviors, cultural influences and intervention ideas that are specific to this population. Moreover, the results of this study were presented back to community stakeholders and they formulate a plan for future interventions. Accordingly, this discussion is divided up into two sections: (1) the discussion on current practices, influences and needs; and (2) the discussion on a future intervention plan developed by community stakeholders.

Current Practices and Needs

Although the study was initially focused on physical activity, the prominence of sedentary narratives changed the focus to include sedentary as a separate behavior from physical activity. Participants elucidated: (1) sedentary behaviors (purpose focused description, actions, reasons/motives and attitudes); (2) unpacked cultural influences (e.g., collectivistic practices, age-appropriate behaviors, role of faith leaders and churches, and gender-appropriate activities); and (3) an intervention research agenda with considerations for future data collection.

Sedentary Behaviors

Sedentary behaviors dominated the physical activity discussions. According to the 2012 FSM STEP Report, Chuukese living in Chuuk spent an average of 180 minutes in sedentary activities (FSM DHSA, 0212). Surveillance data on physical activity revealed that the majority of Pacific Islanders living the US (80%) and Chuukese living in Chuuk (63%) are engaging in low levels of physical activity (less than 600 MET minutes per week) as compared to the U.S (16%) (FSM DHSA, 2012; Moy et. al., 2006). Results from this study, however, provided in-depth and detailed information on the different types and features of sedentary behaviors. The majority of the participants talked about sedentary behaviors referring to them as the act of sitting, being lazy, doing nothing, wasting time and not moving around. They discussed the many peripheral occurrences and activities that often accompanied sedentary behaviors. As one participant said,
We are sitting but that in not all that we do, we just don’t sit, inhale and exhale, we do many things while sitting and most of those things have purpose.

Another participant added,

Many people said we are lazy people and all we do is sit around but that is not true, just because we are sitting doesn’t mean we are lazy. I agree we are lazy sometimes but laziness doesn’t begin to explain why we sit around there is a difference between working while sitting, being lazy and wasting time.

Participants cited five different types of sedentary behaviors (Table 14), some have identical definitions (e.g. lazing and resting) and actions (e.g., wasting time and resting) but reasons behind engaging in these activities, personal attitude toward engaging in these activities and society’s reactions were different and therefore made the five behaviors distinct.
Table 14. Sedentary Behaviors, Actions and Reasons.

<table>
<thead>
<tr>
<th>Sedentary Behavior</th>
<th>Descriptions (Purposed Focused)</th>
<th>Actions</th>
<th>Reason(s) or Motives</th>
<th>Personal Attitude &amp; Community Approval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Purposeful Sitting</td>
<td>Engaging in activities that has purpose or meet the needs of the individual, family, church and community.</td>
<td>Sitting <em>with</em> actions/movements (e.g., sewing, gardening and weaving baskets). Sitting <em>without</em> action/movement (e.g., participating in meetings and watching the house).</td>
<td>Conform to cultural expectations, kindness, and fulfilling family roles</td>
<td>Personal: Fulfilling, proud &amp; satisfaction Community: Approve</td>
</tr>
<tr>
<td>Lazing</td>
<td>Not engaging in purposeful activities when there is a need and individual has the capacity to engage. (Note: Same as Wasting Time and Resting)</td>
<td>Sitting <em>without</em> actions/movements (e.g., watching television, talking story and people watching)</td>
<td>Lack of motivation due to hopelessness, indifference, sadness and emotional pain.</td>
<td>Personal: Guilt and Shame Community: Disapprove</td>
</tr>
<tr>
<td>Wasting Time</td>
<td>Not engaging in purposeful activities when there is a need and individual has the capacity to engage. (Note: Same as Lazy)</td>
<td>Sitting <em>with</em> actions/movements (e.g., playing games). Sitting <em>without</em> actions/movements (e.g., watching television, talking story and people watching)</td>
<td>Expression of anger, frustration and discontentment.</td>
<td>Personal: Satisfaction, Pleasure, Enjoyment, Guilt and Shame Community: Disapprove</td>
</tr>
<tr>
<td>Resting</td>
<td>Resting from purposeful activities (Note: Same as Lazy Sitting and Wasting Time)</td>
<td>Sitting <em>with</em> actions/movements (e.g., playing games). Sitting <em>without</em> actions/movements (e.g., watching television, talking story and people watching)</td>
<td>Taking a break from or reward for purposeful activities</td>
<td>Personal: Fulfilling, proud &amp; satisfaction Community: Approve</td>
</tr>
<tr>
<td>No can move</td>
<td>Not engaging in purposeful activities with actions/movements but individual does not have the physical capacity to engage</td>
<td>Sitting <em>without</em> actions/movements (e.g., watching television, talking story and people watching)</td>
<td>Illness or injuries.</td>
<td>Personal: Guilty, sad, grateful &amp; Blessed Community Approve</td>
</tr>
</tbody>
</table>

In the literature, sedentary behaviors have emerged as a new focus for physical activity and health research and scholars called for further evidence from prospective studies, intervention trials, and population-based behavioral studies (Owen, Healy,
Matthews & Dunstan, 2010). Pates and colleagues (2008) defined sedentary behavior as activities that do not increase energy expenditure substantially above the resting or activities that involve energy expenditure at the level of 1.0-1.5 metabolic equivalent units (METs). They also defined light physical activities (slow walking sitting and writing, cooking food and washing dishes) that involve energy expenditure of 1.6-2.9 METs. Participants’ descriptions of sedentary behaviors were comprehensive and detailed. In order to maintain the richness of the given information they were categorized by purpose, action, motives, attitude and community approval (Table 14). This study’s “sitting with action/sitting with no action” sedentary category is comparable to Pate’s sedentary and light physical activities categories (Pate et al., 2008). Further research is needed to objectively measure MET intensities of “sitting without action” activities (e.g., participating in meetings, watching the house, watching TV, talking story and people watching) and “sitting with action” activities (e.g., sewing, gardening, weaving baskets, and playing games) to ensure they are in the right category. The other value of this study’s result is that it has a list of specific activities (sedentary and light activities) that can be measured and added to a Pacific-specific compendium of physical activity.

Cultural Influences

The influence of collectivistic, gender-appropriate, age-appropriate and religious practices associated with culture was prominent in all the discussions. Collectivistic practices of engaging in activities as a group and putting great value on group approval were central in individuals’ motivation to engage in physical activity. At the core of sedentary and physical activity behavior discourses was the idea of purpose and meeting the needs of not only individuals but also family, church and community. Activities were divided in two different categories purposeful and leisure. The need to conform to cultural norms and approval were cited as motivation to engaging in physical activity. Many view leisure activities as a waste of time and the community frowned upon these activities. These results are in line with surveillance findings that showed the average
time spent in work and transport related were drastically higher than time spent in recreational activities (59.3 and 21.2 versus 5.1 mean minutes per day) (Table 15) (FSM DHSA, 2012).

Table 15. Work, Transport and Recreational Related Physical Activity.

<table>
<thead>
<tr>
<th>Age Group (years)</th>
<th>Work Related Mean minutes per day</th>
<th>Transport Related Mean minutes per day</th>
<th>Recreational Related Mean minutes per day</th>
</tr>
</thead>
<tbody>
<tr>
<td>25 – 34</td>
<td>57.0</td>
<td>21.0</td>
<td>7.6</td>
</tr>
<tr>
<td>35 – 44</td>
<td>70.2</td>
<td>23.3</td>
<td>5.5</td>
</tr>
<tr>
<td>45 – 54</td>
<td>56.9</td>
<td>19.8</td>
<td>3.2</td>
</tr>
<tr>
<td>55 – 64</td>
<td>46.3</td>
<td>19.5</td>
<td>1.0</td>
</tr>
<tr>
<td>25 – 64</td>
<td>59.3</td>
<td>21.2</td>
<td>5.1</td>
</tr>
</tbody>
</table>


Culture dictates the division of activities according to age. Participants reported that, “the older you get, the fewer activities you are expected to do” and the bulk of work especially “heavy work” is required of younger adults who have “strength” and “skills.” Surveillance results from the FSM DHSA’s Chuuk STEPS report (2012) also showed this pattern as the percentage of younger adults (age 44 and younger) engage in higher levels of physical activity than older adults (age 55-64) (Table 16). Surveillance data for individuals over the age of 65 years showed even lower levels of physical activity. Study participants reported that it is not regal for elders to engage in physical activity and they are expected to sit and play the role of advisor.
Table 16. Physical Activity Levels by Age Group.

<table>
<thead>
<tr>
<th>Age Group (years)</th>
<th>Low %</th>
<th>Moderate %</th>
<th>High %</th>
</tr>
</thead>
<tbody>
<tr>
<td>25 – 34</td>
<td>63.0</td>
<td>10.5</td>
<td>26.5</td>
</tr>
<tr>
<td>35 – 44</td>
<td>59.5</td>
<td>11.5</td>
<td>29.0</td>
</tr>
<tr>
<td>45 – 54</td>
<td>64.2</td>
<td>11.0</td>
<td>24.8</td>
</tr>
<tr>
<td>55 – 64</td>
<td>69.1</td>
<td>12.7</td>
<td>18.2</td>
</tr>
<tr>
<td>25 – 64</td>
<td>63.1</td>
<td>11.2</td>
<td>25.8</td>
</tr>
</tbody>
</table>


Culture also dictates the separation of activities by gender. Males were expected to engage in more rigorous, arduous and dangerous purposeful and recreational physical activities. FSM DHSA surveillance showed that the percentage of males engaging in higher levels of physical activity than women (Table 17).

Table 17. Physical Activity Levels for Chuukese in Chuuk by Gender.

<table>
<thead>
<tr>
<th>Levels</th>
<th>Males</th>
<th>Females</th>
<th>Combined</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>58.6%</td>
<td>67.5%</td>
<td>63.1%</td>
</tr>
<tr>
<td>Moderate</td>
<td>9.8%</td>
<td>12.5%</td>
<td>11.2%</td>
</tr>
<tr>
<td>High</td>
<td>31.6%</td>
<td>20.1%</td>
<td>25.8%</td>
</tr>
</tbody>
</table>


Finally, the roles of churches and faith leaders are key to successful interventions. Participants regarded faith leaders as highly respected and influential as they can serve as role models in addition to providing education and motivation through one-on-one counseling, group sessions and sermons. They also would like physical activity
reminders and tips in the Sunday bulletins and on bulletin boards. Participants also would like their church to sponsor exercise programs such as standing during service, physically intensive community cleaning and implement policies such as walking to church. According to a recent comprehensive review, faith-based physical activity interventions shows significant promise for improving physical activity participation and related health outcomes (Bopp, Peterson & Webb, 2012).

**Future Research Agenda**

As mentioned earlier, the scientific study of sedentary is relatively new and in an effort to conceptualize how this emergent knowledge base can be used for health promotion and disease prevention. Marshall and Ramirez (2011) proposed the Sedentary Behavior Epidemiology Research Framework that identified five main research phases in rationally ordered sequences: establish the link between sedentary behavior and health; develop methods for accurately assessing sedentary behavior; identify factors that influence levels of sedentary behaviors; evaluate interventions to reduce levels of sedentary behavior; and translate sedentary behavior research into practice. Results from this study can inform future research within these phases and help move the sedentary research agenda forward. In view of that, this section includes (1) considerations for future data collection; and (2) a discussion on sedentary intervention research.

**Data Collection Considerations**

In the process of collecting data for this research project, the research team noted three needs or considerations when collecting and interpreting data from this population. First, the labeling and meaning of activities were different from conventional meanings. For example, participants cited swimming as one of the physical activities that they do on a regular basis. However, facilitators who are from the same culture observed that individuals in this age group do not engage in the usual act of swimming what mainstream consider “swimming.” The facilitator asked the focus group participants to describe “swimming” and one participant replied,
Sitting in the water and watching kids to make sure they don’t drown or get in trouble.

Another participant added,

It gets hot here so we usually take the cooler out there and just hang out in the water and let the kids cool down.

This underscores the need for researchers to understand context. It also leads to the second issue, assigning accurate Metabolic Equivalent Task (MET) values to activities with same label or name but different intensity. For example, “doing laundry” was different for Chuukese in Chuuk as compared to Hawaii participants because they have to carry their loads to the water source and hand wash their clothes versus putting them in a washer and dryer. This was consistent with findings from Moy (2006) that reported the difference between New Zealand and U.S. MET values based on the activities.

Finally, numeracy was issue as participants used objective and broad estimation for time, distances and weight. When asked how far is your home from the meeting site, many replied “too far” or “not too far” and the same goes for time. For example, participants for the first Hawaii focus group session had to catch the bus and walk from the nearest bus stop to the site. When asked “how long did it take for you to walk” some replied “too long” and “not too long” and when the facilitator propped for specific time many replied “less than an hour.” The facilitator measured the walking time between the bus stop and site to be 12 minutes. We also noticed this with our questionnaire with health care providers and faith leaders as we asked an open-ended question of how long did they work with Chuukese or the Chuukese community. All the non-Chuukese participants gave years such as 8, 9, 10 years and all Chuukese participants answered “over 10 years, under ten years, 20 some years or 30 some years”. These findings and observations underscore the need for future examination of numeracy as it will impact numerous issues from collecting accurate and precise data to communicating physical activity recommendations.
Sedentary Intervention Research

Given the results of this study and the community’s desire to prioritize interventions to address sedentary behaviors as a critical research issue, a review of the literature conducted to look at existing intervention studies. Sedentary is a relatively new health research focus. Few intervention studies have been conducted, and evidence modest from these studies was modest (Owen, Healy, Howard & Dunstan, 2012). Nevertheless, the literature suggests practical approaches that are consistent with ecological perspective (e.g., focus on particular setting such as worksite) and use key intervention messages that are consistent with epidemiological evidence (e.g., limit discretionary sitting time to no more two or three hours a day and to stand up and move at least every 30 minutes) (Owen et al., 2012). Owen and colleagues (2010) developed an ecologic model of four domains of sedentary behavior: leisure time, household, transport and occupation (Figure 3).
Findings from this study and the plan developed by community representatives and stakeholders are in accordance with these suggestions and can benefit from it. For example, community members have already expressed the need for interventions that focus on specific settings but the setting they selected (church) was specific to their context. Moreover, Chuukese would benefit from testing messages with specific
recommendations based on epidemiological evidences as that will address the community’s need for specific information on the amount of sitting time and frequency of standing up and moving around.

In addition, the literature showed investigators primarily use of two theoretical frameworks to guide their interventions: Social Cognitive Theory and Behavioral Choice theories (Gardiner, Eakin, Healy & Owen, 2011; Wilmot et al., 2011). This study gathered information on all three constructs of the Social Cognitive Theory and this community is in a good position to develop interventions based on the social cognitive theory tailored to its cultural-social context. For example, in the literature most studies targeted TV viewing time, computer screen time, worksites and time spent of the phone. Finding from this study showed that sitting often occurred in church (or during church activities) and at home so studies in this population need to consider these differences. This also underscores the importance of collecting community and culture specific data. This study also identified the need for age and gender specific interventions.

Another salient community suggestion is for motivational support. The use of Behavior Choice theories can help guide future research in this community. There are several Behavioral Choice theories in the literature but the one developed by Glasser (1998) is often used in behavioral health. He posits that human behavior is influenced by the genetic need for survival, connecting & belonging, power, freedom and fun. This study revealed some information that can be used to develop an intervention based on this theoretical framework. For example, Chuukese people strive for survival in modern society, the importance of connectivity and the placement of power.

Community Identified Intervention and Research Ideas

In compliance with community based participatory principles, overall findings were presented to community representatives and stakeholders and they drafted the following plan for future intervention research and programs. This community
participatory planning process addressed the need for community to use research data to plan their own activities versus researchers and public health administrators planning activities without the input of community members and stakeholders.

Due to the prominence of sedentary behaviors in the discussions, the planning group decided to focus their planning time on addressing interventions that address the different types of sedentary behaviors (Table 20). In the focus group discussions, participants mentioned both personal and environmental needs. On the personal level, participants expressed the need for motivation, accountability, reminders and interventions that “add-on” or “build-on” to existing purposeful activities. Accordingly, activities to accomplish the research goals and aims addressed these needs. Moreover, the planning group recognized the overall importance of the physical environment (e.g., safe sidewalks, available venues to exercise and bicycle lanes) in decreasing sedentary behaviors and expressed the need for research to determine the effectiveness of environmental support in decreasing sedentary behaviors.
Table 18. Sedentary Behaviors, Goals and Activities

<table>
<thead>
<tr>
<th>Sedentary Behavior</th>
<th>Current Actions</th>
<th>Goals/Aims</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Purposeful Sitting</td>
<td>Sitting <strong>with</strong> actions/movements (e.g., sewing, gardening and weaving baskets).</td>
<td>Increase frequency, duration and intensity of activities.</td>
<td>1. Provide training on how to increase duration and intensity of activities. 2. Set frequency goals.</td>
</tr>
<tr>
<td></td>
<td>Sitting <strong>without</strong> action/movement (e.g., participating in meetings and watching the house).</td>
<td>Promote standing during church meetings and encourage additional activities w/ watching the house.</td>
<td>1. Work with faith &amp; church leaders to increase the frequency of standing during church services and meetings. 2. Provide training on how to “add-on” activities with “watching the house”</td>
</tr>
<tr>
<td>Lazing</td>
<td>Sitting <strong>without</strong> actions/movements (e.g., watching television, talking story and people watching)</td>
<td>Promote purposeful sedentary and physical activity</td>
<td>1. To address motivation and emotional issues provide counseling (by faith leaders). 2. Host support groups in the church. 3. Same activities as “Purposeful Sitting”</td>
</tr>
<tr>
<td>Wasting Time</td>
<td>Sitting <strong>with</strong> actions/movements (e.g., playing games).</td>
<td>Promote playing games with actions</td>
<td>1. To address anger, frustration and discontentment issues, issues provide counseling (by faith leaders) 2. Host support groups in the church. 3. Provide suggestions and trainings on games with action.</td>
</tr>
<tr>
<td></td>
<td>Sitting <strong>without</strong> actions/movements (e.g., watching television, talking story and people watching)</td>
<td>Promote activities with action and purposeful activities</td>
<td></td>
</tr>
<tr>
<td>Resting</td>
<td>Sitting <strong>with</strong> actions/movements (e.g., playing games).</td>
<td>Although resting is important, limiting resting time is needed.</td>
<td>1. Assess amount of time spent “resting” 2. Determine appropriate “resting time” 3. Provide suggestions and trainings on games with action.</td>
</tr>
<tr>
<td></td>
<td>Sitting <strong>without</strong> actions/movements (e.g., watching television, talking story and people watching)</td>
<td>Promote activities with action.</td>
<td></td>
</tr>
<tr>
<td>No can move</td>
<td>Sitting <strong>without</strong> actions/movements (e.g., watching television, talking story and people watching)</td>
<td>Promote sedentary and physical activity that is appropriate and safe.</td>
<td>1. Provide physical activity training specifically for ill or injured individuals.</td>
</tr>
</tbody>
</table>

**Conclusion**

This study elucidates physical activity and sedentary behaviors of Chuukese and cultural influences that are specific to this population. It also revealed the need to address sedentary behaviors and physical activities separately. Moreover, the community
developed an intervention plan that addresses sedentary behaviors through education, motivation and environmental support. Akin to most qualitative studies, the limitations of this study include its small size and convenience sampling. Participants were likely to be different than those who did not. For example, the researchers asked community members who wants to share their experience in diabetes care as individuals with diabetes and caretakers so participants likely reflected the ‘talkative’ rather than the ‘shy’ members. Moreover, the interviews and focus group were also conducted in English so those who are not fluent in English might have different experience and perspectives. Nevertheless, the research team feel confident that findings can be used to develop culturally appropriate diabetes control intervention in the state of Hawaii and Chuuk. They believed that programs and research based on the Pacific values, beliefs and traditions would also appeal to other Pacific communities. Finally, the community members and partners believe that our participatory process using grounded theory principles can serve as a model for other researchers working with minority groups to reduce health disparities.
CHAPTER 5
STUDY 4: PRESCRIPTION MEDICATION ADHERENCE

Introduction

Type 2 diabetes (T2DM) is a chronic degenerative disease with the greatest negative effects on economically productive adults and it has been called the “illness” of the 21st century. Chronic hyperglycemia is the main cause of long-term diabetic complications that ultimately result in damage of key organs, premature deaths, and decreased years of healthy life (American Diabetes Association [ADA], 2005). Diabetes is also a costly disease, annual health care expenditures per capita in 2002 were more than five times greater for patients with diabetes ($13,243) than for individuals without diabetes ($2,560) (Hogan, Dall, & Nikolov, 2003). The diabetes epidemic is especially severe among Pacific Islanders. According to the Office of Minority Health, Native Hawaiians and Other Pacific Islanders living in the U.S. have higher rates of diabetes (20.6%) than Whites (6.4%). The diabetes epidemic is more devastating for Pacific Islanders living in their homeland especially residents of the U.S associated Pacific Islands (USAPI) (Hosey et al., 2009). Although a post-World War II US Navy survey of the USAPI found no cases of diabetes, subsequent population surveys have shown a dramatic increase in diabetes (Institute of Medicine [IOM], 1998). In 2007, the estimated prevalence of diabetes for the US population (adults aged 20 years or older, diagnosed and undiagnosed) was 10.7% (Centers for Disease Control and Prevention [CDC], 2007). In the U.S Pacific diabetes rates range from 24.4% in the Federated States of Micronesia to 47.3% in American Samoa (World Health Organization [WHO], 2002; WHO, 2007).

When patients are not able to control their glucose level with lifestyle changes (diet and exercise), then the next step is generally for physicians to prescribe pharmacological agents (Warren, 2004). Although medications are effective in controlling diabetes their full benefits are often restricted and reduced because approximately 50% of patients
worldwide with chronic illnesses do not take their medications as prescribed (Lee, Grace 
& Taylor, 2006; Sabate, 2003). Due to the high prevalence of diabetes among Pacific 
Islanders and the significant role prescribed medications play in the management of 
diabetes, it is critical for health researchers and practitioners to investigate the current 
state of medication adherence among people with diabetes in this population. Moreover, 
Pacific Island communities, through various meetings in the past ten years prioritized the 
need for diabetes related interventions including drug adherence. Moreover, they 
identified healthcare providers, faith leaders, diabetics and caregivers as study subjects; 
and Chuukese living in Chuuk and Hawaii as target populations. To that end, the primary 
aim of this study was to identify socio-cultural influences that hinder or facilitate 
prescribed medication adherence.

Cramer’s (2004) systematic review of diabetes medication adherence confirms 
that many patients with diabetes took less than the prescribed amount of medication (oral 
hypoglycemic agents and insulin) with adherence rates between 36% and 93%. The 
World Health Organization reports that improving patients’ medication adherence may 
have a far greater impact on population health than any improvement in specific medical 
treatment (Sabate, 2003). Meichenbaum & Turk (1987) defined medication adherence as 
the extent to which a person’s behavior coincides with medical or health advice. 
Adherence to drug treatment is an intermediate outcome variable that has a positive 
correlation with health-related quality of life (Cote, Farris & Feeny, 2003). Contributing 
factors to poor medical adherence are numerous and fall into the categories of patient-
related factors, physician-related factors and health system/team building related factors 
(Brown & Bussel, 2011).

Patients-related factors impacting medication adherence include lack of disease 
knowledge (Ryan, 1999); lack of involvement in the treatment decision making process 
(Haynes, McDonald & Garg, 2002); inadequate health/medication literacy (Raynor, 
2008); patient’s health beliefs and attitudes concerning the effectiveness of the treatment
and their previous experiences (Brunner et al., 2009; Joyner-Grantham et al., 2009; Shiyanbola & Farris, 2010); poor mental health (Joyner-Grantham et al., 2009; Kronish et al., 2006); and socio-economic factors such as cost of medication, lack of transportation, and lack of family or social support (Brunner et al., 2009; Kripalani, Henderson, Jacobson & Vaccarino, 2008; Molloy, Perkins-Porras, Bhattacharyya, Strike & Steptoe, 2008; Molloy, Perkins-Porras, Strike & Steptoe, 2008).

Physicians-related factors impacting T2DM medication adherence include providers’ failure to recognize medication non-adherence in their patients (Kripalani et al., 2008); ineffective provider-patient communication (Steiner & Earnest, 2000); and failing to elicit a history of alternative, herbal or supplemental therapies (Brown & Bussel, 2011). Oladimeji and colleagues (2009) encourage physicians and health care providers to assess patients’ concern beliefs in medication. Moreover, provider-patient discussion of the patients’ beliefs about their drug therapy is likely to affect their expectations and interpretation of symptoms as well as future attributions regarding drug therapy (Oladimeji, Farris, Urmie & Doucette, 2008).

Lastly, health system-related factors impacting medication adherence include lack of health care coordination (Gordon, Smith & Dhillon, 2007) and high cost of medication and insufficient patient-provider consultation time (Kennedy, Tuleu & Mackay, 2008). A recent study on physician/pharmacists collaboration suggested that the reallocation of clinical pharmacists to provide more direct patient management might improve blood pressure control (Carter, Bergus, Dawson, et al, 2008).

In the literature, medication adherence interventions vary greatly, from the commonly used one-on-one oral communication intervention (with or without written supplementation) to group-, videotape-, and audiotape-based interventions and they seem to have a favorable impact on adherence (Haynes et al., 2000). In addition, behavioral strategies (such as reminder notes and special medication containers) and a combination of behavioral and educational strategies have also been effective (Peterson, Takiya &
Finley, 2003). In regards to health systems related factors, a randomized study demonstrated the effectiveness of an intervention that uses community pharmacists (Tsuyuki et al., 2002). A recent review of randomized controlled trails of interventions to assist patients follow prescriptions for medications for long-term treatments like diabetes concluded that almost all of the interventions that were effective were complex (Haynes, Ackloo, Sahota, McDonald & Yao, 2008). They include combinations of more convenient care, information, reminders, self-monitoring, reinforcement, counseling, family therapy, psychological therapy, crisis intervention, manual telephone follow-up, and supportive care. However, even the most effective interventions did not lead to large improvements in adherence and treatment outcomes (Haynes, et al., 2008).

In regards to Chuukese and other Pacific Islanders, there is little information on patient, and health systems related factors that influenced medication adherence and no information on physician related factors. For patient-related factors, there was anecdotal evidence suggesting a reliance on non-Western medical treatments such as traditional and alternative medicines in addition to or instead of medication (Aitaoto, Braun, Ichiho & Kuhaulua, 2005). WHO defined traditional medicine as “the sum total of knowledge, skills, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement of treatment of physical and mental illness.” (http://www.who.int/medicines/areas/traditional/en/index.html).

There is a need to investigate the influence of traditional and alternative medicine reliance on prescribed adherence. Although there are no studies on cultural beliefs and adherence to Western medicine and management of type 2 diabetes in this population, there are several studies in other cultures that argued the use of traditional healing practices can lead to non-adherence to Western treatment (Kleinman, Eisenberg & Good, 2006; Li, Stewart, Stotts, & Froelicher, 2006; Munro et al., 2007; Naidoo, Dick, & Cooper, 2009; Wong, Mouanonoutoua, Chen, Grey, & Tseng, 2005). There is evidence
of poor management of diabetes among Pacific Islander patients and recommendations to consider cultural beliefs in diabetes education (Agban, Elley, Kenealy & Robinson, 2008). In regards to health systems related factors, a Pacific Chronic Disease Coalition assessment revealed numerous health system-related factors such as medication shortage and lack of coordination among health care team members (Aitaoto & Ichih, 2013).

Due to the lack of information on prescribed medication adherence, this formative study explored issues around diabetes medication adherence from four perspectives: health care providers, faith-leaders, diabetes patients and diabetes patients’ family members/caregivers.

**Method**

Given limited previous research about Pacific Islanders and diabetes medication adherence, qualitative methods (key informant interviews and focus group) were chosen for this study. In addition, community representatives initiated the idea for this study and the research team abided by Community Based Participatory Research (CBPR) principles. Accordingly, community representatives approved research topics, methods and study subjects. Through community workshops, community members identified the study of social support (e.g. family and church) and cultural attitudes and beliefs concerning diabetes prevention and control activities (including medication adherence).

They also chose faith leaders, health care providers, people with diabetes and family members of people with diabetes as study subjects. As a result, this study focused on medication adherence behaviors and viewpoints of four stakeholders, people with diabetes, caretakers, health care providers and faith leaders. Furthermore, two community representatives were involved in the development of the tools that were approved by the Pacific Chronic Disease Coalition and the University of Iowa Institute Review Board (IRB). A partnership with two community organizations, Chuuk Women’s Council and Micronesians United assisted with subject recruitment and logistics support for data collection.
Measures

This study was part of a larger data collection. The first set of data on medication adherence was from faith leader and health care provider interviews. The objectives were to (1) obtain their perspective and experience regarding prescribed medication adherence and diabetes prevention and management; and (2) determine whether they were supportive of faith-based physical activity and diabetes initiatives. Participants also completed a one-page demographic questionnaire that included age, sex, religion/denomination, diabetes status and employment status. The second data set was from focus group discussions with people with diabetes and their family members in Chuuk and Hawaii. The objectives were to (1) obtain their perspective, experience and actions regarding prescribed medication adherence and (2) determine whether they were supportive of faith-based diabetes initiatives. Participants also completed a one-page demographic questionnaire that included age, sex, religion/denomination and, diabetes status.

Procedures

Healthcare Provider and Faith Leader Interviews

Participants for the key informant interviews were invited through email and telephone using a script approved by the UI-IRB. They all agreed and interviews were conducted in the CWC office (Chuuk faith leaders and health care providers), Micronesians United’s office (Hawaii faith leaders) and interviewee/provider office (Hawaii providers). Interviews were conducted and recorded by the investigator. Audiotapes were reviewed after each discussion to guide probing questions for the next interview. Interviews lasted approximately 3 hours in Chuuk and 2 hours in Hawaii.

Community Focus Groups

Participants were invited via email and telephone using a script approved by the UI-IRB. In accordance with the CBPR practice of transferring skills, a faith leader and public health practitioner from the U.S Pacific were recruited and trained to facilitate the
sessions and record and transcribe data. This technique was appropriate as the objective of this study was to understand Chuukese beliefs, attitudes and behaviors with regard to diabetes, while also observing the influence of cultural involvement and the church setting. Moreover, focus groups fit in with Pacific culture, which includes an oral-aural tradition, a preference for collective learning, and the importance of face-to-face meetings that allow people to gauge intent, sincerity, and trustworthiness as information is exchanged (Braun et al. 2002). The Chuuk focus group sessions were held at a local hotel (Truk Stop Hotel) and the Hawaii focus groups was held at the Palama Settlement Conference Room. Focus group sessions were recorded and the audiotapes were reviewed after each session in order to guide probing questions for the next session.

Participants

This study included a total of 131 individuals: 12 health care providers (6 in Hawaii and 6 in Chuuk), 17 faith leaders (8 in Hawaii and 9 in Chuuk) and 102 people with diabetes and/or caregivers.

Healthcare Providers and Faith Leaders

A total of 12 health care providers (three alternative medicine practitioners, three nurses and six physicians) and 17 faith leaders (seven pastors, six deacons and four pastor’s wife) participated in the interviews. The majority of health care providers (83%) practiced at least 20 years, 58% were Chuukese, and all five non-Chuukese providers practiced in Hawaii. All 17 faith leaders were Chuukese and served in the ministry full time. In Hawaii, 89% of the interviewees worked outside of their church in addition to full-time ministry as compared to 25% in Chuuk.

Community Focus Groups

Sixteen focus groups were conducted in Chuuk and Hawaii with total of 102 participants (43 in Chuuk and 59 in Hawaii). The average age of participants was 46 years (43 years in Chuuk and 47 in Hawaii). More than half (53%) were female, 58% were Protestants, 53% had diabetes and 90% had a primary care physician.
Data Analysis

To comply with CBPR principles, Pacific representatives from faith-based and healthcare organizations were part of the analysis team. The process was guided by grounded theory and was sensitive to individual, behavioral, and environmental influences consistent with Social Cognitive Theory (Bandura, 1989; 1998). In accordance with grounded theory practices, the first step was coding or naming segments of data with a label that concurrently categorizes, summarizes and accounts for each piece of data followed by a face-to-face group coding meeting (Charmaz, 2006). The group worked quickly through the transcript looking for coding incidences and attentive to In Vivo codes or words/phrases that compress meanings and consist of widely used terms that participants assume everyone shares. These codes, words or phrases helped preserve participants intended meanings within the coding itself. The analysts also scripted early memos, flagged focused codes and noted items to discuss later. This process fractures the data into separate pieces and distinct codes so the next step (axial coding) brought back together these pieces to form a coherent whole. This step sorted the initial codes and grouped them into common themes, developed major categories with subcategories with links and reviewed our early memos to start the clustering process. This produced a tentative and flexible chart of our categories and sub-categories. The final step was identifying future research questions that can elaborate and refine categories in our theory as this helps with finding pertinent data to develop our emerging theory (Charmaz, 2006).

Results

Key interview and focus group participants communicated a variety of behaviors (healing practices and cyclic behaviors), personal factors (knowledge, attitudes and beliefs) and environmental influences (social [family and church], healthcare provider, healthcare system and economic) related to medication adherence. These were consistent with the Social Cognitive Theory and the result section is organized below in this format.
Behaviors

The medication adherence discussion was in the context of adhering to four types of healing practices that participants referred to as “western”, “traditional”, “local” and “new/fad.” These healing practices utilized western, plant-based (including herbal) and/or non-plant based medicines with the assistance and/or facilitation of healers or advisors such as doctors, traditional healers and family members. Participants also articulated the focus of healing as most of the healing practices addressed the physical body in addition to the mind and body (Table 19).

Table 19. Type of Healing

<table>
<thead>
<tr>
<th>Healing Types</th>
<th>Healers/Advisors</th>
<th>Treatments/Remedies</th>
<th>Focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Western</td>
<td>Doctors</td>
<td>Pills, insulin and dialysis</td>
<td>Primary: Body</td>
</tr>
<tr>
<td>Traditional</td>
<td>Traditional Healers</td>
<td>Plant-based (based on traditional knowledge)</td>
<td>Primary: Spirit</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Secondary: Mind and Body</td>
</tr>
<tr>
<td>Local</td>
<td>Traditional Healers, Local Healers</td>
<td>Plant-based (both traditional and other cultures)</td>
<td>Primary: Body</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Secondary: Mind and Spirit</td>
</tr>
<tr>
<td>New</td>
<td>Family, Friends</td>
<td>Plant-based (from other cultures) and non-plant based</td>
<td>Primary Body</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Secondary: Mind and Spirit</td>
</tr>
</tbody>
</table>

Healing Practices

Participants gave in depth descriptions of each of the four healing practices including facilitators (healers/advisors), treatment/remedy types (e.g., pills, herbals and oils), treatment focus (e.g., physical body, spiritual and emotions), and adherence behaviors.

Western Healing Practices

Participants described western healing as going to the doctor, clinic or hospital when something is wrong with the body or feeling pain. It often involved western
medicine or pills from the clinic or store/pharmacy. Patients described four medication adherence behaviors in the order of most mentioned: (1) currently taking medication but not following all the directions (e.g. skipping or taking when only feeling bad/pain); (2) taking medication in the past but now stopped; (3) receiving medication but did not start; and (4) currently taking medication as directed. Health care providers and faith leaders confirmed these behaviors especially the practices of selective adherence. A faith leader from Chuuk affirmed,

People only want the pain to go away so when they start feeling better then they stop. On the other hand, when they don’t feel better they stop. That is why so many are not taking their medicines.

Health care providers also reported that some of the patients who are in compliance have the perception that their medicines give them a “free pass to do whatever” and they did not have to follow dietary and physical activity recommendations. A health care provider from Chuuk reported,

My patients often say that western medicines take care of their diabetes so they can eat whatever I want.

A physician from Hawaii added,

It is harder to treat Chuukese patients as they come in with multiple issues and are lot sicker. They want medicine to make them feel well but stop without letting us know. They miss appointments and they only return when things are at their worst.

Traditional Healing Practices

Participants described traditional healing “as healing of the mind, body and spirit through practices (e.g. prayers, meditations, massages, emotional counseling, encouragement and taking traditional medicines) that were passed down through generations” and involve the collective (family, church and community members). There was sacredness in the healing process that demands respect and reverence. The chief focus was on spiritual and emotional aspects of healing. Medication and other physical treatments play a minor part in the overall healing process. A traditional healer from Chuuk explained,
Traditional healing involves herbal medicines but the real focus is the spirit and mind. I do a lot of praying, teaching and encouraging with my patients.

The community recognized traditional healers as possessing the knowledge and gift of healing. As part of the healing process, traditional healers provided support in the form of prayers, counseling (e.g., health education, encouragement and motivation) and prescribing traditional medicine. On the physical level, traditional healers treat diabetes complications or have a symptom-based approach to treatment. As one traditional healer from Chuuk explained,

I don’t treat diabetes the disease but diabetes causes pain in the legs so I take care of that by massaging their feet, diabetes makes wounds harder to heal so I give them this oil with special herbs for quick healing, and diabetes makes people tired because they don’t sleep well at night so I treat that with herbal medicine.

A caregiver added,

Many use traditional medicine to boost energy, heal wounds, relax sore muscle, settle stomach, make them sleep better and alleviate pain we all know it works and that’s why we continue to use them. They work!

Patients reported taking various types of plant-based medicines including herbs and oils. They also talked about the process and commitment to traditional healing and medicines. One of the patients from Chuuk testified,

When taking traditional medicine there are other things you need to do like picking leaves, taking them on specific times, and not eating certain kind of foods. I take all that stuff very seriously and I follow them.

Traditional healers verified this commitment and as a healer from Hawaii added,

My patients and their family members are very dedicated to their treatment. I know it is hard to go through all the steps but that is why it is important to have faith and mental strength.

Patients also reported not disclosing their use of traditional healers/medicines to their western doctors. As one patient testified,

I didn’t tell my doctor because they will not understand and they will try to discourage us from taking our traditional medicines.

A few of the health care providers reported that they dissuaded their patients. As a provider in Hawaii stated,
I discouraged my patients from traditional medicines because I just don’t know what they are and from my standpoint it seems like it is doing them more harm so I want to be on the safe side.

The majority of the providers do not discourage nor do they encourage the use of traditional medicine even though they felt that they don’t know enough about traditional medicine and there is not enough research on traditional medicines. A physician from Chuuk stated,

I know they are taking it, I see the green herbal medicine on their wounds and I see them with their bottle of medicine outside in the waiting room. I don’t know what they are but I feel that if it is not harming them then I’m OK with it.

In regards to communication, providers from Hawaii reported that their patients do not disclose their usage of traditional medicine, as one provider stated,

I have a feeling they are taking them but they don’t say anything even after I ask.” Another provider added, “I know it takes a lot of trust for patients to disclose their use of traditional medicine and we are not there yet. I do want to get there and we need help with that.

Local Healing Practices

Participants reported a decrease in the utilization of traditional healing practices, however, there was a steady increase in seeking local healing/medicine. Local healing is often mistaken for traditional healing because they share similar principles and treatments but there are major differences such as focus (for the most part, traditional healing primary focus was on the spirit and local healing was primarily focused on healing the body. As one of the local healers who participated in one of the focus groups as a caretaker explained,

My mother was a traditional healer and she always began her healing sessions with a prayer because her main focus was healing the spirit. After the prayers she continued with herbals and encouragements. I learned a lot about healing herbs from my mother and now I’m a local healer and I share my knowledge of herbs with family and friends but my focus is on the herbs and healing of the body.

Don’t get me wrong, I believe in prayers and I do pray with and for my family but that is not my focus.

There was also a discussion on the lack of sacredness in the healing process. As one of the community participants commented,
When I was young, I watched my grandmother participate in traditional healing and there was a sense of reverence and sacredness in the process and rituals. I remember a lot of rituals. I now take local medicines and most of them are the same herbs by grandmother used. I believe in their healing properties, but I don’t get that sense of sacredness and reverence.

Finally, participants reported that local healers can be a traditional healers or women from the community who have the desire to share their knowledge of plant-based remedies and experience. As mentioned in an earlier quote, most of the women learned about medicinal herbals from their mothers and grandmothers and are now sharing that knowledge with their family and community. Although the primary emphasis of local healing was on healing the body, local healers also provide emotional support and incorporate faith and prayers in their healing practices. Similar to traditional healing practices, healers treated symptoms and complications of diabetes and used the same plant-based medicines in addition to plant-based remedies from other cultures. This inclusion of plant-based medicine from other cultures also distinguishes local medicine from traditional medicine. These plants were available on island but they were not used in healing remedies in the past. For example, the Filipinos introduced *ampalya* and the Palauans introduced the “leaf that shape like bowl.” Both plants were grown on island but were not used as medicine before the influence of the Filipinos and Palauans. Participants reported stronger loyalty to local healing and medicine as compared to western healing/medicine.

**New Healing Practices**

Patients and caregivers also reported another type of healing that was on the increase referring, to them as “new cures” or “new healings.” Physicians also mentioned new cures and medicines during their interviews referring to them as fad medicine as these types of medicines were usually popular for a short period of time and currently lack scientific evidence. On the other hand, new cure distributors and advisors declared that,

Some think that what we do is ‘fad’ but our methods are century old. Our methods were there before western medicine.
Like local healing, new healing focused on healing the body but also incorporates motivational and emotional support. It also used plant-based medicines from other cultures (similar to local healing) but unlike local healings some of the medicines derived by plants there were not found usually on island (e.g., mint, goji and coffee). Another major difference was the use non-plant based products such as kanji water, alkaline water and magnetic necklaces. As one of the participants explained,

There are a lot of natural alternatives that can cure us, and I tried them all. I used to do local medicine and I liked it because they are natural, but there are some illnesses and pain that our local medicine can’t handle so I try the new cures because they are a lot more natural than pills. I’m using the oil and special water.

Furthermore, the majority of advisers/distributors were lay people, usually family members or friends and that most of the new/fad medicines originated in Hawaii and brought to Chuuk by Chuukese living in Hawaii. A Chuukese participant in Chuuk reported,

The alkaline water is new to me, my sister who just came back to Chuuk from Hawaii told me about it.

The quick widespread use of new medicine was attributed to faith leaders’ involvement in promoting the items. Participants reported that they took new medicine because their pastor or trusted family friend’s recommendations and encouragement. Another participant from Chuuk commented,

I see a lot more of those special water tanks around town and some of the pastors are spreading the word that it works. I drank some the other day because my pastor who is also my cousin told me that it works.

**Cyclic Behaviors**

The great majority of patients reported that they usually start with non-western medicine, if that doesn’t work then they would go to medical doctor for western medicine and if that does not work then they would go back to non-western medicine. As one patient stated,
When I first start feeling sick my wife gave me local medicines and that helped for a little while but as time went by things got worst to the point where I ended up at the emergency room and the doctor gave me pills. I tried those for a while but eventually they didn’t work either so my wife started me on other stuff. They worked but not for long and I ended up at the emergency room again so now I’m taking pills again.

Health care providers also confirmed this behavior and a physician from Hawaii added,

They come to us when things get bad but when they think the medicine in not working for them then go back to their herbal medicines.

This cyclic behavior pattern between western and non-western medicine was prominent in the all the focus group discussions and key informant interviews. In addition, patients reported taking a combination of treatments. A patient from Hawaii declared,

I take whatever works; it can be pills or herbals and sometime a combination of various pills and herbals.

Personal Factors

Conversations in all 16 focus groups mentioned personal factors that influenced adherence and non-adherence to western and non-western medicines (traditional, local and fad). They include knowledge (e.g., what the medication is for, when to take it and how to take it) and beliefs (e.g., effectiveness and naturalness of the of the medicine). Health care providers and faith leaders also brought up some these factors during their interviews.

Knowledge

The discussion on medication often began with patients listing western medication they are familiar with or taking. They cited only one medicine by name “Metformin” and the rest were described by color, size and shape. The facilitator probed participants on the purpose of the medications. Participants replied “diabetes” and did not go into any other details. Few gave details on frequency and quantity with most saying, “we take this every day” and “we take 6 pills a day.” On the other hand, participants spent most of their time discussing non-western medicines. Patient and caregivers mentioned traditional plant-based by name and described a few (local and new...
medicine) by shape, texture or other unique characteristics. They specified the purpose for medicine (e.g., rash, wound, sleeplessness, sore muscle, diarrhea and headache) described in details the frequency and quantity for each dosage. One of the patients in the Chuuk focus group held up a spoon and her herbal medicine in a bottle saying,

When I get up in the morning I take two of this (waving the spoon and pointing to the bottle) right after I eat my first meal, during the day I usually do church and family stuff so I take it with me so that when I have my mid-day meal then I take it there, and in the evening after I eat I take the last two.

Other participants gave similar detailed descriptions of frequency, quantity and additional requirements (e.g., taking with or without meals and taking before/after meals). For non-plant based new medicines, patients gave general descriptions or showed the items (e.g., bracelet, necklace and water) to the facilitator. They were probed for purpose for the items and they replied, “for diabetes” or “for cleansing.” They also reported that “the rules were lot more relaxed” as they can wear the items (bracelet or necklace) anytime and drinking the alkalized water when it was available.

Beliefs and Attitudes

The discussion regarding beliefs and resulting attitudes focused on the effectiveness, naturalness and trustworthiness of medicines, with constant comparisons between western and non-western medicines. Participants believed that some of the western medications were effective on pain (e.g., headaches, stomachaches, body aches and pain caused by cuts and wounds) and general feeling of illness or malaise. They also believed that non-western medicines (traditional, local and new medicines) were just as effective if not more effective and tried them first because they (1) trust non-traditional healers as most of them are family members, someone from the community and faith leaders; (2) desire the spiritual and emotional support non-traditional healers provided; (3) familiar with the medicines; and (4) prefer natural medicines. Regarding diabetes control medications, some believed that it does not work because they felt worse after
taking them reporting running stomach (diarrhea), dizziness, swollenness and weakness.

As one caregiver declared,

My mother had a runny stomach for a long time after starting her diabetes medication so she stopped.

Others felt that it does work, however, they had concerns over taking them over a long period of time (defined as more than three months). Uneasiness over long-term usage of western medication was related to their naturalness. As one patient testified,

They are made out of chemicals in a factory somewhere out there and they’re not natural. I can’t see myself putting those stuff in my body every day for the rest of my life, it is just not natural.

Another diabetes patient added,

I just got diagnosed and got my pills but haven’t started it yet because when you start your body will get addicted to it and need to take more, and I don’t want to put strange things in my body.

Health care providers presented the same viewpoint during their interviews. A physician from Chuuk stated,

There is a fear of taking diabetes medicine because they think it is not natural and they like traditional medicine because they are plant based and natural.

Patients’ beliefs concerning the naturalness and effectiveness of medications also impacted their decision to use new cures or healing that offers “natural alternatives” such as alkaline water and magnetic necklaces. A health care provider from Chuuk declared,

People are selling special water, essential oils and herbal medicine – not Pacific herbs. Those guys are doing a better job at convincing diabetics that their remedies are natural and effective.

In addition, participants mentioned being overwhelmed with the long-term nature of the disease. A patient reported,

Diabetes is a lifetime disease and that is hard; it is easy to be motivated to do comply to short treatments like some of the cancer therapies than doing something for a lifetime. I need to work hard to control my diabetes for the rest of my life, and that is overwhelming.

This feeling of being overwhelmed lead to feelings of hopelessness and depression, followed by distraction and carelessness (e.g., forgetfulness, not making
adherence a priority) with taking medicines. Moreover, younger patients cited shame of
taking diabetes medicine, as one young patient from Hawaii said,

Diabetes is for old people like my parents and grandparents so I feel shame
having diabetes, and I don’t want to pop those pills in front of people and as you
know we are always with other people so it is hard to find a private time and place
to take medicine.

Environmental Factors

Environmental factors also influenced western and non-western medication
adherence. Participants cited issues related to (1) social support, (2) health care providers,
(3) health care system, (4) and economics.

Social Support

One of the most mentioned facilitator and barrier to western and non-western
medicine was support from family members (especially a wife or female relative
caretaker). A diabetic from Chuuk testified,

The reason why I’m taking my diabetes pills is because my family is very
supportive. My wife is keeps track of everything, and she is good at reminding
when to take them. Other relatives also take the same kind of medicine, and we
talk about our medicines sometimes.

Family support also influenced patients taking non-western medicine. A health care
provider reported,

Family members, especially the spouses, have a lot of influence and we need to
talk to them to support adherence because many times it is the wife who
convinces their husband to see a traditional/local healer, and the wife usually take
them to the healer and make sure they comply.

Participants also cited the importance of friends, especially church friends in introducing
and motivating diabetics to take new/fad medicines. A diabetic and caregiver from
Hawaii testified,

My husband was sick and the medicine from the doctor wasn’t working so I heard
my friends at church talk about this new cure, and that was working very well for
them, so I decided to get it for my husband.

Another participant added,

My wife and I are drinking the coffee for our diabetes and we bought it from our
pastor.
Health care providers also reported these practices during their interviews, a physician reported,

People trust their pastors and pastors really believe that these new cures are helping the people.

In addition to medication recommendations and support, church friends and pastors provide spiritual and emotional support. As a caregiver in Chuuk remarked,

In our culture, there is a spiritual side of healing regardless of the illness and the type of medicine you choose to take.

Healthcare Providers

Health care providers behaviors and relationship with patients also influenced medication adherence. A majority of the patients reported that they were not disclosing their non-western healing behaviors (including taking non-western medicine) to their doctors due to the fear that the doctors will disapprove. A patient from Hawaii cited,

I told my doctor that I drink the special oil. He got really mad and said a lot of negative things about the oil and the person who gave it to me. My pastor gave me the oil so I stopped going to that doctor. Now, I don’t tell any of that stuff to other doctors - it is better they don’t know.

Another patient added,

Some doctors don’t want us to take them (traditional and local medicine) at all and they don’t even know what I’m taking so how do they know if they are working or not. They just want us to do what they say and they don’t listen to us.

Some of the health care providers also acknowledged this relationship dynamic. A physician for Hawaii reported,

I know they are taking it, I sometimes see the herbs on their wounds. Our CHW (Community Health Workers) also share some of the stories with me and our staff but they don’t tell me – they barely talk when they are in my office.

A physician from Chuuk reported,

They usually use traditional medicine for wound care, when they feel weak or when they lose their appetite. They usually don’t tell me because in the past we usually scold them for doing it. I know they all use it because they come with herbs on them or they come in with medicine still left over.
Others providers were supportive of traditional and local medicine but not new cures. A physician from Hawaii stated,

I don’t discourage traditional medicine. Fad medicines, I do have some concerns. I’ve been a physician here for over 20 years and fad medicine does more harm because people spend a lot of time and money on them and some even quit taking their medicine.

Several health care providers (especially nurses) reported providing support for patients who chose traditional/local medicine. A nurse from Chuuk said,

I usually tell them, good for you and continue to care for the wound. As long as I see improvements I’m OK with it.

They also expressed the need to understand traditional medicine better,

I wish we have more information on the different types of traditional medicines so we provide better advice to our patients. I would love to advise my patients on traditional medicine but I don’t know enough about them.

Providers also wanted better communication with patients and their healers;

We need better communication with our patients and their healers. We need to be more open to having healers come to the clinic and share their knowledge – we are not there yet but would love to be there someday soon.

Traditional and local healers were also very supportive of this collaboration. A traditional healer in Hawaii reported,

I tell them to show the medicines to their doctor but most don’t want to do it because the doctor doesn’t want to hear it.

Patients reported their encounter with pharmacy staff, “we get the medicine from the pharmacy and that is just a cashier taking our card and giving us medicine so impersonal” and another participant added, “they rush us out of the store and they don’t take time to explain and encourage us.” Patients also talked and compared this experience with the thorough education, motivation and encouragement they receive from non-western healers.
Healthcare System

Participants reported health care system related barriers specifically patient education, motivation, time allotment, lack of medication (Chuuk) and poor quality of medication. Although physicians and nurses expressed the desire to spend more time with their patients, their patient load does not allow it. They are required to attend to a given amount of patients each day and they had no choice but limit their interaction time with patients. A physician in Hawaii declared,

We have an archaic and obsolete system that was not set up to handle chronic diseases like diabetes.

In addition, patients in Chuuk reported inconsistent supply of diabetes medication supply. Physicians agreed that in the past they had problems with ordering medications but they have resolved the issue and have ample supplies. On the other hand, the clinic started to order medication from Asian countries, and patients questioned the quality of medicines. Patients in Hawaii did not have concerns with supplies but did mention apprehension over generic medication. As one patient put it,

The government is giving us second-class medicine because we are poor and it is not good medicine.

Economic

Patients also reported socio-economic related barriers such as cost of medication as some have to pay a co-payment for medications and lack of bus fare/taxi money to go to the doctor and/or pharmacy. For patients in the outer islands of Chuuk, they spent money to take a boat to the main island and then a taxi to the hospital because there were no buses or public transportation.

Discussion

This was the first study that investigated socio-cultural influences that hinder or facilitate medication adherence for diabetic Chuukese in Chuuk and Hawaii. This study used Grounded Theory to freely explore this topic. In-line with Grounded Theory
practices, the Social Cognitive Theory was used to sensitize the topic and the results showed behavioral, personal and environmental factors related to medication adherence. The results showed barriers and facilitators that were similar to other populations in the U.S. such lack of knowledge, patients’ health beliefs, inadequate mental health support, ineffective physician-patient communication, cost, transportation and family/social support. It also revealed help-seeking behaviors that involve four socio-cultural influenced healing-types (Table 19). The description and discussion of the healing types exposed vital factors that inclined patients’ to comply with treatments. Factors associated with the healer (messenger), medicine/remedy, and focus of healing. Furthermore, this study revealed that many patients not only seek multiple healing types (western, traditional, local and new), they also rotate among the types. These findings were communicated through two narratives: healer characteristics and medication-specific features.

Healer Characteristic Narratives

Study participants communicated medication adherence behaviors by describing attributes of the person(s) who prescribed/recommended the medication. Participants cited two healers’ characteristics that influenced their adherence to treatments: the healer’s (1) trustworthiness and (2) ability and to provide spiritual and emotional support. The trustworthiness of the healer was gauged by the quality and duration of interactions, in addition to their recognition and acknowledgement of patient’s non-health competing needs. Specific to western healers, patients revealed their usage of non-western medicine to healthcare providers that they trust. Traditional/local healers and new/fad medicines distributors had an advantage over western healers as most were family members, faith leaders, friends or neighbors and therefore had an established relationship with patients and is aware of non-health needs of the patients. Moreover, time spent was important in nurturing a trust relationship. Participants equated the time healers spent with patients as a sign of compassion and respect. Again, non-western healers had an advantage as they
can afford to and are spending more time with patients. The healers’ ability and willingness to provide spiritual and emotional support was also important to the participants. One of the primary reasons for seeking non-western healing was their incorporation of emotional and spiritual support in their healing process. Like building trust, time was also an important factor, something western healers reported that they do not have.

In the literature, patient-provider trust was associated with medication adherence behaviors (Nguyen et al., 2009; Wang & Wu, 2007). Studies also showed that low levels of trust are linked to greater depression (Schneider, Konjin, Righetti & Mancuso, 2010) and high likelihood of leaving a hospital against medical advice (Haywood et al., 2010). Moreover, the failure of providers to understand and patients communicate the use of non-western medicine resulted in patients’ dissatisfaction and non-compliance with western treatments (Shahid, Bleam, Bessarab & Thompson, 2010). Bova and colleagues (2006) found that collaborative trust has three factors: interpersonal connection (e.g., establishing an emotional connection), respectful communication, and professional partnering (e.g., sharing knowledge in a matter that is understandable). In addition to trust, the provisions of emotional and spiritual support were also important to study participants. Other ethnic groups in the U.S. such as African American and Mexican American expressed the same needs (Baig et. al., 2012; Lewis & Ogedegbe, 2008). Numerous studies showed that patients with diabetes reported feelings of hopelessness, despondency, discouraged, overwhelmed and chronically frustrated (Polonsky et al., 1995; Polonsky & Welch, 1996).

This study and the literature underscore the need for trusting relationships, emotional support and spiritual support. Given the reality that the healthcare system does afford to spare extra time for patients to address relationship, emotional and spiritual support, it is important to explore alternative ways to provide this needed support. Findings from this study revealed that faith leaders, healers (non-western and western)
and patients preferred integrative care or care that incorporates emotional and spiritual support. Faith leaders and non-traditional healers are willing to work with healthcare providers to provide emotional and spiritual support. This concept of integrated care is not new to diabetes care as most healthcare systems already have multidisciplinary professionals (albeit mostly health specialist) in the care team. Future study is needed to determine the feasibility, particulars and effectiveness of such intervention.

Medication-specific Narratives

Medication adherence discussions also centered on medication concerns, specifically their safety, effectiveness, naturalness and accessibility with constant comparisons between western and non-western medicines. Medication safety and effectiveness concerns were site specific. Participants from Chuuk reported concerns over the safety and effectiveness of western-medications from Asian countries, as they believe that these medicines were either expired or not under strict scrutiny like U.S. medicines. Participants from Hawaii expressed concerns over generic medication, as they believe these medications used sub-standard ingredients, experimental or expired. Moreover, participants also expressed concerns over the effectiveness of western medicines for diabetes. Patients gauge the effectiveness of medicines by their capacity to minimize pain and/or heal other symptoms of diabetes. For traditional and non-local medicines, healers were very specific on the purpose of the medication (e.g., heal a wound and minimize certain pains) and patients were able to assess its effectiveness. For western diabetes medication, patients were not sure how to determine its efficacy, as many were uncertainty on what is controlled diabetes. Other advantages of non-western medications were their naturalness since many derived from plants and their accessibility, as they were plants and patients can gather them at no cost. The literature on medication concerns also reported patients having negative beliefs about their medications, especially generic medications (Frank, 2007; Osterberge & Blascheke, 2005; Piette, Heisler, Harand & Juip, 2010). It also reported patients’ preference for herbal remedies
due to their naturalness and accessibility (Bodeker, Ong, Burford & Shein, 2005; Brown & Bussel, 2011).

**Conclusions**

This study revealed help-seeking behaviors that involve four socio-cultural influenced healing-types (western, traditional, local and new), and factors that inclined patients’ to comply with treatments. Furthermore the participants’ narratives revealed that many patients not only seek multiple healing types they also rotate among the types. From these narratives, the current literature and the critical need to address the epidemic of diabetes in Chuuk and the Pacific, there is a need to further investigate medication concerns among Pacific Islanders. This population could benefit from the reassurance of and education on the safety and efficacy. Moreover, concerns over the naturalness of diabetes medications need to be addressed. Other practitioners suggested that this can be accomplish by reassuring patients that metformin is derived from the French lilac (Brown & Bussel, 2011).

Akin to most qualitative studies, the small size and purposeful sampling limited this study. Participants were likely to be different than those who did not participate. For example, the research team asked community members who wanted to share their experience in diabetes care as individuals with diabetes and caretakers so participants likely reflected the ‘talkative’ rather than the ‘shy’ members. Moreover, the interviews and focus group were conducted in English so those who are not fluent in English might have different experience and perspectives.

Since this study focused on Chuuk and Hawaii used CBPR approach, the research team is more confident that the findings can be used to develop culturally appropriate diabetes control intervention in the state of Hawaii and Chuuk. The researchers believe that programs and research based on the Pacific values, beliefs and traditions would also appeal to other Pacific communities. Finally, they believe that our participatory process
using grounded theory principles can serve as a model for other researchers working with minority groups to reduce health disparities.
CHAPTER 6
CULTURALLY BASED FRAMEWORK FOR DIABETES MANAGEMENT

Introductions

A systematic review of interventions to improve glycemic control in socially disadvantaged populations concluded that successful interventions require environmental support in addition to adaptation to fit the culture and context (Glazier, Kennie, Bajcar & Willson, 2006). Several of the successful interventions included in this systematic review showed reductions of 1% in A1C which is substantial as a 1% drop in A1C has been associated with a 10% reduction in diabetes related deaths and 25% reduction in microvascular end points (Turner, Holmann, Cull, Stratton & the UK Prospective Diabetes Study Group, 1998). Given the severity of the Type 2 Diabetes (T2DM) epidemic in Pacific communities it is vital to adapt interventions (including environmental interventions) to fit the Pacific culture and context.

This study obtained perspectives on diabetes control and identified socio-cultural influences that hinder or facilitate adherence to diabetes management behaviors. These perspectives and influences were used to inform the development of the Pacific Stewardship Framework. This chapter will (1) introduce the framework and describe its constructs; (2) reflect on the development process and its key components; and (3) discuss practical applications.

Pacific Stewardship Framework Introduction

Study participant narratives centered on the importance of hope restoration through the stewardship of the spirit, mind and body, as they believe that this will improve adherence to diabetes management. In addition, the decision to focus on restoring hope and focus of personal and collective stewardships was made during report back sessions as community representatives were convinced that they (individuals with diabetes, family members, caregivers and stakeholders) should be at the center of a
solution. They also recognized that there are broader issues such as discrimination, poverty, social justice and lack of structural support but at the end they acknowledged that although some of those factors are “outside of their control” they are still active participants and can influence some of the changes. The use of the word stewardship in the framing these interventions was also selected by community representatives as this portrays active participation and responsible management of resources (spirit, mind and body). Previous chapters discussed study findings specific stewardship of the spirit, mind and body for nutrition therapy (Chapter 3), physical activity (Chapter 4) and medication adherence (Chapter 5). This chapter will describe each of the stewardships and their function in improving overall diabetes management.

The most salient topics in all the focus group and interview discussions were on diabetes as a major problem and the pervasiveness of hopelessness. Woven into these conversations were narratives on how to address these two issues with stewardships of the spirit, mind and body in an effort to restore hope (Figure 4).

Stewardship of the Spirit

The resurgence of spiritual discourse in the U.S. has occurred, in the past few decades as scientific-based approaches are not fully able to address a number of health problems (Sundblom, Haikonen, Niemi-Pyntarri & Tigertendt, 1994). From the narratives, spirituality has always been a critical and essential component of healing in Chuuk. Other scholars (Aitaoto, Braun, Dang & Soa, 2007; Hosey et al., 2009; Mishra, Luce & Hubbell, 2000) also reported the significant role spirituality plays in the health of other Pacific Islanders. This study found three significant effects: (1) influence etiology of disease beliefs and therefore affects help seeking behaviors; (2) provides strength, resources and motivation to comply to adherence recommendations; and (3) bestows physical healing.

Spirituality’s role in influencing help seeking behaviors is directly linked to spiritual beliefs regarding etiology of Type 2 Diabetes (T2DM). Disease etiology was at
the center of all the discussions because it effected individuals’ decision to seek help, the
type of help they sought, and their compliance to treatment. Patients narrated five
pathways that started with disease etiology beliefs and ended with treatment compliance.
Only one scenario leads to western treatment adherence and that narrative began with the
belief that the etiology of Type 2 diabetes was God’s will (global will for everything to
happen) plus unhealthy behaviors. On the other hand, non-adherence was connected to
the beliefs that the etiology of Type 2 diabetes was God’s will only, unhealthy behaviors
only and other spirits. From these findings it seems like there is benefit in believing in
God’s global will, and given the role faith leaders and churches play in spiritual matters it
is justifiable that they take the lead in stewardship of the spirit. Further research is
needed to explore these pathways and their constructs. .

The other vital factor was accessing spiritual benefits (especially healing) through
prayer. Participants narrated several instances where they experienced healing through
prayers. Although not all prayers led to healing, they believe that God’s has a perfect
will, their ailment can have a greater purpose and it will all work out at the end. A
participant relayed,

When we get sick, the first thing we do is pray for healing. Healing comes in
many forms, God can use doctors and medicines to heal us, sometime He heals us
through our local medicines, healing can also happens without any of those, and
then there are times where healing is not the answer.

Finally, a healthy spiritual life can provide strength to comply to treatment through
prayer, repentance from sin and returning to living a healthy way and fellowship with
other Christians where they give and support (e.g., emotional, spiritual, social and
economic). In order to improve adherence for this population there is a need for
researchers to investigate these pathways and the benefits of a vigorous spiritual life that
can be advantageous to individuals with diabetes: wisdom (e.g., seeing things clearly,
putting life struggles of life into perspective and getting directions), motivation
(especially during long term struggles), and emotional support.
Stewardship of the Mind

Participants’ narratives around stewardship of the mind followed three paths: cognitive stewardship (e.g. increasing diabetes management knowledge); emotional stewardship (e.g. motivating actions by addressing emotional issues) and stewardship of beliefs and ideas (e.g., cultivating healthy culturally based beliefs regarding nutrition and physical activity). All three were essential in promoting diabetes management adherence. On the cognitive level, the knowledge of what causes diabetes, diabetes risk factors and symptoms, and management has proven to be an important component of glycemic control. This study showed that the majority had the knowledge that diabetes is caused by lifestyle behaviors but that was not sufficient in terms of adhering to nutrition and physical activity recommendations. This study exposed gaps in regards to diabetes knowledge, specifically on how to operationalize management recommendations. This underscores the need for health messages that not only provide information on the disease but also practical instructions and guidelines. In addition, participants spent a significant amount of time discussing this culturally and contextually appropriate interventions to address this gap (Chapters 2-5).

Cultural based beliefs can also facilitate or hinder adherence. As mentioned earlier, spirituality-related beliefs played a major role in help seeking behaviors and treatment adherence. There are other beliefs that influence sedentary behaviors, physical activities (e.g., it is regal and respectable for elders to be not move around); nutrition (giving volumes of food is a sign of respect and eating volumes of food is a sign of appreciation) and drug adherence (e.g., western medications are not natural and generic medicines are ineffective). Further research is needed to look at the impact of these beliefs and effective interventions to address concerns.

Lastly, participants discussed the importance of emotions, especially as it relates to motivation. Numerous narratives were centered around the lack of motivation due to being sad, scared and despair. For example, one of the focus group participants said,
It is very hard for me to do what my doctor told me to do….this is a tough illness. I see people with no legs because of diabetes and I start to think what my family will go through if that was me. That scared me and it makes me sad…I get so scared and sad that I can’t do anything…I don’t want to do anything…these things are so heavy on my mind that it is hard to think about other things and it is hard to do things.

Many of these emotions were related to diabetes (e.g., fear of amputation and shame of taking medicine). Patients also mentioned emotions such as anger, sadness and misery related to broader social issues such as discrimination and poverty. A participant in Hawaii bemoaned,

I get treated differently from other local people. I tried to look for a job and they can see that I am Micronesian so they don’t hire because of our reputation. As you know, money is everything here in Hawaii, and I can’t survive without a job. This is very depressing to me and I can’t even start to think about my diabetes. Things spiral downwards and before I knew it my diabetes was so out of control that I ended up at the emergency room. I didn’t get up in the morning and decide not to control my diabetes and I didn’t want to be in the hospital but things just spun out of control

There is a need to explore these emotions especially in the context of motivating patients to adhere. Moreover, some of the emotions related to a collective experience such as historical trauma, racism, discrimination needs to be dealt with as a group.

Stewardship of the Body

The ultimate goal for this study was to find ways to facilitate the stewardship of the body, specifically taking care of T2DM (e.g., being physically active, eating healthy foods and medication adherence). The Stewardship of the Body construct also includes stewardship of one’s physical and social environment. Participants viewed the physical environment as the extension of one’s body and believed that individuals have the responsibility to care for and utilize environmental resources. This study revealed environmental gaps such as lack of access to healthy foods, places to exercise and medicine (Chapters 2-5). Although participants recognized that some of these environmental and structural issues required actions and measures beyond themselves they did want to be at the center of activities or interventions that address these issues.

For example, a faith leader stated,
I know that having safe places to walk, healthy foods at the stores and medicines at the clinic are important in our people’s quest to manage their diabetes. I also know that many believe that these things are out of our control. Yes, the government needs to step up and honor their pledge to our country. Yes, there are businesses that are taking advantage of us and over charge for fruits and vegetables. My question is, should we just sit back and let them do that to us? Should we wait until they feel convicted and do something about it? That might never happen so where does that leave us? My point is that we should be the ones figuring out how to improve the system. There are policies that need changing and we can get involved in that. Major social justice movements started in churches and on the community level. That is what we mean by stewardship of our environment.

Participants also cited the stewardship of relation as critical in diabetes management, particularly the relationship between people with diabetes and their family members, healers/health care providers and faith leaders. These relationships needed to be cultivated and nurtured in order to accomplish glycemic control. A patient from Chuuk stated,

I think that having a trusting relationship between me and my healer make a difference in whether or not I take my local medicine. Sometimes, I don’t feel like following all her instructions but I don’t want to disappoint her and I trust that she gave e those instructions for my own good so I ended up following them. She spent a lot of her time teaching and encouraging me so I show my appreciation by following everything she says and I know she appreciates that also.

Framework Development Process Discussion

Although this framework emerged from the narratives the process that facilitated its development was also important. The process enabled the voice of the community to be heard and it privileged the indigenous perspective. This section will include a discussion of the (1) theories and other frameworks that were used; (2) target population; (3) study subjects; and (4) positionality of researchers.

Use of Theories and Frameworks

This research project inherited the use of Community Based Participatory Research (CBPR) principles as the process began over ten years ago when communities in the Pacific identified their priority health issues. This research continued the CBPR process and it benefited from it on many levels. For instance, the logistic planning process was easier due to the support of two community organizations; investigators did
not have a problem with recruitment because trust was already established; participants were direct and unguarded with their answers.

The richness of the results was also due to the utilization of grounded theory. Although there were prepared probing questions, participants were first given the chance and encouraged to share whatever was on their mind. Moreover, the discussions flowed very freely and it naturally moved from one point to another. For example, many times participants began the discussion with a discourse on diabetes as a problem then it moved to why it is a problem and then on to ideas on how to address the problem. The use of the Social Cognitive Theory was also beneficial in organizing the probing questions and results. Although the purpose of this study was not to determine the presence of the Social Cognitive Theory, participants reported narratives related to behavior, personal factors and environmental influences. During the research planning process, there were some concerns regarding the use of the Social Cognitive Theory (SCT) along with the Grounded Theory as that might limit the conversation to SCT constructs. However, during data collection participants shared information beyond the constructs as they spent a great amount of time discussing diabetes as problem.

**Target Population**

The members of the Pacific Chronic Disease Coalition selected Chuukese as the target population representing Pacific Islanders. Moreover, they chose Chuuk and Hawaii as the two sites for this research project. There were many similarities between the two sites especially with beliefs and adherence behaviors. The major differences were on the organizational and environmental level. Chuukese in Chuuk had better access to local fruits, vegetables and medicinal plants while Chuukese in Hawaii had access to specialists (e.g., nutritionists, podiatrists and endocrinologists) and medical supplies (e.g. variety of medications and glucometers). Although both sites cited access to physical activities as barriers, access issues where different as Chuukese in Chuuk cited lack of infrastructure and safety in terms of dogs on the road and unpaved
roads/sidewalks. Hawaii participants reported that there was infrastructure for physical activities but were uncomfortable using them due to lack of desire and past discrimination. They also reported safety issues such as crime on the street as a major concern. In regards to organizational level differences, providers in Chuuk reported barriers related to resources such as specialists and medical supplies while providers in Hawaii reported language and cultural barriers.

Concerning the generalizability of these findings to other Pacific Islanders, a preliminary review of the findings by members of the Pacific Chronic Disease Coalition (representatives from all six U.S. Pacific jurisdictions) and healthcare providers that serve Pacific Islanders in Hawaii concluded that there are many cultural similarities between these findings and their experience with other Pacific Islanders living in their home jurisdictions and Hawaii. Further review of the data by individual jurisdictions is needed to determine issues that are specific to their ethnic group(s).

Selected Subjects

The three groups (faith leaders, healthcare providers and community) brought different perspectives, insights and profundity on the same issue or topic. For example, in describing problems concerning the scope and prevalence of diabetes, health care providers mentioned the overwhelming burden on the health care system, faith leaders discussed the spiritual effects on church members and community members discussed their personal and day-to-day struggles. The three groups also highlighted and elaborated on different segments of the issue and they complemented and built on each other. For example, in discussing problems around prevention and control, health care providers reported that their patients have sufficient knowledge on what to do to prevent T2DM but are not doing it. Community members agreed and elaborated on issues regarding diabetes knowledge. For example, the majority cited that diabetes can be controlled by eating right, exercising and taking their medication as directed by the doctor, however, specific knowledge on “how to” was lacking. In addition, although they know that
diabetes can be controlled by lifestyle changes they found those changes impossible. Faith leaders elaborated and cited lack of resources, motivation and hope as the cause of inaction.

**Positionality of Researchers**

Three of the four research team members had over ten years of working experience in the region (two public health practitioners and a faith leader). Two were Pacific Islanders and worked in the field of diabetes control and the other member was Filipino and worked as a clergy and a champion of diabetes issues in the region. The fourth team member was not from the Pacific and she played a vital role as an “outsider” reviewer. The team lead was a Pacific Islander who was raised in the Pacific. She had a long work history in the Chuukese community as a public health practitioner. She brought to this research her perspectives on culture, religion and context. Her role in the community as a health practitioner also influenced her perspectives and the way study participants responded to the research questions. Given that research team members had strong connection to the Pacific culture, it was vital that the team added an additional data validation step. At the end of data analysis, the research team reported the findings and analysis to study participants and stakeholders to confirm that their narratives were properly interpreted.

Although there were no predetermined hypothesis for this study, the team acknowledged that they had personal expectations and preconceived ideas based on their experience working in the Pacific and/or being Pacific Islander. The team was not surprised by the pervasiveness of hopelessness and the need for spiritual, emotional and environment support. They were surprised at the amount of time participants spent on discussing emotional and spiritual concerns as the team expected to hear more about environmental factors given major gaps in infrastructure and resources. This highlights the importance of emotional and spiritual support and the need for community and stakeholder inputs at all levels of research. In regards to religiosity and spirituality, three
team members were Christians, the community identified spirituality and religiosity as one of the research topics, and there were prepared probing questions regarding supporting faith based programs. However, the discussions around the issue of spirituality began without probes.

**Practical Applications**

In compliance with community based participatory principles, the overall findings were presented to stakeholders including members of the Pacific Chronic Disease Coalition and they drafted a plan for future intervention research and/or programs. This community participatory planning process addressed the need for community to use research data to plan their own activities versus researchers and public health administrators planning activities without the input of community members and stakeholders. This following section will include the results from these sessions and it illustrates practical applications of the findings from this study.

The most salient topics in all the focus group and interview discussions were on diabetes as a major problem and the pervasiveness of hopelessness. Woven into these conversations were narratives on how to address these two problems with stewardships of the spirit, mind and body in an effort to restore hope (Figure 4).

**Stewardship of the Spirit**

Spiritual beliefs regarding etiology of Type 2 Diabetes (T2DM) is at the core of individual’s decision to seek help, the types of help they seek, reaction to the illness and compliance to treatment. Treatment adherence was related to the belief that the etiology of Type 2 diabetes was God’s will (global will for everything to happen) plus unhealthy behaviors. On the other hand non-adherence was connected to the beliefs that the etiology of Type 2 diabetes was God’s will only, unhealthy behaviors only and other spirits. The other vital factor was accessing benefits of a healthy spiritual life through prayer for healing and strength to comply to treatment; repentance from sin and returning to living healthy; and fellowship with other Christians where they give and support (e.g.,
emotional, spiritual, social and economic). Future research is needed to investigate these pathways and the benefits of a vigorous spiritual life: wisdom (e.g., seeing things clearly, putting life struggles of life into perspective and getting directions), motivation (especially during long term struggles), and emotional support.

**Stewardship of the Mind**

Study participants communicated the importance of the development and utilization of the mind to promote diabetes management adherence through increasing diabetes management knowledge, cultivating healthy culturally based beliefs and motivating actions by addressing emotional issues. Although this study exposed gaps in diabetes management knowledge especially how to operationalize management recommendations, it also revealed culturally appropriate interventions to address this issue (Chapters 2-5). In addition, participants reported culturally based beliefs that can facilitate or hinder adherence (e.g., it is regal and respectable to be sedentary, giving volumes of food is a sign of respect and eating volumes of food is a sign of appreciation). Finally, adherence was influenced by motivation. Motivation is linked to feelings and emotions related to the disease such as denial, fear, shame, passiveness and sadness. Future research is needed to look at these constructs and the effectiveness of intervention that addresses these issues.

**Stewardship of the Body**

The ultimate goal for this study is to find ways to facilitate the stewardship of the body, specifically taking care T2DM (e.g., being physically active, eating healthy foods and medication adherence). Participants reported stewardships related to the spirit and mind but it also included other “body” related stewardships as narratives referred to forming and sustaining a healthy physical and social environment as stewardships that are necessary for diabetes control. This study revealed gaps and culturally appropriate interventions to address these gaps (Chapters 2-5). For example, participants reported lack of access to healthy foods, places to exercise and medicine. In order to improve
glucose control among this population, environmental and social supports needs to be initiated and sustained.

**Future Intervention Research**

In addition to verifying the findings, they drafted a plan for future intervention research and programs. This fulfilled the community’s desire to participate in all the phases of research including identifying future intervention activities and research. Participants identified activities that steward the spirit, mind and the body. They also identified activities, target population and lead implementers.

**Stewardship of the Spirit Intervention Plan**

According to the participants, having a healthy spiritual beliefs and accessing spiritual guidance and support were very important in improving glycemic control. In order to facilitate the stewardship of the spirit, participants proposed activities that includes: (1) sermons on God’s will, etiology of diabetes and the role of spirituality in diabetes management; (2) prayer (one-on-one and group) with diabetes patients, caregivers and family members; (3) scripture reading schedule (e.g. daily devotional) with health messages; and (4) biblical-based messages in bulletins and other church publications.

**Stewardship of the Mind Intervention Plan**

Activities to promote the stewardship of the mind are vital to glycemic control. Participants proposed activities to improve diabetes management knowledge, promote healthy culturally based beliefs and support emotional wellbeing (Table 20). According to participants, the limitation of the churches was that some faith leaders are promoting new/fad medicines and are condoning the availability of unhealthy foods in church gatherings and functions. Therefore, they requested that faith leaders needed to be educated on health issues before the start of the following activities.
Table 20. Stewardship of the Mind Intervention Plan

<table>
<thead>
<tr>
<th>Target Population</th>
<th>Lead Implementers</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Churches in Hawaii &amp; Chuuk</td>
<td>Faith Leaders</td>
<td>Educational Sessions in Churches on characteristics and etiology of diabetes; diabetes prevention; and diabetes control.</td>
</tr>
</tbody>
</table>
| Churches in Hawaii & Chuuk        | Department of Public Health and Churches | • Educational Sessions in Churches on western medication safety and generic medication  
• Multi-media Campaign on western medication safety and generic medication  
• Motivation and encouragement sessions: testimonies, sharing circle, etc. |
| Caretakers & Patients             | Health Care Providers and Faith Leaders | • Educational Sessions for all newly diagnosed diabetics on: characteristics and etiology of diabetes; symptoms and complication of diabetes; diabetes control (secondary and tertiary prevention); diabetes treatments including medications; and side effects of treatments of medications.  
• Motivation and encouragement sessions: testimonies, sharing circle, etc. |
| Healers (Western and Non-Western) | Health Administrators       | Information Exchange Conference for western and non-western healers.                                                                                                                                                                                                                                                                                                       |
| Caretakers                        | Nutrition Specialists      | • Nutrition classes: type of foods, portions, etc.  
• Skill trainings: budgeting, food shopping, food preparation, etc.  
• Motivation and encouragement sessions: testimonies, sharing circle, etc. |
| Patients & Family Members         | Nutrition Specialists      | • Nutrition classes: type of foods, portions, etc.  
• Motivation and encouragement sessions: testimonies, sharing circle, etc. |
| Patients                          | Faith Leaders              | • Provider counseling to address emotional issues  
• Host support groups to address emotional issues |
| Patients                          | Health Care Provider       | • Provide training on how to increase duration and intensity of activities.  
• Set physical activity frequency goals. |

### Stewardship of the Body Intervention Plan

Developing and maintaining a healthy physical and social environment is also necessary for glycemic control. Participants proposed various activities from improve healthcare system and implementing policies (Table 21).
Table 21. Stewardship of the Body Intervention Plan.

<table>
<thead>
<tr>
<th>Target Population</th>
<th>Lead Implementers</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healers (Western and Non-Western)</td>
<td>Health Administrators</td>
<td>System Change: Involve non-western healer in treatment consultation.</td>
</tr>
</tbody>
</table>
| Physicians, Nurses & Pharmacists | Health Administrators | • Patient Communication Training: Nutrition Therapy Recommendations and Referrals  
• Systems Change: Medication safety concerns questionnaire for patients |
| Faith Leaders | Nutrition Specialists | • Train-the-trainer session: nutrition classes  
• Technical Support: developing sermons and church bulletins that incorporate the scripture and nutrition. |
| Faith and Church Leaders | PA Specialists | • Work with faith & church leaders to increase the frequency of standing during church services and meetings.  
• Provide training on how to “add-on” physical activities to existing activities. |
| Patients and Caretaker | PA Specialists | Provide physical activity training specifically for ill or injured individuals. |
| Churches in Hawaii & Chuuk | Faith Leaders | Healthy messages in bulletin bulletins  
Healthy nutrition and physical activity policies |

**Conclusion**

Given the high and growing prevalence rate of T2DM in the Pacific, it is crucial for public health practitioners and researchers to look at Pacific Island culture and paradigms of health. This study found the pervasiveness of hopelessness in regards to T2DM among Chuukese in Chuuk and Hawaii. It also revealed culturally and contextually appropriate interventions to address this issue through the stewardship of the spirit, mind and body. This Pacific Stewardship Framework can assist in the planning and evaluating of future T2DM interventions for this population. On the operational level, this study found that the healthcare system does not have the capacity to provide sufficient spiritual support. However, faith leaders, churches, and community representatives are willing to collaborate in an effort to provide comprehensive support to individuals with T2DM. Future research is needed to further develop and test this
framework in the field. The future of community and culture based research in public health is promising and will yield necessary information to develop and strengthen Pacific-centric health theories and frameworks.
Figure 4: Pacific Stewardship Framework

Restoration of Hope

Stewardship of the Spirit
- Health beliefs
- Access Spiritual Benefits

Stewardship of the Mind
- T2DM Control Knowledge
- Health Beliefs
- Emotions

Stewardship of the Body
- Healthy Environment
- Healthy Social Relationships
APPENDIX A

FAITH BASED LEADER INTERVIEW GUIDE

Research Purpose and Objectives
The purpose of this research is to develop an innovative culturally based conceptual framework that explains relationships between constructs such as culture, religion, family, and diabetes prevention and control. This framework will assist in the design of future diabetes prevention and control interventions.

The specific objectives of the research are to:

1. Identify socio-cultural influences that hinder or facilitate diabetes prevention and management among Pacific Islanders.
2. Identify the role spirituality plays in promoting diabetes prevention and management.
3. Determine how churches can play an effective role in designing and implementing effective diabetes interventions for Pacific Islanders.

The specific objectives of the interviews are to:

1. Obtain faith-based leaders' perspective on their (and/or their congregants') patients', experience and actions regarding diabetes prevention, screening and management.
2. Obtain faith-based leaders' perspective on their (and/or their congregants') experience and actions regarding diabetes prevention, screening and management.
3. Determine whether faith-based leaders are supportive of diabetes initiatives.

Facilitator's Guide
Thank you for taking the time to participate in this interview. My name is Nia Aitaoto, I'm with The University of Iowa. We have asked you to participate as a Micronesian faith-based leader. This interview should last about 90 minutes. I will be asking a lot of questions. Please, do your best to answer them all. However, if you care not to answer a question, you do not have to. Sometimes, I will ask you to say more, or to explain your answer. Please be patient with me. The session will be recorded on audio tape. Your responses will be confidential and reported out as a whole.
There are no right and wrong answers, we are anxious to hear everyone’s thoughts. Please remember what is said here stays in this room and should not be repeated to others.

Questions

The following questions are for Faith-based leader in the Pacific

1. What have you heard about diabetes? Is diabetes a problem in your community/church? Note: probe as necessary.
2. Is diabetes different or similar from other health conditions and its connection to faith/churches? If so, what makes it different? Note: probe as necessary.
3. Some Pacific Islanders think that diabetes is “God’s will” what do you think about that statement? Note: probe as necessary.
4. What is the role of the bible [scriptures] and the church teachings play in explaining illnesses, especially diabetes? Note: probe as necessary.
5. What role do faith-based leaders play in preventing and controlling diabetes? This can be something you are doing already or want to do in the future. Note: probe as necessary.
6. What can help faith-based leaders in that role? Note: probe as necessary
7. What is the role the church can play in prevention and control of diabetes? Probe: Physical Activity, Nutrition, Drug Adherence. Note: probe as necessary.
8. What can help churches in that role? This can be something you are doing or want to do in the future. Note: probe as necessary.
9. What are some of the best practices in involving churches in diabetes prevention (or other health issues)? Note: probe as necessary.
10. Is there something that we haven’t talked about that we need to know? Note: probe as necessary.

The following questions are for Faith-based leader in Hawaii

1. What have you heard about diabetes? Is diabetes a problem in your community/church? Note: probe as necessary.
2. Is diabetes different or similar from other conditions and its connection to faith/churches?
3. Some Pacific Islanders think that diabetes is “God’s will” what do you think about that statement? Note: probe as necessary.
4. What is the role of the bible [scriptures] and the church teachings play in explaining illnesses, especially diabetes? Note: probe as necessary.
5. What role do faith-based leaders play in preventing and controlling diabetes? This can be something you are doing already or want to do in the future. Note: probe as necessary.
6. What can help faith-based leaders in that role? Note: probe as necessary
7. What is the role the church can play in prevention and control of diabetes? Note: probe as necessary.
8. What can help churches in that role? This can be something you are doing or want to do in the future. Note: probe as necessary.
9. What is the difference between being a pastor in Chuuk/RMI and being a pastor in Hawaii? Note: probe as necessary.
10. What is the difference between churches in Chuuk/RMI and Churches in Hawaii?
11. What are some of the best practices in involving churches in diabetes prevention (or other health issues)? Note: probe as necessary.
12. Is there something that we haven’t talked about that we need to know? Note: probe as necessary.

Background Information
That concludes the interview but before I leave I want to give you this short to fill out.
Thank you!
Thank you so much for taking the time to answer my questions. Here is my card if you have any other questions and/or concerns, please feel free to contact me.

University of Iowa
Faith in Action Research Alliance
Background Information Questionnaire
Faith Based Leaders

1. Age:
2. Gender: Male Female
3. Religion/Denomination:
4. Employment Status:
5. Any other concerns that you didn’t mention in the interview?
Research Purpose and Objectives

The purpose of this research is to develop an innovative culturally based conceptual framework that explains relationships between constructs such as culture, religion, family, and diabetes prevention and control. This framework will assist in the design of future diabetes prevention and control interventions.

The specific objectives of the research are to:

4. Identify socio-cultural influences that hinder or facilitate diabetes prevention and management among Pacific Islanders.
5. Identify the role spirituality plays in promoting diabetes prevention and management.
6. Determine how churches can play an effective role in designing and implementing effective diabetes interventions for Pacific Islanders.

The specific objectives of the interviews are to:

4. Obtain health care providers’ perspective on their patients’, experience and actions regarding diabetes prevention, screening and management.
5. Obtain health care providers’ perspective on their experience and actions regarding diabetes prevention, screening and management.
6. Determine whether health care providers are supportive of faith-based diabetes initiatives.

Facilitator’s Guide

Thank you for taking the time to participate in this interview. My name is Nia Aitaoto, I’m with The University of Iowa. We have asked you to participate as a health provider serving Micronesian with Type 2 diabetes. This interview should last about 60 minutes.

I will be asking a lot of questions. Please, do your best to answer them all. However, if you care not to answer a question, you do not have to. Sometimes, I will ask you to say more, or to explain your answer. Please be patient with me.
The session will be recorded on audio tape. Your responses will be confidential and reported out as a whole. There are no right and wrong answers, we are anxious to hear everyone’s thoughts. Please remember what is said here stays in this room and should not be repeated to others.

**Questions**

**The following questions will be about your patients’ perspective, experience or actions.**

1. In your experience, when does someone ‘know’ or suspect they have diabetes? Or what happens to them so that they get a diagnosis? Or what trigger people to come in for a diagnosis? Prove as necessary.

2. From your patients’ perspective, what are some of the barriers to diabetes prevention and screening? Note: Probe as necessary for
   a. knowledge (do they know that there’s such thing as “diabetes screening”, do they know where to get screened, etc.)
   b. beliefs/attitudes (do they believe diabetes can be prevented, what are some of their attitudes toward DM prevention and screening)
   c. socio-economic (cost of screening, transportation, language barriers, family support, etc.)

3. Again, from your patient’s perspective, what are some of the facilitators to diabetes prevention and screening? Note: Probe for knowledge, beliefs/attitudes and socio-economic (same as Question #2)

4. How does a patient/individual know when his/her diabetes is ‘controlled’? or How do you think your patients define and determine ‘control’ of their diabetes? Note: Probe for knowledge, beliefs/attitudes and socio-economic (same as Question #2)

5. From your patients’ perspectives, what are some of the barriers to diabetes control (self-management)? Note: Probe for
   a. Knowledge: do they know that diabetes can be controlled? Do they know how to control their diabetes through
      1) Medication
      2) Regular visit to specialists such as podiatrist, ophthalmologist and nutritionist
      3) Physical activity
      4) Proper nutrition
   b. Beliefs/attitudes: do they believe that diabetes can be controlled? what are some of their attitudes
      1) Medication
      2) Regular visit to specialists such as podiatrist, ophthalmologist and nutritionist
      3) Physical activity
      4) Proper nutrition
   c. Socio-economic (cost of diabetes care, transportation, family support, etc.)

6. From your patients’ perspectives, what are some of the facilitators to diabetes control? Probe: Same as above
a. Follow-up question: Please give an example of how members of one’s family impact a person’s ‘control’ of their diabetes. For example:
   1) Taking medications every day
   2) Follow up with clinic/doctor’s visits (podiatrist, dentist, ophthalmologist, etc.)
   3) Eating correct # carbs (follow nutrition recommendations)?
   4) Engage in physical activity (follow PA recommendations)

7. When or in what circumstances do your patients use traditional medicines in controlling their diabetes? Do they tell you? How do you know they are using traditional medicines?
8. When or in what circumstances do your patients use “fad medicine” in controlling their diabetes? Do they tell you? How do you know they are using traditional medicines?
9. Explain, in your experience, why your patients use Western medicines and traditional/fad medicines together or alternating or in different circumstances.

The following questions will be about your (or your organization’s) perspective, experience or actions.

1. How is a patient’s control of diabetes defined and determined in your practice?
2. Do you give recommendations for XX (see probe list below)? If yes, please state what are and support for those recommendations. Probe: medication, nutrition, PA and visit to other specialists.
3. What are some of the barriers health care providers are facing in providing diabetes care? Note: Probe cultural differences, language, financial, medical systems, attitudes/beliefs, etc.
4. What are some of the facilitators (best practices) in providing diabetes care? Probe: special clinic days for Micronesians, access to translators, etc.
5. How does your ministry of health or health department affect your ability to prescribe the medicines (or give diabetes care recommendations) that you want to use/recommend?
6. What is your reaction to wards patients who use traditional/alternative/fad medicine? Do you suggest the use of traditional, complementary, fad medicine to your patients?
7. Compared to other ethnic groups, are Pacific Islanders/Micronesian patients easier/harder to treat? Why/Why not?
8. Compared to other chronic diseases, are diabetes patients easier/harder to treat? Why/Why not?
9. What are some of the improvements you would like to see in the prevention/treatment/management of diabetes?
10. Role of faith/Church leaders: Is there a role faith/pastors/church leaders can play in diabetes management? Do you think pastors can play a role of health educator? Will your organization/clinic be open to it? How could lay health workers be used in the churches to help people ‘control’ their diabetes?

11. **Role of church:** What role can churches play in diabetes management? Are churches a good place for physical activity/nutrition programs? Announce/remind (cue) people to go to clinics/doctor’s office for screening/appointment?

12. Is there something that we haven’t talked about that we need to know?

**Background Information**
That concludes the interview but before I leave I want to give you this short to fill out.

Thank you!
Thank you so much for taking the time to answer my questions. Here is my card if you have any other questions and/or concerns, please feel free to contact me.
Research Purpose and Objectives

The purpose of this research is to develop an innovative culturally based conceptual framework that explains relationships between constructs such as culture, religion, family, and diabetes prevention and control. This framework will assist in the design of future diabetes prevention and control interventions.

The specific objectives of the research are to:

7. Identify socio-cultural influences that hinder or facilitate diabetes prevention and management among Pacific Islanders.
8. Identify the role spirituality plays in promoting diabetes prevention and management.
9. Determine how churches can play an effective role in designing and implementing effective diabetes interventions for Pacific Islanders.

The specific objectives of the focus groups are to:

7. Obtain the community’s perspective, experience and actions regarding diabetes prevention, screening and management.
8. Obtain the community’s perspective on their experience and actions regarding diabetes prevention, screening and management
9. Determine whether the community is supportive of faith-based diabetes initiatives.

Facilitator’s Guide

Thank you for taking the time to participate in this focus group. My name is xxxx. I’m with The University of Iowa. We have asked you to participate as a Micronesian with Type 2 diabetes or someone with a family with Type 2 diabetes. This focus group should last about 2 hours.

I will be asking a lot of questions. Please, do your best to answer them all. However, if you care not to answer a question, you do not have to. Sometimes, I will ask you to say more, or to explain your answer. Please be patient with me. The session will be recorded on audio tape. Your responses will be confidential and reported out as a whole.
There are no right and wrong answers, we are anxious to hear everyone’s thoughts. Please remember what is said here stays in this room and should not be repeated to others.

**Questions**

**A. Diabetes knowledge, beliefs and attitudes**

2. What are your feelings or views about diabetes? Note: probe as necessary.
   a. Diabetes complications?
   b. Diabetes control?
3. How does spirituality (belief in God), affect how you think about diabetes, if at all? Note: probe as necessary.

**B. Diabetes screening/diagnosis**

1. In your experience, when does someone ‘know’ or ‘suspect’ they have diabetes? Note: probe as necessary.
2. What do they do after they ‘know’ or ‘suspect’ they have diabetes? Note: probe as necessary.
   a. Probe: screening, screening services, who do they talk to?

**C. Diabetes management and control**

1. Once you have diabetes, is there a way you can control it? What can you do to control diabetes? Are there differences between how women control their diabetes compared to men, if so what? Note: probe as necessary.
2. What are your feelings or views toward XX? Note: probe as necessary.
   a. Taking Western medication and traditional medicine?
   b. Going to the doctor regularly (all the time) for check-ups?
   c. Going to see the traditional healer?
   d. Physical activity and exercise (as recommended by your health care provider)?
   e. Nutrition recommendations (as recommended by your health care provider)?
3. How do you know if your (or your family members diabetes) is controlled? Note: probe as necessary.
4. What consequences will diabetes have on your life? For those of you who have diabetes, how did diabetes change your/family’s life. For others, how did your family member’s diabetes change your life? Note: probe as necessary.
5. What are some of the barriers to diabetes control? What things affect your ability to XX? [Probe as necessary for concerns, family, job, community, cost, access, etc.]
a. Take western medication, traditional medicine and complementary medicine?
b. Go to the doctor regularly (all the time) for check-ups? Traditional healers?
c. Engage in Physical activity and exercise (as recommended by your health care provider)?
d. Follow Nutrition recommendations (as recommended by your health care provider)?

6. What are some of the things that help you with diabetes control? [Probe as necessary for family, job, community]
   a. Take western medication, traditional medicine and complementary medicine?
   b. Go to the doctor regularly (all the time) for check-ups? Traditional healers?
   c. Engage in Physical activity and exercise (as recommended by your health care provider)?
   d. Follow Nutrition recommendations (as recommended by your health care provider)?

7. Do you seek (look for) help/advise from other people for your diabetes? What type of support do you receive from XX? Note: probe as necessary.
   a. Probe: traditional healer, family members, faith based healer?
   b. Probe: psychological/mental/emotional help?

8. What role does spirituality (your faith in God) play in diabetes management? [Probe as necessary for role of the bible and church teachings in diabetes management.]

9. What role do faith based leaders play (or want them to play) in diabetes management/control? Probe: physician-pastor team? Note: probe as necessary.

10. What role does your church play (or want them to play) in diabetes management/control? [probe as necessary for taking medicine, seeing a doctor, physical activity and nutrition]

11. How is controlling diabetes different in Hawaii as compared to Chuuk/ Marshall Islands. What things are easier? What things are harder? OR how has moving to Hawaii affected your ability to manage your diabetes or the diabetes of someone in your family? Note: probe as necessary.

12. Is there something that we haven’t talked about that we need to know? Note: probe as necessary.

Background Information
That concludes the focus group but before I leave I want to give you this short form to fill out. This form will ask you to provide some background information such as age and gender (see attached Focus Group Questionnaire for more information).
Thank you!
Thank you so much for taking the time to answer my questions. Here is my card, if you have any other questions and/or concerns, please feel free to contact me.

University of Iowa
Faith in Action Research Alliance
Background Information Questionnaire
Focus Group

1. Age:
2. Gender: Male   Female
3. Religion/Denomination:
5. Do you have diabetes?   Yes or No
6. Do you have a household member with diabetes? Yes or No
6. Primary Health Care Provider:
7. Any other concerns that you didn’t mention in the interview?
REFERENCES


